The experiences of patients and their relatives and carers of communication during the Covid-19 pandemic in Scotland

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Care Opinion
What's your story?

Introduction

The Covid-19 pandemic that has unfolded over the past year has placed significant strain on healthcare systems across NHS Scotland and those who work in them. Decreased staffing levels, increased patient numbers all while fighting an unknown threat have resulted in impacts to many aspects of healthcare delivery. However, never before have healthcare staff had to contend with such barriers to normal, effective communication. With additional layers of PPE to contend with, as well as an absence of family members to help aid them, communication with patients and family members, as well as between patients and family members has become incredibly challenging.

The aim of this project is to analyse the impact of the Covid-19 pandemic on patient and relatives experiences of communication in their care. To do this, we analysed data from Care Opinion, a platform which encourages those who have experienced care to share their experiences, both positive and negative, to help change health and care services for the better. The stories it collects provide an incredibly useful overview of patient experiences in health and care settings in Scotland. For this project, we analysed 267 stories published on the Care Opinion website between 01/04/2020 and 01/03/2021.

When we did this, we found a wide array of perspectives. Broadly, people are still positive about the healthcare they receive in Scotland and are grateful to the NHS for the effort they have put in over the past year, however there is a decrease in satisfaction with the quality of communication in some areas. While there were some negative stories which we could not tie strongly enough to the impact of Covid-19, many detailed aspects that can be clearly linked to that impact. Common themes in these negative stories were hospital visiting, communication between hospital and home, the mental health impacts of the isolation experienced due to visiting rules, and confusion and frustration surrounding mixed messages and a lack of clarity in visiting guidance.

We will thus assess the impact of the Covid-19 pandemic through three lenses. Firstly, What is the impact on communication between healthcare professionals and patients? Secondly, how has communication between healthcare staff and the relatives or guardians of patients changed? Finally, how has the pandemic affected communication between patients and those close to them, and what impact has this had?

Methods

The dataset was sourced from patient feedback submitted to the Care Opinion platform. The site uses a 'tagging' system, whereby all submitted stories are assigned labels relevant to key topics discussed within the body of text. Furthermore, information is sorted by service and health board district. Some stories were copy-edited for clarity.

Thus, a comprehensive report for all stories tagged under "General Medicine" and "NHS Scotland" between 01/04/20 and 01/03/2021 was generated (n=267). The time frame was selected to include the first account published on the platform regarding the mention of Covid-19 (whether directly or indirectly) and the most recent reports at the time of writing (March 2021). We decided on using the "general medicine" treatment function which covers a wide variety of hospital specialties, with an emphasis on general medical receiving wards. This supplied us with a good cross-section of stories from unwell people and their relatives across the NHS, while supplying a small enough number of stories (n=267) to analyse them all individually.

All feedback within the refined data set was then subject to specific inclusion criteria. To be included in the analysis, the feedback must:

1. **Explicitly mention "Covid-19" in the body of text, or allude to the pandemic by using suggestive phrases e.g. "tough times", "health crisis", "current situation".**

Rationale - Chosen to allow the most robust inferences regarding the pandemics effects on communication to be drawn. It was assumed that if narratives did not explicitly make reference to the pandemic, then the author did not view the pandemic as a direct influence on the experience. In those instances, it was assumed the time period of the pandemic merely correlated with the experience, but Covid-19 did not have a direct causal influence on it.

2. **Be related to an in-patient hospital stay.**

Rationale - Chosen to capture a potential dynamic shift in secondary care caused by the Covid-19 pandemic. In-patient stays were chosen to widen the time frame of author's experiences, such that narratives would be less likely to focus on isolated incidents, allowing broader influences to be drawn. It should be noted that whilst numerous other healthcare services continue to be affected by the pandemic, it is outwith the scope of this piece.

3. **Mention or discuss communication.**

<u>Rationale</u> - Since this is the topic of the piece, its inclusion is clear. All forms of communication (i.e. telephone, in person etc.) were included.

All narratives were read by both team members to ensure the accuracy of the data marked for further analysis. The application of the aforementioned inclusion criteria narrowed the data further.

