

8.
General discussion

PART 2/2

In Chapter 1 we met Mrs. Steinberg, an active 88-year-old World War 2 survivor with multiple (chronic) conditions, impaired mobility and light short-term memory problems. Mrs. Steinberg values scientific knowledge and believes there is merit in research, so when her family doctor invited her to participate in the ACT study she said yes. Under the home visit program that the ACT study aims to implement, Mrs. Steinberg is visited at her house by a practice nurse, Elsa. The practice nurse administers RAI-CHA, a web-based instrument to assess Mrs. Steinberg's health and care needs. During the assessment, Elsa asks Mrs. Steinberg various questions about her health and wellbeing, which evolves into a conversation about Mrs. Steinberg's life story and values. Central topics in Mrs. Steinberg's life are her son's struggle with Multiple Sclerosis, her traumatic war memories and her educational activities. At the end of their conversation, Elsa makes some initial suggestions based on the preliminary outcomes of the assessment. First, Elsa has identified that Mrs. Steinberg is at risk for falling. Since Mrs. Steinberg has already removed all her rugs and thresholds, the nurse suggests a fall prevention course and gives Mrs. Steinberg an information leaflet. Mrs. Steinberg accepts the leaflet with the remark that she is not a big fan of reading. Second, Elsa informs Mrs. Steinberg about options for urinary incontinence management. Mrs. Steinberg responds that she is not sure that she will comply to pelvic floor exercises. Third, in light of her memory issues, Elsa asks Mrs. Steinberg if she would consider using something to help her manage her medicine use, to which Mrs. Steinberg replies that she is comfortable with the way things are now. At the end of the conversation Elsa asks Mrs. Steinberg to formulate a care goal. Mrs. Greenberg does not need a lot of time to think: she wants to continue doing things the way she is doing them right now as much as possible.

Elsa schedules time with Mrs. Steinberg's family physician to discuss results of the assessment and to consult him about further actions. The physician takes time for the consultation and the atmosphere is informal. They agree to propose to Mrs. Steinberg to consider the following actions: (1) consult a occupational therapist or physiotherapist to reduce her risk of falling; (2) consult the family physician again to re-evaluate the situation

regarding her urinary incontinence; (3) start using a Baxter for her medications and stop taking Lipitor, a statin. A week later, Elsa visits Mrs. Steinberg a second time to discuss the results of the assessment and the actions that the family physician and Elsa hope Mrs. Steinberg will consider. Elsa has printed out the care plan and gives Mrs. Steinberg a copy as well. Mrs. Steinberg says she agrees with most of the outcomes described in the care plan, and understands why they were included by Elsa and the family physician. Elsa then repeats Mrs. Steinberg's goal (continuing doing things the way she is doing them right now) and invites Mrs. Steinberg to have a conversation about the issues that Elsa and the family physician decided need attention: falling, urinary incontinence, and medication.

In this thesis, we reported the outcomes of a research project that explored the theoretical base of the Geriatric Care Model (GCM), and gained insight in the way in which the GCM was designed and implemented. The GCM was designed to ultimately restructure the way primary elderly care in the Netherlands is organized and delivered. GCM program developers envisioned to improve older people's quality of life through early identification of health and care needs, increased involvement of older people in their own care process, and higher degrees of coordination between care professionals. Core concepts of the GCM were strong central management and coordination of care, a proactive approach and client empowerment. Key GCM components – a comprehensive geriatric assessment (CGA), a tailored care plan, regular care team meetings, multidisciplinary team consultations and regional network meetings – were simultaneously implemented on a client, professional and organisational level with the aim to improve quality of care. By investigating aspects of 'productive interactions', the GCM's implementation process and its context in a real life setting, we aimed to gain a better understanding of the GCM's potential to transition care for frail, older people.

In this final Chapter, we summarize the main study findings. We critically reflect on these findings by discussing issues regarding the intervention's design and content in light of existing literature and address methodological strengths and limitations. We then discuss how these findings relate to outcomes of the effectiveness and cost-effectiveness evaluations of the GCM. Subsequently, we contextualize our findings by placing them against a backdrop of current health care policies and their implications for primary elderly care in the Netherlands. We finalize this thesis by making several recommendations for future research, education and practice.

SUMMARY OF MAIN FINDINGS

- In a 2-year stepped-wedge cluster randomised clinical trial (the ACT study), carried out among 1147 frail, older patients listed in 35 primary care practices in two regions in the Netherlands, the Geriatric Care Model was compared with usual care. The ACT study was one of the first to assess the effectiveness, cost-effectiveness and implementation process of a chronic care model for frail community-dwelling older people in a primary care setting.

- In order to gain insight in the level of implementation of the GCM, we assessed its fidelity using Carroll's framework. A longitudinal investigation of adherence per key component increased our insight in the way in which the level of implementation of the GCM changed over time. We found that for most of the key intervention components, adherence was high throughout the intervention period. Only adherence to multidisciplinary consultations was poor, but increased over time.
- Our study that investigated the prevalence pain as reported in care plans of older people showed that 40% of frail, older people who received a first-time comprehensive geriatric assessment (CGA) experienced any type of pain. While most older people had reported their complaints to their family physician, 60% wanted a pain management plan or change an existing plan. Our findings suggest that usual care may be sufficiently able to identify and diagnose any type of pain in older people who live at home. However, a proactive approach and a CGA can help practice nurses plan interventions to meet this groups' dynamic and continuous pain management needs, and improve frail, older people's access to tailored pain care
- Using cross-sectional baseline data from the ACT study, we described self-reported met and unmet care needs of frail, older people who received a multidimensional needs assessment. Out of 13 needs topics, older people reported an average of 4.2 care needs, of which 0.5 were unmet. Most older people reported to receive sufficient help for their needs in the physical and environmental domain. Unmet needs were mainly psychological in nature, and having unmet needs was associated with younger age and higher educational level.
- To gain insight into the processes that may contribute to a successful proactive home visit program for older people, we investigated the interaction between a practice nurse and an older person during a home visit. Our findings suggest that in a proactive setting, an older person's grant of authority is necessary to successfully implement home visit services. Such a grant of authority has its foundation in a trusting relationship, built when a caregiver meets a care receiver's relational needs, which are needs related to the processes that facilitate the mutual search for solutions and the negotiation of care. Training caregivers to better explore and meet older people's relational needs may increase the success of proactive home visit programs.
- We demonstrated that the client-centered Care Questionnaire (CCCQ), an instrument that measures the client centeredness of home care services from a client's perspective, is sufficiently unidimensional to permit

the use of total test scores when administrated among frail, older people in the Netherlands. We found acceptable reliability values, but considered our results on construct validity inconclusive. Respondents found the CCCQ questions challenging to answer, which is indicative of a high degree of respondent burden. Therefore, we concluded that the CCCQ's acceptability and reliability of the was suboptimal in a population of frail, older people.

METHODOLOGICAL CONSIDERATIONS

Choosing a framework for a process evaluation

The rise in popularity of process evaluations have led researchers of various fields of study to propose frameworks for process evaluations alongside RCTs. When preparing ourselves to assess the implementation process of the GCM, we turned to the literature to see if we could find a framework suited for a Chronic Care Model (CCM)-based intervention. However, while we encountered a range of frameworks and evaluation models (for instance, frameworks for health promotion interventions and frameworks for complex interventions in health care [1-6], we did not come upon any frameworks that were specifically aimed at guiding process evaluation designs for CCM-based interventions. Instead, we found that CCM evaluation studies that feature a process evaluation often use methods that are tailored to the particularities of the program under investigation. In addition, we found large variations in the types of process measures and concepts that were used [7-9]. Initially, we therefore choose to use an approach proposed by Saunders et al. [6], originally designed to assess health promotion program implementation (see Chapter 2). Reason for choosing this framework was that it comprises a systematic and comprehensive approach for guiding the development of an integrated evaluation plan, which allowed us to tune our research methods to the elements of the GCM. In line with Saunders' approach, we aimed to investigate 'fidelity', 'dose delivered' and 'dose received', which are part of the broader construct 'level of implementation' or 'fidelity' (fidelity of the GCM is addressed in Chapter 3). During the intervention period, however, we decided to reconsider the use of Saunders' framework. Our decision was based on two considerations. First, since the publication of Saunders' 2005 article, insight in the use of implementation fidelity as an outcome in evaluation research

has progressed, and more advanced definitions and operationalizations of the construct have been proposed. Second, we became aware that the particularities of the ACT study (a multi-component intervention program implemented by means of a stepped wedge RCT) demanded an approach that would allow us to investigate fidelity per intervention component and (partly) over time. In our opinion, Saunders' operationalization of implementation fidelity did not suffice for this purpose, while the more intricate definition of fidelity proposed by Carroll et al. [3] did. Therefore, in Chapter 3 we used Carroll's instead of Saunders' framework. The research questions that correspond to Saunders' constructs 'dose delivered' and 'dose received' correspond in Carroll's framework to the concepts 'frequency' and 'duration'. It was therefore not necessary to redefine our objectives and data collection methods for these constructs, and it is unlikely that shifting frameworks has led to different outcomes for these constructs. To investigate the concepts 'coverage' and 'content', we formulated new research questions.

