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Psychological distress and morbidity of family members experiencing virtual visiting in intensive care during COVID-19: an observational cohort study

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Abstract

Purpose: During the coronavirus disease 2019 (COVID-19) pandemic, intensive care units (ICUs) around the world introduced virtual visiting to mediate the psychological impact of in-person visiting restrictions. Our objective was to evaluate levels of distress, depression, anxiety, and stress among family members experiencing virtual visits.

Methods: Multi-centre prospective observational study recruiting adult family members of critically ill patients in the United Kingdom (UK) using a bespoke virtual visiting solution (aTouchAway). We recruited participants and administered validated questionnaires digitally via their aTouchAway account. Prior to first virtual visit, participants completed the Distress Thermometer (score range 0–10) and the Depression, Anxiety and Stress Scale (DASS)-21. Following first and subsequent virtual visits, participants repeated the Distress Thermometer and completed the Discrete Emotions Questionnaire.

Results: We recruited 2166 adult family members of ICU patients in 37 UK hospitals. Most were grown up children (33%) or spouses/partners (23%). Most (91%) were ≤ 65 years. Mean (SD) pre-virtual-visit Distress Thermometer score was 7 (2.6) with 1349/2153 (62%) reporting severe distress. Pre-visit Distress Thermometer scores were associated with relationship type (spouse/partner OR 1.65, 95% CI 1.27–2.12) but not family member age, or length of ICU stay. Mean (SD) post-visit Distress Thermometer score provided by 762 (35%) participants was 1.6 (3.2) points lower than pre-visit ($P < 0.001$). Of participants experiencing multiple visits, 22% continued to report severe distress. Median (IQR) pre-visit DASS-21 score was 18 (2–42) (1754 participants). Severe-to-extremely severe depression, anxiety, or stress were reported by 249 (14%), 321 (18%), and 165 (9%) participants, respectively. Participants reported a range of emotions with reassurance being the most common, anger being the least.

Conclusion: Family members exposed to COVID-19 pandemic ICU visiting restrictions experienced severe distress. One fifth of family members reported severe-to-extremely severe anxiety or depression. Distress score magnitude and prevalence of severe distress decreased after undertaking one or more virtual visits.

Keywords: Intensive care, Psychological distress, Family, Virtual visiting, COVID-19

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Introduction

An intensive care unit (ICU) admission is an extremely stressful and generally unexpected experience for relatives and friends of critically ill patients. Clinically relevant levels of anxiety and depression are highly prevalent in family members both during and following an ICU admission [1, 2]. Post-traumatic stress disorder and complicated grief is also common [3–5]. Restrictive in-person visiting policies [pre-dating the coronavirus disease 2019 (COVID-19) pandemic] compound the negative effects of an ICU admission on family member psychological wellbeing [6]. Visiting restrictions limit family member presence in the ICU to provide emotional support for patients, restrict family-centred care, and reduce opportunities for formal and informal communication with the ICU team. Inadequate communication is a well-recognised contributor to family member stress, anxiety, heightened emotional vulnerability, and perceived loss of control [7, 8]. Furthermore, an unrestricted ICU visiting policy is not only a useful and effective strategy to respond to the needs of both patients and families, it represents recognition of a specific and unequivocal right of the patient and the family.

To reduce viral spread, the COVID-19 pandemic resulted in the most restrictive visiting policies seen in ICUs across the world since their inception [9, 10]. Subsequent introduction of virtual visiting was facilitated by ICU personnel, or newly created family liaison teams. Enabling family virtual presence at the patient bedside is a support strategy recommended in the event of such a public health disaster [11] to mediate psychological impacts. Virtual presence also supports people's basic emotional needs i.e., needing to feel safe, calm, and connected [12]. Studies have started to elucidate the psychological impacts of in-person visiting restrictions and strategies used to address them. A single-centre French study of family members receiving a daily update phone call, but no virtual visiting reported anxiety and depression prevalence rates on day 3 of ICU admission that far exceed those previously documented in family members able to visit in-person [6, 13].

Other data on the psychological impact of virtual visiting during the COVID-19 pandemic for family members is primarily qualitative in nature with most family members reporting this as a positive and supportive experience [14–16]. However, some qualitative studies report families struggling to understand information, make sense of the situation, get in contact, feel informed about care, and to build a relationship with the ICU team [17, 18]. Our objective was to evaluate family members' markers of psychological wellbeing prior to and following their first virtual ICU visit and subsequent virtual visits

Take-home message

In this multi-centre cohort of 2166 adult family members experiencing at least one ICU virtual visit during in-person visiting restriction imposed due to COVID-19, we found high levels of psychological distress with over 60% reporting severe distress.

Distress levels were significantly lower on completion of the first virtual visit, however, a substantial proportion of participants continued to experience severe distress measured following subsequent virtual visits for up to 2 weeks after the first visit.

and to measure prevalence of depression anxiety, and stress using validated measures.

Methods

This study is reported in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement [19].

Study design and participants

We conducted a multi-centre prospective observational study recruiting family members who experienced at least one virtual visit in an adult UK ICU during the COVID-19 pandemic. Data were collected from 22nd Dec 2020 to 12th May 2021, which incorporates the entirety of the second COVID-19 pandemic wave in the UK and the largest wave in terms of impact on ICU capacity.

Participants were family members supported by ICU or family liaison team members of a participating ICU to register on the bespoke virtual visiting solution using the e-platform aTouchAway™ (Aetonix, Canada). This solution was developed and delivered by the philanthropic Life Lines initiative (<https://www.kingshealthpartners.org/our-work/lifelines>). All family members using the aTouchAway app for a virtual visit were invited to the study using a recruitment notice on the app. Those that were interested in participating were provided the participation information sheet and consent form via the aTouchAway platform following registration and prior to their first ICU virtual visit.

Study inclusion criteria were self-assessed by the family member participant on the e-platform and comprised: (1) aged 18 and over; (2) sufficient English language skills to complete questionnaires (or have a family member to assist); and (3) consent to participate. There were no exclusion criteria.

Measurements and data collection

All data collection occurred remotely with completion by the family member on their own personal device using the aTouchAway platform. Following electronic informed consent, participants were presented via the aTouchAway

e-platform with a three item demographic questionnaire, followed by the Distress Thermometer (DT), a valid instrument for rapid screening of distress [19] selected for its brevity and ease of use. Participants were asked to rate their current level of distress on the 0–10 (no distress to extreme distress) scale. A score of 0–3 indicates low distress, 4–6 moderate distress, and 7–10 severe distress [20]. To measure emotional wellbeing, participants were then presented via the aTouchAway e-platform with the 21-item Depression, Anxiety and Stress Scale (DASS-21). The DASS-21 is a valid and reliable measure of perceived severity of symptoms related to depression, anxiety, and stress used in clinical and non-clinical adult populations [21, 22]. It comprises 21 items, with 7 items for each subscale. Participants scored each item on a scale from 0 to 3 considering how much each item applied to them over the past week. The DASS-21 has a total score ranging from 0 to 120, and subscale scores from 0 to 42 (raw scores are summed and multiplied by 2). A total score of ≥ 60 is considered an indication for further psychiatric assessment, scores of ≥ 21 , ≥ 15 , and ≥ 27 are considered to represent severe-to-extremely severe depression, anxiety, and stress, respectively.

Participants were presented with the DT to rate distress and a modified version of the Discrete Emotions Questionnaire (DEQ) via the aTouchAway platform after each virtual visit. The DEQ is a validated tool sensitive to eight distinct situationally induced state emotions: anger, disgust, fear, anxiety, sadness, happiness, relaxation, and desire [23]. We modified the DEQ removing the emotions disgust and desire as we perceived these as potentially offensive to ask family members following a virtual ICU visit. We added the term reassured as an appropriate emotion in the context of virtual ICU visiting during a pandemic. Each emotion was scored on a 7-point Likert scale with 1 indicating the emotion was experienced 'not at all' and 7 indicating 'an extreme amount'. On subsequent virtual visits, participants were presented with the DT and the DEQ on virtual visit completion. Participants could dismiss any and all questionnaires on the aTouchAway e-platform if they did not wish to complete them for any reason.

Data management

Data entered by participants via their aTouchAway account were encrypted, anonymized, and stored in a secure dedicated UK Amazon Web Services (AWS) cloud. No data were stored on family member personal devices. On study completion, deidentified data were downloaded by Aetonix from the UK AWS cloud and provided to the study team in encrypted Excel files.

Research Ethics Committee approval was obtained via the National Health Service Health Research Authority

20/SW/0147. Informed electronic consent was documented via the aTouchAway platform.

Statistical analyses

Continuous data were summarized as means and standard deviations (SD) or medians and interquartile ranges (IQR) depending on data distribution (assessed using the Shapiro–Wilk test); categorical data are presented as *n* (%). Baseline DT (severe, moderate, low) and DASS 21 subscale scores were examined using ordinal regression models adjusting for family member relationship to the admitted ICU patient, length of ICU stay at first virtual visit, and family member age. We compared within-subject DT scores before and after the first virtual visit using a repeated measures ANOVA given the normal distribution of the data. We used ordinal regression modelling to examine associations between family member and patient variables and DT scores indicating severe, moderate and mild distress as well as depression, anxiety and stress categories of the DASS-12. Tests were two-tailed and statistical significance was set at $P < 0.05$. Data were analyzed using IBM SPSS Statistics for MacOS, version 27 (IBM Corp., Armonk, N.Y., USA).

Results

Demographics

We recruited 2166 adult family members of ICU patients from 37 hospitals. Most participants were either an adult son or daughter (710, 33%) or a spouse/partner (503, 23%). Most (1971, 91%) were 65 years or under. Twenty-eight per cent of patients had been admitted to a participating ICU for over 2 weeks at the time of the first virtual ICU visit (Table 1).

Distress thermometer scores

Participants provided DT scores a median (IQR) 2 (1–3) times (range 1–99 scores). Prior to the first virtual ICU visit, the mean (SD) DT score provided by 2153 (99%) participants was 7 (2.6). Severe distress was indicated by 1349 (62%) participants, moderate distress by 568 (26%), and low distress by 236 (11%). Pre-visit DT score was associated with spouse/partner status of family member (compared to other relationship types) [odds ratio (OR) 1.64, 95% confidence intervals (CI) 1.27–2.12] but was not associated with family member age, or patient length of ICU stay at time of first virtual visit (Table 2).

Of these 2153 participants, 762 (35%) provided a subsequent DT score following the first virtual visit with a mean (SD) score of 5.4 (3.1) (mean (SD) difference from baseline of 1.6 (3.2) $P < 0.001$). Of the participants that provided 2 or more (up to maximum of 10) DT ratings over a median (IQR) of 13 (8–19) days, the proportion rating distress as 7 or higher (i.e., severe distress)

Table 1 Demographic characteristics

<i>N</i> = 2166	<i>n</i> (%)
Relationship to patient in ICU	
Child	710 (33)
Spouse/partner	503 (23)
Parent	440 (20)
Sibling	235 (11)
Uncle/aunt	58 (3)
Cousin	20 (1)
Other	184 (9)
Not reported	16 (1)
Age	
18–40	948 (44)
41–65	1024 (47)
66+	176 (8)
Not reported	18 (1)
ICU admission duration^a	
< 1 day	172 (8)
1–3 days	474 (22)
4–7 days	506 (23)
8–14 days	391 (18)
> 15 days	603 (28)
Not reported	20 (1)

^a Patient length of stay at time of first virtual ICU visit

at each reporting timepoint decreased further from 247/752 (33%) (timepoint 2) to 25/124 (22%) (timepoint 10) (Fig. 1). The mean (SD) distress score for participants providing repeated ratings after the first virtual ICU visit was 4.7 (2.8).

DASS-21 scores

Of the 2166 participants, 1754 (81%) family members provided complete answers to the DASS-21 questionnaire at baseline. The median (IQR) total DASS-21 score was 18 (2–42), with 246 (14%) scoring greater than ≥ 60 (i.e., indication for further psychiatric assessment). Severe-to-extremely severe depression, anxiety, or stress were scored by 249 (14%), 321 (18%), and 165 (9%) participants, respectively (normal levels of depression, anxiety and stress were scored by 58%, 54%, and 58%, respectively). The number of participants scoring as normal levels of stress, anxiety, and depression i.e., normal in all 3 sub-scores was 899 (51%). Being a spouse or partner was associated with severe/extremely severe stress (OR 1.38, 95% CI 1.08–1.78), anxiety (OR 1.66, 95% CI 1.28–2.15), and depression (OR 1.52, 95% CI 1.18–1.95) compared to other relationship types. Family member age and patient length of ICU stay at time of first virtual visit were not associated with higher DASS-21 scores (Table 3).