Since communication occurs between different groups during the course of an in-patient stay, it was deemed necessary to categorise communication focused narratives based on the status of the parties involved. Reports fell under one of three headings:

1. Communication between healthcare staff and relatives
2. Communication between healthcare staff and patients
3. Communication between patients and relatives

Subcategorization of the data aimed to generate an insight into the pandemics effect on the dynamic of communication between different parties. Unique discussion points pertinent to each category would then be analysed, allowing relevant inferences to be drawn.

To perform a comparative analysis of the period affected by the pandemic and a similar pre-pandemic sample, we pulled reports on both the 11 months pre-pandemic (01/04/19 - 01/03/2020) and 11 months of the pandemic thus far (01/04/20 – 01/03/21), a sample of 267 stories. No stories were discounted or refined from this dataset in order to achieve consistency. The high-level story criticality stats and the comparison of common tags come from using the “Stories in summary” report on Care Opinion’s system. The ratings people assigned to their care were found using the “Services with ratings” report.

Comparison

It is first useful to establish how, if at all, Covid-19 has impacted how people feel about communication in their care. From the headline statistics, story criticality is very similar. Pre-Covid, 63% of stories were rated as not critical (0), compared to 65% of stories during the pandemic. The top-level criticality statistics do not indicate a significant shift in criticality.

However, when we look specifically at views of communication, a slightly different picture emerges. It is possible to combine the common tags (mentioned more than four times) placed on stories by users to ascertain this. In order to get an overview of how people feel about communication in the pre-pandemic period, we can combine the following tags: 'communication', 'staff attitude', 'information', 'should listen' & 'kept informed'. These tags appear negatively in 17.1% of stories. When looking at the pandemic period, we can combine 'communication', 'staff attitude', 'family kept informed', 'conflicting information', 'information', 'not being listened to' and 'understanding'. These tags are mentioned negatively in 25% of stories in the pandemic period. These statistics would point to an uptick in negative feelings towards communication during the Covid-19 era.

In addition, when asked to rate the standard of "Information & decision-making shared appropriately", ratings dropped from 4.45/5 before Covid-19 to 4.04/5 after. This is mirrored in the "Clear information" standard, dropping from 4.4/5 to 4.1/5. Finally, when asked to rate "Being listened to", ratings dropped from 4.53/5 to 4.27/5.

It seems then that the Covid-19 pandemic has negatively impacted patients and relatives' perception of communication in their care and the care of those close to them. We must then delve deeper into the stories and discern the reasons for this.

Before delving into the different aspects of communication identified in the data, is important to make one point. It is evident in the data that communication, more so than any other aspect of care, is often only mentioned negatively – when it goes well the patient doesn't notice, but when communication is disrupted, it is obvious and tends to be commented upon. We are therefore making a slight assumption that when it isn't mentioned in a positive story, communication has not been a significant negative factor.

Communication between healthcare professionals and patients

In the dataset, there are very few stories which make any negative connection between the Covid-19 pandemic and communication between healthcare staff and patients. Some are present, but it is very difficult to make a connection between the two. Indeed, some of the negative stories go out of their way to deny that the impact is due to the pandemic:

"I would like to say that this poor communication was new and that I could put this down to Covid and the new pressures but it was like this last time" [773769]

What is easier to elucidate are the positive feelings so many patients have had about their care during the last year, despite all the pressures NHS Scotland has been under. While no significant themes emerged from the stories that mentioned communication between healthcare staff and patients, there are a broad set of stories in the database praising healthcare staff for their compassion, perseverance and high standard of care. This is despite the backdrop of the pandemic. These are typified in the following stories:

"It was obvious to me that staff had been under great pressure given the current situation [...] I cannot commend highly enough the skill and the very positive and caring attitude of every one of them, for which I am so very grateful." [818440]

"Despite all of the NHS putting themselves at risk on the front line for people like me on a daily basis, they just never stop sharing their care about everyone no matter the ailment." [770025]

"Everyone I came into contact with from the Tea lady to the surgeons was equally supportive and helpful. This is amazing at what must be one of the most stressful times for the NHS ever" [772598]

In the absence of a significant number of stories which expressly link the pandemic to poor communication between healthcare providers and patients, the data does not support a concrete link between the impact of Covid-19 and a downturn in communication between these two groups. In fact, the evidence shows that patients overwhelmingly have positive feelings about this communication. Therefore, to explain the statistical differences outlined in the comparison section, we must look at another type of communication.

