Safety Trade-Offs in Home Care During COVID-19:

A Mixed Methods Study Capturing the Perspective of Frontline Workers

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Background: Home care workers help older individuals and those with disabilities with a variety of functional tasks. Despite their core role providing essential care to vulnerable populations, home care workers are often an invisible sector of the healthcare workforce. The transmission of COVID-19 and the nature of home care work raise several questions about the overall safety of these workers during the pandemic.

Objective: To examine the experiences of home care workers during COVID-19, particularly their access to information about infection status, to testing, and to personal protective equipment (PPE); their understanding of guidelines; and trade-offs associated with protecting workers' safety.

Methods: A mixed methods study including qualitative analysis of guided discussion questions and quantitative analysis of multiple-choice survey questions was conducted. Eleven virtual focus groups in October and November 2020 involved 83 home care workers who care for clients/consumers in Massachusetts. Thirty-nine participants worked as personal care attendants (PCAs) employed directly by a consumer and 44 participants worked for an agency. Ninety percent self-identified as female and 54% had worked in home care for more than five years. Qualitative data was analyzed using thematic analysis, with identification of major and minor themes. Likert scale survey question data on perceptions of COVID-19 exposure, access to resources to prevent transmission, and perceptions of safety at work were dichotomized into agree or disagree.

Results: PCAs and agency-employed home care workers were regularly faced with trade-offs between meeting client/consumer needs and protecting themselves from COVID-19 exposure. Twenty-five percent of participants reported serving a client/consumer who had COVID-19, 75% reported worrying about getting COVID-19 at work, and 29% reported thinking about stopping their work in home care. Despite a low pay structure, participants reported opting to risk exposure rather than to leave their clients/consumers without essential care. However, workers often lacked the resources (e.g., PPE, testing) to feel truly protected. This scarcity of resources combined with insufficient guidance and policies specific to home care settings led many workers to informally collaborate with clients/consumers to assess exposure risks and agree upon safety protocols. Focus group participants expressed uncertainty as to whether workers were truly empowered to ask for changes if conditions seemed unsafe. The burden of determining safety protocols was felt more strongly by PCAs who operate more independently than agency-employed workers who have supervisors to consult.

Conclusions: Home care workers expressed deep commitment to continuing to care for their clients/consumers during COVID-19, but often had to operate with insufficient resources and under conditions that made their work environments feel unsafe. Their ability to identify exposure risks and make decisions on how to protect themselves often hinged on a transparent and trusting relationship with their clients/consumers. These relationships were particularly important for PCAs who did not have access to safety guidance from a home care agency.

Keywords: *home care, COVID-19, frontline staff, focus groups*

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Beyond their experiences as private citizens, healthcare workers have experienced a multitude of additional challenges due to COVID-19. Along with increased risk of personally contracting COVID,[1,2] healthcare workers have navigated concerns about infection spread to their patients and family members.[3,4] Physical and psychological consequences of caring for COVID patients have also been documented, including post-traumatic stress disorder;[5] depression and anxiety;[5-7] sleep disorders;[5,6] fever, cough, and weakness[6]; somatization;[5] and fatigue, discomfort, and helplessness.[3]

COVID-19 transmission raises questions about the safety of home care workers in particular, due to the hands-on nature of their work. Home care workers help older individuals and those with disabilities with a variety of functional tasks (e.g., bathing) and health-related tasks (e.g., medication reminders)[8] that require close personal contact. In Massachusetts, this workforce includes personal care attendants (PCAs) who are employed directly by consumers and aides and other professionals who support the clients of home care agencies. Despite their role providing direct care to people with complex or fragile health conditions, home care workers are often an invisible sector of the healthcare workforce.[9-12]

For these workers, social distancing is seldom possible. Although personal protective equipment (PPE) can help protect against transmission,[13-15] research shows that other than disposable gloves, the home care sector has lower access to PPE than other healthcare settings.[16,17] An individual home care worker may also provide care to multiple individuals per day[18] and work in multiple settings (e.g., nursing homes, assisted living facilities),[19] which makes it more difficult to limit exposure to infectious illness. Finally, it may be more difficult to adhere to safety and infection protocols in a private home rather than a healthcare facility.[20]

There is limited research about home care workers' experiences during COVID-19. Studies show that home health agencies faced challenges testing workers for COVID-19,[21] providing sufficient PPE,[19,22,23] and interpreting or maintaining up-to-date prevention guidelines.[19,23] However, most studies lack the home care worker perspective. Two qualitative studies with frontline agency workers found these workers feel invisible, rely on nonagency sources for support, make difficult trade-offs at and outside of work,[12] and deal with limitations in staffing and equipment despite having to care for patients with increasingly complex conditions.[24] Neither study includes the views of independent workers who may experience different challenges since they do not work within a structure that provides policies and protocols, leaving them to negotiate safety considerations with the individuals and families that employ them.

