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# General discussion



Frail older people with complex and diverse needs, like my grandmother, have to age in place in the community rather than being admitted to residential care or nursing homes. Their number keeps rising due to population ageing and national health policies are increasingly aiming at ageing in place. Health care systems are under pressure and (primary) care professionals keep struggling with the increasing complexity of the frail patient population. Care for frail older people originally is reactive, fragmented and lacks coordination and integrated, preventive care is perceived as a promising solution. The overall aim of this thesis was therefore to gain more insight into the effectiveness and cost-effectiveness of preventive, integrated care for community-dwelling frail older people. This insight is firstly provided by focusing on the (cost-) effectiveness of the Walcheren Integrated Care Model (WICM). Secondly, this WICM evaluation was incorporated in a systematic review to synthesize the current evidence of 46 studies on 29 interventions were studied. In this review, the heterogeneity of the population, community-dwelling frail older people, was highly remarkable and may have possibly influenced the results of evaluation studies. Thirdly, this heterogeneity of frailty was therefore further explored in this thesis by developing frailty profiles with latent-class analysis. These frailty profiles were used to re-determine the effectiveness of the WICM and seven comparable interventions for each of profile separately to explore where integrated care is more effective for certain types of frail older people.

In the discussion of this thesis, the main findings are presented and the theory and research methodology are reflected upon. In order to explore the future directions of the triangle practice, policy and research, we reflect upon the relation of these three domains and one general integrated agenda was formulated.

## Main findings

### **The effectiveness and cost-effectiveness of the Walcheren Integrated Care Model**

As stated above, the first sub-question of this thesis was: is the WICM (cost-)effective? The WICM intervention is a comprehensive model with a broad frailty screening, comprehensive geriatric assessment, follow-up with case management and a multidisciplinary team (chapter 2). Different elements were implemented to realize integration such as multidisciplinary meetings, web-based files and network structure. All elements were combined into the WICM to provide coherent, continuous care according to the needs of frail older people. The effectiveness was studied three and twelve months after implementation of the WICM and the cost-effectiveness was

determined after twelve months. From this thesis can we concluded that the effect of the WICM appears to be limited but increases over time.

After three months, the effectiveness of the WICM was limited to a small effect on the quality of life of the frail older people (chapter 3). The intervention resulted in frail older people being able to receive more love and friendship. No other quick wins of the intervention were found in terms of health outcomes, functional abilities, health care utilization or satisfaction with care.

After twelve months, more effects were substantiated. The WICM still had a positive effect on love and friendship but also on general quality of life (chapter 4). Moreover, frail older people who received care according to the WICM were more satisfied with the care and information given to them, and the patient-centeredness of and the coherence in their care than frail older receiving usual care<sup>2</sup>. However, still no effects were found on health outcomes, functional abilities and health care utilization. The absence of effects on the health care utilization, and hence the costs, combined with the intervention costs (case management, multidisciplinary meetings), and a very small effect on health-related quality of life resulted in the WICM not being cost-effective (chapter 5).

### **The (cost-) effectiveness of the WICM compared to similar interventions**

From a systematic review conducted in this thesis can be concluded that the results of the WICM are in line with the outcomes of other preventive, integrated care interventions (chapter 6). As in the WICM, the effect on health outcomes and functional abilities were limited in most studies, whilst well-being appeared to be positively affected. With respect to health care utilization, similar patterns also emerged between the WICM and the other interventions. Most types of health care utilization of frail older people as well as health-related quality of life were not affected by the integrated care interventions. Also, no effects on the health care costs were found which resulted in limited evidence on the cost-effectiveness. In contrast to most other models, the WICM increased the satisfaction of care.

### **Impact of distinguishing frailty subpopulations on the effectiveness of integrated care**

The last sub-questions of this thesis were: To what extent can frailty subpopulations in integrated care arrangements be distinguished and is preventive, integrated

<sup>2</sup> Not published in this thesis, see Report Walcheren 2013.

care more effective for certain subpopulations of frail older people? For this thesis, latent-class analysis was performed resulting in six frailty profiles that differed in the level of physical, psychological, social and cognitive functioning of the frail older person (chapter 7). In this thesis it is concluded that distinguishing these subpopulations of frail older people does not change the effects of both the WICM and similar preventive, integrated care interventions. This conclusion can be drawn for all six subpopulations and all types of health outcomes, functional abilities and outcomes regarding quality of life (chapter 8).

