COMMUNITY EMPOWERMENT FOR MARGINALIZED PRACTITIONERS:

DESIGNING FOR HOME CARE WORKERS IN NEW YORK CITY

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COMMUNITY EMPOWERMENT FOR MARGINALIZED PRACTITIONERS:

DESIGNING FOR HOME CARE WORKERS IN NEW YORK CITY

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Home care workers (HCWs) are practitioners that deliver essential health services to patients in their own homes yet face a multitude of challenges: HCWs are physically distributed, vulnerable to exploitation, and work long hours with minimal opportunity for advancement. They are underappreciated and underrecognized for their expertise and role in care delivery. While peers can encourage professionalization and challenge exploitation, HCWs' isolation makes it difficult to access peers and other support.

Computer-mediated communications (CMC) may be one way to reduce this isolation. This dissertation explores how HCWs used CMC tools to contact peers, and we describe the types of informational, emotional, and political support they shared. We draw from this exploration and past praxes in social justice to co-design and evaluate a peer-led online support program to connect HCWs to create peer support and collective empowerment. This program used a narrative and non-directive approach that encouraged participants to tell stories of their work and created a sense of voice.

This approach aimed to realize a community-empowerment pedagogy to creating transformative social change by helping HCWs define collective purpose, values, and identity beyond supporting a diverse range of informational and emotional needs. We describe how HCW facilitators encouraged reflection on experiences and focused on the social aspects of home care work. This dissertation suggests how the design of technology interventions can create social change by fostering practitioner communities among HCWs and other distributed and marginalized practitioners in various contexts.

Biographical Sketch

Anthony Poon completed his doctorate in Information Science at Cornell University. A theme of his work is to connect sociological and critical theories of development and social change to an activist research agenda that leverages information technology for marginalized communities. His research engages broad disciplinarian collaboration between technology designers, human-computer interaction scholars, computer system engineers, demographers, critical theorists, and medical doctors alongside local communities. He previously received bachelor's degrees in both Computer Science and Engineering and in Sociology from the University of Washington and worked professionally in secure and scalable enterprise integration systems at Amazon.

Anthony has conducted multiple complex international and domestic research projects. Some of his earlier work involved designing low-resource transportation information systems in the semi-formal minibus transit system of Bishkek, Kyrgyzstan. He has also designed and evaluated digital exam preparation tools for students studying for their baccalauréat in Yaoundé, Cameroon. Through these projects, Anthony has worked with a wide variety of passionate activists, practitioners, government officials, and community organizers. Similarly, the work presented in this dissertation is in partnership with an union representing home care workers in New York City and has been recognized for contributions to diversity and inclusion. By leveraging a multitude of efforts and perspectives, Anthony works towards a more equitable sociotechnical future.

To my parents, for their confidence, support, and sacrifices.

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During my PhD, I also had the privilege of working closely with many other scholars that informed my research. I received advising from Tapan Parikh, François Guimbretière, and Brian DeRenzi, who provided critical support when I was exploring new areas, both physically and academically, and strongly shaped my academic trajectory. Prior to my PhD, I was also was advised by Gaetano Borriello and Charles Hirschman and worked with Beth Kolko and Ruth Anderson, for whom I am grateful. It was their influence that introduced me to my academic interests and set me on the path that would

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Chapter 1

Introduction

Home care workers (HCWs) are healthcare practitioners that provide essential healthcare services inside of patients' own homes. In the United States, HCWs increasingly care for patients who are managing chronic conditions [164], recovering from acute health events [338, 252], undergoing palliative care [315, 75], need instrumental living assistance [81], or have a wide variety of other health needs. Although they care for some of the most health vulnerable, HCWs themselves tend to have low household incomes with limited opportunities for career advancement [282, 258] and are members of marginalized communities, such as immigrants and ethnic minorities [50, 27]. Unlike traditional clinicians, HCWs can spend up to several days per week with patients, creating strong bonds of companionship, irreplaceable emotional support, and an intimate understanding of patients' health conditions [298]. HCWs are also often overtrained for their jobs [81], but despite this, HCWs report feeling underrecognized for their expertise and contributions to patients' health by patients' families, other healthcare professionals,

and the general public [106, 339, 288].

HCWs also face challenges from their unique status as a physically distributed work-force. HCWs spend most of their time in patients' homes with limited opportunity to interact with coworkers or supervisors, which results in a lack of support from their agencies and peers [340]. Without this support, HCWs are vulnerable to prejudice and abuse in the home from their patients or patients' families [105] and report feeling isolated and left to deal with challenging interpersonal and medical situations alone [107]. Isolation makes it hard for HCWs to access information to help them perform effectively and encouragement or empathy for workplace stresses. Additionally, it creates barriers that alienate HCWs from each other and reduces opportunities to collectively challenge inequality, address common interests as a group, and engage in the politics of their work. These barriers make HCWs a group of *marginalized practitioners*.

This dissertation was motivated by a desire to reduce isolation for HCWs towards two goals: first, to create informational and emotional support, and second, to empower HCWs to address issues of marginality and create change in their experience of work. For physically distributed workers such as HCWs, tools for computer-mediated communication (CMC) represent some of the few avenues available to access peers and other support networks. However, past research has demonstrated how difficult it is for technology interventions to produce structural transformation, sustainably address inequality, or result in the liberation of the oppressed [77, 222, 358, 89]. Designing to enable HCWs to leverage peer communities may be one way of creating social change via technology interventions. First, these communities can provide both the information and emotional support that can help HCWs perform their job which is critically important to many vulnerable populations. Second, reducing isolation through such communities can also empower HCWs to collectively address common and overlapping

concerns of structural marginality, underrecognition, and abuse.

It's important to recognize that the dual goals of support and empowerment refer to different things. Supporting distributed and marginalized workers through information and communication technology (ICT) tools is a common subject of past research. ICTs are an effective medium for these workers as they are relatively cheap to deploy. For example, CMC-based tools could be used to monitor and motivate distributed workers [84, 264] or provide them digital materials that help them in their job [243] or learn more effective practices [192]. These tools could be more cost-effective and easier to scale than physical supervisors or paper materials. The digital nature of such tools also makes them more capable of reaching across physical distances, and some projects have taken advantage of this property to connect these workers to each other. For example, forums and social media have been used to enable workers to ask each other questions or for advice relevant to their practice [276]. However, most of these projects were designed at the level of individual interaction with technologies with a focus on what the worker could get out of their usage and engagement with the technology. Even research on forums designed to enable peers to build communities and leverage each other for information and emotional support [276, 293] are focused individual needs rather than needs and desires of the community as a whole. Unlike support, empowerment requires a consideration of the group of workers and their relationships with outsiders. This is because marginality is enforced through social structures beyond the individual level [29], and so research on empowering distributed and marginalized workers must recognize these structures and the politics of how they interact with the group of workers.

In the research presented in this dissertation, we designed, deployed, and evaluated an intervention that enabled an HCW peer community to form in a computer-mediated space. This peer community not only supported the emotional wellbeing and informa-

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tional needs of individuals, but also served as a platform for participants to address their needs as a collective of HCWs. This intervention was an actively facilitated support program led by specifically trained HCWs. Based on prior literature in social justice-oriented groups and communities in other contexts, we designed the structure of the intervention, the training of the facilitators, and the technology used to host and mediate the program. We observed the interactions and types of support that participants were able to build through the course of the intervention, and the work they did towards creating a transformative home care praxis that could shape their identity and experience as HCWs. We discuss future areas for improvement and how similar programs could enable social change, not only by making HCWs and other marginalized practitioners more effective in their practice, but also empowering them to change the social and material conditions around their work.

1.1   Structure and Purpose of Chapters

In Chapter 2, we start by exploring the context of HCWs in New York City. We describe who they are, explain in more detail the breadth of the work that they do, and the importance of HCWs to the US healthcare system. We review literature that describes the challenges that HCWs face in the course of their job. We provide a case study which illustrates how the distributed nature of their work results in a lack of support and contributes to these challenges. In this case study, which was conducted during the coronavirus disease 2019 (COVID-19) pandemic in April and May of 2020, we interviewed HCWs about how their work was impacted by the first wave of the disease and subsequent lockdown. We discovered that the pandemic highlighted the challenges brought on by the distributed nature of their work, as the lockdown further broke what

few in-person support structures that HCWs had access to and created unmet support needs. We describe how other research has used CMC-based tools to provide support for HCWs due to their physical isolation.

In Chapter 3, we explore how peers were an important part of HCWs' support networks through a needs-finding study that we conducted during the COVID-19 pandemic. Because of their relative isolation, HCWs used computer-mediated technologies to not only access resources from their agencies, but also to keep in touch with peers and relied on them for a wide range of emotional and information needs. We also found that HCWs believed that an important part of role of peers was to collectively address the issues of marginality and underrecognition that they felt affected all HCWs. This was a role that HCWs uniquely attributed to peers rather than other sources of support, such as agencies, doctors, and supervisors. In this study, we also conducted a co-design that imagined how CMC-based programs could be better designed to enhance HCWs' access to peers and the support they can provide each other. This study motivated the rest of the dissertation by describing how HCWs relied on peers for support and empowerment, the technological and social barriers they faced to receiving that support, and how a computer-mediated intervention may be designed to address these barriers.

In Chapter 4, we review foundational work in peer support programs in a wide variety of contexts. These programs were relevant to HCWs because they also attempted to address similar support and empowerment needs. These include professional support programs designed to enable learning and sharing of best practices [195, 215], therapeutic support programs for offering emotional and informational support to its members [323, 80], safe spaces for marginalized communities to form away from the expectations of a dominant cultural group [15], and indigenous healing for creating an understanding of one's identity that leads to social transformation [112, 13]. As HCWs expressed

needs around changing the conditions of their work, I also review different therapeutic and pedagogical practices for empowering participants and creating social change. From this work, I identify common themes such as using a non-directive and reflective approach to creating social support [188, 262], a focus the social and communal aspects of participants' experiences [59, 22], and the irreducibility of that experience through storytelling [131, 233]. These themes helped define a social justice-oriented pedagogy and facilitation practice for peer support programs.

We drew inspiration from this broad review of past literature to inform the design of a computer-mediated support program aimed at issues of empowerment for HCWs, described in Chapter 5. We describe the design of this program and how it was inspired by concepts in discussed literature. This program lasted over 12 weeks and included the recruitment and training of HCWs to serve as peer facilitators for two components via regularly occurring video conferencing meetings and a persistent social media group. The structure and pedagogy of the program focused on narrative storytelling and exploring relationships with patients, doctors, and other parties that HCWs interact with in the course of their work. We trained peer facilitators in methods to create non-directive support that used probing questions to prompt reflective dialogue with participants. Thus, this chapter presents a synthesis of past literature in various support programs as represented in the design of a peer support program. We describe the deployment of this program which we evaluate and analyze in later chapters of this dissertation.

In April through July of 2021, during the COVID-19 pandemic, we recruited 42 HCWs to participate as members of this online peer support program. Members met in small groups of no more than nine participants on a weekly basis. In Chapter 6, we describe the results of a qualitative study on the experience of the participants in the program. We observed their interactions in these groups and interviewed participants

to understand what forms of support they drew from their peers in the program and what they felt was the value of this program to their role and identity as HCWs. We discuss how the design of the program, particularly its focus on storytelling, enabled HCWs to address a wide variety of support needs and build legitimacy around otherwise unrecognized tacit expertise that HCWs exercise in their job. This chapter demonstrates the potential for computer-mediated support programs to enable valuable forms of peer support for HCWs, not only to address informational and emotional needs, but also create a space for dialogue around praxis that could transform perceptions around and working conditions in home care.

In Chapter 7, we focus on the experience of the peer facilitators in the program. We deliberately recruited HCWs with prior experience as peer instructors of training programs and could provide an empathetic perspective to the challenges of home care work. Facilitators managed the video conferencing sessions and moderated the social networking group, and we describe how we prepared facilitators for their role using concepts from a social justice-oriented facilitation practice. As these facilitators were also peers, they had unique training requirements and interacted with other HCWs in the program differently than a professional, outsider facilitator would. In addition to observing facilitators' practice throughout the intervention, we also held a group debrief afterwards and interviewed them individually. We found that facilitators had to unlearn the role and expectations of being an instructor or union delegate and instead learn new strategies for handling conflict and engaging with participants. We describe how facilitators leveraged their identity as HCWs to empathize and encourage discussion on relevant issues but often struggled with extra work and challenges brought on by the computer-mediated environment. In this chapter, we discuss how support programs for marginalized and isolated workers can be made more effective by improving the design of peer facilitator training, the support structure for facilitators, and the technology

environment in which they work.

Finally, in Chapter 8, we provide a discussion of where this work can find further applicability. In particular, we address the broader goal of making social change through technology design and compare this to discussions around sustainability in development literature. While social change and sustainability are central goals of many of information and communication technology and development (ICTD) interventionist researchers, most past research has been focused on affecting individual users rather than a community. The work presented in this dissertation demonstrates an alternative approach based on enabling communities of practitioners to form, reflect on their unique identity and role as practitioners, and create a platform for them to discover and advocate for their common goals. Designing technology that enables distributed workers in marginalized contexts to form and leverage peer communities may be a core part of a new liberation and *community-oriented interventionist approach* to social change. We discuss characteristics of such an approach and the potential for research towards other goals and concepts of liberation, such as fostering indigenous knowledge and organic intellectuals. We also discuss how the research presented in this dissertation may address unique challenges in the contemporary workplace, where practitioners are not only alienated from the products of their labor but also from each other, and we identify similar populations of distributed workers in other contexts.

1.2 Contributions

The advent of computer-mediated work has enabled marginalized workforces to be increasingly distributed and isolated. For workers such as HCWs, who provide critical services for the most disadvantaged and vulnerable populations but are also drawn from

these populations, this isolation makes it a challenge to be effective at their jobs and places them in a multi-layered position of marginality. At the same time, while technology interventions can help connect distributed workforces such as HCWs, past CMC-based research with these workers have generally been limited to a focus on supporting the practice of individuals, without a deep treatment of the social relationships and structures that produce marginality. In this dissertation, we argue that the empowerment of HCWs and similar distributed workers requires a social orientation towards the needs and relations of the group. Towards that end, research in this thesis investigates the design of computer-mediated programs for HCWs that make the following major contributions.

This dissertation:

- Explores the value of peer support among HCWs, a critically important but physically isolated group of marginalized practitioners in the US healthcare system.
- Creates a social justice-oriented praxis with a peer-led and community-oriented program, through a co-design with HCWs and a synthesis of foundational work in social support and justice.
- Provides an empirical analysis of how HCWs created shared identity and values through the voice afforded in a computer-mediated environment.
- Proposes a community-oriented approach for designing technology to affect sustainable social support and transformative social change for marginalized and distributed practitioners.

Practitioners, such as HCWs, play important roles in meeting the needs of marginalized and vulnerable populations. Through this work in supporting and empowering these practitioners, we hope to advance the discussion on a community-oriented approach to technology-mediated social change.

Chapter 2

Home Care Workers: An Essential but Marginalized Healthcare Workforce

Home care workers (HCWs) are healthcare practitioners that provide care for community-dwelling patients where the patient is normally living, rather than in a clinic or care facility [81]. HCWs comprise of a variety of different types of workers, such as home health aides, personal care aides, and home attendants, with different legal and training requirements [282]. Unlike other health professionals, whose interactions with patients are relatively brief, HCWs spend hours to days with patients and consequently can have a similarly outsized impact on patients' day-to-day experience of care.

2.1 The Work and Challenges of Home Care

Traditionally, HCWs have provided assistive living services, such as helping with the activities of daily living, such as bathing and dressing, and instrumental activities of daily living, such as preparing meals and cleaning. HCWs also perform many medically oriented tasks critical for maintaining the health of their patients, such as taking vital signs, monitoring patients' status and medications, and managing appointments [26]. Additionally, because HCWs can serve the same patient for extended periods of time, they can build uniquely deep relationships with patients and become important for supporting patients' mental and emotional wellbeing [298, 283]. In the United States, patients that require assistive services are increasingly seeking to live at home with the help of HCWs, rather than in an assisted living facility or nursing home [156].

Increasingly, HCWs provide healthcare services to a wide variety of patient conditions. For example, due to incentives in Medicare's Hospital Readmissions Reduction Program, home care services have been more frequently assigned to patients discharged from hospitals to help manage their recovery and prevent relapse [164]. This is especially applicable to the management of chronic conditions. For example, some research has shown how comprehensive home care services can reduce the hospitalization rate and medical costs of patients suffering from chronic pulmonary disease [126]. HCWs also provide essential medical monitoring and care for patients with heart failure [338, 252] and diabetes [147]. Some HCWs also provide palliative care for patients as many Americans increasingly seek to die at home [315, 75]. HCWs represent a rapidly growing segment of the healthcare workforce and one of the fastest growing occupations in the US [362].

HCWs care for some of the most health-vulnerable populations, including the el-

derly, patients living with chronic conditions, and those with lower household incomes [165]. During the coronavirus disease 2019 (COVID-19) pandemic, HCWs were essential for the continued delivery of healthcare services for patients who had to remain at home and hospitals were overwhelmed with COVID-19 cases. Despite being integral to the care of health-vulnerable patients, HCWs are often themselves an invisible and vulnerable workforce [282, 339]. They work long hours, earn minimum wages, and have limited opportunities for career advancement [258, 106] despite sometimes being overtrained and overqualified for their position [81]. Indeed, one in every six HCWs lives below the federal poverty line [282], and HCWs in the US are often older women of ethnic minority or immigrant status, creating intersectional layers of marginality [50, 27]. These challenging labor conditions have led to high turnover rates and workforce shortages [193, 344].

Furthermore, unlike traditional clinicians, HCWs are a physically distributed workforce and spend significantly more time in patients' homes than they do with peers or supervisors. This physical separation can foment the invisibilization of their work, as HCWs feel isolated and poorly supported in their job, emotionally strained, and unrecognized and unrespected for their expertise and contributions to the healthcare system [19, 106]. Traditional clinicians may be able to rely on coworkers in the form of practitioner communities that can provide feedback and information to help handle complicated cases and emotional support for the stresses of the job [21]. These communities can form and grow organically through shared physical contact and routines [380], but the geographical isolation of HCWs and the invisibility of their work may be barriers to the formation of such peer communities in home care. Instead, HCWs report feeling isolated, left alone to deal with care and interpersonal challenges, and more vulnerable to abuse in the home environment [107]. HCWs can face prejudice or harassment from their patients or patients' families in the home [200].

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During the COVID-19 pandemic, HCWs continued to care for elderly patients and for medically complex patients in the home. While the pandemic stressed many parts of the US healthcare system, it brought particular challenges to this caregiving role given the risk of virus transmission to both patients and workers in the community. With social distancing and lockdown measures, HCWs were also isolated more than ever. With such barriers and challenges, it is likely that the HCW workforce will become increasingly more vulnerable, both physically and financially.

2.2 Interviewing HCWs during the COVID-19 Pandemic

To better understand how the pandemic affected the work that HCWs did and the support they received doing it, we conducted a study of HCWs at a variety of home care agencies in the New York City area. Specifically, we sought to elucidate the challenges HCWs faced regarding disease transmission, preparedness, and well-being to inform future studies, interventions, and policies.

2.2.1 Setting and Study Population

From March 26 to April 30, 2020, during the first wave of the disease in NYC, we conducted a qualitative study with one-on-one semi-structured interviews of 33 HCWs. We used purposeful sampling [271] to achieve a balanced sample of HCWs with respect to the overall size and physical NYC borough of the agencies that employed HCWs in our study.

This study, and other studies in this dissertation, were conducted in partnership with the 1199SEIU Training and Employment Funds, hereafter 1199SEIU TEF. This is a benefit fund of the 1199 Service Employees International Union (SEIU) United Healthcare Workers East, the largest health care union in the US, representing more than 400,000 workers in hospitals, nursing homes, clinics, and home care agencies [3]. The TEF routinely operates training programs for HCWs including occupational certification programs, up-skilling training, and support for continuing education for over 75,000 HCWs employed by 55 home care services agencies in NYC [1].

To be eligible, workers had to be currently employed by a certified and licensed home care agency in NYC and speak English. Using a standardized script, TEF staff members conducted general outreach via telephone calls among HCWs who had in-person training courses at the TEF headquarters that needed to be rescheduled given the COVID-19 pandemic. During these calls, staff assessed workers for their interest and eligibility. Researchers then approached these individuals via email or telephone with a standardized script explaining the details of this voluntary study. To ensure even more perspectives, we also conducted written outreach to a few agencies that represented additional geographic diversity and whose workers had not yet been included in the sample.

This study adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) reporting guideline [357] and was approved by the Cornell University institutional review board (IRB). As interviews were conducted via phone call rather than in person for safety during the COVID-19 pandemic, and participants provided verbal informed consent including permission to record the interview and to publish deidentified excerpts from the interview. Informed consent was obtained in a manner consistent with the Common Rule requirement. Following the interview, participants received $25.00

gift cards as compensation for their time and feedback.

2.2.2 Data Collection and Analysis

Three researchers trained in qualitative methods conducted 1-to-1 interviews using a semi-structured topic guide and Zoom video conference software [399]. The topic guide was informed by prior research conducted by members of our team [339, 336, 337], informal discussions with agency leaders at the beginning of the pandemic, and prior studies on HCWs' preparedness during past epidemics [115, 23]. Interview questions broadly focused on what workers knew about COVID-19, how COVID-19 affected their work, and the challenges they experienced during COVID-19. See Appendix A for a list of questions. In addition, self-reported demographic characteristics data - including age, sex, race and ethnicity, educational level, and employment history - were collected.

Interviews were audio recorded and professionally transcribed. Data were analyzed using grounded theory [103, 235]. To ensure rigor of the method, a constant comparative approach was used at each stage. First, three investigators independently reviewed and open coded three transcripts. Data were analyzed in Excel spreadsheets, and codes were analyzed using a custom-built and Python-based visualization tool which grouped like-coded segments across transcripts. The preliminary coding schema totaled 91 codes. Separately, two lead investigators reviewed the first three transcripts and consolidated the preliminary codes into a final codebook of 66 unique codes. See Appendix B for a list of codes. The three investigators then recoded these three transcripts using the uniform codebook and subsequently applied it to remaining transcripts. The three coders met to revise the codebook every two transcripts, and the two lead investigators reviewed each version of the codebook. Saturation, that is, the point at which no new codes were added, was achieved at the 25th interview. We conducted eight additional interviews

beyond saturation because these participants were already scheduled and had rearranged their work schedules to participate.

Once coding of all interviews was completed, all five coders and lead investigators consolidated the codes into 19 categories by consensus [58]. The team then iteratively consolidated these categories into unifying themes, reconciling discrepancies by discussion [95]. Themes were further refined by three additional team members who had not conducted or coded interviews but who had content expertise.

2.3 Experiences of HCWs in NYC during the COVID-19 Pandemic

In total, 33 home care workers employed by 24 unique home care agencies across five boroughs of NYC participated. (See Table 2.1 for participant demographics.) Participant mean age was 47.6 years, 32 (97%) were women, 21 (64%) were non-Hispanic black participants, 6 (18%) were Hispanic participants, and 22 (67%) completed some college or more education. Overall, participants had a mean of 10.9 years of experience as HCWs. Of 33 participants, 4 (12%) reported that they had become ill with suspected or confirmed COVID-19 during the study period and that they had stopped working once they experienced symptoms. Participants worked in all five boroughs of NYC through 24 unique agencies, although some agencies were headquartered in multiple boroughs. Interview duration ranged from 25 to 40 minutes. The analysis resulted in five major themes with sub-themes, which we present them alongside representative quotations.

Table 2.1

Descriptive statistics of demographic characteristics of 33 participants whom we interviewed about their COVID-19 experiences.

Gender	Women: 32 (97%); Men: 1 (3%)
Age	Mean: 46.8 years; Standard Deviation: 14.0 years
Experience as HCWs	Mean: 10.9 years; Standard Deviation: 7.0 years
Race & Ethnicity	Non-Hispanic black: 21 (64%); Hispanic: 6 (18%); Non-Hispanic white: 3 (9%); Asian: 2 (6%); Mixed or other: 1 (3%)
Education	Some high school: 3 (9%); Completed high school: 8 (24%); Some college: 9 (27%); College degree or more: 13 (39%)
Self-Reported Suspected or Confirmed COVID-19	4 (12%)
Headquarter Boroughs of Home Care Agencies	Total unique: 24; Manhattan: 9; The Bronx: 7; Queens: 6; Brooklyn: 4; Staten Island: 1

2.3.1 On the Front Lines of COVID-19 Medical Management, but Invisible

Participants reported that they were considered essential workers in NYC. As such, they continued to work and care for their patients despite social distancing policies that would otherwise require keeping people six feet apart. Participants reported that the majority of their patients had several chronic conditions, which rendered patients high risk for COVID-19. In addition to their normal caregiving tasks, the participants also monitored patients for COVID-19 symptoms. This process presented new challenges because symptoms, such as cough and shortness of breath, often mimicked patients' usual symptoms. When concern for the potential of COVID-19 arose, participants acted: some participants called their agency, whereas others called the patients' physicians and some called 911 emergency services.

> *I will ask them how long they had the cough ... I know even with a cough,*
> *you can't go to an ER [emergency room] ... So I will call the doctor, who*

will give us information. Then I will try to do that for the patient and myself.

(P10)

Beyond monitoring their patients' physical symptoms, participants also tried to assist with their patients' emotional health. Many reported that this endeavor was worsened by patients watching the news:

It's become a very stressful environment. She watches the news constantly ... As soon as I set foot in the door, "Did you see this, did you see that, about coronavirus?" (P8)

In addition, participants went to great lengths to take COVID-19 precautions while in patients' homes. They described engaging in elaborate cleaning routines whenever possible during their shifts:

I clean like there's no tomorrow. I wipe down every surface: the table, the chair. I walk with the little bleach wipes. (P21)

However, despite these efforts to keep their patients healthy and safe, many described feeling invisible to the health care community and society. One participant described how this experience contrasted with the popular trend during the pandemic for people in lockdown to applaud doctors and other medical personnel at a specific time of the day:

We're definitely a forgotten field ... You hear people clapping, thanking doctors and nurses, even the hospital cleaning staff ... I'm not doing this because I want praise; I love what I do. But it would be nice for people to show us gratitude. (P13)

2.3.2 Heightened Risk for COVID-19 Transmission to Patients and Themselves

Participants explained that providing care to patients placed them in a unique position with respect to COVID-19 transmission. They worried about their patients becoming ill in general and about being the transmission vector for the virus:

> *I feel guilty because since they're not going outside, I know if they catch it, it's because of me. That's my fear going to work.* (P32)

To protect patients, participants went to the grocery store and pharmacy on their behalf, which increased their own risk for contracting COVID-19. Although sometimes they volunteered, other times they were asked:

> *He needs to stay inside the house, so he tells me, "I need you to go there, go here." I really don't want to, but I can't say no. I'm the [HCW]; I'm supposed to do this.* (P8)

Participants also worried about their own risk of contracting COVID-19, and nearly all felt that their dependence on public transportation increased this risk. Many participants reported using public transportation to get to their patients' homes, to run errands for them, and to travel to their agency for supplies:

> *I take three buses to get to work: the 9, the 19, and the 5 ... That's a lot of traveling and different people around.* (P6)

Finally, many participants cared for a patient alongside other workers who entered and left the home each day. This added to their fear of transmitting COVID-19 to their patients and to one another working on the same case:

> *What happens is my [patient] gets sick? We can't leave her alone, she doesn't have anyone and besides her proxy, what happens, and it's five of us that work with her.* (P6)

Owing to this concern, some participants tried to coordinate hygiene and handoff practices with the other HCWs caring for common patients.

2.3.3 Varying Levels of Support from Agencies, Including Information and Equipment

Participants described receiving varying levels of support from their agencies, specifically regarding receiving information about COVID-19, the availability of personal protective equipment (PPE), and receiving COVID-19 training. Although some agencies adapted quickly to the pandemic by providing workers with COVID- 19–related information on a weekly or daily basis, others reportedly barely communicated about the pandemic:

> *Nobody ever told us, "you gotta take precautions" and blah blah. Nobody tell us anything.* (P7)

Many HCWs also reported that they lacked adequate PPE from their agencies, including masks and gloves, which they felt was essential for care:

I'm worried about getting infected because I don't have the right equipment.

The agency has not really been providing for their workers, at all. (P27)

Participants reported that they had not received COVID-19–specific training from their agencies but had hoped that it would be offered in the future. Some agencies asked participants to perform daily "self-assessments." Self-assessments, which were usually automated by phone, were intended to screen HCWs for COVID-19 symptoms. Depending on how they answered, workers would be encouraged to go to work or to call their doctor.

They text a four-question screener everyday. They want to know if something

changes in your body. "Do you have a fever? Do you have a cough?" (P25)

2.3.4 Reliance on Alternative Sources for Support

Owing to varying levels of institutional support, participants often relied on others for information and help. For example, if their agency did not provide information on COVID-19, participants turned to the news media, social media, government briefings, and their worker union:

I watch the television, the news. I listen. I read on my phone, like on Face-

book. I try to read about it everywhere. (P26)

Although some agencies did provide PPE, many participants felt that the amount supplied was insufficient to meet their daily patient care needs. In response, some participants purchased their own supplies or turned to family members and friends:

I don't think we should have to go out and buy masks. I spent $20.00 to get

a box of masks ... I walk all over just to buy a small can of Lysol for $7.00.
(P10)

Some participants also turned to religion and personal faith for emotional resilience or relied on other HCWs through the phone for advice and support:

[We] talk to each other about what you need to do ... to protect ourselves

because we got to do it for the [patients, if you want to keep working. (P7)

2.3.5 Forced to Make Tough Trade-offs between Their Own Health and Finances

Owing to these challenges, participants described constantly navigating hard choices. For example, when patients contracted COVID-19, workers had to decide whether to continue caring for them, which meant potentially exposing themselves. Unlike other jobs during the COVID-19 pandemic, HCWs could not transition to remote work due to the nature of their jobs:

It's just not a job where you can work from home. (P4)

Sometimes, however, patients fearful of contracting COVID-19 declined home care services, leaving workers to decide whether they should accept a new patient who they did not know. Workers also weighed whether they should remove themselves from cases they perceived to be risky. Taken together, they tried balancing the risks of work with their own health and financial wellbeing.

You have to contribute certain hours to get benefits ... I have to go out there

because I have bills to pay. (P3)

In addition, many spoke about balancing the risks of caring for patients during the COVID-19 pandemic with the duty or "calling" they felt to help patients:

I see a fire. Am I going to walk right into that fire? ... If I have the backup,

the proper gear, yes, I'm going to be there on the front lines to help that

person. (P10)

2.3.6   Strengths and Limitations of Study

The strengths of this study include our community-partnered approach to recruit a diverse sample of participants employed by 24 unique home care agencies across NYC. In addition, we analyzed the data using a rigorous, grounded theory approach. We also note limitations. Because this is a qualitative study, the findings were not generalizable but rather convey experiences of participants that may not be captured in quantitative investigations. In addition, owing to our sample's composition, our findings may not reflect the experiences of non-unionized or privately hired workers, non-English speakers, and those in suburban or rural areas. Finally, this study does not include the perspectives of the home care agency leadership or other stakeholders in home care; future research should elicit these perspectives.

2.4 The Pandemic Further Stressed an Already Vulnerable Workforce

To our knowledge, this was the first study to describe HCWs' experiences caring for older adults and for persons with chronic health conditions in the home during the COVID-19 pandemic. Our findings suggested that, although these study participants acted as essential health care professionals, they often felt poorly supported and generally invisible. Not only were they caring for a vulnerable patient population, but, owing to shortages in PPE and a heavy reliance on public transportation, they were at high risk for contracting COVID-19 and for transmitting it to their patients, other HCWs, and their own families. However, many could not afford to stop working, and others continued working out of a sense of duty. Taken together, caring for patients during the COVID-19 pandemic exacerbated this workforce's existing vulnerabilities and professional challenges.

Another key finding was that, across all of the themes above, HCWs expressed feelings of anxiousness stemming from numerous stressors. As health care professionals, they feared what the virus could do to their patients and to themselves. As marginalized workers, however, they also feared the economic toll the virus might have on their ability to maintain their pay and benefits. Prior studies have found that, even before the COVID-19 pandemic, HCWs endured high levels of stress and job insecurity [82, 322]. The additional strain placed on workers by the pandemic, coupled with their already tenuous standing as minimum wage workers, exacerbated this stress. Our findings suggested that additional efforts to support workers' mental and physical wellbeing during the pandemic were needed. Encouragingly, the 1199SEIU TEF began offering wellbe-

ing and resiliency training for this workforce [2].

2.4.1 Policy Recommendations for HCW Pandemic Preparedness

Some of the trade-offs that HCWs navigated during the COVID-19 pandemic were similar to those faced by other health care professionals, but other challenges are unique and warrant separate attention from government officials and policy makers. For example, the financial hardships that HCWs endured point to the need for them to be considered "essential workers" across the US, a designation that would enable them to receive benefits, such as paid sick leave and childcare, during the pandemic [353]. Creating policies at the agency level that geographically organize cases to minimize public transportation use could be important to protect HCWs and patients from community spread.