Table 2 Variables associated with baseline distress thermometer scores

	OR	95% CIs
Relationship to patient		
Child aged > 18 (ref category)	1	
Spouse/partner	1.64	1.27–2.12
Parent	1.25	0.98–1.60
Sibling	1.01	0.80–1.48
Aunt/uncle/cousin	0.65	0.42–1.03
Other	0.52	0.38–0.72
Age of family member		
41–65 (ref category)	1	
18–40	0.87	0.72–1.05
66+	0.82	0.59–1.14
Patient length of stay^a		
> 15 days (ref category)	1	
< 1 day	0.89	0.63–1.25
1–3 days	1.04	0.82–1.34
4–7 days	1.09	0.85–1.39
8–14 days	0.94	0.72–1.21

DT scores were collapsed into severe, moderate and mild distress

OR odds ratio, CI confidence interval

^a Patient length of stay at time of first virtual ICU visit

Discrete emotion questionnaire scores

A DEQ was completed by 320/1249 (26%) participants after their first virtual ICU visit with a score provided for at least 1 virtual ICU visit by 1249 (58%) participants. Scoring of the seven emotions is shown in Fig. 2. Feeling reassured was the emotion most often scored as 6 or 7 (30% of participants providing DEQ scores) indicating it was experienced an extreme amount. Anger was the least commonly experienced emotion overall with 920 (74%) participants scoring this as 'not at all' experienced (Fig. 2). Fear was the second least commonly experienced negative emotion (480 (38%) participants scored as 'not at all'). Twenty-eight percent of participants scored 6 or 7 on the sadness scale indicating it was experienced an extreme amount.

Discussion

In this large multi-centre cohort representing adult family members experiencing at least one ICU virtual visit in 37 UK hospitals during in-person visiting restriction imposed in the second COVID-19 wave, we found high levels of psychological distress with over 60% reporting severe distress meeting the clinical threshold for intervention. Almost one-fifth of participants scored as having severe-to-extremely severe depression or anxiety. Higher levels of distress, depression, anxiety, and stress were associated with being a spouse or partner but were not

