BMJ Open

Moral and exhausting distress working in the frontline of COVID-19: a Swedish survey during the first wave in four healthcare settings

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To cite: Svantesson M, Durnell L, Hammarström E, *et al*. Moral and exhausting distress working in the frontline of COVID-19: a Swedish survey during the first wave in four healthcare settings. *BMJ Open* 2022;**12**:e055726. doi:10.1136/bmjopen-2021-055726

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2021-055726).

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Received 26 July 2021
Accepted 01 June 2022

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ABSTRACT

Objectives To describe the prevalence and sources of experienced moral stress and anxiety by Swedish frontline healthcare staff in the early phase of COVID-19.

Design Cross-sectional survey, quantitative and qualitative.

Participants and setting 1074 healthcare professionals (75% nurses) in intensive, ward-based, primary and municipal care in one Swedish county.

Measures A study-specific closed-ended and an open-ended questionnaire about moral stress and the Generalised Anxiety Disorder 7-item scale measuring anxiety, followed by an open question about anxiety.

Findings Moral stress was experienced by 52% of respondents and anxiety by 40%. Moral stress in concern for others attributed to institutional constraints comprised experiences of being deprived of possibilities to respond to humane and professional responsibility. Staff experienced being restricted in fulfilling patients' and families' need for closeness and security as well as being compelled to provide substandard and inhumane care. Uncertainty about right and good, without blame, was also described. However, a burdensome guilt also emerged as a moral distress, blaming oneself. This comprised feeling complicit in the spread of COVID-19, inadequacy in care and carrying patients' suffering. Staff also experienced an exhausting distress as a self-concern in an uncontrollable work situation. This comprised a taxing insecurity by being in limbo, being alone and fear of failing, despair of being deprived control by not being heard; unable to influence; distrusting management; as well as an excessive workload.

Conclusions We have not only contributed with knowledge about experiences of being in the frontline of COVID-19, but also with an understanding of a demarcation between moral stress/distress as a concern for patients and family, and exhausting distress in work situation as self-concern. A lesson for management is that ethics support should first include acknowledgement of self-concern and mitigation of guilt before any structured ethical reflection. Preventive measures for major events should focus on connectedness between all parties concerned, preventing inhumane care and burn-out.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ A limitation is the low overall response rate but, considering that data collection took place in the midst of the pandemic crisis, along with rich open responses, we consider the response rate for nurses as high and the findings generalisable and transferable to COVID-19-nurses in high-income countries.
⇒ A strength is the timing of the data collection captured during the first peak of COVID-19 and the use of qualitative inquiry with the least response burden possible, while generating rich and trustworthy findings.
⇒ Another strength was the use of software to facilitate the balancing of rigour and creative hermeneutical analysis.

INTRODUCTION

Early in the pandemic, the worldwide focus was placed on mental health issues among COVID-19 frontline staff. The first study was published in March 2020 from Wuhan,[1] followed by an explosion of cross-sectional surveys[2 3] and reviews.[4–8] At the time of our data collection during the peak of the first wave in Sweden, empirical studies of moral stress/distress were conspicuous by their absence.

The demarcation between stress and distress is obscure in literature, particularly regarding moral stress and distress[9] as well as emotional stress and distress. A number of different terms have been used, such as mental health, anxiety, moral incongruence and moral uncertainty, and their definitions are not always clear.[10 11] In our inquiry, we used the Swedish terms 'etisk stress' and 'oro'. We translate 'etisk stress' to moral stress, but we used the predominantly used definition[9] of moral distress by Jameton in our questionnaire, '*When one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action*'.[12] We translated 'oro' to anxiety, one of the measurements used in the early publication from Wuhan.[1]

There is a need to understand the nature of the experienced emotions and sources of stress linked to the COVID-19. Additionally, there is a need to understand the differences between moral stress, and moral distress and anxiety, in order to tailor appropriate clinical ethics and emotional support for frontline staff. Thus, the aim of the study was to describe the prevalence and sources of experienced moral stress and anxiety by Swedish frontline healthcare staff in the early phase of COVID-19.

METHODS

Design

Cross-sectional survey, quantitative and qualitative. The project was approved by the Swedish Ethical Review Authority (2020–01784).

Setting

The county of Örebro in Middle Sweden, with a population of 300 000, contains 3 hospitals, 29 health centres (primary care) and municipal care consisting of 69 nursing homes in the 12 municipalities. During the peak of the first wave, 13 April–6 May 2020, there were 63–78 COVID-19 inpatients per day. There was COVID-19 outbreak in 31 of the 69 nursing homes, with 245 residents (hereafter referred to as 'patients') infected.

Participants

Inclusion criteria: all healthcare professionals working in healthcare settings in Örebro County, Sweden, encountering infected or suspected infected patients: COVID-19 intensive care unit (ICU), COVID-19 wards, emergency department, primary care and nursing homes in municipal care (3000 estimated). All heads of hospital departments (except the emergency department) and of municipal care approved the survey distribution. Of the 29 health centres, 17 agreed to participate.

The questionnaire

We constructed a study-specific questionnaire in the web-based survey and analysis tool, esMaker. In this paper, we report responses of demographic questions and two closed-ended as well as two open-ended responses regarding moral stress and anxiety (responses about support will be published elsewhere). We based moral stress in the questionnaire on the definition by Jameton[12] and adapted to the context of the pandemic '*due to circumstances I do not control, I cannot do what I believe is morally right and should do for patients/families*'. Examples of circumstances were given: lack of resources, organisation, decisions of others and infection control. The statement on moral stress, '*I have experienced moral stress during the COVID-work*', was rated on a five-level Likert scale, ranging from 'strongly disagree' to 'completely agree'. The closed-ended question was followed by a request to describe one or more situations about experiences of moral stress.

For prevalence of anxiety, we used the Generalised Anxiety Disorder 7-item Scale (GAD-7), also used in Wuhan.[1] The instrument measures general anxiety on a four-category rating scale, ranging from 'not at all' to 'nearly every day'.[13] The GAD-7 is a good measure of anxiety severity with a high degree of convergence with other established instruments measuring anxiety.[13] In our study, the GAD-7 serves as an indication of anxiety as a general stress response.[13] An open request to describe their anxiety followed. The survey was pilot-tested and revised through six cognitive interviews with staff from different professions and healthcare areas affected by the pandemic.

Data collection

The web-based questionnaire was distributed by email through the managers at the beginning of May (peak of the first wave) with two reminders sent until the end of June 2020. This was accompanied by information about the voluntary nature of responding, and informed consent was obtained by virtue of them having responded. A total of 1278 questionnaires were distributed in hospital care and 879 to health centres, but the number sent to the municipalities is unclear. This is because of the head of municipal care forwarded the questionnaire to the unit managers, and it is unclear which managers distributed them to staff.

