The effect of COVID-19 on quality of dying among people with dementia in nursing homes

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Abstract

Introduction: The outbreak of COVID-19 is expected to affect the quality of dying among people with dementia. This study answers the question: "what is the effect of the COVID-19 period on the quality of dying among people with dementia living in the nursing home setting from the perspective of their loved ones?". Additionally, it was investigated whether specific dying as a consequence of COVID-19 has an effect on this quality of dying in comparison to dying of other causes.

Methods: This current study was a secondary data analysis of a cross-sectional study measuring perceived quality of dying over time. A questionnaire is used that includes the validated End-of-Life in Dementia (EOLD) instrument. The study population consisted of the bereaved of people with dementia who were deceased within 6 months to 6 weeks ago, receiving care from one of the eight nursing homes of Zuyderland Zorg.

Results: In total, 443 participants filled in the questionnaire. Current study found no significant differences in SWC-, CAD-, and SM-scores between the pre-COVID-19 group and the COVID-19 group. As well as no significant difference was found between the people who died as a consequence of COVID-19 and the people who died of other causes for the SWC-, CAD- and SM-scores. The subitem of the SWC-scale "probably different decision would have been made if I had more information" scored significantly higher in the COVID-19 as cause of death group and "the nurses/carers were attentive to my needs and feelings" scored significantly lower in the COVID-19 as cause of death group. The COVID-19 as a cause of death group also scored significant higher on the "depression" subitem of the SM-scale.

Discussion: The COVID-19 period as well as dying as a consequence of COVID-19 has no effect on the overall level of comfort, overall frequency of symptoms and overall satisfaction of end-of-life care. Dying as a consequence of COVID-19 increases the likelihood that different decisions would have been made if he/she had more information; and decreases the satisfaction about whether the nurses/carers were attentive to his/her needs and feelings. Moreover, it seems that dying as a consequence of COVID-19 decreases the level of depression in comparison to people who die of other causes.

Introduction

Dementia is a major health problem (van der Steen et al., 2013). Currently, nearly 280.000 people live with dementia in the Netherlands (Alzheimer Nederland, 2021). One out of five people will be diagnosed with dementia. In fact, this number is predicted to rise sharply due to aging (Alzheimer Nederland, 2021). By 2040, halve a million people are expected to have dementia in the Netherlands (Alzheimer Nederland, 2021). Dementia is an umbrella term for a clinical syndrome that occurs mainly among the elderly (Koopmans et al., 2014). Dementia is caused by various underlying brain diseases characterized by combinations of multiple disorders in cognition, mood, and behavior (Koopmans et al., 2014). Hence, dementia is a life-limiting progressive illness resulting in severe disabilities that persist until death. Furthermore, dementia is the number one death cause in the Netherlands since 2015 (Alzheimer Nederland, 2021). The life expectancy for people diagnosed with dementia varies from 4.5 years to 10.7 years (Xie et al., 2008). Besides, a third of all people with dementia live in long-term care facilities (Goodman et al., 2010). More than half of the people with dementia eventually die in nursing homes (van der Steen, 2010).

No cure is foreseen for dementia, merely deterioration and symptoms can be inhibited (van der Steen et al., 2013). In the absence of curative strategies, a palliative approach for dementia has been widely recommended (Koopmans et al., 2014). According to the World Health Organisation (WHO), "palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual". As the moment people are diagnosed with dementia, palliative care starts (World Health Organisation, 2018). The loved ones of the person with dementia play an important role in palliative care, because of the cognitive impairments of people with dementia (van Soest-Poortvliet et al., 2015). Therefore, family caregivers often become surrogate decision-makers (Bolt et al., 2019).

The need for dementia-specific palliative care strategies has increased awareness because of the persistence of "prolonged dwindling" among people with dementia (van der Steen et al., 2013). They frequently suffer from burdensome symptoms and disabilities in the last phase of life (Hendriks et al., 2014). Pain and shortness of breath are the most prevalent symptoms that people with dementia experience in this phase (Hendriks et al., 2014). Therefore, end-of-life care is a crucial element of palliative care that requires careful attention. Previous studies reported that the quality of end-of-life care for people with

dementia is often suboptimal (Davies et al., 2014). They are often unable to gain access to hospice care, have undertreated pain and experience avoidable admissions to the hospital (Davies et al., 2014). Because of the loss of decision-making competences that come with dementia, this may interfere with meeting the person's prior preferences for dying (Davies et al., 2014). Quality of death is a remarkable quality indicator for end-of-life care. Quality of death measures the degree that a person's preferences for dying and the moment of death are consistent with observations of how the person actually died as reported by others (Patrick et al., 2001). An example of a quality indicator for end-of-life care in nursing homes is dying peacefully (Bolt et al., 2019; De Roo et al., 2013). A study showed that only half of the people with dementia died peacefully as perceived by their loved ones (De Roo, et al., 2013)

Multiple factors may affect the quality of dying among people with dementia. The outbreak of COVID-19 also affected the quality of dying. On 11 March 2020, the WHO declared the outbreak of COVID-19 (Reyes-Bueno, 2020 et al., 2020). COVID-19 is an infectious disease characterized by respiratory illness (WHO, 2021). Worldwide, as of 18 april 2021, there have been 140,322,903 confirmed cases of COVID-19, including 3,003,794 deaths (WHO, 2021). The elderly population is the group most threatened by COVID-19, with the highest mortality and fatality rates (Reyes-Buono et al., 2020). The study of Reyes-Buono et al., (2020) found a significant higher COVID-19 associated case fatality for patients with dementia, namely 43.3%. Besides, dementia increases the risk of complications and death due to COVID-19 (Want et al., 2020). People with dementia have limited access to accurate information and facts about the COVID-19 pandemic (Wang et al., 2020). Additionally, they experience difficulties following restrictive measures (Simonetti et al., 2020). Consequently, the chance of infection is higher. Moreover, this increased risk death in people with dementia may be due to the cognitive, behavioral, and psychological effects of rapid environmental changes brought by the pandemic (Simonetti et al., 2020). A study of Simonetti et al. (2020) showed that people with dementia suffered more from neuropsychiatric symptoms, including apathy, anxiety, and agitation during the COVID-19 pandemic. This was mainly a consequence of social restrictions and interruption of routine activities (Simonetti et al., 2020). Thus, the quality of life in this group of people may be decreased during this pandemic (Reyes-Buono et al., 2020).

The relationship between COVID-19 and quality of dying of people with dementia in nursing homes has not been studied extensively so far. Therefore, this study answers the question: "what is the effect of the COVID-19 period on the quality of dying among people with dementia living in the nursing home setting from the perspective of their loved ones?".

Additionally, there was investigated whether specific dying as a consequence of COVID-19 has an effect on this quality of dying in comparison to dying of other causes.

2. Methods

2.1 Study design

This current study was a secondary data analysis of a cross-sectional study measuring quality of dying over time. This study was embedded in the ZonM palliantie project 'DEDICATED: Desired Dementia Care Towards End of Life'. DEDICATED is a five-year research and implementation project running from September 2017 till September 2021 (DEDICATED, n.d.). The DEDICTAD project aims to improve the quality of palliative care for people with dementia living at home, in a nursing home, and during nursing home admissions as well as for their bereaved (DEDICATED, n.d.). This secondary data analysis focused on the effect of the COVID-19 period as well as dying as a consequence of COVID-19 on the quality of dying among people with dementia living in nursing homes from the perspective of their bereaved loved ones. Data about the perceived quality of dying is collected via a questionnaire once from each participant. Moreover, this data will be collected continuously during the whole duration of the DEDICATED project. Thus, a difference in outcome could be examined over time.

2.2 Study population

The study population consisted of the bereaved of people with dementia who deceased within 6 months to 6 weeks ago, receiving care from one of the eight nursing homes of Zuyderland Zorg. Recruitment of eligible participants followed a purposive sampling method. The inclusion criteria were (1) being the bereaved of a relative with dementia within the past six months at the time of recruitment, but no earlier than six weeks ago (to reduce the emotional impact of interviewing), (2) their relationship can be considered as closest to the person with dementia, (3) their relative with dementia was at least 65 years old at the time of death, and (4) their relative with dementia died in one of the eight nursing homes of Zuyderland Zorg. People were excluded who had insufficient understanding of the Dutch language (or Dutch dialect). Furthermore, people who were physically or psychologically unable to fill in the questionnaire were excluded.

2.3 Data collection

The main study parameters comprised the perception of the bereaved regarding the quality of dying of the deceased before the COVID-19 period (September 2017 until March 2020) as well as during the COVID-19 period (from March 2020). Secondary study parameters entailed demographic characteristics of participants and the deceased, and characteristics of the involved care organization. This information is derived via a questionnaire (Appendix 1) The questionnaire total encompasses six sections: (1) Your data, (2) Data of your relative, (3) End-of-Life in Dementia (EOLD) scales– Comfort Assessment in Dying (CAD), (4) End-of-Life in Dementia (EOLD) scales– Symptom Management (SM), (5) End-of-Life in Dementia (EOLD) scales – Satisfaction With Care (SWC). The first section comprises information about the bereaved of the relative with dementia who filled in the questionnaire. Specifically, gender, age, and relationship with the deceased. The second section encompasses information about the deceased resident and care receiver. Respectively, gender, age at death, duration of stay in the nursing home or duration of received homecare, suspected dementia, officially diagnosed dementia, cause of death, comorbidities at time of death, involved caregivers, any transfers during the last six months of life, the extent and timing of end-of-life communication, presence of a proxy decision-maker, presence of living will, documented ACP.

The third, fourth and fifth section comprises the scales measuring quality of dying, including the validated End-of-Life in Dementia (EOLD) instrument. The three EOLD scales of this instrument have a good convergent validity (correlation coefficients range from 0.50 to 0.81) as well as a good "internal consistency: reliability (Cronbach's Alpha of 0.68, 0.83, and 0.82) (Kiely et al., 2006). The EOLD-CAD, which is used to measure physical and emotional comfort of the deceased during the last week of life. This scale has 14 items that are scored on a three-point Likert scale (1 = not at all, 2 = somewhat, 3 = a lot). A higher score implies a greater level of comfort. The fourth section comprises the EOLD-SM, which will be used to measure the frequency of symptoms the deceased experienced during the last 3 months of life. This scale is rated on a six-point Likert scale (0 = never, 1 = once (that period), 2 = 2-3 days (that period), 3 = once every week, 4 = some days every week, 5 = every day). The fifth section comprises the EOLD-SWC, which is used to measure overall satisfaction of the bereaved with end-of-life care during the last week of life. This scale consists of 10 items that are scored on a four-point Likert scale (1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree), wherein higher scores indicate greater satisfaction.

Due to the covid outbreak the original questionnaire was adjusted. As a possible cause of death, COVID-19 is added. As well as a question is added whether the deceased or the

relative with dementia were affected by the COVID-19 measures. Also, a question is added about whether there was an ability to say goodbye, whether there was sufficient opportunity for farewell rituals, who was present when the relative passed away, and a rate of the received care.

2.4 Procedure

Questionnaires are sent by post for the whole duration of the DEDICATED project to the bereaved of people with dementia that decease within the participating organization. The questionnaire comes with a letter, which encompasses an introduction. This introduction includes information about the aim of the evaluation (improving the quality of palliative care). The participants are informed that the questionnaire will be used for academic research. Moreover, anonymity is assured. Participating in this study was voluntary, which is also emphasized in this letter. Lastly, the participants are requested to fill in and return the questionnaire with the enclosed envelope. The procedures are matched to the organization's current end of life evaluation as part of the usual aftercare.

2.5 Data analysis

The quantitative questionnaire data and demographic information were analyzed using IBM SPSS version 25. First, a descriptive analysis (i.e. means and standard deviations (SDs for ratio variables and frequencies and valid percentage for ordinal variables) is conducted to analyze the demographic data. Second, an independent T-test is executed to compare means of the variable which are of ratio and ordinal level. For the variables that are of nominal variables, a chi-square test is executed. The sum of the EOLD-scores before the COVID-19 period (till March 2019) are compared to the sum of the EOLD-scores during the COVID-19 period (from March 2019). Likewise, there is examined whether there is a difference in perceived quality of dying scales between pre and during the COVID-19 period. Also, the means of the subitems of the scales are compared. Cases were excluded analysis by analysis for missing values. The significance level is set at a p-value of 0.05.

2.6 Ethical considerations

This study design is assessed by The Medical Ethics Committee (METC) of Zuyderland Heerlen (registration number METCZ20180026). Besides, the study is conducted in line with the principles of Declaration of Helsinki (64th WMA General Assembly, Fortaleza, Brazil, October 2013) of the World Medical Association (WMA). No serious risk is associated with

participating in this study. It is unlikely that adverse events occur as participants only have to fill in a questionnaire. However, the questionnaire covers a sensitive topic. Thus, filling in the questionnaire might be experienced as emotionally demanding. Therefore, participants could choose to withdraw at any time for any reason.

3 Results

3.1 Sample characteristics

In total, 443 participants filled in the questionnaire (Table 1). The pre-COVID-19 period group consists of 136 participants; the COVID-19 period group of 298 participants; and for 16 participants COVID-19 was determined as the cause of death of the deceased. The average age of the bereaved who filled in the questionnaire is 62.4 years. The majority of these people were women (65.1%). Furthermore, 69.8% of the participants were the son (in law) or daughter (in law) from the deceased. The average age of the deceased was 85.9 years. As well as for the bereaved, most of the deceased were women (62.6%). 17.5% of the total population had a transfer during the last six months of life. No significant difference in these demographics described above were ascertained between the pre-COVID-19 and COVID-19 group. Also, for the group where COVID-19 is established as cause of death, most of the bereaved and deceased were women (56.3%; 62.5%) and most of them were the son in law) or daughter (in law) of the deceased (81.3%). Most people of the total population died as a consequence of advanced dementia (34.8%). However, the analysis revealed a significant difference between the pre-COVID-19 group and the COVID-19 group for this cause of death. Wherein advanced dementia occurred significant more often as a cause of death in the COVID-19 group in comparison to the pre-COVID-19 group (43.0% vs 31.4%, p = .020). Moreover, stop eating/drinking appeared significantly more often as a cause of death in the COVID-19 group in comparison to the pre-COVID-19 group (40.0% vs 27.7%, p = .011). The cause of death was significantly more often unknown in the COVID-19 group in comparison to the pre-COVID-19 group (9.8% vs 2.2%, p < .001).

Characteristics	Pre-COVID-19 period (n = 136)	COVID-19 period (n = 298)	Sig.	COVID-19 as cause of death (n = 16)	Total (n = 433)
Bereaved					
Age, mean (SD)	62.8 (10.3)	62.2 (10.7)	.573	59.9 (10.4)	62.4 (10.6)
Gender, number (%)					
Men	54 (39.7)	98 (33.2)	.190	7 (43.8)	152 (43.9)
Women	82 (60.3)	197 (66.8)	.190	9 (56.3)	284 (65.1)
Relationship to deceased, number (%)					
Partner	21 (15.6)	54 (18.4)	.476	2 (12.5)	77 (17.7)
Son (in law) or daughter (in law)	101 (74.8)	200 (68.0)	.154	13 (81.3)	303 (69.8)
Grandson or granddaughter	0 (0)	3 (1.0)	.239	0 (0)	3 (0.7)
Brother (in law) or sister (in law)	4 (3.0)	10 (3.4)	.812	0 (0)	14 (3.2)
Cousin or niece	4 (3.0)	15 (5.1)	.317	0 (0)	19 (4.4)
Other	5 (3.7)	12 (4.1)	.852	1 (6.3)	18 (4.1)
Deceased					
Age, mean (SD)	86.7 (7.7)	85.5 (7.2)	.118	82.3 (6.0)	85.9 (7.4)
Gender, number (%)					
Men	50 (36.8)	110 (36.8)	.976	6 (37.5)	162 (36.9)
Women	84 (61.8)	188 (63.1)	.792	10 (62.5)	275 (62.6)

Suspected dementia, number (%)	128 (96.2)	285 (96.6)	.743	15 (93.8)	418 (96.5)
Official diagnosed dementia, number (%)	118 (87.4)	248 (83.8)	.610	13 (81.3)	371 (85.1)
Cause of death, number (%)					
COVID-19	0 (0)	16 (5.4)	.628	16 (100)	16 (18.4)
Trouble swallowing	16 (11.9)	33 (11.1)	.813	2 (12.5)	49 (11.2)
Pneumonia	23 (17.0)	38 (12.8)	.406	1 (6.3)	62 (14.2)
Heart failure	14 (10.4)	32 (10.8)	.330	0 (0)	47 (10.7)
Infections	17 (12.7)	33 (11.1)	.636	2 (12.5)	52 (11.9)
Cancer	10 (7.5)	15 (5.1)	.312	0 (0)	26 (6.0)
Complications after fall	16 (11.9)	42 (14.1)	.518	1 (6.3)	58 (13.2)
Stopped eating/drinking	54 (40.0)	82 (27.7)	.011	1 (6.3)	136 (31.1)
Advanced dementia	58 (43.0)	93 (31.4)	.020	2 (12.5)	152 (34.8)
Stroke	7 (5.2)	16 (5.4)	.931	1 (6.3)	23 (5.3)
Unknown	3 (2.2)	29 (9.8)	<.001	1 (6.3)	33 (7.5)
Other	28 (20.7)	62 (20.9)	.975	0 (0)	91 (20.8)
Transfers during the last six months of life, number (%)	19 (14.2)	57 (19.4)	.191	3 (33.3)	76 (17.5)

Table 1: Participants characteristics stratified for the pre-COVID-19 period, COVID-19 period, COVID-19 as cause of death and the total population.

3.2 Involved caregivers

In the most cases of the total population (85.2%) a nursing aid was involved (Table 2). As well as for the geriatrician, who was involved in 77.6% of all cases. These caregivers were also the most often involved in the group where COVID-19 is established as cause of death.

Nevertheless, the data showed significant differences between the pre-COVID-19 group and the COVID-19 group for the involved caregivers. The nursing aid was significantly more often involved in the COVID-19 group in comparison to the pre-COVID-19 group (87.5% vs 80.1%, p = .046). This applies likewise for nurses (36.5% vs 26.5%, p = .040), geriatricians (80.4% vs 70.4%, p = .047), dementia case managers (12.5% vs 5.8%, p = .036), psychotherapists (22.3% vs 11.0% p = .005) as involved caregiver.

Items	Pre-COVID-19 period (n = 136)	COVID-19 period (n = 298)	Sig.	COVID-19 as cause of death (n = 16)	Total (n = 433)
Involved caregivers, number (%)					
Nursing aid	109 (80.1)	259 (87.5)	.046	15 (93.8)	373 (85.2)
Nurse	36 (26.5)	108 (36.5)	.040	6 (43.8)	147 (33.6)
General practitioner	37 (27.4)	62 (20.9)	.139	2 (12.5)	100 (22.9)
Geriatrician	95 (70.4)	238 (80.4)	.047	13 (81.3)	339 (77.6)
Case manager dementia	8 (5.9)	37 (12.5)	.036	2 (12.5)	45 (10.3)
Social worker	3 (2.2)	8 (2.7)	.761	0 (0)	11 (2.5)
Psychologist	10 (7.4)	38 (12.8)	.092	3 (18.8)	48 (11.0)
Mental caretaker	15 (11.0)	35 (11.8)	.810	3 (18.8)	51 (11.6)
Dentist	15 (11.0)	41 (13.9)	.417	2 (12.5)	57 (13.0)
Physiotherapist	15 (11.0)	66 (22.3)	.005	3 (18.8)	82 (18.7)
Occupational therapist	20 (14.7)	49 (16.6)	.626	3 (18.8)	70 (16.0)
Dietist	16 (11.9)	35 (11.9)	.997	4 (25.0)	51 (11.7)
Speech therapist	8 (5.9)	23 (7.8)	.475	0 (0)	31 (7.1)

Items	Pre-COVID-19 period (n = 136)	COVID-19 period (n = 298)	Sig.	COVID-19 as cause of death (n = 16)	Total (n = 433)
Activity supervisor	41 (30.1)	94 (31.8)	.737	4 (25.0)	138 (31.5)
Volunteer	42 (30.9)	82 (28.2)	.566	3 (20.0)	125 (28.9)
Not known	7 (5.1)	8 (2.7)	.197	0 (0)	15 (3.5)
Other	8 (5.9)	18 (6.1)	.950	0 (0)	26 (5.9)

Table 2: Involved caregivers stratified for the pre-COVID-19 period, COVID-19 period, COVID-19 as cause of death and the total population.

3.3 Wishes

The analyses showed that in the majority of the participants (68.6%) end-of-life wishes have been discussed (Table 3). End-of-life wishes have been recorded in 54.2% of all cases. Most of the deceased people could not indicate these wishes him/herself (66.2%). Besides, in 85.4% these wishes have been acted upon (85.4%). These ratios also apply for the COVID-19 as cause of death group. Additionally, no significant differences in these items were found between the pre-COVID-19 group and the COVID-19 group.

Items	Pre-COVID-19 period (n = 136)	COVID-19 period (n = 298)	Sig.	COVID-19 as cause of death (n = 16)	Total (n = 433)
End-of-life wishes have been discussed, number (%)					
Yes	89 (69.0)	152 (68.5)	.919	7 (53.8)	243 (68.6)
No	25 (19.4)	45 (20.3)	.840	3 (23.1)	71 (20.1)
Partly	8 (6.2)	17 (7.7)	.609	3 (23.1)	25 (7.1)
Unknown	6 (4.4)	7 (3.2)	.474	0 (0)	13 (3.7)
End-of-life wishes are recorded, number (%)					
Yes	53 (51.0)	105 (55.9)	.422	7 (53.8)	160 (54.2)

No	25 (24.0)	46 (24.5)	.935	3 (23.1)	27 (24.4)
Partly	9 (8.7)	8 (4.3)	.124	3 (23.1)	17 (5.8)
Unknown	17 (16.3)	28 (14.9)	.742	0 (0)	45 (15.3)
Deceased could indicate wishes him/herself, number (%)					
Yes	19 (17.6)	30 (16.4)	.792	2 (16.7)	49 (16.7)
No	75 (69.4)	118 (64.5)	.387	9 (75.0)	194 (66.2)
Partly	14 (13.0)	34 (18.6)	.212	0 (0)	49 (16.7)
Unknown	0(0)	0(0)	1	1 (8.3)	0 (0)
The wishes have been acted upon, number (%)					
Yes	42 (82.4)	74 (87.1)	.453	7 (77.8)	117 (85.4)
No	5 (9.8)	4 (4.7)	.247	1 (11.1)	9 (6.6)
Partly	4 (7.8)	7 (8.2)	.935	0 (0)	11 (8.0)
Unknown	0(0)	0(0)	1	1 (11.1)	0 (0)

Table 3: Wishes stratified for the pre-COVID-19 period, COVID-19 period, COVID-19 as cause of death and the total population.

3.4 Items specific for COVID-19 period

As well as in the COVID-19 group as in the COVID-19 as cause of death group there was most often the ability to say goodbye during the last two days before death (92.9% and 92.3%). In the COVID-19 group, for 78.3% of the participants there was a sufficient opportunity for farewell rituals before death. However, in the group where COVID-19 was established as cause of death, in 46.2% of the cases there was a sufficient opportunity for farewell rituals for before death. In the COVID-19 group, 46.5% of the participants were present themselves when their relative passed away. Nonetheless, in the COVID-19 as cause of death group, 30.8% were present themselves. The bereaved rated the received care in the

last week in 47.8% of the cases as 'excellent'. In the COVID-19 as cause of death 16.7% of the participants rated this care as 'excellent'. Furthermore, in this group, 25.0% of the participants rated the care as 'bad'. In the COVID-19 group 4.3% of them rated the care as 'bad'. Moreover, most of the bereaved in both groups were affected by the COVID-19 measures (58.6% and 61.5%). In the COVID-19 group 34.3% of the participants reported that nobody was affected by the COVID-19 measures. In the COVID-19 as cause of death group less participants recorded this (23.1%). Lastly, both groups often received sufficient support by the institution in the event of the loss (95.6% in COVID-19 group). Yet this number was lower in the COVID-19 as cause of death group (83.3%).

Items	COVID-19 period (n = 298)	COVID-19 as cause of death (n = 16)
Ability to say goodbye during last two days before death [number (%)]	65 (92.9)	12 (92.3)
Sufficient opportunity for farewell rituals before death [number (%)]	54 (78.3)	6 (46.2)
Present when relative passed away [number (%)]		
Yourself	33 (46.5)	4 (30.8)
Other family member or close relative(s)	26 (37.1)	1 (7.7)
Doctor(s)	0 (0)	0 (0)
Nurse(s) and/or carer(s)	23 (32.9)	6 (46.2)
Volunteer Minister, Priest, Pastor or Spiritual Caregiver	1 (1.4)	1 (7.7)
Nobody	17 (24.6)	3 (25.0)
Rate of care relative received from the caregivers in the last week [number (%)]		
Excellent	33 (47.8)	2 (16.7)

Very good	17 (24.6)	3 (25.0)
Good	15 (21.7)	3 (25.0)
Moderate	1 (1.4)	1 (8.3)
Bad	3 (4.3)	3 (25.0)
Affected by COVID-19 measures [number (%)]		
Bereaved	41 (58.6)	8 (61.5)
Deceased	4 (5.7)	1 (7.7)
Nobody	24 (34.3)	18.8 (23.1)
Sufficient supported by the institution in the event of the loss [number (%)]	65 (95.6)	10 (83.3)

Table 4: Items specific for COVID-19 period stratified for COVID-19 period and COVID-19 as cause of death.

3.5 SWC

The mean sum SWC-score for the pre-COVID-19 group was 35.02 and for the COVID-19 group 35.47 (Table 4). The average sum SWC-score for the COVID-19 as cause of death group was 34.25 and for the group who died of other causes was 36.28 (Table 5). The analysis revealed no significant difference in the sum scores of the SWC scale between the pre-COVID-19 group and the COVID-19 group. Also, for the comparison of the sum scores of the SWC scale between the people who died as a consequence of COVID-19 and the people who died of other causes, no significant effect was found. Likewise, the analyses showed no significant differences between the subitems of the SWC-scale for the comparison between the pre-COVID-19 group and the COVID-19 group (Appendix 3). Although, differences were found between the group who died as a cause of COVID-19 and the group who died of other causes (Appendix 6) for the following subitems of the SWC-scale: (1) "probably different decisions would have been made if I had more information" scored higher in the COVID-19 as cause of death group (2.19 vs 1.59, $p = .008$) and (2) "the nurses/carers were attentive to my needs and feelings" scored lower in the COVID-19 as cause of death group (3.06 vs 3.52, $p = .044$).

3.6 CAD

The mean sum CAD-score for the pre-COVID-19 group was 30.90 and for the COVID-19 group 35.47 (Table 4). The average sum CAD-score for the COVID-19 as cause of death group was 31.87 and for the group who died of other causes was 32.05 (Table 5). No significant difference in the sum CAD-score were detected between these groups. Besides no difference is ascertained for the subitems of the CAD-scale between the four groups (Appendix 2 & Appendix 5).

3.7 SM

The mean sum SM-score for the pre-COVID-19 group was 27.21 and for the COVID-19 group 28.61 (Table 4). The analysis showed no significance difference in the sum scores of the SM scale between the pre-COVID-19 group and the COVID-19 group. The average sum SWC score for the COVID-19 as cause of death group was 30.23 and for the group who died of other causes was 27.51 (Table 5). Also, for the comparison of the sum scores of the SM scale between the people who died as a consequence of COVID-19 and the people who died of other causes, no significant effect was found. However, in the COVID-19 as cause of death group the participants scored significant higher on the subitem 'depression' in comparison to the group with other causes of death (3.67 vs 2.44, $p = .029$) (Appendix 7). Furthermore, the data showed no significant difference in subitems between the pre-COVID-19 group and COVID-19 group (Appendix 4).

Scale	n	Mean	Mean difference	SE difference	t	p
Sum SWC			-.45	.54	-.84	.402
Pre COVID-19 period	114	35.02				
COVID-19 period	258	35.47				
Sum CAD			-.23	.52	-.44	.659
Pre COVID-19 period	101	30.90				

COVID-19 period	207	31.13				
Sum SM			-1.40	1.05	-1.33	.184
Pre COVID-19 period	87	27.21				
COVID-19 period	197	28.61				

Table 5: Difference sum scores of SWC, CAD, and SM-scales between pre-COVID-19 period and COVID-19 period.

Scale	n	Mean	Mean difference	SE difference	t	p
Sum SWC			2.03	1.93	1.05	.296
COVID-19 as cause of death	16	34.25				
Other cause of death	57	36.28				
Sum CAD			.18	1.30	.14	.890
COVID-19 as cause of death	15	31.87				
Other cause of death	42	32.05				
Sum SM			-2.72	2.38	-1.14	.258
COVID-19 as cause of death	13	30.23				
Other cause of death	45	27.51				

Table 6: Difference sum scores of SWC, CAD, and SM-scales between COVID-19 as cause of death group and group with other causes of death

4 Discussion

4.1 Main findings

The aim of this study was to examine whether the COVID-19 period had an effect on the quality of dying among people with dementia living in the nursing home setting from the perspective of their loved ones. It was investigated as well whether dying as a consequence of COVID-19 has an effect on this perceived quality of dying. The current study found no significant differences in SWC-, CAD-, and SM-scores between the pre-COVID-19 group and the COVID-19 group. Indicating that there are no differences between these groups in overall level of comfort (CAD-scale), overall frequency of symptoms (SM-scale) and overall satisfaction of end-of-life care (SWC-scale). However, some significant differences were reported between these two groups. First, advanced dementia and stop eating/drinking occurred more often in the COVID-19 group as well as 'the cause was more often unknown'. In the COVID-19 group, nursing aids, nurses, geriatricians, dementia case managers, and psychotherapists, were more often involved as caregivers.

