Anthropology & Aging

Journal of the Association for Anthropology & Gerontology

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Analyzing Affect in the Narratives of Nursing Home Staff During a COVID-19 Outbreak

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Introduction

Chaos reigned as the Life Care Center Nursing Home in Kirkland, Washington, made frontline news in February 2020 when COVID-19 was discovered to have been circulating among residents, staff, and visitors. While this nursing home was originally identified as the epicenter of the US epidemic, it has since become apparent that there were numerous other cases and outbreaks throughout the US. Still, the damage was done, and the nursing home has received significant negative attention ever since (Watkins *et al.* 2020). Data have shown that the older population, especially those in congregate living communities, are being hit hard by this epidemic that has wreaked havoc throughout the country (Gardner, States, and Bagley 2020).

> [COVID-19] just went through the whole building. . . . One day we went from one person that had been sent to the hospital coming back positive, and as soon as that happened, it was like everybody that she was around had it within a matter of a day, two days.

The above is an excerpt from an interview with a direct care worker (DCW) who volunteered to work on a COVID-19 unit in a skilled nursing home (SNH) in central North Carolina, where an early outbreak led to the death of over 20 residents in just under two-and-a-half months. The DCW reported vacillating between feelings of anger, frustration, helplessness, fatigue, and deep-seated grief. She mourned over residents she knew and loved and had watched "suffocate" to death. She felt helpless, unheard, and angered that her experiences weren't being used to prevent mortality. This article is an attempt to make their voices heard and make their anger matter. We foreground the narratives of a group of workers who are often ignored, undervalued and without voice. Four of these workers volunteered to work in a COVID-designated hall during one of the worst outbreaks recorded in North Carolina and the fifth is the administrator. Their interviews are a subset of 60 interviews on perceptions and experiences of workers providing long-term care (LTC) during the COVID-19 epidemic. Studying LTC is crucial in this

pandemic because COVID-19 differentially impacts older Americans, especially those living in LTC communities. In North Carolina, 40% of COVID-19 mortality has been associated with adult congregate care including SNH, assisted living (AL), memory care units, adult family care homes and continuing care retirement communities (CCRC).

Methods

In this paper we draw from findings of an IRB-approved project that entails a rapid qualitative appraisal of the perspectives of workers providing LTC to older adults in North Carolina during the pandemic. We use data from the second phase of this on-going project and focus on staff in adult congregate living communities. We will complete over 70 in-depth, semi-structured interviews by the end of the third phase. The purpose of rapid appraisals is to employ a methodology that collects trustworthy, actionable data and disseminates it to decision-makers in a timely fashion (McNall and Foster-Fishman 2007). These projects are often team-based and involve a collaboration with community leaders, political officials, and/or interested non-governmental or governmental organizations who request information to improve policy and programming. Sampling of participants is typically purposive and not designed to be random or representative, although knowledge about the area of study allows for some degree of representativeness to be built into the design (Vindrola-Padros and Vindrola-Padros 2017). In rapid appraisals, data analysis is an iterative process that is ongoing in order to distribute findings quickly so decision-makers can act on them expeditiously, especially in times of crisis. Rapid ethnographic appraisals are unique in their focus on a narrower range of qualitative research methods. They have not been used previously to study LTC but prove to be very effective to qualitatively analyze the effects of a crisis, such as the one we are facing today.

This paper is a case study of interviews with staff who worked on the COVID-19 unit during a major outbreak. The site is a corporately owned SNH in central North Carolina. Six staff members volunteered to work on the COVID unit: an LPN, RN, three certified nurse assistants (CNAs) and a housekeeper. We interviewed four of these staff members from the COVID unit, and the facility administrator. Interviews were video-recorded using a web-based platform and were transcribed verbatim. We recorded five-and-a-half hours of interviews in total from these five participants and generated codes for these data through a grounded, inductive approach. Through initial and ongoing data analysis, the researchers noted the emotional nature of the interviews and decided on introducing codes on 'affect.' Codes were discussed collectively and were then applied to each of the interviews individually. Researchers thus compared their results, agreed upon data categorization, and coded using Nvivo software. No identifiers (date, facility, names, …) are used to present the data because of its sensitive nature and the small sample, and in order to protect the anonymity of the facility and the individual participants.

Based on our inductive approach, we turned to affect theory, to analyze the narratives of these five participants and maximize the analytical value of their feelings and sensory experiences about providing care through a COVID-19 outbreak. Drawing from their expressed affective experiences, we demonstrate how affect and emotion circulate to structure the experiences and perceptions of LTC workers, through their engagement with each other, with residents, families, administration, policy, and the virus itself. We report on the emotional experiences of direct care workers as they emerged from their narratives of caring for older adults in long-term care during the COVID-19 pandemic. Four affect categories emerged from our data analysis: fear/anxiety, sadness/grief, anger/frustration, and trauma/stress. We report on them separately to illuminate how these feelings are expressed and structure experiences of these DCW.

Circulation and Affect

Scholars – including anthropologists, phenomenologists, philosophers, and feminists – have convincingly demonstrated that affect structures how humans interpret, understand, and make sense of their lives (Ahmed 2004a, 2004b; Griffiths and Scarantino 2008; Skoggard and Waterson 2015; Slaby, Muhlhoff, and Wuscher 2017). However, it is in the fluid and dynamic nature of affect that it remains difficult to document and analyze affective engagements, or to understand and make social scientific claims about subjective, emotive experiences (Ahmed 2004b). With regard to these methodological perils, Sarah Ahmed suggests a narrative approach, arguing one can "read" the affective in texts (2004b, 27). Affect theory has become increasingly popular as a way to make room for ethnographic scholarship that values the emotions, feelings, and subjectivity inherent in the lived experiences of individuals and communities, that are foundational to how they understand and interpret their own and others' lives (Martin 2013; Skoggard and Waterson 2015; Stewart 2007; White 2017). Affect is being used here as a framework that focuses on an examination of one's visceral, emotive experiences within the material world (Lyon 1995). Affective analysis is often understood as that which is individually felt but simultaneously informed by social context (Stewart 2007). "Affective arrangements" are always considered as relational or "transpersonal," because affect is modulated and made through interaction (Slaby, Muhlhoff, and Wuschner 2017).

There is an ongoing debate in academia on the relationship between affect and emotion. Some, looking back to Durkheim, argue that 'emotion' has historically been used to indicate an individual, embodied experience: a feeling that is primitive, primordial, and autonomous (Durkheim 1965 [1915] in Skoggard and Waterson 2015, 110). 'Affect,' according to these scholars, is distinct from emotion, as it is defined by sociality, and refers to the feelings, sentimentalities, and embodied experiences generated from the circulation of bodies with other objects or bodies in the public realm (Richard and Rudnyckyj 2009). Csordas (1990) and Lyon (1995) suggest that visceral, intimate encounters with the material world (including other bodies) is both constituted by and in turn constitutes culture that determines social location and the structuring of everyday lived experiences (Ramos-Zayas 2011). According to Parreñas (2012, 682): "Affect does not reside within a human individual's body and mind nor does it solely reside within the interface of human bodies. . . . It is between bodies that we come to feel affect.

Following Skoggard and Waterson (2015), we are not convinced of the need to distinguish between affect and emotion. Emotion, in our view, is not as individualized as some scholars would suggest. We draw on Ahmed (2004a) to demonstrate that emotions do not exist in a vacuum: they are always already structured by the social context within which someone is born and lives, and by the interactions that occur within their socio-material lives. To put it differently: while we cannot speak of emotions lest they are individually felt/embodied, emotions are induced, shaped, and molded by the social context and the material world, past and present. Since emotions and affect are more similar than they are different, we use them interchangeably. Our emphasis here is on the way emotions are structured by the social, and by circulating between bodies and objects (including policy). Hence, we document DCW emotions as individually felt and expressed, but assess them in terms of how they are constituted by and also constitute the socio-political landscape. The implications of which include allowing a critical review of long-standing structural inequities, ageism, and inadequate policy and programming in LTC.

Findings

We present our findings according to the codes that emerged from the analysis, while recognizing that emotions are rarely discrete categories. They often overlap with some narrators expressing anger, fear, and frustration simultaneously. We do not suggest that the categories we identify as emerging from this analysis are straightforward. Instead, we draw on the range of expressed emotions to illustrate the

broader affective experience of working on a COVID-19 unit in a congregate care community with substantial morbidity and mortality. We distinguish four major affective themes that emerged from the data, from what are, in actuality, a cluster of related feelings. These include fear/helplessness, anger/frustration, sadness/grief, and trauma/stress and exhaustion.

Fear/Helplessness

Each of our interviewees volunteered to work on the COVID hall because they knew "someone had to do it" and some of their colleagues refused to work on the positive unit for fear of contracting the virus. As one of the respondents said: "I did have a little bit of fear. I have four kids at home and a husband. So, I was really worried that I'd take something back home to them, but I was very cautious." By "cautious," they meant wearing full protective personal equipment, changing clothing when they got home before entering the house, showering and washing their hair, and not visiting relatives and loved ones. Fear is evident in relation to the circulation of the virus itself, but also in relation to how workers do or do not circulate among their own loved ones.

