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**Should I stay or should I go? An exploration of the decision-making behaviour of acute cardiac patients during the COVID-19 pandemic**

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## **Abstract**

**Background:** During the SARS-COV-2 (COVID-19) pandemic efforts to reduce virus transmission resulted in non-emergency patients being deterred from seeking help. The number of patients presenting with acute cardiac conditions reduced, significantly

**Objectives:** To explore the decision-making process, and influential factors in that process, of patients and their family during an acute cardiac event.

**Methods:** A qualitative research design was employed using purposive sampling of patients who experienced an acute cardiac event during the social containment mandates. Semi-structured interviews were conducted, with thematic analysis of interview transcripts.

**Results:** Twenty-five participants were recruited from three UK hospitals. Themes identified were reliance on informal support network, lack of awareness of cardiac symptoms leading to delayed help-seeking, and an indirect COVID-19 effect (e.g. avoiding treatment).

**Conclusions:** These results highlight the need for informed public health messages, targeting patients and their support networks, that allow those in need of treatment to access care.

**Key words; decision making, public health, Covid 19, myocardial infarction, heart failure, cardiac surgery**

## **Introduction**

Internationally, the COVID-19 pandemic has resulted in a substantial increase in excess mortality from non COVID-19 conditions<sup>1</sup>. Many countries have imposed social containment mandates ('lockdowns'), to reduce population movement, as a result emergency attendances at hospital have considerably reduced (37%)<sup>2</sup>. Such approaches are designed to reduce a surge in capacity allowing the management of acute and critically ill COVID-19 patients. Nevertheless, this strategy appears to have deterred the most seriously ill non COVID-19 patients from seeking medical help.

In the United Kingdom (UK) the number of people attending hospital suffering a myocardial infarction (MI) halved during the COVID-19 pandemic, equating to 5,000 patients<sup>3</sup>, with similar reductions reported for acute heart failure<sup>4</sup>, arrhythmia<sup>5</sup> and those requiring emergency cardiac surgery<sup>6</sup>. However this is not just a UK phenomenon; a considerable reduction in the number of patients presenting with acute coronary syndromes has also been reported in Europe<sup>7-9</sup>, USA<sup>10</sup> and Asia<sup>11</sup>.

To understand why people delay seeking help, the British Heart Foundation surveyed 167 UK cardiologists. Overall, 71% felt people were afraid to visit hospital due to fear of being exposed to the virus, and 46% believed that people were worried about putting pressure on the National Health Service (NHS). These concerns are reflected in patients narratives where themes relate to protecting the NHS, fear of negative hospital experience and protecting others from infection<sup>12</sup>. Furthermore, google searches increased for chest pain symptoms in temporal proximity to government messages in the UK to social distancing implementation<sup>12</sup> suggesting government messaging may be influencing patient behaviour, with similar findings in mainland Europe, China and America<sup>13,14</sup>.

These reports focus on the decision maker as an isolated individual rather than exploring how the decision is constructed with the support of others. The decision to attend hospital during the pandemic is shared within an informal support network<sup>12</sup>, reflected in previous work that highlighted the importance of community and social networks in facilitating health seeking behaviour and our own work that noted the role of family and social networks in the decision making of patients post MI<sup>12,15,16</sup>.

However, little is known about the interaction between the patient and others and how the decision is made. Decision making is multi-faceted, influenced by heuristic thinking, mutual experiences and understanding<sup>17</sup>, to decide the optimal behavioural response<sup>18,19</sup>. It is therefore important that studies are designed to allow these layers of complexity to be uncovered with the decision-making processes being recounted from the perspectives of all those involved in the making of the decision, which in some instances require multiple and, conflicting accounts.

Recognising these complexities and understanding the processes that lead to patients deciding to seek medical assistance will help tailor future public health messages. The World Health Organisation (WHO)<sup>20</sup> advocates research that helps us to learn from the current pandemic response to better prepare for the next unforeseen pandemic. Only by understanding this complex behavioural web will we ensure that future health messages are appropriately targeted and reduce the loss of life in future pandemics.