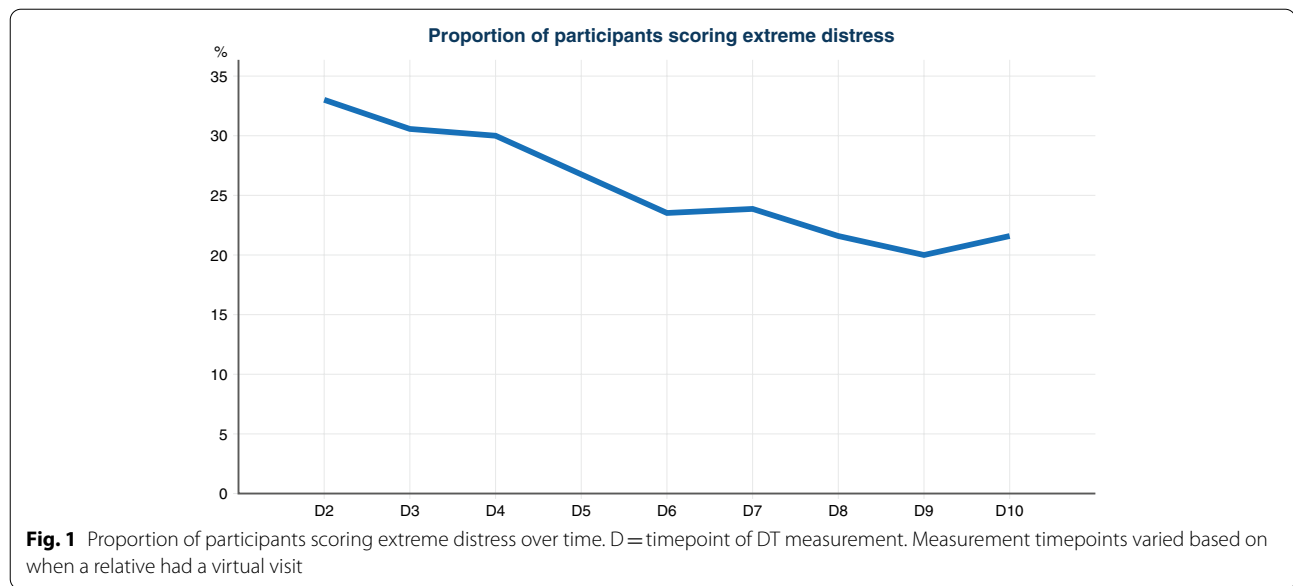


Table 3 Variables associated with DASS 21 subscale scores

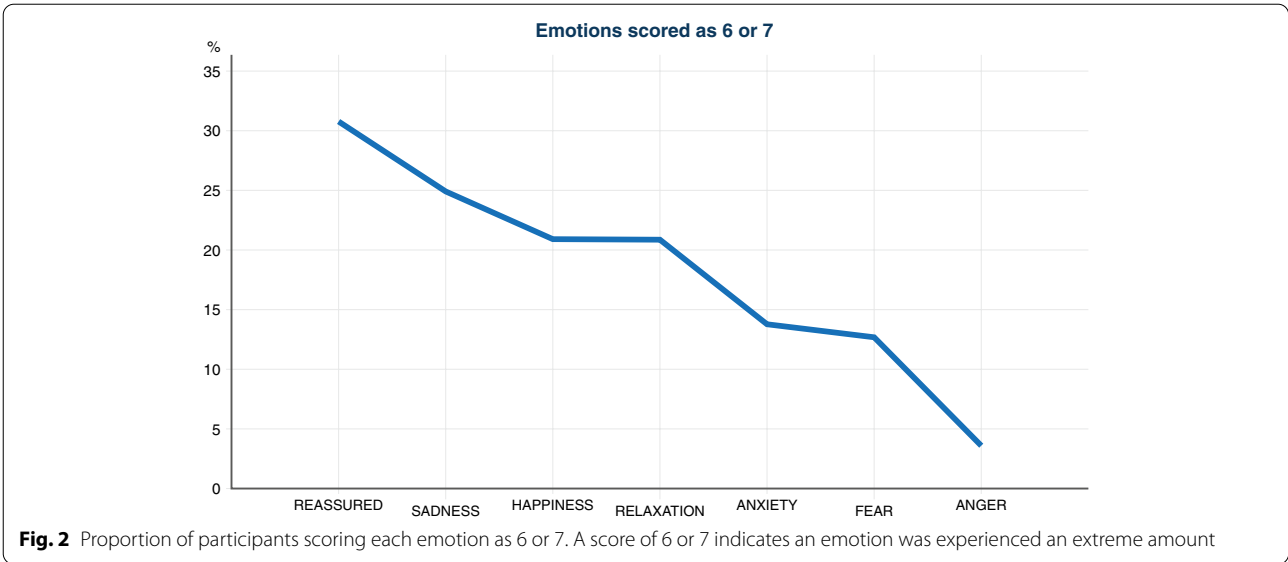
	Stress		Anxiety		Depression	
	OR	95% CIs	OR	95% CIs	OR	95% CIs
Relationship to patient						
Spouse/partner	1.38	1.08–1.78	1.66	1.28–2.15	1.52	1.18–1.95
Parent	1.00	0.77–1.29	1.08	0.82–1.41	1.09	0.84–1.42
Sibling	0.81	0.58–1.13	0.91	0.64–1.29	0.81	0.58–1.13
Other	0.56	0.38–0.82	0.77	0.52–1.14	0.64	0.44–0.95
Aunt/uncle/cousin	0.49	0.27–0.90	0.76	0.43–1.37	0.73	0.42–1.28
Child > 18	1		1		1	
Age of family member						
18–40	0.93	0.76–1.13	1.16	0.94–1.42	1.03	0.84–1.26
66+	0.90	0.63–1.28	0.88	0.61–1.26	0.90	0.63–1.28
41–65	1		1		1	
Patient length of stay^a						
< 1 day	1.01	0.71–1.44	1.05	0.73–1.52	0.78	0.54–1.12
1–3 days	0.83	0.63–1.08	0.94	0.71–1.24	0.77	0.59–1.00
4–7 days	1.04	0.81–1.35	1.04	0.80–1.36	0.89	0.69–1.16
8–14 days	1.11	0.85–1.46	1.11	0.84–1.48	0.96	0.73–1.26
> 15 days	1		1		1	

OR odds ratio, CI confidence interval

^a Patient length of stay at time of first virtual visit

associated with participant age, or patient ICU length of stay prior to the first virtual visit. Distress levels were significantly lower in those participants who re-rated their distress on completion of the first virtual visit. Following

subsequent virtual visits, a substantial proportion of participants continued to experience severe distress up to 2 weeks after the first visit. The most common emotions reported after an ICU virtual visit were feeling reassured



and relaxed; anger and fear were the least common emotions.

