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Agalya Ramanathan, Chantal Rees, Lauren Hookham, Joel Schamroth & Joe Rosenthal

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Relative communicators: evaluation of an innovative hospital role emerging from the Covid-19 pandemic

Agalya Ramanathan [a], Chantal Rees[b], Lauren Hookham[b], Joel Schamroth[b] and Joe Rosenthal [a]

[a]Research Department of Primary Care and Population Health, University College London, London, UK; [b]Royal Free Hospital, London, UK

ABSTRACT

Background: During the COVID-19 pandemic, hospital visiting policies made communication challenging. Effective communication is known to reduce anxiety for patients and relatives, and improve trust in healthcare services. We describe an innovative project in which students and staff were deployed to the role of 'Relative Communicators', enabling routine updates and facilitating video calls between patients and their next of kin (NOK).

The aim of our project was to explore NOK's perceptions of communication about their inpatient relatives and the Relative Communicators.

Method: Participants were asked to complete a structured interview over a telephone call but could use the online form if this was not possible. Hence, we obtained data using a combination of interviews and online surveys. NOK, who utilized the relative communicator service (n = 30), were surveyed. Quantitative data and free-text responses were analysed to understand their perceptions.

Results: 85.7% of respondents (24/28) were satisfied with information they received from Relative Communicators. 43.3% (13/30) of NOK felt they could communicate with their relative 'the right amount', and 56.7% (17/30) felt they were sufficiently involved in care decisions. Qualitative data provided further insights around the demand for proactive updates, frustration with existing communication models, and praise of telecommunication methods.

Conclusions: We suggest proactive updates and telecommunication could improve the experience for patients and NOK. Relative Communicators provided a bridge for inpatients and NOK to connect. The pandemic has exacerbated systemic communication issues and innovations, such as the Relative Communicators, may help to address these challenges.

KEYWORDS
Communication; telecommunication; COVID-19; hospital npatients; patient care; secondary care

Introduction

The coronavirus (COVID-19) pandemic has created a global health crisis, significantly altering how medicine is practiced. These changes include restrictions in the delivery of routine care and increased uptake of telemedicine across primary and secondary care [1]. A significant change in secondary care settings was the nature of the interaction between clinicians, patients, and their next of kin (NOK) [1].

The Royal Free Hospital in London saw some of the earliest confirmed cases of COVID-19 in the UK. As in many other UK hospitals, visiting is limited to a narrow set of exceptional circumstances, such as patients with learning difficulties or those at the end of their lives. It became apparent that next of kin were becoming increasingly distressed, compounded by increasingly high levels of anxiety around a novel infectious disease. This impacted staff who found it hard to keep up with the volume of calls and convey information to family members.

As part of a multidisciplinary team the authors sought to improve communication by adopting various strategies. Firstly, by helping patients maintain direct links with their NOK e.g., facilitating video or telephone calls for patients who lacked the technology or skills to do so independently. Secondly, we sought to improve the flow of information to patients' NOK while they were in the hospital.

Six medical students, unable to attend normal clinical placements, and 4 administrators, released from their usual roles, were deployed by the trust to work as 'Relative Communicators'. They received some basic confidentiality and communication training from the operations team before starting and ongoing support and ad hoc training on the wards by clinical staff, including the authors and palliative care team.

The Relative Communicators performed two main roles: (i) calling patients' nominated NOK to provide regular 'outine' updates on their progress and (ii) to be present with patients to facilitate video or phone calls with NOK. More complex or 'difficult conversations', such as discussing the end of life care or deterioration, remained within the remit of the medical team.

CONTACT Agalya Ramanathan ragalya.ramanathan@nhs.net

Here, we aim to evaluate the introduction of the Relative Communicator role. We hoped that their work would help alleviate family members' concerns and provide comfort for NOK and patients.

Aims

To evaluate the impact of Relative Communicators on NOK satisfaction with communication during a pandemic.

