

## EMPIRICAL STUDIES

# Dignity reflections based on experiences of end-of-life care during the first wave of the COVID-19 pandemic: A qualitative inquiry among bereaved relatives in the Netherlands (the CO-LIVE study)

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## Abstract

**Background:** The COVID-19 pandemic affects care practices for critically ill patients, with or without a COVID-19 infection, and may have affected the experience of dying for patients and their relatives in the physical, psychological, social and spiritual domains.

**Aim:** To give insight into aspects of end-of-life care practices that might have jeopardised or supported the dignity of the patients and their family members during the first wave of the COVID-19 pandemic in the Netherlands.

**Methodology:** A qualitative study involving 25 in-depth interviews with purposively sampled bereaved relatives of patients who died during the COVID-19 pandemic between March and July 2020 in the Netherlands. We created a dignity-inspired framework for analysis, and used the models of Chochinov et al. and Van Gennip et al. as sensitising concepts. These focus on illness-related aspects and the individual, relational and societal/organisational level of dignity.

**Results:** Four themes concerning aspects of end-of-life care practices were identified as possibly jeopardising the dignity of patients or relatives: 'Dealing with an unknown illness', 'Being isolated', 'Restricted farewells' and 'Lack of attentiveness and communication'. The analysis showed that 'Meaningful end-of-life moments' and 'Compassionate professional support' contributed to the dignity of patients and their relatives.

**Conclusion:** This study illuminates possible aspects of end-of-life care practices that jeopardised or supported dignity. Experienced dignity of bereaved relatives was associated with the unfamiliarity of the virus and issues associated with preventive

measures. However, most aspects that had an impact on the dignity experiences of relatives were based in human action and relationships.

Relatives experienced that preventive measures could be mitigated by health care professionals to make them less devastating.

#### KEYWORDS

COVID-19, dignity, end of life, palliative care, quality of care

## INTRODUCTION

The COVID-19 pandemic has significantly affected end-of-life care practices, which may have serious consequences for the experience of dying of patients and the experiences of their relatives. Health care providers were challenged in the provision of high-quality end-of-life care, by the rapid change of events, a shortage in personal protective equipment (PPE) and the largely increased number of dying patients [1,2]. The Dutch government implemented an 'intelligent lockdown', including rules about keeping distance and hygiene, the closing of cafes and restaurants and visitor restrictions for all health care institutions [3,4]. Relatives were confronted with visitor restrictions during the last 2 days of a patient's life in three quarters of all cases and in 9% of all cases, they were not at all allowed to visit their beloved ones [5]. Relatives were often separated from their loved ones and limited access to support for relatives increased their feelings of loss and despair [6]. This holds both for relatives of patients dying with the virus and for relatives of patients dying from other causes. These measures to avoid further spreading of COVID-19 also had a huge, unintended impact on the quality of care at the end of patients' lives and likely impacted the possibility to maintain a dignified end of life.

The preservation of dignity for dying patients is one of the most important goals of end-of-life care and the loss of dignity is associated with feelings of distress [7–9]. Some vagueness around the definition of dignity exists, but for clinical practice successful attempts were made to clarify the meaning of experienced dignity at the personal level. According to Chochinov et al., [7,10] dignity at the end of life refers to the worth we attach to ourselves, is related to personal goals and circumstances and persons' self-esteem. An important component of this model is the relational element: someone's perception of being respected and being worthy of being respected by others. Studies on experienced dignity by patients portray dignity as an overarching concept with facets on the psychological, social, existential, physical and societal levels of experiences [10,11]. Dignity is thus not only potentially affected by the disease but also by personal characteristics, experienced

distress, relational and societal interactions, professional and social support [7,10,11].

Research indicates that family representatives can illuminate important characteristics of care that potentially support or jeopardise a patient's experienced dignity [12–15]. They appear to be better informants about situations in which a patient's dignity was considerably violated than physicians or nurses [16]. Relatives described that the absence of anxiety and fatigue, and a clear explanation by the physician of treatment choices are of great importance to uphold dignity for their loved one at the end of life [15]. Relatives mention that dignity is hindered when patients are anxious, feel abandoned, miss close relatives or feel humiliated, or when the possibility for autonomous decisions and meaningful activities are lacking [13,14,17]. Therefore, dignity-conserving care at the end of life is considered to be person-centred, to respect and advocate the patient's agency and to take the patient seriously at emotional and existential levels. It involves listening and sensitive communication, and encourages family presence [17–20].

