

Summary

We supposed that older adults with joint pain and other chronic diseases like diabetes or heart disease were especially vulnerable to experience functional limitations and encounter a poorer prognosis of functioning over time because of two main reasons: joint pain and comorbidity can have an additional negative effect on functioning and previous research has indicated that joint pain is often poorly recognized and its treatment suboptimal, especially in the presence of comorbidity. As the presence of comorbidity alongside joint pain is more often the rule than the exception in older adults, more information was needed on the impact of both conditions on functioning, functional prognosis and the health care needs of this defined group. Besides two methodological studies (*chapters 3 and 4*), the overall objectives of the studies in this theses were to gain insight into: 1) the frequency and severity of functional limitations (*chapter 5*), contributing factors of functional limitations (*chapters 5 and 7*), the course of physical functioning (*chapter 6*), prognostic indicators 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. We therefore conducted a prospective cohort study which included 407 participants aged 65 years and older with joint pain and comorbidity. The studies and findings described in this thesis were all based on data from this cohort. Only the study described in *chapter 3* used additional data derived from an English cohort of older adults with knee pain.

In **chapter 2**, we presented the study protocol, explained the recruitment process, provided an overview of the four functional outcomes (i.e. physical functioning [PF]; activities of daily living [ADL]; instrumental activities of daily living [IADL] and participation) and selected sociodemographic, physical and psychosocial factors, described the statistical approaches in order to answer the various research questions, and discussed the potential strengths and limitations of the project.

In **chapter 3**, we tested the measurement properties of the Keele Assessment of Participation (KAP) questionnaire. The KAP measures person-perceived participation in 11 aspects of life. The KAP was developed and tested in the UK. Since some important information about the measurement properties was missing (e.g. ability to detect changes over time), we translated the questionnaire and examined the measurement properties of the KAP in our Dutch cohort of n=407 older adults with joint pain and comorbidity. Factor analysis revealed two domains: KAPd1; ‘participation in basic activities’ and KAPd2; ‘participation in complex activities’, with Cronbach’s α of 0.74 and 0.57 and moderate test–retest reliability: ICC of 0.63 and 0.57, respectively. Further analyses of KAPd1 showed poor construct validity and responsiveness. Furthermore, we tested the cross-cultural validity, in which we used a similar UK cohort for comparison. Despite uniform DIF in one item, ‘interpersonal relations’, the total

KAPd1 score seemed comparable between the Dutch and UK sample. In conclusion, only the KAP 'participation in basic activities' domain showed good internal consistency and sufficient reliability. However, the poor responsiveness indicated that this domain was not capable of detecting changes over time and therefore should only be used in cross-sectional studies. KAPd2 lacked sufficient measurement properties for application in studies, although items may be used as single items. On top of these results, we discussed the lack of a clear definition of the concept participation, which makes it extremely difficult to validate participation questionnaires and reach an agreement about the most optimal instrument for measuring participation. Therefore, we encourage further development of the concept 'participation'.

The reason for the study described in chapter 4 was another broader objective of our project. We aimed to develop a prediction model for poor functioning. Since we included four relevant functional outcomes in our study (i.e. PF, ADL, IADL and participation), but wanted to avoid overloading clinicians with four different prediction models, we tested the possibility to aggregate these measures into one general measure of functioning. Such an overall score incorporates all measures, and facilitates a more general approach to identifying older adults at risk of poor functional outcome. Therefore, in our cohort of older adults with joint pain and comorbidity, we tested two models with confirmatory factor analysis: a bifactor model with all four measures and a bifactor model with PF, ADL and IADL and a correlated but distinct subgroup factor for participation. The first model fitted the data well, but the reliability analysis indicated multidimensionality and unique information in the subgroup factor participation. Since this model was not optimal, we tested the second model which showed similar model fits, but better reliability; $ECV = 0.67$, $\omega-t = 0.94$, low $\omega-s = 0.18-0.22$ on the subgroup factors and high ω of 0.82 on participation, which all were in favour of the second model. In conclusion, our results indicated that three of our four selected functional outcomes could be aggregated into one general measure of functioning. Thus, researchers can calculate a summary score for PF, ADL and IADL to assess overall level of functioning and to develop a prediction model for poor functional outcome in older populations. Participation should be considered as a distinct measure.