Although hospitals initially experienced PPE shortages [211, 168], by the time of this study, supplies in many regions of the United States have generally improved. Agencies, on the other hand, remained understocked. Indeed, survey conducted by the Home Care Association of New York found that 67% of home care and hospice agencies in NY did not have sufficient PPE [145]. Given that the number of cases is expected to rise, legislation that makes PPE available to home care agencies is critical. Furthermore, whereas hospitals communicated COVID-19 information to clinicians and staff regularly, our findings showed how the information provided to HCWs varied by agency, which may reflect uncertainty with respect to guidelines in the long-term care sector. To address this situation, we suggest an approach where critical pandemic information is integrated into computer-mediated systems that HCWs already interact with, such as agency websites, check-in tools, and virtual meetings.

2.4.2 Computer-Mediated Communications to Address Lack of Support and Isolation

In Section 2.3.4, we describe how some HCWs relied on talking to peers as an alternative form of support. Because of the pandemic and the already distributed nature of home care, these communications occurred through phone calls and computer-mediated means, such as chat platforms and social media. Due to their physical isolation, computer-mediated technologies may be an appropriate way to support HCWs, and our findings point to the possibility for the extent that CMC-based tools can be used to facilitate valuable peer support for home care workers.

HCWs in our context already used technology tools to conduct their work [308, 137], and some research in health care ICTs have directly addressed home care [40]. For example, the ComputerLink project was a decision-support system designed to improve HCWs' confidence and included peer communication features (e.g. forum, mail, Q&A board) [42, 55]. Bossen et al. tested a tablet-based diary for tracking patient care that allowed HCWs and family members to share information about care tasks [36]. Computer-mediated training programs might give HCWs more specialized knowledge that enables them to better care for patients and increases their value as expert workers [263]. Other researchers have examined how technology design influences the emotional stresses [64] and issues of politics between different parties in home care [360].

Beyond HCWs themselves, technology-enabled professional support has been studied for rural medicine and traditional clinicians [248] or in supporting the learning of community health workers [390] and other populations of practitioners in the Global South [285]. CMC-enabled peer support has been commonly applied for patients and family members coping with long term medical conditions [266], and researchers have

considered the implications designing for ecologies of care that involve many parties and infrastructures [171]. Family and friends also provide informal care, and significant work has focused on designing technology to support informal caregivers. This includes addressing their informational needs [351, 312], emotional burdens and stress of care giving [61, 312], improving coordination between multiple informal caregivers in the home [391, 350] as well as leveraging broader networks of support [327]. This rich body of literature suggests there are similar opportunities for research in the professional home care context.

2.5 Conclusion

In this chapter, we discussed the context of home care workers, healthcare professionals that provide essential care services to health vulnerable populations but are themselves marginalized by a lack of access to support. We describe the important work that they do caring for a variety of patients and how, during the COVID-19 pandemic, HCWs were on the front lines, working to ensure the health of older adults and those with chronic conditions or disabilities. In doing so, these workers placed themselves at considerable risk for contracting COVID-19 themselves, exacerbated by inconsistent delivery of information on what home careworkers should do to protect themselves and their clients, inadequate PPE, and a lack of access to support.

Already a vulnerable workforce, the COVID-19 pandemic placed additional risks on HCWs' physical, mental, and financial wellbeing, exposed gaps in the informational and material support that agencies could provide to their workers, and forced reliance on alternative sources of support, such as family, friends, and coworkers. The pandemic illustrated how HCWs have come to rely on CMC-based tools to receive both infor-

mational and emotional support from their agencies and alternative sources. In future chapters, we explore how the design of these tools and interventions based upon them could be tailored to improve HCWs' access to support.

Chapter 3

Co-Designing a Computer-Mediated Peer Support with HCWs

Our interviews with home care workers in Chapter 2 illustrated how the COVID-19 pandemic broke many agency support systems and forced HCWs to rely on alternative sources of support. One of these sources was peers or coworkers, which some HCWs described as providing valuable information and emotional support that enabled them to process and cope with the stressful situations that the pandemic created. Because of the pandemic and the distributed nature of their work, HCWs had to access peers through CMC technologies. In this chapter, we describe a study in which we explored the value of peer support in the home care context, especially when accessed in computer-mediated environments.

Peer support is the forms of social capital that are shared and given between people

in the same position and may include emotional support, encouragement, knowledge sharing, teaching skills, collective organization, material support, and so on [104]. This type of support is a valuable community asset that could be leveraged to help workers in the day-to-day practice of their job. Furthermore, it could be mobilized to empower marginalized workers to improve their material conditions and experience of work.

While peer support could be valuable to HCWs, its definition is broad. A large portion of the research in peer support involves communities which are not centered around work [300, 266], and it is not obvious what aspects of peer support are important in the labor of providing home care. Many forms of peer support may also be less applicable to HCWs due to their distributed work conditions and limited engagement with peers while isolated in patients' homes. This study explores the types of peer support between HCWs to understand in more detail what forms of peer support currently exist and are practiced, and how this support is relevant to the labor and priorities of HCWs in affecting changes to their work conditions.

To examine these questions, we met with a panel of focus group participants from New York City over the course of six weeks. We used a scenario-based co-design approach [32] to explore possibilities for how computer-mediated communication might enable or foster the types of peer support to address the needs of home care work and promote the priorities of workers. We created scenarios for participants to consider that illustrated different aspects of peer support and how it may be enabled through information technology (ICTs). We created these scenarios based on a detailed review of aspects of peer support in past literature in computer-supported collaborative work (CSCW), our own experiences working with HCWs, and with feedback from community partners.

We show how peer support was instrumental for HCWs to address challenging aspects of their work, such as the emotional labor of home care and conflicts with patients

and other healthcare professionals. Peers provided effective emotional support, helped HCWs regulate their emotions, and refined strategies for performing emotional labor. HCWs also faced negative perceptions of their work as unskilled or domestic, and in response, peers worked to strategically frame HCW practice as skilled and essential by cultivating a body of expertise, setting norms around practice, and encouraging HCWs to stand up to pressure to do work that was outside their job description.

HCWs sat at the bottom of the medical system hierarchy and had less power than other professionals they interact with and their patients. We found that this heavily influenced the priorities of our participants, creating an emphasis on aspects of peer support relevant to collectivization and mobilization. However, these power differences could also fracture communities, as we found many HCWs could be afraid of sharing information and endangering their jobs. We explicate what these results mean in terms of continuing discussions on issues of exploitation in crowd work, the intersection of cooperation and emotional labor, and the ability for computer-mediated environments to expose tacit and invisible expertise.

This chapter shows how the role of power, as well as challenges posed by technology adoption and literacy, interact with HCWs' priorities and values around peer support to create design implications for technology-enabled peer support among HCWs that we take further into the dissertation.

3.1 Communities of Practice and Aspects of Peer Support

To explore the relevance of peer support to the HCW context, we first identified different potential functions of peer support to guide and motivate our study design. We used the *communities of practice* (CoPs) framework to enumerate functional aspects of peer support. We describe how we used this framework below and then review literature on these different aspects.

CoPs are a social configuration between practitioners that help them achieve the goals of practice and perpetuate the practice through knowledge sharing. First conceptualized as a site for situated and social learning through processes of apprenticeship [197], the theory has been expanded and redefined in multiple ways [74] to cover how CoPs maintain and create knowledge [43] and shape the identities and trajectories of participation of their members [379]. We consider such communities to encapsulate structures of peer support between practitioners, and we use this broader definition of CoPs to identify different aspects of peer support in professional contexts.

In describing CoPs, Wenger listed five functions that they have for members. The first is resolving the gap between institutional demands and the reality of work by creating strategies for doing work and interpreting policy. Second and third, CoPs maintain tribal memory and tacit expertise, and help newcomers join the practice by supporting learning this knowledge through apprenticeship. Fourth, CoPs create special language around work and perspectives on how it should be done. Finally, CoPs define the work environment by creating norms, customs, rituals, and routines that influence day-to-day work experiences [383]. Lesser & Prusak further described how CoPs build individu-

als' social capital. They argue that CoPs help practitioners find information about their practice, provide opportunities for members to build supportive relationships with other practitioners, and create knowledge and practice that shapes the future direction of the work [202].

These functions allow us to build a more nuanced understanding of what peer support might entail, particularly for practitioners. While the concept of CoPs has influenced research in CSCW [345, 285] - particularly in areas of studying computer-mediated communities [33, 139], the use of technology in workplaces [158, 133, 231], and training [397] - in this section, we relate the functions of a CoP more broadly to themes of research in computer-supported collaborative work to paint a picture of the variety of *computer-mediated peer support* and how this work may apply to the context of HCWs.

3.1.1 Mobilizing to Resolve Institutional Demands and Conflict

CoPs help practitioners navigate the demands of their employer and the realities of work. Thus, one way peers can support each other is through social mobilization, the mustering of action and allies to resist outside domination in cases of common cause. For example, this might include mobilizing to protect the boundaries of their work and contest new practices [249]. In online spaces, past research has examined how *networked counterpublics*, alternative online spaces for marginalized groups [108], can enable mobilization: firstly, by helping members define common values and ideas for engagement with popular culture [172] and second, by strengthening networks that enable members to reach out to outsiders and move the discourse of the community's needs out of the periphery [352, 191].

In *crowd work*, counterpublics are often difficult to create due to limited platform affordances. Technology platforms for online and distributed labor have been criticized for creating environments of worker invisibilization and exchangeability with a lack of control and career growth [178, 305, 118, 364]. To address information imbalance perpetuated by these platforms, workers have instead used alternative sites, such as Turkopticon, to provide transparency into employers that don't pay for work and give poorly designed tasks. Turkopticon enabled workers to discuss shared concerns and engage in mutual aid [157], as an intermediate step towards forming a networked public.

Finally, crowdsourced *e-governance* systems, such as CGNet Swara which records issues of infrastructural neglect, may enable addressal of systemic issues that would otherwise be ignored by officials [224]. Online *e-petitions* may also provide a way for users to feel like their concerns are heard, though research is mixed on whether they enable participation and effectively drive structural change [170, 272]. Regardless, these tools may be designed to help HCWs mobilize and create strategies for addressing grievances against institutional policies.

3.1.2 Sharing Tribal Knowledge and Tacit Expertise

CoPs maintain a *collective memory* of shared knowledge, values, and ideas [301], and peers often support each other by providing critical access to this memory. CSCW research has focused on knowledge sharing, particularly through question-and-answer (Q&A) systems [5]. Common problems involve motivating experts to answer questions, potentially by improving question quality [333], or using gamification and other social nudges [367]. Some researchers have tried leveraging user's social connections by allowing questions to be forwarded to a potentially more relevant domain expert [6, 302, 277]. Researchers have also tried to predict which users are more likely to

answer questions [316, 159].

Matching a knowledge seeker to the appropriate expert may be especially relevant when the knowledge to be shared is tacit and difficult to explicate [5]. The implied physicality of such knowledge makes it difficult to share through computer-mediated interactions, though some work has explored using novel sensing to represent physical activities [210]. As the relational and physical aspects of home care are highly tacit, creating tools that support tacit knowledge sharing may allow HCWs to improve the overall level of expertise in the community.

3.1.3 Connecting to Apprenticeship and Socialization

One of the most direct forms of peer support in a CoP is apprenticeship, the relationship between newcomers and experienced practitioners that enables the former to learn skills, standards, and knowledge to become a full-fledged member. This process includes socializing newcomers to the CoP's processes and norms. Past research described the importance of such socialization in sustainable, large-scale online co-production. Newcomers to open-source projects must learn the politics of contribution and how to create narratives to fit their work into the larger project [91]. In Wikipedia communities, established members rely on tactics, such as reaching out with constructive criticism, to encourage newcomers' participation [63].

However, distributed and large-scale collaborative work environments present challenges to one-on-one mentorship. This has led to new types of mentorship models between any number of peers with either fixed or shifting mentor roles [152] or focused around different sociotechnical structures, such as groups or friend lists [7]. Research has started to address the challenges of designing for computer-enabled mentorship

[395], such as issues of scale when there are many newcomers but relatively few experts [397]. Some have argued that, through coordinated peer feedback, online communities can enable *distributed mentorship* for developing skills and receiving emotional support from a large number of people, such as peer reviews in online fanfiction communities [54].

Finally, beyond artifacts that can be produced online, such as software or writing, online social networks provide opportunities for practitioners to seek mentorship from experts across the globe. For example, researchers have observed how Brazilian Jiu Jitsu practitioners used YouTube and other online networks to share practices and learn new martial arts techniques [331] and schoolteachers used online communities for professional development [149], creating virtual or online CoPs [90]. Similar tools for mentorship at a distance may be useful in the isolated work context of HCWs.

3.1.4 Facilitating Peer Review and Standards of Practice

Besides simply teaching newcomers, CoPs also create and maintain standards that apply to all members for what is best practice. These standards are propagated and enforced through processes such as peer review and feedback by punishing low effort and rewarding high effort [148]. Researchers have studied how peer review can improve the quality of co-produced work, such as the accuracy of crowdsourced transcription tasks [130], online databases [73], and co-written documents [176].

Beyond quality of outputs, peers can also improve the members' practices and processes of production through feedback to the original contributor. Computer-mediated peer feedback systems have been built to help users learn better practice in a variety of contexts, such as visual designers [217], students giving presentations [317], and learn-

ing to write in a second language [388]. These systems enable users to get feedback with less burden on an instructor [317, 397] and can connect newcomers to experts that might not otherwise be available [217]. Users can also learn to improve their own practice through providing feedback to peers [398].

Researchers have also examined how the design of feedback systems can increase their effects, by reducing the frustration of peers receiving feedback [259], providing tools to create more informed [274], diverse, or focused feedback [138], and encouraging more users to provide feedback [273]. Applying this research to the home care context might help workers improve their skills and could spark dialogue on proper practice. This may result in more explicit and widespread standards of practice that HCWs have a voice in defining.

3.1.5 Influencing the Experience of Work and Facilitating Safe Spaces

CoPs are important in defining the experience of work and creating supportive environments. Because negative perceptions of the supportiveness of the surrounding community can affect perceptions of a platform's helpfulness and reduce usage [309], online communities may attempt to reduce conflict, such as the policy enforcement work observed among Wikipedia contributors [177].

In computer-mediated settings, research has studied how technology can make the experience of work more emotionally supportive. For example, instant messaging can help to maintain interpersonal relationships that support emotional wellbeing and motivation [354] by creating a sense of social presence, respectful exchanges, and statements that build group cohesion [17].

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Outside of the contexts of work or education, some research has focused on digital safe spaces [254]. *Safe spaces* are designed to enable marginalized communities to congregate and share experiences without fear of judgment or reprisal. Social networking sites can serve this role by enabling members to access emotional support from peers, promoting a sense of belonging, creating an environment where members feel encouraged to express and explore their identity [39, 237, 213], and providing an empathetic audience for sharing common experiences and concerns [66]. This may be especially valuable for people from isolated and marginalized groups, such as HCWs, and allow them to maintain and legitimize themselves in networked counterpublics [108, 160].

Finally, supportive environments can also contribute to worker effectiveness. For example, collaborative digital diaries and online knowledge portals can provide sites for coordinating daily activities and discussing persistent problems in ways that improve productivity [186, 363]. As multiple HCWs may need to coordinate work for a single patient, similar tools may be helpful for making the performance of their work easier.

3.2 A Methodology for Exploring and Co-Designing for Peer Support Needs

As demonstrated above, the possible functions of peer support are vast, and similarly so is the variety of research around ICT tools for computer-mediated peer support. In this section we discuss the design and implementation of our study to understand how HCWs conceptualized peer support and explore how computer-mediated peer support could be designed to work in their context. We conducted this study in New York City in partnership with the 1199SEIU Training and Employment Funds (TEF), who assisted

in recruitment, logistics, and reviewing the materials and design of our study.

3.2.1 Study Design

To examine the forms of peer support relevant to HCWs, we engaged with HCWs using a paneled discussion approach. We recruited HCWs to recurring, weekly focus group sessions over the course of six weeks. Participants were encouraged to attend as many sessions as they were able and interacted with the same participants throughout the course of the study. While all sessions discussed concepts of peer support in some fashion, each week covered a different topic and purpose. The first and last sessions served as introduction and conclusion to the study, while the four intermediate sessions focused on different aspects of peer support and uses of technology.

A panel design was chosen for three reasons. Firstly, we could not explore all aspects of peer support in the span of a single focus group discussion. Our design enabled us to discuss peer support in more specific terms throughout the study period and minimized repeated material. Secondly, we wanted our participants to have the context of prior discussions so that we could contrast different needs and discuss the relative priority and challenges of each of them. Finally, because HCWs do not have frequent opportunities to interact with each other in their normal work routine, we wanted to treat the focus groups themselves as a research site to observe how HCWs might use a consistent shared and virtual space to provide each other support.

As the study occurred during the COVID-19 pandemic, all focus groups were held remotely via audio and video conferencing. HCWs participated in the sessions using Zoom [399], a conferencing platform. Participants could either use the Zoom app or dial in via a basic telephone line. During recruitment, recruiters worked with participants to
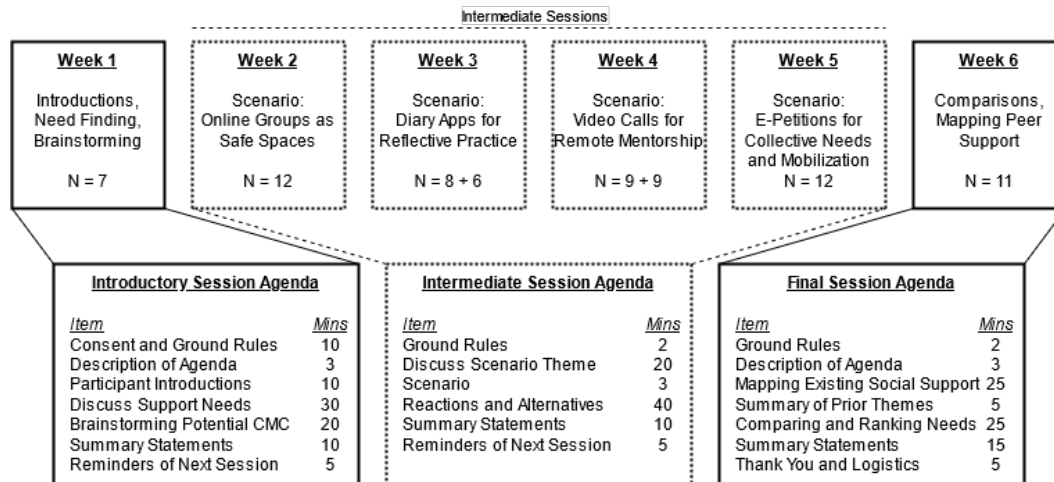
Figure 3.1

Study overview, session agendas, and participation per session. We had unexpectedly high participation and ran two sessions on the same topic in weeks 3 and 4. Logistical barriers prevented this in later weeks.

familiarize them with the conferencing tool. Figure 3.1 shows the study design, and we now describe the contents of the sessions in detail.

3.2.2   Session Materials and Procedure

In the first week's session, we introduced the purpose of the study and reviewed the consent process. Because participants would see each other multiple times, we did a round of introductions and discussed ground rules to begin to establish rapport between participants. In the introductory session, we asked HCWs to describe what the concept of peer support meant to them, where the greatest value of having peer support was in their work, and their existing experiences with peer support. We also explored their familiarity with different types of CMC and brainstormed ways that technology could be used to enable peer support in their professional environment. Sessions concluded with a round of summary statements, where participants could describe what they thought was most important about the week's discussion or what they would like to discuss further in

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future sessions. At the end, the moderator reminded participants of the time of the next session the following week. An overview of session agendas is included in Figure 3.1.

We drew from the introductory week to better tailor subsequent sessions for more specific needs and themes that could be explored in detail. In preparation for the study, we wrote six different potential scripts for the four intermediate sessions, each focusing on a different aspect of peer support as described in Section 3.1. These were constructed with feedback from union staff at 1199SEIU TEF, who have in-depth familiarity with the home care context. After the initial session, we further refined the scripts and wrote an additional script.

Based on our introductory discussion, we chose the four most relevant scripts to use in our second through fifth week. The chosen scripts drew inspiration from examples of technology-enabled peer support in past research, such as online safe spaces [66], Q&A forums [302], remote mentorship [248], and e-petitions [170]. To further illustrate these aspects of peer support and prompt discussion, each intermediate week also included a short hypothetical scenario describing how HCWs might interact with a technology designed to foster peer support per the week's theme.

These scenarios were short skits written from the viewpoint of fictional HCWs and illustrated hypothetical computer-mediated interactions. These scenarios created imaginaries for HCWs that could be assessed and critiqued to identify potential breakdowns [32] and were acted out and prerecorded with 1199SEIU TEF staff. As many participants dialed in via basic phone line, all materials were designed to work using audio only. The exact scenarios are provided in Appendix C.

Each intermediate session started with a brief review of the ground rules and an introduction of the week's theme. Participants were then asked to broadly discuss their

experiences and attitudes. Then, the 2-3 minute, voice-acted, and pre-recorded scenario was played. Participants were asked a series of follow-up questions to gauge their reactions, focusing on applicability, feasibility, values, and sociotechnical challenges. Participants were also asked to imagine alternative conceptions or scenarios based on the week's theme. To ensure all participants had an opportunity to speak, at the end of the session, we asked each participant to give a summary of their thoughts.

In our final session, the moderator started by explaining the agenda. We began with an activity inspired by asset-based community development [227]. Participants were asked to think of the people that they currently turn to for support in their work and describe how they met their supporters and the forms of support received. The moderator then gave a short summary of the scenarios and themes discussed in prior weeks. We asked participants to reflect on their experiences in the study by comparing the intermediate sessions, the aspects of peer support discussed, and the scenarios that they observed. Finally, the moderator invited closing thoughts and thanked the participants.

3.2.3   Recruitment and Participants

We used purposeful sampling to recruit HCWs for our study, focusing on representing a variety of age and experience levels with a wide breadth of agencies in New York City. To schedule our focus groups to be as sensitive to work schedules as possible, we asked participants to describe their availability during recruitment. Finally, because the study was to be conducted remotely, we limited participation to those who had access to a device on which to call into the sessions.

Recruitment was conducted over the phone with the help of a staff member from the TEF, and in total about 90 potential participants were contacted. In addition, midway

Table 3.1

Participant characteristics and demographic information for the peer support needs finding and co-design study. All participants were women.

Participant #	Age	Race & Ethnicity	Education	Years Experience
1	50s	Hispanic/Latinx	Some College	20+
2	60+	Black	College Degree	20+
3	60+	Hispanic/Latinx	Some College	20+
4	20s	White Hispanic/Latinx	High School/GED	1-5
5	60+	Black	Some College	6-10
6	50s	Black	Some College	6-10
7	40s	Black Hispanic/Latinx	No Diploma/Degree	11-15
8	30s	Hispanic/Latinx	College Degree	11-15
9	30s	Black	Some College	6-10
10	50s	Black	High School/GED	6-10
11	60+	Black	Some College	20+
12	50s	Black	No Diploma/Degree	1-5
13	50s	Black Hispanic/Latinx	College Degree	11-15
14	20s	Hispanic/Latinx	High School/GED	1-5
15	50s	Black	High School/GED	16-20
16	50s	Hispanic/Latinx	College Degree	11-15
17	60+	Black	No Diploma/Degree	16-20
18	60+	Hispanic/Latinx	College Degree	16-20

through the study period, one participant decided to join from word of mouth through an acquaintance in the study. In total, our study had 18 unique participants whom, at the time, worked for 12 different agencies.

Table 3.1 provides participants' demographic details. The median age of the sample was 54, and 11 participants had over 10 years experience working in home care. Four participants had immigrated to the US within the last 10 years, while the others had lived in the country at least that long. There were no male or non-Hispanic, white participants, which was consistent with the demographics of this workforce in New York City, which was heavily female dominated, older, and predominantly ethnic and racial minorities [339].

3.2.4 Ethics and Participant Safety

Before their first session, participants were sent an online consent form through email, and recruiting staff followed up to discuss and fill the consent form. These forms described the purpose of the study, some of the topics that would be discussed, as well as the voluntary and confidential nature of participation. Participants all consented to the sessions being audio-recorded.

During the initial session and for any session that had new participants, the moderator also gave a short description of ground rules and framed the focus groups as a safe space. The moderator described the commitment of the researchers that all published details would be anonymized and asked participants to not share any of the discussions that were held in the group.

Since the study occurred during the COVID-19 pandemic in 2020, and HCWs are healthcare workers who worked with populations vulnerable to the disease, the study was conducted remotely, including recruitment and consent. Focus groups were held via video or voice conferencing.

Participants were compensated $25 for each session they attended, for a maximum of $150. All procedures were discussed in advance with our community partners at 1199SEIU TEF and approved by our IRB.

3.2.5 Data Collection and Analysis

Focus group discussions were recorded and professionally transcribed. Discussions were held with a moderator and a note-taker who also performed a retrospective after

each session to highlight interesting topics and themes. Retrospectives were recorded in the session notes.

Qualitative analysis was conducted using MAXQDA [230]. Two coders engaged in open coding with a focus on our research questions, meeting regularly to discuss the codes. Existing codes were modified, merged, and renamed as additional transcripts that were coded. Codes that were previously too large and vague were also selectively re-coded to better characterize the data.

Using a thematic analysis approach [38], we then examined the codes and related codes to each other in the formation of larger concepts and narratives from the data. We reread coded segments within related codes and wrote memos to further refine themes and validate our understanding of the data. This approach allowed different concepts and themes around peer support to emerge from our dataset. These themes and their memos form the basis of our findings.

3.3 Findings on Peer Support in Home Care

We found that HCWs participated in existing mentorship programs that helped address on-the-job training needs of newcomers. Peer support between HCWs also helped workers perform the emotional labor of home care work and supported the strategic framing of the profession as skilled and essential. Finally, we describe challenges of power and technology adoption and their implications designing technology-enabled peer support.

3.3.1 Existing Mentorship Programs for Peer Support

One of the most direct and apparent ways HCWs supported each other was through formal mentorship programs. Some of our participants had experiences with mentorship programs which were offered through agencies and described a typical agency-run mentorship program as lasting 90 days to acclimatize newcomers to the home care profession. Mentors connected with mentees through scheduled calls up to multiple times a week, and some mentors also opted to make themselves available through SMS or WhatsApp to offer advice as needed. Participants described this as helpful as it offered mentees a venue for addressing immediate concerns.

Formal programs were funded by agencies and paid mentors for their time to call mentees. Such programs required mentors to report when they met with mentees, and all participants were required to provide regular feedback on the program. We discuss the value of these programs, the significance of mentorship to both mentors and mentees, and how these programs, though limited, were one of the few opportunities for HCWs to meet and interact with peers.

Mentors Address Newcomer Needs

Mentorship programs were generally designed to help newcomers transition. The first day on the job for an HCW did not allow for a slow learning curve. Recounting their own experiences as newcomers, our participants remembered feeling nervous, uncertain with how to perform aspects of care, and overwhelmed as they acclimatized to the patient's environment and learned about their condition and routine.

Mentors provided a degree of informal on-the-job training. While HCWs receive

onboarding training, this may not be specific to patient contexts, and newcomers may forget particulars. One participant described frequently calling her mentor for support as she had trouble working complex machinery. Another described how newcomers often lacked many skills, from critical tasks to more perfunctory aspects of home care work, such as how to clock in and receive their pay.

Participants who were mentors also emphasized that an important part of their roles was to transmit norms around acceptable behavior and practice to newcomers. New HCWs found themselves in particularly vulnerable positions where they could not resist unreasonable patient demands because of both a lack of context for what constituted reasonable work and inexperience with approaches to refuse politely. Mentors provided perspective to help newcomers understand the scope of their work and encouragement and suggestions for how to approach demanding patients. This is described in more detail in Sections 3.3.2 and 3.3.3.

Mentors were also often more available and responded more quickly than HCWs' managers, or *coordinators*, and could help newcomers resolve their concerns in real-time. Even when coordinators could be reached, many of our participants considered coordinators to be unable to offer effective solutions to issues faced by HCWs due to a lack of practical experience:

> *If you had somebody, a mentor, to call and say, "Hey, I'm in this case, this situation, have you ever experienced that?" They can say, "Oh yes. I had a case like that. Just don't worry. Do whatever, whatever." And then that'll probably help you more than you sitting around waiting for the coordinator to get back to you.* (P9)

Benefits to Mentors

Mentees were not the only ones to benefit from involvement in a mentorship program. Our participants who were mentors described the experience as gratifying and related instances where they were thanked by their mentees. In addition to direct appreciation, mentorship also empowered mentors to develop their network of contacts, with increased access to information, coordinators, and agency management, which made mentors more central and able to serve as a clearinghouse for resolving issues. Being a mentor was also a form of social capital and prestige that located an HCW as a master of their practice.

Participants also described being a mentor as an opportunity to learn and develop interpersonal skills. One participant liked how her role as a mentor allowed her to interact with peers from diverse backgrounds. Another participating mentor reported that mentoring helped her develop her ability as an active listener. Finally, some formal mentorship programs compensated HCWs for acting as mentors, such as providing additional stipend and a laptop to help keep track of mentees.

Limited Opportunities to Meet Other HCWs

While participants found them valuable, mentorship programs were not widespread. About half of participants did not have a mentorship program offered by their agency. Beyond mentorship, HCWs described having few opportunities to connect with peers and being constrained by their isolated work environments.

Training was one of the few places to meet other HCWs. HCWs in our study were typically required to attend *in-service training* at their agencies two to three times a

year, as a form of continuing medical education. These training sessions, and other professional development courses offered by 1199SEIU, provided a rare opportunity to interact with peers:

> *The only time I meet other [HCWs] is during in-service. I'm just sitting in the classroom for hours together. You kind of start making those conversations, and you learn that you have a lot of common grievances when it comes to the workplace, and that is kind of how you will start that friendship. (P8)*

However, in-services trainings were infrequent, which required HCWs to actively follow up to maintain those relationships. Furthermore, participants described how over time these trainings were reduced or transitioned online, preventing them from being social spaces.

Other informal settings where HCWs interacted with peers include church gatherings, education unrelated to home care, or public settings. One participant described how the medical uniforms worn by HCWs allowed her to identify and strike up conversations with other workers while waiting for public transportation. Finally, participants described introducing friends to the home care field and thus had existing relationships with a peer. Unlike other workplaces where employees have access to each other, social connectivity at work for HCWs depended on workers being able to identify and actively seek out HCWs, requiring more maintenance work. Mentorship programs remained one the few venues available for HCWs to meaningfully connect with peers.

3.3.2 Emotional Labor in Home Care and the Role of Peer Support

Mentors were able to support mentees during their stressful and uncertain first few months and provide advice for interacting with patients. These forms of peer support were not just valuable to newcomers but featured prominently in HCWs' interactions with peers of all experience levels. We now describe the types of *emotional labor* [140, 153, 121] that HCWs performed and the ways that peers aided each other in collaborating on or creating strategies for conducting this labor.

HCWs Perform Emotional Labor

HCWs faced socially and emotionally challenging situations in patients' homes. Patients could be distrustful of HCWs and become emotionally or physically taxing or abusive. One participant described being struck by a patient, while others recounted instances of rude and disrespectful patients and families who caused emotional distress. Patients could also get angry and object to part of the HCWs' duties:

> *One of my patients falls constantly and every time they come to get him,*
> *he refuse.... "Don't call your agency. Don't do this, don't do that." I say,*
> *"Calm down.... This is a part of my job to report that you fell. You can call*
> *your doctor and let them know you fell as well." "Oh, I can?" So it gives*
> *them a little sense of independence.... So I try and engage them as much as*
> *possible because they get very mad when I have to report this. (P2)*

Despite these challenges, HCWs were required to regulate their emotions, act in a professional manner, and provide empathetic care. As described above, HCWs had to

find ways to frame their duties—whether reporting falls, or requiring patients to take their medicine, eat, bathe, or exercise—in engaging and persuasive ways to obtain patient cooperation. The effort to meet these requirements constituted the emotional labor for HCWs.

Because HCWs were in contact with patients much more than a traditional physician, they often developed deeper relationships with their patients. One participant described experiencing depression since the recent passing of two of her long-term clients. 1199SEIU recently instituted a new training program focused around grief and loss due to such experiences. Because of the inherent risk and responsibility of home care, participants also described situations where they were fearful of doing something wrong and potentially harming the patient.

These challenges were compounded by complex social situations where HCWs were often required to coordinate care with family members who were involved in patients' lives. HCWs also had to build working relationships of trust with their patients, who may resent feeling a loss of control or independence by allowing an HCW into their home. Several participants described how some patients could be suspicious or hostile towards HCWs actions, even when those actions were considered good practice, as described further in Section 3.3.4.

