

Original Article

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Author for correspondence:

Ramona Schenell, University of Gothenburg, The Sahlgrenska Academy, Institute of Health and Care Sciences, Box 457, 405 30 Gothenburg, Sweden. Email: ramona.schenell@telia.com or ramona.schenell@centrum.goteborg.se

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Residents' and family members' perceptions of care quality and self-determination in palliative phase in residential care

Ramona Schenell, R.N., M.Sc.^{1,2}, Anneli Ozanne, R.N., Ph.D.^{1,3}, Susann Strang, R.N., Ph.D.¹ and Ingela Henoch, R.N., Ph.D.^{1,4}

¹The Sahlgrenska Academy, Institute of Health and Care Sciences, Gothenburg, Sweden; ²Centrum City District Committee, Health Care Unit, The City of Gothenburg, Gothenburg, Sweden; ³Department of Neurology, Sahlgrenska University Hospital, Gothenburg, Sweden and ⁴Angered Hospital, Gothenburg, Sweden

Abstract

Objective. Dependency on others can compromise self-determination for older persons in the palliative phase in residential care. Family members can support the residents' self-determination but may also jeopardize it. Quality of care (QoC) is linked to respecting the autonomy of the residents and providing opportunities to participate in decision-making. The aim of the study was to provide knowledge about residents' and family members' perceptions of QoC and self-determination and to detect possible differences between their experiences.

Method. This cross-sectional study used an abbreviated version of the questionnaire, Quality from the Patients' Perspective, with additional items about decision-making. Wilcoxon's signed rank test was used to analyze the perception of QoC and to detect differences between residents' and family members' perceptions.

Result. QoC was perceived as lower than preferred in the majority of items and there was a high level of agreement between residents and family members. Lowest mean values in QoC were found in: support when feeling lonely; support when feeling worry, anxiety or fear; and staff's time to talk to the residents. Decision-making in everyday life and in life-changing situations showed that neither residents nor family members trusted staff to know about the residents' preferences.

Significance of results. Broad improvements are needed, especially in psychosocial care. Several of the negative outcomes on QoC and self-determination seem to derive from a focus on practical tasks and the lack of trustful relationships between residents and staff. An early implementation of palliative care, with a focus on what brings quality to each resident's life, could facilitate QoC and self-determination, in both everyday life and at the end of life.

Introduction

Nursing home care is complex in that many residents live with several chronic conditions (WHO, 2011), with increasing symptom prevalence (Estabrooks et al., 2015), and that it includes both curative services and palliative care (Nakrem, 2015). In Sweden, there is a wide range in time of residency in residential care: almost 50% die within the first year (Schön et al., 2016), but nearly 30% of the women and 20% of the men are alive after 4 years (National Board of Health and Welfare, 2018). Regardless of the length of residency, each resident's length of stay is often equal to the length of their remaining life (Schön et al., 2016); because of this, there is a high prevalence of palliative care needs in residential care (Morin et al., 2016). The residents are affected both physically and mentally by age and illness: 57% need help in activities of daily life, and 67% have cognitive impairment (SOU, 2017).

The high prevalence of cognitive impairment in nursing homes makes autonomy, when conceptualized as assuming full decisional capacity, difficult to apply. Instead, the interpretation of the autonomy concept as relational is more appropriate (Jacobs et al., 2015). The relational view of autonomy suggests that individuals can never be fully independent (MacDonald, 2002) and that there is no conflict in being autonomous and engaging others in decision-making (Walter & Ross, 2014). Self-determination can be regarded as the process of exercising the individual's right to autonomy (Beauchamp, 2013). In palliative care, self-determination is defined as a decision-making process that includes the support and advice of others, for example, family members and healthcare professionals (Bakitas, 2005). When physical frailty progresses, the possibilities to carry out personal choices are limited, and dependency on others can entail a loss of both executional and decisional control. However, loss of physical performance does not justify loss of freedom to make decisions, and it is crucial to protect the decisional, as well as the executional, autonomy in older persons with frailty to preserve their self-determination (Collopy, 1988).

Decision-making and quality of care (QoC) are connected as having the opportunity to participate in decisions about one's own health and welfare is an attribute of QoC (Donabedian, 1990). In nursing homes, aspects related to the persons who provide the care and institutional aspects of the care process are perceived as pillars of QoC by residents and relatives. QoC in nursing homes is, according to family members, enhanced by care routines that are mutually developed with residents and, conversely, is obstructed when residents are expected to adapt to existing care routines (Vinsnes *et al.*, 2012). A nonpaternalistic attitude with respect for the autonomy of the residents, a close relationship between staff and residents, and possibilities for relatives to take part in decision-making are also described to enhance QoC (Rodríguez-Martin *et al.*, 2013). Staff in nursing homes recognize and want to achieve a relationship with the residents, although organizational factors limit their ability to shift their focus away from task-based activities (Beck *et al.*, 2012).

Older people can delegate end-of-life decision-making to others by indirectly expressing their wishes and describing their desired end-of-life outcomes. They believe that their appointed delegate will make appropriate decisions on their behalf and they can thereby achieve a sense of control without being directly responsible for specific decisions (Romo *et al.*, 2017). Nurses and physicians do not always involve nursing home residents in end-of-life discussions, although they are capable of decision-making (Dreyer *et al.*, 2010). This can be remedied by having family members monitor the care (Davies & Nolan, 2006) and, by proxy decision-making, they can achieve autonomy and participation for the residents (Hedman *et al.*, 2017). However, being a proxy decision-maker in end-of-life care can be a burden for family members because they perceive themselves as being responsible for the decisions that are made (Dreyer *et al.*, 2009). Family members can also jeopardize the residents' autonomy at end of life when they want more active, life-prolonging treatments for the residents than the residents do themselves (Gjerberg *et al.*, 2010).

According to Swedish law, care should be of good quality and build on respect for the patients' self-determination (SFS, 2017). Despite this, daily routines, rather than individual preferences, direct life for those who live in nursing homes (Hellström & Sarvimäki, 2007) and concern about the care quality is reported by residents' family members as being one of their main anxieties (Davies & Nolan, 2006). This study aimed to provide knowledge about residents' in the palliative phase, and family members' perceptions of QoC and self-determination, conceptualized as having executional and decisional control, and to detect any differences between their experiences. The research questions were as follows.