Additionally, no significant difference was found between the people who died as a consequence of COVID-19 and the people who died of other causes for the SWC-, CAD- and SM-scores. Indicating no differences between these groups in overall level of comfort (CAD-scale), overall frequency of symptoms (SM-scale) and the overall satisfaction of end-of-life care (SWC-scale). Nonetheless, the subitem of the SWC-scale "probably different decision would have been made if I had more information" scored significantly higher in the COVID-19 as cause of death group and "the nurses/carers were attentive to my needs and feelings" scored significantly lower in the COVID-19 as cause of death group in comparison to the people who died of other causes. Moreover, the COVID-19 as a cause of death group also scored significant higher on the "depression" subitem of the SM-scale.

Lastly, some notable considerations can be argued about the group where COVID-19 was established as cause of death in comparison to the COVID-19 group. First, for the COVID-19 as cause of death group it seems there was less often a sufficient opportunity for farewell rituals before death. Second, the bereaved were less often present themselves when their relative passed away. Besides, it appears that this group rated the received care in the last week in general as less in comparison to the COVID-19 group. This group also reported less frequently that nobody was affected by the COVID-19 measures. Last of all, they declared less commonly that they received sufficient support by the institution in the event of loss.

4.2 Reflection on the overall findings

Simonetti et al. (2020) found that people with dementia suffered more from apathy, anxiety, and agitation during the COVID-19 pandemic. This does not align with the current study. Since current findings showed no differences in overall level of comfort, overall frequency of symptoms, and overall satisfaction of end-of-life care for people with dementia during the COVID-19 pandemic in comparison to people with dementia before the COVID-19 pandemic. However, this study did find that dying as a consequence of COVID-19 among people with dementia leads to a higher level of depression. The study of Lara et al., 2020 analyzed the impact of the COVID-19 pandemic on the neuropsychiatric symptoms and their quality of life on patients with Alzheimer disease after 5 weeks of lockdown in Spain. These people suffered significantly more from agitation, apathy, and aberrant motor activity. Other symptoms, such as depression, also worsened, but were not statistically significantly different. Furthermore, study of Bolt et al. (2019) found that families of nursing homes residents with dementia essentially complained about 2 issues in the care of their loved one at the end of life. Namely, a feeling that they were being neglected, and a feeling they were treated in a disrespectful manner (Bolt et al., 2019). Also, Hennings et al (2010) found that families witnessing the end of life of a loved one with dementia in nursing homes need supportive communication, adequate information, and sufficient attention from professional caregivers. This may explain why people with dementia who died as a cause of COVID-19 scored higher on the item "probably different decision would have been made if I had more information" and lower on the item "the nurses/carers were attentive to my needs and feelings", since these items are seen as important aspects in high quality end-of-life care.

4.3 Limitations and strengths

The current study has several limitations and strengths. First, this study is conducted at one care organization, Zuyderland Zorg. Therefore, this may lower the generalizability. However, there has been focused on eight locations of this organization. Second, the questionnaire is sent by post to the participants. After filling in the questionnaire, they are asked to return the questionnaire via post. Consequently, many missing values are reported since it is possible to return a partly filled in questionnaire. Furthermore, participating in completely voluntary. As a consequence, it may be possible that only people who were extremely positive or negative fill in the questionnaire. Specifically, this could induce selection bias. On the other side, by sending the questionnaire by post, many potential participants can be reached. Another strength of current study is that the questionnaire included questions about COVID-19. Nevertheless, the questionnaire is filled by proxies, the next of kin of the deceased. These

people are not able to adequately judge about medical conditions. Besides, McPherson & Addington-Hall (2003) showed that the agreement of patient views and proxy views is poor for subjective aspects, such as pain, anxiety, and depression. This may affect the reliability. However, the three used scales in this study (CAD, SM, and SWC) is also a strength since these scales are validated and can be used as outcome measures in studies investigating effectiveness of interventions aimed to improve end-of-life care for individuals with dementia (Volicer et al., 2001). Lastly, at the beginning of the COVID-19 pandemic, COVID-19 was less recognized as cause of death. It was harder to diagnose since less knowledge was available about the virus. At an older age, COVID-19 is harder to recognize because of atypical clinical presentation of COVID-19 that may supersede classical COVID-19 infection symptoms (Bianchetti et al., 2020). This could interfere with the identification of COVID-19 for elderly with dementia (Isaia et al., 2020).

4.4 Suggestions for further research and practice

It seems dying as a consequence of COVID-19 has an effect on the perceived quality of care. However, the group who died as a consequence of COVID-19 consisted of only 16 participants. Although this could be due to the fact that COVID-19 was less recognized as cause of death at the beginning of the pandemic. However, further research could focus more on this group of people and therefore focus on a bigger group of people where COVID-19 is the cause of death. Also, to increase reliability, further research could use doctor files instead of proxy measures. Moreover, it seems dying as a consequence of COVID-19 has a negative effect on the opportunities for farewell rituals before death, the overall rated received care, presence of loved ones during death, received support by the institution in the event of loss, and consequences of COVID-19 measures. However, more research is needed to explore this more extensively. Based on the findings of current study, there are a few points the practice should focus on to improve quality of palliative care, and therefore the quality of death, for people with dementia who die as a consequence of COVID-19. First, providing more information so based on this information the loved ones of the person with dementia can make to the most optimal best-informed decisions. Furthermore, nurses/carers should be more attentive to the needs and feelings of the loved ones of the people with dementia. Lastly, more focus should be on preventing and decrease depressive symptoms. However, more research is needed for a strategy on how to implement this in practice.

4.5 Conclusion

In conclusion, the COVID-19 period as well as dying as a consequence of COVID-19 has no effect on the overall level of comfort, overall frequency of symptoms and overall satisfaction of end-of-life care. However, looking at the subitems of the scales, indicated that dying as a consequence of COVID-19 increases the likelihood that different decisions would have been made if he/she had more information; and decreases the satisfaction about whether the nurses/carers were attentive to his/her needs and feelings. Moreover, it seems that dying as a consequence of COVID-19 decreases the level of depression in comparison to people who die of other causes.

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Appendix 1 - Questionnaire

Zorgcentra

Introductie

Onlangs is uw dierbare overleden. Zuyderland verleende zorg tijdens de laatste levensfase van uw dierbare. We streven er bij Zuyderland naar om optimale zorg te verlenen. Als naaste maakte u deze zorg van dichtbij mee. Om de zorg in de toekomst verder te kunnen verbeteren, is het belangrijk om te onderzoeken wat daarvoor nodig is. Om hier inzicht in te krijgen, willen wij u vriendelijk vragen om deze vragenlijst in te vullen.

Daarnaast kan de informatie uit de vragenlijst (anoniem) gebruikt worden binnen een onderzoek naar zorg in de laatste levensfase waaraan Zuyderland meewerkt. Dit onderzoek wordt uitgevoerd door de Universiteit Maastricht.

Deze vragenlijst is anoniem, u hoeft dus nergens uw naam in te vullen. Uw antwoorden zijn niet direct herleidbaar naar u of uw naaste.

Mocht u niet willen deelnemen, dan hoeft u verder niets te doen. Als u wel wilt deelnemen, dan kunt u de ingevulde vragenlijst door middel van bijgevoegde antwoordenvelop terug sturen.