Communication between healthcare staff and relatives/carers

Overall communication

Overall, feedback was varied. From the sample of feedback discussing healthcare-relative communication (n=40), 45% of accounts were positive, 47.5% were negative and 7.5% were mixed. Four relevant discussion points emerged from the data, which will be discussed in turn.

Frequency of communication

The first evident theme within the subgroup centred around the frequency of communication between healthcare staff and relatives - 63% of feedback (n=25) commented on the frequency of contact between healthcare providers and relatives.Chiefly, 60% of these accounts (n=15) were positive in nature, 40% (n=10) were negative and 0% were mixed. When analysed further, a slight majority (60%) of positive feedback was submitted in the first half of the sample period, whilst a slight majority (60%) of negative stories were submitted in the latter half of the sample period.

Feedback which was positive in nature tended to describe a high *frequency* of communication - in the majority of cases communication between healthcare providers and relatives was daily.

"To keep a long story short I just want to say a massive thank you to everyone in ward 42 who was involved in my mum's care - from nursing staff to AHPs and doctors. Due to COVID measures, it has been extremely difficult and stressful not being able to see my mum in hospital. My dad was always well informed by nursing staff and was able to speak to a doctor on many occasions. My mum was so well cared for during her stay and my family are extremely grateful for that" [801122]

"I will never be able to thank the nurses and doctors that cared for him in his final days enough. They updated my family daily (who unfortunately could not visit) they looked after myself when I was with him." [759015]

Furthermore, positive accounts cited an *increased* frequency of contact when the patient in question suffered from neurological conditions such as Alzheimer's.

My mother suffers from dementia which always makes us anxious when she has to come into hospital. This was exacerbated by the fact that visiting was suspended due to Covid-19 … Despite us not being able to visit, my family were involved and consulted throughout her stay. [771261]

Feedback described the increased frequency of contact as a significant source of relief, as concerns were raised with regard to the patient's ability to comprehend the medical information being discussed at the bedside. Therefore, from the positive accounts it seemed healthcare providers recognised the need to maintain high levels of contact with relatives, and acknowledged the requirement to increase contact when patients had relative comorbidities, despite the greater pressures caused by the virus.

One major reason was cited for negative experiences. Many relatives described a complete inability to contact the ward providing care to the patient, despite numerous attempts to do so.

"[...] we (the relatives) found it frustrating waiting at home. We phoned regularly, often with the phone ringing out." [805229]

"[...] His wife has repeatedly tried to phone but is cut off or unable to get any answer…" [803228]

This shows the significance relatives place on access to communication with healthcare providers. The added pressures of the virus on healthcare staff, coupled with greater uncertainty and anxiety of relatives could potentially explain the root of the negative experiences. However it would be unfair to attribute these solely to the pandemic - extreme lack of communication, even in 'normal times' would most definitely lead to a negative experience also. The current climate may simply have exacerbated its occurrence.

<u>Visiting</u>

Visiting policies had a significant effect on communication between healthcare providers and relatives. In total, 72.5% of feedback (n=29) made reference to this fact. Overall, 41% of accounts (n=12) were positive, 52% (n=15) were negative and 7% (n=2) were mixed, offering a balanced picture in this domain.

From the negative feedback, several consistent themes emerged. Numerous accounts detailed misunderstandings between healthcare staff and relatives with regard to the correct application of government guidance in force at that particular time.

"I have been told by several staff members in this ward as well as the nurse specialist for the elderly I can not go and visit and provide care for my mother to whom I am a full-time carer and also having Guardianship order. Staff in this ward report this is due to Covid- 19 restrictions and that they are sorry for any distress that this has and may cause both to me and mother. I feel that staff are not well informed of the visiting guidelines as it clearly states in GGC visiting guidelines under the Special Arrangements [...] Due to their lack of

demonstrated understanding and awareness of the policy, I feel both me and my mother have been treated far from person-centred care." [800729]

"She went to A&E and asked to see my grandmother, the nurse said no [...] I have read on NHS Greater Glasgow that there are exceptions allowed for visiting: 1. End of life care. 2. Birthing partners. 3. Children in hospital. I understand Greater Glasgow is not NHS Tayside. However, this is basic human rights." [768359]

This issue can most definitely be attributed to the pandemic, and the uncertainty it afforded with regards to visitation rights. The pandemic resulted in a mismatch of goals between relatives and healthcare providers - while relatives were eager to visit patients, providers were keen to minimise footfall in an attempt to reduce transmission within hospitals. In addition, the dynamic nature of pandemic policy changes also meant that providers could not be as clear as they normally would regarding hospital policy. Thus, it resulted in a decline in the *quality* of communication between the two parties.