- How do the residents perceive QoC and decision-making in everyday life and in life-changing situations?
- Do residents hand over decision-making to staff or family members; and do staff or family members make decisions against the residents' will?
- Are there differences between residents' and family members' perceptions of QoC and decision-making in everyday life and in life-changing situations?

Methods

Design

This cross-sectional study was based on data gathered from residents and family members in residential care facilities, representing both municipal and private operators, in all 10 districts of a

large city in the southwest of Sweden. Data were collected during 2017 and 2018, using the instrument, Quality from the Patients' Perspective (QPP) (Larsson & Larsson, 2002).

Procedure and participants

One registered nurse working at each residential care facility was designated as the main contact for the study and assisted in recruiting the residents. The main inclusion criteria were that the residents should reside in a general unit and be in a palliative phase, defined as having a maximum life expectancy of one year. The contact nurse used the "surprise question" (SQ) (Lynn, 2005), asking herself or himself, "Would I be surprised if this resident die within a year?" If the answer was no, the resident could be asked to participate in the study. The included residents then asked one family member to participate to obtain their perspectives. Speaking and understanding Swedish was also an inclusion criterion. Participating residents did not have to be able to read the questions or write their answers by themselves, as the first author (R.S.) assisted when necessary. Because of conditions such as impaired vision, paresis, or reduced strength, 83 residents were assisted when completing the questionnaire. Some residents did not have family members or did not want to ask them to participate. Two residents and one family member declined participation, and 18 family members did not return their questionnaires. Two of the residents' questionnaires had to be excluded because of the amount of missing data. The study was approved by the Regional Ethics Committee in Gothenburg (Dnr1036-15).

Data collection

Data on residents' and family members' perceptions of QoC, with a focus on self-determination, were collected using an abbreviated version of the QPP, specially designed for residential care facilities. The instrument measures the perception of the actual care received, called the perceived reality (PR), and the importance of each aspect of care, called the subjective importance (SI). Significantly lower PR than SI indicates a need for quality improvement (Wilde *et al.*, 1994) and can also be interpreted as a low level of self-determination, as the instrument measures both executional and decisional activities. Both the QPP for residents and for family members had 24 original items and six additional study-specific items about decision-making in everyday life and in life-changing situations, all formulated as statements such as "I/My family member is treated with respect." The statements were evaluated on a 4-point Likert scale, ranging from 1 (do not agree at all) to 4 (fully agree) for PR, and from 1 (of little or no importance) to 4 (of very great importance) for SI. Additional "not applicable" and "do not know" responses were used in both questionnaires when appropriate. To further investigate the decision-making process, four items about residents handing over decision-making to staff and family members and having decisions made against their will by staff and family members were added to both questionnaires, as were two items about perceived physical and mental health. The added items were formulated and designed with help from ImproveIt (www.improveit.se/kupp/), the company that provides QPP, to fit in with the other items in the questionnaires.

Data analysis

The IBM SPSS Statistic Data Editor Software, version 23, was used to analyze data. The responses from the total sample of residents

($n = 112$) were used in calculations of the residents' perceptions of care. When comparing residents' and family members' perceptions of care, the sample consisted of the residents whose family member had completed the questionnaire ($n = 83$). Demographic and clinical characteristics were examined with descriptive statistics. Wilcoxon's signed rank test was used for examining differences between PR and SI of QoC and in decision-making in everyday life and lifechanging situations in the separate groups of residents and family members. Wilcoxon's signed rank test was also used for investigating differences between residents' and family members' experiences in the paired analyses.

Results

Demographic and clinical characteristics

As presented in Table 1, the study population consisted of 112 residents and 83 family members, mostly from municipal residential care operators, with considerably more women in both groups. Heart disease was the most reported disease, and many residents had comorbidities. The residents' mental health was rated as generally better than their physical health by both residents and family members, but the family members rated the physical health as being worse than the residents did. The residents were significantly older than the family members because the majority of the residents had asked their children to participate. Most of the family members visited the residents once or several times a week.

Residents' perceptions of QoC and decision-making

As presented in Table 2, there were statistically significant differences between PR and SI values in 17 of 24 of the ordinary QPP-items, indicating that the QoC was lower than preferred in these areas. Lowest mean values in PR were found in support when feeling lonely; support when feeling worry, anxiety or fear; and in staff's time to talk to the residents. Highest mean values in PR were found in access to technical aid, support with personal hygiene, and support during meals.

In decision-making in everyday life and in life-changing situations, there were statistically significant differences between PR and SI values in four of six items, indicating that the actual experiences were not consistent with the residents' expectations. The lowest mean values in PR were found in staff knowing about the residents' will in life-changing decisions, whether staff would make the right decisions according to the residents' will, and family members knowing about the residents' will in life-changing decisions. The items concerning staff had both lower PR and SI values than the related items concerning family members (Table 2).

Concerning the residents' handing over of decision-making to staff or family members, and about residents having decisions made against their will, 65% ($n = 73$) never handed over decisions to the staff, and 60% ($n = 63$) never handed over decisions to their family members. Decisions made against the residents' will were not common: 81% ($n = 90$) reported that this never happened with staff and 96% ($n = 103$) that it never happened with family members (Table 1).

Comparison of residents' and family members' perceptions of QoC and decision-making

Mean values for the comparison between residents' and family members' perceptions are presented in Table 2. Concerning

QoC, in 14 of the 24 QPP items, both residents and family members had statistically significant differences between PR and SI values, indicating that both groups perceived QoC as being lower than preferred. Lowest mean values in PR were found in support when feeling lonely; support when feeling worry, anxiety or fear; and support to go outside. Both residents and family members rated these items with lowest mean values, but not in the same order. The highest PR values, for both residents and family members, were in access to technical aids and being treated with respect. Residents' third-highest PR values were in support with personal hygiene, and support to sit and lie comfortably, which were equally rated. Family members' third-highest PR was support during meals, which was also the only item in which both residents and family members were satisfied with the QoC. In the remaining 9 items, residents were content, but family members perceived QoC as being low. Generally, residents rated PR higher than family members did, although not all differences became statistically significant.

In decision-making in everyday life and in life-changing situations, there were statistically significant differences between PR and SI values in four of six items (the same as in the residents' group), for both residents and family members, indicating that their actual experiences were not consistent with their expectations. In addition, the family members also had statistically significant differences between PR and SI values in the item about them making the right decisions according to the residents' will.

Discussion

The main findings of the present study were that neither residents nor family members were satisfied with the QoC that the residents received. There were significant differences between the PR and SI values in both groups concerning QoC and decision-making in both everyday life and in life-changing situations. Generally, residents were more satisfied than family members were because they rated PR higher and had fewer differences between PR and SI. Even in the family members' highest ratings, there were significant differences between PR and SI, indicating a wish for better quality. The self-determination of the residents can be considered as being compromised, as both decisional and executional control were affected.

The results indicate a need for broad improvements; however, in access to technical aids, support during meals, support with personal hygiene, and support when visiting the toilet, the QoC was satisfactory. Prioritizing the residents' most basic needs of bodily care and practical tasks is common in residential care facilities (Beck et al., 2012; Holmberg et al., 2018). Routine and task-based care has been found to have a negative effect on residents' autonomy (Rodgers et al., 2012), because promoting autonomy requires opportunities to make genuine choices (MacDonald, 2002). When the staff's working day follows routines rather than acknowledging the residents' desires and wishes, the opportunity for making choices is less prevalent (Murphy & Welford, 2012).

In the present study, both residents and family members claimed that staff did not have enough time to talk to the residents and, consequently, they perceived support when feeling lonely, and support when feeling worry, anxiety, or fear as low. In Sweden, 66% of residents in residential care facilities are troubled by loneliness. Residents who often perceive loneliness are less satisfied with the care they receive and the possibility for self-determination, participation, and individual adjustments (National Board of Health and Welfare, 2016). Loneliness is

Table 1. Demographic-, health-, and social-related characteristics of residents and family members

	Residents <i>n</i> = 112	Residents* <i>n</i> = 83	Family members <i>n</i> = 83
Age			
Median	91.0	92.0	65.0
Mean (<i>SD</i>)	89.7 (7.9)	90.6 (7.0)	64.7 (8.6)
Minimum-maximum	68–102	70–102	47–86
Sex			
Men	35 (31.3%)	25 (30.1%)	31 (37.3%)
Women	77 (68.8%)	58 (69.9%)	52 (62.7%)
Origin			
Sweden	105 (93.8%)	79 (95.2%)	83 (100%)
Remaining Nordic countries	4 (3.6%)	2 (2.4%)	
Remaining European countries	3 (2.7%)	2 (2.4%)	
Remaining world	0	0	
Educational level			
Elementary school	57 (50.9%)	45 (54.2%)	14 (16.9%)
High school	32 (28.6%)	20 (24.1%)	31 (37.3%)
University	22 (19.6%)	17 (20.5%)	37 (44.6%)
Other education	1 (0.9%)	1 (1.2%)	1 (1.2%)
Time of residency			
<6 months	12 (10.7%)	10 (12.0%)	
6–12 months	24 (21.4%)	16 (19.3%)	
1–2 years	24 (21.4%)	15 (18.1%)	
2–3 years	23 (20.5%)	22 (26.5%)	
3–4 years	11 (9.8%)	8 (9.6%)	
>4 years	18 (16.1%)	12 (14.5%)	
Illnesses			
Heart disease	61 (54.5%)	45 (54.2%)	
Lung disease	15 (13.4%)	12 (14.5%)	
Cancer disease	21 (18.8%)	14 (16.9%)	
Neurological disease	15 (13.4%)	10 (12.0%)	
Other disease	44 (40.0%)	40 (48.2%)	
Filled in the questionnaire without help			
Yes	29 (25.9%)	26 (31.3%)	
No	83 (74.1%)	57 (68.7%)	
Residential care operator			
Municipal	98 (87.5%)	73 (88.0%)	
Private	14 (12.5%)	10 (12.0%)	
Occupational status			
Employed			37 (44.6%)
Retired			45 (54.2%)
Student			0
Other (retired but working)			1 (1.2%)
Relation to the resident			

(Continued)

Table 1. (Continued.)

	Residents n = 112	Residents* n = 83	Family members n = 83
Spouse/partner			5 (6.0%)
Child			64 (77.1%)
Other relative			10 (12.0%)
Friend			2 (2.4%)
Other relation			2 (2.4%)
How often have you seen the resident in the last month?			
Never			1 (1.2%)
Once			4 (4.9%)
2–3 times			11 (13.4%)
Once a week			34 (41.5%)
Several times a week			27 (32.9%)
Every day			5 (6.1%)
How often have you spoken to the resident on the phone in the last month?			
Never			7 (8.5%)
Once			4 (4.9%)
2–3 times			5 (6.1%)
Once a week			11 (13.4%)
Several times a week			26 (31.7%)
Every day			29 (35.4%)
How do you perceive your (the resident's) physical health?			
Very poor	9 (8.0%)	5 (6%)	6 (7.4%)
Fairly poor	30 (26.8%)	23 (27.7%)	30 (37%)
Neither good nor poor	26 (23.2%)	21 (25.3%)	14 (17.3%)
fairly good	42 (37.5%)	30 (36.1%)	29 (35.8%)
Very good	5 (4.5%)	4 (4.8%)	2 (2.5%)
How do you perceive your (the resident's) mental health?			
Very poor	3 (2.7%)	2 (2.4%)	3 (3.7%)
Fairly poor	19 (17.0%)	14 (24.4%)	20 (24.4%)
Neither good nor poor	26 (23.2%)	21 (25.3%)	17 (29.7%)
Fairly good	45 (40.2%)	31 (37.3%)	32 (39.0%)
Very good	19 (17.0%)	15 (18.1%)	10 (12.2%)
How often do you (the resident) let the staff make decisions for you (him/her)?			
Never	73 (65.2%)	55 (66.3%)	23 (27.7%)
Once a month	8 (7.1%)	3 (3.6%)	3 (3.6%)
2–3 times a month	8 (7.1%)	6 (7.2%)	1 (1.2%)
Once a week	11 (9.8%)	10 (12%)	3 (3.6%)
Several times a week	4 (3.6%)	3 (3.6%)	3 (3.6%)
Every day	8 (7.1%)	6 (7.2%)	3 (3.6%)
Do not know	—	—	47 (56.6%)
How often does the staff make decisions against your (the resident's) will?			
Never	90 (81.1%)	66 (80.5%)	32 (39%)
Once a month	5 (4.5%)	2 (2.4%)	1 (1.2%)

(Continued)

Table 1. (Continued.)

