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ORIGINAL ARTICLE

A multi-centre study on patients dying from COVID-19: Communication Between Clinicians, Patients, and their Families

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Abstract:

Background: COVID-19 has led to challenges in providing effective and timely communication in healthcare. Services have been required to adapt and evolve as successful communication remains core to high quality patient-centred care.

Aim: This study aims to describe the communication between admitted patients, their families and clinicians (medical, nursing, allied health) during end-of-life care.

Methods: This retrospective review included all patients (n=230) who died directly due to COVID-19 at five Melbourne hospitals between 1 January and 31 December 2020. Contacts and modality used (face to face, video, telephone) during the 8 days prior to death were recorded.

Results: Patients were predominantly elderly (median age 86 years) and from residential aged care facilities (62% (*n*=141)). Communication frequency increased the closer the patient was to death, where on day of death, contact between clinicians and patients was 93% (*n*=213) clinicians and families 97%(*n*=222) and between patients and families 50% (*n*=115). Most contact between patients and families was facilitated by a clinician (91.3% (*n*=105) day of death) with the most commonly used mode being video call (*n*=30 day of death).

Conclusion: This study is one of the first and largest Australian reports on how communication occurs at the end of life for patients dying of COVID-19. Contact rates were relatively low between patients and families, compared to other cohorts dying from non COVID-19 related causes. The impact of this difference on bereavement outcomes requires surveillance and attention.

Introduction:

Since its beginning in 2020, the COVID-19 pandemic has had an impact on almost every area of healthcare. While in Australia, and even despite the most recent Omicron wave, there have been comparatively fewer deaths and people with serious illness compared to many other international settings[1]. Several hundred of those deaths occurred in the state of Victoria during the second wave of infections from June to September 2020[2], prior to the introduction of vaccines[3]. During that period, hospitals adopted measures to prevent infections, minimise spread and protect staff. These measures included the use of personal protective equipment (PPE), restrictions to visitors into hospital, and a push towards virtual modes of communication. Each of these restrictions had an impact upon the ability for clinicians, patients, and their families to communicate in usual ways, and this was particularly evident in communication with those dying due to COVID-19 infection[4]. Effective communication is an essential part of high quality health care to inform families, offer emotional support and facilitate shared decision making including in the context of the emotional and psychological impacts of restrictions described[5-8].

Early goals-of-care discussions with patients and families, as well as the broader use of telecommunication can promote understanding and empower both the patient and family[9]. Such discussions are a core component of quality end of life and palliative care delivery. The COVID-19 pandemic has required health care services to rapidly adopt greater use and expand capability of technological and teleconferencing platforms. Effective and timely remote communication can improve the patient, family, and clinician experience particularly during the challenging discussions at end-of-life[10-12].

There are little data describing communication during end-of-life care for COVID-19 in an Australian setting. Several smaller studies have reported on the palliative care involvement for COVID-19 patients[7,13], and internationally the involvement of palliative care teams have been reported to significantly improve end of life care experiences for COVID-19 patients and families[5,11,12,14].

This multi-site study aims to describe the communication between clinicians (nursing, medical, allied health including pastoral care), patients and their families during end-of-life care for hospitalised patients who died from COVID-19 in Victoria. It also describes the involvement of specialist palliative care teams during end-of-life care and the potential impact.

Methods:

Design: This was a retrospective medical record review of all inpatient deaths due to COVID-19 occurring in five metropolitan hospitals in Victoria, Australia. Given the challenging care of high numbers of COVID-19 patients, the documentation around the communication episodes was limited. There were 3 "types" of communication episodes recorded, with different corresponding levels of accuracy:

(1) frequency of contact between clinician and patient – these are reliably and routinely documented in the clinical record. Nursing contacts were excluded as it is not usual for every contact between the nurse and the patient to be recorded.

(2) frequency of contact between clinician and patients' families – these are reliably documented in the clinical record.