When the quality of information remained at a high degree despite the lack of visitation, positive feedback was generated.

"Unfortunately due to Covid 19 we were not allowed to stay with him. Although this was worrying it quickly became apparent that he was in the best possible hands. Every member of staff from receptionist to medical staff were exceptional. I was also given the opportunity to speak with the doctor from A&E over the phone and felt completely reassured by this." [806350]

"We couldn't visit for 10 days but the staff were great!... Thanks to all the staff for caring for him ... especially Dr Deeny! He phoned me with regular updates (and) was a great support to me through an awful time when other family members couldn't be. Myself & my family will be forever grateful." [772368]

This once again highlights the balanced nature of the pandemics effects on the quality of communication discussed between healthcare providers and relatives. In some instances, the lack of visitation resulted in the deterioration of communication, however stories which generated positive ratings showed providers willingness to adapt to the uncertainty of the external environment. This effort was recognised in numerous positive accounts.

"...during these difficult times we never felt we were left out of mums care, it's hard on families who are used to being with their loved ones to be apart however we were kept informed of all aspects of mums care." [772753]

Discharges

Communication between healthcare providers and relatives regarding the *discharge process* was discussed in 25% of accounts (n=10). Interestingly, 90% of feedback (n=9) was negative in this domain, and only one account described positive healthcare-relative communication. Furthermore, no significant discrepancies in the data could be ascertained when defined by time frame. It was possible to establish several consistent reasons for the overwhelmingly negative outlook of stories in this domain.

Numerous accounts described occasions in which relatives were subject to considerable uncertainty regarding the expected duration of the patient's stay in hospital. This resulted in substantial confusion and additional anxiety for the relative, since healthcare staff did not communicate a definitive action plan.

"...we (the relatives) found it frustrating waiting at home... When we did manage to speak with a nurse we were told that our relative would be possibly discharged that day. We waited for the phone call to say our relative was being discharged home however this didn't happen. Instead we phoned in the early evening to be told that our relative would be staying in." [805229]

"... thinking she would be discharged each day mum had to chase the staff on a new ward at 6pm to find out when she could leave. the answer was there is no note about discharge here. There was no sense that the one person that should be informed about if the are going home or not was told nothing" [773769]

It would be extremely harsh to attempt to connect this factor to the pandemic alone, since diagnostic uncertainty is inherent in all medical systems, regardless of the external environment. However, an argument regarding the impact of the pandemic on the *perceptions* of relatives regarding communication could be made. Due to the stressors inherently generated by the pandemic, relatives are perhaps more eager to discover a patient's expected length of stay in hospital, compared with 'normal times'. If one were to assume diagnostic uncertainty as a constant factor, a mismatch could be observed - relative's information demands regarding discharge have increased, yet diagnostic uncertainty remains unchanged. This could potentially explain the friction in communication between the two parties, since healthcare providers are simply unable to provide the new levels of information required by relatives.

Feedback also detailed occasions where the lack of communication led to patients being discharged without any notice to relatives.

"On Monday there was no plan about her coming home and I was to call back on Tuesday. When I called on Tuesday they thought she might get home in the afternoon. A further phone call identified that she may get home on Wednesday but they thought it may be Thursday or

Friday. On Wednesday I got a call to say if transport and STARs could be organised she may get home that afternoon but they would call back. I was absolutely stunned when the doorbell rang in the evening and this was transport bringing her home!"
[Added response, 786140]

"Mum was discharged with no information given to us and we discovered at home that she had two fractured vertebrae! She had travelled home by private car" [774345]

Despite each account's extreme nature, it would be unjust to exclusively link them to the pandemic, since these would be viewed negatively regardless of the external climate.