## **Aims**

The aim of the study was to explore the decision-making of patients and their family members/support networks (where involved) when experiencing an acute cardiac event during the COVID-19 pandemic.

## **Methods**

The study adopted an inductive qualitative approach using semi structured interviews, underpinned by Braun and Clarke's <sup>21</sup> flexible orientation to Thematic analysis. This method allowed the data to drive the themes rather than looking for answers to specific questions. Whilst we were interested in exploring decision making, questions were broad, allowing the patient and their family member to tell their story, allowing themes to emerge from the data.

## **Participants**

Participants were recruited during November 2020 till March 2021, using purposive sampling, from three UK cardiac centres in Liverpool, London and Oxford. Ethical approval was granted by the North West- Preston Research Ethics Committee (rec reference 20/NW/0327). Participants were sent the study information sheet and consent form, prior to a phone call from the researcher who took consent verbally. At least a week after the consent taking process the telephone or video interview was scheduled. To be eligible, participants must have experienced a cardiac event during a lockdown period in the UK.

## **Procedure**

A semi-structured interview schedule (see Supplementary Materials) was used to inform interviews. A pilot interview was completed and the transcript reviewed by the research team. The interview schedule was refined to allow more open questioning that would enable the participants to tell their story in line with the underlying inductive approach, interviews ranged from 50 to 85 minutes in length.

Interviews were conducted between November 2020 and March 2021 on a one-to-one or one-to-two (if support person was involved) basis, with a male research assistant (SB), via

zoom video conferencing facility or telephone, dependent on participant preferences and was undertaken at a time that was mutually convenient. No repeat interviews were conducted. Sample size was not pre-determined, recruitment ended once 'data saturation' had been reached and no new or relevant data was gained <sup>22</sup>.

## **Analysis**

Interviews were audio recorded, transcribed verbatim and fully anonymised on an ongoing basis. Member checks were used to ensure that transcripts accurately reflected the patient's experiences. An inductive thematic analysis approach was used, allowing for themes and codes to be strongly linked to the data <sup>21</sup>. This methodology involves six phases; familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report <sup>21</sup>. Codes were associated with inductive rather than deductive reasoning, allowing meaning to be explored rather than testing hypotheses <sup>23</sup>.

In the initial phase of 'open coding', concepts were identified within the text <sup>24</sup>. Data were coded, starting with small sections of transcripts to understand initial concepts, and codes were grouped into themes which represented more of the data. A sample of extracts were randomly selected and sent to a second coder, along with a developed codebook to establish procedural reliability and conceptual credibility <sup>25</sup>. Coded extracts were reviewed to establish coding consistency and disagreements were resolved in a meeting. Final themes were decided upon using saturation appraisal with redundant codes being discarded. Members of the research team were invited to provide critique on decisions and methodology employed, providing an 'external audit' of the work, all themes were approved by the research team. The sample size and purposive method increased the

volume of data collected and maximised the chance for 'negative cases' to be explored <sup>26</sup>.

Data that was not consistent with current patterns or explanations was actively discussed, which reduced researcher bias surrounding researcher preconceptions and allowed reflexivity.

## **Results**

We recruited 25 participants (Table 1) with a mean age of 68.08 ( $\pm 12.28$ ), ranging from 54 to 98 years of age, 48% were female. 56 participants were initially contacted across all three sites by local research staff, six declined to take part, thirteen did not answer the call, one was not eligible, and one did not have a sufficient proficient level of English. The remaining 29 individuals were approached by the researcher (SB) with four individuals not being able to participate at the time or were uncontactable. In the sample, six received surgical repair of aortic dissection, one was diagnosed with atrial fibrillation, eight with a myocardial infarction, five with heart failure and four received coronary artery bypass surgery. Of the sample, nine were early presentation to hospital and sixteen were late presentation. Participants were classified as early presentation if they attended within two hours of symptoms onset, this cut off point was informed by previous research.<sup>27-29</sup>

Three overarching themes relating to cardiac patients' decision making during the COVID 19 pandemic were generated from the study (Table 2).

