CHAPTER 9

General discussion
The overall aim of this thesis was to gain insight into: 1) the frequency and severity of functional limitations (chapter 5), factors that contribute to functional limitations (chapter 5 and 7), the course of physical functioning (chapter 6), prognostic factors for deterioration in physical functioning (chapter 6), and current health care use, needs and possible bottlenecks (chapter 8), all in order to improve primary care for older adults with joint pain and comorbidity. In this final chapter, we describe the main findings of the thesis as summarized in Table 1, discuss the methodological considerations, provide an overview of clinical implications and make suggestions for future research.

**Frequency, severity and determinants of functional limitations**

As expected, in chapter 5 we found substantial limitations in functioning in our sample of older adults with joint pain and comorbidity. Of the participants, 66% were limited in physical functioning (PF; walking, climbing), 31% needed help with performing activities of daily living (ADL; self-care, getting dressed), 61% needed help with performing instrumental activities of daily living (IADL; running the household, doing groceries) and 47% were restricted in participation in basic activities. Additionally, about 22% of the participants reported restrictions in all four functional outcomes. In comparison with population-based studies, our sample reported notably worse functioning1-5. For example, we found a lower mean score on the PF subscale (mean PF score 49) in comparison with another Dutch population-based study performed in older adults aged 63 years or older (mean PF score 61)4. Furthermore, in a population with a mean age of 80 years, Buchman et al. found limitations in ADL and IADL in 9% and 46% of the participants respectively1. Studies performed in more specific older populations with joint pain were more in line with our findings. For instance, the KNEST study performed in a primary care sample of older adults above the age of 50 with persistent knee pain showed a mean PF score of 51, which even declined to 47 after three years of follow-up6.

The findings from the cross-sectional study (chapter 5) showed that besides frailty and higher pain intensity, especially more symptoms of depression, more activity avoidance and less social support were indicative of more functional limitations, whereas higher perceived self-efficacy was indicative of better functioning. The identified relationship between frailty and functional limitations was in line with findings from previous studies7,8. Although pain intensity was related to functional limitations, the results in chapter 5 suggest that not the pain itself, but rather the way in which participants evaluated pain (appraisal) and managed pain (coping), explained the relationship with functional limitations. This was again confirmed in chapter 7 in which we used longitudinal data to study five cognitive appraisals and four coping strategies in relation to changes in PF over time. We found that more negative thoughts about consequences of pain, more catastrophizing and
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| 2       | Design          | Not applicable        | Not applicable                   | Not applicable             | – Description of the protocol  
– Potential strengths and limitations                                                                                                                                                                        |
| 3       | Cross-sectional | Validity              | Social participation             | Not applicable             | – Two underlying domains were identified in the 11-item KAP  
– Only the first domain, ‘participation in basic activities’, showed sufficient internal consistency and reliability  
– The construct validity and responsiveness of this domain require further testing, but without a clear definition of the concept participation, this remains a challenge |
|         |                  | Reliability           |                                  |                            |                                                                                                                                                                                                             |
|         |                  | Responsiveness        |                                  |                            |                                                                                                                                                                                                             |
|         |                  | Cross-cultural        |                                  |                            |                                                                                                                                                                                                             |
|         |                  | comparison with UK    |                                  |                            |                                                                                                                                                                                                             |
| 4       | Cross-sectional | Bifactor model        | – Physical functioning           | Not applicable             | – The measures physical functioning and (instrumental) activities of daily living could be aggregated into one general measure of functioning  
– Social participation should be assessed separately                                                                                                                                                     |
|         |                  |                       | – Activities of daily living     |                            |                                                                                                                                                                                                             |
|         |                  |                       | – Instrumental activities of     |                            |                                                                                                                                                                                                             |
|         |                  |                       | daily living                     |                            |                                                                                                                                                                                                             |
|         |                  |                       | – Social participation           |                            |                                                                                                                                                                                                             |
| 5       | Cross-sectional | Logistic regression   | – Physical functioning           | Sociodemographic factors   | – Our sample reported substantial functional limitations  
– Besides frailty and pain severity, especially the psychosocial determinants were related to functional limitations |
|         |                  |                       | – Activities of daily living     | Physical factors           |                                                                                                                                                                                                             |
|         |                  |                       | – Instrumental activities of     | Psychosocial factors       |                                                                                                                                                                                                             |
|         |                  |                       | daily living                     |                            |                                                                                                                                                                                                             |
|         |                  |                       | – Social participation           |                            |                                                                                                                                                                                                             |
| 6       | Longitudinal    | Latent class growth   | Physical functioning             | Sociodemographic factors   | – We identified three trajectories of functioning, which either improved or deteriorated over time  
– Four variables were identified that could best predict poor physical functioning                                                                                                                                           |
|         |                  | modelling             |                                  | Physical factors           |                                                                                                                                                                                                             |
|         |                  | Multiple regression   |                                  | Psychosocial factors       |                                                                                                                                                                                                             |
| 7       | Longitudinal    | Generalized estimated | Physical functioning             | Four cognitive appraisals   | – Four out of nine coping strategies were related to poorer physical functioning  
– Age and pain severity influenced this relationship                                                                                                                                                     |
|         |                  | equations: auto-      |                                  | Five coping strategies     |                                                                                                                                                                                                             |
|         |                  | regressive model      |                                  |                            |                                                                                                                                                                                                             |
| 8       | Cross-sectional | Quantitative: linear  | Environmental needs             | Sociodemographic factors   | – Unmet needs were especially present in the social domain  
– Especially giving up social activities and losing membership and a role in community constituted unmet needs |
|         | Mixed-method    | and logistic regression| Physical needs                   | Physical factors           |                                                                                                                                                                                                             |
|         |                  |                       | Social needs                     | Psychosocial factors       |                                                                                                                                                                                                             |
|         |                  | Qualitative: thematic | Not applicable                   | Not applicable             |                                                                                                                                                                                                             |
|         |                  | analysis of interviews|                                  |                            |                                                                                                                                                                                                             |
more activity avoidance were significantly associated with subsequent deterioration in PF, whereas higher perceived self-efficacy was associated with subsequent improvement in PF. These findings are in line with previous studies.9–17