<u>End of life discussions</u>

Relative's experiences of communication with healthcare staff when family members were palliative comprised 20% of accounts (n=8). Interestingly, 100% of feedback was positive. The ability to visit relatives in their final moments and open, consistent dialogue between healthcare staff and relatives was cited in numerous accounts as a substantial relief, affording relatives peace of mind prior to and after their family member's death.

"During this health crisis, they showed compassion and consideration by allowing us to be with her during her last hours of her life. They also went out of their way to check on our wellbeing and offer emotional support." [759751]

"When dad became poorly I was allowed to visit just for an hour each day. Sadly dad passed away [...] Thankfully I was with him holding his hand. Thanks to all the staff for caring for him, [...] especially Dr Deeny! He phoned me with regular updates. He was a great support to me through an awful time when other family members couldn't be. Myself & my family will be forever grateful." [772368]

"...The young doctors, who amongst doing critical work, took the time to call us and keep us informed…" [758987]

The overwhelmingly positive responses in this area highlight the importance of continual, open dialogue in patient care. Attempts to negate any added grief afforded to families of patients in end of life care during the crisis (due to restricted visiting) seems to have been somewhat successful, even in less than ideal circumstances. The positive affection displayed towards healthcare staff highlight the powerful impact consistent, high quality discussions have had on relatives throughout the pandemic.

Communication between patients and their relatives

One of the defining aspects of the last twelve months is the ability or lack thereof of relatives to speak to and visit their family members in hospital. Early on in the pandemic, visitation rights were curtailed dramatically. As time went on, visiting policies were slowly worked out in a patchwork fashion across different health boards, before a full, Scotland-wide policy was published on June 30th 2020.

Of stories that featured communication between patients and those close to them (n=27), 56% (n=15) were predominantly negative, with 44% (n=12) predominantly positive.

From the stories that touched on this topic, it is obvious that people's experiences are dramatically improved when people understand the restrictions, believe they are implemented justly, and are able to be with those close to them when it matters most. Particularly, the themes which emerged from the data were the impact of visiting restrictions on mental health, frustrations with perceived unnecessary regional discrepancies and mixed messages, and the positive power of small adaptations to allow contact between patients and families.

Mental health

In every story that mentioned the impact of visiting restrictions, patients cited negative mental health impacts of not having their relatives be able to accompany or visit them, or relatives felt that their mental health suffered as a result of this. In some cases, there was a perceived danger to physical health too. This is typified in the following stories:

"I suffer with severe anxiety which is made worse being in situations I find upsetting/stressful without one of my family members with me." [794229]

"Given my mother's medical history and language barrier, I am extremely anxious leaving her in this ward where she is unable to communicate her own needs" [800729]

"It is truly heart-breaking not being able to visit your family member or speak to them directly" [821208]

Patients and relatives are also clearly grateful and feel their mental health is improved when visitation and accompaniment is allowed.

"The hospital has allowed visits as my dad is calmer when he sees me and isn't so anxious." [801596]

Evidently then, a key determinant in the mental health of those admitted to hospital, and their relatives, is the ability of those close to the patient to access them. This should be something we strive for, and allow accompaniment and visiting wherever possible.

Clear and consistent messaging

People, while frustrated, understood strict visitation rules. However, when the messaging was mixed or there were regional discrepancies, emotions were significantly more negative. There are many stories on Care Opinion such as the following, which along with others like it indicate that the relatives understand the reasoning behind the lack of visitation. We can infer here that communication was well undertaken.

"In November I took my dad to A&E at Dr Gray's hospital after he suddenly took unwell. Unfortunately due to Covid 19 we were not allowed to stay with him. Although this was worrying it quickly became apparent that he was in the best possible hands" [806350]

However, people begin to feel negatively about communication when messaging is not clear, or there appear to be regional discrepancies. Both of these elements are outlined in a story entitled "*Mixed messages regarding seeing a dying relative*". In it, the person explains:

"My mother has asked to see my grandmother one last time. She was first told this would not be possible but then was told she would be allowed 1 hour at some point when they see fit. [...] She went to A&E and asked to see my grandmother, the nurse said no. She went back upstairs and brought someone else down who said the nurse who said she would get to see her mum before she passes was wrong. I have read on NHS Greater Glasgow that there are exceptions allowed for visiting: 1. End of life care. 2. Birthing partners. 3. Children in hospital. I understand Greater Glasgow is not NHS Tayside. However, this is basic human rights." [768359]

