

1 **Full Title: Experiences of staff providing specialist palliative care during COVID-19**

2 *A multiple qualitative case study.*

3 **Short Title: Providing palliative care during COVID-19**

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41 centres, with input from CW. AB, LD, and IG analysed the data with critical input from the CovPall
42 team. All authors had access to all study data, discussed the interpretation of findings and take
43 responsibility for data integrity and analysis. AB, and LD drafted the manuscript. All authors
44 contributed to the analysis plan and provided critical revision of the manuscript for important
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54 **Abstract**

55 **Objectives:** To explore the experiences of, and impact on, staff working in palliative care during the
56 COVID-19 pandemic.

57 **Design:** Qualitative multiple case study using semi-structured interviews between November 2020
58 and April 2021 as part of the CovPall study. Data were analysed using thematic framework analysis.

59 **Setting:** Organisations providing specialist palliative services in any setting.

60 **Participants:** Staff working in specialist palliative care, purposefully sampled by the criteria of role,
61 care setting and COVID-19 experience.

62 **Main outcome measures:** Experiences of working in palliative care during the COVID-19 pandemic.

63 **Results:** Five cases and 24 participants were recruited (n=12 nurses, 4 clinical managers, 4 doctors, 2
64 senior managers, 1 healthcare assistant, 1 allied healthcare professional). Central themes demonstrate
65 how infection control constraints prohibited and diluted participants' ability to provide care that
66 reflected their core values, resulting in experiences of moral distress. Despite organisational, team,
67 and individual support strategies, continually managing these constraints led to a 'crescendo effect' in
68 which the impacts of moral distress accumulated over time, sometimes leading to burnout. Solidarity
69 with colleagues and making a valued contribution provided 'moral comfort' for some.

70 **Conclusions:** This study provides a unique insight into why and how healthcare staff have
71 experienced moral distress during the pandemic, and how organisations have responded. Despite their
72 experience of dealing with death and dying, the mental health and well-being of palliative care staff
73 was affected by the pandemic. Organisational, structural, and policy changes are urgently required to
74 mitigate and manage these impacts.

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79 **Background**

80 COVID-19 has additionally stressed already stretched healthcare systems, influencing how
81 organisations, and professionals that work within them, are able to respond to patient and carer needs.
82 A combination of dealing with death and dying, risks of infection, personal loss/grief, and operating
83 in insufficiently resourced services has resulted in many experiencing anxiety, depression, insomnia,
84 burnout, and post-traumatic stress disorder.¹⁻⁵

85
86 Palliative care is a unique speciality in that staff are used to dealing with dying and may have been
87 less affected by this aspect of the COVID-19 pandemic. Nevertheless, in responding to COVID-19,
88 palliative care professionals have been confronted with constraints (e.g., making complex and difficult
89 decisions, infection control, dealing with uncertainty, and recognising deep inequities^{3,6,7}) that have
90 challenged their ability to provide care in accordance with their professional values. These values
91 include alleviating suffering and enhancing the quality of life of dying patients and their families
92 through the adoption of a holistic, compassionate, person-centred, dignified, safe, and
93 multidisciplinary approach.

94
95 Understanding how palliative care professionals, who choose to work with those who are dying,
96 responded to the pandemic is key. It is important to understand how individual, organisational, and
97 policy-based changes can be made to alleviate and manage the impact of the pandemic on staff.⁸ The
98 aim of this study, therefore, was to explore the experiences of, and impact on, palliative care staff
99 working during the COVID-19 pandemic to illuminate both their experiences and how this may help
100 an understanding of supporting healthcare staff and organisations more generally.

101
102 **Methods**

103 A descriptive qualitative multiple case study,⁹ part of the ‘CovPall study’; a project aiming to
104 understand the multinational response of specialist palliative and hospice care services to the COVID-
105 19 pandemic. It was guided by the following research questions:

- 106
- How has the COVID-19 pandemic impacted staff working in palliative care?

- 107 • How did organisations respond to the impact of the COVID-19 pandemic on staff well-
108 being?

109 **Case definition, selection, and recruitment**

110 Cases were defined as organisations providing specialist palliative care services across any setting.
111 Potential sites that met the inclusion/exclusion criteria were identified from responses to an initial
112 CovPall survey, with cases sampled for maximum variability against key criteria until sufficient
113 organisations were recruited (Table 1).

114 **Within case participant selection and recruitment**

115 Key contacts within each case study site identified potential participants who met the inclusion
116 criteria (Table 1), purposively sampled to reflect variations in professional role, work setting, and
117 experience in responding to COVID-19. Key contacts distributed study information (participant
118 information sheets and consent forms) to those who could provide rich insight into the aims of the
119 study.

120 **Theoretical propositions**

121 In line with case study research strategies,⁹ we used the survey data to develop initial theoretical
122 propositions to guide data collection and analysis:

- 123 1. The type of service provider organisation made a difference to the way that specialist
124 palliative care responded to COVID-19.
- 125 2. The context within which the service provider organisation operated affected their response.
126 This may include geography (e.g., when they first experienced COVID-19, local healthcare
127 organisational factors) and factors known to affect service use (e.g., deprivation, ethnicity).
- 128 3. Exposure to COVID-19 patients (e.g., numbers of patients, and whether patient were dying
129 with or from COVID-19 or other diseases) made a difference to the service response to
130 COVID-19.
- 131 4. Systems or processes that supported responsive decision-making affected response to
132 COVID-19 which included aspects of integration with other services and organisational
133 leadership.