In **chapter 5**, we explored the frequency, severity and determinants of functional limitations in our cohort of $n=407$ older adults with joint pain and comorbidity. The rationale behind this study was to provide greater insight into the impact that joint pain and comorbidity can have on functioning. Based on the ICF model, we incorporated four functional outcomes in our study: PF, ADL, IADL and participation (one domain of the KAP, as described in *chapter 3*). Of the participants, 66% were limited in PF, 31% needed help with performing ADL, 61% needed help with performing IADL and 47% were restricted from participating in basic activities. Additionally, about 22% of the participants reported restriction in all four functional outcomes. Subsequently, we identified determinants of functional limitations with multivariate regression

analysis whereby we added determinants in two steps: 1= only physical determinants, 2= physical and psychosocial determinants. The analysis revealed that of the physical determinants, frailty and pain severity were associated with poorer functioning. However, adding the psychosocial determinants to the model weakened some of these relationships. In particular, having anxiety or symptoms of depression, applying passive coping, experiencing less self-efficacy, experiencing less social support and having poorer general health perception were related to poor PF and participation restriction. In conclusion, our sample of older adults with joint pain and comorbidity reported substantial functional limitations. 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. Such psychosocial determinants should receive more attention in research.

Clinicians need to be aware of the different trajectories of PF over time and their prognostic indicators, as it is important for patients to receive information on prognosis during consultation. Therefore, in **chapter 6** we used latent class growth modelling (LCGM) to identify underlying subgroups (clusters) with distinct trajectories of PF, characterized these subgroups and applied multivariable logistic regression analysis to develop a prediction model for deterioration in PF. Three clusters were identified. Cluster 1 ('good PF') was comprised of 140 participants with good baseline PF and small improvements over time. Cluster 2 ('moderate PF') was comprised of 130 participants with moderate baseline PF and deterioration over time. Cluster 3 ('poor PF') was comprised of 137 participants with poor baseline PF and deterioration over time. After backward selection, the final prediction model that could best distinguish between improved participants (cluster 1) and deteriorated participants (clusters 2-3) included the following prognostic indicators: more advanced age, more symptoms of depression, less perceived self-efficacy and more activity avoidance. This information on the trajectories of PF and their related factors can help health care providers to better inform older adults with joint pain and comorbidity during consultation. However, more research is necessary to externally validate these results before the prediction model can be used in practice.

Sustantial variation exists in physical functioning among patients with comparable levels of pain, which may be partly explained by underlying psychological processes, like cognitive appraisal of pain and coping with pain. It remains unclear to what extent such determinants contribute to changes in PF over time, especially in older populations. Therefore, in **chapter 7** we examined longitudinal associations of five cognitive appraisals and four coping strategies with PF in our cohort of $n=407$ older adults with joint pain and comorbidity. We used Generalized Estimated Equations (GEE) and tested auto-regressive models in which we adjusted for covariates. Our results revealed that more negative thoughts about consequences of pain ($\beta=-0.54$, 95% CI= -1.02; -0.06), more catastrophizing ($\beta=-0.67$, 95% CI= -1.26; -0.07) and more activity avoidance ($\beta=-0.32$, 95% CI= -0.57; -0.08) were significantly associated with subsequent

deterioration in PF, whereas higher perceived self-efficacy ($\beta=0.22$, 95% CI=0.12; 0.31) was associated with subsequent improvement in PF. Neither concerns, emotional representations, ignoring pain, positive self-statement, nor increasing activity levels were longitudinally related to PF. This knowledge may contribute to future management of functional limitations in older adults with joint pain and comorbidity, whereby more attention can be paid to psychosocial factors that contribute to poorer functioning over time. For example, health care providers can facilitate participation in therapies, e.g. cognitive behaviour therapies, that help patients to cope with pain or therapies that educate patients about how to manage fear and pain-related avoidance of activities.

In order to provide adequate care, it is important to identify care needs. Therefore, in **chapter 8** we presented the results of a mixed-method study that assessed care delivery. In the quantitative part, we used the Camberwell Assessment of Need for the Elderly (CANE) to assess self-perceived care needs in our cohort of $n=407$ older adults with joint pain and comorbidity. The results showed 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 the high level of met needs indicated that most of these needs were taken care of by various health care services or informal caregivers. Most unmet needs were identified in the social domain, especially in arranging daytime activities and company. In particular it were the frail participants, who lived alone, reported depressive symptoms and perceived less social support, who reported unmet needs in this social area. In the qualitative part, data derived from eight in-depth interviews corresponded with the quantitative findings; most older adults seemed to be capable of accepting and adapting to their physical and environmental problems. However, giving up social activities and losing their membership and role in the community constituted unmet needs. This domain should receive more attention, preferably in an integrated setting of primary care and social care services to improve the social well-being of older adults with joint pain and comorbidity.

In **chapter 9**, we discussed the main findings of the thesis, provided an overview of clinical implications and made suggestions for future research. In conclusion, our research confirmed our 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 participation 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. It was confirmed more than once that, in addition to some well-known physical factors that contribute to poorer physical function, psychosocial factors play an important role in physical functioning and the prognosis of physical functioning. Therefore, we recommend a more holistic approach in the assessment and management of joint pain in the presence of comorbidity, with more attention being paid to the medical, social and psychological needs of individuals.