Methodology

Design

A structured interview was designed which could be completed by participants on the telephone or online, if they were unable to do this. The survey questions were uploaded online via google forms; we did not use paper surveys given the need for strict infection control measures. Hence, we planned to obtain data using a combination of structured interviews and online surveys.

The questions (see appendix) were designed to assess the NOK perceptions of communication in the context of the restrictive hospital visiting policy during the pandemic. The questions were selected to understand the impact of Relative Communicators, and identify areas for improvement. The survey responses included multiple-choice, yes/no, and free-text sections. The authors intended to assess how NOK perceived communication with Relative Communicators compared to communication with doctors, nurses, or other health care professionals.

Ethical approval

Ethical approval was waived by the hospital ethics committee as it was considered part of a service evaluation and was registered as a quality improvement project. Participants provided consent verbally and electronically.

Participants and procedure

Survey data were collected between May and August 2020. Surveys were distributed by one of the Relative Communicators to family members of patients whose care they had directly been involved with. The communicators were typically used for patients who could not contact NOK directly and only covered a few inpatient wards initially, so the total number of patients they interacted with is around 200. The type of sampling was convenience sampling. The survey closed once we felt thematic saturation was likely to have been achieved; the data were analyzed contemporaneously during the survey period by the authors, and recurring themes became apparent during this process.

Depending on respondent preference, survey questions were discussed on the telephone with the NOK and recorded in real-time by the relative communicator, or NOK were emailed the survey and encouraged to fill it in at their convenience. It is important to note that the NOK surveyed were those on wards where Relative Communicators worked. As a result, there is no control sample for this intervention.

In some cases, Relative Communicators had been in contact with NOK of patients who were for end-of-life care or had passed away during their admission. It was deemed that it would be insensitive to survey these NOK, and they were, therefore, excluded from the study.

Analysis

The quantitative data include a mix of categorical or dichotomous data, presented as statistics and percentages. Thematic analysis (TA) of the free-text responses was performed to identify recurring patterns in the participants' written responses. Braun and Clarke's step-by-step guide to TA was closely followed to provide structure [2]. NVivo software was used to code the data systematically into potential themes at a semantic level. These were later reviewed and refined into dominant themes that voiced the feedback from the NOK.

Dominant themes were later broadly subdivided to help navigate the meaning and implications of the results concerning our intervention and previous literature surrounding the nuances of NOK communication in a hospital setting.

Results

Survey responses were obtained from 30 NOK during data collection.

Direct communication between NOK and relatives

NOK communicated with their relatives using a combination of methods; however, the most commonly used modes were video calls (73% (22/30)), phone calls (60% (18/30)), or via hospital staff (53% (16/30)), while SMS/messaging apps were only used by 10%. Video calls were often facilitated by the Relative Communicators (Figure 1).

Given the extra measures put in place to facilitate direct communication with hospitalized relatives (via phone and video calls), 43.3% (13/30) of NOK felt they could communicate with their relatives 'the right amount'. The majority, however, felt that they could communicate with their relatives often enough (17/30 or 56.7%) (Figure 2).

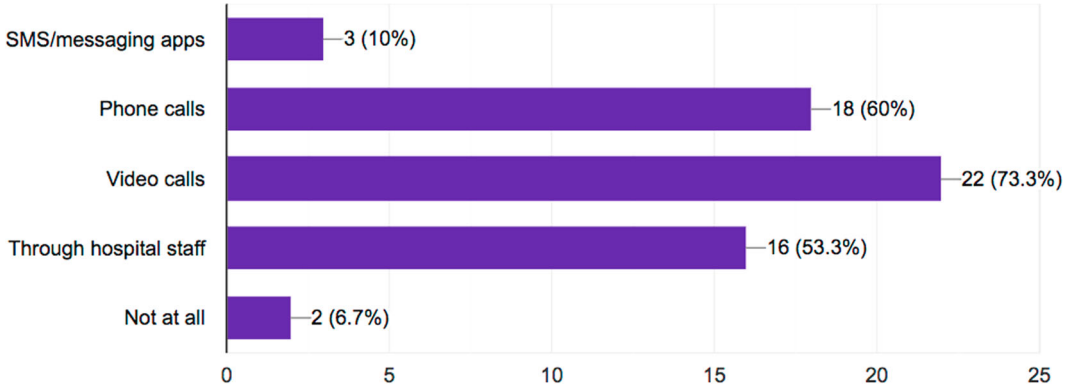

Figure 1. How did you communicate with your relative? (select all that apply).

