BMJ Open

BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (http://bmjopen.bmj.com).

If you have any questions on BMJ Open's open peer review process please email
info.bmjopen@bmj.com

BMJ Open: first published as 10.1136/bmjopen-2021-059577 on 19 May 2022. Downloaded from http://bmjopen.bmj.com/ on June 10, 2025 at Agence Bibliographique de l Enseignement Superieur (ABES) .
Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

BMJ Open

Pandemic impact on patients with advanced non-COVID-19 illness and their family carers receiving specialized palliative home care: a qualitative study

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2021-059577
Article Type:	Original research
Date Submitted by the Author:	24-Nov-2021
Complete List of Authors:	Nyblom, stina; Sahlgrenska Academy, Palliative Center; University of Gothenburg, Medicine Benkel, Inger; Sahlgrenska Academy, Palliative Center Carling, Linnéa; Sahlgrenska University Hospital, Palliative Center Löfdahl, Elisabet; Sahlgrenska universitetssjukhuset Molander, Ulla; Sahlgrenska Academy, Palliative Center Öhlen, Joakim ; University of Gothenburg, Institute of Health and Care Sciences
Keywords:	COVID-19, PALLIATIVE CARE, QUALITATIVE RESEARCH

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

For peer review only

Enseignement Superieur (ABES) .
Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

Pandemic impact on patients with advanced non-COVID-19 illness and their family carers receiving specialized palliative home care: a qualitative study

Stina Nyblom[1,2], Inger Benkel[1,2], Linnéa Carling[2], Elisabet Löfdahl[2], Ulla Molander[1,2], Joakim Öhlén[2,3]

[1]Institute of Medicine, University of Gothenburg, Sweden
[2]Sahlgrenska University Hospital, Department of Palliative Care, Gothenburg, Sweden
[3]Institute of Health and Care Sciences, University of Gothenburg, Sweden

(F) Stina Nyblom, MD, PhD http://orcid.org/0000-0002-4998-0324
(F) Inger Benkel, MSW, PhD, Associate professor http://orcid.org/0000-0002-5919-3877
(F) Linnéa Carling, RN, MSc
(F) Elisabet Löfdahl, MD
(F) Ulla Molander, MD, PhD, Associate professor http://orcid.org/0000-0002-6593-3130
(M) Joakim Öhlén, RN, PhD, Professor http://orcid.org/0000-0003-2429-8705

Corresponding author: Stina Nyblom

Mailing address: Palliative Center, Hogsbo hospital, Box 30110, 40043 Gothenburg, Sweden
E-mail: stina.nyblom@vgregion.se
Telephone: +46 767841620

Abstract

Objectives

To investigate the experiential impact of the COVID-19 pandemic on patients with non-Covid life-threatening disease and their family carers.

Design:

An interpretative qualitative design informed by phenomenological hermeneutics and based on data from in-depth interviews, performed between June to September 2020.

Setting

Patients receiving specialized palliative home care and their family carers living in Sweden.

Participants:

22 patients (male/female 11/11) and 17 carers (male/female 5/12) all aged 50 years and older. All patients received specialized palliative home care and the majority were diagnosed with cancer.

Inclusion criteria: aged 18 years or older, diagnosed with an incurable life-threatening non-Covid disease, sufficient strength to participate and capacity to provide informed consent. Participants were selected through a combination of convenient and consecutive sampling.

Results:

The significance of the pandemic for both patients and carers shows a continuum from being minimally affected in comparison to the severe underlying disease to living in isolation with constant fear of becoming infected and falling ill with COVID-19, which some likened to torture.

Most patients and carers found access to specialized palliative home care was maintained despite the pandemic and of paramount importance for their sense of security.

Conclusions:

The imposed restrictions on social contact due to the pandemic are particularly palpable for this group of people with a non-COVID-19 life-limiting condition, as it steals valuable moments of time that has already been measured.

In the pandemic situation, highly accessible support from health- and social care at home, is particularly important in order to create security for both patients and carers, and is often their sole visiting social contact. Thus, to provide appropriate support, it is important for health- and social care personnel to be aware of the great diversity of reactions patients in palliative care and their carers may have to a pandemic threat.

Keywords: COVID-19, Palliative care, Qualitative research**.**

Strengths and limitations of this study

- A strength of this study is the empirical anchorage through first person narratives.
- All interviews were performed by professionals trained in conversation methodology.
- Demographics data were varied and showed a broad age range, although few men were represented among carers
- Strategic sampling would have been stronger than the combined convenient and consecutive sampling applied

- The majority of patients were diagnosed with cancer and only few participants had migrated, which could limit transferability of the result.

Introduction

The COVID-19 pandemic has resulted in the development of national recommendations for care of infected patients, as well as for society as a whole. Thus, the pandemic does not only influence those who are infected. In a review by Dubey et al. the psychosocial impact of COVID-19 is described as affecting the whole population, whether you are sick or healthy[1]. Numerous deaths caused by the pandemic have been reported daily, with excessive exposure in the media, resulting in death becoming unusually palpable in society. The resulting fear – that naturally arises when humans are faced with infectious disease – is present in the COVID-19 pandemic, and shows a positive correlation to anxiety and depression[2]. Patients admitted to palliative care with a non-COVID life-threatening disease constitute a particularly vulnerable group, with a higher risk of adverse outcome from a COVID-19 infection[3, 4]. These patients are under life threat from both the underlying disease – most often cancer – and from impending pandemic infection. Moreover, the significant overlap of COVID-19 and cancer-related symptoms can result in recurrent uncertainty whether the person is infected or not[5, 6].

To our knowledge, the impact of the COVID-19 pandemic on this group of patients and their family carers (in the following 'carers') has only been scarcely studied[6]. It is therefore important to explore the perspectives of these groups in the wake of the ongoing pandemic to aid our understanding of how their needs can be met in clinical practice.

Aims and objectives

To investigate the experiential impact of the COVID-19 pandemic on patients and their carers receiving specialized palliative home care.

Methods

Design

An interpretative qualitative design informed by phenomenological hermeneutics was chosen[7-9].

Setting and participants

From an international perspective, the policy response to the COVID-19 pandemic in Sweden can be considered moderate according to a composite of response indicators (e.g. workplace closure, travel bans), with restrictions proposed and recommended that build on the population's high confidence in the official authorities and personal responsibility[10]. At the time of data collection (June to September 2020) the recommendations were soft (as compared to later during the pandemic). No vaccines against COVID-19 were available at the time of data collection.

A large, specialized palliative home care service (ca. 160 patients) covering a city with a diverse population in western Sweden was chosen for the study. Advanced palliative care is provided at home until death, including home visits by nurses and physicians as often as needed, around the clock. The median period of care is 2 months.

Inclusion criteria were: aged 18 years or older, diagnosed with an incurable life-threatening disease, not previously or currently infected by the COVID-19 virus, sufficient strength to participate and capacity to provide informed consent. Participants were selected through a combination of convenient and consecutive sampling. Details thereof are described in Figure 1. For demographic and diagnostic data, see Table 1.

Table 1. Demographic and diagnostic data

	Patients (n=22)	Carers (n=17)
Gender		
Female	11	12
Male	11	5
Age years		
50-60 years	5	5
61-70 years	5	7
71-80 years	7	4
81-90 years	3	1
91-- years	2	0
Employment status		
Employed	1	8
On sick leave	6	1
Retired	15	8
Living situation		
Living alone	10	2
Living together	10	15
no answer	2	0
Education		

Elementary school	4	1
High school	7	5
College/University	11	11
Country of birth		
Sweden	19	14
Other European	2	3
Outside of Europe	1	0
Patient's disease		
Cancer*	18	-
Heart failure	2	-
Lung fibrosis	1	-
no answer	1	-
Patient´s disease duration		
<1 year	2	-
1-2 years	3	-
2-5 years	6	-
5-10 years	7	-
>10 years	3	-
no answer	1	-
Relationship to patient		
Spouse/partner	-	12
Child	-	3
Sibling	-	2

* colon-, breast-, prostate-, ovarian-, bile duct-, lung-, pancreas cancer and malignant melanoma

Data collection

In-depth interviews with all the participants were conducted in Swedish over the telephone, digitally recorded and transcribed verbatim. Duration of interviews were 9-33 minutes for patients and 7-54 minutes for carers. Transcripts were not returned to or commented on by the participants. Patients and the carers had the option of being interviewed separately or together. However, due to the ongoing pandemic, the option of performing in-person interviews was omitted. All authors took part in the interviews, among them physicians, nurses and social workers trained in interviewing, but none of the authors was involved in the care of any of the participants they interviewed. Questions used as prompts in the interviews were: Can you describe what it was like when the pandemic started? How is your daily life now? Has something become difficult for you now or is there anything you have been missing? Have you found something helpful? An additional question was used with carers: What are your thoughts about the [patient's] situation today?

Data analysis

Data were analysed in interrelated phases: firstly naïve reading of the transcripts to acquire a general perception of the data and to generate analytical questions, then structural analyses based on the analytical questions, and finally an interpreted whole[7,8]. For the naïve reading, all authors read transcripts from both patients and carers and met to discuss their reflections from both the readings and having performed the interviews. This resulted in the following analytical questions which guided the structural analyses: What are the meanings of the changed situation as a result of the pandemic? How has the changed situation been handled? What support has been received and/or wished for in the situation? For the structural analyses, all transcripts were scrutinized for text segments (meaning units) answering each of the questions, and subsequently, data related to each of these questions were analysed with a focus on experiential meanings. For the interpreted whole, the results of the naïve reading and meanings disclosed in the structural analyses were interwoven and discussed in the team to interpret the meaning of the studied phenomenon. All phases in the analysis were interrelated and repeated. The principle of data saturation is not applicable[7,8]. All analyses were performed manually and supported by software for text only (Microsoft Office, Word).

Patient and public involvement

Patients´ perspectives and topics of relevance were obtained through researchers´ everyday clinical practice and previous research. There were no patient representatives involved in the research team.

Results

Naïve reading

Both patients and carers described the impact of the COVID-19 pandemic as being framed by the patient's underlying, non-COVID life-threatening, progressive disease and receiving palliative care. In this way, the participants' descriptions of the impact of the pandemic were explicitly or implicitly related to the advanced condition. This was especially emphasized by patients as "a tough diagnosis", with all its implied restrictions in terms of limiting social activities, having to live day by day, and preparing for death and feeling increasingly vulnerable.

First structural analysis: Meaning of the pandemic

The meaning of the impact of the pandemic was revealed as the themes worry and fear, taking personal responsibility, and being dependent on others acting responsibly.

A worry and fear spectrum

The COVID-19 pandemic with its subsequent recommended and perceived restrictions were related to worry and fear among both patients and carers about how to adhere to restrictions and prevent getting infected. However, there was a wide spectrum of emotions among the participants, from almost no worry at all to a constant fear of getting infected, and/or infecting others, with profound consequences for everyday life. In addition to worry as related to risk of infection, some patients expressed fear there would be insufficient healthcare resources for themselves due to increased overall societal need, or they feared they would not get help from family, friends and other organisations outside health care due to their fear of infecting the patient or getting infected themselves. Moreover, what was perceived as an unnatural way of living during the pandemic caused some to worry about not dying normally.

Restrictions also made many social activities impossible, with some participants expressing fear of losing time that was already limited, as emphasized by this patient: "We're losing time we thought was our time – that we would do good things with – in this [situation]." (P7).

The participants described distressing fear as a reason for isolating themselves in their homes, saying it was 'terrible' to have to cancel all non-essential services and support, including visits from carers. This was related to a considerable reduction in social contacts and of support, in time also making patients feel depressed and lonely. Some individual participants described it as 'torture-like'. What remained was the perceived necessary support from healthcare personnel, that consequently also gained importance as the sole source of social contact. For carers, distressing fear was related to the risk of infecting the patient, with emphasis on strictly adhering to recommendations and minimizing interpersonal contacts with others. For carers living in the same household as the patient, this was described as living in joint isolation, with much anxiety about needing to leave the house. Significant others outside of the patient's household said they dare not visit. They described being torn between the risk of infecting the patient and their longing for a personal encounter, which was considered especially important due to the patient's need for support and the limited time they had left. Some participants expressed this strongly, describing it as unbearable and bordering on torture.

On the other end of the spectrum there were descriptions of the pandemic having only minimal impact and vague indications of worry, largely related to an awareness of death being imminent regardless. As one patient said: "Yes, but personally I wasn't that concerned that I would be affected because either I die of that or the other [illness]" (P19). Carers also commented: "Yes Corona would kill him but he's reaching the end anyway" (N5).

This was taken as a reason to put all focus on the present situation with advanced illness, but also to consider the situation proportionally: "My illness is bigger than the pandemic, so to speak, right? In our family" (P4).

Alternatively, daily life could already be very limited due to the advanced illness and severely reduced general condition. Consequently, the pandemic restrictions did not entail any change and had hardly been noticed. Some found that their previously limited lives were now common to many and that the pandemic may even have affected them less than others: "Perhaps the pandemic has affected us less than other people who are completely healthy, fully able to work and like, be in the thick of it – for those people the pandemic came like a

smack in the face and we've already had ours – that meant we were at home more, well, for other reasons" (N14).

In between these opposite ends of the worry spectrum examples were given in relation to weighing the risks against the benefits and trying to find creative solutions to problems while adhering to recommendations. This could still involve isolation, especially from peripheral contacts, but most often allowed personal meetings with family and friends. Such personal contact was motivated by efforts to maintain the practical as well as spiritual support said to be needed by both patients and carers. In these situations, the impact of the pandemic was expressed as very palpable although bearable. Regardless of the individual's initial reaction to the pandemic, the amount of lived time was said to influence their worry in either directions. While some said the persistent threat of the pandemic gradually increased their fear, others became less fearful as they became accustomed to the situation.

When there was disparity in the fear felt by patients and their carers, deciding how to handle a situation could be problematic. For example, fearful patients described being stressed by less fearful carers who wanted to socialize and vice versa. Different expressions of fear and subsequent behaviour were perceived, leading to disputes between carers, which sometimes also affected the patient.

Second structural analysis: Handling of the situation

The participants described a number of ways in which they handled the pandemic situation, with actions related to seeking information and knowledge in different ways, creating solutions to stay connected socially (primarily through digital devices) and limiting their physical social contacts. Participants described their handling of the situation as governed by their degree of worry and fear, as well as notions of responsibility.

Taking personal responsibility and being dependent on others acting responsibly

Carers explicitly described how, due to the pandemic and the patient’s illness, they repeatedly needed to take responsibility in different ways in terms of caring for the patient and protecting him/her against COVID-19 infection. They also described how they personally could take action, by refraining from certain activities to avoid infection and in order to take personal responsibility in the role of carers. Patients also often gave details about the measures they took and changes to their daily routines to avoid infection, but in this regard, taking responsibility was usually implicit in their narrative. Carers often re-emphasized their responsibility, for example: “I’m probably more careful because of him than if it had only been about me, I really am.” (N16).

At the same time, needing and wanting to take responsibility for oneself personally and as a carer was associated with uncertainty in several senses. Although the participants referred to the public health authority’s guidelines regarding the pandemic, they were indecisive about how they should best be applied, especially in a family with a seriously ill person. This uncertainty also applied to the actual disease situation. Carers talked about a reduction in their necessary ‘breathing space’ in the care of the sick. Sometimes, participants confessed to telling a few ‘white lies’ in order to preserve their image of being a responsible carer and to avoid fuelling the sick person’s anxiety: “So it’s the same thing if I want to see the grandchildren a bit more and he thinks I shouldn’t or if I want to use public transport, then it means you sometimes actually have to lie or not tell the whole truth, so I don’t think that’s good but it’s very difficult to manage. Because you don’t want the person who’s worried to worry even more” (N6).