## Theoretical considerations

In the literature it is assumed that integrated care is beneficial for vulnerable groups with complex and multiple problems (Kodner, 2009). The conclusion of this thesis challenges this assumption since the effects of preventive, integrated care for frail older people are limited and do not meet up to the high expectations of integrated care (Kodner, 2009; Kodner & Spreeuwenberg 2002). However this does not mean that the general assumption about the benefits of integrated care should be rejected.

### The alignment between subpopulations and interventions

A first reason is that integrated care interventions may not be customized to the heterogeneity of frail older people. The diversity within the population of older people labelled as being frail is enormous. The concept of frailty has also been broadened over time and now includes the physical, psychological and social domains of functioning (Gobbens, Luijckx, Wijnen-Sponselee, & Schols, 2010; Markle-Reid & Browne, 2003; Rockwood & Mitnitski, 2007a; Schuurmans, Steverink, Lindenberg, Frieswijk, & Slaets, 2004). In addition, this thesis shows that the frail older person does not exist and that a wide variety of subpopulations can be distinguished. This heterogeneity of frail older people is increasingly acknowledged (Manthorpe & Iliffe, 2015) and a tendency to distinguish subpopulations of (frail) older people can be observed in the literature (Gellert et al., 2017; Lafortune, Béland, Bergman, & Ankri, 2009; Liu, Tian, & Yao, 2014; Liu et al., 2017; Newcomer, Steiner, & Bayliss, 2011). Heterogeneity is also a possible explanation for the limited effectiveness of integrated care (Eklund & Wilhelmson, 2009; Ferrucci et al., 2004; Hoogendijk, 2016; Spoorenberg, 2017), as the approach to frailty has changed time, but the beliefs in effective components of integrated care have not.

Currently, these beliefs are that highly integrated care interventions are most effective (Kodner & Spreeuwenberg, 2002; Valentijn, Schepman, Opheij, & Bruijnzeels,

2013). Moreover, there is still a general consensus that effective interventions contain specific elements such as comprehensive geriatric assessments, case management and multidisciplinary teams (Fabbriotti, 2007; Hebert, Durand, Dubuc, Tourigny, & Group, 2003; Johri, Beland, & Bergman, 2003; Kodner & Kyriacou, 2000). However, not all elements might be necessary or beneficial for the entire and heterogeneous population of frail older people. Case management with care coordination might not be necessary for less complex frail older patients (van Eissens, van Offenbeek, Broekhuis, & Slaets, 2014), for example for mild physically or psychologically frail older people. And comprehensive geriatric assessment, for example, is proven to be effective for more specific patients groups, for example for older people with chronic conditions or in acute care settings, rather than for all subtypes of frail older people (Hoogendijk, 2016; Stuck, Egger, Hammer, Minder, & Beck, 2002). Furthermore, there is still a debate who would benefit most from (integrated) care interventions and when intervening is most appropriate: in an early phase of frailty or when the condition is more severe (Elkan et al., 2001; Metzelthin, 2014; Stuck et al., 2002). Thus, aligning integrated care interventions to specific subpopulations of frail older people seems necessary (Vuik, Mayer, & Darzi, 2016). The misalignment might be the reason why the effectiveness of integrated care interventions, discussed in this thesis, with multiple components in terms of health outcomes could not be demonstrated for the six frailty subpopulations separately. It is possible that the diversity of frail older people has not been taken into account sufficiently within integrated care interventions by professionals and researchers. In sum, further acknowledging the heterogeneity of frail older people and aligning integrated interventions to the specific needs of frail older people might enhance the (cost-) effectiveness of integrated care.