Communication through staff

Most of NOK respondents were satisfied to receive information from the Relative Communicators (85.7% (24/28)), suggesting that this was a highly acceptable means of communication.

36.7% (11/30) of NOK felt they received the right amount of information about their relatives' condition or treatment from hospital staff. 60% (18/30) of respondents felt that they would have appreciated more communication; however, 66% (12/18) of these individuals expressed an understanding that the staff were busy (Figure 3).

Although the majority of respondents felt they received responses that they could understand when speaking to doctors/nurses (66.7% (20/30)), a significant proportion felt this was only true sometimes (33.3% (10/30)) (Figure 4).

When it came to sharing their concerns about their relatives openly with hospital staff, 58.6% of NOK (17/29) felt that they definitely could do so, while 31% (9/29) felt they were able to do this to some extent, and 10.3% (3/29) did not feel able to at all.

4/30 respondents were not aware which ward their relative was on, but the majority were (26/30).

A majority (56.7% (17/30)) of NOK responded in the affirmative that they were involved in decisions about care and treatment as much as they or their inpatient relative wanted them to be, while a further 20% (6/30) of respondents said they were involved in decision making 'to some extent'. This leaves just under a quarter of NOK who felt they were not as involved in decision-making as much as they had wanted.

Most participants received information from a variety of sources; however, the most common were through nurses (23/30)/doctors (21/30) and physiotherapists (11/30), and the Relative Communicators. All participants had interacted with the Relative Communicators (only 50% of respondents selected this option); however, they may have been unclear about whether medical students/family communicators were the same.

Thematic analysis

Table 1 demonstrates the dominant themes and subthemes coded from the qualitative survey data.

The following four key themes emerged: (i) frustration with communication, (ii) difficulties in not being

Figure 2. How much were you able to communicate with your relative?

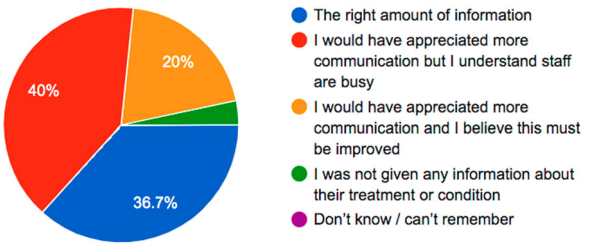

Figure 3. How much information about your relative's condition or treatment was relayed to you by RFH staff during their admission?

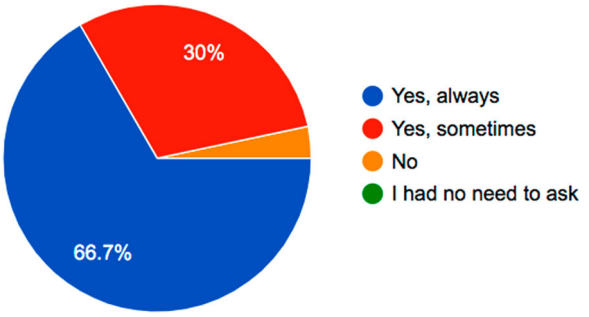

Figure 4. When you had important or specific questions to ask a doctor or nurse, did you get answers that you could understand?

Table 1. The dominant themes and subthemes coded from the qualitative survey data.