Considering these challenges, our participants described the importance of empathy to providing quality care. Participants described how part of being a professional HCW was to be passionate about the work in order to bear the emotional burdens and react calmly and with self-control.

Peers Support Each Others' Emotional Regulation

With few avenues to share about their work, participants often leaned on peers for emotional support and to help them perform emotional regulation. *Venting*, the ability to talk about issues to a peer who would listen and make you feel heard, was described by all participants as beneficial for stress levels. Participants with experience being mentors described the importance of being active and empathetic listeners, and one explained how having a peer listen to their issues validated their experiences and emotions:

> *It's just something that you're venting what you're feeling at that point in time, to have a second opinion, to give you support, to make you feel like what you're doing is valid.* (P7)

While listening to peers vent and providing reassurances and sympathy, HCWs also encouraged their peers to calm down and relax. HCWs urged peers to use techniques such as slow breathing and counting to address immediate anxiety and improve their affective state. Some participants described calling peers to seek someone to help them calm down. By helping each other regulate their emotions, HCWs were able to collaboratively perform the emotional labor of home care work:

> *If you're upset, if you're frustrated, I can tell you, "It's not going to do nothing. Just calm down. Take a deep breath, and then think about what you're going to do tomorrow."* (P12)

Peers Share Advice and Techniques for Handling Stressful Social Situations

Through peers, HCWs had access to advice on how to address social problems with patients and families. Sharing this advice constituted a form of peer support aimed at refining HCWs' skill at the emotional labor these workers performed. Participants described experiences where they either gave or received such advice. When an example situation was raised during the focus group, HCWs were quick to suggest different ways to approach the issue to minimize conflict. Example techniques provided by participants included involving patients in decision-making for instrumental activities, such as tasting food for seasoning, or narrating your process as you work.

Generally, these strategies emphasized good communication between HCWs and their patients. Several participants described how patience was crucial to avoid upsetting patients. Participants emphasized how important it was for peers to share techniques to address social conflicts within the home. Interpersonal skills were an important part of the tacit knowledge that HCWs learned and maintained to perform their jobs successfully, especially in positions of vulnerability:

> *The best to hear is good communication. If there is good communication, there is always mutual understanding between you and the client, and also to exercise your patience because they always have the upper hand. So you being the aide, you have to come down with a good approach or attitude towards whatever happens.* (P10)

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Peers Provide Effective Emotional Support Due to Shared Experience

Over other parties, participants preferred venting and discussing their emotional labor with peers due to shared experiences. In describing why a hypothetical HCW would seek support from peers, one participant highlighted the potential for peers to have similar experiences, which could make encouragement and advice more relevant and effective:

> *I think [the HCW] was very smart because she looked for help in the right place of people who might understand her. Because the practitioner did go through also the experience, they have experience in the same thing in some moment, and they are better prepared to give support and some kind of advice too.* (P18)

While HCWs worked with coordinators to provide care, coordinators' role was managerial, and HCWs did not perceive them to be the primary source of emotional support. Our participants had negative experiences with unsupportive agency coordinators. HCWs often felt that coordinators were not empathetic to their concerns and didn't understand the challenges they faced on the job.

The role of peers in providing emotional support may be especially pertinent for issues related to a patient shared between multiple HCWs. One participant described how, because of patient privacy restrictions, she could not discuss her work stresses with family or friends.

3.3.3 Strategic Framing of Home Care as Skilled Work and the Role of Peers

As described in Section 3.3.2, techniques for minimizing and performing emotional labor were a part of HCWs' tacit knowledge. Despite this, our participants felt that they were often not respected as skilled workers and healthcare professionals. This included respect from a variety of sources, from other medical professionals to the general public and the patients they serve. In response to this, HCWs engaged in several actions targeted at peers to strategically define the scope of their work and promote the perception of it as a skilled and specialized practice.

HCWs Are Not Recognized as Essential and Medical Professionals

HCWs aid their patients by performing medical tasks such as regularly monitoring patient vitals, operating equipment, making appointments, and summarizing and relaying information to doctors to help make informed decisions. While HCWs delivered this care, they felt that public respect and recognition for the specialized and essential nature of their work was lacking. Instead, they felt that public awareness of home care work focused on their peripheral functions, such as housekeeping work:

> *And you have all the knowledge about certain things: taking the pulse, a temperature, other things, setting up the nebulizers, doing this, and yeah. We do all those things, but it's like that section is never recognized. Only the cleaning, and the cooking, and going here and there is all that people think about us.* (P10)

HCWs felt undervalued compared to the rest of the health services supply chain and struggled to be recognized as essential workers by the public. During the COVID-19 pandemic, as popular media honored the role of doctors, nurses, workers in grocery stores or restaurants, HCWs were left out. This made participants feel overlooked and further invisibilized.

These perceptions may influence how patients and family members treat HCWs. Though patients and families were supposed to be given information on what they can expect from an HCW, in reality, there was often lax adherence to HCWs' scope of practice. Participants described many situations where they felt patients didn't recognize their expertise and instead asked them to do housework. HCWs thus felt underutilized and frustrated that patients didn't understand how HCWs contributed to their wellbeing.

Disappointingly, some of these misconceptions were perpetuated by other healthcare professionals who may also misunderstand the role of HCWs. Doctors and nurses may misassign patients who don't need HCWs or miss out on assigning HCWs because they do not consider HCWs as part of the extended care team. One participant suggested training medical providers to provide more accurate information on the role of HCWs in order to clear up misconceptions with patients.

HCWs also felt like they were not treated as healthcare professionals by other practitioners that they worked with. HCWs were disappointed that nurses sometimes ignored the input HCWs could provide when checking the patients' condition. Most participants had poor experiences with coordinators, who talked down to HCWs or tried to manipulate them to stay with abusive patients or disregarded their preferences for work hours and environments.

In response, HCWs engaged in activities to strategically contest the perception of

home care work as unskilled. This occurred in three ways: curating and expanding HCWs' expertise, setting norms on professional behavior, and setting boundaries on the scope of work. By impacting the practice of peers and advocating on their behalf, these activities constituted a form of peer support that was rallied to the contested definition of home care work.

Peers Cultivate Collective Expertise through Teaching and Advocacy

HCWs saw cultivating their expertise as a way to demonstrate that home care work is a skilled practice. This is partly covered in previous sections, which describe how HCWs mentored newcomers on daily practice and how peers helped minimize emotional labor by sharing techniques for resolving stressful situations.

Beyond these two situations, HCWs highlighted the practical knowledge they gained on the job, such as intimate understanding of patients' conditions, tacit skills for highly embodied activities (e.g., moving patients safely), and tacit skills for highly interpersonal activities (e.g., being able to anticipate and interpret patients' needs). One HCW described how a patient's needs could be highly contextual and not necessarily explicitly provided by the patient, and that a good HCW would be able to identify and attend to those needs:

> *Every person has different needs ... only a professional understand that probably today, I need to sit and only converse. I need to sit to make sure that when she gets up, she don't fall. I need to sit and look around while she eating her food, to turn down the stove.* (P13)

Because of the wide variety of situations that HCWs could find themselves in, all of our participants described the importance of learning from each others' experiences.

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Participants who had mentor groups on WhatsApp used these to ask each other questions, while some of our participants described calling their friends or discussing issues with coworkers during shift changes. In cases where HCWs shared a patient, physical practices may also be demonstrated during times of handoff. One participant described an example where she and three other HCWs on the same case experimented and shared tactics to care for a patient that became sick:

We developed some tricks to help this patient get well by how we try to feed her. Because she didn't want to eat, but we tried to give her soup. We strain the soup, we put straw in it ... We do all those things. Anybody develop a different style, then we share, and we put this food to this lady for about three or four weeks. She was able to get healthy. (P5)

Finally, participants advocated for expanding the expertise of HCWs through continued training. This included advocating for more in-service and optional training to equip HCWs with more knowledge and skills, and reinforce existing knowledge. HCWs, especially those who were mentors, encouraged continued education as a means to expand the scope of home care work or further HCWs' careers beyond home care. In general, participants felt that HCWs could and should handle additional responsibilities and that training would give them the confidence to do so.

Peers Set Norms on Professionalism

However, our participants also recognized that not all knowledge shared by HCWs was correct. All of our participants felt that there were a lot of bad practices conducted by other workers, enabled by infrequent and ineffective supervision, lack of communication between HCWs, or simply inexperience with less common medical conditions.

Participants felt that these incorrect practices contributed to a perception of HCWs as unprofessional.

To challenge this, HCWs attempted to set and enforce norms on proper professional practice. They emphasized the importance of having high standards of care, including keeping patients clean, being punctual, following care policies, and reporting on patients' health. As described by the following participant, peers can support an HCW by helping them communicate these norms to a patient without angering a patient, a problem described further in Section 3.3.4.

> *The most, that is the support that we need.... Encourage the relative or the client what they're expecting from us, because they know, but sometimes they forget. So to know how [to use] beautiful word[s] that we could tell them without hurting their feeling.* (P1)

Participants also felt it was important for HCWs to present themselves professionally in patient environments. HCWs who were mentors described chastising mentees to encourage high standards of practice or professionalism. Some participants also described how wearing a uniform publicly signaled their status as a healthcare worker and could contribute to their safety in dangerous neighborhoods. Others described wearing the uniform as a way to create a positive impression with patients:

> *If you come, and you dress like a comedian, [patients'] respect can be diminished. So, we need to show our professionalism in the way we work, the way we dress.* (P5)

Peers Encourage Boundary Setting on Scope of Practice

HCWs frequently faced problems with patients who wanted workers to perform tasks that were beyond the scope of practice. This was exacerbated by "overachieving" peers that accepted these requests to please patients but could produce and perpetuate unwelcome expectations for subsequent workers. In response to this, HCWs encouraged each other to reject unreasonable requests, report issues to formal channels for redress, and to set consistent standards on what would be appropriate to expect of an HCW.

This encouragement was particularly evident when there was a structured relationship between two HCWs, such as with a mentor and mentee, but also happened between experienced HCWs in less formal settings. One participant described how, without peers consistently enforcing boundaries, HCWs wouldn't be able to address violations of their scope of practice:

> *Don't be afraid to complain because when we complain about something in our job, [the agency] know[s] that something is wrong; it has to be fixed.* (P4)

3.3.4   Marginalization Affects Conduct of Peer Support

Despite collective efforts of encouragement and cultivating norms, HCWs had to work within the constraints of power that marginalized them relative to both patients and other healthcare professionals. In this section we describe the effects of marginalization in more detail, how this affected HCWs' priorities for mobilization, and how this mobilization should be conducted.

Exploitation and Lack of Power

As the lowest rung in the healthcare hierarchy, HCWs were pressured into doing extra work by both patients and coordinators. HCWs described how some patients would interview them and refuse service if they were not willing to cook certain dishes or do out-of-scope cleaning tasks. Because a patient may have multiple HCWs, one participant described how family members pressured each worker to do extra tasks, resulting in an accumulation of exploited labor. Coordinators often encouraged HCWs to do out-of-scope services and stay with exploitative patients, emphasizing hours the HCW could lose by changing cases.

At the same time, HCWs were aware that they would be held responsible for any negative consequences of deviation from policy, such as leaving a patient alone while being sent to pick up groceries in violation of the care plan. Agencies encouraged HCWs to report any such occurrences, but attempting to reinforce policy by raising issues with coordinators or patients often comes with its own repercussions in the form of loss of hours and cases:

> *A lot of agencies stress report, report, report, but here she is reporting, and you're threatening her as far as removing her from the case. So it's like, you tell me to report, and when I do report, you threaten to take my job, so I'm not sure what you can do to better that.* (P9)

In this way, HCWs are stuck between poor choices of either performing extra work beyond their scope of practice or losing hours or the job. One participant described her choice to report and risk losing hours, but she also understood a peer in her situation might have acted differently:

But I just think, in case this happened to another co-worker, they don't do anything, they feel intimidated, they feel afraid, and they stop calling, stop complaining. The family, clients start taking advantage of her job. (P3)

Chilling Effects on Information Sharing between Peers

The lack of power and HCWs' precarious socioeconomic positions had *chilling effects* on HCWs' willingness to share information with peers or the agency. In Sections 3.3.2 and 3.3.3, we described how HCWs shared techniques and skills for patient care. HCWs also shared information for handoff purposes to maintain awareness of a patient's health and important events or appointments made while in the care of a peer.

Despite the value of peer information sharing, patients could be hostile to this practice due to sensitivity around confidentiality. HCWs were well aware of HIPAA laws that protect the patient, and incorporated patient confidentiality into their practice, for example, by never referring to their patient's names in their notes. Despite this, participants described many patients being uncomfortable seeing HCWs write notes in a care diary and preferred to do their note-taking during breaks or on the bus to avoid these situations, though it meant extra work for them.

In addition to making it difficult for HCWs to record information for themselves, the potential disapproval of patients also influenced HCWs' decisions on how to share information with other workers during handoff. A couple of participants expressed that they would rather share information with their coworkers verbally instead of in a written record, and others described making sure they were not around patients who could listen in before asking their coworkers questions.

Recording information in shared case notes or reporting issues, especially through

official channels, was dangerous if HCWs did work that was not in the care plan or outside of their scope of practice, as this exposed workers to potential negative consequences. Participants felt that this made it unlikely for HCWs to share information through an ICT-enabled platform:

They're not going to put in what they're not supposed to do on that, because you have to follow the care plan. They're not going to put they picked up nobody's kid on no app. (P7)

This environment of suspicion and potential retaliation silenced HCWs and invisibilized many of the concerns and policy violations they faced. This made it difficult to do their jobs as healthcare professionals and potentially impacted the quality of care that HCWs could provide. Participants also recognized that peers were unlikely to volunteer to discuss their complaints in public, which further reduced HCWs' power and made it difficult for them to protect their scope of practice:

A lot of people are afraid to sign things because of their name being put out there. That's one big thing that I felt. Like a lot have to get that fear out of their head: fear of losing their job, if they don't do this. Fear that if they speak up, they're going to get fired. (P9)

Social Mobilization and Challenges

Participants saw solidarity as a way to support each other to reduce exploitation. This included large acts of collectivization, such as union participation and marching for a higher wage and better benefits, but also smaller, individual acts, such as a willingness to stand up to or walk away from abusive cases and encouraging peers to do the same.

Actively engaging the mediation processes provided by the union gave HCWs one of the few recourses for addressing uncaring coordinators or exploitative patients. By protecting the boundaries of their scope of practice, more formal structures of collective action served as extensions of less formal practices of peer support addressing the same goals.

However, participants described mobilization as difficult to achieve in their current environment. HCWs often declined to discuss their problems with the union because it was additional effort or a risk to their job. Participants recognized that union participation sometimes required sacrifice, particularly in time and travel costs. HCWs already had very busy schedules and may work multiple jobs, so making time and paying to travel to union events was often a difficult barrier to overcome.

Implications for Technology-Enabled Peer Support for HCWs

Participants identified different ways in which ICTs, specifically virtual meetings and e-petitions, could enable information sharing, collaboration, or mobilization for HCWs. First, these tools had a potential to increase participation by lowering the barriers of travel time and cost. Secondly, broader participation could mean additional input to identify common issues within the HCW population and broader awareness of these issues. One participant offered a more concrete solution and suggested that sending HCWs petitions via automated calls using interactive voice response systems:

> *What about making a phone call announcement? Like they give you op-*
> *tions... [L]ike if you agree on something press one, press one or two, if you*
> *want something.* (P12)

Because HCWs worked in economically and politically precarious positions, de-

ploying these tools could cause unintentional harm to HCWs. Participants discussed different ways to protect users and avoid harm. For example, while discussing the value of a technological aid that could provide advice in socially challenging situations, participants described the importance of advice that minimized risk to HCWs. They were particularly wary of the potential for technology to set undesirable precedents with patients such as non-adherence to the plan of care.

Limiting participation in online spaces designed for HCWs and the potential for users to be anonymous are other potential ways to protect HCWs. While inviting influential outsiders might enable HCWs to reach and engage potential allies with their problems, a closed membership might result in more honest discourse that better supports peers. Some participants argued for involving only those with past experience as HCWs to create an understanding and sympathetic environment:

> *If it's just between coworkers, then maybe they will be more prone to write exactly what's happening as opposed to being afraid of the agency seeing what they're writing.* (P9)

Participants were divided on the value of anonymity. In spaces sympathetic to the needs of HCWs, having names attached made for more personal and authentic interactions. However, in public forums, anonymity might make some HCWs feel more comfortable participating.

Finally, participants noted that writing case notes and records in an electronic diary instead of a physical one might lend a sense of officiality and impartiality that an HCW could then refer to and use to give themselves cover when discussing problems with coordinators, nurses, and doctors.

3.3.5   Existing Technology Adoption among HCWs is a Mixed Bag

To better understand how technology for peer support might be received by HCWs, we also asked participants to discuss their existing use of ICTs for home care work. We found that technology use was prevalent and embraced by agencies and unions. HCWs used video conferencing and mobile instant messaging apps to connect with peers, coworkers, union members, family and friends for support in home care work and beyond. At the same time, ICT adoption and familiarity was very uneven and many concerns remained around the adoption of technology for peer support.

Existing Uses of Information Technology

Participants described familiarity with a wide variety of apps. Agencies used apps such as HHAeXchange, to offer and schedule on-demand and one-time patient cases [137], and Santrax, to verify HCWs visited patients and clock in [308]. 1199SEIU also provided a way for workers to sign up for notifications via SMS or phone calls about union events.

With the COVID-19 pandemic, trainings were increasingly held via video conferencing with Zoom. One participant described how an app provided by her agency had videos on how to perform tasks including and beyond what is covered through regular in-service training. One HCW described using YouTube to learn how to use a computer. Others used video conferencing to join community events such as online church service, and some HCWs mentioned that embracing technology resulted in cost savings due to reduced need to commute to different locations.

The distributed nature of their work meant that, even before the pandemic, HCWs

predominantly connected through calls, text, or instant messages. Participants described using messaging platforms, such as WhatsApp or Facebook Messenger, and voice or video calls to connect with peers.

Concerns about Technologies for Peer Support

Participants were apprehensive about conducting peer support through a computer-mediated platform and the future role of ICTs in home care. They said that some HCWs might not be familiar with ICTs and would need training to make peer support accessible to them. A few participants expressed concern about online security, fraud, and identity theft. A lack of equipment and resources may also prevent adoption. Participants felt these challenges created headwinds to any technology-enabled peer support system:

> *Whatever that you decide, it's always a problem. You're going to hear "I don't have a computer, I don't have a smartphone, is they paying for my Internet? ... We're not computer savvy, we don't know how to use this, we don't know how to use that...." That's a given, that's going to be in everything.* (P7)

As this study was also conducted virtually, significant effort was made to ensure participants had access to a capable device, either their own or provided by the union, and training users in how to use it to connect to Zoom. Despite this, many participants still elected to connect via basic phone line. Some HCWs joined the sessions while commuting from their patients' house. For these participants, video-based participation over mobile internet connections may be less desirable.

Most participants preferred to interact with peers in-person. One participant described how her reliance on virtual interactions during the COVID-19 pandemic felt

more isolating. Another believed that virtual interactions lacked honesty as individuals can turn away from the screen. In general, while HCWs today rely on a broad range of information technology to do their work, very few such technologies provide unequivocally positive experiences.

3.4 Designing for Peer-Based Empowerment and Support

As described earlier, peer support plays several important roles in home care despite the lack of a shared physical workspace. Our participants also described their feedback on different hypothetical ICT tools for accessing peer support. Here, we discuss how these findings relate to broader concepts of exploitation in crowd work, research on emotional labor, and efforts to expose tacit and invisible knowledge through computer-mediated mentorship. These relate the design implications from our study to these areas to suggest potential applications for computer-mediated peer support.

3.4.1 Peer Support in Platform Capitalism versus Distributed Labor

Our paper focused on HCWs, an isolated and distributed workforce. We found that HCWs have peer support needs that were similar to those served by CoPs in other domains, including mentorship, enforcing boundaries, shaping professional norms of practice, and mobilizing towards common goals. However, HCWs needs were only served in piecemeal and ad hoc ways as described in Sections 3.3.1 and 3.3.3. To this end,

we seek inspiration from how isolated workers in other contexts have sought to create communities via computer-mediated technologies.

A prominent example is in crowd work, where peer-to-peer workers sell their services through an online marketplace. These workers exist in systems of *platform capitalism* [290] which rarely include affordances for workers to interact and provide peer support. Crowd workers face similar problems of invisibilization and have turned to online websites, social networking apps, and forums to collectivize around common work-related interests [305, 157, 219].

One issue that these communities have tried to address is the surveillance and information asymmetries built into platform capitalism that favor the employer rather than the worker [305, 157]. However, surveillance, though perhaps easier to accomplish via a platform, is not exclusive to them. For example, technology-enabled surveillance has been used to create information asymmetries in other industries with isolated workers, such as long-haul trucking [203]. We see such surveillance in the HCW context with the use of electronic visit verification systems which monitor when a worker is with a patient and whether they perform certain activities in the care plan [308].

Beyond surveillance, platforms work to make themselves immune to risks that are borne by the workforce through policy and language [118] and rely on an excess of potential workers to treat them as replaceable. Thus, industries that require higher skilled labor or longer-term relationships, such as HCWs, are less likely to pursue the platform capitalism model [364]. Indeed, despite the existence of ad-hoc scheduling apps like HHAeXchange [137], our HCWs were formally employed by agencies, can have consistent schedules with the same patients, and are represented by a union. Thus, these HCWs likely had more job security than a crowd worker in a contractor position.

Despite this, we found that HCWs were subject to many of the same problems of unbalanced power relationships that made it difficult for crowd workers to mobilize around common interests. A common theme in our discussions was a fear of losing cases and hours. This fear and perception of being replaceable, regardless of actual job security, was a strong motivator for HCWs to perform labor that they would not have otherwise. This fear also made HCWs hesitant to share information with each other and other members of the care team, even when allowed by HIPAA restrictions, for fear of angering a suspicious patient, as discussed in Section 3.3.4. Though recording notes in electronic devices might bolster their legitimacy, as described with clinicians in other contexts [85] or in our findings in Section 3.3.4, it is questionable whether this effect would manifest when the power dynamic between the care worker and patient is reversed.

In considering the ethical and social challenges of crowd work, Kittur et al. explicitly left out what they called "offline crowd work" as these structures are not as scalable, and thus the potential for exploitation may be smaller [178]. We see offline crowd work as another way to describe distributed and remotely managed workforces such as HCWs. HCWs should not be excluded from the crowd work conversation because they are one of the largest medical workforces in the US [362] and experience similar treatment as *"exchangeable and untrustworthy, having low or static skill sets, and strong motivations to shirk"* [178].

Furthermore, we believe that HCWs' highly-relational work, where they may serve the same patient for years and build a deep relationship with them, leads to further challenges that other crowd workers do not experience. Far from being a reprieve from platform capitalism, the fact that HCWs were in long-term, subservient relationships with clients made it difficult for HCWs to engage in peer support by silencing information

sharing.

Thus, it is difficult for peer support tools and programs designed in other contexts to be implemented for HCWs. In traditional clinical contexts, doctors and nurses are less threatened by an unequal power dynamic with their patients and have the advantage of physical co-location for seeking peer support and building CoPs. In other contexts that we traditionally think of crowd work, such as rideshare drivers and food delivery, workers are not embedded in long term relationships with their clients that can affect their interactions with each other.

Instead, our results on how HCWs use peer support to contest issues of unequal power and dominance in their workplace might similarly be applicable to other distributed labor contexts where workers are close to clients but isolated from each other. These might include domestic workers, extension workers, tutors, and social workers. Domestic workers and tutors, for example, may not meet professional peers if employed directly or through a platform. Extension workers and social workers may spend the vast majority of their time away from peers and engaging with clients.

Thus, these worker populations may also benefit from tools designed to empower HCWs. For example, in Section 3.3.4, we described the need for safe spaces to enable discussion free from agency or client repercussions, record-keeping to support worker narratives and provide cover for workers, and opportunities to interact with peers to set strategic norms around practice. However, recontextualizing these tools will require an understanding of the forms of dominance and power dynamics that affect worker populations in different contexts and what aspects of peer support these tools rely on to be effective.

3.4.2 CMCs for Collaborative Emotional Labor

As described in Section 3.3.2, the emotional labor of care work was a large part of HCWs' job. Hochschild divides emotional labor into two components: *surface acting*, where a worker controls their emotional expression despite mismatched felt emotions, and *deep acting*, where a worker puts effort into creating and feeling emotions to fulfill occupational expectations [140].

We saw both forms of emotional labor in our study. We see surface acting when HCWs provide empathetic, patient, and friendly care despite weathering abuses and frustrations from patients and families. Surface acting, due to the strain of emotional dissonance, is considered to have a particularly strong influence on worker wellbeing [153]. HCWs also perform deep acting due to their long-term relationships with patients, as many HCWs care deeply about their patients. While this avoids emotional dissonance, it leaves HCWs emotionally vulnerable when a patient dies.

In traditional health care, clinicians engage in both generating empathetic emotions and acting empathetically in the absence of such emotions, and emotional labor is an important part of medicine [196]. Empathetic deep acting can result in more honest interactions with patients, higher patient satisfaction, and better job satisfaction [196, 153]. Empathy may be cultivated to improve medical practice [129], and training programs may be designed for empathy and related skills [304, 34].

Researchers have also discussed how crowd workers (e.g., rideshare drivers) perform emotional labor to provide a good experience for clients and are often held accountable for this labor by platform review systems [297]. This has led researchers to argue that emotional labor is a form of control enacted by the platform on its distributed workers [121]. HCWs are also evaluated on their work primarily via patient satisfaction. As

HCWs interact with patients much more than clinicians, how well they perform emotional labor may play an even bigger role in patient satisfaction.

In our findings, we discuss how HCWs support each other by sharing the burden of emotional labor. Some researchers have argued for the concept of *interpersonal emotional regulation*, where one regulates their own emotions through social interactions such as venting, or seeks to regulate the emotions of a peer through cheering or calming statements [25, 261]. Because regulation can be made easier with social support, peers can help each other perform emotional labor [260].

We observed stories of similar interpersonal emotional regulation. As HCWs are a distributed workforce, they may represent an opportunity to design for computer-mediated and collaborative emotional labor. Such tools might include affordances to demonstrate active listening in online interactions, or finding someone who will validate and advise on emotional experiences, as described in Sections 3.3.2 and 3.3.2. This form of CSCW is distinct from more traditional forms of knowledge seeking and artifact co-production and may also be valuable in other contexts for isolated service workers. By making it easier for workers to collaboratively perform and regulate emotions, such technologies may increase worker job satisfaction and client satisfaction with the work.

3.4.3 Exposing and Sharing High-Quality Tacit Knowledge in Communities

To gain recognition as skilled professionals, HCWs were concerned with how to grow knowledge in their community: by mentoring newcomers, teaching each other skills and practices, or participating in training. Situated learning, particularly via apprenticeship, are central parts of CoPs, and research has explored how computers can facilitate

these forms of teaching in large-scale collaborative environments (see Sections 3.1.2 and 3.1.3). Similar tools may be relevant in home care, but our findings imply challenges around knowledge quality and tacit quality of this knowledge.

For example, research on fanfiction writers has discussed how online communities can provide distributed mentorship for newcomers and help them develop skills via peer feedback [54, 97]. Research found that aggregating responses and interactions with multiple reviewers created more substantive feedback than individual reviewers and enabled members to identify broader themes that helped them develop as writers [97]. In our study, we saw how HCWs, both new and experienced, found suggestions from a knowledgeable peer helpful to resolve patient care concerns. Similarly, aggregating advice from HCWs may create distributed mentorship that improves home care practice.

However, more research is needed on how to identify quality advice. HCWs shared how peer advice may fall short when peers lack of relevant experience. HCWs were also concerned about spreading bad practices that reduce perceptions of professionalism. Thus, in distributed mentorship models, it will be important to both identify quality knowledge and provide ways to filter this knowledge and avoid teaching harmful practices. In addition, because HCWs' knowledge is often tacit and difficult to explain succinctly, it may be especially important to match a knowledge seeker to an appropriate expert to enable a longer-term learning relationship.

There is substantial literature on computer-mediated knowledge systems in medical domains, including the use of peer-generated content in wikis [37] or voice recordings used in training [366]. These may be applicable in home care contexts, and explicating and exposing the knowledge in the HCW profession might help to de-invisibilize the labor that HCWs perform. However, since our participants desired recognition and appreciation for HCWs' specialized knowledge and skills, care should be taken to

avoid enabling the deskilling and automation of home care work, for example, through decision-support systems [42, 55] which might be deployed to remove control and knowledge from HCWs. Designing technology tools that acknowledge and respect their tacit knowledge and invisible work may better serve the interests of HCWs [346].

3.5   Conclusion

Though it has the potential to empower workers, peer support is broad and can be defined in many ways. We examined how HCWs in NYC conceptualized and valued peer support. We found that peer support helped HCWs perform some of the most challenging aspects of their jobs, including the emotional labor of care work and addressing the politics of professionalization. Thus, peers were important to both supporting the practice of home care and empowering each other towards addressing shared interests as HCWs. We also considered how the power dynamics of home care contexts influence priorities and discussed design implications for tools to foster peer support for HCWs.

HCWs provide a unique context to explore how ICTs can be designed to encourage the formation of CoPs. Such a formation process will likely expose tensions within a practitioner community. For example, the definition of best practices in a CoP is an example of the production of a hegemonic understanding of home care which can push certain peers to the margins. Exploring who gets to define such practices may require an intersectional lens, as HCWs consist of a diverse mix of ethnic minorities and immigrant populations. These issues of power and the production of shared values become relevant in later chapters, as we explore and evaluate what it means to design a computer-supported and peer-based intervention in more detail.

Chapter 4

Foundational Praxes in Social Support and Justice

In earlier chapters, we described how HCWs relied on peers to provide informational and emotional support as well as address shared issues of professionalization, underappreciation, and marginalization of their work. This understanding of the role of peers influenced our decision to investigate how a peer-led support program could be designed to foster these forms of support in a computer-mediated setting.

A *peer support program* is a broad term for services designed to address the informational, emotional, and tangible needs of a specific population by grouping members of that population together. These programs have existed in a variety of contexts for creating support and empowerment in different populations. Past research has specifically examined online or computer-mediated programs designed with various intentions.

These programs have been used to foster professionalization and mastery of practice [269, 68, 195], provide information and empathy for patients facing challenging life events [226, 371, 35], and create safe spaces where issues of identity can be explored and aggressions of inequality addressed as a first step towards healing [254, 66, 218]. While some programs focused primarily on supporting the needs of individual members, others were explicitly geared towards creating places for community mobilization and collective action for transforming society in a way that supports the justice and liberation of a marginalized group [359, 66].

In this chapter, we describe these types of peer support programs in more detail as well as explore how others have created praxes for creating social support and social justice for the needs of marginalized populations. As HCWs have similar overlapping intersectional support needs, we also consider how those praxes might relate to the needs of home care workers. In future chapters, we draw on this literature to design and evaluate a computer-mediated support program appropriate to the context of home care.

4.1 The Value of Peer Support Programs

HCWs have a wide variety of support needs related to improving the experience of home care work, empowering HCWs as experts and professionals, and addressing the emotional burdens and stresses of the job [288]. Peer support programs in other contexts have focused on specific subsets of these needs, such as professional development, group therapy, and safe spaces. Below, we review these three areas of research and describe how they relate the context of HCWs and their specific needs.

4.1.1 Caregiver and Professional Support

Despite HCWs' increasing importance in US healthcare, training requirements can vary widely and many HCWs have reported performing medical tasks that were not in their formal training [298]. In the US, HCWs are often migrant workers who may be overqualified for their position [81] and can develop repertoires of tacit skills and knowledge that are important for delivering quality care [288]. Despite this, HCWs are largely viewed as unskilled domestic laborers [339] and seek training and upskilling programs to combat this perception [360]. This need is central to professional support programs that focus on learning practice and career advancement.

CMC platforms, such as forums, social media sites, or chat rooms, might be useful for creating needed professional support groups for HCWs. Most directly, past research in CSCW has focused on understanding how HCWs' support and informational needs could be addressed by computer-mediated programs [288, 40]. Work on informal caregivers has explored various CMC-based support systems, from small, closed communities with question-and-answer boards [55] to social media and journaling websites for sharing between family caregivers [327]. Such programs can reduce the sense of burden members felt while providing care [201].

Beyond home care, online mentorship programs have been designed to connect isolated practitioners, such as doctors in rural settings [248] or enabling collaborative learning with community health workers [390]. Various other research has also tried to support community health workers by providing feedback on their practice [86], highlighting the invisibilized maintenance work they perform [368], and enabling computer-mediated training [189]. Finally, there is a large body of research in how online environments can host *communities of practice* which enable learning and mastery of spe-

cialized skills and norms among a wide variety of practitioners [46, 63, 142, 285].