134

135 *Table 1: Inclusion and exclusion criteria for the recruitment of case study sites and participants*

Cases			
Inclusion criteria	<ul style="list-style-type: none"> • Organisation providing specialist palliative care services. 137 • Respondent to CovPall survey, with agreement for further contact. 138 • Restricted to English Hospice organisation respondents due to constraints of research approvals. 139 		
	Sampled against criteria to maximise variability: 140		
	<ul style="list-style-type: none"> • Number of services and setting types that organisations provided 141 • Whether adult and/or paediatric services were provided 142 • Experience of providing care to those with COVID-19 143 • Whether minority ethnic populations were served 144 • Variability in their initial service changes to COVID-19 145 		
	Participants within selected cases		
	Inclusion criteria	<ul style="list-style-type: none"> • Working or volunteering within the chosen case and able to provide rich data on the experience of care provision during COVID-19 (e.g. senior managers, clinical managers, direct healthcare staff). 146 • Aged 18+ 147 	148
		<ul style="list-style-type: none"> • Patients known to the service, or their family carers. 149 	150
	Exclusion criteria		

151 **Data collection**

152 Single online (via Microsoft teams) or telephone semi-structured interviews were conducted. The
 153 interview guide (eTable 1) was iteratively developed throughout the study. Participants were asked to
 154 reflect on how they had experienced working throughout the COVID-19 pandemic, how they felt their
 155 organisation had responded to challenges during this time, and ways in which we could learn from the
 156 pandemic to inform future practice. Interviews were conducted by AB and IG, both of whom had
 157 previous interviewing experience. They were digitally recorded, anonymised, and transcribed
 158 verbatim. Field notes were made during and after each interview. On average, interviews lasted 39
 159 minutes (range 22-80 minutes). Data were collected between November 2020 and April 2021. This
 160 coincided within (September 2020 - January 2021) and after the second wave of the COVID-19
 161 pandemic in England.

162 **Data analysis**

163 Thematic framework analysis was used to analyse data.¹⁰ This approach allowed us to conduct
164 within- and between-case pattern matching, thus enabling a process in which we could identify and
165 explore where participant responses converged/diverged, and how this may have been affected by
166 different contextual factors.¹⁰ This approach involved constructing themes through five
167 interconnected stages: (i) familiarisation; (ii) coding transcripts to construct an initial analytic
168 framework; (iii) indexing and further refinement of the analytic framework; (iv) charting; (v) mapping
169 and interpreting the data theory/theoretical concepts to make sense of and explain our data. Data were
170 initially analysed within cases and then between cases.

171

172 Whilst engaging with data during early analysis, we recognised that many participants had
173 experienced distress that was attributable to wanting, but not being able, to provide palliative care in
174 specific ways. Thus, moral distress was identified as a useful lens through which these data could be
175 viewed. Generally, moral distress refers to ‘the experience of being seriously compromised as a moral
176 agent in practicing in accordance with accepted professional values and standards.’¹¹ The origins of
177 moral distress are in the fields of nursing, military and humanitarian medical ethics. Within the
178 context of health, it has historically focused on institutional/organisational obstacles that impact
179 healthcare professionals’ ability to deliver care in accordance with their values.^{6,7} Recent literature,
180 however, has recognised the importance of also appreciating sources of moral distress that derive
181 from ‘broad[er] challenges of the health services system’,⁸ incorporating regional, national, and
182 global issues.¹² We adopt the latter perspective when referring to moral distress throughout this
183 paper.

184

185 The analysis process was primarily conducted by AB, LD, and IG. Throughout this process, co-
186 authors CW and NP (and the wider CovPall team) acted as ‘critical friends’. This was through cross-
187 checking coding, and discussing, debating, and providing alternative interpretations of data until the
188 research team were happy that interpretations of data accurately reflected participant accounts.

189 **Ethics committee and other approvals and registrations**

190 Research ethics committee approval was obtained from King’s College London Research Ethics
191 Committee (21/04/2020, Reference; LRS19/20-18541), with additional local approval from Lancaster
192 University FHMREC 24.11.2020 Reference FHMREC20057). The study was registered on the
193 ISRCTN registry (27/07/2020, ISRCTN16561225) and reported in line with the COREQ checklist.

194 **Findings**

195 Five cases drawing from the experiences of 24 participants were included (Table 2). The findings are
196 presented as a cross case analysis and are represented as four themes and two subthemes (see figure
197 1). Additional example quotes for each theme and sub-theme are in supplementary materials (eTable
198 2).

199 **Theme 1: Infection control constraining professional values**

200 The most common constraints to practicing in line with professional values were directly or indirectly
201 related to infection control policies/procedures. These constraints triggered moral distress by either
202 prohibiting or diluting the abilities of individuals and organisations to uphold and practice in
203 accordance with their professional values. A unifying pattern across the cases was that the root cause
204 of moral distress was not primarily the result of looking after patients who were dying, but because of
205 care constraints impacting on *how* they were able to care for dying patients.

206

207 ***Sub-theme 1: Prohibited values***

208 In some instances, the impacts of infection control procedures prohibited staff’s ability to provide care
209 in accordance with their professional values. In particular, restricted visiting policies forced
210 participants to make decisions and operate in ways that were opposed to the holistic and
211 person/family-centred values of palliative care. In the hospital setting, staff had to inform families that
212 no visiting was allowed (even at the end of life) whereas in the hospice settings only a limited number
213 of visitors were generally permitted. Witnessing patients die without loved one’s present, alongside
214 having to deal with the conflicts that visiting restrictions caused was particularly distressing:

Table 2: Case and participant characteristics

	Case one	Case two	Case three	Case four	Case five
Case characteristics					
Region	North West England	South East England	North West England	North East England	South East England
% NHS funding	Approx. 35 %	Approx. 25%	Approx. 30 %	Approx. 25 %	Approx. 40 %
Patients served	Adult	Adult/children	Adult/children	Adult	Adult
Services provided	Inpatient palliative care unit, home palliative care team, home nursing	Inpatient palliative care unit, home palliative care team, home nursing	Inpatient palliative care unit, hospital palliative care team, home palliative care team, home nursing	Inpatient palliative care unit, hospital palliative care team	Inpatient palliative care unit, hospital palliative care team, home palliative care team, home nursing
Population served*	Urban, suburban and rural Approx. 80% White	Urban, suburban and rural Approx. 80% White	Suburban and rural Over 95 % white	Suburban and rural Approx. 90 % white	Urban and suburban. Approx. 70 % white
Study participant characteristics					
Data collected	11/20-04/21	11/20-03/21	12/20-01/21	03/21	04/21
COVID wave (UK)†	Wave 2/post wave 2	Wave 2/post wave 2	Wave 2	Post wave 2	Post wave 2
Professional role	Nurse n= 4 Clinical manager n = 1 Doctor n= 1	Nurse n= 3 Clinical manager n=2 Health care assistant n= 1	Nurse n= 2 Senior manager n =1 Doctor n= 3	Nurse n=1 Clinical Manager n= 1 Allied Health Care Professional n=1	Nurse n=2 Senior manager n=1

Ethnicity	White n= 6	White n= 5 Asian/Asian British=1	White n= 6	White n= 3	White n= 2 Missing =1
Time worked in palliative care (months) mean/range	98 months (48-360)	108 months (36-192) Missing=1	109 months (18-180)	196 months (60-360)	192 months (360-24) Missing=1
Time worked in current position (months) mean/range	93 months (12-240)	15 months (3-36) Missing=1	61 months (18-120)	72 months (60-96)	78 months (132-24) Missing=1

* Data derived from the Hospice UK PopNat tool (<https://popnat.hospiceuk.org/>)

† For the purposes of the research: Wave 1 includes cases presented from March 2020 to end of August 2020 and wave 2 includes cases presenting to services from September 2020 to January 2021

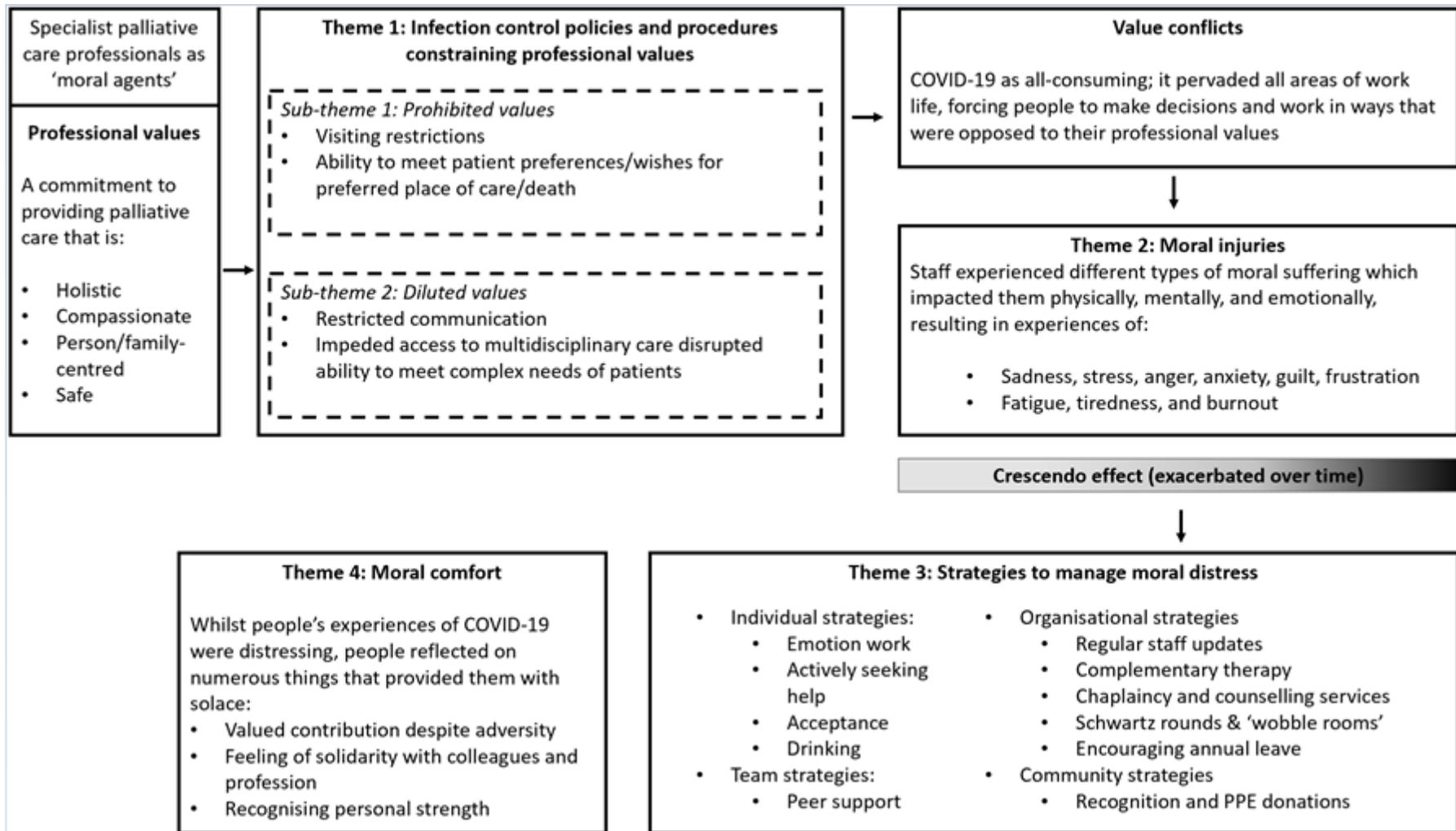


Figure 1: An overview of the themes and sub-themes that represent the processes through which participants in this case study experienced moral distress

