CHAPTER 8

Self-perceived needs in older adults with joint pain and comorbidity; a mixed method approach

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Submitted
ABSTRACT

**Objective:** to explore self-perceived care needs, determinants of identified needs and experiences concerning needs in older adults with joint pain and comorbidity, by using a mixed method approach.

**Design and methods:** a prospective cohort study of older adults (≥65 years) with joint pain and comorbidity provided baseline data (n=407). We used the Camberwell Assessment of Need for the Elderly (CANE) to assess self-perceived care needs. Regression analyses were conducted to examine the associations between needs and sociodemographic factors (age, gender, partner status and educational level), physical factors (pain intensity, comorbidity, frailty and physical functioning) and psychosocial factors (anxiety, depression and social support). Eight of the participants were interviewed in-depth to explore their needs and experiences concerning needs.

**Results:** although we found high levels of environmental (household, food) and physical needs (physical illness, mobility/falls), most needs were met. Only few people reported social needs, but a large proportion of these needs was unmet, especially regarding company and daytime activities. Frail participants that lived alone, perceived less social support and reported more depressive symptoms had more social unmet needs. Thematic analysis of the interviews corresponded with the quantitative findings; older adults seemed to be capable to accept and adapt to their physical and environmental problems. However, giving up social activities and losing membership and role in the community constituted unmet needs.

**Conclusions:** unmet needs are especially present in the social domain and should therefore receive more attention, preferably in an integrated setting of primary care and social care services to improve social well-being of older adults with joint pain and comorbidity.
INTRODUCTION

In later life, joint pain is a common complaint. Previous research showed that 68-85% of older adults with joint pain also have at least one other chronic disease (comorbidity), like diabetes or ischemic heart disease. The distinct consequences of joint pain and those of several other chronic diseases such as disability are well-documented. However, less is known about the impact of joint pain, in the presence of comorbidity, on levels of functioning and subsequent care needs of this specific population. Identifying care needs is regarded as an essential first step in optimizing health care, as it facilitates the implementation of early treatment strategies that aim to improve health, physical functioning and quality of life, and subsequently can prevent or delay deterioration in functioning, hospital (re)admission, placement in nursing homes and mortality. Therefore, it is important to assess the needs of older adults with joint pain and comorbidity.

The Camberwell Assessment of Need for the Elderly (CANE) is a structured interview that was developed to identify needs in 24 patient-related care items. Till now, the CANE instrument was mostly used in populations with dementia or depression. So far, only two studies explored care needs in an older primary care population. The most frequently identified unmet needs in these studies were in the care items visual/hearing, information, physical illness, mobility/falls, and incontinence. Furthermore, a more recently published study in frail older adults found most unmet needs in the items company, daytime activities, information, accommodation and caring for another. However, it is not known if these results are applicable to a more specific older population with joint pain and comorbidity. Also, only little is known about factors that are associated with more self-perceived needs on the CANE, whilst one can imagine that many of the sociodemographic, physical and psychosocial factors that have been previously linked to levels of pain and disability, also influence care needs in older adults. Apart from conducting the structured CANE interview, it could be interesting to obtain deeper knowledge about experiences concerning identified needs, by using a complementary qualitative approach, while this could enhance understanding and explanation of present needs. Unfortunately, no such studies are available yet.

Therefore, this study used a mixed method approach to gain insight into the care needs of a primary care sample of older adults with joint pain and comorbidity. In the quantitative component, we identified the most prevalent needs and assessed possible associated factors. We added a qualitative component to the study to obtain detailed information about the interpretation of the identified needs, the impact of especially the unmet needs in daily life and possible solutions for addressing these needs.
METHODS

Design
We used a mixed method approach to study care needs in our sample. The rationale behind this study design was to integrate two research methods and to explore if the quantitative findings correspond with the qualitative findings. Whereas the quantitative part systematically explored needs and related factors, the qualitative part focused more on personal perspectives and experiences of perceived needs in older adults with joint pain and comorbidity. The advantage of this approach is enhancing understanding and explanation for identified needs. The Medical Ethics Committee of the VU University Medical Center Amsterdam approved the study protocol. Written informed consent was obtained from all participants.

