

Lived Experience of Emergency Health Care Utilization during the COVID-19 Pandemic: A Qualitative Study

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Abbreviations:

COVID-19: coronavirus disease 2019
ED: emergency department
EHS: emergency health care service
PPE: personal protective equipment

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Abstract

Introduction: As the understanding of health care worker lived experience during coronavirus disease 2019 (COVID-19) grows, the experiences of those utilizing emergency health care services (EHS) during the pandemic are yet to be fully appreciated.

Study Objective: The objective of this research was to explore lived experience of EHS utilization in Victoria, Australia during the COVID-19 pandemic from March 2020 through March 2021.

Methods: An explorative qualitative design underpinned by a phenomenological approach was applied. Data were collected through semi-structured, in-depth interviews, which were transcribed verbatim and analyzed using Colaizzi's approach.

Results: Qualitative data were collected from 67 participants aged from 32 to 78-years-of-age (average age of 52). Just over one-half of the research participants were male (54%) and three-quarters lived in metropolitan regions (75%). Four key themes emerged from data analysis: (1) Concerns regarding exposure and infection delayed EHS utilization among participants with chronic health conditions; (2) Participants with acute health conditions expressed concern regarding the impact of COVID-19 on their care, but continued to access services as required; (3) Participants caring for people with sensory and developmental disabilities identified unique communication needs during interactions with EHS during the COVID-19 pandemic; communicating with emergency health care workers wearing personal protective equipment (PPE) was identified as a key challenge, with face masks reported as especially problematic for people who are deaf or hard-of-hearing; and (4) Children and older people also experienced communication challenges associated with PPE, and the need for connection with emergency health care workers was important for positive lived experience during interactions with EHS throughout the pandemic.

Conclusion: This research provides an important insight into the lived experience of EHS utilization during the COVID-19 pandemic, a perspective currently lacking in the published peer-reviewed literature.

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Introduction

A growing evidence-base has explored the lived experience of health care providers throughout the coronavirus disease 2019 (COVID-19) pandemic^{1–6} and reported major changes in the utilization of health care services.^{7–10} What is less understood is the lived experience of people utilizing emergency health care services (EHS) during the pandemic.

In qualitative phenomenological research, lived experience refers to a representation of the experiences and choices of a given person, and the knowledge that they gain from these experiences and choices. It stresses that only those that have experienced phenomena can communicate them to others and provide an understanding of an experience from those who have lived it.¹¹

The earliest report of patient-perspective lived experience during COVID-19 was a description of what three patients with mental health issues experienced in hospital isolation units.¹² Further research sought to provide rich and contextual insight into patient lived experience in the context of hospital isolation.¹³ More recently, the body of work has shifted to a focus on health-related beliefs,¹⁴ along with describing the mental health impact of the pandemic¹⁵ and documenting the persisting symptoms associated with the virus.¹⁶

In light of the on-going impact of the pandemic around the world, there is an increased need to glean more insight into the lived experiences of patients utilizing EHS in order to inform evidence-based practice.

Australian Experience of COVID-19

With a population of around 25 million, Australia has experienced lower infection and death rates for COVID-19 than many comparable countries.¹⁷ Australia's response to the pandemic to date, along with the experiences of those utilizing EHS, offers valuable and actionable insight for decision makers around the world.

Australians experienced two distinct spikes in COVID-19 cases during 2020; the first occurring in March–April, followed by a subsequent second spike in July–September. With a population of around 6.6 million,¹⁸ the south-eastern state of Victoria primarily attributed to this second wave of cases,¹⁹ with people in metropolitan Melbourne and some parts of regional Victoria experiencing some of the most stringent restrictions imposed anywhere in the world.²⁰

The objective of this research was to explore the experiences of Victorians when utilizing EHS, including emergency ambulance transport and presentation to a hospital emergency department (ED) during the COVID-19 pandemic.

Methods

Recruitment

Saturation sampling was undertaken by inviting all members of a commercially available pre-recruited panel of more than 6,000 Australians to participate. All members of the pre-recruited panel were invited to login to a website and complete a related survey which included an invitation to participate in this follow-up qualitative study. Pre-recruited panel members then indicated their availability for participation. Panel members who met the eligibility criteria of (a) residing in the state of Victoria and (b) had utilized EHS during March 2020–March 2021 were invited to be interviewed. Recruitment continued until a saturation of themes was identified by the research team.

