Chapter 9

General Discussion
This thesis focused on the evaluation and implementation of personalized psychosocial care interventions for people with dementia and informal caregivers who live in the community. We investigated the existing literature for studies reporting on characteristics of people with dementia and informal caregivers that appeared to be related to positive outcomes of the psychosocial intervention and are therefore relevant to take into account when providing personalized dementia care (Chapters 2 and 3). In addition, we studied four different types of personalized care interventions that aim to provide individualized care based on the needs of people with dementia and/or those of their informal caregivers (Chapters 4 through 7). We traced facilitators and barriers to these interventions to determine the feasibility of, and issues regarding, their further (nation-wide) implementation. This was done systematically using the Theoretical model of adaptive implementation (Dröes et al., 2003; Meiland et al., 2004). Based on the findings of the conducted studies, we concluded our research with the composition of an evidence-based model for the implementation of personalized psychosocial care interventions that incorporates core components of personalized care and as such provides a checklist for future researchers, care professionals and policy makers who wish to develop and implement personalized psychosocial interventions in dementia care (Chapter 8).

In this final Chapter, we will review the main findings of our research, followed by a discussion of its limitations and methodological issues, relevance of findings for scientific research, psychogeriatrics and society, and implications for future research and practice.

**Main findings and conclusions**

*Are specific characteristics of people with dementia and informal caregivers related to positive outcomes of individual psychosocial interventions?*

To investigate this question we conducted a systematic literature review on review studies published between 1990 and 2008 that described effect studies in which a relation was found between positive outcomes of psychosocial interventions and personal characteristics or subgroups of people with dementia or informal caregivers. We included 32 reviews for people with dementia. These were further analyzed resulting in 71 studies that met our inclusion criteria. Of these studies 45 were institution based and 26 were community based. These numbers indicate that the majority of published research in the selected period focused on the intramural setting. Type (Alzheimer’s disease) and severity of dementia (mild to moderate and moderate to severe dementia) as well as the living situation (living with a caregiver) were frequently reported in studies as characteristics related to positive
intervention outcomes for people with dementia living in the community. Other characteristics that were reported on in only a few studies for this group were: gender, presence of depression, agitation or other behavioral problems, and receiving no care services at baseline. The intervention effects were found most frequently on the outcome measures cognitive functioning and behavioral functioning (agitation, aggression, repetitive behaviors and social functioning).

Institution-based studies focused mostly on subgroups of people with a diagnosis of dementia syndrome (not otherwise specified) and people with moderate to severe dementia, with the most investigated outcome measures again being cognitive functioning and behavioral functioning (agitation, aggression, repetitive behaviors and social functioning).

For informal caregivers we included 26 studies that reported effects for subgroups. Characteristics of informal caregivers that were frequently found to be related to positive effects of interventions were gender of caregivers (being female), having mental problems at the start of the intervention and specific characteristics of the person with dementia they care for (type (Alzheimer's disease) and severity of dementia (early stage and mild to moderate) and living situation (living with a caregiver)). Effects on caregivers were most often found on the outcome measures mental health problems, sense of competence of caregivers and burden.

What are the benefits of four tailored psychosocial care interventions for people with dementia and their caregivers and which facilitating and impeding factors influence the implementation of these interventions?

