

# Health-related quality of life among cognitively intact nursing home residents with and without cancer – a 6-year longitudinal study

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**Background:** Limited information exists regarding the natural development of health-related quality of life (HRQOL) and its determinants among mentally intact nursing home (NH) residents. We aimed to examine HRQOL over time during a 6-year period among residents of NHs, who are not cognitively impaired, and to examine whether sense of coherence and a diagnosis of cancer influence HRQOL.

**Methods:** The study was prospective and included baseline assessment and 6-year follow-up. After baseline assessment of 227 cognitively intact NH residents (Clinical Dementia Rating score  $\leq 0.5$ ), we interviewed 52 living respondents a second time at the 5-year follow-up and 18 respondents a third time at the 6-year follow-up. We recorded data from the interviews using the Short Form-36 (SF-36) Health Survey and the Sense of Coherence Scale. To study different developments over time for residents without and with cancer, we tested interactions between cancer and time.

**Results:** The subscores of physical functioning and role limitation–physical domains declined with time ( $P < 0.001$  and  $P = 0.02$ , respectively). Having a diagnosis of cancer at baseline was negatively correlated with general health ( $P = 0.002$ ). Sense of coherence at baseline was positively correlated with all the SF-36 subscores from baseline to follow-up ( $P < 0.001$ ).

**Conclusion:** The study indicates that the HRQOL changed over time during the 6 years of follow-up, and the sense of coherence appeared to be an important component of the HRQOL. Finally, our results showed that having a diagnosis of cancer was associated with decline in the general health subdimension.

**Keywords:** health-related quality of life, nursing home, cancer, follow-up, sense of coherence

## Introduction

Life expectancy is increasing worldwide.<sup>1</sup> The expanding number of older adults is resulting in increased pressure on health care services and long-term care provision, resulting in considerable fiscal burden to governments around the world. In Norway, 70% of people older than 80 years reside in full-time care institutions.<sup>2</sup> This is comparable with figures reported in the US<sup>3</sup> and across the European Union.<sup>4</sup> The move to a nursing home (NH) is usually triggered by increasing frailty, loss of independence, and poor health, and residents often need assistance in completing daily tasks and personal care.<sup>5</sup> This change of situation and loss of autonomy resulting from aging can strongly influence well-being and mental health, and this is often overlooked among residents who are otherwise cognitively healthy. Health-related quality of life (HRQOL) is, therefore, a major issue among NH residents. A key additional factor

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in the HRQOL among NH residents is chronic illness and comorbidity.<sup>6,7</sup> Cancer is common, affecting up to 26% of people on admission.<sup>8,9</sup> It is associated with several key symptoms, including pain, nausea, dyspnea, and fatigue, all of which influence HRQOL.<sup>9-13</sup>

Several studies have examined HRQOL across populations,<sup>14-18</sup> with a general consensus across the studies that HRQOL gradually declines with age, as measured by the validated Short Form-36 (SF-36) Health Survey, with the steepest decline among people older than 80 years.<sup>16</sup> This evidence includes one large longitudinal study of 6539 women and 2884 men from a general population of nine cities and surrounding rural areas in Canada over a 5-year period (1996/1997–2001/2002) that reported a clear age-related decline in HRQOL, especially related to physical decline. Age-related decline in HRQOL is also reported among NH residents.<sup>19-21</sup> Our previously published work has described the impact of cancer on HRQOL among NH residents, reporting lower HRQOL and a higher rate of hospital admissions among cognitively intact NH residents with a diagnosis of cancer compared with people without cancer.<sup>7,8</sup>

One previously unexplored potential factor in HRQOL in care homes is coping, as a sense of coherence. The construct of sense of coherence is based on Antonovsky's<sup>22</sup> theory of salutogenesis, in which stress in the sense of tension and appropriate load is viewed as potentially promoting health. The assumption is that a strong sense of coherence is associated with the resources to cope with stressful life events or situations. Sense of coherence contains three components: comprehensibility, manageability, and meaningfulness. Further, sense of coherence indicates individuals' general resistance resources and their ability to use them. General resistance resources represent integral, biological, material, and psychosocial resources supporting individuals in perceiving their lives as consistent, structured, and understandable. Coping has been shown to be an important resource in relation to HRQOL among older people living in the community, in hospital settings,<sup>23-25</sup> and NHs.<sup>26</sup> Further, sense of coherence has been shown to be important in relation to health<sup>27-29</sup> and hospitalization for older people.<sup>30</sup> The relationship between sense of coherence and cancer among NH residents has not yet been explored. NHs emphasize mental and physical well-being for the residents as an internationally recognized goal,<sup>31</sup> and this is considered an important indicator of health outcome.<sup>32</sup> For the treatment of individual people in cancer care, prolonging survival and maintaining or improving HRQOL are highlighted as two important goals.<sup>33</sup> In this context, studying HRQOL over time in relation to sense of

coherence may provide important information regarding the most appropriate treatment and care approaches for people with cancer. This study, therefore, sought to examine HRQOL among cognitively intact adults living in NH and to establish whether sense of coherence and having a diagnosis of cancer influence HRQOL for these individuals.

## Methods

### Design and setting

This was a prospective study carried out in 30 NHs in Norway that was conducted as part of an ongoing HRQOL study among 227 cognitively intact NH residents: 60 with a diagnosis of cancer and 167 without. We invited all NHs in this cohort that offered long-term residential care to participate. We contacted the managers of the NHs included at baseline 5 and 6 years later for follow-up data collection. The principal investigator (JD) who also performed all interviews directly contacted all managers at the NHs and the respondents. No resident was contacted without previous written informed consent from the resident and the management. The Norwegian Social Science Data Services and the Western Norway Regional Committee for Medical and Health Research Ethics approved the study (REK.Vest nr. 162.03/2009/1550).

### Participants

We recruited residents with no cognitive impairment in 2009 and followed up after 5 and 6 years. All residents were living in the same NH at follow-up as at baseline. The inclusion criteria at baseline (and both follow-ups) were as follows: age 65 years and older, cognitively intact, capable of carrying out a conversation, as assessed by a physician, and residing in the NH for at least 6 months. Cognitively intact was defined as having a Clinical Dementia Rating (CDR) of  $\leq 0.5$ <sup>34</sup> as assessed by trained nurses who had observed participants for 4 weeks before baseline. The CDR is a widely used clinical measure for dementia comprising a global score derived from six domains of cognitive and functional performance: memory, orientation, judgment and problem-solving, community affairs, home and hobbies and personal care.<sup>35</sup> We also applied the CDR before follow-up. The same principal investigator (JD) who had performed the baseline interviews ( $n = 227$ ) carried out the follow-up interviews. We obtained written informed consent from all participants.

## Outcome measures

### Demographic and medical information

We assessed sociodemographic and clinical data such as age, sex, and comorbidity from the residents' medical

records. We assessed comorbidity (not cancer) using the Functional Comorbidity Index (FCI), a clinically based index<sup>36</sup> that includes the sum of 18 diagnoses (not cancer), scored 1 for “yes” and 0 for “no” as recommended by Groll et al.<sup>36</sup> The maximum score (18) indicates the maximum number of comorbid illnesses among NH residents.<sup>36</sup> The FCI does not include cancer diagnoses, so we obtained these separately. The residents with cancer had cancer at baseline. All cancer diagnoses were included, including skin cancer (basal cell carcinoma). We obtained the cancer diagnoses from medical records and included active cancer and previously treated cancer. Cancer diagnoses may have changed over time, but in this study, we wanted to analyze the relationship between cancer and HRQOL 5 and 6 years after the initial interview.

## HRQOL

We measured HRQOL at baseline and after 5 and 6 years using the SF-36 Health Survey,<sup>37</sup> which has been used extensively in observational studies and clinical trials among individuals with a wide range of illnesses, ages, and other characteristics.<sup>38,39</sup> It has demonstrated high reliability (Cronbach’s alpha: 0.72–0.94),<sup>40,41</sup> good construct validity,<sup>40</sup> and convergent validity.<sup>42</sup> The SF-36 comprises 36 questions (items) along eight dimensions: physical functioning (10 items), general health (five items), mental health (five items), bodily pain (two items), role limitation related to physical problems (four items), role limitation related to emotional problems (three items), social functioning (two items), and vitality (four items). An additional item, reported health transition, notes changes in general health over the past year. The response scores for each dimension are added, and the total is converted to a score between 0 and 100 (highest).<sup>37,43</sup> A higher score indicates a higher HRQOL.

## Sense of coherence

We used the short-form version of Sense of Coherence Scale (SOC-13, 13 items) at baseline to estimate the sense of coherence.

