

## **Title**

Change in activity of palliative care services during the Covid-19 pandemic: a multi-national survey (CovPall)

## **Abstract (150)**

**Objectives** To identify factors associated with palliative care services being busier during Covid-19.

**Methods** Cross-sectional online survey of UK palliative care services (April-July 2020) (CovPall). The primary outcome was change in busyness (five-point ordinal scale). Ordinal logistic regression investigated factors associated with the primary outcome.

**Results** Of 277 responses, 71 (26%) reported being a lot more busy, 62, (22%) slightly more, 53 (19%) about the same, 50 (18%) slightly less and 28 (10%) much less busy. Increased business was associated with homecare services (OR 1.93, 95% CI 1.15-3.25), nursing care at home (OR 3.24, 95% CI 1.70-6.19), publicly-managed services (OR 2.20, 95% CI 1.11-4.34), Covid-19 cases (OR 1.01, 95% CI 1.00-1.01), and staff shortages (OR 2.71, 95% CI 1.64-4.48).

**Conclusion** Services providing community care, and publicly-managed services, may have been better able to respond to escalating needs during Covid-19. This has potential implications for both service delivery and funding models.

## **Introduction**

The Covid-19 pandemic gave rise to a rapid increase in the level of need for palliative care [1-3]. In parallel, there were changes in patient and family priorities, with people who might otherwise have been admitted to a hospice choosing to be cared for at home due to fear of infection and visiting restrictions[4, 5]. In response, many hospice and palliative care services rapidly innovated, reconfiguring services, increasing community outreach and adopting new technology for communication with patients, families and professionals[6].

During the first months of the pandemic, some hospice and palliative care services reported being more busy, while others reported being less busy than before[7]. We know little about which services experienced increased activity levels, and which experienced reduced activity levels. Understanding whether services that reported becoming more (or less) busy share certain characteristics could help identify strategies and/or structures to maximise the contribution of hospice and palliative care services to the wider health and social care system, particularly during current and future pandemics. The aim was to identify factors associated with palliative care and hospice services being busier during the Covid-19 pandemic.

## **Methods**

### *Study design and participants*

CovPall is a multicentre multinational observational study of specialist palliative care during the Covid-19 pandemic. The first component of CovPall was an on-line survey of palliative care services (opened April 23rd 2020, closed July 31st 2020); detailed methods including the full survey have been reported previously[7]. Ethical approval was received from King's College London Research Ethics committee (LRS-19/20-18541). The survey is reported according to the MORECARE[8] statement.

### *Procedures and questionnaire*

Survey procedures have been previously described[7]. In brief, services were contacted through palliative care and hospice organisations and provided with a link to the brief (~30 minutes) on-line participant information sheet and survey. Data were anonymised before analysis.

### *Inclusion criteria*

For the current study, we limited analysis to responses from the four nations of the United Kingdom (England, Scotland, Wales and Northern Ireland) to reduce heterogeneity and enable us to draw more meaningful conclusions. In the UK, hospice and palliative care services work across community (home and care home), inpatient hospice unit and hospital settings (inpatient advisory teams), and provide care for adults and children. Management of services varies, with around 30% of hospice funding from public sources[9, 10].

### *Analysis*

For the analysis, the primary outcome was change in busyness ("Would you say overall you are more busy or less busy than before the Covid-19 Pandemic"?), measured using a five-point ordinal scale (1=much less busy, 2=a little less busy, 3=about the same, 4=a little more busy, and 5=a lot more busy)[7]. We used descriptive statistics to explore the relationship between change in busyness and explanatory variables. Explanatory variables included those related to (i) service organisation: funding model (public, charitable, other), type of service provided (inpatient hospice unit, hospital advisory team, specialist palliative home care service, hands on nursing care in the community); (ii) clinical factors: number of confirmed (by test) cases of Covid-19 (continuous variable), number of suspected cases of Covid-19 (continuous variable), PPE shortages (yes/no), medication shortages (yes/no), staff shortages (yes/no); and (iii) geography: Scotland, Northern Ireland, Wales, and the nine regions of England. The population size of Scotland, Northern Ireland and Wales approximates to that of the regions of England.

Unadjusted ordinal regression was used to examine the relationship between explanatory variables and the outcome (a higher level of busyness). For the multivariable model, explanatory variables were selected according to a priori hypotheses (that busyness would vary in relation to setting, management type and number of Covid-19 cases) and significance in unadjusted analyses ( $p < 0.1$ ), after checking that the assumptions for ordinal logistic regression (absence of multicollinearity and presence of proportional odds) had been met[11]. Although this was a cross-sectional survey, our a priori hypotheses paid attention to the likely temporal sequence between potential cause and effect. We were interested in factors that might lead to being more busy, rather than those that were more likely to be a consequence of being busy. The decision of whether variables were considered factors that led to being more busy or a consequence of being more busy was made by the CovPall Study Steering Group after discussion. A sensitivity analysis was performed in which services that exclusively provided children's services were excluded, as Covid-19 is likely to have affected children's services differently to adults' services[12]. Analysis was performed in Stata v16 (StataCorp)[13].

## Results

There were 277 responses from clinical leads (medical director/lead medical clinician, nurse director/lead nurse clinician or other) of UK palliative care services: 33 from Scotland, 4 from Northern Ireland, 15 from Wales, and 225 from the nine regions of England. Many services provided care in more than one setting; 168 (61%) provided inpatient hospice services, 135 (49%) hospital advisory teams, 160 (58%) home care services, and 92 (33%) hands on care in the community. 16 services (6%) provided children's only services. 143 services (52%) were charitably managed, 103 (37%) were publicly managed. Table 1 describes busyness according to service-level, clinical and geographical variables.

In unadjusted analyses, being more busy was positively associated with: providing a specialist palliative home care service; providing hands on care in the community; being publicly managed; having more confirmed and suspected cases of Covid-19; reporting staff shortages; and geographical location (Table 1). For the multivariable analysis, we excluded the number of suspected cases of Covid-19 as it correlated closely with confirmed cases. All of the included explanatory variables remained statistically significantly associated with being more busy (Table 1). The sensitivity analysis, excluding children's only services, showed similar results (Appendix).

## **Discussion**

In this large survey of hospice and palliative care services across the United Kingdom, just under half of services reported being slightly or a lot more busy during the early months of the Covid-19 pandemic, while one in three services reported being slightly or much less busy. Being busier was associated with services that provided hands on care at home and in the community and home care services, those that were publicly (rather than charitably) managed, those that had experienced more confirmed cases of Covid-19, and those that had experienced staff shortages.

Hospice and palliative care services that provided hands on and home care services in the community had greater odds of being busier than services that did not provide care in these settings. During the Covid-19 pandemic there were a shift in patient and family preferences as visiting restrictions and fear of infection meant many people preferred to remain at home rather than go to hospitals or to inpatient hospice units[4], and deaths in inpatient hospices fell while home deaths increased[5]. With more people choosing to remain at home, services providing care in the community may have been able to respond to these changes in preferences. This is in keeping with findings from a survey of General Practitioners and District Nurses which found that primary care teams provided both higher volume and higher complexity of community palliative care during the pandemic [14].

Services that were publicly managed had greater odds of being busier compared to services that were charitably managed. In the UK only 30% of hospice funding overall is from public / government sources, with 70% from charitable sources[9] [10]. It is not clear why there should be a difference in busyness according to funding type. A possible explanation is that publicly managed services may be better integrated into the wider health and social care system, and so more able to contribute to a system-wide response. Further investigation is needed.

### *Strengths and limitations*

This was a large survey, with 277 responses across the UK. It is estimated that there are 200 hospice services in the UK[15], we received a good response rate from these services with 168 (~84%) completing our survey. We measured services' self-reported change in busyness, based on a single question, usually reported by the clinical lead. Busyness is a subjective concept and may be perceived differently by different stakeholders. Correlation with a change in the number of patient consultations or referrals was not possible from the available data. We relied on information collected from clinical service leads, which may have introduced bias. Further research should explore the views of other frontline end of life care workers. This survey was not able to capture any changes in care provision outside of palliative care and hospice teams as the survey was completed by clinical leads of UK palliative care services. We also do not have any information about the number of patient consults or referrals to validate how busy services were. Missing data for the variables of interest was low. However, responses were not evenly distributed across the UK; there were only four responses from Northern Ireland. The survey was carried out between April and July 2020, a period of time during which Covid-19 case numbers across the UK varied greatly and changed rapidly, for example London was affected earlier and more severely in the first wave of Covid-19 in the UK. Adjustment for geographical area will have accounted for some but not all of the regional variation. Unmeasured confounders such as capacity of services may influence the findings.

The cross-sectional design means that causal relationships cannot be determined. Our a priori hypotheses were designed to distinguish between causes of busyness (our interest) and the consequences of it, though this was not always clear. Previous analysis of free text data from CovPal identified increased clinical activity, increased education and increased use of technology as contributing to busyness of services [16]. However, we cannot rule out other reasons for being busier such as greater administrative burden, or less efficient structures and processes. Therefore, it cannot be inferred that being busier means better patient access; there may be circumstances where busyness detracts from direct patient care rather than contributes to it. Future studies should examine the practical implications of a service being more busy such as quality of care and patient outcomes.

## **Conclusion**

Being busier was associated with services that provided community care, and those that were publicly managed. This may indicate that service and funding models influence the ability of hospices and palliative care services to respond rapidly to changing needs and priorities. Our study provides a starting point for further research exploring the ability of hospice and palliative care services to respond rapidly to changing patient preferences and societal needs.

## **Disclosures and Acknowledgments**

This work was supported by UKRI (United Kingdom Research and Innovation) and NIHR (National Institute for Health Research) [COV0011; MR/V012908/1]. Additional support was from the National Institute for Health Research (NIHR), Applied Research Collaboration, South London, hosted at King's College Hospital NHS Foundation Trust, and Cicely Saunders International (Registered Charity No. 1087195).

We thank all collaborators and advisors. We thank all participants, partners, PPI members and our Study Steering Group. We gratefully acknowledge technical assistance from the Precision Health Informatics Data Lab group (<https://phidatalab.org>) at National Institute for Health Research (NIHR) Biomedical Research Centre at South London and Maudsley NHS Foundation Trust and King's College London for the use of REDCap for data capture.

author accepted manuscript



## References

1. Bradshaw, A., Dunleavy, L., Walshe, C., Preston, N., Cripps, R., Hocaoglu, M. B., Bajwah, S., Maddocks, M., Oluyase, A., Sleeman, K. E., Higginson, I. J., Fraser, L. K. & Murtagh, F. E. M. & CovPall study team. (2020). *Understanding and addressing challenges for Advance Care Planning in the COVID-19 pandemic: An analysis of the UK CovPall survey data from specialist palliative care services*. *Palliative Medicine*. In Press.
2. Moriyama, D., Scherer, J. S., Sullivan, R., Lowy, J., & Berger, J. T. (2021). *The Impact of COVID-19 Surge on Clinical Palliative Care: A Descriptive Study From a New York Hospital System*. *Journal of Pain and Symptom Management*, 61 (3), e1-e5.  
<https://doi.org/10.1016/j.jpainsymman.2020.12.011>.
3. Kates, J., Gerolamo, A. & Pogorzelska-Maziarz, M. (2020). *The impact of COVID-19 on the hospice and palliative care workforce*. *Public Health Nursing*.  
<https://doi.org/10.1111/phn.12827>.
4. Mitchell, S., Oliver, P., Gardiner, C., Chapman, H., Khan, D., Boyd, K., Dale, J., Barclay, S. & Mayland, C. (2021). *Community end-of-life care during the COVID-19 pandemic: Initial findings of a UK primary care survey*. *MedRxiv*.  
<https://doi.org/10.1101/2021.02.15.21251756>.
5. Bone, A. E., Finucane, A. M., Leniz, J., Higginson, I. J., & Sleeman, K. E. (2020). *Changing patterns of mortality during the COVID-19 pandemic: Population-based modelling to understand palliative care implications*. *Palliative medicine*, 34(9), 1193-1201.  
<https://doi.org/10.1177/0269216320944810>.
6. Dunleavy, L., Preston, N., Bajwah, S., Bradshaw, A., Cripps, R., Fraser, L. K., Maddocks, M., Hocaoglu, M., Murtagh, F.E.M., Oluyase, A., Sleeman, K.E., Higginson, I. & Catherine Walshe, C. CovPall study team. (2020). *'Necessity is the mother of invention': Specialist palliative care service innovation and practice change in response to COVID-19. Results from a multi-national survey (CovPall)*. *Palliative Medicine*.  
<https://journals.sagepub.com/doi/full/10.1177/02692163211000660>.
7. Oluyase, A.O., Hocaoglu, M., Cripps, R.L., Maddocks, M., Walshe, C., Fraser, L.K., Preston, N., Dunleavy, L., Bradshaw, A., Murtagh, F.E.M., Bajwah, S., Sleeman, K.E. & Higginson, I.J. & CovPall study team. (2021). *The challenges of caring for people dying from COVID-19: a multinational, observational study (CovPall)*. *Journal of Pain and Symptom Management*.  
<https://doi.org/10.1016/j.jpainsymman.2021.01.138>.
8. Higginson, I.J., Evans, C.J., Grande, G., Preston, N., Morgan, M., McCrone, P., Lewis, P., Fayers, P., Harding, R., Hotopf, M., Murray, S.A., Benalia, H., Gysels, M., Farquhar, M. & Todd, C. (2013). *Evaluating complex interventions in End of Life Care: the MORECare Statement on good practice generated by a synthesis of transparent expert consultations and systematic reviews*. *BMC Med*, 11. <https://link.springer.com/article/10.1186/1741-7015-11-111>.
9. Hospice UK (2020). *Hospice Accounts Report 2020*. Available at:  
<https://www.hospiceuk.org/what-we-offer/hospice-finance/benchmarking> (Accessed 04 March 2021).
10. The United Kingdom Palliative Care Funding Review Team (2011). *Funding the Right Care and Support for Everyone: Creating a Fair and Transparent Funding System; the Final Report of the Palliative Care Funding Review*. Available at:  
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215107/dh\\_133105.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215107/dh_133105.pdf) (Accessed 04 March 2021).

11. *UCLA Institute for Digital Research & Education Statistical Consulting. Retrieved from: <https://stats.idre.ucla.edu/stata/webbooks/logistic/chapter5/logistic-regression-with-statachapter-5-ordinal-logistic-regression/> (Accessed 24th February 2021).* .
12. *Götzinger, F., Santiago-García, B., Noguera Julián, A., Lanaspá, M., Lancelli, L., Calò Carducci, F.I., Gabrovska, N., Velizarova, S., Prunk, P., Osterman, V., Krivec, U., Lo Vecchio, A., Shingadia, D., Soriano-Arandes, A., Melendo, S., Lanari, M., Pierantoni, L., Wagner, N., L'Huillier, A.G., Heininger, U., Ritz, N., Bandi, S., Krajcar, N., Roglič, S., Santos, M., Christiaens, C., Creuven, M., Buonsenso, D., Welch, S.B., Bogyi, M., Brinkmann, F. & Tebruegge M. (2020). COVID-19 in children and adolescents in Europe: a multinational, multicentre cohort study. *The Lancet Child & Adolescent Health*, 4 (9), 653-661. <https://www.sciencedirect.com/science/article/abs/pii/S2352464220301772>.*
13. *StataCorp. 2019. Stata Statistical Software: Release 16. College Station, TX: StataCorp LLC.*
14. *Mitchell, S., Oliver, P., Gardiner, C., Chapman, H., Khan, D., Boyd, K., Dale, J., Barclay, S. & Mayland, C.R. (2021). Community end-of-life care during COVID-19: Findings of a UK primary care survey. *BJGP Open*, 5(4). <https://bjgpopen.org/content/5/4/BJGPO.2021.0095.abstract>.*
15. *Hospice UK (2020). Facts and figures about hospice care. Available at: <https://www.hospiceuk.org/about-hospice-care/media-centre/facts-and-figures> (Accessed 20 April 2021).*
16. *Sleeman, K.E., Murtagh, F.E.M., Kumar, R., O'Donnell, S., Cripps, R.L., Bone, A., McAleese, J., Lovick, R., Barclay, S., & Higginson, I.J. (King's College London, Cicely Saunders Institute; Hull York Medical School, University of Hull; and University of Cambridge, UK). Better End of Life 2021. Dying, death and bereavement during Covid-19. Research report. London (UK): Marie Curie. 2021 April. <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2021/better-end-of-life-research-report.pdf>*