Analysis

Descriptive statistics were calculated for the prevalence of moral stress and anxiety. We used univariate and multiple logistic regression analysis and calculated a two-tailed Spearman's correlation coefficient (box 1). In the qualitative analysis, the first author adapted more 'linear' analysis methods[14–16] likened to a hermeneutical circle, facilitated by the use of software. This implied iterative reciprocal actions of coding, moving and reformulating categories on different abstraction levels in an emerging understanding between the whole and the parts as well as between practice and theory[17] (see detailed description in box 1). Finally, the frequencies of the meaning units were computed for each main category, that is, quantifying qualitative findings.[14]

Findings

Of the 1074 respondents, one-half of the staff worked in hospital care and the other half in primary or municipal care. Nurses comprised 75% (registered and assistant nurses). The remaining respondents consisted of doctors (6%), physiotherapists (6%) and other professions (rehabilitation staff, some managers responded themselves and had also distributed questionnaires to home care services and support for persons with disability). The response rate in hospital care was 42%, with a higher rate for nurses (49%) and lower for doctors (17%) (see further characteristics in table 1).

Prevalence of moral stress and anxiety

The prevalence of moral stress, defined as at least partly agreeing on the question, was 52%, whereas 11% of these respondents completely agreed (table 1, online

Box 1 Quantitative and qualitative analysis

Quantitative analysis

We used IBM SPSS Statistics for Windows, V.25.0.

1. Logistic regression analyses were performed with moral distress and anxiety as dependent variables and healthcare setting, profession and reason for working with COVID-19 patients as independent variables. Nagelkerke R^2 was calculated as a measure of the proportion of explained variation in the dependent variables. The variance inflation factor was calculated to assess the presence of multicollinearity.
2. Independent variables with a χ^2 p-value <0.10 in the univariate logistic regression analysis was entered (using the 'Forward stepwise (conditional)' command) in a multiple logistic regression analysis, in which χ^2 p-values <0.05 were considered statistically significant.
3. A two-tailed Spearman's correlation coefficient was calculated for the association between the answers on the moral distress question and anxiety, as measured by the GAD-7 sum score.

Qualitative analysis

We used NVivo V.12 (QSR International)

1. Get a sense of the whole: the unit of analysis[16] consisting of responses divided into healthcare settings, were read iteratively.
2. Sorting phase: creating meaning units, codes and content areas: the responses were divided into meaning units (words or phrases that describe one experience[16 52]) and simultaneously formulating codes. A code is, according to Graneheim,[16 53] a label of a condensed meaning unit, which allows a certain interpretation. Here, to facilitate the analysis in NVivo, we used codes as one sentence of condensation (manifest shortening of meaning unit while still preserving the core),[16 54] using verbatim meaning unit as codes or interpretations when longer meaning units. Next, when codes became numerous, they were sorted into content areas, that is, '*area of content identified with little interpretation*'. This functioned as a way to sort the codes without abstracting[16 55 56] while at the same time preventing premature interpretation.
3. Abstraction phase: creating categories and moving codes with coassessment. Abstraction is the categorisation on 'a higher logical level',[16] using the terms 'subcategories' and 'main categories'. This phase was not linear; instead, an iterative process of simultaneously categorising upwards and downwards. The categorisation implied either abstracting and reformulating the content areas, or creating new main categories and moving codes from other content areas. Simultaneously, codes that shared similar meanings were moved under newly created subcategories, reflecting both the meanings of the main category and codes. After developing a matrix of a preliminary categorisation, the process continued with iterative coassessment by the second (LD) and third (EH) authors. In this process, we used a hermeneutic reciprocal action[17] . This implied moving between the data, our preunderstandings and theories of moral distress[28 57 58] and burn-out[39] to interpret the pattern in the responses. Our preunderstanding stems from being a COVID-19 ICU nurse (MS)/behaviourist inoccupational injuries(LD) and being a psychologist in psychiatry (EH)).
4. Writing up findings and recategorising simultaneously with coassessment: the recategorisation continued while writing up the results by alternating between NVivo (categorisation and raw data) and the result text. Here, the last authors (GJ and LS) contributed with their main input.

supplemental data 1). Moral stress was more prevalent at hospitals than in primary and municipal care (57 vs 48%, χ^2 test, p=0.022). Moral stress was also most prevalent among registered nurses and staff who had been redeployed to COVID-19 workplaces. There was no substantial correlation between the independent variables in the logistic regression analyses (highest variance inflation factor was 3.1). In the univariate logistic regression analyses, moral stress was associated with healthcare setting (p<0.001, Nagelkerke R^2=0.030), profession (p<0.001, R^2=0.039) and reason for working with COVID-19 patients (p=0.003, R^2=0.021). Healthcare setting and profession remained statistically significant in the multiple logistic regression analysis (p<0.001, R^2=0.054).

The prevalence of anxiety measured by GAD-7 and reporting at least mild anxiety, was 40%, whereas 7% of these respondents reported severe anxiety (≥15 points) (table 1, online supplemental data 2). Anxiety was more prevalent in hospital care compared with primary and municipal care (45 vs 35 %, χ^2 test, p=0.001) and most prevalent among registered nurses. In the univariate logistic regression analyses, it was associated with healthcare setting (p=0.018, Nagelkerke R^2=0.017), profession (p<0.001, R^2=0.026) and reason for working with COVID-19 patients (p<0.001, R^2=0.041). Profession and reason for working with COVID-19 patients remained statistically significant in the multiple logistic regression analysis (p<0.001, R^2=0.058). Moral stress and GAD-7 sum score were positively correlated, that is, respondents who reported more moral stress also reported higher levels of anxiety (Spearman's correlation coefficient 0.39, p<0.001).

Experiences of moral stress or distress and exhausting distress

Stress was described differently and varied between and within the two open-ended questions '*Please, describe something you were anxious about*' and '*Please describe one or more situations where you felt moral stress*'. We interpreted several responses about anxiety instead as descriptions of moral stress/distress in concern of patients/family. In a similar manner, several responses to the question about moral stress were interpreted as rather being related to anxiety and exhausting distress as self-concern in an uncontrollable work situation. Responses interpreted as moral stress appeared either as experiencing deprived of possibilities to respond to humane and professional responsibility, uncertainty about right and good or as a form of moral distress as burdensome guilt (table 2). Responses interpreted as exhausting distress appeared as taxing insecurity, despair of being deprived control and an excessive workload in an uncontrollable work situation (table 3). Experiences being deprived of possibilities to respond to humane and professional responsibility and taxing insecurity dominated the experiences. See the quantitative distribution of experiences between moral stress/distress and exhausting distress in figure 1.