This mixed methods study elicited the experiences of agency-employed and nonagency-employed home care workers during the pandemic and highlights the safety risks these workers face. Findings can inform programs and policies for strengthening the home care sector in the long term.

Methods

Design

The Betsy Lehman Center for Patient Safety, a nonregulatory Massachusetts state agency, conducted a mixed methods study in which home care workers participated in semistructured discussions and responded to multiple-choice survey questions during a series of virtual focus group sessions. Although the study did not require institutional review board (IRB) approval, participants provided verbal consent for participation and additional steps were taken to maintain confidentiality as noted below.

Sampling and recruitment

Home care workers who provided services in Massachusetts during the COVID-19 pandemic and who spoke English or Spanish were eligible to participate. Workers included PCAs hired directly by individual consumers, some of whom qualify for services through MassHealth (Medicaid), and workers affiliated with home care agencies, including medical-based agencies. Agency workers included any type of employee that was employed by a home care agency, including home care aides, home health aides, and other types of more specialized workers.

PCAs were recruited with help from the 1199SEIU United Healthcare Workers East Massachusetts, which sent emails and text messages to members. Massachusetts home care associations and agencies helped recruit agency workers. Interested participants filled out a secure online registration form that collected demographic- and work-related information. The Betsy Lehman Center did not disclose information about who participated to clients, consumers, or agency managers. Each participant was able to use the video and audio features of the Zoom online meeting platform; individual coaching sessions were available in advance. Participants self-selected into participation, and no participant was forced or coerced to participate. Recruitment was on a first-come, first-served basis until the desired sample was reached. The Betsy Lehman Center monitored the number of PCAs compared to agency-employed workers to help ensure sufficient participation from both groups.

Participants gave consent to participate and received $75 stipends for 3–4 hours of their time (including registration).

Focus group data collection

Virtual sessions took place in October and November 2020. Each 2.5-hour session included an audio/visual check, use of participant first names only for confidentiality, an overview of the session, multiple-choice survey questions, and group discussions. Zoom breakout rooms allowed for multiple discussion groups to occur simultaneously; each breakout group will further be referred to as an individual focus group.

There were six focus groups with English-speaking agency workers, four with English-speaking PCAs, and one with Spanish-speaking PCAs. Home care workers who worked for the same agency were assigned to different groups to preserve confidentiality. A trained facilitator and notetaker led each focus group.

Facilitators used a semistructured discussion guide that was consistent across PCA and agency worker focus groups, with slight adaptations for role-specific terminology; all were translated for the Spanish language session. Participants responded to survey questions using the electronic survey/poll feature in Zoom at three intervals. Survey questions were primarily four-point Likert scales relating to home care workers' experiences during the pandemic; general attitudes about COVID-19 challenges; access to PPE, testing, and infection control information; and perceptions about safety at work. Vaccination was not explored, as COVID-19 vaccines were not approved for use in the United States at the time.

Discussion questions centered on scenarios in which a fictional home care worker faced difficult COVID-related decisions, as well as open-ended questions about challenges and ideas for change. The overall structure and use of hypothetical scenarios followed Fain and colleagues' (2014) format.[25] The topics and wording of survey and discussion questions were informed by previous research[19,25,26,27] and vetted with leadership from 1199SEIU United Healthcare Workers East Massachusetts, the Disability Policy Consortium, Massachusetts' Executive Office of Elder Affairs, Home Care Aide Council, Home Care Alliance of Massachusetts, Mass Home Care, and the Safe Home Care Project at the University of Massachusetts Lowell.

Focus group sessions were recorded with participants' permission, transcribed, and then cross-checked with notes taken by trained notetakers to ensure inclusion of all relevant information.

Analysis

Qualitative Analysis

Qualitative data was analyzed using inductive thematic analysis, following Nowell and colleagues' (2017) steps for establishing trustworthiness.[28] Two researchers (JCP, GKO-P) independently reviewed a subset of session notes and transcripts to familiarize themselves with the data and generate initial codes. They then reached consensus on preliminary themes. JCP and GKO-P independently coded transcripts in Excel based on these themes, iteratively revising them during the coding process. Researchers met to discuss themes, and a third researcher (AAP) flagged and arbitrated discrepancies in coding. All three researchers reached consensus on names and definitions of major and minor themes and selected exemplary quotes for each theme.

Quantitative Analysis

Descriptive frequencies of survey questions were calculated. Most questions were dichotomized into agree versus disagree based on the responses to the four-point Likert scale questions (strongly disagree, disagree, agree, and strongly agree). Participants who were undecided in their response could elect not to answer the question, but this happened rarely. Frequencies were stratified by PCAs and agency workers.

Results

Participant characteristics

Eighty-three home care workers participated: 39 PCAs and 44 agency workers. Participants reflected the Massachusetts home care workforce in gender, race, and Hispanic/Latino ethnicity (**Table 1**). Ninety percent were women (86% women in Massachusetts home care workforce). Nearly a quarter reported that they were non-Hispanic Black or African American (20% in Massachusetts) and 26% reported a Hispanic or Latino ethnicity (any race) (26% in Massachusetts).[29] Participants had higher education levels than the overall Massachusetts home care workforce, with 65% holding college or advanced degrees (46% college, 19% advanced degree, 21% associate degree or higher in Massachusetts).[29] Approximately half (52%) of participants were age 25–44 and approximately half (54%) had a five-plus year tenure in home care.

Table 1. Participant Characteristics

Participant Characteristics	%
Age (Years) (n=80)	
18–24	4%
25–44	52%
45–64	39%
65+	5%
Gender (n=80)	
Female	90%
Male	8%
Other/Prefer not to say	2%
Race and Ethnicity (n=80)	
Asian	4%
Black or African American	23%
Hispanic or Latino ethnicity (any race)	26%
Mixed	5%
White	42%
Education Level (n=80)	
Less than high school	3%
High school	16%
Some college	16%
College degree	46%
Advanced degree	19%
Tenure in Home Care (Years) (n=81)	
Less than 1	10%
2-5	36%
5+	54%
PCA Lived With Consumer (n=31)^	
Yes	19%
No	81%

^ This question was not asked of the pilot group so it includes 31 of the 39 PCAs

COVID-19 Exposure and Workplace Factors

Concerns About the Risks of COVID-19

COVID-19 exposure and transmission are tied to a number of factors integral to home care. Over 60% of participants provided services to more than one client/consumer in a typical shift and more than a quarter cared for five or more people in a shift (**Figure 1**). Over a quarter provided care in more than one type of setting (e.g., private home, assisted living residence). Agency-employed workers were significantly more likely to serve more than one client in a shift and provide care in more than one type of setting.

Close and prolonged physical contact makes observance of social distancing impossible. Overall, 86% of participants reported helping clients/consumers with activities of daily living, and more than two-thirds helped with healthcare needs. Participants expressed concerns that many clients/consumers are highly dependent on the services they offer and that meeting those needs risks COVID-19 exposure.

Responding to a hypothetical scenario, home care workers described the dilemma between what workers "should" and "would" likely do if their client/consumer had COVID-like symptoms but had not yet received COVID-19 test results. If a client/consumer could not complete critical tasks such as getting up from bed or eating without support and there were no other individuals who could provide care that day, workers said they or colleagues would likely risk potential COVID-19 exposure to meet their client's/consumer's needs.

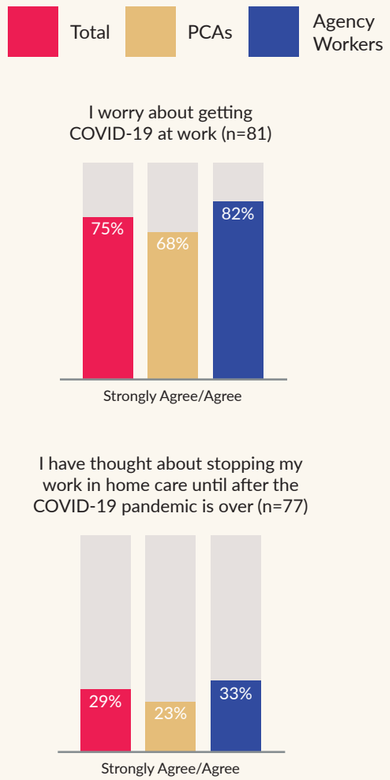
> *"Because if they can't get out of bed without me coming in, I am gonna suit up in PPE and take care of them." (PCA 3-P7)*

> *"I think they would just see the person anyway 'cause they wouldn't want to leave them without their shower or whatever it is they were going to be doing with them that day. I think most aides are very good caretakers… they want to be sure that that person doesn't get missed." (agency worker 2-P5)*

Figure 1. Work Factors and Perceptions of COVID-19 Exposure/Risk

	Total	PCAs	Agency workers
Number of clients/consumers they serve in a typical shift (n=81)			
1	38%	57%*	23%
2-4	33%	30%	36%
5 or more	28%	14%	41%
Settings they provide care in (n=81)			
Private home	88%	89%	86%
Assisted living residence	25%	8%*	39%
Nursing home	4%	0%	7%
Group home	9%	0%	16%
Other	14%	11%	16%
More than one type of setting	27%	8%*	43%
Type of tasks (n=81)			
Activities of daily living	86%	97%*	77%
Housekeeping	77%	92%*	64%
Healthcare services	67%	84%*	52%
Essential errands	65%	84%*	50%
Transportation services	52%	81%*	27%
I have worked with a client/consumer who had COVID-19 (n=81)			
Yes	25%	11%*	36%
No	67%	73%	61%
Not sure	8%	16%	2%

*Chi-square significant at P < 0.05



That said, participants were highly concerned about COVID exposure. Nearly all (99%) agreed that people should take COVID-19 more seriously (data not shown), and three-quarters worried about getting COVID-19 at work. One-quarter knew they had worked with a client/consumer with COVID (36% of agency workers and 11% of PCAs) and almost 3 in 10 said they had thought about stopping their work in home care during the pandemic (**Figure 1**).