### **Reliance on informal support networks**

#### ***Disclosure of symptoms and concerns***



The majority of participants initially disclosed their symptoms and concerns to their informal support network (family, friends, neighbours). One participant noted how they immediately rang their wife in the first instance:

*“I knew obviously it wasn’t right. So, I think I rang you at that point, didn’t I? I rang you [their wife] and said, I can’t remember what I said, I said I don’t feel very well, I’m coming home.”*

*Participant 5*

Another participant, who developed a sudden pain while travelling, initially contacted their daughter, who suggested contacting their neighbour; showing the extension of the informal support network outside of family to neighbours.

*“I turned round and slowly made my way home and then I texted my daughter to say I didn’t feel very well at all, I’ve got an awful pain and she said, phone your next-door neighbour or phone 999.” Participant 9*

### ***Co-decision making with informal support network***

When informal support networks are confided in, a process of co-decision making is enacted between the patient and the supporting individual. Supporting individuals suggested seeking medical help for the participant’s symptoms in the form of non-emergency routes:

*“She actually suggested ring 111. And I did, you know, but she’s more knowledgeable about this than I am, she’s a nurse. Oh, okay. So she was pushing me all the time to, you know, see a doctor, go and see your GP and in the end I rung 111.” Participant 3*

Another participant discussed how, through conversation with their wife, they realised they needed medical help. The decision-making process continued from this point, and following frustration with non-emergency routes, emergency services were called directly:

*“Initially before we rang the emergency services, she rang 111 and the automated message was going on about COVID and various things and at this point, as I’m listening to the call on speaker phone, I’m getting more and more panicky that we can’t get through to somebody and in the end, we decided, I said to her could she ring an ambulance” Participant 12*

The decisions of family members who possessed no clinical or caring experience, was driven by a fear of the unknown and urgency surrounding symptoms presentation:

*“So I automatically just dialled 999. Just the sheer fact, the colour of Participant 17 and the pain he was in. And he was on the floor. It was just the whole scenario. I just needed to do something quite quickly. “Participant 17’ wife*

Whereas family or friends of participants, who possessed clinical or caring experience, adopted a more formal approach of support. Accounting for the patient’s family and past medical history, and demographics:

*“His father had a full cardiac history. Um, died quite young. Participant 2’s always been really fit and healthy. We had no warning of this at all. But I thought I know when things are serious and when they’re not, and I could tell this one more serious. So, I did get the ambulance straight away.” Participant 2’s wife*

### **Lack of awareness of cardiac symptoms leading to delayed help-seeking**

#### ***Symptoms were not directly attributed to a cardiac event***

Despite symptoms starting in the participant’s chest, the majority of participants did not attribute symptoms to a cardiac event. The majority attributed their symptoms to mild problems such as indigestion and heartburn:

*“I was sitting at the kitchen table, sat having a cup of tea, and I started feeling this pain and burning feeling in my chest. I thought it was heartburn” Participant 8*

*“I’d had chest pains two weeks prior to that, so I...and last year I had three bouts of these chest pains. So, I just, I’ve always put it down to indigestion, always. “Participant 10*

Another participant discussed how they didn’t attribute symptoms as a cardiac event due to the symptoms not being in their chest:

*“The only thing that I know is when people clutch their chest and that from having pain. So, I wouldn’t have... I think at that time, looking back, I wouldn’t have put it down to being anything to do with my heart” Participant 13*

### ***Symptoms were not severe enough to warrant immediate action***

Instances in which symptoms had eased following the initial onset meant participants did not seek medical help. As symptoms had eased and were no longer acute, the underlying issue was not deemed as serious:

*“It wasn’t debilitating in any way. So, up to that point I was pretty much just to carry on with things, pretty much happy just to carry on with things. Yeah. Because it wasn’t prolonged, I didn’t wake up with any symptom, I was in no discomfort.” Participant 15*

Some participants tried to alleviate the symptoms using a range of methods including simple analgesia, antacids and breathing exercises. Upon easing of symptoms their concerns appear to have dissipated, and they felt able to return to their prior activities:

*“It dissipated, I went for a walk around the house, got back in bed, made some purposefully shallow breaths, relaxed myself and just went back to sleep” Participant 14*

## COVID-19 indirectly effects access to healthcare

### *Avoidance of treatment due to not wanting to burden the health service*

Participants were asked explicitly whether COVID-19 and related government messages had influenced their decision to seek treatment. One participant explicitly stated it didn't influence their decision, and they realised medical help was required:

*"I just never thought about it. You know, I thought, I've got to get this seen to and whatever it is I have to get medical help, you know, whether there's COVID-19 or not, I still have to get medical help." Participant 3*

Public health messages related to COVID-19 may have deterred people from seeking medical help, based on their perception as to what constitutes an emergency.