Table 1 Prevalence of moral stress and anxiety in work situation

	Moral stress				Anxiety: Generalised Anxiety Disorder 7-item Scale (GAD-7)			
	Median (IQR)	Moral stress, n (%)	Univariate logistic regression, OR (95% CI)	Multiple logistic regression, OR (95% CI)	Median (IQR)	Anxiety (GAD-7 ≥5p), n (%)	Univariate logistic regression, OR (95% CI)	Multiple logistic regression, OR (95% CI)
All respondents, n=1074	2 (1–3)	563 (52)			3 (0–7)	430 (40)		
Healthcare setting, n (%)*								
Hospital care, 518 (48)	2 (1–3)	296 (57)			4 (1–8)	233 (45)		
COVID-19 wards, 243 (23)	2 (1–3)	140 (58)	2.4 (1.5 to 3.9)	2.1 (1.2 to 3.5)	3 (1–8)	102 (42)	1.6 (1.0 to 2.6)	
COVID-19 ICUs 179 (17)	2 (1–3)	112 (63)	2.8 (1.7 to 4.5)	2.2 (1.3 to 3.8)	4 (1–8)	86 (48)	2.1 (1.3 to 3.3)	
Other workplace, 96 (9)	2 (1–3)	44 (46)	1.6 (0.9 to 2.9)	1.5 (0.8 to 2.8)	4 (1–8)	45 (47)	2.0 (1.1 to 3.4)	
Primary care and municipal care, 556 (52)	2 (0–2)	267 (48)			3 (0–7)	197 (35)		
Primary care, 234 (22)	2 (0–2)	113 (48)	1.7 (1.1 to 2.8)	1.9 (1.1 to 3.2)	3 (0–7)	85 (36)	1.3 (0.8 to 2.0)	
Nursing homes with COVID-19, 192 (18)	2 (0.8–3)	112 (58)	2.5 (1.5 to 4.0)	2.1 (1.3 to 3.5)	3 (0–7)	72 (38)	1.4 (0.8 to 2.2)	
Nursing homes without COVID-19, 130 (12)	1 (0–2)	42 (32)	1 (reference)	1 (reference)	2 (0–6)	40 (31)	1 (reference)	
Profession, n (%)*								
Registered nurse, 393 (37)	2 (1–3)	237 (60)	2.5 (1.7 to 3.8)	2.0 (1.3 to 3.2)	4 (1–9)	184 (47)	2.2 (1.5 to 3.4)	2.0 (1.3 to 3.0)
Assistant nurse, 412 (38)	2 (1–3)	216 (52)	2.1 (1.4 to 3.1)	1.8 (1.2 to 2.8)	3 (0–8)	161 (39)	1.6 (1.1 to 2.5)	1.5 (1.0 to 2.4)
Doctor, 61 (6)	1 (0–2)	29 (48)	1.3 (0.7 to 2.4)	1.1 (0.6 to 2.0)	2 (0–5)	17 (28)	1.0 (0.5 to 1.9)	0.9 (0.5 to 1.8)
Physiotherapist, 63 (6)	1 (0–2)	26 (41)	1.1 (0.6 to 2.0)	0.9 (0.5 to 1.7)	3 (2–6)	27 (43)	1.9 (1.0 to 3.5)	1.8 (0.9 to 3.3)
Other profession, 145 (14)	1 (0–2)	55 (38)	1 (reference)	1 (reference)	2 (0–5)	41 (28)	1 (reference)	1 (reference)
Reason for working with COVID-19 patients, n (%) *								
The patients are on my ordinary workplace, 417 (39)	2 (1–3)	244 (59)	1.7 (1.3 to 2.4)		3 (1–7)	158 (38)	1.1 (0.8 to 1.5)	1.0 (0.7 to 1.4)
Redeployed to another workplace, 200 (19)	2 (1–3)	119 (60)	1.8 (1.3 to 2.7)		5.5 (2–10)	113 (57)	2.4 (1.6 to 3.4)	2.0 (1.4 to 2.9)
Voluntarily changed workplace, 123 (11)	2 (0–2)	61 (50)	1.2 (0.8 to 1.9)		2 (0–6)	37 (30)	0.8 (0.5 to 1.2)	0.7 (0.4 to 1.1)
Other reason, 13 (1)	3 (0–4)	7 (54)	1.9 (0.6 to 6.7)		7 (3–10)	8 (62)	2.9 (0.9 to 9.1)	2.7 (0.8 to 8.5)
Do not work with COVID-19 patients, but affected by the pandemic, 321 (30)	1 (0–2)	132 (41)	1 (reference)		2 (0–7)	114 (36)	1 (reference)	1 (reference)

*Professions, workplaces and reasons with n<50 are included in the 'Other' category. Other professions include managers, occupational therapists, social workers and social psychiatry supporters.
ICUs, intensive care units.

Table 2 Experiences of moral stress in concern for others, categorisation and quotes

DEPRIVED OF POSSIBILITIES TO RESPOND TO HUMANE AND PROFESSIONAL RESPONSIBILITY	
Restricted to fulfil patients' and families' needs of closeness and security	
Exclude family	**Leave patients in isolation**
Quote 1: 'Not being able to offer to see each other before being anaesthetised, when we know so well that it may be the last chance to be seen'. COVID-19 ICU	Q4: 'An anxious and demented patient who was quarantined. We were not staffed to be able to be with her and she climbed over the rails and screamed in anguish. We had to give her sedation when it was closeness she needed'. COVID-19 ward
Q2: 'I feel stress over colleagues not facilitating contact between family and patient. It seems that we nurses are so different. The anaesthesia nurses don't seem to think about how crucial family is for returning to life'. COVID-19 ICU	Q5: 'Interrupt important chats with the patient, or avoid them completely, because the procedure of removing and putting on protective equipment takes time. To be present and empathetic, that part has been completely left behind'. COVID-19 ward
Q3: 'Informs a daughter of palliative care and that we will remove the high-flow treatment. Talking to her through an ffp3 mask, my own glasses and visor fogged up, I feel dizzy and warm, feel sick from the smell in the face mask, while the daughter is very sad, crying, her mother will soon be gone'. COVID-19 ward	**Violating integrity in messy environment** Q6: 'It is difficult to protect the patient's integrity in nursing because there's lots of staff and patients in the same place. It is crowded and therefore difficult to set up screens'. COVID-19- ICU
Compelled to provide substandard and inhumane care	
Reducing quality of care and down-prioritise nursing care	**Provide undignified care at the end of life**
Q7: 'A lady found dead not COVID-19-positive but due to no extra staff deployed and 4 patients tested positive, no time to check on her'. Nursing home	Q12: 'A patient who clearly shows they will not survive the infection. Palliative care decision is made. Still, checks and diet registers are taken, trying to nag the patient to drink. I wanted to make it was as comfortable as possible for him, not to force anything'. Nursing home
Q8: 'Patients in an abdominal position for 1.5 days and pressure injuries all over the body and face. Risk of going blind….' COVID-19 ICU Q9: 'Patients not washed daily, not mobilised to the same extent. Oral care not done as it should be, turning not done in time'. COVID-19 ward	Q13: 'When pathology technicians require a dead person to be packed in a body bag because they are worried about infection. According to infection control, doctor not necessary. We are used to doing it with dignity'. COVID-19 ward
Risking patient safety for acutely ill and uninfected patients	**Deprioritisation of elderly and uninfected patients**
Q10: 'A patient deteriorates and we have to go to the X-ray/ICU. Remaining patients do not receive sufficient supervision'. COVID-19 ward	Q14: 'To be restricted to sending in patients from nursing homes with corona symptoms is unfair. You should make an individual assessment of each patient.' Primary care
Q11: 'The management has considered that our infection control routine has been sufficient, but I have not. I have been worried, partly due to risk of infection as we have old people and with multiple illnesses in the waiting room, and partly due to the rumours in the village'. Primary care	Q15: 'The patient visits due to mental health issues were cancelled. I know now that they deteriorated'. Primary care