Study population
Quantitative component
A prospective cohort study in older adults with joint pain and comorbidity provided baseline data, which were collected by means of a postal questionnaire and the structured CANE interview. Participants were recruited from 22 general practices (GPs) in the region of Amsterdam and were eligible for participation if they were aged 65 years or over, had ≥2 chronic diseases registered in the electronic medical files of the GPs, and reported joint pain on most days in the past month (questionnaire) in at least one of eight joint pain sites: neck, back, shoulder, elbow, wrist/hand, hip, knee and ankle/foot. Details about the study design and recruitment process have been previously described. In summary, almost 800 participants were eligible for participation, of which eventually 407 participants were included in the study. Within the group of eligible patients, we found no differences between participants and non-participants in age and gender. However, the non-participants had fewer chronic diseases, reported fewer joint pain sites and less pain.

Qualitative component
Within the sample of 407 participants, we asked eleven participants to participate in the in-depth interviews. The participants were purposively sampled in terms of age, gender and number of reported needs to gain a sample that reflected the heterogeneity of the study population. The selected participants were invited by telephone to participate in the additional study. Three participants refused to participate, because of health related problems. All above mentioned data were collected between November 2010 and May 2013.
Measurements and procedures

Quantitative approach

Outcome: While the CANE was originally developed to identify needs in 24 care items, Walters et al. (2001) showed that 11 items are not appropriate for a more general older population. Therefore, we decided to assess only the remaining 13 items. The Dutch CANE showed good validity and reliability in older populations with dementia. By means of a structured interview, all 13 items were assessed. In case of an unmet need, further questioning provided insight into the nature of the need, current help received and expectations concerning care needs. A met need was defined as receiving sufficient help to solve or reduce the problem, whereas an unmet need was defined as lack of help or insufficient help to reduce or solve the problem.

The percentages of needs can be assessed on individual care item level, but also on domain level as previously shown by Field et al. Assessing environmental needs, physical needs and social needs helps to identify most frequent needs, which subsequently may help to narrow the focus and facilitate more targeted interventions. The CANE interviews were conducted by three trained interviewers, including the first author.

Sociodemographic: age, gender, education (primary, secondary, college/university) and living situation (alone, not alone).

Physical: Pain intensity: 3 items of the Chronic Pain Grade (CPG); score range 0-100; higher score indicates more pain; number of chronic diseases; score range 2-19; dichotomized to 2, ≥3; frailty (no, yes): positive when participants met three or more of five frailty component criteria: weight loss, weakness, slowness, exhaustion, low activity; physical functioning: 10-item physical functioning subscale of the RAND-36; score range 0-100; lower score reflects more limitations.

Psychosocial: anxiety/depressive symptoms: 14-item Hospital Anxiety and Depression Scale (HADS); score range 0-21; higher score indicates more symptoms; social support: 12-item Social Support Scale (SSS); score range 12-60; higher score indicates less perceived social support.

Qualitative approach

We developed a topic guide. This topic guide was further improved with help from two older adults who fulfilled the criteria of the study population and participate in our project group as experts from the field. They did not participate in the study itself. The approved topic guide was piloted by the interviewer during the interview training. The interview started with an introductory question probing the activities of a random day during the week. This introduction question was followed by in-depth questioning about difficulties in performing specific activities, help that participants received for their difficulties, current care needs and expected needs in the future, as this may provide explanations for the identified needs. Furthermore,
the interviewer asked participants about possible barriers and limitations regarding health care. During the interviews, participants had the opportunity to elaborate on particular topics. All eight interviews were conducted by the first author (LH) who was trained in interviewing older adults. The interviews took place at the participants’ homes to create a comfortable and familiar environment. The average duration of the interviews was 102 minutes (range 73-143).

Analyses

**Quantitative component**

We used descriptive statistics to describe the study population and the proportion of care needs on care item level and domain level. Linear regression analysis was applied for physical needs. Since the needs in the other two domains and unmet needs in all three domains were not normally distributed, we dichotomised these outcomes. For the needs, we distinguished participants with one or more needs from those without needs in the particular care domain. For the unmet needs, we distinguished participants with one or more unmet needs from those without unmet needs. The dichotomized outcomes were analysed with logistic regression analyses. Univariate associations between the selected variables and six outcomes were tested (data not shown). The variables with \( p < 0.10 \) on the outcomes were entered in the multivariable models. We presented the standardized regression coefficients (beta) or odds ratios (OR) with 95% confidence intervals (95% CI). In case of collinearity (spearman \( r > 0.80 \)), we included only the determinant with the strongest association in the model. Data were analysed using SPSS version 20.0.