Various restrictive measures during the COVID-19 pandemic were underpinning value-based care that conserves dignity. Understanding the preservation of dignity at the end of life is crucial for supporting patients and their relatives in future comparable situations. Learning from these experiences is important. Therefore, the aim of this study is to get in-depth insight into the possible dignifying and undignifying aspects of end-of-life care practices during the COVID-19 pandemic. The leading question is: Which aspects of the end-of-life care practices were potentially jeopardising or supporting dignity during the first wave of the COVID-19 pandemic in 2020 in the Netherlands?

## METHOD

The study design was a qualitative framework analysis of in-depth interviews with 25 bereaved relatives of people who died during the COVID-19 pandemic [21,22]. This study is embedded within a national open online questionnaire survey of experiences during the COVID-19 pandemic in the Netherlands. The name of this wider study is the CO-LIVE

study. Ethical approval was obtained from the Erasmus MC Medical Ethical Committee [ref. MEC-2020-0254].

## Participants and sampling

A total of 25 relatives (reporting about 26 patients) participated in the study. We selected the relatives from the COLIVE database of individuals who expressed an interest to be interviewed after completing the online questionnaire survey (between April and September 2020). Individuals were considered eligible if they were bereaved relatives of people who died between March and July 2020 and resided in the Netherlands. Purposive sampling was used to include relatives with a variety of background characteristics in terms of age, gender, relationship to the deceased and end-of-life care setting. Twenty-six eligible relatives were approached by the researcher (AG) via telephone and informed about the study aims. All relatives were willing to participate in the interview, but due to the limited availability of one relative, 25 relatives were interviewed. Table 1 shows the characteristics of the bereaved relatives and the patients. Sixteen were bereaved children and five were partners; furthermore, we included one sibling, one cousin, one daughter-in-law and one grandchild. Most relatives were female (80%), their mean age was 58 years (range 25–79). Eleven relatives had experienced the death of a loved one in a hospital, one in a mental hospital, 11 in a nursing home, two at home or in a sheltered house and one in a hospice. Twenty patients had died with (suspicion of) COVID-19 infection.

## Data collection

Interviews were conducted by AG ( $n = 24$ ) and RP ( $n = 1$ ) with the use of video or telephone. A topic guide was developed by the research team, informed by the research aims (see Table 2). Before the start of the interview, written and verbal informed consent was obtained from all relatives. The interviews started with the open question: ‘What happened from the moment your loved one fell ill until the moment of dying?’ The interviewer further explored the experiences of the relatives using the interview topics. The duration of the interviews varied between 30 and 80 min. At the end of the interview, attention was paid to aftercare. If necessary, relatives were advised to talk to someone about their experiences or to contact their GP.

## Data analysis

First, interviews were transcribed verbatim by an external party. Secondly, narrative summaries, focusing on

**TABLE 1** Characteristics of the relatives ( $n = 25$ ) and the deceased patients ( $n = 26$ )

Variable	<i>n</i> (%)
Relatives $n = 25$	
Gender	
Female	20 (80%)
Male	5 (20%)
Age	
20–29	1 (4%)
30–39	0 (0%)
40–49	3 (12%)
50–59	11 (44%)
60–69	5 (20%)
70–79	5 (20%)
Relation to patient	
Spouse/partner	5 (20%)
Adult child	16 (64%)
Sister	1 (4%)
Adult grandchild	1 (4%)
Daughter-in-law	1 (4%)
Cousin	1 (4%)
Deceased patients $n = 26$	
Gender	
Female	12 (46%)
Male	14 (54%)
Age	
60–69	2 (8%)
70–79	7 (27%)
80–89	12 (46%)
90+	4 (15%)
Missing	1 (4%)
COVID–19	
Yes	16 (62%)
Probably	4 (15%)
No	6 (23%)
Place of death	
Hospital (COVID–19 ward, $n = 6$ ; ICU, $n = 4$ ; General ward, $n = 1$ ; unknown, $n = 1$ )	11 (42%)
Mental hospital	1 (4%)
Nursing home	11 (42%)
Hospice	1 (4%)
Sheltered house	1 (4%)
Home	1 (4%)

relatives’ concerns, were made of all the 25 interviews by AG and YB, checked by EW to get a sense of the meaning of the whole experience per person. After familiarisation, we performed an in-depth content analysis using a