Data Collection

Interviews were conducted by telephone or via electronic media. A semi-structured script was utilized during the interviews to prompt discussion while still allowing for flexibility in probing and phrasing of questions. Prescribed questions were included, asking if the participants suffered from a chronic health condition, and if so, what the nature of their chronic health condition(s) were, as well as whether or not the participant felt they had delayed utilizing EHS during the pandemic. Further prescribed questions asked if participants had utilized EHS during the pandemic for acute health conditions, and if so, what type of acute health condition. The questions were developed following discussion by four members of the research group and were designed to elicit responses around the participants understanding of, and experience of utilizing, EHS during the COVID-19 pandemic in Victoria, Australia. Each interview was approximately 30–45 minutes in duration. With the permission of participants, all interviews were audio recorded.

Data Analysis

Interviews were conducted independently by two members of the research team and were transcribed verbatim and analyzed using Colaizzi's approach.²¹ Colaizzi's approach is used to identify, understand, and describe the experiences of research participants, also revealing emergent themes and their interwoven relationships.

This research also utilized phenomenology, a useful qualitative methodological approach for enabling researchers to put aside their perceptions of a phenomenon and give meaning to a participant's experiences.²² Exploring the experiences of others enables previously unavailable insights to be discovered.

Due to the exploratory nature of the interviews, a coding protocol was developed for data analysis using a combination of several qualitative analytic approaches. Analysis began with manual, unrestricted coding of the data to identify relevant segments and to open up the inquiry.²³ This process included initial review of all transcribed interviews, identification of key segments, and the subsequent coding or labeling in margin notations. Axial coding was then conducted to relate the data together in order to reveal codes, categories, and sub-categories within the research participants' voices. Selective coding was then used to identify any overarching themes represented in the data.

For core coding categories, two independent members of the research team coded 25% of the data. Inter-coder agreement was assessed using the kappa coefficient, and agreement was high (0.90) for all coding. Discrepancies were resolved through discussions until 100% agreement on themes was achieved, and the remaining transcripts were divided between the two coders for independent coding. Ethical approval was granted by the Edith Cowan University Human Research Ethics Committee (Joondalup, Perth, Western Australia; Project # 2020-01858).

Results

(*Names have been changed to protect the identity of individual research participants.)

Qualitative data were collected from 67 participants using semi-structured, in-depth interviews. Participants were aged from 32 to 78-years-of-age (average age of 52) and all self-reported utilization of an EHS in Victoria during the COVID-19 pandemic (from March 2020 through March 2021). Just over one-half (54%) of participants were male, and the majority (75%) lived in metropolitan Melbourne compared to participants residing in rural and regional Victoria. A total of 43 participants self-reported having a chronic health condition for which they had utilized EHS during the COVID-19 pandemic. Twenty-four participants self-reported an acute health condition for which they utilized EHS for during COVID-19, of these, 19 also self-reported an acute health condition. A total of ten participants self-reported that they were carers of someone living with a sensory or developmental disorder, and nine participants self-reported that they were parents or carers of children or older people who had utilized EHS during the COVID-19 pandemic.

Four key themes emerged from data analysis: (1) Concerns regarding exposure and infection delayed EHS utilization among participants with chronic health conditions; (2) Participants with acute health conditions expressed concern regarding the impact of COVID-19 on their care, but continued to access services as required; (3) Participants caring for people with sensory and developmental disabilities identified unique communication needs during interactions with EHS during the COVID-19 pandemic; communicating with emergency health care workers wearing personal protective equipment (PPE) was identified as a key challenge, with face masks reported as especially problematic for people who were deaf or hard-of-hearing; and (4) Children and older people also experienced communication challenges associated with PPE, and the need for connection with emergency health care workers was important for positive lived experience during

interactions with EHS throughout the pandemic. Each of these themes will be discussed in further detail.