Theme and subthemes	Number of respondents that raised this issue (out of total=30)	Total number of times the theme was raised (including multiple mentions from the same respondent)
Demand for proactive medical updates	9	16
Positive feedback of relative communicators	10	17
Difficulties in not being able to visit in person	11	12
Poor patient mental health due to visiting restrictions	5	6
Visiting restrictions- negative effects on relatives	6	7
Visiting restrictions-other	2	2
Frustration with communication	18	46
Comments on communication methods previously in place	10	16
Evidence of harm to patient care due to poor communication	1	1
Praise of telecommunication and demand for future use	16	26
Telecommunication- positive effects on mental health	6	6
Other	0	0
Different ways of communicating	1	1
Praise of staff during the inpatient stay	7	9
Relative understanding of communication due to current restrictions	15	19

able to visit in person, (iii) demand for proactive updates, and (iv) demand for future use of telecommunication.

Frustration with communication

Many of the respondents experienced difficulty with communicating with ward staff:

> *'If I don't call up to find what is going on then I don't hear anything, nurses will sometimes update me and sometimes they won't. (I am) Not made aware of ward transfer … had to phone around to find out where (my relative) was. Had to rely to family in medical profession, to interpret/ understand what the doctors were saying.'*

Some respondents also mentioned that they only received comments such as 'doing well' or 'stable' rather than anything more substantial:

> *'Information was basic and staff didn't give any solid information.'*

Discussions surrounding the management of patient care with the medical team appeared to be highly valued, yet frustrations arose when this failed to be arranged. The sporadic organization of telephone calls with doctors was frequently identified in the responses as a poor element of communication.

> *'A lot of the time staff will say, I'll have to leave a number for doctor to call you back. More communication is needed, (I) understand (this) is a busy time- but false promises of call back is frustrating.'*

Difficulties of not being able to visit in person

NOK wish to support their family in their time of illness and during their recovery and worry that not being present will delay their recovery, at least partly due to feeling afraid and not having their usual support network.

> *'Believe lots of patients may be taking longer to recover as they cant emotional grasp what is happening and when this is dampened you don't feel yourself'.*

> *'Nothing can replace seeing a person and being there. The knowledge when mum is scared and can't go there and support her- can't go there and hold her hand'*

> *'Not being able to be with him in A&E was the most difficult''*

In normal circumstances, NOK would be able to bring in items that may aid patients in their recovery and make them feel more comfortable. By not being allowed to visit, they could not do this (unless arrangements allowed for items to be dropped off).

> *'Did find it hard as relative has dementia- hard when can't go in and see him and just bring him the things he likes e.g- Fanta from the shops. But staff were good and generally able to meet these requests themselves.'*

Family members may feel reassured by seeing their relatives directly, in the sense of seeing improvement in their condition and understanding progress. When they could be present in person, relatives feel they are better enabled to advocate and ask questions on behalf of the patient, especially when they are in a condition where they might not be able to do so effectively. The impact was felt when NOK could not physically be present with their family.

> *'Truly knowing how they are doing (we) only can really see in person- especially as (the patient) finds it difficult to communicate.'*

> *'Phone did not work at bedside so whilst ipad communication was good was evidently limited to 1 time a day and could not speak to anyone without facetime etc'*

Demand for proactive medical updates

Good communication eased NOK worries and fears (about being helpless if patients felt lonely and scared), but 'good' communication fluctuated and did not always meet the demands of relatives/NOK.

NOK reported wanting proactive rather than reactive updates, with calls etc., arranged in advance with

some regularity. Respondents typically described communication from clinical teams to family members to be 'reactive rather than proactive' communication.

> *'We had push to get information and be very proactive …. finding a doctor was nearly impossible.'*

Patients and their families had expectations significantly greater than what was initially delivered by clinical teams, with suggestions of 'daily calls from the nurse in charge'. This mismatch between expectation and reality was a critical area that the Relative Communicators aimed to address.

In wards, where the Relative Communicator system was active, feedback positively highlighted cases of proactive communication with NOKs.While this occurred on some wards, the variation in responses highlights the lack of uniformity across different settings.

> *'When the medical communicators arranged calls this was very good … (without them) I'm unsure whether we would have been contacted to ask if we wanted to speak to patient … (the) service was very good … '*

> *'The family communicator contacted me the next day and was very helpful … We had discussed my frustration at not being able to get clinical updates and when she called me the following day she was fully prepared with appropriate information, which I really appreciated.'*

Respondents also noted that NOKs with less knowledge of the health system might not be able to 'navigate the system' and, therefore, be disadvantaged in receiving information about their relatives. This highlights the need for a basic model of communication that could be rolled out across wards while visiting restrictions are in place.

Praise of telecommunication and demand for future use

The Relative Communicator intervention was well-received. Updates from Relative Communicators were clearly valued by patients:

> *'The idea of medical students communicators is fantastic'*

In particular, the communicators' facilitation of video calls with patients was highly praised. Video calls were used for 22 (73.3%) out of 30 family members surveyed. Many relatives/NOK specifically explained that video calls directly benefited the well-being of the patient and their own. Relatives/NOK identified that such communication was particularly beneficial for those who were hard of hearing or had language barriers.

> *'The facetime and zoom call facilities provided by the medical students was fantastic especially as my mother didn't know how to use a personal mobile and language was a big issue for her.'*

> *'The video calls were awesome and allowed us to see my father's daily improvements … .the video calls were engaging and very helpful in understanding things. We are so thankful to the hospital staff for arranging this.'*

Many of the participants expressed a desire for more video calls and these to continue beyond the Covid pandemic. One expressed how they felt they had 'time to talk, not feel rushed and not battle to make contact'.

> *'Without the iPad, given we couldn't come and see her there would've been 0 contact- it will help cheer her up and on road to recovery. Keeping the iPads going is essential for the wellbeing of the patient and their mental health.'*

> *'My father is 94, partially deaf and visually impaired. Telephone calls are difficult for him to hear. The Zoom meeting as mentioned above was brilliant. The Patient Communications staff member was next to my father and was able to tell him what we were saying when he was unable to hear well enough. This is a brilliant system to have in place at any time, not just during the Coronavirus outbreak.'*

Discussion

The 'Relative Communicators' project attempted to provide humane care by creating a vital bridge for inpatients and their relatives/NOK to connect in times where the only remaining social link is virtual.

Many studies have shown that communication with NOK can be one of the most highly valued aspects of care [3–5]. Critically, strong communication between NOK, patients, and clinical staff can lead to improved, holistic decision-making in the patient's best interests. Existing literature describes how relatives and NOK can take on an advocacy role [6].

When key stakeholders are not present in person, vital aspects of non-verbal communication are lost [7,8]. Families find it beneficial to speak to hospital staff in person [9]. When communication is virtual, clinicians need to make significant changes how they work to convey empathy and accurate information. NOK experience is likely to be poorer if clinicians fail to adapt.

In our cohort, relatives reported concerns about the impact of isolation on their inpatient relatives. Multiple studies have shown a negative psychological effect when patients are isolated in the hospital [11]. For patients, who lack access to or confidence with virtual communication tools, isolation can create additional anxiety [12]. It became impossible, or at least harder, for family and informal carers to provide the vital practical and emotional support they usually would for older adults with severe health conditions [13,14].

The Relative Communicators intervention helped address many of the areas above. By relying on Relative Communicators to maintain routine contact we were able to establish on-going and bi-directional communication, which Akgun et al [15] suggest can help ease the fear of uncertainty and abandonment. In an unprecedented environment where clinical staff were unable to communicate with NOK in the usual manner, it is likely that patient and NOK anxiety washigh. Small acts of compassion can make a meaningful difference for patients [16]; indeed, our data suggests short telephone calls for 'routine' updates are of utmost importance for the patient and NOK groups.

While telehealth has previously been focused on primary care and outpatient clinics, this pandemic has created new challenges and opportunities to introduce it into inpatient care. Many healthcare organisations have found short-term stop-gap solutions to provide video calling. Our experience using video calls to improve communication adds to a growing body of literature in this area. Fang et al. [12] describe a pragmatic guide to implementing a system for video-calling between family and inpatients. Our work also provides insights into one model of how a video-calling system may be implemented and function as part of inpatient care. The results from relatives and NOK strongly suggest that scheduled clinical updates, in addition to social video gatherings with NOK a few times a week, could be an effective way to overcome the current limitations of communication methods in the NHS.

Of course, virtual communication methods are not a panacea. One problem associated with virtual communication is the potential for patients' privacy to be compromised [17]; for these methods to be used, patients and NOK may be required to interact with additional people. Additionally, relatives cannot provide physical aspects of care, which patients may be unable to request or prefer to be given by their relatives [18].

Despite the positive feedback on the aspects of care and the Relative Communicators, the survey data capture significant mismatches between relatives' expectations and reality. Half of our respondents said they wanted more interaction with relatives, and 60% wanted more information. Many experienced difficulties in communicating with staff. Another common issue was that in the first 24 hours of admission, families received little information about their relatives' whereabouts or progress. While the feedback we captured was focused on communication during the pandemic, many of the shortfalls described are longstanding. They may have been exacerbated by the pressures on the system due to Covid-19.

It is likely that innovative solutions designed to address communication challenges experienced by patients and their relatives will be relevant beyond Covid-19. The authors are confident that these initial interventions have the scope to contribute to the creation of meaningful, lasting tools, and processes to positively impact improving the experience for patients and their family members. Indeed these tools could also increase the flexibility of hospital visiting, which has been suggested to improve patient experience [19] and reduce the burden of extra work associated with these measures for NOK [10].

Limitations

The Relative Communicators project itself and the data collection approach were forced to adapt to the evolving dynamics of the pandemic and the hospital's response. At times, this compromised our ability to stick rigorously to our QIP methodology.

One major limitation is the range of participants we were able to survey. Feedback is taken only from those wards where Relative Communicators were active. There is no comparator group with other wards or the same wards during periods where the Relative Communicators were not working. Additionally, the survey was delivered by the Relative Communicators, which may have led to bias as the next of kin may not have felt comfortable delivering negative feedback.

Data about the NOK, including their age, sex/gender, relationship to the patient, or data about which particular ward the patient was on or patient demographics, were not collected. However, while this would be useful to understand how to target this type of intervention, it does not limit the applicability of our findings regarding the acceptability of the services offered by the 'Relative Communicators'.

Another limitation was that relatives and NOK of patients who experienced poor clinical outcomes, i.e., death during the admission or in the immediate period after this, were not surveyed. This could have skewed our findings towards more favorable responses.

Conclusions

Our work adds to existing literature, which describes communication barriers and frustrations experienced by NOK long before the pandemic. Restrictions introduced to combat the spread of Covid-19 have compounded existing problems and caused new obstacles for NOK/relatives to contend with.

Communication is a cornerstone of modern medical practice, and our study emphasiszs the need to review policies and ward structures to improve the experience of inpatients and their NOK. One key way to do this may involve the use of the Relative Communicator role and video calling software, which already has

evidence of favorable responses from NOK. Further research is vital to facilitate the most efficacious application of this intervention.

As the pandemic continues, a more detailed evaluation of different approaches involving a wider range of participants, for example, NOK of those other than stable medical inpatients and triangulation of other quantitative and qualitative methods, may be informative. There are currently several studies building on the work of the Relative Communicator project on-going in our hospital trust, which, we hope, will further understanding and knowledge in this area.

Declarations

Ethical approval: This was waived by the Royal Free London NHS Foundation Trust on 28th April 2021, following a meeting with the trust research lead as this study was part of a trust service evaluation and was formally registered for this purpose following the meeting. Participants provided consent on the survey forms (completed electronically) and verbally.

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Authors' contribution: Dr Hookham, Dr Ramanathan, and Dr Schamroth worked on the COVID-19 wards at the Royal Free Hospital during the first wave. Chantal Rees worked as a 'Relative Communicator'. All four of these authors were involved equally in the design and write-up of this study. Professor Rosenthal reviewed the manuscript prior to submission.