Wij hopen dat u wilt meewerken aan de kwaliteitsverbetering van zorg in de laatste levensfase en danken u alvast voor uw medewerking.

zuyderland

1. Uw gegevens

1.Wat is uw geslacht?	□ Vrouw □ Man
2.Wat is uw leeftijd?	| | Jaar
3.Wat was uw relatie tot uw naaste/familielid?	□ Partner □ (Schoon)zoon of dochter □ Kleinzoon of kleindochter □ (Schoon)broer of (schoon)zus □ Neef of nicht □ Anders: | |

2. Gegevens van uw naaste

4.Wat was het geslacht van uw naaste?	□ Vrouw □ Man
5.Wat was de leeftijd van uw naaste?	| | Jaar
6. Wanneer is uw naaste overleden?	maand-jaar |
7.Wanneer werd uw naaste opgenomen in het verpleeghuis?	maand-jaar |
8.Hoe heette de afdeling waar uw naaste werd opgenomen?	| |

Er is bij dementie sprake van een geheugenstoornis. Vormen van dementie zijn bijvoorbeeld de ziekte van Alzheimer, vasculaire dementie, Lewy body dementie en fronto-temoporale dementie (FTD)

9. Was er sprake van een vermoeden van dementie?	□ Ja □ Nee
10. Was er een officiële diagnose gesteld door een arts of op de geheugenpoli?	□ Ja □ Nee □ Weet ik niet
11. Hoe at uw naaste een maand voor het overlijden?	□ At zelfstandig □ Minimale hulp en/of aanmoediging nodig □ Tamelijk veel hulp en/of aanmoediging nodig □ Volledig afhankelijk

zuyderland

12. Wat was de oorzaak van overlijden?
(meerdere antwoorden mogelijk)

□ COVID-19/Corona symptomen
□ Problemen met slikken
□ Longontsteking (Pneumonie)
□ Hartfalen
□ Infectie(s)
□ Kanker
□ Complicaties na val
□ Gestopt met eten/drinken
□ Beroerte
□ Gevorderde dementie
□ Weet ik niet
□ Anders nl.

13. Welke zorgverleners waren betrokken bij de zorg in de laatste 3 maanden van uw naaste?
(meerdere antwoorden mogelijk)

□ Verzorgende
□ (Wijk)verpleegkundige
□ Huisarts
□ Verpleeghuisarts/specialist ouderengeneeskunde
□ Casemanager dementie
□ Maatschappelijk werker
□ Psycholoog
□ Geestelijk verzorger
□ Tandarts
□ Fysiotherapeut
□ Ergotherapeut
□ Diëtist
□ Logopedist
□ Activiteitenbegeleider
□ Vrijwilliger
□ Weet ik niet
□ Anders, nl.

14a. Is uw naaste in de **laatste drie maanden** voor overlijden nog op een andere afdeling of bij een andere organisatie opgenomen geweest?

□ Ja
□ Nee

14b. Indien ja, kunt u aangeven waar?

□ Spoedeisende hulp
□ Ziekenhuis
□ Hospice
□ Bijna Thuis Huis
□ Andere afdeling binnen het verpleeghuis
□ Revalidatie afdeling
□ Weet ik niet
□ Anders, nl

zuyderland

15a. Zijn de wensen van uw naaste rondom het levenseinde met de zorgverleners besproken en vastgelegd?

□ Ja
□ Nee
□ Deels
□ Weet ik niet

15b. Indien ja, was uw naaste nog in staat zijn/haar wensen aan te geven toen dit werd besproken/vastgelegd?

□ Ja
□ Nee
□ Deels
□ Weet ik niet

15c. Is er volgens deze besproken wensen gehandeld?

□ Ja
□ Nee
□ Deels
□ weet ik niet

16a. Heeft een zorgverlener u kort voor het overlijden van uw naaste erop attent gemaakt dat het overlijden op korte termijn te verwachten was?

□ Ja
□ Nee
□ Weet ik niet

16b. Was u in de gelegenheid persoonlijk afscheid te nemen gedurende de laatste twee dagen voor het overlijden van uw naaste?

□ Ja onbeperkt
□ Ja beperkt
□ Ja dat mocht, maar ik ging niet op bezoek, want

□ Nee

16c. Is er voldoende gelegenheid geweest om afscheidsrituelen te laten plaatsvinden voor het overlijden?

□ Ja
□ Nee, want

16d. Wie waren er aanwezig toen uw familielid/naaste overleed? (*meerdere antwoorden mogelijk*)

□ Uzelf
□ Ander familielid of naaste(n)
□ Arts(en)
□ Verpleegkundige(n) en/of verzorgende(n)
□ Pastoraal werker, priester, dominee of geestelijk verzorger
□ Iemand anders, namelijk:

□ Niemand

16e.Hoe zou u de zorg die uw familielid/naaste in de laatste week ontving van de zorgverleners over het geheel genomen beoordelen?

□ Uitstekend
□ Zeer goed
□ Goed
□ Matig, want:

□ Slecht, want:

16F. Heeft u of uw naaste last gehad van COVID-19 maatregelen in het verpleeghuis?

□ Ja ikzelf, want:

□ Ja mijn naaste, want:

□ Nee
□ N.v.t.

16G. Bent u voldoende ondersteund door de instelling bij het verlies van uw naaste?

□ Ja
□ Nee, want:

End-of-Life in Dementia (EOLD) scales– Comfort Assessment in Dying (CAD)

Als u terugdenkt aan de lichamelijke en emotionele toestand van uw familielid/naaste, kunt u dan aangeven in welke mate hij of zij het volgende ondervond **tijdens de laatste week van het leven**? *(Per regel graag een kruisje zetten in de kolom die van toepassing, graag ook aangeven wat u denkt als u het niet zeker weet)*

		veel	*Enigszins*	*niet*
a.	Onbehagen	□	□	□
b.	Pijn	□	□	□
c.	Rusteloosheid	□	□	□
d.	Kortademigheid	□	□	□
e.	Verslikken	□	□	□
f.	Rochelen	□	□	□
g.	Moeite met slikken	□	□	□
h.	Angst	□	□	□
I.	Ongerustheid	□	□	□
j.	Huilen	□	□	□
k.	Kreunen	□	□	□
l.	Sereniteit (innerlijke rust)	□	□	□
m.	Vrede	□	□	□
n.	Kalmte	□	□	□

zuyderland

Hoe vaak denkt u dat uw familielid/naaste het volgende ondervond **in de laatste 3 maanden** voor overlijden? (*Per regel graag een kruisje zetten in de kolom die van toepassing is*)

		ooit	één keer (die periode)	2 of 3 dagen (die periode)	één keer per week	Enkele dagen per week	Elke dag
a.	Pijn	☐	☐	☐	☐	☐	☐
b.	Kortademigheid	☐	☐	☐	☐	☐	☐
c.	Doorligwond(en)	☐	☐	☐	☐	☐	☐
d.	Rust	☐	☐	☐	☐	☐	☐
e.	Depressie	☐	☐	☐	☐	☐	☐
f.	Angst	☐	☐	☐	☐	☐	☐
g.	Ongerustheid	☐	☐	☐	☐	☐	☐
h.	Opwinding	☐	☐	☐	☐	☐	☐
I.	Weerstand bieden tegen zorg	☐	☐	☐	☐	☐	☐

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*Als u denkt aan de artsen, verpleegkundigen, ziekenverzorgenden en ander personeel met wie u contact had tijdens de **laatste 3 maanden** van het leven: in welke mate vindt u dan dat de volgende uitspraken uw ervaringen weergeven? (Graag één vakje per rij aankruisen)*

		Helemaal **niet** mee eens	Niet mee eens	Mee eens	Helemaal mee **eens**
a.	Ik voelde mij volledig betrokken bij alle beslissingen	☐	☐	☐	☐
b.	Er zouden waarschijnlijk andere beslissingen zijn genomen als ik meer informatie had gehad	☐	☐	☐	☐
c.	Alle maatregelen werden genomen zodat mijn familielid/naaste zich zo comfortabel mogelijk voelde	☐	☐	☐	☐
d.	Het behandelteam had oog voor mijn behoeften en gevoelens	☐	☐	☐	☐
d1.	De arts had oog voor mijn behoeften en gevoelens	☐	☐	☐	☐
d2.	De verpleegkundigen/verzorgenden hadden oog voor mijn behoeften en gevoelens	☐	☐	☐	☐
e.	Ik begreep de toestand van mijn familielid/naaste niet echt	☐	☐	☐	☐