The SOC-13 has shown good acceptability among older people,<sup>44</sup> has been used in several NH studies,<sup>26,45</sup> and has shown high internal consistency in a review of 127 studies (Cronbach’s alpha ranges from 0.70 to 0.92<sup>44</sup>). The SOC-13 is a seven-point rating scale with two anchor responses: “never” and “very often”. The items measured were comprehensibility (believe that the challenge is understood) (five items), manageability (believe that resources to cope are available) (four items), and meaningfulness (be motivated to cope) (four

items). The score ranges from 13 to 91, and higher score indicates a stronger SOC.<sup>22</sup>

## Statistical analysis

We presented descriptive statistics as mean, range, and standard deviation (SD). To analyze HRQOL, we used a mixed linear model to regress each of the eight subscores on time for interview, age, sex, diagnosis of cancer, FCI, and sense of coherence. To study various developments over time for people with and without cancer, we tested the interactions between cancer and time. We similarly did this for time and sex and for sense of coherence and time. The mixed linear model accounts for correlations between the repeated measurements within each resident, assuming a compound symmetry correlation.

## Results

### Cohort demographics

Of the 227 residents, 174 had died before the 5-year follow-up. Thus, 53 residents remained at 5 years, and 19 were alive after 6 years. Of these, 1 resident declined to participate and 52 completed follow-up assessment at 5 years; after 6 years, 1 resident declined to participate and 18 completed the follow-up. The mean age was 80 years (range 65–102), with 72% being women. Of the 18 respondents at follow-up, 11 (62%) were women and the mean age was 84.8 years (SD: 7.6 years). The mean number of comorbid illnesses at baseline was 1.9 (median: 2.0, SD: 1.3, range: 0–5). The most common cancer diagnoses at baseline were breast cancer among women (20%) and prostate cancer among men (12%). Among both men and women, colorectal cancer was the second most common cancer that was diagnosed (18%). The overall survival after 5 years was 17% for residents with cancer and 22% for residents without cancer.<sup>46</sup>

### Correlates of HRQOL

The subscores for physical functioning and physical role limitation were both negatively correlated with time ( $P < 0.001$  and  $P = 0.02$ , respectively) and physical functioning showed a linear trend. The other subscales, except general health and social functioning, were negatively correlated. None of the other subscales was significant. Having a diagnosis of cancer was negatively correlated with general health ( $P = 0.002$ ). Sense of coherence was positively correlated with all the SF-36 subscales from baseline to follow-up in all subscores ( $P < 0.001$ ). Cancer and time did not interact, nor did sex and time. The interaction between sense of coherence and time was not significant ( $P = 0.06$ ). Compared with baseline,

people with cancer reported more pain after 6 years. Table 1 presents all regression analysis outputs.

## Discussion

The aim of this study was to investigate whether HRQOL among cognitively intact NH residents changed over time during a 6-year follow-up period and whether sense of coherence and having a diagnosis of cancer influenced HRQOL among these individuals. Our longitudinal cohort study showed a change in HRQOL over time. This was observed for all subdimensions of the SF-36 after adjusting for age, sex, diagnosis of cancer, FCI, and sense of coherence. Of these, the physical functioning and role limitation–physical domains reached statistical significance.

These findings emphasize the specific impact on physical functioning over time and align closely with previously published work. This includes two separate studies<sup>14</sup> among 65 community-dwelling older men and women and the general population, respectively, both of which reported a decline in physical health sum scores over 5 years.<sup>16</sup> These findings were expected, since many studies<sup>11,12,47,48</sup> report decline in physical functioning with increased age and that it is part of the aging process.<sup>48,49</sup> This is particularly the case for NH residents, who frequently have multiple morbidities that, in turn, may affect physical functioning.<sup>48</sup> Chronic conditions greatly influence the activities of daily living and dependence,<sup>48</sup> which are critical factors driving major outcomes, including mortality.<sup>32,50,51</sup> Of note, the findings of this study are in contrast to those published by Rønning and Stavem,<sup>17</sup> in which HRQOL was reported to rise in the 6 months following an acute stroke. However, people experiencing acute stroke have a markedly different prognostic trajectory compared with people with cancer and other frail adults and often show improvement in overall functioning following the initial stroke event. This probably contributes to this differential finding.

A diagnosis of cancer was significantly negatively correlated with general health. This also correlates with previous work reporting poorer general health among older people with cancer compared with their healthy counterparts, both in the community and in NH.<sup>8,11,52</sup> Poorer general health is closely associated with older age, presence of other chronic conditions, and types of cancer.<sup>11,53</sup> The poorer health among NH residents with cancer in this study is also probably related to the decline in physical functioning, which has also previously been reported among older people in general<sup>54</sup> and among people with cancer.<sup>54,55</sup> Although the finding was not statistically significant, people with cancer reported more pain after 6 years compared with baseline in this study. NH

residents with cancer often report pain,<sup>56,57</sup> and untreated pain is probably an important factor for the decline in general health subdimensions.

With regard to the sense of coherence, this study demonstrated a positive correlation with all the SF-36 subdimensions after adjusting for age, sex, diagnosis of cancer, and FCI. These findings are in accordance with Antonovsky's view and with recent findings about the relationship between people's sense of coherence and quality of life.<sup>58</sup> In light of this, the findings could suggest that a higher HRQOL is directly related to residents' ability to mobilize available resources to deal with challenges in everyday life and to experience meaning by doing this.

The stronger the sense of coherence, the better the quality of life.<sup>58</sup> Thus, these findings indicate that strengthening the sense of coherence among NH residents could be a valuable means of improving well-being. The work also highlights the potential value of monitoring residents' sense of coherence and investigating means of improving it as a route to improving HRQOL. There are several potential approaches to achieve this, such as identifying residents' previous strengths and the resources they can use within their current physical limitations. These approaches would require clear training for NH personnel to enable them to build on this and provide understandable information on health care, inform the residents about the resources available, and assist the residents in using them. Interventions and strategies to strengthen sense of coherence could be important. This will be an interesting area to pursue for future research. For example, Langeland et al<sup>59</sup> have shown that therapy groups based on salutogenic treatment principles improve coping among people with mental health problems, and the manageability component contributed most to this improvement.

## Strengths and limitations

This study has provided robust, high-quality data by using in-depth data collected on HRQOL and sense of coherence that have allowed clear conclusions to be drawn. Importantly, very few data were missing from the HRQOL and SOC-13 at baseline and at follow-up. Additional strengths of the study include the high response rate of surviving participants and that the care personnel in the NH were not directly involved in the interviews performed by the principal investigator (JD). However, there are limitations. The sample size is fairly small, and surviving participants may not be representative of the wider NH population. The small number of residents alive after 6 years could also have been the fittest residents

**Table 1** Mixed linear regression analysis for HRQOL among 227 cognitively intact nursing home residents in Bergen, Norway, in 2004–2006 at baseline, 5, and 6 years of follow-up

Predictors	Physical functioning		Role limitations, physical		Bodily pain		General health perceptions		Vitality		Social functioning		Role limitations, emotional		Mental health	
	b (95% CI)	P-value	b (95% CI)	P-value	b (95% CI)	P-value	b (95% CI)	P-value	b (95% CI)	P-value	b (95% CI)	P-value	b (95% CI)	P-value	b (95% CI)	P-value
Intercept	-1.63 (-31.1, -1.5)		-6.6 (-38.9, 27.7)		45.5 (16.7, 66.3)		4.1 (-10.6, 18.7)		1.5 (-13.2, 16.3)		10.7 (-10.2, 31.6)		-1.0 (-39.9, 17.9)		6.5 (-5.9, 18.8)	
Sex																
Men	0.0 (reference)		0.0 (reference)		0.0 (reference)		0.0 (reference)		0.0 (reference)		0.0 (reference)		0.0 (reference)		0.0 (reference)	
Women	-3.1 (-8.5, 2.4)		-0.3 (-20.9, 1.7)		-10.4 (-19.2, 1.7)		-2.2 (-5.2, 4.8)		1.4 (-3.7, 6.5)		3.1 (-4.2, 10.5)		1.2 (-9.0, 11.5)		0.0 (-4.1, 4.2)	
P-value	NS		NS		0.020		NS		NS		NS		NS		NS	
Age (years)																
65–74	0.0 (reference)		0.0 (reference)		0.0 (reference)		0.0 (reference)		0.0 (reference)		0.0 (reference)		0.0 (reference)		0.0 (reference)	
75–84	10.3 (1.8, 18.9)		-5.8 (-21.9, 10.4)		-7.7 (-21.2, 5.9)		2.3 (-5.2, 9.7)		-10.0 (-17.8, -2.1)		1.6 (-9.7, 12.8)		-1.0 (-15.9, 17.0)		-6.7 (-12.8, 0.5)	
85–94	4.0 (-4.4, 12.5)		-5.5 (-26.6, 10.7)		-2.3 (-16.6, 11.1)		2.1 (-5.3, 9.5)		-12.6 (-20.3, -5.0)		4.6 (-6.5, 15.8)		-0.5 (-16.4, 15.3)		-4.3 (-10.5, 1.9)	
≥95	7.7 (-3.0, 18.3)		-2.7 (-23.9, 25.8)		-3.0 (-20.0, 14.0)		6.6 (-3.0, 16.2)		-14.7 (-24.6, -4.7)		-1.2 (-15.4, 13.0)		1.6 (-18.4, 26.6)		-3.4 (-11.4, 4.6)	
P-value	0.040		NS		NS		NS		0.011		NS		NS		NS	
Time																
Baseline (n = 227)	0.0 (reference)		0.0 (reference)		0.0 (reference)		0.0 (reference)		0.0 (reference)		0.0 (reference)		0.0 (reference)		0.0 (reference)	
5 years (n = 52)	-9.5 (-14.1, -4.8)		-17.6 (-31.0, -8.4)		-0.4 (-9.2, 8.4)		1.0 (-4.8, 6.9)		1.0 (-4.6, 6.5)		-1.7 (-9.2, 5.9)		-5.5 (-15.4, 4.3)		0.5 (-4.5, 4.2)	
6 years (n = 18)	-15.6 (-22.5, -8.7)		-11.6 (-31.5, -4.7)		-6.5 (-19.9, 6.8)		9.9 (1.0, 18.8)		-2.9 (-11.3, 5.5)		7.2 (-4.2, 5.8)		-3.9 (-18.8, 21.6)		-3.4 (-11.0, 11.7)	
P-value	<0.001		0.023		NS		0.091		0.694		NS		NS		0.051	
Cancer																
No cancer	0.0 (reference)		0.0 (reference)		0.0 (reference)		0.0 (reference)		0.0 (reference)		0.0 (reference)		0.0 (reference)		0.0 (reference)	
Cancer	-3.7 (-9.1, 1.7)		-4.9 (-14.8, 6.9)		-7.7 (-16.4, 0.9)		-7.9 (-12.9, -3.0)		-4.6 (-9.7, 0.5)		-3.8 (-11.0, 3.4)		-0.3 (-9.8, 10.5)		-1.1 (-5.3, 3.0)	
P-value	NS		NS		0.080		0.002		0.076		NS		NS		NS	
Groll's index	-7.0 (0.28, 0.64)		0.8 (4.5, 2.9)		-2.6 (-5.4, 0.1)		0.0 (-1.6, 1.7)		1.0 (-0.7, 2.7)		1.5 (-0.8, 3.8)		-2.4 (-5.6, 0.75)		0.1 (-1.5, 1.3)	
P-value	NS		NS		0.062		NS		NS		NS		NS		NS	
SOC	0.5 (0.3, 0.6)		1.2 (0.8, 1.5)		0.7 (0.4, 1.0)		0.7 (0.6, 0.9)		0.7 (0.5, 0.9)		0.8 (0.6, 3.5)		1.2 (0.9, 1.6)		1.0 (-1.5, 1.1)	
P-value	<0.001		<0.001		<0.001		<0.001		<0.001		<0.001		<0.001		<0.001	

**Note:** Interactions between cancer and time and between sex, Groll's index (0–18), and cancer were tested, but none were found to be statistically significant.

**Abbreviations:** NS, not significant; b, regression coefficient; HRQOL, health-related quality of life; CI, confidence interval; SOC, sense of coherence (0–90).



from the beginning and may have overcome their diagnosis of cancer or been in remission.

Further, information could not be gathered about the time since cancer was diagnosed and about whether the residents were diagnosed after being admitted to an NH. These factors may influence HRQOL.<sup>11</sup> Thus, further research is needed to substantiate these findings.

## Conclusion

This study indicates that the HRQOL changes over time in NH residents and indicates that sense of coherence is an important component of the change in the HRQOL. Finally, this study has shown that having a diagnosis of cancer is clearly associated with a decline in general health. Follow-up studies with a larger sample size in the same age groups are needed to study this relationship more carefully.

## Disclosure

The authors report no conflicts of interest in this work.

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