

Quality of life among frail older persons (65+ years) in nursing homes: A cross-sectional study

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Abstract

Aim: To assess the quality of life in frail older persons (65+ years) living in nursing homes and to examine differences between quality of life perceptions among different gender and age groups.

Design: Cross-sectional.

Methods: Data were collected during 2015-2017 based on two questionnaires (WHOQOL-OLD and WHOQOL-BREF). Seventy-eight older persons living in nursing homes in southern Sweden answered the questionnaires in structured interviews. Descriptive and comparative statistics were used to analyse the data. The study was guided by Transparent Reporting of Evaluations with Nonrandomized Designs (TREND) guidelines.

Results: The frail older persons reported low autonomy related to few opportunities to engage in everyday activities and were unable to do the things they liked to do and not feeling in control of their future. Another important result was that frail older persons seemed to have no or little fear of death and dying. No significant differences between gender or age on quality of life were revealed.

KEYWORDS

ageing, frailty, multi-morbidity, nursing homes, older persons, quality of life

1 | INTRODUCTION

Obtaining the highest possible quality of life (QoL) for a frail older person suffering from issues associated with a life-threatening illness is a cornerstone within person-centred care (Edvardsson et al., 2008; Ekman et al., 2011) and also the goal of care in nursing homes. The Swedish policy of “aging in place” (Wiles et al., 2012) means that the care needs of older people as a result of sickness and multi-morbidity should be met in their own homes for as long as possible. The ideology behind “aging in place” is that people maintain their autonomy, independence and close connections with their family and friends (Gomes et al., 2013; Wiles et al., 2012). On the other hand, this approach implies that it is the frailest older persons that live in

nursing homes (Håkansson et al., 2015; Hall, Petkova, et al., 2011; Houttekier et al., 2010), with extensive needs for help several times during the day (e.g. help with movements, taking drugs, taking care of personal hygiene or participating in activities) and with a limited time to live.

1.1 | Background

The average mean time living in a Swedish nursing home has decreased during the last years and varies between six to nine months (National Board of Health & Welfare, 2018). In Sweden, 38% deaths in Sweden occur in nursing homes (Håkansson et al., 2015) and 88%

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of all people who died in Sweden in 2019 were 65 years or older (Statistic Sweden, 2020). Loss of autonomy, independence and privacy following relocation to a nursing home may negatively influence the QoL (Guse & Masesar, 1999; Hall, Petkova, et al., 2011). Previous research has shown that both frailty (Kojima et al., 2016), in terms of the need for greater help with activities of daily living (ADLs) and a higher number of self-reported diseases and complaints (Hellström et al., 2004) determine a low QoL.

Quality of life is a multidimensional concept that includes both objective and subjective dimensions, and individual's physical health, psychological state, independence level, social relationships, personal beliefs and relationship with the environment and is related to the person's goals, expectations, standards and concerns (Lawton, 1991). Aspects that constitute a good life among older persons can be understood as turning inwards to come to peace with the past and the present and approach death (Andersson et al., 2008) and the attitude towards death may change as people age (Hallberg, 2004). Several factors have been shown to negatively affect an older person's experience of QoL as they age (Hall, Opio, et al., 2011; Hall, Petkova, et al., 2011), including a depressive emotional status (Dragomirecká et al., 2008), limited economic resources, such as not owning the own home, or having a suitable physical environment (von Dem Knesebeck et al., 2007), lower health and functional status and fewer social relationships and poorer social support (Sparks et al., 2004). Additionally, an older person's ability to adjust to life in relation to changes and new conditions with a preserved self-image, self-esteem and meaningful existence is important for QoL (Borglin et al., 2006).

How older people handled difficult situations earlier in life and the support the older person has received are important for their experiences of living in a nursing home (Andersson et al., 2007). Older persons moving into a nursing home can feel lonely in an unfamiliar place and may be waiting for death or see death as a release, whereas for others knowing that the staff is close at hand when needed can be calming (Österlind et al., 2017), which enables people to live well in the last part of their life and to die well when the time comes to pass (Hall, Petkova, et al., 2011). Despite the importance of QoL in end-of-life care, little attention has been focused specifically on QoL estimations of frail older persons living in nursing homes. One reason for not investigating QoL could be the difficulties in gaining access to frail older persons living the last part of their life in nursing homes (Lang et al., 2007). This situation can also explain the focus of studies on proxies, including the perceptions of the staff (Andersson et al., 2018) or relatives (Ekeström et al., 2014), rather than the perceptions of the frail older persons themselves about their QoL. In relation to the above phenomena, the aim of the study was to assess the QoL in frail older persons (65+ years) living in nursing homes. The hypothesis underpinning this study was that being male and younger were associated with a higher QoL, and therefore, a further aim was to examine differences between QoL perceptions among different gender and age groups.