Evaluation of DEM-DISC

In the DEM-DISC study we evaluated the previously developed and adapted Digital Interactive Social Chart (Dröes et al., 2005; Van der Roest et al., 2008, 2010) that aims to support informal caregivers of people with dementia to find appropriate care and welfare services that match their needs and takes into account personal characteristics, such as living situation and gender. The effectiveness of DEM-DISC was studied in a nested cluster randomized controlled trial with measurements at baseline, 6 and 12 months. The intervention group consisted of 41 informal caregivers and 13 case managers who had access to DEM-DISC during 12 months. In the control group, 32 informal caregivers and 14 case managers did not have access to DEM-DISC. Informal caregivers from both groups received case management. The study showed mixed results. Informal caregivers and case managers judged DEM-DISC as easy to use and user-friendly. Informal caregivers with access to DEM-DISC reported higher levels of sense of competence than controls after twelve months. A subgroup of users who accessed DEM-DISC more frequently reported more met needs after six months compared to controls. However, informal caregivers with access to DEM-DISC also reported
more total needs after twelve months, including more unmet needs, than controls. Also, there was a significant decrease in the amount of behavioral problems in control patients after six months compared to the experimental group. DEM-DISC use had no effect on any of the secondary outcome measures: quality of life, emotional distress due to neuropsychiatric problems and quality of life of people with dementia. Within the group of informal caregivers who had access to DEM-DISC there were high frequent and low frequent users. These subgroups differed in background characteristics: High frequent users reported more mental health problems at baseline, more often did not have paid work and were older compared to low frequent users. These results suggest that not all informal caregivers would be inclined to use DEM-DISC regularly or benefit from personalized provision of information provisioning via the internet. Case managers who used DEM-DISC said the tool could be helpful for case managers who are new to the job, but the majority of experienced case managers said the system did not provide them with new information.

To investigate barriers and facilitators of future nation-wide implementation of DEM-DISC, semi-structured interviews were conducted with 10 stakeholders. An expected crucial element of success is to keep the information in DEM-DISC up to date. Methods to accomplish this are of great importance and need to be further investigated. Generating enough support among professional caregivers who can refer informal and professional caregivers to DEM-DISC was also mentioned as a precondition for successful implementation.

**Evaluation of Dementelcoach**

The Dementelcoach intervention aims to provide personalized support by telephone to a group of informal caregivers who experience barriers to participating in support services outside their home. The effect of telephone coaching according to Dementelcoach principles (individual coaching of informal caregivers once every two to three weeks over a time period of 20 weeks by a trained personal coach with psychogeriatric expertise) was evaluated in a pre-test/post-test comparison group design with three groups of informal caregivers. The two experimental groups received either telephone coaching alone or telecoaching combined with psychogeriatric day care for the person with dementia. The third group was a comparison group and consisted of informal caregivers who take care of persons with dementia who had just started day care. Results showed that informal caregivers who received combined support (telecoaching and day care) reported less burden compared to informal caregivers who received telecoaching only, as well as fewer mental health problems compared to informal caregivers whose relative received day care only.

Overall, informal caregivers expressed a high satisfaction with the intervention. They particularly valued the listening ability of the coach, the opportunity to open
up about their problems, not feeling judged, receiving emotional support for their problems, receiving knowledge on dementia and receiving new insights into their own situation. However, some informal caregivers indicated they would have preferred more personal (face-to-face) contact with their coach and would have liked to have the option to contact their coach in case of crisis situations.

**Evaluation of two case management models**

In a process evaluation we investigated facilitators and barriers to the implementation of two different case management models in dementia care: the linkage model and the combined intensive case management/joint agency model. In the linkage model, the dementia network comprises multiple case management providers and case managers act as a liaison between clients and many care organizations. In the intensive model, case management and additional care services (such as diagnostics and medical treatment) are embedded in one independent organization.

We conducted semi-structured interviews on implementation issues with 22 stakeholders (e.g. project leaders, case managers, health care insurers, municipalities). The two models appeared to differ considerably in the way they are organized and how well they were implemented in dementia care practice. Stakeholders who worked within the linkage model expressed many barriers to the implementation of case management, specifically factors related to the organizational structure of the dementia care network and how partners collaborate with each other in that network. The most significant success factor in the implementation of the intensive case management proved to be the independence of the case management organization. In the linkage model, the presence of multiple competing case management providers caused collaboration problems that impeded the implementation. In addition, case managers in the linkage model had more difficulty providing quality of care for people with dementia and their caregivers as it was more difficult for them to access an expert team and they found it difficult to stay focused on needs of their clients. Case managers could also feel pressured to refer clients to their own organization due to the existing competition. Our conclusion was that case management according to the intensive case management model was better implemented and easier to implement than case management in the linkage model. However, without top-down measures the preferred independence of case management in the intensive model might be difficult to realize in some regions, because of differences in structure of the dementia care network and the presence of market forces. This means that, although our results indicate that implementation of the intensive model is preferable, it will not always be feasible in actual practice.
Evaluation of a follow-up visit to improve the transfer to the nursing home

In a qualitative explorative pilot study we evaluated an intervention that was aimed at providing continuity of care for people with dementia with complex behavior problems who are admitted to a nursing home. Continuity of care was provided by means of a follow-up visit 6 weeks after nursing home admission conducted by a community psychiatric nurse of the Mental Health care service. This nurse provided professional nursing home carers with advice on how to manage behavioral problems of the person with dementia and also provided (closing) support to the informal caregiver.

Semi-structured interviews were conducted with participants who were exposed to the intervention (i.e. community psychiatric nurses, family caregivers and nursing home carers) as well as with other relevant stakeholders, such as the director of the Mental health care organization, a health care insurer and a general practitioner to identify facilitators of, and barriers to, a future structural implementation of the intervention. The results of the study indicated that the follow-up visit met the need of nursing home carers for background information of newly admitted patients and helped informal caregivers to close off the period prior to admission.

Nursing home staff valued the biographical information of clients highly as it enabled them to better understand the problem behaviors as well as better attune their care approach to the personal needs of their clients. However, we did not find that the original purpose of the follow-up visit was achieved (providing advice on problem behaviors). Nursing home carers felt that the follow-up visit was conducted too late and would have preferred receiving the information at the time of admission or shortly after.

While we found that the lack of information transfer during nursing home admission facilitated the implementation of the intervention at present, there were also some distinct barriers that could make further implementation challenging: Implementation will require a change in the way community psychiatric nurses and nursing home carers work and collaborate. Time constraints for both professionals and culture differences can make this difficult, especially when nursing homes are intramurally oriented. In those cases nursing home carers will choose to consult their own multidisciplinary team for advice over the expert knowledge of a community psychiatric nurse.

Which factors are essential for developing and implementing personalized care interventions for people with dementia and their caregivers?

In our final model for the implementation of personalized care interventions, we have synthesized the knowledge obtained through our two literature reviews as well as the empirical studies evaluating examples of personalized care
interventions. This resulted in the construction of an evidence-based model and checklist of implementation of personalized care. The model focuses on the community setting, and is based on the generic Theoretical model of adaptive implementation (Dröes et al., 2003; Meiland et al., 2004), which we used for the process analysis in the conducted empirical studies. Components that were important for the implementation of personalized care were described, as well as potential barriers and considerations. Additional literature searches to complement the new model revealed studies investigating barriers and facilitators of the implementation of personalized care in both the community and intramural setting that confirmed our own findings.

Components that we found to be important to consider at the start and during the entire process of implementation, when developing or implementing personalized care, were:

- personal characteristics of the informal caregivers or people with dementia that may influence the intervention outcomes (such as the presence of mental health problems or gender of caregiver, severity of dementia);
- the way in which the intervention is offered and whether it is tailored to the experience as well as needs of clients;
- the presence of a clear initiator;
- whether staff that will deliver the intervention has the necessary competencies and attitude towards individualized care;
- tools for staff to help them provide personalized care;
- involvement of all organizations and professionals; they believe in the value of personalized care;
- management that supports staff to work according to a personalized care method; and
- the willingness of other care organizations to collaborate and if necessary adopt a personalized care mindset.

Factors that were important to consider during the execution and continuation phase of implementation were:

- the ability of staff to actually focus on delivering personalized care aspects of the intervention;
- whether the intervention provides continuity of staff;
- whether a personalized care plan is present for each client;
- whether there is a complete transfer of information to another professional carer that takes place when a client is transferred to their care;
- the level of transparency regarding the intervention that is provided to other (competing) care organizations and
- whether law and regulations allow clients or professional caregivers to engage in buying and managing their care based on personal budgets.
Methodological issues and limitations

Reviews
While some studies we included in our literature reviews regarding effective interventions for people with dementia and for their caregivers reported on specific post-hoc subgroup effects, based on a post-hoc comparison of subgroups within their study sample, other studies used a homogeneous specific sample of participants. The studies with post-hoc comparisons of subgroups allow us to make stronger assumptions about the relationship between personal characteristics and intervention outcomes. However, these effects should still be interpreted with caution, as post-hoc subgroup analyses are usually not sufficiently powered (Rothwell, 2005). These findings are reason to conduct another trial to re-confirm these subgroup results. Studies that used a homogeneous sample were included in the reviews but need a more careful interpretation: A positive intervention outcome in a study that only included people with Alzheimer’s disease, for instance, does not necessarily mean the intervention would not be beneficial for people with a another type of dementia. In some of the studies the sample was characterized by more than one characteristic, which in combination proved related to positive intervention outcomes. In our reviews we considered these characteristics as independently related to the positive outcomes, while in fact we do not know this for sure. This was another limitation of our reviews.

DEM-DISC
The results of the cluster randomized controlled trial are to be interpreted with the following limitations in mind. Our sample size was relatively small compared to what we had aimed for based on the power calculation beforehand. A large number of people that were eligible for inclusion did not have access to a computer or did not know how to use it. The small sample size caused the power of the tests to remain small and may have caused potential effects to remain unnoticed. Furthermore, not all informal caregivers who had access to DEM-DISC actually used the system. In addition to an intention to treat analysis we therefore conducted a modified intention to treat analysis (ITT) (Abraha & Montedori, 2010), in which we excluded the informal caregivers who never used the system. To test the impact of frequency of use of DEM-DISC on the intervention outcomes, we also divided users in the experimental group into low frequent and high frequent users and performed post-hoc analyses on these subgroups compared to the control group. The results of this modified ITT analysis as well as the post-hoc analyses should be interpreted with care. Characteristics such as motivation, may have differed between high and low frequent users and could be related to the outcomes, which may have led to a biased comparison.
Last, technically the DEM-DISC interface did not always function properly. Sometimes care services outside the specified geographical search region were displayed among the search results in DEM-DISC, or it took quite long before care services appeared after a search. These technical problems may have negatively influenced the user satisfaction with DEM-DISC and may have discouraged some informal caregivers from using DEM-DISC.

**Dementelcoach**

For the evaluation of Dementelcoach, we included a lower number of participants than planned based on the power calculation beforehand. It proved especially difficult to recruit participants for the comparison group (receiving day care only). This was partly caused by the fact that, for a good comparison with the other two intervention groups (telecoaching only and telecoaching combined with day care) only caregivers of people with dementia who had recently started attending psychogeriatric day care could participate in the comparison group. Within the study period only few people with dementia started day care in the selected regions. The small study sample may affect the generalizability of the results and caused the power of the tests to be very small. Furthermore, our study sample consisted predominantly of female caregivers. It is therefore unclear whether we can generalize the study results to male caregivers as well. Last, it was not feasible within this project to include (and locate) informal caregivers who received no care at all, and we could therefore not investigate the effect of telephone coaching compared to not receiving any care.

**Process evaluation of case management models**

A limitation of this study was that it was not always clear if our study revealed actual differences between models. Although comparable interviews were conducted with stakeholders in both models, it is possible that specific facilitators or barriers were present, but were not mentioned by the stakeholders. Moreover, the fact that case management had been implemented for several years in the participating regions may have made it difficult for stakeholders to remember facilitators and barriers from the early stages of implementation, so perhaps the information that was gathered was not complete. However, it is expected that stakeholders were likely to remember the barriers and facilitators from the early stages that had a major influence on the implementation and that they therefore did mention these during the interviews.

