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# Suffering and mental health among older people living in nursing homes - a mixed-methods study

Jorunn Drageset, Elin Dysvik, Birgitte Espehaug, Gerd Karin Natvig, Bodil Furnes

**Background.** Knowledge about mixed-methods perspectives that examine anxiety, depression, social support, mental health and the phenomenon of suffering among cognitively intact NH residents is scarce. We aimed to explore suffering and mental health among cognitively intact NH residents. **Methods.** This study used a mixed-methods design to explore different aspects of the same phenomena of interest to gain a more comprehensive understanding. The qualitative core component comprised a qualitative interview from 18 nursing home residents ( $\geq 65$  years) about experiences related to pain, grief and loss. The supplementary component comprised interview from the same respondents using the SF-36 Health Survey subscales, the Hospital Anxiety and Depression Scale and the Social Provisions Scale. **Results.** The individual descriptions reveal suffering caused by painful experiences during life. The quantitative results indicated that symptoms of anxiety and depression were related to mental health and symptoms of anxiety were related to bodily pain and emotional role limitations. Attachment and social integration were associated with vitality and social functioning. **Discussion.** To improve the situation, more attention should be paid to the residents' suffering related to anxiety, depression and psychosocial relations.

**Mental health and suffering among older people living in nursing homes – a mixed-methods study**

Jorunn Drageset<sup>1,2</sup>, Elin Dysvik<sup>3</sup>, Birgitte Espehaug<sup>1</sup>, Gerd Karin Natvig<sup>2</sup> and Bodil Furnes<sup>3</sup>

**Authors' affiliations**

<sup>1</sup>Faculty of Health and Social Sciences, Bergen University College, Norway

<sup>2</sup>Department of Global Public Health and Primary Care, University of Bergen, Norway

<sup>3</sup>Department of Health Studies, Faculty of Social Sciences, University of Stavanger, Norway

**Corresponding author:**

Jorunn Drageset, PHD, RN

Faculty of Health and Social Sciences,

Bergen University College, Bergen, Norway

Innedalsveien 28

N-5063 BERGEN

NORWAY

Telephone: 47-55 585589 Fax: 47-55 585556

E-mail: [Jorunn.Drageset@hib.no](mailto:Jorunn.Drageset@hib.no).

26

## 27 **Introduction**

28 Nursing home (NH) residents without cognitive impairment comprise a minority of NH residents and  
29 often have somatic and/or other mental health conditions (Nygaard, Naik & Ruths, 2000; Linton &  
30 Lach, 2007; Selbaek et al., 2007). NH residents may also experience stressful events such as relational  
31 losses, loss of home and loss of spouse, relatives and friends. Such conditions may cause them to  
32 experience suffering (Morse, 2001; Cassel, 2004; Ferrell & Coyle 2008) and affect both mental and  
33 physical health (Travis et al., 2004; Garcia et al., 2005). Morse (2011) describes suffering as basic  
34 emotional experience that follows illnesses that threaten one's physical or psychosocial integration.  
35 Thus, suffering refers to human existence as a whole, whereas experiencing suffering can mean being  
36 unable to keep oneself together as a whole entity. Alleviating suffering implies lessening people's  
37 sense of vulnerability (Rehnsfelt & Eriksson, 2004). Studies from Canada (Daneault et al., 2004) and  
38 Finland (Kuuppelomaki & Lauri, 1998) found that people report suffering in three dimensions;  
39 physical, mental and social well-being. Physical suffering includes pain, mental suffering is mostly  
40 expressed as depression and social suffering is often caused by disease that results in isolation and  
41 withdrawal from social contact (Kuuppelomaki & Lauri, 1998).

42 Depression is common among older people living in NHs (Smalbrugge et al., 2005a;  
43 Smalbrugge et al., 2006a; Drageset, Eide & Ranhoff, 2011, 2013); the prevalence is 34–41%.  
44 Depression is often experienced together with anxiety, where anxiety tends to follow traumatic events  
45 and loss situations (Bland, 2012), such as loss of significant others but also functional abilities and loss  
46 caused by disease.

47 Only a few studies of the associations between the experience of anxiety and depression and  
48 quality of life among older cognitively intact people in NHs have been published. In Spain, Rodriguez-  
49 Blazquez et al. (2012) found that depression, health status and the interaction of age and

50 institutionalization were related to well-being. In a study in the Netherlands among NH residents,  
51 Smalbrugge et al. (2006b) studied the impact of depression and anxiety on well-being and found that  
52 depression and/or anxiety were associated with significantly worse psychosocial well-being.

53 Another source of suffering may be social isolation, resulting from difficulty in maintaining  
54 social contact because of disabilities and loss of spouse and friends (Drageset, Kirkevold & Espehaug,  
55 2010). For some NH residents, it means that they no longer have anyone close in their social network.  
56 The experience of suffering may be a reaction to the lack of someone close (Morse, 2011).