> *"I'm really burnt out and I don't feel safe working in home care right now, so I just think there needs to be … a lot better communication and transparency." (agency worker 6-P4)*

> *"I've seen so many of my co-workers just leave during the pandemic. They did not care. They just quit, right on the spot." (PCA 4-P5)*

Partnering with Clients/Consumers to Maintain Safety

Home care workers recognized the importance of partnering with their clients/consumers to protect everyone's safety, and in survey questions the vast majority agreed they had strong partnerships. Over 80% agreed that their clients/consumers would tell them if they had COVID-19, wear a face mask if asked, and want them to stay away for two weeks postexposure to COVID-19. Eighty-seven percent agreed with the statement that their clients/consumers felt safe having them come into their home during the pandemic, and 86% agreed that they would know what to do if a client/consumer asked them to work in a way that was not safe (**Figure 2**).

Furthermore, workers said they could report safety concerns and their concerns would be heard. Agency-employed workers (98%) were significantly more likely to have a way to report concerns about safety at work than PCAs (86%), but similar percentages of both groups believed their concerns would be taken seriously (**Figure 2**).

However, in discussions, participants expressed worry that they lacked control over the COVID-19 precautions of their clients/consumers and family members who might frequent the clients'/consumers' homes.

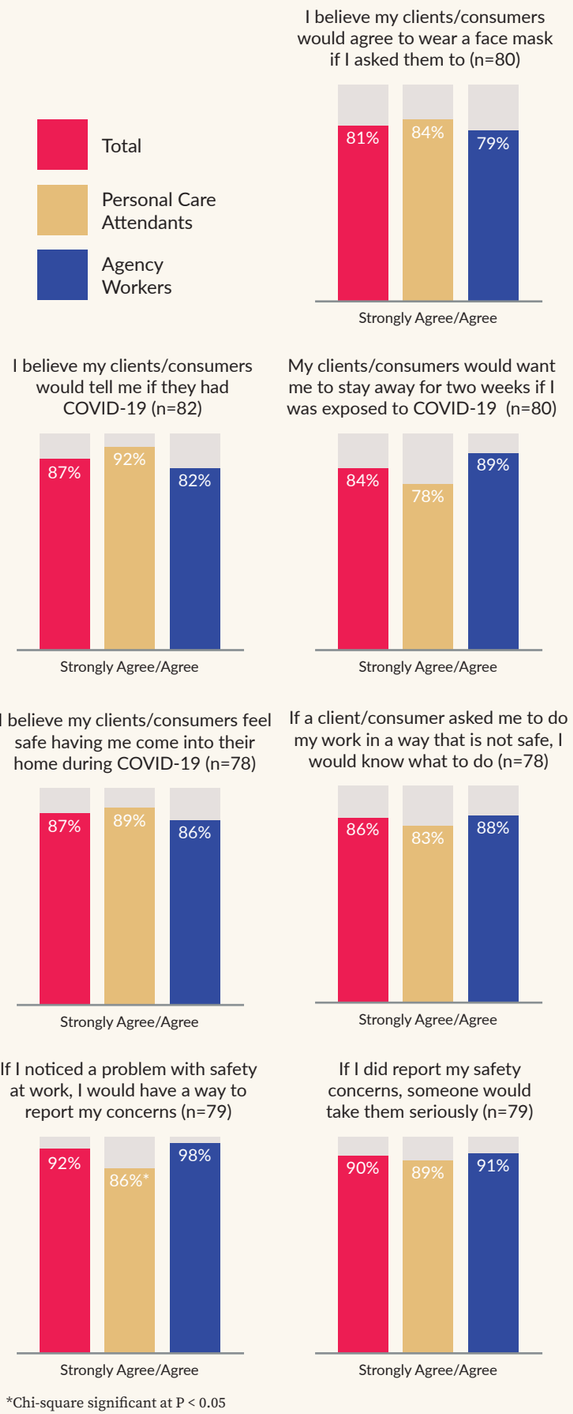
> *"As well as we… social distance and we limit our company and we're safe in our homes, I think the consumer should have some responsibility as well. They shouldn't be able to have whoever they want there without wearing masks. They should have a little responsibility to be safe for us too, not just themselves." (PCA 4-P6)*

> *"We've all had cases where you've been in the house, and, you know, the patient may not be sick, but then somebody comes in and they go, '…my neighbor was over again this morning hugging me and she has COVID.' And they say it casually, like it's not a big deal. And then you're panicked because you don't have… I don't know. It gives you a bad feeling." (agency worker 2-P5)*

These concerns raised questions about how empowered workers were to request changes in practice or refuse to provide care when a situation felt unsafe. In the discussion, both PCAs and agency workers struggled with questions of empowerment.

> *"Our agency is affiliated with a hospital and so in the hospital, you can't walk in without a mask or a face shield, you can't have visitors. In home care, I can ask my clients and their families*

Figure 2. Perceptions of Partnering With Clients and Consumers to Protect Safety



*Chi-square significant at P < 0.05

to put a mask on and if they say 'no,' I'm not allowed to leave. I still have to stay there and provide care. That doesn't make any sense to me." (agency worker 6-P4)

"So what do we do then about the ones that are offended by that question? [They say] this is my house, I dress the way I want to, I do what I want to… I have heard a lot of stories since COVID, where they say you can't come back if you want me to wear a mask." (PCA 3-P1)

Instead, home care workers reported relying on trust and ongoing communication to minimize risk. Some discussed agreements with their clients/consumers about what steps to take if they do not feel well or were potentially exposed to COVID-19.

"I see like 30 patients a week and none of my patients or any in their family have gotten sick and nobody at my house has gotten sick and I think that's because me and my clients, I've had them for a while, we're kind of on the same page. We appreciate helping each other, you know what I'm saying?" (agency worker 2-P1)

"Every single day starts with a conversation about our risks. My risks, her risks, other contacts. And it's the only way we've kept our sanity through it." (PCA 2-P5)

Participants recognized that some clients/consumers do not know or are reluctant to admit when they have been exposed or are sick.

"Yeah, so the patients don't want to reveal that to you, that they're sick or their family members are sick. 'Cause they're afraid you won't come." (agency worker 2-P2)

"I think like a lot of people's asymptomatic, a lot of people don't know they have COVID. So if I don't know I have COVID and somebody come around me, um if you ask them um are you… did you come in contact with anybody with COVID-19? They're going to say no because I wasn't showing symptoms of COVID-19 so really, we really don't know." (agency worker 5-P5)

"While we work as part of a team, I was not notified by the nursing agency that [there was] a COVID positive nurse that goes to my client's house, nor was my client nor were any of the other clients. But you know there is a small network of people who know this nurse and when you have someone for a long time, it was another nurse that told us weeks later." (PCA 1-P7)

Pay and Benefit Structure

In instances where it's not clear if a worker or client/consumer has COVID-19, participants said that they or colleagues may be willing to risk COVID-19 exposure for financial reasons. Seventy-six percent of PCAs and 64% of agency-employed workers said they could not afford to quarantine for two weeks without pay if they were exposed to COVID-19. Participants were aware that Massachusetts had taken steps to improve paid leave for frontline workers who needed to quarantine and offered short-term "hazard" pay at the outset of the pandemic, but they expressed confusion and frustration over the evolving nature of these policies, which influenced decisions about when to stay home from work.

"If it was simple, she [hypothetical home care worker] should just stay home and get tested for COVID and not expose any other clients in case it is COVID. But that said, I think that it's not that simple because it's, not everybody has the money to do that and you also care about your clients. But I think that, you don't, when you need the money and you don't know if you are sick, you don't want to take the chance sometimes of staying home for nothing." (PCA 2-P6)

"I know my employer says you have a choice. You can go in and take care of the patient and get paid, or you can refuse to go in and see the patient and not get paid." (agency worker 2-P1)

Finally, there was uncertainty about job security. Many feared being permanently replaced if they had to quarantine or losing a client/consumer if they enforced safety protocols.

"So it's kind of hard if there's no protection for the PCA. People can just fire you during these times when you're bringing up… valid reasons. So I think it's kind of hard that there's less protection for us as well, especially if you have multiple people you are assisting… where if we have valid concerns that are within the guidelines of our state and local officials and we're seeing someone not following them, that there is some sort of protection." (PCA 4-P8)

Resources to Prevent COVID-19 Transmission

There was strong agreement among participants about the resources they needed to protect themselves and their clients/consumers from COVID-19, including PPE, testing, and relevant guidance.

Access to Personal Protective Equipment (PPE) and Training

Home care workers reported difficulty in accessing sufficient PPE, especially early in the pandemic. Twenty percent disagreed with the statement that they had been able to get the PPE they needed (**Figure 3**). Items, including sanitizing wipes and hand sanitizer, were in short supply and the agencies, consumers, and union they relied on to get the items to them were often scrambling to secure and efficiently distribute the protective equipment and supplies.