2 | METHODS

2.1 | Design

This study is part of a larger project named "Implementation of knowledge-based palliative care in nursing homes," which is abbreviated the KUPA project (trial registration: NCT02708498) (Ahlström et al., 2018). This study had a cross-sectional design, and data were collected based on two QoL questionnaires (WHOQOL-OLD and WHOQOL-BREF). Seventy-eight older persons living in 30 nursing homes in two counties in southern Sweden answered the questionnaires in structured interviews. The study was guided by Transparent Reporting of Evaluations with Nonrandomized Designs (TREND) Guidelines (see Supplementary Material).

2.2 | Sample

Thirty nursing homes were included in the study and consisted of a mixture of both larger and smaller nursing homes situated in both urban and rural areas. A total of 85 persons were strategically included in this study. The number of older persons per nursing home was selected according to the sizes of the nursing homes. The selection of participants followed the inclusion criteria that the older person (≥ 65 years) should be able to respond to questions in Swedish and have sufficient energy and cognitive function to manage a structured interview for up to two hours, based on the contact person's knowledge of the older person. Seven participants were excluded because more than 20% of the answers were missing. The final sample consisted of 78 older persons. The older persons in this study had an average age of 87.9 years (range 66–102 years), most were women (64%) and 91% were born in Sweden. Most of the participants were widows or widowers (60%) and had attended elementary school as their highest education level (62%) (Table 1).

2.3 | Instrument

The questionnaires used in this study were the WHOQOL-BREF (WHO, 1996) and the WHOQOL-OLD (WHO, 1995), which are often used together. The PI of the KUPA project received permission from the World Health Organization (WHO) to use these two questionnaires in the project.

The WHOQOL-BREF consists of two overall questions: the first concerns general health and the second concerns the overall QoL. Additionally, the questionnaire includes 24 items covering four domains (physical health with seven items, psychological health with six items, social relationships with three items and environment with eight items). Each item is answered on a 1–5 Likert scale, on which 5 is the most positive rating (WHO, 1996). The range of possible scores are as follows: General health 1–5, Overall QoL 1–5, Physical health 7–35, Psychological 6–30, Social

TABLE 1 Demographic data of the older persons in the study (N = 78)

Characteristics	N	%
Age		
Mean 87.9. Range 66–102		
66–88	43	55
89–102	35	45
Gender		
Female	50	64
Male	28	36
Marital status		
Single	7	9
Married/partner	18	23
Divorced	6	8
Widow/widower	47	60
Educational level		
Elementary school	48	62
Professional school	20	26
High school	3	4
University	7	9

relationships 2–10 and Environment 8–40. The WHOQOL-BREF questionnaire has been validated for older persons with acceptable psychometric properties. Cronbach's alpha was shown to be between $\alpha = 0.73$ and $\alpha = 0.79$ for each domain (Liang et al., 2009) and has demonstrated high test-retest reliability and validity in older adults (Chachamovich et al., 2007; Steinbüchel et al., 2006). One question (How satisfied are you with your sex life?) in the instrument was removed with reference to ethical concerns according to the Swedish Ethical Board (no 2015/69); this removal was also approved by the WHO.

The WHOQOL-OLD contains 24 items that measure the QoL in six domains with four items each: (1) Sensory abilities; (2) Autonomy; (3) Past, present and future activities; (4) Social participation; (5) Death and dying; and (6) Intimacy. Similarly, each item was answered on 1–5 Likert scale, where 5 was the most positive rating. The possible scores ranged from 4–20. Domain scores are scaled in a positive direction, with a higher score indicating a higher QoL (WHO, 1995). The WHOQOL-OLD questionnaire has been validated with acceptable psychometric properties for older persons in several countries. Cronbach's alpha showed a range from $\alpha = 0.72$ to $\alpha = 0.88$ for each domain, and the total score displayed a consistency coefficient of $\alpha = 0.89$ (Power et al., 2005). Additionally, socio-demographic data were collected from the older persons, including age, gender, marital status and education.