57 Social support may alleviate the experience of suffering and, in turn, may affect mental and  
58 physical health. Social support involves qualitative aspects of human relationships, such as the content  
59 and the availability of relationships with significant others (Sarason, Sarason & Pierce, 1990). Social  
60 support is conceptualized in the literature from three dimensions (affect, affirmation and aid (Kahn,  
61 1979)) to five dimensions (emotional support, esteem support, material support, instrumental support  
62 and active support (Cobb, 1979; Cohen, Lynn & Gottlieb, 2000). Most authors include dimensions  
63 related to emotional support, confirmation support and practical support. Few relevant studies of social  
64 support and quality of life among mental intact NH residents have been conducted. In a quantitative  
65 study, Tseng & Wang (2001) found that social support from nursing aides and the frequency of  
66 interaction with family significantly predict the quality of life of NH residents. In a qualitative NH  
67 study in Norway, Bergland & Kirkevold (2005) found that residents reported positive peer  
68 relationships, and positive relationships with family were essential for thriving. A qualitative study in  
69 Canada (Welsh, Moore & Getzlaf, 2012) explored meaning in life for NH residents. Connectedness  
70 and engaging in “normal” activities emerged as enhancing meaning in life for the residents. A  
71 systematic qualitative review of NH life in relation to residents’ quality of life reported connectedness  
72 with others as being essential for residents’ quality of life (Bradshaw, Playford & Riazi, 2012).

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We have recently found that NH residents reported symptoms of anxiety and depression (Drageset, Eide & Ranhoff, 2013), and some dimensions of social support (attachment, nurturance and reassurance of worth) have been shown to be important for health-related quality of life (Drageset et al., 2009a). Based on our recent findings and the present literature review, one may question that cognitively intact NH residents who report symptoms of anxiety and depression and a lack of social contact are particularly prone to reduced health-related quality of life (HRQOL) and the increased experience of suffering.

Some studies have investigated the association between anxiety, depression, social support and HRQOL among cognitively intact NH residents, but we found no relevant studies about mixed-methods perspectives that examine this association and the phenomenon of suffering. Better care and treatment for older people with no cognitive impairment living in NHs requires focusing on well-being at a holistic level. This means including emotional well-being and the availability of meaningful social relationships. Meeting this challenge requires extending the perspectives beyond what one specific research approach can give.

## **Aim**

The aim of this study was to investigate suffering and mental health among cognitively intact NH residents more broadly by using a mixed-methods design. The specific research questions were as follows.

- How do older people living in NHs experience their life situation?
- What is the association between sociodemographic and illness variables and anxiety, depression and health-related quality of life for NH residents?
- How can the quantitative findings extend findings from qualitative analysis for NH residents?

96

## 97 **Methods**

### 98 *Design and population*

99 Since we wanted to explore different aspects of the same phenomena, we used a qualitative mixed-  
100 methods design with concurrently components: qualitative and quantitative (Morse & Niehaus, 2009).

101 The theoretical drive or the inductive direction of a research project guides the qualitative  
102 methodological core (Morse et al., 2006) and allows researchers to explore experiences qualitatively  
103 and to build a theoretical model of suffering during anxiety, depression and social support  
104 subdimensions and health-related quality of life. These methods differ from other approaches because  
105 the qualitative core component is guiding the study, which may stand alone, and the supplementary  
106 quantitative component is used to expand certain details of the findings to indicate the validity of the  
107 core findings.

108  
109 The qualitative core component in the study comprised a qualitative interview about life experiences  
110 related to pain, grief and loss and psychosocial topics from 18 respondents. The supplementary  
111 component in the study comprised the same 18 respondents, in which we interviewed the participants  
112 face to face using the SF-36 Health Survey subdimensions bodily pain, vitality, social functioning,  
113 role–emotional and mental health; the Hospital Anxiety and Depression Scale (HADS); and the Social  
114 Provisions Scale (SPS). The supplementary component (findings from the quantitative analysis)  
115 enabled us to explore significant relationships and may inform the qualitative findings.

116

117 This study used a simultaneous design (figure). Once we analyzed the qualitative core component and  
118 completed the supplementary components, we first described the findings on the core component. We

then integrated the final descriptions from the quantitative components, and these constitute a results narrative on which the discussion is based (Figure).