For most participants, keeping up to date with the latest information about the pandemic was included in taking responsibility. Some patients said their constant interest in media reports could annoy their carers, while others consciously chose to limit their exposure to information: “I don’t take it in. Today, now, I’m not reading anything – it’s a strategy – barely read any news, don’t watch anything of hardly any news on TV, kind of shut it out” (P9).

In the present situation, the value of relationships was often said to come to the fore as a core value. Changed and often creative ways of socializing were described to avoid risk of infection to the patient, for example, meeting outside or using digital devices. Relationships with health professionals and staff appeared to take on greater significance. In the carers’ narratives, taking responsibility by being careful and avoiding risks were highlighted.

To protect the patient from infection the carers also depended on and had to trust others to act responsibly. This became particularly obvious in the meetings with healthcare staff at home. Even though staff were perceived as demonstrating responsibility by not greeting with a handshake or close contact, patient care usually required body contact. Both patients and carers indicated that it was difficult not to worry and to be confident that the professionals were taking responsibility and not working if they were at risk of being infected. Several participants gave examples of how safety routines could vary between teams and units, which seemed incomprehensible, and for some, distressing and violating.

Third structural analysis: Received or lack of support

All the participants described various types of support they received. Although the situation was framed by support related to the advanced illness, support as related to the pandemic was often interwoven with this. Many participants (both patients and carers) also mentioned support they were lacking or wished for, and were quite animated in describing this. Both received and lack of support were described in relation to a range of actors, including self, family members, friends, healthcare professionals/staff and a range of services, volunteers and organizations in civil society and public health authorities (see Table 2).

Table 2. Support: received, lacking or wished for

Support from	**Described by the patient**		**Described by the informal carer**	
	received	***lacking or wished for***	***received***	***lacking or wished for***
Family and friends	Practical support Personal support when meeting outdoors, calling by phone, FaceTime etc.	In-person social contacts Practical help	Giving support to their next-of-kin is considered self-evident and important Focus on practical chores	Spending time together External support (e.g. social services) Understanding from bystanders Wanted to give support, but could not due to health problems
Palliative home care service	Support and safety at home through competent carers Psychosocial/psychological support Use of protective equipment creates security	Too few visits from the home care team Lack of psychosocial support Better use of technical solutions such as	Support from palliative home care makes it possible to remain at home Help at home minimizes the risk of getting infected when	Better use of technical solutions such as videoconferences Protective equipment was not used consistently

		videoconferences Protective equipment was not used consistently	visiting e.g. the hospital Accessibility 24/7 creates safety Holistic thinking, problem solving, good contacts with other forms of care Use of protective equipment creates security Psychosocial support	
Other healthcare and ***social services***	Hospital care and social services have been supportive Use of protective equipment creates security	In-person visits e.g. to hospital. Telephone calls makes it harder to be spontaneous and harder for their next-of-kin to participate Lack of psychosocial support More use of technical solutions such as videoconferences Protective equipment was not used consistently	Being allowed to visit in the hospital despite restrictions Use of protective equipment creates security	Not being able to take their ordinary supportive role due to restrictions for accompanying visitors in the hospital Lack of information and involvement in the care process/disease progression

				The pandemic has made things take longer than promised
From society	Practical support from e.g. the Red Cross or churches	Lack of clarity in the official recommendations	(not mentioned)	Lack of practical support Insufficient and contradictory information from the authorities

Interpreted whole

Here, the interpretation is taken further. Living in a society with restrictions following the COVID-19 pandemic and receiving specialized palliative care was revealed as interrelated and not always possible to distinguish. The pandemic, implying a risk of life-threatening infection for both patients and careers, is framed by patients being aware of their mortality, with limited remaining life-span due to their advanced life-limiting condition, and carers living with impending loss. The meaning of the pandemic's impact relates to a spectrum from mild indications of worry at one end to distressing fear at the other, leading to avoidance of personal encounters and resulting in isolation and loneliness. Individuals may hover between the two ends of the spectrum or move to either end over time. However, taking personal responsibility and managing the situation is at the same time dependent on how others do the same – hence, personal responsibility is interdependent on others. Taking action and handling the situation through various (in some cases creative) solutions seems to require being free from distressing fear. This underlines the importance of supportive actions, which could be provided in personal encounters with family, friends, volunteers and professionals. Such encounters were in place to various degrees but were also found lacking and wished for.

Discussion

The impact of the pandemic on patients and carers in the context of specialized palliative home care was framed by the patient’s underlying non-COVID, end-stage disease. Most participants said they were aware of the patient’s vulnerability, that their daily life was already limited to varying degrees, and that death was inevitable. Despite the participants’ similar circumstances, their reactions to the pandemic varied greatly. While some found the threat of the pandemic of little significance due to a reduced general condition and a life span that was already limited, others reacted with great fear for the same reason, as they were afraid of losing the little time they had left. Further, the value of social contacts became apparent. The loss of such contacts due to isolation was devastating for some, while others found creative solutions to maintain relationships. In many cases, visits from health professionals became the sole social contact and most participants found highly available palliative home care of utmost importance for their support and security.

During the pandemic, much interest has focused on palliative care needs for patients infected with COVID-19[11-14]. A few studies have also explored how to practically perform and maintain high quality palliative care for non-COVID patients during the pandemic[15]. However, there is a lack of studies focusing on the experiential impact of the COVID pandemic on patients receiving specialized palliative home care for reasons other than COVID. To our knowledge, this is the first study directly addressing patients with an end-stage, non-COVID disease, receiving specialized palliative home care, and their carers, to investigate how they experience consequences of the COVID-19 pandemic.

Although the impact of the pandemic on the participants in the present study varied greatly, some participants described great fear, that along with strict isolation, bordered on torture. A similar significant impact of the pandemic has been shown in populations worldwide. Already at the beginning of the pandemic, while death rates were low, polls found that about one third of adults in Canada and the USA were very concerned about COVID-19[16] and in China, fear of the disease was reported to cause a perceived moderate-to-severe impact on more than half of the respondents[17]. Research from previous pandemics suggests that perceived vulnerability to disease is an important factor inducing fear[18]. As all the patients in the present study can be classified as vulnerable due to underlying life-threatening disease, most often cancer, an increased risk of adverse outcome of an infectious disease follows[4, 19]. Thus their perceived fear is affected not only by the societal threat of the pandemic but also has valid reason due to their condition, which is also recognized by their carers.

The overhanging life-threat from the patients' underlying disease might be a reason for why many in this group of patients describe the pandemic as having a great impact on their lives.

Despite soft national recommendations for restrictions at the time of the study, all participants practised isolation to a greater or lesser degree. While having to abstain from visits to the gym, theatre and shopping mall was mentioned, there was an overwhelming consensus among the participants that the primary negative consequence of isolation was lack of social contact with close and significant others. This is consistent with the finding that increased mortality salience can enhance the value of the person's closest significant others[20] and that basic human conservation values are endorsed during the COVID-19 pandemic[21].

Many patients, as well as carers, expressed regrets that fellowship with family and friends could not be maintained for the short time remaining of their lives, and for some this resulted in strong feelings of loneliness, blues and anxiety. From previous studies it is known that isolation and quarantine can cause distressing problems, and that older people, like those in the present study, are more prone[1, 22]. Moreover, isolation adds to the distress already present among seriously ill patients receiving palliative care.

To relieve anxiety, many participants emphasized the importance of receiving continuous support from healthcare professionals and official authorities in promoting their knowledge-seeking and understanding in order to proactively manage their lives. However, some chose a different management tactic in completely abstaining from media, while others said they became addicted to media news. Participants with the latter behaviour expressed more anxiety, which could be due to exaggerated news reports and sensational headlines fuelling anxiety and fear[23]. The great differences in participants' reactions to the pandemic threat, despite similar basic conditions, could speculatively be dependent on personality type, an important factor in determining stress[24].

To a large extent, patients with end-stage life-threatening disease and their carers are already exposed to the type of threats and restrictions that a subsequently imposed pandemic entails. With this starting position, participants could find the COVID pandemic to be of little significance to them, while at the other end of the spectrum, some participants were almost paralysed with fear. For health and social care professionals, awareness of these diverse reactions to a pandemic threat is important in order to provide appropriate support to patients in palliative care and their carers.

Implications and future directions

The sometimes extreme emotions among the participants elicited by the pandemic (describing it as torture) emphasizes the importance of the holistic view characterizing palliative care and the need for the entire care team to practice person-centred competence as related to communication and care practice[25]. It also underlines the importance of maintaining high availability of specialized palliative care during future pandemics, and the need to further study other challenging societal situations involving major part of populations.

Conclusion

The double burden of chronic, non-COVID, life-threatening disease and the ongoing pandemic which patients in specialized palliative home care and their carers were subjected to elicited a great variety of emotional and practical responses among the participants.

For some, awareness of an already limited life span and reduced general condition meant they were minimally concerned by COVID-19 and could choose less isolation, while at the other end of the spectrum, participants said this awareness gave rise to extreme fear, with strict isolation being perceived as torture-like. This spectrum of reactions could be found among both patients and carers and provides a heuristic value. Tensions and stress could arise in cases where there was disparity in the level of concern for COVID-19 between the individual patient and his/her carers, adding to the already difficult situation.

Most patients and carers found access to specialized palliative home care was maintained despite the pandemic. Easy access to a competent palliative team was said to be supportive and instil a sense of security, which is of particular importance during a pandemic, and for some, it also took on importance as the sole social contact.

Acknowledgements

We thank the patients and carers who participated in the study.

Contributors

All authors took part in collecting, analysing, and interpreting the data. SN was the main authors of the manuscript, and all authors contributed to the writing. All authors read and approved the final manuscript.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sector.

Competing interests

None declared.

Patient consent for publication

Obtained.

Ethics approval

This study was approved by the Swedish Ethical Review Authority (No. 2020-0214106; date of approval: 2020-06-17).

Data availability statement

Data are available upon request to the corresponding author.

References

1. Dubey S, Biswas P, Ghosh R, et al. Psychosocial impact of COVID-19.

Diabetes Metab Syndr 2020; 14: 779-788. 2020/06/12. DOI: 10.1016/j.dsx.2020.05.035.

2. Ahorsu DK, Lin CY, Imani V, et al. The Fear of COVID-19 Scale: Development and Initial Validation. *Int J Ment Health Addict* 2020: 1-9. 2020/04/01. DOI: 10.1007/s11469-020-00270-8.

3. Fillmore NR, La J, Szalat RE, et al. Prevalence and Outcome of COVID-19 Infection in Cancer Patients: A National Veterans Affairs Study. *JNCI : Journal of the National Cancer Institute* 2021; 113: 691-698. DOI: 10.1093/jnci/djaa159.

4. Johannesen TB, Smeland S, Aaserud S, et al. COVID-19 in Cancer Patients, Risk Factors for Disease and Adverse Outcome, a Population-Based Study From Norway. *Front Oncol* 2021; 11: 652535. 2021/04/13. DOI: 10.3389/fonc.2021.652535.

5. Papachristou N, Barnaghi P, Cooper B, et al. Network Analysis of the Multidimensional Symptom Experience of Oncology. *Scientific reports* 2019; 9: 2258-2258. DOI: 10.1038/s41598-018-36973-1.

6. Miaskowski C, Paul SM, Snowberg K, et al. Oncology patients' perceptions of and experiences with COVID-19. *Support Care Cancer* 2021; 29: 1941-1950. 2020/08/19. DOI: 10.1007/s00520-020-05684-7.

7. Berndtsson I, Claesson S, Friberg F, et al. Issues about Thinking Phenomenologically while Doing Phenomenology. *Journal of Phenomenological Psychology* 2007; 38: 256-277.

8. Lindseth A and Norberg A. A phenomenological hermeneutical method for researching lived experience. *Scandinavian journal of caring sciences* 2004; 18: 145-153. Submitted 14 July 2003, Accepted 8 January 2004. DOI: 10.1111/j.1471-6712.2004.00258.x.

9. Ricœur P. *From text to action : essays in hermeneutics II*. London: London : Athlone, 1991.

10. Data OWi. https://ourworldindata.org/policy-responses-covid (2020).

11. Strang P, Bergström J, Martinsson L, et al. Dying From COVID-19: Loneliness, End-of-Life Discussions, and Support for Patients and Their Families in Nursing Homes and Hospitals. A National Register Study. *Journal of pain and symptom management* 2020; 60: e2-e13. DOI: 10.1016/j.jpainsymman.2020.07.020.

12. Etkind SN, Bone AE, Lovell N, et al. The Role and Response of Palliative Care and Hospice Services in Epidemics and Pandemics: A Rapid Review to Inform Practice During the COVID-19 Pandemic. *J Pain Symptom Manage* 2020; 60: e31-e40. 2020/04/12. DOI: 10.1016/j.jpainsymman.2020.03.029.

13. Rao A and Kelemen A. Lessons Learned from Caring for Patients with COVID-19 at the End of Life. *J Palliat Med* 2021; 24: 468-471. 2020/08/25. DOI: 10.1089/jpm.2020.0251.

14. Fadul N, Elsayem AF and Bruera E. Integration of palliative care into COVID-19 pandemic planning. *BMJ Support Palliat Care* 2021; 11: 40-44. 2020/06/13. DOI: 10.1136/bmjspcare-2020-002364.

15. Harasym P, Brisbin S, Afzaal M, et al. Barriers and facilitators to optimal supportive end-of-life palliative care in long-term care facilities: a qualitative descriptive study of community-based and specialist palliative care physicians' experiences, perceptions and perspectives. *BMJ Open* 2020; 10: e037466. 2020/08/08. DOI: 10.1136/bmjopen-2020-

037466.

16. Asmundson GJG and Taylor S. Coronaphobia: Fear and the 2019-nCoV outbreak. *J Anxiety Disord* 2020; 70: 102196. 2020/02/23. DOI: 10.1016/j.janxdis.2020.102196.

17. Wang C, Pan R, Wan X, et al. Immediate Psychological Responses and Associated Factors during the Initial Stage of the 2019 Coronavirus Disease (COVID-19) Epidemic among the General Population in China. *Int J Environ Res Public Health* 2020; 17 2020/03/12. DOI: 10.3390/ijerph17051729.

18. Taylor S. *The psychology of pandemics : preparing for the next global outbreak of infectious disease*. Newcastle upon Tyne: Cambridge Scholars Publishing. 2020.

19. Mirzaei R, Karampoor S, Sholeh M, et al. A contemporary review on pathogenesis and immunity of COVID-19 infection. *Mol Biol Rep* 2020; 47: 5365-5376. 2020/07/01. DOI: 10.1007/s11033-020-05621-1.

20. Heine SJ, Proulx T & Vohs KD. The meaning maintenance model: on the coherence of social motivations. *Personality and Social Psychology Review* 2006; **10**, 88-110.

21. Bonetto E, Dezecache G, Nugier A, et al. Basic human values during the COVID-19 outbreak, perceived threat and their relationships with compliance with movement restrictions and social distancing. *PLoS One* 2021; 16: e0253430. 2021/06/19. DOI: 10.1371/journal.pone.0253430.