### **The medical dominance**

Another consideration that has to be taken into account before rejecting the beneficial effects of integrated care, is that more attention should be devoted to the care and support that frail older people actually receive, in addition to the emphasis on how to integrate medical components of care. Integrated interventions still have a strong medical focus whereas a holistic, person-centered approach also includes the psychological and social domains (Kodner & Spreeuwenberg, 2002; World Health Organization, 2015). The medical dominance in the integrative solutions of care is seen throughout this thesis. The investigated integrated care interventions for community-dwelling frail older people were mostly situated in the medical spheres in primary care in which GPs were important integrators in the interventions. The systematic review in this thesis also showed that structures are indeed created to improve collaboration and coordination between medical health care professionals and

organizations, mostly with case management and sometimes with multidisciplinary meetings, protocols, teams and information systems. Even the follow-up is mostly GP-oriented and disease-specific and medically orientated according to how primary care professionals were originally trained (De Lepeleire, Iliffe, Mann, & Degryse, 2009; Lette, Baan, van den Berg, & de Bruin, 2015). For instance, within the WICM, the case managers also worked from the GP practice and were originally trained as practice nurses or district nurses. Process evaluation of comparable integrated care interventions also showed that practice nurses and GPs tend to mainly focus on existing diseases and disability rather than psychosocial problems (Metzelthin et al., 2013) and that mostly physical problems appeared in care plans (Stijnen, Jansen, Duimel-Peeters, & Vrijhoef, 2014). Recent research showed that even though practice nurses agree about the importance of collaboration with professionals outside the GP practice, they still experience barriers in this collaboration, such as ambiguity about responsibilities and time constraints (de Groot, de Veer, Versteeg & Francke, 2018). Our systematic review also confirmed that the role of social care and welfare organizations in integrated care interventions is generally limited (see also (Hoogendijk, 2016)), just like the role of informal caregivers. A holistic approach requires attention for psychological and social domains and most of all for the well-being of frail older people (Nicholson, Meyer, Flatley, & Holman, 2013). This requires additional knowledge and skills of professionals (Leichsenring, 2004; Lloyd & Wait, 2005; van Dijk, Cramm, & Nieboer, 2016). Hence, the benefits of integrated care for frail older people may improve by a more holistic approach that goes beyond the medical domain encompassing all domains of functioning.

### **The 'limited' vision on prevention**

The third theoretical consideration on the benefits is that the preventive elements might not be well integrated yet in integrated care arrangements. Prevention is often not part of integrated care arrangements for frail older people (Oliver et al. 2014) or the vision on prevention for frail older people is limited. It appears that a focus on secondary prevention prevails. Our systematic review showed that prevention mainly encompasses a comprehensive geriatric assessment. In a few studies the population of older people were systematically screened for frailty. However, tertiary prevention - in terms of health education, self-management and empowerment - is often lacking in integrated care interventions for community-dwelling frail older people (Harrison, Clegg, Conroy, & Young, 2015). The role of prevention is particularly limited compared to disease management programmes for chronic conditions (Ouwens, Wollersheim, Hermens, Hulscher, & Grol, 2005; Rijken et al., 2018; Wagner, Davis, Schaefer, & Von Korff, 1999), although the positive effects have been proven. Research shows, for example, that frail older people could benefit from physical

activities and nutrition (Puts et al., 2007) and older people from self-management support programmes (van het Bolscher-Niehuis, den Ouden, de Vocht & Francke, 2016). Also self-management is important for maintaining well-being (Cramm et al., 2012; Steverink, Lindenberg, & Slaets, 2005) and is not necessarily related to specific chronic conditions (van het Bolscher-Niehuis et al., 2016; Rijken et al., 2018). Hence, integrated care interventions for community-dwelling frail older people should adopt a broader vision on prevention which might result in more (cost-) effective integrated care interventions.

## Methodological considerations

Besides the questions with whom and how we intervene, a crucial question is how do we research these preventive, integrated interventions. In this thesis, different – mostly quantitative - methods were used to study preventive, integrated care for frail older people. An evaluation study of the transition experiment WICM investigated the short and long-term effects and also included a cost-effectiveness study with a quasi-experimental design. A systematic review provided a comprehensive overview of the current literature. Based on this systematic review, subpopulations of frail older people were developed with a latent-class analysis and a qualitative focus group. These subpopulations were incorporated in an IPD-analysis of comparable interventions. With this combination of methodologies, we were able to provide further insights into the potential of integrated care for frail older people. However, this thesis also has some methodological limitations.