**Qualitative component**

All interviews were audio-taped and transcribed verbatim. The anonymous transcripts were coded and analysed using the framework method of qualitative data analysis\(^{17}\). Themes were derived from the data and were coded in software package Atlas.Ti version 5.2. Two independent researchers (LH and LdV) conducted the thematic analysis. They identified codes and combined them into a coding framework. This was followed by a consensus meeting. The researchers optimized and refined the coding framework in a so-called iterative process.

**RESULTS**

**Quantitative component**

The baseline characteristics of the 407 participants are outlined in Table 1. Our sample was on average 76.8 years old (range 65.2-92.8) and about 65% was female. About 60% of the participants lived together. The mean number of joint pain sites was 4.0 (SD 1.9), in which worse pain was most often reported in the back (27%), knee (18%), hand/wrist (15%) or
hip (13%). Furthermore, almost half had more than 2 chronic diseases. The most prevalent diseases were chronic ischemic heart disease (62%), diabetes mellitus (37%) and chronic respiratory disease (24%).

Our sample reported on average 4.0 care needs (SD 2.1), mostly physical needs (mean 2.5, SD 1.2) and to a lesser extent environmental needs (mean 1.2, SD 1.0) and social needs (mean 0.3, SD 0.7) (Table 1). Looking at care item level, most needs were identified in the items physical illness (91%), household activities (61%), mobility/falls (53%) and visual/hearing impairment (44%) (Table 2). Further evaluation of these care needs showed that the vast majority of the care needs were met. However, this was not the case for all items. Almost one quarter of our sample had at least one unmet need in the 13 care items, of which most unmet needs were identified in the social and environmental domains, especially in the care items company (67%), daytime activities (37%), caring for another (31%), information (26%) and accommodation (18%) (Table 2). Although only few people had needs regarding these care items, a large proportion was unmet.

Univariate associations were most pronounced between care needs and frailty, physical functioning, depression and social support and between unmet care needs and frailty, physical functioning and depression (data not shown). Remaining factors showed more variety in associations. The results of the multivariable analyses are presented in Table 3. Participants who were older, female, frail or had poor physical functioning reported more environmental needs. Higher age and poor physical functioning were also related to more physical needs, and additionally more chronic diseases seemed to be an important covariate. In the social domain, it were not so much the sociodemographic factors, but being frail, having depressive symptoms and perceiving less social support that were related to more social needs. Looking at unmet needs, poor physical functioning was related to both more environmental and physical unmet needs, whereas less perceived social support and additionally living alone were related to more unmet social needs.

Overall, the sociodemographic and physical factors seemed most importantly related to environmental and physical needs, whereas the psychosocial factors were more strongly related to social needs.

**Qualitative component**

The characteristics of the eight participants with joint pain and comorbidity that participated in the interviews are outlined in Table 4. Most of the interviews were conducted without non-participants being present. Only in the case of participant IV, the partner was present and responded to some questions. In the analysis, we mainly focused on the contribution of the participant. In this qualitative component, we described the most obvious explanations of identified needs.
Table 1 | Baseline characteristics of the study population (n=407)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender; female</td>
<td>254</td>
<td>62.4</td>
</tr>
<tr>
<td>Age, mean (SD)</td>
<td>76.8</td>
<td>6.3</td>
</tr>
<tr>
<td>Living situation; alone</td>
<td>165</td>
<td>40.5</td>
</tr>
</tbody>
</table>

**Highest education; n (%)**
- Primary: 121 (29.7)
- Secondary: 199 (48.9)
- College/university: 87 (21.4)

| Pain intensity (0-100), mean (SD)  | 64.4| 17.3 |
| Chronic diseases; ≥3 n(%)          | 197 | 48.4 |
| Frailty; yes n(%)                  | 75  | 18.4 |
| Physical functioning (0-100), mean (SD) | 48.7| 25.8 |
| Anxiety symptoms (0-21), mean (SD) | 5.1 | 3.7  |
| Depressive symptoms (0-21), mean (SD) | 5.4 | 3.5  |
| Social support (12-60), mean (SD)  | 19.1| 8.4  |