22. Taylor HO, Taylor RJ, Nguyen AW, et al. Social Isolation, Depression, and Psychological Distress Among Older Adults. *J Aging Health* 2018; 30: 229-246. 2017/05/30. DOI: 10.1177/0898264316673511.

23. Dong M and Zheng J. Letter to the editor: Headline stress disorder caused by Netnews during the outbreak of COVID-19. *Health Expect* 2020; 23: 259-260. 2020/04/01. DOI: 10.1111/hex.13055.

24. Dumitru VM & Cozma D (2012) The relationship between stress and personality factors. *Human & Veterinary Medicine* 2012; **4**(1), 34-39.

25. Öhlén J, Carlsson G, Jepsen A, et al. Enabling sense-making for patients receiving outpatient palliative treatment: A participatory action research driven model for person-centered communication. *Palliative & supportive care* 2016; 14: 212-224. DOI: 10.1017/S1478951515000814.

Figure 1. Inclusion of participants. Note. First, physicians responsible for the patients were asked to evaluate patients according to study criteria. Subsequently, eligible patients received the first oral information about the study over telephone by a research nurse. Those who showed interest to participate were asked if they had a family carer that could be informed about the study. All written information, consent forms and prepaid envelopes were mailed to the patient. Those who returned the consent form were contacted by telephone to agree on a time for the interview over telephone. Reasons for declining were not investigated.

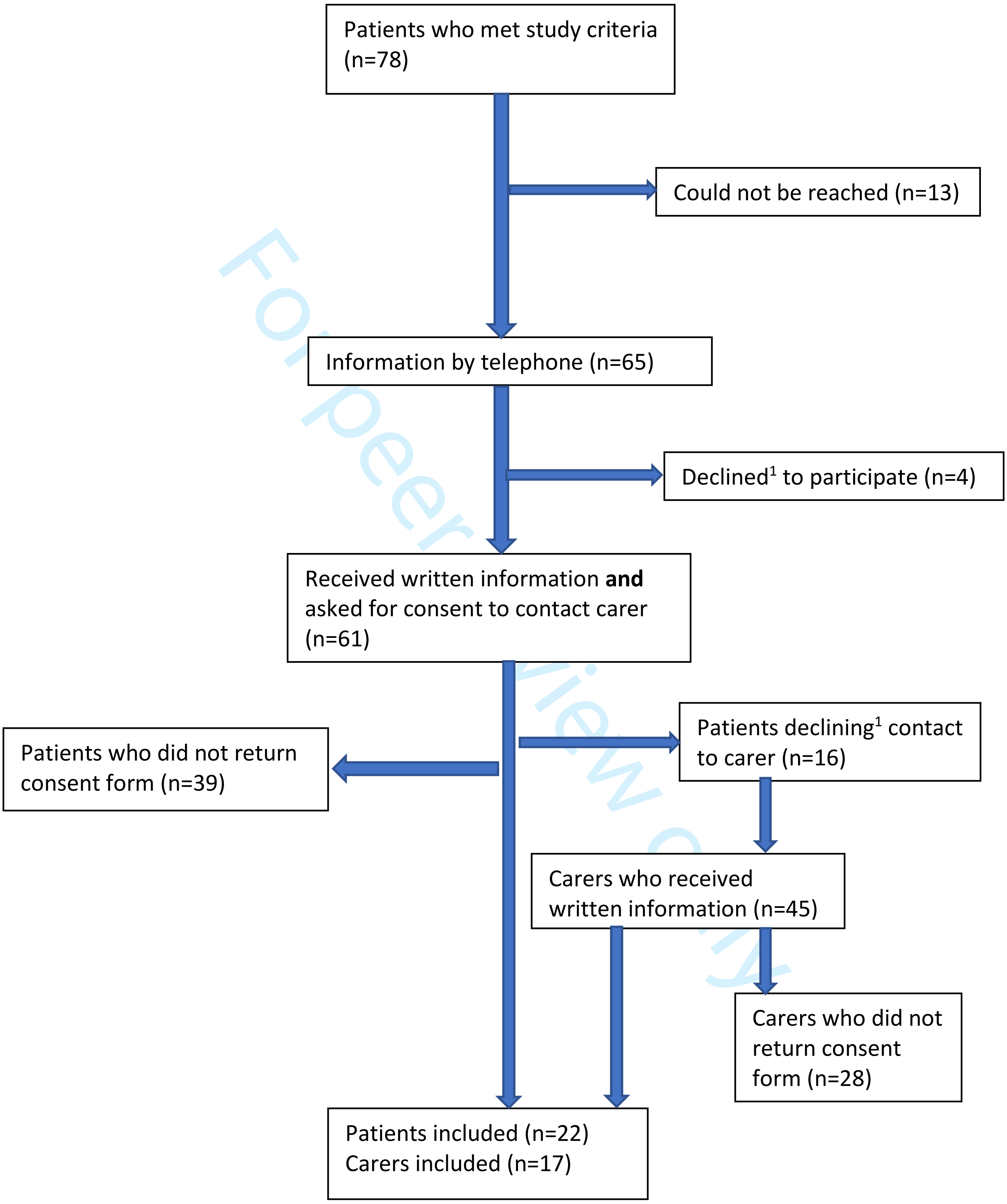

Figure 1. Inclusion of participants.

Note. First, physicians responsible for the patients were asked to evaluate patients according to study criteria. Subsequently, eligible patients received the first oral information about the study over telephone by a research nurse. Those who showed interest to participate were asked if they had a family carer that could be informed about the study. All written information, consent forms and prepaid envelopes were mailed to the patient. Those who returned the consent form were contacted by telephone to agree on a time for the interview over telephone. Reasons for declining were not investigated.

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Please indicate in which section each item has been reported in your manuscript. If you do not feel an item applies to your manuscript, please enter N/A.

For further information about the COREQ guidelines, please see Tong *et al.*, 2017: https://doi.org/10.1093/intqhc/mzm042

No.	Item	Description	Section #
Domain 1: Research team and reflexivity			
Personal characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	
3.	Occupation	What was their occupation at the time of the study?	
4.	Gender	Was the researcher male or female?	
5.	Experience and training	What experience or training did the researcher have?	
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? *E.g. Personal goals, reasons for doing the research*	
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? *E.g. Bias, assumptions, reasons and interests in the research topic*	
Domain 2: Study design			
Theoretical framework			
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study? *E.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	
Participant selection			
10.	Sampling	How were participants selected? *E.g. purposive, convenience, consecutive, snowball*	
11.	Method of approach	How were participants approached? *E.g. face-to-face, telephone, mail, email*	
12.	Sample size	How many participants were in the study?	
13.	Non-participation	How many people refused to participate or dropped out? What were the reasons for this?	
Setting			
14.	Setting of data collection	Where was the data collected? *E.g. home, clinic, workplace*	
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	

16.	Description of sample	What are the important characteristics of the sample? *E.g. demographic data, date*	
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	
20.	Field notes	Were field notes made during and/or after the interview or focus group?	
21.	Duration	What was the duration of the interviews or focus group?	
22.	Data saturation	Was data saturation discussed?	
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	
25.	Description of the coding tree	Did authors provide a description of the coding tree?	
26.	Derivation of themes	Were themes identified in advance or derived from the data?	
27.	Software	What software, if applicable, was used to manage the data?	
28.	Participant checking	Did participants provide feedback on the findings?	
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? *E.g. Participant number*	
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	
31.	Clarity of major themes	Were major themes clearly presented in the findings?	
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	

When submitting your manuscript via the online submission form, please upload the completed checklist as a Figure/supplementary file.

If you would like this checklist to be included alongside your article, we ask that you upload the completed checklist to an online repository and include the guideline type, name of the repository, DOI and license in the *Data availability* section of your manuscript.

Developed from: Allison Tong, Peter Sainsbury, Jonathan Craig, Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups, International Journal for Quality in Health Care, Volume 19, Issue 6, December 2007, Pages 349–357, https://doi.org/10.1093/intqhc/mzm042

BMJ Open

Pandemic impact on patients with advanced non-COVID-19 illness and their family carers receiving specialized palliative home care: a qualitative study

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2021-059577.R1
Article Type:	Original research
Date Submitted by the Author:	21-Mar-2022
Complete List of Authors:	Nyblom, stina; Sahlgrenska Academy, Palliative Center; University of Gothenburg, Medicine Benkel, Inger; Sahlgrenska Academy, Palliative Center Carling, Linnéa; Sahlgrenska University Hospital, Palliative Center Löfdahl, Elisabet; Sahlgrenska universitetssjukhuset Molander, Ulla; Sahlgrenska Academy, Palliative Center Öhlen, Joakim ; University of Gothenburg, Institute of Health and Care Sciences
Primary Subject Heading:	Palliative care
Secondary Subject Heading:	Qualitative research
Keywords:	COVID-19, PALLIATIVE CARE, QUALITATIVE RESEARCH

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

Pandemic impact on patients with advanced non-COVID-19 illness and their family carers receiving specialized palliative home care: a qualitative study

Stina Nyblom[1,2], Inger Benkel[1,2], Linnéa Carling[2], Elisabet Löfdahl[2], Ulla Molander[1,2], Joakim Öhlén[2,3]

[1]Institute of Medicine, University of Gothenburg, Sweden
[2]Sahlgrenska University Hospital, Department of Palliative Care, Gothenburg, Sweden
[3]Institute of Health and Care Sciences, University of Gothenburg, Sweden

(F) Stina Nyblom, MD, PhD	http://orcid.org/0000-0002-4998-0324
(F) Inger Benkel, MSW, PhD, Associate professor	http://orcid.org/0000-0002-5919-3877
(F) Linnéa Carling, RN, MSc	
(F) Elisabet Löfdahl, MD	
(F) Ulla Molander, MD, PhD, Associate professor	http://orcid.org/0000-0002-6593-3130
(M) Joakim Öhlén, RN, PhD, Professor	http://orcid.org/0000-0003-2429-8705

Corresponding author: Stina Nyblom

Mailing address: Palliative Center, Hogsbo hospital, Box 30110, 40043 Gothenburg, Sweden

E-mail: stina.nyblom@vgregion.se
Telephone: +46 767841620

Abstract

Objectives

To investigate the experiential impact of the COVID-19 pandemic on patients with non-Covid life-threatening disease and their family carers**.**

Design

An interpretative qualitative design informed by phenomenological hermeneutics and based on data from in-depth interviews, performed between June and September 2020.

Setting

Patients receiving specialized palliative home care and their family carers living in Sweden.

Participants

22 patients (male/female 11/11) and 17 carers (male/female 5/12) all aged 50 years and older. All patients received specialized palliative home care and most were diagnosed with cancer. Inclusion criteria: aged 18 years or older, diagnosed with an incurable life-threatening non-Covid disease, sufficient strength to participate and capacity to provide informed consent. Participants were selected through a combination of convenient and consecutive sampling.

Results

The significance of the pandemic for both patients and carers shows a continuum from being minimally affected in comparison to the severe underlying disease to living in isolation with constant fear of becoming infected and falling ill with COVID-19, which some likened to torture.

The imposed restrictions on social contact due to the pandemic are particularly palpable for this group of people with a non-COVID-19 life-limiting condition, as it was told to steal valuable moments of time that has already been measured.

Most patients and carers found access to specialized palliative home care was maintained despite the pandemic and of paramount importance for their sense of security and is often their sole visiting social contact.

Conclusions

In the pandemic situation, highly accessible support from health- and social care at home, is particularly important in order to create security for both patients and carers. Thus, to provide appropriate support, it is important for health- and social care personnel to be aware of the great diversity of reactions patients in palliative care and their carers may have to a pandemic threat.

Keywords: COVID-19, Palliative care, Qualitative research**.**

Strengths and limitations of this study

- A strength of this study is the empirical anchorage through first person narratives.
- All interviews were performed by professionals trained in conversation methodology.
- Demographics data were varied and showed a broad age range, although few men were represented among family carers.
- Strategic sampling would have been stronger than the combined convenient and consecutive sampling applied.

- The majority of patients were diagnosed with cancer and only few participants had a migration background. Moreover, the study is performed in a country with tax-financed health care, comparably soft restrictions and no lock-down during the Covid pandemic, which could limit transferability of the result.

Introduction

The COVID-19 pandemic has resulted in the development of national recommendations for care of infected patients, as well as for society as a whole. Thus, the pandemic does not only influence those who are infected. In a review by Dubey et al. the psychosocial impact of COVID-19 is described as affecting the whole population, whether you are sick or healthy[1]. Numerous deaths caused by the pandemic have been reported daily, with excessive exposure in the media, resulting in death becoming unusually palpable in society. The resulting fear – that naturally arises when humans are faced with infectious disease – is present in the COVID-19 pandemic, and shows a positive correlation to anxiety and depression[2]. Patients admitted to palliative care with a non-COVID life-threatening disease constitute a particularly vulnerable group, with a higher risk of adverse outcome from a COVID-19 infection[3, 4]. These patients are under life threat from both the underlying disease – most often cancer – and from impending pandemic infection. Moreover, the significant overlap of COVID-19 and cancer-related symptoms can result in recurrent uncertainty whether the person is infected or not[5, 6]. Thus, we found it important to explore the perspectives of these groups in the wake of the ongoing pandemic

At the time of data collection (June to September 2020) the pandemic was classified under the Communicable Diseases Act but, in contrast to many other countries worldwide, restrictions in Sweden were soft, meaning no mandatory rules or lock-down, only recommendations (as compared to later during the pandemic). From an international perspective, this policy response to the COVID-19 pandemic in Sweden can be considered moderate according to a composite of response indicators (e.g. workplace closure, travel bans), with restrictions proposed and recommended that build on the population's high confidence in the official authorities and personal responsibility[7]. For health care personnel, protective equipment gradually became mandatory when working in close contact with patients. Regardless of the infection status of the patient or family, home visits were continued, although more often than before the pandemic, exchanged by telephone or digital contact. No vaccines against COVID-19 were available at the time of data collection.

To our knowledge, the impact of the COVID-19 pandemic on patients with a non-Covid end-stage disease, receiving specialized palliative care at home, has only been scarcely studied[6, 8]. We therefore conducted interviews with both patients and their family carers (in the following 'carers') in order to aid our understanding of how their needs can be met in clinical practice.

Aims and objectives

To investigate the experiential impact of the COVID-19 pandemic on patients and their carers receiving specialized palliative home care.

Methods

Design

An interpretative qualitative design informed by phenomenological hermeneutics was chosen[9-11].

Setting and participants

Patients, and their family carers, were recruited for interview from a specialized palliative home care service (ca. 160 patients; covering a city with a diverse population) in western Sweden, which provided care at home until death. Visits by nurses and physicians were provided as often as needed, around the clock. Besides health care, patients often had help from social home care. This support allowed family carers, when present, to choose to what extent they wanted to take part in the patient´s daily care. The median period of time allocated to specialized palliative home care was 2 months.

Inclusion criteria were: aged 18 years or older, diagnosed with an incurable life-threatening disease, not previously or currently infected by the COVID-19 virus, sufficient strength to participate and capacity to provide informed consent. Participants were selected through a combination of convenient and consecutive sampling; patients available at the service and scheduled for home visits were given written information about the study during the recruitment period. Details thereof are described in Figure 1. Participants provided written consent by mail to the researchers. For demographic and diagnostic data, see Table 1.