	Residents <i>n</i> = 112	Residents* <i>n</i> = 83	Family members <i>n</i> = 83
2–3 times a month	2 (1.8%)	2 (2.4%)	1 (1.2%)
Once a week	5 (4.5%)	4 (4.8%)	1 (1.2%)
Several times a week	2 (1.8%)	2 (2.4%)	1 (1.2%)
Every day	2 (1.8%)	1 (2.4%)	1 (1.2%)
Do not know	5 (4.5%)	0	46 (56%)
How often do you (the resident) let your family member (you) make decisions for you (him/her)?			
Never	63 (58.9%)	47 (57.3%)	38 (46.9%)
Once a month	17 (15.9%)	15 (18.3%)	19 (23.5%)
2–3 times a month	16 (15.0%)	12 (14.6%)	8 (9.9%)
Once a week	4 (3.7%)	4 (4.9%)	8 (9.9%)
Several times a week	7 (6.5%)	4 (4.9%)	7 (8.6%)
Every day	0	0	1 (1.2%)
How often does your family member (you) make decisions against your (the resident's) will?			
Never	103 (96.3%)	79 (96.3%)	75 (91.5%)
Once a month	2 (1.9%)	2 (2.4%)	2 (2.4%)
2–3 times a month	1 (0.9%)	0	2 (2.4%)
Once a week	0	0	3 (3.7%)
Several times a week	0	0	0
Every day	0	0	0
Do not know	1 (0.9%)	1 (1.2%)	0

SD, standard deviation.

*Residents from the total sample whose family member has completed the Quality from the Patients' Perspective.

described by older persons as a complex and private matter requiring good relationships to discuss (Kharicha et al., 2017). This might constitute a problem for the participants in the present study as there were significant differences between PR and SI in receiving help from staff known to the resident, which indicates that there was a lack of close relationships between residents and staff. Both residents and family members also perceived a lack of engagement from staff. Residents depend on staff, not only for clinical care, but also for their psychosocial wellbeing (Nakrem et al., 2011), and commitment to the care relationship should be promoted to maintain and develop QoC for older people (Hägström et al., 2010). In-depth knowledge and interaction are necessary to promote autonomy (Moser et al., 2007), and nursing home staff need to recognize the individuality and know the habits, preferences, and tastes of the residents (Naess et al., 2016).

In the present study, both residents and family members were discontent with the staff knowledge about the residents' preferences in daily decision-making as well as in life-changing decisions, such as hospital admission, intravenous fluids, and cardiopulmonary resuscitation (CPR). They also perceived insufficient QoC in having the opportunity to participate in decisions about healthcare, care and rehabilitation, and in having the opportunity to influence how the support will be provided. These results indicate a need for improvement in the cooperation between residents, staff, and family members. Vinsnes et al. (2012) found that family members perceive themselves as an

essential communication link between residents and staff and in having a unique ability to interpret the residents' wishes. In the present study, the residents seemed to adhere to the perception about the family members' ability to interpret their needs, as they trust them to make the right decisions according to their will if they were to take over their decision making. This is interesting because both residents and family members rated PR lower than SI in decision-making in life-changing situations, indicating a need for more discussions between them in this regard. This result is consistent with those of Bollig et al. (2016), who found that most residents believed that their relatives would know their wishes in end-of-life-care without having discussed them. In the present study, as well as in Bollig et al. (2016), the family members are unsure about their ability to make the right decisions and, according to Bollig et al. (2016), the relatives perceived decision making as a burden when they were not aware of the residents' wishes.

Nursing home residents consider death to be a natural end to a long life, but they rarely speak about it to staff or relatives (Österlind et al., 2017). Speaking about dying and death can be seen as an unpleasant and sad topic by the residents, but also as unnecessary, as they perceive themselves as being in fairly good health (Ingravallo et al., 2018). In the present study, many residents rated their health as being fairly good or very good, despite having several diagnoses and being dependent on staff for activities of daily living. This might partly explain the lack of conversations about life-changing situations, but it is surprising

Table 2. Comparisons between perceived reality and subjective importance in the group of residents and between residents and family members

	Residents (n = 112)		p	Residents* (n = 83)		Family member (n = 83)	p for differences between residents and family members	Residents* (n = 83)		Family member (n = 83)	p for differences between residents and family members	p = PR and SI differences	p = PR and SI differences
	Perceived reality	Subjective importance		Perceived reality	Perceived reality			Subjective importance	Subjective importance				
Ordinary QPP items	Mean (SD)	Mean (SD)		Mean (SD)	Mean (SD)		Mean (v)	Mean (SD)		p	p	p	
I (my family member) receive the best possible support with meals	3.48 (0.89)	3.35 (0.71)	0.276	3.48 (0.90)	3.18 (0.85)	0.024	3.30 (0.75)	3.08 (0.90)	0.177	0.109	0.614		
I (my family member) receive the best possible support to get outside	2.51 (1.25)	3.18 (0.82)	<0.001	2.40 (1.24)	2.13 (1.04)	0.108	3.30 (0.75)	3.08 (0.90)	0.114	<0.001	<0.001		
I (my family member) receive the best possible support with personal hygiene	3.49 (0.79)	3.52 (0.56)	0.759	3.49 (0.81)	3.12 (0.83)	0.006	3.51 (0.59)	3.46 (0.76)	0.736	0.785	0.001		
I (my family member) receive the best possible support with oral care	3.10 (1.14)	3.57 (0.51)	0.031	3.00 (1.16)	2.45 (1.09)	0.317	3.50 (0.52)	3.07 (0.93)	0.406	0.084	<0.001		
I (my family member) receive the best possible support when visiting the toilet	3.38 (0.83)	3.59 (0.67)	0.062	3.44 (0.83)	3.04 (0.87)	0.159	3.60 (0.70)	3.26 (0.92)	0.870	0.182	<0.001		
I (my family member) receive the best possible support to sit and lie comfortably	3.34 (0.83)	3.55 (0.63)	0.042	3.49 (0.75)	3.09 (0.80)	0.007	3.54 (0.64)	3.38 (0.81)	0.827	0.617	<0.001		
I (my family member) receive the best possible support when feeling lonely	2.15 (1.16)	3.15 (0.89)	<0.001	2.09 (1.11)	2.30 (0.97)	0.157	3.09 (0.88)	3.27 (0.84)	0.163	<0.001	<0.001		

(Continued)

Table 2. (Continued.)

Ordinary QPP items	Residents (n = 112)			Residents* (n = 83)			Residents* (n = 83)			Residents* (n = 83)		
	Perceived reality	Subjective importance		Perceived reality	Perceived reality	<i>p</i> for differences between residents and family members	Subjective importance	Subjective importance	<i>p</i> for differences between residents and family members	<i>p</i> = PR and SI differences	<i>p</i> = PR and SI differences	
	Mean (SD)	Mean (SD)	<i>p</i>	Mean (SD)	Mean (SD)	<i>p</i>	Mean (v)	Mean (SD)	<i>p</i>	<i>p</i>	<i>p</i>	
I (my family member) receive the best possible support when feeling worry, anxiety, or fear	2.39 (1.13)	3.37 (0.76)	<0.001	2.38 (1.13)	2.31 (0.93)	0.508	3.29 (0.81)	3.37 (0.96)	0.011	<0.001	<0.001	
I (my family member) receive the best possible support with spiritual and cultural needs	2.74 (1.09)	2.88 (0.96)	0.320	2.62 (1.07)	2.44 (0.96)	0.117	2.80 (0.97)	2.67 (0.98)	0.831	0.265	0.031	
I (my family member) receive effective pain relief	2.83 (0.93)	3.59 (0.55)	<0.001	2.78 (1.00)	2.92 (0.90)	0.373	3.54 (0.55)	3.37 (0.82)	0.268	<0.001	<0.001	
I (my family member) receive effective symptom relief (regarding other symptoms than pain)	2.90 (1.06)	3.74 (0.52)	<0.001	3.54 (0.55)	3.37 (0.82)	0.333	3.73 (0.54)	3.37 (0.83)	0.012	<0.001	<0.001	
The staff treat me (my family member) with respect	3.40 (0.73)	3.58 (0.64)	0.033	3.52 (0.65)	3.30 (0.73)	0.025	3.64 (0.53)	3.70 (0.46)	0.423	0.187	<0.001	
The staff show engagement, care about, me (my family member)	3.14 (0.95)	3.42 (0.75)	0.003	3.23 (0.89)	3.05 (0.85)	0.092	3.49 (0.62)	3.61 (0.56)	0.102	0.025	<0.001	
The staff have time to talk to me (my family member)	2.46 (1.03)	3.27 (0.85)	<0.001	2.44 (1.01)	2.46 (0.94)	0.822	3.29 (0.83)	3.40 (0.70)	0.428	<0.001	<0.001	

(Continued)

Table 2. (Continued.)

	Residents (n = 112)			Residents* (n = 83)			Family member (n = 83)			Residents* (n = 83)			Family member (n = 83)		
	Perceived reality	Subjective importance		Perceived reality	Perceived reality	<i>p</i> for differences between residents and family members	Subjective importance	Subjective importance	<i>p</i> for differences between residents and family members	<i>p</i> = PR and SI differences		<i>p</i> = PR and SI differences			
Ordinary QPP items	Mean (SD)	Mean (SD)	<i>p</i>	Mean (SD)	Mean (SD)	<i>p</i>	Mean (v)	Mean (SD)	<i>p</i>	<i>p</i>		<i>p</i>			
The staff have good skills in performing their duties	3.00 (0.85)	3.58 (0.53)	<0.001	3.01 (0.80)	2.88 (0.90)	0.415	3.56 (0.52)	3.63 (0.56)	0.547	<0.001		<0.001			
I (my family member) have good opportunity to participate in decisions about healthcare, care, and rehabilitation	2.99 (1.09)	3.28 (0.82)	0.009	3.04 (1.04)	2.91 (0.93)	0.330	3.28 (0.80)	3.54 (0.62)	0.015	0.041		<0.001			
I (my family member) have good opportunity to influence how the support will be provided	2.75 (1.05)	3.22 (0.77)	<0.001	2.64 (1.05)	2.82 (0.98)	0.582	3.16 (0.77)	3.33 (0.75)	0.382	<0.001		<0.001			
I (my family member) have good opportunity to take part in the amusements I (my family member) want	2.94 (1.07)	3.19 (0.79)	0.019	2.91 (1.06)	2.58 (1.02)	0.018	3.18 (0.77)	3.26 (0.79)	0.482	0.045		<0.001			
I (my family member) have good opportunity to socialize with others to the extent I (my family member) want	3.15 (1.00)	3.21 (0.83)	0.659	3.15 (1.01)	3.03 (0.85)	0.420	3.23 (0.83)	3.04 (0.95)	0.050	0.593		0.950			
I (my family member) receive help from staff known to me (my family member)	2.94 (0.79)	3.34 (0.69)	<0.001	2.84 (0.80)	2.84 (0.86)	0.989	3.33 (0.67)	3.55 (0.63)	0.034	<0.001		<0.001			

(Continued)

Table 2. (Continued.)

	Residents (n = 112)		p	Residents* (n = 83)		p for differences between residents and family members	Residents* (n = 83)		p for differences between residents and family members	Residents* (n = 83)	
	Perceived reality	Subjective importance		Perceived reality	Perceived reality		Subjective importance	Subjective importance		p = PR and SI differences	p = PR and SI differences
Ordinary QPP items	Mean (SD)	Mean (SD)		Mean (SD)	Mean (SD)		Mean (v)	Mean (SD)		p	p
I (my family member) dare to express my (my family member's) views to the staff	3.35 (0.91)	3.42 (0.73)	0.606	3.40 (0.86)	3.09 (0.90)	0.012	3.42 (0.72)	3.50 (0.61)	0.293	0.992	<0.001
It is easy for me (my family member) to get in contact with the staff via the alarm	3.11 (0.96)	3.77 (0.47)	<0.001	3.15 (0.95)	3.09 (0.96)	0.575	3.81 (0.40)	3.65 (0.66)	0.079	<0.001	<0.001
I (my family member) receive food and drink that I (my family member) like	2.77 (1.02)	3.50 (0.62)	<0.001	2.75 (1.02)	2.61 (1.03)	0.064	3.46 (0.65)	3.58 (0.55)	0.237	<0.001	<0.001
I (my family member) have access to the technical aids I (my family member) need	3.69 (0.68)	3.66 (0.60)	0.639	3.68 (0.71)	3.47 (0.75)	0.018	3.63 (0.62)	3.70 (0.49)	0.495	0.459	0.006
Study-specific item about decision-making											
The staff knows how I (my family member) want daily decisions such as food, drink, and clothes	3.04 (0.89)	3.28 (0.81)	0.011	3.04 (0.88)	3.09 (0.75)	0.339	3.31 (0.81)	3.48 (0.60)	0.039	0.016	<0.001
The staff knows how I (my family member) want life-changing decisions such as intravenous fluids, hospital admission, and CPR	1.62 (1.11)	3.26 (0.97)	<0.001	1.74 (1.17)	2.15 (1.01)	0.094	3.30 (0.97)	3.14 (0.99)	0.185	<0.001	<0.001

(Continued)

Table 2. (Continued.)

	Residents (n = 112)			Residents* (n = 83)			Residents* (n = 83)			Residents* (n = 83)		
	Perceived reality	Subjective importance		Perceived reality	Perceived reality	<i>p</i> for differences between residents and family members	Subjective importance	Subjective importance	<i>p</i> for differences between residents and family members	<i>p</i> = PR and SI differences	<i>p</i> = PR and SI differences	
Ordinary QPP items	Mean (SD)	Mean (SD)	<i>p</i>	Mean (SD)	Mean (SD)	<i>p</i>	Mean (v)	Mean (SD)	<i>p</i>	<i>p</i>	<i>p</i>	
The staff would make the right decisions according to my (my family member's) will if they were to take over the decision-making	2.48 (0.82)	3.30 (0.87)	<0.001	2.53 (0.86)	2.57 (0.93)	0.388	3.29 (0.89)	3.41 (0.78)	0.343	<0.001	<0.001	
My family member (I) knows how I (the resident) want daily decisions such as food, drink, and clothes	3.48 (0.88)	3.40 (0.80)	0.215	3.56 (0.78)	3.40 (0.75)	0.109	3.47 (0.75)	3.37 (0.67)	0.181	0.144	0.686	
My family member (I) knows how I (the resident) want life- changing decisions such as intravenous fluids, hospital admission, and CPR	2.61 (1.35)	3.47 (0.78)	<0.001	2.78 (1.30)	3.10 (1.07)	0.055	3.51 (0.77)	3.51 (0.77)	0.962	<0.001	0.001	
My family member (I) would make the right decisions according to my (the resident's) will if he/she (I) were to take over the decision-making	3.51 (0.83)	3.46 (0.85)	0.547	3.56 (0.78)	3.58 (0.62)	0.737	3.55 (0.77)	3.72 (0.54)	0.049	0.903	0.012	

p values refer to differences in Wilcoxon signed rank test. *p* values also shown for differences between perceived reality and subjective importance within the residents' group, *n* = 83, and within the family member group, *n* = 83. Statistical significance assumed at *p* ≤ 0.05.

PR, perceived reality; SD, standard deviation; SI, subjective importance.

*Residents from the total sample whose family member has completed the Quality from the Patients' Perspective.

that the topic was not raised by staff more often, as the residents in the study were included because staff estimated their remaining lifetime to be a maximum one year.

Advance care planning (ACP), where people can make legally binding decisions about care in advance or appoint a specific person as a surrogate decision-maker for the future, is beneficial in nursing homes. It gives residents a voice in healthcare decisions, even after they have lost the capacity to take part in such discussions (Martin *et al.*, 2016). Few nursing homes have routine procedures for discussing these questions with residents and relatives at an early stage (Gjerberg *et al.*, 2011), even though death is regarded, by staff, as being natural and expected (Holmberg *et al.*, 2018). Caregivers find it difficult to talk about palliative care unless the residents or their relatives initiate the dialog themselves (Häggström *et al.*, 2010). This constitutes a problem because most people in nursing homes seem to need a person from outside the family to start conversations about ACP (Bollig *et al.*, 2016). Discussing ACP also requires trust and closeness (Ingravallo *et al.*, 2018), and the results of the present study have already established a lack of time to talk, a lack of engagement, and insufficient relationships between residents and staff. This might further explain the staff lacking knowledge about decision-making in daily life and in life-changing situations as well as the low values relating to trust in the staff's ability to make the right decisions according to the residents' will.

The majority of residents in the present study claimed that they never handed over decision making to staff or family members. This finding is consistent with previous research showing that having decision-making power is important in residents' everyday life, as well as being a factor of QoC (Donabedian, 1990). Although the residents in the present study claimed that they made most of their decisions by themselves, and were not afraid to express their views to the staff, both residents and family members perceived that they would like the residents to participate more in decisions about healthcare, and care and rehabilitation, and to be able to influence how the support would be carried out to a greater extent. In addition, 14% of the residents claimed that staff sometimes made decisions against their will. A reasonable explanation might be that the residents try to hold on to their self-determination, but, in reality, have little opportunity to make genuine choices as they depend on the circumstances in the residential care facility. As one resident wrote in the comment field in the questionnaire: "Since I moved to the residential care facility I have become used to doing as others say, although I don't always want to. Woman, aged 99 years."


Methodological considerations and study limitations

Because people are considered to be approaching the end of life when they are likely to die within the next 12 months (General Medical Council, 2010), the palliative phase in this study was defined as having a maximum life expectancy of one year. The accuracy of the SQ in predicting survival or death in nursing homes varies, from 57% to 67%, depending on the specific timeframes used (3 months, 6 months, or seasonal) (Rice *et al.*, 2018). However, no timeframe of one year has, to our knowledge, been tested with residential care facilities as the only context. This means that the accuracy of the SQ was not tested for the timeframe and context of the present study, which might be a limitation in the sample procedure. Assisting in reading and/or filling in the questionnaire allowed residents who usually cannot participate in this kind of study to make their voices heard. This strategy

aligns with the World Medical Association's (WMA) declaration of Helsinki, which states that groups that are underrepresented in research should be provided appropriate access to participation (WMA, 2013). However, it is a limitation that people who are unable to speak Swedish were excluded because the QPP has not been translated into other languages.

Conclusion and implications

The shortcomings in QoC and self-determination in the present study demonstrate a need for broad improvements, especially in the area of psychosocial care. As confiding in staff about end-of-life preferences or when feeling lonely or worried requires closeness and trust, the managers in residential care facilities must ensure that appropriate conditions for building trustful relationships are established. Continuity and time are important factors when building relationships, which implies a need for at least one specially assigned staff to each resident (i.e. contact person). Time should be set aside for regular activities or conversations between the resident and the contact person and focus on areas important to the resident. These regular meetings can serve as a basis for improving the staff's knowledge about the residents' preferences and ultimately will help staff interpret wishes and accomplish activities when the residents can no longer express their will. Residents and their family members agree on the areas in need of improvement and the high consistency between them suggests that family members are appropriate proxy decision-makers, although there are some differences in their perceptions. There is a need to support family members when acting as proxy decision-makers in end-of-life care and facilitate discussions about end-of-life preferences between them in time. Because there is a high prevalence of palliative care needs in residential care, a palliative approach early in the residents' illness trajectory would be beneficial. Palliative care both affirms life and regarding dying as a normal process (WHO, 2002), which makes a palliative approach suitable in decision-making in the residents' everyday life as well as in planning for end-of-life care. An early implementation of palliative care with a focus on what brings quality to each resident's life could facilitate the shift from task-based care to what really matters to the resident and thus enhance the possibilities for self-determination.

Author ORCIDs.  R.N. Ramona Schenell, 0000-0002-6991-8798

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References

- Bakitas MA** (2005) Self-determination: Analysis of the concept and implications for research in palliative care. *Canadian Journal of Nursing Research* 37(2), 22–49.
- Beauchamp TL** (2013) *Principles of biomedical ethics*, 7th ed. New York, NY: Oxford University Press.
- Beck I, Törnquist A, Broström L, et al.** (2012) Having to focus on doing rather than being—Nurse assistants' experience of palliative care in municipal residential care settings. *International Journal of Nursing Studies* 49(4), 455–464. doi:10.1016/j.ijnurstu.2011.10.016
- Bollig G, Gjengedal E, & Rosland JH** (2016) They know!-Do they? A qualitative study of residents and relatives views on advance care planning,