Mixed methods

The process evaluation of the ACT study was characterized by the use of mixed methods. Using different methods can provide a more complete insight into the issues or processes that are being investigated [10;11]. Various researchers have been advocating the use of multiple methodological approaches, proposing that it is the most adequate way to manage the complexity of researching the implementation of innovative practices and intervention programs [10;12]. Generally, in mixed methods designs, qualitative research methods are used to gain in-depth understanding of the intervention's underlying processes with the aim to expose barriers and facilitators to successful implementation and their causes, while quantitative research methods are used to obtain more information about potential indicators of program impact [13]. The choice for a mixed methods design allowed us to investigate quantifiable research objectives, such as exploring the prevalence of strategies for pain management in care plans (Chapter 4) or investigating intervention fidelity (Chapter 3), as well as non-quantifiable research objectives, such as exploring the nature of the interaction between older people participating in the ACT study and the practice nurse (Chapter 6). Without the use of mixed methods, our understanding of the intervention and its process would have been less comprehensive, and large parts of the black box would have remained unopened.

Longitudinal assessment of fidelity

In Chapter 3, we report the results of a longitudinal evaluation of adherence to evaluate fidelity of the GCM. This design was partly based on our use of a stepped wedge design: the phased introduction of the intervention resulted in variations in starting time between the clusters of participating primary care practices, which in turn resulted in different lengths of intervention periods, and subsequently in different levels of exposure to the intervention. The degree of exposure to an intervention may impact the relationship between program content, context and fidelity. Since a longitudinal approach allows for a comparison between clusters with different starting times, it can contribute to an insight in the influence of length of exposure on fidelity outcomes. As we briefly addressed in Chapter 3, insight into the way in which fidelity changed over time also gave us a more dynamic understanding of the implementation process. Trends in program component coverage may predict the future potential of low-fidelity components and about the sustainability of high-fidelity components. In addition, observed trends may be indicators for context-specific barriers and facilitators to implementation. For instance, the increase of Multidisciplinary Team Consultations (MTCs) adherence over time can be explained by the fact that throughout the intervention period, primary care physicians had gone through a learning process regarding MTCs, which evolved their ideas about usefulness of MTCs and reduced their resistance. The outcomes of a longitudinal assessment of fidelity, therefore, could provide valuable insights for future implementation. Unfortunately, it was not feasible to assess all aspects of implementation fidelity over time. In addition, we investigated two factors that potentially influence adherence to an intervention (i.e. participant responsiveness and facilitation strategies), while the framework that we used includes six [14]. For instance, we did not investigate the quality of intervention delivery. This lack of insight in the way in which the content of the intervention was delivered can be considered a limitation, as variations in quality of intervention delivery on a practice nurse level have the potential to influence the level of implementation and, as a result, impact overall intervention effects.

Evaluating flexible interventions

The intervention with the GCM was flexible, meaning that it allowed for adaptation to local circumstances [3]. The implementation strategy of the GCM comprised of self-regulation of the expert teams managing the prac-

tice nurses, which means that the teams were authorized to change protocols and practices as they saw fit, and could adjust their management and educational activities based on feedback from the field. Adapting interventions to local conditions has several advantages. First, it has the potential to improve program effectiveness by means of increased program feasibility and increased user adoption [3]. Second, based on our own findings, we argue that allowing care professionals to adapt the intervention could improve the level of participant responsiveness (i.e., the level of satisfaction and involvement of professionals who carry out the intervention). Inflexible interventions that do not allow space for modifications could be perceived by (local) professionals as ignoring or underestimating their experience, knowledge and skills. Participant responsiveness plays an important role in implementation: a higher participant responsiveness may lead to a higher degree of fidelity [3;14].

Flexible interventions such as the GCM pose a potential challenge for evaluators, as current methods to evaluate intervention implementation are based on a fixed idea of the imagined nature and delivery of intervention components. In addition, often a linear relationship is assumed between the level of implementation of these components and their impact on intervention outcomes. Adaptations to improve the fit of the program within a local environment therefore require a redefinition of the imagined intervention, in order to draw adequate conclusions about the (possible) relation between implementation outcomes and intervention effects. If such a redefinition does not happen, the incorrect conclusion might be drawn that the intervention is not fully implemented as intended (an issue we addressed in Chapter 3). I would like to refer to this incorrect conclusion as a “type 4” error: the flawed assumption that an intervention is not adequately implemented due to a flexible intervention in combination with a fixed definition of the intervention as imagined. A “type 4” error could cloud the interpretation of intervention outcomes. For example, the absence of positive effects could be wrongfully attributed to a low level of implementation of certain intervention components, while in reality the intervention was adapted to local circumstances. Current methods to investigate the level of implementation of an intervention do not correspond to the complexity and fluidity of everyday practice. It can be argued that the risk of a “type 4 error” is higher for programs carried out in a real life setting, since the dynamics of everyday practice and between-site differences may call for an intervention that is highly adaptable to local circumstances. To further improve our knowledge of the relationship between level of implementation and inter-

vention success, it is necessary to explore the use of evaluation methods or frameworks that take into account the possible benefits of adapting or changing interventions so that they fit within local contexts.

When we evaluated the implementation process of the GCM, we took into account possible changes in protocol and practice routines by exploring actual program content through qualitative techniques. As described in Chapter 3, we indeed found that changes were made. Some of these changes may, in fact, have resulted in an intervention that was more tailored to practice: we found that some nurses did not always write a care plan and did not schedule a follow-up evaluation visit when an assessment had yielded no health or care needs. According to our measurements, the absence of these care plans and visits decreased adherence; however, taking into account the possibility of a “type 4 error”, it may not automatically imply a potential loss of intervention effect.

Evaluating at a client level

The aging of the population and the corresponding increased interest in geriatric and gerontological issues consequentially has brought about a rise in the number of studies that investigate frail, older people’s health and wellbeing. In order to tailor interventions to the needs of older people, including their own perspective is important when evaluating a program. However, including this perspective is not free of challenges, and when carrying out the process evaluation of the ACT study we were confronted with several of these challenges, specifically related to data reliability, which occurred during both quantitative and qualitative data collection at a client level.

Challenges related to quantitative data collection mostly involved issues related to interpretation of interview questions. The Camberwell Assessment of Needs for the Elderly (CANE), for instance, should be administered through a conversation about care between a trained health care professional and an older person [15]. The health care professional uses information from the conversation to fill out the CANE instrument. This is done because older people often have difficulties understanding the concept of care needs and the questions that aim to assess them – especially when there is loss of cognitive functioning – which may influence data reliability [15]. However, in the ACT study, the CANE was administered by project interviewers (see Chapter 5). When carrying out data quality control activities, we found that some interviewers did not always administer the questionnaire as intended

(this information was later used to optimize training content). As a result, older people had trouble interpreting or fully grasping the intention of the CANE questions. In addition, the CCCQ questions (that inquire about the client-centeredness of received home care) were perceived by older people as difficult to understand and relate to (see Chapter 7). The initial developers of the questionnaire, who tested the instrument in a younger population, did not report encountering such interpretation and feasibility issues. Our experience suggest that frail, older people may have more difficulties answering abstract or complicated questions, and that these difficulties may be related to cognitive functioning and their complex health and care needs.

The qualitative evaluation was also impacted by the specific circumstances and characteristics of frail, older people. Initially, we aimed to assess older people's experience with the home visits and the practice nurse through semi-structured qualitative interviews, which were planned to take place after the first home visit. This objective changed when, after four interviews, we found that none of the participants was able to reflect on the practice nurse's visit. Their memories were nonspecific – even when we mentioned the practice nurse's name or reminded older people of the advice that she had given – and convoluted by home visits of other care providers. Based on these experiences, we concluded that interviewing older people after the home visit would not result in reliable qualitative data about their experience with the intervention. We therefore decided to shift the methodological focus: instead of taking a general qualitative approach to gain insight in the client's perspective, we took a case study approach: collecting as much in-depth information as possible about the particularities of the interaction between one older person and one practice nurse, taking into account the older person's context, life history and value system, and the perspectives of both client and practice nurse. We decided to follow the care receiver and caregiver throughout the GCM care process (two home visits), and subsequently interview the care receiver. This allowed us to gain a detailed insight in the processes that guided interactions between practice nurses and older people during the implementation of the GCM.