Table 1. Demographic and diagnostic data

	Patients (n=22)	Carers (n=17)
Gender		
Female	11	12
Male	11	5
Age years		
50-60 years	5	5

61-70 years	5	7
71-80 years	7	4
81-90 years	3	1
91-- years	2	0
Employment status		
Employed	1	8
On sick leave	6	1
Retired	15	8
Living situation		
Living alone	10	2
Living together	10	15
no answer	2	0
Education		
Elementary school	4	1
High school	7	5
College/University	11	11
Country of birth		
Sweden	19	14
Other European	2	3
Outside of Europe	1	0
Patient's disease		
Cancer*	18	-
Heart failure	2	-
Lung fibrosis	1	-
no answer	1	-
Patient´s disease duration		

<1 year	2	-
1-2 years	3	-
2-5 years	6	-
5-10 years	7	-
>10 years	3	-
no answer	1	-
Relationship to patient		
Spouse/partner	-	12
Child	-	3
Sibling	-	2

* colon-, breast-, prostate-, ovarian-, bile duct-, lung-, pancreas cancer and malignant melanoma

Data collection

In-depth interviews with all the participants were conducted in Swedish over the telephone, digitally recorded and transcribed verbatim. Duration of interviews were 9-33 minutes for patients and 7-54 minutes for carers. Transcripts were not returned to or commented on by the participants. Patients and the carers had the option of being interviewed separately or together. Three patient-carer pairs chose joint interview. However, due to the ongoing pandemic, the option of performing in-person interviews was omitted. All authors took part in the interviews, among them physicians, nurses and social workers. To ensure trustworthiness, all researchers were professionals with long experience of conversations with patients in their daily work and were aware of differences in conversation strategy in interviews. None of the authors were involved in the care of any of the participants they interviewed. Specific probing questions identified to clarify the narrative in relation to the research questions were[12]: Can you describe what it was like when the pandemic started? How is your daily life now? Has something become difficult for you now or is there anything you have been missing? Have you found something helpful? An additional question was used with carers: What are your thoughts about the [patient's] situation today?

Ethical considerations

Considering the potential vulnerability of the participants, no reminder were given to potential participants provided with written information about the study. For the same reason convenient and consecutive sampling was chosen, since a strategic sampling would have involved a selection process. All participants were invited to choose how to perform the interview.

Data analysis

Data were analysed in interrelated phases: firstly, naïve reading of the transcripts to acquire a general perception of the data and to generate analytical questions, then structural analyses based on the analytical questions, and finally an interpreted whole[10, 11, 13]. For the naïve reading, all authors read transcripts from both patients and carers and met to discuss their reflections from both the readings and having performed the interviews. This resulted in the following analytical questions which guided the structural analyses: What are the meanings of the changed situation as a result of the pandemic? How has the changed situation been handled? What support has been received and/or wished for in the situation? For the structural analyses, all transcripts were scrutinized for text segments (meaning units) answering each of the questions, and subsequently, data related to each of these questions were analysed with a focus on experiential meanings. For the interpreted whole, the results of the naïve reading and meanings disclosed in the structural analyses were interwoven and discussed in the team to interpret the meaning of the studied phenomenon. All phases in the analysis were interrelated and repeated. The principle of data saturation is not applicable[10, 11, 13]. All analyses were performed manually and supported by software for text only (Microsoft Office, Word).

Patient and public involvement

Patients´ perspectives and topics of relevance were obtained through researchers´ everyday clinical practice and previous research. There were no patient representatives involved in the research team.

Results

Naïve reading

Both patients and carers described the impact of the COVID-19 pandemic in different ways related to the patient’s underlying, non-COVID life-threatening, progressive disease and receiving palliative care. In this way, the participants’ descriptions of the impact of the pandemic were explicitly or implicitly related to the advanced condition. This was especially emphasized by patients as a challenging living situation due to their life-limiting illness; by a few labelled “a tough diagnosis”, with all its implied restrictions in terms of limiting social activities, having to live day by day, and preparing for death and feeling increasingly vulnerable.

First structural analysis: Meaning of the pandemic

The meaning of the impact of the pandemic was revealed as the themes worry and fear.

A worry and fear spectrum

The COVID-19 pandemic with its subsequent recommended and perceived restrictions were related to worry and fear among both patients and carers about how to adhere to restrictions and prevent getting infected. However, there was a wide spectrum of emotions among the participants, from almost no worry at all to a constant fear of getting infected, and/or infecting others, with profound consequences for everyday life. In addition to worry as related to risk of infection, some patients expressed fear there would be insufficient healthcare resources for themselves due to increased overall societal need, or they feared they would not get help from family, friends and other organisations outside health care due to their fear of infecting the patient or getting infected themselves. Moreover, what was perceived as an unnatural way of living during the pandemic caused some to worry about not dying normally.

Restrictions also made many social activities impossible, with some participants expressing fear of ‘losing time’ that was already limited, as emphasized by this patient: “We’re losing time we thought was our time – that we would do good things with – in this [situation].” (P7).

The participants described distressing fear as a reason for isolating themselves in their homes, saying it was ‘terrible’ to have to cancel all non-essential services and support, including visits from carers. This was related to a considerable reduction in social contacts and of support, in time also making patients feel depressed and lonely. Some individual participants described it as ‘torture-like’. What remained was the perceived necessary support from healthcare personnel, that consequently also gained importance as the sole source of social contact. For carers, distressing fear was related to the risk of infecting the patient, with emphasis on strictly adhering to recommendations and minimizing interpersonal contacts with others. For carers living in the same household as the patient, this was described as living in joint isolation, with much anxiety about needing to leave the house. Significant others outside of the patient's household said they dare not visit. They described being torn between the risk of infecting the patient and their longing for a personal encounter, which was considered especially important due to the patient's need for support and the limited time they had left. Some participants expressed this strongly, describing it as unbearable and bordering on torture.

On the other end of the spectrum there were descriptions of the pandemic having only minimal impact and vague indications of worry, largely related to an awareness of death being imminent regardless. As one patient said: "Yes, but personally I wasn't that concerned that I would be affected because either I die of that or the other [illness]" (P19). Carers also commented: "Yes Corona would kill him but he's reaching the end anyway" (N5).

This was taken as a reason to put all focus on the present situation with advanced illness, but also to consider the situation proportionally: "In our family, my illness is bigger than the pandemic, so to speak" (P4).

Alternatively, daily life could already be very limited due to the advanced illness and severely reduced general condition. Consequently, the pandemic restrictions did not entail any change and had hardly been noticed. Some found that their previously limited lives were now common to many and that the pandemic may even have affected them less than others: "Perhaps the pandemic has affected us less than other people who are completely healthy, fully able to work and like, be in the thick of it – for those people the pandemic came like a

smack in the face and we've already had ours – that meant we were at home more, well, for other reasons" (N14).

In between these opposite ends of the worry spectrum examples were given in relation to weighing the risks against the benefits and trying to find creative solutions to problems while adhering to recommendations. This could still involve isolation, especially from peripheral contacts, but most often allowed personal meetings with family and friends. Such personal contact was motivated by efforts to maintain the practical as well as spiritual support said to be needed by both patients and carers. In these situations, the impact of the pandemic was expressed as very palpable although bearable. Regardless of the individual's initial reaction to the pandemic, the amount of lived time was said to influence their worry in either directions. While some said the persistent threat of the pandemic gradually increased their fear, others became less fearful as they became accustomed to the situation.

When there was disparity in the fear felt by patients and their carers, deciding how to handle a situation could be problematic. For example, fearful patients described being stressed by less fearful carers who wanted to socialize and vice versa. Different expressions of fear and subsequent behaviour were perceived, leading to disputes between carers, which sometimes also affected the patient.

Second structural analysis: Handling of the situation

The participants described a number of ways in which they handled the pandemic situation, with actions related to seeking information and knowledge in different ways, creating solutions to stay connected socially (primarily through digital devices) and limiting their physical social contacts. Participants described their handling of the situation as governed by their degree of worry and fear (in relation to the spectrum presented above), as well as notions of responsibility.

Taking personal responsibility and being dependent on others acting responsibly

Carers explicitly described how, due to the pandemic and the patient's illness, they repeatedly needed to take responsibility in different ways in terms of caring for the patient and protecting him/her against COVID-19 infection. They also described how they personally could take action, by refraining from certain activities to avoid infection and in order to take personal responsibility in the role of carers. Patients also often gave details about the measures they took and changes to their daily routines to avoid infection, but in this regard, taking responsibility was usually implicit in their narrative. Carers often re-emphasized their responsibility, for example: "I'm probably more careful because of him than if it had only been about me, I really am." (N16).

At the same time, needing and wanting to take responsibility for oneself personally and as a carer was associated with uncertainty in several senses. Although the participants referred to the public health authority's guidelines regarding the pandemic, they were indecisive about how they should best be applied, especially in a family with a seriously ill person. This uncertainty also applied to the actual disease situation. Carers talked about a reduction in their necessary 'breathing space' in the care of the sick. Sometimes, participants confessed to telling a few 'white lies' in order to preserve their image of being a responsible carer and to avoid fuelling the sick person's anxiety: "So it's the same thing if I want to see the grandchildren a bit more and he thinks I shouldn't or if I want to use public transport, then it means you sometimes actually have to lie or not tell the whole truth, so I don't think that's good but it’s very difficult to manage. Because you don’t want the person who’s worried to worry even more” (N6).

For most participants, keeping up to date with the latest information about the pandemic was included in taking responsibility. Some patients said their constant interest in media reports could annoy their carers, while others consciously chose to limit their exposure to information: “I don’t take it in. Today, now, I’m not reading anything – it’s a strategy – barely read any news, don’t watch anything of hardly any news on TV, kind of shut it out” (P9).

In the present situation, the value of relationships was often said to come to the fore as a core value. Changed and often creative ways of socializing were described to avoid risk of infection to the patient, for example, meeting outside or using digital devices. Relationships with health professionals and staff appeared to take on greater significance. In the carers’ narratives, taking responsibility by being careful and avoiding risks was highlighted.

To protect the patient from infection the carers also depended on and had to trust others to act responsibly. This became particularly obvious in the meetings with healthcare staff at home. Even though staff were perceived as demonstrating responsibility by not greeting with a handshake or close contact, patient care usually required body contact. Both patients and carers indicated that it was difficult not to worry and to be confident that the professionals were taking responsibility and not working if they were at risk of being infected. Several participants gave examples of how safety routines could vary between teams and units, which seemed incomprehensible, and for some, distressing and violating.

Third structural analysis: Received or lack of support

All the participants described various types of support they received. Although the situation was framed by support related to the advanced illness, support as related to the pandemic was often interwoven with this. Many participants (both patients and carers) also mentioned support they were lacking or wished for, and were quite animated in describing this. Both received and lack of support were described in relation to a range of actors, including self, family members, friends, healthcare professionals/staff and a range of services, volunteers and organizations in civil society and public health authorities (see Table 2).

Table 2. Support: received, lacking or wished for

Support from	Described by the patient		Described by the informal carer	
	received	*lacking or wished for*	*received*	*lacking or wished for*
Family and friends	Practical support Personal support when meeting outdoors, calling by phone, FaceTime etc.	In-person social contacts Practical help	Practical support adapted to current restrictions	Spending time together Understanding from bystanders More support (not given due to health problems and fear of infection)
Palliative home care service	Support and safety at home through competent carers Psychosocial/psychological support Use of protective equipment creates security	More visits from the home care team More psychosocial support Better use of technical solutions such as videoconferences	Home care including holistic thinking, psychosocial support, problem solving and accessibility 24/7 creates security for both patient and carer and makes it possible to remain at home Help at home also minimizes the risk of getting infected when visiting e.g.	Better use of technical solutions such as videoconferences More consistent use of protective equipment

		More consistent use of protective equipment	the hospital with the patient Good contacts with other forms of care Consistent use of protective equipment creates security	
Other healthcare and social services	Hospital care and social services have been supportive Use of protective equipment creates security	In-person visits e.g. to hospital. Telephone calls makes it harder to be spontaneous and harder for their next-of-kin to participate More psychosocial support More use of technical solutions such as videoconferences More consistent use of protective equipment	Being allowed to visit in the hospital despite restrictions Use of protective equipment creates security	Being able to take their ordinary supportive role (not possible due to restrictions for accompanying visitors in the hospital) More information and involvement in the care process/disease progression Faster processing (the pandemic has made things take longer than promised External support (e.g. social services)
Society	Practical support from e.g. the Red Cross or churches	More clarity in the official recommendations	(not mentioned)	More practical support More information from the authorities (has been insufficient and contradictory)

Interpreted whole

Here, the interpretation is taken further. Living in a society with restrictions following the COVID-19 pandemic and receiving specialized palliative care was revealed as interrelated and not always possible to distinguish. The pandemic, implying a risk of life-threatening infection for both patients and carers, is framed by patients being aware of their mortality, with limited remaining life-span due to their advanced life-limiting condition, and carers living with impending loss. The meaning of the pandemic's impact relates to a spectrum from mild indications of worry at one end to distressing fear at the other, leading to avoidance of personal encounters and resulting in isolation and loneliness. Individuals may hover between the two ends of the spectrum or move to either end over time. However, taking personal responsibility and managing the situation is at the same time dependent on how others do the same – hence, personal responsibility is interdependent on others. Taking action and handling the situation through various (in some cases creative) solutions seems to require being free from distressing fear. This underlines the importance of supportive actions, which could be provided in personal encounters with family, friends, volunteers and professionals. Such encounters were in place to various degrees but were also found lacking and wished for.

Discussion

The impact of the pandemic on patients and carers in the context of specialized palliative home care was framed by the patient's underlying non-COVID, end-stage disease. Most participants said they were aware of the patient's vulnerability, that their daily life was already limited to varying degrees, and that death was inevitable. Despite the participants' similar circumstances, their reactions to the pandemic varied greatly. While some found the threat of the pandemic of little significance due to a reduced general condition and a life span that was already limited, others reacted with great fear for the same reason, as they were afraid of losing the little time they had left. Further, the value of social contacts became apparent. The loss of such contacts due to isolation was devastating for some, while others found creative solutions to maintain relationships. In many cases, visits from health professionals became the sole social contact and most participants found highly available palliative home care of utmost importance for their support and security.

During the pandemic, much interest has focused on palliative care needs for patients infected with COVID-19[14-17]. A few studies have also explored how to practically perform and maintain high quality palliative care for non-COVID patients during the pandemic[18]. However, there is a lack of studies focusing on the experiential impact of the COVID pandemic on patients receiving specialized palliative home care for reasons other than COVID. To our knowledge, this is the first study directly addressing patients with an end-stage, non-COVID disease, receiving specialized palliative home care, and their carers, to investigate how they experience consequences of the COVID-19 pandemic.

Even though some of our results are in accordance with other international studies, the present study is performed in a country with tax-financed health care, comparably soft restrictions and no lock-down during the Covid pandemic, which could limit transferability.