### Design

As randomized controlled designs are perceived as the golden standard providing the highest quality of evidence, one could argue that using a quasi-experimental design for the evaluation of the WICM is a limitation. A first reason is the non-random assignment of the frail older people to the experimental and control group. This could lead to selection bias and non-random imbalance of observed and unobserved factors between the experimental and control group (Black, 1996; Craig et al., 2008). Regarding the background covariates, the experimental group in the WICM consisted of more women, more individuals in assisted living facilities and more individuals with a lower level of education than the control group. However, we were able to correct for these variables in the analyses and no effects were found of these variables on the outcomes of the evaluation study. Concerning the outcome variables, the experimental group had a lower general quality of life at baseline than the control group but we also adjusted for the baseline differences in the linear mixed models



of repeated measures. Therefore, the differences in observed factors may have only limited effects on our results.

Second, randomizing patients in integrated care interventions with a key role of the GP practice such as the WICM is impossible and undesirable (Berkhout, 2000). In the Dutch healthcare system, frail older people have their own GP with whom they have a longstanding relation. A change in GP leads to discontinuity of patient-centered care and a breakdown in the trusting relations between the elders and their GP. Also, randomizing patients increases the chance of contamination between caregiving according to the experimental way of working and usual caregiving, which could lead to biased estimates of the effects of the intervention (Craig et al., 2008). When randomizing frail older people, GPs would have to provide integrated care and usual care at the same time. It is likely that the care given to the patients in the control group will then be influenced by (parts) of the intervention (Black, 1996). However, contamination can also occur in a quasi-experimental design, if the experimental way of working is occurring in the proximity of the region in which usual care is given. To avoid this type of contamination and to ensure that frail older people could keep receiving care from their own GP, three GP practices in the south-east Walcheren formed the experimental group, whilst the control group consisted of five GPs in other parts of the Walcheren region.

A popular and valid alternative for RCTs would have been a cluster-randomized controlled trial in which the GP practices are randomized rather than the patients. Because this requires a certain number of GP practices (Eldridge, Ashby, Feder, Rudnicka, & Ukoumunne, 2004), this design was not applicable for the WICM. Moreover, since other organizations and professionals outside the GP practices were involved, such as district nurses and physiotherapists, even a cluster-randomized controlled trial might have led to contamination and spill-over effects as mentioned above. In sum, a quasi-experimental design was the most optimal design for the main intervention in this thesis.

Furthermore, the use of rigid designs such as randomized controlled trials and quasi-experimental designs is increasingly questioned for the evaluation of complex interventions (Campbell et al., 2000; Craig et al., 2008). The main reason is that due to the complexity, the level of control on the conditions is limited. This level of control is crucial in rigid designs to estimate the effect of the intervention and diminish confounding factors. Integrated care is a complex intervention since integration occurs at various levels with different interacting components that involve many actors and involves changing behaviour of both professionals delivering the intervention

and the frail older people receiving the intervention (Craig et al., 2008; Raine et al., 2016). Consequently, researchers have limited control in how the various professionals actually deliver the intervention. The same holds for the frail older people in experimental and control group who are exposed to external factors in the long time frame of the evaluation study that may also influence the outcomes of the intervention (see also (Blom et al., 2016)), like fall incidents or bereavement. Another drawback of rigid designs is that they imply standardization and should preferably not be adjusted during the study. This standardization also means inflexibility to adapt to the local context (Craig et al., 2008; RVS, 2017), which is crucial for the intervention in our study and for many other complex interventions in health care (Craig et al., 2008; RVS, 2017). Interventions should be constantly adjusted, as integrated care is demand-driven care, and as there is no blueprint for integrated care (Leijten et al., 2018; Tsiachristas, Stein, Evers, & Rutten-van Mólken, 2016; Valentijn et al., 2013; Wehrens, Oldenhof, Verweij, Francke, & Bal, 2017). Moreover, the effectiveness of integrated care is expected to increase when it is adapted to the local context (Eyre, Farrelly, & Marshall, 2017). Thus, for evaluating integrated care interventions the drawbacks of rigid design should be considered carefully.