2.4 | Data collection

The data collection was performed during 2015–2017, using structured interviews. A contact person was assigned at each nursing

home. The contact person informed older persons who fulfilled the inclusion criteria about the study and asked whether they were interested in participating. If the older person was interested, the researcher was given the older person's name by the contact person. Then, a time and a place for the interview were booked. Before the interview began, the researchers gave oral and written information about the study and a written consent document was signed. The data collection was performed by four researchers, all of whom were registered nurses with long experience working with frail older persons and conducting interviews. The structured interview was performed at the older person's own apartment at their nursing home. To make it easier for the older person to answer the questionnaires, the answer alternatives were enlarged on a separate paper and used during the interview. The interviews lasted from 45 min to two hours.

2.5 | Statistical analyses

The data were analysed in one descriptive and one analytical section. In the descriptive section, numbers and percentages were calculated on a group level. A mean score was calculated for each domain using both the raw domain score, a standardized domain score (SDS) with the raw domain score divided by the number of items in the domain (1–5) and a transformed domain mean score (TDS 0–100) according to the instrument manuals (WHO, 1995, 1996). The different calculations were performed to enable comparison of our results with those from other studies.

In the analytical section, the participants were divided into two age groups (66–88 years and 89–102 years) by the population median age and gender (female and male). To examine differences in QoL, a comparison of medians was conducted using the Mann–Whitney *U* test. The significance level was set to a *p*-value < 0.05. The analyses were performed using IBM SPSS Statistics version 23 (IBM Corp, 2015).

2.6 | Ethics approval and consent to participate

This study is part of the KUPA project approved by the Regional Ethics Review Board in Lund, Sweden (no. 2015/4). The research project is guided by the ethical principles for medical research (the Declaration of Helsinki). The study was conducted in agreement with the Swedish Ethical Review of Research Involving Humans Act (SFS, 2003:460), the General Data Protection Regulation [GDPR] (European Data Protection Board, 2018) and the Public Access and Secrecy Law (SFS, 2009:400).

The participants' confidentiality is accounted for when reporting the findings, which have been analysed at a group level. The older persons were provided with information, including their right to withdraw from the study at any time without suffering any consequences, before each interview and written informed consent was received from each of the participating older persons. In

the interview situation, respect was shown for the participants' signs of tiredness, which are a common part of frailty and a high symptom burden.

3 | RESULTS

Table 2 shows the QoL scores from the four domains of the WHOQOL-BREF, the *general QoL* and *general health* of the study

participants. A total of 40% of the participants perceived their *general QoL* as good or very good, 39% perceived it as neither good nor bad, and 22% perceived it as bad or very bad. Almost half of the population of older persons (47.5%) reported that they were satisfied or very satisfied with their *general health*, 30.6% were unsatisfied or very unsatisfied, and 21.8% were neither satisfied nor unsatisfied. When we compared the scores of the four domains, the *social relationships* domain had the highest score with a mean of 4.0, followed by the *environment* domain with a mean score of

TABLE 2 The answers of the items for the WHOQOL-BREF module by the older persons in nursing homes (N = 78)

WHOQOL-BREF	1 ^a N (%)	2 ^a N (%)	3 ^a N (%)	4 ^a N (%)	5 ^a N (%)	IMS	DMS (SD)	SDS 1-5	TDS 0-100
Overall QOL	4 (5)	13 (17)	30 (39)	27 (35)	4 (5)	3.2			
General health	4 (5.1)	20 (25.5)	17 (21.8)	30 (38.5)	7 (9.0)	3.2			
Physical Health									
Activities of daily living	3 (3.8)	21 (26.9)	17 (21.8)	33 (42.3)	4 (5.1)	3.2	31.6 (3.7)	3.1	51.8
Dependence on medication	4 (5)	32 (41)	30 (39)	11 (14)	1 (1)	2.7			
Energy and fatigue	3 (4)	17 (22)	42 (54)	9 (11.5)	7 (9.0)	3.0			
Mobility	9 (11.5)	20 (25.6)	41 (52.6)	8 (10.3)	0 (0)	2.6			
Pain and discomfort	2 (2.6)	15 (19.2)	20 (25.6)	10 (12.8)	31 (39.7)	3.7			
Sleep and rest	0 (0.0)	5 (6.4)	21 (26.9)	25 (32.1)	25 (32.1)	3.9			
Work Capacity	10 (12.8)	30 (38.5)	25 (32.1)	13 (16.7)	0 (0.0)	2.6			
Psychological									
Body image	3 (3.8)	5 (6.4)	31 (39.7)	14 (17.9)	25 (32.1)	3.7	20.2 (3.6)	3.4	59.4
Negative feelings	3 (3.8)	9 (11.5)	14 (17.9)	39 (50.0)	13 (16.7)	3.6			
Positive feelings	6 (7.7)	3 (3.8)	40 (51.3)	25 (32.1)	4 (5.1)	3.2			
Self-esteem	3 (3.8)	14 (17.9)	17 (21.8)	35 (44.9)	9 (11.5)	3.4			
Spirituality/religion/Personal beliefs	8 (10.3)	11 (14.1)	41 (52.6)	14 (17.9)	4 (5.1)	2.9			
Thinking, learning memory and concentration	1 (1.3)	12 (15.4)	34 (43.6)	28 (35.9)	3 (3.8)	3.3			
Social relationships									
Personal relationships	0 (0.0)	4 (5.1)	8 (10.3)	45 (57.7)	21 (26.9)	4.1	8.0 (1.4)	4.0	^c
Practical social support	2 (2.6)	3 (3.8)	14 (17.9)	41 (52.6)	18 (23.1)	3.9			
Environment									
Financial resources	1 (1.3)	5 (6.4)	32 (41.0)	12 (15.4)	28 (35.9)	3.8	29.2 (3.6)	3.6	68.0
Physical safety and security	1 (1.3)	2 (2.6)	31 (39.7)	39 (50.0)	5 (6.4)	3.6			
Access to health and social care	2 (2.6)	0 (0.0)	10 (12.8)	48 (61.5)	18 (23.1)	4.0			
Home environment	0 (0.0)	1 (1.3)	15 (19.2)	36 (46.2)	26 (33.3)	4.1			
Recreation and leisure	8 (10.3)	18 (23.1)	30 (38.5)	15 (19.2)	7 (9.0)	2.9			
Physical environment	1 (1.3)	1 (1.3)	42 (53.8)	30 (38.5)	4 (5.1)	3.5			
Transport	3 (3.8)	2 (2.6)	21 (26.9)	39 (50.0)	13 (16.7)	3.7			
Information and skills	0 (0.0)	6 (7.7)	34 (43.6)	25 (32.1)	13 (16.7)	3.6			

Abbreviations: IMS = Item Mean score (1-5). DMS = Domain score: General QOL 1-5, General health 1-5, Physical health 7-35, Psychological 6-30, Social relationships 2-10, Environment 8-40. SDS = Standardized Domain Score: Raw Domain mean Score divided by number of items 1-5. TDS = Transformed Domain Score transformed according to instrument manual (0-100).

^a1—Low QOL 5—High QOL.

^bScores < 1SD.

^cNot able to calculate related to one missing item.

	Total mean (SD)	Female mean (SD)	Male Mean (SD)	p-value
WHOQOL-BREF				
General QOL	3.13 (0.94)	3.05 (1.00)	3.27 (0.83)	.46
General health	3.26 (1.04)	3.19 (0.98)	3.38 (1.13)	.36
Physical health	21.52 (3.72)	21.42 (4.01)	21.69 (3.25)	.69
Psychological	20.22 (3.55)	20.14 (3.64)	20.35 (3.46)	.64
Social relationships	6.26 (1.31)	6.28 (1.12)	6.23 (1.61)	.92
Environment	29.13 (3.42)	28.79 (3.55)	29.69 (3.17)	.20
WHOQOL-OLD				
Sensory abilities	14.00 (3.23)	13.88 (3.15)	14.19 (3.42)	.64
Autonomy	11.59 (2.56)	11.40 (2.76)	11.92 (2.21)	.35
Past, present and future abilities	13.12 (1.99)	12.91 (1.91)	13.46 (2.10)	.22
Social participation	12.01 (2.48)	11.81 (2.64)	12.35 (2.19)	.68
Death and dying	16.70 (3.36)	16.70 (2.75)	16.69 (4.24)	.28
Intimacy	12.43 (3.53)	12.30 (3.37)	12.65 (3.83)	.25

TABLE 3 Differences between quality of life perceptions regarding gender

	Total mean (SD)	Age 89–102 mean (SD)	Age 66–88 mean (SD)	p-value
WHOQOL-BREF				
General QOL	3.13 (0.94)	3.24 (0.87)	3.05 (0.99)	.45
General health	3.26 (1.04)	3.14 (0.88)	3.35 (1.15)	.31
Physical health	21.52 (3.72)	20.97 (3.44)	21.92 (3.90)	.41
Psychological	20.22 (3.55)	20.31 (3.13)	20.15 (3.87)	.67
Social relationships	6.26 (1.33)	6.17 (1.00)	6.33 (1.51)	.49
Environment	29.13 (3.42)	28.90 (3.47)	29.30 (3.41)	.62
WHOQOL-OLD				
Sensory abilities	14.00 (3.23)	13.38 (2.80)	14.45 (3.48)	.22
Autonomy	11.59 (2.56)	11.66 (2.57)	11.55 (2.60)	.96
Past, present, and future abilities	13.12 (1.99)	12.87 (2.05)	13.30 (1.95)	.44
Social participation	12.01 (2.48)	12.24 (2.36)	11.85 (2.58)	.47
Death and dying	16.70 (3.36)	16.86 (2.67)	16.58 (3.81)	.68
Intimacy	12.43 (3.53)	13.45 (2.89)	11.78 (3.82)	.15

TABLE 4 Differences between quality of life perceptions regarding age groups

3.6. The domain *physical health* scored the lowest (3.1). No significant differences were found in any of the QoL domain scores on the WHOQOL-BREF between men and women (Table 3) or between the two age groups (Table 4). Table 5 shows the QoL scores for the six domains of the WHOQOL-OLD. The highest domain scores in the WHOQOL-OLD were found for the domains *death and dying* (4.2) and *sensory abilities* (3.6). The *autonomy* domain had the lowest score with a mean of 2.9. No significant differences were found in any of the QoL domains of the WHOQOL-OLD between men and women (Table 3) or between the two age groups (Table 4).

4 | DISCUSSION

The results from this study showed that most frail older persons had no or little fear of death and dying. Social relationships were also rated highly. However, the study also revealed that the participants perceived lack of autonomy and opportunities to engage in everyday activities. The fact that older persons had no or little fear of dying has likewise been shown in previous research. A study from Turkey (Bilgili, & Arpaci, 2014) that also used the WHOQOL-OLD showed similar results, with a high mean score in the death and dying domain. Another study from Australia (Tan et al., 2012) showed

TABLE 5 The answers of the items for the WHOQOL-OLD module by the older persons in nursing homes ($N = 78$)

WHOQOL-OLD	1 ^a N (%)	2 ^a N (%)	3 ^a N (%)	4 ^a N (%)	5 ^a N (%)	IMS 1–5	DMS 4–20 (SD)	SDS 1–5	TDS 0–100
Sensory abilities									
Impairments of senses affect daily life	3 (3.8)	18 (23.1)	28 (35.9)	18 (23.1)	11 (14.1)	3.2	14.3 (4.5)	3.6	64.4
Loss of sensory abilities affect participation in activities	1 (1.3)	13 (16.7)	23 (29.5)	19 (24.4)	22 (28.2)	3.6			
Problems with sensory functioning affect ability to interact	1 (1.3)	8 (10.3)	19 (24.4)	19 (24.4)	30 (38.5)	3.9			
Rate sensory functioning	4 (5.1)	10 (12.8)	37 (47.4)	23 (29.5)	4 (5.1)	3.2			
Autonomy									
Freedom to make own decisions	4 (5.1)	7 (9.0)	26 (33.3)	27 (34.6)	14 (17.9)	3.5	11.7 (2.8)	2.9	48.1
Feel in control of your future	29 (37.2)	18 (23.1)	21 (26.9)	9 (11.5)	1 (1.3)	2.2			
People around you are respectful of your freedom	1 (1.3)	11 (14.9)	35 (44.9)	24 (30.8)	7 (9.0)	3.3			
Able to do things you'd like	8 (10.3)	28 (35.9)	29 (37.2)	9 (11.5)	4 (5.1)	2.7			
Past, present and future abilities									
Satisfied with opportunities to continue achieving	19 (24.4)	27 (34.6)	23 (29.5)	6 (7.7)	3 (3.8)	2.3	13.2 (2.4)	3.3	57.5
Received the recognition you deserve in life	3 (3.8)	9 (11.5)	33 (42.3)	20 (25.6)	13 (16.7)	3.4			
Satisfied with what you've achieved in life	1 (1.3)	2 (2.6)	9 (11.5)	40 (51.3)	26 (33.3)	4.1			
Happy with things to look forward to	2 (2.6)	8 (10.3)	31 (39.7)	36 (46.2)	1 (1.3)	3.3			
Social participation									
Have enough to do each day	10 (12.8)	29 (37.2)	21 (26.9)	14 (17.9)	4 (5.1)	2.7	12.0 (2.7)	3.0	50.0
Satisfied with the way you use your time	3 (3.8)	6 (7.7)	26 (33.3)	38 (48.7)	5 (6.4)	3.5			
Satisfied with level of Activity	5 (6.4)	16 (20.5)	28 (35.9)	26 (33.3)	3 (3.8)	3.1			
Satisfied with opportunity to participate in community	4 (5.1)	17 (21.8)	41 (52.6)	16 (20.5)	0 (0.0)	2.9			
Death and dying									
Concerned about the way you will die	2 (2.6)	5 (6.4)	10 (12.8)	22 (28.2)	39 (50.0)	4.2	16.7 (3.2)	4.2	79.3
Afraid of not being able to control death	1 (1.3)	8 (10.3)	11 (14.1)	19 (24.4)	39 (50.0)	4.1			
Scared of dying	2 (2.6)	2 (2.6)	4 (5.1)	16 (20.5)	54 (69.2)	4.5			
Fear pain before death	2 (2.6)	6 (7.7)	16 (20.5)	26 (33.3)	28 (35.9)	3.9			
Intimacy									
Feel a sense of companionship in life	1 (1.3)	9 (11.5)	45 (57.7)	21 (26.9)	2 (2.6)	3.2	13.0 (3.0)	3.3	56.3
Experience love in your life	4 (5.1)	8 (10.3)	33 (42.3)	28 (35.9)	5 (6.4)	3.3			
Opportunities to love	10 (12.8)	10 (12.8)	24 (30.8)	20 (25.6)	14 (17.9)	3.2			
Opportunities to be loved	3 (3.8)	7 (9.0)	37 (47.4)	20 (25.6)	11 (14.1)	3.4			

Abbreviations: IMS = Item Mean score (1–5). DMS = Raw Domain mean score (4–20). SDS = Standardized Domain Score: Raw Domain mean Score divided by number of items 1–5. TDS = Transformed Domain Score transformed according to instrument manual (0–100).

^a1—Low QoL 5—High QoL.

that most participants living in nursing homes did not worry about dying and had an opinion that death was natural and inevitable because of their age. This result was also confirmed in earlier Swedish and British studies in nursing homes (Fleming et al., 2016; Melin-Johansson et al., 2014), where most of the participants stated that they were not afraid of dying. Some older persons have even been shown to be longing for and looking forward to death without fear or despair (Fleming et al., 2016; Ternstedt & Franklin, 2006). This attitude can be understood as an ageing development based on the theory of gerotranscendence developed by Tornstam (2005). The theory of gerotranscendence describes a development in old age that leads to significant changes in the way we perceive self, relationships with other people and life as a whole. In contrast, nurse assistants, who are the professionals closest to the older persons, feel insecure when talking about emotional and existential issues (Beck et al., 2012; Towsley, et al., 2015) and use distraction strategies, such as comforting, which disregard the older person's desire to talk about death (Alftberg et al., 2018). One reason could be that the staff members fear their own deaths (Österlind et al., 2017) or have a lack of education in palliative care (Fryer et al., 2016; Goddard et al., 2013; Smets et al., 2018). Therefore, care professionals in nursing homes should have sufficient knowledge of palliative care to ensure that they have awareness and feel secure having these conversations with older persons at nursing homes (Alftberg et al., 2018; Towsley, et al., 2015). Furthermore, our results may increase the staff's understanding of an older person's attitudes towards death and dying. The knowledge that older persons do not fear death and dying may facilitate this conversation. The opportunity to discuss death- and dying-related questions cannot be stressed enough—since they offer an opportunity to collect knowledge about the older person's individual preferences in the end stage of life and upholding these preferences should be considered an essential part of adequate end-of-life care.

The results also revealed areas for improvement, since only one-fifth of the older persons reported that they were able to do the things they liked to do and they did not feel in control of their future, which indicated that the participants in this study had low autonomy. This finding was reported previously in nursing homes by older persons, their relatives and nurse assistants (Andersson, et al., 2007). Ternstedt and Franklin (2006) found that older persons had a strong desire to be involved in their personal care and everyday lives at the nursing home. Furthermore, Towsley et al. (2015) found that older persons wanted to be asked about their preferences, but the staff rarely asked about their preferences or failed to pass along this information. Moreover, nurses have been shown to often make decisions on an older person's behalf (Andersson, et al., 2007; Murphy et al., 2007). The more dependent the older person is on staff managing their lives, the less likely they are to have a choice (Murphy et al., 2007). The ageing in place ideology has resulted in a situation where the most dependent persons live in nursing homes. These persons often move to the nursing home when they are in their final phase of life and are very much dependent on help from the staff. Thus, the autonomy of older persons in nursing homes needs to be

safeguarded. This process can be ensured through interactions between the older person and the staff by asking for their opinion, involving the older person in everyday activities and care planning and offering choices (Custers et al., 2012; Hedman et al., 2019). If the staff listens to and understands the older person's views and experiences, person-centred care can be delivered at the nursing home. However, diseases related to old age, such as dementia, can contribute to difficulties in expressing needs and preferences (WHO, 2020) and thus achieving person-centred care. Therefore, welcoming the family with their unique knowledge about the older person into the care and care plans is also greatly important (Edvardsson et al., 2008). The staffing level does not determine whether the staff can facilitate residents' choices; instead, the staff should focus on being available rather than focusing on routines (Murphy et al., 2007).

The environment in which care is provided has the greatest potential to enhance or limit the facilitation of person-centred care and a sense of identity and integrity is promoted by living in a familiar environment surrounded by well-known objects and continuing their habits (McCormack, 2004). In contrast to the findings described above the older persons in our study assessed the nursing home environment as rather high, with rather high scores for the home environment and access to health and social care. This result contrasted with another study in Turkey (Bodur & Dayanir, 2009), which found that those living in nursing homes rated the environment domain lower than those living in their own homes. One explanation for the contrasting result may be the standard of residential homes or that the residents in Sweden do not pay for their care to the same extent as residents in other countries.

One result that stands out from the domain *Social participation* is that nearly half of the older persons in this study reported that they did not have enough to do during the day but at the same time were satisfied with how they used their time and their activity level. Although we do not know the reasons for this discrepancy, one explanation may be that frail older persons are often hindered by a lack of energy and reduced mobility as a result of both ageing and various types of disabilities related to multi-morbidity (Gustavsson et al., 2015; Vaughn et al., 2015). The finding in this study can be explained as a wish to receive a meaningful life, which includes having meaningful activities and being able to continue performing everyday activities. In an interview study concerning activities in the context of a nursing home, the older persons emphasized the importance of having something to do and stated that both shared and individual activities were important for them (Gustavsson, et al., 2015). Another study (Edvardsson et al., 2014) revealed that being able to participate in everyday activities, such as making coffee, watering plants and setting or clearing the table, was related to a significantly higher QoL. Therefore, since QoL is an important outcome of health care (Holmes, 2005), efforts should be made to increase everyday activities in nursing homes.

From the other questionnaire (the WHOQOL-BREF), we found a high score in the *social relationship* domain. This domain generated high scores for both personal relationships and practical social support. Previous studies have shown that social

relationships have a positive impact on QoL, including both new contacts made when the older person moves into a nursing home (Cho, et al., 2017) and old relationships with family and friends (Bahramnezhad et al., 2017). In a recent study of next of kin of older persons in nursing homes (Wallerstedt, et al., 2018), the results highlighted the importance of building and maintaining relationships. This process includes telling the older person about what has happened outside of the nursing home but also includes simply socializing without extended activity. Thus, our result implies that nursing homes contribute to a social environment that has an important and positive influence on frail older persons' QoL.