"How do you move with two masks from three houses or four houses?" (agency worker 1-P7)

"So I'd say maybe once a month, they send me an email with a link and I click on that link and I am allowed to request gloves, masks, sanitizing wipes, sanitizer, but these things are limited and first come first serve. So there are times when I'll get a package, and I'm like, 'Oooh, I got gloves and masks,' but it'll be just like 20 masks because they didn't have gloves available. But they do their best to provide me with PPE." (PCA 4-P4)

When working with clients/consumers who have COVID-19, home care workers said they would feel safe with universal PPE, including N95 masks, face shields or goggles, and gowns that cover their clothing, as well as hair coverings and booties. Several participants noted that working in full PPE can be uncomfortable, but that they and their colleagues would use it when caring for individuals with COVID-19.

"[Workers caring for someone who has or might have COVID-19] should have the full suit, I call it the marshmallow suit. I had my boyfriend get me some from his job so I have it just in case too. I have it in my car right now…I would put bags on my shoes and everything." (PCA 3-P2)

"Yeah, I'd say that, um, generally if I'm seeing someone that is suspected or confirmed, I'll wear like a gown, an N95, another mask on top, a face shield, um, shoe coverings, and, you know, just bring minimal things into the home." (agency worker 3-P4)

Yet, the PPE participants were consistently using was much more limited, especially when considering workers were often unaware of the COVID-19 infection status of their clients/consumers and family members. Over half of the PCAs said they usually wore a cloth face mask and only 10% regularly used an N95, KN95, or other respirator-style mask. In contrast, over half of agency workers said they usually wore paper masks and 28% used respirator-style masks. The only other type of PPE that was commonly used was gloves (80%). The majority of participants did not usually wear any other PPE (**Figure 3**).

Home care workers also reported limitations in their training on how to safely wear PPE. Eighty-five percent indicated they had been trained on how to use PPE. Only 43% said that someone had watched them practice donning and doffing techniques, which is considered a best practice for evaluating safe PPE use.[30]

"I think the CDC guidelines change almost daily and I know at my facility like we have to now wear eye wear no matter what, every single time we are even handing over meals, so I think since those protocols change so frequently now I think that … we have to be retrained and brought up on to the proper protocol." (PCA 3-P8)

"Nobody comes to tell you, 'This is how you're supposed to put the gloves, this is how you're supposed to put the PPE on.' And so unfortunately for those people who don't know, they go and then there's nothing they can do. They say, 'Oh, I'm just gonna work.'" (agency worker 1-P7)

COVID-19 Testing

Eighty-six percent agreed that regular testing of home care workers would help protect workers and clients/consumers, and three-quarters agreed that they would want to be tested on a regular basis if they did not have to pay (**Figure 3**).

"I feel like companies, agencies like most of ours, should be incentivized to test every employee. Ideally, it should be every day. … And I feel like testing is the part that we're really not doing enough of, especially for folks in our business. I know there are people in my agency that I work with that are clinicians that haven't been tested the entire pandemic. Not once." (agency worker 1-P4)

"I think that [agency] or your company, they should provide free testing for us." (PCA 4-P6)

Participants were particularly interested in testing after a potential exposure. Although 97% of PCAs and 81% of agency workers agreed they could get a COVID test if they wanted one, the discussion highlighted logistical challenges. Costs, convenience of testing sites, long lines or waits for appointments, and turnaround time for results fluctuated and varied by community, especially early in the pandemic.

"Well, if you've already been near [a client/consumer who has/may have COVID], so you're going to want to get tested yourself right away. You don't know if [they've] got it or not, and you want to find out if you've got it, because if you've got little children or grandchildren, you don't want to pass it on to anybody. So if you stay there, you're more apt to be around it. Especially if [they've] got family and friends there that aren't wearing masks." (agency worker 1-P3)

"I think there should be like more COVID testing spots where you can just drive up at any time because you think that the person you just left sneezed. You know like my client sneezes a lot and she doesn't know it, her mum works, is next door, and I am always giving her the stuff but who knows where it will spread to me." (PCA 3-P6)

COVID-19 Guidance and Policies

Home care workers reported that relevant, consistent guidance and policy from authoritative sources, including federal and state agencies, unions, and employers, was hard to access or implement, especially early in the pandemic. When PCAs lacked guidance, they often felt like the sole decision-makers about what to do to keep themselves and their consumers safe. This lack of guidance also intersected with the potential inability to meet consumer needs.

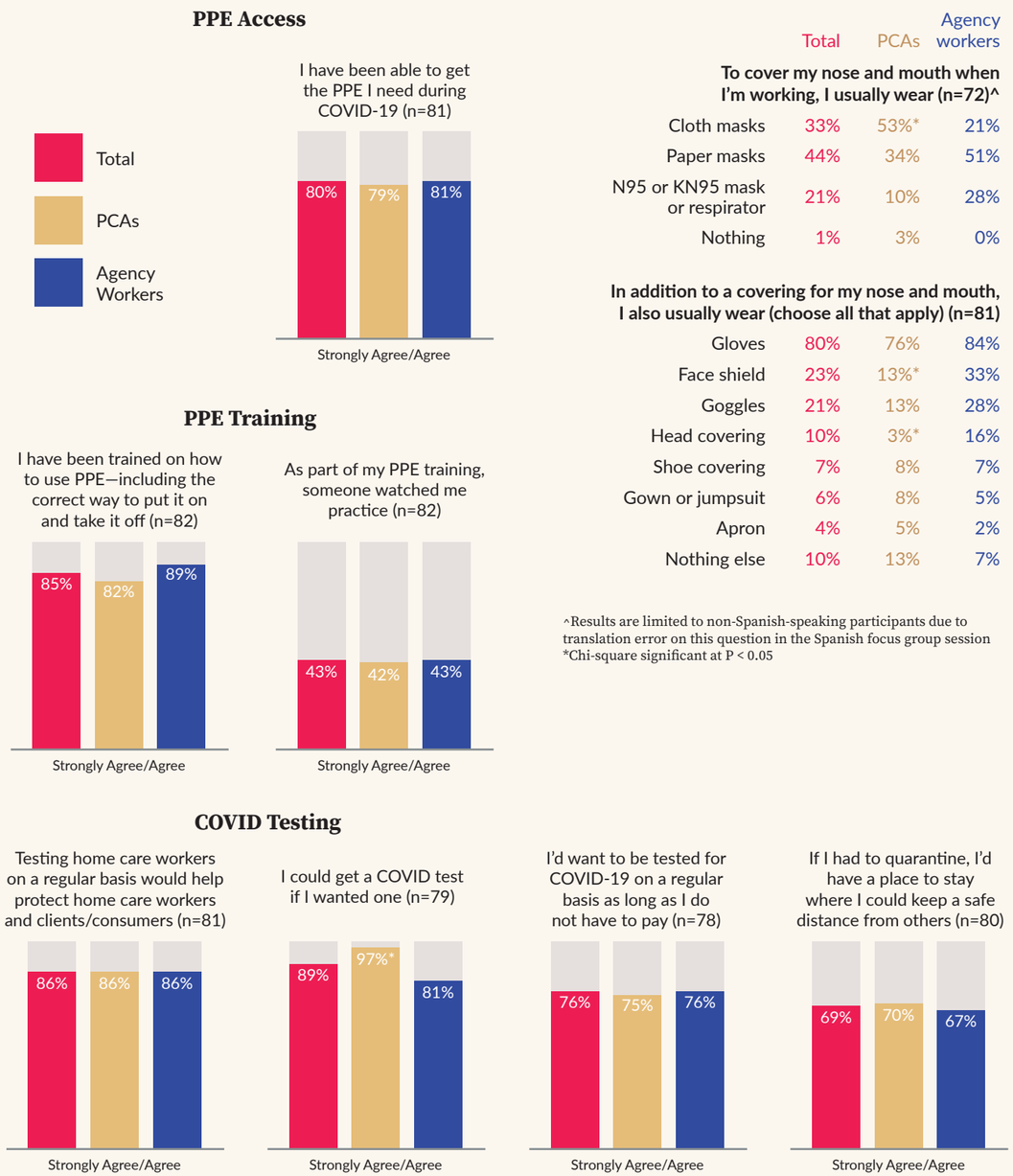
"They should be providing us information. I don't feel like we should have to search for it. They're our employer. I never heard from [Agency], honestly. Only one time I heard from the union and they sent me 20 masks and I never heard ever since then." (PCA 4-P2)

"I just went through… [a] required course… They addressed COVID, all the risk and symptoms and all these other stuff that we should do in terms of protecting ourselves but at no point did they ever say if your consumer has COVID you should not go or you should arrange other care or anything. If anything, the message like almost verbatim was if your consumer has COVID, make sure that you are wearing proper PPE and so I remember thinking that was really odd… our job is to show up but at the same time it's a pandemic… I had that conversation shortly after with my consumer and… we kind of just agreed that if either one of us had COVID or even had an inkling that we might have COVID or if we just test positive, then we might not interact at all." (PCA 3-P4)

Though many home care agencies had contingency plans that anticipated client illness or worker absence, workers employed by multiple agencies said inconsistent approaches across agencies, as well as gaps in communication, caused confusion.

"I think every agency needs to follow the same protocol. We need more guidance because everyone's doing something different… [If someone thought their client] might be a presumptive positive, you know, there should be a whole protocol that [they call] the manager, you know, and they go through all that, and if people don't follow the protocol, you know, they get reprimanded." (agency worker 1-P6)

Figure 3. Resources to Prevent COVID-19 Transmission and Attitudes Regarding PPE and COVID-19 Testing



	Total	PCAs	Agency workers
To cover my nose and mouth when I'm working, I usually wear (n=72)^			
Cloth masks	33%	53%*	21%
Paper masks	44%	34%	51%
N95 or KN95 mask or respirator	21%	10%	28%
Nothing	1%	3%	0%
In addition to a covering for my nose and mouth, I also usually wear (choose all that apply) (n=81)			
Gloves	80%	76%	84%
Face shield	23%	13%*	33%
Goggles	21%	13%	28%
Head covering	10%	3%*	16%
Shoe covering	7%	8%	7%
Gown or jumpsuit	6%	8%	5%
Apron	4%	5%	2%
Nothing else	10%	13%	7%

^Results are limited to non-Spanish-speaking participants due to translation error on this question in the Spanish focus group session
*Chi-square significant at $P < 0.05$

"That's just part of the drill, like if there's any issues, you call and talk to a manager. That's just the way it is. Now the response that you get back from your agency can have quite a bit of variability and I have to tell you since the beginning of this, the CDC guidelines to the 'essential workers' has also changed, so it's been very confusing throughout this." (agency worker 3-P3)

Discussion

Well over 100,000 workers provide home care services to Massachusetts residents,[29] easing the burden on hospitals and nursing homes at critical times throughout the pandemic. They serve a population that is particularly vulnerable to severe illness and death from COVID-19, and workers themselves are often members of communities that experience impacts and disparities due to the social determinants of COVID-19.[30,31] The nature of home care services makes it challenging for workers to maintain physical distance from the people they care for, yet workers experienced chronic shortages of the most basic protective equipment, received inconsistent or unworkable guidance on infection control, and faced daily trade-offs that affected the health and safety of their clients/consumers, their families, and themselves.[12]

As described in this study, home care workers often prioritized their clients'/consumers' needs despite the relatively high-risk nature of their work and a low pay and benefit structure. They noted that they or colleagues might worry about losing pay or job security if they had to quarantine after a potential exposure, missed time because they were sick, or challenged safety practices in a client's/consumer's home, thereby creating dangerous disincentives to follow public health guidance. PCAs, who have not been considered in previous studies, often did not have access to backup care for their consumers and felt personally responsible for sifting through conflicting guidance to decipher what actions to take.

Participants in this study identified the need to prioritize and engage home care workers and their clients/consumers in public health strategies to combat a pandemic or other outbreak, including mass testing, PPE training and distribution, and vaccination plans. These findings are reinforced by previous research. Long-term care workers considered mass testing a critical turning point for preventing transmission in British Columbia.[32] Studies in Massachusetts and New York found agencies did not have enough PPE or lacked fit-testing of essential PPE.[12,19] Recognizing the value of this workforce, Massachusetts was one of only a few states to prioritize this workforce for COVID-19 vaccines.[33,34]

Our findings highlight that clear policies and safety protocols specific to a home care setting should be relayed from experts to workers and their clients/consumers through associations, agencies, unions, and other trusted communicators. Recognizing that worker and client/consumer safety are closely linked, empowering home care workers to implement policies and protocols through adequate training and certification will improve the safety of home care during a pandemic and beyond.

As the population ages, the demand for home care services that allow people to age in place will continue to rise.[31] Ensuring an adequate supply of safe, quality services will likely require increased compensation, job security, and comprehensive paid leave policies for the home care workforce.[11,31,35,36] These costs may be offset with savings garnered by better integrating home care workers into the healthcare system. Because of their close relationships and frequent interactions with their clients/consumers, most are well-positioned to observe significant clinical changes and relay them to other members of the care team. Systems that have embraced a comprehensive team approach find decreased hospital and nursing home utilization, lowering healthcare costs.[37-39]

This is the first mixed methods study of home care workers during COVID-19. This approach allowed for better identification of the trade-offs with which these workers struggled. No other study has included PCAs who work directly for the consumer, potentially shifting informational resources and power dynamics. Yet, the study is not without limitations. Participants were recruited through home care agencies and the union that represents PCAs. The experiences of other self-employed home care workers are not represented. Although participants were representative of the Massachusetts home care workforce in terms of race/ethnicity and gender, they were younger and more likely to have completed college, which may impact the generalizability of findings.[29] For example, more educated workers may be more comfortable reporting safety concerns at work.

Safety challenges in home care garnered attention during the pandemic but will likely persist without additional structural supports for the home care sector. Future research is needed on the most effective policies and interventions to empower workers to protect their own safety and the safety of their clients/consumers without concern about job security. This study highlights that frontline home care workers have important change ideas such as backup PCA pools or comprehensive sick leave.

During COVID-19, home care workers cared deeply about meeting the needs of their clients/consumers but were often left to do so without the benefits of resources, information, or structures within the larger system to keep themselves and the people they care for safe and secure. Healthcare has an opportunity to learn from this experience and translate their difficult experiences into lasting changes for this vital link in the care continuum.

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