Continued

Table 2 Continued

UNCERTAINTY ABOUT RIGHT AND GOOD		
Torn between different concerned and interests		
Impossible prioritisation between patients		
Q16: 'Checks several times an hour on many patients at the same time as one or more calls'. COVID-19 ward		
Difficult balancing of considerations between patients, family and colleagues		
Q17: 'Dementia patients who are to be isolated due to infection and persuade them to stay in their room. How much can we "persuade", when will it be coercion?' Nursing home	Q18: 'A patient who was seriously ill. Her husband was on COVID-ICU, even sicker. He died but no one told his wife, everything was put on their son who wanted to keep it a secret from the mother because she "would recover faster"'. COVID-19 ward	
Doubting about what is good for the patient		
Promoting security/mental health and protection against infection?	**Safety infection control or well-being?**	**What is a good decision?**
Q19: 'My patients who are normally in great need of our activities (social psychiatry) cannot come because they are a high-risk group. I am concerned about how much their health is affected'. Municipal care	Q20: 'Had to cancel asthma/COPD reception. Patients who may feel worse in their respiration might be missed, have they had a greater risk of severe COVID-19 then?'. Primary care	Q22: 'I struggle with how long we should continue with aggressive care when I feel uncertain whether the patients will survive the infection. How much do we make humans suffer?'. COVID-19 ward
	Q21: 'Avoidance of unnecessary patient contacts leads to postponement of visits, which leads to moral stress regarding what is best for the patient'. Primary care	
BURDENSOME GUILT		
Feeling complicit		
Be the reason for patients' infection and death	**Inadequacy in the interaction with patients and family**	**Bad conscience of acting wrongly**
Q23: 'To be the person who risks and infects me without knowing it'. Nursing home	Q25: 'I felt inadequate talking to family as it felt as I as a nurse was expected to provide information about eventual ICU care. Torn between family's need and a feeling of lack of competence not to be able to respond to them'. COVID-19 ward	Q27: 'Don't keep an eye on the lady even though we assistant nurses have said that she is so unwell. That day I couldn't sleep because it was playing in my head what I could have done differently'. Nursing home
Blaming oneself for others' responsibility		
Q24: 'Goes from a COVID positive to a very frail patient back from ICU, who would never survive infection. Would never be able to admit to a patient or family that I had just been to see an infected patient'. COVID-19 ward	Q26: 'When you cannot comfort … that I cannot stroke their cheek without gloves. It feels so cold-hearted'. Nursing home	Q28: 'Not wanting to sit with the patients who want company/talk/have anxiety because I don't want to be with them longer than necessary'. COVID-19 ward
Carrying suffering of patients		
Saddened over patients' and families' unfulfilled need for each other	**Burdened over patients' plight**	
Q29: 'A dreadful situation, where the patient and family are not allowed to meet. IT is tough! It affects me personally as well'. COVID-19 ICU	Q30: 'A patient who so desperately wants to survive the infection, she grabs me by the upper arm and says she has promised the granddaughter she will not die, You won't give up on me now, will you? I have decided not to initiate mechanical ventilation'. COVID-19 ward	Q31: 'Patients waited to seek care and then they apologise for burdening the congested care service. It feels tough to accept that the patient who is looking for treatment of 'ordinary' diseases feels that way.' Primary care

Table 3 Experiences of exhausting distress in an uncontrollable work situation: categorisation and quotes

TAXING INSECURITY		
Anguish of being in limbo	**Being alone**	**Fear of failing**
Fear of being hit by COVID-19 and spread to family	**Lonely responsibility for inexperienced and anxious colleagues**	**Making mistakes or near misses**
Lacking control of foresight: 'Schedule - not knowing where to be the next shift …, which colleagues you get to work with and how much competence they have'. COVID-19 ward	No support: 'New employees were left in the lurch. Managers were not there to support the new ones. There were nurses who were immediately responsible from day one. The management preferred to go to meetings instead of being there for the staff'. COVID-19 ward	**Not meeting others' expectations** **Failing in the new professional role:** 'I don't feel like a good nurse because I don't want to be here. I don't have the knowledge of how to care for these patients'. COVID-19 ward
DESPAIR OF BEING DEPRIEVED CONTROL		
Not being heard	**Unable to influence own situation**	
Not being acknowledged to be right: 'The beginning, which was extremely tough, we inexperienced decided to share responsibility for patients. This due to all procedures were new and taking longer time. When it came to the knowledge of the manager, we were reprimanded that we didn't follow the routines and that the doctors complained. Although we explained why; that it was a matter of coping with the tasks at all, that "excuse" was not accepted. I and others felt frustration over a total lack of understanding'. COVID-19 ward	**Unable to influence leave or recuperation:** 'That my life is affected by a changed work situation so everything but work is unimportant from the employer's point of view. Feel that my person is run over and that I am being held hostage'. COVID-19 ICU **Involuntary redeployed:** 'Redeployed to the municipality's elderly care … short notice and there was no preparatory training'. Primary care	
	Distrusting management	
Not being able to influence infection control measures: 'I have wanted to take several measures as we have found infection in the working group, but the managers have not taken this into account and have not allowed us to take measures to reduce the spread of infection'. Nursing home	**Ambiguous information and constant change of directives:** 'Managers have said different things, it has been unclear. I experience lack of knowledge of managers. We nurses are forced to be the ones who decide everything'. Nursing home **Unfair division of work tasks** **Poor collaboration:** 'First, we have strengthened collaboration with municipal care, created a team feeling that together we can help each other and protect our elderly. Blurred the boundaries between municipal and primary care. After just a few weeks, the boundaries were set again'. Primary care	
EXCESSIVE WORKLOAD		
Burdening extraordinary work		**Private life threatened**
More patients and in worsening condition together with staff shortage	**Heavier workload while inexperienced**	**No recuperation time**
Not keeping up **Heavier to take the lead**	'New workplace/environment/co-workers and patients. New drugs and equipment. Patients demand total, 100%, attention, which creates total fatigue after the work shift'. COVID-19 ward	Lack of energy: 'My private life, my energy. I work evenings, days and nights, every other weekend and extra shifts. My holiday is shortened and moved'. COVID-19 ward
'What is our task? What should we do? What guidelines to apply? Lots of questions from staff to me who is experienced'. COVID-19 ICU		

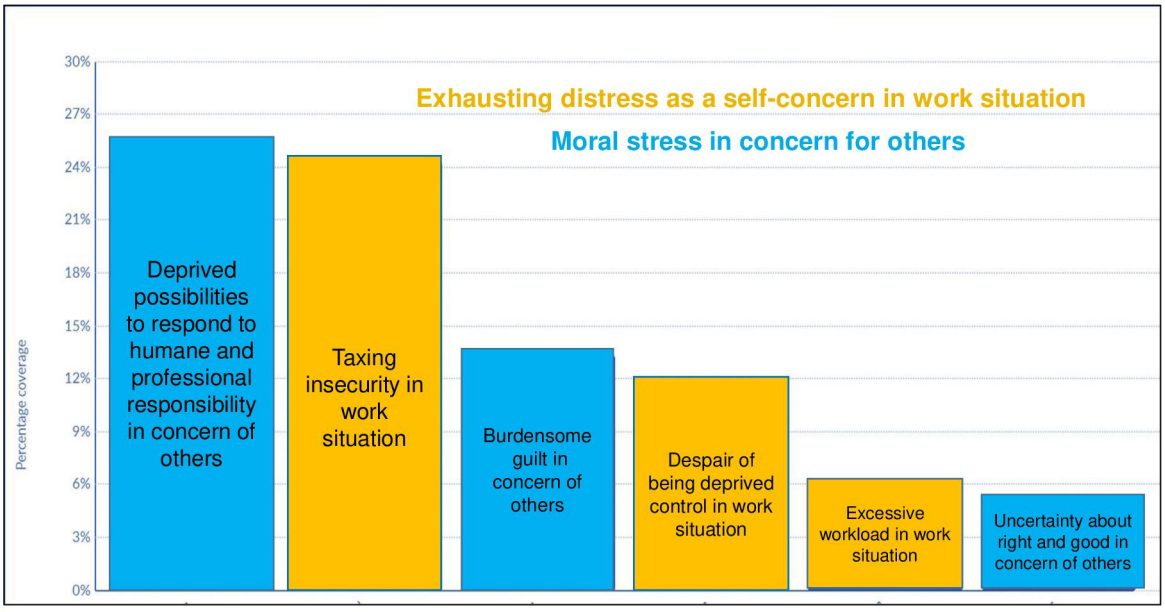

Figure 1 Distribution of healthcare staff's experiences of moral stress/distress in concern for others (blue bars) and exhausting distress in uncontrollable work situation (yellow bars). Distribution of the main categories containing in total 1365 meaning units (responses or part of responses), exported from NVivo software.

Moral stress or distress in concern for others

Deprived of possibilities to respond to humane and professional responsibility

The main sources of stress were being restricted in fulfilling patients' and families' need of closeness and security, inability to provide good care, protecting patients' safety and fair prioritisation of care. *Being restricted from fulfilling the need of closeness and security* in patients and families (table 2) was perceived to be due to others' decisions, infection control and staff shortages. Excluding family dominated the experiences of moral stress. This implied denying family visits, where denying a farewell (see quote Q1, table 2), vigil or viewing the deceased was expressed as most stressing. The frustration mainly concerned the management's decision to restrict visiting, thus threatening the well-being of families as well as patients, but also towards coworkers' attitudes that families were not a care responsibility (Q2). The stress of excluding families included being unable to provide face-to-face support (Q3).

On COVID-19 wards and in nursing homes, it felt distressing to leave patients in isolation. Patients were experienced as being anxious in being quarantined (Q4), where staff felt they could not replace the family's role in maintaining patients' mental health. They were unable to stay with the patients and, during short stays, they felt the protective equipment made humane contact impossible (Q5). A severe stress was described when letting the patient die alone or only shortly being able to provide company as '*a stranger in space-suit*'. COVID-19 ICU staff described a different kind of loneliness for the patients, not being able to interact with them due to language barriers, where family had been needed. Instead, they felt that they violated patient integrity in a messy environment, such as when exposing them during nursing care (Q6).

Staff felt *compelled to provide substandard and inhumane care* (table 2). On the COVID-19 wards, reducing quality of care was described as knowing what should be done for the patients, but lacking resources such as materials, medication and time. Reduced quality of care was sometimes described as neglect. Staff described patients climbing out of bed or developing screaming behaviour, and sudden deaths due to lack of attention and also severe pressure ulcers (Q7–8). In primary care, being restricted from face-to-face encounters was perceived to lead to impaired care for patients in high-risk groups. A dominating stress was having to downprioritise basic nursing care (Q9) and rehabilitation. At COVID-19-ICU, '*conveyor belt care*' was expressed, being restrained from providing individualised care (Q10) with lack of carer continuity.

Within the perceptions of substandard care, there was also experiences of risking patient safety. This was due to lack of time and resources as well as lack of knowledge, information and competence regarding COVID-19 disease, acute conditions and being unable to locate necessary equipment and supplies in emergency situations. Lack of time implied, for instance, being unable to check vital signs or leaving patients unattended. A major experience of concern was placing patients at risk of COVID-19 by alternating between wards with infection and without, or mixing infected and uninfected patients in the same ward or waiting room (Q11). Lack of basic hygiene routines and lack of protective equipment were perceived to contribute to the outbreaks in the nursing homes. At the other COVID-19 workplaces, staff expressed

concern about the reuse of materials or extending their durability.

Being forced to provide undignified care at the end of life emerged strongly. Nurses experienced doctors not listening to their concerns about exposing patients to suffering by overtreatment despite a palliative decision (Q12). Lack of symptom relief was also experienced, particularly lack of oxygen in nursing homes. Undignified dying and death were described, such as allowing dying under a plastic sheet in an abdominal position and placing the deceased in a body bag as in waste management (Q13). Finally, there were experiences of moral stress, mainly in primary care, regarding deprioritisation of elderly and uninfected patients. Frustrations comprised excluding elderly from visiting emergency room care and receiving hospital care or ICU admission (Q14). Moral stress was also about down-prioritisation of patients with other care needs, such as chronic health issues, women's healthcare, psychological health support and rehabilitation (Q15).

Uncertainty about right and good

Another source of concern was feeling uncertain about right and good. This emerged as interest conflicts, feeling torn between different concerned parties and value conflicts for the individual patient. Feeling torn mainly implied impossible prioritisation of needs and interests between patients. Prioritisation regarding treatment emerged from the doctors' perspective. Primary care doctors struggled with difficulties of '*deciding who is not medically important*' and, in COVID-19 wards, having to choose between patients to provide high-flow oxygen treatment. For assistant nurses, it was a matter of prioritising time between patients, being there for one while knowing that someone worse off was waiting (Q16). Difficult balancing of considerations between patients, family and coworkers was also experienced. In municipal care, there was a balance between the individual's self-determination to move freely and consideration for the health of others, risking infection (Q17). Uncertainty regarding whose consideration to prioritise signified balancing between patients' interpreted needs and families' expressed needs (Q18). However, it could also be about loyalty conflicts towards coworkers.