**TABLE 2** Topic guide

Opening question: What happened from the moment your loved one fell ill until the moment of dying?
Can you describe this in detail?
Covid-19 disease – if applicable
Personal Protective Equipment
Setting (nursing home, hospital)
Communication between relative, patient and health care professionals (GP, nurses, specialists)
Staying connected with the patient (video calling and other options)
Treatment and care (symptom management; social and emotional support; existential care, saying farewell)
Support for relatives and patient
Treatment restrictions and involvement relatives
Visitor restrictions
Can you tell us something about the death itself?
Presence during death
Possibilities to say farewell
Received end-of-life care and support
What was important, what helped you?
What was difficult
What could or should have been done differently

theory-inspired analytical framework [22] developed by YB, WvdG and AG, and based on the dignity models for end-of-life experiences by Chochinov and Van Gennip [10,11]. This analytical framework consists of major dignity categories and themes derived from the Chochinov model, supplemented by us with themes that were specific to the COVID-19 situation such as the COVID-19 policy. These categories and themes were ordered in the individual, relational and societal/organisational level according to the model of Van Gennip (See Table 3, first column). In the first coding stage, two researchers (YB, WvdG) coded more deductively the data, using the analytical framework, as sensitising concepts to identify possible characteristics of care that jeopardised or supported dignity. Coding was done digitally using ATLAS-ti®. After the selection of meaningful interview segments based on the sensitising concepts, open coding took place. Codes could refer to aspects of end-of-life care that could both positively and negatively influence the dignity of patients, as perceived by relatives, and the dignity of relatives themselves. After coding the meaningful segments, differences in coding were compared and discussed among AG, WvdG and YB to enhance the validity of the interpretation [23]. Codes were grouped together and refined into themes (See Table 3, second column). After discussing and interpreting the data, the researchers (YB, WvdG, AG) came to the final themes (See Table 3, last column).

## FINDINGS

Looking at aspects of care that potentially jeopardised the dignity of patients and relatives, we identified four themes: 'Dealing with an unknown illness', 'Being isolated', 'Restricted farewells' and 'Lack of attentiveness and communication'. These aspects of care made relatives feel powerless and guilty. Two themes emerged as potentially supporting dignity: 'Meaningful end-of-life moments' and 'Compassionate professional support'.

### Aspects of the end-of-life care practice potentially undermining dignity

#### Dealing with an unknown illness

Especially at the beginning of the pandemic the confrontation with an unknown illness led to care practices that could undermine dignity. Relatives reported potential signs of a COVID-19 infection of their family member to health professionals such as shortness of breath, raised temperature, sometimes diarrhoea or an overall feeling of malaise. However, relatives reported that nurses or GPs were not always able to accurately determine when to interpret these symptoms as potentially indicating COVID-19. According to the relatives, GPs seemed reluctant to visit patients out of fear of contamination. Some GPs firstly diagnosed the signs as symptoms of a general flu, bladder infection or pneumonia and advised patients to sit in the sun or take things slowly.

I went to the GP three times for Corona consultations: 'guys, we are so sick, my husband had a fever of forty, he has epilepsy'. We phoned the GP in the evening and they played a tape. Well, I called back three times, and they asked – 'do you have any bruises?' - 'No, I haven't'. - 'Oh, then you don't have Corona, have a good day, sir'.

(Child, 58 years)

Relatives were overwhelmed by the rapid progress of the disease and did not foresee that the end of life was near. Relatives mentioned their concerns about the medical treatment for their loved ones, both with and without COVID-19. Especially when medicines were no longer available, relatives reported that wrong or experimental treatments were provided, treatment policy was not clear or treatments were postponed or stopped.

Then a nurse came and said, - 'I'll take the oxygen off because it doesn't help any more'.[...]