Before the use of CMC, professional support programs have existed among health-care practitioners and professionals in other domains for a long time. In medicine, clinicians may participate in professional associations that can help underperforming practitioners by providing peer consultation [377] or in groups with other clinicians of the same domain but varying experience levels to leverage collective expertise [269]. In-person support groups and peer-to-peer matching programs can also foster social support between caregivers and improve their psychological well-being [62, 78]. Some medical institutions have created peer support programs to address traumatic or emotionally harmful events that clinicians may experience in the course of their work [194, 96].

In education, schoolteachers use online groups to share information about pedagogical practices and seek advice [174]. These groups can be a useful resource to help new teachers learn and develop professional practices [195, 215] and may be especially critical during initial training or to help new teachers cope with a challenging workplace [234]. While some researchers have found that learning from online peer communities can vary based on the engagement of the individual teacher [60, 255], in-person teacher support groups have been shown to enhance the motivation of teachers by mediating effects on their professional commitment [324].

Overall, professional support programs focus on learning and mentorship that lead to mastery in a practice, accessing advice for handling challenges in the workplace, and emotional support to deal with the stresses and burdens of work. These issues are relevant to HCWs who seek continuing education in care practice and feel unsupported on the job.

4.1.2 Therapeutic and Medical Support

HCWs build long-term and trusting relationships with patients, and doing so requires significant emotional intelligence and labor [283]. These relationships lead to better care and more fulfilling work [107], but can also leave HCWs emotionally vulnerable when they experience the death of a patient or abuse in the patients' home [288]. Home care is a high-stress job that can have a significant impact on HCWs' mental health [83]. Thus, we also drew inspiration from peer support programs designed for therapeutic or medical purposes, and we briefly describe relevant literature.

CSCW work plays a large role in this space as online therapeutic groups have increased access to support programs for a variety of wellness issues. For example, researchers have studied discussion boards and forums that enabled patients to share informational and emotional support, such as with cancer patients [371, 375], or around other health issues, such as first time mothers' transitions to parenthood [257, 124] or for healthy behaviors such as exercise and weight loss [57]. Beyond forums, some online communities have been designed around different features, such as chat groups and digital spaces for recording mementos for bereavement [226], sharing step counts with friends to encourage physical activity [69], or audio recordings for around nutrition plans and goals [123]. Online groups can be more accessible than in-person support programs, particularly for women and younger participants [384].

Although online communities for this support are relatively new, they are influenced by a history of *group therapy* approaches which leverage peers to address shared needs for participants coping with similar medical conditions or life experiences [35]. For example, in the US, there exists a rich tradition of *mutual help* programs for substance abuse [173, 154], mental health [284], prisoner reentry [199], and other issues. Overall,

these programs focus creating an environment where members can express their emotions and receive empathetic support [300] that can help them better understand and cope with their emotions and make better use of outside support structures, such as family and doctors [332, 35]. Peer support in these groups can have many forms, such as directed advice and feedback, statements of affirmation and compliments, or positive social interactions [24], and group therapy has been shown to impact self-efficacy and esteem, quality of life, and access to and use of health care services [45]. By reducing barriers to facilitate care-seeking behavior [80], group therapy can reduce hospital admission rates [300].

While theories of peer support have attempted to explain how the informational and emotional support that can be attained through peer relationships can influence health outcomes [323, 80], the efficacy of group therapy in both traditional and online settings is still debated [141, 146]. Furthermore, the models and outcomes of peer support relevant to therapeutic interventions may not translate into HCW contexts as the home care profession is not a disease or condition to treat. However, HCWs do have a need for emotionally affirming and informational support, and creating accessible online support groups is also relevant as HCWs are geographically distributed.

4.1.3 Safe Spaces and Indigenous Healing

In the US, HCWs are at the bottom of the healthcare hierarchy and often come from marginalized backgrounds [26]. Due to their gender, race, and immigrant status, as well as their physical isolation in the patient's home, HCWs can suffer from intersecting processes of power that lead to harassment at work [27] and many report facing discrimination on the job [200]. Most therapeutic and professional support programs do not address issues of power, marginalized identities, or the relational struggles of their

members, so we looked to Indigenous scholarship and safe spaces to better understand how to design support groups for HCWs.

Safe spaces are places for members of a marginalized community to gather, socialize, feel a sense of belonging, and share experiences of marginality while minimizing the potential for harassment and other silencing practices from the dominant cultural group [318, 66]. The safe space concept originally stemmed from feminist literature that highlighted the role and need for female-only spaces [15]. It has since been applied to other contexts, such as with LGBTQ+ populations and in social justice education [155]. However, the latter definition of "safe spaces" in educational settings have a divergent meaning and are usually heterogeneous groups that have less in common with peer support in terms of intent and outcomes [12, 369]. Thus, we focus on the feminist and LGBTQ+ scholarship.

Although safe spaces has referred to physical locales in the past, recent research in CSCW and related fields has focused on how online groups and social media may constitute virtual safe spaces. Online groups can connect isolated individuals to valuable peer support, but can also create opportunities for harm and trolling [127], and so online safe spaces are often closed groups, and moderators must engage in boundary work to enforce who [237] and what discourse belongs in the group [116]. Safety also implies an environment where certain actions are possible that may not be outside the group. For example, social media in deeply patriarchal societies can enable women to discuss otherwise taboo subjects [394]. Among LGBTQ+ youth, online safe spaces provide opportunities for members to explore their sexual identities [213], "see themselves" [310], and foster a sense of community and group membership [307].

In safe spaces, members can share stories of their experiences while maintaining and re-enforcing their authority and validity over those experiences [66]. This un-

derstanding of the centrality of personal experience and narrative storytelling is also present in Indigenous healing and encapsulated in the concept of *storywork*. Storywork is the use of story to facilitate learning through telling experiential knowledge, knowing through reflection, and healing through sharing [13]. We focus on *sharing circles*, sometimes called "talking circles" or "healing circles" [218], a form of discussion group that serves as a platform for storywork. Similar approaches have also been applied in non-Indigenous contexts as "narrative psychology" [233].

Sharing circles are openly structured discussions intended to enable participants to share narratives within the context of tribal cultural protocols and Indigenous epistemology [348, 183]. Sharing circles do not assume that knowledge can be separated from experience through empirical observation. Instead, these groups use storytelling and reflection to create *knowing* [70] that is intentful and helpful towards a transformative and decolonizing practice [183]. To encourage equitable speaking opportunities, deep listening, and reflection, while discouraging direct debate, sharing circles may use an object to designate the current speaker [218]. Visual and physical prompts may also elicit storytelling [112].

In computer-mediated environments, some researchers have designed custom conferencing tools to enable online sharing circles and provide affordances for tone setting, turn-taking, and encouraging a feeling of social presence [150]. Other relevant work in CSCW, although it does not directly relate to storywork and sharing circles, include technology designed for reflection and storytelling [68, 123]. For example, similar to elicitation, some researchers have designed specialized interfaces to enable users to explore and tell stories around digital archives of photographs and videos [319]. In another project, participants made and shared audio recordings of their experiences trying to eat healthily, and through this process, performed reflection and felt a sense of empow-

erment [122, 123]. Some researchers have found that encouraging reflection on self-tracking data, such as diabetics monitoring their blood sugar levels, can inspire users to feel more agency and control and could encourage healthy behaviors [221]. Finally, some work has explored designing culturally appropriate apps with Indigenous youth [370].

However, unlike the quantified self, it's important to note that the stories told in sharing circles are not positivist forms of knowledge or information, but are instead heavily situated within the experience of the teller and translated through the relationship between participants [185]. The knowing created through storywork may help participants make sense of their own experiences, inform their own practices, and feel a sense of comfort and support [181]. Thus, the healing of storytelling methods is a holistic approach which respects participant's experiences as undecontextualizable, and through the telling of those experiences, enables participants to explore and understand their identity [112]. As this understanding is built through the relationships between participants, sharing circles aim to encourage vulnerability and fluid interactions in a space of trust [348]. Continued engagement in vulnerable storytelling can improve individual perceptions of their own health outcomes and overall wellbeing [218].

Both safe spaces and sharing circles focus on the validity of personal experiences and exploring identity in a welcoming environment. Sharing circles also emphasize a reflective and vulnerable approach to building an understanding of situated knowledge. While safe spaces are created to counter the experiences of marginalization, sharing circles also focus on decolonializing practice to address internalized forms of marginality. We find these elements relevant to home care, as HCWs report conflicting norms and values about what it means to be an HCW, feel a desire to build a cohesive identity as an HCW, and can face discriminatory practices from challenging work environments.

We aimed to create a support program where HCWs can share, reflect upon, and feel validated in their experiences, as we now discuss.

4.2 Approaches for Social Justice Facilitation

Regardless of the type of peer support program, groups of peers are typically led by a *facilitator*. Facilitators manage discussion and activities in support group sessions, keep groups focused on their goals, handle conflicts between participants, and help create comfortable environments that encourage participation [67]. Facilitators play an important role in enacting the support goals of a peer support program.

Some facilitators are outside professionals, for example a doctor, therapist, educator, social worker, or volunteer, who are not part of the peer group. Other facilitators are peers, who may or may not have received specialized training to perform the facilitation, and the choice of peer and non-peer facilitation varies by program [323]. While professional facilitators are often valued due to their expertise or credentials, peer-leadership can increase the effectiveness of support programs because peers can leverage their first-hand experiences to provide more useful and credible support [313, 278, 321]. As we were interested in empowering home care workers to collective pursue mutual interests, we felt that having HCWs facilitate and lead the program would most effectively accomplish that goal. Thus, in this section, I discuss past work that explored how to best prepare peers for a transformative and social justice-oriented facilitation practice.

4.2.1   The Role of the Peer Facilitator and Training

While it is common for facilitators to be professionals, such as doctors or therapists, many support programs have instead used peer facilitators [323], which may be preferable and produce similar outcomes to professionally-led support groups [330]. Peer leadership can provide unique advantages. Peer facilitators may have first-hand, experiential knowledge relevant to the issues and problems members face [313, 321] or are seen as role models who can provide examples of success [80]. Their experiences can make peer facilitators more credible and increase the confidence members have in the group [278] and able to encourage communication and information exchange [109]. Peers facilitators may also help illustrate what is possible for members [245] or provide a basis for members to interpret their own experiences and feelings [101].

Since peer facilitators can significantly influence the success of support groups, research has focused on how to improve their effectiveness [79]. A few studies have shown that training can improve facilitator confidence and well-being, with trained facilitators experiencing fewer difficulties than untrained facilitators [401] and feeling more comfortable in their role [400]. Facilitator training could also be important to ensure they understand and align with the program's goals [109]. Past examples of training efforts could be more involved, such as multi-day programs involving group discussions and role play [240, 373, 400], or less structured, with self-driven video and online resources [400]. However, research also suggests that training of peer facilitators is generally understudied [79, 361], with reports suggesting that most medical peer-led support programs do not train their facilitators at all [361].

Other research has focused on training peers as educators, such as community health workers and extension educators who are tasked with disseminating health education

and teaching health practices to their communities [325, 28, 94]. Training programs for these generally focus on improving workers' knowledge of health issues, confidence and self-efficacy, and retention [71, 167]. Although peer educators have been acknowledged as important in community education in low-resource settings, training resources in these contexts can be lacking, outdated, or inaccessible [28]. Training peer educators can also require significant time and energy [94].

Research has also focused on leveraging technology for training peer educators, such as training via easily disseminated audio recordings [366]. Technology can also supplement the practices of peer educators, such as educational videos to help extension workers [190, 53] or scripts to help CHWs interact with patients [292]. Finally, because of a lack of training, peer educators may have difficulty finding reliable information [329], and researchers have also designed peer-to-peer information exchange systems to address workers' informational needs [320].

4.2.2 Approaches and Concepts for Social Justice Facilitation

In earlier chapters, HCWs described how peers not only supported the informational needs and emotional burdens of individual practice, but also helped build towards the shared interests of HCWs as a whole. HCWs often faced abuse in their work, felt their labor is undervalued [339, 107], and wanted a space to explore the identity, skills, and values of home care, to redefine the profession as skilled, essential, and human-centric. Thus, in addition to addressing support needs, we explored pedagogies for creating social change around the home care profession. As described in Section 4.1.3, some support group programs have played a role in helping marginalized populations to create a transformative praxis towards social justice outcomes [183, 66]. As facilitators are important to the effectiveness of support programs as whole, we also wanted to understand

how to prepare facilitators for a facilitation practice oriented towards social change.

However, the educational and therapeutic traditions that have shaped prior research on facilitation practices have been criticized for reproducing existing structures of power and domination by treating participants as passive subjects to be taught or cured without a critical awareness of social and historical circumstances [110, 48]. By contrast, a transformative approach should ally itself with the oppressed to develop a critical understanding of the roots of their oppression [110]. These approaches include critical pedagogy [110], liberation psychology and theology [246, 216], indigenous healing [183, 112], and, to some extent, community and humanistic psychology [22, 131]. For the purposes of this paper, we refer to these collectively as approaches to *social justice facilitation*. Many of these approaches have overlapping perspectives, methodologies, and goals [59, 355, 49], particularly influenced by the work of Paulo Freire [359, 275]. Here, we briefly review common concepts that are relevant to our support program, including non-directive support, problem-posing education, social orientation, and irreducibility of the human experience.

Non-directive support comes from the tradition of person-centered therapy, which focuses on a person's right to determine their own life and therapeutic goals [188]. A therapists' role is not to interpret or offer advice, but to provide an environment where the patient can describe and explore their own problems and reactions [328]. In group settings, a non-directive facilitator should approach the group without preconceived goals and avoid criticism or persuasion, instead encouraging participants to collectively and individually discover their problems, goals, and desires [262]. For example, Nelson et al. described a non-directive program addressing intimate partner violence that encouraged attitudinal shifts through self-reflection and discussion rather than traditional persuasive strategies [256].

Non-directive support often goes hand-in-hand with a *problem-posing* approach to education. In problem-posing, which is central to Freire's critical pedagogy, the role of the facilitator is not to provide knowledge but to ask questions that create a reflective dialogue. Via this process, students and teachers aim to build a critical consciousness that can recognize the causes of a student's social oppression and enable them to engage in transformative praxis against it [110]. Freire's work has also been influential in liberation psychotherapy and theology, which aim to address the realities of social oppression for various marginalized groups [246, 175, 239]. A problem-posing approach may be particularly appropriate for minority populations who may not share the same values as the dominant social group [239].

Inherent to social justice facilitation is a *social orientation* that shifts the focus away from individual treatment towards social problems. In liberation psychology, this orientation may be historical, such as reclaiming the history and social identity of the oppressed [59]. In community psychology, this orientation is contextual, such as how the social context can change the role of facilitators, who must sometimes work as instigators of social change, mediators between multiple parties, or advocates [22]. In liberation theology, this orientation focuses on structural sources of oppression and how clergy should work with the oppressed to inform policy that creates "preferential options for the poor" [216].

Finally, many social justice traditions approach therapy by assuming that the human experience is *irreducible*, that humans are complex, unique, and cannot be understood via their component parts or in isolation from social and historical contexts [131]. Therapists should thus focus on understanding a patient's environmental and social contexts, and recognize how they influence a person's understanding of events [59]. Along these lines, scholars have advocated for narrative approaches that reflect the continuity of hu-

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man experience [303]. For example, narrative psychology and indigenous healing use storytelling to address suffering, explore meaning, and re-imagine participant identities [233, 112].

In summary, social justice facilitation approaches aim to create social change by helping participants build a critical understanding of their social reality and their role and ability as social actors. Despite the thematic similarities, our goal is not to argue for the creation of a merged or new social justice practice, and indeed many of these traditions also have substantial epistemological and methodological differences. Instead, we take inspiration from the concepts described here and apply them to the design of our support group for home care workers, the role we envisioned for peer facilitators, and the corresponding training that we created for them.

4.3 Conclusion

As discussed in Section 4.1, peer-led support programs have been deployed in a range of settings based on diverse definitions of peer membership. These programs have had a variety goals based on the specific support needs of those populations, from knowledge gain and improved practice to improving the emotional wellbeing of practitioners. These works are foundational to a community-oriented approach to designing technology for the needs of HCWs, but few examples directly translate to the context of home care. Many programs which focused on empowerment and self-expression were focused on marginalized identities that did not include practice, such as women [15], LGBTQ+ youth [307], and religious [239] and ethnic minorities [112]. Programs that focused on emotional support and informational exchange were similarly targeted at non-practitioners, and those that did address practitioners often did so in environments

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with far more support structures, such as teachers at a school [324] or doctors at a hospital [269]. Furthermore, most programs took taken place in-person rather than through computer-mediated platforms.

There are additional questions around social justice facilitation practice, particularly for peer facilitators. In the approaches described in Section 4.2.2, the facilitator is usually conceptualized as a professional. However, peers are not the same as professional educators or therapists. Facilitators hold an elevated position of power that can change the nature of the relationship with peers [175]. While professional facilitators may have training, expertise, and symbolic legitimacy that is valuable to members of a support program, peers are much closer to the issues and identity of the participant group [51]. The non-directiveness of professional facilitators may be helped by the separation between participant and facilitator roles, but that line is blurred with peer facilitators. This blurring may make it difficult for peer facilitators to adopt approaches and techniques used by professionals. Finally, many peer-led programs do not provide training for their facilitators at all [361], and this suggests an area of possible further research.

We hope to contribute to this literature by exploring and evaluating the design of a computer-mediated and peer-led support program for home care workers. We discuss how the design of this program drew from both the needs and co-design described in Chapter 3 and the foundational praxes described here. As we hoped to address both support and empowerment needs, we draw heavily from the concepts of a social justice-oriented facilitation practice, and we explore how to design a training for peer facilitators that prepares them for such a practice. The discussion of this design and pedagogy is provided in Chapter 5 and its evaluation in Chapters 6 and 7.

Chapter 5

Design and Deployment of an HCW Peer Support Program

The conception and design of this program was a collaborative effort between researchers in multiple fields and long-term community partners at the 1199SEIU Training and Employment Funds (TEF). Researchers included medical doctors, technologists, and labor and employer relations scholars with several years of experience working broadly in the home care space and specifically in partnership with the TEF. The TEF is the continuing education and training services of 1199SEIU, one of the largest healthcare worker unions in the US, and have a deep understanding of home care in New York City. This research was made possible by this history of joint work through this multi-disciplinary partnership.

This program was sparked by observing the challenges of HCWs during the COVID-

19 pandemic and subsequent lock downs, which saw the breakages of existing support structures and the increased isolation of HCWs [340]. Prior research in this context explored the variety of support needs that HCWs have: not only informational and emotional, but also a need to build professional identity, self-efficacy, and esteem [288]. However, because of a lack of regular interaction, there are few opportunities for relationships to naturally develop between HCWs, resulting in sparse endogenous peer support networks and professional communities [19, 107].

Our goal was to design a computer-mediated support program that addressed intersectional peer support needs. While past work in CSCW has recognized that participants' intersectional identities can influence their experiences and needs in online spaces [310, 288], most identity-oriented research focuses on one aspect at a time [311]. We hope to address this gap by building on several bodies of literature summarized in Chapter 4, which described how support programs might serve HCW's needs as healthcare professionals but also as marginalized workers in stressful and traumatic situations who are primarily ethnic minority women.

Simultaneously addressing these different needs motivated the design of a support program intervention, which is summarized in Table 5.1 and described in more detail in this chapter. This program consisted of (a) a synchronous, moderated group sessions on a video conferencing platform and (b) an asynchronous group on a social networking site. We designed the program around a flexible pedagogy oriented towards encouraging narrative storytelling to build rapport between participants and encourage reflection around shared experiences, values, and praxes. We also trained peer facilitators to lead and moderate both of these components, and we describe how we prepared them for this pedagogy. In total, the program ran for 12 weeks with participants, with an additional two weeks spent on training and data collection.

Table 5.1

Our design goals and their relationship to the goals and foundational praxes of support groups in other contexts, as described in Chapter 4.

Context	Goals	Design Features
Caregiver and Professional Support	• Learning • Career Advancement	• Topics about different care situations. • Open floor for problems experienced in the workplace. • Follow-up questions for advice or feedback. • Engaging peers with diverse experiences and experience levels.
Therapeutic and Medical Support	• Emotional Support • Informational Support • Self-Efficacy	• Topics about common problems. • Topics about positive aspects of care and successes. • Open floor for current stresses and frustrations. • Follow-up questions on related experiences.
Safe Spaces and Indigenous Scholarship	• Reflection and Knowing • Validity and Identity • Addressing Experiences of Marginality	• Ground rules to give space to share experiences. • Unstructured sessions with maximal time for storywork. • Open floor for issues facing HCWs as a whole. • Summary statements on meaning of sessions. • Engaging peers with diverse experiences.

5.1   Structure of a CMC-Based Peer Support Program

The support program consisted of weekly meetings held in video conferencing and a private group on a social networking site. These two components were tied together by a weekly topic that focused the discussion and by facilitators who implemented the pedagogy of the program. We describe each of these in more detail.

5.1.1 Sharing Circles

The main feature of the support program was virtually conducted *sharing circles*. Inspired by sharing circles in Indigenous scholarship, we hoped to create a respectful environment where HCWs could collaboratively reflect and share stories on lived experiences and practices. Through this process, HCWs could share informational and emotional support around the experiential and relational aspects of home care work and potentially create discourses that lead to knowing and transformative understanding [70, 183].

The sharing circles were intended to be small groups with a consistent subset of the participants, a *sharing circle panel*. Participants were assigned to a designated panel for sessions scheduled at the same day and time of the week so that they would meet the same set of peers. The panel assignment enabled continued interaction with the same peers, which would allow participants to socialize and build a history of interactions. We hoped this developed history would lead to interpersonal trust and participants feeling comfortable expressing more personal experiences [143], build trust and hopefully create more effective informational and emotional support [349]. Panels were kept small to maximize the amount of speaking time each participant could have. The largest panels had nine participants assigned, while the smallest panel had six participants, although week-to-week attendance varied.

Sharing circles were conducted by peer facilitators and held weekly via the Zoom platform [399]. Participants had the choice of joining via video or voice-only conferencing via a normal phone call, and each session lasted between 60-75 minutes. The sharing circles ran weekly for eight weeks, which prior literature suggested would be sufficient for building rapport among participants [141, 288]. The circles had five dif-

ferent elements: ground rules and introductions, a topic, open floor for issues, summary statements, and final reflection and feedback. However, any individual session incorporated at most three of these elements. As our goal was to give participants the space to have long speaking turns for storywork and deep listening, the structure of the sharing circles was kept as minimal as possible.

The initial session started with asking participants to introduce themselves and describe their background as HCWs to help members build rapport with each other. In addition, facilitators spent time in the first session describing four *ground rules*. The first two, drawn from safe spaces literature, were to frame participation as voluntary and that all experiences were valid and deserving of respect. To encourage an environment of trust and comfort, the third ground rule was confidentiality. To help make this legible, this rule was explicitly described to mirror HCWs' existing understanding of patient confidentiality. Finally, because the circles were designed for participants to tell and relate to narrative experiences, the fourth ground rule encouraged HCWs to give each other the space to speak and empowered facilitators to manage speaking turns. See Appendix D for a list of ground rules and the text used to explain them.

After the initial week, sessions began with a welcome, and then most of the time was spent discussing the *weekly topic*. Circles built on past work in therapeutic and professional support groups for different types of support. After one participant finished sharing a story, facilitators encouraged others to continue the conversation by discussing their own similar or contrasting experiences. Similar experiences were valuable from a therapeutic perspective as these emphasized common histories and shared characteristics to create commiseration and empathy [141]. Different experiences were valuable for professional support because they provided opportunities to explore new perspectives on the possibilities in home care and to leverage the combined experiences of the

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circle [16]. Facilitators asked participants to reflect on past experiences and actions and to consider what they would do if faced with the same situations as their peers to encourage both relatability and discussion.

Starting in the fifth week, after participants were familiar with the group, we also started each session with an *open floor for issues*, allowing participants to bring up and discuss concerns not necessarily related to the weekly topic. The open nature of the issues helped make the sharing circles more relevant to participants' position and day-to-day experiences as HCWs and helped direct the sharing circles towards more immediate support needs. For example, participants could discuss a workplace problem that they were currently experiencing to receive professional advice or emotional support from their peers in the circle. Alternatively, a participant could discuss issues that they felt were facing the home care field as a whole and relevant to their professional identity as HCWs.

Finally, at the end of each session, facilitators asked each participant to provide a *summary statement* or closing comment on the session. This was intended to allow every participant at least one chance to speak and also encouraged reflection on their interactions in the circle. Participants could use their summary to describe what they learned or was important to them personally in the session. In the final week of sharing circles, we also gave participants some time to reflect and give feedback on their experiences in sharing circles as whole. For more detail on the various activities in the sharing circles and how they were scheduled, see Figure 5.1.
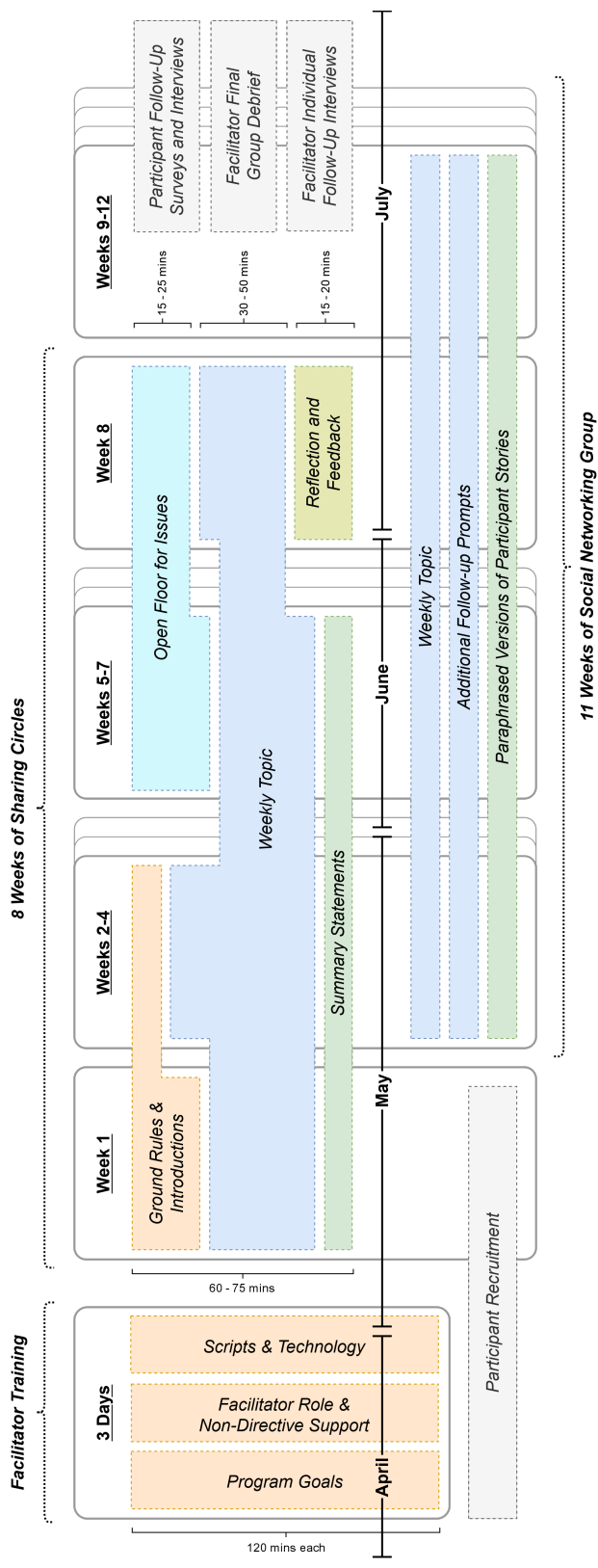
Figure 5.1

An overview of the peer support program, describing the features of the sharing circles and social networking group, the approximate amount of time spent on elements within each session, and the overall schedule of the program.

5.1.2 Weekly Topics

Weekly sharing circles included a discussion topic that focused on the relational and experiential aspects of home care work. To create the list of topics, we focused initially on peer support needs our prior work on HCWs, as described in Chapter 3. These included topics about emotionally stressful situations and emotional labor, feeling respected in their job and efforts at professionalization and training, and challenging events where an HCW felt marginalized or treated unfairly by their agencies or patients. By including topics on problems and challenges, we hoped that participants could provide informational and emotional support to their peers facing these challenges. In addition, we also wrote topics around positive experiences in home care to explore professional pride and identity, such as success stories, good memories, and demonstrations of good practices, particularly where HCWs felt they contributed to the well-being of a patient. Topics on positive experiences were intended to affirm and validate participants' identity as HCWs and help support their self-efficacy.

After writing an initial list of 30 potential topics, we solicited feedback from our facilitators and partners at 1199SEIU TEF to assess their appropriateness and refine their wording. We selected 12 topics that we felt were most likely to engage participants to cover the duration of the support program. We interleaved topics around positive experiences and challenges on alternating weeks to try to keep the discussion from overly focusing on specific issues and ensure that we addressed different support needs equally. Because care work is highly interpersonal, we tried to select topics with an equal distribution around relationships with other groups an HCW interacted with at work: patients and their families, other HCWs, supervisors, and clinicians. Finally, in line with the goal of sharing stories, these topics were formatted as open-ended invitations to speak on experiences rather than interrogative questions on beliefs or perspectives. For exam-

ple, instead of asking "what" or "why," topics may use the verbs "tell us", "think back", "when", and "how" to encourage participants to think through their past actions during their recalled experiences. See Appendix E for a schedule of topics used in the support program.

5.1.3   Social Networking Group

The support program also included a *social networking group* that was hosted on Facebook using their Groups feature [98]. This was strictly optional and intended to connect HCWs to a broader community of peers from other sharing circles. Thus, while sharing circles were a smaller panel of participants, all participants who wished to participate in the social networking group were added to the same group on Facebook.

As a larger community, the social networking group could potentially enable access to further informational and community resources and be available to meet support needs at irregular times and beyond the duration of the circles. Similar to other online safe spaces [237], we made the Facebook group a private and closed group. Members needed to be approved by a moderator to join and posts were not visible to non-members. By only inviting participants after they had been introduced to the social networking group in the first sharing circle session, we hoped to assure participants that only HCWs would be allowed as members and the group was safe [266].

The Facebook component ran concurrently with, and as an extension to, the sharing circles and adopted the same ground rules and structure. The weekly topic discussed in the sharing circles was posted to the group at the beginning of the week and another followup question related to the topic was posted later in the week. At the end of the week, a researcher typed up and posted an anonymized and paraphrased version of a story an

HCW had shared in the circles in response to the topic. The sharing circle facilitators moderated the social networking group, frequently liked posts, added comments, and reminded participants of the group's availability in the circles.

5.2 Peer Facilitators

Each sharing circle was led by two HCW facilitators. We chose peer facilitators because we felt they could better relate to HCWs' experiences and create more credible support [278]. Our community partners at the 1199SEIU TEF also felt this fit well with the goals of the program which was to create an environment for peer support.

5.2.1 Facilitator Recruitment and Role

With the help of our partner organization, we recruited six HCWs to be our peer facilitators. The 1199SEIU TEF routinely operated training programs for HCWs including occupational certification programs, up-skilling training, and support for continuing education. Some of these programs were led by peer instructors, HCWs who receive specialized training to be instructors and were paid to lead in-person and online training for other HCWs [2].

The facilitators we recruited had all completed multiple rounds of training to be peer instructors and had experience leading training for the 1199SEIU TEF. We targeted HCWs with experience as instructors because they possessed several skills that we hoped would transfer to our support program, including experience delivering a pedagogical intervention, engaging with students, handling conflicts in the classroom, and

being comfortable speaking in front of a group. As the TEF was already in the process of moving many of their training programs online via Zoom due to the COVID-19 pandemic, our facilitators also had experience using the same technology tools we used to run our program. Finally, since we modeled our program's logistics, recruitment, and participant management on existing TEF practices, our facilitators were familiar with the logistics of how such a program operated.

The facilitators were all women and had been HCWs for between 11 and 32 years. They had between 3 and 7 years of experience as peer instructors, and between a high school level of education up to college graduate. All facilitators were non-white and between the ages of 48 and 65 years. Five of the six facilitators had been involved with the union as a delegate for at least 5 years, while the sixth had no such experience. During recruitment, the scope of their participation was explained to facilitators, including attending training sessions, debriefs, and interviews, and their consent was obtained via an online form. At the recommendation of our partner, facilitators were compensated $18 per hour for time spent on all facilitation-related training and activities.

During the program, facilitators were in charge of managing the circle, opening and closing the sessions, and setting the pace of the discussion. Facilitators played an important role in ensuring that HCWs were given ample time to speak by calling on participants and giving speakers space. This encouraged longer-form stories to be shared and reduced the fragmentation of participants' narratives [184]. Facilitators debriefed with researchers after their sharing circle sessions, and all facilitators met for a group debrief after the second week and a final debrief at the end of the eight weeks of sharing circles. In the debriefs, facilitators discussed what went well, important interactions in the circles, strategies for encouraging conversation, and points of discussion in future topics.