*"I know what they're trying to tell you, they're trying to tell you that if it's not an emergency then don't come in, because otherwise you can put too much pressure on the A&E"*

*Participant 11*

Later in the interview, they stated how they realise that medical assistance was required, taking precedent over government guidance:

*"I know the severity of the COVID-19, but at the same time, as I said, I might be a bit selfish thinking that ... well, I need to see ... I had to go in to find out is there anything else ... severely wrong me" Participant 11*

Participants suggested hospital attendance was associated with increased risk of contracting COVID-19 from current inpatients. One participant, highlights here how their concern over the virus deterred them from seeking medical help, and particularly emphasised the risk within the hospitals:

*“What I was worried about was obviously the ... I’m thinking, you know, I’m going into the environment where obviously ... the A&E or acute bit, where people are going in and they’re ... you know, they might be carrying the COVID.” Participant 7*

One participant in particular discussed how they had avoided seeking treatment due to COVID, but also had avoided any crowded places, in response to why they were avoiding hospital:

*“Just for safety. It’s better we stay away. I won’t go out as well, I must stay at home. If I want to go out, I just go in a quiet time for a little walk in the park. But I don’t go shopping or busy places, I try to avoid.” Participant 25*

The perception of risk appears to be influenced by the information via media outlets and government briefings that hospitals are under increased pressure, with participants assuming they would automatically be exposed to COVID-19:

*“Because obviously hospitals are full aren’t they and the beds are scarce really. I just in my mind if I was being kept in would I go on a COVID ward” Participant 8*

The inter-play between risk of contracting COVID-19 and the burden on the health service is intensified in cases that have prior direct or indirect exposure to the virus. A participant who had known of someone dying as a result of COVID-19, of a similar demographic background, discussed how there were so many patients diagnosed with the virus and increasing the pressure on the system. Such factors caused the individual to avoid seeking treatment, requiring another individual to make the decision:

*“I mean there are so many... you had so many patients at that time and the numbers were going up all the time, that’s why we went into lockdown. So, I think, unless it was something*

*that really needed treating, if it could wait, then... it would seem the right thing to do to wait. Because... it was running out beds and everything from what it says on the news."*

*Participant 13*

### ***Lack of access to formal/traditional healthcare***

Multiple participants, just under half, held a perception that formal healthcare options were limited as a result of the COVID pandemic, primarily GP service. Participant 3, explicitly states that they would normally ring their GP, but due to the urgency of the situation and the level of care being provided by the GP services, they decided to ring 111 (used for urgent problems when unsure what to do, in comparison to 999 for emergencies):

*"No, the only difference it made was the GPs don't see anybody. You know, they said, well, it would be a telephone conversation, consultation rather, and the doctor would ring you tomorrow. You know, and I thought, you know, the way I was, you know, I had to get medical help, you know, at least find out what the hell happened. "Participant 3*

Participants who had seen their GP prior to lockdown, described how they normally wouldn't hesitate to seek medical help. However, media messages and self-help techniques meant formal help was avoided:

*"As I say, two weeks before that I didn't hesitate. When I couldn't see the doctor and I felt unwell, I didn't hesitate, I just took myself off on my own. But on this occasion, it was ... you know, on the news and everything, about these cases of people unwell and then ... That's why I wouldn't have ... and also, I didn't think I was that unwell, because I felt a bit better and I thought, 'Well, if I can try and sort it out myself it would be better'." Participant 7*