**TABLE 3** Coding list of experiences potentially challenging/supporting dignity

Initial categories and themes analytical framework	Refined themes	Final themes
Individual level		
Illness-related concerns: - <i>Existential/Spiritual distress</i> (loss of identity, loss of meaning etc.) - <i>Psychological distress</i> (medical uncertainty, death anxiety etc.) - <i>Physical distress</i> (pain, short of breath etc.)	<ul style="list-style-type: none"> <li>- Loneliness of the patient (-)</li> <li>- Patients losing meaning in life and giving up (-)</li> <li>- Missing physical contact by patients and relatives(-)</li> <li>- Meaningful moments for relatives and patients (+)</li> <li>- Relatives anxious about patients dying alone</li> <li>- Relatives' fear of coming too late (-)</li> <li>- Relatives' uncertainty and having to make decisions related to patient's treatment (-)</li> <li>- Fear of patients and themselves becoming infected (-)</li> <li>- Relatives advocating comfort for the patient (-)</li> <li>- Patients with dementia not understanding the situation (-)</li> <li>- Unrecognised symptoms of COVID-19 by GP (-)</li> <li>- Relatives' concerns about patient not wanting to eat (-)</li> <li>- Rapid physical deterioration of the patient (-)</li> <li>- Relatives not understanding end of life is near (-)</li> <li>- Burdensome symptoms of patient (shortness of breath, agitation and pain) (-)</li> <li>- Patients not receiving physical care or treatment (-)</li> <li>- Good palliative treatment for comfort (+)</li> </ul>	<ul style="list-style-type: none"> <li><i>Dealing with an unknown illness</i></li> <li>- Relatives overwhelmed by the rapid process of the disease</li> <li>- GPs unfamiliar with COVID-19</li> <li>- Nurses not taking the risk of infection seriously</li> <li>- Relatives' concerns about medical treatment</li> <li>- Relatives' fear of vulnerable family members becoming infected</li> <li><i>Being isolated</i></li> <li>- Relatives unable to visit patient in nursing homes</li> <li>- Missing physical contact</li> <li>- Patients being alone and isolated</li> <li>- Parents separated from each other</li> <li>- Not understanding 'window visits' by patients with dementia</li> <li>- Relatives failing to stay in contact at distance: video calls did not work out</li> <li>- Patients losing meaning and courage to go on</li> <li>- Patients not wanting to eat anymore</li> <li>- Accumulation of factors leading to death</li> <li><i>Restricted farewells</i></li> <li>- Saying farewell at the ambulance</li> <li>- Relatives' fear of themselves becoming infected</li> <li>- Abrupt farewells</li> <li>- Patients dying alone</li> <li>- Fear of being absent or too late</li> <li>- Family frictions; having to choose who is going</li> <li>- Relatives having to wear gloves, masks and suits</li> <li><i>Lack of attentiveness and communication</i></li> <li>- Relatives missing attention and attentiveness from HCP</li> <li>- Relatives wishing more contact with GP or Physician</li> <li>- Relatives and patients losing role in the decision-making process</li> <li>- Relatives having to make decisions about to stop the oxygen</li> <li>- Relatives making an effort to speak the GP</li> <li>- Relatives' limited contact with GP/ HCP through telephone or video calls</li> </ul>
Dignity-conserving repertoire: <i>Personal characteristics and perspectives</i> - <i>Personal protective practices</i>	<ul style="list-style-type: none"> <li>- Patient's wish/promise fulfilled (+)</li> <li>- Relatives acceptance of the COVID-situation (+)</li> <li>- Relatives grateful for certain moments or that the suffering of the patient has been spared (+)</li> <li>- Relatives' or patients' spiritual or religious believes (+)</li> <li>- Relatives picking up daily life (+)</li> <li>- Relatives sharing their story (+)</li> <li>- Relatives' meaningful moments (+)</li> </ul>	

(Continues)

TABLE 3 (Continued)

Initial categories and themes analytical framework	Refined themes	Final themes
<b>Relational level</b>		
Social Dignity	- Not being able to physically see each other (-)	- Nontactical communication from HCP to relatives <i>Meaningful end-of-life moments</i>
- Social support (feeling connected and supported by essential others)	- Relatives not being able to embrace the patient (-)	- Extended visiting opportunities
- Interactions with family and friends	- Staying in contact via window contact (+ -)	- Relatives' gratefulness for certain moments
- Virtual calls	- Saying farewell at the ambulance (-)	- Relatives' broader perspective of death
	- Contact possibilities at the end of patient's life (+-)	- Further suffering of patient has been spared
	- Not saying goodbye at end of life (-)	- Patients' wishes were fulfilled
	- Saying goodbye at end of life via phone (-)	- Relatives' and patients' spiritual/religious belief
	- Relatives saying goodbye in protective equipment (-)	- Relatives' overall acceptance <i>Compassionate professional support</i>
	- Fear within the family of becoming infected (-)	- Compassionate nursing care for patients and relatives
	- Support within the family (-)- Relatives staying in contact with the patient by telephone or video calls (+-)	- Nurses stood up for relatives' emotions and needs
	- Virtual calls not facilitated by nursing staff (-)	- Open and clear communication
Professional support (Being taken seriously, being respected, feeling burdened):	- Less contact or communication with HCP (-)	
- Interaction with health care professionals (HCP), such as nurses	- Relatives effort needed to get contact with HCP (-)	
- Interaction with GP, medical specialist, physician.	- Communication via mail, app, phone (-)	
	- No communication between disciplines (-)	
	- Clear communication with HCP(+)	
	- Relatives felt compassion from HCP (+)	
	- Relatives felt no compassion (-)	
	- No respectful interaction with HCP (-)	
	- HCP being lax and not acting appropriately in care situation (-)	
	- HCP standing up for relatives' needs and emotions (+)	
	- Not receiving attention and care for the patient that was needed (-)	
	- Loving care for the patient (+)	
	- Less contact with GP (-)	
	- Difficult for relatives to speak/reach GP (-)	
	- Regular contact with GP (+)	
	- Nontactical communication from GP toward relatives and patients (-)	
	- Less compassion (-)	
	- Patients and relatives not taken seriously by GP (-)	
<b>Societal/organisational level</b>		
COVID-19 Policy:	- No visits anymore after the lockdown (-)	
- Visiting rules and possibilities	- Relatives being present by the patient all day (+)	
- Isolation rules and Personal Protective Equipment	- Visiting possibilities were extended in terminal phase (+)	
	- Relatives not being able to be present during decease (-)	
	- Visitor policies differed between organisations/ departments and changed over time (-)	
	- Limited number of visitors; relatives had to make choices and not everyone could say goodbye (-)	
	- Relatives' appreciation of nursing staff's handling of visitor policy (+)	
	- Limited or no protective equipment for relatives and nursing staff (-)	
	- Unprotected care was provided by nurses (-)	
	- Relatives saying farewell in protective equipment (-)	
	- Not being able to touch/embrace each other (-)	
	- Relative not recognisable in PPE by patient (-)	