Notes on contributors

Dr. *Lauren Hookham* is a clinical research fellow at MU-JHU/St George's, having completed core medical training and worked as a medical registrar in London. Her areas of interest include global health, infectious diseases, and medical education.

Dr. *Agalya Ramanathan* is a GP registrar and NIHR academic clinical fellow working in London. Her areas of interest include medical education, generalism, and chronic disease management.

Dr *Joel Schamroth* works as a medical advisor at GSK, UK, and Ireland. His areas of interest include infectious diseases, public health, and health system innovation.

Dr. *Chantal Rees* completed her medical degree at Sheffield and is working as a junior doctor in London. She is interested in Global and Public Health and is looking forward to applying her learning to clinical practice.

Professor *Joe Rosenthal* is a GP in Islington and Professor of Primary Care Education at the Primary Care & Population Health department, UCL. His interests include educational evaluation, students' attitudes, and communication between primary and secondary care.

ORCID

Agalya Ramanathan http://orcid.org/0000-0003-4651-6427

Joe Rosenthal http://orcid.org/0000-0002-7649-2940

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Appendix 1. COVID family/NOK survey

For family members/NOK of patients admitted with COVID-19 or found to have COVID-19 during their hospital admission. Thank you for taking part in this survey! Please be reassured your views are very important and will be used by the trust to plan further interventions.

How much information about your relative's condition or treatment was relayed to you by RFH staff during their admission?

❏ The right amount of information
❏ I would have appreciated more communication, but I understand staff are busy
❏ I would have appreciated more communication, and I believe this must be improved
❏ I was not given any information about their treatment or condition
❏ Don't know/can't remember

How did you receive this information? (select all that apply)

❏ Discussions with doctors
❏ Discussions with family communicators (usually medical students)
❏ Discussions with the nursing staff
❏ Discussions with physiotherapists, occupational therapists, dieticians, or speech and language therapists
❏ Written information (paper or digital)
❏ I did not receive any information about my relative's treatment/condition
❏ Don't know/can't remember

How much were you able to communicate with your relative?

❏ The right amount
❏ I would have appreciated more communication, but I understand the wider context makes this harder
❏ Not enough, and I believe this must be improved
❏ I was not able to communicate with my relative
❏ Don't know/can't remember

How did you communicate with your relative? (select all that apply)

❏ SMS/messaging apps
❏ Phone calls
❏ Video calls
❏ Through hospital staff
❏ Not at all

Were you made aware of which ward your relatives were being cared for in?

❏ Yes
❏ No

When you had important or specific questions to ask a doctor or nurse, did you get answers that you could understand?

❏ Yes, always
❏ Yes, sometimes
❏ No
❏ I had no need to ask

If you spoke with the medical student communicators, were you happy to do so?

❏ Yes
❏ No

Were you involved as much as you/your family member wanted you to be in decisions about their care and treatment?

❏ Definitely
❏ To some extent
❏ No

Were you able to speak with hospital staff about your worries and fears?

❏ Definitely
❏ To some extent
❏ No

Was there anything particularly good or anything that could be improved?

What in particular did you find hard about being unable to visit your family member, and what can we do to address this?

Do you agree to have your answers used anonymously as data as part of a quality improvement project?

❏ Yes
❏ No

Do you agree for your answers to be quoted anonymously when we present this quality improvement project?

❏ Yes
❏ No

Appendix 2. Coding manual extract example

Category	Subcategory	Code	Description	+ve example	-ve example
Difficulties in not being able to visit in person	Negative effects on relatives	Adverse mental health effects for NOK	NOK express negative effects on their own mental health when they are not able to visit in person	'The separation from my mum when she had suffered a brain injury as a result of a severe stroke and was confused was very distressing. I felt bereft.'	
	Negative effect on patients	Adverse mental health effects for patients	NOK express their worries about how not visiting in person negatively affects the patient's mental well-being	'Believe lots of patients may be taking longer to recover as they cant emotional grasp what is happening and when this is dampened you don't feel yourself.'	