Although the impact of the pandemic on the participants in the present study varied greatly, some participants described great fear, that along with strict isolation, bordered on torture. A similar significant impact of the pandemic has been shown in populations worldwide. Already at the beginning of the pandemic, while death rates were low, polls found that about one third of adults in Canada and the USA were very concerned about COVID-19[19] and in China, fear of the disease was reported to cause a perceived moderate-to-severe impact on more than half of the respondents[20]. Research from previous pandemics suggests that perceived vulnerability to disease is an important factor inducing fear[21]. As all the patients in the present study can be classified as vulnerable due to underlying life-threatening disease, most often cancer, an increased risk of adverse outcome of an infectious disease follows[4, 22]. Thus their perceived fear is affected not only by the societal threat of the pandemic but also has valid reason due to their condition, which is also recognized by their carers. The overhanging life-threat from the patients' underlying disease might be one reason why many in this group of patients describe the pandemic as having a great impact on their lives.

Despite soft national recommendations for restrictions at the time of the study, all participants practised isolation to a greater or lesser degree. While having to abstain from visits to the gym, theatre and shopping mall was mentioned, there was an overwhelming consensus among the participants that the primary negative consequence of isolation was lack of social contact with close and significant others. This is consistent with the finding that increased mortality salience can enhance the value of the person's closest significant others[23]. It is also shown that basic human conservation values, like favouring security, adhering to tradition, are endorsed during the COVID-19 pandemic[24], which could contribute to the reported importance of close relations. Many patients, as well as carers, expressed regrets that fellowship with family and friends could not be maintained for the short time remaining of their lives, and for some this resulted in strong feelings of loneliness, blues and anxiety. From previous studies it is known that isolation and quarantine can cause distressing problems, and that older people, like those in the present study, are more prone[1, 25, 26]. Moreover, isolation adds to the distress already present among seriously ill patients receiving palliative care.

To relieve anxiety, many participants emphasized the importance of receiving continuous support from healthcare professionals and official authorities in promoting their knowledge-seeking and understanding in order to proactively manage their lives. However, some chose a different management tactic in completely abstaining from media, while others said they became addicted to media news. Participants with the latter behaviour expressed more anxiety, which could be due to exaggerated news reports and sensational headlines fuelling anxiety and fear[27]. The great differences in participants' reactions to the pandemic threat, despite similar basic conditions, could speculatively be dependent on personality type, an important factor in determining stress[28].

To a large extent, patients with end-stage life-threatening disease and their carers are already exposed to the type of threats and restrictions that a subsequently imposed pandemic entails. With this starting position, participants could find the COVID pandemic to be of little significance to them, while at the other end of the spectrum, some participants were almost paralysed with fear. For health and social care professionals, awareness of these diverse reactions to a pandemic threat is important in order to provide appropriate support to patients in palliative care and their carers.

Major limitations are related to the convenient and consecutive sampling from only one palliative care service. Although the number of participants is in line with suggestions in the literature for the chosen methodology, it should be recognized that the majority of the patients had cancer as well as were native-born. Further, having the interviews performed over telephone and that they varied in length is a limitation. However, all of the participants shared sensitive issues and distressing experiences, though to varying extent. In-person interviews could have opened for further elaboration and thus generated richer data.

Implications and future directions

The sometimes extreme emotions among the participants elicited by the pandemic (describing it as torture) emphasizes the importance of the holistic view characterizing palliative care and the need for the entire care team to practice person-centred competences as related to communication and care practice[29]. It also underlines the importance of maintaining high availability of specialized palliative care during future pandemics, and the need to further study other challenging societal situations involving major part of populations. Further research in the field into patients with chronic non-cancer conditions and people who have migrated is suggested.

Conclusion

The double burden of chronic, non-COVID, life-threatening disease and the ongoing pandemic which patients in specialized palliative home care and their carers were subjected to elicited a great variety of emotional and practical responses among the participants. This study discloses meaning of the pandemic's impact to be related to a spectrum from mild indications of worry to distressing and unbearable fear, where the latter hampers the opportunity to take action and find solutions to handle the situation.

For some, awareness of an already limited life span and reduced general condition meant they were minimally concerned about COVID-19 and could choose less isolation, while at the other end of the spectrum, participants said this awareness gave rise to extreme fear, with strict isolation being perceived as torture-like. This spectrum of reactions could be found among both patients and carers and provides a heuristic value. Tensions and stress could arise in cases where there was disparity in the level of concern for COVID-19 between the individual patient and his/her carers, adding to the already difficult situation.

Most patients and carers found access to specialized palliative home care was maintained despite the pandemic. Easy access to a competent palliative team was said to be supportive and instil a sense of security, which is of particular importance during a pandemic, and for some, it also took on importance as the sole social contact.

Acknowledgements

We thank the patients and carers who participated in the study.

Contributorship statement

SN, IB, UM and JÖ planned the study and, together with LC and EL, took part in conducting the interviews and contributed to the discussion of the data, reviewed and edited the manuscript, performed critical review of the manuscript, interpreted the analyses and gave the final approval of the manuscript before submission. SN was the main author of the manuscript and JÖ and IB revised the manuscript for important intellectual content. SN is responsible for the overall content as guarantor.

Funding

This work was supported by Hjalmar Svensson's Research Foundation, grant number HJSV2021035.

Competing interests

None declared.

Patient consent for publication

Obtained.

Ethics approval

This study was approved by the Swedish Ethical Review Authority (No. 2020-0214106; date of approval: 2020-06-17).

Data availability statement

Data are available upon request to the corresponding author.

References

1. Dubey S, Biswas P, Ghosh R, et al. Psychosocial impact of COVID-19. *Diabetes Metab Syndr* 2020; 14: 779-788. 2020/06/12. DOI: 10.1016/j.dsx.2020.05.035.
2. Ahorsu DK, Lin CY, Imani V, et al. The Fear of COVID-19 Scale: Development and Initial Validation. *Int J Ment Health Addict* 2020: 1-9. 2020/04/01. DOI: 10.1007/s11469-020-00270-8.
3. Fillmore NR, La J, Szalat RE, et al. Prevalence and Outcome of COVID-19 Infection in Cancer Patients: A National Veterans Affairs Study. *JNCI : Journal of the National Cancer Institute* 2021; 113: 691-698. DOI: 10.1093/jnci/djaa159.
4. Johannesen TB, Smeland S, Aaserud S, et al. COVID-19 in Cancer Patients, Risk Factors for Disease and Adverse Outcome, a Population-Based Study From Norway. *Front Oncol* 2021; 11: 652535. 2021/04/13. DOI: 10.3389/fonc.2021.652535.
5. Papachristou N, Barnaghi P, Cooper B, et al. Network Analysis of the Multidimensional Symptom Experience of Oncology. *Scientific reports* 2019; 9: 2258-2258. DOI: 10.1038/s41598-018-36973-1.
6. Miaskowski C, Paul SM, Snowberg K, et al. Oncology patients' perceptions of and experiences with COVID-19. *Support Care Cancer* 2021; 29: 1941-1950. 2020/08/19. DOI: 10.1007/s00520-020-05684-7.
7. Data OWi. https://ourworldindata.org/policy-responses-covid (2020).
8. Dhavale P, Koparkar A and Fernandes P. Palliative Care Interventions from a Social Work Perspective and the Challenges Faced by Patients and Caregivers during COVID-19. *Indian J Palliat Care* 2020; 26: S58-s62. 2020/10/23. DOI: 10.4103/ijpc.Ijpc_149_20.
9. Lindseth A and Norberg A. Elucidating the meaning of life world phenomena. A phenomenological hermeneutical method for researching lived experience. *Scand J Caring Sci* 2021 2021/10/24. DOI: 10.1111/scs.13039.
10. Berndtsson I, Claesson S, Friberg F, et al. Issues about Thinking Phenomenologically while Doing Phenomenology. *Journal of Phenomenological Psychology* 2007; 38: 256-277.
11. Ricœur P. *From text to action : essays in hermeneutics II*. London: London : Athlone, 1991.
12. Malterud K. Qualitative research: standards, challenges, and guidelines. *Lancet* 2001; 358: 483-488. 2001/08/22. DOI: 10.1016/s0140-6736(01)05627-6.

13. Lindseth A and Norberg A. A phenomenological hermeneutical method for researching lived experience. *Scandinavian journal of caring sciences* 2004; 18: 145-153. Submitted 14 July 2003, Accepted 8 January 2004. DOI: 10.1111/j.1471-6712.2004.00258.x.

14. Strang P, Bergström J, Martinsson L, et al. Dying From COVID-19: Loneliness, End-of-Life Discussions, and Support for Patients and Their Families in Nursing Homes and Hospitals. A National Register Study. *Journal of pain and symptom management* 2020; 60: e2-e13. DOI: 10.1016/j.jpainsymman.2020.07.020.

15. Etkind SN, Bone AE, Lovell N, et al. The Role and Response of Palliative Care and Hospice Services in Epidemics and Pandemics: A Rapid Review to Inform Practice During the COVID-19 Pandemic. *J Pain Symptom Manage* 2020; 60: e31-e40. 2020/04/12. DOI: 10.1016/j.jpainsymman.2020.03.029.

16. Rao A and Kelemen A. Lessons Learned from Caring for Patients with COVID-19 at the End of Life. *J Palliat Med* 2021; 24: 468-471. 2020/08/25. DOI: 10.1089/jpm.2020.0251.

17. Fadul N, Elsayem AF and Bruera E. Integration of palliative care into COVID-19 pandemic planning. *BMJ Support Palliat Care* 2021; 11: 40-44. 2020/06/13. DOI: 10.1136/bmjspcare-2020-002364.

18. Harasym P, Brisbin S, Afzaal M, et al. Barriers and facilitators to optimal supportive end-of-life palliative care in long-term care facilities: a qualitative descriptive study of community-based and specialist palliative care physicians' experiences, perceptions and perspectives. *BMJ Open* 2020; 10: e037466. 2020/08/08. DOI: 10.1136/bmjopen-2020-037466.

19. Asmundson GJG and Taylor S. Coronaphobia: Fear and the 2019-nCoV outbreak. *J Anxiety Disord* 2020; 70: 102196. 2020/02/23. DOI: 10.1016/j.janxdis.2020.102196.

20. Wang C, Pan R, Wan X, et al. Immediate Psychological Responses and Associated Factors during the Initial Stage of the 2019 Coronavirus Disease (COVID-19) Epidemic among the General Population in China. *Int J Environ Res Public Health* 2020; 17 2020/03/12. DOI: 10.3390/ijerph17051729.

21. Taylor S. *The psychology of pandemics : preparing for the next global outbreak of infectious disease / by Steven Taylor [Elektronisk resurs].*

22. Mirzaei R, Karampoor S, Sholeh M, et al. A contemporary review on pathogenesis and immunity of COVID-19 infection. *Mol Biol Rep* 2020; 47: 5365-5376. 2020/07/01. DOI: 10.1007/s11033-020-05621-1.

23. <2006 Heine. The meaning maintenance model.pdf>.

24. Bonetto E, Dezecache G, Nugier A, et al. Basic human values during the COVID-19 outbreak, perceived threat and their relationships with compliance with movement restrictions and social distancing. *PLoS One* 2021; 16: e0253430. 2021/06/19. DOI: 10.1371/journal.pone.0253430.

25. Taylor HO, Taylor RJ, Nguyen AW, et al. Social Isolation, Depression, and Psychological Distress Among Older Adults. *J Aging Health* 2018; 30: 229-246. 2017/05/30. DOI: 10.1177/0898264316673511.

26. Becqué YN, van der Geugten W, van der Heide A, et al. 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). *Scand J Caring Sci* 2021 2021/10/10. DOI: 10.1111/scs.13038.

27. Dong M and Zheng J. Letter to the editor: Headline stress disorder caused by Netnews during the outbreak of COVID-19. *Health Expect* 2020; 23: 259-260. 2020/04/01. DOI: 10.1111/hex.13055.

28. <2012 Dumitru. Stress and personality.pdf>.

29. Öhlén J, Carlsson G, Jepsen A, et al. Enabling sense-making for patients receiving outpatient palliative treatment: A participatory action research driven model for person-centered communication. *Palliative & supportive care* 2016; 14: 212-224. DOI: 10.1017/S1478951515000814.

Figure 1. Inclusion of participants. Note. First, physicians responsible for the patients were asked to evaluate patients according to study criteria. Subsequently, eligible patients received the first oral information about the study over telephone by a research nurse. Those who showed interest to participate were asked if they had a family carer that could be informed about the study. All written information, consent forms and prepaid envelopes were mailed to the patient. Those who returned the consent form were contacted by telephone to agree on a time for the interview over telephone. Reasons for declining were not investigated.

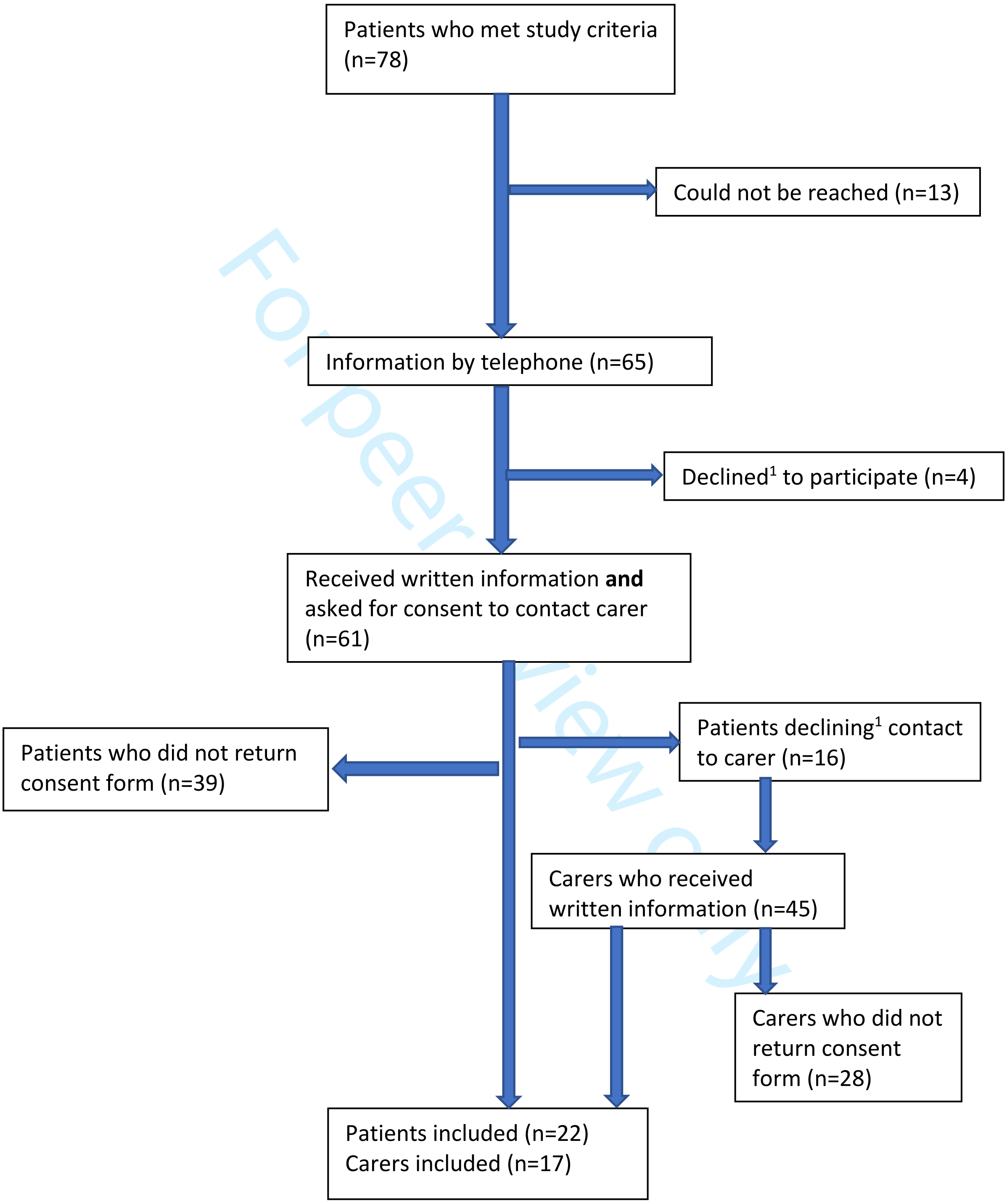

Figure 1. Inclusion of participants.
Note. First, physicians responsible for the patients were asked to evaluate patients according to study criteria. Subsequently, eligible patients received the first oral information about the study over telephone by a research nurse. Those who showed interest to participate were asked if they had a family carer that could be informed about the study. All written information, consent forms and prepaid envelopes were mailed to the patient. Those who returned the consent form were contacted by telephone to agree on a time for the interview over telephone. Reasons for declining were not investigated.

Interview guide patients

Can you describe what it was like when the pandemic started?

How is your daily life now?

Has something become difficult for you now or is there anything you have been missing?

Have you found something helpful?

What has been supportive in your situation now?

Interview guide carer

Can you describe what it was like when the pandemic started?

How is your daily life now?

Has something become difficult for you now or is there anything you have been missing?

Have you found something helpful?

What has been supportive in your situation now?

What are your thoughts about the [patient's] situation today?

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Please indicate in which section each item has been reported in your manuscript. If you do not feel an item applies to your manuscript, please enter N/A.

For further information about the COREQ guidelines, please see Tong *et al.*, 2017: https://doi.org/10.1093/intqhc/mzm042

No.	**Item**	**Description**	**Section #**
Domain 1: Research team and reflexivity			
Personal characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	
3.	Occupation	What was their occupation at the time of the study?	
4.	Gender	Was the researcher male or female?	
5.	Experience and training	What experience or training did the researcher have?	
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? *E.g. Personal goals, reasons for doing the research*	
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? *E.g. Bias, assumptions, reasons and interests in the research topic*	
Domain 2: Study design			
Theoretical framework			
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study? *E.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	
Participant selection			
10.	Sampling	How were participants selected? *E.g. purposive, convenience, consecutive, snowball*	
11.	Method of approach	How were participants approached? *E.g. face-to-face, telephone, mail, email*	
12.	Sample size	How many participants were in the study?	
13.	Non-participation	How many people refused to participate or dropped out? What were the reasons for this?	
Setting			
14.	Setting of data collection	Where was the data collected? *E.g. home, clinic, workplace*	
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	

16.	Description of sample	What are the important characteristics of the sample? *E.g. demographic data, date*	
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	
20.	Field notes	Were field notes made during and/or after the interview or focus group?	
21.	Duration	What was the duration of the interviews or focus group?	
22.	Data saturation	Was data saturation discussed?	
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	
25.	Description of the coding tree	Did authors provide a description of the coding tree?	
26.	Derivation of themes	Were themes identified in advance or derived from the data?	
27.	Software	What software, if applicable, was used to manage the data?	
28.	Participant checking	Did participants provide feedback on the findings?	
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? *E.g. Participant number*	
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	
31.	Clarity of major themes	Were major themes clearly presented in the findings?	
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	

When submitting your manuscript via the online submission form, please upload the completed checklist as a Figure/supplementary file.

If you would like this checklist to be included alongside your article, we ask that you upload the completed checklist to an online repository and include the guideline type, name of the repository, DOI and license in the *Data availability* section of your manuscript.

Developed from: Allison Tong, Peter Sainsbury, Jonathan Craig, Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups, International Journal for Quality in Health Care, Volume 19, Issue 6, December 2007, Pages 349–357, https://doi.org/10.1093/intqhc/mzm042

BMJ Open

Pandemic impact on patients with advanced non-COVID-19 illness and their family carers receiving specialized palliative home care: a qualitative study

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2021-059577.R2
Article Type:	Original research
Date Submitted by the Author:	04-May-2022
Complete List of Authors:	Nyblom, stina; Sahlgrenska Academy, Palliative Center; University of Gothenburg, Medicine Benkel, Inger; Sahlgrenska Academy, Palliative Center Carling, Linnéa; Sahlgrenska University Hospital, Palliative Center Löfdahl, Elisabet; Sahlgrenska universitetssjukhuset Molander, Ulla; Sahlgrenska Academy, Palliative Center Öhlen, Joakim ; University of Gothenburg, Institute of Health and Care Sciences
Primary Subject Heading:	Palliative care
Secondary Subject Heading:	Qualitative research
Keywords:	COVID-19, PALLIATIVE CARE, QUALITATIVE RESEARCH

I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our licence.

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which Creative Commons licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

For peer review only

Enseignement Superieur (ABES) .
Protected by copyright, including for uses related to text and data mining, AI training, and similar technologies.

Pandemic impact on patients with advanced non-COVID-19 illness and their family carers receiving specialized palliative home care: a qualitative study

Stina Nyblom[1,2], Inger Benkel[1,2], Linnéa Carling[2], Elisabet Löfdahl[2], Ulla Molander[1,2], Joakim Öhlén[2,3]

[1]Institute of Medicine, University of Gothenburg, Sweden
[2]Sahlgrenska University Hospital, Department of Palliative Care, Gothenburg, Sweden
[3]Institute of Health and Care Sciences, University of Gothenburg, Sweden

(F) Stina Nyblom, MD, PhD	http://orcid.org/0000-0002-4998-0324
(F) Inger Benkel, MSW, PhD, Associate professor	http://orcid.org/0000-0002-5919-3877
(F) Linnéa Carling, RN, MSc	
(F) Elisabet Löfdahl, MD	
(F) Ulla Molander, MD, PhD, Associate professor	http://orcid.org/0000-0002-6593-3130
(M) Joakim Öhlén, RN, PhD, Professor	http://orcid.org/0000-0003-2429-8705

Corresponding author: Stina Nyblom

Postal address: Palliative Center, Högsbo hospital, Box 30110, 40043 Gothenburg, Sweden

E-mail: stina.nyblom@vgregion.se
Telephone: +46 767841620

Abstract

Objectives

To investigate the experiential impact of the COVID-19 pandemic on patients with non-Covid life-threatening disease and their family carers**.**

Design

An interpretative qualitative design informed by phenomenological hermeneutics and based on data from in-depth interviews, performed between June and September 2020.

Setting

Patients receiving specialized palliative home care and their family carers living in Sweden.

Participants

22 patients (male/female 11/11) and 17 carers (male/female 5/12) aged 50 years and older. All the patients received specialized palliative home care and most were diagnosed with cancer. Inclusion criteria: aged 18 years or older, diagnosed with an incurable life-threatening non-Covid disease, sufficient strength to participate and capacity to provide informed consent. Participants were selected through a combination of convenient and consecutive sampling.

Results

The significance of the pandemic for both patients and carers showed a continuum from being minimally affected in comparison to the severe underlying disease to living in isolation with constant fear of becoming infected and falling ill with COVID-19, which some likened to torture.

The imposed restrictions on social contact due to the pandemic were particularly palpable for this group of people with a non-COVID-19 life-limiting condition, as it was said to steal valuable moments of time that had already been measured.

Most patients and carers found access to specialized palliative home care was maintained despite the pandemic. This care was of paramount importance for their sense of security and was often their sole visiting social contact.

Conclusions

In the pandemic situation, highly accessible support from health- and social care at home is particularly important to create security for both patients and carers. Thus, to provide appropriate support, it is important for health- and social care personnel to be aware of the great diversity of reactions patients in palliative care and their carers may have to a pandemic threat.

Keywords: COVID-19, Palliative care, Qualitative research**.**

Strengths and limitations of this study

- A strength of this study is the empirical anchorage through first person narratives.
- All interviews were performed by professionals trained in conversation methodology.
- Demographics data were varied and showed a broad age range, although few men were represented among family carers.
- Strategic sampling would have been stronger than the combined convenient and consecutive sampling applied.

- The majority of patients were diagnosed with cancer and only a few participants had a migration background. Moreover, the study was performed in a country with tax-financed health care, comparably soft restrictions and no lock-down during the Covid pandemic, which could limit transferability of the results.

Introduction

The COVID-19 pandemic has resulted in the development of national recommendations for the care of infected patients, as well as for society as a whole. In this way, the pandemic is not only influencing those who are infected. In a review by Dubey et al. the psychosocial impact of COVID-19 is described as affecting the whole population, whether you are sick or healthy[1]. Numerous deaths caused by the pandemic have been reported daily, with excessive exposure in the media, resulting in death becoming unusually palpable in society. The resulting fear – that naturally arises when humans are faced with infectious disease – is present in the COVID-19 pandemic, and shows a positive correlation to anxiety and depression[2]. Patients admitted to palliative care with a non-COVID life-threatening disease constitute a particularly vulnerable group, with a higher risk of adverse outcome from a COVID-19 infection[3, 4]. These patients are under life threat from both the underlying disease – most often cancer – and from impending pandemic infection. Moreover, the significant overlap of COVID-19 and cancer-related symptoms can result in recurrent uncertainty whether the person is infected or not[5, 6]. We therefore found it important to explore the perspectives of these groups in the wake of the ongoing pandemic.

At the time of data collection (June to September 2020) the pandemic was classified under the Swedish *Communicable Diseases Act* but unlike many other countries worldwide restrictions in Sweden were soft, meaning no mandatory rules or lock-down, only recommendations (as compared to later during the pandemic). From an international perspective, this policy response to the COVID-19 pandemic in Sweden can be considered moderate according to a composite of response indicators (e.g. workplace closure, travel bans), with restrictions proposed and recommended that build on the population's high confidence in the official authorities and personal responsibility[7]. For health care personnel, protective equipment gradually became mandatory when working in close contact with patients. Regardless of the infection status of the patient or family, home visits were continued, although more often than before the pandemic these took the form of telephone or digital contact. No vaccines against COVID-19 were available at the time of data collection.

To our knowledge, the impact of the COVID-19 pandemic on patients with a non-Covid end-stage disease receiving specialized palliative care at home has only been scarcely studied[6, 8]. We therefore conducted interviews with both patients and their family carers (in the following 'carers') in order to aid our understanding of how their needs can be met in clinical practice.

Aims and objectives

To investigate the experiential impact of the COVID-19 pandemic on patients and their carers receiving specialized palliative home care.

Methods

Design

An interpretative qualitative design informed by phenomenological hermeneutics was chosen[9-11].

Setting and participants

Patients and their family carers were recruited for interview from a specialized palliative home care service (ca. 160 patients from a city with a diverse population) in western Sweden, which provided care at home until death. Visits by nurses and physicians were provided as often as needed, around the clock. Besides health care, patients often had help from social home care. This support allowed family carers (when present) to choose the extent to which they wanted to take part in the patient's daily care. The median period of time allocated to specialized palliative home care was 2 months.

Inclusion criteria were: aged 18 years or older, diagnosed with an incurable life-threatening disease, not previously or currently infected by the COVID-19 virus, sufficient strength to participate and capacity to provide informed consent. Participants were selected through a combination of convenient and consecutive sampling. Patients who were available at the service and scheduled for home visits were given written information about the study during the recruitment period. Details thereof are described in Figure 1. Participants provided written consent by postto the researchers. For demographic and diagnostic data, see Table 1.

Table 1. Demographic and diagnostic data

	Patients (n=22)	Carers (n=17)
Gender		
Female	11	12
Male	11	5
Age years		
50-60 years	5	5

61-70 years	5	7
71-80 years	7	4
81-90 years	3	1
91-- years	2	0
Employment status		
Employed	1	8
On sick leave	6	1
Retired	15	8
Living situation		
Living alone	10	2
Living together	10	15
no answer	2	0
Education		
Elementary school	4	1
High school	7	5
College/University	11	11
Country of birth		
Sweden	19	14
Other European	2	3
Outside of Europe	1	0
Patient's disease		
Cancer*	18	-
Heart failure	2	-
Lung fibrosis	1	-
no answer	1	-
Patient's disease duration		

<1 year	2	-
1-2 years	3	-
2-5 years	6	-
5-10 years	7	-
>10 years	3	-
no answer	1	-
Relationship to patient		
Spouse/partner	-	12
Child	-	3
Sibling	-	2

* colon-, breast-, prostate-, ovarian-, bile duct-, lung-, pancreas cancer and malignant melanoma

Data collection

In-depth interviews with all the participants were conducted in Swedish over the telephone, and digitally recorded and transcribed verbatim. Due to the ongoing pandemic, the option of performing in-person interviews was omitted. The duration of the interviews was 9-33 minutes for patients and 7-54 minutes for carers. Transcripts were not returned to or commented on by the participants. Patients and their carers had the option of being interviewed separately or together, and three patient-carer pairs chose joint interview. All authors took part in the interviews, among them physicians, nurses and social workers. To ensure trustworthiness, all the researchers were professionals with long experience of conversations with patients in their daily work and were aware of differences in conversation strategy in interviews. None of the authors were involved in the care of any of the participants they interviewed. Specific probing questions (see interview guide, supplementary file 1) identified to clarify the narrative in relation to the research questions were[12]: Can you describe what it was like when the pandemic started? How is your daily life now? Has something become difficult for you now or is there anything you have been missing? Have you found something helpful? An additional question was used with carers: What are your thoughts about the [patient's] situation today?

Ethical considerations

Considering the potential vulnerability of the participants, no reminders were sent to potential participants who were provided with written information about the study. For the same reason, convenient and consecutive sampling was chosen, since a strategic sampling would have involved a selection process. All participants were invited to choose how to perform the interview.

Data analysis

Data were analysed in interrelated phases: firstly, naïve reading of the transcripts to acquire a general perception of the data and to generate analytical questions, then structural analyses based on the analytical questions, and finally an interpreted whole[10, 11, 13]. For the naïve reading, all authors read transcripts from both patients and carers and met to discuss their reflections, both from the readings and from having performed the interviews. This resulted in the following analytical questions which guided the structural analyses: What are the meanings of the changed situation as a result of the pandemic? How has the changed situation been handled? What support has been received and/or wished for in the situation? For the structural analyses, all transcripts were scrutinized for text segments (meaning units) answering each of the questions, and subsequently, data related to each of these questions were analysed with a focus on experiential meanings. For the interpreted whole, the results of the naïve reading and meanings disclosed in the structural analyses were interwoven and discussed in the team to interpret the meaning of the studied phenomenon. All phases in the analysis were interrelated and repeated. The principle of data saturation is not applicable[10, 11, 13]. All analyses were performed manually and supported by software for text only (Microsoft Office, Word).

Patient and public involvement

Patients' perspectives and topics of relevance were obtained through researchers' everyday clinical practice and previous research. There were no patient representatives involved in the research team.

Results

Naïve reading

Both patients and carers described the impact of the COVID-19 pandemic in different ways related to the patient's underlying, non-COVID life-threatening, progressive disease and receiving palliative care. In this way, the participants' descriptions of the impact of the pandemic were explicitly or implicitly related to the advanced condition. This was especially emphasized by patients as a challenging living situation due to their life-limiting illness – a few labelled this "a tough diagnosis", with all its implied restrictions in terms of limiting social activities, having to live day by day, and preparing for death and feeling increasingly vulnerable.