He became terribly short of breath. For a moment he came out of his pillows completely upright. Huge eyes, he really grabbed both sides of us like, help me. Tears ran down his cheeks, so he had a very horrible deathbed.

(Child, 45 years)

Relatives were also confronted with nurses not taking the risk of infection seriously, working without PPE or using them with carelessness. Relatives of nursing home residents feared that their loved one would be infected in the institution without being able to prevent this.

## Being isolated

Before the lockdown, relatives visited their loved ones in the nursing home typically on a daily or weekly basis, which was suddenly not allowed anymore. They resented that nursing staff could walk in and out of the nursing home, while they were not allowed to. Relatives stated that it was inhumane that their family members were alone and isolated, lacking any physical contact with family members or other people. Relatives described this like being 'imprisoned' or 'abandoned':

Monday morning, they still went outside. When I came back, they were not allowed to go out any more. The next day they were no longer allowed to leave the room. We were not allowed to come, it all stopped. This has all occurred to them. A feeling of, this is even worse than war.

(Child, 64 years)

The isolation of their loved one gave relatives a feeling of powerlessness. Relatives tried to stay in contact with their loved ones at a distance through phone calls, video calls and window contacts. However, they were largely dependent on the support of the nursing staff. They had to wait for a call or did not want to call to burden nursing staff. Relatives experienced difficulties with calling when patients with COVID-19 were out of breath and video calls did not always work out, especially when their loved one suffered from dementia.

He got very confused during the video calls with my mother because he saw her through that screen, but he didn't really understand how that was possible.

(Child, 61 years)

Relatives reported situations where parents were separated from each other. For example when both parents were

admitted to different wards or hospitals or when both parents had to be quarantined together and had to help themselves, without family support.

They had to endure a lot on their own, we couldn't do anything. We just stood by helplessly was very difficult.

(Child, 64 years)

Relatives had to witness their loved one with dementia living in a nursing home, asking them to come inside and not understanding the idea of 'window visits', or questioning why their relative no longer came to see them. Relatives believed that patients had lost all meaning in life, and that due to loneliness and sadness they lost the courage to live further. Relatives frequently mentioned that their loved one did not want to eat anymore, but they were prohibited to help with food intake.

I think he lost his courage. At a certain moment I was allowed to visit him. Then I was terribly shocked how he was doing.

(Partner, 56 years)

Furthermore, relatives expressed that their loved one did not receive the care that was needed and were locked up in their room for isolation. Shortness of staff, work load, working in PPE and isolation policy made nurses limit their physical contact with patients according to the relatives.

He was lying alone. And they [nursing staff] were allowed to go into his room for two minutes three times a day, to bring some food down and to quickly drop something off.

(Child, 58 years)

In addition, relatives reported that all daytime activities, speech therapy, physiotherapy and spiritual care were stopped. According to some relatives, it was this accumulation of limitations, not only the illness itself, that led to the death of their relative, which they experienced as unnecessary and jeopardising humaneness. Some relatives were left with a feeling of guilt after the passing away of their relative, and wondered if they should have taken their family member out of the nursing home.