In this study into the implementation of case management we did not include the perspective of informal caregivers and people with dementia who received case management. This could have potentially provided us with different information about the implementation of the two models.
Process evaluation of improving transfer to nursing home
Due to busy schedules of both community psychiatric nurses and nursing home carers (who work irregular hours) appointments were not all made around the same time points and often set later than the proposed 6 weeks after admission. This resulted in a variation in the way the intervention was offered. The fact that the follow-up visit was difficult to schedule did not contribute to a positive evaluation of the follow-up visit by the nursing home carers. Sudden admissions of people with dementia to a nursing home in case of a crisis for instance, made it difficult to schedule interviews or assessments by the community psychiatric nurse (because he was not, or only at a later stage, informed about the admission) and also led to missing data. Furthermore, as this was an explorative pilot study, we did not investigate the effects of the follow-up visit on people with dementia and informal caregivers. Last, the feasibility of future implementation of this intervention was studied only in one region in the Netherlands, which means that we must be careful when generalizing the results on the facilitators and barriers we found. Implementation issues may differ across regions, both national and international.

Evidence-based model for implementation of personalized care
The core components of the model we composed are based on evidence found in the literature and in our own empirical research. However, they were not independently extracted by different evaluators or researchers. This raises a question regarding the completeness and inter-rater reliability of the content of our model. On the other hand, many of the components we incorporated in our model were confirmed by results of studies other than our own, mentioned in the literature. We found that many of the preconditions for successful implementation of personalized care interventions in the community and nursing home setting that were described in the literature, corresponded with implementation factors we found relevant in our own studies for the community setting. This enhanced the scientific basis of our model. Another limitation was that our additional literature search was not systematic, which means that potentially relevant studies may have been missed.
Relevance of the study for science, psychogeriatrics, and society and recommendations for future research and practice

Scientific relevance
The studies described in this thesis fill different scientific gaps in the existing literature. Our reviews (Chapters 2 and 3) revealed that little research has been done into the effectiveness of psychosocial interventions in subgroups of people with dementia and informal caregivers. In other words, little is known about which interventions are effective for whom. We made a first attempt to categorize studies that report on effective interventions based on the characteristics of the sample under study, the type of intervention and the outcome variables on which effects were achieved. This resulted in a unique overview of characteristics of people with dementia and caregivers that appear to be related to intervention effects, both in the community and in institutional care settings. These specific characteristics of subgroups (i.e. relationship between person with dementia and their caregiver, living situation, presence of mental health problems, gender) that were relevant for personalized care were also evaluated in our effect studies DEM-DISC and Dementelcoach. We found some overlap between the results of the reviews and the effect studies we conducted as well as a new characteristic relevant for personalized care. In Chapter 4, which describes the evaluation of DEM-DISC, a number of factors proved to be relevant as indicators whether caregivers would use DEM-DISC and may benefit from this, i.e. being older, having mental health problems and not having a paid job. Being older as a caregiver was previously found to be related to a positive intervention outcome of an automated telephone support system in female caregivers (Winter & Gitlin, 2006): Older caregivers (> 65 years) experienced less depression than the control group after the intervention. It was explained that older caregivers often experience greater distress than younger caregivers because of their own increasing physical vulnerability. This may explain why they are more likely to search for help and are more accepting towards care support. Second, having mental health problems was also previously found in multiple studies after post-hoc analysis as a relevant characteristic of subgroups that benefit from psychosocial interventions (Coon et al., 2003; Mahoney et al., 2003). Last, not having a paid job was a characteristic of the subgroup that used DEM-DISC more often and benefited from it. This is a characteristic that was not previously found during our systematic reviews. It can be considered closely related to age, as older people tend to have retired from work more often. Nevertheless, knowing that this factor can influence the effectiveness of the intervention can be considered important for personalized care.
Unfortunately, we were unable to perform any subgroup analysis in Chapter 5, in the evaluation of Dementelcoach, due to a limited sample size. Our study sample consisted primarily of female caregivers, which corresponds with the sample studied by Gitlin & Winter (2006) in their evaluation of telephone support. Female caregivers may be more open to talking about their problems in daily life than male caregivers (Gant et al., 2007) and thus could have been more susceptible to the effects of telephone coaching.