(3) frequency and type of assisted contact between patients and their families. It is possible the recording of these episodes was less accurate, as it relied upon staff to document that this contact occurred. However, we have included this due to the high likelihood that an elderly, frail patient that is close to death would most likely require assistance from staff members to facilitate communication with their families.

Differences in communication were also examined, stratified by the presence or absence of concurrent palliative care referral, age (>86, median age in our cohort), comorbidities, and >2 symptoms present. One site (n=38) was excluded in the palliative care analysis on the basis that their COVID patients had a default palliative care involvement via the general physician caring for the COVID ward being also a palliative care specialist.

Participants: The study included all patients who died from 1 January to 31 December 2020 due to COVID-19, with diagnosis determined by DRG (diagnosis related group) coding identified from the patients' discharge summary performed following death. Deaths not documented as directly caused by COVID-19 in death certificates were excluded.

Data collection: Data were collected from electronic medical records by trained members of palliative care clinical staff using an electronic standardised case report form (REDCap, Vanderbilt University). A detailed data dictionary was available and data quality checks were completed by a senior consultant. Data collected included demographic and clinical characteristics, including the Australian-modified Karnofsky Performance Status (AKPS) and the Charlson Comorbidity Index (CCI). Final admission characteristics including treating unit, length of stay, palliative care referral, goals of care documentation, and place of death were also recorded. Contacts were recorded as detailed above.

Project approval and ethics: The study was approved by the institutional research ethics committees of each hospital (The Royal Melbourne Hospital (QA2020141), Austin Health (Audit 18/384), Western Health (QA2021.41), Werribee Mercy Health (2021-031), and Northern Health (21.2021)).

Statistical analysis: Descriptive statistics were utilised to summarise each variable collected. Continuous variables were expressed as median with interquartile range (IQR) and categorical variables as number (percentage). We assessed the relationship between patient demographic and clinical factors with the communication outcome measures using Pearson's Chi-squared test (for categorical variables) or the Wilcoxon rank-sum (for continuous non-normally distributed variables) as appropriate. A p-value of <0.05 was considered to be significant. All analyses were performed using Stata version 15.1 (Stata Corp, College Station, Texas, United States of America).

Results:

A total of 230 COVID-19 deaths were recorded. Patient demographics and admission characteristics are summarised in Table 1. The median age of patients dying from COVID-19 was 86 years (IQR 79-90 years). Most were male (56%, n=129), lived in a Residential Aged Care Facility (62%, n=141), and had a Charlson Comorbidity Index score of >6. Most people died in designated COVID wards (36%; n=82;), followed by Acute Medical Wards (31%; n=72). Few people died in the intensive care unit (4%; n=9), and just 1 person died in a palliative care ward. 118 patients (51.3%) were referred to palliative care services, with the median time between referral and death 3 days (IQR 1-6). There was no statistically significant difference in the number of communication episodes (contacts as defined in methods) in any category between those patients referred to palliative care compared to those not (Table 3).

All patients had Goals of Care documented. This was done a median of 6 days (IQR 3-12) prior to death. With a median length of stay of 9 days (IQR 4-16), Goals of Care documentation was performed relatively early in the hospitalisation. Most patients were identified as not for resuscitation (73.9%) on initial Goals of Care. Goals of Care were updated for 51% (n=117) of patients, and subsequently for another 18% (n=42) of patients, with progressively more patients identified not for resuscitation (93.5% and 95.6% respectively). The median number of days between final Goals of Care and death was 3, coinciding with an increase from 88% of families contacted by clinicians 4 days prior to death, to 90% on 3 days prior to death, and 95% 2 days prior to death (Figure 1).

There was a general trend towards clinicians seeing patients more frequently as they approached death, with the lowest frequency being 86% on Day 7 prior to death, and the highest frequencies during the final 3 days of life (95.3%, 94.2%, and 92.6% respectively). Figure 1 illustrates the proportion of patients contacted by clinicians each day remained similar over the 8 days up to and including day of death. In comparison, the percentage of families contacted by clinicians increased on the days leading up to death, as did the recorded contacts between families and patients.

There was also a tendency for clinicians to contact patients' families more frequently the closer they were to death, with 78% of clinicians contacting families at 7 days prior to death, increasing daily to 96.5% on day of death. The frequency of clinician contacts also increased on day of death (Table 2) to twice in that day, compared to once daily on previous days.

Similarly, patients contacted their families more frequently the closer they were to death, with 16.5% patients contacting their families at 7 days before death, increasing to a maximum of 50% on day of death (Table 2). Most contacts were assisted by clinicians, again with more assistance provided the closer they were to death (76% at 7 days to 91% on day of death). The majority were assisted by nursing staff (60-83%), predominantly via video call (26-53%) (Table 2). Face to face contact was the commonest form of communication between patients and families on day of death (33%; n=38), while telephone contacts reduced in proportion closer to day of death.

Discussion:

This study is one of the first and largest to describe communication for patients dying of COVID-19 in Australia. Our cohort was predominantly elderly and frail, admitted from Residential Aged Care Facilities with a baseline performance status and comorbidity score indicating significant pre-existing care needs. The location of death was consistent with local policies for patients with COVID-19 to be cared for in specific wards (designated COVID-19 wards, Acute Medical Wards or single rooms in Intensive Care Units). Only one person died in the palliative care unit from COVID-19. Therefore, the bulk of palliative care involvement occurred through palliative care consult teams. Although this was available through each hospital, there were inconsistencies with their level of involvement. One hospital had a dual trained palliative care physician/general physician leading its COVID-19 ward. In other hospitals, palliative care involvement was primarily driven by whether a patient was referred to palliative care or not, but also limited by location (patients dying on a different campus to the palliative care team), and local hospital policy preferencing phone rather than face to face communication, particularly earlier in the pandemic. The extent of what was done by palliative care teams was unclear, and there was no standardised pathway in patients who are at high risk of dying from COVID-19. In future pandemic planning palliative care services should be designed to be delivered via a consult model supporting dedicated wards, with standardised plans for review and communication planning.

A vital part of end-of-life care is to provide a way for patients to communicate and connect with family members, as well as ensuring clear communication between clinicians and families[15,16]. This study highlights the important role that clinicians take on when familes are restricted from visiting, balancing the challenges of minimising staff exposure to preserve the workforce whilst trying to effectively communicate remotely and with PPE. Despite these challenges, clinicians in this study were generally good at maintaining relative frequency of contact with patients and their families. Clinicians had increasing contact with patients and families as patients were closer to death (93% and 96.5% respectively on day of death). However, only 50% of patients had any form of contact with their family on the day of death. This differs to a report involving the general dying population before COVID-19, in a similar setting, where almost 60% of families were physically present at the time of patients' death[17]. Martinsson et al (2021) found due to visitor restrictions patients dying from COVID-19 were more likely to die without family present[18]. This difference may represent a gap in clinical guidelines regarding "best practice" for communication where family visitation is not feasible, leading to more ad-hoc clinician practices on facilitating this. The ability to visit patients towards death is known to impact carer bereavement outcomes[15,19], which needs to be balanced against the public health measures to limit spread. This is an area that deserves more attention and insertion within local and international guidelines for patients dying from COVID-19.

Palliative care has been highlighted as an important part of the COVID-19 response both in Australia and internationally, with reports indicating significantly improved end-of-life care[9-11]. Only half of this high-risk patient demographic were referred to palliative care, and when referred, only 3 days prior to death, despite most being identified as not suitable for resuscitation at the outset. Our results did not show any significant difference in contacts between clinicians, patients or families with palliative care team involvement. This may be in part due to the implementation of clear COVID-19 clinical guidelines in all sites including recommendations for regular communication[14,20]. Overall contact between clinicians and families was high in our study indicating the emphasis placed on this. The decision for

inclusion of palliative care was left up to the decision of the treating clinician. Importantly, recording of number of contacts does not take into account the quality of those contacts or the full impact of palliative care involvement. This may underestimate the benefit from earlier referral to palliative care than what has been demonstrated in this cohort.

Patients' families were contacted by clinicians more towards death, indicating somewhat of a rush towards communication occurring, despite death being highly likely in this frail cohort very close to death and documented not for resuscitation. In our study as goals of care changed there was a corresponding increase in contact with families, indicating that patient deterioration was communicated with families. Early and consistent communication between clinicians and patients/familes fosters trust, provides advocacy, and helps to relieve fear and suffering for both patients and their loved ones[21]. This trust is particularly important when discussions around goals of care are required, with decisions requiring knowledge and understanding regarding the patient's current status. When restricted from visiting, families can be less able to advocate for their loved ones, particularly when elderly and potentially confused. It may be challenging to understand the terminal outcomes when rapport, and thus, trust, in the clinician's opinion is not as well built compared to if this were done face-to-face. Finally, the inability of families to witness a decline in health may cause disbelief or shock when they are contacted to inform of the terminal nature of their loved one, and contribute to poor bereavement outcomes[19,22,23].

Only 33% of patients were able to visit families face-to-face on the day of death. There are several factors responsible for this low number, such as visitor factors (personal concerns over contracting COVID-19 when visiting, visitors co-infected with COVID-19 disallowed to visit), hospital factors (inter- and intra-hospital inconsistency in visitation allowance), and mandatory public health orders (government-imposed interstate/overseas travel restrictions, family members in government-mandated isolation)[24].

Video calls were the commonest form of communication in the final week of life, indicating that this was possibly a preferred option, keeping in mind limitations to face-to-face visitation discussed above. E-communication infrastructure was not routinely in place in our centres. Virtual communication can be limited by the cost of buying tablets, privacy concerns, usability/literacy and access[15]. In Australia digital literacy is improving but inequity remains for those over 75 years, with lower income and/or in public housing, due to reduced access to and ability with technology[25]. Video calling relied either on availability of a patient's own device, or, in some cases, donations from the public of such devices. It is likely that more patients would have utilised video calling if the infrastructure and support was available. A systematic approach to encourage communication would likely reduce the inequity here. With increasing evidence on the importance of telemedicine in palliative care particularly in the COVID-19 context further planning and infrastructure and training are recommended[23,26].

The challenges of working with critically ill COVID-19 patients have been documented, with resource and workforce pressures noted, leading to reports of moral distress and adverse effects[7,9,24,27-29]. Communicating with patients and families separately and via various modalities, though vital, can be time consuming and emotionally taxing on clinicians already stretched. In this cohort most contacts were made by nursing and medical staff, indicating a shift required for allied health, including pastoral care, to more virtual work in the context of COVID-19 patients. It is important to consider who is best placed to provide updates and ensure

equitable access to communication. Locally and internationally, centres have reported family communication teams to overcome these challenges, enabling those staff who may have reduced face to face contact with patients (such as pastoral care and social work) on COVID-19 wards to be utilised[6,14].

Study limitations: This study is limited by the retrospective design, and metropolitan setting in one state; however these were also where most COVID-19 deaths have occurred in Australia. Contacts were recorded from the electronic patient record, and relied on each contact being recorded by staff introducing the potential for information bias. Patients who were less unwell, or with language barriers, with sufficient digital literacy were likely communicating independently with familes and subsequently these contacts would not have been documented by staff. Thus there is potential for differential bias with those unable to communciate independently with family having more 'contacts' recorded in the notes. The time period during 2020 preceded rollout of COVID-19 vaccinations which did not commence in Australia until February 2021. However in large part hospital restrictions have remained in place for those patients diagnosed with COVID-19 despite widespread vaccination and therefore these findings remain relevant as we continue to manage the pandemic.