Please insert figure here

This study is part of a study conducted in 2004–2005 (Drageset et al., 2009b), with follow-up until 2011. At the end of follow-up, 19 NH residents were still alive, and 18 were included based on the inclusion criteria: aged 65 years and older, cognitively intact, capable of carrying out a conversation and residing in the NH for at least 6 months. Cognitively intact was defined as having a Clinical Dementia Rating (CDR)  $\leq 0.5$  (Hughes et al., 1982). CDR was developed as a staging instrument for dementia and is scored as no (0), questionable (0.5), mild (1), moderate (2) and severe (3) dementia, and the overall level of dementia is derived by using a standard algorithm (Morris, 1993). Trained nurses who had observed the residents for at least 4 weeks assessed CDR and were instructed to base their CDR scoring on mental functioning and not to include physical frailty. The CDR has shown high interrater reliability for physicians and other health professionals (McCulla et al., 1989). Exclusion criteria were: lived shorter than 6 months in an NH, CDR score  $>0.5$  and those who had their general health status assessed by a doctor or nurse, who indicated that the residents could not converse with the researcher. A primary care nurse invited them to participate.

### *Ethical approval*

The project involved a sample collected during 2009–2010. We obtained informed consent. The Western Norway Regional Committee for Medical and Health Research Ethics and the Norwegian Social Science Data Services approved the study (REK.Vest nr. 62.03/2009/1550).



143 Data collection

144 *Qualitative data*

145 We collected data through individual interviews. We developed a semistructured interview guide based  
146 on our previous research findings. We asked informants about mental health and physical health  
147 (including their experience of depression, anxiety, loss and pain). We performed interviews in the  
148 residents' room, and they lasted 45–90 minutes. The interviewer (first author) conducted conversations  
149 in which participants were encouraged to describe their experience regarding the questions in the  
150 interview guide. The respondents' answers to the questions also led to spontaneous follow-up questions  
151 from the interviewer. The 18 interviews were taped and transcribed verbatim. In all, this resulted in  
152 detailed descriptions.

154 *Quantitative data*

155 We obtained the quantitative data through face-to-face data collection. The 18 interviews took place in  
156 the respondent's room or at another appropriate location in the NH. The principal investigator (JD)  
157 performed the quantitative interviews: read the questions to the participants, circled the indicated  
158 answer and recorded the demographic information. This was necessary, since many of the residents  
159 have problems holding a pen and have reduced vision.

161 *Assessment instruments*

162 We collected sociodemographic variables such as age, sex, marital status, education level and  
163 comorbidity from patient records. We scored comorbidity using the Functional Comorbidity Index, a  
164 clinically based measure (Groll et al., 2005). This index includes 18 diagnoses scored "yes = 1" and  
165 "no = 0". A maximum score of 18 indicates the highest number of comorbid illnesses.

166 We measured health-related quality of life using the SF-36 (Ware & Sherbourne, 1992; Ware,  
167 2005). The SF-36 comprises 36 questions along eight dimensions: physical functioning (10 items),  
168 general health (five items), mental health (five items), bodily pain (two items), role limitation related to  
169 physical problems (four items), role limitation related to emotional problems (three items), social  
170 functioning (two items) and vitality (four items). An additional item, reported health transition, notes  
171 changes in general health during the past year. The response scores for each dimension are added, and  
172 the total is converted to a score on a scale from 0 (poor health) to 100 (optimal health) (Ware, 2005). In  
173 this study, we used the subdimensions bodily pain, vitality, social functioning, role-emotional and  
174 mental health. The SF-36 has been used in numerous studies in geriatrics and appears to be reliable:  
175 Cronbach's alpha: 0.68–0.94 (Lyons et al., 1994; Berlowitz et al., 1995; Pit et al., 1996). It has also  
176 demonstrated good construct validity (Lyons et al., 1994) and convergent validity (Andresen et al.,  
177 1999).

178 We used HADS (Zigmond & Snaith, 1983) to assess depression and anxiety symptoms. HADS  
179 is well validated (Bjelland et al., 2002). HADS has seven items for anxiety (HADS-A) and seven for  
180 depression (HADS-D). Each item is scored on a four-point scale from 0 (not present) to 3  
181 (considerable). The maximum score is 21 on each subscale, and a higher score indicates a higher  
182 symptom load (Zigmond & Snaith, 1983). A score of 8–10 indicates possible cases of anxiety or  
183 depression, and a score  $\geq 11$  indicates cases of anxiety or depression that require further investigation  
184 and possibly treatment (Zigmond & Snaith, 1983). HADS has been translated into Norwegian and has  
185 been found to be reliable and valid for older people (Stordal et al., 2001, 2003) and reliable and valid  
186 among NH residents (Haugan & Drageset, 2014).

187 We assessed social support using the revised SPS (Cutrona & Russell, 1987). The scale  
188 contains 24 items, four for each of the six social provisions worked out in detail by Weiss (1974).  
189 Russell et al. (1984) simplified the response format to a four-point rating scale: “strongly disagree”,

190 “disagree”, “agree” and “strongly agree”. According to Cutrona and Russell (1987), Andersson &  
191 Stevens (1993) and Mancini & Blieszner (1992), four of the original six subscales were selected:  
192 “attachment” (emotional closeness from which one derives a sense of security); “social integration”  
193 (relationships in which the person shares concerns and common interests); “opportunities for  
194 nurturance” (being responsible for the care of others); and “reassurance of worth” (a sense of  
195 competence and esteem). High scores indicate high social provision. The SPS, with four  
196 subdimensions “attachment”, “social integration”, “nurturance” and “reassurance of worth”, has been  
197 used in studies of older people living in the community (Andersson & Stevens, 1993; Bondevik &  
198 Skogstad, 1996; Saevareid et al., 2010) and among NH residents (Bondevik & Skogstad, 1998;  
199 Drageset, 2002; Drageset et al., 2009b).

200

## 201 **Data analysis**

### 202 *Qualitative data*

203 We analyzed the interview data by using elements of qualitative content analysis (Graneheim &  
204 Lundman, 2004; Kvale & Brinkmann, 2009). The analytical process occurred in six stages (see Table 3  
205 for details): 1) transcribing the interview; 2) open independent reading of all material to gain an overall  
206 impression of the text; 3) identifying meaning units; 4) categorization; 5) abstracting two subthemes  
207 and a theme (Table 3); and 6) reflection and discussion.

208

### 209 *Quantitative data*

210 Table 1 presents descriptive statistics for the demographic variables and the comorbidity variables. We  
211 applied nonparametric test statistics to test for distributional differences in SF-36 subscales among  
212 groups defined by sex (Mann-Whitney *U*-test) and marital status (Kruskal-Wallis test). We calculated  
213 Spearman correlation coefficients to study associations between comorbidity, age, anxiety, depression,

214 social support dimensions and SF-36 subdimensions: bodily pain, social functioning, role–emotional,  
215 vitality and mental health (Table 2).

216

217 [Please insert Tables 1–3 about here]

218

## 219 **Results**

### 220 Respondents' characteristics

221 Of the 19 NH residents, 18 (95%) met the inclusion criteria; 1 (5%) declined to participate.

222 Of the 18 respondents, 11 (62%) were women. The mean age was 84.8 years (SD 7.6). The mean  
223 number of comorbid illnesses was 1.9 (median 2.0, SD 1.3, range 0–5).

224

### 225 Qualitative data

226 During the interviews, the informants often strived to express their feelings verbally. Nevertheless, the  
227 qualitative data reveal many previous and current life experiences related to psychosocial aspects and  
228 suffering. Among these, the informants described several loss and traumatic experiences related to  
229 death (of parents, siblings, relatives and friends), war, starving and isolation. During the conversation,  
230 the individuals often return to stories from childhood and upbringing. According to the qualitative  
231 analysis, one main theme was suffering as a complex psychosocial entity and two subthemes “pain  
232 from experience in early life” and “painful experience in recent life” (Table 4).

233 [Please insert Table 4 about here]

234

235 Such early-life experiences are often related to loss by death, instability and lack of hope in  
236 their upbringing. Several descriptions reflect this, and representative quotations are presented here to  
237 give the participants a voice:

238                   • “I have a lifelong grief caused by traumatic experiences from the war.” (P)

239                   • “I feel grief caused by difficult experiences during my childhood.” (Q)

240                   • “Unstable upbringing and hopelessness have been painful.” (F)

241   The interviewees strongly emphasized earlier painful life experiences. Loss and grief seem to be  
242   especially attached to these.

243           Current life experiences are also related to loss by death, and lack of social relations, lack of  
244   courage to live and lack of hope are prominent. Many descriptions revealed resignation and  
245   hopelessness:

246                   • “I just sit here.” (O)

247                   • “I am in despair and lonely, but that’s life for us old people, and I cannot do anything  
248                   about it.” (F)

249                   • “I feel like a prisoner and several times I wish that I did not exist. I have had enough!”  
250                   “I live in a cemetery.” (Q)

251                   • “I am crying all day long.” (A)

252                   • “I lie in bed, feel totally isolated, and cannot take care of myself.” (F)

253                   • “Noise from other people all the time is quite stressful.” (D)

254   The qualitative data reveal clear patterns and similarities in the descriptions. In their present life  
255   situation, loneliness, despair and depressive thoughts are prominent, and they express several attempts  
256   to endure their situation.

257                   • “If you are unable to come into contact with others, you will feel the loneliness strongly  
258                   and you also feel invisible.” (P)

259   The current life experiences also contained several contradictory descriptions:

260                   • “[Life] is very sad, it is terrible, but I have nothing to complain about.” (J)

- "..., I just have to accept." (H)

The individual stories consistently described existence as a state the informants have to endure and adapt to. In this process, several expressed that good relationships (staff and relatives) and mobility are very important. The relationships with health care providers are especially important.