Our study quantifies the substantial psychological distress experienced by family members exposed to the restrictive in-person ICU visiting practices imposed during the COVID-19 pandemic. Distress is often used as an umbrella term for any multi-factorial, unpleasant emotional experience [24]. Although distress is commonly considered a transient phenomenon and a normative emotional reaction to a stressful event [25], it is also an indicator of a person’s state of mental health [26]. In the field of oncology where distress is routinely measured using the DT in clinical practice, a score ≥ 7 indicates a need for urgent intervention [27]. The degree of distress and the proportion of our participants experiencing severe distress far exceeds levels reported in other family member or patient populations. For example, in a study of 324 family caregivers of children and adolescents with schizophrenia, the mean (SD) DT score was 6.3 (2.5) [26]. A recent systematic review including 37 studies and 3870 women with breast cancer reported the pooled prevalence rate of severe distress (DT score ≥ 7) was 37% (95% CI 35–40%) [28]. The degree of psychological distress reported in our study also exceeds levels reported in family members of ICU patients prior to the pandemic. Although distress is not a commonly measured phenomenon in studies of critically patients or family members, a study conducted prior to the COVID-19 pandemic by Shaffer and colleagues [29] conducted in a neuroscience ICU setting and recruiting 83 patient-family dyads reported mean (SD) DT scores of 4.7 (3.3) and 4.5 (3.2) for patient and family members, respectively.

We found family member psychological distress scores decreased following the first virtual visit and declined further following subsequent visits. This reduction may be due to improved condition of their relative in ICU or the reassurance provided by seeing their relative and gaining some familiarity with the ICU environment. Other studies suggest ICU virtual visiting is associated with reduction of family member distress. Improved psychological wellbeing once ICU virtual visiting is established is reflected in themes arising from several qualitative studies reporting family member experience during the COVID-19 pandemic [15, 16, 30]. Prior to the pandemic, improved satisfaction [31] and reduced psychological morbidity has been shown with in-person visiting policies that enable greater family access. In the largest randomised controlled trial recruiting ICU family members to-date, Rosa and colleagues [6] demonstrated that an intervention comprising a flexible in-person visiting policy resulted in lower family member anxiety and depression scores compared to a restrictive policy. Therefore, open and in-person visiting should be viewed as the gold standard, with virtual visiting an adjunct that can further promote an open ICU for family members unable to visit in-person due to geographical or other constraints.

We observed a disparity between the magnitude of distress detected by the distress thermometer described above and the degree of psychological morbidity reported via the DASS-21. Just over 50% of our cohort reported no psychological morbidity; less than 20% experienced severe-to-extremely severe stress, anxiety, or depression. This may reflect the reporting time-frame—distress was measured in the moment and other

psychological morbidity reflected a 7-day look back timeframe. Also distress is conceptually different from depression, anxiety, or stress [32]. Although direct comparison of DASS-21 scores in family members of ICU patients is challenged by a lack of other studies using this measure, the psychological morbidity during a relative's in-patient ICU admission in our cohort appears lower than that reported in other studies conducted during and before the pandemic. In a cohort of 88 family members experiencing COVID-19 visiting restrictions in a single French ICU, Cattelan and colleagues report prevalence rates of anxiety and depression measured using the Hospital Anxiety Depression Scale (HADS) at 83% and 73%, respectively [13]. In the aforementioned trial of flexible in-person visiting, moderate-to-severe anxiety, again measured using the HADS, was found in 64% of participants [33]. Reasons for the lower levels of psychological morbidity detected in our study are unclear. One reason may be a high proportion of family members in our cohort that were not spouses or partners with the majority being adult children given our data suggest spouses or partners experienced the greatest psychological morbidity. Furthermore, given we were unable to collect data on patient characteristics or status during the virtual visit our sample could conceivably reflect family members experiencing visits with a less sick patient population. However, given that the relatively large sample and that these data were collected during the second UK COVID-19 pandemic wave we think this unlikely.