217 *‘Throughout this whole Covid experience, what stays with me the most are those*
218 *conversations with loved ones and family members to say: ‘I am really sorry, we can’t enable*
219 *a visit’, or if you do it is a one-off kind of hour visit... they have been some of the hardest*
220 *conversations that I have had in my whole nursing career ... you can’t help but feel that you*
221 *have not done enough, even though I know that we have ... it just goes against the grain of*
222 *everything we do.’ participant 5, case 1, nurse*

223

224 Visiting restrictions also impacted staff’s ability to visit patients’ homes. As referrals increased in the
225 community, staff were required to triage who did and did not require an in-person visit to reduce the
226 risk of infection. Consequently, some participants felt that the care they were providing was
227 different/inadequate and compromised compared to before COVID-19. Feeling care was
228 compromised, as well as managing disagreements with family carers over whether an in-person visit
229 was necessary, was a source of moral distress for some:

230 *‘we cut down the visits we were doing, so in the home care team the visits would be done if*
231 *they really needed to... But, anybody where we could do it over the phone, because you were*
232 *just minimising contact and obviously reducing the risk of spreading the virus. But, I think*
233 *some family members did see that as ‘but you are not really here, you are not coming out and*
234 *doing visits, you are just over the phone’ ... it is trying to find a ... tactical way of saying that*
235 *there is no need to increase that risk for something that can be done over the phone.’*
236 *participant 3, case 2, nurse*

237 Infection control issues also prohibited staff’s capacity to provide care that was aligned with patient
238 preferences. Not being able to admit patients requiring aerosol generating procedures into hospice
239 inpatient units, or an inability to discharge patients out of hospital or hospice, placed staff in situations
240 where they were sometimes unable to honour peoples wishes regarding preferred place of care/death:

241 *‘not being able to get the patients out of hospital because care homes won’t accept COVID-*
242 *positive patients. people who don’t have long left to live and don’t want to die in hospital,*
243 *you know, delaying that, there’s more chance that they are going to die in hospital if we can’t*
244 *get them out. It’s been one of the biggest challenges, discharge, it’s so difficult to juggle on a*

245 *daily basis. The number of beds, patients coming in, trying to get patients out, it's*
246 *horrendous.'* Participant 3, case 3, doctor

247

248 ***Sub-theme 2: Diluted values***

249 In some situations, whilst staff were able to carry on providing palliative care within infection control
250 constraints, they recognised it diluted their ability to provide care in line with their professional
251 values. Many raised concerns about how their ability to care for patients and families with the same
252 level of compassion and empathy as prior to the pandemic was constrained by visiting restrictions,
253 social distancing, and unprecedented staff shortages. Sensitive conversations, such as breaking bad
254 news or GP verification of death were carried out remotely, whilst in-person communication was
255 impeded by Personal Protective Equipment. Being unable to draw on non-verbal communication
256 skills and visual cues made care feel physically and emotionally detached, undermining practitioners'
257 capacity to develop relationships, fully support, and comfort patients and carers at profoundly
258 important moments. This posed a moral dilemma for staff; whilst many participants recognised the
259 necessity of these safety measures, witnessing and managing the suffering and pain that they caused
260 families and patients was deeply distressing:

261 *'PPE is just such a barrier between us and the patients.... it's a bit more impersonal.*

262 *Obviously, we deal with patients and their families that are dying, and often patients and*
263 *family, they're quite emotional, and we can sort of maybe just sort of put our arm round them*
264 *or embrace them in some way, which is something we can't do at the moment ... And it is*
265 *harder for us, because obviously we do this job because it's a very rewarding job to do, and*
266 *so I think it is different for us, not being able to comfort somebody.'* participant 4, case 2,
267 *health care assistant*

268 Infection control policies also impeded access to the wider multi-disciplinary team and diluted the
269 level of support they were able to provide. In some cases, this was due to services being suspended,
270 adapted, or provided remotely, or staff and volunteers having to self-isolate or shield. This led to
271 moral distress as staff were concerned that patients with complex needs were not receiving the level
272 of support they required:

273 *'the other big thing that the staff have been seriously challenged with is their professional*
274 *values of very comprehensive holistic patient-centred care that is the hallmark of good*
275 *palliative care and ... so many restrictions have had to be put in place and the services that*
276 *we've had to suspend really and perhaps day surgery [therapy] or complementary services,*
277 *things have had to go to remote conversations and consultations. They've found it very, very*
278 *difficult to accept that change in standards or those constraints to being able to get that high*
279 *standard of personal care.'* participant 1, case 3, doctor

280

281 **Theme 2: Moral injuries**

282 At the beginning of the pandemic, clinicians reported feelings of anxiety/fear due to dealing with an
283 unknown disease and new infection control procedures. As more was known about COVID-19 and
284 access to PPE improved, participants reported that they generally became less fearful and worried.
285 Instead, these feelings were replaced by those of sadness, stress, anger, guilt, frustration, and fatigue
286 as a result of repeated exposures to morally distressing scenarios in which they were forced to act in
287 ways that did not always align with their professional/moral values. Across cases settings and roles,
288 these responses represented 'moral injuries', exemplifying the enduring psychological, emotional, and
289 physical harms of repeated exposure to moral distress:

290 *'some days I have really struggled – I am not going to lie. I have absolutely sobbed my heart*
291 *out, thinking about stuff that I have gone through and seen and conversations that I have had*
292 *to have with family members. But, ultimately you go back into work the next day and you*
293 *carry on, because you know that you have to because you have got a job to do, and there are*
294 *patients and people there that are relying on you to do that, do you know what I mean? So,*
295 *yes it has been ... it has been challenging, mentally and physically.'* participant 5, case 1,
296 *nurse*

297 Whilst experiences of moral injuries were similar across cases, the source of moral distress was
298 sometimes role dependent. Whilst policies around infection control were often the source of moral
299 distress for healthcare professionals providing direct patient care, those in managerial positions had to
300 make difficult decisions on suspending/reducing services, furloughing staff, and/or making

301 redundancies (case one and three) because of reduced income. They also worried about and felt
302 responsible for their staff's wellbeing and safety:

303 *'when I look back on it now, really quite - difficult's the wrong word - but conversations with*
304 *colleagues where we were basically discussing the ethics of putting our staff in front of*
305 *patients with COVID knowing that they might catch it and they might die from it and that was*
306 *really hard. We were asking them to do superhuman things.'* participant 1, case 5, senior
307 *manager*

308 Across cases, a 'crescendo effect' occurred in which the effects of moral distress accumulated and
309 escalated progressively over time. This was likened to 'a drip, drip effect' [participant 5, case 1,
310 nurse] and explained how tiredness, fatigue, and frustration affected team dynamics and, in some
311 cases, led to or exacerbated staff conflicts. Moreover, it also exemplifies the process through which
312 some staff became burnt out which, in worst case scenarios, led to staff leaving their roles:

313 *'when wave two hit, there was a real oh my God can we do this again? I think it is that whole*
314 *thing – you didn't have any of the fight that you had the first time – it was a case of right*
315 *come on, we have got to do it, but it has definitely been done very well, but it is hard. It is*
316 *more of a slog this time than it was the first time... I think the actual day-to-day care wasn't*
317 *more difficult, I think people were more tired. And, I think the fact that the impact it has had*
318 *on people, on staff, externally so your whole lifestyle – people haven't got that ... same*
319 *resilience I don't think, from the first wave.'* participant 2, case 1, clinical manager

320 Laced throughout some participant accounts was a sense that they perceived themselves to be
321 relatively powerless in addressing the fundamental causes of moral distress:

322 *'ultimately the saddest thing about it all is that really there isn't anything that we can do to*
323 *take that away – this is the situation that we are in and it is awful and it is horrible, and*
324 *people are struggling with it up and down the country, and all you can do at times is just let*
325 *somebody talk or just let somebody get upset or get angry.'* participant 5, case 1, nurse

326

327 **Theme 3: Strategies to manage moral distress**

328 The detrimental impacts of moral distress were recognised early, and a variety of individual, team,
329 and organisational strategies were used to help manage its effects. At an individual level, participants
330 undertook emotion work and adopted their own strategies to manage their moral distress. This could
331 include less healthy strategies (such as drinking alcohol more heavily), but also strategies such as
332 accepting their situation, embracing the normality of work, actively seeking help, and empathising
333 with patients and families:

334 *'I think my mental health has deteriorated but I think everyone's has so I think that's fine. I*
335 *definitely reached a point where I thought, "I'm drinking too much" because it became...*
336 *When you're at home and you're stressed you're like, "What can I do? I can't go to the gym,*
337 *I could go out for a run but it's dark and I don't want to be murdered so I'm going to have a*
338 *glass of wine". And then you have one glass of wine and you're like, "Oh that does feel*
339 *better. If I have another one that'll make me feel even better ... And then the next day I'm*
340 *like, "I'm not going to drink today" then I have a really stressful meeting and I'm like, "No, I*
341 *am, I'm going to have a drink tonight" ... But yeah, so mental health, definitely, weight,*
342 *alcohol dependency.'* participant 5, case 2, nurse

343

344 *'And just tend to sit and cry with relatives ... on the one hand it's not really the done thing, but*
345 *on the other hand I guess it shows that you're human and it shows that you are absorbing*
346 *some of the impact of that emotional situation. And it's showing that you kind of respect that*
347 *it is so sad.'* participant 2, case 4, nurse

348 At a team level, participants noted the value of peer support in helping them to manage moral distress.
349 Moreover, across cases, participants felt organisations did the best they could to support staff in very
350 difficult circumstances through providing regular staff updates, 'wobble rooms', access to patient
351 therapy/support services, Schwartz rounds (opportunities for staff to regularly meet to discuss the
352 emotional impact of their work) and encouraging leave. There were some concerns that staff did not
353 always have the time to access support and strategies that required staff to be on site were not
354 accessible to all:

355 *'They created a wobble room for people to go and wobble in, it's difficult again though with*
356 *everybody off site now and working from home I think for me anyway personally the main*
357 *impact of that wobble room is just knowing that they've thought about it that's reassuring that*
358 *they're mindful of our mental health and our emotional needs but it's not actually in practice*
359 *that useful because nobody... especially for the community staff, they don't get that.'*
360 *participant 3, case 1, nurse*

361 On a practical level, ensuring the hospice had adequate supplies of PPE was important to reassure
362 staff. The wider community donated gifts and supplies of PPE and food so staff *'knew that people out*
363 *there were still thinking about us.'* [Participant 1, case four, clinical manager].

364

365 **Theme 4: Moral comfort**

366 Despite the impacts of moral distress, some participants spoke about how they experienced comfort
367 and solace in their situation as they felt they were making a valued contribution to the pandemic
368 response. Staff also recognised their own personal strength and how solidarity with colleagues was
369 developed or strengthened in responding to the pandemic:

370 *'What we learnt as a service was that we are a good team, that we can respond, that we're*
371 *respected and valuable members of our local health and social care system and that we can*
372 *add real value to that, that certainly as a management team we've been able to be very*
373 *flexible and adapt very quickly and move people around the service and that we've been able*
374 *to reach more people and keep our education going virtually, that we've been able to still*
375 *have a big impact and, you know, without undermining the quality of the care that we give too*
376 *much.... when we look back on this what will we be proud of in terms of what was our*
377 *contribution.'* *participant 1, case 3, doctor*

378

379 **Discussion**

380 By using palliative care as a clinical exemplar, this study highlights how staff working across
381 healthcare settings are likely to have been affected by the pandemic. In the context of modern
382 healthcare – where funding and resources are tight – the complete prevention/elimination of moral

383 distress is unlikely. However, this paper provides lessons on how moral distress may be alleviated or
384 mitigated across healthcare settings/specialties.

385

386 In summary, constraints related to COVID-19 infection control policies and practices were central to
387 experiences of moral distress by prohibiting and/or diluting staff's capacity to provide care that was
388 aligned to their professional caring values. Experiences of moral distress had a detrimental impact on
389 the well-being of staff by causing 'moral injuries' in which participants experienced feelings of
390 sadness, stress, anger, guilt, frustration, and fatigue. These feelings crescendoed over time whereby
391 the impacts of moral distress had a cumulative effect that worsened as the pandemic progressed.
392 Various individual, team, organisational, and community strategies were drawn on to address the
393 impacts of moral distress (see Figure 1). Despite working through adversity, some participants
394 reported feelings of 'moral comfort' by making valued contributions in response to the pandemic. The
395 final theoretical propositions were elaborated as:

396

- 397 1. All organisations recognised the risks of moral distress and responded in similar ways.
- 398 2. Whilst experiences and signs of moral distress were similar across cases, settings and
399 participants, the sources of moral distress were setting and role dependent.
- 400 3. As the length of the pandemic continued, the impacts of moral distress progressively
401 accumulated and worsened for some.
- 402 4. Despite the accumulation of moral distress, some staff experienced a sense of comfort and
403 solace because they felt they were making a valued contribution to the pandemic response.

404

405 Fundamental to staff's experiences of moral distress was a sense of discordance between wanting to
406 deliver care in specific ways, but not being able to. Whilst some constraints were COVID-specific
407 (i.e., infection control policies), many (such as decision-making conflicts, insufficient resources, staff
408 shortages, funding issues, and patient complexity) already existed prior to the pandemic.^{13, 14} The
409 increased risk of moral distress for health care staff during the pandemic has been acknowledged by
410 regulatory bodies and governments internationally,^{14, 15} and this concern is supported by emerging

411 evidence in the fields of acute care, ¹⁶ community care, ¹⁷ intensive care, ¹⁸ medical family therapists,
412 ¹⁹ mental health, ²⁰ and medicine more generally. ⁷ Compared to many of these specialities, due to
413 their specialist training and knowledge, palliative care staff may have been expected to be better
414 prepared to manage experiences of death and dying on the scale seen during the COVID-19
415 pandemic. That many staff within palliative care experienced moral distress in witnessing *how* people
416 died, there is a likelihood of even more profound distress, stress, and burnout in generalist staff who –
417 alongside dealing with structural and policy constraints of COVID-19 – were exposed to death and
418 dying on a scale unimaginable to most healthcare professionals outside of the pandemic.

419

420 The detrimental impact of moral distress on staff well-being aligns with literature demonstrating how
421 repeatedly occupying spaces of moral distress can negatively affect the physical, mental, and
422 emotional wellbeing of healthcare workers. ²¹⁻²³ If the impacts of moral distress are sustained without
423 being recognised or dealt with appropriately, it can decrease the capacity of health professionals to
424 deliver high quality care, lead to burnout, and increase the likelihood of staff making errors and
425 leaving roles. ^{7, 13, 24} Considering there are already high levels of burnout and staff shortages in many
426 healthcare settings, with shortages projected to worsen by 2030, ^{15, 25} retention of skilled personnel is
427 crucial. This is so that healthcare systems retain the capacity to meet projected increases in global
428 demand/need for palliative care ²⁶ and across all healthcare sectors more generally. ^{15, 27} Therefore,
429 understanding what changes can be made to alleviate and manage the short and long-term impacts of
430 moral distress on all healthcare staff is crucial to the future provision of healthcare. ⁸

431

432 In effectively mitigating and managing moral distress across healthcare settings, interventions need to
433 be targeted at multiple levels of practice (individual, interpersonal, organizational, and policy-levels).

434 ¹² However, strategies to manage moral distress should not solely be placed on individuals;
435 governments and organisations have a duty of care to healthcare staff, and it is important that they
436 bear responsibility in developing structures and processes of care that address the causes of moral
437 distress in order to facilitate staff well-being and prevent and/or mitigate workforce shortages. ²⁴

438 Accordingly, Rodney ¹² proposes the adoption of a relational ethical lens in managing moral distress

439 whereby underpinning any intervention is an appreciation of the interconnectedness of people and
440 structures. Supporting any individual or team level strategies to mitigate moral distress, therefore,
441 should be national policy and organisational level solutions that create environments where staff feel
442 supported and capable in delivering care. The British Medical Association propose numerous
443 structural solutions that government and institutions may consider in achieving this. These include
444 ensuring adequate funding and resourcing, increasing staffing, empowering doctors, developing an
445 open and sharing workplace culture, providing organisational support to staff, and streamlining
446 bureaucracy.¹⁴ Potentially useful interventions may include Schwartz rounds, attention to staffing
447 levels, and flexible working policies.²⁸ It may also be worthwhile for moral distress to be recognised
448 and addressed within medical education/training through validating it as a common feature of clinical
449 practice and supporting students during medical training. This may be through teaching ethical
450 reasoning so that they can identify, analyse, and manage morally distressing scenarios and providing
451 them with ‘structural empowerment’ (e.g., the capacity to influence institutional culture and policy in
452 ways that may help mitigate moral distress).²⁹ Future research on how to best achieve these solutions,
453 alongside how organisations can ensure that they are accessible to staff across all roles and settings of
454 care (including remotely), is needed.

455

456 A strength of this study lies in the adoption of a case study research design. This assisted us in
457 providing rich and detailed insights into the processes through which responding to the COVID-19
458 pandemic impacted staff working in real-life clinical settings. Through purposefully sampling cases
459 and participants, using theoretical propositions, and constructing thick descriptions of findings and
460 methods, we propose that ‘naturalistic generalisations’ may be made through findings resonating with
461 healthcare staff within and outside of palliative care.³⁰ ‘Analytic generalisations’ may also be made
462 through demonstrating the applicability and value of moral distress as a concept to understand
463 healthcare staff’s experiences of responding to the pandemic.^{9,30} A limitation of this study, however,
464 is that it relied on single individual interviews collected at only one timepoint. Whilst these provide a
465 snapshot in which participants could retrospectively reflect on the impact of COVID-19, the long-
466 term impact of COVID-19 on staff, alongside the sustainability/effectiveness of organisational

467 responses, is not clear. Further longitudinal work that addresses these gaps will be a useful addition to
468 the literature. Moreover, these data represent staff experiences of responding to COVID-19 from
469 within a particular sector, and whilst there is likely to be overlap in experiences between healthcare
470 settings, the nuances in experiences across other healthcare contexts (e.g., the public and private
471 sectors) is not captured.

472 **Paragraph 6: Conclusion**

473 Despite their experience of dealing with death and dying, the mental health and well-being of
474 palliative care staff was affected by the pandemic. Key findings demonstrated how infection control
475 constraints prohibited and diluted participants' ability to provide care that reflected their core values,
476 causing moral distress. Despite feeling some sense of comfort through contributing to the pandemic
477 response, and although different strategies were used to manage moral distress, the impacts of the
478 COVID-19 pandemic on staff well-being progressively worsened over time. Organisational,
479 structural, and policy changes are urgently required to mitigate and manage these impacts to ensure
480 quality of care and retention of staff.

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eTable 1: Interview guide

Question 1	What is your role/duties within your specialist palliative care service?
Question 2	How do you feel your organisation has responded to the COVID 19 pandemic?
Question 3	What opportunities, if any, has the pandemic brought for your service? I. Impact of opportunities on patients and family carers II. Impact of opportunities on clinical/non-clinical staff III. Facilitators and barriers to identifying/responding to opportunities.
Question 4	What do you think have been some of the main challenges of running your service during the COVID-19 pandemic? I. What was it about these issues that made adjusting to them so challenging? II. How has this impacted on patients and family carers? III. Impact of challenges on clinical/non-clinical staff?
Question 5	Can you tell me a bit more about some of the innovations and changes in practice made in response to some of these issues? For example: I. What innovations and changes do you think were particularly effective in achieving what you wanted it to? What do you think helped in implementing these changes? II. Alternately, what changes were made that are no longer practiced? And why do you think these changes were not effective, especially when compared to changes that were highly effective? III. If there was something you could alter in relation to the changes in practice to make it more effective, what would it be?
Question 6	What changes that have been made in your setting do you think would be effective in other palliative care settings. Why?

eTable 2: Additional quotes for each theme and sub-theme

Theme	Sub-theme	Example quotes from participants
Infection control constraining professional values	<i>Prohibited values</i>	<i>'I think we tried to facilitate as much as we could kind of remote contact so through FaceTime, that kind of thing, phone calls. And, again, that depends on that patient's ability to be able to engage in that. But just holding a phone up to somebody's ear while somebody said goodbye to them down the phone and things like that. Monumentally distressing ... you nurse in a hospice because you want to give that kind of gold standard of care and it's felt at time difficult to do that because we've not been as holistic as we ordinarily would be because of the kind of constraints around visiting and things like that.'</i> participant 2, case four, nurse
	<i>Diluted values</i>	<i>'normally I would be getting patients out of the rooms and into corridors, walking more and I have a physiotherapy room which I haven't been able to bring patients down to so they have been confined to the rooms so they've been more deconditioned than normal, I've not been able to do the same amount of rehab. I have a set of steps in the therapy room so I can't bring patients in here because I can't move them around, can't move patients around the ward and also the extra cleaning and like many therapy rooms across the country, have turned into PPE rooms because I'm sat in here now and there must be about 20 boxes of PPE.'</i> participant 3 case four, Allied health care professional
Moral injuries		<p><i>'one of other big challenges is we lost pretty much all our volunteers that were supporting all of this because many of them were in their 60s and 70s and when you take Covid age into account with multiple comorbidities quite a lot their Covid ages went above 70, and at that point people still didn't know how dangerous this was so it was like, "Sorry, guys, you'll have to go home", and then of course that then has impacts on their emotional health so we then created virtual networks and friends groups and things like that but it's not the same as their feelings of self-worth when wherever they volunteered they were feeling they were making a difference.'</i> participant 2, case three, CEO</p> <p><i>'You have to think about properly what you're doing and you're exhausted. It's hard. ... you do, you feel kind of guilty in a way or you feel pressured, you think, "God, you know, if it [COVID-19] spreads then it's going to be my fault" ... I was definitely worried about it... One of the male bay did end up, all of them in the bay ended up testing positive and obviously we don't know how that happened ... I know a lot of people on the team were really, really sort of upset about it and anxious and things being, you know, was it me that give it them?'</i> participant 6, case one, nurse</p> <p><i>'we've had to have redundancies ... even though it's a very well-resourced hospice and very well managed in terms of reserves and things... so that's not a positive obviously ... there's no way of managing it well, is there, really, it's not great... the biggest stress for people is not having a job and not being able to maintain their family and themselves and stuff, so it's not easy at all ... you're having to make people redundant, it's awful.'</i> participant 20, case 3, doctor</p> <p><i>'I think everybody's quite at this point now, I mean god we're nearly a year into it, everybody's a bit fractious and a bit sensitive and a bit tired and do you know what I mean, picking up on everything that other people say and that's quite difficult... everybody's just tired, anxious, Covid-ed out with it all ...it's been a really long anxious time and I never would have thought it was going to go on this long ...</i></p>

	<p><i>people are a little bit twitchy and a little bit short with each other and it's about just mustering up that last bit of patience and trying to keep the team going' participant 6, case three, nurse</i></p> <p><i>'I think I felt more the second wave than the first wave. And when I had – I kind of resignation within myself and I was saying every time this needs to be done, it won't be forever. On the second one I was like, "Oh God, here we go again' participant 3, case five, nurse</i></p>
<p>Strategies to manage moral distress</p>	<p>Individual strategies</p> <p><i>'I was just saying to kind of anyone them like mental health advice lines and your colleagues and everyone are there for you so just take advantage of them because there's no – I mean like I say the job is hard enough but especially when you're in lockdown and you can't even go to the gym, you can't see your friends, you can't, you know, do things that would normally feel benefit... I would definitely advise everyone to kind of seek, you know, some kind of advice or help or just speak to people that you can speak to and trust and feel comfortable with because that's what got me through the last 12 months.' participant 6, case one, nurse</i></p> <p><i>'I think second lockdown we were more used to it. You know, it was sort of like a, yeah, well we'll just have to go through it again. We just accepted it.'</i> participant 1, case four, clinical manager</p> <p>Team strategies</p> <p><i>'I also think we have got a fantastic team, even prior to Covid... that support from your colleagues is vital really, because ultimately you can come home and you can ... you can say to your loved ones you have had a bad day, but nobody really kind of understands what you have gone through that day, other than the people that are dealing with it as well, so I think teamwork has been a massive, massive factor for us, in just kind of supporting each other.'</i> participant 5, case 1, nurse</p> <p><i>'we seem to be a very close-knit team now which is really nice ... You just try to listen to each other and we could tell when someone was down, so we were there for each other. And I would say that, yeah, probably nine out of ten times we would know what the other one is going through or feeling. It's not always the same. I understand that. But most of the time we were trying to predict how someone else is feeling or what their day is going to be like. So we just be there, extra motivating, encouraging and just a little bit of light relief, a little bit of fun, and just joking around. Funny apps on the phone. You know, where you change your voice, faces, all that kind of thing. It was just a little bit of laughter in those challenging times.'</i> participant 6, case two, nurse</p> <p>Organisational strategies</p> <p><i>'So then you come in to work and not being busy which didn't feel right, you felt almost a fraud coming to work and not having anything specifically to do with patients but sort of stepped up on staff wellbeing really so we developed what we call a wobble room and I put loads of resources in there for staff to do with, you know, breathing techniques and mindfulness.'</i> participant 3 case four, Allied health care professional</p> <p><i>'I've spoken to him (chaplain), and he is really busy with staff members coming and talking to him about stuff. And I think at this kind of...at a time like this, spirituality is really important to a lot of people, and they will want to speak to someone about those kind of things, and so our chaplain's finding that he's giving himself...he's offering a lending ear to some of these staff as well. So (inaudible 00:21:54) and listening to them has been really important, and we've kind of put that quite high on our priority list and we do have things in place.'</i> participant 2, case two, clinical manager</p> <p>Community strategies</p>

		<p><i>'We were very lucky in the community. We did a lot of appeals and a lot of schools and communities were donating PPE and we were just prioritising when to wear it. Obviously we had the masks which we were wearing all the time and our own visors. As the staff you look after the patient. But we had schools that were producing visors and people that were donating which was really, really helpful at the start because we just couldn't order PPE at all. And there was always that sorry that we run out. But we didn't luckily.'</i> participant 2, case five, nurse</p>
Moral comfort		<p><i>'when you kind of doubt things sometimes, you think oh God I wish I could have done more – I always say this to staff, just have a little read of some of the cards we have been sent through, during this time. About the difference that actually we have made. We have gone not above and beyond, because it makes it sounds like you are doing something way above what you should but I know that our staff on that ward have done 100% what they could have done for our patients and relatives, in a really, really awful, difficult time. And, I don't doubt that, but that doesn't make it any easier when you are thinking gosh if only it could have been this way – do you get what I mean? I am aware that we have done what we could have done'</i> Participant 5, case 1 , nurse</p>