Chronic Health Conditions

As the world continues to navigate the COVID-19 pandemic, many EHS are actually less busy than usual, with fewer patients utilizing emergency ambulance transport and presenting to hospital EDs in Australia and around the world.^{24–26} People may be choosing to stay away for fear of exposure to, or infection with coronavirus, a concern reflected among research participants in this study. Fear of exposure was a concern expressed by nearly all participants with a chronic health condition, while fear of becoming infected with coronavirus was reported by 11 participants. The fear of being exposed was discussed by Manuel*:

I just feel safer at home, so unless it's really an emergency, I'm not going to go to the busy emergency room. That's where the sick people are, so that's where the virus is, so if I go there, then I'm going to be surrounded by it, you know, exposed to it. I'd rather just stay away. – Manuel*, 53-year-old male participant.

Concern regarding exposure and infection among participants with chronic ill health was justified. People living with chronic health conditions tended to get sicker than the overall population if they catch coronavirus, and were more likely to die.²⁷

Of the 43 participants with self-reported chronic health conditions, almost one-half reported that they had delayed utilizing EHS during the pandemic for acute exacerbations of their condition. Maria* had heart disease and lived alone. The 64-year-old reflected on how she delayed seeking emergency health care for her health condition during COVID-19:

I had been feeling unwell for a couple of days, so I had an appointment with my doctor over the phone and he told me to call an ambulance and go to the hospital. But I really didn't want to get COVID. So, I thought I would wait and see how I felt the next day, I thought I would get better. But I woke up in the middle of the night with some pain in my chest, and I was worried that it was my heart, because I have a heart condition. So, I called an ambulance then. – Maria*, 64-year-old female participant.

Maria* was not alone in delaying her EHS utilization during the pandemic. A study from the Netherlands reported that one-in-five respondents delayed seeking emergency care, with almost one-half of those indicating that the pandemic was the cause for the delay.²⁸ By June 30, 2020, 12% of adults in the United States had delayed or avoided utilizing emergency medical care due to concerns about COVID-19.²⁹

During the first spike in COVID-19 cases in Victoria, Australia during March through April 2020, cancer diagnoses and monitoring of immuno-compromised people with chronic health conditions declined as Australia's pathology sector recorded a 40% drop in routine testing.³⁰ From fear of coronavirus to wariness about first responders bringing the virus into their homes, chronically ill research participants reported delaying or avoiding utilization of EHS during the pandemic due to fear of exposure and infection. When they did utilize EHS, they reported increased levels of fear and anxiety.

Joan* lived with a chronic respiratory illness. She woke up during the pandemic short of breath, her regular medication not providing the usual relief. Concern of exposing herself to a waiting room full of potential COVID-19 patients kept her away from the hospital:

Before COVID, if I was short of breath and not getting much relief from my medications at home, I wouldn't have thought twice about going to the

hospital. But now, I often stay away because I don't want to be among other people who have it. I don't even want the paramedics coming into my home and bringing the virus in with them on their feet or on their equipment. – Joan*, 71-year-old female participant.

Joan* knew that her chronic condition could potentially lead to serious, even life-threatening episodes, but that did not outweigh her concern about being exposed to coronavirus. This feeling of “not wanting to take a risk” was reported by many research participants living with a chronic health condition.

Acute Health Conditions

The COVID-19 pandemic did not appear to impact utilization of EHS for participants experiencing self-reported acute health conditions. When participants experienced an acute health episode or exacerbation of their chronic health condition during COVID-19, they utilized EHS the same way they would have prior to the pandemic:

I had an asthma attack; it was quite frightening. I didn't think twice! I called 000 [the Australian emergency telecommunications number]. The ambulance still came on time, it was harder to talk to the paramedics because of all the protective gear, but I still received the same care. The pandemic didn't change any of that. – Sue*, 35-year-old female participant.

Participants emphasized that while their utilization of EHS did not change, their lived experience was influenced by COVID-19. All participants who had utilized emergency ambulance transport during the pandemic reported how they found PPE on paramedics confronting. Face masks posed significant barriers to effective communication, as previously documented.³¹ When combined with the additional PPE often required in hospital ED settings in order to safely administer treatment, such as visors, goggles, and gowns, one emergency health care worker could become visually indistinguishable from the next:

I was in excruciating pain, and I was on my own [in the ED]. There were so many doctors and nurses coming in and out, they all had protective clothing and face masks on, so it was difficult to tell them apart. When you are feeling scared, alone, and in pain, it helps to have a friendly face, and even that was taken away. But there was one nurse that stood out, she came over and held my hand, I remember her, because she said to me, “you can't see it, but I'm smiling at you.” That helped. – Therese*, 46-year-old female participant.