In contrast to an earlier study that reported that being male and younger were associated with a higher QoL (Holmes, 2005), the results from this study did not reveal any significant differences in QoL between the gender or age groups. One possible explanation is that the statistical power was not sufficient to detect differences, because all included persons were in the high age range (mean 87.9 years) and nearly two times as many women as men were included in the study sample. However, since the ageing in place ideology promotes older persons living at home for as long as possible, the high median age is representative of nursing homes in Sweden. Furthermore, the high numbers of women in the study can be explained by the higher life expectancy for women. Other factors than age and sex, such as social relations, health, economic status and skills (Netuveli et al., 2006), might have a greater impact on QoL which care professionals at nursing homes needs to consider when caring for an older person.

We would like to focus on other methodological issues. The sample consisted of participants from both small and large nursing homes and from both urban and rural areas, which increased the generalizability of the study, even though our sample is rather small ($N = 78$). Concerning the generalizability, one inclusion criterion was sufficient cognitive function to manage a structured interview lasting for up to one hour. Therefore, the sample may not be representative of the frailest population in nursing homes, since a large proportion of older persons in nursing homes have been shown to suffer from cognitive impairment (National Board of Health & Welfare, 2018). Another possible approach is use of a proxy rater for the frailest population. However, Kane et al. (2005) reported that although family proxy domain scores were significantly correlated with the older person's scores, the level of correlation suggested that they could not simply be substituted for the older person's reports of QoL. Furthermore, mobility and cognition have been shown to be associated with wellbeing and health related QoL (Davis, et al., 2015). Hence, our results may overrate the QoL of older persons in nursing homes.

According to the WHO (2006), the WHOQOL instruments can be used in a variety of studies, which gives high validity to the results. However, in our study, one question in the WHOQOL-BREF was excluded for ethical reasons based on decisions from the Ethical board. This fact produces bias when calculating the domain mean

scores and made comparisons to other studies difficult for the *Social relationship* domain.

Furthermore, the questions in the WHOQOL-BREF and WHOQOL-OLD were assisted by an interviewer, who was a registered nurse and filled in the answers. The presence of another person may have affected the older persons' answers to the questions. They may not have answered the question truthfully in either direction, which thereby lowered the reliability of the study. This aspect may be one explanation for why so many older persons scored three, which indicated moderate. Another aspect that may have affected the answers is that the participants are frail, and the interviews lasted for 45 min to up to 2 hr in a few cases. A break was offered if the interviews lasted more than one hour, but the questions may have been tiring for the participants. However, the four interviewers were experienced in conducting interviews with older persons, which could increase the reliability.

5 | CONCLUSIONS

The results revealed areas for improvement, since the frail older persons reported low autonomy related to few opportunities to engage in everyday activities, were unable to do the things they liked to do and not feeling in control of their future. This needs to be taken into consideration to enhance frail older persons' QoL. Nursing home staff should frequently offer, invite and involve them in interactions. This interaction can be enabled by asking for their opinions, involving the older person in meaningful everyday activities, care planning and offering choices.

Another important conclusion that can be made from this study is that frail older persons seem to have no or little fear of death and dying. This result can increase the staff's understanding of older persons' attitudes towards death and dying and thereby ease and opening conversations about death and dying according to frail older persons' eventual needs. The actions suggested promoting person-centred care.

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CONFLICT OF INTEREST

The authors declare that they have no competing interests.

AUTHORS' CONTRIBUTIONS

AS developed the design together with the project leader of KUPA. AL, LA and CB conducted the analysis and drafted the article. All authors contributed to the content of the manuscript text and critical revised, read, discussed and approved the final manuscript.

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DATA AVAILABILITY STATEMENT

The datasets generated and/or analysed during the current study are not publicly available due to sensitive information for a very vulnerable group, namely frail older persons living in nursing homes. Although the data are anonymized, the study contains sufficient details to enable identification of individuals. The data are available from the responsible researcher (GA) after approval from the ethics board.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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