The literature from the reviews as well as the results of the DEM-DISC (where informal caregivers and people with dementia in the experimental group received case management as well as access to DEM-DISC) and Dementelcoach studies support the existing literature that promotes combined support as more beneficial to people with dementia and informal caregivers than offering only one intervention to one of them. Combined psychosocial support can be interpreted in several ways. Smits et al., (2007) interpret combined support as providing care for both the person with dementia and their caregivers, as for instance in the Dementelcoach study, where telecoaching for the informal caregivers was combined with psychogeriatric day care for the person with dementia. The concept can also be interpreted as using multiple(-component) interventions for a person with dementia or an informal caregiver (Olazáran et al., 2010). Chiu et al. (2009) for instance, combined the concepts of individual coaching (as in Dementelcoach) with information provisioning (as in DEM-DISC) by offering an internet-based caregiver support service which comprised an online caregiver information handbook, including a listing of community resources, and allowed for personalized e-mail communication with a professional caregiver for additional support and guidance. Informal caregivers experienced a decrease in burden after using the service. Multi-component interventions qualify as personalized interventions because its different components can be offered to care recipients based on their individual needs. Future studies, as well as professional caregivers, should aim to combine proven effective psychosocial interventions to create more integrated support programs from which care elements can be selected to offer to individual persons with dementia and/or their caregivers based on their needs. Such holistic care approaches are expected to have a greater impact on the quality of life of the target group in the community and also contribute to a delay in nursing home placement (Olazárán et al., 2010). Implementation of proven effective multi-component interventions in daily dementia care practice should be stimulated.

This thesis also addressed the implementation of psychosocial interventions for people with dementia and their informal caregivers. Positive intervention effects are not always a prerequisite for implementation. Sometimes interventions are implemented on a wide scale without proper scientific evidence on the effects of
these interventions. A good example of this is case management for dementia, which was studied in the research described in Chapter 6. Although this type of support has been implemented on a large scale both nationally and internationally, research is yet to show strong evidence in favor of case management (Pimouguet et al., 2012). The presence of many different case management models makes it difficult to interpret effects of case management interventions described in the literature (Koch et al., 2014). Our process evaluation of the implementation of two different case management models contributes to knowledge about which model is easier to implement, which factors can impede the implementation and which model best enables case managers to provide personalized care to their clients.

Relevance for psychogeriatrics

Our reviews provide a unique overview of characteristics of people with dementia and informal caregivers that appear to be related to positive outcomes of a range of psychosocial interventions. This overview can be used by professional caregivers, such as general practitioners, case managers, practice nurses and elderly care specialists, to better attune care to subgroups of people who are most likely to benefit from an intervention. Our thesis also evaluated four personalized care interventions that can be tailored to specific needs of individuals. The results of these studies indicate that the use of personalized care interventions can support people with dementia and informal caregivers effectively. Our studies show that the use of personalized care interventions can result in a decrease in burden, fewer mental health problems and more met needs in informal caregivers. This supports the (increased) use of personalized care interventions in dementia care practice as they can lead to more efficient care use and can decrease the time spent on searching for the right intervention, as well as costs associated with such a trial and error care approach.

In order for care professionals to be able to use and refer patients to personalized care interventions, knowledge about their benefits is essential. It is also necessary that these interventions are well implemented so they can be used accordingly. This is where our evidence-based model and checklist for the implementation of personalized care can be of value. The implementation of personalized care interventions depends on a number of core components that are outlined in Chapter 8 and should be considered by individuals who wish to implement personalized care or adopt a “personalized-care mindset”. Important core components directly related to professional caregivers who aim to perform personalized interventions are: having the necessary competencies and attitude, being supported by their management and having access to tools to assist them in providing individualized care (such as an expert team). For personalized care interventions to be most effective, it is essential that they can be executed or used...
by care professionals in the way they are intended. The components described in our model in Chapter 8 all contribute to this.