As result of the obstacles we encountered assessing older people's experiences with the GCM is that more general information about older people's experiences with the home visits is lacking. In hindsight, one way to overcome barriers to collecting reliable responsiveness data on a patient level might have been to evaluate immediately after the home visits. For instance, the qualitative interviews could have taken place on the same day of the home visit, or practice nurses could have left an addition short evaluation form for

older people to fill out after each or a designated encounter (although this would have led to less in-depth data). Both evaluation methods could have been developed and carried out with an older person as co-researcher, such as reported by Bindels et al. [16]. Insight into the client's perspective could have enhanced the feasibility of methods; for instance, increasing our understanding of what older people find important or pay attention to during interactions with caregivers would have allowed us to ask questions that corresponded with the experiences of older people. In addition, working with an older person as a co-researcher could have given us insight in how and when to best reach our target population.

Evaluating at a care provider level

We evaluated at the care provider level to both understand the process that underlies the interaction between a client and a practice nurse during a GCM home visit, and to gain insight in the implementation process of the GCM. Qualitative data was collected through semi-structured interviews with practice nurses, geriatric expert team members (i.e. geriatric nurses) and primary care physicians (see Chapter 3, 6). Quantitative data at a care provider level was collected through care plans (Chapter 3, 4), time sheets, geriatric expert team logbooks, MTC reports and minutes of care team meetings (Chapter 4).

We carried out semi-structured interviews with 16 of a total of 19 practice nurses who implemented the GCM. Three nurses were not interviewed for various reasons – one nurse had quit working for the program, one nurse had only just started working for the program, and one nurse could not be reached for an interview appointment. The interviews used in Chapter 4 were carried out subsequently and at various moments throughout the intervention period, which allowed us to include those practice nurses who, due to the stepped wedge intervention design, joined the program at a later stage of its implementation. However, a limitation of this approach is that several practice nurses who had carried out the GCM activities since the start of the intervention were interviewed at an early intervention stage, which means that we were not able to report whether and how the experiences of individual nurses changed over time. A recommendation for future research would be to perform in-depth interviews with practice nurses at multiple stages throughout the intervention period in order to gain a more complete insight in individual nurse's experiences over time. Primary care physicians and geriatric

nurses were interviewed either through face to face interviews (one physician, three geriatric nurses) or by telephone (nine physicians). All telephone interviews lasted between 10 and 15 minutes; it has been suggested that telephone interviews can be used productively in qualitative research, and are deemed most suitable for qualitative data collection if they are short [17].

To investigate fidelity of the intervention, we used data collected or generated by care professionals, i.e. care plans, time sheets, geriatric expert team logbooks, MTC reports and minutes of care team meetings. As mentioned in Chapter 3 and 4, we identified several barriers to collecting data through care professionals. First, data were not always complete. Practice nurses explained that they experienced a heavy case load and were limited in the time they could spend carrying out tasks related to data collection, such as filling out time sheets or keeping logs. In addition, data were not collected in a standardized way. Care plans, log books, reports and minutes were designed to be used in practice, and use varied per practice nurse. As a result of incomplete or unstandardized data, we could, for instance, not report the duration of key intervention components and moderating factors over time. Future investigations of fidelity that use data collected or generated by care professionals in practice should explore the feasibility of collecting such data prior to the start of the intervention, which should include an exploration of care professional capacity and the acceptability of data collection tools. Ideally, such should be co-developed with engaged care professionals prior to the data collection period to optimize data collection.

STUDY STRENGTHS

The studies presented in this Thesis have several strengths. First, strengths are related to the study methods used to gain insight in the implementation process of the GCM. We used mixed methods and a theoretical framework to investigate fidelity, and performed a longitudinal assessment of adherence to three key intervention components (i.e. RAI, care plan, and MTC) which allowed us insight in the way in which adherence developed over time. We further opened the 'black box' of the intervention by analysing pain care-related plans in care plans written by practice nurses, which improves our understanding of the burden of pain in a community of frail, older people, as well as of older people's pain care needs at the time of the first CGA. Second, strengths are related to our investigation of the theoretical foundations of the

GCM by means of a case study approach. This approach allowed us to gain in-depth insight in the particularities of the interaction between an older person and a practice nurse in the home setting.

Finally, strengths are related to the quality of the qualitative data collection. To safeguard quality of the data collected by means of semi-structured interviews with older people and care professionals and observations, we carried out several quality procedures. These procedures took place during the sampling period, data collection period and data analysis period. During the sampling period, we used maximum variation sampling to gain insight in different perspectives. The sample of primary care physicians consisted of physicians who varied in gender, age, region, and type of practice. The case we reported in Chapter 6 was chosen from a sample of three cases; the three older people included in that initial sample varied in terms of age, gender, ability, family situation and marital status, and level of (relational) autonomy as perceived by their practice nurse. We did not use maximum generation sampling when we recruited practice nurses, as we aimed to include all practice nurses who implemented the GCM.

During the data collection period, we carried out the following quality procedures. First, we used triangulation of methods (i.e., participant observations, interviews) when collecting our data [18]. Second, every interview (both the in-depth and the short interviews) was summarized and sent to the respondent for a member check (if the respondent agreed), which allowed respondents to correct or add interview content. Third, the researcher who carried out the interview kept a log book and wrote personal, methodological and theoretical reflections throughout the field period (the period during which qualitative interview data were collected). Both member checking and reflections increase the quality and rigor of the qualitative data [19]. In addition, when collecting data for the case study (Chapter 6) we used prolonged engagement and persistent observation to maximise exposure to the case and its setting, which facilitated the development of rapport and our understanding of the case, its context and the construction of meaning (www.qualres.org). Moreover, we took a cyclic approach: after interviews were carried out we first performed a preliminary analysis, which allowed us to add new topics that emerged from the analysis to our topic list, and use those topics in subsequent interviews [19]. Finally, to ensure quality of the analyses, all interview analyses were carried out by two researchers independently to achieve inter-subjective agreement and improve reliability of our findings [20].

REFLECTIONS ON STUDY OUTCOMES

Below, I will discuss study outcomes in relation to this study's two objectives, which were to gain insight in the implementation process of the GCM, and in aspects of 'productive interactions' and in older people's care needs at stake during these interactions.

Caregiver-care receiver interactions: meeting needs for trust

At the start of this Chapter, we can read what took place when Mrs. Steinberg was visited at home by a practice nurse, Elsa, who administered a CGA. Based on the results of the CGA, Elsa and the primary care physician identified that Mrs. Steinberg had several care needs. However, when Elsa addressed these needs, Mrs. Steinberg response was reluctant. Such reluctance may not be uncommon among older people who take part in a home visit program. While in Chapter 6 we report how Mrs. Peters opened up to practice nurse Ann's recommendations and advice after only two home visits, often a 'grant of authority' is not given easily by older people. Practice nurses who carried out the GCM reported that it often took more than one visit before older people accepted interventions or started taking action. A similar finding was reported by Bindels and colleagues, who found that practice nurses needed several home visits and prolonged contacts before older people shared their stories [21]. It is indeed a well-documented phenomenon that older people do not always accept care that is offered to them right away, even if this care could improve their situation [22]. Our findings in Chapter 3 support this: almost 20% of older people with pain complaints chose to not to formulate a care management plan at the first CGA. In their article about the implementation process of a home visit program, Stijnen et al. reported that over 10% of all older people 'rarely' or 'never' complied with advice given by a practice nurse during a first home visit [23]. In order to understand what makes older people comply to advice during interactions, understanding what causes an older person to reject or accept care is essential.

The phenomenon of older people keeping care at arm's length may be related to several factors. First, one explanation is that the advice given is not tailored to an older person's needs, either because the care professional does not have enough insight into their needs, or because the quality of the advice is insufficient. Second, a rejection of care may be due to a lack of a trusting relationship with the health professional who visits an older person at home [24;25], which can lead to older people not accepting the care that is offered

despite an existing need, or can even lead to so-called ‘countermoves’ [22]. The importance of a trusting relationship between a client and a care professional has been described by several Dutch researchers who studied in-home interventions for older people. For instance, in their article about nurse experiences with delivering a complex care intervention to older people, Bleijenberg et al. report that nurses found trust and a confidential relationship pivotal for carrying out actions (especially actions related to mood problems), and that this trust-building was a time consuming process [26]. The same finding was reported by Bindels et al, who also found that a trusting relationship was essential, especially when an older person avoided care [21]. The outcomes presented in Chapter 6 of this thesis support the idea that trust plays a central role in the client-caregiver interaction in the home setting. In the Chapter we argue that, in order for an older person to trust a care professional and adopt an intervention, a care professional (among other things) needs to be skilled at establishing a relationship that corresponds to the relational needs of her client, i.e. needs related to collaborating and negotiating care with a care professional. A third explanation for older people rejecting care is that older people may not always experience a need for care, even when care is indicated and appropriate advice is given. In such cases, older people may not always recognize themselves in the advice of a care professional. This does not necessarily imply that compliance to the advice will never occur. It can be assumed that whether a situation is interpreted by an individual as requiring care is subjective, relying, for instance, on the experienced gravity or urgency of that situation. Interaction with a competent care professional who can meet the relational needs of an older person and build trust may initiate an awareness process that could result in a recognition of the situation’s impact and possible consequences and an acknowledgement of existing needs, and may eventually motivate an older person to comply with professional advice.