Interviewees also expressed fear associated with helplessness. They discovered that a group of residents had tested positive, after initially being told all the tests came back negative and their initial wave of relief was immediately overtaken by dread. One explained:

> Our unit supervisor walked in and she was like, "Everybody's positive, we read the test wrong." Yeah, so I think that was the first day I literally cried because as soon as she told me that, I dropped to the floor and I just bawled like a baby 'cause I knew, I knew we were gonna be in for it after that.

This respondent's visceral response of crying like a baby embodied their all-too-correct fear about what was about to happen to the residents they cared for. This respondent cried during the interview when she talked about having to say goodbye to residents because their family members were too afraid to come into the COVID unit while their loved ones were *transitioning* (the phrase commonly used in this field when someone is dying). Fear, helplessness, and grief collided in their narratives. Grief and sadness was something that all respondents experienced and spoke of in-depth. They demonstrated these feelings in the interviews through crying and cracking voices.

Sadness/Grief

All five respondents, including the administrator, expressed a deep connection and respect for the residents they cared for on a daily basis. Participants evoked fictive kinship as they referred to residents as being like family, saying "they are the reason I get up and go to work every day. . . I really love them all …" Remembering residents they loved that died was emotional for them all and two of them cried during interviews. One explained that "If it weren't for [a colleague] I probably wouldn't have made it through that two and a half months, 'cause I literally, I cried on a daily basis." In one interview, a participant was overwhelmed with grief when describing how the virus took a resident she had a strong relationship with. She regularly took walks with this older, male resident she described as "healthy." He contracted the virus and died within days. She talked about his loss several times in the interview and a co-worker independently recalled how sad her colleague was when that particular resident died. Another caregiver explained that it was too painful and sad to deal with and the only way they could "survive" the experience was to "just shut down." They explained:

> You can't feel anymore. I think after the tenth person dying, I was like, "Okay, I can't, I can't. If I keep feeling like this, I will not walk into that door." And after that, I was just

like, "Okay, so they died. Okay, so they died. Okay, so they died." And now. . .we're going from the hall where everybody was and where we started, and it's not the same people, we've lost them, we've lost them all. And you're just like: "Why?"

Another participant shared how they struggled to control their own emotions in ways that had never happened before. They said:

I've done this for a long time and never, ever have I not been able to make it out of the room [without crying]. . . . It just overwhelmed me at that point that all these people we were testing, you knew they were gonna come back positive, and you knew in your heart that they probably weren't gonna make it 'cause they're already sick to begin with.

Grief was tied not just to the affective encounters between staff and residents, but also as staff bore witness to the suffering and grief of family members trying to console the residents. One interviewee recalled how husbands came to visit their wives daily by standing outside the windows. They explained:

The resident doesn't even know they're there because of their level of dementia, but that husband is still there all day. One brings a bar stool and an umbrella, and he does that during the rain, whenever. . . he has a cooler with water, and he sits there at the window with her. So that's really sad to watch. It's really great that you're loved that much, but it's gotta be heartbreaking for all of them.

Anger/Frustration

The COVID unit staff were isolated in a very real sense. They didn't feel like people were listening which led to extreme frustration and anger. There was generalized anger at the virus itself for taking so many lives in such a violent way. Anger and frustration were directed at policies and procedures that did not take into account their perspectives and experiences. Finally, there was a sense of anger and helplessness in relation to the broader community for not taking COVID-19 seriously enough and not following CDC and health department guidelines. During one interview, a participant became agitated and raised their voice as they discussed anger at death, not being listened to, and also at colleagues and other staff who did not acknowledge the suffering and grief DWC experienced as they watched residents die. They explained:

I had a lot of anger during this process: I was angry at the fact that these people had to die the way they had to die, and that no one cared. I really honestly felt like the people who were on the floor, living it day by day got it, and the people who weren't there, it's like we couldn't get them to see it. … And it's like, "I can't process this person just died. Now, you want me to hurry up, pack their stuff up, . . . so somebody else who tested positive can come right in this room?"

Since this was an early outbreak, there was little understanding of the virus, and the participants expressed frustration at the plan that was initially instituted to contain the virus. This SNH has several different halls, and each could be somewhat isolated. One hall became a 'COVID Unit' where anyone who tested positive, along with their roommate, would be moved to. Once in the COVID unit, both would be tested to see if they were positive. The caregivers believed that close proximity to COVID

positive roommates all but ensured conversion to positive. They watched initially negative roommates test positive and then die. One caregiver explained:

> . . . we had two roommates. One tested positive, one tested negative, but just because the roommate tested positive, they moved both of them over to COVID. So, she got tested again when they moved over there . . . came back negative. Two days later, she was moved back out to her room. And then literally within a day of her being moved back, the PA sent her out to the hospital with a 102 fever, respiratory distress and we knew damn well what was wrong with her. We didn't have to have a test to tell us.

Another caregiver echoed frustration about the decisions to move residents excessively, as administration and corporate worked out procedures. The administrator said it felt like there were 100 room changes in 100 days, which he acknowledged was an exaggeration but said he felt like that, because it was so "mentally and physically exhausting." One DCW explained:

> ... And our whole thing was, "Why are they not listening to any of us?". . . "We were there, we're in the midst of this. We're trying to tell you what we need to do that might, could help this situation. And you're not wanting to listen.

This same respondent said they did not feel like they had a voice as "lower-tier staff," adding that even the nurses expressed concern about the movement of residents that went unacknowledged. The administrator expressed his admiration for the corporate office that worked tirelessly to create and implement strategies during the early chaotic days of the epidemic when little was known about the virus and its transmissions. He rightfully said, "Nobody was prepared for this." He went on to explain that protocols and procedures changed almost daily in an effort to consolidate ever evolving recommendations and policies from the level of the federal government, state, and county. In trying to juggle the needs of his COVID-positive patients, the protection of himself and his staff, as well as the quickly shifting policies and procedures he did acknowledge some mistakes were made explaining, "I wish I could have known then what I know now."

Trauma/Stress and Exhaustion

Stress, trauma, and exhaustion were discussed by all five participants. Trauma was expressed in several ways including vivid descriptions of the violent death residents faced since many had orders refusing transportation to the hospital for life saving procedures. Two caregivers stated they suffered from PTSD. Sleeplessness, exhaustion, and disturbing images of death and dying haunted the staff following the major COVID-19 outbreak at their SNH. One of the caregivers shared that when the initial outbreak occurred the attending physician wrote prescriptions for morphine for all the residents saying, "you're going to need it."

All interviewees discussed the helplessness and violence associated with dying from COVID-19 that related to their traumatic experiences working on the COVID unit. One respondent explained this violence and their frustration at what they felt might have been preventable:

> … they're literally smothering to death, they're literally choking to death. And all you can do is sit there and hold their hand and try to make them comfortable . . . 'cause there's nothing else you can do. And then you look and you go, "You know what? This possibly could have been prevented."

Another participant provided a similar depiction of the traumatic experience of watching residents suffocate:

> Even the morphine wasn't helping. . . .They were still fighting for air . . . and it was like somebody holding a trash . . . bag over their heads, and smothering them.

One participant clarified that they had confirmed the residents' wishes and families' for those who were unable to make that decision:

> We did send all residents that indicated they would want to be transferred to the hospital when their symptoms became the level for that type of intervention.

Witnessing violence and death can be associated with PTSD and two participants believed it was affecting their mental health in sustained ways. One of these two stated plainly:

> Me, personally, with my experience, I have PTSD . . . Going through this trauma, I'm still trying to come out of it. . . . I don't ever wanna do it again. . . . I say that I don't think I mentally could do it, but I sit here and I tell myself, like I just told you, if I had to do it, I would do it again . . . I probably wouldn't be the same, second time around, as this took a lot to get back to a normal life for myself after coming off of it.

Another said they suffered flashbacks that they relate to their sleeplessness and associated trauma, "It's just that I close my eyes and it's like I'm there again. I see and I hear. And that's something I don't wanna see and hear ever again."

Conclusion

These narratives demonstrate the multifaceted, socially embedded nature of affective engagements that reflect the way we generate feelings through circulation between a range of actors, objects, and policies. The virus, co-workers, family members, residents, and policy restrictions in turn structure how participants understand and manage their experiences. We argue that troublesome cultural values, social injustices, and structural failings, which are all too often easily ignored or erased, can be made visible through chronicling these affective dimensions.

We amplify the voices of the formal caregivers in this work to demonstrate how their sensorial and emotive experiences can speak to the unjust human suffering they bore witness to, the underlying ageism that permeates our culture, and the social hierarchy that devalues their labor and their worth as they serve on the frontlines during this unprecedented global pandemic. This perspective is particularly important in light of the media coverage on the failures of nursing homes and the larger healthcare system to respond effectively to the pandemic. This media coverage generally positions administrators and facility staff in conflict with long-term care residents and their families. These DCW perspectives add a valuable, nuanced view of the heroic measures being taken, including risk to the self, by administrators and staff, to protect the lives of residents.

We must keep considering the structural barriers they face within these long-term care congregate communities, that are informed by the broader socio-political context that – both historically and in this contemporary epidemic – limit their agency in caring for those they serve. Their expressions of sadness, helplessness, and grief illuminate both their individual devaluation as low-paid formal caregivers, and that of their aging residents, by the larger society. Their palpable anger, frustration, and trauma speak to the violent, unnecessary suffocation and perhaps preventable deaths, as well as despair at the social

hierarchy that prevents formal caregivers' voices and perspectives from having value. Their fear is shared to some extent by all of us living in the chaotic age of COVID-19.

Acknowledgements

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