First structural analysis: Meaning of the pandemic

The meaning of the impact of the pandemic was revealed as the themes ‘worry’ and ‘fear’.

A worry and fear spectrum

The COVID-19 pandemic with its subsequent recommended and perceived restrictions were related to worry and fear among both patients and carers about how to adhere to restrictions and prevent getting infected. However, there was a wide spectrum of emotions among the participants, from almost no worry at all to a constant fear of getting infected, and/or infecting others, with profound consequences for everyday life. In addition to worry as related to risk of infection, some patients expressed fear there would be insufficient healthcare resources for themselves due to increased overall societal need, or they feared they would not get help from family, friends and other organisations outside health care due to their fear of infecting the patient or getting infected themselves. Moreover, what was perceived as an unnatural way of living during the pandemic caused some to worry about not dying normally.

Restrictions also made many social activities impossible, with some participants expressing fear of ‘losing time’ that was already limited, as emphasized by this patient: “We’re losing time we thought was our time – that we would do good things with – in this [situation].” (P7).

The participants described distressing fear as a reason for isolating themselves in their homes, saying it was ‘terrible’ to have to cancel all non-essential services and support, including visits from carers. This was related to a considerable reduction in social contacts and in support, which over time also made patients feel depressed and lonely. Some individual participants described it as ‘torture-like’. What remained was the perceived necessary support from healthcare personnel that consequently also gained importance as the sole source of social contact. For carers, distressing fear was related to the risk of infecting the patient, with emphasis on strictly adhering to recommendations and minimizing interpersonal contacts with others. For carers living in the same household as the patient, this was described as living in joint isolation, with much anxiety about needing to leave the house. Significant others outside of the patient's household said they dare not visit. They described being torn between the risk of infecting the patient and their longing for a personal encounter, which was considered especially important due to the patient's need for support and the limited time they had left. Some participants expressed this strongly, describing it as unbearable and bordering on torture.

At the other end of the spectrum there were descriptions of the pandemic having only minimal impact and vague indications of worry, largely related to an awareness of death being imminent regardless. As one patient said: "Yes, but personally I wasn't that concerned that I would be affected because either I die of that or the other [illness]" (P19). Carers also commented: "Yes Corona would kill him but he's reaching the end anyway" (N5).

This was taken as a reason to put all focus on the present situation with advanced illness, but also to consider the situation proportionally: "In our family, my illness is bigger than the pandemic, so to speak" (P4).

Alternatively, daily life could already be very limited due to the advanced illness and severely reduced general condition. Consequently, the pandemic restrictions did not entail any change and had hardly been noticed. Some found that their previously limited lives were now common to many and that the pandemic may even have affected them less than others: "Perhaps the pandemic has affected us less than other people who are completely healthy, fully able to work and like, be in the thick of it – for those people the pandemic came like a

smack in the face and we've already had ours – that meant we were at home more, well, for other reasons" (N14).

In between these opposite ends of the worry spectrum examples were given in relation to weighing the risks against the benefits and trying to find creative solutions to problems while adhering to recommendations. This could still involve isolation, especially from peripheral contacts, but most often allowed personal meetings with family and friends. Such personal contact was motivated by efforts to maintain the practical as well as spiritual support said to be needed by both patients and carers. In these situations, the impact of the pandemic was expressed as very palpable, although bearable. Regardless of the individual's initial reaction to the pandemic, the amount of lived time was said to influence their worry in either directions. While some said the persistent threat of the pandemic gradually increased their fear, others became less fearful as they became accustomed to the situation.

When there was disparity in the fear felt by patients and their carers, deciding how to handle a situation could be problematic. For example, fearful patients described being stressed by less fearful carers who wanted to socialize and vice versa. Different expressions of fear and subsequent behaviour were perceived, leading to disputes between carers, which sometimes also affected the patient.

Second structural analysis: Handling of the situation

The participants described a number of ways in which they handled the pandemic situation, with actions related to seeking information and knowledge in different ways, creating solutions to stay connected socially (primarily through digital devices) and limiting their physical social contacts. Participants described their handling of the situation as governed by their degree of worry and fear (in relation to the spectrum presented above), as well as notions of responsibility.

Taking personal responsibility and being dependent on others acting responsibly

Carers explicitly described how, due to the pandemic and the patient's illness, they repeatedly needed to take responsibility in different ways in terms of caring for the patient and protecting him/her against COVID-19 infection. They also described how they personally could take action, by refraining from certain activities to avoid infection and in order to take personal responsibility in the role of carers. Patients also often gave details about the measures they took and changes to their daily routines to avoid infection, but in this regard, taking responsibility was usually implicit in their narrative. Carers often re-emphasized their responsibility, for example: "I'm probably more careful because of him than if it had only been about me, I really am." (N16).

At the same time, needing and wanting to take responsibility for oneself personally and as a carer was associated with uncertainty in several senses. Although the participants referred to the public health authority's guidelines regarding the pandemic, they were indecisive about how they should best be applied, especially in a family with a seriously ill person. This uncertainty also applied to the actual disease situation. Carers talked about a reduction in their necessary 'breathing space' in the care of the sick. Sometimes, participants confessed to telling a few 'white lies' in order to preserve their image of being a responsible carer and to avoid fuelling the sick person's anxiety: "So it's the same thing if I want to see the grandchildren a bit more and he thinks I shouldn't or if I want to use public transport, then it means you sometimes actually have to lie or not tell the whole truth, so I don't think that's good but it's very difficult to manage. Because you don't want the person who's worried to worry even more" (N6).

For most participants, keeping up to date with the latest information about the pandemic was included in taking responsibility. Some patients said their constant interest in media reports could annoy their carers, while others consciously chose to limit their exposure to information: "I don't take it in. Today, now, I'm not reading anything – it's a strategy – barely read any news, don't watch hardly anything of any news on TV, kind of shut it out" (P9).

In the present situation, the value of relationships was often said to come to the fore as a core value. Changed and often creative ways of socializing were described to avoid risk of infection to the patient, for example, meeting outside or using digital devices. Relationships with health professionals and staff appeared to take on greater significance. In the carers' narratives, taking responsibility by being careful and avoiding risks was highlighted.

To protect the patient from infection, the carers also depended on and had to trust others to act responsibly. This became particularly obvious in the meetings with healthcare staff at home. Even though staff were perceived as demonstrating responsibility by not greeting with a handshake or close contact, patient care usually required body contact. Both patients and carers indicated that it was difficult not to worry and to be confident that the professionals were taking responsibility and not working if they were at risk of being infected. Several participants gave examples of how safety routines could vary between teams and units, which seemed incomprehensible, and for some, distressing and violating.

Third structural analysis: Received or lack of support

All the participants described various types of support they received. Although the situation was framed by support related to the advanced illness, support as related to the pandemic was often interwoven with this. Many participants (both patients and carers) also mentioned support they were lacking or wished for, and were quite animated in describing this. Both received and lack of support were described in relation to a range of actors, including self, family members, friends, healthcare professionals/staff and a range of services, volunteers and organizations in civil society and public health authorities (see Table 2).

Table 2. Support: received, lacking or wished for

Support from	**Described by the patient**		**Described by the informal carer**	
	received	***lacking or wished for***	***received***	***lacking or wished for***
Family and friends	Practical support Personal support when meeting outdoors, calling by phone, FaceTime etc.	In-person social contacts Practical help	Practical support adapted to current restrictions	Spending time together Understanding from bystanders More support (not given due to health problems and fear of infection)
Palliative home care service	Support and safety at home through competent carers Psychosocial/psychological support Use of protective equipment creates security	More visits from the home care team More psychosocial support Better use of technical solutions such as videoconferences	Home care including holistic thinking, psychosocial support, problem solving and accessibility 24/7 creates security for both patient and carer and makes it possible to remain at home Help at home also minimizes the risk of getting infected when visiting e.g.	Better use of technical solutions such as videoconferences More consistent use of protective equipment

		More consistent use of protective equipment	the hospital with the patient Good contacts with other forms of care Consistent use of protective equipment creates security	
Other healthcare and social services	Hospital care and social services have been supportive Use of protective equipment creates security	In-person visits e.g. to hospital. Telephone calls make it harder to be spontaneous and harder for their next-of-kin to participate More psychosocial support More use of technical solutions such as videoconferences More consistent use of protective equipment	Being allowed to visit in the hospital despite restrictions Use of protective equipment creates security	Being able to take their ordinary supportive role (not possible due to restrictions for accompanying visitors in the hospital) More information and involvement in the care process/disease progression Faster processing (the pandemic has made things take longer than promised External support (e.g. social services)
Society	Practical support from e.g. the Red Cross or churches	More clarity in the official recommendations	(not mentioned)	More practical support More information from the authorities (has been insufficient and contradictory)

Interpreted whole

Here, the interpretation is taken further. Living in a society with restrictions following the COVID-19 pandemic and receiving specialized palliative care was revealed as interrelated and not always possible to distinguish. The pandemic, implying a risk of life-threatening infection for both patients and carers, is framed by patients being aware of their mortality, with limited remaining life-span due to their advanced life-limiting condition, and carers living with impending loss. The meaning of the pandemic's impact relates to a spectrum from mild indications of worry at one end to distressing fear at the other, leading to avoidance of personal encounters and resulting in isolation and loneliness. Individuals may hover between the two ends of the spectrum or move to either end over time. However, taking personal responsibility and managing the situation is at the same time dependent on how others do the same – hence, personal responsibility is interdependent on others. Taking action and handling the situation through various (in some cases creative) solutions seems to require being free from distressing fear. This underlines the importance of supportive actions, which could be provided in personal encounters with family, friends, volunteers and professionals. Such encounters were in place to various degrees but were also found lacking and wished for.

Discussion

The impact of the pandemic on patients and carers in the context of specialized palliative home care was framed by the patient's underlying non-COVID, end-stage disease. Most participants said they were aware of the patient's vulnerability, that their daily life was already limited to varying degrees, and that death was inevitable. Despite the participants' similar circumstances, their reactions to the pandemic varied greatly. While some found the threat of the pandemic of little significance due to a reduced general condition and a life span that was already limited, others reacted with great fear for the same reason, as they were afraid of losing the little time they had left. Further, the value of social contacts became apparent. The loss of such contacts due to isolation was devastating for some, while others found creative solutions to maintain relationships. In many cases, visits from health professionals became the sole social contact and most participants found highly available palliative home care of utmost importance for their support and security.

During the pandemic, much interest has focused on palliative care needs for patients infected with COVID-19[14-17]. A few studies have also explored how to practically perform and maintain high quality palliative care for non-COVID patients during the pandemic[18]. However, there is a lack of studies focusing on the experiential impact of the COVID pandemic on patients receiving specialized palliative home care for reasons other than COVID. To our knowledge, this is the first study directly addressing patients with an end-stage, non-COVID disease receiving specialized palliative home care and their carers to investigate how they experience consequences of the COVID-19 pandemic.

Although some of our results are in line with the findings of other international studies, it must be noted that the present study was performed in a country with tax-financed health care, relatively soft restrictions and no lock-down during the Covid pandemic, which could limit transferability.

The impact of the pandemic on the participants in the present study varied greatly, with some participants describing great fear, that along with strict isolation, bordered on torture. A similar significant impact of the pandemic has been shown in populations worldwide. Already at the beginning of the pandemic, while death rates were low, polls found that about one third of adults in Canada and the USA were very concerned about COVID-19[19] and in China, fear of the disease was reported to cause a perceived moderate-to-severe impact on more than half of the respondents[20]. Research from previous pandemics suggests that perceived vulnerability to disease is an important factor inducing fear[21]. As all the patients in the present study can be classified as vulnerable due to underlying life-threatening disease, most often cancer, an increased risk of adverse outcome of an infectious disease follows[4, 22]. Thus, their perceived fear is not only affected by the societal threat of the pandemic but also has valid reason due to their condition, which is also recognized by their carers. The overhanging life-threat from the patients' underlying disease might be one reason why many in this group of patients describe the pandemic as having a great impact on their lives.

Despite soft national recommendations for restrictions at the time of the study, all participants practised isolation to a greater or lesser degree. While having to abstain from visits to the gym, theatre and shopping mall was mentioned, there was an overwhelming consensus among the participants that the primary negative consequence of isolation was lack of social contact with close and significant others. This is consistent with the finding that increased mortality salience can enhance the value of the person's closest significant others[23]. It has also been shown that basic human conservation values, like favouring security and adhering to tradition, were endorsed during the COVID-19 pandemic[24], which could contribute to the reported importance of close relations. Many patients, as well as carers, expressed regrets that fellowship with family and friends could not be maintained for the short time remaining of their lives, and for some this resulted in strong feelings of loneliness, blues and anxiety. From previous studies it is known that isolation and quarantine can cause distressing problems, and that older people, like those in the present study, are more prone[1, 25, 26]. Moreover, isolation adds to the distress already present among seriously ill patients receiving palliative care.

To relieve anxiety, many participants emphasized the importance of receiving continuous support from healthcare professionals and official authorities in promoting their knowledge-seeking and understanding in order to proactively manage their lives. However, some chose a different management tactic in completely abstaining from media, while others said they became addicted to media news. Participants with the latter behaviour expressed more anxiety, which could be due to exaggerated news reports and sensational headlines fuelling anxiety and fear[27]. The great differences in participants' reactions to the pandemic threat, despite similar basic conditions, could speculatively be dependent on personality type, an important factor in determining stress[28].

To a large extent, patients with end-stage life-threatening disease and their carers are already exposed to the type of threats and restrictions that a subsequently imposed pandemic entails. With this starting position, participants could find the COVID pandemic to be of little significance to them, while at the other end of the spectrum, some participants were almost paralysed with fear. For health and social care professionals, awareness of these diverse reactions to a pandemic threat is important in order to provide appropriate support to patients in palliative care and their carers.

Major limitations of this study are related to the convenient and consecutive sampling from only one palliative care service. Although the number of participants is in line with suggestions in the literature for the chosen methodology, it should be recognized that the majority of the patients had cancer and were native-born, thus limiting diversity. A further limitation is having the interviews performed over the telephone and that they varied in length. However, all of the participants shared sensitive issues and distressing experiences to a varying degree. In-person interviews could have opened up for further elaboration and thus generated richer data.

Implications and future directions

The participants' sometimes extreme emotions elicited by the pandemic (describing it as torture) emphasizes the importance of the holistic view characterizing palliative care and the need for the entire care team to practise person-centred competences as related to communication and care practice[29]. It also underlines the importance of maintaining high availability of specialized palliative care during future pandemics, and the need to further study other challenging societal situations involving major sections of populations. Further research in the field of patients with chronic non-cancer conditions and people who have migrated is suggested.

Conclusion

The double burden of chronic, non-COVID life-threatening disease and the ongoing pandemic experienced by patients in specialized palliative home care, as well as by their carers, elicited a great variety of emotional and practical responses. This study reveals the pandemic's impact to be related to a spectrum from mild indications of worry to distressing and unbearable fear, where the latter hampers the opportunity to take action and find solutions to handle the situation.

For some, awareness of an already limited life span and reduced general condition meant they were minimally concerned about COVID-19 and could choose less isolation, while at the other end of the spectrum, participants said this awareness gave rise to extreme fear, with strict isolation being perceived as torture-like. This spectrum of reactions could be found among both patients and carers and provides a heuristic value. Tensions and stress could arise in cases where the level of concern for COVID-19 differed between the individual patient and his/her carers, adding to the already difficult situation.