With delays expected in national health services, some participants turned to private medical services (i.e. paid through health insurance rather than publically funded services). Yet this was not exclusive to the pandemic, delays were expected irrespective of this, particularly due to administrative issues and lack of resources:

*“I believe that to get through to the GP now, whether we’re in this crisis that we find ourselves in with COVID or not, it’s firstly an online enquiry, and then you have to wait for them to get back to you when someone is available. But through my Health Insurance there were contact slots available every ten to fifteen minutes, so, to me that was clearly a faster option.” Participant 14*

## **Discussion**

This study explored the decision-making process of acute cardiac patients during the COVID-19 pandemic. Our findings suggest a lack of symptom awareness, transfer of support to informal care networks, when combined with media and government messaging results in the delaying of seeking medical help. Themes presented show the complex nature of decision-making, whereby a range of both cognitive and contextual factors interact with individuals and their support networks.

Findings are consistent with previous work on patient decision-making, whereby a variety of approaches are used to encompass decision-making<sup>30</sup>. Patients appraise the situation and the cost of not making a decision, in relation to alternatives, resulting in commitment and adherence to their choice in relation to personal and situational factors. This suggests a systematic approach to decision making is being subconsciously used by individuals, as proposed by Mann (1968) in the form of the Decisional Conflict Theory (DCT). Furthermore the Fuzzy Trace Theory<sup>31</sup>, Differentiation & Consolidation (Diff Con) theory<sup>32</sup>, and Decisional

Model of Stress and Coping<sup>33</sup>, propose individuals internalise, evaluating current and prior experiences, leading to execution of decision cognitions. Such cognitive processes are deemed to be rapid<sup>34</sup>, following heuristics to guide decision-making, particularly in situations with a high degree of uncertainty<sup>35</sup>. Findings presented in the current study suggest participants made decisions in a combined approach of the aforementioned theories, internalising how they feel in relation to the risk of COVID-19 and their symptoms, resulting in an outcome decision to seek medical treatment eventually being made. Our findings extend the current literature by showing how others are involved in patient decision making, and in some cases make the decision on behalf of the patient.

Some decision making theorists claim that the process is un-systematic, in the sense that individuals defer decision making to an expert, e.g. doctor, known as the 'expert opinion heuristic'<sup>36,37</sup>, yet evidence for this notion is tenuous<sup>38</sup>. COVID-19 lockdowns meant individuals perceived such 'expert opinions' to be blocked and led to patients seeking help from informal support networks. Decision making has long been a shared process, in which there was a dialogue between the patient and their support network surrounding medical aid, which is enhanced during a pandemic due to the nature and risks that are involved. Previous work has shown the role of more informal support networks in patient decision making<sup>12,39,40</sup>, with the former finding that, during the COVID-19 pandemic individuals rely heavily on informal networks which often contain healthcare professionals. Our analysis provides a unique distinction within these informal networks, namely those with previous medical knowledge adopt a systematic and heuristic based approach to aid patient decision making, while those without act on a much more primal fight or flight-based system.



Lack of symptom awareness and a failure to link symptoms to a cardiac condition is consistent with previous work. We found participants mainly expected pain around their chest for a cardiac condition. Indeed, a recent review has shown that patients have good knowledge of said hallmark symptoms of myocardial infarction but not the more infrequent types <sup>41</sup>, with similar concerns for heart failure <sup>42</sup> and arrhythmia<sup>43</sup>. Previous work exploring myocardial infarction symptomology has proposed that public health campaigns should specifically target this lack of knowledge <sup>44</sup>, with our findings supporting this proposal with an extension to other acute cardiac conditions.