- "I do not always trust the health care workers, but they are okay." (F)

Or more explicitly stated: "We need health care workers who care for us."

## Quantitative data

In general, residents scored highest on role–emotional and social functioning and lowest on vitality (Table 2). Women reported lower, but not statistically significantly lower, scores than men on all subdimensions except for vitality and bodily pain.

The health-related quality of life subdimensions bodily pain ( $P = 0.02$ ), role–emotional ( $P = 0.02$ ) and mental health ( $P < 0.001$ ) were negatively associated with anxiety. Increasing depression scores were negatively associated with mental health ( $P = 0.007$ ). Attachment was positively associated with vitality ( $P = 0.02$ ) and social integration with social functioning ( $P = 0.02$ ). Nurturance was negatively associated with role–emotional ( $P = 0.04$ ).

Cronbach's alpha for the SF-36 subscales ranged from 0.60 to 0.85, with role–emotional showing the highest values and vitality the lowest.

## Results narrative

The results narrative summarizes the core component findings, with the supplementary component adding certain information to specific areas (Morse & Niehaus, 2009). Both data sets showed that suffering is prominent and that anxiety and depression predict worse mental health. Findings from both

284 the qualitative findings and quantitative data highlight social relationships as important for mental  
285 health and, conversely, lack of social relationships as a source of suffering. The qualitative data  
286 provided many descriptions of the life situation in an NH in which many difficult experiences  
287 throughout a long life are prominent. As such, the qualitative data provided detailed information about  
288 several psychosocial aspects and experienced suffering. Additional, the supplementary component,  
289 quantitative data, showed that emotional closeness and relationships with people who share concerns  
290 and interests is important.

291 The combined findings call for several improvements in care among the residents, which more  
292 accurately reflects their concerns aimed at alleviating suffering.

## 294 Discussion

295 This study among cognitively intact NH residents showed that the individual stories reveal that  
296 psychosocial aspects and the phenomenon of suffering are related to painful experiences during life.  
297 The quantitative data showed that symptoms of both anxiety and depression were related to mental  
298 health. The association between anxiety and depression and mental health may suggest that more  
299 symptoms of both anxiety and depression contribute to worse mental health. Other studies among NH  
300 residents (Smalbrugge et al., 2005b, 2006b; Rodriguez-Blazquez et al., 2012) reported associations  
301 between the presence of depression and/or anxiety symptoms and worse well-being. One explanation  
302 for our results could be that most of our respondents were widows or widowers, have multiple  
303 diagnoses and were dependent in the activities of daily living. All these circumstances may be  
304 experienced as losses, contribute to symptoms of depression (Bland, 2012) and influence mental health  
305 (Ferrell & Coyle, 2008) and the experience of suffering (Kuuppelomaki & Lauri, 1998; Ferrell &  
306 Coyle, 2008; Morse, 2011). The informants also clearly expressed the experience of suffering by telling

307 stories containing both earlier and current life events. Morse (2011) emphasizes the significance of  
308 assisting the residents in moving from endurance to emotional release when coping with suffering.  
309 Interpersonal encounters seem to play an important role here to help the person who is suffering in this  
310 process (Yalom, 2005), and nurses must maintain a culture that includes such basic elements of  
311 nursing.

312 Symptoms of anxiety were related to the bodily pain subdimension of the health-related quality  
313 of life. This dimension of the SF-36 measures the intensity of bodily pain and the extent to which  
314 bodily pain interferes with normal activities (Ware, 2005). Among older NH residents, Smalbrugge et  
315 al. (2006b) found associations between anxiety and well-being. But in contrast to our study, the  
316 diagnosis of anxiety was reported and the study did not explicit focus on pain. Pain is a source of  
317 suffering (Cassel, 2004; Ferrell & Coyle, 2008) and a primary source of physical suffering  
318 (Kuuppelomaki & Lauri, 1998).

319 Our study indicated that higher levels of attachment and social integration are associated with  
320 higher levels of vitality and social functioning, or conversely, a lower level of attachment and social  
321 integration corresponds to lower levels of vitality and social functioning.

322 The positive relationship between attachment and vitality suggests that the emotional content of  
323 the relationship with significant others is an important component of vitality. In addition, the stories  
324 from the residents underline the importance of social relationships and mobility as important aspects of  
325 this. Our extended findings are in accordance with other studies that report positive associations  
326 between social support and well-being (Tseng & Wang, 2001; Bergland & Kirkevold, 2005; Drageset  
327 et al., 2009b; Rodriguez-Blazquez et al., 2012). Weiss (1973, 1974) emphasizes that significant others  
328 are spouses and very close friends who provide the feeling of intimacy, security and peace, and a lack  
329 of significant others contributes to experiencing negative feeling as emotional loneliness. Because of  
330 the respondents' advanced age, disability and dependence, they are more likely to have difficulty in



331 maintaining close social contact. Social and emotional support seems to be important in combating  
332 depression in the general population (Grav et al., 2012) and loneliness among NH residents (Drageset,  
333 Kirkevold & Espehaug, 2010).