**CANES**
- Total needs (0-13): Mean (SD) 4.0 (2.1) ≥1 needs n (%) 393 (98.3)
- Total unmet needs (0-13): Mean (SD) 0.3 (0.8) 88 (22.0)
- Environmental needs (0-4): Mean (SD) 1.2 (1.0) 277 (69.3)
- Physical needs (0-5): Mean (SD) 2.5 (1.2) 381 (95.3)
- Social needs (0-4): Mean (SD) 0.3 (0.7) 90 (22.5)
- Environmental unmet needs (0-4): Mean (SD) 0.10 (0.33) 34 (8.5)
- Physical unmet needs (0-5): Mean (SD) 0.14 (0.39) 49 (12.3)
- Social unmet needs (0-4): Mean (SD) 0.11 (0.41) 32 (8.0)

Table 2 | Descriptives of total needs, met needs and unmet needs for all 13 care items

<table>
<thead>
<tr>
<th>Category</th>
<th>Total needs</th>
<th>Met needs</th>
<th>Unmet needs</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Environmental needs</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accommodation</td>
<td>78 (19.5)</td>
<td>64 (82.1)</td>
<td>14 (17.9)</td>
</tr>
<tr>
<td>Household activities</td>
<td>243 (60.8)</td>
<td>232 (95.5)</td>
<td>11 (4.5)</td>
</tr>
<tr>
<td>Food</td>
<td>126 (31.5)</td>
<td>122 (96.8)</td>
<td>4 (3.2)</td>
</tr>
<tr>
<td>Caring for another</td>
<td>29 (7.3)</td>
<td>20 (69.0)</td>
<td>9 (31.0)</td>
</tr>
<tr>
<td><strong>Physical needs</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical illness</td>
<td>364 (91.0)</td>
<td>351 (96.4)</td>
<td>13 (3.6)</td>
</tr>
<tr>
<td>Medication use</td>
<td>146 (36.6)</td>
<td>143 (97.9)</td>
<td>3 (2.1)</td>
</tr>
<tr>
<td>Visual/hearing impairment</td>
<td>176 (44.0)</td>
<td>160 (90.9)</td>
<td>16 (9.1)</td>
</tr>
<tr>
<td>Mobility/falls</td>
<td>212 (53.0)</td>
<td>189 (89.2)</td>
<td>23 (10.8)</td>
</tr>
<tr>
<td>Self-care</td>
<td>91 (22.8)</td>
<td>91 (100)</td>
<td>0</td>
</tr>
<tr>
<td><strong>Social needs</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Memory</td>
<td>36 (9.0)</td>
<td>31 (86.1)</td>
<td>5 (13.9)</td>
</tr>
<tr>
<td>Company</td>
<td>30 (7.5)</td>
<td>10 (33.3)</td>
<td>20 (66.7)</td>
</tr>
<tr>
<td>Daytime activities</td>
<td>27 (6.8)</td>
<td>17 (63.0)</td>
<td>10 (37.0)</td>
</tr>
<tr>
<td>Information</td>
<td>38 (9.5)</td>
<td>26 (74.3)</td>
<td>9 (25.7)</td>
</tr>
</tbody>
</table>

* % of met and unmet needs are based on the numbers of the total needs
Table 3 | Results of multivariable regression analyses of sociodemographic, physical and psychosocial factors associated with needs and unmet needs on care domain level