**Table 1. Characteristics of palliative care services by busyness, and unadjusted and multivariable ordinal logistic regression to identify factors associated with hospice and palliative care services reporting being more busy**

	Descriptive statistics: busyness							Unadjusted analysis				Multivariable analysis N = 241			
	Much less busy N=28	Slightly less busy N=50	About the same N=53	Slightly more busy N=62	A lot more busy N=71	Missing N=13	Total Sample N=277	Odds ratio	CI lower	CI upper	P value	Odds ratio	CI lower	CI upper	P value
<b>Setting n (%)*</b>															
Inpatient hospice/palliative care unit – yes (ref no)	18 (11)	32 (19)	33 (20)	36 (21)	39 (23)	10 (6)	168	0.76	0.49	1.18	0.23				
Hospital palliative care advisory team - yes (ref no)	13 (10)	24 (18)	22 (16)	31 (23)	38 (28)	7 (5)	135	1.23	0.80	1.88	0.35				
Specialist palliative home care service - yes (ref no)	10 (6)	28 (18)	27 (17)	43 (27)	43 (27)	9 (6)	160	<b>1.63</b>	<b>1.05</b>	<b>2.53</b>	<b>0.03</b>	<b>1.93</b>	<b>1.15</b>	<b>3.25</b>	<b>0.01</b>
Providing hands on nursing care at home/in the community - yes (ref no)	3 (3)	16 (17)	21 (23)	19 (21)	28 (30)	5 (5)	92	<b>1.54</b>	<b>0.98</b>	<b>2.43</b>	<b>0.06</b>	<b>3.24</b>	<b>1.70</b>	<b>6.19</b>	<b>&lt;0.01</b>



No	22 (11)	39 (20)	39 (20)	44 (23)	48 (25)	0 (0)	192	1 (Ref)								
Yes	6 (10)	10 (16)	13 (21)	15 (24)	19 (30)	0 (0)	63	1.30	0.78	2.16	0.31					
Missing	0 (0)	1 (5)	1 (5)	3 (14)	4 (18)	13 (59)	22									
<b>Staff shortages n (%)</b>																
No	19 (14)	27 (20)	38 (28)	34 (25)	20 (14)	0 (0)	138	1 (Ref)				1 (Ref)				
Yes	9 (8)	21 (18)	14 (12)	26 (22)	47 (40)	0 (0)	117	<b>2.50</b>	<b>1.59</b>	<b>3.93</b>	<b>&lt;0.01</b>	<b>2.71</b>	<b>1.64</b>	<b>4.48</b>	<b>&lt;0.01</b>	
Missing	0 (0)	2 (9)	1 (5)	2 (9)	4 (18)	13 (59)	22									
<b>Nation/Region n (%)</b>																
South East England	6 (14)	7 (17)	7 (17)	9 (21)	12 (29)	1 (2)	42	1 (Ref)				1 (Ref)				
Scotland	4 (12)	8 (24)	5 (15)	6 (18)	8 (24)	2 (6)	33	0.80	0.34	1.88	0.61	1.72	0.65	4.56	0.27	
Wales	0 (0)	6 (40)	1 (7)	6 (40)	2 (13)	0 (0)	15	0.84	0.30	2.34	0.74	1.70	0.51	5.66	0.39	
Northern Ireland	0 (0)	0 (0)	2 (50)	2 (50)	0 (0)	0 (0)	4	1.04	0.22	4.97	0.97	1.73	0.30	10.05	0.54	
England																
North East	1 (8)	3 (25)	4 (33)	0 (0)	4 (33)	0 (0)	12	0.85	0.26	2.75	0.79	0.89	0.27	2.90	0.85	
North West	5 (14)	6 (17)	9 (25)	8 (22)	6 (17)	2 (6)	36	0.72	0.32	1.63	0.44	1.26	0.54	2.96	0.59	
Yorkshire & The Humber	3 (12)	3 (12)	4 (15)	9 (35)	5 (19)	2 (8)	26	1.07	0.44	2.62	0.88	2.02	0.75	5.48	0.17	
East Midlands	2 (17)	0 (0)	4 (33)	2 (17)	3 (25)	1 (8)	12	1.02	0.31	3.37	0.97	2.39	0.58	9.84	0.23	
West Midlands	3 (20)	2 (13)	4 (27)	1 (7)	4 (27)	1 (7)	15	0.68	0.22	2.11	0.51	1.52	0.49	4.72	0.47	