### **Process evaluation**

The absence of a process evaluation in this thesis might have led to a lack of insights in the benefits of integrated care for frail older people. Process evaluations are strongly encouraged for complex interventions to improve understanding of the implementation process and to explain the (lack of) outcomes of an intervention (Craig et al., 2008; Moore et al., 2015). In the WICM, we assumed that the implementation of structures would enhance integration processes that would result in certain outcomes. However, previous research shows that the implementation of structures does not lead automatically to integration processes (Fabbriotti, 2007; Kirst et al., 2017; Valentijn et al., 2013; van Dijk et al., 2016). Besides structural integration, also other types of integration are important to realize integrated care such as mutual goals, shared values and an integrative culture (Fabbriotti, 2007; Valentijn et al., 2013). In this thesis, the insights in these types of integration processes were generally limited, not only in WICM but also in the systematic review of comparable interventions and might have related to the limited effects. In addition, process evaluations would also have provided useful insights in the implementation fidelity of the integrated care interventions. It remains unclear what specific structures of the interventions were actually implemented and what care the frail older people actually received. Also, the medical dominance and the limited vision on prevention that were described above could have been verified in a process evaluation. Previous process evaluations have confirmed that professionals tend to focus on specific problems of frail older people

(Metzelthin et al., 2013). Therefore, it could be possible that in the assessments, care plans and follow-up within the integrated care interventions, mostly medical problems were addressed. Moreover, processes and outcomes were not modelled and the mechanisms leading to specific outcomes were not explored. For complex interventions, a process evaluation enables to clarify causal mechanisms (Craig et al., 2008). For the WICM, we were not able to prove what mechanisms within the WICM have led to the effect on love and friendship and quality of life. Our possible explanation is the improved relation with the informal caregivers whose subjective burden decreased because of the intervention (Janse, Huijsman, de Kuyper, & Fabbriotti, 2014). Yet, this explanation could not be confirmed within the process evaluation. At last, a process evaluation could also have provided insights in unexpected outcomes (Craig et al., 2008) which could be important benefits established by the intervention. We know from project meetings that the GPs involved in WICM experienced feelings of control and grip on their (increasing) frail patient population and to more tranquillity in the GP practice. These types of findings are also found in other studies and deemed important (Glasby, 2016). However, they were not considered in rigid designs (Wehrens et al., 2017). Hence, better insights in the process of integration and implementation in relation to the outcomes would have provided better understanding of integrated care for frail older people.

### **Outcomes for frail older people in evaluation research**

Another limitation is related to the outcomes used. In the evaluation study of the WICM mostly traditional outcomes were adopted focusing on health outcomes and functional abilities. The traditional outcome measures might not be suitable to assess the benefits of integrated care for frail older people. Frailty can be perceived as a progressive condition (Gill, Gahbauer, Allore, & Han, 2006; Harrison et al., 2015) and frail older people mostly experience deterioration of their health and functioning (Clegg, Young, Iliffe, Rikkert, & Rockwood, 2013; D'Avanzo et al., 2017). Improvement of their health and functioning is therefore not expected. Moreover, research shows it is extremely difficult to influence these outcomes such as ADL at an older age at all (Beswick et al., 2008; van der Vorst et al., 2016). The evaluation of the WICM and the systematic review also confirm that the effects of preventive, integrated care on traditional outcomes are limited. For example, the choice of health-related quality of life in cost-effectiveness analysis might lead to the absence of effects (Comans, Peel, & Gray, 2013; Makai et al., 2015) because of the natural deterioration in health of frail older people.

The outcomes were part of The Older Person and Informal Caregiver Survey Minimum Dataset (TOPICS-MDS), which had to be used in our research. TOPICS-MDS is

a standardized instrument developed within the NCEP (Lutomski et al., 2013) and is a large data-sharing initiative in the Netherlands. Researchers within all NCEP projects had to collect data consistent with the TOPICS-MDS. Researchers were allowed to complement the TOPICS-MDS with other questionnaires (and hence outcomes). However, given the length of the TOPICS-MDS, trade-offs between time and the concentration span of the elderly, and the validity of the data on the added outcomes had to be taken into account. Thus, the ability to add new questions was limited.

Another reason for the use of traditional outcome measures lies in the time-frame of the study. The TOPICS-MDS was composed before the start of the NCEP projects by a working group and was extensively discussed with an expert panel (Lutomski et al., 2013). The TOPICS-MDS provided unique research opportunities such as the development of frailty profiles in this thesis. However, in the period after the development of the TOPICS-MDS and the use of the instruments in the empirical evaluations, new insights appeared in the literature. For example, the concept of well-being became increasingly important in practice, policy and research (Linton, Dieppe, & Medina-Lara, 2016). There is also a growing awareness that well-being for older people differs from well-being in the general population and consists of other dimensions (Coast et al., 2008). Moreover, the traditional definition of health of the WHO (a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity) was complemented with Huber's positive health defined as the ability to self-manage and adapt (Huber et al., 2011). This change in perspective involves a shift in focus from weaknesses to strengths and adopts a broader perception of health including well-being, social and societal participation and spiritual/existential dimension (Huber et al., 2016). This change in perspective should also be considered in evaluation research of integrated care so outcomes are more properly aligned to the population of frail older people.

## **Bridging practice, policy and research**

In this thesis, the effectiveness of preventive, integrated care for frail older people was unravelled by switching three buttons: the population of frail older people (with whom do we intervene?), the integrated care interventions (how do we intervene?) and the research on these topics (how do we research this?). The limited effectiveness of preventive, integrated care for frail older people could not fully be explained by answering these questions. Nor a comprehensive integrated care intervention, nor discriminating between subpopulations of frail older people were able to yield effectiveness with the current research designs and outcomes related to functioning.

Therefore, a future agenda is crucial; now more than ever. A transition in research is required to integrate the information (or evidence) on frailty, integrated care and outcomes. Bridges should be built between practice, policy and research and therefore an agenda is proposed for the three together. This triangle should be balanced with close attention for the older people facing frailty.

## Frailty

A first task is that researchers should work more closely together to reach consensus on the conceptualization of frailty for practice and policy to actually answer the question: with whom should we intervene? Frailty has become a buzzword and many different conceptualizations have emerged in the literature (Dent, Kowal, & Hoogendijk, 2016; Manthorpe & Iliffe, 2015). This disagreement in conceptualization also resulted in the development of an impressive range of screenings instruments such as frailty phenotype, frailty indexes, Groningen Frailty Indicator, Tilburg Frailty Indicator, ISCOPE, U-PRIM, EASY-CARE-TOS and PRISMA-7 (Bleijenbergh et al., 2012; Blom et al., 2016; Gobbens, van Assen, Luijkx, Wijnen-Sponselee, & Schols, 2010; Rockwood & Mitnitski, 2007b; Ruikes et al., 2012; Van Leeuwen et al., 2015). These instruments also have several variations, for example Fried's phenotype has 262 modifications (Dent et al., 2016; Theou et al., 2015). This results in more ambiguity whilst the need of consensus is increasing (Dent et al., 2016). If it remains unclear with whom we intervened in the past, the answer to the question with whom should we intervene in the future becomes more difficult to answer. Also conducting reviews (Carpenter et al., 2015; Clegg, Rogers, & Young, 2014; Dent et al., 2016; Drubbel, 2014; Pialoux, Goyard, & Lesourd, 2012), even resulting in an umbrella review of screening instruments (Apostolo et al., 2017) has not resulted in consensus or a standard instrument of frailty. A good point of departure would be to agree on what specific domains should be included in the conceptualization of frailty.

Besides moving towards consensus in the frailty conceptualization, researchers should also more carefully consider the needs of professionals, policy makers and frail older people themselves. The focus on screenings instruments does not align with their needs. Frail older people, for example, perceive screenings instrument as 'patronizing'. They also indicate that screenings instrument are mostly limited to problems in the physical domains and therefore do not align with the needs of frail older people who experience problems in other domains as well-being and participation (de Bruin, Lette, Baan, & van den Berg, 2016). Professionals increasingly agree that using screenings instruments to screen the GPs elderly population is not useful since the added value is not proven (NHG, 2017; Verlee et al., 2016). According to the professionals, screening is time consuming and not valuable at itself. Also,

professionals do not know how to intervene effectively after the screening (de Bruin et al., 2016; Verlee et al., 2016). This means that the focus on the development of screenings instrument or on modifications of existing screenings instrument might not be justified.