Conclusion:

Given the importance of clear and regular communication in improving patient quality of life and carer bereavement outcomes, it is important for communication strategies to be in place for patients, clinicians, and families, particularly those who are frail and at high risk of death from COVID-19. In addition, early and increased palliative care involvement may improve end of life experiences in COVID-19 patients. Access to digital communication is growing and this is an important factor in maintaining equitable and vital contact whilst restrictions remain during the COVID-19 pandemic and beyond.

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Figure 1: Prevalence of communication between clinicians, patients and family in the final week of life

*excludes nursing contact

Table 1: Demographics

	n=230
Gender	
Female	101 (44)
Male	129 (56%)
Age (Median (IQR))	86 (79-90)
Place of residence	
Home	82 (36%)
Residential Aged Care Facility	141 (62%)
Other	7 (3%)
Unit of death	
Acute medical ward	72 (31%)
Aged care ward/Rehabilitation	66 (29%)
Covid ward	82 (36%)
Intensive care unit	9 (4%)
Palliative Care Ward	1 (0.4%)
Patient referred to Palliative Care	118 (51%)
Days from Pal Care referral to death (Median (IQR))	3 (1-6)
1st Goal of Care Documentation	
Full Resuscitation	13 (6%)
Limited Resuscitation	47 (20%)
Symptom management only	113 (49%)
End-of-life care	57 (25%)
Days from first goals of care to death (Median (IQR))	6 (3-12)
Days from last GOC set to death (Median (IQR))	3 (1-6)
Days from admission to death (Median (IQR)	9 (4-16)
CCI total (not including age) (Median (IQR))	3 (2-5)
CCI total (including age) (Median (IQR))	7 (6-8)

Table 2: Contact Between Clinicians, Patients, and their Families in the final Week of Life
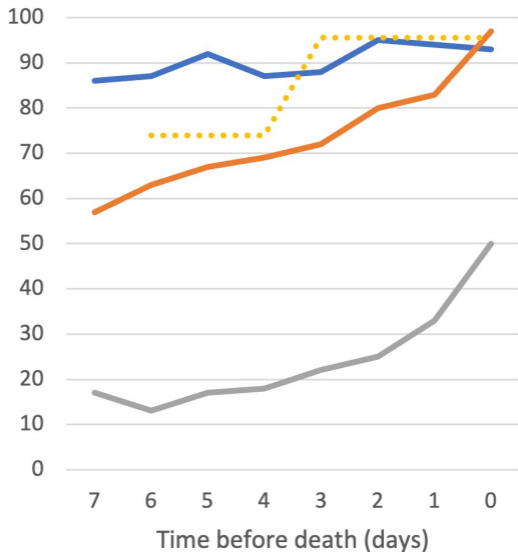
	N	Clinician contact with patient*	Clinician contact with family	Patient contact with family
Frequency of contacts *n* (%)				
Day of death	230	213 (93)	222 (97)	115 (50)
- 1 day	224	211 (94)	186 (83)	73 (33)
- 2 days	212	202 (95)	170 (80)	53 (25)
- 3 days	206	182 (88)	149 (72)	45 (22)
- 4 days	188	163 (87)	129 (69)	34 (18)
- 5 days	164	151 (92)	109 (67)	27 (17)
- 6 days	156	136 (87)	98 (63)	20 (13)
- 7 days	136	117 (86)	78 (57)	21 (17)

Patient contact with families

	All clinicians	Medical	Allied health	Nursing
Contact facilitated by clinician *n* (%)				
Day of death	105 (91)	31 (42)	11 (15)	54 (74)
- 1 day	56 (95)	15 (25)	10 (17)	46 (77)
- 2 days	50 (94)	11 (21)	5 (9)	44 (83)
- 3 days	38 (86)	4 (9)	7 (15)	35 (78)
- 4 days	31 (91)	7 (21)	3 (9)	27 (79)
- 5 days	24 (89)	6 (22)	4 (15)	21 (78)
- 6 days	16 (80)	5 (25)	4 (20)	12 (60)
- 7 days	16 (76)	2 (10)	2 (10)	15 (71)