Based on the above, it could be argued that a share of older people who did not report having care needs at the first GCM home visit or at the baseline measurements of the ACT study may have eventually reported care needs during home visits or measurements further along in the ACT study. In addition, older people who initially rejected practice nurses’ suggestions for interventions or actions may have eventually accepted these suggestions. To further explore the processes that play a role in older people’s compliance with care professionals’ advice, more research is needed.

Measuring client-centeredness

In Chapter 7, we present the outcomes of a study that investigated the measurement properties of a questionnaire to evaluate the client-centeredness of home care services from the client's perspective (CCCQ). The questionnaire is divided in two sections, A and B, that respectively aim to measure the constructs 'conduct by caregiver' and 'autonomy'. By retesting the questionnaire among participants of the ACT-study, we hoped to gain more insight in whether such a measurement instrument could be adequately used in an older, more frail population.

We found that the questionnaire was sufficiently reliable, but we could not draw any firm conclusion about the instrument's validity, which limits its use in practice. Our results also suggest that respondents who answered the CCCQ experienced respondent burden, which may have resulted in a high number of 'don't know/no opinion' responses. Item 5 ("I can tell that the carers respect my decision even though I disagree with them"), a question that is part of CCCQ's subsection 'conduct by caregiver', yielded the highest number of 'don't know/no opinion' responses. The reason for item 5's poor performance is unclear. As results of Chapter 7 suggest, the item may have been too abstract (i.e. older people did not recognize themselves in the question for several reasons). Another explanation could be that the norm that underlies the question – entitlement to autonomy and self-determination in interactions with carers – did not always correspond to the norms and expectation of the respondents: a 'totally agree' response to item 5 requires that a respondent values assertiveness and has a sense of entitlement to equality (indicated by the use of the words 'respect' and 'disagree'), while the other items in subsection 'conduct by caregiver' do not emphasize this norm as strongly. Finally, most of the older people who answered the CCCQ were women (75%). This poses the question to what extent gendered aspects of care receiving play a role in the way in which questions about autonomy, self-determination and empowerment are answered. A nonresponse analysis could have contributed to our knowledge of possible gender differences.

If a questionnaire does not sufficiently correspond to daily experiences of its target population, it will fail to capture what it aims to measure. Self-reported investigations of client-centered care require the respondent to critically reflect on the level of empowerment or autonomy experienced during the care process. Ideas about the nature of client-centered care interactions that underlie a questionnaire are based on values and norms of the researchers who developed the questionnaire, on the specific study population in

which the questionnaire was developed, or on sociocultural or healthcare trends. If, therefore, the questionnaire is used in a population that gives a different meaning to interactional client-centeredness (as may be the case with frail older people), the validity of a questionnaire measuring client-centeredness could be affected. Although we did not find conclusive evidence about the validity of the use of CCCQ in our population, we argue that it is not only necessary to tailor instruments that measure self-perceived client-centeredness to the specific circumstances of frail, older people, but that it may also be necessary to reconsider the meaning of the concept 'client-centeredness'.

Several considerations should be kept in mind when developing a questionnaire that measures client-centeredness of care for frail, older people who live at home. Ideally, a questionnaire should be co-developed with frail, older people themselves in order to increase its validity. In addition, as we already conclude in Chapter 7, client-centeredness of (home) care services may rely on more than the client-perceived quality of the care interaction: other factors such as accessibility, flexibility, and quality of information provided by customer services may also influence the way in which care is received and perceived. Finally, although literature is inconclusive as to whether older people are more prone than other age groups to give socially desirable answers (socially desirable responding (SDR)¹) [28;29], it has been shown that SDR is more likely to occur when socially sensitive questions are asked, as in care-related research [27;30]. As SDR leads to overreporting satisfaction, it should be a key point of concern in the development process of any instrument that aims to evaluate client-centeredness of care services.

REFLECTIONS ON GCM IMPLEMENTATION

Coordinating comprehensive care

Comprehensive elderly care requires an optimal coordination between care professionals. Three GCM components were envisioned to enhance coordination of care: care plans (through providing clients and care professionals involved with the client with a written summary of a client's current health and care needs), MTCs (through regular multi-disciplinary meetings in case

1 The tendency of respondents to answer questions in a way that will be viewed favourably by others, a process that can lead to so-called 'social desirability bias' [27].

of complex care situations), and community care networks (through networking activities carried out by geriatric expert team members). We found that adherence to care plan delivery, MTC delivery and community networks was influenced by factors at a client and care professional level. Often, older people refused to accept to keep care plans at home, and practice nurses did not always write and deliver care plans as intended. Adherence to MTC delivery was low at the outset of the intervention, but improved over time; our findings show that several primary care physicians were initially reluctant to participate in the MTCs, considering them redundant, too time consuming or inefficient. In one of the GCM implementation regions, expert team members experienced obstacles to building active community networks, which was due to a hesitance to enter the networking process and the challenge of identifying and locating network partners in a saturated and fragmented field.

Factors that influence care coordination exist at a micro (individual patient and provider attributes), meso (the organizational context) and macro (the external environment) level [31]. Some of these factors, such as use of health information technology (HIT), appropriate communication between all providers and the degree of community support, and are associated with better care coordination [31]. The success of HIT in improving coordination suggests that the use of a paper care plan may be insufficient to improve care coordination in a time when digital support and management systems are leading the way toward innovation. In order to improve the implementation of and adherence to care plans in primary elderly care, opportunities to develop electronic care plans that meet the needs of both care professionals and client should be explored. The need for ongoing multidisciplinary meetings has also been identified as a predictor of better coordination of care [31], while at the same time our findings show that, although slowly, the adherence to implementation of MTCs improved over time. If barriers to implementation of MTCs can be overcome, widespread implementation may be successful in achieving optimal care coordination in primary elderly care. Finally, care coordination has been shown to improve through community support [31], which urges a targeting of current barriers to successful implementation of collaborations in the community, such as a fragmented and saturated field. To achieve this, future research and policy should focus on developing interventions at a provider and organisational level that can overcome these challenges. Such efforts should avoid a top-down implementation of fixed measures and strategies, but aim to tailor measures to locally defined goals and opportunities [32].

Participant responsiveness of practice nurses and physicians

According to Carroll's framework of implementation fidelity, the responsiveness of intervention users (such as their satisfaction and involvement) can be a moderator in the relationship between intervention and implementation fidelity [3]. Insight in the opinions of care professionals who implemented the GCM is therefore essential to increase understanding of how satisfaction and involvement facilitated or hindered implementation. In addition, such insights can help to improve future efforts to implement the GCM. We therefore asked both practice nurses and primary care physicians to rate their satisfaction and involvement with carrying out the GCM on a scale of 1 to 10.

Practice nurses carried out the large majority of the GCM activities. In Chapter 3, we report that practice nurses rated their involvement with the GCM with a 7.1 (range 2-10) and their satisfaction with their work with a 6.5 (range 3-8). Although we did not find an association with individual adherence rates, these numbers do give us some insight in individual experience. Some practice nurses felt very involved and were very satisfied with their work, while others felt the opposite. Data from semi-structured interviews with practice nurses suggest that differences in experience may due to several factors, such as the (un)availability of resources, workload, the extent to which intervention components and the pre-intervention training program corresponded with their needs, the relationship with the primary care physician, the nature of the GCM-related activities (which in turn was related to the needs of the target population), logistic, organizational and contractual factors, and the extent to which personal expectations of the practice nurse were met during the intervention.