334 The relationship between opportunity for nurturance and emotional role limitations (whether  
335 emotional problems interfered with such social activities as visiting friends and relatives) suggests that  
336 providing more support for others would contribute to increasing role limitations. Weiss (1974)  
337 emphasizes that nurturance differs from the other provisions by enquiring whether older people  
338 themselves provide support. Responsibility for someone, usually children, gives meaning to an  
339 individual's life in meeting obligations in various activities. One explanation for our results could be  
340 loss of the ability to give the necessary support: the relationship does not make sense to the extent that  
341 one wishes.

342 The individuals detailed many stories that reveal existential experiences related to suffering.  
343 These findings clearly give nuances in a holistically way and with information from the results from  
344 the quantitative supplementary component the researcher is able to build synthesis of the qualitative  
345 findings to the quantitative results which is necessary to draw conclusion. This could also clarify  
346 clinical significance and contribute to more clinically meaningful approaches. Such extended findings  
347 represent a valuable contribution in planning individual care.

#### 349 *Methodological considerations*

350 There are quantitative studies examining anxiety and depression, social support and the quality of life,  
351 but this type of study has limitations. Suffering is a life phenomenon that provides deeper  
352 understanding and different types of knowledge. Integrating quantitative and qualitative results using  
353 mixed methods could therefore provide more meaningful findings than one method alone (Tashakkori  
354 & Creswell, 2007).

Because we used a cross-sectional study design, we cannot firmly conclude on the direction of a possible causal effect or preclude that these associations are effects of other unmeasured determinants. However, the supplementary component can explain and contribute to deeper knowledge about psychosocial aspects and well-being so that this relationship appears more clearly. Further, because the study followed a cohort ( $n = 227$ , 30 NHs) of frail cognitively intact NH residents from 2004–2005 to 2011, the sample size was small at the end of follow-up. Despite small sample size and low statistical power, we found meaningful statistical associations that inform the qualitative findings.

As discussed, the research problem is multifaceted and complex. The integrated research strategy offered by a mixed-methods design therefore enabled us to clarify different aspects of the phenomena (Richards & Morse, 2007). This tradition maintains that one method alone will not comprehensively answer our research questions. As such, both qualitative and quantitative methods are used to collect and analyze the data (Morse & Niehaus, 2009). Here, the core component is qualitative data. The supplementary component (the quantitative results) informed and supported the core component (the qualitative data), as described by Morse et al. (2006). In this way, the mixed-methods design validated our findings while conforming to the rules inherent in each paradigm.

Two of the authors have skills primarily in the quantitative core method, and two authors were primarily qualitative researchers. In addition, a statistician was responsible for the quantitative data analysis. In that way, the researchers represented the different and overlapping research fields necessary for using a mixed-methods design. In terms of validity, we believe that our different platforms and expertise represented a critical contribution in the continuous discussion about possible interpretations during the whole research process.

## **Conclusion and clinical implications**

378 The individual stories reveal that psychosocial aspects and the phenomenon of suffering are related to  
379 painful experiences during life. Symptoms of anxiety and depression were positively associated with  
380 mental health, and symptoms of anxiety were associated with bodily pain. Attachment and social  
381 integration were associated with vitality and social functioning. As demonstrated, the supplementary  
382 component informed and supported the core component and contributes to extending knowledge about  
383 the study topic. To improve the situation of residents, more attention should be paid to the residents'  
384 suffering related to anxiety, depression and relationships. Here, the challenge for health care providers  
385 is to grasp the individual experience and their inner meaning in the specific situation.