Sensory and Developmental Disabilities

Participants caring for people with sensory disabilities identified that communicating with emergency health care workers wearing PPE during the pandemic was a challenge. Specifically, difficulties arose when face masks impeded facial visibility and made lip-reading problematic or distorted speech sounds.

Julie* emphasized the unique needs of the deaf and hard-of-hearing who experience significant communication barriers in normal times, with the COVID-19 pandemic further exacerbating pre-existing disadvantages and making it difficult to communicate and receive appropriate care during the pandemic:

My brother is deaf, and when he had a seizure during the pandemic, he found it really difficult to understand what was going on with both the ambulance and emergency department staff. You could tell he was frightened, and everyone was in full gowns and masks, which we understood, but it just meant that he didn't know what was being said. The use of clear masks would have been great because he can lipread. It also would have been good just to see people's faces, he takes so much from people's visual cues. It's amazing how reassuring a smile is. – Julie*, 52-year-old female participant.

Participants caring for people with developmental disabilities highlighted how changes in routine and general uncertainty associated with the pandemic impacted interactions with emergency health care workers during COVID-19. Mary* reflected on the experience she had when utilizing EHS for her son James* who has autism:

My child is autistic, and routine is really important for managing his anxiety. But the pandemic has meant that so much of his usual routine has been disrupted. I've noticed a real spike in his anxiety, and he has taken to obsessively using hand sanitizer as a way to cope. When we recently needed to call the ambulance, the paramedic kept trying to take his sanitizer away to examine him. He was quite young; I don't think he had ever dealt with an autistic kid before. Between the protective gear and him trying to take his sanitizer away, James* became really, really distressed. – Mary*, 42-year-old female participant.

Adrian* had a brother with a developmental disability. He reflected on an experience during the pandemic when his brother had required emergency ambulance transport and subsequent treatment at the ED:

I had to keep telling them not to touch him, I know it's hard when they are trying to treat him, but he hates being touched by people, he doesn't even like me touching him and I'm his brother. So, I know that's hard, because when everyone is wearing all this PPE and we can't see faces and people are using touch to try and communicate, but we have to remember that touch may not be wanted, and that sometimes any touch can be upsetting, even distressing. – Adrian*, 33-year-old male participant.

Children and Older People

Research participants identified that children and older people had unique needs when utilizing EHS during COVID-19. Participants who had children, and older people who had utilized EHS during the pandemic, reflected on the need for effective communication and the provision of clear, concise information which may often need to be repeated to ensure it was appropriately understood.

This need for clear, repeated communication was demonstrated by Gina*:

We needed to call an ambulance for my husband, he became ill at night. When the paramedics arrived, they told us that they couldn't take him to hospital and to call back if he got worse. In the middle of the night, he was sicker, but I didn't want to be a bother and call those paramedics back again, so I waited until the morning and called my daughter. – Gina*, 76-year-old female participant.

By the time Gina's daughter Angela* arrived the following morning, her father was unconscious. Another ambulance was called, and her father was rushed to hospital. He died of sepsis in the intensive care unit later that day:

Mum didn't understand that she could call back. She thought she was being a nuisance. Paramedics need to make sure that the elderly clearly understand what they are telling them, especially when English is their second language. – Angela*, 32-year-old female participant.

It was also important that a sense of connection was established to improve the likelihood that instructions would be followed, and patient outcomes would be improved. A sense of connection was also recognized as being important for parents during EHS utilization, as well as children, and it was acknowledged by participants that creating this connection and rapport was more difficult due to the physical barriers created by PPE. In addition to the physical limitations created by PPE, communication challenges were exacerbated by heightened levels of anxiety and stress created by the current fears associated with the pandemic.

