

## Original Article

## Expressions of Compassion during COVID- 19 Pandemic

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### Abstract

**Purpose of study:** The purpose of this qualitative research study is to describe COVID-19 survivors understanding and experiences of compassionate care during their hospitalization

**Design of study:** A qualitative exploratory design was utilized to discern participant's perceptions of compassion.

**Methods:** A purposive sample of adult survivors of COVID-19 hospitalization was obtained through announcements on the social media platform Facebook. Criteria for study enrollment included individuals over the age of eighteen who had been hospitalized as a result of complications from COVID-19. A semi structured interview was utilized to explore participant's experiences of compassionate care practices by health care workers. Thematic analysis, a method for identifying, analyzing and reporting patterns (themes) within data was utilized until saturation was reached.

**Findings:** An analysis of findings revealed four themes: Compassion without fear; Compassion with confidence; Compassion through physical presence; Compassion through listening. These themes were repeated throughout all interviews.

**Conclusions.** The COVID-19 survivors in this study provided profound examples of the compassionate care they experienced during their hospitalization. The study participants shared stories of being on the receiving end of compassionate practices which helped them to feel connection at a time when they were most isolated and vulnerable.

**Key words:** COVID-19, Caring, Compassion, Health care workers, Nurses, qualitative research

### Introduction

Coronavirus disease (COVID-19), a highly infectious disease caused by a newly discovered coronavirus, was first confirmed in the United States on January 21, 2020 (U.S., 2020). Although many cases are mild with symptoms that are usually self-limiting, some people with the illness have become severely ill quickly and required immediate hospitalization. Patients with a severe form of the illness can develop acute respiratory distress syndrome (ARDS) and septic shock, and eventually develop multiple organ failure (Wu & McGoogan, 2020). In an effort to curb the spread of the virus to the public, healthcare delivery systems put in place strict isolation practices, including no visitors and limited interaction with health care personnel for hospitalized patients with COVID-19. When interactions took place, hospital staff were in full personal protective equipment, which included gown, gloves, face shield and mask. Only the healthcare workers' eyes could be seen beneath their mask or goggles. The ability to provide compassionate care in

the midst of such isolative restrictions presented a challenge for healthcare workers. Yet compassion is at the very core of the work of healthcare personnel. The purpose of this qualitative research study was to describe COVID-19 survivors understanding and experiences of compassionate care during their hospitalization

### Literature Review

Compassion generally involves the recognition of and desire to alleviate suffering (Seppälä et al., 2017). Compassion is the acknowledgement of emotional distress in others (or oneself) and the desire to reduce suffering (Lazarus, 1991). Following a systematic literature review of the topic, authors defined compassion as the "sensitivity shown in order to understand another person's suffering, combined with a willingness to help and to promote the wellbeing of that person, in order to find a solution to their situation" (Perez-Bret et al., 2016).

Patients experiences of compassion provided by healthcare workers have been found to contribute to positive patient health outcomes and patient satisfaction (Del Canale et al.,2012; Hojat et al.,2011). Patients' and families' perceptions of healthcare providers compassion have been correlated with patient trust, satisfaction and health enablement (Sinclair, et al.,2016). These findings provide support for the use of compassion by health care workers in their practice.

Unfortunately, patients do not always perceive that their healthcare workers provide compassionate care. A large study of 800 hospitalized patients and 510 physicians contrasted the understanding of compassion with the real time experienced of compassion. The findings uncovered that compassionate care is "very important" to successful medical treatment. Yet, when study physician and patient participants were asked about compassionate care, 78 percent of the physicians indicated that most healthcare professionals provide compassionate care, but only 54 percent of patients in the same study agreed that compassionate care is provided (Lown et al.,2011). Barriers to providing compassionate care are often employment related in nature. Organizational factors such as inadequate staffing, excessive paperwork and perceived time constraints may interfere with health care worker's ability to provide compassionate care (Valizadeh et al.,2018)

This study seeks to describe patient care experiences of compassionate practices by healthcare workers while being hospitalized with serious complications of COVID 19.

**Study Design: Settings, Subjects, Instrument and ethical Considerations:** Since compassion is a subjective experience, a qualitative exploratory design was utilized to more accurately discern participant's perceptions. The richness of the participant's perspective was seen as an essential component to understanding the participant's perception of compassion.

Institutional Review Board approval to conduct the study was obtained from the investigator's university. A purposive sample of adult survivors of COVID-19 hospitalization was obtained through announcements on the social media platform Facebook in September 2020. Initial announcement indicated that volunteers would be interviewed for a qualitative study to uncover aspects of compassionate care experienced during their hospitalization. Criteria for the enrollment in the study included: 1. individuals over the age of eighteen; 2. individuals who had been hospitalized as a result of complications from COVID-19. Once participants initially responded to the announcement, they received a full written description of the study, including risks and benefits, via email. Once participants had the

opportunity to read the information and respond that they were willing to participate a mutually agreed upon time for a Zoom interview. Since face to face interviews were contraindicated due to the pandemic, each interview took place over Zoom. Zoom is a collaborative, cloud-based videoconferencing service which offers online meetings with secure recording of sessions (Zoom, 2020). Prior to beginning the interview, participants were asked if they had any questions about the study. Verbal consent to participate in the study was obtained. The audio transcripts were saved to Zoom's cloud, where they are encrypted and stored (Zoom, 2020). The researcher was the only one who had access to the data collected during the interview.

Data collection occurred over September to November of 2020. A semi structured interview guide with three related questions was developed. A semi structured interview was utilized to give interviewees more opportunities to fully express themselves. The interview began with asking each participant, "Can you tell me what compassion means to you?" This question was followed by, "What were some compassionate practices you experienced by healthcare workers while you were in the hospital?". The final question was, "Are there compassionate practices that you wish your care workers could have done to relieve your emotional distress?"

Participant interviews lasted 30-90 minutes. The audiotaped sessions were transcribed verbatim. Thematic analysis, a method for identifying, analyzing and reporting patterns (themes) within data was utilized (Braun, & Clarke, 2006). Data analysis began with reading the transcripts to gain familiarity and understanding of the discussion in the interview. A second reading focused on the development of preliminary codes and concluded with the development of for patterns or themes across the different interviews. Interviews continued simultaneously as data was analyzed. The interview process continued until a pattern of themes was evident without the occurrence of new themes. This led to the conclusion that saturation had taken place. Saturation is evident when no additional data are being found whereby the researcher can develop properties of the category (Glaser & Strauss, 1967; Jinks,2018).

## Results

Demographic data collected included age, race, employment, previous hospitalization(s), presence of chronic illness, and location. A total of eight participants were interviewed for this study, including seven females and one male, with ages ranging from thirty-six to sixty-three years. All participants were from the United States with seventy-five percent of the participants from the Northeast and twenty-five percent

from the Midwest and Southwest respectively. Half of the participants worked in healthcare with four registered nurses and one occupational therapist. All were Caucasian, seven of them identifying as of European ancestry and one Hispanic. Half of the participants had chronic illnesses. All were hospitalized due to severe respiratory symptoms with hypoxia, and three of the eight were intubated and treated in the intensive care unit.

Although participants were asked to provide a definition of compassion, none provided an actual definition, but rather gave examples of compassionate practices they witnessed by healthcare workers. All participants described an experience where a healthcare worker interacted infrequently or minimally when providing care. Many of the participants expressed distress when recalling at least one instance when their healthcare worker appeared to be fearful when caring for them. Half of the participants described the experience of physicians not coming into the room to provide care but rather performing exams for outside the room via computer tablet. This type of experience grieved participants and added to their social isolation. The participants were quick to point out that this was the exception and they praised the dedication of their healthcare workers as they discussed positive experiences with them.

An analysis of findings revealed four themes: Compassion without fear; Compassion with confidence; Compassion through physical presence; Compassion through listening. These themes were repeated throughout all interviews.

**Compassion without fear:** All of the participants were hospitalized due to difficulty breathing. Many participants described feeling afraid and anxious as their shortness of breath worsened. Participants, alone in their rooms with only members of the healthcare team as their sole human link to the outside world, felt isolated and disconnected. These feelings were exacerbated as participants recognized when members of their healthcare team were fearful while caring for them. With the death tolls rising as the pandemic raged on, participants understood the fear on the part of their healthcare providers. Healthcare workers who did not exhibit fear as they cared for participants were lauded as being especially compassionate.

EC, a 57-year-old teacher, described compassion as healthcare workers who despite their own fear were able to care for him in a way that made him feel special.

*“They made me feel like I was their only patient. They never appeared overwhelmed. They never showed fear even though I know they were feeling it. They were dealing with the unknown, for the most part, and their lives were in danger. Not showing fear. It's a comfort.*

*That's an important piece. Never let them see you sweat. To me that's compassion.”*

TH, a 59-year-old artist with chronic illness, described how important it was as she struggled to catch her breath, for healthcare workers not to add to her apprehension by acting as if they were afraid of her.

*“It's important not to be the circuit breaker and make their fear explode. You want to find a way to take steps to help them either face it, or help them if they've already faced it to deal with it in constructive, proactive ways. You know not to sink into the fear too much because I think that makes you sicker”.*

LY, a 56-year-old nurse, described her amazement with the physical therapist who spent time with her helping her build her strength and balance, despite the danger of close proximity. As she described the incident in detail she expressed her amazement at the compassionate, selfless act.

*“She literally had her hands on me. She had her hands on me. She was helping me sit to stand. She was assessing my balance. She was helping me try to walk across the floor. She wasn't afraid to be close to me.”*

**Compassion with confidence:** Participants commented positively on those who could confidently provide knowledge about their health status based on factual information. Hearing “You're not going to die” or “You will be better” along with factual information supporting the positive statements was extremely comforting to the participants.

CC, a 57-year-old customer service representative with chronic illness, described how she craved factual information. She wanted reassurance based on real facts. She described meeting with the physician who took the time to explain what the expected course of her illness and treatment was.

*“I was spacey and anxious and thinking, ‘Am I going to be okay?’ I needed someone to be able to give me information and talk me out of my anxiety, to say, this is why you're going to be okay and to intellectualize with me. I needed personal connection, physical, intellectual, emotional acknowledgement that I was going to be okay. And if I wasn't, to give me straight information. He came over and just held my hand for like a minute or two and said ‘We're going to save you. Because I'm going to give you Remdesivir. Don't worry, because this is going to work. I know it works. It's worked for my colleagues in Italy.’ He talked me off the ledge for ten minutes.”*

LY, a 56-year-old nurse who was struggling to walk as she regained her strength, discussed the compassionate practices of her physical therapist who assured her that she would walk again.

*"I told the physical therapist 'I can't walk right' and she said 'I'm going to help you' and she has that slow lilting voice that has this monotonous but comforting feeling like you just 'slipped into a cup of tea' voice. Which was so nice to hear and she's calm and she smiles, and you can tell through the mask that she's smiling, and I will never forget that. I said, 'I'm going to be okay. Right?' 'And she's like, 'Yeah, right.'"*

WL, a 63-year-old occupational therapist who also had chronic illness, described how the combination of her preexisting condition and COVID-19 infection placed her in an especially weakened state dependent on healthcare workers for assistance with all of her physical needs. When discussing compassionate practice, she described how comforting it was to have her healthcare worker care for her with confidence.

*"She was a nurse, and she came in and took command. She made me feel so cared for and secure. She just had a sense of confidence about her and would come in and just say, 'How about we get up for breakfast? I'm going to come back in at nine o'clock with your meds, we're going to turn you every two hours. We're going to do this', and she had command and she did it in front of her CNA, so her CNA knew exactly what the expectations were."*

**Compassion through physical presence:** Due to the extremely contagious nature of COVID-19 healthcare workers were required to limit patient contact. Participants reported the deep sense of isolation they felt while alone in their room day after day. They also described feeling marginalized as some healthcare providers interacted minimally while running in and out of the room to give care. Thankfully most of the participants were able to experience feeling deeply cared for by healthcare workers who provided support through their physical presence. Participants described fearless, confident healthcare workers that stood by them in their suffering through their very presence.