## Restricted farewells

Isolation policies and the visitors ban restricted the possibility of saying farewell. In some cases, there was no opportunity to visit at all and relatives had to say their farewell by phone. In some cases, relatives decided to not

to say goodbye when their loved one passed away for fear of becoming infected themselves.

But I was actually so afraid of Corona for myself as well. I am 64, I am also at risk. As much as I wanted to say farewell to Mum, I was so afraid.

(Child, 64 years)

Suddenly hospital admissions made them say their farewell in the ambulance, which was painful. Some patients were transported alone in the ambulance and respondents realised that they would probably not see each other again.

Then there was a knock at the door and then the ambulance came with my mother in it [...], and we held each other for a moment, but then they came and told me to leave. That was actually the last time I was able to hold her properly and that she recognised me.

(Child, 57 years)

Some relatives experienced that their loved ones were afraid of dying alone, which indeed occurred. Relatives also expressed their own fear of being absent or too late, unable to say goodbye at the end of life. Frictions within families arose over who should take care of their critically ill relative. The restricted visiting possibilities, such as one person per day or demarcated time, meant that relatives had to make difficult choices:

And only one daughter was allowed. I said, we have six children. Well, make your choice.

(Partner, 75 years)

Relatives could not support each other as one relative mentioned he had to watch his father sitting alone beside his mother's bed in the hospital and not being able to share his emotions with anyone. Saying goodbye to a loved one was also impaired by the fact that relatives had to wear PPE, which was experienced as 'very distant' and 'cold'. Relatives could not embrace their loved ones or were unrecognisable for them.

So there you are with all the adult family members in that suit. You can't leave the room, because then you need to wear new protective materials. So you can't go to the toilet, you can't eat. Well, it was six o'clock in the morning and then my sister said; 'oh boy, I can't take it, I'm leaving'. And at half past six the second one went off. I thought,

that's not going to happen to me. But half past seven I also got dizzy; I had to throw up. So, I went home. Very sad, I didn't make it. Half past eight I was called [with the message of death].

(Child, 56 years)

## Lack of attentiveness and communication

Not all patients received affectionate nursing care according to the bereaved relatives. A relative, whose husband and son were admitted to the same hospital, was not allowed to personally inform her son about his father's death. Her son at the ICU was informed by text message without human attention of the nursing staff. Another relative expressed that her father had died alone in an empty room without personal belongings and lacking human attention.

So I think that's just really painful because you couldn't say farewell to your father. [...] at eleven o'clock he is declared dead while he already died during the night. You can go into that room, they don't walk with you, you stand there at the bedside, my father is lying there dead.

(Child, 58 years)

Several relatives reported that they also had missed personal attention when they came to say farewell to their loved one or when they came to tidy up the room after the patient's death. Relatives expressed that nursing staff left them alone, offered neither condolences nor practical support and showed no sympathy.

They called a day later [after death], and well, I didn't think that was respectful either. Because that was about cleaning the room and that had to be done before the funeral. And I said, 'where are my mother's things?' In her own room. I said, where the lady with Corona is? – 'Yes'. I said, 'and you thought I was going in there? Oh, no'. – 'We'll put it in the corridor'.

(Child, 56 years)

Many relatives also felt that they were not involved in their loved one's admission to hospital or ICU admission, nutrition policy, pain management and isolation policy. They experienced a lack of communication and felt excluded in medical decision-making. Relatives reported that the medical specialist had already decided to stop further



treatment or not admit the patient to the ICU, without communication.

## Potentially dignifying aspect of the end-of-life care practice

### Meaningful end-of-life moments

In most cases visiting opportunities were extended in the terminal phase so that relatives could say their farewell. Related patients admitted to the same facility were sometimes brought together by nursing staff, to enable them to say goodbye.

His sister-in-law also had Corona and had been admitted the day before. And she was terribly ill, but they put her in his room so that they could say goodbye in the evening. They [nursing staff] sent us a photo. The fact that they made this effort despite all the hectic and busy times is very special.

(Child, 45 years)

While relatives were on site they experienced loving support from the nurses who checked-in multiple times, facilitated food and beverages during the wake period and comforted relatives during the process of death. Relatives spoke about the gratefulness for certain moments they had with their loved one.

Other potentially dignifying care aspects were related to the physical domain: dying without too much pain, suffering, anxiety or shortness of breath. Besides, relatives sometimes experienced a sense of meaning by placing the illness and the death of their loved one in a broader perspective, like recognising the impact of the underlying diseases such as dementia or Parkinson's. They were grateful that further suffering was avoided or that their loved one's end-of-life wishes were fulfilled. Other relatives drew strength from their spiritual or religious belief or had an overall acceptance of the COVID-19 situation.

### Compassionate professional support

Multiple relatives felt that their loved one had received compassionate nursing care indicating that their humanity and dignity was preserved by being loved by the nurses and taken care of with affection. According to the relatives, this was shown in the efforts of nurses to arrange window visits, telephone calls or making short videos of residents to send to their relatives.

But even in the nursing home they looked really well after him and they really took the time to see if they could feed him, give him water. They shaved him neatly in the morning until the very last day, to maintain his humanity and his dignity.

(Daughter-in-law, 49 years)

Relatives really appreciated extra efforts by nurses for their loved one and felt this was 'the best they could do within the circumstances'. In addition, some relatives themselves received pleasant personal attention and compassion such as a personal condolence card or phone call or a warm embrace or sympathy from health care professionals.

I remember very well that the neurologist was sitting with tears in her eyes in the large conference room, because she said, 'yes, I'd love to hug and comfort you now, but I'm not allowed to do anything, I'm sitting here in a corner'.

(Child, 50 years)

Relatives mentioned that the nurses were sensitive to the situation and used the right words at the right moment and they stood up for their emotions or needs. They experienced adequacy and integrity in the way medical protocols were followed and treatment was provided with transparency about the possibilities and limits. Open and clear communication with professionals by the physician was important. Relatives expressed that although straightforward communication about treatment limitations sometimes was painful, it also directly cleared the air. Relatives stated some GPs took the time to sit with their patients to speak about their end-of-life wishes and advance care planning and involved the family in these conversations. Some relatives were called daily and felt the space to call back anytime they wanted and ask multiple questions when needed.

## DISCUSSION

This article focuses on the question: 'Which aspects of end-of-life care practices were potentially jeopardising or supporting dignity during the first wave of the COVID-19 pandemic in 2020 in the Netherlands?'. We analysed the qualitative data of bereaved relatives with a focus on experienced dignity. Of the broader literature about dignity, the models of Chochinov et al. and Van Gennip et al. [10,11] appeared most compatible to end-of-life care and experiences of dying. Using these models

as a sensitising concept in the analysis, we found that gratefulness for meaningful end-of-life moments and compassionate support seemed to increase experiences of dignity. However, the unfamiliarity with COVID-19, visiting restrictions, patient's isolation and lack of attentiveness and communication all potentially jeopardised a dignified end-of-life experience. In our analyses the level classification (individual, relational and societal/organisational) of the dignity models of Chochinov et al. and Van Gennip et al. [10,11] appeared less helpful since in our data these levels could not be strictly distinguished from each other and were too intertwined in their influence of experienced care to appear helpful. Although this article is not aiming to discover causality, the entanglement between the various dignifying and undignifying aspects of care seemed to be an interesting topic for further research.

Our identified themes illuminate that relational aspects within the care practice were of utmost importance for the relatives in their experience. Our results show that further tinting of the relational dimension could enhance the existing dignity models. Ethics of Care theory provides insights for discernment between care relations that support or undermine dignity in care. Sensitive attention for the experienced vulnerability of the other is the key [24,25].

On the level of society, our findings indicate that with the COVID-19 pandemic, came the fear within society, stigmatisation of possible infected people, exclusion or separation of certain groups such as nursing home residents and fragile elderly. All of these are expected to influence the experienced dignity [15,17]. Some relatives state clearly that they felt that not COVID-19 but the effect of social exclusion and inactivity had caused the death of their loved one, especially for those with dementia or Parkinson's. Also restrictive measures at national and organisational levels and the lack of knowledge about the symptoms played a role in potentially threatening dignity.

The results show that given the disease and the restrictive measures that were hardly unchangeable, care professionals could enhance the experience of dignified end-of-life care with offering and facilitating relational closeness. We found this included moments in which care professionals created room for bending the rules which made family members being able to be physically present in the last phase of their loved one's life and to say farewell. Other studies within the context of the COVID-19 pandemic support our identified theme and also emphasise the importance of staying connected with family members and saying farewell [6,26–28]. When wishes concerning how to say farewell are not met, relatives can less easily find peace in the death of their loved ones. It

creates distress and possibly complicated the grief processes of bereaved relatives [28,29].

Congruent with other studies, compassionate support and end-of-life care that suites personal values and ensures personal preferences supported experienced dignity [30,31]. To see the dignity needs and attempts to adapt to them made a difference for relatives. This type of dignity affirmative behaviour was highly appreciated by relatives and often experienced in small things: accompanying their loved one and providing attentive bodily care until the last moment.