Course and prognostic factors
The good – though unexpected – news was that our sample of older adults with joint pain and comorbidity only showed modest changes in PF over a period of 18 months (chapter 6). Despite the small changes in PF over time, latent class growth modelling (LCGM) still revealed underlying variations in PF and identified three homogeneous subgroups with two distinct trajectories of PF. The 140 participants in cluster 1 showed good baseline PF and some improvement over time, whereas the 130 and 137 participants in clusters 2 and 3 showed moderate and poor baseline PF respectively, both with some deterioration over time. The small changes in physical functioning in our sample were in line with a recently performed study in older adults with hip or knee pain, which found a similar stable course of PF over a period of five years.18 Further comparison of these findings remains difficult, as most available studies used different techniques to analyse the course of PF.

Prognostic factors for poor PF identified in our study were: more advanced age, more symptoms of depression, less perceived self-efficacy and more activity avoidance (chapter 7). In other musculoskeletal pain studies, all these prognostic indicators were repeatedly identified.9,10,14,19,20 However, in contrast with these studies, in our study higher pain at baseline and more chronic diseases at baseline were not prognostic for poor physical functioning. Instead, again it were the psychosocial factors that contributed most to deterioration in PF over time.

Health care needs
We found that many of the participants reported environmental (e.g. running the household or preparing food) and physical needs (e.g. receiving help for their physical illness, mobility problems), but it seemed that most of these needs were taken care of by various health care services or informal caregivers (chapter 8). In contrast, some unmet needs were identified in the social domain, especially in arranging daytime activities and company. Unmet needs in this social area were mainly reported by frail participants who lived alone, who reported symptoms of depression and who perceived less social support. The interview data corresponded with the quantitative findings; most older adults seemed capable of accepting and adapting to their physical and environmental problems. However, giving up social activities and the loss of membership and a role in the community constituted unmet needs. As lack of social support is associated with decreased quality of life, more mental health problems and poorer social well-being21–23, it seems important to target the social needs in clinical practice, by paying attention to patients’ networks and their social care use.
METHODOLOGICAL CONSIDERATIONS

When interpreting the results of the studies presented in this thesis, readers should bear in mind certain methodological considerations as discussed in the following section.

Design
In all seven chapters we described and discussed findings from studies that used data from the same prospective cohort study in older adults with joint pain and comorbidity. This cohort comprises a large sample. To our knowledge, no previous studies have extensively explored a group of older adults with joint pain and comorbidity, while joint pain in the presence of comorbidity could have additional negative effects on functioning and on the prognosis of functioning. This makes the studied cohort and the findings presented in this thesis unique.

A pleasant surprise while conducting the cohort was the process of including participants. The way this process proceeded went beyond expectations: relatively quickly and without too many problems. We presume that participants were acknowledging the need to study the problems these people face in daily living.

We focused on a primary care sample which is highly relevant as the general practitioner is often the first professional whom patients consult for their pain complaints. Furthermore, we think that our sample adequately reflects the older population with pain complaints, as we focused on widespread pain instead of regional pain sites, as is often done in other pain studies. A previous study showed that the majority of older adults suffer from more than one pain complaint.

We had longitudinal data with repeated measures available for 317 of the 407 participants. A great deal of effort was put into keeping our participants in the study. For instance, instead of inviting people to attend our institute, we visited all participants in their homes for the baseline measures. Furthermore, we offered help in completing the questionnaires when participants encountered problems. The high proportion of participants who remained in our cohort and the repeated measures over time enabled us to perform more sophisticated analysing techniques to study the research questions, for instance generalised estimated equations (chapter 7) and latent class growth mixture modelling (chapter 6).

While the vast majority of studies were quantitative in nature, we decided to extend our knowledge by including a qualitative section and performing a mixed-method study (chapter 8). This provided more detailed information about possible explanations for identified needs in care-giving and tackled some of the complexities regarding the presence of such needs.

In this cohort we decided to select participants based on self-reported joint pain in eight joint pain sites, instead of deriving information from medical records of general practitioners. Selection based on medical records would have resulted in underestimating the number
of people with joint pain, as only a minority of older people consult their doctor for joint pain. Thus, selection based on medical files would have provided a population sample that is not representative for the actual prevalence of joint pain in the older population. We believe, therefore, that we made the right decision in relation to the selection procedure. Unfortunately, we had no data on the actual diagnosis of musculoskeletal complaints (e.g. osteoarthritis, rheumatic diseases) for performing a subgroup analysis. For instance, in chapter 6 one could argue that participants with similar types of arthritis are grouped into similar clusters: the symptoms of participants with osteoarthritis (OA) may differ from the symptoms of participants with rheumatoid arthritis (RA), which could result in one cluster with largely OA participants and another cluster with RA participants.

An inevitable consequence of cohort studies is loss of follow-up, especially in older adults with multimorbidity, as in our sample. Of the included 407 participants, 317 completed the study (77.9%). There were some dropouts: 9.1% after 6 months, 7.8% after 12 months and 6.5% after 18 months. Most important reasons were death and deteriorated health. Further analysis showed no baseline differences in gender, number of chronic diseases, number of joint pain sites and pain intensity between completers (i.e. participants with all four measures) and non-completers (i.e. drop-outs, thus participants with incomplete data). However, compared with the completers, the non-completers were older, had received a lower education, reported poorer physical functioning, more anxiety and more symptoms of depression at baseline. Such findings may implicate some under-estimation of the associations. On the other hand, in chapters 6 and 7 we used analysing techniques that facilitated the inclusion of all participants in the analysis, regardless of missing data, which indicates that under-estimation was probably limited in our study.

One could challenge the length of our follow-up period. A systematic review showed limited evidence of minor deterioration in physical functioning over 3 years in hip and knee osteoarthritis20. Although this evidence suggests the need for longer follow-up periods, up till now it remains unclear whether this evidence would be valid in our sample of older populations with complex health issues. We decided to measure our participants over 18 months, but the small changes in physical functioning that we detected (chapter 6) may indicate that 18 months is not sufficiently long enough to examine changes in physical functioning in our sample.

**Measurements**

Following the ICF model, we focused on several relevant aspects of functioning, in contrast with many other previous studies. Besides measuring mobility (e.g. walking, climbing stairs) and the capacity to fulfil basic tasks (performing self-care, doing groceries, running the household), we included social participation as outcome in our cross-sectional study. Social participation is meaningful to older people as it is relevant to daily life; it encompasses being
part of the community and fulfilling a role in society\textsuperscript{5,25}. Our findings therefore contribute to existing knowledge. Apart from the selected outcome measures, we included a broad set of possibly related determinants, in which we focused not only on physical determinants, but also included various psychosocial determinants. As both the outcomes and the determinants were repeatedly measured over time, we were able to investigate longitudinal trajectories, thus prognosis, and to take into account the time-varying nature of the determinants. This enabled us to obtain deeper knowledge about determinants that might contribute to poor functioning over time. Furthermore, it enabled us to make corrections in analyses in order to provide results of the actual relationship between outcome and determinants.

**Operationalization of concepts**

One could argue about the definition of comorbidity or multimorbidity. Some studies define multimorbidity as the presence of more than two chronic diseases, whereas others define multimorbidity as the presence of more than three chronic diseases\textsuperscript{26-28}. Moreover, the various studies included different diseases for their multimorbidity count. For instance, one study included hypertension, which tends to be a risk factor for heart disease\textsuperscript{29}. Since we decided to specifically include 29 common chronic diseases in our selection\textsuperscript{30} and included potential patients based on the presence of at least 2 other chronic diseases besides joint pain, the above-mentioned variation could hamper direct comparison.

We were unable to assess the full ‘participation’ concept using the Keele Assessment of Participation (chapter 3). This is unfortunate, as older adults indicated that participation is an important aspect of life\textsuperscript{25,31}. The methodological study that we performed (chapter 3) revealed at least two underlying constructs in the 11-item KAP, of which only the ‘participation in basic activities’ domain was usable\textsuperscript{32}. The ‘participation in complex activities’ domain showed poor measurement properties, which made this domain inapplicable. The only solution for including this latter domain was to apply the three items as separate outcomes. However, due to practical considerations we decided to exclude this second domain and the items from further analysis. In addition, we excluded the first domain of the KAP from further analysis in the longitudinal studies due to poor responsiveness\textsuperscript{32}. Although this was the right thing to do, we still feel that this was unfortunate, as the extent to which joint pain and comorbidity may affect social participation in more complex activities remains unclear, while it seems to be especially these complex activities, like joining clubs, going to church, meeting people, that people want to be able to maintain.

Finally, in chapter 4 we explored the possibility of aggregating our four selected functional measures (based on the ICF model) into one general measure. The rationale behind this study was to develop one overall prediction model for deterioration in functioning (chapter 6), which would still include all four important aspects of functioning. Despite the finding that three
out of four measures could be aggregated, we decided to use only physical functioning for developing the prediction model in chapter 6. The reasons were comparability with other studies and the observation that ADL limitations were limited in our sample.

CLINICAL IMPLICATIONS FOR PROFESSIONALS

This study contributed to greater knowledge about the impact of joint pain and comorbidity on functioning and the course of functioning over time, which professionals can use in daily practice. First, professionals should fulfil a more pro-active role in asking patients about the occurrence of functional limitations in different functional domains such as performing daily activities and social participation. Second, professionals should provide patients with more detailed information about the course of functioning, which previous studies have also shown to be extremely important. Third, professionals should pay more attention to those at greater risk of deterioration in functioning. Chapter 6 showed that advanced age, more symptoms of depression, less perceived self-efficacy and more activity avoidance were prognostic for poor physical functioning. If patients fit this profile, we recommend that professionals monitor the course of functioning in more detail, create more awareness of problems that might occur in terms of physical functioning and provide appropriate treatment in order to prevent (further) deterioration in functioning. Fourth, we identified some unmet care needs in the social domain. In the Netherlands, there could be a role for general practitioners and practice nurses to tackle these unmet needs. While consultation is often requested for disease-specific purposes, the unmet social needs demand a more pro-active approach to identifying problems in the social domain. An instrument to facilitate such a pro-active approach could be a geriatric assessment tool, i.e. case-management, to identify needs and tackle these needs with immediate delivery of services. However, up till now evidence of the effectiveness of geriatric assessment tools remains uncertain. Such tools should be further developed and examined to improve care delivery for older adults.

Overall, our findings suggest that the principles of good care for older adults with joint pain in the presence of comorbidity encompass more than merely treating symptoms such as pain, and should focus more on a person’s function, quality of life, mood, relationships and leisure activities. People with joint pain and comorbidity experience a number of challenges in their lives as a consequence of their symptoms. Some of these challenges will affect the individual’s ability to carry out activities of daily living, to contribute to society and to enjoy a reasonable quality of life. Social and psychological factors contribute greatly to facing such challenges. All our observations suggest the need of a more holistic approach to the assessment and management of joint pain in the presence of comorbidity. Every patient brings
his/her own thoughts, health beliefs, experiences, concerns and expectations to the general practitioner’s consultation. As we have shown that psychosocial factors are more closely related to functional status than measures of disease severity such as pain, pain severity and number of pain locations, these psychosocial factors should be taken into account in the principles of good care. The assessment of an individual’s medical, social and psychological needs (biopsychosocial model) enables a customised approach to management of joint pain in the presence of comorbidity and also provides a wider range of treatment possibilities (besides exercise and pain medication) in terms of training in coping skills for managing pain and other related symptoms: understanding pain, relaxation, goal setting, identifying and challenging negative thoughts, problem-solving, the scheduling of pleasant activities, all in order to assist patients with OA to apply these coping skills to valued activities. The holistic approach is gaining interest in the field of guideline development for various health conditions. For example, the National Institute for Health and Care Excellence (NICE) updated the guideline for the care and management of adults with osteoarthritis in February 2014 and incorporated the holistic approach as a firm component in the guideline. Unfortunately, Dutch guidelines for knee and/or hip osteoarthritis as provided by the NHG (Dutch College of General Practitioners) and NOV (Netherlands Orthopaedic Association) do not yet explicitly mention this holistic approach, though these guidelines have already been dated. We hope that the guideline developers will include the holistic approach in future updates of these guidelines. Still open to debate is which professional should play a key role in this care delivery in which physical and the psychosocial perspectives will be integrated. Alongside the general practitioner, there could be a role for the physiotherapist. In Australia, there are some initial results of successful training strategies whereby physiotherapists provide pain-coping skill programs. A physiotherapist-delivered integrated exercise and pain-coping skills training intervention for patients with knee OA is currently being studied in a randomised controlled trial, though the results are not yet available.

CLINICAL IMPLICATIONS FOR POLICY-MAKERS

The implications of the findings from the mixed-method study, as described in chapter 8 are that 1) the Dutch Health Care system has good facilities for arranging help for disabled people, 2) people are becoming more assertive in finding appropriate help themselves or 3) people simply do not report needs as they attribute pain and other complaints to the normal process of ageing. Nevertheless, improvements can be made in the social domain. Although the numbers of unmet needs in the social domain were relatively small, this area should receive more attention in the future. For example, it is well-known that social networks decrease with
age as older adults retire from work, outlive their friends and have children who grow up, start a family and move away. Also, pain and comorbidity cause more health-related disabilities which hamper people from participating in social engagement. Smaller social networks, isolation and loneliness are all indicative of the presence of a social need, which subsequently can lead to less perceived social support, as support is often obtained from social networks. To tackle such problems, more integrated care and closer collaboration is needed between health services (e.g. general practitioners, specialists, nurses) and social services (e.g. personal care, domestic help, social workers, transportation), which can subsequently help to better address individual care needs. Such services can facilitate the social integration of older adults with joint pain and comorbidity in terms of organising group activities to increase their social engagement in order to improve social well-being and perhaps target isolation and loneliness.

The municipalities in the Netherlands could also promote more active engagement in social programmes and community exercise programmes, especially since the high prevalence rates of joint pain and comorbidity indicate a public health problem. Such programmes already exist in the USA, for instance ‘fit and strong’, ‘people with arthritis can exercise’, which were developed by the Center for Disease Control and Prevention (CDC). Besides the more proactive role of health and social services and the municipalities, it remains very important that older adults and their social networks also take their own responsibility in signalling and tackling these problems, in terms of entering into dialogue with spouse/family, approaching clinicians for advice and support, and active coping solutions (self-management) that, for example, increase participation in social activities.

RECOMMENDATIONS FOR FUTURE RESEARCH

External validation of the prediction model

In this thesis, we have taken an initial step in developing a prediction model to identify those at risk of poor physical functioning. However, more research will be needed before this model can be used in practice. First of all, it is important to test our model in another primary care sample of older adults with joint pain and comorbidity, thus to externally validate the model with a replication analysis. In the case of a valid prediction model, the included factors should be translated back into practice in order to create a tool that professionals can actually apply to identify patients who are at risk. We recommend a study in which professionals, researchers, patients and other relevant experts in the field are brought together, for instance in organised focus groups, to discuss the content and design of a screening tool. The rationale behind such focus groups is to arrive at an agreement about a screening tool that is applicable in practice. Finally, implementing the screening tool in primary care should be further examined to see if
the tool does indeed identify patients who are at risk of poor physical functioning and, at a later stage, whether this earlier identification improves health outcomes, e.g., in relation to quality of life or hospital admission.

**Social needs**
The results presented in *chapter 8* indicate that improvements can still be made in the social domain in terms of organising group activities for greater social engagement in order to improve social well-being and perhaps target isolation and loneliness. More research in this field is highly recommended regarding the effects of social networks, social support and loneliness on functioning and well-being of older adults with joint pain and comorbidity, and in order to realise interventions or other solutions for tackling such problems.

**Psychosocial domain**
An important reason why research in the psychosocial domain is gaining interest may be the increased demand for non-drug and non-surgical interventions for chronic pain in older adults. Because of poly-pharmacy and over-treatment, recent studies suggest the use of alternative approaches, such as psychosocial interventions. These psychosocial interventions are not substitutes for conventional pharmacological and physical interventions, but may act as supplementary reinforcement of the effects of treatment. For example, psychosocial interventions could benefit life-style changes, more appropriate coping behaviour as well as tackling negative beliefs around pain, reducing negative psychosocial effects and improving adherence to exercise and other physical treatment strategies. There is already some evidence of successful interventions, such as exercise in combination with self-management and cognitive behaviour therapies (CBT)\(^{42-47}\). However, these results are still limited, inconsistent and need further exploration.

**Extend the follow-up?**
There are pros and cons to continuing the cohort of older adults with joint pain and comorbidity. The pros are that this specific group is important, since comorbidity is more often the rule than the exception in older adults with joint pain, and comorbidity can have additional effects on functioning. An important disadvantage for continuing this cohort is the inevitable loss to follow-up. This was an older population with complex disease combinations, which makes loss-to follow-up highly likely. Selective loss-to follow-up (death or deterioration in health) will inevitably increase with an extension of the study period. Furthermore, many different cohorts are emerging in older populations with substantial overlap. It might be better to extract data on specific disease combinations from larger population-based cohorts. This would enable
the use of control groups and decrease the burden on participants who are often asked to participate in more than one study at a time.

CONCLUSION

Our research confirmed the hypotheses that older adults with joint pain and comorbidity are prone to experience functional limitations in daily living, in terms of worse physical functioning, greater dependency in performing (instrumental) activities in daily living and greater restriction in participating in basic activities. The good news is that our sample of older adults with joint pain and comorbidity only showed modest changes in PF over a period of 18 months. Besides some well-known physical factors that contribute to poorer physical function, this thesis confirmed more than once that psychosocial factors play an important role in physical functioning and the prognosis of physical functioning. Therefore, we recommend a more holistic approach to the assessment and management of joint pain in the presence of comorbidity, with more attention for the medical, social and psychological needs of individuals.
REFERENCES