East	0 (0)	3 (20)	5 (33)	2 (13)	4 (27)	1 (7)	15	1.13	0.39	3.26	0.82	1.44	0.46	4.52	0.53
London	3 (7)	6 (14)	3 (7)	9 (21)	20 (48)	1 (2)	42	<b>2.41</b>	<b>1.01</b>	<b>5.45</b>	<b>0.04</b>	<b>3.24</b>	<b>1.30</b>	<b>8.05</b>	<b>0.01</b>
South West	1 (4)	6 (24)	5 (20)	8 (32)	3 (12)	2 (8)	25	0.84	0.35	2.04	0.71	1.43	0.55	3.73	0.46

\* Each service could provide care in more than one setting

Note: Percentages are row percentages

author accepted manuscript

## Appendix

**Table 1. Sensitivity analysis removing children only services from the multivariable ordinal logistic regression**

	<b>Sensitivity Analysis</b>			
	<b>N = 227</b>			
<b>Buyness (Ref – A lot less busy)</b>	Odds ratio	CI lower	CI upper	P value
<b>Setting</b>				
Specialist palliative home care service – yes (ref no)	<b>1.94</b>	<b>1.13</b>	<b>3.31</b>	<b>0.02</b>
Providing hands on nursing care at home/in the community – yes (ref no)	<b>3.64</b>	<b>1.84</b>	<b>7.21</b>	<b>&lt;0.01</b>
<b>Management type</b>				
Charitable/non-profit	1 (Ref)			
Public	<b>2.17</b>	<b>1.07</b>	<b>4.40</b>	<b>0.03</b>
Other	1.33	0.43	4.13	0.62
<b>Confirmed number of Covid-19 cases</b>	<b>1.01</b>	<b>1.00</b>	<b>1.01</b>	<b>0.02</b>
<b>Staff shortages – yes (ref no)</b>	<b>2.53</b>	<b>1.51</b>	<b>4.24</b>	<b>&lt;0.01</b>
<b>Country/Region</b>				
South East England	1 (Ref)			
Scotland	1.56	0.54	4.48	0.41
Wales	1.46	0.43	4.93	0.55
Northern Ireland	1.43	0.24	8.50	0.69
England				
North East	1.06	0.29	3.92	0.93
North West	1.04	0.43	2.50	0.93

Yorkshire & The Humber	1.59	0.57	4.46	0.38
East Midlands	1.96	0.47	8.28	0.36
West Midlands	1.82	0.55	6.00	0.33
East	1.38	0.42	4.56	0.60
London	<b>2.80</b>	<b>1.11</b>	<b>7.09</b>	<b>0.03</b>
South West	1.18	0.44	3.14	0.74

author accepted manuscript