We also found that despite the hectic COVID-19 situation, the importance of sensitive communication and the tone of voice made patients and relatives felt seen and heard in what was important for them. Similar findings have been reported in other studies, in which relatives reported that the communication was predominantly focused on the physical care and wished for more holistic approach and psychological support [26–28].

Unfortunately, despite the efforts of health care professionals, several respondents reported that their relatives died in disgraceful or inhumane ways (In Dutch: 'mensonterend'). This included without being able to say farewell properly to spouses and children, insufficient treatment of pain, anxiety or shortness of breath. Relatives described that for loved ones living in nursing homes the forced isolation, the lack of physical closeness of relatives, became life threatening. Relatives used the words inhumane and disgraceful in their stories. This might illustrate that relatives experienced that the so called 'intrinsic dignity' of their loved one was threatened. This type of dignity can be understood as a lower limit, and can underpin values of things or situations that no human should experience [32].

The question arises whether health care professionals recognised their own ethical position in these moments in which residents of nursing homes 'gave up on life'. An earlier study highlighted the importance of health care professionals to ethically act against dehumanising care practices which require courage and willingness to speak up or disobey [33]. These moments can be described as 'tipping points' (In Dutch; Kantelmoment [34]); a critical moment in which different key values clash and a professional is unsure about what is the right thing to do. Care professionals might have been torn between restrictive measures and dignity-conserving behaviours. Research indicates that health care professionals were under a lot of (moral) pressure within the COVID-19 pandemic which caused them feeling morally distressed [35,36].

Studies already indicate that family representatives are important for understanding a patients' experienced dignity [13–15]. In addition, we found that reflecting about

dignity of patients is intertwined with experienced dignity of family members. This was earlier found in research on migrant patients' informal caregivers which indicated that when health care jeopardised the dignity of their loved one, it affected their dignity as well and vice versa [37]. Being cut off, ill-informed and not included in the care and medical decisions might have hindered both the experienced dignity of the dying person and the dignity of the relative. This underlines that besides interactions with care professionals, relational interactions with relatives can form a powerful counter force for situations in which experienced dignity at the end of life is undermined through illness or circumstances of professional care [37].

### Implications for practice

The results show that health care professionals have a crucial role to maintain and enhance the dignity of patients in their end-of-life phase and of their relatives during a pandemic. Their way of 'reading' experienced vulnerability and needs addressed aspects of dignity of dying patients and their relatives. This was the opening to offering small gestures of respect during inhumane end-of-life circumstances. Sometimes against regulations. Therefore, in the next pandemics, health care professionals could reflect further to increase their sensitivity regarding those (dignity) moments in which they can make a difference or by recognising tipping points at which the elderly give up due to isolation. The most important dimension of dignity models to protect and enhance dignity appeared to be the relational dimension. This includes staying emotionally connected with family members, saying goodbye physically, holding each other and sensitive communication with health care professionals. This relational dimension could be explored further in end-of-life dignity theory.

### Limitations of this study

Our findings are limited to relatives of patients who have died mainly in hospitals and nursing homes and hardly represent the experiences of relatives whose loved one died at home or in a hospice. Another limitation is that participants with a migration background were underrepresented in this study. So the findings might be culture specific. Future research could focus on the experiences of relatives from other ethnic backgrounds and on experiences gained in other settings. Although we were only able to perform interviews through a telephone or video connection, the quality of the interviews seemed good and not less than face to face interviews.

## CONCLUSION

This study identifies aspects of end-of-life care practices potentially jeopardising or enhancing dignity observed by relatives during a pandemic. Aspects related to this unknown virus and factors arising from preventive measures seemed to be important in the experience of dignity in end-of-life care during a pandemic. However, despite these contextual factors potentially undermining experienced dignity, most aspects found were based on human interaction. The isolation at the end of life was experienced as something no human should experience, as a threat to human dignity. Relatives reported further that health care professionals were able to soften the undignifying preventive measures.

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### CONFLICT OF INTEREST

The authors declare no conflicts of interest.

### AUTHOR CONTRIBUTIONS

All authors contributed to the conception and design of the study. AG and RP performed the data collection. YB, WvdG and AG analysed the data and drafted the article. All other authors revised the article critically for important intellectual content. All authors approved the version to be published, and have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

### ETHICAL APPROVAL

Ethical approval was obtained from the Erasmus MC Medical Ethical Committee [ref. MEC-2020-0254].

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