Two perspectives on the concept of personalized care can be distinguished. Personalized care can be viewed based on the characteristics of the intervention (e.g. the possibility to match it to individual needs and preferences), or by considering which subgroups a particular intervention should be offered to. The interventions described in Chapters 4 and 5 (Dementelcoach and DEM-DISC) can be characterized as personalized support because their content can be adjusted to the individual needs of clients. For instance, informal caregivers can decide which problems to discuss with their telephone coach, or which information to search for on DEM-DISC. In addition, attention should also be given to the individuality of care recipients and which type of support fits that person best (some people prefer group therapy over individual therapy for instance). Both approaches are equally important for future dementia care practice and can contribute to better and more efficient use of care and professional resources.

Hopefully the content of this thesis convinces professional caregivers and their managers of the value of personalized dementia care. It will ideally stimulate and help them to adopt a personalized care work method (if they haven’t already), and contribute to the education about personalized care as well as improve the way professionals practice individualized care in their work.

Results of the evaluation of the follow-up visit in the nursing home by the community psychiatric nurses, described in Chapter 7, revealed that nursing home carers felt that the follow-up visit enabled them to provide more personalized care to their residents. The target group we used in our explorative study was a more complex group of people with dementia (i.e. with severe behavioral problems under the supervision of the Mental Health service) who did not have case managers. A far larger group of people with dementia in the community, however, does have a case manager or district nurse and is not supported by Mental Health services. In practice, the transfer of information during follow-up visits can also be carried out by other professional caregivers, for instance case managers or district nurses who know a client prior to the admission to a nursing home. Based on our study results it is expected that the focus of these visits is probably more on a client’s biographical information than on how to deal with their behavioral problems. It would be interesting to study the effects of a better transfer to the nursing home in general on the ability of staff to deliver personalized care to people with dementia in general, and not only in a complex population with dementia.

**Societal relevance**

The studies described in this thesis provide new and important insights into the effects and importance of personalized interventions in dementia care and
advocate the use of these interventions instead of non-personalized interventions. The obtained insights provide policy makers and professional caregivers with evidence that the application of personalized care for people with dementia and informal caregivers should be stimulated and implemented in the dementia care system.

The implementation of personalized care in general, can be an efficient and effective care solution for the growing population of people with dementia and the informal caregivers that have to support them.

Health insurers are urged to consider the advantages of personalized care interventions and stimulate the implementation of these interventions. Based on the results of Chapter 7 on the follow-up visit, they are urged to stimulate long-term collaboration between nursing homes and Mental Health care as well as other care organizations that can conduct this visit by means of collaborative financial contracts. Continuing changes in financing for Mental Health Care, case management and nursing homes pose a challenge for the implementation of the personalized care interventions described in Chapters 6 and 7.

The results of the process evaluation of two case management models in the Netherlands is a step for a possible restructuring of case management towards a more uniform and better model, though we are aware that this is also dependent on the actions and convictions of health insurers who, at least in the Netherlands, do not offer structural funding for these care professionals.

Economic forces and policies make it necessary for people with dementia and their informal caregivers to increase their self-management skills with regard to dealing with the consequences of their disease. This trend is driven by the future shortage of professionals in dementia care in relation to the growing incidence of dementia (Martin et al., 2013). The personalized care interventions described in Chapters 3, 4 and 5 fit very well with the concept of self-management of dementia by informal caregivers and people with dementia. Informal caregivers and people with dementia need to be stimulated, but also equipped, by professional caregivers to make their own decisions about which care and welfare services they need (in other words manage their individualized care) and should ideally be able to find them on their own (Laakkonen et al., 2012). Studies are increasingly investigating the concept of self-management to promote this (Quinn et al., 2014; Mountain & Craig, 2012).

It will not always be easy to stimulate self-management, as informal caregivers are used to relying on professional caregivers, such as their general practitioner or case manager who perform a central role in care provisioning. This is also reflected in the DEM-DISC study where a large number of informal caregivers stated they were already being supported by their case manager and did not need to use DEM-DISC.
Wiersma et al. (2011) state that self-management programs should focus on change at three levels: at the level of clients, to improve their access to information and knowledge; at the level of the care professional, who should be steered towards providing more flexible, personalized care; and at the service level, to improve access to adequate services for clients. Self-management support can be provided in a group or individual setting and may include components of computer use and email contact (as in DEM-DISC), telephone contact (as in Dementelcoach) or face-to-face contact (such as in case management).

This thesis focused on how to provide personalized care and the elements that are considered important in doing so. We addressed the implementation of personalized care in the community setting, whereas in the past studies have usually focused on the implementation of this concept in the intramural setting. Realization of individualized care in the community is more difficult than in the intramural setting. In addition to the barriers relating to management and staff that are often present during implementation of interventions in both extramural and intramural settings, community-based care also has to deal with collaboration and competition issues between different care providers in the dementia care network that can impede the delivery of personalized care.

The challenge for future dementia care is that it should become more personalized. The content of this thesis aims to stimulate this change, specifically for community dementia care.

**Recommendations**

Our recommendations for future research and practice, based on the results of the studies on personalized care described in this thesis, are:

*Future research investigating the effects of psychosocial interventions should incorporate (post-hoc) subgroup analyses.*

The different studies in which we evaluated four personalized care interventions made it clear that although positive effects were found on a group level, not all persons benefited or experienced a positive effect from these interventions. Our reviews revealed that many existing studies on effective interventions did not perform post-hoc subgroup analyses. In Chapter 4 a number of factors proved to be of relevance as indicators whether caregivers would use DEM-DISC and might benefit from it. These characteristics were: having mental health problems, not having a paid job and being older.

Researchers should therefore not only focus on the effects of new psychosocial interventions, but are encouraged to also conduct post-hoc subgroup analyses to identify subgroups that could possibly benefit from the intervention under study. Subsequently, these post-hoc subgroup results should be confirmed by adequate
trials that are powered to detect valid subgroup effects in order to draw strong conclusions about which subgroups a certain intervention should target (Rothwell, 2005).

*Interventions aimed at supporting people with dementia and informal caregivers in the community setting should be better tailored to their individual needs and characteristics.*

The results of this thesis provide evidence that personalized dementia care is important and care should be directed towards this. In theory the personalized psychosocial interventions discussed in this thesis can all be delivered to persons with dementia and their caregivers in a time frame from prior to diagnosis to institutionalization. We encourage researchers and other health care professionals to develop and evaluate individualized psychosocial interventions for people with dementia and informal caregivers that ideally comprise multiple components, are adaptable to different needs of the target group and stimulate self-management in people with dementia and informal caregivers.

*We recommend the use of our evidence-based model and checklist to promote, stimulate and guide the implementation of personalized care interventions in the community.*

The implementation of personalized care interventions can be facilitated and impeded by many factors. This thesis concluded with a Chapter that describes essential elements of implementation of personalized care. These elements are part of an evidence-based model and checklist for implementation of personalized care which offer a unique tool that can be used to develop and implement new personalized care interventions, and to adapt current interventions in practice to make them more individualized.

**Concluding remarks**

Our research shows that not all people with dementia and all informal caregivers benefit from, or are satisfied with, the same psychosocial interventions, and that certain subgroups may benefit more from particular interventions than others. To promote the more efficient and effective use of care, it is crucial to utilize this knowledge and to consider the personal needs and preferences and individual characteristics of clients so it becomes possible to individualize the care provided to them.

This thesis focused on the implementation of personalized care interventions in care practice. It outlined and discussed elements that need to be considered by professional caregivers, care organizations and policy makers who aim to provide individualized psychosocial care to people with dementia and their informal caregivers.
References