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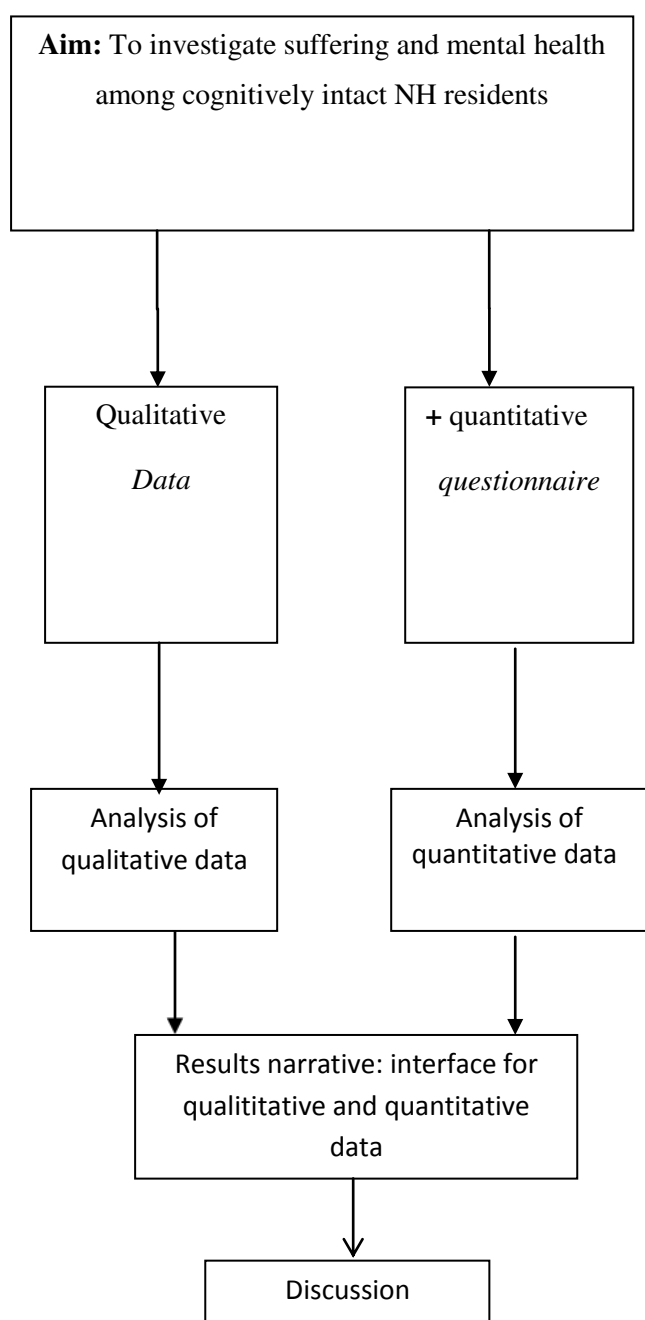
## Figure 1(on next page)

### Schematic overview

The left pathway illustrates the core component of the project (qualitative data). The right pathway illustrates the supplemental components of the project (qualitative data). The point of interface is the position at which the core and supplemental components meet. The “results narrative” refers to the write-up of the core-component findings with the addition of the results of the supplemental components.



Figure 1





## **Table 1**(on next page)

Characteristics of the respondents

Functional Comorbidity Index includes 18 diagnoses scored "yes = 1" and "no = 0". A maximum score of 18 indicates the highest number of comorbid illnesses

**Table 1.**

|   | <i>n</i> | %    |
|---|----------|------|
|   | 18       | 100  |
| <b>Sex</b>                                |          |      |
| Male                                      | 7        | 38.9 |
| Female                                    | 11       | 61.1 |
| <b>Age (years)</b>                        |          |      |
| 65–74                                     | 3        | 16.7 |
| 75–84                                     | 7        | 38.9 |
| 85–94                                     | 8        | 44.4 |
| ≥95                                       | 0        | 0    |
| <b>Marital status</b>                     |          |      |
| Widowed                                   | 11       | 61.1 |
| Married or cohabiting                     | 4        | 22.2 |
| Unmarried                                 | 3        | 16.7 |
| <b>Education</b>                          |          |      |
| Lowest: primary school                    | 8        | 44.4 |
| Middle: <3 years after<br>primary school  | 4        | 33.3 |
| Highest: ≥3 years after<br>primary school | 4        | 22.2 |
| <b>Illnesses<sup>1</sup></b>              |          |      |
| Yes                                       | 17       | 94.1 |
| No  | 1        | 5.9  |

## Table 2 (on next page)

[p] Means and Standard deviation (SD) for each of five subscales of SF-36 according to sociodemographic and comorbid illnesses, and correlation coefficient for anxiety, depression and social support dimensions (  $n = 18$  ) [

Table 2.