Emotional responses to a virtual visit were highly variable in terms of both negative and positive emotions, however, anger was most infrequent and reassurance most common. Given reassurance was an emotion we added to the DEQ for this study objective, further studies are needed to incorporate this emotion in to validated measures for developing further understanding of how best to support family members during in-person and virtual visiting. Given our pragmatic remote digital data collection methods, we were unable to collect data on clinical events that might have occurred during the virtual visit. Therefore, emotional variability likely reflects heterogeneous experiences and psychological dispositions of family members during a visit, as well as visits occurring at different timepoints in the patient's ICU stay trajectory. Furthermore, in the UK, while many ICUs conducted virtual visits for all patients, some only facilitated virtual visiting during end of life or acute deterioration, others only facilitated virtual visits in awake and stable patients [9]. Infrequent anger following a virtual visit may be reflective of an attitude of acquiescence also demonstrated in a Canadian study of family members bereaved during the pandemic [34].

Strengths and limitations

This large multi-centre observational cohort evaluated family member psychological distress and morbidity during their relative's ICU admission in the context of in-person visiting restrictions during the second UK wave of the COVID-19 pandemic using validated measures provided remotely via a digital platform. Recruitment of family members from 37 hospitals means our findings are likely highly generalizable. Study limitations include those related to the pragmatic remote data collection methods and observational study design. First, we were unable to correlate participant distress and emotional reactions to real-time events occurring in the ICU, the status of their relative, or other characterising information regarding the relative in the ICU they were virtually visiting. Second, the digital nature of data collection may have resulted in selection bias towards more technologically savvy family members and under representation of those aged over 65. However, 33% of our sample were grown up children and so there was likely good representation of patients over 65 receiving a virtual visit. We did not collect data on gender or ethnicity and therefore are not able to comment on the association of these variables on psychological distress and morbidity. We modified the DEQ for use in this study and had insufficient time to conduct a formal validation study, nor has it been previously validated in an ICU family member population. However, we believe it still provided helpful data on the breadth of emotions experienced. Finally, although we observed a reduction in distress following the first virtual visit, we cannot comment on the causal nature given the observational study design.

Conclusion

Family members exposed to in-person visiting restrictions during the COVID-19 pandemic were experiencing severe distress prior to their first virtual ICU visit. This distress was somewhat alleviated by a virtual visit, however, some family members continued to experience severe distress despite multiple virtual ICU visits over several days. Approximately a fifth of our cohort were also experiencing symptomatology indicative of severe-to-extremely severe anxiety and depression. Our data emphasize the need for ICU teams to establish mechanisms to support family members unable to visit in-person. Further work is also required to establish family level distress during in-person visiting as well as interventions that ameliorate this distress.

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Author contributions

LR had full access to all study data and takes responsibility for the integrity of the data analysis. LR, AC, VM, JM conceptualized and designed the study. All authors contributed to the analysis and/or interpretation of the data. LR drafted the original manuscript. All authors critically revised the manuscript for important intellectual content.

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Data sharing

A deidentified dataset and the study protocol may be made available to researchers with a methodologically sound proposal, to achieve the aims described in the approved proposal. Data will be available upon request following article publication. Requests for data should be directed at louise.rose@kcl.ac.uk to gain access, and requestors will need to sign a data access agreement.

Declarations

Conflicts of interest

LR and JM are the co-founders of Life Lines, a philanthropic COVID-19 rapid response project that received charitable donations to enable provision of over 1400 4G enabled Android tablets and a bespoke virtual visiting solution to ICUs across the UK. LR and JM have no financial or commercial interests in Life Lines or the virtual visiting solution. Major philanthropic contributors to Life Lines include Google, True Colours and the Gatsby Trust. British Telecom contributed in-kind time and resources to facilitate the supply of 4G enabled tablets to UK ICUs.

Ethics approval and consent to participate

Approval was obtained via the NHS Health Research Authority 20/SW/0147. Informed verbal consent was documented via a participant's aTouchaway account and retained in the AWS cloud.

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