Primary care physicians played a key role in the delivery of the GCM through their participation in MTCs and regular consultations with the practice nurse. As Mrs. Steinberg's case illustrates, these consultations allowed the practice nurse and physician to discuss GCA outcomes, decide preliminary care plan content and coordinate care around a patient. Overall, primary care physicians rated their involvement with the GCM with a 6.7 (range 2-9) and their satisfaction with a 6.3 (range 3-9), which demonstrates that there were large differences in experience between physicians. Findings based on semi-structured interviews with physicians suggest that several factors contributed to these differences: ideas about the feasibility or necessity of the intervention or components of the intervention, the relationship with and evaluation of the practice nurse, their ideas about elderly care (re)organization and the future role of the physician, and professional characteristics (for instance the

type of practice and the size of the elderly population in the practice). Physician experiences may have influenced the way in which physicians interacted with the GCM, adopted its methodology and implemented its components, as illustrated by differences in physicians' opinions about and adherence to carrying out MTCs. Final results of the investigation of factors that may have influenced satisfaction of practice nurses and primary care physicians (i.e. barriers and facilitators) are forthcoming.

Our investigation of participant responsiveness has limitations. Since participant responsiveness was measured quantitatively (by means of ratings) and at the end of the intervention period, we were able to collect little information about what exactly explained each individual rating. In addition, measuring participant responsiveness solely at the end of the intervention period limited our insight in whether and how the time spent carrying out the intervention influenced experiences of satisfaction and involvement. Also, we did not investigate the influence of practice nurse and physician characteristics (for instance gender, age, professional background, type of practice, size of elderly population or attitudes toward elderly care) on satisfaction and involvement rates. Finally, we did not explore the extent to which participant responsiveness influenced the quality of the intervention delivery. We therefore recommend that future researchers who aim to investigate participant experiences measure participant responsiveness at multiple times during the intervention period, collect quantitative and qualitative data simultaneously so that ratings can be explained, and explore the relationship between participant responsiveness and quality of intervention delivery. Moreover, future research into GCM implementation should include a thorough investigation of physician and practice nurse characteristics, including preferences and opinions regarding elderly care structure and delivery, and the relation of these factors to experiences of satisfaction and involvement. And, last but not least, as mentioned earlier in this Chapter, future research should include an assessment of client responsiveness.

Deviations from protocol

In Chapter 3, we report the outcomes of an assessment of fidelity of the intervention components. Results of an exploration of the intervention's content revealed that the intervention was not always carried out as intended. Practice nurses regularly deviated from GCM protocol when carrying out CGAs and writing care plans. These deviations suggest that the CGA was not

always tailored to practice nurse's needs. In order to understand why these deviations took place, i.e. what factors influenced or moderated adherence to CGA and care plan delivery, we interviewed practice nurses about their experiences (described earlier in this Chapter). We found, for instance, that nurses rather engaged in a 'natural' conversation with older people about their needs than adhere to a predetermined order of CGA questions. Also, nurses felt that the pre-intervention CGA training had insufficiently prepared them for working with the instrument (see Chapter 3). Unpublished qualitative data shows that some nurses considered the instrument used lengthy (and therefore burdensome for older people) and not always reliable in terms of outcome accuracy. In addition, practice nurses indicated that they did not always draft the care plans as intended. While analyzing the written care plans for the study described in Chapter 4, this was confirmed: we found that care plans were not always written according to protocol – they were, for instance, incomplete. Similar findings are reported by Stijnen et al. and by Metzeltin et al. [23;33]. Future investigations should focus on what type of care plan design and methodology is best suited to be used in primary elderly care, and what competencies practice nurses need in order to adequately incorporate the use of care plans in their daily activities. Such an investigation should foremost include an exploration of practice nurses' own experiences, opinions and needs.

REFLECTIONS ON EFFECTIVENESS OUTCOMES

As explained in Chapter 1, one of the objectives of the investigation of an intervention's implementation process is to (attempt to) explain outcomes of effectiveness evaluations. Results of investigations into impact of the GCM showed no effect on the ACT study's primary outcome, quality of life measured by the SF-12. In addition, no effects were found for most secondary outcomes: health-related quality of life, ADL limitations, psychological well-being, self-rated health, social functioning and hospital admissions. A significant but small effect was found on IADL (Independent Activities of Daily Living) limitations at 18 months after the start of the intervention. Based on these outcomes, Hoogendijk concluded that the GCM is not effective compare to usual care [34]. After evaluating the GCM's cost-effectiveness, van Leeuwen concludes that the GCM is not cost-effective compare to usual care [35]. Negative outcomes of intervention studies may be the result of either

program failure or implementation failure. In addition, negative outcomes may be explained by methodological choices, such as type of study design or sample. Both Van Leeuwen and Hoogendijk mention several possible explanations for their findings at a program, implementation and methodology level. Based on the outcomes of the studies described in this Thesis, I propose several more factors at a methodological, program and implementation level that could have played a role in the outcomes of the effectiveness and cost-effectiveness evaluations of the GCM.

Methodological factors

Several study-related factors could explain the intervention outcomes. First, the outcome measures used in the ACT study may not have been able to capture the effects of the various types of care interventions. Such effects may have been small, and may have only been achieved for certain unidentified subgroups or may have happened in domains that were not covered by measurements. Second, as mentioned earlier, a trusting relationship between an older person and a practice nurse may be pivotal in order for older people to share their care needs and comply to practice nurses' advice [21;26]. Such a trusting relationship often takes time to build, as it requires that a practice nurse has sufficient insight in an older person's background and value system to meet her or his relational needs. It may take practice nurses several months, sometimes even years, to literally get a foot in the door, let alone receive an older person's grant of authority. Therefore, we argue that a 24-month (or a 18-month, 12-month, or 6-month) period may not always allow an older person enough time to adopt the intervention. In other words, the actions that should lead to any effect may not have been carried out yet at 24 months. Another explanation for a lack of effect may be related to bias in the selection of the study population. It can be argued that older people who are prone to avoid care are less likely to participate in a research project that centers on delivering care, whereas older people who appreciate receiving care are more inclined to join. The latter group may already have a higher number of met care needs (or less care needs in general), and may therefore benefit less from the care program. Furthermore, practice nurses reported that, contrary to the primary care physician, they did not always perceive their clients as frail: several practice nurses mentioned that a large share of their client population did not have any health or care needs that required action. A similar finding is reported by Bindels et al. [21], who found that

practice nurses had visited people who they believed did not belong in the program. Nurses in Bindels' study attribute this to the fact that frailty instruments often catch a 'snapshot', and that outcomes of frailty measurements may therefore be determined by the mental or physical state of an older person in a particular moment. Since in the ACT study, frailty was determined by the PRISMA-7 instrument (which has been tested to reliably distinguish between frail and non-frail older people [36]) and by the professional opinion of a primary care physician (who has insight in an older person's background and current situation) we believe that we limited the influence of the 'snapshot' phenomenon reported by Bindels. The experience of nurses in the ACT study may be explained by the fact that frailty does not always imply the existence of (unmet) care needs.

Intervention and implementation-related factors

Several implementation and intervention-related factors could be proposed to explain effect outcomes. A first intervention-related factor that could explain intervention outcomes is that the GCM or one or more of its individual components are not effective. The lack of intervention effect could also be attributed to the limited added value of the GCM as compared to usual care due to the high quality of primary elderly care in the Netherlands. The finding that frail, older people reported few unmet care needs at baseline (Chapter 5 of this thesis) could support this idea. However, earlier in this Chapter we addressed that the CANE instrument (that was used to measure care needs) was not always administered as intended by project interviewers, and that some older people found the CANE questions challenging to answer, which may have influenced the reliability of the CANE data. Moreover, in line with what we argue in Chapter 6 and in this Chapter, older people may not have reported their care needs to an interviewer, for instance because they were unaware of their needs or because they did not trust the interviewer. In addition, analysis of care plans (Chapter 4) suggest that the majority of older people did experience needs regarding pain care that were not met (pain is not covered in the CANE questionnaire). The existence of few care needs at baseline does therefore not provide conclusive evidence for the lack of contrast between usual care and the GCM.

In Chapter 3, we argued that adherence to the key components of the GCM was adequate. While this suggests that the lack of intervention effect cannot be attributed to a lack of fidelity, it is not conclusive. First, although

there is a relationship between program implementation and outcomes, this relationship is not necessarily linear as is often assumed, and it is unknown at what degree of implementation the GCM becomes effective. In other words, we do not know how thoroughly the GCM should be implemented before its success can be measured. Furthermore, we assessed fidelity of the key intervention components based on the assumption that these components are the ‘working’ components, i.e. that these components are in essence effective. However, this might not be the case – in addition, we might have overlooked other potentially effective components when investigating fidelity.

Another argument that underscores why the adequate fidelity of the GCM does not rule out implementation issues is that we did not investigate several moderating factors, including quality of the intervention. The latter has the potential to influence the relationship between implementation and effectiveness [3]. Practice nurses indicated that they experienced that the RAI-CHA training they received at the start of the intervention was not tailored to their needs, which may have initially impacted the quality of the CGA administration. In addition, practice nurses who carried out the GCM had different professional backgrounds, which may have caused individual practice nurse competencies to vary. The nurse competencies essential to provide high quality care during productive interactions are related to working adequately with the intervention components, to aspects of clinical tasks and coordinating care in the community (such as knowledge of – and experience working with – evidence-based procedures, adherence to assessment and treatment guidelines and knowledge of local care providers and organisations), and to the interaction with a client (such as being able to explore a client’s life style, value system and preferences regarding decision making, building a trusting relationship with a client, and tailoring advice to a client’s needs). As we did not investigate the extent to which practice nurses possessed these competencies, considerations about overall quality of the delivery are merely speculative.

In conclusion, whether the absence of intervention effect can be attributed to factors related to study design and methodology, to program weaknesses or to implementation issues is – and remains – unclear: tying program characteristics and implementation outcomes to effect outcomes is challenging (for instance, due to the abovementioned reason that the relationship between implementation and outcomes may not be linear), and the methods used in this thesis are insufficient to perform such an analysis.

REFLECTIONS ON GCM OBJECTIVES

In Chapter 1, we mentioned that the GCM has three main objectives: to identify health and care needs at a timely stage, to improve older people's involvement in their own care process, and to increase coordination between health care professionals. Below, I will discuss whether these objectives were achieved, and briefly address implications for future implementation.

Timely identification of health and care needs

By proactively identifying frail, older people within primary care practices and carrying out in-home CGAs and regular follow-up, the GCM aimed to identify frail, older people's health and care needs at a timely stage. Chapter 3 of this Thesis suggests that indeed, proactive home visits and CGAs administered by practice nurses could facilitate the early identification of new or changed care needs and expand access to tailored pain care by overcoming barriers to adequate pain care for older people. A continuous monitoring and follow up after initial identification of pain or pain care needs may further enhance trust, and may allow practice nurses to respond quickly to changing needs. It can be speculated that the approach implemented with the GCM could expand access to care for other conditions and complaints than pain. For instance, preliminary results of an analysis with ACT data show that proactive home visits and CGAs may also improve access to urinary incontinence (UI) care (abstract Jansen et al., poster presented at forum on Quality and Safety in Health Care, London, 2015). UI is – just like pain – a condition that has a high prevalence among frail, older people, is associated with a high impact on health and quality of life, and is known to have a marked economic impact due to the pervasive use of pads [37]. Moreover, UI is associated with several barriers to care seeking behaviour [38;39]. The fact that the GCM has the potential to improve access to care supports the argumentation that implementing the GCM can indeed contribute to a more timely identification of frail, older people's health and care needs.

Although the GCM was evaluated to not be cost-effective, data in this Thesis show that this does not mean that the identification of needs by practice nurses did not have an impact on individual lives. Neither does the lack of GCM's success lead to a definite conclusion about its effectiveness. Based on their potential to expand access to care, it can therefore be recommended that proactive home visits, CGAs and regular follow ups may

be more widely implemented into practice. However, this implementation should be accompanied by a re-evaluation of the way in which the individual intervention components are delivered. CGA type and frequency of follow-up should be tailored to the situation of the older person. For instance, when a frail, older person does not experience many physical, mental or social functioning limitations, has care needs that are stable and mostly met, or regularly visits the primary care practice, a practice nurse's care activities may consist of a singular entry CGA and a shorter half or one-year follow up assessment. When an older person experiences multiple impairments in daily functioning, has more or dynamic care needs or experiences a high level of frailty, evaluative CGAs may be carried out as seen fit by the practice nurse and the primary care physician. Which assessment instruments are most appropriate should be decided in consultation with their users in practice (in this case practice nurses), so as to optimize adoption and adherence.

Involving frail, older people in their own care process

A second objective of the GCM was to improve frail, older people's involvement in their care process. It was envisioned that during the two home visits, practice nurses encouraged their clients to actively take part in the decision making process and in arranging care services, placing their client's wishes at the center of every advice and action. Care plans, to be left with the client, were envisioned to provide clients with insight into their own health and care situation. Making an across-the-board conclusion about whether the GCM succeeded in improving older people's involvement in their own care is not possible, as we did not collect data that could answer this question in both intervention and control group at a patient level. However, our results leave room for speculation. The information below is derived from interviews and focus groups with practice nurses, of which final results are forthcoming. First, practice nurses were almost unanimously positive about what they had learned at the Motivational Interviewing training, which could indicate that they had increased their skills to motivate older people during the caregiver-care receiver interaction. However, practice nurses also indicated that older people they encountered did not always desire a more active involvement in their care, and that some older people could only partly be involved due to physical or mental disabilities. As a result, they found it challenging to determine when to leave an agreement or action to be arranged by a client or when to arrange it themselves. Second, practice nurses mentioned that older

people appreciated it when practice nurses discussed with them the content of care plans, and that older people regularly asked practice nurses to change or leave out information. On the other hand, older people often refused to keep the care plan, or could not retrieve it the next time the practice nurse visited. We can therefore argue that practice nurses all carried out their activities with the aim to prioritize the client's perspective and to make decision together with their clients. However, involving older people in their own care in terms of sharing practical responsibilities might have only been feasible in a subgroup of frail, older people who desired this involvement and whose mental or physical state allowed them to be involved. Furthermore, it can be argued that care plans were helpful to give older people insight in CGA results and tailoring the care plans to older people's own preferences, while at the same time the care plan adoption at a client level was limited.

The above conclusions do not undermine the importance of this second objective. We therefore recommend that involving older people in their own care continues to be a major aim for future primary elderly care programs. We also recommend that during such programs, practice nurses actively explore older peoples preferences regarding involvement, and tailor their communication and activities according to these preferences. Care plans in their current form may not contribute to involvement as intended. Below we will make recommendations for future care plan use.

Coordination of care

A third and final objective of the GCM was to improve coordination of care between professionals involved with care for frail, older people. It aimed to do this in several ways: by means of motivating older people to share the care plans with other care providers, by means of discussing older people with complex situations in MTCs, and through establishing networks of care organisations and professionals at a local or regional level by means of organising community network meetings. Preliminary results of focus groups and interviews with practice nurses (final results forthcoming) suggest that the first aspect of the objective (i.e. older people sharing care plans with other care providers) did not take place as intended. As mentioned before and in Chapter 3, older people often did not keep the care plans at home; in addition, practice nurses indicate that other caregivers, such as home care professionals, did not read the care plans. It can therefore be argued that in their current form, care plans did not contribute to improved coordination. MTC

adherence was low at the start of the intervention, but Chapter 3 shows that adherence increased over time. Several times, MTCs were specially organised to coordinating care delivery. While some primary care physicians were critical towards MTCs, others were more positive and considered them an opportunity to consult colleagues and align management. In the West-Friesland region, MTCs were sometimes joined by a client's family member or informal caregiver, which resulted in positive experiences for all attendants. Based on these findings, we can argue that MTCs did contribute to an increase in coordination between care professionals. Finally, one of the objectives of the GCM was to build local networks. Our results show that adherence to network activities could be improved, especially in the Amsterdam region. This may indicate that network building contributed more to coordination of care in the West-Friesland region than in the Amsterdam region.

Overall, it can be speculated that the GCM did contribute to care coordination between professionals, but that this contribution did not reach its full potential. Despite that, we argue that this potential may be approached through adjusting the intervention components and improving the circumstances of their implementation. For instance, in order for care plans to contribute to coordination of care, we recommend a different care plan layout and form. Since frail, older people's situation is often unstable and may change at any moment, it is essential that care plans offer practice nurses the option to continuously add or change care plan content. In addition, to allow for care plans to facilitate coordination of care, care plans should be readily accessible to relevant care providers. This need for a user-friendly document that is suitable for use in interdisciplinary settings informs our advice that future implementors consider developing digital (stand-alone or web-based) care plan formats, using HIT (health information technology). In order to ensure optimal tailoring of care plan design to the practical needs of users, all potential users (including primary care physicians and home care professionals) should be involved in every step of the development process; in addition, practice nurses should be thoroughly trained in how to interact with the care plan format, how to decide and write content, and how to integrate its use in everyday practice. Successful MTC implementation requires motivated health care professionals as well as practice nurses with the ability to identify situations that warrant an MTC. We argue that the composition of MTCs should depend on the nature and complexity of the situation discussed: if relevant and appropriate, coordination of care could benefit from having family members and informal caregivers as attendants. Building strong local networks requires time and progressive insight, as well as networking agents who

possess the capacity to identify and locate network partners and the skills to navigate a fragmented field. However, its implementation is essential, as improving linkages between organisations in a network and increased insight in each other's activities and efforts has been shown to empower organisational properties that could improve integrated community care [32]. In conclusion, it can be speculated that all GCM components that aimed to improve coordination of care have the potential to do so, however, before their potential can be reached a re-evaluation of their form and ideal circumstances for implementation is necessary.