NT, a 60-year-old with chronic illness, described in detail the absolute terror she felt as she struggled to draw air into her lungs. As her breathing difficulties increased it was clear that intubation was inevitable. She described how the physical presence of the nurse lessened her fear during this traumatic time.

*"The second time when I was getting intubated I was scared. I didn't want to be by myself. So one of the nurses stayed and held my hand, the whole time. You know they're anticipating anything they can do to help"*

EC described how physical presence through touch was an important example of compassion.

*"So for me it was putting their hand on my shoulder. You know, at certain times I needed someone to just put their hand on my shoulder and give me a squeeze. It*

*made me feel like I was more connected, and they could understand that I was very isolated."*

**Compassion through listening:** The diagnosis of COVID-19 created a state of fear for the participants. Participants described feeling afraid for their family's health and their own mortality. Isolation left participants alone with only their thoughts for hours on end. Participants described their deep appreciation for the healthcare workers who listened to their fears and concerns. Many participants made the distinction between healthcare workers who passively interacted versus those who authentically listened.

SG described their experience, stating that,

*"Listening is really the biggest thing. My doctor was amazing. She was so great. And she, you know, really, she would really talk to me and really listen. So I was grateful for her, because so many people don't listen. You know they have an agenda, a lot of times they're just waiting for the space to start talking. They're just waiting for a space for themselves to say something and they haven't really listened. But that's, to me that's everything. just like, good bedside manner -coming in and listening and not just being task oriented."*

LG, a 36-year-old nurse, shared

*"I had doctors that would come in and sit at the side of my bed and talk to me. And just made me feel comfortable. Like they cared. And that made me feel good, as opposed to some others, just communicated to me on computer. There was one doctor that actually took the time and sat down in my room and listened to what I had to say and just made me feel comfortable. I could talk to him."*

**Discussion and Recommendations:** The findings in this study describe patient experiences as they reflected on compassionate practices they experienced while hospitalized with COVID 19 complications during the 2020 pandemic. Jean Watson describes compassion as 'the capacity to bear witness to, suffer with, and hold dear with in our heart the sorrow and beauties of the world' (Watson, 2008 p 78). When asked to provide their definitions of compassion, all participants were able to provide examples of compassion delivered by care providers. Many of the compassionate practices described were consistent with Jean Watson's Caritas Processes, described in her Theory of Human Caring Theory. At the heart of Jean Watson's theory is the idea of practicing loving kindness by being an authentic presence to those who are suffering. The participants in our study described a level of vulnerability both due to fear from being afflicted with a highly contagious, potentially life limiting, poorly understood virus and the mandated isolation necessitated to prevent transmission of the virus. Those hospitalized with COVID-19 were isolated to their rooms with no visitors. Healthcare

workers were instructed to limit time with the infected. This resulted in very ill patients spending day after day alone, confined to their rooms. Many participants described healthcare workers who provided care from beyond the door of their hospital rooms by way of telephone calls and computer tablets which were set up to allow two-way conversation. Participants said this added to their feelings of isolation and contributed to fear that a serious health issue could be overlooked. Participants also described the palpable fear from some healthcare workers who ran into their rooms to perform a task, interact minimally, and quickly leave. Fear among healthcare workers has been described in other highly contagious deadly disease outbreaks such as SARs in Hong Kong (Chung et al.,2005) and Ebola in Sierra Leone (Andertun et al., 2017). Studies reveal that healthcare personnel fears are associated with lack of protective personal equipment (PPE), which placed them at risk for the disease (Chung et al.,2005; Andertun et al., 2017; Tan et al., 2020). Since many of the participants in this study were hospitalized early on in the pandemic when lack of PPE was an issue for many US hospitals, the concern for safety was real. Fear on the part of the healthcare worker may weaken the confidence of healthcare professionals (Shanafelt et al.,2020). Perhaps this is the reason why most participants discussed compassionate practices as those care providers who cared for them fearlessly and with confidence.

Our participants also found that having healthcare personnel who kept them informed was also a great comfort. This is consistent with study participants experience in China during the COVID-19 pandemic. Though study participants were found to be moderately to severely anxious and depressed, a high level of confidence in healthcare providers and satisfaction with health information were found to be protective factors (Ran et al.,2020). Participants shared the importance of the physical presence of the healthcare workers. Presence is understood in terms of “being there” for patients and providing support in times of distress (Perry, 2009). Being a physical presence was a contradictory practice as healthcare workers were advised to limit contact with patients for fear of contracting and spreading the virus. When healthcare workers entered patients’ rooms they were completely covered with personal protective equipment. Many of our participants commented that only the eyes could be seen behind the goggles. Participants commented that the eyes of their healthcare workers were able to convey compassion. Eye contact has been found to be an effective form of non-verbal communication of caring (Patel et al., 2019). Other simple acts of presence such as appropriate use of touch- i.e. a gentle hand on the shoulder meant so much to our participants. This is consistent with findings of a meta-ethnography which examined literature across all health professions and

uncovered a consistent finding that patients value touch as a medium of caring communication (Kelly et al.,2018). Participants also discussed an important compassionate practice as being listened to and heard. This is consistent with conclusions of a study of patient’s perceptions of compassion. Researchers found that patients whose physicians provided evidence of deep listening practices such as sitting rather than standing during interactions, detecting patients’ non-verbal cues of emotion; and providing verbal statements of acknowledgement, validation, and support were found to improve patient perception of physician empathy and/or compassion (Patel et al.,2019). A qualitative study which examined the behaviors of nurses who were identified by patients as providing exceptional care, concluded that connection and engagement were important aspects of being present for the patient (Costello, 2017).

The COVID-19 pandemic presented unique challenges to healthcare workers. Maintaining a compassionate practice while under the fear of the deadly contagion is an insurmountable task. A study of nurses in Wuhan, China, first to experience the ravages of COVID-19, found that the heavy workload and unfamiliarity with the disease contributed to nurses fears and anxiety while providing care (Tan et al.,2020). The practice of safely donning and doffing personal protective equipment is time consuming and adds to staff work load. However, errors in donning and doffing personal protective equipment either due to rushing to provide care or unfamiliarity with correct steps to can lead to viral contamination which can have serious consequences (Silva et.al.,2020)

Health care leaders can play an important role in supporting the work of health care workers who are at the bedside. One recommendation for health care leaders is to provide staff education of appropriate infection control guidelines and having adequate amounts of personnel protective equipment. Furthermore, the extra time required for safely donning and doffing personal protective equipment requires additional staffing to support prevention of viral contamination.

In addition to recommendations for health care leaders, there are lessons to be learned which can advise health care workers practices. Our study participants did not have much time with their health care workers as health care workers were advised to limit time spent with patients to prevent exposure to COVID. Despite this recommendation, our participants described spending high quality time with health care workers that included authentic presence. Authentic presence can be conveyed through eye contact, deep listening, and responding to patients concerns in a manner that demonstrates true understanding of the meaning behind the patient’s words.

**Conclusion:** The COVID-19 survivors in this study provided profound examples of the compassionate care they experienced during their hospitalization. The study participants shared stories of being on the receiving end of compassionate practices which helped them to feel connection at a time when they were most isolated and vulnerable. The participants recognized that health care workers lives were at risk while providing their care. The ability to provide compassionate care in the midst of isolative restrictions due to the COVID-19 pandemic is challenging. Healthcare workers in this study were able to rise above the challenge to support their gravely ill patients. This article includes examples of compassionate practices and recommendations for health care leaders to support health care workers in providing safe compassionate care to their patients.

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