- end-of-life care, and decision-making in nursing homes. *Palliative Medicine* 30(5), 456–470. doi:10.1177/0269216315605753
- Collopy BJ** (1988) Autonomy in long term care: Some crucial distinctions. *Gerontologist* 28(Suppl), 10–17.
- Davies S and Nolan M** (2006) 'Making it better': Self-perceived roles of family caregivers of older people living in care homes: A qualitative study. *International Journal of Nursing Studies* 43(3), 281–291. doi:10.1016/j.ijnurstu.2005.04.009
- Donabedian A** (1990) The seven pillars of quality. *Archives of Pathology and Laboratory Medicine* 114(11), 1115–1118.
- Dreyer A, Førde R, & Nortvedt P** (2009) Autonomy at the end of life: Life-prolonging treatment in nursing homes—relatives' role in the decision-making process. *Journal of Medical Ethics* 35(11), 672–677. doi:10.1136/jme.2009.030668
- Dreyer A, Førde R, & Nortvedt P** (2010) Life-prolonging treatment in nursing homes: How do physicians and nurses describe and justify their own practice? *Journal of Medical Ethics* 36(7), 396–400. doi:10.1136/jme.2010.036244
- Estabrooks CA, Hoben M, Poss JW, et al.** (2015) Dying in a nursing home: Treatable symptom burden and its link to modifiable features of work context. *Journal of the American Medical Directors Association* 16(6), 515–520. doi:10.1016/j.jamda.2015.02.007
- General Medical Council** (2010) Treatment and care towards the end of life. Available from https://www.gmc-uk.org/-/media/documents/treatment-and-care-towards-the-end-of-life---english-1015_pdf-48902105.pdf.
- Gjerberg E, Forde R, & Bjørndal A** (2011) Staff and family relationships in end-of-life nursing home care. *Nursing Ethics* 18(1), 42–53. doi:10.1177/0969733010386160
- Gjerberg E, Forde R, Pedersen R, et al.** (2010). Ethical challenges in the provision of end-of-life care in Norwegian nursing homes. *Social Science & Medicine* 71(4), 677–684. doi:10.1016/j.socscimed.2010.03.059
- Hedman M, Häggström E, Mamhidir AG, et al.** (2017) Caring in nursing homes to promote autonomy and participation. *Nursing Ethics* 969733017703698. doi:10.1177/0969733017703698
- Hellström UW and Sarvimäki A** (2007) Experiences of self-determination by older persons living in sheltered housing. *Nursing Ethics* 14(3), 413–424. doi:10.1177/0969733007075888
- Holmberg B, Hellström I, & Österlind J** (2018) End-of-life care in a nursing home: Assistant nurses' perspectives. *Nursing Ethics* 969733018779199. doi:10.1177/0969733018779199
- Häggström E, Mamhidir AG, & Kihlgren A** (2010) Caregivers' strong commitment to their relationship with older people. *International Journal of Nursing Practice* 16(2), 99–105. doi:10.1111/j.1440-172X.2010.01818.x
- Ingravallo F, Mignani V, Mariani E, et al.** (2018) Discussing advance care planning: Insights from older people living in nursing homes and from family members. *International Psychogeriatrics* 30(4), 569–579. doi:10.1017/s1041610217001983
- Jacobs L, Snow A, Allen RS, et al.** (2015) An applied conceptual framework of everyday resident autonomy in the nursing home: Results of a grounded theory investigation. *The Gerontologist* 55(Suppl 2), 701–702. doi:10.1093/geront/gnv354.06
- Kharicha K, Iliffe S, Manthorpe J, et al.** (2017) What do older people experiencing loneliness think about primary care or community based interventions to reduce loneliness? A qualitative study in England. *Health & Social Care in the Community* 25(6), 1733–1742. doi:10.1111/hsc.12438
- Larsson BW and Larsson G** (2002) Development of a short form of the Quality from the Patient's Perspective (QPP) questionnaire. *Journal of Clinical Nursing* 11(5), 681–687. doi:10.1046/j.1365-2702.2002.00640.x
- Lynn J** (2005) Living long in fragile health: The new demographics shape end of life care. *Hastings Center Report* 35(7), S14–S18.
- MacDonald C** (2002) Nurse autonomy as relational. *Nursing Ethics* 9(2), 194–201. doi:10.1191/0969733002ne4980a
- Martin RS, Hayes B, Gregorevic K, et al.** (2016) The effects of advance care planning interventions on nursing home residents: A systematic review. *Journal of the American Medical Directors Association* 17(4), 284–293. doi:10.1016/j.jamda.2015.12.017
- Morin L, Aubry R, Frova L, et al.** (2016) Estimating the need for palliative care at the population level: A cross-national study in 12 countries. *Palliative Medicine* 31(6), 526–536. doi:10.1177/0269216316671280
- Moser A, Houtepen R, & Widdershoven G** (2007) Patient autonomy in nurse-led shared care: A review of theoretical and empirical literature. *Journal of Advanced Nursing* 57(4), 357–365.
- Murphy K and Welford C** (2012) Agenda for the future: Enhancing autonomy for older people in residential care. *International Journal of Older People Nursing* 7(1), 75–80. doi:10.1111/j.1748-3743.2012.00309.x
- Naess A, Fjær EG, & Vabo M** (2016) The assisted presentations of self in nursing home life. *Social Science & Medicine* 150, 153–159. doi:10.1016/j.socscimed.2015.12.027
- Nakrem S** (2015) Understanding organizational and cultural premises for quality of care in nursing homes: An ethnographic study. *BMC Health Services Research* 15, 508. doi:10.1186/s12913-015-1171-y
- Nakrem S, Vinsnes AG, & Seim A** (2011) Residents' experiences of interpersonal factors in nursing home care: A qualitative study. *International Journal of Nursing Studies* 48(11), 1357–1366. doi:10.1016/j.ijnurstu.2011.05.012
- National Board of Health and Welfare** (2016) Så tycker de äldre om äldreomsorgen. Available from <http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/20356/2016-10-2.pdf>.
- National Board of Health and Welfare** (2018) Vård och omsorg om äldre. Available from <https://www.socialstyrelsen.se/publikationer2018/2018-2-7>.
- Österlind J, Ternstedt BM, Hansebo G, et al.** (2017) Feeling lonely in an unfamiliar place: Older people's experiences of life close to death in a nursing home. *International Journal of Older People Nursing* 12(1), e12129. doi:10.1111/opn.12129
- Rice J, Hunter L, Hsu AT, et al.** (2018). Using the "Surprise Question" in nursing homes: A prospective mixed-methods study. *Journal of Palliative Care* 33(1), 9–18. doi:10.1177/0825859717745728
- Rodgers V, Welford C, Murphy K, et al.** (2012) Enhancing autonomy for older people in residential care: What factors affect it? *International Journal of Older People Nursing* 7(1), 70–74. doi:10.1111/j.1748-3743.2012.00310.x
- Rodriguez-Martin B, Martinez-Andres M, Cervera-Montegudo B, et al.** (2013) Perception of quality of care among residents of public nursing-homes in Spain: A grounded theory study. *BMC Geriatrics* 13, 65. doi:10.1186/1471-2318-13-65
- Romo RD, Allison TA, Smith AK, et al.** (2017) Sense of control in end-of-life decision-making. *Journal of the American Geriatrics Society* 65(3), e70–e75. doi:10.1111/jgs.14711
- Schön P, Lagergren M, & Kareholt I** (2016) Rapid decrease in length of stay in institutional care for older people in Sweden between 2006 and 2012: Results from a population-based study. *Health & Social Care in the Community* 24(5), 631–638. doi:10.1111/hsc.12237
- SFS** (2017) Hälso- och sjukvårdslag. Available from <https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/halso-och-sjukvardslag-sfs-2017-30>
- SOU** (2017) Läs mig! Nationell kvalitetsplan för vård och omsorg om äldre personer. Available from https://www.regeringen.se/4969b7/contentassets/9378aff4b35a427c99b772345af79539/sou-2017_21_webb_del1.pdf
- Vinsnes AG, Nakrem S, Harkless GE, et al.** (2012) Quality of care in Norwegian nursing homes - typology of family perceptions. *Journal of Clinical Nursing* 21(1–2), 243–254. doi:10.1111/j.1365-2702.2011.03857.x
- Walter JK and Ross LF** (2014) Relational autonomy: Moving beyond the limits of isolated individualism. *Pediatrics* 133(Suppl 1), S16–S23. doi:10.1542/peds.2013-3608D
- Wilde B, Larsson G, Larsson M, et al.** (1994) Quality of care. Development of a patient-centred questionnaire based on a grounded theory model. *Scandinavian Journal of Caring Sciences* 8(1), 39–48.
- WHO** (2002) *National Cancer Control Programmes. Policies and behavioral guidelines*, 2nd ed. Available from <https://www.who.int/cancer/media/en/408.pdf>.
- WHO** (2011) *Palliative care for older people: Better practices*. Geneva: World Health Organization. Available from http://www.euro.who.int/__data/assets/pdf_file/0017/143153/e95052.pdf.
- WMA** (2013) *WMA declaration of Helsinki: Ethical principles for medical research involving human subjects*. Available from <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>