<table>
<thead>
<tr>
<th>Environmental needs (0- ≥1)</th>
<th>Physical needs (0-5)</th>
<th>Social needs (0- ≥1)</th>
<th>Environmental unmet needs (0- ≥1)</th>
<th>Physical unmet needs (0- ≥1)</th>
<th>Social unmet needs (0- ≥1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>OR (95% CI)</td>
<td>Beta (95% CI)</td>
<td>OR (95% CI)</td>
<td>OR (95% CI)</td>
<td>OR (95% CI)</td>
<td>OR (95% CI)</td>
</tr>
<tr>
<td>Age (years)</td>
<td>1.07 (1.02-1.13)**</td>
<td>0.02 (0.00; 0.04)*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender (female)</td>
<td>5.23 (2.87-9.53)***</td>
<td>0.06 (-0.15; 0.28)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living situation (alone)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>2.64 (0.83-8.43)</td>
</tr>
<tr>
<td>Education: Primary</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1.62 (1.13-2.31)**</td>
</tr>
<tr>
<td>Secondary</td>
<td>1.44 (0.71-2.92)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>College/university</td>
<td>0.84 (0.37-1.89)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain intensity (0-100)</td>
<td>1.00 (0.99-1.02)</td>
<td>0.00 (-0.01; 0.01)</td>
<td></td>
<td>1.01 (0.99-1.03)</td>
<td></td>
</tr>
<tr>
<td>Chronic diseases (≥3)</td>
<td>0.35 (0.15; 0.56) **</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frailty (yes)</td>
<td>4.36 (1.17-16.26)*</td>
<td>-0.11 (-0.41; 0.19)</td>
<td>2.40 (1.25-4.61)**</td>
<td>1.15 (0.48-2.75)</td>
<td>1.24 (0.59-2.62)</td>
</tr>
<tr>
<td>† Physical functioning (0-100)</td>
<td>0.95 (0.93-0.96)**</td>
<td>-0.02 (-0.02; -0.02)***</td>
<td>1.01 (0.99-1.02)</td>
<td>0.96 (0.95-0.98)**</td>
<td>0.97 (0.96-0.99)***</td>
</tr>
<tr>
<td>Anxiety symptoms (0-21)</td>
<td></td>
<td></td>
<td></td>
<td>1.10 (0.99-1.22)</td>
<td>1.02 (0.91-1.14)</td>
</tr>
<tr>
<td>Depressive symptoms (0-21)</td>
<td>1.00 (0.91-1.09)</td>
<td>0.00 (-0.03; 0.03)</td>
<td>1.17 (1.07-1.26)**</td>
<td>1.05 (0.92-1.19)</td>
<td>1.03 (0.93-1.14)</td>
</tr>
<tr>
<td>‡ Social support (12-60)</td>
<td>1.05 (1.01-1.08)**</td>
<td>1.02 (0.97-1.06)</td>
<td>1.03 (0.99-1.06)</td>
<td>1.07 (1.02-1.12)**</td>
<td></td>
</tr>
</tbody>
</table>

† Higher scores means protective for needs; ‡ higher score means less social support; OR= Odds Ratio, 95% CI= 95% Confidence Interval, Beta= Standardized Regression Coefficient

*=P<0.05, **=P<0.01, ***=P<0.001
Environmental needs
The quantitative results showed that the participants reported substantial needs in the environmental domain, of which most needs were met and supported. The interview data revealed that older adults with pain often adapted to situations of constant pain and learned to live with the circumstances, as they felt that nothing would change in the near future. Most participants also mentioned that complaining should be avoided, because this would only worsen the situation.

“I really don’t like it, but you have to deal with the situation. It is as it is. If I would sit down and complain the entire day, it wouldn’t help at all. I would also like to just go somewhere, like taking a walk, but that just isn’t possible”. (I)

“I am probably good at accepting my fate. I always say: ‘There is no person that does this to you.’ It’s maybe a way of understanding, because nobody can change it for you. So you can complain, but...”. (II)

The interviews revealed that most participants seemed assertive in finding help, when it came to performing certain basic activities, like running the household, preparing a decent meal or going shopping. So, despite the high needs reported on these domains, the impact on daily life seemed to be only limited in this sample of older adults with joint pain and comorbidity.

“There is no change in the future, so you have to accept every thing as it is. So simple, I am 77 years old and probably don’t play the hula-hoop again. So, I am happy with my home and all the adjustments/devices, and the fact that I still are able to go outside with my scoot mobile, which makes me really happy”. (VI)

In the cases that participants were indeed restrained or reluctant to ask for help in performing basic activities from home care services, reasons were concerns about allowing home care workers into their houses, most importantly because of the constant swings in time-schedules and persons that deliver help.

Physical needs
Although we found high numbers of physical needs, most needs were met. The interview data indicated that often participants were satisfied with their usual health care and available recourses. Some participants just decided not to use health care recourses for pain complaints as they accept pain as part of normal ageing and downplay the impact of pain on functioning. This was illustrated in our interviews as follows:
Table 4 | Characteristics of the eight interviewed participants

<table>
<thead>
<tr>
<th></th>
<th>I.</th>
<th>II.</th>
<th>III.</th>
<th>IV.</th>
<th>V.</th>
<th>VI.</th>
<th>VII.</th>
<th>VIII.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>81.8</td>
<td>85.0</td>
<td>65.8</td>
<td>75.1</td>
<td>77.0</td>
<td>76.8</td>
<td>75.2</td>
<td>76.9</td>
</tr>
<tr>
<td>Gender</td>
<td>f</td>
<td>f</td>
<td>f</td>
<td>f</td>
<td>m</td>
<td>f</td>
<td>f</td>
<td>f</td>
</tr>
<tr>
<td>Living situation</td>
<td>TC</td>
<td>ARH</td>
<td>TC</td>
<td>TC</td>
<td>TC</td>
<td>ARH</td>
<td>AC</td>
<td>AC</td>
</tr>
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<td>Education</td>
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<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Joint pain sites (1-8)</td>
<td>3</td>
<td>6</td>
<td>3</td>
<td>8</td>
<td>1</td>
<td>5</td>
<td>6</td>
<td>2</td>
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<tr>
<td>Chronic diseases (2-19)</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>5</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Frailty</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Physical functioning (0-100)</td>
<td>15</td>
<td>20</td>
<td>30</td>
<td>100</td>
<td>5</td>
<td>10</td>
<td>5</td>
<td>70</td>
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<tr>
<td>Anxiety symptoms (0-21)</td>
<td>9</td>
<td>2</td>
<td>2</td>
<td>8</td>
<td>1</td>
<td>12</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Depressive symptoms (0-21)</td>
<td>10</td>
<td>5</td>
<td>3</td>
<td>8</td>
<td>7</td>
<td>16</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Social support (12-60)</td>
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<td>18</td>
<td>28</td>
<td>31</td>
<td>55</td>
<td>20</td>
<td>34</td>
</tr>
<tr>
<td>Total needs (0-13)</td>
<td>4</td>
<td>6</td>
<td>6</td>
<td>7</td>
<td>6</td>
<td>6</td>
<td>8</td>
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<td>Total unmet needs (0-13)</td>
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<td>1</td>
<td>1</td>
<td>0</td>
<td>4</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

TC = together in community | ARH = alone residential home | AC = alone in community

“Pain is something that you learn to live with”. (II)

“The pain is present, but not to the extent that it becomes unbearable. When it hurts,
I take some paracetamol, which controls the pain. It is just some form of older people’s
pain complaints”. (I)

Another finding from the interviews was that people with long-lasting complaints, like joint
pain, were constantly looking for new strategies and solutions to face problems, based on prior
experiences. Inventive strategies that people came up with were: performing only straight
forward tasks, more targeting of work tasks, more spreading in performing tasks during the
day, insertion of rest and relaxation periods, imposing time limits, asking for help, avoiding
certain movements, changing body position regularly, diverting attention (watching tv, reading
etc.), finding new activities as replacement.

However, participants also mentioned some reasons for unmet needs in this domain. There
was uncertainty about the justified threshold for consulting a doctor for pain complaints. Also,
prioritizing was mentioned, especially when having joint pain in combination with
other chronic conditions. Furthermore, participants often had low expectations concerning
treatment outcomes, particularly since they often had already tried several options without
much result. It was mentioned more than once in the interviews that nothing can be done
to take away the pain. Some participants saw surgery as the final solution, but in practice
this is not always possible, especially when doctors take age into account. Above barriers are illustrated in the following quotes:

“Sometimes I am afraid to go (to the doctor), because I think that it is not that important. I am afraid that the professional thinks that I am exaggerating the complaint”. (III)

“If I say that it hurts, they just react (general practitioner): oh that knee is worn out. There is nothing that I can do about it. I always have the feeling that they take into account the age factor, when it comes to treatment. In a negative way”. (I)

“I could go to the general practitioner for my pain. But now I first have to deal with bone spurs on the heel and the cystitis. So, I will wait”. (I)

Participants found it important that health care professionals take more time to listen to their stories, that they take problems seriously, and that they look more to the human body as a whole, instead of only focussing on the complaint that ‘justifies’ consultation.

“It would be good if the doctor has an interest in the human being as a whole (which includes the psychosocial part and symptoms like stress), instead of answering only the question during consultation. The doctor should look at me, instead of looking at the computer”. (VIII)

Some participants referred to the times when the general practitioner visited them at home once in a while, just to see how things were going. Several participants mentioned their preference for such informal home visits, although they were also aware of the strict time schedules of clinicians these days.

Social needs
Contrary to the low numbers of unmet environmental and physical needs, our participants had some unmet social needs, as seen in the quantitative part of the study. This finding was further explored in the interviews, which revealed some sort of hierarchy, in which participation in social activities is generally lost at an earlier stage of life than for example self-care or running the household. Social participation seemed to be the first domain in which people make adjustments and drop activities, as these activities require more complex involvement of environmental interactions (e.g. transportation). Prioritizing is important, as people want to live in their own homes, preferably independent, as long as possible and they will do whatever it takes to achieve this to retain in control. Therefore, they will start by giving up participating in social activities. The interviews revealed that, despite the relatively low numbers of social needs in the CANE, the unmet needs have a substantial impact on people’s life. When we asked participants about specifying the dropped activity that they regretted most, none mentioned
basic activities, but instead all mentioned social activities, like travelling, dancing, meeting people, joining clubs and going to museums.

“Doing groceries is not something that bothers me, but on the other hand it is also not that delightful. So that I can’t do that anymore is not the worst. After my retirement, I hoped for a chance to travel further abroad and especially to visit more museums. Well, none of it happens now”. (III)

“I really try as much as possible. But in the end, you decide to do what needs to be done. Because if I had the choice, I would undertake more social/leisure activities”. (II)

“Most devastating is the fact that I don’t have a function anymore for my husband, children and in society (having work, performing voluntary work). I miss some form of social engagement”. (VIII)

The participants highlighted the importance to remain independent, especially in transportation, thus the ability to go shopping, having drinks outside the home, go to museums and the theatre, as and when they preferred to. Eventually, it all came back to making your own decisions concerning performing activities and being part of the community.

“That is something essential in life, the ability to move yourself”. (V)

“Standing still is deterioration. You want to move yourself from A to B, preferable independently. That bothers me tremendously, becoming dependent”. (I)

“Every moment, you hand in something, one day it is your husband, than after you get everything back together, you lose your friends, your home (because of deterioration), your car and your freedom”. (VII)

The participants found it important to have decent social networks, as this creates a lower threshold to ask for help and support. The family and in particular the partner were mentioned. However, one of the participants also highlighted the presence of some sort of generation gap, which also could explain the difficulties these days in receiving appropriate help from family members.

“There is a generation gap. I took care of my mother in another way as my girls do these days. I lived close to my mother and we drank coffee every day and had lunch together, and sometimes she also had dinner at my place. My daughters work, have to take care of their own families, live further away and are always busy”. (VII)

“I don’t complain, when my children are around and I don’t want to bother them too much. I don’t expect them to walk in and out every day, but if you would ask me about my preferences, deep inside I would like to seem them more often”. (VIII)
The participants highlighted that neighbours and acquaintances become less important. Partly, because these days there is a constant flow in neighbourhoods and the threshold to ask ‘outsiders’ for help becomes higher. Despite the relatively low proportion of needs in the care item information, the interview data revealed a gap in information provision by clinicians.

“Well, last time I asked my general practitioner again. He sent me to the neurologist, who said: No, you should keep it like it is. So I accepted his advice, however without any explanation. It is unfortunate that they don’t explain things”. (III)

“There are things that I pick up myself, but what if you have less friends or less education. Then you are completely dependent on others”. (III)

“Doctors just prescribe and prescribe and I don’t know what I swallow and how the medications interact”. (VIII)

**DISCUSSION**

In this study, we explored self-perceived care needs, factors that are related to identified needs and experiences concerning needs in older adults with joint pain and comorbidity, by using a mixed method approach. Our sample reported an average of 4.0 needs on 13 care items, mostly in the physical and environmental domains. The multivariable models showed that participants who were older, female, frail, had more chronic diseases or poor physical functioning reported more environmental and physical needs, of which especially poor physical functioning was related to more unmet needs. However, most needs in these domains were met. In contrast, although only few people reported social needs, a large proportion of these needs were unmet. It were especially the participants who lived alone, perceived less social support and reported more depressive symptoms that had more social needs.

Thematic analysis of the interviews corresponded with the quantitative findings; older adults seemed to be capable to accept and adapt to their physical and environmental problems. However, this was only partly the case for the social needs. Although the CANE identified small numbers of social needs, most interviewed participants stated that the hardest part was giving up social activities and losing their membership and role in the community.

Our sample of older adults with joint pain and comorbidity reported most needs in the care items physical illness, household activities and mobility/falls, but most of these needs were met. We were able to compare the proportion of identified needs in our sample with a more general population\textsuperscript{14} and a frail population\textsuperscript{16}. As compared to our study, the general population had more unmet needs in the physical domain, but less unmet needs in the social domain, whereas the frail population had higher unmet needs on almost all individual care
Mixed-method study to explore self-perceived needs

items. The most obvious difference, compared to both mentioned studies was the relatively high percentage of needs in the item accommodation in our sample. Nearly all older adults prefer to stay in their own home as long as possible. This preference is captured in the term ‘aging in place’, and was also heard during our interviews. Maybe the threshold to look for an alternative accommodation is higher in our group, as the pain complaints indeed are present, but in their view too mild to actually plan actions, similar to the higher thresholds to visit the GP.