Implications for practise and research

The evaluation of the GCM has given us insight in how the GCM was delivered in practice, and how interactions between caregivers and care receivers played a role in the implementation of the GCM. Based on our outcomes, we argue that elements of the GCM have the potential to positively contribute to the quality of primary elderly care, and that full implementation of these elements in practice can facilitate an adequate response to upcoming changes in the care sector. Below, we briefly describe these changes, and make several more recommendations for practice and further research.

Transforming primary elderly care

As we described in Chapter 1 and throughout this Thesis, rapid changes are taking place in society: people live longer with more disabilities, while at the same time the health care workforce is shrinking. As a result, health care expenditures are growing. In the Netherlands, this challenging outlook has fostered new health care legislature. Through implementing stricter rules and regulations with the aim to narrow access to care services and through an increased focus on social participation and civil responsibility, the Dutch government has been mobilising its citizens to play a role in the organisation of their own care, with the ultimate goal to keep health care affordable. However, the consequences of these austerity measures and funding cuts have the potential to especially impact frail, older people who live at home. As a result of a new law, the national budget for special (i.e. longer-term or chronic) care costs, the AWBZ (*Algemene Wet Bijzondere Ziektekosten*), which was previously controlled by a State-level program, has been placed under management of

local governments. This shift is accompanied by a tightening of AWBZ reimbursement policies. Consequently, older people – especially older people who suffer from multiple chronic conditions – will be less likely to get their care costs covered. In addition, the new law includes more rigorous eligibility criteria for admission to long-term care facilities. Both measures could result in older people living at home longer with more unmet care needs. These future unmet needs may consist of both psychosocial and physical needs, which would imply a further increase in pressure on the Dutch primary care system. Primary elderly care will have to transform, in order to be prepared for the increased demand for care tailored to the complex needs of a rapidly diversifying population of older people.

Practice nurses in primary elderly care

Several traits of the GCM could contribute to the transformation of primary elderly care. One of these traits is the central role of practice nurses. A first (and important) argument for assigning practice nurses a more central role in primary elderly care is the increased level of patient satisfaction following contact with nurses. For instance, in their article about differences in self-management support and communication between nurse case managers and primary care physicians, Matthias et al. reported that “Patients reported feeling supported, encouraged, and listened to by their NCMs², whereas they tended to be dissatisfied with their primary care physicians, citing issues such as lack of continuity of care, poor listening skills, and under- or overprescribing of medication” [40]. Moreover, there is evidence that skill mix in primary care (i.e. the expansion of the primary care workforce to include nonphysician health professionals [41]) can maintain access to primary care and improve quality of care and client outcomes, and potentially lower costs [42;43]. As Laurant et al. describe in their review about the impact of task shifting from physicians to non-physician health professionals, these beneficial outcomes take place under the conditions that the nurses carry out effective treatments and play a role in their delivery [42]. It implies that assigning a central role to practice nurses in primary elderly care requires practice nurses to have optimal knowledge of existing (nursing and multidisciplinary) guidelines.

Introducing practice nurses in primary elderly care requires, therefore, that practice nurses receive adequately training. The findings presented in this thesis suggest that such a training program should at least involve the following learning objectives: (1) practice nurses should possess the competencies to uncover clients' needs regarding the nature of their preferred caregiver-care receiver relationship; (2) practice nurses should possess the competencies to create a safe and trusting environment in which clients feel motivated to reflect on their own health or care situation and share their (unmet) health or care needs with care providers; (3) practice nurses should possess the competencies to perform in-home CGAs, adequately interpret CGA outcomes and report the outcomes to a physician or other care professional; (4) practice nurses should possess the competencies to present older people with tailored health and care options, support older peoples' involvement in the decision making process, and motivate older people to make choices that best represent their needs; (5) practice nurses should possess the competencies to adequately inform older people of the outcomes of interdisciplinary consultations; (6) practice nurses should possess adequate knowledge about local and regional health and social care organisations and resources, and the skills to determine which resources are appropriate for their client and how their client could benefit from them; (7) practice nurses should possess the competencies to practice in a multidisciplinary team setting.

Recommendation for research

We can make several recommendation for future research, related to measuring client-centeredness in a population of frail, older people and evaluating the implementation process of comprehensive care programs.

In Chapter 7, we argue that the evaluation of client-centeredness of care services is essential for the ongoing evaluation of care for frail, older people who live at home. Since the CCCQ did not show high feasibility and acceptability and we were not able to establish validity, we recommend that researchers who wish to evaluate client-centered care in a frail population use an instrument that corresponds to the unique situation of frail populations. Such a list should, in our opinion, possess several characteristics. First, as argued earlier in this Chapter, it should be valid, adequately representing frail, older people's expectations and norms surrounding interactions with a carer. Furthermore, it should be low in respondent burden, which means that questions should be simple (i.e. no double-barred questions) and concrete. Items

should also represent older people's lived realities of receiving care in the home situation; for instance, questions should inquire about experiences regarding receiving care from multiple care professionals and for multiple conditions. Finally, the instrument should not only measure client-centeredness in domains of autonomy and treatment, but also in the domains of availability of services, accessibility, information provision and delivery, etc. As far as we know, however, such an instrument currently does not exist. We therefore recommend that researchers interested in evaluating quality of care services for frail, older people explore possibilities for its development. Insight in client-centeredness could help us advance in-home care delivery, so that it meets the needs of clients. As the number of older people who receive care at home is rapidly increasing, the benefits of such advancements may be widespread.

We suggest that researcher who aim to implement comprehensive care programs and evaluate its implementation process take the following recommendations into account. First, as was also experienced during the research reported in this thesis, it often takes time for an intervention to be implemented as intended due to, for instance, the learning process that users go through. The nature and speed of this learning process determines adoption, and therefore the level of implementation at a given time. In order to ensure rapid implementation, future researchers should increase their focus on facilitating users' learning process. Providing regular tailored training activities could therefore be a useful implementation strategy. Evaluating results of the training may improve insight in users' learning process. Researchers who choose to outsource these activities should set up an additional quality assurance program. Second, as complex, comprehensive interventions in primary elderly care are known to display a high degree of variation, studies that evaluate their implementation are naturally tailored to the programs they evaluate. Future researchers of implementation processes should first and foremost invest in finding a feasible framework that helps them customize their study design. Due to the current body of knowledge in this field and variations between available concepts and theories, this choice may not always be an easy one. Third, as proposed in Chapter 3, implementation fidelity should be investigated over time and for each intervention component separately. When doing this, researchers should realize that longitudinal fidelity assessment may be complicated by delayed intervention delivery, i.e. an accumulation of intervention tasks that could potentially impact coverage and frequency per time interval, but does not automatically imply poor fidelity. In addition, an implementation process evaluation should include an assessment of most, if not all moderating factors, including an evaluation of participant

responsiveness (satisfaction, involvement) at a patient and a health provider level an evaluation of quality of intervention delivery, and an investigation of physician and practice nurse characteristics (including preferences and opinions regarding elderly care structure and delivery). Finally, in order to avoid a “type 4 error”, researchers should take into account that deviations from an intended protocol may be interpreted as low adherence, but may potentially lead to an enhanced fit of the intervention in practice.

IN CONCLUSION

All people are entitled to high quality health care. During the last stages of life, when people are at high risk of suffering from chronic conditions, functional impairments and social isolation, this right should be especially protected. In light of current changes in health care legislation and organisation (which focus on a shift from secondary to primary care, an increased emphasis on self-management, and decentralisation of care), governments and policy making bodies, researchers, and care professionals must work together in order to secure sustainable delivery of high-quality care services for people like Mrs. Steinberg. This process comes with both challenges and opportunities. Through evaluating the implementation process of the GCM, we have aimed to contribute to the knowledge necessary to meet these challenges. In addition, we have presented insights that could help to take advantage of opportunities to optimize the situations of care receivers as well as providers.

Comprehensive care models such as the GCM may provide the framework for future organisation and delivery of primary elderly care. But where future randomised controlled studies will need to provide the evidence these models’ effectiveness, one aspect of the care system does not need scientific justification to prove its worth. It goes undoubted that the tireless efforts of skilled professionals working in elderly care, dedicated to provide optimal health and social care services to their clients, make a difference in the lives of frail, older people everyday. While we may not always be able to capture the effects of these efforts in numbers and statistics, our task as a society is to give these professionals the recognition they deserve. And that, in my opinion, should never be a challenge.

REFERENCES

- 1 Bradley F, Wiles R, Kinmonth AL, Mant D, Gantley M: Development and evaluation of complex interventions in health services research: case study of the Southampton heart integrated care project (SHIP). *BMJ* 1999; 318(7185):711-715.
- 2 Campbell M, Fitzpatrick R, Haines A, Kinmonth AL, Sandercock P, Spiegelhalter D, Tyrer P: Framework for design and evaluation of complex interventions to improve health. *BMJ* 2000; 321(7262):694-696.
- 3 Carroll C, Patterson M, Wood S, Booth A, Rick J, Balain S: A conceptual framework for implementation fidelity. *Implementation Science* 2007; 2(1):40.
- 4 Grant A, Treweek S, Dreischulte T, Foy R, Guthrie B: Process evaluations for cluster-randomised trials of complex interventions: a proposed framework for design and reporting. *Trials* 2013; 14(1):15.
- 5 Oakley A, Strange V, Bonell C, Allen E, Stephenson J, RIPPLE Study Team: Health services research: process evaluation in randomised controlled trials of complex interventions. *BMJ: British Medical Journal* 2006; 332(7538):413.
- 6 Saunders RP, Evans MH, Joshi P: Developing a process-evaluation plan for assessing health promotion program implementation: a how-to guide. *Health Promotion Practice* 2005; 6(2):134-147.
- 7 Haggstrom DA, Taplin SH, Monahan P, Clauser S: Chronic Care Model implementation for cancer screening and follow-up in community health centers. *Journal of health care for the poor and underserved* 2012; 23(3):49-66.
- 8 Hroszkowski MC, Solberg LI, Sperl-Hillen JM, Harper PG, McGrail MP, Crabtree BF: Challenges of change: a qualitative study of chronic care model implementation. *The Annals of Family Medicine* 2006; 4(4):317-326.
- 9 Pearson ML, Wu S, Schaefer J, Bonomi AE, Shortell SM, Mendel PJ, Marsteller JA, Louis TA, Rosen M, Keeler EB: Assessing the implementation of the chronic care model in quality improvement collaboratives. *Health services research* 2005; 40(4):978-996.
- 10 Palinkas LA, Horwitz SM, Chamberlain P, Hurlburt MS, Landsverk J: Mixed-methods designs in mental health services research: A review. *Psychiatric Services* 2011; 62(3):255-263.
- 11 Creswell JW, Klassen AC, Plano Clark VL, Smith KC: Best practices for mixed methods research in the health sciences. Bethesda (Maryland): National Institutes of Health 2011;2094-2103.
- 12 Aarons GA, Fettes DL, Sommerfeld DH, Palinkas LA: Mixed Methods for Implementation Research Application to Evidence-Based Practice Implementation and Staff Turnover in Community-Based Organizations Providing Child Welfare Services. *Child maltreatment* 2012; 17(1):67-79.
- 13 Teddlie C, Tashakkori A: Mixed methods research. Denzin, N; Lincoln, Y (eds) 2011;285-300.
- 14 Hasson H: Systematic evaluation of implementation fidelity of complex interventions in health and social care. *Implementation Science* 2010; 5(1):67.
- 15 Walters K, Iliffe S, Tai SS, Orrell M: Assessing needs from patient, carer and professional perspectives: the Camberwell Assessment of Need for Elderly people in primary care. *Age and Ageing* 2000; 29(6):505-510.
- 16 (16) Bindels J, Baur V, Cox K, Heijing S, Abma T: Older people as co-researchers: a collaborative journey. *Ageing and Society* 2014; 34(06):951-973.
- 17 Sturges JE, Hanrahan KJ: Comparing telephone and face-to-face qualitative interviewing: a research note. *Qualitative Research* 2004; 4(1):107-118.
- 18 Tashakkori A, Teddlie C: Sage handbook of mixed methods in social & behavioral research. Sage, 2010.
- 19 Green J, Thorogood N: Qualitative methods for health research. Sage, 2014.
- 20 Barbour RS, Barbour M: Evaluating and synthesizing qualitative research: the need to develop a distinctive approach. *Journal of evaluation in clinical practice* 2003; 9(2):179-186.
- 21 Bindels J, Cox K, Widdershoven G, Schayck OC, Abma TA: Care for community-dwelling frail older people: a practice nurse perspective. *Journal of clinical nursing* 2014; 23(15-16):2313-2322.
- 22 Agich G: Dependence and autonomy in old age: An ethical framework for long-term care. Cambridge University Press, 2003.
- 23 Stijnen MM, Jansen MW, Duimel-Peeters IG, Vrijhoef HJ: Nurse-led home visitation programme to improve health-related quality of life and reduce disability among potentially frail community-dwelling older people in general practice: a theory-based process evaluation. *BMC family practice* 2014; 15(1):173.
- 24 McNaughton DB: A synthesis of qualitative home visiting research. *Public Health Nursing* 2000; 17(6):405-414.
- 25 Spiers JA: The interpersonal contexts of negotiating care in home care nurse-patient interactions. *Qualitative Health Research* 2002; 12(8):1033-1057.

- 26 Bleijenberg N, Ten Dam VH, Steunenber B, Drubbel I, Numans ME, Wit NJ, Schuurmans MJ: Exploring the expectations, needs and experiences of general practitioners and nurses towards a proactive and structured care programme for frail older patients: a mixed-methods study. *Journal of Advanced Nursing* 2013; 69(10):2262-2273.
- 27 Van de Mortel TF: Faking it: social desirability response bias in self-report research. 2008.
- 28 Herzog AR, Dielman L: Age differences in response accuracy for factual survey questions. *Journal of gerontology* 1985; 40(3):350-357.
- 29 Sherbourne CD, Meredith LS: Quality of self-report data: a comparison of older and younger chronically ill patients. *Journal of gerontology* 1992; 47(4):S204-S211.
- 30 Hays RD, Ware Jr JE: My medical care is better than yours: social desirability and patient satisfaction ratings. *Medical care* 1986;519-525.
- 31 Mazurenko O. [Thesis]. An Examination of the Relationship Between the External Environment and Care Coordination. 2012. The University of Alabama at Birmingham.
- 32 Janssen BM, Snoeren MW, Van Regenmortel T, Abma TA: Working towards integrated community care for older people: Empowering organisational features from a professional perspective. *Health Policy* 2015; 119(1):1-8.
- 33 Metzelthin SF, Daniëls R, van Rossum E, Cox K, Habets H, de Witte LP, Kempen GI: A nurse-led interdisciplinary primary care approach to prevent disability among community-dwelling frail older people: a large-scale process evaluation. *International journal of nursing studies* 2013; 50(9):1184-1196.
- 34 Hoogendijk E. [Thesis]. The challenge of frailty in older adults. Risk factors, assessment instruments and comprehensive community care. 2015. VU University, Amsterdam, the Netherlands.
- 35 van Leeuwen K. [Thesis]. Integrated care and quality of life of frail older adults. How can we measure what we aim to improve? 2015. VU University, Amsterdam, the Netherlands.
- 36 Hoogendijk EO, van der Horst HE, Deeg DJH, Frijters DHM, Prins BAH, Jansen APD, Nijpels G, van Hout HPJ: The identification of frail older adults in primary care: comparing the accuracy of five simple instruments. *Age and Ageing* 2013; 42(2):262-265.
- 37 CVZ. *Attentie voor incontinentie* [in Dutch]. 2006.
- 38 Teunissen D, van Weel C, Lagro-Janssen T: Urinary incontinence in older people living in the community: examining help-seeking behaviour. *British Journal of General Practice* 2005; 55(519):776-782.
- 39 Monz B, Pons ME, Hampel C, Hunskaar S, Quail D, Samsioe G, Sykes D, Wagg A, Papanicolaou S: Patient-reported impact of urinary incontinence - results from treatment seeking women in 14 European countries. *Maturitas* 2005; 52:24-34.
- 40 Matthias MS, Bair MJ, Nyland KA, Huffman MA, Stubbs DL, Damush TM, Kroenke K: Self-management support and communication from nurse care managers compared with primary care physicians: a focus group study of patients with chronic musculoskeletal pain. *Pain Management Nursing* 2010; 11(1):26-34.
- 41 Green LV, Savin S, Lu Y: Primary care physician shortages could be eliminated through use of teams, nonphysicians, and electronic communication. *Health Affairs* 2013; 32(1):11-19.
- 42 Laurant M. [Thesis]. Changes in skill mix. The impact of adding nurses to the primary care team. Chapter 10: The effectiveness of nurse supplementation in primary care: a systematic review and meta-analysis. 2007. Nijmegen, Radboud University, Nijmegen, the Netherlands.
- 43 Freund T, Everett C, Griffiths P, Hudon C, Naccarella L, Laurant M: Skill mix, roles and remuneration in the primary care workforce: Who are the healthcare professionals in the primary care teams across the world? *International journal of nursing studies* 2015; 52(3):727-743.