	Telephone	Video Call	Face to face	Other
Mode of patient contact with family *n* (%)				
Day of death	16 (14)	30 (26)	38 (33)	2 (2)
- 1 day	15 (21)	30 (41)	23 (32)	2 (3)
- 2 days	12 (23)	28 (53)	14 (26)	2 (4)
- 3 days	15 (33)	20 (44)	11 (24)	1 (2)
- 4 days	13 (38)	14 (41)	9 (26)	0 (0)
- 5 days	6 (22)	13 (48)	7 (26)	3 (9)
- 6 days	7 (35)	8 (40)	2 (10)	2 (10
- 7 days	11 (52)	7 (33)	4 (19)	0 (0)

*excluded nursing contact

Table 3: Communication stratified by palliative care referral, age, Charlson comorbidity score, and symptoms

	Clinical communication with family n (%)		
Variables	Positive for variable	Negative for variable	p value
Day of Death n=230			
Palliative care referral (n=192)*	102 (93%)	82 (99%)	0.07
Age (over 87years)	119 (95%)	103 (98%)	0.23
CCI (over 7)	101 (96%)	121 (97%)	0.8
>2 Symptoms present	151 (96)	71 (99%)	0.24
- 1 day n=224			
Palliative care referral (n=189)*	86 (80%)	67 (82%)	0.82
Age (over 87years)	103 (84%)	83 (82%)	0.76
CCI (over 7)	87 (86%)	99 (81%)	0.26
>2 Symptoms present	118 (82%)	68 (85%)	0.56
- 2 days n=212			
Palliative care referral (n=181)*	78 (76%)	66 (85%)	0.14
Age (over 87years)	93 (80%)	77 (80%)	0.99
CCI (over 7)	69 (73%)	101 (86%)	0.027
>2 Symptoms present	105 (78%)	65 (84%)	0.24
	Clinical communication with patient ** n (%)		
	Positive variable	Negative variable	p value
Day of Death n=230			
Palliative care referral (n =192)*	103 (95%)	81 (98%)	0.29
Age (over 87years)	115 (92%)	98 (93%)	0.55
CCI (over 7)	95 (91%)	118 (94%)	0.26
>2 Symptoms present	145 (92%)	68 (94%)	0.47
-1 Day n+224			
Palliative care referral (n =189)*	101 (95%)	77 (94%)	0.89
Age (over 87years)	117 (95%)	94 (93%)	0.51
CCI (over 7)	96 (95%)	115 (94%)	0.62
>2 Symptoms present	134 (93%)	77 (96%)	0.33
- 2 Day n=212			
Palliative care referral (n=181)*	96 (93%)	76 (97%)	0.19
Age (over 87years)	110 (95%)	92 (96%)	0.73
CCI (over 7)	87 (93%)	115 (98%)	0.09
>2 Symptoms present	129 (96%)	73 (95%)	0.8
	Patient communication with family n (%)		
	Positive variable	Negative variable	p value
Day of Death n=230			
Palliative care referral (n=192)*	61 (56%)	37 (45%)	0.12
Age (over 87years)	69 (55%)	46 (44%)	0.085
CCI (over 7)	61 (58%)	54 (43%)	0.024
>2 Symptoms present	72 (46%)	43 (60%)	0.047
-1 Day n=224			
Palliative care referral (n=189)*	41 (38%)	32 (39%)	0.92
Age (over 87years)	39 (32%)	34 (34%)	0.76
CCI (over 7)	32 (32%)	41 (33%)	0.79
>2 Symptoms present	45 (31%)	28 (35%)	0.57
- 2 Day n=212			
Palliative care referral (n=181)*	29 (28%)	24 (31%)	0.7
Age (over 87years)	29 (25%)	24 (25%)	1
CCI (over 7)	20 (21%)	33 (28%)	0.26
>2 Symptoms present	32 (24%)	21 (27%)	0.56

**Different N due to exclusion of one site ** excludes nursing contact