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f.	Ik wist altijd welke arts of verpleegkundige/verzorgende belastwas met de zorg voor mijn familielid/naaste	☐	☐	☐	☐
g.	Ik vind dat mijn familielid/naaste allenoodzakelijke verpleegkundige/ verzorgende hulp kreeg	☐	☐	☐	☐
h.	Ik vind dat het medicijngebruik duidelijk aan mij werd uitgelegd	☐	☐	☐	☐
i.	Mijn familielid/naaste kreeg, voor zover ik dat weet, alle behandelingenof maatregelen waar hij of zij baat bij kon hebben	☐	☐	☐	☐
j.	Ik ben van mening dat mijn familielid/naaste betere medische zorg had moeten krijgen aan het einde van zijn of haar leven	☐	☐	☐	☐

Ik ervaarde de plaats waar mijn familielid/naaste **het laatst** verbleef als een plek waar:

(*graag één vakje per rij aankruisen*)	helemaal **niet**	een beetje	in redelijke mate	grotendeels	**helemaal**
a. zorgverleners verstand van zakenhebben	☐	☐	☐	☐	☐
b. mijn familielid / naaste veilig was	☐	☐	☐	☐	☐
c. mijn familielid / naaste echt welkomwas	☐	☐	☐	☐	☐
d. zorgverleners tijd leken te hebbenvoor mijn familielid / naaste	☐	☐	☐	☐	☐
e. het huiselijk aanvoelde	☐	☐	☐	☐	☐
f. zorgverleners zich extra inspanden voor het comfort van mijn familielid /naaste	☐	☐	☐	☐	☐
g. mijn familielid / naaste net dat 'beetjeextra' kon krijgen	☐	☐	☐	☐	☐

Probeert u voor onderstaande vragen terug te denken aan de **laatste maand** van het leven van uw familielid/naaste. Hieronder staan enkele uitspraken die wel als belangrijk worden beschouwd in de laatste fase van het leven. In welke mate gold elke uitspraak voor (de situatie van) uw familielid/naaste?

(*graag één vakje per rij aankruisen*)	helemaal **niet**	een beetje	in redelijke mate	grotendeels	**helemaal**
a. de kleding en het lichaam van uwfamilielid / naaste waren schoon	☐	☐	☐	☐	☐
b. uw familielid / naaste ontving elkedag liefdevolle aanrakingen	☐	☐	☐	☐	☐
c. de waardigheid van uw familielid /naaste werd behouden	☐	☐	☐	☐	☐
d. de behandelend arts van uw familielid / naaste kende zijn / haarleven en persoonlijkheid	☐	☐	☐	☐	☐
e. er was een verpleegkundige of verzorgende bij wie uw familielid /naaste zich op zijn / haar gemak voelde	☐	☐	☐	☐	☐
f. uw familielid/naaste behield zijnof haar gevoel voor humor	☐	☐	☐	☐	☐
g. uw familielid/naaste gaf aan dat hij of zij gereed was om te sterven	☐	☐	☐	☐	☐
h. uw familielid/naaste leek vrede tehebben	☐	☐	☐	☐	☐
i. uw familielid/naaste had behandelwensen op schrift staan	☐	☐	☐	☐	☐
j. uw familielid/naaste had iemandaangewezen die besluiten kon nemen in het geval dat hij of zij dat niet langer meer zou kunnen	☐	☐	☐	☐	☐
k. de begrafenis of crematie vanuw familielid/naaste was voorbereid	☐	☐	☐	☐	☐

Wilt u nog iets anders kwijt, of iets toevoegen aan uw antwoorden? Dat kan hieronder.

Wij danken u hartelijk voor uw medewerking, uw antwoorden zijn zeer waardevol.

Appendix 2 - Analysis per item CAD I

Scale item	n	Mean	Mean difference	SE difference	t	p
Discomfort			.03	.08	.39	.700
Pre COVID-19 period	114	2.04				
COVID-19 period	259	2.01				
Pain			.02	.08	.23	.774
Pre COVID-19 period	117	2.12				
COVID-19 period	262	2.10				
Restlessness			.03	.09	.37	.715
Pre COVID-19 period	118	1.92				
COVID-19 period	267	1.88				
Shortness of breath			-1.00	.09	-1.16	.247
Pre COVID-19 period	116	2.12				
COVID-19 period	165	2.22				
Choke			-.23	.16	-1.43	.155
Pre COVID-19 period	115	2.38				
COVID-19 period	250	2.61				
Gurgle			-.07	.09	-.83	.406

Pre COVID-19 period	114	2.15				
COVID-19 period	256	2.22				
Difficuly swallowing			-.02	.09	-.22	.826
Pre COVID-19 period	113	2.09				
COVID-19 period	249	2.11				
Fear			.00	.09	.03	.973
Pre COVID-19 period	111	2.21				
COVID-19 period	245	2.20				
Anxiety			.04	.09	.49	.628
Pre COVID-19 period	110	2.21				
COVID-19 period	250	2.16				
Crying			-.09	.08	-1.08	.281
Pre COVID-19 period	116	2.50				
COVID-19 period	249	2.59				
Moaning			-.07	.08	-.79	.428
Pre COVID-19 period	112	2.34				
COVID-19 period	250	2.40				
Serenity			.02	.09	.28	.781
Pre COVID-19 period	109	2.17				
COVID-19 period	246	2.15				

				.00	.08	.06	.953
Peace							
Pre COVID-19 period	111	2.01					
COVID-19 period	247	2.00					
Calmness				.05	.08	.66	.512
Pre COVID-19 period	110	2.02					
COVID-19 period	248	1.96					

Table 7: Difference subitem scores of CAD scale between COVID-19 as cause of death group and group with other causes of death.

Appendix 3 - Analysis per item SWC I

Scale item	n	Mean	Mean difference	SE difference	t	p
I felt complete involved in all decisions			-.04	.08	-.51	.613
Pre COVID-19 period	128	3.36				
COVID-19 period	284	3.40				
Probably different decisions would have been made if I had more information			.06	.08	.68	.497
Pre COVID-19 period	123	1.76				
COVID-19 period	279	1.70				
All measures were taken so that my relative felt as comfortabel as possible			-.06	.08	'-.83	.410
Pre COVID-19 period	126	3.38				
COVID-19 period	283	3.45				
The treatment team had an eye for my needs and feelings			-0.5	0.07	.74	.460
Pre COVID-19 period	125	3.34				
COVID-19 period	280	3.40				
The doctor was attentive to my needs and feelings			-.01	.07	-.18	.860
Pre COVID-19 period	125	3.32				
COVID-19 period	273	3.33				
The nurses/carers were attentive to my needs and feelings			-.76	.45	-.05	.446
Pre COVID-19 period	125	3.45				
COVID-19 period	279	3.50				

	N	Mean				
I did not really understood the condition of my relative			-.04	.23	-1.84	.854
Pre COVID-19 period	124	1.65				
COVID-19 period	279	1.69				
I always knew which doctor or nurse/carer was in charge of taking care of my relative			-.17	.09	-1.84	.067
Pre COVID-19 period	128	2.91				
COVID-19 period	278	3.08				
I think my relative received all necessary nurse/nurturing help			-.14	0.07	-1.87	0.062
Pre COVID-19 period	127	3.34				
COVID-19 period	281	3.48				
I think the drug use was clearly explained to me			-.06	.08	-.78	.433
Pre COVID-19 period	127	3.26				
COVID-19 period	277	3.32				
My relative received all treatments or measures that could benefit him or her			-.12	.08	-1.57	.117
Pre COVID-19 period	127	3.30				
COVID-19 period	279	3.42				
I think my relative should have received better medical care at the end of his or her life			.09	.09	1.00	.317
Pre COVID-19 period	126	1.67				
COVID-19 period	278	1.58				

Table 8: Difference subitem scores of SWC scale between COVID-19 as cause of death group and group with other causes of death.