Although our sample reported high numbers of needs in the environmental and physical domains, most of these needs were met. Some explanations come to mind. First, the Dutch health care system already has several facilities that arrange help when older adults become disabled and need help, in terms of appropriate treatment, medication, living adjustments and social services. Second, older adults with more problems in life become better in finding solutions themselves and being assertive in asking for help in their close environment. Third, participants often scored a need on the item physical illness because of amongst others (present chronic diseases) their daily pain, but in many cases these needs were met. This may be due to appropriate treatment strategies, but could also be explained by the observation that many older people attribute pain and related problems to the normal process of ageing. They accept the situation and learn to live and deal with the circumstances. A possible reason for the small numbers of unmet needs in the care item physical illness can be explained by the higher threshold to consult clinicians, which eventually can cause a need on this domain. But maybe the low levels of unmet needs in both domains just confirm that we have an adequate health care system in the Netherlands.

Despite the low numbers of needs in the social domain, the multivariate regression analyses showed that especially living alone and perceiving less social support were associated with more social needs. It is well known that social networks decrease with age, as older adults retire from work, outlive friends and have children that grow up, start a family and move away. Also, pain and comorbidity cause more health related disabilities, which prevents people from social engagement. Smaller social networks, isolation and loneliness are all indicative of the presence of a social need, which subsequently can cause less perceived social support, as support is often obtained from social networks. As lack of social support has been associated with decreased quality of life, more mental health problems and poorer social well-being, it seems important to target the social needs in clinical practice, by paying attention to the patient’s networks and their social care use. In the Netherlands, there could be a role for general practitioners. While consultation is often requested for disease-specific purposes, the social unmet needs ask for a more pro-active approach to identify problems in the social area. As quoted in one of the interviews, “More attention should be paid to patient-centered outcomes as well-being and quality of life, instead of only treating the disease in question.”
This may ask for more integrated care and close collaboration between health services (e.g. general practitioners, specialists, nurses) and social services (e.g. personal care, domestic help, social workers, transportation), which subsequently helps to better address individual care needs. There are already some studies that have reported good results about the use of geriatric assessment tools to identify needs and tackle these needs with immediate delivery services\textsuperscript{35}. Such tools should be further developed and examined to improve care delivery for older adults.

Besides the more pro-active role of health and social services, it remains very important that older adults and their social networks also take their own responsibility in signalling and encountering these problems, in terms of starting the dialogue with spouse/family, approaching clinicians for advice and support and active coping towards solutions (self-management) that for example increase participation in social activities.

**Strengths**

The CANE results are based on structured interview data. Indeed, this provides knowledge that is strong in terms of generalisation, precision and control. However, the strength of qualitative methods is that it provides the opportunity to obtain deeper knowledge and understanding from a patients’ perspective. By using a mixed-method approach, we have obtained deeper knowledge about possible explanations for the identified needs and tackled some of the complexity around the presence of needs in our sample of older adults with joint pain and comorbidity. Furthermore, we used validated instruments and included variables that assessed mental health status, i.e. anxiety and depression. It was already mentioned that these variables could be important when assessing health care needs\textsuperscript{36}, but most studies failed to include these factors.

**Limitations**

Overall, the CANE provides information about the presence of specific unmet care needs, which is important to optimize care for this specific population. However, conducting a structured CANE interview is quite burdensome, which makes it difficult to use this instrument in clinical practice. The CANE was originally developed to compare self-perceived care needs between patient, informal care giver and clinicians. We only assessed patients’ self-perceived care needs. However, in practice estimations about presence or absence of needs are often made by the clinicians or informal caregiver and it would be interesting to know to what extent these assessments are in agreement with the patients reported needs, because low agreement could indicate lack of awareness/knowledge of current needs of the patient.
This study was not able to examine objective health care needs. Comparison between objective and subjective health care needs could provide more information about factors that contribute to possible differences (e.g. social support, patients’ preferences etc.).

CONCLUSION

Older adults with joint pain and comorbidity seemed to be capable to accept and adapt to their physical and environmental problems. Unmet needs are especially present in the social domain and should therefore receive more attention, preferably in an integrated setting of primary care and social care services to improve social well-being of older adults with joint pain and comorbidity.
Chapter 8

REFERENCES