Facilitator availability played a large part in determining the scheduling of the sharing circle sessions. Times were chosen while accommodating facilitators' work schedules as HCWs while also trying to ensure that sessions would be available at different days of the week and different times of day. We ended up with a total of five panels, scheduled each at Monday afternoon, Tuesday morning, and Monday, Tuesday, and Thursday evenings. Four of the six facilitators led two sharing circles per week, while the remaining two facilitators led one each.

5.2.2 Facilitator Training

Ten days prior to the first support program session, we conducted a three-day training for facilitators. Each day consisted of a two-hour video conferencing session. In line with prior work comparing different mediums for peer facilitator training [400], we decided that an interactive training with live instructors would be the most effective and helpful. We deliberately kept the sessions short and split them across three days to reduce fatigue and create opportunities to emphasize important points across multiple days. We accommodated facilitators' schedules, and all facilitators attended all three days of training. Training was led by two researchers, one a professional social worker with experience developing training programs for HCWs.

The first training session started with introductions of both the researchers and facilitators. We discussed the goals of the program: to create a space where participants could talk about emotionally challenging experiences, discuss problems they face on the job, seek support and advice, and reflect on what it means to be an HCW. We described the three main components of the support program: the sharing circles, the social networking group, and the weekly topics. We explained how participants might interact in the groups and went over the ground rules. This first training was intended to help

facilitators understand the overall structure of a sharing circle, the intended focus on sharing stories and narratives, and their role in the program. Finally, we practiced by having facilitators play-act as participants in an example sharing circle.

We started the second training session with a review of the goals and components of the support program. We went into more detail about the timeline, schedule of sharing circles, and when they should expect topics and surveys to be sent to participants. The majority of the time in this training was spent discussing the role of a non-directive facilitator. Inspired by social justice facilitation themes, we explained this role in terms of four principles: listen, accept, question, and share. We asked facilitators to create an environment for listening, where participants would feel comfortable describing their experiences, and accept those experiences without judgment. We brainstormed ways to show active listening, encourage participants to speak, and observe non-verbal cues that might be recognizable in a video call. The third principle was to ask follow-up questions that help participants better understand the experiences being shared and encourage reflection. Finally, the fourth principle was to not provide recommendations or direct participants but instead share personal experiences. Facilitators play-acted practiced ways of asking different, non-directive, follow-up questions and handling a scenario with a simulated conflict. The remainder of the time was spent reviewing potential weekly topics and thinking about which would be most engaging and relevant.

In the final training, we reviewed the facilitator role and the principles of non-directive support. We provided facilitators with more detail about the structure of sharing circles and play-acted important parts of the session, such as welcoming participants, providing help using Zoom, explaining the ground rules, and asking participants to give summary statements. Finally, we spent time practicing how to do facilitation actions on Zoom and Facebook. As facilitators would also be moderating the social network-

ing group, we ensured facilitators were familiar with how Facebook's Groups feature worked and how to perform moderation actions, such as deleting and approving posts. At the facilitators' request, we also walked through how to change one's personal privacy settings in Facebook.

In addition to the training sessions, we mailed facilitators physical copies of scripts to use as reference during the support groups and other informational resources, including the ground rules, the schedule and list of topics, example follow-up questions to encourage participants to speak, and a list of contacts for various therapeutic, abuse, and labor dispute hotlines. We included copies of all the training materials and made sure both researchers were available for at least the first three weeks of support groups to debrief and provide feedback to facilitators. As this was the first time facilitators were running this type of program, and to accommodate the possibility for absences, they were paired with another facilitator throughout the program so they would not be managing groups alone.

5.3 Participant Recruitment and Context

We ran the peer support program for 12 weeks in New York City with 42 HCWs in five sharing circle panels. We describe our participants in more detail and the context surrounding the peer support program.

Table 5.2
Descriptive statistics of demographic characteristics of 42 participants who joined the peer support program.

Gender	Women: 40; Men: 2
Age	Min: 25 years; Max: 72 years; Avg: 46.8 years
Experience as HCWs	1-5 years: 13; 6-10 years: 13; 11-15 years: 5; 16-20 years: 7; 20+ years: 4
Race	Black: 26; American Indian or Alaska Native: 1; White: 1; Mixed: 1; Other: 4; Unreported: 9
Ethnicity	Hispanic or Latinx: 12; Non-Hispanic/Latinx: 20; Unreported: 10
Birth Nation	U.S.: 7; Caribbean: 14; West Africa: 10; South America: 4; Mexico: 3; Unreported: 4
Education	Some high school: 4; Completed high school: 12; Some college: 11; College degree: 3; Graduate degree: 12

5.3.1 Recruitment and Participant Details

We recruited participants with the help the 1199SEIU TEF. Using a randomized list of HCWs who had participated in prior TEF training activities, a staff member contacted prospective participants via phone call, described the program, and asked if they would be interested in joining our study. Participants who expressed interest were sent an online form to record their consent and gather contact information. During recruitment, participants were assigned to a one of the five different panel based on their personal schedule and availability. Participants were also offered technical support to help them complete the form and join the sharing circle and social networking group.

In total, we recruited 42 participants who worked for 19 different home care agencies throughout all five boroughs of NYC. Table 5.2 describes participants' demographics in more detail. Similar to the general demographics of HCWs in the United States [339, 50, 27], our sample was predominantly Latinx and non-white. A large majority of participants (74%) were immigrants but most (62%) also had at least some college level education. All participants except for two were women.

We were concerned with recruiting participants from a diverse set of agencies and experience levels. Caregivers can build specialized bodies of tacit knowledge based on their experience in past practice [288, 321]. In professional development efforts, bringing diverse experiences to a group setting might enable all members to benefit by accessing a broader body of knowledge [16, 269] or enable mentorship of newcomers [197]. Furthermore, we hoped that adding diverse perspectives to the sharing circles would foster the development of a deeper knowing about home care practice by enriching collaborative reflection. By learning about and relating to each others' telling of tacit knowledge and experiences of practice, participants may develop a more critical understanding of their work that is transformative to their identity and practice as an HCW.

We were careful to protect participant confidentiality, especially because the sharing circles could discuss sensitive issues and problems related to participants' employment. We emphasized confidentiality in our ground rules and deliberately did not record the circles. As the program occurred during the COVID-19 pandemic, all program interactions, including consent, facilitator training, sharing circles, debriefs, and interviews, were conducted remotely. Participants were not compensated for attending the sharing circles, as we wished to avoid incentivizing participation. However, they did receive a $25 gift card for each research-oriented form, survey, or interview they participated in, for a maximum compensation of $75 per participant. All study procedures were approved by our community partner and our IRB.

5.3.2 Timeline and Broader Context

As described in Figure 5.1, the peer support program ran from the end of April through most of July 2021. This was a tumultuous time in the home care context in New York

City. The program ran during the tail end of the wave of COVID-19 cases caused by the SARS-CoV-2 Delta variant in NYC, a period of some of the largest case counts of the disease to date [11]. In response to the pandemic, much of HCWs' work practices gained further reliance on virtual spaces and computer-supported collaborative work tools, such as remote training [337], electronic visit verification [308], and app-based scheduling tools [137]. Many agency offices remained closed, and administrative and supervisory staff continued to work remotely. This period also marked the first celebration of Juneteenth, a commemoration of the emancipation of African-American slaves in the US, as a federally recognized holiday. As it was only recent recognized, HCWs, like many government-funded workers were concerned how policies around holiday pay and time off would apply to the new federal holiday [306].

5.4   Conclusion

Based on exploratory and co-design work with HCWs and a review of foundational praxes in social support and emancipatory traditions of education and therapy, we designed and deployed a 12 week support program. This program leveraged narrative methods of support focused around topics that invited participants to reflect on their practices and their relationships with patients, patients' families, doctors, nurses, agencies, coordinators, and others in their work environment. Facilitators were trained in non-directive methods of support and leadership to encourage participants to tell stories and emphasize the validity of participant experiences.

In later chapters, we describe how we evaluated this program along two axes. In Chapter 6, we analyze the participant experience, the types of support and relationships they were able to build during the program, and how the support program influenced

them as HCWs. Chapter 7 focuses on the experience of facilitators, how they contended with their role in the program, and lessons learned from the training intended to prepare them to engage in a social justice-oriented fascination practice. We discuss how programs such as this can support and empower HCWs and other marginalized and distributed practitioners and how CMC technologies can be leveraged for intersectional peer support.

Chapter 6

Addressing Participants' Support and Empowerment Needs

Our study with a computer-mediated support program for HCWs ran for 12 weeks, from the end of April to July 2021, with 42 participants. The support program contained a total of 40 sharing circle sessions over the course of 8 weeks. Despite the lack of financial incentives for attendance, the sharing circles had good turnout, and an average participant joined between five and six sessions out of their maximum of eight.

At the end of the program, all participants were given a survey to collect demographic information. We also conducted 17 semi-structured follow-up interviews with a subset of participants that we identified using stratified sampling to capture a range of participation levels. Interviews sought an understanding of participants' experiences in the program and how the design and content of the program related to their support

needs and identity as HCWs. Interviews were conducted individually via Zoom video conferencing [399] or basic phone call, lasted 30-45 minutes, and were audio-recorded with participants' consent.

In addition to the interview data, at least one researcher was present in each sharing circle session to observe and take detailed notes. The researcher was available to help troubleshoot any technical issues during the circles, such as a participant who is having trouble joining, but researchers were not participants, stayed off camera, and limited their interactions to technical support. Additionally, researchers frequently debriefed with facilitators after sessions and answered a set of questions during this debrief that contributed to the research notes. Finally, researchers also observed activity in the social networking group, such as posts and likes. In total, our data consisted of survey data with participant demographic details, copious notes from sharing circle sessions, interactions on the Facebook group, and audio recordings of participant interviews.

Our detailed notes from the sharing circles were analyzed inductively, with each transcript independently coded by at least two researchers who met regularly to reconcile their codes. Because we were less interested in the topic of the speech than in it was used in the course of supportive interactions, we followed a discourse analysis approach [236] that focused on identifying the intent and purpose of participants speaking in the circles. Our final codebook consisted of 20 codes, and example codes include "*referencing peer*," "*relating*," or "*advising*."

Participant interviews were professionally transcribed and also coded inductively by at least two researchers with several rounds of reconciliation. Example codes include "*support is opportunities to interact with peers*," "*sharing to give authentic experiences*," and "*facilitators can relate/understand*." Our final codebook for the interviews consisted of 53 codes. This data was then analyzed using a thematic approach to group

codes into themes [38]. We focused on identifying where participants felt, or did not feel, supported in the program and how that support was affected by the design of the program, actions of the facilitators, or other participants. Finally, we integrated these themes with the codes from our discourse analysis of the sharing circles, producing high-level themes that comprehensively represent our data.

In this chapter, we present findings related to how participants' support and empowerment needs were or were not addressed by the program and discuss their experiences in relation to the design intentions of the program's pedagogy and use of technology.

6.1 Findings on Participants' Experiences in the Peer Support Program

Our findings show how the peer support program was a valuable space for HCWs to share in multiple forms of support, from emotional validation to exercising a voice around workplace issues. HCWs also used the sharing circles to build a broader awareness of care situations and a better understanding of good care practice, which led to discussions on their values, role, and identity as HCWs. Finally, participants discussed the relative advantages or disadvantages of an online support program compared to in-person interactions.

6.1.1 Program Validated HCWs' Emotional Experiences and Mitigated Isolation

The peer support program enabled participants to reciprocally share stories that reduced isolation and affirmed and validated their emotional experiences. HCWs have the unique challenge of managing their job site on their own and usually do not interact heavily with other HCWs. In the follow-up interviews, some participants described how their feelings of isolation were exacerbated by the COVID-19 pandemic, as the few opportunities to meet peers on the bus or during in-service training were lost. Training that used to happen in-person was replaced by online offerings which did not offer the same opportunities for supportive interactions. In contrast, the support program combined its online nature with an open structure and intentional design that allowed participants to meet with peers they could not access otherwise and share similar situations and experiences in front of an empathetic audience. One participant explicitly compared the circles to online training on whether they provided space for HCWs to discuss their problems:

> *When we go to the training I said, "The nurse will come and preach and preach and preach, and then we write the test and we go away." But with this, it was marvelous. Everyone was able to say everything.* (E8, Interview)

Some participants described a need to talk to peers because they could not discuss their experiences with friends and family for fear of violating HIPAA privacy regulations or because they felt that their friends and family did not fully understand their experiences and challenges. The support program provided an opportunity for participants to meet new aides who had similar experiences to create empathetic and validating support. During the program, when an HCW shared an experience on the topic, other

participants often recalled a story of their own. For example, in one session, a participant (D6) shared a story expressing her frustrations with coworkers who would do the bare minimum in a case and rush to leave. This prompted another participant to build on this theme by sharing an instance where she was a substitute on a case:

> *My case is similar to what [D6] have. But not as tough as she had it. ... So there was a day that I went to a patient's house to fill in for one of the aides. And when I got there, I saw that night aide was going. ... Unfortunately, what she showed me was amazing. They had a pile up of laundry, close to the ceiling.* (D8, Sharing Circle)

These kinds of reciprocal sharings had two effects. First, by sharing similar stories, participants learned that others faced similar challenges in their jobs. Being an isolated worker meant that when HCWs had a problem or other experience, they often felt like they were the only one with that issue. As relayed below, an opportunity to hear similar experiences made participants feel less alone and helped address the perception of isolation in their work:

> *When I was listening to other people's stories, it made me feel good to hear that it's not I, alone, in going through it. I didn't know other people experiencing the same thing that I have been experiencing because sometimes you think you're out there, and you're alone. "Why does it alone happening to me?" Or when you hear other people stories, it comes like you're in the same position as them ... getting the same kind of problems.* (B2, Interview)

The second effect was that HCWs provided affirmation for each other, by agreeing with the challenges in each others' experiences, validating emotional responses, and

providing encouragement. In D8's story about laundry, she began by acknowledging how tough D6's situation was. Participants also complimented and reassured each other. In one session, a facilitator (F6) shared a story about being discriminated against even though she went through the effort of learning the patient's native language. Another participant complimented her dedication:

> *You made a point to learn the language because you wanted to know what was said in front of you, behind you. I think that was commendable. ... Wow, I'm impressed by that.* (E9, Sharing Circle)

Many participants had experienced racial discrimination and shared stories that highlighted patterns of abuse, such as being called derogatory names. During a topic around safety, multiple participants related similar stories that validated each others' experiences of feeling unsafe in patients' homes, such as dealing with angry or unstable patients who had visible weapons, such as knives or large sticks. This may have been especially relevant for female participants who face additional gendered concerns around safety. For example, one participant described once being followed onto a train by a male family member after the end of her shift. The participant below described feeling unsafe because of the presence of drugs in the home and being pressured by a male family member:

> *The time in this job when I feel unsafe is when I go the patient's house, and they have some family, son or daughter, that use drugs. And they asked me for some money. I say no, I never got cash with me, I wanted he know that, that he doesn't ask me anymore about money because sometimes he ask me.* (C3, Sharing Circles)

The fact that facilitators of the support program were also HCWs furthered an environment that reduced isolation, as they could relate to participants' experiences. Facilitators could share similar stories, as happened above between F6 and E9, which indicated to the participants that they were able to offer support from a place of real knowledge and understanding about home care work. This reduced the gap between facilitator and participant, as described below:

[The facilitators] was great, because they was participating too. And they were people who were like us. Not just speakers or teachers who work in the office. They were home care workers. They were sharing experience. So we feel confident about it. We feel like, "Oh, she's one of us." She was talking about the situation, the clients, what she do, what she thought. So she was like another student too. (B8, Interview)

Through a program structure that created opportunities for reciprocal storytelling, the sharing circles became a computer-mediated space where HCWs could vent about their experiences and receive emotional support from empathetic peers. This created a sense of rapport, which participants ultimately saw as therapeutic. Because of this, some participants described this form of social support as most valuable for HCWs who do not have large personal networks of friends or family. By relating to similar situations and stories from peers, the support program reduced feelings of isolation on the job:

[In the support program,] you're able to see the benefits that we have working, from doing this job, we have seen the challenges that people go through. And then, they make [you] know also that I'm not alone. (D8, Interview)

6.1.2 Program Built Understanding toward Resolving Workplace Issues

Many problems that HCWs shared were related to their workplace. The support group allowed HCWs to speak on and raise awareness around common job-related problems and grievances. Because their audience was other HCWs, for whom this information was very relevant, participants felt like they had an effective "voice" in the support program. One participant described that it was important to have this voice in the sharing circles due to a lack of it in the workplace:

> *Home care, we don't really have a voice. Because the thing, no matter who you complain to is sometimes no changes, but it's important for us to have our own little circle to talk over stuff.* (A2, Interview)

The confidentiality of the support program, through relevant ground rules and HCW-only membership, enabled participants to turn their voice towards discussing issues in their workplace, such as what they felt was appropriate treatment by agencies and their rights as workers in the context of challenges they faced. Participants shared stories about employment situations, including problems taking vacation, agencies not respecting working hours, being assigned cases they were uncomfortable with, and issues of unemployment and worker's compensation. The support program provided a place for participants to vent about frustrating workplace issues, build understanding about their causes, and seek advice for how they should address them. For example, one HCW described trying to get compensation for a workplace injury that occurred right outside the patient's home. The sharing circle discussed how she was being treated and why she was unable to get compensation. Eventually, one participant provided an explanation

that was accepted by the group:

> *Listen, they're not going to consider she got hurt on the job. She clocked out, so after that, they're not responsible. That's what they're going to say; that's why she's not compensated. Because she clocked out.* (A2, Sharing Circle)

In follow-up interviews, some participants cited this incident as an example of being able to learn from the experiences of peers and that it helped them be aware of the possibility of not being protected from injuries once they clocked out, even if it occurred on the patients' premises. Peers made suggestions for how to address the problem, and a facilitator offered to help the HCW contact a paralegal. Hearing peers' experiences and advice for handling these issues may be a useful resource that enables HCWs to better navigate the workplace:

> *People can benefit from this program because some of them have a problem with their [supervisor]. Some of them don't know how to work with the union. ... They don't even know how to explain the problem or who to contact. When they're in the circle they explain their problem. Someone else in the program takes their name and their number to give them after the program to help them.* (A1, Interview)

Finally, by sharing these issues and hearing the reactions of peers, the support program also helped HCWs develop shared values around work, such as the importance of self-care, setting boundaries with patients, and seeking outside support. These were topics that participants brought up without being prompted by researchers and could form the basis for shared workplace norms. Participants also provided advice to their

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peers for practices around these values, such as how to cope with a stressful work environment, how to approach supervisors, and who to talk to about workplace issues. Communicating these norms and values might be especially important for HCWs who have immigrated to the United States and whose unfamiliarity with work practices might lead to them being taken advantage of:

> *The kind of home care worker that sometimes comes to me, they feel they don't have right to talk about how they feel, because they are in other country, not their country. ... They need to be in this program, because they feel they don't have the right to talk about nothing that happened in the job. They have to be quiet and support and work with the same problem for many years.* (C3, Interview)

6.1.3 Program Enabled Sharing of Experiential Knowledge to Improve Care Practice

Besides workplace norms and situations, participants also felt that the sharing circles were valuable for learning about and building efficacy in their work as HCWs. HCWs used the program to teach and give each other advice on proper practice, which could lead to confidence in handling different situations and improved practice. However, in doing so, the sharing circles also became a contested space.

While the emotional validation described in Section 4.1 was driven by sharing similar experiences, learning about care practice was a result of discussion on different situations. This was further aided by recruiting participants from different agencies, who saw patients with a variety of conditions, and the online nature of the program, which made

it easier for HCWs from all parts of NYC to join the same sharing circle. This diversity of experiences allowed participants to expand their understanding of the variety of care possibilities and outcomes they may face. One participant described how the sharing circles allowed them to contribute to and access a shared body of knowledge to improve their own skills and enable them to better do their job as a care provider:

> *People talk about difficult kinds of clients they have. And then me? I don't have that client, but years ago, I experienced some of them. I didn't have experience with all the things they were explaining. After you heard everybody talking about that. I can explain what I have, and then I can fulfill all my work.* (A1, Interview)

Another participant who was new to home care described the support program as a way to learn from others' experiences. This was a sentiment echoed by multiple interviewees, who agreed that the program would be especially valuable to newcomers, who have limited familiarity with handling care situations for which their patients are at risk. Newcomers could bring their circumstances before the group for advice, and peers could propose alternative practices that provide insight into how to handle their situation:

> *Being in the program, [HCWs] will have the opportunity to speak about what they're going through: What was the experience of a certain topic? How did they go about it by the same topic? What would they change about the situation if they didn't go about it? Would they choose A, B or C, et cetera?* (E2, Interview)

For example, in one of the sharing circles, a participant described a situation with an elderly couple. The HCW was assigned to the husband, but the wife felt uncomfortable

when the HCW bathed him, a task that was part of the job. Another participant in the session gave advice for how to work with the wife by including her in this activity:

> *Engage her. "Okay, I'm going to wash this part, and you wash that part."*
> *Sometimes even if it the same client, even if they cannot use their hands, you*
> *could put the rag wet with soap and hold their hand, and they could feel.*
> *... Because she's still in charge her house, she don't want another woman*
> *touching her man. So let's get her involved too, so we could avoid problems.*
> (C2, Sharing Circle)

Handling the relational aspects of patient care is an example of tacit knowledge and expertise that HCWs develop in the course of their practice. Because this knowledge is grounded in experience, it needs to be transmitted in ways that emphasize that experience. In follow-up interviews, participants described how the advice they received in the support program was valuable because it was given by other HCWs while sharing stories of their work. This made the advice more authentic and often included discussion of issues that wouldn't be covered in training. As described below, HCWs felt they were contributing by sharing their stories, which led to further affirmation of the value of those experiences:

> *It made me feel good and it made me feel that I can share what I know with*
> *each other. I can give them whatever little experience that I have, as a home*
> *care worker, with each other. So at least they could take whatever little that*
> *I give and go with it.* (B2, Interview)

However, as a space for discussing advice on what HCWs should do, the presentation of opposing viewpoints was a source of conflict. There were a few instances where an

HCW admonished another participant, directly disagreed with someone's past actions, or tried to end a line of conversation about what they should have done. Participants also disliked it when they felt a peer was pushing an agenda with off-topic conversation. In one of the sharing circles, a participant described how couching advice in the context of personal experience could minimize conflict:

Share your experience, and let them understand, 'I'm not criticizing you, but I have a problem, issue like this before, and this is how I handled it, and I find it work for me.' Get them to soften.... (B3, Sharing Circle)

Generally, these conflicts did not occur frequently, and interviewees described being unfazed by disagreements when they did occur. Participants described conflicts as a minimal part of their experience in the circles. The technological affordances of the online sharing circles may also reduce conflict by making it difficult for multiple people to speak at once. Differing viewpoints could also be constructive and lead to better care by reinforcing best practices, as described by the participant below:

There are a lot of things we do which we don't practice. We learn, but we don't practice. But as we continue to discuss it, I think we should also go and tell to the others and then it creates reinforcement. Help them to know that we have to do this and that in the correct way. (E8, Interview)

Overall, though the support program was not designed with learning materials, many participants mentioned that the program helped them learn and improve their practice. Some participants believed that, in future iterations, the program could also provide space to explicitly discuss best practices, add educational materials and videos, and invite knowledgeable guest speakers, such as doctors. But even without including these

canonical sources of expertise, telling stories of practice highlighted the value of, and enabled participants to share, their own experiential knowledge.

6.1.4 Program Explored Collective Purpose and Identity through Reflection

The support program not only gave participants a space to exchange advice around care practices, but also to reflect upon and develop collective values about care. By sharing their stories, HCWs expressed their values around care work. These included motivations to continue in home care and how to balance between competing demands, such as work boundaries and financial needs versus providing the best possible care. As described by the participant below, the support program enabled HCWs to collaboratively create and understand common values around home care:

> *It's a fine line. Everybody wants financial gain, but this profession has to be more about empathy than anything else to be successful at this field. I feel like having people that first year come into these groups, it helps them sort out those feelings. "We know you're not getting paid, but don't you feel great about helping Ms. Jones do her PT exercises? Doesn't it feel great that you make her laugh so much that she's out of depression?"* (B6, Interview)

Multiple aspects of the support program design were important in encouraging reflective discussion around values. The first was that facilitators used follow-up questions to probe participants' feelings, thoughts, and reactions to their own and others' experiences and gave space for participants to recall and discuss their feelings and thoughts

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in detail. A follow-up question might be to ask a participant to think through how they would approach their past situations differently with the advantage of their current knowledge. The summary statements at the end of each session were also an opportunity for reflection, which helped connect practice to values. For example, one participant used her summary to describe how she learned to talk with clients and how this skill was connected to her motivation to be a care worker:

> *I like healthcare because everyone like to help a person. I learn it's really important to listen to client, sometimes the client have problems, they don't have somebody to talk about that. It's not only the person feel sick. Sometimes, they have bad sentimental thing. So it's important to talk to your client everyday.* (A8, Sharing Circle)

The program's topics were also important to frame discussion around motivations and values around home care, such as the importance of patience and empathy, and enabled participants to vocalize what they felt was their purpose as HCWs. Because home care is a demanding job, describing these values helped inspire participants and built a sense of pride in their role as HCWs. This was particularly evident during weeks when the support program took up a positive topic, such as recalling stories about when an HCW had fun with a patient and describing moments that they shared with their clients that made the job rewarding. Topics such as these allowed positive aspects of care to be brought to the forefront of the care experience and may have been particularly valuable for more senior or experienced participants, as it reminded of their own reasons for being an HCW, as described below:

> *[Listening to peers] made me realize, it reminded me that I like helping people. And I was relieved ... I said to myself, "This is a good reminder,"*

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because like I said, there are times that you're not lucky and you get people

that are angry or cannot handle it, but you also get to maybe understand or

learn something, and that's why you always getting certain patients, maybe

just to learn something. That's a lesson. (D7, Interview)

For some participants, the sharing circle helped build a deeper knowing about the role of home care and how values connect to practice. Participants also could champion the commitment displayed by the circle's members and discuss the importance of home care, during the pandemic or for aging populations. The support program may provide a space to socialize newcomers, as described by B6 above, and serve as a platform for the work of HCWs to be recognized and celebrated.

6.1.5   Program Used Online Affordances to Enable Remote

Support and Storytelling

This was the first time most participants had engaged in a support program online. We asked them to compare their experiences in the program with how they accessed and sought support in their normal interactions with peers or traditional in-person gatherings of HCWs. Although participants felt in-person environments enabled more natural interactions and meetings, online environments enabled HCWs to join in different modalities, accommodated more diverse schedules, and provided affordances that bettered the storytelling experience.

A major disadvantage of the online nature of the support program was the relative lack of accessible backchannels. Participants said that, while meeting peers during in-person training, they could exchange contact information and phone numbers after-

wards or during breaks to maintain relationships. This was difficult to accomplish in the support program as the Zoom platform did not enable participants to easily meet individually after sessions. While participants could message each other privately using Zoom's text chat, many participants called in via basic phone service and did not have access to this feature. Instead, in the final week of sharing circles, some participants elected to announce their personal phone numbers to the entire group, but this was not something that everyone was comfortable doing.

In designing this program, we included an optional social networking group on Facebook to enable participants to stay in contact with each other as an attempt to build a more sustainable online community. However, this was also not a sufficient replacement for backchannel sharing of personal contact information. While 18 of our participants joined the Facebook group in total, participants only wrote posts on the group a few times during the program period. Instead, HCWs generally preferred to use it primarily to consume or react to content rather than as a place for in-depth engagement or as a space for self-expression:

> *In Facebook, I'm like the person who like to read, because I don't use Facebook a lot ... because I think when you speak, you open up more. You open more than when you are writing.* (B8, Interview)

Participants were also wary of the privacy implications of a social networking group and felt they had less control over what information they disclosed. While posts and comments in the group were not visible to non-members, this was not readily evident to participants from the way that group-only content were presented in their news feed. Participants were also nervous about the visibility of information in their Facebook profiles and whether they could participate in the support program under pseudonyms. For

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example, one participant had set up their Facebook account to use a fake name. As described earlier in Sections 6.1.1 and 6.1.2, a sense of confidentiality was important to allowing participants the voice to speak about issues relevant to their work, and some participants were concerned that their names and other information visible on their profile would make it easier for information offered in the support program to make it back to their agency:

> *I think that we should use more the person's last name and not the first name or either you use the first name and not the last name. Just use one name. So in that way, we won't be identified by other people. ... I just don't trust people. You might be in the same agency discussing certain things about the coordinators and whatever. You don't know who will go back and say, because that person is from the same agency I'm from.* (B2, Interview)

We also spent considerable effort handling technical issues during recruitment and the course of the program. Staff helped participants install the Zoom app and join the sharing circles using the app or via a basic phone call. Participants took some time to become comfortable using the conferencing system, such as learning how to mute and unmute, use the camera, and end the call. We had frequent issues of noise or disconnections due to the environments that participants joined from, which distracted from the discussion in the circles. Some participants joined from work, while taking care of their own family and children, or while preparing and eating dinner. Others joined during their commutes, which meant that they were in noisy environments with unstable Internet connections, such as busses and trains.

However, the ability for participants to join from different environments and different points of their daily routine was also an advantage of the online nature of the support

program. This may have enabled participants to join who otherwise would have been unavailable due to constraints of physical travel or schedule availability. The online modality enabled HCWs to meet peers from different agencies across the city, lowered the cost of entry, and allowed participants more flexibility in attending the program. As described in Section 6.1.3, this was valuable because it helped include more diverse perspectives and a broader body of experiences. However, it was important to ensure that sessions ended on time, so HCWs could fit the program into busy schedules. Although participants may be less attentive, interviewees still found it valuable to be able to listen in while, for example, having a lunch break:

> *We have to travel a lot in the field. Sometimes we have two visits a day, so we're in between trains, and just having this platform where you could be home in your pajamas and share your opinion I think it's awesome. ... You don't have to worry about losing money on transportation to get to a building.* (B6, Interview)

Because the online nature of the program allowed participants to join from different physical places, this may have enabled HCWs to participate from environments they felt most comfortable with. Contrasting her experience to an in-person program, one participant described feeling more comfortable online because she was participating from home and felt that it was much less likely that she would be unintentionally overheard. At least one participant joined from their home and invited some friends to listen in to the sharing circle over speakerphone and tea. This might enable hybrid online and in-person support programs that might reach more HCWs or create layered forms of engagement. Participants having control over what was visible and audible to others via camera and microphone controls may have also contributed to an increased sense of comfort, especially for participants who were camera shy:
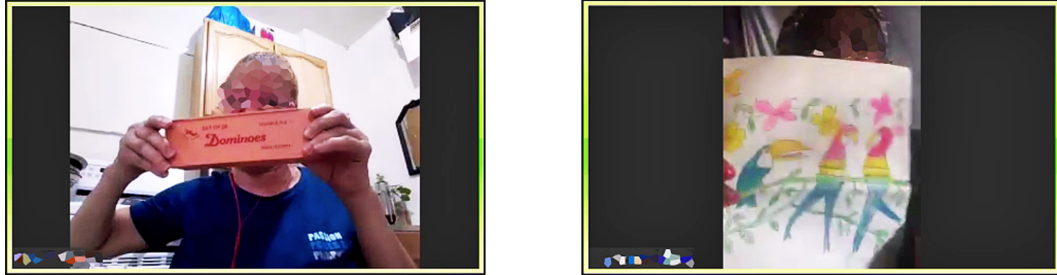
Figure 6.1
Participants from separate sessions used the video to show objects to the sharing circle. On the left, a participant shows the dominoes set that she used to play with her patient. On the right, a participant shows a drawing that a patient gifted her.

> *For me, it will give me more confidence. ... If I like it, I will going to talk, give you my opinion. But I don't know what happened in the camera and the things like that. I'm scared to talk.* (E3, Interview)

The use of video conferencing in different environments also enabled some unique affordances. As shown in Figure 6.1, participants used the camera to show off things from their home environment to support their stories, such as artwork that a patient made for them, figurines and objects that represented a personal connection to a patient, cards, letters, and certificates. Other HCWs enjoyed seeing these items, and it encouraged comments and questions. In this way, participants could use the video as a storytelling aid to illustrate their narratives and engage their peers.

Finally, as described earlier in Section 6.1.3, the affordances of the video conferencing platform discouraged multiple participants from speaking at once because they were not understandable when multiple audio sources were muxed. Similar to how in-person sharing circles may use an object to designate the current speaker, this affects the type of interpersonal engagement in the sharing circles by encouraging longer speaking turns, equitable speaking time, and reducing overt conflict.

6.2 Design Lessons for Intersectional Needs of Support and Empowerment

At a high-level, our findings show how the program addressed the diverse peer support needs of HCWs and highlight design implications for creating online and intersectional peer support programs. We now discuss how our work builds on past literature in considering how computer-mediated tools can be designed to enable support programs and flexible pedagogies such as storytelling. We then discuss relevant issues in the sustainability of peer support programs, particularly in relation to institutions such as peer communities and unions.