Appendix 4 - Analysis per item SM I

Scale item	n	Mean	Mean difference	SE difference	t	p
Pain			-.02	.20	-.11	.914
Pre COVID-19 period	115	3.94				
COVID-19 period	257	3.96				
Shortness of breath			-.08	.21	-.39	.694
Pre COVID-19 period	114	2.69				
COVID-19 period	259	2.78				
Pressure ulcer(s)			.19	.22	.89	.376
Pre COVID-19 period	112	2.46				
COVID-19 period	257	2.27				
Peace			.32	.22	1.48	.141
Pre COVID-19 period	105	4.54				
COVID-19 period	237	4.22				
Depression			-.28	.23	-1.24	.217
Pre COVID-19 period	104	2.49				
COVID-19 period	247	2.77				
Fear			-.40	.23	-1.73	.084
Pre COVID-19 period	106	2.89				

COVID-19 period	241	3.29				
Anxiety			-.38	.22	-1.69	.092
Pre COVID-19 period	108	3.24				
COVID-19 period	153	3.62				
Excitement			-.25	.22	-1.14	.255
Pre COVID-19 period	109	2.72				
COVID-19 period	247	2.97				
Resisting care			-.10	.22	-.44	.658
Pre COVID-19 period	116	3.11				
COVID-19 period	263	3.21				

Table 9: Difference subitem scores of SM scale between COVID-19 as cause of death group and group with other causes of death.

Appendix 5 - Analysis per item CAD II

Scale item	n	Mean	Mean difference	SE difference	t	p
Discomfort			-.10	.213	-.45	.644
COVID-19 as cause of death	16	2.06				
Other cause of death	55	1.96				
Pain			-.08	.219	-.36	.721
COVID-19 as cause of death	15	2.13				
Other cause of death	55	2.05				
Restlessness			-.10	.23	-.46	.649
COVID-19 as cause of death	15	2.00				
Other cause of death	58	1.90				
Shortness of breath			.42	.22	1.90	.061
COVID-19 as cause of death	16	1.94				
Other cause of death	59	2.36				
Choke			-1.31	.70	-1.86	.067
COVID-19 as cause of death	16	2.56				
Other cause of death	55	3.88				
Gurgle			.16	.23	.69	.492
COVID-19 as cause of death	16	2.13				
Other cause of death	56	2.29				

	N	Mean				
Difficuly swallowing			.27	.24	1.15	.253
COVID-19 as cause of death	16	1.94				
Other cause of death	52	2.21				
Fear			-.21	.23	-.94	.350
COVID-19 as cause of death	15	2.32				
Other cause of death	53	2.53				
Anxiety			.03	.22	.13	.893
COVID-19 as cause of death	15	2.27				
Other cause of death	54	2.30				
Crying			.31	.18	1.75	.084
COVID-19 as cause of death	15	2.40				
Other cause of death	55	2.71				
Moaning			.08	.18	.45	.658
COVID-19 as cause of death	16	2.38				
Other cause of death	55	2.45				
Serenity			.22	.21	1.05	.296
COVID-19 as cause of death	15	1.87				
Other cause of death	55	2.09				
Peace			.03	.23	.13	.894
COVID-19 as cause of death	15	1.93				

Other cause of death	55	1.96				
Calmness			-.04	.22	-.19	.852
COVID-19 as cause of death	15	1.93				
Other cause of death	56	1.89				

Table 10: Difference subitem scores of CAD scale between COVID-19 as cause of death group and group who died of other causes.

Appendix 6 - Analysis per item SWC II

Scale item	n	Mean	Mean difference	SE difference	t	p
I felt complete involved in all decisions			.19	.23	.85	.397
COVID-19 as cause of death	16	3.19				
Other cause of death	66	3.38				
Probably different decisions would have been made if I had more information			-.59	.22	-2.71	.008
COVID-19 as cause of death	16	2.19				
Other cause of death	64	1.59				
All measures were taken so that my relative felt as comfortabel as possible			.29	.22	1.23	.199
COVID-19 as cause of death	16	3.19				
Other cause of death	65	3.48				
The treatment team had an eye for my needs and feelings			.27	.19	1.40	.168
COVID-19 as cause of death	16	3.19				
Other cause of death	64	3.45				
The doctor was attentive to my needs and feelings			.28	.23	1.23	.223
COVID-19 as cause of death	16	3.06				
Other cause of death	62	3.34				
The nurses/carers were attentive to my needs and feelings			.45	.22	2.05	.044
COVID-19 as cause of death	16	3.06				

	N	Mean				
Other cause of death	64	3.52				
I did not really understood the condition of my relative			.50	1.25	.40	.692
COVID-19 as cause of death	16	1.69				
Other cause of death	65	2.18				
I always knew which doctor or nurse/carer was in charge of taking care of my relative			.05	.26	.18	.860
COVID-19 as cause of death	16	2.94				
Other cause of death	63	2.98				
I think my relative received all necessary nurse/nurturing help			.30	.20	1.50	.138
COVID-19 as cause of death	16	3.25				
Other cause of death	62	3.55				
I think the drug use was clearly explained to me			.15	.24	.62	.537
COVID-19 as cause of death	16	3.19				
Other cause of death	63	3.33				
My relative received all treatments or measures that could benefit him or her			.11	.21	.52	.603
COVID-19 as cause of death	16	3.31				
Other cause of death	62	3.42				
I think my relative should have received better medical care at the end of his or her life			-.39	.27	-1.43	.156
COVID-19 as cause of death	16	2.00				
Other cause of death	62	1.61				

Table 11: Difference subitem scores of SWC scale between COVID-19 as cause of death group and group who died of other causes.

Appendix 7 - Analysis per item SM II

Scale item	n	Mean	Mean difference	SE difference	t	p
Pain			.56	.51	1.10	.274
COVID-19 as cause of death	15	3.73				
Other cause of death	61	4.30				
Shortness of breath			-.72	.54	-1.34	.185
COVID-19 as cause of death	16	3.25				
Other cause of death	60	2.53				
Pressure ulcer(s)			.08	.58	.14	.889
COVID-19 as cause of death	16	2.38				
Other cause of death	57	2.46				
Peace			.24	.58	.42	.673
COVID-19 as cause of death	15	3.87				
Other cause of death	54	4.11				
Depression			-1.23	.55	-.24	.029
COVID-19 as cause of death	15	3.67				
Other cause of death	55	2.44				
Fear			-.33	.58	-.56	.579
COVID-19 as cause of death	16	3.25				

Other cause of death	53	2.92				
Anxiety			-.05	.57	-.09	.925
COVID-19 as cause of death	16	3.56				
Other cause of death	59	3.51				
Excitement			.04	.58	.08	.940
COVID-19 as cause of death	15	2.87				
Other cause of death	56	2.91				
Resisting care			.21	.58	.36	.721
COVID-19 as cause of death	16	3.25				
Other cause of death	61	3.46				

Table 12: Difference subitem scores of SM scale between COVID-19 as cause of death group and group who died of other causes.