|   | Bodily pain    | Vitality       | Social functioning | Role limitations, emotional | Mental health      |
|---|----------------|----------------|--------------------|-----------------------------|--------------------|
| <b>All</b>                              | 64.1 (27.4)    | 43.9 (12.7)    | 81.2 (17.3)        | 72.2 (36.6)                 | 68.4(13.1)         |
| <b>Sex <sup>a</sup></b>                 |                |                |                    |                             |                    |
| Women                                   | 61.7 (28.2)    | 46.8 (11.9)    | 78.4(17.8)         | 66.7(42.2))                 | 66.2 (13-2)        |
| Men                                     | 61.7(28.2)     | 40.0 (13.4)    | 85.7 (16.8)        | 80.9 (26.2)                 | 72.0 (13.1)        |
| <b>P*</b>                               | 0.791          | 0.211          | 0.425              | 0.659                       | 0.425              |
| <b>Age (years) <sup>b</sup></b>         | -0.14          | 0.125          | 0.10               | 0.08                        | 0.04               |
| <b>P*</b>                               | (0.572)        | (0.684)        | (0.684)            | (0.745)                     | (0.883)            |
| <b>Marital status <sup>c</sup></b>      |                |                |                    |                             |                    |
| Widowed                                 | 69.5 (29.4)    | 45.0 (13.6)    | 83.0 (16.7)        | 69.7 (40.7)                 | 68.0 (13.6)        |
| Married                                 | 61.2 (31.1)    | 47.5 (8.7)     | 81.2 (21.7)        | 75.0 (38.5)                 | 70.0 (16.5)        |
| Unmarried                               | 48.3 (6.4)     | 35.0 (13.2)    | 75.0 (21.7)        | 77.8 (38.5)                 | 68.0 (10.6)        |
| <b>P*</b>                               | 0.71           | 0.41           | 0.83               | 0.94                        | 0.93               |
| <b>Anxiety<sup>b</sup></b>              | -0.56          | -0.23          | -0.34              | -0.58                       | -0.86              |
| <b>P*</b>                               | <b>(0.018)</b> | (0.385)        | (0.178)            | <b>(0.016)</b>              | <b>(&lt;0.001)</b> |
| <b>Depression<sup>b</sup></b>           | -0.05          | -0.23          | -0.26              | -0.16                       | -0.62              |
| <b>P*</b>                               | (0.845)        | (0.157)        | (0.309)            | (0.535)                     | <b>(0.007)</b>     |
| <b>Attachment<sup>b</sup></b>           | -0.145         | 0.562          | 0.257              | -0.111                      | 0.214              |
| <b>P*</b>                               | (0.566)        | <b>(0.015)</b> | (0.304)            | (0.661)                     | (0.395)            |
| <b>Social integration<sup>b</sup></b>   | 0.391          | 0.014          | 0.536              | -0.108                      | -0.146             |
| <b>P*</b>                               | (0.109)        | (0.957)        | <b>(0.022)</b>     | (0.670)                     | (0.564)            |
| <b>Reassurance of worth<sup>b</sup></b> | -0.407         | 0.334          | 0.258              | -0.243                      | 0.005              |
| <b>P*</b>                               | (0.094)        | (0.175)        | (0.301)            | (0.331)                     | (0.983)            |
| <b>Nurturance<sup>b</sup></b>           | 0.430          | 0.035          | 0.030              | -0.486                      | -0.125             |
| <b>P*</b>                               | (0.075)        | (0.889)        | (0.907)            | <b>(0.041)</b>              | (0.622)            |
| <b>Grolls index <sup>b, d</sup></b>     | -0.412         | -0.48          | -0.15              | -0.40                       | -0.44              |
| <b>P*</b>                               | (0.101)        | (0.050)        | (0.555)            | (0.108)                     | (0.078)            |

<sup>a</sup> = Mann-Whitney U test; <sup>b</sup> = Spearman correlation coefficient; <sup>c</sup> = Kruskal-Wallis test

<sup>d</sup> Functional Comorbidity Index. A maximum score of 18 indicates the highest number of comorbid illnesses

\*bold = statistical significance at 0.05

## Table 3 (on next page)

Stages of the qualitative analytical process.

2 **Table 3.**

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|                              |   |
|------------------------------|---|
| 1. Transcription             | Data were transcribed and organized according to the interview guide  |
| 2. Open reading              | Two co-authors carefully and independently read and discussed the interview text to obtain an overall impression of the participants' experiences |
| 3. Identifying meaning units | Patterns in the data were identified by dividing the text into meaning units  |
| 4. Categories                | Important nuances were discovered by searching for common and distinctive features as well as variation and agreement about suitable categories   |
| 5. Forming themes            | Two subthemes were formulated<br>Thereafter, analytical reflection and abstraction were performed by searching for an overall theme               |
| 6. Reflection and discussion | Dialogue was searched for relevant theory to illuminate and deepen understanding of the findings  |

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## **Table 4**(on next page)

The qualitative content analysis.

2 **Table 4.**

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| Categories                      | Subtheme                            | Theme                                      |
|---------------------------------|-------------------------------------|--|
| <b>Earlier life experiences</b> | Painful experiences in earlier life | Suffering as a complex psychosocial entity |
| Loss by death                   |                                     |  |
| Instability                     |                                     |  |
| Lack of hope                    |                                     |  |
| Mental strain                   |                                     |  |
| Traumatic events                |                                     |  |
| <b>Present life experiences</b> | Painful experiences in recent life  |  |
| Loss by death                   |                                     |  |
| Loss of health                  |                                     |  |
| Lack of social relationships    |                                     |  |
| Lack of courage to live         |                                     |  |
| Lack of hope                    |                                     |  |

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