Taking into account patients' and families' needs opposed the showing of respect for the competence of co-workers. Doubt about what is good for the patient was primarily about a conflict between promoting security/mental health and protection against infection (Q19). It was perceived as exposing patients to insecurity when you have to '*repel them*' through distance and quarantine. Primary care struggled with infection control versus long-term well-being among patients with chronic disease (Q20–21). Uncertainty about what is a good decision about level of care was mainly described by doctors (Q22).

Burdensome guilt

A third source of concern was feeling complicit or carrying the suffering of others, and this emerged as a moral distress. Staff expressed feeling complicit (table 2) in contributing to patients becoming infected and dying (Q23) and blaming themselves for bad care when the responsibility actually with someone else. Nurses blamed themselves and felt coresponsible for patients' deterioration, bad care or neglect. Staff described quickly enrolling patients in palliative care when this should be done respectfully by a doctor in quiet dialogue with patients and families together, or infecting patients when actually the COVID-19 cohorting had failed (Q24).

There were also feelings of inadequacy in interactions with patients and families, for example, an inability to connect with the patient, such as helping patients with dementia understand why they needed to be quarantined, or families to understand the visitor restrictions or how ill the patient was (Q25). Understanding needs but not being able to meet them due to lack of communication gave a feeling of inadequacy (Q26). Staff also described having a bad conscience over acting wrongly, and some explicitly used the term 'bad conscience'. It could also be about examining whether you could have done something differently (Q27), not standing up for the patient or not anticipating rapid deteriorations. Guilt could also be about feeling selfish about avoiding contact with the patients with COVID-19 or staying with them (Q28). Experiences were conveyed about carrying the suffering of others (table 2), a concern about patients' and families' unmet needs for each other (Q29). Staff also felt burdened by patients' plight, such as not able to save young patients' lives (Q30) and their rapid deterioration. In nursing homes and primary care, great concern was expressed about how their patients would cope with the disease but at the same time worrying over them not daring to seek care (Q31).

Exhausting distress in an uncontrollable work situation

Self-concern in the work situation manifested as exhausting distress. It appeared as mentally taxing distress, described as being wound up, anguished, having dysphoria and weariness. Weariness was described as complete exhaustion, feeling spent, worn out or hitting the wall and as reduced attention, mood swings and absent-mindedness.

> Huge imbalance in positive and negative input last 3 months makes me much more unstable, see things in black, worry about smaller things compared to when I feel stable. Primary care

We have not described this part as much detail as the part related to moral stress, but please see the quotations in table 3 for facilitating further understanding. *Taxing insecurity* was experienced as being in limbo from fear of being hit by COVID-19 and spreading it to family or of no control of foresight at work. There was also a sense of being alone with responsibility for inexperienced coworkers and without support. Staff also conveyed a

fear of failing, not managing the new professional role by making medical errors, missing something important or not meeting the expectations of others, foremost coworkers.

Staff felt *despair in being deprived control over their work situation* (table 3) by not being able to influence one's situation and not being heard. This could be about being unable to determine annual leave and recuperation or being involuntary redeployed but also not being able to influence or being acknowledged to be right. This produced a *distrust for management* with ambiguous information and constant changing of directives as well as unfair division of work tasks. An *excessive workload* (table 3) was experienced, with the burden of being unable to keep up with the numerous patients in worse condition in relation to fewer staff due to sickness. This also implied a burden of having to lead the work but also for the inexperienced staff coming to a new workplace environment as new coworkers. Lack of recuperation and energy was also experienced as a threat to private life.

DISCUSSION

Our findings illustrate examples of stress and distress caused by a pandemic, resulting in a strain on the healthcare system that is unprecedented in a high-income country such as Sweden. We found that moral stress and anxiety in work situations were common during the first wave of COVID-19, particularly among nurses. This aligns with previous studies of COVID-19 related moral stress and anxiety.[1 18–21] A conspicuous finding was that redeploying staff to work with patients with COVID-19 increased the risk of anxiety, as also supported by others.[5 22] However, the anxiety seemed to emerge as exhausting distress and the moral stress mostly as moral distress, as described by Gustavsson *et al*.[9] In figure 2, we have tried to sort different terms and suggest potential interconnections between emotional stress and distress. This in relation to experienced sources of stress, emotions and responsibility.

Sources of stress and their link with emotions and perceived responsibility

Sources of stress

Situations of moral stress in our findings that might be considered unavoidable include the depriorisation of other patient groups and down-priorisation of quality of care. However, the down-priorisation of the psychosocial well-being of patients and families is an important observation and must be further discussed post-COVID-19. The salient findings of not being able to fulfil the needs of closeness and security for patients and families can be seen as an example of a good moral reason to change practice. A major concern was excluding family, which also included leaving patients alone, including undignified dying. To not be able to cater to social needs is a violation of the code of ethics for nurses: '*to meet the health and social needs of the public, in particular those of vulnerable populations*'. [23] The threats to family-centred care during

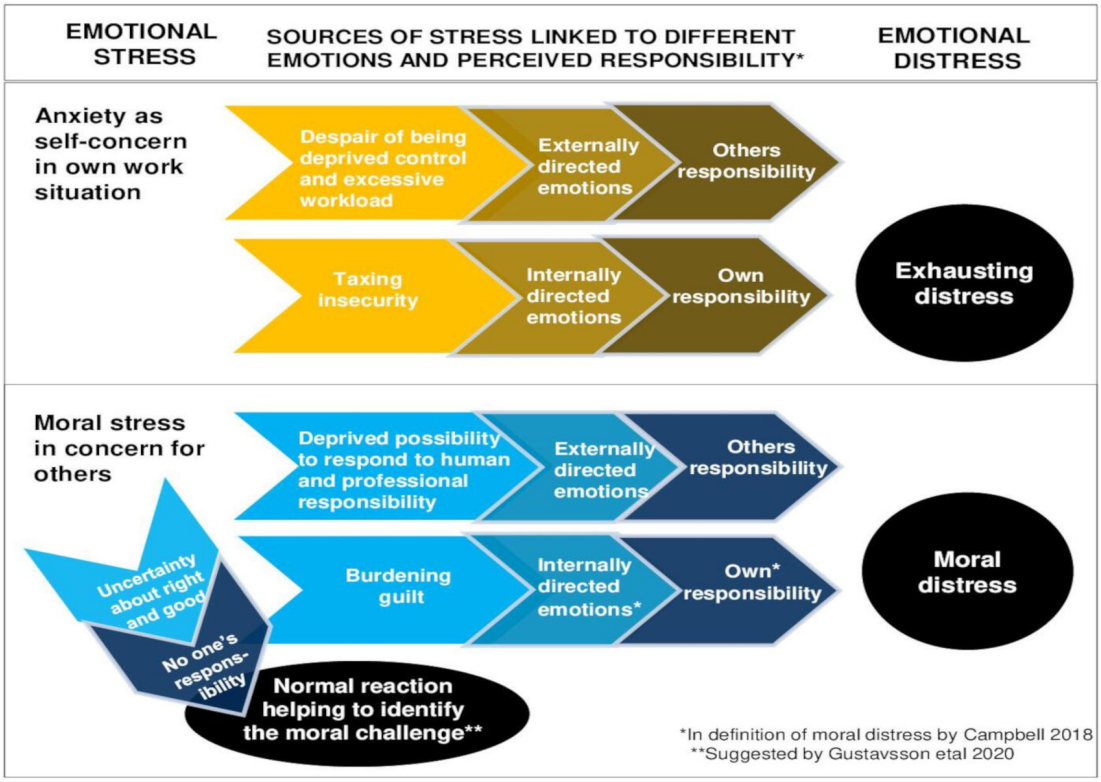

Figure 2 Potential interconnections between emotional stress and distress, in relation to experienced sources, emotions and responsibility perceived by the COVID-19 staff. *In definition of moral distress by Campbell 2018. **Suggested by Gustavsson *et al*[9] 2020.

COVID-19 has been acknowledged.[24] There ought to be, and have been, potential procedures to circumvent restrictions on physical presence for patients in the palliative phase (including dementia). For other patients, other communication routes with family could have been used, such as making contact and providing support via telephone or internet devices.[24]

Although the pandemic entailed a new situation for staff, the sources of moral stress were not necessarily new. For example, limited hospital visitations, policies that prevent the involving of families in care decisions and the rationing of lifesaving therapies have been present before.[25] Thus, the pandemic amplified existing sources of moral stress rather than introduced new ones. The same applied for exhausting distress from work overload. However, COVID-19 changed the scenario drastically into an extraordinary situation of 'not-knowing'. Finland initially had a mild outbreak, yet staff still felt anxiety due to facing a new situation, forcing them to change routines.[26] This corresponds very well with the respondents in our study, who felt a taxing insecurity from an uncertain future, lonely responsibility and fear of failing, as well as despair in lack of control with ambiguous information in a 'not-knowing' situation—all closely related to the risk factors of work-related burnout syndrome.[27]

Emotions

Emotional content was more richly present in the responses we interpreted as distress in self-concern than those we found to be related to moral stress/distress in concern for others. In the former category, the emotional content revealed emotion-regulation difficulties, problems with attention, serious fatigue and dysphoria. In the latter category, distress was found to be in the form of diffuse frustration over not being able to respond in a moral and professional manner and feelings of burdening guilt. In both categories, though, it was clear that emotions were directed both internally, highlighting one's own part, role and responsibility, and externally, focusing on organisational and environmental constraints. In figure 2, we use the term 'internally directed emotions' to signify emotions directed inwards, towards oneself, which is in line with the broader definition of moral distress by Campbell *et al*,[28] the laying of responsibility on one's shoulders. With the opposite we use the term 'externally directed emotions', that is, directing the emotions outwards, and the laying of the responsibility outside oneself (figure 2). Clearly, emotions are an important aspect of reactions in relation to moral stress. Acknowledging them can increase the ability to identify moral challenges need be addressed (figure 2).[9] In the more recent definitions of moral stress/distress, emotions are included. Gustavsson *et al*[9] include feelings of frustration and powerlessness in their suggested definition of moral stress, and Campbell *et al*[28] describe self-directed emotions associated with moral distress.

Responsibility

The notion of responsibility is complex in the pandemic context. This is in part due to uncertainty about the nature of the disease as well as the taxing insecurity and workload that has made staff overextend what they define as the limits of their professional responsibilities. A situation as dire as the COVID-19 pandemic could be expected to further add to a sense of urgency and readiness to act—the core of human services professions. Conspicuously in our result was the burdening guilt, as also showed by others,[29] laying responsibility on one's shoulders. The elevated sense of responsibility in concern for the vulnerable fellow human being accompanies the risk of misattributing the responsibility and guilt that is inherent in the work situation. Although some staff may be well aware of being unable to take full responsibility for 'the other', they still feel guilt. It seems warranted to revisit the important distinction made by Martin Buber,[30] that guilt is an existential and interpersonal matter of not doing right towards others, while 'guilt feelings' can be experienced regardless of whether an actual transgression occurs. From this aspect, respondents seemed to be very keen to uphold their professional standards and attributed feelings of guilt with not doing right and good.

Demarcation between emotional stress and distress

Our findings facilitate making sense of and sorting terms linked to stress. Stress in general terms has long been understood as a non-specific reaction by an organism to environmental demands, where an initial alarm in the organism is followed by resistance or adaptation. If unresolved, exhaustion and death will eventually follow.[31 32] We see emotional stress as an umbrella term for anxiety and moral stress, leaning on the definition presented in the *APA Dictionary of Psychology:* a tension state with negative tone, associated with danger, lack of security and internal conflicts.[33] We connect the latter, internal conflicts, with moral stress, as also pointed out by Lützén *et al*.[34] We then see emotional distress, as the negative response to emotional stress, as an umbrella term for exhausting and moral distress (figure 2). Here we lean on the Legal Information Institute for the definition: a mental suffering in an emotional response to an experience that arises from an event, occurrence[35] such as a pandemic.

Distinguishing anxiety from moral stress

Moral stress and anxiety in work situations seem to overlap in our findings, but there is also confusion between the two terms. In the quantitative analyses, the same people tended to report moral stress and anxiety. In the qualitative analyses, respondents described anxiety as self-concern under the question of moral stress and described moral stress as a concern for others under the question of anxiety. An explanation of respondents' lack of discrimination between moral stress and anxiety might align with an unfamiliarity with the concept of moral stress (or distress) but may also illustrate the conceptual confusion raised by others.[9 36 37] Our contribution to distinguishing

that concern can signify both anxiety or worry about one's work situation, that is, self-concern, as well as worry or care for the other. For concern for others, we lean on the ethical demand according to Løgstrup, that is, 'concern for the other'.[38]

Distinguishing moral stress from moral distress

In our analysis, we detected a pattern, more compatible with a broader definition of moral stress/distress than by Jameton,[12] including self-directed emotions and different attitudes of responsibility. One that resembles our findings well is the definition by Campbell *et al*:[28] '*One or more negative self-directed emotions or attitudes that arise in response to one's perceived involvement in a situation that one perceives to be morally undesirable*'. After conducted analysis, we found the review and conceptual model of moral distress in disaster settings by Gustavsson *et al*.[9] They suggest a definition of moral distress encompassing emotions, but they also distinguish moral stress from moral distress. They suggest moral stress is an initial reaction during morally challenging situations and may give rise to moral distress as a reactive stress in the aftermath if there is an absence of a solution or support. Unmitigated moral distress may have psychological consequences, such as burnout.[9] The distinction is in line with our findings and are illustrated in figure 2 along with 'self-directed emotions' and 'perceived involvement' (responsibility), according to the definition suggested by Campbell *et al*.[28] In our findings, we found signs of burnout, but these were not clearly linked to moral distress as these feelings were mostly described in connection with stress in one's own work situation. This exhausting distress is in many ways akin to the more specific model of work-related burnout mentioned previously.[39]

Need of support to prevent moral distress and burn-out

To cope with this moral distress, that is, reactive stress, there may be three general routes to take: change the context to better achieve professional standards; change or realign our moral professional standards to better fit the context; or understand and possibly accept why our standards cannot be realised in the context at hand. The mismatch between the context (in terms of available resources and what is done to use existing resource as wisely as possible or to redistribute resources; what is done to contain the virus) and the moral ideal is therefore exacerbated. Now, an important and generally accepted assumption in ethics is that what 'ought imply can', that is, to have a duty to act in a specific way, we must be able to act in that way. In this case, the 'can' is not only related to physical restrictions, but is rather being restricted to act in alignment with our moral professional standards for good care. Here we need careful analysis when we experience moral stress: is this a sign of a situation that we have good moral reasons to change (ie, it is based on the wrong decisions) or is it unavoidable in the sense that it is tragic but still based on decision that ethically is warranted given the context? This tragically indicates that, in an extreme situation such as a pandemic, even if we do things right (in terms of the most ethically justified actions), we might still experience moral distress. Clinical ethics support, such as moral case deliberation, leading to insights that certain acts are inevitable, might ease this distress.

Support is also crucial to prevent burnout, as also concluded by others,[22 40] and is reported as lacking.[5] The presence of managers seems crucial to acknowledge the need for safety, calming and hope in a catastrophic event.[41] According to an expert panel consensus report by the National Institute of Mental Health and allied authorities, there is a need during a large-scale crisis to communicate a sense of safety, calming, self-efficacy and community efficacy, connectedness and hope.[41] This study is about staff, but, nota bene, the very presence of first-line managers in care is crucial for giving emotional support to coworkers and to ensure the concern of patients and families as a relational inclusion, that is, ethics of care. Ness *et al*,[42] for instance, showed that lack of support during COVID-19 increased moral distress. The frustration caused by the pandemic might risk the exacerbating of an already unhelpful narrowing of identification of belonging, in order to emotionally endure these stressing circumstances. Greene calls these spontaneous groups 'moral tribes', with the aim of parting 'us and them'.[43] In the 'us' here, patients and families may not be included.

To include patients and family in 'us' and acknowledge a concern for them, moral case deliberation might be beneficial. Moral case deliberation is a facilitator-led collective moral inquiry by staff into a concrete moral issue connected to a real patient situation in their practice.[44] Goals, among others, are enhancing moral sensibility and responsiveness to the needs of patients and families.[45] However, the deliberation needs to be adapted to first depart from participants' experiences of their own stress to be able to focus on the suffering of the patient and family.[46]

Strengths and limitations of this study

One limitation is the low overall response rate, but considering that data- collection took place in the midst of the pandemic crisis along with rich open responses, we consider the response rate for nurses as high and the findings generalisable and transferable to nurses working during the first wave of COVID-19 in high-income countries.

The findings of a demarcation between stress/distress in self-concern and moral stress/distress in concern of others based in a pandemic context may be transferable to everyday clinical work. It might be argued that building a case about relations between moral and non-moral emotional stress and distress with only two open-ended questions is not trustworthy. Conversely, we believe that the timing of the data- collection, captured in real time during the peak of COVID-19, combined with the use of qualitative inquiry, has generated rich

and trustworthy findings. At this time, the world was in a totally new situation, and we did not find any suitable and valid moral distress instrument for capturing this in unknown context. Additionally, we felt a moral responsibility to keep the survey burden as low as possible. After our data collection, we did find other studies that used the 11-point single-item Moral Distress Thermometer,[47–49] the single-item Moral Distress Questionnaire[50] and the COVID-19 Moral Distress Scale.[51] Nota bene, we consider that the qualitative findings have contributed with new knowledge, not the quantitative findings.

Finally, the use of software facilitated the balancing of rigour and creative hermeneutical analysis. With this, we mean that the software both facilitated a structured inductive approach, keeping all data in order while at the same time facilitating rethinking with the possibility to totally change the categorisation tree. This was particularly the case when we detected a pattern in the responses and was able to break up the previous categorisation and easily rebuild, now with help of theory.

CONCLUSION

We have not only contributed with knowledge about being in the frontline of COVID-19, but also an understanding of the differences between moral stress and moral distress in a disaster context, as well as the demarcation between moral stress/distress as a concern for patients and family on one hand and exhausting distress in work situation as self-concern on the other hand. However, clarity regarding moral stress and distress in disaster context needs to be further studied.

We hope our contribution can be helpful for tailoring support for pandemic frontline staff. A take-home message for managers when planning post-COVID-19 support is to adapt clinical ethics support by first mitigating self-concern in the work situation as well as preventing moral injuries by emotions of guilt before any structured ethical reflection. This may help morally sensitive staff to adapt to a more 'realistic' and temporary ideal and relief from a sense of guilt, given the extreme situation. Ethics support may also be beneficial for staff who deny moral stress to train their moral sensibility to acknowledge feelings of guilt and vulnerability as resources in human service professions. A lesson for management is that a major event such as a pandemic concerns everyone and that being prepared for connectedness between healthcare staff and patients/families) to prevent inhumane care and burn-out is crucial. This presupposes the very presence of managers. A final concrete message is, to the highest extent, to let extraordinary work in the frontline be voluntary, that is, avoid any involuntary redeployment.

Acknowledgements First of all, we are indebted to the strained respondents who shared their experiences in the pandemic turmoil. We would also like to thank Isabell Fridh, Marie Matérne and Daniel Pichler for their contribution in the study design, survey construction and data collection, Marit Silén and Martina Gustavsson for helpful comments and Aileen Ireland for excellent language review.

Contributors MS was the main project leader and responsible for the overall content as the guarantor and accepts full responsibility for the work and the conduct of the study, access to the data, the qualitative analysis, writing the manuscript and decision to publish. LS was coproject leader, participating in the study design, cowriting and philosopher expertise to discussions. GJ conducted the quantitative analyses and was responsible for writing the quantitative methods, findings and discussion sections. LD conducted the literature review, participated in data collection and coassessment in the qualitative analysis and in theoretical elements. EH coassessed the analysis and participated in the writing of the discussion with a psychology and stress expertise perspective.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval Swedish Ethical Review Authority, Gothenburg 1 Medicine Reference number: 2020-01784. The questionnaire was accompanied by an information letter about the voluntary nature of responding, and informed consent was obtained by virtue of them having responded.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement No data are available. Raw data cannot be shared due to research participant confidentiality and Swedish law.

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