The majority of participants sought medical aid from their local emergency department. However, it appears that there is a concern of over-burdening services during the COVID-19 pandemic. Such views are not exclusive to this time period <sup>45,46</sup>, but have been enhanced due to frequent news reports and government messages. Such cognitions were coupled with patient concerns of contracting the virus while in hospital, due to the quantity of cases, leading to further delays to presentation at hospital. Delays may be explained through the health belief model, in which health behaviours are influenced by the perceived threat and consequence as a result of disease <sup>47</sup>. Individuals are faced with the decision to seek medical advice for their current symptoms, with the potential of contracting the virus in a burdened health service, or delay seeking treatment waiting for an alternative option. Such forms of decision making are similar to value-based models, in which depending on the patient's intrinsic value of a behaviour (i.e. seeking help) it can be constantly updated in relation to external factors (i.e. informal support network, intensifying symptoms). Communication strategies to reduce community spread of the virus are intended to have a positive effect <sup>48</sup>; however said strategies can increase unhealthy behaviour <sup>49</sup>, increased inequity in access to healthcare <sup>50</sup>, and reduce primary care contact. <sup>51</sup>

There were limitations within the study. We aimed to capture a wide range of patients across all genders, experiencing differing acute cardiac conditions, including both early and late presentations. Whilst we achieved this goal our sample was mainly limited to white British participants. A more culturally diverse sample should be used in future research to account for culturally specific factors, such as religion and family beliefs <sup>16</sup>. Further to this, while we interviewed participants over multiple lockdowns, we did not account for differences across the lockdowns. In addition, some interviews were undertaken long after some participants' admission, impairing recall for specific details (i.e. conversations with family), losing the nuance of these interactions. Future research should seek to investigate such decision-making processes in a variety of populations, to assess the influence of culture and socio-economic status on such processes.

## **Conclusion**

In conclusion, our findings suggest that decision making during the COVID-19 pandemic was influenced by both individual participant views and their wider support network. Particularly government and media messages should be carefully tailored as to not inadvertently deter people from seeking emergency healthcare. In addition, there is an urgent need to educate the public regarding symptoms of acute cardiac conditions, outside of the hallmark traits, to facilitate rapid treatment of patients and enable the best possible outcome.

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## **Conflicts of interest**

IJ has received research grant funding from Bristol Myers Squibb and Astra Zeneca. DJW provides consultancy services to Boston Scientific and Medtronic. All other authors have no conflicts of interest.

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<b>Participant number</b>	<b>Age</b>	<b>Gender</b>	<b>Ethnicity</b>	<b>Early or Late presentation</b>	<b>Reason for hospital attendance</b>
1	71	Male	British	Early	Myocardial Infarction
2	62	Male	British	Early	Aortic Dissection
3	69	Male	British	Late	Myocardial Infarction
4	53	Male	British	Early	Aortic Dissection
5	74	Male	British	Late	Coronary Artery Bypass Surgery
6	73	Female	British	Early	Aortic Dissection
7	61	Female	British	Early	Atrial Fibrillation
8	65	Male	British	Early	Myocardial Infarction
9	80	Female	British	Late	Myocardial Infarction
10	63	Female	British	Late	Myocardial Infarction
11	54	Female	Chinese	Late	Aortic Dissection
12	49	Male	British	Late	Myocardial Infarction
13	67	Female	British	Early	Aortic Dissection
14	48	Male	British	Late	Myocardial Infarction
15	98	Female	British	Late	Heart Failure
16	58	Male	British	Late	Myocardial Infarction
17	85	Female	British	Late	Heart Failure
18	76	Female	British	Late	Heart Failure
19	80	Male	British	Early	Coronary Artery Bypass Surgery
20	80	Female	British	Late	Heart Failure
21	76	Male	British	Late	Heart Failure
22	80	Female	British	Early	Coronary Artery Bypass Surgery
23	55	Male	British	Late	Aortic Dissection
24	66	Male	British	Late	Coronary Artery Bypass Surgery
25	59	Female	Pakistani	Late	Coronary Artery Bypass Surgery

Table 1 Participant characteristics

<b>Patient decision making during acute cardiac episodes</b>		
<b>Reliance on informal support network</b>	<b>Lack of awareness of cardiac symptoms leading to delayed help-seeking</b>	<b>Indirectly COVID-19 effects access to healthcare</b>
Disclosure of symptoms and concerns	Symptoms were not directly attributed to cardiac event	Avoidance of treatment due to not wanting to burden the health service
Co-decision making with informal support network	Symptoms were not severe enough to cause immediate action	Lack of access to formal health care options

Table 2 Themes and sub-themes of the thematic analysis