6.2.1 Storytelling Is a Flexible Pedagogy for Intersectional Support Needs

In Chapter 3, we described how HCWs had a diversity of support needs stemming from their position as both caregivers and marginalized workers in the healthcare system. As described in Section 6.1.3, we found that needs could vary by experience level, such as newcomers using the sharing circles to access and leverage the knowledge of other HCWs. Other researchers have proposed designing programs specific to experience levels, for both supporting the informational needs of newcomers [270, 234] or the emotional support needs of more experienced workers [392, 371]. Furthermore, as noted in Section 6.1.1, HCWs who are immigrants and minorities may have unique support needs stemming from shared experiences of migration, language barriers, or ethnic and gender discrimination and harassment. Other researchers have also noted that work-

ers from underrepresented groups may benefit from peer support programs specifically designed for their needs [209, 31].

Overall, our findings demonstrate that HCWs have intersectional support needs that vary widely based on their backgrounds both inside and outside the home care practice and can shift over time as workers gain experience. Because of this, HCWs are not fully served by programs designed only for professional development, therapy, or as community safe spaces. In Chapter 4, we reviewed how professional support programs can promote improved practice [269, 377, 215], how therapeutic programs can address members' emotional and informational needs [24, 300], and how safe spaces can help members explore shared identity [213], discuss taboo or sensitive issues [254], and collectivize against discriminatory practices [310]. The goal of the peer support program presented here was to address several of these needs by creating a space for a flexible pedagogy around storywork.

Past research in CSCW and related fields have also noted that online support communities can have diverse needs that can shift over time [124, 128, 151] and have observed that different technology environments can provide affordances for different types of support, as discussed further in Section 6.2.2. Despite this, most past work in HCI grasping with intersectional identities generally focus on a single type of identity at a time [311]. It's clear that simply creating a support program in a computer-mediated space does not automatically enable intersectional support. Instead, the pedagogies of technology interventions are important mediators of participant experiences and are as critical a part of the sociotechnical environment as the specific ICT tool used. The design of such pedagogies deserves appropriate consideration and research. While some past work presented an activity-oriented pedagogy to encourage reflection [68], we found that our comparatively unstructured and narratively-oriented approach created a flexi-

bility that was important for addressing various support needs.

Firstly, storytelling served the professional development needs of HCWs by fostering the transmission of experiential knowledge around practice even while in an online environment. Past work has noted that much of the knowledge in professional communities is tacit [93], and caregivers, in particular, develop experiential knowledge that is critical for their own practice and well-being [321]. Because it is not explicit, learning this knowledge occurs best while doing the work in the environment of practice, a process called *situated learning* [197, 381]. However, online groups are usually far removed from the context of practice and thus do not provide an environment for situated learning to occur. The importance of situated learning is particularly relevant to HCWs who spend most of their time in patients' homes and leverage highly interpersonal and tactic skills, yet interact with peers and perform most of their training through CMC platforms.

Storytelling may be a way to foster the transmission of tacit knowledge in online support programs. Stories based in personal experience gave our participants relational and contextual details that were important to building an understanding of the environment of practice. As described in Section 6.1.3, participants valued stories and the advice given because they were grounded in and invoked experience. HCWs felt more confident in handling potential care situations after hearing the stories of peers and felt that the variety of experiences was particularly valuable to expanding their understanding of the environment and practice of home care. By recreating the environment through storytelling, online professional development programs may be able to teach tacit knowledge even in removed contexts [347].

Secondly, we also observed how storytelling could enable the emotionally affirming and informational support associated with therapeutic support programs. In Section

6.1.1, we described how participants performed storywork to relate to each other and share similar stories of both good and bad experiences. This enabled participants to acknowledge each other's struggles and created empathetic support that reduced feelings of isolation. These stories also provided a basis for discussing advice and seeking help, such as dealing with the workplace issues described in Section 6.1.2. Peers asked each other clarifying questions which both created a sense that their problems were being listened to and produced relevant advice and information for the storyteller. In this way, the circles helped enable emotional and informational aspects of support through supportive interactions around stories of authentic and pertinent experiences.

Finally, storytelling can lead to a deeper knowing on collective identity and practice. As described in Section 6.1.4, participants used the sharing circles as a space to create understanding around their role as HCWs by creating identity and relating practices to values through reflective storytelling. Because this knowing was based on stories of practice, it was relevant to HCWs' day-to-day work and could lead to personal change and more confident practice [296]. By using narratives around work to explore their values and create a sense of pride in their roles as HCWs, participants collaboratively created knowing about how their practices and values connect to a shared identity as home care workers. As described in Section 6.1.1, hearing stories of similar experiences also helped create common ground between participants and may also have reinforced this shared identity and helped create a community that can advocate for shared interests.

Intersectional peer support creates a tension where the population can have diverse and conflicting needs, yet peer support is more effective when it is well-matched and specific to the needs of individual members. HCWs have intersectional needs, and creating a single peer support program to address diverse needs involves designing for flexible pedagogies such as storytelling.

6.2.2 Computer-Mediated Programs' Affordances for

Intersectional Peer Support

Past research on the relative effectiveness of online versus in-person peer support is mixed [146, 266], and there are disadvantages to online programs, some of which are described in Section 6.1.5. However, we also found that computer-mediated programs have specific affordances that can be leveraged to design for intersectional peer support needs. In this section, we further discuss two strategies for doing so: by designing to enable flexible pedagogies such as storytelling and by creating more tailored support program experiences.

As described in our findings, HCWs addressed a wide variety of support needs by telling and relating to each other's stories. However, storytelling is a distinct skill that HCWs do not necessarily learn in the course of their normal practice. Thus, not all participants may be experienced at telling persuasive and cohesive narratives about their experiences. Other participants were shy or uncomfortable speaking in front of strangers. While participants in a program built around storywork can still benefit from listening and reflection regardless of storytelling ability [18], participants who cannot communicate their stories effectively may find it more difficult to relate to, engage, and receive support from other participants and may not experience the same benefits.

To address this, online support groups could integrate tools for assisting storytelling through both technology and program design. As shown in Figure 6.1, participants used video conferencing to show and tell stories about objects around them. Some participants only turned on their video feeds when they had something to show. A pedagogical change to the program to encourage storytelling may be to have a weekly topic explicitly focused around show-and-tell. This might encourage participants to use

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the video feature more often and helped participants create more engaging stories in the sharing circles. Some past research has explored different types and levels of reflection [102], and a design approach that considers all levels might produce technologies that are more effective than at encouraging storytelling.

An online program, due to its computer-mediated nature, could also more easily integrate other applications and features that are designed to aid in storytelling. For example, one could imagine a photo journaling app that helps participants gather and organize pictures and videos through their smartphones [166, 112] that would then later be easily shared in the video conferencing space to perform multimedia storytelling [319]. Such a technology might make the support program more closely connected with participants' everyday experiences. In text-based spaces, such as a Facebook group, the platform could potentially employ built-in conversational agents, such as chatbots [280] or AI-powered feedback [161], to suggest ways for participants to better organize and describe their stories.

A second advantage of computer-mediated support programs may be the ability to match participants to create more relevant and effective support. In therapeutic settings, support programs usually focus on patients with the same disease or condition [386, 141], and more specific matching on support needs [371], treatment plans, lifestyles [266], or common lived experiences can further improve program effectiveness and participant satisfaction [52, 143, 119]. Online programs may be able to more easily match participants simply because they can have wider reach due to fewer geographical limitations and lower temporal and monetary costs to participate [318], as described in Section 6.1.5. An online programs with access to a larger population may find it easier to match participants into homophilic groups.

Participants may also be interested in tailoring their support program experience by

the types of support they seek. An online support program could simultaneously offer the option of multiple types of more focused sessions within the same week. These sessions could have different topics focused on, for example, informational support for HCWs with patients suffering from heart failure, emotional support for HCWs who recently lost a client, or other specific needs. Beyond the topic, groups could be made to vary by size. Past research has shown how smaller groups can encourage reflection, self-disclosure, and reciprocity, while larger groups better foster information sharing [393, 128]. Different types of ICT environments, such as forums versus chat, could also encourage different types of support [128, 65]. An online peer support program which offers a variety of different options to participants might also use algorithmic tools to match or recommend particular types of sessions to participants.

Designing for intersectional peer support needs and enabling storytelling is something that can also be done in in-person support programs. However, the computer-mediated context offers opportunities to more deeply integrate storytelling aids and leverage a broader audience reach to create more tailored support experiences.

6.2.3 Hybrid Computer-Mediated Programs and Designing for Transparency

The computer-mediated nature of the program was important beyond simply making it more convenient for participants to join the program and reduce travel time and costs. As described in Section 6.1.5, it also enabled participants to feel more safe and comfortable in the sharing circles because they were able to join from an environment in which they controlled. This included the comfort of their physical space, such as being in their own home and living room, and the control of their interaction with the online environment,

such as being able to mute or hide their camera view.

However, while the computer-mediated environment enabled control in some ways that increased the privacy and comfort of our participants, it also removed controls in other ways. As described in Section 6.1.5, some participants could have their sharing circles on speakerphone while they performed other tasks or had others in the room. This is another way in which remote participation enabled by video conferencing can create hybrid spaces. While participants could bring their physical environment into the online space by sharing and showing off physical items, this demonstrates that hybrid spaces also work in reverse, where participants can bring the online environment into their home by broadcasting the sharing circles. One could imagine how a localized group of HCWs in the same physical environment may listen in and create discussion and interaction as an extension of the online sharing circle. However, that discussion may not be visible to the participants in the online portion of the program. In fact, we did not endorse participants inviting others to listen in and, from that perspective, this represented a breach of trust in the group where there could be unknown participants in the sharing circles. In this way, participants lose some control and visibility over who is actually listening in and participating on the other end of the line.

We found that video conferencing, while it provides specific affordances that enable participants to feel more in control and comfortable and enables hybrid spaces with their own affordances and advantages, these two aspects are also in conflict as hybrid spaces represent a loss of control and transparency for other participants in the group. This is an opportunity for improved design of computer-mediated spaces. For example, video conferencing might address this by decoupling a caller from an individual participant and provide a way for individual members of a physical space to "check-in" and announce their participation. The Zoom UI could also be better designed to provide participants

an easier way to parse the list of members, such as highlighting people that had joined a reoccurring meeting for the first time, and making this information more accessible to users on the phone app or connecting via a basic phone call.

6.2.4 Storytelling Enables Tacit Knowledge Exchange by Creating Legitimacy

In our findings, we were surprised by how many participants considered the sharing circles to be an effective professional learning space. While not explicitly designed as a training program, participants found that the experiential knowledge expressed in their peers' stories was valuable. As described in Sections 6.1.2 and 6.1.3, participants learned how to navigate the workplace or gained advice for handling hypothetical care situations. However, storytelling did more than simply help illustrate and explain experiential knowledge. Presenting this knowledge as stories also contributed to its authenticity and thus elevated it and made it worthy of consideration. In this way, storytelling legitimized the knowledge and the storyteller in a way that increased the value of the knowledge and encouraged learning.

This role of storytelling in legitimizing experiential knowledge may be due to the fact that the sharing circles were relatively egalitarian. HCWs were not told how experienced other participants were, and the ground rules emphasized that everyone was afforded equal opportunities to speak. In traditional mentorship, there are distinct roles. Newcomers' learning first occurs at the periphery [381], while old-timers play a central and esteemed role as sources of expertise [295]. However, when these roles were not clear and authority was minimized, we found participants instead created legitimacy through the telling of experiences. In doing so, participants created authentic narratives

that were valued by other HCWs and persuasively supported the advice they gave.

The legitimizing effect of storytelling has been observed in other professional contexts. For example, management scholars have described how entrepreneurs use storytelling to create an identity around a venture. The legitimacy of this identity helps entrepreneurs marshal stakeholder support from both workers and potential investors [225, 212]. Our participants also used stories to help them marshal informational and emotional support resources from peers, but legitimacy was more important when participants used their storytelling to communicate their understanding of peers' situations and give tacit informational resources to other participants. In the sharing circles, the value of expertise hinged upon the fact that it was embedded and created through personal experience and reflection on that experience [285] and storytelling served as a way to communicate this embedding [183].

6.2.5   Institutions and Sustaining Peer Support Programs

Peer support is a continual need for HCWs, but sustaining peer support programs requires time and energy from participants and the involvement of larger institutions. While our participants volunteered their time and emotional energy, it is questionable whether they would continue do so for longer duration programs or if the program did not have the tacit support of researchers and 1199SEIU. For this program, researchers and community partners provided funding and logistical support, something that must be maintained to continue to offer the program. In this section, we discuss the role of different potential institutions in sustaining peer support programs. One such institution might be online peer communities, and we discuss how support programs might be only a smaller part of fostering self-sustaining peer communities. Other institutions might be unions and agencies, and we discuss relevant issues of power and influence around who

operates peer support programs in such a relationship.

Online peer communities are larger but looser social structures that are organically self-sustaining due to common interests and goals. In professional settings, one form of such communities may be *networks of practice* which enable members to seek help, learn, and exchange information about a profession [44]. In literature around safe spaces, a community might take the form of *counterpublics*, spaces to put attention to and explore taboo issues and shared identities that are not in the dominant public discourse [108, 191]. These communities are generally based in weak-ties, where members have few deep and sustained interaction with specific individuals [135], but have access to a persistent and highly available set of peers [266].

Peer support groups, particularly those in synchronous environments such as video conferencing, can help build and add resources to peer communities. As described in Section 6.1.1, support programs can provide an opportunity to meet and build rapport with peers, and participants can create identities around their membership [92]. In this way, a support program could provide entry points to a community that encourages sustained membership and engagement. Furthermore, synchronous support programs use more intensive engagement pedagogies and may result in deeper, strong-tie relations [387] that are more lasting and important for certain types of emotional and information support [187]. On the other hand, online peer communities could improve the sustainability of support programs, by providing an audience that would be interested in the continuation of the program and a population from which future peer facilitators could be recruited. The community could also serve as a site for backchannel interactions to occur, as described in Section 6.1.5. Designing for this symbiotic relationship was the intent of our Facebook group.

Other, more formal institutions, such as unions and agencies, might also be well

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positioned to support peer support programs through their existing capability to provide funding and logistical support. However, particularly for formal institutions, who operates the program has implications for who participates, and participants may feel uncomfortable being forthright about issues related to the institution hosting the program. In our case, our program was offered in partnership with 1199SEIU TEF and was thus heavily affiliated with the union. This helped create a space where HCWs could be less worried that discussion about problems at their agencies would make it back to coworkers and supervisors, as described in Section 6.1.5, but alternatively, participants may have felt uncomfortable criticizing the union.

Agency or union hosting of support programs can also change how the purpose of such programs are perceived, particularly by transmitting incentives to participants or shaping the discourse of the program. For example, agencies may wish to encourage more learning around care practice to improve the effectiveness of their workers. One way this could be done is by leveraging agency records to match together participants in a group specifically for HCWs with patients with certain health conditions, such as heart failure [128]. An agency could also incentivize or mandate participation in this program. While such support might be more relevant and thus more effective for these participants, as described in Section 6.2.2, it also shapes and shifts the program away from other potential support and empowerment needs of HCWs and towards serving the needs of the agency.

6.3   Limitations and Future Work

The chapter was centered around a computer-mediated program to foster intersectional peer support in marginalized workforces such as home care workers. Designing support

programs for these populations is a challenge because peer support is most effective when it is relevant to an individual's needs and context, but intersectionality implies diverse and interacting needs that vary by participant characteristics and time. We draw from multiple domains of past literature to design a program based on sharing circles. This work was an initial attempt to design for intersectional peer support, and questions of effectiveness, broader theoretical applicability, and transferability to different contexts remain.

Regarding effectiveness, while our findings describe the types of support participants engaged in and received, further work could quantitatively test how such programs might impact outcomes such as stress, feelings of social isolation, learning, and job satisfaction. For example, while participants appreciated talking about their experiences, many of those experiences occurred long ago, and so the benefit of reflecting on them in the sharing circles may be muted by the time passed. We also did not specifically design and evaluate for different sub-populations beyond the capabilities of a flexible pedagogy, as described in Section 6.2.1. And while we made several efforts to encourage comfortable and safe participation, low-engagement participants may not have felt at ease, and the program did invite the potential for conflict, as described in Section 6.1.3, which could create undesirable outcomes. These provide opportunities to refine the design of this support program and explore more granular outcomes.

Our use of sharing circles and focus on storywork was heavily influenced by Indigenous scholarship. However, our research is also a hybrid work because it comes from a tradition of participatory action research [385] and does not fully embrace non-positivist Indigenous epistemologies [183, 182, 14]. Compared to our program, Indigenous sharing circles may be more focused on preventing reactive speech [218] and include a more through treatment of spiritual [326] and physical health. Exploring these issues may

move support programs closer towards a holistic understanding of health that is more compatible with Indigenous healing [112]. However, our work did not occur within a tribal context, so Indigenous epistemologies may or may not be fully appropriate for a diverse audience which cannot rely on shared cultural and tribal grounding [218]. Future work could explore this continuum of what a Indigenous epistemic approach to peer support might look like in non-tribal contexts.

Some of the concepts explored in our discussion also warrant further research. As discussed in Section 6.2.5, future work could explore the relationship between support programs and institutions. These relationships could be critical towards creating sustainable programs for peer support but also influence the nature of those programs, and deeper and longer research engagements may expose dense descriptions about these relationships. As described in Section 6.2.4, future work might also examine how storywork mediates legitimacy and conflict in contexts beyond support programs. Similar to how the structure of the sharing circles limited overt conflict and direct challenges to legitimacy by encouraging long speaking turns and framing advice as telling of personal experience, future work could also design for enabling participants to support their own legitimacy and esteem as professional caregivers to outside parties.

Finally, our work focused on HCWs in New York City. Designing for intersectional peer support needs is also relevant to other populations. Many marginalized workforces are intersectional populations and the same design implications may apply in these contexts. We also relied on CMC technologies to provide peer support to an isolated workforce who could spare little time for additional travel. Future work may apply a similar approach to increase access to peer support for other populations who are geographically or temporally constrained, such as farmers, parents of children with disabilities, community health workers, and so on.

Chapter 7

Peer-Led Facilitation and Producing a Social Justice Pedagogy

Facilitators are essential for creating a positive experience for participants and working towards the goals of any support program, and our program also heavily relied on our peer facilitators. In this chapter, we discuss the experience of our facilitators and the role they played in the program for our participants. We identify challenges they faced adapting to a social justice-oriented facilitation practice and discuss areas in which our training of facilitators, as well as the structure and technological environment of the support program, could be improved.

In Chapter 5, we described how we recruited HCWs to serve as our facilitators and designed a training that emphasized non-directive methods of support to encourage storytelling in weekly sharing circles. Facilitators all went through 3 days of training and

were assigned two to a sharing circle panel. This helped ensure that they were not performing their role alone and would have someone available to handle exception cases where one facilitator could be absent. In additional, facilitators monitored and engaged with the social networking group.

All sharing circle sessions were observed by at least one researcher. Researchers did not manage the groups and minimized their interaction with participants unless a technical issue was occurring that facilitators could not address alone. Instead, researchers observed and made field notes on the group interactions and the effect of facilitators on the circle. At the end of each session, researchers also conducted a short debrief with the facilitators, typically less than 15 minutes. In this debrief, researchers and facilitators answered questions about the tenor the sessions, identified challenges, issues, and conflicts, and reviewed the next week's topic. Researchers wrote any issues discussed during this debrief into the notes.

As described in Figure 5.1, at the end of the eight weeks of sharing circles, we held a final debrief that was attended by five of the six facilitators. We asked what they found challenging about the facilitation, what they learned through the course of the program, and how we could improve the facilitators' training and the support program as a whole. We also interviewed each facilitator individually to gather their reactions in private, asking them to reflect on how they might improve as facilitators, and what they think they did well. The final debrief lasted 75 minutes, and each individual interview between 30 to 45 minutes. The debrief and interviews were audio recorded and professionally transcribed.

The notes and observations taken throughout the support groups and transcriptions of the final debrief and facilitator interviews comprised the data we analyzed to understand the facilitator experience. We used a thematic analysis [41] approach in which

transcripts and notes were both read over multiple times and segments were coded. We had a total of 55 low level codes, examples of which include *"challenges being non directive"* and *"facilitation rewarding"*. Codes were then grouped and re-grouped into higher level themes. During the coding and theming process, researchers had frequent discussions to ensure codes were consistent with their observations. The final themes are reported here as our findings.

7.1 Findings on the Role and Challenges of Peer Facilitators

Our findings describe how facilitators faced challenges adapting to their role and how they leveraged their experiences, resources, and identities as peers to support and engage with participants.

7.1.1 Facilitators Unlearned the Role of the Instructor and Union Delegate

Our facilitators were all HCWs who were highly engaged with the union and had prior experience as instructors in peer training programs. On one hand, this was beneficial since facilitators already had experience speaking in front of groups and operating video conferencing tools. On the other hand, the role of facilitator is different from that of instructor or union delegate, and we saw in interviews and observations how facilitators faced challenges translating their prior experiences. To be effective in the support program, they had to unlearn aspects of being an instructor or union delegate and embrace

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new techniques for approaching conflict, engaging participants, and creating discussion, which were made harder by the virtual and computer-mediated environment of the program.

One major conceptual difference between peer support facilitation and peer instruction in training programs is that the latter is designed to transmit canonical knowledge and has correct answers endorsed by an organization. At the end of the training programs that our facilitators taught, students would be tested on what they learned, and this could affect their certification and ability to continue working as HCWs:

> *I feel worried [in the training program] because I have to be sure that they understand, because at the end of the session, they have to take a test. And they need to pass the test ... If they pass the test, they can keep the job.* (F3)

Thus, it was important that instructors communicated the correct information and made sure students understood and were able to retrieve this information on their own. Instructors spent significant time studying up on the textbook and memorizing exercises and answers to common questions. These high stakes focused the role of the instructor around reproducing canonical knowledge. By contrast, in the support program, the facilitator did not have a "correct" answer for participants' challenges and situations. Instead, facilitators learned to encourage peers or draw from their own experiences to provide alternative perspectives for discussion. Facilitators faced challenges adapting to this mindset and practice. One facilitator described how it took her some time to get used to this dynamic, where she could encourage discussion but, contrary to her experience as an instructor, should not be focused on correcting errors or teaching participants:

> *Because I still had in my mind the dynamic that we used when we [teach] the different classes ... Until I learned that, no, ... it's not to teach anybody*

anything, it's just talk. Talk like you talk to your friend. You could talk and
give your opinion and how it worked for you, and I probably get an idea if I
have to go through the same situation ... There was nothing right, there was
nothing wrong. (F4)

Facilitators were not the only ones who had to reset their expectations. Participants were also more familiar with training programs than a support program and may have expected the discussions to end with facilitators presenting a "correct" way of approaching problems. Facilitators believed that this contributed to a fear among participants that others would judge them for having poor practices or being in bad situations. For those who spoke English as a second language, the prospect of not only describing their experiences but also needing to defend themselves in English was daunting. Facilitators had to work to overcome this fear to encourage participants to share their experiences:

Sometimes people want to say something, and they say, "I don't want to
say nothing wrong. I don't want them to misunderstand me." Sometimes,
communication, especially with accents and different things, some people
don't feel comfortable speaking. But once they start going, that's it. (F1)

Facilitators also had to learn how to handle conflict differently than an instructor. Conflicts most often occurred when a participant made strong directive statements rather than descriptions of personal experiences, as described in Section 6.2.4. When framed outside of storytelling, these statements could be interpreted as judgment or criticism of another's practices or experiences. An instructor might resolve these conflicts by providing an authoritative answer from a textbook. While facilitators remained in elevated positions due to their role managing the circles, they were not expected to have authoritative, canonical knowledge. Thus, they had to learn other techniques, such as asking

the group for alternative perspectives, reminding participants to respect the validity of others' experiences, or focusing on the shared experiential aspects of stories. In some sessions, facilitators asked participants to imagine themselves in each others' situations to encourage empathy. One facilitator described trying to handle conflict by re-framing a participant's statements so they would not be as prescriptive:

> *Like when it would get heated, when somebody would say something like, "I don't believe." We swayed what she's saying ... make it more what she wanted to say, but in a different, decent way than just saying it hard like how she would say, "You shouldn't do this."* (F6)

Our facilitators were also peers and often shared their own experiences in the groups. While this dual role was beneficial, as described later in Section 7.1.3, it also enabled facilitators to be drawn into conflicts. Strong opinions from facilitators could be misinterpreted as canonical knowledge, so facilitators had to be careful to manage their dual and shifting positionality. While the support program did enable many discussions on values and best practices, we did not want to privilege the facilitators in ways that might devalue the experiences and opinions of other participants as incorrect. For example, in one session, two participants were sharing stories of being given cases that they could not handle due to physical lifting requirements or pet allergies. Both facilitators in the circle were also union delegates and pushed participants to seek help from the union or report issues up the chain of command at their agencies. This created a divide between facilitators and participants. The participants were focused on the experiential and emotional aspects of their narratives and how they felt agencies did not respect their boundaries. Facilitators did not acknowledge these aspects, and as nuances of body language may be lost in the online format, their comments might be interpreted as criticism of the participants' past actions. Avoiding these conflicts brought on by their dual po-

sitionality as both facilitator and peer was a balancing act that our facilitators had to learn.

The lack of canonical knowledge also changed facilitators' patterns of interaction with participants. In training, an instructor asks questions to students and expects an answer before moving on to the next student or question. This creates a "hub-and-spoke" form of interaction between instructor and students, and we observed this practice in early sharing circles. In one such session, the facilitator went down the participant list, asked each one to share a story, received a brief answer, and then responded by summarizing their story or giving encouragement before moving to the next participant. This resulted in early sessions that were facilitator-centric, "interview-like," and resembled instruction in that it focused on getting answers rather than creating interactions between participants.

This interview-like process also meant that facilitators spoke more. Facilitators had to learn to cede speaking time to participants and use active listening to encourage participants to share details in their stories. Facilitators learned to highlight and encourage supportive interactions between participants instead of providing the support directly. In follow-up interviews, facilitators described intentionally trying to step back to avoid interrupting participants. We observed that facilitators did speak less relative to participants as the program progressed, creating more interactive circles. One facilitator described how being in the support program helped her work on her patience, and another discussed how the program required her to learn listening skills:

> *I think [the program] was excellent because as [peer trainers], we do a lot*
> *of talking because we're like teachers. But as support group host or how*
> *you call us, facilitators, you do more listening. So I develop a listening skill*
> *… because when you listen, you learn more from the home care workers.*

This is how we can help them by listening. (F2)

Another feature that differentiated the support program from training was its open structure, lack of strict adherence to a topic, and ability for participants to bring their own issues to the group for discussion. This open structure was important for providing participants with a space and opportunity to discuss issues that were most relevant to them or weighed heavily on their minds. One facilitator described this as *"freedom of speech"* that created a more authentic experience in the sharing circles, enabling more relevant emotional and informational support. To preserve this space for expression, it was important that facilitators learned when to allow participants to go off topic. While instructors typically stuck closely to a script with highly structured classrooms, our facilitators had to learn to judge when tangential conversations would lead to supportive or engaging discussions between participants and allow them to occur. Facilitators also had to learn how to broaden or shift a topic if participants could not relate to its original formulation. It was a new experience for our facilitators to balance these competing demands of maintaining the schedule of the sharing circles, providing all participants opportunities to speak, and allowing for longer and tangential discussions to occur. One facilitator described how this differed from their experience as an instructor and how she had to unlearn practices designed to bring participants back to a strict adherence to a topic:

What [was] challenging was to remember that not everything had to be on
topic ... Like not to stick to script. It was okay if they went the other way.
They can discuss what they wanted and still be okay. (F6)

7.1.2 Facilitators Served as Intermediaries to Create

Informational and Network Support

Although facilitators had to unlearn some aspects of being peer instructors or union delegates, they possessed significant and valuable expertise about home care as well as robust networks of contacts that they used to navigate the practice and practical aspects of their work. This allowed facilitators to serve as loci of network support for participants, and they provided access to informational and material support that participants otherwise did not have. Facilitators also used their relationship with program staff and researchers to raise participants' technical concerns and explain how confidentiality would be protected. In this way, facilitators used their own professional networks and expertise to become conduits for resources and information that were outside of the strict scope of the support program.

For example, in one sharing circle, a participant described an issue where she slipped on the stairs as she left a patient's home, injuring herself. She could not work but was denied worker's compensation. After discussing the problem in the group, a facilitator gave the participant contact information for legal aid and made herself available outside the group to help with the situation. In other circles, participants asked facilitators to help them get in touch with the union to address various workplace issues because they did not know the right person to contact. Facilitators directed participants to their union delegate, the union hotline, and resources such as wellness programs. One facilitator described a benefit of the program was simply to give participants access to people who could help them with their problems and questions:

They learned more, because they were able to ask questions that weren't

getting answered by agency or the union. A lot of them didn't even know

who their union representative was. We gave them the ... different programs.

(F6)

Although our facilitator training included a review of resources available to HCWs and how to recognize when to connect a participant to those resources, we did not originally intend for facilitators to play this loci role. This may have occurred because facilitators had prior experience as union delegates, and understood the delegate role to overlap with their roles in the support program. In multiple circles, facilitators advocated for participants to seek and make use of union resources. One facilitator equated the ability provided by the support program - for participants to express their issues, promote their interests, and address them via informational and network support - to the role of the union:

[The support program] helped us in a way that we have a voice, because we

have no voice in home care. We have no voice with the people who's ahead

of us. The people who's the head of the company..., but I can say that it will

help them to know that 1199 is behind them. 1199 is a listening ear for they

successes and they problems." (F2)

Facilitators also served as intermediaries between participants and researchers, particularly to address concerns about confidentiality. Participants wanted to know who could hear what they shared in the support program. The technologies and policies that affected their confidentiality were not entirely legible to participants. For example, we chose to use Facebook Groups to implement the social networking component of our program due to its high adoption rate. Although we configured the Facebook Group to make posts only visible to members and repeatedly reassured participants, this was

not legible to participants via the Facebook interface, as Group posts would show up on their general feeds and break this logical segregation. As a consequence, one facilitator described how participants were concerned that posts in the Group would be similarly visible to agency coordinators in their friend network:

> *Most people don't feel comfortable on Facebook because everybody knows your business ... And then my coordinator is on Facebook. So then I have to watch what I say, you know what I'm saying?* (F5)

Participants brought their concerns, and others about the operation of the support program, to facilitators. Facilitators approached researchers to ask if the sharing circles would be recorded or clarify issues, serving as a more approachable intermediary. Facilitators also pointed out that the support program itself helped build participants' professional networks by fostering a sense of belonging that led to friendships. Facilitators played a central role in producing these relationships as they were the most visible and present members of the group. For example, when discussing whether participants should be allowed to attend a sharing circle at a different time of the week to give them more schedule flexibility, one facilitator described the importance of balancing flexibility against ensuring that participants recognized the peers in their group and suggested a compromise of allowing participants to join only the other time slots led by the same facilitators, to maintain that sense of familiarity. Facilitators regularly greeted participants in the Facebook Group and responded to posts, and one facilitator described how she occasionally checked in with participants outside of the groups to foster relationships:

> *But it's that you develop friendships from [the support program] too, home care friendship. I try to call everybody to say, "Hello, how you doing," and see how they doing.* (F1)

7.1.3 Facilitators Created an Empathetic and Comfortable Space for Participants

Our facilitators played a crucial role in creating a comfortable space for participants to share their experiences. They did this by helping to set expectations of confidentiality and leveraging their experiences and positionality as HCWs to build rapport. Facilitators used their understanding of home care to manage discussion of salient issues and empathized with participants in ways that encouraged them to speak. Because facilitators were peers, their role in the program led to meaningful and fulfilling support for both participants and facilitators, creating a sense of collective ownership.

Perhaps the most defining feature of the support program was the expectation of confidentiality. This was important because many participants were afraid that their stories, particularly bad experiences with agencies or other HCWs, could get back to their workplace. This could have negative repercussions, such as damaging working relationships or retaliation in the form of lost work or undesirable cases. Thus, confidentiality was carefully designed into the structure of the program via closed membership, ground rules, and a private Facebook Group and Zoom calls. However, facilitators were also important in enacting and creating a confidential space. Facilitators learned to emphasize and enforce ground rules, and one facilitator described how creating confidentiality was an important part of her role:

> *You have to make sure and let them know it's confidential ... When we introducing ourselves, this is confidential. Whatever you say here, stays here ... It doesn't go outside. The same way you give the patient confidentiality, we're going to give the confidentiality right here as well. And you keep*

addressing that or even put it on the board. (F2)

More broadly, facilitators played an important role building a comfortable environment and leveraged their personal experiences and identity as HCWs to do so. For example, in cases where participants were hesitant to speak or could not relate to a weekly topic, facilitators used their own stories as HCWs to break the ice. Participants may have found it easier to relate to facilitators' experiences rather than abstract generalities provided by the topic sentence. Facilitators also modified the topics, such as narrowing it to specific instances or flipping the formulation from negative to positive (e.g., discussing good instead of bad experiences with patients' families). One facilitator described how leaning on her own experiences was especially helpful early on:

When we first started after week one, week two went pretty good. We had a big group. People wasn't talking. We would discuss and say what our experience was, and that opened up the book for everyone to speak. (F1)

Creating engagement was challenging in a virtual support group because it could be difficult to notice who wanted to speak. For example, not all participants used video, which made it difficult to know if participants were interested in the topic, wanted to speak, or uncomfortable and wished to move on. Even when cameras were on, it was challenging for facilitators to read body language in the relatively low resolution, especially for members of the group who were not actively speaking and highlighted in the video. Furthermore, some facilitators were moderating the group from the Zoom app on their phone, and the layout of the app meant that not all participants were visible on the screen at the same time, which made it even more difficult to identify low participators who would have benefited from being invited to speak.

Instead, facilitators had to learn how to recognize other cues for when a participant wanted to speak, such as unmuting or moving the camera to more directly face themselves. Facilitators also had to create workarounds for organizing the flow of conversation and expression non-verbal support. For example, to ensure that all participants were engaged, facilitators kept track of which participants had joined. As there were usually two facilitators per session, some facilitators split up the roles, allowing one to focus on speaking with participants, while another made a note of who was waiting to speak and kept track of time. One facilitator described using Zoom's text chat to message her co-facilitator for this purpose:

I always talk to [my co-facilitator] in a chat and just let her know, "Okay, time's up. Let's go." I said to her a couple of times, "Call on somebody else. Okay. Let's go." And she heard me and said, "Thank you for letting me know." (F1)

Finally, facilitators leveraged their personal experiences as HCWs to create engagement and support. For example, participants could bring their own issues to discuss related to their profession and experiences as HCWs, such as issues on COVID-19 vaccination policies, whether HCWs were eligible for perks that companies were offering to health care workers, and how the new federal holiday of Juneteenth would affect their pay and benefits. Because facilitators were HCWs, they had context for these issues which helped them empathize and provide emotionally affirming support. This empathy was important to allay participants' fears of being judged or criticized and encourage them to share. As one facilitator described:

We agree with what she's doing, because I'm trying to put [myself] in her position. Probably, that person may feel comfortable that somebody lis-

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tened to her, and they don't take it personal, we try to understand the posi-

tion. (F3)

Facilitators also used their experience to ask follow-up questions that probed for details to make stories more concrete or explore emotional reactions to encourage reflection. When a participant described an experience or problem, facilitators called on others to share related experiences. Hearing from others who go through similar challenges could break the isolation of home care work. One facilitator described how, by encouraging participants to interact with each other, she helped them feel less alone and that their problems were not as threatening:

We might help them to see that maybe the problem is not the real problem

... the situation is not really bad ... but your own problems make the other

situation bigger than it is. [Other] people have it too. (F3)

Encouraging participant interaction was important because, as one facilitator argued, while some members might enjoy simply listening to the experiences of other HCWs, they would only get the full benefit of the support program by speaking. By making participants feel comfortable to speak, facilitators created a space where participants had a voice and enabled the celebration of shared values and experiences. This was also true for the facilitator experience, who described feeling camaraderie with participants and a sense of collective ownership over their community:

To hear the other [HCWs] went through the same experience was fulfilling.

A lot of them were appreciative for what we're still able to go through and

still going. They had certain minor disagreements and stuff, but it was ful-

filling to hear that a lot of people are still willing to go out there and do [the

work], even though we're in a pandemic. (F6)

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7.2 Design Lessons for Enabling Social Justice Peer Facilitation

We discuss how our findings are relevant to our goal of creating a social justice oriented peer facilitation practice in a computer-mediated support program and how the design of the technology environment, training, and structure of the program could be improved to support peer facilitators.

7.2.1 Designing Technology for Better Support Program Facilitation

As described in Chapter 6, the computer-mediated nature of our program, via video conferencing and social networking, was critical for these workers to access support. Participants were physically distributed throughout the city and did not have a shared and safe space to meet and work with their peers. We found that several participants preferred the virtual nature of the program because meeting from their own homes made them feel more relaxed and comfortable, and it was easier to fit into their busy schedules [reference redacted for review]. However, as described in Section 7.1.3, we found that the technology involved in running a computer-mediated support program also led to extra work for facilitators and more difficult than an equivalent in-person program. This is in line with prior research that discussed how facilitators in computer-mediated support groups must also take the time to understand technology tools and explain them to participants in a way that promotes members' comfort with and understanding of the technical environment [67] and create workarounds for organizing the flow of the

discussion [268].

To address these issues, the virtual environment may be designed to provide affordances to manage the process of running a support program. For example, one facilitator suggested that a persistent display would be helpful to remind participants who joined late of the weekly topic. As HCWs were busy and often joined the support group while commuting, working, or taking care of their own family, they could be interrupted or distracted and may further benefit from a display that tracks the context of the group's conversation. A constant reminder of the ground rules may also be helpful, although accommodation would be needed for participants joining via phone. Other researchers have tried to create custom conferencing tools that encode some of these expectations around turn-taking and tone setting in the virtual environment [150].

Finally, the computer-mediated nature of the program made coordination between pairs of facilitators challenging. For example, the facilitator tasks and roles described in Section 7.1.3 may switch between weeks. In an in-person group, it is relatively easy to connect with a co-facilitator because they could meet before or after the group in the same room without additional logistical costs. While the Zoom platform provided a text chat that facilitators used for this purpose, this was cumbersome to use and not available outside of the sharing circle times. Facilitators thus had to arrange meetings themselves, which presented a barrier to co-facilitator coordination. Not all facilitator pairs exchanged contact information and coordinated outside of the sharing circles.

These technical challenges highlight opportunities to improve the design of tools used for computer-mediated peer support programs. For example, being able to pull up a list of participants and update a state marker for them, such as if they had spoken or not, would make it easier for a facilitator to keep track of a circle. Zoom meetings also do not have a persistent communication channel beyond the temporal scope of

the meeting. A text chat or other way to easily communicate to the group before or after a meeting might make it easier to coordinate and provide persistent information to participants, even those absent. Finally, teaching participants to use the reactions and other non-verbal cues available on Zoom, or creating non-verbal cues that are accessible from a basic phone call, may close the feedback loop and make it easier for facilitators to create an engaging support program experience.

7.2.2 Training for Peer-Led Social Justice Facilitation

Our work explored the possibility for peer-led social justice facilitation of an HCW support group. We found that such a practice was possible and that the non-directive facilitation and treatment of participant experiences as irreducible encouraged participants to share narratives about their experiences that were important to the feelings of support they had in the program. Additionally, facilitators were very attuned to the relational aspects of home care work and created a program that was able to delve into how doctors, nurses, patients, and patients' families affected HCWs' experiences.

We trained facilitators based on our understanding of what they needed to learn to effectively deliver the program, drawing on literature in transformative critical pedagogy and liberation therapy. However, our findings show that the facilitation role was also very different from what facilitators were familiar with as peer instructors, and these differences led to challenges around comfort with non-directive approaches and addressing issues of power in the group. This required facilitators to learn new skills and adapt their mindset about their role in the group. Although facilitators grew more comfortable as the program progressed, we also saw opportunities to improve facilitator training.

One critical skill facilitators learned throughout the program was how to engage participants by asking follow-up questions that encouraged more contextual and personal details in the narratives shared. This helped move discussion away from generalized or vague comments on appropriate values and practices. Instead, facilitators asked questions that uncovered the personal and social experiences that underlie those values and practices, allowing participants to examine them in a more critical light that led to a deeper understanding. Furthermore, facilitators learned to handle conflict in new ways by engaging additional voices and reminding participants not to critique the validity of others' experiences. More focus on these skills in the training could help facilitators be more effective. While we provided sample follow-up questions that facilitators could use, it took time for them to internalize this practice in a way that they could find the right questions. Training sessions could further use play-acting to give facilitators practice with scenarios where they have to ask follow-up questions or handle conflicts.

As described in Section 7.1.1, facilitators encountered challenges adjusting to the purpose of the support program, which asked them to create an open space for discussion and enable participants to talk about their experiences, even if they strayed from the topics. At the same time, not all tangential conversations would be helpful, and facilitators had competing demands of allowing free-flowing conversation and ensuring the circles ended on time. Training might focus on helping facilitators learn when to encourage more discussion on a tangent and when to move on. For example, our training included a unit on recognizing non-verbal communication cues, which could be useful for identifying when to encourage more conversation or pull back, but we did not explicitly tie this skill to the support program's open structure.

Finally, although our facilitator training emphasized the goals of the support program, we did not explicitly contrast the design of the program with peer-led instruction

or therapy. Facilitators confused their role with their experiences as instructors and with directly providing support to participants. More effort could have been spent not only explaining the program's goals, but also the facilitator role and how it differed from being an instructor or union delegate.

7.2.3 Directiveness in Professional vs. Peer-Led Social Justice Facilitation

In this project, we attempted to engage in a design approach that recognized the politics surrounding home care work and enabled HCWs to pursue their mutual interests [88]. Similar to liberation theologists [216], we believe that technology designers should create tools with a "preferential option" towards marginalized populations. We did this primarily by adapting facilitation techniques that enabled HCWs to recognize, share resources towards pursuing, and ideate new practices that supported these shared interests. However, there were aspects of social justice facilitation that we could not directly translate from past literature in professional-led practices. Unlike professional therapists, our peer facilitators could not just step back and act as non-directive "outsiders" because, as HCWs themselves, they had a personal stake and experiences with the topics being discussed. These stakes made it difficult to be non-directive when there was a disagreement between participants on what those shared interests were or the best way to pursue them, as described in Section 7.1.1.

As demonstrated by this conflict, for designers hoping to support and empower a marginalized population to create transformative change, the assumption of a coherent set of shared interests for that population may not be reflected in reality. There may be different conflicting interests within the community, and it is not enough to assume that

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a tech intervention can simply "take the side" of the community at large. Instead, designers need to create processes for handling that conflict, enabling the various interests to be explored and resolved in a democratic fashion. Traditionally, non-directive methods are one way to enable marginalized populations to come to a shared understanding of those interests [110], and while peer facilitators did learn techniques to handle these conflicts, as described in Section 7.1.1, we also found that this produces a tension between facilitators personal experiences and identity as peers.

Furthermore, there are other reasons that a social justice facilitation approach could be less appropriate. For example, a purely non-directive approach may also be ethically fraught, particularly in domains such as health care where participants are not only choosing their own goals but also potentially impacting patient outcomes. Facilitators may wish to step in and prevent participants from advocating for practices that are not medically sound or might harm patients. Finally, HCWs are a diverse and intersectional population and, throughout the program, participants shared stories of experiencing discrimination and harassment. To create an ethically just and welcoming space, facilitators may need to enforce values around inclusivity and respect that preclude discriminatory positions. Finally, encouraging HCWs to refrain from directing the conversation could also reduce the unique value that peer facilitation can bring to a program by devaluing facilitators' experiences.

Prior research has also discussed the apparent contradiction between the need for directive support within a non-directive program. Snyder noted how, among non-directive psychologists, some still used directive statements, and not all directive statements were received poorly by patients [328]. Chambers argued that Freire's own writings never advocated for the complete lack of directive methods and how non-directive does not necessarily mean "neutral" in a critical pedagogy. Since the purpose of a Freirian edu-

cation is to help students imagine their own conception of utopia and equip them with the understanding and skills to achieve it, this education is inherently emancipatory and has values. While a teacher should not use their directive authority to manipulate students, it is important that the teacher play a role in directing students to what they should be studying and thinking critically about [56].

These authors suggest that directive support is still necessary in a social justice facilitation practice and that facilitation practice must embody a constant balancing act that changes with different participants and audiences. In our work, we found that facilitators' dual positionality as peers had a strong effect on this balance, making them even less "neutral" than professional facilitators. This dual positionality may have made the program more challenging to facilitate, but also provided a more persuasive and engaging experience for participants. Past research comparing peer and professional educators found that peer instructors are sometimes more trustworthy to participants because they can provide information more relevant to participants' context and needs [278, 245]. A similar effect may make directive aspects of peer facilitation more effective than with a professional facilitator.

For example, on a controversial topic (e.g., whether or not HCWs should perform chores for their patients outside of the house), a facilitator might provide a personal example but then explain that her reaction may have been influenced by the circumstances of her experience. The facilitator could then solicit counterexamples that become an invitation for dialogue and encourage participants to examine what aspects of the social and environmental context of their experiences were important to their reactions. Facilitators could encourage participants to look at these experiences critically and reflect on how those contextual factors influenced their decisions in different scenarios and how these were or were not in line with their goals as HCWs. In this way, facilitators

can create a facilitation practice that is simultaneously directive and non-directive, that encourages dialogue and reflection while leveraging their own experiences as peers.

Future training may equip facilitators with ways to explicitly invite contradictory experiences or opinions and how to step back without diminishing their legitimacy and control of the group. This could be done by focusing on the qualitative and contextual aspects of a facilitators' experience, being clear that their experiences may be limited, and inviting other participants to fill in the gaps. Having two facilitators, as we did in our program, could also serve as a benefit, enabling one facilitator to play a more non-directive role while the second facilitator leveraged their experience and leadership skills to provide more directive feedback. Designing ways to more clearly indicate these roles in a computer-mediated setting could also make interactions within the support program smoother.

7.3   Limitations and Future Work

This research explored what it means to produce a peer-led social justice facilitation practice in computer-mediated support programs. Inspired by critical pedagogy and liberation psychology, we designed a training course for HCW peer facilitators and observed as they led weekly sharing circles via video conferencing. We found that our HCW facilitators played critical roles in producing supportive interactions and enacting the non-directive and socially oriented pedagogy of the program.

Our findings also highlight rich opportunities for future work. For example, we ran a single program, and our sample size was small. More research is needed to validate whether peer facilitators in other contexts have similar experiences, either with HCWs

or other marginalized and distributed workforces. Our study was also descriptive, and future work could compare the efficacy of different facilitation models, different training programs, or the effect of computer-mediated vs. in-person facilitation.

Our work was motivated and informed by common themes in critical pedagogy, liberation psychology, and other emancipatory and humanistic traditions. However, as noted in Chapter 4, these literatures are not the same and there are also areas in which these traditions differ, and future work could explore how those differences could impact peer-led support programs, the power and interaction dynamics between participants and facilitators [300], and the design of facilitator training. Furthermore, our training lasted only three days, and there are many opportunities to improve facilitator training, including providing more time to prepare or incorporating different training modes, such as shadowing a more experienced facilitator.

Finally, we saw how peer-led facilitation also led to unique benefits stemming from facilitators' own experiences and personal networks, and there may be ways to design peer-led support programs to center these benefits, such as providing facilitators with resources they could distribute. Another advantage to peer-led programs is that facilitators themselves benefited, finding the experience fulfilling and educational for both their home care and facilitation practices. A support group program might be designed to empower a population by enabling members to learn social justice facilitation skills and encouraging information exchange. We discuss the goals of empowerment and transformative social change in Chapter 8.

Chapter 8

Towards Community-Empowerment Technology Design for Marginalized Practitioners

The motivation of the research in this dissertation was to explore a way for the design of technology interventions to create transformative social change that addresses global inequalities. This is an exceedingly challenging and ambitious proposition. Past work has argued that introducing technology can amplify inequalities within a context without making any substantive transformative change [358]. Other times, the technology does not produce sustainable impact because the incentives that they introduced could not be maintained once research interest waned or the funding ran out [77, 222], and researchers leave without engaging with and influencing existing policy and practice

[132]. In the worst cases, the technology is merely another manifestation or reinforcement of outside control and colonialism that reduces the agency of marginalized populations, even if it is in their presumed interests [89, 208]. As development researchers, we should be careful about claims social change precisely because the challenge is intractable and it is easy for researchers to inadvertently cause harm. For example, because the work of development interventionism involves many parties in complicated political configurations [265, 88], researchers need to be aware of the possibility entering into a context with conflicting interests and doing work that only benefits local elites [214, 208]. Thus, designing technology that addresses inequalities and leads to the liberation of marginalized populations requires a careful consideration of *for whom* social change is created.

8.1 Centering Practitioners as Producers of Impact and Social Change

For many ICTD researchers, one strategy to address this problem is to look towards supporting the efforts of *ground-level development practitioners* who directly work for and with marginalized populations, answering the *for whom* of social change with a *by whom*. These practitioners, through their continued work, are important in the process of "producing development" by creating impact for the vulnerable groups they serve and sometimes belong to. As described in Section 2.1, home care workers are one example of such practitioners, and other examples include community health workers (CHWs), as well as workers in other domains, such as agricultural extension workers, rural schoolteachers, and smallholder farmers. These practitioners may also be non-professionals, such as students in formal education or citizen journalists, but all have
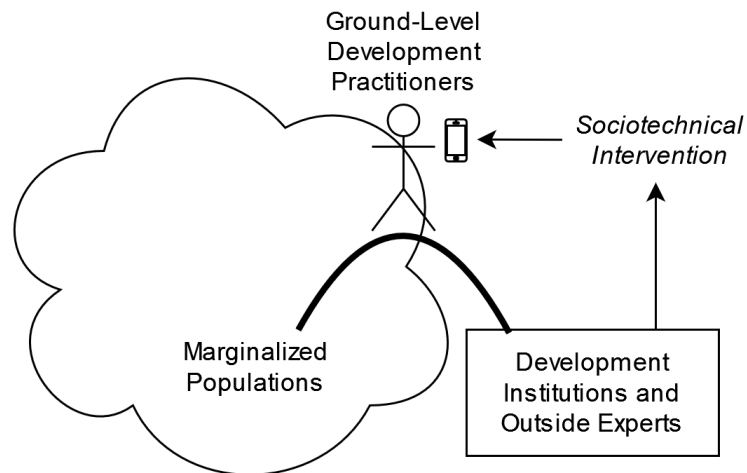
Figure 8.1
Ground-level development practitioners often do the work of development and stand as a bridge between marginalized populations and outside experts. They sometimes come from the very populations that they serve. Outside experts often target these practitioners with ICTD interventions, focusing on making them more effective.

specialized practices and expertise that they conduct to produce eusocial outcomes. Because of this direct relationship between their practice and social impact, ground-level practitioners are often a target of sociotechnical development interventions, as designing technology that enables them to be more effective may be one way for that technology to create social impact [285].

Ground-level practitioners are also attractive targets of interventions for other reasons. They are typically employed by or work with development institutions, such as NGOs, schools, and the government, and thus already have some familiarity with the processes and languages of development at the institutional level. As a result, they are easier for researchers, who are outsiders, to access and collaborate with. At the same time, ground-level practitioners often come from or are deeply involved in the context of marginalized populations that they serve. As described in Figure 8.1, this position as both within or working closely with marginalized populations while able to converse with outside experts means that ground-level practitioners may be able serve as a

crucial bridge in the processes of development. This positionality may enable ground-level practitioners to play a leadership role, where they leverage their specific contextual expertise to present different imaginaries to represent the interests of marginalized populations in interaction with outside experts and the design of development programs. In this way, ground-level practitioners may be a type of Gramscian *organic intellectuals* who can help their community create the agency to engage in their own processes of development [120, 205, 204].

Finally, practitioners provide an existing sociotechnical context of practice that outside technology intervention can target. New technologies are more likely to be adopted, maintained [9], and, above all, useful when they are designed to fit into existing social configurations and support existing practices of workers. In fact, many technology tools for workers receive institutional support precisely because they become highly relevant to their work [169]. Technologies which improve the effectiveness of an existing group of workers are also more likely to be maintained and receive funding. Though many development practitioners currently lack the expertise to maintain their own technology [232], structuring interventions so that the day-to-day use of technology tools is managed and maintained by a community of practitioners may be one way to encourage the development of expertise and build a sense of ownership [294, 396]. Furthermore, such communities can provide a social structure that helps disseminate knowledge about maintenance and use of technology tools [376, 396].

8.2 Existing Types of Technology Interventions and Approaches for Practitioners

Although ground-level practitioners exist in diverse domains, such as healthcare, agriculture, and education, because all practitioners deal in the knowledge and action of development-related activities, technology interventions targeting them can have common typologies across domains. One way to understand these interventions is to categorize them by the intentions of outsider researchers when those tools were designed and deployed. Broadly, these intervention types can be grouped into interventions which attempt to influence or teach practitioner knowledge or processes, those which attempt capture or leverage existing practitioner knowledge, and those which attempt to motivate increased or improved practice. We examine these approaches in detail to better understand how they might different from an approach focused on empowering practitioners to create social change.

8.2.1 Structuring Practice via Programming

One of the most common ways that technology interventions worked was to structure the practice of practitioners via processes that were programmed into the intervention. An explicit example is e-IMCI, an application on a personal digital assistant (PDA) that implemented the Integrated Management of Childhood Illness (IMCI) algorithm developed by UNICEF. IMCI was a workflow for diagnosing and treating common symptoms in young children, traditionally described in paper flowcharts. Unlike paper, clinicians could easily carry and navigate e-IMCI during a client visit, which increased usage of

and adherence to the protocol [85].

Similar work with CHWs includes Ramachandran et al.'s use of persuasive scripts to guide a CHW's consultation with a client. These scripts structured the consultation around different discoursive tactics, such as using a Socratic, dialogic approach. CHWs reported feeling more comfortable performing counseling with the aid of the scripts and were more likely to pause and offer explanations with dialogic strategies, resulting in longer sessions [292].

Many ICTD interventions included artifacts which impacted multiple aspects of practice. An example is Varanasi et al.'s case study on Meghshala, an Android app that structured content for creating and teaching lessons, and its use by schoolteachers around Bangalore, India. Meghshala's features centered around lesson-planning but also changed how teachers prepared for their classes, taught their lessons, and what administrative work needed to be done [365]. For example, teachers using Meghshala and similar systems spent more time looking for content from outside sources and including it in their lesson [365, 229, 113].

Changing the environment of practice also had effects on its structure. For example, students' roles and responsibilities changed centered around the tablet, as some teachers recruited students to assist with device management, making them "Meghshala leaders" [365]. Similarly, Koradia and Seth provide the example of an automated answering machine and how introducing it to community radio stations to save messages from listeners changed the practices of broadcasters towards engaging with their audience [179].

Community-led video education (CVE) are a class of interventions that are also interventions on the process of extension work, as they included practices of script

writing and video production that were new to CHWs, extension workers, and teachers [229, 365, 190, 244, 291]. Both the Digital Green and Projecting Health projects describe the effort involved in training existing extension workers to storyboard, feature in, film, and edit videos [114, 190]. Digital Green's intervention also introduced technologies and processes for the storage and dissemination of CVE content [114]. Finally, because workers mediated the screening of videos, CVE changed the structure of CHWs' existing interactions with their clients. This included CHWs who, uninvolved with video production, had to invent and learn new practices using video to teach, such as how and when to pause and explain key points, allow the video to play through, or replay important segments [190, 291, 241].

These process changes could be introduced for multiple reasons. In educational domains there may be pedagogical motivations, such as encouraging more collaborative learning [198, 365, 279] or better study habits [287]. Researchers and development organizations might deploy technology to encourage adherence to existing canonical procedures, such as assuring medical protocols are observed [10, 85] or client consultations are carried out by CHWs [292]. Other interventions may propose entirely new processes to cover gaps caused by low resources, such as using mobile phones to distribute educational content [111, 144], mesh-network devices to collect community feedback [341], or enabling volunteer educators to hold remote office hours [374].

Altogether, the goal of interventions in this category is to create impact and support practitioners by introducing new routines, ways of doing, and the attendant changes in schedule, skills, and relations.

8.2.2 Training Skills and Knowledge

Introducing new practices often also means introducing new skills and knowledge. CVE interventions included at least some initial training on video production [114, 190]. ICTD interventions, as a whole, often involve some degree of training, even when only using existing technology, like basic cell phones [389].

However, interventions in this category are educational and place knowledge gain as a central goal with defined pedagogies. The most direct of these is using ICTs to deliver training materials, such as the mCME project, which sent questions for continuing medical education (CME) to CHWs via SMS [117]. Other interventions served the educational goals of traditional extension efforts. For example, Digital Green was interested in teaching smallholder farmers sustainable farming practices, such as composting and organic pest control [114]. Ramachandran et al.'s persuasive scripts tried to convince new mothers of the importance of anemia prevention by addressing widely held myths, barriers to adoption, and providing useful details for specific practices [292]. ICTD researchers have also provided educational videos directly to practitioners [189, 76].

Educational interventions targeted at students are not included this category by default, as most of those interventions are about learning course material rather than learning in the practice of being a student. One notable exception may be Maitland and Obey-sekare's study on students taking MOOCs from multiple countries in the Global South. They found that students gained social capital from participating in online courses. Such capital may include experience with the pedagogical style of an American university course, practice using English, and exposure to different approaches to learning [220]. Though this was not the intent and subject matter of the MOOCs in that study, one could imagine an intervention designed explicitly to improve students' learning capital.

Overall, interventions following this strategy are attempting to increase practitioners' knowledge, skills, and cultural capital through direct and indirect training. These interventions have defined learning goals set by a development organization, outside researchers, or institutions.

8.2.3 Informing Existing Practice

The interventions described in sections 8.2.1 and 8.2.2 tended to be program-driven, with the curriculum decided by an NGO or government agency. They also tended to be more intrusive, as they focused on teaching new knowledge or skills, introducing new practices, or changing existing ones. However, interventions in this category are information services intended to better inform practitioners' existing practices by providing targeted information.

The most direct examples are market information systems (MIS) [356], one of the earliest of which was the Kenya Agricultural Commodity Exchange (KACE) [251]. Providing price information on commodities that a farmer or fisherman is already trading in is unlikely to substantively change their practices, such as what crops a farmer grows [267]. Instead ICTs may allow farmers and fishermen to discover price information and sell in markets with higher demand [299, 4, 162]. Though the overall impact of MIS is contested [356, 47, 334] due to usability issues and costs of access [389] or loss of usefulness due to erasure of purchasing commitments [47], MIS in some contexts have led to higher profits [162].

Another example is on-demand weather forecast systems. In rural China, Burrell and Oreglia reported that receiving the weather forecast via SMS was the most successful information system relevant to farming, as farmers used it to alongside information from

other sources and personal judgment to determine what the weather would be and how to respond [267, 47].

Beyond market and weather information, some researchers have built more general question and answer systems which allow practitioners seek the advice of experts. In ICTD, tools for this type of knowledge exchange were typically agricultural. The aAqua project was an early example using the Internet via web cafes and kiosks [293]. Avaaj Otalo used an interactive voice interface to allow even low-literate farmers with basic phones in rural India to listen to questions and answers from NGO experts, as well as record their own questions [276]. Query or question-answering applications could also exist on other platforms, such as smartphones [299].

Broadly speaking, these types of interventions are information services to address the existing information needs of practitioners and rely on practitioners understanding and pursuing those needs.

8.2.4 Leveraging Practitioner Knowledge

One commonality between the first three categories is that those projects were interested in increasing knowledge within a group of practitioners. A different type of ICTD intervention attempts to capture or expose knowledge already within a group so that it can shared with other members. One such adaptation is turning question and answer systems into systems for peer information exchange, like that described in Awaaz.De, where moderators could assign submitted questions to other knowledgeable farmers, thus providing a clearinghouse for accessing knowledge already in the community [277]. Social networks targeted at farmers can also potentially be used to share agricultural information [125].

Another reason that practitioner knowledge may be valuable to an ICTD intervention is because it can be mobilized to address needs in the practitioner's community. The clearest example is in citizen journalism. Soliciting information about local issues was often the central purpose of interventions targeting journalists, and that information can then be used to create mobilizing narratives. For example, the CGNet Swara platform allowed journalists to source information about civic issues, which in turn enabled them to rally activism to address grievances, such as broken wells and other infrastructure [250, 223, 224]. Another example is the Abalobi project, which targeted fishermen and enabled them to report catch counts to build a community-sourced understanding of fish populations. In turn, this information was used to inform the national fisheries agency's decision-making in a way that reflects the realities of small-scale fishermen's experiences [281].

Empirical accounts have documented how groups of practitioners maintain knowledge about how to conduct their practice, such as cell phone repairmen's ability to fix a phone that won't charge [8]. There is also some research around the concept of "community-sourcing," in which targeting a specific group of practitioners using physical locality can leverage practitioner knowledge towards specialized tasks [136]. Both of these findings fit into the general thread of "asset-based" approaches to development which seek to mobilize social capital within communities as a starting point [228].

Finally, many interventions were made more credible and effective by incorporating the knowledge of ground-level practitioners, a tactic exemplified by participatory techniques which use locally produced content. For example, the Projecting Health project incorporated local storytelling techniques and songs created by CHWs to enliven their health education videos and make them more engaging [190].

8.2.5 Motivating Practice

The final category of interventions is those intended to motivate practitioners. The best example of this is the SMS-based tool created by DeRenzi et al. to remind CHWs in Tanzania of pending client visits and escalated delayed visits to a supervisor. These messages were automatically sent both proactively, before and during the scheduled visit day, and retroactively to encourage CHWs to catch up on missed visits. This setup significantly reduced the average number of days that a client was overdue for a visit [84].

ASTA was a system that used visual and voice-based feedback to motivate CHWs working in child immunizations and maternal health in Uttar Pradesh, India [86]. CHWs were provided either individual or group feedback on their past performance, such as the monthly number of visits. Users receiving such feedback visited an average of 21.5% more clients per month than in the control group [87]. For high school students in Cameroon, the PICHNET system used a self-performance feedback strategy on SMS-based quizzes to motivate students to participate [286]. These quizzes also prompted students to study at regular intervals and review related material in preparation for their graduating exams [287].

Beyond encouraging more work, researchers have also explored how to motivate better quality work from practitioners. In Kenya, Okeke et al. created an application that enabled patients to submit feedback on their experiences with CHW visits. CHWs felt encouraged when they received positive messages and wanted more specific negative feedback on how to improve their practices. Administrators could also use these responses to address systematic problems for CHWs based out of certain facilities [264].

Researchers have also noted how motivation is often a side effect of well-funded and

important-looking academics being involved in your practice [292]. Ramachandran et al. have tried to capture this effect by asking CHWs to solicit and film testimonials, particularly from villagers and other people with high social standing. They described how such testimonials made CHWs feel proud about the importance of their work and improved their self-efficacy, potentially leading to higher motivation [291].

One common factor between these motivating strategies is that they relied on social factors, whether peer pressure, surveillance, fear of a supervisor, or the acknowledgement of an important personage. As such, they leveraged participants' role and identity as practitioners. Longer-term studies have not yet been done to see if motivating effects become internalized and intrinsic or can change practitioner identity. For example, DeRenzi et al. found that CHW performance decreased when the escalation to a supervisor was removed from the SMS reminder system [84].

8.3   Marginalized Practitioners and Designing for Community Empowerment

The above typology of technology interventions reveals that the majority of approaches focuses on practitioner as an individual. These interventions imagine the practitioner in a triadic relationship between themselves, their work, and the technology tool intended to support their practice and make them more effective. Two strategies leverage the social role and identity of practitioners: sharing knowledge from fellow practitioners, as described in Section 8.2.4, and motivating practitioners through social pressures from peers and supervisors, as described in Section 8.2.5. However, the extent of the role of peers is much broader and many practitioners rely on peers to not only perform their

practice and make use of technology tools that are part of their everyday work [202], but also to access emotional and political support, as described in our own research in Chapters 3 and 6. Peers enabled HCWs to access information about how to do their job, navigate complicated workplace policies, receive emotional support about the stresses and frustrations of the job, and mobilize to encourage each other and build a professional identity as an HCW. Communities of practitioners are important to maintain knowledge about how to do their work, including the use of technology tools, and as we described in Section 3.3.1, those HCWs who had access to mentors benefited from their ability pass along these knowledges.

When practitioners work in the same physical environment, such communities are thought to form organically through incidental interactions through the course of their work [195, 380]. However, many practitioners don't have opportunities to interact and participate in resilient and robust practitioner communities. This is particularly true for a subset of distributed and ground-level development practitioners, such as HCWs, community health workers, extension workers, and rural workers, who often work most closely with the populations they serve and spend less time in an office or clinic with peers. Without a central space, such practitioners are physically isolated and more likely to lack frequent interaction with peers and less likely to form communities around shared practice. Without such communities, workers lack the ability to easily access informational resources on how to use tools and maintain their practice. Furthermore, due to the importance of peer communities for mobilizing around shared interests of work [249], these practitioners are alienated from their peers and from participation in the political discourses around their own practice.

Technology tools designed in this environment have the potential to be less effective and are an example of how such alienation is reified and exacerbated. This is because,

in the absence of a community of practitioners, such tools must instead be maintained by institutions, such as agencies which employ HCWs, or NGOs that manage extension workers. These institutions may be beyond the control of ground-level practitioners, and without peer communities, the voices of practitioners is isolated and marginalized. Thus, tools that are designed for these institutions run the risk of underrepresenting practitioners' interests in favor of outside experts and can result in a narrow perspective that reduces complex social and political issues to simple technical fixes [205, 99]. Technology designed top-down at the institutional level without the perspective of ground-level practitioners are focused on enforcing canonical knowledges and practices, as described in Sections 8.2.1 and 8.2.2. These knowledges may include flawed assumptions and thus be be less effective because they misrepresent the realities of practice. But beyond effectiveness, without a cohesive community to voice and raise issues, these interventions can easily become vehicles for enforcing technical fixes which depoliticize the process of development and undermine the agency of workers and their ability to pursue their mutual interests [205]. It is in this way that these ground-level practitioners are not only simply working with marginalized populations but are themselves marginalized through their lack of political power created through isolation and collective alienation. They are *marginalized practitioners*.

For marginalized practitioners who are isolated and alienated from their peers, it is not enough to design interventions focused on supporting more effective individual practice. Instead, technology interventions should be designed to empower practitioners by connecting them to each other to create peer communities, advocate for their shared interests, and eventually create transformative social change. This is an approach to designing sociotechnical interventions that "empowers the community" of ground-level development practitioners, and we discuss further how this is different from interventions built on the previously described assumption of individualistic relationships

between practitioner, technology, and practice.

8.3.1 Community Empowerment and Social Change versus Individual Support and Sustainable Practice

In this context, I refer to community "empowerment" as a political and social process of enabling the marginalized to have the agency to discover and create social change in their shared interests. Empowerment is often an overloaded term and has been used to refer to simply gaining skills or support necessary to lead to more sustainable futures and practices. However, as described by Stirling, it's important to point out that sustainability and social change refer to different things. An intervention that creates sustainable impact implies that it is supporting and meeting the needs of practitioners to do their job and that this support can be maintained in the future. Conversely, the goal of social change is to empower marginalized groups to transform their social and material conditions irreversibly and shift the trajectory of society towards subaltern perspectives outside of dominant and incumbent narratives. In this way, sustainability is constructed as endogenous while change is exogenous to existing systems of governance and structures of power [342]. This relationship is illustrated in Figure 8.2.

This is not to imply that sustainability refers to unchanging social structures, and in fact designing technology for sustainability may mean changing how an institution operates to handle, adapt, and be resilient to exogenous shocks. Both the rhetoric of sustainability and social transformation in development literature are concerned with creating social good through meeting the needs of marginalized populations. And perhaps the most sustainable interventions are the ones that have created a permanent change in social structures. In this way, sustainability and change are two sides of a coin when deal-
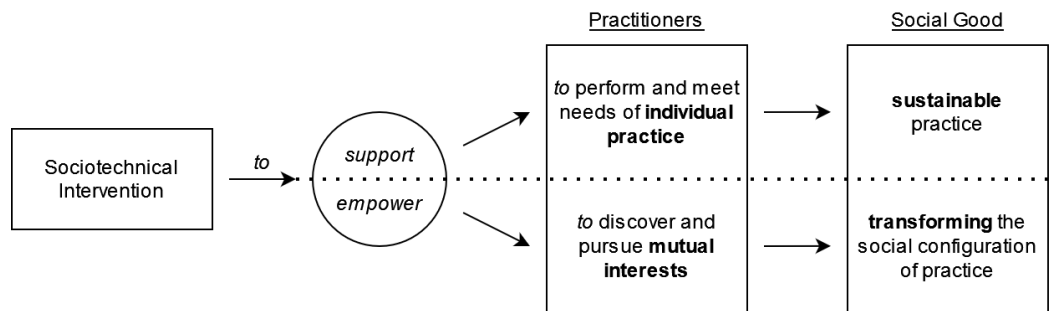
Figure 8.2
While many past technology interventions have supported the needs of individual practitioners, an orientation towards empowering practitioners to create social change necessitates a recognition of the social structures and politics that enforce marginality.

ing with marginalized practitioners, and the most sustainable technology interventions may be those that in the service of the justice or liberation of a marginalized workforce. Technology interventions for social good may focus on one half of this coin based on whether their action is framed as supporting the needs of practice or empowering practitioners to pursue mutual interests.

As described in Section 8.2, past work in ICTD for marginalized practitioners has generally focused on the first half of this coin and creating social good by supporting the individual practitioner and providing them the resources needed to meet the needs of their practice. Even interventions designed around a group or community of development practitioners were focused primarily on leveraging the group or social roles to address the effectiveness of a practitioner rather than building community or political power between members.[1] An individually oriented intervention can create positive outcomes for some practitioners, but these outcomes can be uneven because they rely on the intent of individuals [358]. Empowerment is not impossible from an such an intervention. For example, they can elevate indigenous expertise in CVE [114] or question-and-answer systems [276] or create new responsibilities that may increase the

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[1]While this research most certainly involved building communities and had effects on those communities, the focus of this research was on the effect of the communities on individual members and individual standing within communities. See [125, 281] for potential exceptions.

value of these practitioners [365]. However, such an individualistic focus ignores how marginality is produced through practitioners' interactions with dominant social structures and the political and communal processes needed to challenge that marginality [29]. Thus, sociotechnical interventions focused on individual action and outcomes do not seek to fundamentally change the politics and institutions [247] around the practice of marginalized practitioners.

In contrast, the intent of this research has been to differentiate between empowerment versus support, a communal versus individual design focus, and creating change in the social structures of practice rather than simply supporting and sustaining existing practices. We engaged directly with the second half of the coin described in Figure 8.2 and explored what it meant to design technology for social transformation. While individual support outcomes were also observed in the form of informational and emotional support around the challenges of home care work and advice on how to handle situations with their agencies and patients, as described in Sections 6.1.1, 6.1.2, and 6.1.3, we focused on how technology interventions could be designed to foster communities of practitioners discovering and pursuing mutual interests. Because this means enabling marginalized practitioners politically [247], we describe this as a *community-empowerment approach* to technology interventionism.

8.3.2 Aspects of a Community-Empowerment Design Approach for Practitioners

What are aspects of a community-empowerment approach to technology design for marginalized practitioners and how does it different from other forms of collective action for marginalized groups? As described earlier, practitioners are marginalized when

they do not have opportunities to communally express and advocate for mutual interests in relation to outsiders, yet all our participants were members of a union which represented their interests. However, the institutional scale at which the union operates leaves few opportunities for individual participation in voice expression and building shared values and identity. Even within the sample of participants who participated in the support program described in Chapters 5 through 7, who had previously taken advantage of union training services and thus were more likely to have engaged with the union than the typical HCW, more than half reported attending a union-sponsored event or training no more than twice in the past year. Over a quarter of our participants had not attended any union-sponsored events in the past year. Thus, though the union fought for HCWs' interests, such as better pay and benefits, union membership did not constitute a community for most of our participants and likely the majority of HCWs.

Instead, we describe three aspects of a community-empowerment approach. First, that such an approach is centered in fostering a community in which individuals believe they belong to, engage in, and are impacted by. Second, practice should be centered in the discussion of the communities' interests such that individual engagement enables practitioners to internalize and manifest shared values in the course of their practice. Third, a community-empowerment approach should address the relationship between the practitioner community and other parties that influence the social context of practice. Other potential aspects may exist, but as a starting point, we describe these three aspects in more detail.

Firstly, a community-empowerment approach should foster individual engagement with peers. As described in Section 6.1.1, this engagement was what enabled participants to have a "voice" by expressing problems and issues. These issues were both salient to ongoing events that defined the experience of HCWs - such as the first June-

teenth holiday, COVID-19 vaccine requirements, or types of events that frequently occurred among HCWs - and also extremely intimate to the experience of an individual participant - such as abuse by a patient's family member. This sense of voice was important because it meant that participants' opinions on a topic or personal experiences were recognized as central to the discourse of a group. It is thorough this centering created through direct participation that HCWs may recognize themselves as members of a community with shared interests and identity [382].

Secondly, because practice and the values surrounding it play such central roles in defining practitioner communities, social change for such communities can occur not only through traditional collective action, such as protests, strikes, awareness campaigns, and so on, but also through shaping their practice in a way that is informed by and reinforces their shared values and desires. In the support program intervention described in Chapter 5, we did this by inviting HCWs to share a variety of positive and negative experiences, and the discussions around these experiences enabled HCWs to debate and build both their identity and practice around shared values. Participants in the support program used the sharing circles to push narratives about what it meant to be an HCW and what was good and appropriate practice. For example, as described in Sections 3.3.3 and 6.1.3, this might include ways to gently but firmly set boundaries with patients or creating recourses for different types of abusive or challenging scenarios. Connecting these values to practice serves as a bridge between the community and individual action, and fostering such communities can lead to transformative praxes that change how marginalized practitioners work and outcomes for them and the populations that they serve.

Finally, as described in Section 8.1, the production of development that HCWs and other ground-level practitioners engage in is inherently social and involves many parties,

such as agencies, doctors, patients, and outside experts such as researchers. And while HCWs must work alongside these parties, the same configuration of social relations also contributes to the marginality and exploitation that they experience, as described in Section 6.1.1. Thus, this process of discovery of mutual identity and interests most include recognizing, confronting, and reflecting on the social contexts of HCWs' work. In the support program described in Chapter 5, we did this through the design of our topics, but multi-stakeholder participatory methods [30, 265] may be another way to more directly and explicitly engage with the social context.

In summary, a community-empowerment approach fosters and encourages practitioners to engage in a community that can reflect on the relationship between themselves and outside parties in the context of their work. These communities provide access to communal resources and enable voice to challenge the social structures of marginality, but also enable practitioners to shape their own practice towards pursuing shared interests.

8.4 Future Work in Community Empowerment

In Chapter 6, we saw evidence of how CMC-based tools can be designed to overcome isolation, enable individual voice and participation, and explore HCWs' shared identity and values. However, as described in Figure 8.3, these are only the first two building blocks towards how a community-empowerment approach might lead to social justice outcomes for marginalized practitioners. In this section, we describe some other potential empowerment goals that ICT-based interventions may support. While far from the only goals[2], we hope it outlines opportunities and encourages future research and

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[2]See [88] for different potential framework for pursing this research.
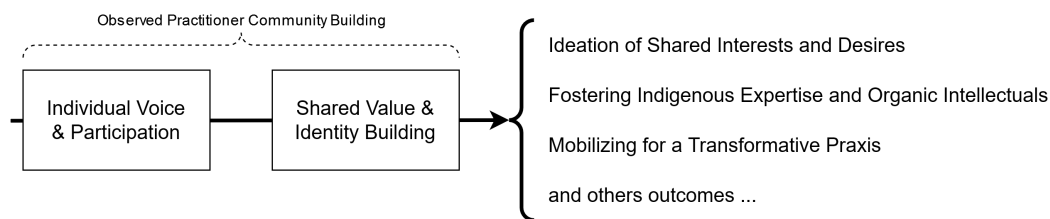
Figure 8.3
We observed how CMC-based tools can be used to help isolated practitioners form communities by centering their experiences through individual voice and exploring shared values. However, there are other social justice outcomes that technology interventions could foster practitioner communities.

design.

One further building block might include ideation about the type of social change that practitioners believe they should strive to achieve as a community. This means moving from discussing shared interests to creating shared desires. For example, from HCWs recognizing a shared problem of abusive patients to discussing how they would like to be better supported by agencies in such cases. Ideation can encourage democratic participation in a process of imagining alternative futures that fulfill unmet desires. This process is a prominent part of "design empowerment" approaches to development, and ICT-based interventions may play a useful, enabling role here [314]. For example, in the co-design study in Chapter 3, one of the scenarios explored using reflective diaries apps to help HCWs think about their work and how the conditions and social relations of their job could be different. Visualization tools could also enable members of a community to better express and communicate their desires and ideas [314].

More broadly, technology tools which engage speculation or creative play may be useful to enable practitioner communities to ideate shared desires. Games that enable play and other less serious approaches may also be a good way to encourage engagement and be generative towards the problems of everyday life [100]. For example, virtual avatars and computer-generated worlds might be useful for play-acting [134] or

imaging what idealized self-image or social and technological arrangements might look like [163, 335]. Overall, speculative design techniques in the field of human-computer interaction have been applied to the problem of creating positive social change through the use of scenarios, personas, and fictitious stories to imagine alternatives to past histories, current sociotechnical reality, and dominant hegemonic understanding of the future [289, 253, 72, 20], and could be similarly relevant to practitioners. For example, HCWs may use these tools to imagine, play-act, and communicate how they would like to be treated as healthcare professionals.

Another building block may be to enable peer communities as a space for ground-based or *indigenous knowledge* to be collected, shared, and learned as an alternative or supplement to canonical knowledges that are provided by institutions. Such knowledge may be related to tacit practices in the community, as described in Chapter 3, for example HCWs' interpersonal skills in how they relate to patients, physical skills in the performance of certain care-oriented tasks, and emotional skills in the production of emotional labor. Alternatively, this knowledge may be related to community maintenance, such as the skills that HCW facilitators gained while learning to lead the support program, as described in Chapter 7.

ICT-based tools may foster processes of sharing, learning, maintaining, and potentially creating new indigenous knowledge in a practitioner community. For example, collaborative and participatory approaches of content creation may be geared towards enabling practitioners to express and develop a shared body of indigenous knowledge. Wikis are already used to enable some types of communities to do so [343], but for HCWs and many other marginalized practitioners, much of this knowledge is tacit and or otherwise not easily representable in text format [180]. Video may be one way instead transit tacit knowledge, and some research has shown how online video-sharing

platforms, such as YouTube, have enabled isolated practitioners to share tacit knowledge across large distances [331]. In the Global South, participatory video or CVE is a common model for video-based interventions [114, 53], where community members create videos about their practices to make knowledges and practices visible and encourage reflexivity around those practices [238]. Such reflexive approaches may help practitioners expose and create new indigenous knowledge [321]. For example, HCWs could share video stories or reenactments about different interpersonal situations they've experienced and use these videos as scenarios to elicit discussion and brainstorming about how to handle those situations in a manner consistent with their values.

Sharing and collecting this indigenous knowledge may lead to more individuals being able to play a leadership role in the community, where they serve as both clearinghouses of knowledge and leaders who are able to keep the community organized and represent them in engagements with outsiders. Such individuals may become organic intellectuals [205, 206, 120] who can mobilize peers and engage with outsiders in the design of development interventions. Through this engagement, organic intellectuals may play an important role in reifying the interests and desires of their community into new technologies, objects, and social configurations that support a new socially transformative praxis [378]. Thus another building block for community empowerment may be to support the creation of organic intellectuals and their ability to interface with outside experts. For example, we discuss in Section 7.1.3 how facilitators in our support program played this role by interfacing with researchers to present participants' concerns around privacy.

ICT-based interventions are particularly relevant here due to their ability to structure practice, as described in Section 8.2.1, and reframe social relations as technical and procedural [207]. For example, many HCWs in NYC current used an app to check-in

to their cases [308], and as described in Chapter 2, during the COVID-19 pandemic, this app was updated to include a self-evaluation questionnaire to test if the HCW was feeling symptoms of illness before starting a shift. In this way, the app represented a reification of the interests of the agency to ensure that their workers would not pass illnesses on to patients. However, this same application could be redesigned to reify the interests of HCWs, such as by protecting the HCW from transmissible disease by instead directing the HCW to ask the patient to perform a self-evaluation. Such an app might also be used to address other interests of HCWs. For example, in Section 6.1.1, some HCWs had described abuse that made them feel unsafe in the home. In such cases, the app could ask the HCW to check-in at multiple times throughout the shift to monitor the safety of the HCW and give them a discrete way to call for help. Some ICTD interventions have built explicit processes for incorporating the feedback, practices, and needs of marginalized practitioners in their development [242] or for addressing and acknowledging the social relations between different parties in the context [265].

To reify their community's interests, organic intellectuals need to not only understand the practices of the community, but also be able to speak in the language that legitimizes and makes persuasive their engagement with outside experts, such as technology designers or development officers [205]. Technology could also be designed to support organic intellectuals in building this legitimacy by enabling them to gather and build evidence for their community's desires that helps them engage and persuade institutions. For example, the Abalobi project enabled small boat fishermen to become organic experts of fish populations in their areas by collecting and aggregating data on catch counts [281]. E-petitions have also been used to gather and demonstrate grass-roots support for community needs [170]. By building interventions which support the legitimacy of indigenous knowledge and organic experts, ICTD researchers can potentially empower practitioners to enter into effective conversations to represent the desired

futures of their community in the process of global development.[3]

8.5 Future Work with Marginalized and Distributed Practitioners

This dissertation was centered on home care workers in New York City, and several characteristics of this population were important to the design of our intervention. The physically distributed and isolated nature of their work meant that HCWs had few organic opportunities for peer communities to form [107], and so we focused on connecting practitioners to each other through a computer-mediated support program. The topics and pedagogy of this intervention were possible because HCWs shared practices and had strong opinions about their own personal journeys and motivations in the practice [372, 340]. Finally, HCWs had shared experiences of marginality stemming from both their practice - as they felt underappreciated for their work and underrecognized for their invisibilized knowledge and skills [81] - and from intersectional identities - as HCWs in our context were often older women, who were ethnic minorities or immigrants, and paid low wages [282, 27, 50].

Populations exist in a variety of contexts that might also benefit from a similar community-building and community-empowerment approach and share similar characteristics. For example, HCWs' isolation means that they were alienated from each

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[3]In this chapter, we generally discuss communities as practitioner communities. However, as mentioned in Section 8.1, many marginalized practitioners are not just working for marginalized populations, but also are of those populations. For example, a community health worker could also be a resident of the village she serves. Similar to how HCWs have a deeper understanding of their patients due to time spent with them, ground-level practitioners may also generally have a deeper understanding of the marginalized populations they work with. For such cases, such practitioners may be able to serve as organic intellectuals, not only for themselves and peer practitioners, but also the populations that they serve.

other, but, as care workers who built strong and lasting relationships with patients, were strongly connected to the process of their labor. While HCWs could derive satisfaction from this strong relationship [372], it also made HCWs vulnerable to emotionally challenging situations and abuse [106, 107]. This description may also apply to other worker populations who are physically distributed and are strongly influenced by the experience and relations of work, such as domestic laborers, community extension workers, and rideshare drivers. Other worker populations, such as gig workers or delivery drivers, may also experience alienation from each other. The computer-mediated aspects of this intervention would be especially relevant for addressing the isolation of such practitioners and the marginality that such isolation produces.

As the gig economy expands and the health care system in the United States increasingly relies on HCWs, the number of distributed practitioners will likely increase. As these are typically not high-paying positions, many workers are ethnic minorities, women, or of low socioeconomic status. As described in Chapter 6, support programs with flexible pedagogies may be appropriate for such groups because participants will have a variety of support needs. Beyond issues of practice or physically isolation, such pedagogies may be relevant for populations of intersectional marginality, who face overlapping concerns and issues from different sources of social oppression or shared challenges. For example, a flexible pedagogy for cancer patients in ethnic minority neighborhoods may be able to simultaneously address the challenges of the cancer disease, the challenges of being a minority, and the intersectional issues of undergoing cancer treatment as a minority.

Finally, while this dissertation was focused around the characteristics of practice, physical distribution, and marginalization, it is important to note that these characteristics are fuzzy and instinct in all dimensions. For example, smallholder farmers may

have shared practice and be marginalized due to their low income and disadvantaged market positions relative to aggregators or larger agricultural corporations, but they may not be necessarily isolated as they may have communities relevant to their practice in their physical location. The unemployed and underemployed may not have shared practices but might have shared experiences of marginality and isolation. A community-empowerment approach may still transfer to these contexts if there are shared political interests with which to focus the community and the shared identity of its members. Broadly, we believe that research focused on enabling political action and transformative social change within communities of marginalized ground-level practitioners is a rich avenue for future work in the field of ICTD and development scholarship.

Chapter 9

Conclusion

This dissertation explored a community-empowerment approach to creating transformative social change for home care workers through the design, deployment, and evaluation of a computer-mediated and peer-led support program. HCWs, like many ground-level practitioners, provide essential services for vulnerable populations, yet are poorly supported themselves and face isolation and alienation that make it difficult for them to collectively address the politics of their work. This dissertation contains an empirical accounting of how HCWs conceptualized the value of peers and how technology tools could help them better connect with and leverage peers. Combined with foundational work in support programs and emancipatory and critical pedagogies, we designed a peer support program centered around narrative storytelling about HCWs' practice and their relationships with their agencies, patients, and other parties in the home care context. This program occurred entirely in a computer-mediated space, and we evaluated it during the peak of the COVID-19 pandemic. We found that it enabled HCWs to share

informational and emotional support around their practice and encouraged HCWs to collaboratively reflect on their shared role, values, and identity. We also discuss how we prepared peer facilitators in their role in managing an online support program and enacting the goals and methods of the storytelling pedagogy. Overall, this dissertation contributes to research around how technology design can foster positive social change, particularly for marginalized and distributed groups of practitioners such as HCWs who are increasingly relevant, not only in United States, but also global and subaltern contexts.

Appendix A

Interview Questions on COVID-19

These interview questions were based on prior research experience with HCWs, previous work on the role of HCWs in epidemics and with infections diseases, and feedback from our community partners, as described in Section 2.2.2 of Chapter 2.

A.1   Warm Up Question

1. Tell me, how long have you been a home care worker?

A.2   Interview Questions

1. Please tell me what you currently know about coronavirus (COVID-19)?

Probe: Where are you getting information on COVID-19?

Probe: How do you verify whether the information is accurate?

2. Has COVID-19 affected your day-to-day work? If so, how?

Probe: How has COVID-19 affected your workflow?

Probe: How has COVID-19 affected your clients' (patients') health and your care for them?

Probe: Have your patients or their families asked you to do anything differently because of COVID-19?

Probe: How will COVID-19 affect your wages, benefits, and leave/sick benefits?

3. Has your agency provided you with training on COVID-19?

Probe: What kind? How (mode of delivery)?

Probe: Do you feel prepared, based on the training you have received?

4. Has your agency instructed you to take certain precautions for COVID-19? If so, what?

Probe: What extra precautions are you taking outside of what your agency recommends? (from who?)

5. Has your agency asked for your input or information about your COVID-19 experiences?

6. Have you talked to other home care workers about COVID-19 experiences?

Probe: About COVID-19 training? About precautions and best practices?

Probe: If you could speak with a peer about their experience with COVID-19, what would you like to know or talk about?

7. Do people in your community ask you questions about COVID-19?

Probe: Your family? Your clients?

Probe: What are their questions? What are your answers?

Probe: Did you play this role in your community before the pandemic?

8. Have you cared for a client with COVID-19 or suspected COVID-19 yet?

Probe: If so, please describe that experience.

9. Have you yourself had symptoms for COVID-19 (shortness of breath, fever, cough, etc)?

Probe: If so, what did you do?

10. What worries you about the current coronavirus situation in terms of your job as a home care worker?

Probe: Has caring for a child or parent impacted your ability to work during the COVID-19 pandemic?

11. When working with clients, what situations (related to COVID-19) worry you the most?

Probe: Which patients do you worry about the most (comorbidities?)

Probe: What symptoms are the most frightening?

12. What would make you feel more comfortable as a home care worker during the coronavirus situation?

Probe: What do you wish the agency could do differently to better support you?

13. Are there additional concerns or issues you would like to talk about? Do you have any questions for us?

Appendix B

Codebook for COVID-19 Interviews

The follow is the list of final codes used to analyze the interviews of HCWs regarding their experiences during COVID-19. As described in Section 2.2.2 of Chapter 2, these codes were created using a grounded and constant comparative approach with multiple coders.

Code	Description
HCW anxiety	Codes in this category relate to whether HCWs are anxious about something specific due to COVID-19.
HCW anxiety: balancing with family responsibilities	Due to difficulties balancing job duties with obligations to their own families.
HCW anxiety: balancing with school	Due to difficulties balancing job duties with their own schooling/education.
HCW anxiety: catching COVID-19	Of catching COVID-19 and getting sick.

Code	Description
HCW anxiety: increasing hours	Regarding whether HCWs are concerned they will need to work *more* because of the crisis (e.g. getting more hours at less desirable times).
HCW anxiety: job + financial security	Regarding whether HCWs fear loss of hours, benefits, or wages.
HCW anxiety: clients' / patients' comorbidities / high-risk cases / unhealthy practices	HCW is anxious about clients' specific comorbidities (e.g. respiratory conditions) or risk factors (e.g. old age) and susceptibility to COVID-19, and these comorbidities place the HCWs at risk.
HCW anxiety: personal protective equipment (PPE) + supplies	HCW is anxious about potentially running out of PPE, effectiveness of PPE, cleaning PPE, etc.
HCW anxiety: transmitting COVID-19 to own family	HCW is anxious of transmitting COVID-19 to family members and getting them sick.
HCW as knowledge source: for clients	HCW serving as a knowledge source regarding COVID-19 for clients.
HCW as knowledge source: for own communities	HCW serving as a knowledge source regarding COVID-19 in their communities.
HCW avoiding risky cases	HCW actually turns down, or wants to turn down, new cases due to increased COVID-19 risk (e.g. because they would have to travel on public transportation to the case or because the client is risky).
HCW family involvement	Regarding the HCWs' family interceding.
HCW is not concerned about COVID-19	HCW response to "What about COVID-19 worries you?"

Code	Description
peer support	Regarding whether HCWs get support from their colleagues, e.g., do they speak with other HCWs.
religiosity	HCW expresses faith or religion is helping them get through COVID-19 uncertainty.
HCW response	Codes in this category are for how HCWs describe their responses would be to emergent issues with client or their own health. Category code is used for complete lack of response OR responses not specifically delineated.
HCW response: calling 911	Calling 911.
HCW response: calling a doctor (PCP or specialist)	Calling primary care physician, or a specialist (e.g. nephrologist).
HCW response: calling coordinator	Calling the HCWs' coordinator at the agency.
HCW response: calling patient's family member	Calling the client's family or unrelated point person.
HCW response: going with patient to doctor / hospital	Going with the patient to the hospital (either in an ambulance or otherwise), or to their doctor.
HCW responsibility to patient	HCW feels duty to patient, emotional attachment to patient, concern for patient, job is a "calling", don't want to leave patients alone, etc.
Self-assessments	HCWs completing self-assessments of their health prior to attending work during COVID-19.
HCW knowledge source	Codes related to where workers are receiving or finding information about COVID-19.

Code	Description
HCW knowledge source: agency nurse + coordinator	From agency staff (e.g. nurses, coordinators). Official communication from agency should not be tagged here.
HCW knowledge source: doctors	From workers, clients', or other personal doctors (not health authorities via the media).
HCW knowledge source: friends + family	From friends and family, e.g., closed family, WhatsApp groups or email threads.
HCW knowledge source: general media	From the "general media" or not specified.
HCW knowledge source: government authorities	From authorities (e.g. Centers for Disease Control, Cuomo, DeBlasio).
HCW knowledge source: online + social media	From less personal online sources, including online news and social media.
HCW knowledge source: TV	From TV news.
HCW knowledge source: union	Through communications from the HCW's union.
COVID-19 confirmed	Regarding manifestation of symptoms with HCWs or client where COVID-19 has been tested and confirmed.
COVID-19 training	HCWs discussing whether they received training regarding COVID-19, and how that training was conducted. Category code used for lack of training.
COVID-19 training: in-person	HCWs discussing in-person training, including cases where it was canceled.
COVID-19 training: remote	HCWs discussing training through remote means (e.g. a video).

Code	Description
COVID-19 transmission between HCW and client	Transmission between HCWs and client.
patient family involvement	Regarding the patient's family interceding, or their concerns or responsibilities intersecting with the HCW's job.
patient: watching COVID-19 news	Patients are spending all their time watching the news.
patient: worries about COVID-19	Regarding whether the patient is or isn't worried about COVID-19.
precautions	Codes related to what HCWs do as a precaution to protect themselves / others from COVID-19.
precautions: hygiene + sanitation	Including hand-washing, masks, gloves, sanitation (e.g. use of Lysol).
precautions: monitoring patient symptoms	Monitoring the patient for any COVID-19 symptoms.
precautions: remedies	Folk remedies (e.g. drinking certain teas).
precautions: social distancing	Following social distancing.
supplies: agency-provided	Tracking discussion of whether agency is providing supplies (e.g.: PPE, thermometers, etc.) upon request, proactively sent, or unavailable.
supplies: HCWs' source themselves	Used when a HCW purchases PPE / supplies using their own personal finances, or otherwise sources them on their own (e.g. from another job).
supplies: patient or patient family-provided	Tracking discussion of when a HCW's client (or client's family member) provides the HCW with supplies .

Code	Description
travel: to agency for supplies	Discussion around traveling to the agency for supplies (PPE, thermometers).
travel: to clients	Discussion around traveling to clients.
travel: via public transportation	Discussion around use of public transportation.
uncertainty: clinical care	Around who to call, what treatments to apply, and whether treatments work.
uncertainty: clinical diagnosis	Around what a diagnosis actually might be (e.g. Is it COVID-19?).
uncertainty: precautions	Around whether their precautions are the right ones or are effective.
uncertainty: what's going to happen?	General uncertainty about the state of the world.
verifying COVID-19 information	Regarding tactics or thought processes around how HCWs verify information they receive about COVID-19, whether present or not.
agency apps	Electronic apps used by agencies to communicate with their HCWs.
agency COVID-19 communication	Codes in this category relate to whether agencies have communicated information to HCWs relevant to COVID-19, and how they do so. Category code is also used for lack of communication.
agency COVID-19 communication: email	E-mail to the HCW.
agency COVID-19 communication: letter	Physical letters delivered in person or via mail.

Code	Description
agency COVID-19 communication: phone calls	Phone calls to the HCWs.
agency COVID-19 communication: phone clock-in system	Existing phone clock-in system.
agency COVID-19 communication: technical issues	Technical issues that prevented HCWs from receiving COVID-19 communication from the agency.
agency COVID-19 communication: text message	SMS text messages.
agency illness policy	What is the agency's illness policy for HCWs, or what do HCWs believe is the illness policy? Covers what HCWs should do if they're sick, and what recourses and resources they believe they would get.

Appendix C

Computer-Mediated Peer Support

Co-Design Scenarios

These scenarios were developed based on prior literature on computer-mediated peer support systems, as described in Chapter 3. We solicited feedback on the scenarios from union staff, and the scenarios were voice-acted and the audio recordings were played during the co-design sessions to encourage discussion and reflection.

C.1 Week 2: Online Groups as Safe Spaces

- **Narrator:** Debbie gives a sigh of relief as she gets out of the building. Today was a rough day. Her client, Mr. Nowak, can be picky and difficult, and today she got into an argument with him. He didn't like her cooking and said it was bland and

tasteless. He made her cook it again and then made her reclean the kitchen!

- **Narrator:** Debbie fumed as she waited for the train. She really wanted to vent! Her husband would listen to her, but he wouldn't really understand. "Well, I like your food," he'd say, but Debbie had to make meals with low-salt for Mr. Nowak's heart condition. Her patient didn't really understand that she wasn't just there to cook and clean, she was there to look after his health!

- **Narrator:** Debbie glanced up at the board. Her train was 6 minutes away. She opened up her phone and went on Facebook. There's a private group she joined that is only for home care workers like her.

- **Narrator:** Debbie writes a short post venting about her day. She doesn't mention her client's name, but she talks about how her client made her redo his meal, breaking his care plan. She says she feels angry when he treats her like a maid!

- **Narrator:** Debbie submits her post before the train comes. The moderators will have to approve it before anyone can see it. They'll check it to make sure she didn't write anything inappropriate.

- **Narrator:** When Debbie gets off the train that night, she sees her post has been approved, and several people in the group have already given it a thumbs up.

- **Narrator:** Another person responded, "I feel this way too!"

- **Narrator:** Reading this makes Debbie feel a bit better as she walks home.

C.2   Week 3: Diary Apps for Reflective Practice

- **Narrator:** It's the middle of the afternoon on a Tuesday and Rylee's doing some minor cleaning in Mrs. Davis's kitchen when she hears her call.

- **Mrs. Davis:** Rylee! Go pick up Sam from school.

- **Narrator:** Sam is Mrs. Davis's grandson, and he's attending middle school nearby. It's only a 15 minute walk, but Rylee is hesitant to leave Mrs. Davis alone. Rylee comes out to the living room wiping her hands.

- **Rylee:** Mrs. Davis, I'm not supposed to do those kinds of things.

- **Narrator:** Mrs. Davis scowls.

- **Mrs. Davis:** Go on, you have to do what I tell you, and what are you doing otherwise anyway?

- **Narrator:** Rylee sighs. Sometimes it's not worth arguing with Mrs. Davis when she gets like that. Rylee gets her coat and gets ready to go outside.

- **Rylee:** I'll be back in 45 minutes, Mrs. Davis.

- **Narrator:** On the way over, Rylee's phone buzzes. Rylee pulls it out to check, and it turns out to be a reminder to put in a diary entry. