ON A QUEST
TO REDUCE FRAGMENTATION
IN THE CARE OF
FRAIL OLDER PEOPLE

Development and implementation
of an e-health intervention

Sarah H.M. Robben
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I

GENERAL INTRODUCTION AND OUTLINE
Background

With the aging of the population in developed countries, the number of frail older people will increase as well. This will result in healthcare systems facing an increased demand for care, while at the same time the number of people in a working age, including people employed in healthcare, will decrease. Unfortunately, the fragmented healthcare systems of many developed countries, including the Dutch healthcare system, are not well equipped to deal with these demographic changes. Therefore, the Dutch government launched the National Care for the Elderly Program, a program specifically focused on improving the care for frail older people. In this thesis, we describe one of the experiments within this program, the Health and Welfare Information Portal (ZWIP), an e-health innovation aimed at improving the care for frail older people by means of facilitating their involvement in their own care, and by means of improving coordination of care through enhancing collaboration among their professionals.

The problem of fragmentation

“The sometimes I have the problem that a patient says: “Last week I went to see someone named A. over at the hospital.” Yes, which department? “Well, I don’t know, it was A., and last time I went to see B.” And then, I have no way of knowing, whether that was at the department of Geriatric Medicine, at the department of Internal Medicine, or whether that person is a municipality worker”

(General Practitioner)

“I know quite a lot, but there keep coming new organizations, they have different abbreviations and different names... I feel I can’t see the wood for the trees. I have problems with that.”

(Frail older person)

“Three quarters of a year later, I receive a message concerning an intake... That really doesn’t help me at all, for they really do try, but too late. And in the mean time, all kinds of things have happened to the patient.”

(General Practitioner)

The quotes above illustrate some of the major problems that professionals and frail older people experience as a consequence of the current fragmentation of healthcare. This fragmentation, which can be defined as “focusing and acting on parts without giving attention to how these parts relate to the evolving whole”, is especially problematic in the care for patients with more complex needs, such as frail older patients. However, this fragmentation is the result of many developments within healthcare systems that were initially considered beneficial. Historically, healthcare systems were designed to deal with the acute diseases presenting the major health problem of that time. However, when chronic diseases became more
prevalent over the years, healthcare systems failed to change accordingly. In addition, the continuing advances of medicine resulted in increased specialization in order to be able to deal with the increasing complexity, and with an already existing separation between health and social services, this resulted in patients receiving care from a number of professionals. As these professionals are mostly paid based on a fee-for-service system, this rewards them for a higher number of treatments or contacts, while it fails to compensate them for the time-consuming activities needed for care coordination. On top of this, the more recent introduction of a free market ideology in healthcare resulted in a large increase in the number of organizations providing healthcare and social services, which again contributed to fragmentation of care.

Currently, care for patients with more complex needs, such as frail older people, is frequently provided by a large number of professionals from a variety of organizations. In such cases, continuity of care, the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with a patient’s medical needs and personal context, is limited. This results in decreased quality of care, as well as in rising healthcare expenditures due to e.g., unnecessary duplicate testing.

Healthcare system changes

In recognition of the fact that the current fragmented healthcare systems are not ready to face the increasing demands that will be placed upon them by the aging of the population, many governments have launched programs aimed at improving their healthcare systems and reducing fragmentation. Except for initiating programs directed at the healthcare system in general, the Dutch government has initiated a program specifically targeting care for frail older people: the National Care for the Elderly Program. This program aims to improve their care by enhancing the identification of frailty; by improving the involvement of frail older people in their own care; and by improving coordination of care across settings and services. However, instead of dictating beforehand which projects should be implemented, the program followed a different approach. First, the program initiated the formation of collaboratives of stakeholders in healthcare and welfare services as well as patient representatives around the Dutch University Medical Centers; for Nijmegen, this was the Care for the Elderly and Welfare Network Nijmegen (ZOWEL NN). Next, these collaboratives were invited to develop, implement, and evaluate transition-experiments which agreed with the aims of the program. These transition-experiments are practical experiments of innovative healthcare interventions which enable learning from the use of the innovation in everyday practice, and which facilitate processes of adaptation and institution building. One of the transition-experiments of ZOWEL NN was the ZWIP, which was intended to facilitate the involvement of community-dwelling frail older people and informal caregivers in their own care, and to improve the collaboration among all healthcare and welfare professionals involved in their care, by means of an e-health intervention. The ZWIP focused initially on primary care, as most community-dwelling frail older people receive the majority of their health and social services within this setting.

Frail older people

As the ZWIP aimed to improve care for frail older people, it is important to consider what constitutes a frail older person, and how frailty is defined. However, even though many articles have been written about frailty, there is still no consensus about its definition. Some authors have defined frailty merely in terms of biomedical functioning, a commonly used definition in this regard is the definition by Fried et al: “Frailty is a biologic syndrome of decreased reserve and resistance to stressors, resulting from cumulative declines across multiple physiologic systems, and causing vulnerability to adverse outcomes”. As a result, frail older people would be older people who are suffering from several biomedical problems. However, many authors consider this definition insufficient, as it fails to give attention to the older person as a whole, and disregards the influence of non-medical issues such as social isolation and financial problems. Therefore, they suggest a more extensive definition of frailty which includes psychological and social factors as well. In this thesis, frailty is defined in accordance with the latter view, using the definition by Gobbens et al: “Frailty is a dynamic state affecting an individual who experiences losses in one or more domains of human functioning (physical, psychological and social) that are caused by the influence of a range of variables and which increases the risk of adverse outcomes”. Consequently, the frail older people described in this thesis can be frail for suffering from a range of problems, which may include multimorbidity, cognitive problems, sensory losses, falls, psychological problems, and problems in their social environment.

Patient involvement

The first aim of the ZWIP was to improve the care for these frail older people by enabling them to become involved in their own care. Historically, the involvement of patients in their own care has been limited. Doctors focused on diseases and treatments, while often neglecting patients’ illness experiences as well as patients’ values and preferences. However, over the last decades, the involvement of patients in their own care has been increasingly advocated, for several reasons. First, because the inescapable fact is that patients are involved in their own care, as they decide on a daily basis whether they will follow the advice provided by professionals or whether they will take the prescribed medication. Second, because patient involvement is considered a patients’ right. Last, because studies
have shown that patient involvement can have positive effects on patient outcomes. Nevertheless, older people tend to be highly heterogeneous in their preferences for involvement, and these preferences do not only differ between patients, but also within a specific patient, as they are likely to change with time, stage of disease, and the type of decision at hand. Therefore, it is important for professionals to assess patients’ individual preferences for involvement, and to enable them to become involved accordingly. However, several barriers exist for enabling the involvement of frail older patients in their own care, including time constraints, professionals’ attitudes towards involving (older) patients, and barriers related to frail older people, such as hearing impairments or (severe) cognitive problems.

**Coordination of care**

The second aim of the ZWIP was to improve coordination of care by increasing collaboration among all healthcare and welfare professionals involved in the care of a specific frail older person. As care for frail older people is often provided by a number of professionals from a multiplicity of organizations, this puts them particularly at risk for receiving fragmented care. Consequently, coordination of their care is badly-needed.

Coordination of care can be defined as “the deliberate organization of patient care activities between two or more participants (including the patient and informal caregiver) involved in a patient’s care to facilitate the appropriate delivery of healthcare and welfare services”. Therefore, it is not necessarily a task for professionals alone, as frail older patients and their informal caregivers can be involved in coordination as well. Important requirements for this coordination are the timely exchange of information between all professionals involved and the patient and informal caregiver, as well as interprofessional collaboration. However, studies have shown that several problems exist with the exchange of information between for example hospital-based and primary care physicians, as well as with collaboration among professionals.

**E-health**

A frequently mentioned solution to these problems, which has the potential to facilitate both patient involvement and coordination of care is the use of information technology, i.e., e-health. This can facilitate patient involvement, by allowing patients to view their own electronic health records, by providing online educational materials and self-management support tools, and by enabling electronic communication with their professionals. On the other hand, multidisciplinary shared electronic health records and systems that support communication between professionals can facilitate the sharing of information and collaboration among professionals, thus facilitating coordination of care. However, several barriers for the adoption of e-health need to be addressed, such as time-constraints, funding, privacy concerns, and anxiety that e-health will have a negative impact on the patient-professional relationship. An important and powerful way to address some of these barriers and to facilitate the adoption of e-health interventions is the involvement of future users in the development process.

**Intervention Mapping**

For the development of the ZWIP, Intervention Mapping was used, which is a method for the evidence- and theory-informed development of complex interventions (interventions consisting of several interacting components). Intervention Mapping consists of six consecutive steps, in which the future target populations are involved extensively: (1) a thorough needs assessment, (2) deciding on the goals the intervention should achieve through designing matrices of change objectives, (3) the selection of theories and strategies underlying the intervention, (4) the design of the separate intervention components, (5) planning for the implementation of the intervention, and (6) planning for the evaluation of the program. Although Intervention Mapping has mostly been used for the development of health promotion programs in the past, its thoroughness, and especially its strong focus on the involvement of the future target populations, make it a very suitable method for the development of a complex e-health intervention focused on facilitating patient involvement and improving interprofessional collaboration such as the ZWIP.

**Aims and outline**

In this thesis we describe the development and the implementation of the Health and Welfare Information Portal (ZWIP), an e-health intervention which aims (1) to facilitate the involvement of community-dwelling frail older people and their informal caregivers in their own care, and (2) to increase collaboration among primary care professionals involved in their care. We will describe the studies conducted during this development and implementation process in three consecutive chapters.

In **Chapter 2**, we describe two studies which were conducted to inform the development of several components of the ZWIP program, targeting the involvement of frail older people in their own care. **Chapter 2A** presents the results of a qualitative study which explored the experiences of frail older people and...
informal caregivers with receiving information from healthcare professionals and the preferences that they have for receiving information. In Chapter 2B, we describe the goals that community-dwelling frail older people have. Knowledge of these goals can help professionals to provide frail older people with care that is more patient-centered. Last, in a small addendum in Chapter 2Bis, we argue that more patient involvement is not likely to result in rising healthcare expenditures, as patient involvement will merely enable professionals to focus the care delivered on what is desired most by patients.

Chapter 3 focuses on the development of the ZWIP program. In Chapter 3A, we describe the development of the complete ZWIP program by means of Intervention Mapping. This was done in six consecutive steps in which future users were involved extensively. In Chapter 3B, we provide a more detailed description of the development of and first experiences with an important aspect of the ZWIP program, i.e., a method for discussing goals with community-dwelling frail older people.

In Chapter 4, we describe the implementation of the ZWIP program. In Chapter 4A, we evaluate the effects of the interprofessional educational program, one of the main implementation strategies, on interprofessional collaboration among primary care professionals. In Chapter 4B, we describe the implementation process of the ZWIP. This includes a description of the outcomes of the implementation process, the barriers and facilitators experienced during the implementation process, as well as recommendations for a future implementation.

Chapter 5 provides a summary and a discussion of the main findings of this thesis.

References


2

FACILITATING
PATIENT INVOLVEMENT
Preferences for receiving information among frail older adults and their informal caregivers: A qualitative study

Sarah Robben, Janneke van Kempen, Maud Heinen, Sytse Zuidema, Marcel Olde Rikkert, Henk Schers, René Melis

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Abstract

Background: Patient involvement in clinical decision making is increasingly advocated. Although older patients may be more reluctant to become involved, most do appreciate being informed. However, knowledge about their experiences with and preferences for receiving information is limited, and even less is known about these topics for frail older people.

Objective: To explore the experiences of frail older people and informal caregivers with receiving information from healthcare professionals as well as their preferences for receiving information.

Methods: We conducted semi-structured interviews with frail older people (n=11; 65-90 years) and informal caregivers (n=11; 55-87 years). Interviews were transcribed verbatim and analyzed using a grounded theory approach.

Results: Frail older people and informal caregivers varied in their information needs and discussed both positive and negative experiences with receiving information. They preferred receiving verbal information from their physician during the consultation; yet would appreciate receiving brief, clearly written information leaflets in addition. They employed several strategies to enhance the information provided, i.e., advocacy, preparing for a consultation and searching their own information. Contextual factors for receiving information, such as having enough time and having a good relationship with professionals involved, were considered of great importance.

Conclusion: Participants described a wide range of experiences with and preferences for receiving information. However, even if the information provided would meet all their preferences, this would be of limited significance if not provided within the context of an ongoing trusting relationship with a professional, such as a general practitioner or practice nurse, who genuinely cared for them.

Introduction

Over the last years, patient involvement in clinical decision making has been increasingly advocated. Except for being generally valued for moral and ethical reasons,\(^1\) enhanced patient involvement can also lead to improved health outcomes,\(^2,4\) increased patient satisfaction,\(^2,3\) and decreased costs of care.\(^5,6\) Therefore, patient involvement in clinical decision making has become an important concept for patients, professionals, and policymakers alike.

Patients vary in the degree to which they wish to be involved in decision making, and older people are less likely to prefer an active role.\(^7\) Also, they have quite a different understanding of what involvement means than professionals. For most older people, building a trusting relationship, having enough time and receiving information is fundamental for involvement, whilst they give limited attention to the actual decision making process. Although not all older patients want to be involved in the actual decision making, most do appreciate being thoroughly informed.\(^8\) Therefore, informing older people seems an essential first step towards facilitating their involvement.

However, knowledge about older people’s experiences with and preferences for receiving information is limited, and even less information is available about the experiences and preferences of frail older people. Yet, due to the complexity of demands placed on them,\(^9\) they are likely to have an even higher need for information. Therefore, as part of a larger study aimed at improving care for frail older people, we explored the experiences of frail older people and informal caregivers with receiving information from healthcare professionals as well as their preferences for receiving information.

Methods

We conducted a qualitative study, which consisted of semi-structured interviews with frail older people and informal caregivers of frail older people. The study was carried out in the provinces Gelderland and Noord-Brabant, the Netherlands.

Participants

Frail older people (≥ 65 years) and informal caregivers, who were expected to meet the eligibility criteria, were informed about the study by their general practitioner (GP) or welfare organization. Frailty was defined as having one or more of the following problems: cognitive impairment, handicaps, psychosocial problems, multimorbidity, polypharmacy or social isolation. Because of the nature of the study, we excluded people from participating who did not understand Dutch; had
speech disorders or severe hearing loss; or had a life expectancy of ≤ six months. Further, we excluded people with severe cognitive impairment that interfered with their ability to make an informed decision about participation or to express their views. People who were interested in participating were contacted by a researcher to determine eligibility. Written informed consent was given at the time of the interview. We used purposive sampling to arrange for a diverse study population, which reflected the heterogeneity of frail older people. Therefore, we aimed for variation in living situation, socioeconomic position, health and social problems, as well as for participants who had a variety of experiences with the study topic.

Data collection and analysis
We developed a topic list for the interviews using evidence from previous studies. Members of the research group, which consisted of several experts in geriatric medicine or primary care, then discussed this topic list until consensus was reached. During the study, adjustments to the topic list were made whenever preliminary analysis of data demonstrated that this was required. The final topic list is shown in Table 1.

Table 1 Interview guide

<table>
<thead>
<tr>
<th>Question</th>
<th>Frail older people (n=11)</th>
<th>Informal caregivers (n=11)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Often, many professionals are involved in the care of older people like yourself/your relative, such as the general practitioner, a practice nurse, etc.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. Could you tell me about your experiences with those professionals in general?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. In your/your relative’s contacts with these healthcare professionals you receive information.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a. What do you think of the information you receive about your own/your relative’s health situation?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. If there is something you could improve in the information you receive from your healthcare professionals, what would you prefer?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Between March and December 2009, semi-structured interviews were conducted at the homes of participants by one of the researchers (JvK, SR). Both researchers were physicians who had never been involved in the care of the participants. Interviews were tape-recorded and transcribed verbatim; a grounded theory approach was used for data collection and analysis. Atlas.ti software was used to support this. The first interviews were coded collectively by both researchers (JvK, SR), while the next interviews were coded by one researcher and checked by the other. In case of disagreement about coding, discussion followed until consensus was reached. We thoroughly explored deviant statements and new emerging themes in subsequent interviews. Interviews were conducted until theoretical saturation was achieved.

Results
Twenty-two interviews were conducted with frail older people and informal caregivers who were not related to the included frail older people (with one exception). The characteristics of the frail older people and informal caregivers are shown in Table 2. During the interviews, several themes emerged. Participants discussed content of information; preferences for receiving information; strategies used to enhance the information supply; and preferences for the context in which information is provided. Figure 1 provides an overview of the items discussed. As there were no major differences in viewpoints between frail older people and informal caregivers, we did not analyze their statements separately.

Table 2 Characteristics of participants

<table>
<thead>
<tr>
<th></th>
<th>Frail older people (n=11)</th>
<th>Informal caregivers (n=11)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, average (range)</td>
<td>78.8 (65-90)</td>
<td>70.2 (55-87)</td>
</tr>
<tr>
<td>Male, number (%)</td>
<td>2 (18.2)</td>
<td>2 (18.2)</td>
</tr>
<tr>
<td>Social economic status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low, number (%)</td>
<td>4 (36.4)</td>
<td>3 (27.3)</td>
</tr>
<tr>
<td>Intermediate, number (%)</td>
<td>3 (27.3)</td>
<td>3 (27.3)</td>
</tr>
<tr>
<td>High, number (%)</td>
<td>4 (36.4)</td>
<td>5 (45.5)</td>
</tr>
<tr>
<td>Cognitive problems, number (%)</td>
<td>2 (18.2)</td>
<td></td>
</tr>
<tr>
<td>Handicaps, number (%)</td>
<td>6 (54.5)</td>
<td></td>
</tr>
<tr>
<td>Psychosocial problems, number (%)</td>
<td>3 (27.3)</td>
<td></td>
</tr>
<tr>
<td>Multimorbidity, number (%)</td>
<td>6 (54.5)</td>
<td></td>
</tr>
<tr>
<td>Polypharmacy, number (%)</td>
<td>10 (90.9)</td>
<td></td>
</tr>
<tr>
<td>Social isolation, number (%)</td>
<td>5 (45.5)</td>
<td></td>
</tr>
<tr>
<td>Living accommodation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Own home, number (%)</td>
<td>9 (81.8)</td>
<td></td>
</tr>
<tr>
<td>Old people’s home or nursing home, number (%)</td>
<td>2 (18.2)</td>
<td></td>
</tr>
</tbody>
</table>
Participants varied in their information needs, especially in the level of detail desired for the information provided. Some preferred a limited amount of general information, e.g., because they felt that extensive information would be too difficult to understand or because they preferred to search for their own information; others wanted extensive and detailed information.

“Well, it shouldn’t be too [extensive], because then I won’t understand it of course...because I’m just an ordinary person, I haven’t learned anything” (Patient9: Female, 80 years)

“For us it was some general information, and then we continue the search by ourselves...I think the little bit of mistrust we have, it’s in our family, [wanting to] ferret it out by ourselves anyway” (Informal caregiver2: Female, 55 years)

“But you have to make sure that you know as much as possible about it.” (Informal caregiver6: Female, 80 years)

Participants remarked that they would like information about their medical condition, prognosis, and about problems they might face over the course of the disease. Participants also said they had a need for practical guidelines about e.g., caring for a relative with dementia. Lastly, they described a need for information on how to arrange healthcare and welfare services.

“If I had to arrange it myself, I would not get any [care] at all. I don’t know where I should go…” (Patient8: Female, 85 years)

There also was diversity in participants’ opinions about whether they had received sufficient information. Some participants described occasions where they felt insufficiently informed by the professional involved. They felt they had not received enough information about the disease and prognosis, or about changes in their relative’s medication in the nursing home.

“Because he [physician] would cut back [medication] without telling me. And the result was ... that [my husband] became more aggressive again. And we had agreed that if he would change medication, he would let me know” (Informal caregiver7: Female 55 years)

However, others described instances in which they were informed completely to their satisfaction.

“With my own GP...And he explains it to me in detail...and I am listening attentive to what he tells me about it...I think he does that all the time” (Informal caregiver1: Male, 80 years)

“Yes, they explain everything quite well” (Patient6: Female, 81 years)

In relation to the content of information, some participants also described receiving contradictory information or being confronted with different points of view among professionals. They felt this was particularly confusing.

“And then he said: your heart valve is a bit open and therefore, you should have each year, you should have an examination. And, they never do it…I have said so many times that I would like to have it done, but they don’t…I think those things are strange” (Patient9: Female, 80 years)

Preferences for receiving information

Several participants discussed that they had really appreciated it when information was presented visually to them, e.g., sketched or demonstrated on a scale model; or when they were asked to repeat the information provided to check their understanding.

“And then he explained about the kidneys and exactly how everything was and then he drew it on a piece of paper. And then he says: Did you understand it? I say, yes, I really understood it very well. Then he says: then draw it, explain it to me...I liked that, I really thought it was very good...” (Patient9: Female, 80 years)

Participants preferred information to be provided by their physician during the consultation. However, in addition, they would like to receive a written information leaflet with information about the topics discussed. Participants considered this useful as they were usually very nervous at a doctor’s appointment, making it difficult to remember the information provided, or as they might forget things after a few months.
“Yes, perhaps I would [like a written information leaflet] …because if you’re there… you’re extremely nervous, eh. Let’s be fair, you go to a cardiologist and then you have an idea like, well I hope everything is OK, so, you’re already nervous” (Patient8: Female, 85 years)

Some participants had experienced receiving such written information leaflets, others had not. Participants felt that written information leaflets should provide information in a clear and understandable manner; should not include too much information; and should be to the point. One informal caregiver described what she perceived as the ideal situation for receiving information:

“I still think that it is something of the doctor, who should have some kind of written information leaflet there and say: why don’t the two of you read this at home, and if you have any questions left, or if there are any problems, you can always contact my assistant…” (Informal caregiver4: Female, 71 years)

**Strategies to enhance the information supply**

Participants used several strategies to enhance the quality or amount of information provided by professionals, these included advocacy, i.e., bringing their children to their doctor’s appointment to receive more information.

“Once, I brought X … for X asked more questions, of course, and perhaps I didn’t. And then, he wrote everything down, and that was quite a report, which was good…yes, he really had asked many questions and had been given the answers needed” (Patient2: Male, 85 years)

Others thoroughly prepared for their contacts with healthcare professionals by making a list of questions in advance or writing down important symptoms, and making sure these were discussed during their visit.

“No, I write everything down on paper in advance… I have been doing that for years, it is really my way of, otherwise, I will forget things [at the doctor]” (Patient3: Female, 65 years)

Participants reported searching for their own information, either in advance to prepare for a consultation or afterwards to seek more information about the topics discussed or services available. Sources used to find this information included magazines, written information leaflets, books, television programs, the internet, and patient organizations. One participant went to the GP to explain things mentioned by the specialist. Several participants mentioned that they felt they were quite capable of searching and finding their own information; however, they were worried that other people would not be able to do so.

“So, in the period that my mother-in-law was quickly deteriorating, we searched the internet, read books and you also receive some information, er, yes, also from each other” (Informal caregiver8: Female, 55 years)

“Since I heard about this, er, atrial fibrillation… it was Friday afternoon so I went home, and I would receive a call from the cardiologist on Monday…So then I thought, well, I’m going to look on the internet, you search for atrial fibrillation and well, you can look for ages” (Patient10: Female, 65 years)

Another major theme mentioned by many participants was the need to be empowered, by asking questions and being bold, in order to receive the information required. Whereas some blamed professionals for this, others felt that they were responsible too for not receiving sufficient information, because of their lack of assertiveness.

“Because doctors are not so obliging, that you dare to ask questions if you are not that empowered yourself…it is their entire behavior, and that they almost turn around again towards their computer” (Informal caregiver4: Female, 71 years)

“But it’s mainly about thoroughly asking questions, and also… it’s about the character eh, of the patient, whether he is assertive. And I am a little bit forbearing, let’s be fair. And one shouldn’t be, at the doctor. You really need to dig in.” (Patient2: Male, 85 years)

**Preferences for the context in which information is provided**

Participants reflected on the importance of a good relationship with professionals within the context of receiving information. They discussed the importance of listening to patients and taking them seriously; respecting them; and the importance of being friendly and genuinely interested. Participants described a wide range of experiences concerning these topics, varying from very positive to very negative.

“But not explaining anything and saying, when you ask for it, as he never had an exercise tolerance test no more: ‘er, yes, no, we won’t do that’. Well, why not? He won’t explain it” (Informal caregiver10: Female, 80 years)

“I remember, when I was really depressed and he would put his arm around your shoulder and then he would say, come on, eh, and…you felt he was genuinely concerned about you” (Patient7: Female, 80 years)

In addition, participants discussed that they had really appreciated it when professionals took time for them. Several discussed that they had often felt hurried through a doctor’s visits, and that a ten minute visit was just not enough for an older patient, e.g., because of hearing problems, physical impairments or cognitive impairment.

“And sometimes I say, doctor, my husband did not hear you, shall I tell him? I think, well, that is clear enough, eh…yes, and also too fast, because that is also his problem, of course, when things go fast, he cannot comprehend them anymore” (Informal caregiver4: Female, 71 years)

“And then even the nicest doctor is fast, fast, fast. And I am thoroughly aware of his problem, of course, when things go fast, he cannot comprehend them anymore” (Informal caregiver10: Female, 80 years)

“Since I heard about this, er, atrial fibrillation… it was Friday afternoon so I went home, and I would receive a call from the cardiologist on Monday…So then I thought, well, I’m going to look on the internet, you search for atrial fibrillation and well, you can look for ages” (Patient10: Female, 65 years)
Facilitating patient involvement

Having said this, participants were willing to make excuses for the shortcomings of professionals in these areas. They felt it was understandable, as professionals were very busy.

A final highly valued contextual factor was provider continuity; i.e., having the same professional over time. Participants felt that their own professional had extensive knowledge of their (relative's) medical history and social background, which made it unnecessary to repeat this information with each visit. However, most important in relation to the provision of information was that they considered provider continuity a prerequisite for building a trusting relationship, which was considered necessary to assess the value of the information provided.

“…but the trust, er, that you receive the same information over time…that you believe in…I think, if I don’t have faith in someone, then I would, er, less quickly accept what he says, whether that, well, not that that isn’t the truth, but, er, I would put less of an effort in it…” (Patient10: Female, 65 years)

Discussion

This study has shown that frail older people and informal caregivers have diverse information needs: while some participants prefer receiving limited general information, others prefer extensive and detailed information. Participants did not always consider these information needs met during their contacts with healthcare professionals. Other studies, studying different populations, have consistently shown that patients’ information needs are not always met. Yet, meeting information needs has been shown to be associated with increased patient satisfaction and quality of life.

Participants in this study did acknowledge that informing frail older patients may present professionals with a challenge. They were thoroughly aware that professionals already struggle with time constraints, and that a consultation with a frail older person often requires more time than they have available, for several reasons. These include hearing problems or cognitive problems, which may limit frail older persons’ abilities to readily understand the information provided. These factors, combined with their overall reluctance to ask questions and fear of bothering busy professionals with unnecessary questions, might make frail older people especially at risk for receiving insufficient information. Nevertheless, even though there are time constraints, stimulating frail older people and their informal caregivers to employ the strategies discussed earlier to improve the provision of information, such as bringing along a relative, or making a list of questions in advance, can help increase the amount of information provided, while not necessarily taking that much more time.

However, meeting information needs was not the only important aspect for participants. They considered the context in which the information was provided just as important. For information to be passed on effectively, it should be provided by a trusted and caring professional, who takes enough time and who has been providing care to the frail older person over an extended time period. The value of a good relationship with professionals has been consistently described by older people participating in other studies as well. Therefore, enabling provider continuity is very important.

To our knowledge, our study is among the first to address frail older people and informal caregivers’ experiences and preferences for receiving information. However, it had some limitations. First, although we aimed to explore the views of frail older people, we had to exclude some of the frailest people (e.g., those with severe cognitive problems, speech disorders or severe hearing loss) from participating, as they would not have been able to complete the interview. This may have affected the generalizability of our results. Second, we cannot exclude that people who had experienced more problems with receiving information were more willing to participate. Last, although we asked participants to reflect on information provided by all healthcare professionals, they most often discussed information from physicians. This may have been provoked by the interviewers being physicians; yet, physicians simply are an important source of information for these participants.

In summary, frail older people and informal caregivers participating in this study varied in their information needs and discussed both positive and negative experiences with receiving information. They preferred receiving verbal information from their physician during the consultation; yet would appreciate receiving brief, clearly written information leaflets in addition. They employed several strategies to enhance the information provided, i.e., advocacy, preparing for a consultation and searching their own information. However, participants considered the context in which the information was provided equally important as the information itself. For them, even if the information provided would meet all their preferences, this would be of limited significance if not provided within the context of an ongoing trusting relationship with a professional, who genuinely cared for them.

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References

Care-related goals of community-dwelling frail older patients

Sarah Robben, Marieke Perry, Marcel Olde Rikkert, Maud Heinen, René Melis

Abstract

Background/Objectives: Patients are increasingly encouraged to become involved in clinical decision making. However, the extent to which patients wish to be involved differs, with most older patients preferring their physician to decide. Yet, they do want their physician to take their concerns and wishes into account when making care decisions, which stresses the importance of knowing what a particular older patient values most. Therefore, as a first step towards shared decision-making, this study aimed to identify the care-related goals of community-dwelling frail older patients.

Design: Retrospective study

Setting: Primary care

Participants: Community-dwelling frail older patients (n=366)

Measurements: Goals were identified using the datasets of two previous studies, which identified goals with an open-ended question: If there is one thing we can do for you to improve your situation, what would you like? Goals were then characterized by domain and specificity.

Results: 140 participants identified 162 goals that concerned several domains. These included: health problems (20.4%), mobility (15.4%), emotions (9.9%), independence and autonomy (3.7%), social and family relationships (17.3%), activities (4.9%), living accommodation (18.5%), healthcare and welfare services (6.2%), finances (1.2%) and other (2.5%). Of these goals, 12.3% were global (e.g., staying healthy), 50.6% were intermediate (e.g., not forgetting so much) and 37.0% were specific (e.g., a referral to the department of geriatric medicine to examine cognitive problems).

Conclusion: This study has shown that the care-related goals of community-dwelling frail older patients are diverse and cover several domains. These domains concerned well-being just as much as they concerned health and functioning. Having knowledge of the goals a particular patient has, will assist clinicians in providing care that is more patient-centered.

Introduction

In recent years patients have been increasingly encouraged to participate in clinical decision making. However, the extent to which patients wish to be involved differs, with older patients preferring a less active role. In fact, most older patients prefer their physician to make the final decisions about their medical care. Yet, they do wish to be informed and they want their physician to take their concerns and wishes into account when making these care decisions. Therefore, it is important for clinicians, as a first step towards shared decision making, to know what a particular patient values most and what his or her care-related goals are.

Goals of older patients are diverse and may differ from the goals set for the patients by their healthcare teams. This underlines the importance of gaining knowledge of the goals a specific patient has, which can be done by incorporating goal discussions into the clinical encounter. However, a study by Schulman-Green et al. has shown that time constraints, a focus on symptoms, having the impression that either patients or clinicians are not interested in goal discussions and the incorrect assumption that all patients have the same goals (e.g., to be healthy), limit the application of these goal discussions in everyday clinical practice.

Despite these barriers, discussion of goals is worthwhile for several reasons. First, goal-setting can facilitate shared decision making by enhancing communication and improving agreement on treatment goals. Second, incorporating patients’ goals into the treatment plan, increases the likelihood that the plan will be followed, which can improve the outcomes of clinical interventions.

Several methods to discuss goals with patients have been described. These include interviewing patients using open-ended questions in order to elicit their goals; using a predefined goal-setting menu to guide the interview; and assisting patients in formulating their goals by the use of an agenda setting chart, which shows patients examples of goals they may want to work on. For the last two methods to be most effective, it is imperative that they build on existing knowledge of the goals of their target population. Since knowledge about the goals frail older people have is still limited, the primary aim of this study was to give an overview of the care-related goals community-dwelling frail older patients have.

Methods

For this study, we used data collected during two studies. The first was the Dutch EASYcare study, which was conducted between 2003 and 2005 in and around the city of Nijmegen, the Netherlands. This study evaluated the effects of an in-home intervention program compared with usual care. Participants were frail older people...
identified one or more goals. For six participants, these goals were not written down in the case records, leaving 140 participants whose goals were recorded. For 101 (40.9%) participants the records stated that no goal was identified. Reasons for not identifying a goal were: not having a goal, e.g., because of being perfectly content (n=45; 44.6%), not being able to identify a goal due to cognitive or physical problems (n=14; 13.9%), not being asked to identify a goal, mostly because the nurse forgot to ask for goals or because it would be done later (n=30; 29.7%) or unknown (n=12; 11.9%).

Characteristics of participants are shown in Table 1. We found no significant differences on these baseline characteristics between participants who did identify one or more goals and those who did not.

Table 1 Characteristics of participants

<table>
<thead>
<tr>
<th></th>
<th>Total (n=247)</th>
<th>Goal(s) identified (n=146)</th>
<th>Goal not identified (n=101)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male, number (%)</td>
<td>75 (30.4)</td>
<td>41 (28.1)</td>
<td>34 (33.7)</td>
<td>.348a</td>
</tr>
<tr>
<td>Age, average (range)</td>
<td>81.2 (61-99)c</td>
<td>81.2 (61-99)c</td>
<td>81.3 (62-94)d</td>
<td>.923c</td>
</tr>
<tr>
<td>MMSE, average (range)</td>
<td>23.1 (9-30)</td>
<td>23.5 (10-30)</td>
<td>22.5 (9-30)</td>
<td>.114c</td>
</tr>
</tbody>
</table>

*χ² test; a n=230; b n=135; c n=95; d student’s t-test; e n=207; f n=122; g n=85

Goal domains

The 140 patients whose goals were recorded identified a total of 162 goals that concerned several domains. Interrater agreement (SR and MP) about the domains these goals belonged to was 87.7%. Goals relating to health problems (20.4%), living accommodation (18.5%), social and family relationships (17.3%) and mobility (15.4%) were mentioned most frequently (Table 2). Below, we will discuss the goals mentioned for each domain in more detail. Illustrative examples of the goals mentioned will be provided for each domain.

Health problems: In the domain of health problems, many (n=10; 30.3%) of the goals mentioned were related to cognitive problems. Participants wanted to improve their memory, or at least they did not want their memory to deteriorate any further. Further, goals related to getting to know more about the nature of their cognitive problems. Other goals frequently mentioned related to improvement of general health and improvement in either hearing or vision.

Would like to gain understanding of the memory problems and to be treated with medication, if possible (Female, 80 years)

Results

Participants

A total of 366 patients participated in the intervention groups of both studies. Of these, 85 participated in the Dutch EASYcare Study and 281 participated in the study that investigated the effects of an EASYcare based DTP. For 119 patients, there was no information recorded on whether or not goals were discussed or identified. Of the remaining 247 participants, 146 (59.1%) were reported to have

aged 70 years and over who lived in their own home or in a retirement home and were referred by their General Practitioner for problems with cognition, nutrition, behavior, mood or mobility. The second study, which was conducted between 2006 and 2009 in the province of Gelderland, the Netherlands, investigated the effects of an EASYcare based Dementia Training Program (DTP) for pairs of General Practitioners and nurses. The targeted population consisted of frail older people suspected of cognitive impairment.

In the intervention arm of both studies, the EASYcare assessment was used for in-home geriatric assessment of the target population. This assessment was administered by a nurse, who was, depending on the study, either a geriatric specialist nurse or a primary care nurse. In the assessment, an item was included aimed at identifying patients’ goals: “If there is one thing we can do for you to improve your situation, what would you like?” These goals were then recorded by the geriatric specialist nurse, either directly following the assessment or during the telephone consultation that was done to coach the primary care nurses as part of the DTP.

We retrospectively identified these goals from the case record forms. Although the goal-setting item asked for one goal, some patients mentioned more than one. Since they had not been asked to prioritize their goals, we included all these goals in our study. After identification from the record forms, the goals were reviewed by two of the authors independently (SR and MP), and were classified according to the taxonomy for goal-setting in the care of persons with dementia as developed by Bogardus et al. This taxonomy characterizes goals on the attributes: domain, specificity, time frame and level of challenge. Although the taxonomy provides several goal domains, these were not readily applicable to the goals of our study population. Therefore, we made some adjustments to these domains. Further, since our databases did not include data on the attributes time-frame and level of challenge as perceived by the patient, we did not classify the goals on these attributes. In case of disagreement about classification between the two reviewers, consensus was reached through discussion. Goals that concerned more than one domain were classified according to the domain they concerned most.

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Facilitating patient involvement

During the interviews, patients prioritized different goals that varied from individual to individual and across different domains. These domains covered well-being as much as health and functioning. To the authors’ knowledge, this study is one of the few that add to the evidence concerning goals of frail older people. In 2005, Huang et al. reported on the goals of people of 65 years and older with type 2 Diabetes Mellitus. They found that patients’ main healthcare goals were focused on maintaining independence and their mobility.

### Mobility
In the domain of mobility, many goals related to being able to walk better, prevention of falling, being able to go somewhere independently and obtaining an aid to improve mobility, such as a stairlift.
- Being able to walk from the old people’s home to the shop at the gas station on my own (Female, 81 years)
- Hopes not to fall anymore and that her fear of falling decreases (Female, 99 years)

### Emotions
In the domain emotions, goals were diverse including goals relating to acceptance, feeling more comfortable and reduction of anxiety.
- Wants to feel more comfortable with respect to his mood (Male, 74 years)
- Wants to accept that his lifework won’t be finished without feeling a failure himself (Male, 81 years)

### Independence and autonomy
In the domain independence and autonomy goals were related to staying independent, the need to be taken seriously and acceptance of autonomy by others.
- Above all, wants to stay independent (Female, 75 years)

### Social and family relationships
In the domain social and family relationships goals having more social relationships, resolving loneliness, having a new life companion, having more contact with the children, having someone to depend on in case of emergency and wishing to unburden a caregiving spouse.
- Would like to have a friend that visits her every week, so she has something to look forward to (Female, 68)

### Activities
Goals in this domain all concerned the wish to have more activities to be occupied with.
- Wants more activities during the day (Male, 76 years)
- Wants the coziness from former days back; he loved music and going out (Male, 75 years)

### Living accommodations
Goals in the domain living accommodations broadly concerned wanting to continue living in their own home, wanting to move to an accommodation where more care or facilities were present, such as an old people’s home, or wanting to go back to their old house or living environment.
- To continue living in her current house, but knows that some things need to be taken care of, in order to make that possible (Female, 91 years)
- To be admitted to an old people’s home soon (Female, 82 years)

### Healthcare and welfare services
In general, goals in this domain concerned the wish to receive more assistance from healthcare or welfare services, to obtain a referral or not being content with the care provided.
- Wants the homecare nurses not to mash the food (Female, 87 years)
- Would like to get one extra day of daycare (Female, 86 years)

### Finances
Only two participants mentioned goals related to finances. These goals were obtaining clarity about the payments that were due to the homecare organization and resolving financial problems.

### Goal specificity
Participants’ goals varied in their specificity from global (e.g., staying healthy) to intermediate (e.g., not forgetting so much) to specific (e.g., a referral to the department of geriatric medicine to examine the cognitive problems). Interrater agreement on goal specificity was 79.0%. Of the 162 goals, 12.3% were global, 50.6% were intermediate and 37.0% were specific. Specificity of goals varied across domains, with ten out of ten goals being specific in the domain of healthcare and welfare services, and zero out of eight goals being specific and seven of eight goals being intermediate in the domain of activities (Table 2).

#### Table 2 Goals of participants

<table>
<thead>
<tr>
<th>Domain</th>
<th>Number of goals (%) (n=162)</th>
<th>Specific</th>
<th>Intermediate</th>
<th>Global</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health problems</td>
<td>33 (20.4)</td>
<td>10 (30.3)</td>
<td>14 (42.4)</td>
<td>9 (27.3)</td>
</tr>
<tr>
<td>Mobility</td>
<td>25 (15.4)</td>
<td>9 (36.0)</td>
<td>15 (60.0)</td>
<td>1 (4.0)</td>
</tr>
<tr>
<td>Emotions</td>
<td>16 (9.9)</td>
<td>4 (25.0)</td>
<td>9 (56.2)</td>
<td>3 (18.8)</td>
</tr>
<tr>
<td>Independence and autonomy</td>
<td>6 (3.7)</td>
<td>3 (50.0)</td>
<td>1 (16.7)</td>
<td>2 (33.3)</td>
</tr>
<tr>
<td>Social and family relationships</td>
<td>28 (17.3)</td>
<td>11 (39.3)</td>
<td>14 (50.0)</td>
<td>3 (10.7)</td>
</tr>
<tr>
<td>Activities</td>
<td>8 (4.9)</td>
<td>0 (0.0)</td>
<td>7 (87.5)</td>
<td>1 (12.5)</td>
</tr>
<tr>
<td>Living accommodation</td>
<td>30 (18.5)</td>
<td>11 (36.7)</td>
<td>19 (63.3)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Healthcare and welfare services</td>
<td>10 (6.2)</td>
<td>10 (100.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Finances</td>
<td>2 (1.2)</td>
<td>1 (50.0)</td>
<td>1 (50.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>Other</td>
<td>4 (2.5)</td>
<td>1 (25.0)</td>
<td>2 (50.0)</td>
<td>1 (25.0)</td>
</tr>
</tbody>
</table>

### Discussion
This study has shown that care-related goals of community-dwelling frail older people differ between individuals and cover several domains. These domains concerned well-being just as much as they concerned health and functioning. To the authors’ knowledge, this study is one of the few that add to the evidence concerning goals of frail older people. In 2005, Huang et al. reported on the goals of people of 65 years and older with type 2 Diabetes Mellitus. They found that patients’ main healthcare goals were focused on maintaining independence and their...
activities of daily living. In a study by Bradley et al., which identified care goals described by patients undergoing outpatient geriatric assessment, and their informal caregivers, physicians and case managers, most common goal areas for patients were maintaining general health and well-being, and maintaining functioning and independence. In our study, we also found that many participants had goals relating to health and functioning, however, goals relating to well-being were mentioned just as much. We classified patients’ goals according to the taxonomy for goals as developed by Bogardus et al. This taxonomy proved to be a valuable framework; however, some adjustments to the domains of the taxonomy were required to make them more appropriate for our study population. This can be explained by the fact that the taxonomy was originally developed based on goals mentioned by patients, primary family caregivers, case managers and physicians, whereas our study only involved goals mentioned by patients themselves. Since our participants did not name goals related to the domains of behavioral issues and safety, we omitted these domains. Further, we added the domains: living accommodation; activities; and health and welfare services to the taxonomy, since these domains were not included in the taxonomy and many participants mentioned goals that related explicitly to these subjects. Although we classified goals into single domains, we noticed that many domains were interrelated, which made classification more difficult. For example, some participants mentioned that it was their goal to move into an old people’s home, in order to have more social relationships or to improve their mood. For many frail older people, achievement of one goal can be instrumental in achieving another goal, making it important to clarify which goal they want to achieve most. In this study, such interrelated goals were therefore categorized according to the ultimate goal of the participant. Further, less than half of goals mentioned by participants were specific. As it is hypothesized that people who set more specific goals are more likely to be successful in achieving them, this might be considered unfortunate. Although these findings emphasize the need for professionals to assist patients in clarifying their goals and in making their goals as specific as possible, the achievement of goals is not the only purpose of discussing goals with patients. Even for patients who are not able to describe their goals very specifically or are not able to formulate goals at all, discussing goals provides information on their preferences that can assist clinicians in making care more patient-centered. Our study had some limitations that need to be addressed. Two were related to its retrospective nature. First, although a goal-setting item was included in the assessments, studying goals of frail older people was not the primary aim of the studies used. This was reflected in the case records, which sometimes lacked data concerning goals. However, although the missing data might have influenced our results concerning the number of goals elicited with the goal-setting item, it is unlikely that they had a major influence on the nature of the goals. As it was not known at the time of data recording that we would conduct a study concerning participants’ goals, we can assume that these missings occurred at random. Second, the retrospective nature and the use of two separate studies resulted in a limited amount of baseline characteristics, as only few baseline characteristics were available for the study that concerned the EASYcare based DTP. This made it difficult to determine whether baseline characteristics of participants who were able to mention one or more goals were comparable to those who were not. A last potential limitation concerns the study population. In the second and larger study that concerned the EASYcare based DTP, cognitive problems were the main reason for geriatric assessment. Therefore, cognitive problems were highly prevalent in the study population. This may explain why goals related to cognitive problems were mentioned frequently. It is unclear if such goals would be mentioned just as much in a frail population selected in a different way, where cognitive problems might be less prevalent. An important strength of the study was the incorporation of the goal-setting item in a structured geriatric assessment that covers many aspects of health and well-being. Discussion of the items included in the assessment will have enabled participants to evaluate their needs. As the goal-setting item was included at the end of the assessment, this will have assisted participants in defining their goals. In conclusion, this study has demonstrated that care-related goals of frail community-dwelling older people are diverse and individual. This stresses the importance of discussing goals in clinical practice. Although it is important to assist patients in clarifying their goals and in describing them as specifically as possible, we believe that the process of discussing goals with patients is valuable in its own right. For even when patients are unable to define specific care-related goals, discussing goals will reveal preferences that can help clinicians understand what a particular patient values most and will thus assist in making more patient-centered care decisions. Moreover, knowledge of the goals of a particular patient, whether specific or not, can assist in motivating patients for a certain treatment or care plan (e.g., if a patient knows that taking his medications will enable him to remain independent, he might feel more motivated to take them), thus improving treatment efficiency and adherence. Even though implementing goal discussions in everyday practice requires overcoming several barriers (e.g., time constraints), we expect that its gains will outweigh the investments needed, both for patients and clinicians.
References


Addendum: Cost consciousness and medical education

Sarah Robben, René Melis, Marcel Olde Rikkert

To the Editor: Dr. Cooke rightly points at the moral, societal, and economic reasons for educating students in medically sound strategies for cost containment, and we whole-heartedly support her argument for a value-based approach in choosing treatment. However, we do not agree that patient-centred care contributes to the increasing health care costs. In fact, patient-centred care might hold the solution. We physicians have conceived ourselves as advocates for each patient, whereas research shows that healthcare professionals agree little with patients and family caregivers on treatment goals. It is therefore a misconception that doctors know best what creates value for a patient. Patient-centred care, shared decision-making and collaborative goal-setting can help us understand what a patient values most. Will this result in additional health care spending? We doubt it. Although strong evidence on the effectiveness of collaborative goal-setting is lacking, its promise for improving cost-effectiveness is evident: it would do so first by increasing patient satisfaction and adherence, and second by ensuring that the limited available resources are allocated to the care that matters most to the patient.
References

Development of the Health and Welfare Information Portal
Filling the gaps in a fragmented healthcare system: development of the Health and Welfare Information Portal (ZWIP)

Sarah Robben, Mirjam Huisjes, Theo van Achterberg, Sytse Zuidema, Marcel Olde Rikkert, Henk Schers, Maud Heinen, René Melis, for the ZOWEL NN Study Group

Abstract

Background: Current healthcare systems are not optimally designed to meet the needs of our aging populations. First, the fragmentation of care often results in discontinuity of care, which undermines the quality of care provided. Second, patient involvement in care decisions is insufficiently facilitated.

Objective: To describe the development and the content of a program aimed at: (1) facilitating self-management and shared-decision making by frail older people and informal caregivers, and (2) reducing fragmentation of care by improving collaboration among professionals involved in the care of frail older people, through a combined multidisciplinary electronic health record and personal health record.

Methods: We used Intervention Mapping to systematically develop our program in six consecutive steps. Throughout this development, the target populations: professionals, frail older people, and informal caregivers, were involved extensively through their participation in semi-structured interviews and working groups.

Results: We developed the Health and Welfare Information Portal (ZWIP): a personal, internet-based conference table for multidisciplinary communication and information exchange for frail older people, their informal caregivers and professionals. Further, we selected and developed methods for the implementation of the program, which included an interdisciplinary educational course for professionals involved in the care of frail older people; and planned the evaluation of the program.

Conclusions: This article describes the successful development and the content of the ZWIP as well as the strategies developed for its implementation. Throughout this development, representatives of future users were involved extensively. Future studies will establish the effects of the ZWIP on self-management and shared-decision making by frail older people as well as on collaboration among the professionals involved.

Introduction

Current healthcare systems are not optimally designed to meet the needs of our aging populations. First, they are characterized by fragmentation, which leads to inefficiency and ineffectiveness of healthcare provided. Second, they do not facilitate the incorporation of patient perspectives in care decisions, as they are designed according to a medical model that relies on care decisions being made by professionals with limited patient involvement. Yet, the roles of patients and informal caregivers in our healthcare system are changing. Patients are now increasingly encouraged to become involved. There are several reasons for this. First, the inescapable fact is that patients are involved in their care, as they decide on a daily basis how they manage their disease: e.g., they decide whether they take their medication or follow the lifestyle advice provided by professionals. Second, patient involvement is valued for moral and ethical reasons and considered a patient’s right. Third, research has shown that increased patient involvement can have favorable effects such as improved health outcomes and improved adherence. Therefore, increasing the involvement of patients in their own care by enabling them to participate in decision making and by supporting them to manage their disease to the best of their ability is highly recommendable. However, increased patient involvement may be difficult to achieve in a healthcare system that suffers from fragmentation, as both patients and professionals may already struggle to meet the complex demands placed on them by such a healthcare system. In a fragmented healthcare system, care for a single patient, especially care for a frail older patient, is often provided by multiple professionals who work in a variety of settings. As a consequence, continuity of care, which is the degree to which a series of discrete healthcare events is experienced as coherent, connected and consistent with the patient’s medical needs and personal context, is limited. This undermines the quality of care provided. Consequently, coordination of care across settings and services, by the sharing of accurate information between professionals and by the effective collaboration of professionals, patients and informal caregivers, is badly-needed.

Therefore, we developed a program aimed at: (1) facilitating self-management and shared-decision making by frail older people, and (2) reducing fragmentation of care by enhancing collaboration among professionals involved in the care of frail older people, through a multidisciplinary shared electronic health record (EHR) and personal health record (PHR). This article describes the development of this program.
Methods

The program, the Health and Welfare Information Portal (ZWIP), was initiated by ZOWEL NN, a collaborative of stakeholders in healthcare and welfare services, located in the city of Nijmegen, the Netherlands. The two main objectives for the program were: (1) to facilitate self-management and shared-decision making by frail older people and their informal caregivers and (2) to improve collaboration among professionals by enhancing and facilitating information sharing, through a multidisciplinary shared EHR and PHR. Intervention Mapping, a stepwise approach for the systematic development of theory and evidence-informed interventions,16 was chosen as method for the development of the program. In the following sections, we will discuss the consecutive steps taken in this process, an overview is provided in Table 1.

Step 1: needs assessment

First, we assembled a planning group that would develop the intervention. This planning group involved the project manager, the project leader (RM), two researchers (SR, MHu), two general practitioners, a geriatrician, a nurse scientist experienced in Intervention Mapping (MHe), an Information Technology consultant, and a nursing home physician. This planning group analyzed the existing problems with self-management of frail older people and interprofessional collaboration in primary care. First, we performed a literature search for barriers to patient self-management and interprofessional collaboration. Second, we conducted semi-structured interviews at the homes of frail older people (n=11) and informal caregivers (n=11). They were invited to participate by their general practitioner (GP) or welfare organization and were purposively selected based on variation in living situation, socioeconomic position and health and social problems. Interviewees were asked for their experiences with receiving information from healthcare and welfare professionals, informational continuity, i.e., whether information concerning their health or situation was exchanged between professionals, and interprofessional collaboration. Third, we established two working groups. The first consisted of healthcare and welfare professionals (n=15) who were involved in the care of frail older people. They were recruited through their employing organizations and were financially compensated for their time investments. Members included GPs (n=3), primary care nurses (n=3), geriatricians (n=2), municipality workers (n=2), social workers (n=2), a nursing home physician (n=1), a pharmacist (n=1) and a psychologist (n=1). The second working group consisted of older people (n=2) and informal caregivers (n=2), who were asked to participate by older people participating in the user panel of ZOWEL NN. Both groups were asked to discuss which problems they experienced with self-management of frail older people and collaboration among professionals; and they were asked to review and comment the results from the literature search, semi-structured interviews and the other working group.

Results of this needs assessment were integrated into a logic model. This model is derived from the PRECEDE model15,17 that displays behaviors, its consequences and its determinants in a structured manner. As the problems described for each topic (self-management and collaboration) were too distinct to be compiled into one single logic model, we constructed a separate logic model for each program objective.

Step 2: preparing matrices of performance objectives and determinants

Based on the problem analysis, we defined performance objectives, which are behaviors required to achieve the program objectives, for each target population. These performance objectives were then crossed in matrices with those determinants of behavior that were known to have a major influence on behavior and were amenable to change. On the crossings of performance objectives and determinants, change objectives were formulated, which are the highly specific outcomes the program should be aiming for. We designed these matrices for all target-populations involved, i.e., frail older people and their informal caregivers, professionals, and their employing organizations.

Step 3: selecting theory-informed intervention methods and practical strategies

We searched the literature for theories that were either proven to be effective in changing the determinants identified, or that were successfully used to enhance patient self-management or to promote collaboration among professionals. From these theories, we selected methods and strategies for our program. In this selection, we aimed for an optimal balance between the expected advances towards our program objectives and the investments required from the target populations.

Step 4: producing program components and materials

Requirements for the program components were defined in additional meetings of the working groups of professionals and older people and informal caregivers. Subsequently, members of the planning group started development of program components. These components were reviewed by the working group of professionals and by two new working groups of (frail) older people in an iterative process involving several rounds of reviewing by the working groups, the working groups making suggestions for improvement and members of the planning group making adjustments. In this process, development and reviewing coincided, each working group being presented with the latest version of the components at the time of their meeting. Final versions of the program components were tested in a
Table 1 Overview of the Intervention Mapping process

<table>
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<th>Step</th>
<th>Methods</th>
<th>Results</th>
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| **Step 1: needs assessment** | Problems analysis based on:  
• Literature search  
• Semi-structured interviews with frail older people and informal caregivers (n=22)  
• Two meetings of working group of professionals (n=15)  
• One meeting of working group of older people and informal caregivers (n=4) | Logic model for self-management (Figure 1) and interprofessional collaboration (Figure 2) |
| **Step 2: preparing matrices of performance objectives and determinants** | Building matrices of performance objectives, determinants and change objectives based on the needs assessment | Matrices of performance objectives and determinants for frail older people and informal caregivers, professionals, and the organizations of professionals (Appendix 1, 2 and 3) |
| **Step 3: selecting theory-informed intervention methods and practical strategies** | Literature search for theories and methods and their effectiveness for the target populations  
Selection of theories and methods | Main theory for the program: Social Cognitive Theory  
Other theories used: Goal-Setting Theory and elements of theories of organizational change  
Methods and strategies used:  
(1) For professionals: modeling, active learning, direct experience and creating facilitating conditions  
(2) For frail older people and informal caregivers: tailoring, modeling, guided practice, collaborative goal-setting and action planning |
| **Step 4: producing program components and materials** | Requirements for Health and Welfare Information Portal (ZWIP) were defined in:  
• 3 additional meetings of working group of professionals (n=15)  
Subsequently, development of ZWIP in parallel with reviewing by working groups (4 meetings of working group of professionals; 3 meetings of two working group of (frail) older people (n=6 and n=4)) | Main program component:  
• ZWIP  
Target population: frail older people ≥ 70 years, informal caregivers, and their professionals |
| **Step 5: planning program adoption, implementation, and sustainability** | Program initiated by network of local stakeholders in healthcare and welfare services; future users involved extensively in development; necessity for healthcare system changes for frail older people felt at several levels (government, organizations, professionals) | Implementation strategies: Professionals:  
• Involvement in development  
• Starting with early adopters  
• Educational program (CME credits available) and e-learning  
• Telephonic helpdesk available  
• Coaching and e-coaching available  
• Financial compensation  
• Publicity and flyers  
• Incentives  
Employing organizations:  
• Financial compensation  
• Educational program for employees  
Frail older people and informal caregivers:  
• Involvement in development  
• Flyers  
• Involvement of informal caregiver  
• Involvement of General Practitioner  
• IT and paper version of ZWIP  
• Instruction in ZWIP by volunteer  
• Telephonic helpdesk available |
| **Step 6: planning for evaluation** | Design of an evaluation plan | Framework for process evaluation and evaluation of effects. |
small pilot study involving two frail older people, two informal caregivers and seven professionals.

Step 5: planning program adoption, implementation, and sustainability
A prerequisite for adoption and implementation of the program was met by the extensive involvement of the target population in its development and the commitment of the local collaborative of stakeholders in healthcare and welfare services. Further, implementation was facilitated by selecting implementation strategies that were tailored to the needs of each target population. Planning for sustainability was started early in the development of the program by searching for funding for incorporation of the program in everyday practice.

Step 6: planning for evaluation
In this final step we designed a plan for the evaluation of the program. This involved an evaluation of the effects of the program as well as a process evaluation.

Results

Step 1: Results of the needs assessment
An overview of the results of the needs assessment for self-management of frail older people is provided in the logic model shown in Figure 12-21,31-34 a second logic model, concerning collaboration among professionals is shown in Figure 22-23,24,26-31,33-44 Each logic model describes the problem (the last two columns), followed by behavioral and environmental factors that contribute to the problem (the second column) and the determinants that influence those factors (the first column). We will briefly discuss the results of the needs assessment in the next two paragraphs. As knowledge of the Dutch healthcare system may help the interpretation of the results of this needs assessment, a summary of its characteristics is provided in Box 1.

Needs assessment concerning frail older people’s involvement in self-management
(Frail) older people, informal caregivers, professionals and previous research reported problems with patient involvement in self-management. These problems related to frail older people and informal caregivers not performing the activities required and professionals not encouraging or facilitating involvement. Identified behaviors of frail older people and informal caregivers that contributed to these problems included: (1) not adequately informing professionals about their health situation and asking sufficient questions;25,30 and (2) not adhering to medications prescribed or advice given.25,26,34 These behaviors were influenced by many determinants such as attitude towards self-management, as not all frail older people want to be involved extensively;25,30 emotions such as fear of loss of independence;25,26 self-efficacy for self-management;25,26,29 knowledge about disease, symptoms and its treatments;28,29,34 skills;35 personal problems;25,26,31 perceived social norms;33 social support such as advocacy;25,26,29,34 financial constraints;25,26,29 and the high complexity of the healthcare system.34 Important contributing behaviors of professionals were (1) not providing the frail older person with adequate information for self-management25,26,29,34 and (2) not being genuinely interested in the frail older person and not encouraging questions.25,26,29 Important determinants affecting these behaviors were attitude towards patient self-management;22,33 knowledge;22 skills for self-management support20,22 and determinants related to the healthcare system.20,33

Needs assessment concerning collaboration among professionals
Professionals, patients and informal caregivers, as well as the literature, cited problems with the collaboration among professionals. The main behaviors that contributed to these problems were a lack of communication or insufficient communication;30,34,47 delays in the transfer of information or information not being transferred at all;24,47 giving either insufficient information45,46 (e.g., not giving the information required by a particular discipline) or too extensive information, which was not read by professionals with already demanding work schedules; and not involving the frail older person in the collaboration between professionals. Important determinants influencing these behaviors included attitudes towards collaboration;45,46 beliefs in the advantages of collaboration;46 knowledge about the information needed by other disciplines;46 communication skills;25,46 and external factors such as time constraints31 and legal restrictions to the sharing of information.45 However, for professionals in the working groups, more practical determinants were most important, such as not knowing which other professionals were involved
Figure 1 Logic model for self-management of frail older people

**Personal determinants**
- Frail older person and informal caregiver
  - Attitude towards self-management
    - Lack of motivation or not wanting to have responsibility
    - Diversity in desired level of self-management
  - Emotions
    - Fear for medical examinations or for a serious illness
    - Fear for loss of independence
  - Beliefs about causes of symptoms
  - Self-efficacy concerning self-management skills
  - Knowledge
    - Insufficient knowledge about the disease(s) and its treatment(s)
    - Insufficient knowledge about the assistance healthcare and welfare services can offer
  - Skills
    - General and disease specific self-management skills
  - Personal limitations
    - Low health literacy; problems with eyesight or hearing; cognitive problems; depression
    - Case complexity: experiencing a number of problems due to a single disease or experiencing problems due to interactions between the treatments required for different diseases

**External determinants**
- Frail older person and informal caregiver
  - Perceived social norms
    - Accept physician authority
  - Social support
    - Advocacy: informal caregiver accompanies person to the consultation
    - Transport to healthcare or welfare services
  - Financial constraints: cost of care and medications

**Environmental factors**
- Professionals
  - Problems in the interaction with the frail older person
  - Do not show interest
  - Have a patronizing style
  - Communication problems
  - Do not listen to the older person
  - Do not encourage questions
  - Do not ask person for priorities and wishes
  - Problems with information
    - Do not give sufficient information
    - Give information that is unclear for the older person
    - Give conflicting advice

**Behavioral factors**
- Frail older person and informal caregiver
  - Problems in the interaction with professionals
    - Do not or incorrectly inform professionals
    - Do not discuss own wishes and preferences
    - Do not ask questions
    - Do not prepare for a consultation
  - Non-adherence
    - Do not use medication as prescribed or do not follow lifestyle advice given
    - Do not perform activities required to ameliorate symptoms or slow down disease progression
  - Badly monitoring health
    - Do not interpret or report symptoms correctly
    - Problematic coping
    - Do not use effective strategies for dealing with the emotional, social and economic consequences of (chronic) diseases

**Suboptimal quality of life**
- Suboptimal quality of care
  - Patient related outcomes:
    - Health status:
      - Lower reported health status
      - Increased mortality
      - Lower reported physical functioning
  - Healthcare system:
    - Increased use of care

**Suboptimal self-management**
- Behavioral factors
  - Frail older person and informal caregiver
    - Problems in the interaction with professionals
  - Non-adherence
  - Badly monitoring health
  - Problematic coping
- Environmental factors
  - Professionals
    - Problems in the interaction with the frail older person
  - Badly monitoring health

**Personal determinants**
- Professional
  - Attitude
    - Towards patient self-management
    - Towards frail older people and informal caregivers
  - Knowledge about the advantages of self-management
  - Skills for self-management support

**External determinants**
- Healthcare system
  - Government cuts
    - Insufficient staff
    - Time limitations
    - Problems with accessibility
  - Lack of reimbursement for patient education and coordination of care
  - Lack of inter-personal continuity
  - Complexity
Figure 2 Logic model for collaboration among professionals

Personal determinants
- Frail older person and informal caregiver
  - Attitude
    - Not expecting involvement
  - Knowledge
    - Having less knowledge than professionals
  - Self-efficacy
    - Not feeling competent for decision-making

External determinants
- Frail older person and informal caregiver
  - Social norms
  - Professionals are gatekeepers to healthcare services

Personal determinants
- Professional
  - Attitude
    - Attitude towards collaboration
    - Acknowledging frail older person as partner in collaboration
    - Acknowledging frail older person as expert on consequences of their condition and on values and preferences
  - Beliefs
    - Belief in advantages of collaboration
    - Trust and respect for other professionals
  - Knowledge
    - Lack of knowledge of: available services; other professionals involved and their treatment goals; skills of other disciplines
  - Skills
    - Communication skills

External determinants
- Professionals
  - Time constraints
  - Accessibility of other professionals
  - Accommodation
    - Professionals work in different buildings
  - Social norms
    - Hierarchy
  - Interprofessional education

Determinants
- Organization
  - Organizational culture
  - Government cuts and finances
  - Fragmentation
    - Many professionals and organizations involved
  - Bureaucracy
  - Legislation
    - Legal restrictions to sharing information

Suboptimal collaboration
- Behavioral factors
  - Frail older person and informal caregiver
    - Passive attitude
      - Do not ask questions
      - Do not tell what they value most
    - Do not ask professionals to collaborate
    - Not taking responsibility for own care
    - Do not inform professionals
    - Ask for help too late or avoid care
    - Bad adherence

Behavioral factors
- Professionals
  - Problems with communication
    - Communicate insufficiently or not at all
  - Do not have agreements on allocation of tasks and responsibilities
  - Have inter-disciplinary conflicts
  - Do not organize team meetings
  - Problems with sharing information
    - Give either insufficient or too extensive information
    - Transfer information too late or not at all
  - Not providing patient-centered care
  - Do not involve the frail older person in collaboration
  - Do not ask the frail older person for wishes, needs or goals for improvement

Behavioral factors
- External determinants
  - Professionals
    - Problems with communication
    - Accessible services
    - Interprofessional education

Suboptimal quality of care
- Patient related outcomes:
  - Health status:
    - Increased mortality and adverse events
    - Polypharmacy: too many investigations and interventions
    - Increased readmission rate
    - Increased length of stay
  - Satisfaction:
    - Decreased satisfaction with care

Professional related outcomes:
- Decreased job satisfaction

Healthcare system:
- Increased costs of care

Suboptimal quality of life
- Decreased job satisfaction
- Increased costs of care
in the care of the frail older person; not knowing them personally; \cite{35,40,42,48} and not being able to contact these professionals, \cite{35,39,40,42,48,49} e.g., due to part-time work or busy telephone lines.

Step 2: Results on matrices of performance objectives and determinants

Based on our needs assessment, we defined performance objectives for both program objectives and for each target population involved (Appendix 1 and 2). Also, we reviewed the determinants shown in Figures \cite{1,5,7,19,20,21,22,23,29,31,33,34,40,41,42,43,44,45,46,47,48,49} in order to select those determinants of behavior that were considered both important to target and modifiable. For the first program objective, aimed at facilitating self-management, we developed two matrices: one for frail older people and informal caregivers and one for professionals. For frail older people and informal caregivers, targeted determinants were attitudes, skills and self-efficacy, knowledge, and social support; and for professionals, targeted determinants were attitudes, knowledge, skills and organization. For the second program objective, aimed at enhancing collaboration, we designed three matrices: one for professionals; one for their organizations; and one for frail older people and informal caregivers. For professionals, targeted determinants were attitudes and beliefs, knowledge, skills, and accessibility; for their organizations, the targeted determinant was organizational culture; and for frail older people and informal caregivers, targeted determinants were attitude, self-efficacy, knowledge, skills, social norms and social support, and accessibility. We then crossed the performance objectives with these determinants to design matrices of change objectives. For example, for the performance objective “professional communicates with other professionals involved”; and the determinant “knowledge”, a change objective was “professional states that problems in communication lead to adverse outcomes for frail older people”. Therefore, we wanted our program to increase professionals’ knowledge about the effects of communication problems. Appendix 3 provides an example of a matrix of change objectives.

Step 3: Selected theories, methods and strategies

Social Cognitive Theory \cite{51} was selected as main theory behind the program, as it has been successfully used in the past for interventions aimed at improving patient self-management as well as in internet-based interventions focusing on improving self-management. \cite{32,33,34} A key concept of Social Cognitive Theory is perceived self-efficacy: the beliefs people have about their capabilities to produce the effects they desire by their own actions. \cite{52} If self-efficacy is low, people are less likely to either act or to continue trying when facing difficulties. \cite{53} We included several methods and strategies derived from this theory in the program, based on their ability to change the targeted determinants of behavior. For professionals, we included active learning, direct experience, modeling and facilitation. For frail older people and their informal caregivers, we included modeling, guided practice and tailoring. Further, elements of goal-setting theory, \cite{54} i.e., goal-setting and action planning, \cite{55} were included in the program in order to assist frail older people and informal caregivers in describing what is most important to them, to help them to achieve their goals and to increase their involvement in the care-process. Goal-setting theory highlights the importance of setting specific, difficult goals, as people who set such goals will perform better that those merely asked to do their best. \cite{56} Last, we incorporated elements of several theories of organizational change in the program. Methods used from these theories were providing training and coaching, and creating facilitating conditions. \cite{16,58}

Step 4: Characteristics of ZWIP

Taking the former steps of the Intervention Mapping process into account, we developed the main component of the program: the Health and Welfare Information Portal (ZWIP). The ZWIP is a personal, internet-based conference table for multidisciplinary communication and information exchange for frail older people, their informal caregivers and professionals. It can be considered to be both a shared Electronic Health Record and a Personal Health Record. The ZWIP is aimed at frail older people identified through a specific screening method and includes (1) a tool for multidisciplinary communication in a secure environment, which enables communication through sending messages between the frail older person, informal caregiver and the professionals involved; (2) an overview of healthcare and welfare professionals involved in the care of the frail older person and their contact information; (3) information about the frail older person’s health, functioning and social situation as well as the care provided; (4) the goals and action plans of the frail older person and informal caregiver, which are formulated with them during home visits by nurses or social workers by means of a goal-setting tool; and (5) tailored educational materials for the frail older person and informal caregiver. Fundamental to ZWIP is the central position of the frail older person, who can view the information included and who decides which professionals are granted access to his personal ZWIP. As a rule, messages that are communicated within the ZWIP are visible for all professionals with access to the ZWIP as well as for the frail older person and informal caregiver. This allows everyone concerned to remain informed about the frail older person’s situation and enables everyone to bring up their own relevant observations in an ongoing conversation. However, at the request of (frail) older people as well as professionals, we also included the option of sending a private message to a single person.

After development, as a final step before implementation, we conducted a small
pilot study of the ZWIP. The most important lessons learned from this pilot were practical issues such as the need to communicate as unambiguously as possible.

**Step 5: ZWIP program adoption and implementation**

Strategies used for the adoption and implementation of the program were tailored to the needs of each particular target population. We will describe the main strategies used in the next paragraphs; an overview of all strategies is provided in Table 1 (step 5).

For healthcare and welfare professionals, our most important strategy was an interdisciplinary educational program for healthcare and welfare professionals involved in the care of frail older people. This program consisted of three three-hour meetings concerning the following subjects: (1) the concept of frailty and identification of frailty, as this was required to identify the frail older people that were the program’s target population; (2) providing self-management support to frail older people by thoroughly informing them and using collaborative goal-setting; (3) interdisciplinary collaboration, including information about what each discipline has to offer in the care for frail older people; and (4) working with the ZWIP. Except for its educational content, the educational program also served as a method for identifying and bringing together local healthcare and welfare professionals involved in the care of frail older people, as the program enabled professionals to get acquainted with each other. The educational meetings were held in (the neighborhood of) local GP’s offices and all local professionals working with frail older people were invited to participate. Another important strategy was that we aimed to ensure the participation of intrinsically motivated early adopters. Further, we tailored the implementation of the program to each setting by providing GP-practices with several options for implementation, which allowed them to choose the method that would best meet their local needs and circumstances. Also, we provided financial compensation for time invested in the program; we gave coaching and e-coaching in using the ZWIP; and had a telephonic helpdesk available.

For frail older people and informal caregivers, we had two main strategies. First, we involved their GP in the project, who actively promoted their participation. Second, we aimed to either facilitate the use of Information Technology or to make the use of Information Technology by frail older people redundant, as we were thoroughly aware that they often have low computer literacy. Hence, we provided them with an internet-based version of the ZWIP as well as a paper version of the ZWIP, which held all information that was included in the internet-based ZWIP except for the communication; we offered them a home visit by a volunteer, who could either demonstrate the ZWIP to inform them about its possibilities or could train them in using the ZWIP themselves; and we had a telephonic helpdesk available during office hours.

**Step 6: Preparing for evaluation of the ZWIP**

As a final step in the Intervention Mapping process we planned the evaluation of the ZWIP. This evaluation will involve both a process evaluation and an effect evaluation. In the process evaluation, we will evaluate the implementation of the intervention; exposure of the target populations to the intervention; experiences of the target populations with the intervention; and barriers and facilitators to the use of the intervention. This will be studied using a combination of quantitative and qualitative data, i.e., surveys, data about both the use of the ZWIP and exposure to its implementation strategies, and semi-structured interviews. The effects of the ZWIP program will be evaluated by means of a controlled clinical trial. Outcome measures will be the effects of the program on interprofessional collaboration; patient self-management and autonomy; patient outcomes such as functioning and quality of life; and use of care. Also, cost-effectiveness of the ZWIP will be evaluated. Last, as we consider the interprofessional educational program an important part of the implementation, the effects of this program on interprofessional collaboration will be evaluated separately. This will be done in a before and after study using several validated questionnaires, i.e., the Attitudes Toward Health Care Teams Scale, the Interprofessional Attitudes Questionnaire, and (3) the Team Skills Scale, followed by semi-structured interviews with purposively selected participants.

**Discussion**

This article describes the successful development of an intervention aimed at facilitating self-management and shared-decision making by frail older people and their informal caregivers and at reducing fragmentation of care through improving collaboration among professionals. For this development, the Intervention Mapping framework was used and future users were involved extensively. In the past, this framework has also been successfully used for the development of health promotion programs aimed at such diverse topics as leg ulcers, physical activity of employees in sedentary occupations, sexually transmitted disease, pregnancy and HIV prevention and asthma self-management. To our knowledge, it is the first time that Intervention Mapping was successfully used to develop an intervention that specifically targets collaboration between professionals.

A major advantage of the use of Intervention Mapping was that it facilitated the systematic incorporation of the needs and preferences of the target population as well as evidence from previous research. We can exemplify this with our first program objective, which concerned self-management and shared-decision making. Previous research had shown that most older people prefer a less active role in medical
cases, the planning group made a final decision. These decisions were made based on a thorough deliberation on all the arguments available from the literature and working groups as well as arguments concerning feasibility. Although the ZWIP is a systematically developed evidence-informed intervention, its future success depends highly on its successful implementation and its use by professionals in everyday practice. Implementation and use will be monitored and adaptations will be made whenever required. Further, future use of the ZWIP in everyday practice will have to establish the added value of the communication tool of ZWIP in relation to already existing communication methods.

In summary, this article describes the successful development of the ZWIP: a personal, internet-based conference table for multidisciplinary communication and information exchange for frail older people, their informal caregivers and professionals. We expect that the ZWIP will be able to increase the involvement of frail older people and informal caregivers in their care and will improve collaboration among professionals. The ZWIP will therefore contribute to filling the gaps in our fragmented healthcare systems.
References

Agrees on a plan for follow-up with the older person
Responds adequately to changes in health status
Uses supportive services in the community
Assesses what activities the frail older person already performs to self-manage
Underlines the central role the patient has in caring for him- or herself
Collaborates with the frail older person to make shared-decisions about the
Participates actively in problem solving
Builds up an adequate patient-caregiver relationship with the frail older person
Deals adequately with disease, limitations and treatment
Participates actively in designing a treatment plan aimed at maintaining and
Copes effectively with the emotional and psychological consequences of
Provides the frail older person with customized information about his/her
Teaches the frail older person skills for monitoring and interpreting symptoms
Interacts with healthcare and welfare professionals
Encourages the frail older person to be active in the management of his/her
Participates in effectuating the treatment plan that has been agreed upon with
Provides ongoing follow-up
Assesses the knowledge the frail older person has about his/her diseases
Assesses the assumptions the frail older person has about his/her diseases
Participates actively in designing a treatment plan aimed at maintaining and improving health
Participates actively in the development of specific action plans targeting parts of the treatment plan
Participates in effectuating the treatment plan that has been agreed upon with professional
Deals adequately with disease, limitations and treatment
Uses supportive services in the community
Copes effectively with the emotional and psychological consequences of disease
Professional...
Builds up an adequate patient-caregiver relationship with the frail older person
Underlines the central role the patient has in caring for him- or herself
Assesses the assumptions the frail older person has about his/her diseases
Assesses the knowledge the frail older person has about his/her diseases
Assesses what activities the frail older person already performs to self-manage his/her diseases
Provides the frail older person with customized information about his/her chronic conditions, which agrees with his health condition and the information he/she already has
Teaches the frail older person skills for monitoring and interpreting symptoms
Encourages the frail older person to be active in the management of his/her own diseases
Collaborates with the frail older person to make shared-decisions about the care plan
Agrees on a plan for follow-up with the older person
Provides ongoing follow-up

Appendix 1 Performance objectives for each target population related to self-management

<table>
<thead>
<tr>
<th>Performance objectives (PO)</th>
<th>Frail older person and informal caregiver…</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PO.1.1.</strong></td>
<td>Monitors health status</td>
</tr>
<tr>
<td><strong>PO.1.2.</strong></td>
<td>Responds adequately to changes in health status</td>
</tr>
<tr>
<td><strong>PO.2.1.</strong></td>
<td>Interacts with healthcare and welfare professionals</td>
</tr>
<tr>
<td><strong>PO.2.2.</strong></td>
<td>Participates actively in problem solving</td>
</tr>
<tr>
<td><strong>PO.2.3.</strong></td>
<td>Participates actively in designing a treatment plan aimed at maintaining and improving health</td>
</tr>
<tr>
<td><strong>PO.2.4.</strong></td>
<td>Participates actively in the development of specific action plans targeting parts of the treatment plan</td>
</tr>
<tr>
<td><strong>PO.3.1.</strong></td>
<td>Participates in effectuating the treatment plan that has been agreed upon with professional</td>
</tr>
<tr>
<td><strong>PO.4.1.</strong></td>
<td>Deals adequately with disease, limitations and treatment</td>
</tr>
<tr>
<td><strong>PO.4.2.</strong></td>
<td>Uses supportive services in the community</td>
</tr>
<tr>
<td><strong>PO.4.3.</strong></td>
<td>Copes effectively with the emotional and psychological consequences of disease</td>
</tr>
</tbody>
</table>

**Professional…**

- **PO.1.** Builds up an adequate patient-caregiver relationship with the frail older person
- **PO.2.** Underlines the central role the patient has in caring for him- or herself
- **PO.3.1.** Assesses the assumptions the frail older person has about his/her diseases
- **PO.3.2.** Assesses the knowledge the frail older person has about his/her diseases
- **PO.3.3.** Assesses what activities the frail older person already performs to self-manage his/her diseases
- **PO.4.1.** Provides the frail older person with customized information about his/her chronic conditions, which agrees with his health condition and the information he/she already has
- **PO.4.2.** Teaches the frail older person skills for monitoring and interpreting symptoms
- **PO.5.1.** Encourages the frail older person to be active in the management of his/her own diseases
- **PO.5.2.** Collaborates with the frail older person to make shared-decisions about the care plan
- **PO.6.1.** Agrees on a plan for follow-up with the older person
- **PO.6.2.** Provides ongoing follow-up
**Appendix 2** Performance objectives for each target population related to collaboration

<table>
<thead>
<tr>
<th>Performance objectives (PO)</th>
<th>Professional…</th>
</tr>
</thead>
<tbody>
<tr>
<td>PO.1. Shares relevant information with other professionals</td>
<td></td>
</tr>
<tr>
<td>PO.1.1 Asks client permission for sharing of information</td>
<td></td>
</tr>
<tr>
<td>PO.2. Communicates with other professionals involved</td>
<td></td>
</tr>
<tr>
<td>PO.2.1 Communicates regularly and effectively</td>
<td></td>
</tr>
<tr>
<td>PO.2.2 Clarifies the roles and responsibilities other professionals have</td>
<td></td>
</tr>
<tr>
<td>PO.2.3 Asks other professionals for their treatment goals and discusses own treatment goals</td>
<td></td>
</tr>
<tr>
<td>PO.3. Involves client in collaboration</td>
<td></td>
</tr>
<tr>
<td>PO.3.1 Asks client for wishes and goals and discusses these</td>
<td></td>
</tr>
<tr>
<td>PO.3.2 Gives priority to client’s goals in care plan and discusses other goals</td>
<td></td>
</tr>
<tr>
<td>Frail older person and informal caregiver…</td>
<td></td>
</tr>
<tr>
<td>PO.1. Contacts professionals when necessary</td>
<td></td>
</tr>
<tr>
<td>PO.2. Gives professionals permission to exchange information about him/herself</td>
<td></td>
</tr>
<tr>
<td>PO.3. Asks professionals involved to consult each other</td>
<td></td>
</tr>
<tr>
<td>PO.4. Discusses goals for care plan with professional</td>
<td></td>
</tr>
<tr>
<td>PO.5. Aims to achieve goals of care plan</td>
<td></td>
</tr>
<tr>
<td>Organization…</td>
<td></td>
</tr>
<tr>
<td>PO.1. Facilitates collaboration</td>
<td></td>
</tr>
<tr>
<td>PO.1.1 Facilitates the communication of staff with professionals outside the organization</td>
<td></td>
</tr>
<tr>
<td>PO.1.2 Evaluates the results of employees’ collaboration with professionals from different organizations</td>
<td></td>
</tr>
</tbody>
</table>
### Appendix 3 Section of matrix of change objectives on enhancing collaboration of professionals

<table>
<thead>
<tr>
<th>Professional …</th>
<th>Attitudes and Beliefs</th>
<th>Knowledge</th>
<th>Skills</th>
<th>Accessibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>PO2. Communicates with other professionals involved</td>
<td>A82.a. Describes that a single discipline is not able to meet all the care and welfare needs of a particular frail older person</td>
<td>K2.a. States that teams that are not collaborating produce worse health outcomes in frail older people, and lower satisfaction by clients and professionals at increased costs</td>
<td>S2.a. Demonstrates ability to collaborate</td>
<td>A2. Other professionals involved are available for consultation</td>
</tr>
<tr>
<td></td>
<td>A82.b. Expresses the conviction that communicating with other professionals involved improves the quality of care delivered</td>
<td>K2.b. States that problems in communication lead to adverse outcomes for frail older people</td>
<td>S2.b. Demonstrates ability to access available database for the up-to-date address and telephone numbers of other professionals involved</td>
<td></td>
</tr>
<tr>
<td></td>
<td>A82.c. Expresses respect for, and trust in the other professionals involved</td>
<td>K2.c. Describes which professionals are involved in the care of a particular frail older person</td>
<td>S2.c. Demonstrates ability to keep own address and telephone number in database up-to-date</td>
<td></td>
</tr>
<tr>
<td></td>
<td>A82.d. Expresses the conviction that the involvement of other professionals improves the care provided to and the welfare of frail older people</td>
<td>K2.d. Describes how and when other professionals involved can be contacted</td>
<td>S2.d. Demonstrates using different methods for communication</td>
<td></td>
</tr>
<tr>
<td>PO.2.1. Communicates regularly and effectively</td>
<td>A82.1.a. Describes that a single discipline is not able to meet all the care and welfare needs of a particular frail older person</td>
<td>K2.1.a. States that communication improves by having regular face-to-face contact</td>
<td>S2.1.a. Demonstrates the ability to listen and to provide own perspective</td>
<td>A2.1. Other professionals involved are available for consultation</td>
</tr>
<tr>
<td></td>
<td>A82.2. Describes the benefit of regular and effective communication</td>
<td>K2.1.b. States that better communication leads to better health outcomes for frail older people</td>
<td>S2.1.b. Demonstrates the ability to negotiate in case of disagreements and to reach consensus</td>
<td></td>
</tr>
<tr>
<td></td>
<td>A82.2.a. Expresses the importance of clarity about the allocation of tasks</td>
<td>K2.2.a. Describes the roles, skills and expertise of other disciplines involved</td>
<td>S2.2.a. Demonstrates the ability to discuss the sharing of roles and responsibilities</td>
<td>A2.2. Other professionals involved are available for consultation</td>
</tr>
<tr>
<td></td>
<td>A82.2.b. Expresses the importance of respecting the roles other professionals have</td>
<td>K2.2.b. Describes how care tasks can be delegated</td>
<td>S2.2.b. Demonstrates the ability to delegate, share and transfer tasks in the care of a frail older person</td>
<td></td>
</tr>
<tr>
<td></td>
<td>A82.3. Describes the goals other professionals have as important</td>
<td>K2.3. States the treatment goals other professionals involved have</td>
<td>S2.3. Demonstrates the ability to write down own care goals in database</td>
<td>A2.3. Other professionals involved are available for consultation</td>
</tr>
</tbody>
</table>
First experiences with a two-step method for discussing goals with community-dwelling frail older people

Sarah Robben, Maud Heinen, Marieke Perry, Theo van Achterberg, Marcel Olde Rikkert, Henk Schers, René Melis

Submitted.
Abstract

**Background:** Although frail older people can be more reluctant to become involved in clinical decision-making, they do want professionals to take their concerns and wishes into account. Discussing goals can help professionals to achieve this.

**Objective:** To develop a two-step method for discussing goals with frail older people in primary care, and to describe professionals’ first experiences with it.

**Methods:** The method consisted of (1) an open-ended question: *If there is one thing we can do for you to improve your situation, what would you like?*; if necessary followed by (2) a bubble diagram with goal subject categories. We reviewed the goals elaborated with the method and surveyed professionals’ (primary care nurses and social workers) experiences, using questions concerning time investment; reasons for not formulating goals; and perceived value of the method.

**Results:** 137 community-dwelling frail older people described 173 goals. These most frequently concerned mobility (n=43; 24.9%), well-being (n=52; 30.1%), and social context (n=57; 32.9%). Professionals (n=18) were generally positive about the method, as it improved their knowledge about what the frail older person valued. Not all frail older people formulated goals, reasons for this included being perfectly comfortable; not being used to discussing goals; or cognitive problems limiting their ability to formulate goals.

**Conclusions:** This brief two-step method for discussing goals can assist professionals in gaining insight into what a frail older person values. This can guide professionals and frail older people in choosing the most appropriate treatment option, thus increasing frail older people’s involvement in decision making.

Introduction

Over the last years, patients have been increasingly encouraged to become involved in clinical decision making, for several reasons. First, patients simply are involved, as they decide on a daily basis whether they will follow the advice or prescriptions given by professionals. Second, patient involvement is valued for moral and ethical reasons as it improves autonomy. And last, previous research has shown that patient involvement can lead to improved patient outcomes. However, especially the increasing population of frail older people may be more reluctant to become involved in clinical decision making, which may present a challenge to professionals.

While not all frail older people want to be involved in the actual decision making, most do want professionals to take their concerns and wishes into account when making decisions. Discussing goals with frail older people may help professionals to achieve this, as knowledge of the goals a particular frail older person has can guide subsequent clinical decisions.

In the past, few studies have described successfully determining goals with (frail) older people. Glazier et al. described determining goals with inpatients of a geriatric rehabilitation unit using a standardized goal menu, which took between 10 and 25 minutes to complete. Bradley et al. described determining goals with outpatients of a geriatric assessment centre by asking them to describe their goals in six pre-specified domains; the time required for these discussions was not reported. However, to our knowledge, no methods for determining goals with frail older people in primary care have been described, while in fact many clinical decisions are made in this setting. Also, in primary care, less time is available for engaging in goal discussions. Therefore, we aimed (1) to develop an efficient and brief two-step method for discussing goals with frail older people in primary care, in order to increase their involvement in decision making; and (2) to evaluate primary care professionals’ first experiences with this method.

Methods

Development

The development of the method for discussing goals was an important aspect of a larger project, the Health and Welfare Information Portal, which aims to facilitate the involvement of community-dwelling frail older people and informal caregivers in their own care, and to improve collaboration among primary care professionals by means of a multidisciplinary shared electronic health record.

Development of the method started with a literature search for methods used to discuss goals with older people, and with studying the major theories underlying...
goal-setting, i.e., social cognitive theory\textsuperscript{11} and goal-setting theory.\textsuperscript{12} Further, the method was built on previous experiences of members of the research team with determining goals with frail older people.\textsuperscript{13} The thus developed method was then reviewed by a group of primary care professionals and geriatricians (n=8), and adjustments were made according to their comments.

As a first step of the method, frail older people are asked an open-ended question derived from the Elderly Assessment System (EASYcare):\textsuperscript{14} \textit{If there is one thing we can do for you to improve your situation, what would you like?} However, in a previous study, not all frail older persons had been able to describe a goal in response to this question.\textsuperscript{13} Therefore, for people who were not able to formulate a goal in the first step, an agenda-setting chart or bubble diagram\textsuperscript{15-17} was added as a second step, to increase the likelihood of successfully elaborating goals. This diagram gives an overview of several broader subject categories in which the frail older person may have a goal and includes empty bubbles in which the frail older person can fill out his or her own goal. The diagram can be left for review by the frail older person. The diagram used was an adaptation of the American Medical Association’s bubble diagram for older people;\textsuperscript{17} in which we changed some items and added new items, to make it both more in line with goals previously mentioned by frail older people,\textsuperscript{13} and less focused on behaviour change, as behaviour change was not the primary aim of the method. The final diagram is provided in Figure 1.

Implementation

As the goal-setting method was part of a larger project, it followed its implementation. The project started from September 2010 in the area of seven general medical practices in the Netherlands. Nurses and gerontological social workers screened selected patients of these practices of \(\geq 70\) years for frailty, which was defined as “experiencing losses in one or more domains of human functioning (physical, psychological, social) as a result of the influence of a range of variables, which increases the risk of adverse outcomes”,\textsuperscript{18} during a home visit. This screening, which was preferably conducted with the informal caregiver present, addressed topics concerning health, functioning and well-being, and took about 45 minutes. At the end of the screening, persons were asked for their goals with the open-ended question (Step 1). When they could not think of a goal, the bubble diagram was left for review by the frail older person and informal caregiver, as discussing the diagram with an informal caregiver might assist the frail older persons in formulating a goal. For frail older persons, a second home visit followed within two months, in which, among other things, the reviewed bubble diagram was discussed with the frail older person to establish whether the frail older person had a goal (Step 2). If goals were formulated, they were handed over to an appropriate professional (e.g., a physical therapist for goals related to mobility). Depending on whether the

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{bubble_diagram.png}
\caption{Bubble diagram}
\end{figure}


formulated goal was suitable for this, this professional then assisted the frail older person in designing an action plan which specified which actions the frail older person would undertake as a first step toward achieving the goal; this professional also provided follow-up for this action plan.\textsuperscript{16,17} The goals and action plans were recorded in the project’s multidisciplinary shared electronic health record by the nurse or gerontological social worker, to make them available for all professionals involved. In this record, each goal was classified according to the taxonomy for goals as developed by Bogardus et al.,\textsuperscript{21} i.e., by domain, specificity, timeframe and level of challenge.

Professionals were trained in using the method for discussing goals by means of role-play and group-discussions during the project’s educational meetings. Further, an experienced practice nurse coached them in using the method during their first visits to frail older persons.
Evaluation
The evaluation consisted of two components. First, characteristics of the goals recorded were studied. To ensure unity of classification, goals were reclassified on goal domain and specificity by two of the researchers (SR, MP). Second, experiences with the method were studied by inviting nurses or social workers who had worked with the method to fill out an online questionnaire, which included items concerning estimated time spent on elaborating goals; whether or not they had succeeded in determining goals; reasons for not being able to formulate goals with the frail older person (more than one answer was allowed); and the perceived value of the method. The study was reviewed by our local ethics committee, which stated that no formal approval was required.

Results
Goals of community-dwelling frail older people
Participants
Information concerning goals was electronically recorded for 139 participants (50.7% of the 274 frail older people included in the study). Of these, 87 (63.5%) were female. Their mean age was 80.8 (SD 5.6) years. Two participants said they did not have any goal; the remaining 137 participants mentioned a total of 173 goals. The number of goals mentioned by a participant varied between one (n=109; 79.6%), two (n=22; 16.1%), three (n=4; 2.9%) and four (n=2; 1.5%).

Goals
The most frequently mentioned goals concerned the domains of mobility (n=43; 24.9%); well-being (n=52; 30.1%); and social context (n=57; 32.9%). An overview of the distribution of goals over the domains, including some illustrative examples, is provided in Table 1. Goals varied in their specificity; 100 goals (57.8%) were global, 42 (24.3%) goals were moderately specific, and 31 (17.9%) goals were specific. Further, goals differed in their timeframe; 94 (54.3%) were goals that should be reached immediately; 28 (16.2%) were short term goals; and 51 (29.5%) were long term goals. Professionals considered 57 (32.9%) of the goals difficult to achieve for the frail older person; 14 (8.1%) were considered easy to achieve; and 102 (59.0%) were considered challenging but feasible to achieve.

Experiences of professionals
Participants
Of the 25 professionals who had worked with the goal-setting method, 18 (72.0%) filled out the questionnaire. All 18 (100%) were female, and their average age was 45.3 years (SD 8.5). Their occupations varied: 3 (16.7%) were practice nurses, 5 (27.8%) were district nurses, 4 (22.2%) were other nurses, 2 (11.1%) were gerontological social workers, and 4 (22.2%) had other occupations. They had a mean 11.8 (SD 9.4) years of working experience. Most professionals (11; 61.1%) had used the method for goal-setting with 1-5 frail older persons; 5 (27.8%) had used the method with 5-20 frail older persons, and 2 (11.1%) had used the method with ≥ 20 frail older persons.

Experiences of professionals with the method
Professionals spent about 16 (SD 13) minutes discussing goals with frail older people during the first step. Discussing goals during the second step also took about 16 (SD 7) minutes. When describing how often goals were formulated by frail older people during the first step of the method, 3 (16.7%) said that they always or often formulated a goal with the frail older person during the first step, 6 (33.3)
said they had sometimes formulated a goal, and 9 (50.0%) said they had rarely formulated a goal during the first step of the method. After completing both steps of the method, 8 (47.1%) professionals (n=17) had always or often formulated a goal with the frail older person, 4 (23.5%) had sometimes formulated a goal, and 5 (29.4%) had rarely formulated a goal. The most frequent reasons for not formulating a goal with the frail older person, as described by professionals (n=18), were: the frail older person not having a goal because of being comfortable with the current situation (n=14, 77.8%); the frail older person not being used to discussing goals (n=9, 50.0%); the frail older person not being able to formulate a goal due to cognitive problems (n=7, 38.9%); the frail older person not understanding the situation (n=12, 66.7%).

Table 2  Perceived value of the method for determining goals with frail older people

<table>
<thead>
<tr>
<th>Reason</th>
<th>Disagree n (%)</th>
<th>No opinion n (%)</th>
<th>Agree n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The bubble diagram was useful</td>
<td>1 (5.6)</td>
<td>4 (22.2)</td>
<td>13 (72.3)</td>
</tr>
<tr>
<td>This method takes too much time</td>
<td>6 (33.3)</td>
<td>6 (33.3)</td>
<td>6 (33.3)</td>
</tr>
<tr>
<td>This method helps me to determine what a frail older person values</td>
<td>1 (5.6)</td>
<td>0 (0.0)</td>
<td>17 (94.4)</td>
</tr>
<tr>
<td>This method helps me to provide better care to frail older people</td>
<td>2 (11.1)</td>
<td>2 (11.1)</td>
<td>14 (77.8)</td>
</tr>
<tr>
<td>This method helps me to put the wishes of frail older people first</td>
<td>0 (0.0)</td>
<td>3 (16.7)</td>
<td>15 (83.3)</td>
</tr>
<tr>
<td>I think it is useful to discuss goals with frail older people</td>
<td>1 (5.6)</td>
<td>1 (5.6)</td>
<td>16 (88.9)</td>
</tr>
<tr>
<td>Even when the method does not result in concrete goals, it is useful</td>
<td>0 (0.0)</td>
<td>1 (5.6)</td>
<td>17 (94.4)</td>
</tr>
<tr>
<td>This manner of patient-centered working increases my work satisfaction</td>
<td>2 (11.1)</td>
<td>9 (50.0)</td>
<td>7 (38.9)</td>
</tr>
<tr>
<td>Frail older people appreciate having their goals discussed</td>
<td>3 (16.7)</td>
<td>7 (38.9)</td>
<td>8 (44.5)</td>
</tr>
<tr>
<td>I intend to use (part of) this method for determining goals more often</td>
<td>1 (5.6)</td>
<td>5 (27.8)</td>
<td>12 (66.7)</td>
</tr>
<tr>
<td>I would recommend (part of) this method for determining goals to other professionals</td>
<td>1 (5.6)</td>
<td>10 (55.6)</td>
<td>7 (38.9)</td>
</tr>
</tbody>
</table>

*Total may not equal 100% due to rounding

Discussion

This study has shown that this two-step method for discussing goals has the potential to assist professionals in determining goals with frail older people. Goals elicited from frail older people most frequently concerned mobility, well-being and social context, which corresponds with the results of previous studies. As a result, engaging in goal discussions with frail older people may enable professionals to focus their interventions somewhat more on well-being and functioning. Further, most of the goals mentioned by frail older participants were either global or moderately specific. However, whereas goals intended for behavioural change need to be specific, goals intended to guide clinical decision-making can give direction to care or treatment decisions even when they are less specific. Professionals who had worked with the method were generally positive, as they felt that it had improved their knowledge about what the frail older person valued, even when the method did not result in the frail older person articulating a goal. Still, they did describe several barriers to determining goals with frail older people. These included factors related to the frail older person, i.e., having cognitive problems, not being used to discussing goals, or being overwhelmed by questions previously asked; and factors related to the professional, as one-third considered the method too time-consuming. These findings agree with the barriers for discussing goals with older people that were found in a previous study. However, when considering these barriers, it is important to realize that our study aimed to describe the first experiences with the method, and that most professionals had only determined goals with a limited number of frail older persons. Those who had determined goals with ≥ 20 frail older persons reported that they often or always determined a goal with the frail older person. Therefore, it is likely that when professionals gain more experience with the method, they may be better equipped to overcome some of the barriers found. The study had some weaknesses that need to be discussed. First, professionals did
not always fill out the electronic goal-setting form for their frail older persons. As a result, the total number of goals may be underestimated. Second, in this study, the goal-setting method was sometimes used by professionals who were not involved in the everyday care of the frail older person. As a previous study found that not knowing professionals well enough is an important barrier for older people to engage in goal discussions, this may have resulted in frail older people being less motivated to formulate goals. Considering professionals’ generally positive experiences with the method as well as the barriers and limitations found, several recommendations can be made for use of the method for discussing goals in everyday practice. First, the method should be used by professionals who are actually involved in the everyday care of a particular frail older person. Second, to avoid overwhelming the frail older person, professionals should incorporate the method at the right time in their consultation, when the frail older person is not too fatigued by e.g., history taking. Third, although cognitive problems were a reason for not determining goals in this study, professionals should not interpret this as a reason for not engaging in goal discussions with frail older people with cognitive problems, because, as was pointed out by professionals in this study, the process of discussing goals is valuable in itself, and previous studies have shown that many frail older people with cognitive problems are able to formulate a goal. Last, professionals should realize that determining a goal is not an end in itself. What matters most is how professionals, frail older people and informal caregivers incorporate these goals in decision-making. Future studies will have to show whether frail older people and informal caregivers do indeed experience more involvement in decision making as a result of the method.

Conclusions

This study has shown that a brief two-step method for goal-setting can assist professionals in determining goals with frail older people and can help professionals to gain insight into what a frail older person values most, even when the frail older person is not able to actually describe a goal. This knowledge has the potential to guide professionals, and possibly frail older people, in choosing the most appropriate treatment or care option, thereby increasing frail older people’s involvement in decision making.

References

Impact of interprofessional education on collaboration attitudes, skills, and behavior among primary care professionals

Sarah Robben, Marieke Perry, Leontien van Nieuwenhuijzen, Theo van Achterberg, Marcel Olde Rikkert, Henk Schers, Maud Heinen, René Melis

J Contin Educ Health Prof. In press.
Abstract

Introduction: Care for frail older people is often provided by several professionals. Collaboration between them is essential, but remains difficult to achieve. Interprofessional education (IPE) can improve this collaboration. We developed a nine-hour IPE program for primary care professionals from seven disciplines caring for frail older people, and aimed to establish whether the program improved professionals’ interprofessional attitudes and attitudes towards collaboration, collaboration skills, and collaborative behavior. We also evaluated learners’ reactions to the program.

Methods: Before-after study, using the Interprofessional Attitudes Questionnaire (IAQ, score:1-7); Attitudes Toward Health Care Teams Scale (ATHCTS, score:0-105); and Team Skills Scale (TSS, score:17-85). Additionally, semi-structured interviews were conducted with ten selected participants.

Results: Participants’ (n=80) overall interprofessional attitudes improved (IAQ baseline: 5.49; follow-up: 5.67, p=0.001); attitudes toward geriatric teams did not change (ATHCTS baseline: 69.9; follow-up: 69.1, p=0.32). Participants’ self-reported team skills improved (TSS baseline: 45.7; follow-up: 48.1, p=0.001). In the interviews, many interviewees reported increased collaboration with professionals of other disciplines due to the program. Interviewees considered the program’s interprofessional nature and attending the program with local professionals important contributing factors to the experienced improvements in collaboration. However, they also noted that not all parts of the program had met the needs of all participating disciplines, due to differences in professional background and knowledge.

Discussion: A brief IPE program can improve interprofessional attitudes, collaboration skills and collaborative behavior. That such a program allows professionals to get acquainted with each other and each other’s viewpoints appears to be as important as the educational content.

Introduction

Due to the current fragmentation of care, care for a single patient is often provided by a large number of professionals from a variety of disciplines. This applies particularly to patients with complex care needs, such as frail older people. In order to be able to provide frail older people with the best care possible, collaboration between all professionals involved is essential. Previous studies have shown that problems in collaboration and coordination between professionals can negatively affect patient outcomes, lead to decreased work-satisfaction of professionals and result in waste of resources. Unfortunately, there are many factors that may prevent effective collaboration among professionals. These include factors related to the professional (such as lack of knowledge about and trust in other professionals’ skills and expertise, and lack of understanding of the roles of other professionals) as well as external factors such as professional culture, time constraints, problems contacting other professionals, and lack of reimbursement for collaborative work.

One approach to improving interprofessional collaboration in the care for frail older people is targeting several of these factors at once through the provision of interprofessional education. These are occasions when members of two or more professions learn with, from and about each other to improve collaboration and quality of care. However, due to the heterogeneity of interprofessional educational interventions and the limited number of published studies, evidence about their effectiveness remains limited. In addition, the majority of studies have focused on the evaluation of undergraduate interprofessional education. Therefore, we developed an interprofessional educational program for primary care professionals involved in the care of frail older people. We then evaluated this educational program to establish whether the program was able to (1) improve primary care professionals’ interprofessional attitudes and attitudes towards collaboration; (2) improve primary care professionals’ collaboration skills; and (3) increase collaborative behavior among primary care professionals. Further, we evaluated learners’ reactions to the program.

Methods

We evaluated the interprofessional educational program by means of a mixed methods design, consisting of a before-after study followed by semi-structured interviews. The study was reviewed by the local ethics committee, the Committee on Research involving Human Subjects Arnhem-Nijmegen, which determined that no formal approval was required.
Participants
The interprofessional educational program was taught between September 2010 and May 2011 in a geographical area encompassing seven general practices in the Netherlands. These general practices invited all local primary care professionals involved in the health care or social care of frail older people (such as general practitioners (GPs), pharmacists, nurses, physiotherapists, occupational therapists, dieticians, and gerontological social workers) to participate. Participation in the educational program was voluntary; however, it was encouraged by providing financial compensation for the hours spent attending the workshops and by providing Continuing Medical Education credits. All professionals who attended the educational program were invited to participate in the evaluation study; no incentives were provided for this.

Educational program
The interprofessional educational program was conducted in association with another project titled the Health and Welfare Information Portal (ZWIP). ZWIP is a personal, internet-based portal for interdisciplin ary communication and information exchange for frail older people, their informal caregivers and professionals. Its goals are improving care for community-dwelling frail older people by improving interprofessional collaboration and facilitating self-management of frail older people. Although parts of the educational program were dedicated to teaching professionals how to use this portal, the evaluation of this portal was not part of the current study. The entire project, including the interprofessional educational program, was developed by means of Intervention Mapping, a method for the theory- and evidence-informed development of health promotion and health education programs. As part of this method, we conducted a thorough analysis of the problems currently existing with interprofessional collaboration and defined specific outcomes that we wanted the educational program to achieve. Social Cognitive Theory was chosen as main theory underlying the project, and methods derived from this theory, such as modeling and active learning, were incorporated in the educational program. The educational program consisted of three interactive interprofessional workshops for primary care professionals, which took between two-and-a-half and three hours each. The workshops were taught by varying combinations of four members of the research group (a GP experienced in teaching collaborating physicians and nurses, a nurse scientist experienced in teaching professionals of varying disciplinary backgrounds, a physician, and a human movement scientist). To ensure that participants in each workshop included professionals who were likely to meet each other in their everyday work, we organized separate workshops on location for each general practice. The total number of participants for each workshop varied between five and twenty-three.

The first workshop concerned the concept of frailty and identification of frailty; these topics were addressed during interdisciplinary group discussions and case-based learning. Main learning objectives for this workshop were that professionals would know what constitutes a frail older person, know which aspects of frailty are important for other disciplines, and be able to identify frailty in the older people. The second workshop concerned providing self-management support to frail older people; interprofessional collaboration, including an assignment in which participants from different disciplines informed each other about their expertise and skills; and collaborative use of the portal. These topics were addressed during short lectures, case-based exercises, and group discussions. Main learning objectives for this workshop were that professionals would be able to communicate information required for self-management to the frail older people and discuss goals with them, know the expertise of other disciplines in the care of frail older people, and be aware of the benefits of the contributions of other professionals in the care of frail older people. The third workshop, which took place at least three months after the second workshop, concerned all topics addressed in the first two workshops with special attention to collaborative goal-setting in a role-play. It also provided a forum for discussing to experiences with the topics at hand. The main educational objective for this workshop meeting was to ensure that professionals were confident that they could put everything taught in the first two workshops into practice.

The overall aim for the educational program was that professionals would get acquainted with each other’s viewpoints and area of expertise, as well as with each other. To facilitate the latter, we included a break in each workshop meeting, to allow participating professionals to get to know each other personally.

Evaluation
Our evaluation addressed the first three levels of Kirkpatrick’s model for the classification of interprofessional training outcomes as adapted by Barr et al. The main outcomes were learners’ reactions (Level 1), changes in perceptions and attitudes toward collaboration (Level 2a), acquisition of collaboration skills and knowledge (Level 2b), and change in collaborative behavior (Level 3). We selected a mixed methods approach because it allowed us to combine both methods for developmental purposes, as the quantitative study informed the purposive sampling for the interviews, as well as for reasons of complementarity and expansion. We integrated the findings of both methods during data collection and during the reporting of the results. Both methods were considered equally important.

The quantitative aspects of the evaluation focused on assessing learners’ reactions to the interprofessional educational program and the program’s effects on professionals’ attitudes toward collaboration, attitudes towards other professionals
and on their collaboration skills. Questionnaires were administered prior to and within one week after completion of the program. Questionnaires included: (1) questions concerning demographics; (2) two scales for assessing changes in attitudes (the Attitudes Toward Health Care Teams Scale and the Interprofessional Attitudes Questionnaire); and (3) the Team Skills Scale to measure changes in collaboration skills. In addition, the follow-up questionnaire contained questions about participants’ reactions to the program.

The Attitudes Toward Health Care Teams Scale measures attitudes about geriatric healthcare teams. The 21-item scale (score 0-105) has three subscales: team value (11 items, score 0-55), team efficiency (5 items, score 0-25), and shared leadership (5 items, score 0-25). Higher scores reflect a more positive attitude towards teamwork.

The Interprofessional Attitudes Questionnaire measures interprofessional attitudes. This questionnaire assesses several characteristics of disciplines, which are selected based on the disciplines involved. We used characteristics previously developed by Hean et al. Participants rated members of other disciplines on these characteristics using a 7-point scale (1=very low; 7=very high).

The Team Skills Scale measures changes in team skills of geriatric healthcare professionals. Higher scores on the 17-item instrument (score 17-85) represent a higher self-reported skills level.

The qualitative component of the evaluation aimed to assess learners’ reactions to the interprofessional educational program, changes in their attitudes toward collaboration and toward other professionals, and changes in collaborative behavior as a result of the program. A research assistant (LvN) who had not been involved in the design and the delivery of the educational program conducted semi-structured interviews with ten purposefully selected participants at least four months after their completion of the program. We sampled for professionals from a variety of disciplines and focused on participants who had either been very positive or very negative about the educational program in the quantitative evaluation. The interview guide included questions concerning professionals’ experiences with the program, their attitudes toward collaboration, and whether they had made changes in their work with regard to collaboration. Interviews lasted 23 minutes on average (range: 12-38 min) and were tape-recorded and transcribed verbatim.

Analysis
We analyzed the baseline characteristics of participants using descriptive statistics. Independent t-tests and Chi-Square tests were used to compare demographic data for workshop participants who did and who did not return both questionnaires. We used a dependent t-test to compare the means of the Attitudes Toward Health Care Teams Scale, the overall Interprofessional Attitudes Questionnaire and the Team Skills Scale at baseline and at follow-up. Mixed linear models (SAS Proc mixed) modeling the change over time between baseline and follow-up in the Team Skills Scale and Attitudes Toward Health Care Teams Scale for each participant, were used to study whether there was heterogeneity in the change over time that could be explained by the participants’ discipline or the general practice area. The qualitative data were analyzed by two researchers (SR, MP) using conventional content analysis. Interviews were coded by one researcher and then checked by the other. In case of disagreement about coding, discussion followed until consensus was reached. We conducted the data analysis in parallel with the interviews, to be able to explore new themes that came up in the first interviews in subsequent interviews. Atlas.ti software was used to support this analysis.

Results
Participants
A total of 132 primary care professionals representing seven disciplines involved in the care of frail older people participated in the educational program, which was delivered as planned. Of these, 119 (90.2%) returned a questionnaire. Hundred-and-eight returned the baseline questionnaire (90.8% of 119). Ninety-one completed the follow-up questionnaire (76.5% of 119) and 80 (67.2% of 119) returned both. Participants’ characteristics are shown in Table 1. On average, participants who did not return both questionnaires attended significantly fewer educational meetings (M = 2.2, SD = 0.7) than those who did (M = 2.7, SD = 0.6, p<0.001). There were no significant differences in sex, age, or years of work-experience.

Ten professionals participated in the semi-structured interviews. Of these, 5 were females. Participants were GPs (n=3), nurses (n=4), a pharmacist, a physiotherapist, and a gerontological social worker.

Learners’ reactions to the program
Participants filling out the follow-up questionnaire (n=91) rated the educational program an average of 6.9 out of 10 (SD = 0.8). Most participants (n = 64; 70%) said they would recommend the educational program to others; furthermore, a majority of participants felt that the educational program had increased their knowledge about interprofessional collaboration (Table 2). Most interviewees expressed positive reactions, indicating they had enjoyed parts of the program such as the role plays. However, some believed the program was trying to teach too many topics in a short time and that the third workshop meeting had been scheduled too soon after the second session to allow time for extensive exchange of experiences. Some interviewees considered the pace of the program high and would have liked...
All participants who answered the question concerning whether they valued the program's interprofessional nature (n=85) answered affirmatively. Values identified were that they felt it had facilitated collaboration, provided an opportunity to get to know each other, increased knowledge about other disciplines, and enabled discussing problems in a broader perspective. Interviewees echoed this assessment. However, some did feel that it was not necessary to make all three meetings interprofessional. Further, they pointed out an important difficulty related to the interprofessional nature of the educational program, as differences in levels of knowledge between disciplines meant that not all parts of the program were relevant for all participating disciplines. Illustrative quotes of interviewees are provided in Exhibit 1.

Change in perceptions and attitudes toward other disciplines and collaboration

A total of 78 participants filled out the Attitudes Toward Health Care Teams Scale. Before the start of the program, their mean score on this scale was 69.8 (SD=6.1). Scores did not change significantly following the educational program (mean score Table 1 Characteristics of participants

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>General practitioners (GP)</th>
<th>Pharmacists</th>
<th>Nursing disciplines</th>
<th>Paramedical disciplines</th>
<th>Social disciplines</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female, number (%)</td>
<td>16 (61.5)</td>
<td>5 (55.6)</td>
<td>37 (100.0)</td>
<td>28 (80.0)</td>
<td>11 (91.7)</td>
<td>97 (81.5)</td>
</tr>
<tr>
<td>Age in years, mean (SD)</td>
<td>43.6 (10.9)</td>
<td>41.3 (12.8)</td>
<td>42.1 (10.5)</td>
<td>41.5 (12.9)</td>
<td>46.8 (10.2)</td>
<td>42.7 (11.3)</td>
</tr>
<tr>
<td>Disciplines, number (%)</td>
<td>GP 25 (96.2)</td>
<td>Pharmacist 9 (100.0)</td>
<td>Nurse 29 (78.4)</td>
<td>Physiotherapist 25 (71.4)</td>
<td>Social worker 10 (83.3)</td>
<td>80 (94.8)</td>
</tr>
<tr>
<td></td>
<td>GP in training 1 (3.8)</td>
<td></td>
<td>Nursing assistant 3 (8.1)</td>
<td>Occupational therapist 6 (17.1)</td>
<td>Other 2 (16.7)</td>
<td>12 (11.3)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Medical assistant 3 (8.1)</td>
<td>Dietician 4 (11.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work experience in years, mean (SD)</td>
<td>12.4 (9.9)</td>
<td>9.8 (8.8)</td>
<td>10.4 (9.2)</td>
<td>16.3 (12.1)</td>
<td>9.1 (7.8)</td>
<td>12.4 (10.4)</td>
</tr>
<tr>
<td>Number of workshops attended, mean (SD)</td>
<td>2.4 (0.8)</td>
<td>2.3 (0.7)</td>
<td>2.5 (0.7)</td>
<td>2.6 (0.6)</td>
<td>2.7 (0.5)</td>
<td>2.5 (0.6)</td>
</tr>
<tr>
<td>Total</td>
<td>n=26</td>
<td>n=9</td>
<td>n=37</td>
<td>n=35</td>
<td>n=12</td>
<td>n=119</td>
</tr>
</tbody>
</table>

Table 2 Participants' reactions to the educational program

<table>
<thead>
<tr>
<th>Change in perceptions and attitudes toward other disciplines and collaboration</th>
</tr>
</thead>
<tbody>
<tr>
<td>I would recommend this educational program to others, number (%)</td>
</tr>
<tr>
<td>The time that I have spent on this educational program was time well spent and worthwhile, number (%)</td>
</tr>
<tr>
<td>The educational program has increased my knowledge about frail older people, number (%)</td>
</tr>
<tr>
<td>The educational program has increased my knowledge about self-management support, number (%)</td>
</tr>
<tr>
<td>The educational program has increased my knowledge about interdisciplinary collaboration, number (%)</td>
</tr>
<tr>
<td>The educational program has increased my knowledge about people with disabilities, number (%)</td>
</tr>
<tr>
<td>The educational program has increased my knowledge about older people in general, number (%)</td>
</tr>
<tr>
<td>Due to this educational program I am better equipped to collaborate with other primary care professionals, number (%)</td>
</tr>
<tr>
<td>Agreement</td>
</tr>
<tr>
<td>----------------</td>
</tr>
<tr>
<td>10 (11.0)</td>
</tr>
<tr>
<td>13 (14.4)</td>
</tr>
<tr>
<td>13 (14.4)</td>
</tr>
<tr>
<td>13 (14.4)</td>
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<tr>
<td>13 (14.4)</td>
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<td>13 (14.4)</td>
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<tr>
<td>13 (14.4)</td>
</tr>
<tr>
<td>13 (14.4)</td>
</tr>
</tbody>
</table>

On the Attitudes Toward Health Care Teams Scale, all participants answered affirmatively. Values identified were that the program had facilitated collaboration, provided an opportunity to get to know each other, increased knowledge about other disciplines, and enabled discussing problems in a broader perspective. Interviewees echoed this assessment. However, some did feel that it was not necessary to make all three meetings interprofessional. Further, they pointed out an important difficulty related to the interprofessional nature of the educational program, as differences in levels of knowledge between disciplines meant that not all parts of the program were relevant for all participating disciplines. Illustrative quotes of interviewees are provided in Exhibit 1.
Interviewees indicated that the group discussions of case descriptions had increased their knowledge of the viewpoints of other disciplines. They also felt that their knowledge about the expertise of members of disciplines less known to them, such as occupational therapists and gerontological social workers, had increased due to the interprofessional nature of the educational program (Exhibit 1).

Change in collaborative behavior

Interviewees offered several reasons why they had not collaborated more with other disciplines prior to their participation in the educational program. These included lack of reimbursement, time constraints, not having a reason to collaborate with other disciplines, and not knowing members of the other disciplines. Interviewees felt that during the interprofessional educational program they had gotten to know the other professionals in their locality better. While some already knew many other local professionals before the start due to some form of multidisciplinary collaboration already in place, others had met the other local professionals for the first time.

Interviewees varied in their opinions about whether collaboration had changed as a result of the educational program. Some said that they did not collaborate more; however, many said that collaboration had improved due to the educational program, as they were less reluctant to contact each other and did so more frequently. They also more often asked other professionals to become involved. Some interviewees observed that the effects on collaborative behavior diminished over time (Exhibit 1).

Change in collaboration skills and knowledge

Seventy-eight participants completed the Team Skills Scale. They reported significantly higher team skills after completion of the educational program (mean score=48.1; SD=6.8) than before the start of the educational program (mean score=45.7; SD=6.8, p=0.001 (Table 3). Site and discipline were unable to explain the variance in mean change from baseline.

### Table 3 Effects of the educational program on collaboration attitudes and skills

<table>
<thead>
<tr>
<th>Measure</th>
<th>Baseline (n=78)</th>
<th>Follow-up (n=78)</th>
<th>Effect size (Cohen's d)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>ATHCTS total, mean (SD)</td>
<td>69.8 (6.1)</td>
<td>69.1 (6.6)</td>
<td>-0.1</td>
<td>0.317</td>
</tr>
<tr>
<td>ATHCTS team value, mean (SD)</td>
<td>39.6 (4.0)</td>
<td>38.9 (4.7)</td>
<td>-0.2</td>
<td>0.173</td>
</tr>
<tr>
<td>ATHCTS team efficiency, mean (SD)</td>
<td>16.1 (3.0)</td>
<td>16.1 (3.1)</td>
<td>0.0</td>
<td>0.879</td>
</tr>
<tr>
<td>ATHCTS, shared leadership, mean (SD)</td>
<td>14.2 (3.6)</td>
<td>14.2 (3.4)</td>
<td>0.0</td>
<td>0.857</td>
</tr>
<tr>
<td>IAQ overall, mean (SD)</td>
<td>5.5 (0.5)</td>
<td>5.7 (0.5)</td>
<td>0.3</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>TSS, mean (SD)</td>
<td>45.7 (6.8)</td>
<td>48.1 (6.8)</td>
<td>0.3</td>
<td>0.001</td>
</tr>
</tbody>
</table>

ATHCTS = Attitudes Toward Health Care Teams Scale (score 0-105, higher scores reflect a more positive attitude); IAQ = Interprofessional Attitudes Questionnaire (score 1-7, higher scores reflect a more positive attitude); TSS = Team Skills Scale (score 17-85, higher scores reflect higher self-reported team skills).

*dependent t-test; **n=79; ***n=80
This study has shown that our brief interprofessional educational program has resulted in small but significant improvements in participants’ attitudes towards other professionals and in self-reported team skills. Many interviewees reported that, as a result of their participation in the program, they collaborated more with other disciplines. Participants felt that the interprofessional character of the educational program, especially attending the program together with local professionals, had contributed to the experienced improvements in collaboration. Previous research has shown that attitudes towards other professionals are not likely to be positively influenced by interprofessional education. Yet, we did find a small overall improvement. Unfortunately, attitudes toward working in teams, which is more of an overall measure of attitudes toward collaboration, did not change. Previous interprofessional education studies that used the Attitudes Towards Healthcare Teams Scale for students have found mixed results. Curran et al. found no change in attitudes; whereas Fulmer et al., studying the effects of the Geriatric Interdisciplinary Team Training program, found significant improvements. However, in these studies the program was considerably longer (2-36 weeks, didactic hours 5-144). Also, their program was delivered to students, whereas attitudes of practicing professionals are probably more difficult to change, as their attitudes have developed over the years and have been shaped by their experiences. Although we found significant improvements in interprofessional attitudes and collaboration skills, the effect sizes were small. This might be explained by the limited duration of the program; by challenges inherent to interprofessional education, such as not always being able to meet the varying needs of all participating professionals; and by the short follow-up period, since follow-up questionnaires were filled out almost immediately after completion of the program. Importantly, in the semi-structured interviews, which were conducted after a longer follow-up period, several participants did report increased collaboration with other professionals of specific disciplines. Therefore, one might argue that the small immediate improvements found are relevant, as they have resulted in changes in collaborative behavior. However, it is also likely that factors other than attitudes and skills exert an important influence on collaborative behavior, as e.g., getting to know other professionals personally can diminish reservations to contact other professionals.

Participants felt that the interprofessional group discussions and role-plays had advanced their understanding of other professionals’ viewpoints and areas of expertise. In addition, they felt that attending the interprofessional education together with local professionals had facilitated collaboration. From this we conclude that interactive interprofessional education in small groups comprising...
local professionals and using role-play and group discussions of case descriptions has potential for improving interprofessional attitudes, collaboration skills and collaborative behavior. However, as our interviewees noted, differences in professional background make tailoring of the information provided to specific professionals challenging at best. As organizing interprofessional education requires a great deal of effort and resources, and transferring knowledge can be achieved more effectively within other educational settings, we recommend that other strategies for knowledge transfer be considered.

Our study had some limitations that need to be discussed. First, as in many evaluations of interprofessional education, the educational program was designed and evaluated by the same research group. However, we did use objective measurement instruments and had an independent research assistant conduct the interviews. Second, as participation in this course was voluntary, participants were likely to be more motivated to engage in collaboration than professionals in the general population. This limits the generalizability of our results. Last, we did not include a control group, leaving the study vulnerable to confounding factors such as history and the Hawthorne effect. Major strengths of the study were the mixed methods design, the use of validated instruments with good psychometric properties that have been successfully used to evaluate interprofessional educational programs, and the variety of disciplines participating in the program and its evaluation.

This study has shown that a brief interprofessional educational intervention for primary care professionals involved in the care of frail older people has the potential to improve attitudes toward other disciplines, increase self-reported team skills, and might even be able to improve collaborative behavior. In an era in which the number of frail older people is increasing, and considering that interdisciplinary collaboration behavior. However, as our interviewees noted, differences in professional background make tailoring of the information provided to specific professionals challenging at best. As organizing interprofessional education requires a great deal of effort and resources, and transferring knowledge can be achieved more effectively within other educational settings, we recommend that other strategies for knowledge transfer be considered.

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This study has shown that a brief interprofessional educational intervention for primary care professionals involved in the care of frail older people has the potential to improve attitudes toward other disciplines, increase self-reported team skills, and might even be able to improve collaborative behavior. In an era in which the number of frail older people is increasing, and considering that interdisciplinary teamwork is essential in the care for this population, these results are promising.

References

Supplementary appendix 1

Interprofessional Attitudes Questionnaire at baseline and follow-up

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Pre n=64</th>
<th>Post n=64</th>
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<th>Pre n=69</th>
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<td><strong>Academic ability</strong></td>
<td>5.9</td>
<td>6.3</td>
<td>4.1</td>
<td>4.5</td>
<td>4.9</td>
<td>4.2</td>
<td>4.6</td>
<td>3.8</td>
<td>4.1</td>
<td>4.9</td>
<td>5.1</td>
<td>5.8</td>
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<tr>
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<td>6.3</td>
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<td>5.6</td>
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<td>6.1</td>
<td>6.2</td>
<td>5.7</td>
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<td>6.0</td>
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<td>6.0</td>
<td>6.1</td>
<td>5.7</td>
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<tr>
<td><strong>Leadership abilities</strong></td>
<td>5.2</td>
<td>5.6</td>
<td>4.7</td>
<td>4.8</td>
<td>4.7</td>
<td>4.8</td>
<td>4.9</td>
<td>4.4</td>
<td>4.8</td>
<td>5.0</td>
<td>5.2</td>
<td>5.1</td>
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<tr>
<td><strong>The ability to work independently</strong></td>
<td>6.2</td>
<td>6.5</td>
<td>6.0</td>
<td>6.0</td>
<td>5.6</td>
<td>5.7</td>
<td>5.8</td>
<td>6.0</td>
<td>5.4</td>
<td>5.6</td>
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<td>6.3</td>
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<td><strong>The ability to be a team player</strong></td>
<td>5.1</td>
<td>5.2</td>
<td>5.9</td>
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<td>5.7</td>
<td>5.9</td>
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<td>5.5</td>
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<td><strong>The ability to make decisions</strong></td>
<td>6.2</td>
<td>6.5</td>
<td>5.4</td>
<td>5.3</td>
<td>5.3</td>
<td>5.4</td>
<td>5.3</td>
<td>5.6</td>
<td>5.0</td>
<td>5.3</td>
<td>5.7</td>
<td>5.8</td>
</tr>
<tr>
<td><strong>Practical skills</strong></td>
<td>5.7</td>
<td>5.8</td>
<td>6.1</td>
<td>6.3</td>
<td>5.8</td>
<td>6.0</td>
<td>5.2</td>
<td>5.4</td>
<td>5.1</td>
<td>5.4</td>
<td>6.0</td>
<td>5.6</td>
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<tr>
<td><strong>Confidence</strong></td>
<td>6.1</td>
<td>6.3</td>
<td>5.5</td>
<td>5.4</td>
<td>5.5</td>
<td>5.6</td>
<td>5.5</td>
<td>5.8</td>
<td>5.4</td>
<td>5.5</td>
<td>5.9</td>
<td>5.6</td>
</tr>
</tbody>
</table>

Interprofessional Attitudes Questionnaire: score 1-7, higher scores reflect a more positive attitude; n varies as professionals did not fill out the questionnaire for their own discipline. (n=63; n=59; n=60; n=61; n=62; n=67; n=68; n=73; n=71; n=75; n=62; n=74; n=72; n=79)
Implementation of an innovative web-based conference table for community-dwelling frail older people, their informal caregivers and professionals: a process evaluation

Sarah Robben, Marieke Perry, Mirjam Huisjes, Leontien van Nieuwenhuijzen, Henk Schers, Chris van Weel, Marcel Olde Rikkert, Theo van Achterberg, Maud Heinen, René Melis

Abstract

Background: Due to fragmentation of care, continuity of care is often limited in the care provided to frail older people. Further, frail older people are not always enabled to become involved in their own care. Therefore, we developed the Health and Welfare Information Portal (ZWIP), a shared Electronic Health Record combined with a communication tool for community-dwelling frail older people and primary care professionals. This article describes the process evaluation of its implementation, and aims to establish (1) the outcomes of the implementation process, (2) which implementation strategies and barriers and facilitators contributed to these outcomes, and (3) how its future implementation could be improved.

Methods: Mixed methods study, consisting of (1) a survey among professionals (n = 118) and monitoring the use of the ZWIP by frail older people and professionals, followed by (2) semi-structured interviews with purposively selected professionals (n = 12).

Results: 290 frail older people and 169 professionals participated in the ZWIP. At the end of the implementation period, 55% of frail older people and informal caregivers, and 84% of professionals had logged on to their ZWIP at least once. For professionals, the exposure to the implementation strategies was generally as planned, they considered the interprofessional educational program and the helpdesk very important strategies. However, frail older people’s exposure to the implementation strategies was less than intended. Facilitators for the ZWIP were the perceived need to enhance interprofessional collaboration and the ZWIP application being user-friendly. Barriers included the low computer-literacy of frail older people, a preference for personal communication and limited use of the ZWIP by other professionals and frail older people. Interviewees recommended using the ZWIP for other target populations as well and adding further strategies that may help frail older people to feel more comfortable with computers and the ZWIP.

Conclusions: This study describes the implementation process of an innovative e-health intervention for community-dwelling frail older people, informal caregivers and primary care professionals. As e-health is an important medium for overcoming fragmentation of healthcare and facilitating patient involvement, but its adoption in everyday practice remains a challenge, the positive results of this implementation are promising.

Background

Our current healthcare system is not well equipped to meet the needs of the growing population of frail older people. Due to fragmentation, care for a single frail older person is often provided by a number of professionals who work for a variety of organizations and services, which results in discontinuity of care. Also, the healthcare system is not designed to facilitate the incorporation of patient perspectives in decision making, which becomes even more difficult when care is delivered by an interprofessional team. This is unfortunate, as involving patients in their care is mandatory and can improve patient outcomes. Information Technology has the potential to diminish these problems, by means of a multidisciplinary shared Electronic Health Record that is accessible to patients as well. Therefore, we developed a program which included such a record: the Health and Welfare Information Portal (ZWIP). The program aimed to facilitate shared decision-making and self-management by frail older people and informal caregivers, as well as to reduce fragmentation of care by improving collaboration among professionals involved.

As the program consisted of a number of interacting components and was delivered to several different general practices, conducting a process evaluation to study its implementation was considered critical. First, because information concerning barriers and facilitators experienced during the implementation may be able to guide improvements to the implementation plan and the intervention itself. Second, because it can help identify critical factors for the intervention’s implementation in other settings or by other research groups. Such process evaluations are especially useful for e-health interventions, as the number of studies concerning their implementation is limited, while their adoption remains a challenge. Therefore, this article aims to establish (1) the outcomes of the implementation process of the ZWIP, (2) which implementation strategies and experienced barriers and facilitators contributed to these outcomes, and (3) how its future implementation could be improved.

Methods

We evaluated the implementation of the ZWIP with a mixed methods study, consisting of (1) a quantitative evaluation by means of a survey and data collected during the implementation and use of the ZWIP, followed by (2) a qualitative evaluation by means of semi-structured interviews with purposively selected participants. The local ethics committee, the Committee on Research involving Human Subjects Arnhem-Nijmegen, reviewed the study and stated that no formal approval was required.
Participants
Participants of the study were community-dwelling frail older people, who were patients of participating general practices in the province of Gelderland or Noord-Brabant, the Netherlands; their informal caregivers; and healthcare and welfare professionals involved in their care. They participated in the ZWIP during its implementation phase, which started in September 2010 and ended on the first of July 2011. We monitored the use of the ZWIP and its implementation strategies for both frail older people and professionals. Further, professionals were surveyed and interviewed. We chose not to survey or interview frail older people and informal caregivers as the project had already been time-consuming for them, and they would be surveyed and interviewed as part of the project’s future effect evaluation as well.

Intervention: the Health and Welfare Information Portal
The ZWIP was developed by means of Intervention Mapping,14 a method for the systematic development of evidence-informed interventions. Throughout this development, future users, i.e., primary care professionals and geriatricians (n=15), as well as (frail) older people and informal caregivers (n=14), were involved extensively to trough their participation in working groups. These working groups started with participants specifying which problems related to interprofessional collaboration and self-management by frail older people should be solved by the ZWIP, for example not knowing which professionals are involved in the care of a particular frail older person and professionals not being able to contact each other. Then, theories matching the identified determinants of these problems were used to support the development of the intervention. These included Social Cognitive Theory,15 Goal Setting Theory16 and elements of organizational change theories.17 The involvement of the target populations continued during the iterative development process of the ZWIP.

The ZWIP can be considered a combination of an Electronic Health Record accessible to the frail older person, informal caregiver and all professionals involved, with a tool for interprofessional and patient-professional communication. The ZWIP consists of (1) information about the frail older person’s health, functioning and social situation, contact information about professionals involved in their care, and care-related goals formulated by or with the frail older person, (2) a secure messaging system for communication between the frail older person and one or more professionals or between professionals, and (3) tailored educational materials for the frail older person and informal caregiver. The frail older persons hold the key to the ZWIP, as they decide which professionals are granted access to their personal ZWIP. The ZWIP can be entered by logging on to a website which conforms to Dutch security regulations. This website, which runs in Dutch, can be accessed from any computer. Frail older persons and their informal caregivers can log on by means of a shared user name and password, while professionals need a security token for logging on.

Implementation of the Health and Welfare Information Portal
The ZWIP implementation team consisted of the project manager, physicians, a nurse, a nurse scientist experienced with implementation, and research assistants working for the department of Geriatric Medicine of the Radboud University Nijmegen Medical Centre. They implemented the ZWIP using tailored implementation strategies for each target population, i.e., frail older people and informal caregivers, professionals and the employing organizations of professionals. An overview of the implementation strategies used is provided in Box 1.

We invited general practices affiliated with this University Hospital or involved in the program’s development to participate in the ZWIP, which was made available to them at no charge for the duration of the study. The participating practices invited local primary care professionals from all relevant disciplines involved in the care of frail older people, such as physiotherapists, district nurses and social workers, to take part in the programs’ interprofessional educational program. This program, for which continuing medical education credits were available, addressed screening for frailty, self-management support, interprofessional collaboration, and use of the ZWIP during three three-hour workshop meetings. In addition, professionals received coaching in specific components of the program, and were supported by a telephonic helpdesk. Further, financial compensation was provided for the time invested in the program.

The general practices screened their populations of ≥70 years for frailty using a two-step screening questionnaire (Easycare-TOS). In the first step, the general practitioner (GP) selected patients which were considered (possibly) frail. In the second step, the thus selected patients were screened for frailty on the physical, psychological and social domain during a home visit by a nurse or gerontological social worker. During a second home visit, all people who were frail were invited to participate in the ZWIP. If they gave informed consent, a ZWIP was installed for them. Further, professional (GP) selected patients which were considered (possibly) frail. In the second step, the thus selected patients were screened for frailty on the physical, psychological and social domain during a home visit by a nurse or gerontological social worker. During a second home visit, all people who were frail were invited to participate in the ZWIP. If they gave informed consent, a ZWIP was installed for them. We supported frail older people and informal caregivers in using the ZWIP by a telephonic helpdesk. Further, financial compensation was provided for the time invested in the program.

Quantitative evaluation
The quantitative evaluation of the implementation of the ZWIP consisted of a survey for professionals, and an evaluation of the data collected about the use of the
Implementation of the Health and Welfare Information Portal

Implementation strategies and the data from the ZWIP itself. Data collected included the numbers of older people screened, the number of participants, the number of messages sent, the number of professionals participating in a frail older person’s ZWIP, the number of participants who logged on to the ZWIP, the number of calls to the telephonic helpdesk and the number of visits to frail older people by volunteers. The survey for professionals was sent out at the beginning of July 2011. The survey was developed building on existing questionnaires used previously to evaluate the implementation of complex interventions and on previous experience of the authors. The survey included questions concerning demographics, time spent on using the ZWIP, perceived value of the implementation strategies, and barriers and facilitators for the use of the ZWIP. We used separate questionnaires for GPs, for nurses and gerontological social workers conducting the screening, and for other professionals. Participants were asked to fill out the survey online, those who did not respond were sent a paper version.

Qualitative evaluation
The qualitative evaluation consisted of semi-structured interviews about experiences with the implementation process and perceived barriers and facilitators for the use of the ZWIP. A topic list for these interviews was developed by members of the research group and was adjusted until consensus was reached. We conducted these interviews with 12 purposively selected professionals, who had a variety of experiences with the implementation process of the ZWIP. This was arranged by selecting professionals from several disciplines and with different roles in the implementation process, who came from three general practices with varying levels of adoption of the ZWIP. In addition, we interviewed members of the implementation team, who were not involved in conducting its evaluation. Interviews were conducted by members of the research group (LvN, MP, SR) and were transcribed verbatim by a research assistant.

Analysis
We used descriptive statistics to describe baseline characteristics of participants, data collected about the implementation and the actual use of the ZWIP, and data derived from the survey for professionals. The qualitative data gathered in the semi-structured interviews were analyzed by two members of the research group (SR, MP) using content analysis. Interviews were conducted in parallel with data analysis, using Atlas.ti to support this. We conducted interviews until theoretical saturation was achieved.

Box 1. Implementation strategies as planned for each target population

<table>
<thead>
<tr>
<th>Recruitment strategies</th>
<th>Professionals</th>
<th>Employing organizations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frail older people and informal caregivers</td>
<td>Involvement in development</td>
<td>Financial compensation</td>
</tr>
<tr>
<td>Flyers about the program</td>
<td>Flyers about the program</td>
<td>Educational program for employees</td>
</tr>
<tr>
<td>Involvement of GP who asked for participation in screening</td>
<td>Starting with intrinsically motivated early adopters by inviting general practices affiliated with the university hospital to participate</td>
<td></td>
</tr>
<tr>
<td>Involvement of informal caregiver</td>
<td></td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Supporting strategies</th>
<th>Professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Visit by a volunteer who instructs them in the use of the ZWIP</td>
<td>Interprofessional educational program (Continuing Medical Education credits available)</td>
</tr>
<tr>
<td>Internet and paper version of ZWIP</td>
<td>E-learning</td>
</tr>
<tr>
<td>Telephonic helpdesk</td>
<td>Coaching of professionals conducting the screening</td>
</tr>
<tr>
<td></td>
<td>Telephonic helpdesk</td>
</tr>
<tr>
<td></td>
<td>Newsletter</td>
</tr>
<tr>
<td></td>
<td>Tailoring of intervention to meet local circumstances</td>
</tr>
<tr>
<td></td>
<td>Deviations from inclusion criteria, such as including younger frail older people, allowed to gain experience</td>
</tr>
<tr>
<td></td>
<td>Financial compensation</td>
</tr>
<tr>
<td></td>
<td>Incentives such as the general practice receiving a cake after including the first frail older person</td>
</tr>
</tbody>
</table>

GP = General Practitioner; ZWIP = Health and Welfare Information Portal
Results

Participants
Fourteen general practices were invited to participate in the study, seven of these (50%) agreed to participate. The characteristics of these practices are shown in Table 1. In total, 290 frail older people and 169 professionals participated in the ZWIP.

A total of 158 professionals received a survey, i.e., 39 GPs, 26 nurses and gerontological social workers conducting the screening, and 93 other professionals. Eleven professionals could not be reached. Hundred-eighteen professionals (75%) returned the questionnaire, 34 were GPs, 26 were nurses and social workers who conducted the screening and connected frail older persons to the ZWIP, and 62 were other professionals, such as physiotherapists, pharmacists, nurses and social workers.

Twelve purposively selected professionals participated in the semi-structured interviews. Three of them were GPs, three were nurses and gerontological social workers conducting the screening at the homes of participants, three were other professionals, i.e., pharmacists (n=2) or physiotherapist (n=1) and three were members of the implementation team, i.e., project manager, nurse providing coaching, or research assistant.

Outcomes of the implementation process

The 290 frail older people who had a ZWIP account installed constituted 49% of all frail older people invited. The percentage of frail older people agreeing to participate varied over the separate general practices. Interviewees suggested that this may have been caused by variation in local professionals’ attitudes towards the ZWIP, as well as by variation in computer literacy due to social-economic differences between the general practices. An overview of the outcomes of the implementation process is provided in Table 2.

Most interviewees described being involved in the ZWIP of at least some frail older people, varying from one to tens of people. Some used the ZWIP quite often for a limited number of frail older people, whereas others rarely used it. Interviewees described that most frail older people and their informal caregivers made limited use of the ZWIP. On the other hand, they also gave examples of frequent users of the ZWIP. One interviewee described that the use of the ZWIP was limited when the frail older person was in good health, but that its use increased when the frail older person became ill. Box 2 provides some illustrative examples of quotes by interviewees.
### Table 2  Outcomes of the implementation of the ZWIP

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Number of older people screened, n</td>
<td>705</td>
<td>365</td>
<td>284</td>
<td>426</td>
<td>200</td>
<td>621</td>
<td>169</td>
<td>2770</td>
</tr>
<tr>
<td>Number of older people screened who were frail, n (%)</td>
<td>71 (10.1)</td>
<td>80 (21.9)</td>
<td>49 (17.3)</td>
<td>116 (27.2)</td>
<td>25 (12.5)</td>
<td>213 (34.3)</td>
<td>43 (25.4)</td>
<td>597 (21.6)</td>
</tr>
<tr>
<td>Number of frail older people participating in the ZWIP, n (%)</td>
<td>61 (85.9)</td>
<td>25 (31.3)</td>
<td>11 (22.4)</td>
<td>55 (47.4)</td>
<td>8 (32.0)</td>
<td>118 (55.4)</td>
<td>12 (27.9)</td>
<td>290 (48.6)</td>
</tr>
<tr>
<td>Female, n (%)</td>
<td>34 (55.7)</td>
<td>15 (60.0)</td>
<td>4 (36.8)</td>
<td>40 (72.7)</td>
<td>6 (75.0)</td>
<td>73 (61.9)</td>
<td>10 (83.3)</td>
<td>182 (62.8)</td>
</tr>
<tr>
<td>Age, mean (SD)</td>
<td>81.8 (5.4)</td>
<td>81.6 (4.8)</td>
<td>79.2 (5.8)</td>
<td>82.0 (6.2)</td>
<td>82.5 (7.5)</td>
<td>81.1 (5.6)</td>
<td>82.8 (7.5)</td>
<td>81.2 (5.7)</td>
</tr>
<tr>
<td>Number of frail older people in the ZWIP who logged on to the ZWIP once, n (%)</td>
<td>9 (14.8)</td>
<td>2 (8.0)</td>
<td>2 (18.2)</td>
<td>8 (14.5)</td>
<td>3 (37.5)</td>
<td>18 (15.3)</td>
<td>1 (8.3)</td>
<td>43 (14.8)</td>
</tr>
<tr>
<td>Number of frail older people in the ZWIP who logged on to the ZWIP more than once, n (%)</td>
<td>25 (41.0)</td>
<td>17 (68.0)</td>
<td>5 (45.5)</td>
<td>23 (41.8)</td>
<td>5 (62.5)</td>
<td>36 (30.5)</td>
<td>6 (50.0)</td>
<td>117 (40.3)</td>
</tr>
<tr>
<td>Number of professionals participating in the ZWIP, n</td>
<td>31</td>
<td>17</td>
<td>25</td>
<td>43</td>
<td>16</td>
<td>30</td>
<td>16</td>
<td>169</td>
</tr>
<tr>
<td>Female, n (%)</td>
<td>21 (67.7)</td>
<td>12 (70.6)</td>
<td>18 (72.0)</td>
<td>33 (76.7)</td>
<td>12 (75.0)</td>
<td>23 (76.7)</td>
<td>13 (81.3)</td>
<td>126 (74.6)</td>
</tr>
<tr>
<td>Occupation, n (%)</td>
<td>General practitioner</td>
<td>6 (19.4)</td>
<td>4 (23.5)</td>
<td>9 (36.0)</td>
<td>8 (18.6)</td>
<td>5 (31.3)</td>
<td>9 (30.0)</td>
<td>3 (18.8)</td>
</tr>
<tr>
<td></td>
<td>Practice nurse</td>
<td>0 (0.0)</td>
<td>1 (5.9)</td>
<td>1 (4.0)</td>
<td>1 (2.3)</td>
<td>1 (6.3)</td>
<td>6 (20.0)</td>
<td>1 (6.3)</td>
</tr>
<tr>
<td></td>
<td>District nurse</td>
<td>7 (22.6)</td>
<td>1 (5.9)</td>
<td>3 (12.0)</td>
<td>8 (18.6)</td>
<td>2 (12.5)</td>
<td>0 (0.0)</td>
<td>4 (25.0)</td>
</tr>
<tr>
<td></td>
<td>Pharmacist</td>
<td>1 (3.2)</td>
<td>1 (5.9)</td>
<td>2 (8.0)</td>
<td>6 (14.0)</td>
<td>2 (12.5)</td>
<td>1 (3.3)</td>
<td>3 (18.8)</td>
</tr>
<tr>
<td></td>
<td>Physiotherapist</td>
<td>7 (22.6)</td>
<td>4 (23.5)</td>
<td>3 (12.0)</td>
<td>6 (14.0)</td>
<td>3 (18.8)</td>
<td>5 (16.7)</td>
<td>2 (12.5)</td>
</tr>
<tr>
<td></td>
<td>(Gerontological) social worker</td>
<td>1 (3.2)</td>
<td>2 (11.8)</td>
<td>3 (12.0)</td>
<td>2 (4.7)</td>
<td>0 (0.0)</td>
<td>1 (3.3)</td>
<td>1 (6.3)</td>
</tr>
<tr>
<td></td>
<td>Hospital-based specialist</td>
<td>1 (3.2)</td>
<td>0 (0.0)</td>
<td>1 (4.0)</td>
<td>2 (4.7)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>8 (25.8)</td>
<td>4 (23.5)</td>
<td>3 (12.0)</td>
<td>10 (43.3)</td>
<td>3 (18.8)</td>
<td>8 (26.7)</td>
<td>2 (12.5)</td>
</tr>
<tr>
<td>Number of professionals in the ZWIP of a frail older person, mean (range)</td>
<td>2.5 (0-5)$^a$</td>
<td>4.1 (0-8)$^a$</td>
<td>1.9 (0-4)</td>
<td>1.8 (0-5)</td>
<td>4.1 (2-6)</td>
<td>2.6 (1-6)$^a$</td>
<td>3.0 (1-5)</td>
<td>2.6 (0-8)$^a$</td>
</tr>
<tr>
<td>Number of professionals in the ZWIP who logged on to the ZWIP once, n (%)</td>
<td>2 (6.5)</td>
<td>5 (9.2)</td>
<td>2 (8.0)</td>
<td>7 (16.7)$^a$</td>
<td>2 (12.5)</td>
<td>3 (10.3)$^a$</td>
<td>8 (50.0)</td>
<td>25 (15.0)$^a$</td>
</tr>
<tr>
<td>Number of professionals in the ZWIP who logged on to the ZWIP more than once, n (%)</td>
<td>22 (71.0)</td>
<td>14 (82.4)</td>
<td>20 (80.0)</td>
<td>26 (61.9)$^a$</td>
<td>11 (68.8)</td>
<td>23 (79.3)$^a$</td>
<td>6 (37.5)</td>
<td>116 (69.5)$^a$</td>
</tr>
<tr>
<td>Number of messages sent in the ZWIP by professionals, mean (range)</td>
<td>3.6 (0-24)</td>
<td>5.7 (0-46)</td>
<td>0.3 (0-5)</td>
<td>1.3 (0-17)$^a$</td>
<td>0.3 (0-3)</td>
<td>0.9 (0-6)$^a$</td>
<td>0.7 (0-9)</td>
<td>1.9 (0-46)$^a$</td>
</tr>
<tr>
<td>Number of messages sent in the ZWIP by frail older people and informal caregivers, mean (range)</td>
<td>1.2 (0-21)</td>
<td>3.2 (0-31)</td>
<td>0.6 (0-2)</td>
<td>0.9 (0-34)</td>
<td>0.1 (0-1)</td>
<td>0.1 (0-4)</td>
<td>0.2 (0-1)</td>
<td>0.8 (0-34)</td>
</tr>
<tr>
<td>Number of frail older people in whose ZWIP ≥ 5 messages have been sent, n (%)</td>
<td>7 (11.5)</td>
<td>8 (32.0)</td>
<td>2 (18.2)</td>
<td>3 (5.5)</td>
<td>0 (0.0)</td>
<td>1 (0.8)</td>
<td>0 (0.0)</td>
<td>21 (7.2)</td>
</tr>
</tbody>
</table>

ZWIP = Health and Welfare Information Portal; $^a$n=46; $^b$n=24; $^c$n=42; $^d$n=117; $^e$n=29; *as some professionals were involved in the network of more than one general practice, the total number of professionals is less than the sum of professionals in all general practices; $^f$n=273; $^g$n=167
Factors contributing to the implementation outcomes

Exposure to the implementation strategies

All but one of the planned implementation strategies targeting professionals (Box 1) had been available during the implementation period. The development of e-learning for professionals took longer than expected and was therefore not used during the implementation phase. We added one implementation strategy for professionals during the implementation period, i.e., the designation of one key person in each general practice who coordinated the required activities and helped colleagues with questions, as coordinating everything from one central point became too demanding for the implementation team. For frail older people and informal caregivers all planned implementation strategies had been available. Exposure of professionals and frail older people and informal caregivers to the separate implementation strategies varied over the participating general practices (Table 3). For instance, professionals’ participation in the educational program varied between 60% and 100%. Their overall exposure to coaching was 47%; it was 95% (20 of 21) for professionals conducting the program’s screening for frailty. Of the participating frail older people and informal caregivers, only 62% had used the offered but not obligatory visits by a volunteer to explain the ZWIP, 63% of GPs (19 of 30) had always or often called their frail older patients themselves to ask them to participate in the screening.

Appreciation of the implementation strategies

Of the surveyed professionals who had participated in the educational program, 70% (63 of 89) considered it (very) necessary for being able to work with the ZWIP. Interviewees confirmed this, as they felt that meeting each other and gaining knowledge about each others’ expertise during the educational program facilitated collaboration, and they appreciated the opportunity to ask questions and to practice working with the ZWIP. However, they did feel that the educational program could have been shorter, and that too much time had elapsed between the educational program and the first frail older persons having a ZWIP. As for the coaching, only 26% (14 of 53) of surveyed professionals who had received coaching felt they would not be able to work with the ZWIP without it. However, interviewees did consider coaching necessary, as they appreciated the assistance of someone experienced in conducting the screening and entering data in the ZWIP. The helpdesk was considered (very) necessary by 77% (41 of 53) of surveyed professionals who had contacted it, and interviewees agreed that it was useful (Table 4 and Box 2).

Barriers and facilitators

Interviewees stated that for all target populations experiencing problems with interprofessional communication or contacting professionals had been an important
Table 4. Perceived value of the implementation strategies used

<table>
<thead>
<tr>
<th>Implementation strategy</th>
<th>n=115*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Involvement of professionals in development</td>
<td></td>
</tr>
<tr>
<td>Involvement of GPs/professionals important; yes, n (%)</td>
<td>95 (86.4)</td>
</tr>
<tr>
<td>Flyers</td>
<td></td>
</tr>
<tr>
<td>Flyers important for deciding about participation, yes, n (%)</td>
<td>35 (59.3)</td>
</tr>
<tr>
<td>Estimated relevance to future users on a scale of 1-10, mean (SD)</td>
<td>6.8 (1.6)</td>
</tr>
<tr>
<td>Educational program</td>
<td></td>
</tr>
<tr>
<td>Necessary for being able to work with ZWIP; yes, n (%)</td>
<td>63 (70.8)</td>
</tr>
<tr>
<td>Estimated relevance to future users on a scale of 1-10, mean (SD)</td>
<td>7.5 (1.6)</td>
</tr>
<tr>
<td>Coaching</td>
<td></td>
</tr>
<tr>
<td>Able to work with ZWIP without coaching; no, n (%)</td>
<td>14 (26.4)</td>
</tr>
<tr>
<td>Estimated relevance to future users on a scale of 1-10, mean (SD)</td>
<td>6.9 (1.7)</td>
</tr>
<tr>
<td>E-coaching</td>
<td></td>
</tr>
<tr>
<td>Necessary for being able to work with ZWIP; yes, n (%)</td>
<td>8 (38.1)</td>
</tr>
<tr>
<td>Estimated relevance to future users on a scale of 1-10, mean (SD)</td>
<td>6.7 (1.6)</td>
</tr>
<tr>
<td>Telephonic helpdesk</td>
<td></td>
</tr>
<tr>
<td>Necessary for being able to work with ZWIP; yes, n (%)</td>
<td>41 (77.4)</td>
</tr>
<tr>
<td>Estimated relevance to future users on a scale of 1-10, mean (SD)</td>
<td>7.3 (1.6)</td>
</tr>
<tr>
<td>Newsletter</td>
<td></td>
</tr>
<tr>
<td>Newsletter important for staying up-to-date about the program; yes, n (%)</td>
<td>35 (46.7)</td>
</tr>
<tr>
<td>Estimated relevance to future users on a scale of 1-10, mean (SD)</td>
<td>5.9 (1.5)</td>
</tr>
<tr>
<td>Financial compensation</td>
<td></td>
</tr>
<tr>
<td>Financial compensation necessary for future professionals; yes, n (%)</td>
<td>27 (56.3)</td>
</tr>
<tr>
<td>Estimated relevance to future users on a scale of 1-10, mean (SD)</td>
<td>6.7 (2.0)</td>
</tr>
<tr>
<td>Possibility to adapt the ZWIP to meet local circumstances</td>
<td></td>
</tr>
<tr>
<td>Estimated relevance to future users on a scale of 1-10, mean (SD)</td>
<td>8.0 (1.4)</td>
</tr>
</tbody>
</table>

ZWIP = Health and Welfare Information Portal; *Professionals could answer affirmatively, neutral or negatively, n varies as questions concerning necessity and importance were only answered by professionals exposed to the implementation strategy; n=110; n=99; n=106; n=89; n=107; n=53; n=105; n=104; n=75; n=115

Table 5. Experienced barriers and facilitators to working with the ZWIP

<table>
<thead>
<tr>
<th></th>
<th>n= 105</th>
<th>Disagree, n (%)</th>
<th>Neutral, n (%)</th>
<th>Agree, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The data included in the ZWIP are sufficiently safeguarded</td>
<td>2 (2.0)*</td>
<td>48 (49.0)*</td>
<td>48 (49.0)*</td>
<td></td>
</tr>
<tr>
<td>The data included in the ZWIP are accurate</td>
<td>5 (5.1)*</td>
<td>45 (45.5)*</td>
<td>49 (49.5)*</td>
<td></td>
</tr>
<tr>
<td>The data included in the ZWIP are not up-to-date</td>
<td>32 (32.3)*</td>
<td>54 (54.5)*</td>
<td>13 (13.1)*</td>
<td></td>
</tr>
<tr>
<td>The data included in the ZWIP provide me insufficient information</td>
<td>30 (30.3)*</td>
<td>51 (51.5)*</td>
<td>18 (18.2)*</td>
<td></td>
</tr>
<tr>
<td>The data included in the ZWIP are way too extensive</td>
<td>38 (38.0)*</td>
<td>61 (61.0)*</td>
<td>1 (1.0)*</td>
<td></td>
</tr>
<tr>
<td>I feel that the ZWIP is very user-friendly</td>
<td>11 (11.1)*</td>
<td>42 (42.4)*</td>
<td>46 (46.5)*</td>
<td></td>
</tr>
<tr>
<td>I feel that working with computers is uncomfortable</td>
<td>81 (81.8)*</td>
<td>11 (11.1)*</td>
<td>7 (7.1)*</td>
<td></td>
</tr>
<tr>
<td>I feel that the instruction during the educational program was sufficient to be able to work with the ZWIP</td>
<td>6 (6.3)*</td>
<td>17 (17.7)*</td>
<td>73 (76.0)*</td>
<td></td>
</tr>
<tr>
<td>Working with the ZWIP is too complicated</td>
<td>45 (46.9)*</td>
<td>38 (39.6)*</td>
<td>13 (13.5)*</td>
<td></td>
</tr>
<tr>
<td>Working with the ZWIP ultimately saved me time</td>
<td>46 (48.9)*</td>
<td>42 (44.7)*</td>
<td>6 (6.4)*</td>
<td></td>
</tr>
<tr>
<td>I feel that the ZWIP does not fit into my regular working pattern</td>
<td>68 (66.7)*</td>
<td>20 (20.2)*</td>
<td>11 (11.1)*</td>
<td></td>
</tr>
<tr>
<td>Working with the ZWIP gives me the enough leeway to incorporate the goals of the frail older person in decisions about his/her care</td>
<td>10 (10.9)*</td>
<td>41 (44.6)*</td>
<td>41 (44.6)*</td>
<td></td>
</tr>
<tr>
<td>Working with the ZWIP is difficult since other professionals involved do not use the ZWIP much</td>
<td>8 (8.5)*</td>
<td>36 (38.5)*</td>
<td>50 (52.1)*</td>
<td></td>
</tr>
<tr>
<td>Working with the ZWIP is difficult since the frail older person and informal caregiver do not use the ZWIP much</td>
<td>7 (7.4)*</td>
<td>31 (33.0)*</td>
<td>56 (59.6)*</td>
<td></td>
</tr>
</tbody>
</table>

ZWIP = Health and Welfare Information Portal; Total may not amount to 100.0% due to rounding; *n=98; †n=99; ‡n=100; ††n=96; †‡n=94; †¶n=92

Incentive for participating in the ZWIP. Additional facilitators for professionals were appreciating that the ZWIP could be used at a time of their choosing, sympathizing with the idea of the ZWIP, enjoying participating in something new, the ZWIP application being user-friendly and receiving sufficient support in working with the ZWIP. Additional facilitators for frail older people were wanting to keep control of their own care, appreciating that their message in the ZWIP was directly and quickly safeguarded, although the idea of the ZWIP, working with the ZWIP, ultimately saved me time, I feel that the ZWIP is difficult since other professionals involved do not use the ZWIP much, I feel that working with computers is uncomfortable.
On the other hand, preferring to have face-to-face contact presented an important barrier to the use of the ZWIP for all target populations. Barriers specific for professionals were considering the ZWIP too early for the current generation of older people whose computer-literacy is limited and having doubts about whether the ZWIP is the best way to improve care. In addition, interviewees considered time constraints an important barrier, even though 67% (64 of 96) of surveyed professionals considered the time spent on using the ZWIP (very) limited. Further, limited use of the ZWIP by both professionals and frail older people presented a barrier to respectively 52% (50 of 94) and 60% (56 of 94) of surveyed professionals (Table 5). Interviewees agreed with this, as they considered not being invited into the ZWIP of frail older people much, receiving few messages, and not all professionals in their work area being familiar with the ZWIP an important barrier for its use. A final barrier described were the start-up problems experienced by professionals, which included the ZWIP application not working correctly, lack of clarity about the eligibility criteria for older people, and receiving financial compensation too late. Interviewees felt that at the start of the project, the implementation team had struggled with translating the ideas behind ZWIP into everyday practice, sometimes causing support to be lacking or too late. Interviewed members of the implementation team acknowledged these start-up problems, and explained the problems with the ZWIP application by the limited time available for its initial development, resulting in improvements of the ZWIP continuing alongside its implementation. Further, interviewees of the implementation team described that the need for local professionals and organizations to get ready to work together first, and the obligated but time-consuming population-based screening had slowed down the implementation of the ZWIP. Barriers specific for frail older people included considering the ZWIP not useful or quite a fuss, and considering the ZWIP something for professionals. In addition, frail older people were not always invited to participate by a motivated professional or were not considered eligible to participate by professionals. However, the main barriers for frail older people related to computers, i.e., not having a computer, not being comfortable with or capable of working with a computer, concerns about the security of the ZWIP and not yet being familiar with the ZWIP. Although we did direct several implementation strategies at these barriers, such as asking an informal caregiver to use the ZWIP for the frail older person and offering a visit by a volunteer to explain the ZWIP, one interviewee remarked that sometimes, although explicitly offered, frail older people did not want to use these strategies as they did not want to burden them or did not want yet another unknown person in their house (Box 2).

Improving a future implementation of the ZWIP

Interviewees made several recommendations for improving future implementations of the ZWIP. These included shortening the educational program, having an e-learning and a website available and using early adopters as advocates for the program. For frail older people, interviewees suggested the use of an additional implementation strategy, i.e., organising meetings for all frail older people in which they can learn about the ZWIP and practice its use, in order to familiarise them with the ZWIP within a more comfortable context. Interviewees considered the ZWIP useful for other populations as well, e.g., for frail people younger than 70 years, non-frail older people, psychiatric patients, palliative patients, patients with diabetes or COPD and for problematic family situations. Last, interviewees shared some considerations for improvements of the ZWIP itself, which included linking the ZWIP to their own electronic health records, and enabling professionals to use the ZWIP more flexibly, i.e., to use only those parts needed (Box 2).

Box 2 Illustrative quotes of participants

**Outcomes of the implementation process**

“I have one patient who actually ended up with a ZWIP…and I never hear anything from him” General practitioner

“But I think that everyone who participates in the ZWIP here in the municipality…they have asked me to become involved in their network….so it’s tens of people” Other professional

“Whereas this week I saw, with another man here in X, he communicates [over the ZWIP] with the general practitioner by himself” Professional conducting the screening

**Appreciation of the implementation strategies**

“But those other disciplines, you never or rarely talk to them, and in those three [educational] meetings that we had here it was very interesting to see that, yes, what everyone does, yes, what the added value is of everyone...so you put people in primary care, also due to this project, around the table” Other professional

“Yes, it [the educational program] helped, but then it was too lengthy to send all eight general practitioners there” General practitioner

“Yes, I really felt [coaching] was very important, for example, starting up a ZWIP account for the first time….just to accompany her one time and to see, and how it is done, yes, that just works better than a paper manual” Professional conducting the screening

**Barriers and facilitators to the ZWIP**

“Or older people that say like, yes, I need to call the general practitioner so often, and that is so difficult because he is so difficult to reach, because then I need to tell him my blood sugar for example, and then I have to be on hold and then I finally have the medical assistant, and then there’s an emergency call and I have to wait again. And now I can just type it through a secure system, and then I’m done” Implementation team

“I thought it was really good, you [the implementation team] just gave a lot of time and attention, and were very easy to contact and yes, that was very nice, and everyone was really enthusiastic” General practitioner
Box 2 Continued

“But the advantage of the ZWIP is of course that it's a secure network, but that you can choose your own time for responding” Other professional

“Yes, I think the application is quite easy to work with” Professional conducting the screening

“And in that way I keep thinking like, well, that study has actually come ten years too early... with a generation that’s not, that didn’t grow up with computers, I think that’s a pity” General practitioner

“And also, last year it was of course also that issue around the, er, National Electronic Health Record, that made people think like, yes, is everything really that reliable….” Implementation team

“Or the security token didn’t work or they had the wrong token or you know, those actually small things but those were really annoying for the general practitioners” Implementation team

“For in these kind of projects, and there’s no way to do it differently, you have parallel development lines, you have simultaneously the trajectories of the educational program that’s being developed, that should start, the information technology, but at a certain time the information technology is not just as ready, and then the information technology is, but the goals or the patient education materials aren’t ready yet. So, and that’s because we were under a lot of pressure with the time…” Implementation team

“And then I’m quite a bad one to persuade people [to participate]. Probably because I’m not one-hundred percent convinced myself” Professional conducting the screening

Recommendations for future implementation of the ZWIP

“You can use it for every disease or every target population...and indeed, also with dementia, in palliative phases of patients when patients are still active themselves...” Implementation team

“Yes, those [non-frail older people] who don’t, those who are still quite vital, who do have that age. They would...those are people who are much quicker eh, could work with it before they, before they really,...and I think they might be able to benefit from it” Professional conducting the screening

“You could stimulate its use in small groups...for once I was in a community centre...then, we just sat with X and some older people, and then really around a round table, just re-enacting it. And then you see that people understand it much quicker and can also see that you are actually communicating” Implementation team

“I think that a lot of registration systems that those people have, eh, we have a different kind of registration system and the ZWIP is another, I think that many things can be linked to each other” Professional conducting the screening

ZWIP = Health and Welfare Information Portal

Discussion

This study describes the implementation of the ZWIP. By the end of the implementation period, 290 frail older people and 169 professionals were involved in the ZWIP. Their use of the ZWIP varied. The implementation strategies were generally delivered as planned for professionals. However, the exposure of frail older people and informal caregivers to some of the implementations strategies, such as their use of the optional instruction about the ZWIP application by volunteers was less than intended. Professionals were generally positive about the implementation process, especially about the interprofessional educational program and the helpdesk. Factors that facilitated the implementation of the ZWIP were frail older people and professionals feeling the need to enhance interprofessional collaboration and the ZWIP application being user-friendly; barriers were the low computer-literacy of frail older people, start-up problems, a preference for personal contact and limited use of the ZWIP by others. Interviewees recommended adapting the implementation strategies to make them more efficient, for example by shortening the educational programme, to use the ZWIP for other target populations as well, and to add new strategies that may help frail older people to feel more comfortable with computers and the ZWIP.

Outcome of the implementation process

Overall, the results of the implementation were positive. First, the frail older people who were the target population of the ZWIP are likely to be among the most difficult populations to engage in an e-health intervention, as they feel less comfortable and competent with computers than younger populations. Therefore, the recruitment of 290 frail older participants (49% of those invited to participate), who were not previously selected for having computer skills, is quite a positive outcome. Of course, their actual use of the ZWIP during the implementation period varied, but those who never or rarely used the ZWIP may not have had a reason to use it, as all went well. In addition, for several frail older people a ZWIP was created near the end of the implementation period, which resulted in them having had limited time to use it. However, participants could continue to use the ZWIP for one year following the end of the implementation period. Additional positive results of the implementation are that the interviewed professionals recommended using the ZWIP for other target populations as well, and that professionals and frail older people not yet involved in the current research project had approached us to ask whether they could use the ZWIP as well.

Important factors that contributed to these outcomes were the involvement of future target populations throughout the development process; the implementation strategies such as the interprofessional educational program and the helpdesk,
which were considered particularly useful by professionals; and the widely acknowledged need to improve the care for the growing number of frail older people and to improve the communication and collaboration among professionals.\textsuperscript{21,22} As the ZWIP incorporates many components of the currently advocated introduction of the patient-centred medical home, e.g., patient-centeredness, care-coordination and the use of e-health such as shared Electronic Health Records to improve quality of care,\textsuperscript{23} it fits very well in the improvements currently recommended for primary care.

**Comparison to the literature**

To our knowledge, the ZWIP is one of the first e-health interventions to combine a multidisciplinary shared Electronic Health Record with interprofessional and patient-professional communication. This, added to the limited number of publications concerning the results of the implementation of e-health interventions,\textsuperscript{24} makes comparisons to other studies difficult. However, there have been several articles published concerning the barriers for the implementation of e-health interventions such as electronic medical records or electronic communication. These largely agree with the barriers found in this study, i.e., preferring personal contact, being worried about security of data and time constraints\textsuperscript{13,24-26} even though the results on this latter barrier were somewhat mixed in our study, with about two-third of professionals reporting that they considered the time spent on using the ZWIP limited, whereas interviewees reported that time constraints did present a barrier to using the ZWIP. Additional barriers specific to this study were the low computer-literacy of frail older people and the experienced start-up problems.

**Strengths and limitations**

Our study had some limitations. First, as a result of a deliberate choice, frail older people and informal caregivers’ experiences with the implementation process were only evaluated indirectly. We do acknowledge the limitations of receiving such indirect information. However, we expect that we have been able to give an overall impression of their experiences with the projects’ implementation. Second, the implementation was evaluated by members of the project team who were involved in its implementation. Although we used objective quantitative data sources, and ensured that the interviews with primary care professionals were conducted by an objective research assistant, this may have affected our results. Third, the study was conducted in the Netherlands, which healthcare system is characterized by each patient having their own GP, usually over an extended time period. This may limit the generalisability of our findings to healthcare systems which do not have such a strong primary care foundation. On the other hand, the study had several important strengths, which include the large number of participants, including a large number of frail older people who are usually more difficult to recruit for such projects and a large group of professionals of whom a large majority (87%) had not been involved in the development process themselves, the use of a mixed-methods design which combined multiple data sources, and the ZWIP being implemented directly in everyday practice for use in regular care.

**Conclusions**

This study has described the implementation of an innovative e-health intervention for community-dwelling frail older people, informal caregivers and primary care professionals, which had positive results. The implementation strategies for professionals, especially the involvement of the target populations in its development, the educational program which resulted in professionals getting to know each other personally and the helpdesk, as well as the experienced need for improving care for frail older people contributed to this. However, the strategies intended to improve frail older people’s computer literacy did not always succeed as exposure to these strategies was limited. Therefore, both additional strategies targeting frail older people’s computer literacy and reviewing the ZWIP to optimise its user-friendliness are needed. Nevertheless, as e-health is an important medium for overcoming healthcare fragmentation and facilitating patient involvement, but its adoption in everyday practice remains a challenge, the results of this implementation are promising.

**Practice implications**

Based on the current study, several recommendations can be made for the implementation of comparable e-health interventions. First, when e-health innovations are directed at populations who currently have limited computer literacy, such as frail older people, implementation efforts should focus on improving this by e.g., a comprehensive training program.\textsuperscript{27} Piloting the implementation strategies selected for this aim, to ensure that they are able to meet the needs of the target population, is highly recommendable. Second, as a preference for personal contact continues to be an important barrier for the use of e-health by both patients and professionals, it should be addressed during the implementation, e.g., by emphasizing that e-health is meant to be an addition to and not a replacement of the existing spectrum of communication methods and by providing professionals engaging in the use of electronic communication the opportunity to get acquainted with each other during the implementation. Last, although some ongoing development is probably unavoidable with many innovative e-health interventions, the resulting inconvenience for professionals should be restricted to a minimum, as the start-up problems caused by working with an application under development are likely to deter participants who were hesitant to adopt these techniques to begin with.
References

5

SUMMARY AND GENERAL DISCUSSION
This thesis describes the development and the implementation of the Health and Welfare Information Portal (ZWIP). The ZWIP is a multidisciplinary shared Electronic Health Record combined with a tool for interprofessional and patient-professional communication for community-dwelling frail older people, their informal caregivers, and their primary care professionals. The primary aims of the ZWIP were to facilitate the involvement of frail older people and informal caregivers in their care and to increase interprofessional collaboration among primary care professionals. This chapter starts with a summary of the main findings of this thesis, followed by a discussion of these findings.

**Summary**

Overall, this thesis focuses on several aspects of patient involvement and on the development and implementation of the ZWIP. Since providing frail older people and informal caregivers with information is a prerequisite for patient involvement, we focused in Chapter 2A on the preferences of frail older people and informal caregivers for receiving information. These proved to be diverse, and interviewees emphasized the importance of the context in which information was provided. In Chapter 2B we assessed the care-related goals of frail older people, which were related to well-being just as much as to health and functioning. In Chapter 3B, we used this knowledge to develop a method for discussing goals with frail older people. This method was incorporated in the ZWIP program, which development by means of Intervention Mapping is described in Chapter 3A. Last, Chapter 4B describes the largely successful implementation of the ZWIP. Important reasons for this success were the widely acknowledged need for improvements in the care for frail older people and interprofessional collaboration, as well as the successful application of several implementation strategies, i.e., the helpdesk and the interprofessional educational program. This educational program, which was evaluated in Chapter 4A, proved to be effective in improving interprofessional attitudes and collaboration skills; and improved the collaboration of several interviewed professionals with other professionals of specific disciplines. Below, we will describe the main findings for each chapter in more detail.

**Chapter 1: Introduction**

In Chapter 1, the reasons for the development of the ZWIP are described. Our fragmented healthcare systems are not ready to face the increasing demand for care that will be placed upon them as a result of the aging of the population. In recognition of this, the Dutch government started the National Program for Elderly...
Care, a program which specifically focuses on improving healthcare for frail older people, which are older people suffering from a range of problems on the physical, psychological and social domain. One of the transition-experiments within this program is the ZWIP, an intervention with two aims. The first aim was to facilitate the involvement of frail older people and informal caregivers in their care, in order to increase the quality of the care provided to them. The second and equally important aim was to improve interprofessional collaboration, as this will help to facilitate the urgently needed coordination of care. Considering that e-health has major potential for facilitating the achievement of both aims, e-health was a fundamental aspect of the ZWIP.

Chapter 2: Facilitating patient involvement

Chapter 2 presents the results of two studies that were conducted to inform the development of several components of the ZWIP which specifically targeted patient involvement.

In Chapter 2A, we describe the results of a qualitative study into the experiences of frail older people and informal caregivers with receiving information from healthcare professionals as well as their preferences for receiving information. For this study, we conducted semi-structured interviews with 22 frail older people and informal caregivers. They described varying needs for information and discussed both positive and negative experiences with receiving information. Interviewees valued receiving verbal information from their physician; yet would appreciate receiving brief, clearly written information leaflets in addition. Further, they described several strategies that they used to enhance the information provided, i.e., advocacy, preparing for a consultation, and searching their own information. However, interviewees stressed the importance of the context in which information was provided as well. For them, even if the information provided would meet all their preferences, this would be of limited consequence if not provided within the context of an ongoing trusting relationship with a professional, who genuinely cared for them.

Chapter 2B presents the results of a retrospective study aimed at identifying the care-related goals of community-dwelling frail older patients. For this study, we used the datasets of two previous studies, in which goals had been identified by means of an open-ended question. One hundred and forty frail older participants of these studies described one or more goals, resulting in a total of 162 goals. These goals concerned several domains: health problems (20.4%), mobility (15.4%), emotions (9.9%), independence and autonomy (3.7%), social and family relationships (17.3%), activities (4.9%), living accommodation (18.5%), healthcare and welfare services (6.2%), finances (1.2%) and other (2.5%). These results have shown that the care-related goals of community-dwelling frail older patients are diverse, and concern well-being just as much as they concern health and functioning. We used the goals identified in this study for the development of a tool for discussing goals with frail older people (Chapter 3B).

Chapter 3: Development of the Health and Welfare Information Portal

In Chapter 3, the development of the ZWIP and the development of a specific component of the ZWIP, i.e., a method for determining goals with community-dwelling frail older people, are described.

In Chapter 3A, we provide an overview of the development of the ZWIP by means of Intervention Mapping. This was done in six consecutive steps, in which the future target populations were involved extensively. In Step 1, we conducted a thorough needs assessment concerning frail older people’s involvement in self-management and interprofessional collaboration. The main problems identified with regard to self-management were frail older people and informal caregivers not performing the activities required for self-management, and professionals’ not encouraging or facilitating the involvement of their frail older patients. The problems identified for interprofessional collaboration included insufficient communication, problems with exchanging information, and not involving the frail older person in collaboration. In Step 2, matrices of change objectives were designed. In Step 3, we selected methods derived from Social Cognitive Theory, Goal-Setting Theory and from theories for organizational change for use within the ZWIP program. In Step 4, the actual ZWIP was designed during an iterative process; the final ZWIP is a personal, internet-based conference table for multidisciplinary communication and information exchange for community-dwelling frail older people, their informal caregivers and professionals. In Step 5, we selected and developed methods for the implementation of the program, which included an interactive interdisciplinary educational course for professionals involved in the care of frail older people. Last, in Step 6, we planned for the evaluation of the program.

In Chapter 3B, the development of and first experiences with a two-step method for discussing goals with community-dwelling frail older people are described. The developed method consisted of (1) an open-ended question: “If there is one thing we can do for you to improve your situation, what would you like?” which was followed by (2) reviewing a bubble diagram with goal subject categories when needed. This method was then used to discuss goals with frail older people by
primary care nurses and social workers, which resulted in 137 frail older people describing 173 goals. These most frequently concerned mobility (n=43; 24.9%), well-being (n=52; 30.1%), and social context (n=57; 32.9%). Not all frail older people formulated goals, frequent reasons for this included the frail older person being comfortable with the current situation; not being used to discussing goals; or cognitive problems limiting their ability to formulate goals. Professionals (n=18) were generally positive about the method, as they felt it improved their insight into what the frail older person valued most. Therefore, this method can assist professionals and frail older people in choosing the most appropriate treatment or care option, thus increasing frail older people’s involvement in decision making.

Chapter 4: Implementation of the Health and Welfare Information Portal

Chapter 4 describes the implementation of the ZWIP. It starts with the effects of one of the main implementation strategies of the ZWIP, the interprofessional educational program, and continues with a process evaluation of the total implementation of the ZWIP.

In Chapter 4A, we examined the effects of the ZWIP’s nine-hour interprofessional educational program for primary care professionals on their collaboration attitudes, skills, and behavior. This was done with a before-after study using the Interprofessional Attitudes Questionnaire (IAQ), Attitudes Toward Health Care Teams Scale (ATHCTS), and Team Skills Scale (TSS); followed, at least four months after completion of the educational program, by semi-structured interviews with selected participants (n=10). Participants’ (n=80) overall interprofessional attitudes improved (IAQ baseline: 5.49, follow-up: 5.67; p=0.001); attitudes toward geriatric teams did not change (ATHCTS baseline: 69.9, follow-up: 69.1; p=0.32); and their self-reported team skills improved (TSS baseline: 45.7, follow-up: 48.1; p=0.001). Further, many interviewees reported that their collaboration with professionals of specific disciplines had increased due to the program; even though some reported that they did not collaborate more. Interviewees felt that the program’s interprofessional nature, and attending the program with local professionals, had contributed significantly to the experienced improvements in collaboration. Yet, they also noticed that not all parts of the program had met the needs of all participating disciplines, due to differences in professional background and knowledge. Our results indicate that a relatively brief interprofessional educational program can improve interprofessional attitudes, collaboration skills, and even collaborative behavior. In addition, such a program provides professionals with the opportunity to get acquainted with each other and each other’s viewpoints which is likely to be just as important as its educational content.

Chapter 4B presents the results of a process evaluation of the implementation of the ZWIP. Main purposes for conducting this process evaluation were to establish (1) the outcomes of the implementation process; (2) which implementation strategies and barriers and facilitators contributed to these outcomes; and (3) how its future implementation could further be improved.

Therefore, we conducted a mixed-methods study consisting of a quantitative evaluation by means of data extraction of the monitoring of the use of the ZWIP and surveying professionals (n=118), followed by a qualitative evaluation by means of semi-structured interviews with purposively selected professionals (n=12). A total of 290 frail older people and 169 professionals consented to have a ZWIP account installed, which we consider quite successful. Facilitators for the ZWIP were feeling the need to enhance interprofessional collaboration and the ZWIP application being user-friendly; barriers were low computer literacy of frail older people, preferring personal contact, and limited use of the ZWIP both by professionals and by frail older people and informal caregivers. Interviewees recommended to use the ZWIP for other target populations as well, to use the implementation strategies more efficiently, and to use additional strategies to help frail older people to feel more comfortable with computers and the ZWIP.

General discussion

Development of the Health and Welfare Information Portal

Intervention Mapping

The ZWIP can be qualified as a highly complex intervention, as it is directed towards two different aims, involves several target populations, and consists of many interacting components. Therefore, we selected Intervention Mapping, which is a method for the evidence- and theory informed development of complex health promotion programs, as a method for its development, even though the ZWIP’s aims are not entirely within the field of health promotion. However, there are other methods for the development of complex interventions. These include the Medical Research Council’s framework for developing complex interventions and the model for developing evidence-based nursing interventions developed by van Meijel et al. To a large extent, the components of all these methods are similar; each of them involves a problem analysis, the selection of theoretical methods for the intervention, the design of the actual intervention, pilots of (components of) the intervention, and the implementation and evaluation of the intervention. In addition, all methods advocate adjusting the intervention based on their evaluations; and encourage the involvement of stakeholders in the development process, although this is most strongly embedded within the Intervention Mapping.
However, Intervention Mapping stands out in particular by its emphasis on designing matrices of change objectives, which are the highly specific outcomes the program should be aiming for. This process of splitting up the overall intervention aims into smaller very specific objectives, enables researchers to ensure that their intervention consists of all necessary components for the achievement of the overall intervention aims. Overall, it is not possible to single out one of these three methods as best suited for the development of all complex interventions, as this depends highly on the complex intervention at hand, the time available for their development, and individual preferences and experiences of the research team. Yet, for researchers developing more complex interventions, we would recommend Intervention Mapping, as it provides the most detailed framework for structuring their development.

**Involvement of future target populations in the development process**

The involvement of future target populations in the development process is a vital aspect of Intervention Mapping. This involvement is essential for the successful development and adoption of e-health interventions in general. The involvement of future target populations was certainly important throughout the development process of the ZWIP, for several reasons. First, the involvement of (frail) older people, informal caregivers, and professionals improved our understanding of which problems with patient involvement and interprofessional collaboration cited in the literature were most pressing in everyday practice. Second, their involvement resulted in the inclusion of an additional component in the ZWIP, a tool for interprofessional and patient-professional communication, which is currently one of the most appreciated components of the ZWIP. Third, their involvement in the iterative development process of the ZWIP application helped to design an application that is user-friendly for all populations involved. Last, their involvement was considered very important by most professionals participating in the evaluation of the implementation, and is likely to have facilitated their adoption of the ZWIP.

However, especially the involvement of frail older people in the development process was a challenge. During the needs assessment, conducting individual semi-structured interviews at the homes of frail older people and informal caregivers proved to be the right approach for involving them (see Chapter 2A). However, we had to exclude some of the frailest older people from participating, such as those with severe hearing or speech problems or severe cognitive problems, as they would not have been able to participate in the interviews. During the iterative development process of the ZWIP application, recruiting frail older people to participate in working groups held on location proved to be difficult. Therefore, we involved non-frail older persons in this iterative development process as well.

However, to secure the participation of frail older people or other vulnerable populations in development processes comparable to the ZWIP, we would recommend enabling them to participate by means of individual interviews at their homes. Although such an approach is more time-consuming, it would allow even the most vulnerable populations to become involved, thus improving the intervention developed.

**Enabling frail older people to become involved in their own care**

One of the aims of the ZWIP was to facilitate the involvement of frail older people in their own care. We incorporated this in the ZWIP application by having the frail older person decide which professionals can access their personal ZWIP; by providing the frail older person with feedback about their personal health, functioning and social situation which was gathered during the screening and during a second home visit; by providing the frail older person with educational materials which suited their situation; and by enabling the frail older person to communicate with professionals through the ZWIP and to view all communication by professionals within their ZWIP account. Especially this communication tool caused considerable debate during the development and implementation of the ZWIP. First, because professionals (and frail older people) were worried about how this would affect communication, as professionals would need to communicate very clearly without using any jargon, as this might be confusing for the frail older person. Second, because professionals were concerned about receiving an overload of messages by frail older people and informal caregivers, a concern which is also cited in the literature. However, we have received no indication that such an overload of messages has actually occurred.

Furthermore, in order to enhance involvement of frail older people we taught professionals how to facilitate patient involvement during our interprofessional educational program, and we developed a tool to assist professionals in discussing goals with frail older people (Chapter 3B). This tool can help them to elicit patient goals that can be incorporated in care plans, thus making care more patient-centered. The tool consisted of an open ended question, if necessary followed by a bubble diagram with goals subject categories. The goals elaborated with the tool were recorded in the ZWIP of the frail older person; and if possible an action plan, detailing what the frail older person would do as a first step toward achieving this goal, was made with the frail older person and was again recorded in the ZWIP.

**Implementing the Health and Welfare Information Portal**

**The challenges of implementing complex interventions**

As even proven study results translated into guidelines are not likely to be applied in everyday practice without investing in their adoption and implementation,
should be no surprise that highly complex interventions such as the ZWIP, which have not yet been thoroughly evaluated, require even more effort to implement in everyday practice. Therefore, we set out to implement the ZWIP using a range of strategies, tailored to the needs of the target populations. We specifically selected strategies which had shown promise during the implementation of other interventions, such as involving stakeholders in the development, having an interactive educational program, and having a helpdesk available. In order to evaluate these strategies, we conducted a thorough process evaluation of the implementation of the ZWIP. However, determining whether the implementation of such a complex intervention has been successful is difficult. First, success of an implementation is defined differently across studies. This is to be expected, as each complex intervention will have different aims and therefore different targets to achieve with its implementation. Second, defining success or failure in evaluating a complex intervention such as the ZWIP can be complicated, especially since the ZWIP should mainly be used when there is a reason to communicate or check the frail older person’s situation, for example when the frail older person is ill. This makes it extremely difficult to determine whether limited use of the ZWIP would represent implementation failure or is in fact justified. Last, deciding when the implementation process ends and should be evaluated can be difficult for many complex interventions, including the ZWIP, as it is not always obvious when the implementation phase, i.e., the use of the program until a certain endpoint in the study, should end, and use in everyday practice starts.

**Using mixed methods to evaluate the implementation of the Health and Welfare Information Portal**

For the evaluation of the studies concerning the effects of the interprofessional educational program and the implementation of the ZWIP we used a mixed methods design, for two reasons. First, we combined the methods for developmental purposes, i.e., the quantitative results were used to inform the purposive selection of interview participants with diverse experiences with the study topics. Second, we combined them for complementarity, as we used each method to answer a different component of the research question, e.g., the quantitative data were used to answer questions concerning the outcomes of the implementation process, whereas the qualitative data were used to answer questions related to participants’ experiences with the implementation process. The mixed methods studies in this thesis have shown that such designs are extremely helpful in understanding the effects of complex interventions and the mechanisms that contribute to these effects. For instance, in the evaluation of our interprofessional educational program, we used questionnaires to address some determinants of collaboration such as perceptions and attitudes towards collaboration and collaboration skills, while the semi-structured interviews addressed overall collaborative behavior. These interviews actually showed that the collaborative behavior of interviewees had improved and indicated that the most important contributing factor to these effects was the interdisciplinary nature of the educational program, which had allowed local professionals to get acquainted with each other.

**Frail older people and e-health interventions such as the Health and Welfare Information Portal**

One of the most important challenges for the implementation of the ZWIP was the low computer literacy of frail older people. Although problems with older people’s access to a computer and to support in using a computer are diminishing, they can still present a barrier for the use of computers. Further, older people tend to be less comfortable with and less competent in using computers, and older people with health problems, including frail older people, are even less likely to use computers. Therefore, we decided on two approaches for overcoming these strategies. First, for frail older people who were willing to work with the ZWIP application themselves, we had a helpdesk available and offered home visits by local volunteers to explain the use of the application. However, frail older people made limited use of the latter strategy, among other things because they did not want yet another unknown person in their home. Second, for frail older people who were not willing to work with the ZWIP application themselves, we used approaches that made it unnecessary for them to use the application, by ensuring that everything in the ZWIP application could be easily printed on paper and by having an informal caregiver or a professional coordinate the ZWIP on their behalf. However, this coordination by someone else was not always considered desirable by frail older people, as some felt uncomfortable with asking their informal caregiver or professional to coordinate the ZWIP on their behalf on top of their other tasks. This desire of not burdening professionals was found in other studies as well. Therefore, while our strategies targeting low computer literacy were appropriate for some frail older people, they were not able to meet the needs of them all. Frail older people present a very heterogeneous population and there are many factors which can affect their use of information technology. As a result, there is no one size fits all approach that can guarantee their use of e-health interventions. However, their use can be facilitated by the use of a combination of strategies, such as providing sufficient support, proving the benefits of the e-health intervention at hand, and having a proper training program available. For a future implementation of the ZWIP, we would therefore recommend to include additional strategies targeting computer literacy of frail older people, such as the introduction of a training program for ZWIP in community centers, in which frail older people can
become more comfortable with using both computers and the ZWIP. Nevertheless, it is likely that the use of computers will present less of a problem to future generations of frail older people.

The interprofessional educational program as an implementation strategy for the ZWIP

Expecting to improve interprofessional collaboration in primary care by merely facilitating the sharing of information and communication through an e-health intervention would represent a failure to truly appreciate the complexity of the problems that exist with interprofessional collaboration. As the logic model of interprofessional collaboration in Chapter 3A has shown, there are many factors which contribute to these problems. Some of these are practical, such as lack of knowledge about which professionals are involved in the care of a particular frail older person, and problems contacting each other; whereas others are more fundamental, such as lack of trust in and respect for the contributions of other professionals, lack of knowledge about the expertise of other professionals, and professional cultures not encouraging collaboration. Therefore, an e-health intervention which merely solves the more practical problems is a step forward, but will never be able to solve the problem by itself. As a result, our interprofessional educational program was an indispensable addition, as it could address several of the more fundamental problems with collaboration by for example teaching which skills and expertise other professionals have. The program had even been able to improve collaboration among several professionals on its own.

We designed the interprofessional educational program to be taught in groups of local professionals, who were likely to meet each other in their everyday work. Participants considered this attendance of the program with other local professionals an important contributing factor to the experienced improvements in collaboration, as it allowed them to get acquainted with each other, and as the discussions of case-descriptions helped them to gain knowledge about what each discipline can contribute in the care of frail older people. Therefore, both getting together and discussing cases are important requirements for an educational program intended to improve collaboration. Considering these effective components, we would not recommend to replace the educational program by an e-learning module alone, especially not for the core group of professionals involved in the care for frail older people around a specific general practice.

Although we expect that the combination of the ZWIP and our educational program will be able to improve interprofessional collaboration among the professionals participating in our study, who had a positive attitude toward interprofessional collaboration to begin with, this will probably not be enough for less motivated groups of professionals. Additional changes in healthcare financing, which include the reimbursement of activities aimed at coordinating care, may assist in establishing improvements in collaboration among these professionals.

Conclusions

This thesis has described the development and the implementation of the ZWIP. The main conclusions that can be drawn from our findings are listed below.

1. Frail older people and informal caregivers vary in their information needs, and use several strategies to ensure that the information provided meets their needs, such as advocacy, preparing for a consultation, and searching their own information. Professionals should encourage the use of these strategies, as receiving sufficient information is an important requirement for patient involvement. However, they should also be aware that frail older people and informal caregivers prefer information to be provided within the context of an ongoing trusting relationship with a caring professional.

2. The care-related goals of frail older people are diverse and relate to well-being just as often as to health and functioning. It is therefore important for professionals to engage in goal discussions with frail older people. The method for discussing goals with frail older people presented in this thesis was able to assist professionals in gaining insight into what a particular frail older person values most. This can guide them, as well as frail older people, in deciding on the most appropriate care or treatment option, thus increasing the involvement of frail older people in decision-making.

3. The interactive interprofessional educational program of the ZWIP was an indispensable implementation strategy. The program was able to realize improvements in interprofessional attitudes and collaboration skills; and, as reported by several interviewees, was even able to improve their collaborative behavior. The interprofessional nature of the program, and teaching the program in groups of local professionals was essential, as it allowed local professionals to get acquainted with each other and to get to know each other’s area of expertise.

4. Considering the high number of frail older people who eventually participated in the ZWIP, we consider its implementation a success. The implementation strategies for professionals, especially the helpdesk and the educational program contributed to this. However, for a future implementation it is important to focus even more implementation efforts on the low computer literacy of frail older people.
Practice implications

Implications for everyday practice
This thesis presents several important lessons for improving patient centeredness and interprofessional collaboration in everyday practice. First, when providing information to frail older people and informal caregivers, professionals should carefully assess their information needs, as these are highly heterogeneous among this population. Professionals should also appreciate that frail older people and informal caregivers prefer to receive information from a trusted and caring professional who they have known for an extensive time period, which underlines the importance of provider continuity in the care for frail older people. Second, professionals should realize that frail older people have diverse goals, and that for them, well-being is at least as important as being in good health. As knowledge of the goals a specific frail older person has can direct the care provided, this emphasizes the importance of professionals assessing these goals. Last, this thesis has shown that even a relatively small intervention such as our educational program can improve interprofessional collaboration, and that discussing case-descriptions in groups of local professionals can help to gain understanding of each others’ viewpoints and area of expertise. Organizing such meetings locally might be an important first step for professionals aiming to improve their collaboration with other local professionals.

Implications for researchers
Although involving future target populations in the development processes of complex interventions can be time-consuming, it proved to be indispensable during the development of the ZWIP. Therefore, we strongly recommend their involvement, as it assists in developing an intervention which meets their needs, thus increasing the chances of the intervention being successful. However, involving more vulnerable populations in such development processes can present a challenge. Enabling more vulnerable participants to express their opinions during home visits may facilitate their involvement.

Further, this thesis provides a useful starting point for future research related to the ZWIP. First, as this thesis ends with a description of the implementation of the ZWIP, the effects of the ZWIP on the involvement of frail older people and informal caregivers in their own care and on interprofessional collaboration need to be evaluated. In addition, it is important to establish which subgroups of frail older people are most likely to benefit from the ZWIP. Second, as recommended by professionals, it would be interesting to use and evaluate the effectiveness of the ZWIP in other populations, such as patients with chronic diseases and patients receiving palliative care.

Implications for policymakers
Developing complex interventions in conjunction with their future target populations is a time-consuming, yet highly rewarding process, as the interventions thus developed are most likely to be effective in everyday practice. In general, such developments cannot be undertaken without funding. However, for funding agencies time is of the essence, which often leaves researchers with too little time to develop interventions which truly involve the target populations throughout the development process. Also, funding agencies generally require a detailed description of the project beforehand, thus leaving limited room for deviations of the submitted proposal based on knowledge acquired through the involvement of target populations. During the ZWIP development, we did deviate from the proposal by including a tool for communication in the ZWIP application as this was considered an essential feature by the target populations. This communication tool proved to be one of the most appreciated tools within the ZWIP application. Therefore, we were fortunate that the ZWIP was a transition experiment within the National Care for the Elderly Program in which such deviations were negotiable. However, this does call for other funding agencies and policymakers to reconsider their policies, as the most meaningful interventions in healthcare cannot be planned in detail in advance.

Outlook
Although future studies will have to show whether the ZWIP is indeed effective in facilitating the involvement of frail older people and informal caregivers in their care and in improving collaboration among professionals, we can discuss some of our expectations for the ZWIP. As total provider continuity in the care for frail older people is not likely to be attainable, e-health interventions such as the ZWIP, which facilitate coordination of care, are likely to present a solution to the current problem of fragmentation of care. Of course, the ZWIP may need some adjustments, but considering that it addresses several of the most pressing problems currently experienced in healthcare, we expect that it will be effective for selected target populations. On the other hand, having a tool such as the ZWIP available will not be enough, as having personal contact will remain important in the care for frail older people. Therefore, training professionals in facilitating patient involvement, and providing professionals with the opportunity to get acquainted with each other and each others’ area of expertise will continue to be of the utmost importance.
Summary and general discussion


References

6

NEDERLANDSE SAMENVATTING
Nederlandse samenvatting

Dit proefschrift beschrijft zowel de ontwikkeling en implementatie van het Zorg- en Welzijnstraktaal (ZWIP) als enkele belangrijke aspecten van het betrekken van kwetsbare ouderen bij hun eigen zorg. Hieronder worden de belangrijkste bevindingen kort samengevat.

In Hoofdstuk 1 beschrijven we de achtergronden voor de ontwikkeling van het ZWIP. Ons huidige gefragmenteerde zorgstelsel is onvoldoende in staat om het hoofd te bieden aan de toegenomen zorgvraag die de komende jaren zal ontstaan door de vergrijzing. Dit is een van de redenen dat de Nederlandse overheid het Nationaal Programma Ouderenzorg heeft opgestart. Dit programma richt zich specifiek op het verbeteren van de zorg voor kwetsbare ouderen: ouderen met meerdere problemen op het gebied van het lichamelijk, psychisch en sociaal functioneren. Een van de experimenten binnen dit programma is de ontwikkeling van het ZWIP, een interventie die als doel heeft om (1) kwetsbare ouderen meer te betrekken bij hun eigen zorg en (2) om de samenwerking tussen bij hen betrokken hulpverleners te verbeteren. Omdat nieuwe technologieën een belangrijke bijdrage kunnen leveren aan het bereiken van deze doelen, werd besloten om deze optimaal toe te passen binnen het ZWIP.

In Hoofdstuk 2 gaan we in op twee belangrijke aspecten van het betrekken van kwetsbare ouderen bij hun eigen zorg. Daarbij hebben we ons in de eerste studie gericht op het verstrekken van informatie door hulpverleners. Het ontvangen van voldoende informatie is voor kwetsbare ouderen en mantelzorgers een belangrijke voorwaarde om mee te kunnen beslissen over de verleende zorg. Daarom onderzochten we wat kwetsbare ouderen en mantelzorgers belangrijk vinden bij het ontvangen van informatie. Uiteraard varieerde dit van persoon tot persoon, maar de meeste ouderen en mantelzorgers gaven aan een sterke voorkeur te hebben voor het krijgen van mondelinge informatie van hun arts. Daarnaast wilden sommigen graag een beknopte en duidelijke informatiefolder ontvangen. Deelnemers aan de studie gaven aan dat zij verschillende strategieën gebruikten om voldoende informatie te krijgen, zoals iemand meenemen naar een afspraak met een hulpverlener, het maken van een lijstje met vragen voorafgaand aan een afspraak en het zelf zoeken naar informatie. Deelnemers benadrukten echter het belang van de context waarin de informatie gegeven werd, omdat informatie voor hen het meeste waardevol is als deze gegeven wordt door een betrokken en vertrouwde hulpverlener, waarmee ze over een langere periode contact hebben.
In de tweede studie van dit hoofdstuk hebben we onderzocht welke zorggerelateerde doelen kwetsbare ouderen hebben, omdat kennis van deze doelen hulpverleners kan helpen om de verleende zorg af te stemmen op hun individuele wensen. De doelen die de deelnemende kwetsbare ouderen noemden waren divers, en ze betroffen net zo vaak gezondheid en functioneren als welzijn. De meest genoemde doelen waren gerelateerd aan gezondheid, woonsituatie, mobiliteit en sociale contacten.

De resultaten van deze tweede studie hebben we in Hoofdstuk 3 gebruikt bij het ontwikkelen van een methode voor het bepalen van doelen met thuiswonende kwetsbare ouderen. De ontwikkelde methode bestond uit twee stappen. Eerst werd de kwetsbare ouder een open vraag gesteld: “Indien er één ding gedaan zou kunnen worden om de situatie voor u te verbeteren, wat zou dat dan zijn?”. Als de oudere geen antwoord kon geven op deze vraag, werd hem een doelenwijzer gegeven, waarop domeinen stonden waarbinnen de oude een doel zou kunnen hebben. Deze methode werd vervolgens in de praktijk toegepast door verpleegkundigen en ouderenadviseurs. Zij waren over het algemeen positief over de methode, omdat deze hen hielp om beter inzicht te krijgen in wat de oudere belangrijk vond. Toch konden niet alle kwetsbare ouderen met behulp van deze methode een doel formuleren, sommigen hadden geen doelen omdat ze helemaal tevreden waren, anderen waren niet gewend om doelen te bespreken of hadden cognitieve stoornissen die het formuleren van een doel moeilijk maakten.

Naast deze methode voor het bepalen van doelen met kwetsbare ouderen, beschrijven we in Hoofdstuk 3 ook de stapsgewijze ontwikkeling van het ZWIP met behulp van Intervention Mapping. Hierbij waren de toekomstige gebruikers van het ZWIP: kwetsbare ouderen, mantelzorgers en hulpverleners intensief betrokken. Allereerst werden de belangrijkste problemen op het gebied van betrokkenheid van ouderen bij hun eigen zorg en samenwerking tussen hulpverleners in kaart gebracht. Zo bleek dat betrokkenheid van kwetsbare ouderen en mantelzorgers vaak onvoldoende gefaciliteerd werd door hulpverleners, dat kwetsbare ouderen en mantelzorgers niet altijd deden wat vereist is om betrokken te zijn, dat hulpverleners niet wisten welke andere hulpverleners betrokken waren bij de zorg voor een kwetsbare ouder, en dat hulpverleners soms moeite hadden om elkaar telefonisch te bereiken. Het ZWIP werd daarom specifiek gericht op het oplossen van deze problemen. Het uiteindelijke ZWIP is een persoonlijke, via internet toegankelijke overlegtafel voor kwetsbare ouderen, hun mantelzorgers en hulpverleners. Via het ZWIP kunnen zij met elkaar communiceren, krijgen zij toegang tot informatie over de kwetsbare oude en zijn doelen (die in kaart zijn gebracht met de eerder beschreven methode), en krijgen de oude en mantelzorgers daarnaast nog toegang tot voorlichtingsmateriaal. Behalve het ZWIP zelf ontwikkelden we ook methoden voor de implementatie en evaluatie van het ZWIP.

In Hoofdstuk 4 wordt verder ingegaan op de implementatie van het ZWIP. In de eerste studie richten we ons op het scholingsprogramma, een van de belangrijkste implementatiestrategieën van het ZWIP. Dit scholingsprogramma voor eerstelijns hulpverleners betrokken bij de zorg voor kwetsbare ouderen bestond uit drie avondbijeenkomsten, die ieder ongeveer drie uur duurden. Deze scholingsbijeenkomsten werden georganiseerd op locatie, in groepen van lokale hulpverleners uit de zorg- en welzijnssector, die elkaar bij hun werk ook daadwerkelijk tegen konden komen. Uit de evaluatie na afloop van het scholingsprogramma bleek dat de deelnemers hulpverleners van andere disciplines positiever beoordeelden en dat hun zelfgerapporteerde vaardigheden om in een team te werken waren verbeterd ten opzichte van voor deelname aan het scholingsprogramma. Daarnaast vertelden verschillende geïnterviewde deelnemers dat ze door het scholingsprogramma meer samenwerkten met hulpverleners van bepaalde disciplines. Ze hadden de indruk dat het interdisciplinaire karakter van het scholingsprogramma en het volgen van het scholingsprogramma in groepen van lokale hulpverleners hier een belangrijke bijdrage aan had geleverd. Aan de andere kant merkten ze ook dat niet alle onderdelen van het programma even relevant waren voor alle in het scholingsprogramma vertegenwoordigde disciplines.

In de tweede studie van dit hoofdstuk beschrijven we de resultaten van de procesevaluatie van de implementatie van het ZWIP. Een belangrijke uitkomst van die implementatie was dat 290 kwetsbare ouderen (ongeveer de helft van de ouderen die gevraagd werden om deel te nemen) toestemming hebben gegeven om voor een ZWIP aan de maken. Op het ZWIP van deze ouderen waren in totaal 169 hulpverleners aangesloten. Uit de procesevaluatie bleek dat met name de betrokkenheid van de doelgroepen bij de ontwikkeling, het scholingsprogramma en de helpdesk belangrijke implementatiestrategieën waren. De gevoelde noodzaak om samenwerking tussen hulpverleners te verbeteren en het gebruiksgemak van het ZWIP waren factoren die de implementatie van het ZWIP bevorderden. Factoren die de implementatie belemmerden waren onder andere het feit dat kwetsbare ouderen weinig ervaring hadden met computers, het hebben van een voorkeur voor persoonlijk contact en het beperkte aantal kwetsbare ouderen, mantelzorgers en hulpverleners die gebruik maakten van het ZWIP. Deelnemers aan de studie adviseerden om het ZWIP in de toekomst ook voor andere doelgroepen te gebruiken en om extra strategieën in te zetten om kwetsbare ouderen meer vertrouwd te maken met het gebruik van computers.
Concluderend beschrijft dit proefschrift de ontwikkeling van een bruikbare methode om de doelen van kwetsbare ouderen in kaart te brengen en de ontwikkeling en de geslaagde implementatie van het ZWIP. Hoewel de resultaten van studies naar de effecten van het ZWIP op betrokkenheid van kwetsbare ouderen en samenwerking tussen hulpverleners nog zullen volgen, wordt het ZWIP al in een toenemend aantal huisartsenpraktijken gebruikt.
7

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En dan vrienden en vriendinnen, ook jullie bedankt voor al jullie steun de afgelopen jaren. Want soms kwam ik nauwelijks aan jullie toe en op andere momenten was ik jullie tot vervelens toe aan het overladen met verhalen over werk en onderzoek.

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Sarah Robben was born on the October 12, 1982 in Huissen, the Netherlands. In 2000, she graduated from secondary school, the Stedelijk Gymnasium Arnhem. Subsequently, she went to Law School at the Radboud University Nijmegen, and completed her first year. In 2001, she transferred to Medical School at the Radboud University Nijmegen Medical Centre. She completed Medical School in 2007 with a research internship at the Jeroen Bosch Hospital in Den Bosch concerning the development of a screening tool for Parkinson's Disease Dementia. After graduating, she worked at the Department of Geriatric Medicine of the Jeroen Bosch Hospital in Den Bosch. As she was highly interested in both doing research and in the specialty of Geriatric Medicine, she became a PhD student at the Department of Geriatric Medicine of the Radboud University Nijmegen Medical Centre in 2008. Her research involved the development and implementation of the Health and Welfare Information Portal, which resulted in the publication of this thesis. In 2012, she started her training in Geriatric Medicine. She currently works as a resident at the department of Geriatric Medicine of the Radboud University Nijmegen Medical Centre.
Publications


Additional information

Additional information concerning the ZWIP is available online: http://zwip.nl/. This website also contains several movies demonstrating the experiences of frail older people, informal caregivers and professionals with the ZWIP: http://zwip.nl/hulpverleners-startpagina/ervaringen/.