Another point on the future agenda is that we need to move beyond the current approach of differentiating frail older people based on the accumulation of their deficits to an approach in which the distinction is made based on (a combination of) domains of functioning. Translating frailty into a cut-off score based on a screenings instrument or frailty index is too restricted and does no justice to the complexity of frailty. This thesis shows that the type and severity of problems strongly differ between frail older people. The frailty profiles demonstrate that problems do not only occur in the physical domain but also the psychological, social and cognitive domains are deemed important. Moreover, frail older people also suffer from (interacting) problems in different domains. Chronic conditions could go together with severe problems in the psychological and social domain. Additionally, including the combinations of domains in conceptualizing frailty also has another implication, which is that frailty should also account for assets rather than only deficits. In the 1990s the transition from singular frailty problems into combination scores was highly innovative (Dent et al., 2016). Currently, in screenings instruments the number of deficits are still added up to calculate the total score and in frailty indexes the number of existing deficits are divided by the total number of possible deficits. However, these 'deficits' – now also including the psychological, social and cognitive domains - could also function as assets. These assets could help frail older people with coping or self-managing their condition (Rockwood, Fox, Stolee, Robertson, & Beattie, 1994; van Campen, 2011). For example, bad mental health is considered as a deficit in screenings instrument, for example by asking whether people have been feeling down or depressed, or nervous or anxious (Schuurmans et al., 2004). However, good mental health could also help frail older people coping with their deficits. Our research shows that older people in the mild and physically frail profiles have a better perceived health than the older people in the psychologically frail profile. Frailty should therefore move towards the ability to adapt to ageing and deterioration, in line with the positive health movement (Huber et al., 2011) rather than on focusing on the number of deficits. The response to the deterioration is “what distinguished people who managed to maintain well-being, from those who did not” (D’Avanzo et al., 2017). The balance between deficits and assets and the adaptation to deterioration should be acknowledged in relation to frailty and could be useful in determining with whom do we intervene and also how we intervene.

### *Integrated care*

Research on integrated care should be increasingly integrated in order to add value for frail older people, to policy and to practice. As Eyre (2017; 5) stated: “Integrated care is a good example of a policy initiative characterized by enthusiastic system leaders, frustrated practitioners and largely unhelpful research evidence”. Research has mostly focused on the question: is this integrated care intervention effective? The answer to this question is rather short and simplistic (no or yes, on these specific outcomes) and applicable to a specific context which makes evidence fragmented (Eyre et al., 2017). This evidence is mostly disseminated among other researchers rather than among professionals (Schrijvers, 2016). And if the evidence reaches professionals, it appears not to be useful for professionals willing to translate this knowledge in providing integrated care in their daily practice (Eyre et al., 2017). The future research agenda on integrated care needs some redirection to explore the full potential of integrated care.

Firstly, future research should provide a better answer to the question: how do we intervene with whom? Integrated care should take the heterogeneity of frail older people into account. This heterogeneity could be captured into frailty subpopulations. Subpopulations emerged of frail older people experiencing singular problems in either the physical or psychological domain or constellation of problems that extended to the social and cognitive domains. This implies that the full range of health care, social care, welfare and prevention should be covered. Health and social care should be increasingly person-centered and integrated according to the needs of specific frail older people. Research should provide insights in what frail older people benefit from what specific elements of integrated care.

Secondly, other research designs such as mixed-methods evaluations or participatory research should be adopted to do justice to the complexity of integrated care (Eyre et al., 2017; Meyer, 2000). Performing mixed-methods process-evaluations is recommended alongside rigid designs to provide better insights in the black box of integrated care interventions (see also (Moore et al., 2015)). It is important to determine what elements of the intervention were actually implemented and how these elements were used within the intervention (de Vos et al., 2013; Hasson, Blomberg, & Dunér, 2012). Interviews with important stakeholders such as frail older people, their informal caregivers, professionals involved in the intervention and project leaders could identify barriers and facilitators of integration which could be useful for the design and implementation of future interventions (Metzelthin et al., 2013; van Dijk et al., 2016). Process evaluations could elucidate the results of the rigid designs so these results could be translated to other contexts. Moreover, interviews might reveal



outcomes of preventive, integrated care that were not measured in the quantitative evaluations. These results could be process outcomes such as professional satisfaction with the care delivery according to the intervention (Metzelthin et al., 2013; Poot, Caljouw, de Waard, Wind, & Gussekloo, 2016; Wehrens et al., 2017). Also outcomes for frail older people themselves should be deliberated on, for example feelings of independence (Metzelthin et al., 2013) and control (Spoorenberg et al., 2015).

In action research, professionals and researchers, and frail older people could solve also practical problems by and while optimizing the care for frail older people (Eyre et al., 2017; Wehrens et al., 2017). In the action research process, integrated care could adapted to the local context which is important for complex interventions (Craig et al., 2008) and in line with the current movement in the Netherlands from strict evidence-based to context-based practice in health care (RVS, 2017). By continuously adjusting the care practice for frail older people, the learning curve is high for both professionals and researchers. Involvement of frail older people is crucial (Sunderji, Ion, Lin, Ghavam-Rassoul, & Jansz, 2018), also to be able to take the heterogeneity of frail older people into account. Action research could provide insights in how professionals could adapt a holistic approach to frail older people or how professionals could incorporate prevention within integrated care for frail older people. Thus, research providing deeper understanding of integrated care for frail older people should be integrated between professionals, policy makers and researchers with a central role for the frail older people.

However, it is important to emphasize that integrated care research so far has generated value. The scientific value might have been somewhat limited because research has mostly focused on whether integrated care is effective. Still, research has also resulted in other types of value. In the Netherlands for example, the National Care for the Elderly Programme (NCEP) was set up, a large implementation and research initiative, including the WICM. NCEP resulted in an increased participation of older people: researchers and professionals tend to talk more with older people than about older people. Research also led to collaborations in regional networks, including approximately 650 different organizations. And also practical value was created since professionals have indicated that the care delivery has improved (van Rossum & van Hout, 2016; Wehrens et al., 2017).

## **Outcomes**

Important on the future research agenda is to gain more insights in outcomes for frail older people. An important point of attention is to explore how older people are enabled to live independently in the community since national policies strongly



aim at ageing in place and preventing institutionalization (Wiles, Leibing, Guberman, Reeve, & Allen, 2012). Outcomes should be properly aligned with this policy aim and to the adaptation to ageing and deterioration. This is also important for professionals who have to deal with the increasing complexity of older people living in the community longer. Outcomes related to independence are self-management (Cramm, Strating, de Vreede, Steverink, & Nieboer, 2012), goal-setting (Rockwood et al., 2003) but also autonomy and resilience (Wiles, Wild, Kerse, & Allen, 2012). More specifically, this thesis showed that well-being is a promising outcome that deserves further exploration. National policies have increasing interest in the well-being of their citizens (Linton et al., 2016) and maintaining well-being for frail older people is the most important aim of recent guidelines of primary care (NHG, 2017; Verlee et al., 2016). Still, there is no golden standard of well-being and there is an ongoing discussion on the various domains and its measurement (Linton et al. 2016). Domains of well-being are different for frail older people than for the general population. Health seems less important for example (Farquhar, 1995; Puts et al., 2007) which is line with the result that health-related quality of life is not the most suitable outcome measure for frail older people (see also (Comans, Peel, Gray, & Scuffham, 2013). Instruments on well-being of frail older people should be more subtle and focus on things that are important for frail older people and that could still be influenced. Promising instruments aimed at frail older people are the ICECAP-O (Coast et al., 2008) and SPF-IL scale (Nieboer, Lindenberg, Boomsma, & Bruggen, 2005). Other dimensions of well-being are emphasized such as love and friendship (such as attachment in ICECAP-O and affection in SPF-IL) and doing things that make you feel valued (defined as role in ICECAP-O and behavioural confirmation in SPF-IL). Future research should focus on dimensions of well-being and the mechanisms that improve well-being for frail older people, policy and practice.

## Concluding remarks

Integrated care is a complex phenomenon even as the target population of frail older people who have complex and diverse needs. The expectations of integrated care are high but evaluation research increasingly showed that integrated care could not fully live up to these expectations. Also, acknowledging the determined heterogeneity of the frail older people or comprehensive integrated care interventions could not solve this puzzle. This thesis did show that no blue print is available for effective integrated care. Research on integrated care for frail older people should move forwards in order to add value to practice and policy. Research could carefully consider the principles of integrated care: we should and could practice what we preach.

Effective integrated care also requires research that is integrated, continuous, and person-centred. Bridges should be built between research, practice and policy and also researchers should work together. Continuity could be improved by exchanging knowledge (or context-based evidence) between practice and research more quickly in order to keep learning. Person-centeredness is deemed extremely important because **the** frail older person does not exist. The outcomes of integrated care should be closely aligned to the differentiated target populations of frail older people. Because most of all, it is about the older people facing frailty. They should be able to say (as my grandmother always said): “I have had a beautiful life”.

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