Discussion

Throughout the COVID-19 pandemic, emergency health care workers have worn combinations of surgical face masks, particulate filter respirators (such as P2 or N95), face shields, gloves, goggles, glasses, gowns, and aprons, or a combination of these options. While providing protection for both patient and emergency health care worker,³² some forms of PPE can create barriers to effective communication. Face masks can reduce the ability to hear and impede the use of lip-reading. They can also impact visualization of facial cues, which support non-verbal communication and directly influence feelings of connection and trust. A study of over 1,000 patients randomized to mask-wearing and non-mask-wearing physicians revealed a significant negative effect on patient perception of physician empathy in consultations performed by mask-wearing physicians.³³

The use of transparent face masks could potentially mitigate the communication barrier associated with this form of PPE. In a randomized clinical trial, surgeons wearing clear face masks compared to standard surgical masks were rated significantly higher by patients for providing understandable explanations, demonstrating empathy, and eliciting trust, suggesting that not seeing the surgeon's face may have negative consequences for the doctor-patient relationship.³⁴ Although efforts have been made to develop medical-grade, transparent face masks to facilitate lip-reading, these have not yet been made available for wide-spread clinical use on a global scale.

Further miscommunication may stem from patient reluctance to request clarification. Pamungkasih, et al³⁵ found that in situations where patients were unable to hear or interpret information provided by a clinician, patients were inclined to "make a guess" as to the topic or nature of discussion, or regarding treatment or care instructions. This lack of understanding may directly impact patient outcomes, and therefore, emergency health care workers have a responsibility to recognize these communication challenges and actively adjust their own practices to compensate for any barriers to communication.

Methods for optimizing communication during the challenging circumstances presented by the COVID-19 pandemic include practical strategies that can be implemented across all EHS. The following recommendations are based on the lived experience of the participants in this research study:

1. Clearly introduce yourself and make sure your identification tag is visible; if you wear a clear face visor/shield, you could write your name on it (this is particularly helpful for older patients).
2. Attach a photo of yourself to the front of your PPE or around your neck on a lanyard, if possible.
3. Wear transparent face masks, if possible.
4. Provide a clear explanation of the need for PPE (including how often it has been changed). While many patients will be aware of the COVID-19 pandemic, they may not understand why they are being approached with such caution.
5. Speak clearly using short sentences, repeat yourself if necessary to ensure you have been understood. Asking patients to repeat information back to you is a good way to ensure information has been understood.
6. Communicate through exaggerated body language and facial expressions through clear face masks and face visors/shields, where possible.
7. Verbalize how you are feeling or what your facial expression is to your patient when they can't see it (eg, "I'm smiling right now even though you can't see it behind my mask").

8. Be aware that a high proportion of people aged over 65 will have mild or moderate hearing loss. When appropriate, supply PPE to family members or carers to assist in effective facilitation of communication. Where possible, utilize the services of an interpreter.
9. People with developmental disabilities such as autism may present as nonverbal when highly stressed; the presence of PPE may add to existing anxiety. Try communicating with short sentences and explain any assessment or treatment in advance. If transporting the patient, explain where they are going and what and who they may see on arrival, including any PPE they may be wearing. This may avert unnecessary anxiety. Individuals who present as nonverbal may be able to write or type responses. When possible, avoid use of lights and sirens. Sound and light sensitivity is common in autism and may cause further anxiety during the COVID-19 pandemic.

Limitations

The findings reported in this publication are subject to several limitations. From a methodological perspective, the sampling methods utilized are an example of non-probability sampling. However, researchers often use non-probability samples for projects that are qualitative in nature where the research question is exploratory in nature and the researcher's goal is in-depth, contextual understanding rather than more general, nominal understanding. The results are based on the responses of a small number of participants ($n = 67$) from the Australian state of Victoria. Future research should repeat this methodology with a broader range of community

members who have utilized EHS during the COVID-19 pandemic.

The qualitative methodologies utilized throughout this research allow for exploration of individual perceptions, feelings, and needs. They are not, however, without their limitations. For example, individual descriptions of lived experience by individual research participants will potentially be biased by their reliability of recall, previous experience, and the way in which the discussion is framed. Furthermore, an individual's intrinsic psychological processes may also influence how they experience certain types of events. Notwithstanding these methodological limitations, this study has provided an important contribution of new knowledge and is the first published account of lived experience during the COVID-19 pandemic from the perspective of those utilizing EHS.

Conclusion

This research provides an important insight into the lived experience of EHS utilization during the COVID-19 pandemic, a perspective currently lacking in the published peer-reviewed literature. While PPE provides protection for both patient and emergency health care worker during the pandemic, some forms including face masks create barriers to effective communication, potentially impacting patient outcomes and influencing lived experience during EHS utilization. This research has identified evidence-informed, practical strategies that can be implemented by emergency health care workers to mitigate the communication and connection barriers identified in this research.

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