Most patients and carers found access to specialized palliative home care was maintained despite the pandemic. Easy access to a competent palliative team was said to be supportive and instil a sense of security, which is of particular importance during a pandemic, and for some, it also took on importance as the sole social contact.

Acknowledgements

We thank the patients and carers who participated in the study.

Contributorship statement

SN, IB, UM and JÖ planned the study and along with LC and EL, took part in conducting the interviews. The above authors all contributed to the analysis of the data, reviewing and editing the manuscript, performing critical review of the manuscript, interpreting the analyses and giving final approval of the manuscript before submission. SN was the main author of the manuscript, and together with JÖ and IB revised the manuscript for important intellectual content. SN is responsible as guarantor for the overall content.

Funding

This work was supported by Hjalmar Svensson's Research Foundation, grant number HJSV2021035.

Competing interests

None declared.

Patient consent for publication

Obtained.

Ethics approval

This study was approved by the Swedish Ethical Review Authority (No. 2020-0214106; date of approval: 2020-06-17).

Data availability statement

Data are available upon request to the corresponding author.

References

1. Dubey S, Biswas P, Ghosh R, et al. Psychosocial impact of COVID-19. *Diabetes Metab Syndr* 2020; 14: 779-788. 2020/06/12. DOI: 10.1016/j.dsx.2020.05.035.
2. Ahorsu DK, Lin CY, Imani V, et al. The Fear of COVID-19 Scale: Development and Initial Validation. *Int J Ment Health Addict* 2020: 1-9. 2020/04/01. DOI: 10.1007/s11469-020-00270-8.
3. Fillmore NR, La J, Szalat RE, et al. Prevalence and Outcome of COVID-19 Infection in Cancer Patients: A National Veterans Affairs Study. *JNCI : Journal of the National Cancer Institute* 2021; 113: 691-698. DOI: 10.1093/jnci/djaa159.
4. Johannesen TB, Smeland S, Aaserud S, et al. COVID-19 in Cancer Patients, Risk Factors for Disease and Adverse Outcome, a Population-Based Study From Norway. *Front Oncol* 2021; 11: 652535. 2021/04/13. DOI: 10.3389/fonc.2021.652535.
5. Papachristou N, Barnaghi P, Cooper B, et al. Network Analysis of the Multidimensional Symptom Experience of Oncology. *Scientific reports* 2019; 9: 2258-2258. DOI: 10.1038/s41598-018-36973-1.
6. Miaskowski C, Paul SM, Snowberg K, et al. Oncology patients' perceptions of and experiences with COVID-19. *Support Care Cancer* 2021; 29: 1941-1950. 2020/08/19. DOI: 10.1007/s00520-020-05684-7.
7. Data OWi. https://ourworldindata.org/policy-responses-covid (2020).
8. Dhavale P, Koparkar A and Fernandes P. Palliative Care Interventions from a Social Work Perspective and the Challenges Faced by Patients and Caregivers during COVID-19. *Indian J Palliat Care* 2020; 26: S58-s62. 2020/10/23. DOI: 10.4103/ijpc.Ijpc_149_20.
9. Lindseth A and Norberg A. Elucidating the meaning of life world phenomena. A phenomenological hermeneutical method for researching lived experience. *Scand J Caring Sci* 2021 2021/10/24. DOI: 10.1111/scs.13039.
10. Berndtsson I, Claesson S, Friberg F, et al. Issues about Thinking Phenomenologically while Doing Phenomenology. *Journal of Phenomenological Psychology* 2007; 38: 256-277.

11. Ricœur P. *From text to action : essays in hermeneutics II*. London: London : Athlone, 1991.

12. Malterud K. Qualitative research: standards, challenges, and guidelines. *Lancet* 2001; 358: 483-488. 2001/08/22. DOI: 10.1016/s0140-6736(01)05627-6.

13. Lindseth A and Norberg A. A phenomenological hermeneutical method for researching lived experience. *Scandinavian journal of caring sciences* 2004; 18: 145-153. Submitted 14 July 2003, Accepted 8 January 2004. DOI: 10.1111/j.1471-6712.2004.00258.x.

14. Strang P, Bergström J, Martinsson L, et al. Dying From COVID-19: Loneliness, End-of-Life Discussions, and Support for Patients and Their Families in Nursing Homes and Hospitals. A National Register Study. *Journal of pain and symptom management* 2020; 60: e2-e13. DOI: 10.1016/j.jpainsymman.2020.07.020.

15. Etkind SN, Bone AE, Lovell N, et al. The Role and Response of Palliative Care and Hospice Services in Epidemics and Pandemics: A Rapid Review to Inform Practice During the COVID-19 Pandemic. *J Pain Symptom Manage* 2020; 60: e31-e40. 2020/04/12. DOI: 10.1016/j.jpainsymman.2020.03.029.

16. Rao A and Kelemen A. Lessons Learned from Caring for Patients with COVID-19 at the End of Life. *J Palliat Med* 2021; 24: 468-471. 2020/08/25. DOI: 10.1089/jpm.2020.0251.

17. Fadul N, Elsayem AF and Bruera E. Integration of palliative care into COVID-19 pandemic planning. *BMJ Support Palliat Care* 2021; 11: 40-44. 2020/06/13. DOI: 10.1136/bmjspcare-2020-002364.

18. Harasym P, Brisbin S, Afzaal M, et al. Barriers and facilitators to optimal supportive end-of-life palliative care in long-term care facilities: a qualitative descriptive study of community-based and specialist palliative care physicians' experiences, perceptions and perspectives. *BMJ Open* 2020; 10: e037466. 2020/08/08. DOI: 10.1136/bmjopen-2020-037466.

19. Asmundson GJG and Taylor S. Coronaphobia: Fear and the 2019-nCoV outbreak. *J Anxiety Disord* 2020; 70: 102196. 2020/02/23. DOI: 10.1016/j.janxdis.2020.102196.

20. Wang C, Pan R, Wan X, et al. Immediate Psychological Responses and Associated Factors during the Initial Stage of the 2019 Coronavirus Disease (COVID-19) Epidemic among the General Population in China. *Int J Environ Res Public Health* 2020; 17 2020/03/12. DOI: 10.3390/ijerph17051729.

21. Taylor S. *The psychology of pandemics : preparing for the next global outbreak of infectious disease / by Steven Taylor [Elektronisk resurs]*.

22. Mirzaei R, Karampoor S, Sholeh M, et al. A contemporary review on pathogenesis and immunity of COVID-19 infection. *Mol Biol Rep* 2020; 47: 5365-5376. 2020/07/01. DOI: 10.1007/s11033-020-05621-1.

23. <2006 Heine. The meaning maintenance model.pdf>.

24. Bonetto E, Dezecache G, Nugier A, et al. Basic human values during the COVID-19 outbreak, perceived threat and their relationships with compliance with movement restrictions and social distancing. *PLoS One* 2021; 16: e0253430. 2021/06/19. DOI: 10.1371/journal.pone.0253430.

25. Taylor HO, Taylor RJ, Nguyen AW, et al. Social Isolation, Depression, and Psychological Distress Among Older Adults. *J Aging Health* 2018; 30: 229-246. 2017/05/30. DOI: 10.1177/0898264316673511.

26. Becqué YN, van der Geugten W, van der Heide A, et al. 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). *Scand J Caring Sci* 2021 2021/10/10. DOI: 10.1111/scs.13038.

27. Dong M and Zheng J. Letter to the editor: Headline stress disorder caused by Netnews during the outbreak of COVID-19. *Health Expect* 2020; 23: 259-260. 2020/04/01. DOI: 10.1111/hex.13055.

28. <2012 Dumitru. Stress and personality.pdf>.

29. Öhlén J, Carlsson G, Jepsen A, et al. Enabling sense-making for patients receiving outpatient palliative treatment: A participatory action research driven model for person-centered communication. *Palliative & supportive care* 2016; 14: 212-224. DOI: 10.1017/S1478951515000814.

Figure 1. Inclusion of participants. Note. Firstly, physicians responsible for the patients were asked to evaluate them according to the study criteria. Eligible patients then orally received the first information about the study from a research nurse by telephone. Those expressing interest in participating were asked if they had a family carer who could be informed about the study. All written information, consent forms and prepaid envelopes were posted to the patients. Those who returned the consent form were contacted by telephone to agree on a time for a telephone interview. Reasons for declining were not investigated.

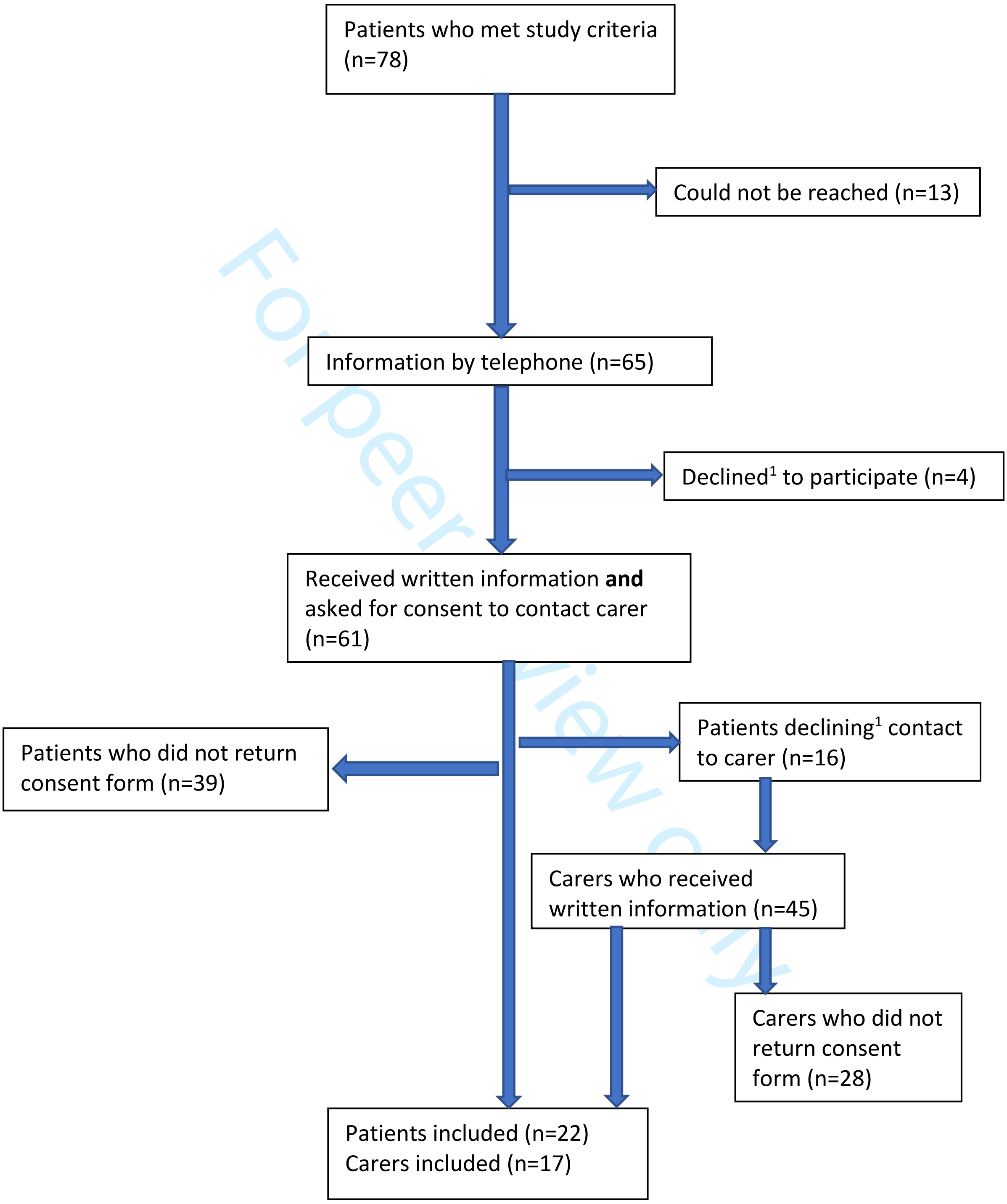

Figure 1. Inclusion of participants.

Note. First, physicians responsible for the patients were asked to evaluate patients according to study criteria. Subsequently, eligible patients received the first oral information about the study over telephone by a research nurse. Those who showed interest to participate were asked if they had a family carer that could be informed about the study. All written information, consent forms and prepaid envelopes were mailed to the patient. Those who returned the consent form were contacted by telephone to agree on a time for the interview over telephone. Reasons for declining were not investigated.

Interview guide patients

Can you describe what it was like when the pandemic started?

How is your daily life now?

Has something become difficult for you now or is there anything you have been missing?

Have you found something helpful?

What has been supportive in your situation now?

Interview guide carer

Can you describe what it was like when the pandemic started?

How is your daily life now?

Has something become difficult for you now or is there anything you have been missing?

Have you found something helpful?

What has been supportive in your situation now?

What are your thoughts about the [patient's] situation today?

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Please indicate in which section each item has been reported in your manuscript. If you do not feel an item applies to your manuscript, please enter N/A.

For further information about the COREQ guidelines, please see Tong *et al.*, 2017: https://doi.org/10.1093/intqhc/mzm042

No.	**Item**	**Description**	**Section #**
Domain 1: Research team and reflexivity			
Personal characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	
3.	Occupation	What was their occupation at the time of the study?	
4.	Gender	Was the researcher male or female?	
5.	Experience and training	What experience or training did the researcher have?	
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? *E.g. Personal goals, reasons for doing the research*	
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? *E.g. Bias, assumptions, reasons and interests in the research topic*	
Domain 2: Study design			
Theoretical framework			
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study? *E.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	
Participant selection			
10.	Sampling	How were participants selected? *E.g. purposive, convenience, consecutive, snowball*	
11.	Method of approach	How were participants approached? *E.g. face-to-face, telephone, mail, email*	
12.	Sample size	How many participants were in the study?	
13.	Non-participation	How many people refused to participate or dropped out? What were the reasons for this?	
Setting			
14.	Setting of data collection	Where was the data collected? *E.g. home, clinic, workplace*	
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	

16.	Description of sample	What are the important characteristics of the sample? *E.g. demographic data, date*	
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	
20.	Field notes	Were field notes made during and/or after the interview or focus group?	
21.	Duration	What was the duration of the interviews or focus group?	
22.	Data saturation	Was data saturation discussed?	
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	
25.	Description of the coding tree	Did authors provide a description of the coding tree?	
26.	Derivation of themes	Were themes identified in advance or derived from the data?	
27.	Software	What software, if applicable, was used to manage the data?	
28.	Participant checking	Did participants provide feedback on the findings?	
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? *E.g. Participant number*	
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	
31.	Clarity of major themes	Were major themes clearly presented in the findings?	
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	

When submitting your manuscript via the online submission form, please upload the completed checklist as a Figure/supplementary file.

If you would like this checklist to be included alongside your article, we ask that you upload the completed checklist to an online repository and include the guideline type, name of the repository, DOI and license in the *Data availability* section of your manuscript.

Developed from: Allison Tong, Peter Sainsbury, Jonathan Craig, Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups, International Journal for Quality in Health Care, Volume 19, Issue 6, December 2007, Pages 349–357, https://doi.org/10.1093/intqhc/mzm042