This story highlights two of the main issues encountered in the database. Firstly, as soon as mixed messages appear, the strength of the visiting restrictions suffers. Secondly, when regional disparities are present, the restrictions seem arbitrary and unnecessary, and people feel unfairly affected as a result. However the responses to this story also reveal further detail. Firstly, it appears NHS Tayside policy at this time did allow visiting in the case of palliative patients, so the problem lies with communication rather than policy. Secondly, it is evident that the mother was informed of this and the hospital made all efforts to allow her to be there when her mother died, which she was. This adaptation made by the hospital significantly improved the experience of this person, as they detail in the reply:

"My granny passed away at 4am this morning. My mum spent the night with her and was there with her. Thank you for making it possible for her to spend as much time as she could with my granny" [768359]

In addition as a result of this feedback, the hospital made changes to the communication surrounding its visitation policy. Interestingly, if we look at the palliative stories chronologically, after this story in early May, every other story about palliative care is positive, as outlined above. This suggests that uniform, clear and well-communicated visiting policies, once in place, significantly improve the experiences of patients and their families.

What we can infer then, is that people report positive experiences of communication when they feel it is justified, obvious, and the same for everyone. However, when they feel unnecessary red tape is preventing them from seeing those close to them, they report more negative experiences.

Positive impact of adaptations

The impact of even small amounts of adaptation by staff to allow contact between patients and relatives is present throughout the data, and is evident in this story, in which a patient was admitted to a ward with limited phone signal. They write:

"When I first arrived in Ward 6, there was no phone signal from the bed. [...] In all, it felt utterly peculiar and disturbing that when I most wanted the comfort of my husband and children, I was unable to see, text or talk to them." [759758]

However, they improved significantly following intervention by staff:

"Within the constraints of Covid-19, the nursing team found ingenious ways to make my stay more bearable. For example, realising that a room with a lower window where I could sit and prop my phone up to make a call would be better, they moved me to a new room. Being on the ground floor, they then arranged for my husband to visit outside the window, so I could see him. What a difference that made!" [759758]

This story emphasises the point made in the section above, that the smallest, simplest changes can have drastic impacts on patient mood and wellbeing. When patients and relatives feel that staff are on their side and putting their wishes above all else, reported satisfaction improves dramatically.

Conclusion

From the data and analysis performed above, there are a few conclusions we can draw. Firstly, people are still broadly very happy with how the NHS in Scotland has been functioning. Overall criticality levels are similar to the year before, and the stories demonstrate an outpouring of love and support for the NHS in Scotland. Numerous stories cite exemplary care despite the circumstances, and people remain positive about our healthcare system. However, it is clear that there has been a decrease in satisfaction with communication in NHS Scotland during the Covid-19 pandemic, as evidenced in the satisfaction numbers, and we have tried to ascertain why this is.

Firstly, from the data it is difficult to attribute this increased criticality to a deterioration in the quality of communication between healthcare staff and patients. There are negative stories tied to poor communication in this regard, but it is difficult to concretely tie these to the impact of Covid-19, thus we must look elsewhere.

The answer comes partially when analysing accounts of communication between healthcare staff and the relatives or carers of those in hospital. The impact of the pandemic can be clearly seen in the form of reduced communication and visiting of those in hospital. Negative accounts of inability to visit form a significant reason why people rated their care lower during the pandemic. This is particularly true when people feel the rules are not clear, different regionally or being applied unfairly. However, it is worth noting that feedback regarding palliative care is significantly more positive, showing that in an area where allowances were made, people's experiences improved significantly.

A decrease in the quality of communication between patients and their relatives is also evident in the stories. When people were unable to visit their relatives in hospital, it had a significant negative effect on the mental health of both the patient and the relatives, something which caused stories to be significantly more negative. Again though, when people understood the restrictions and felt that staff were doing everything they could despite the rules in place, experiences were significantly more positive.

In summation, when they are unwell people feel happiest when they are able to be with those close to them, understand the reasons when they can't and believe those reasons are fair. They appreciate when care is person-centred and individual adjustments are made to facilitate their wishes.

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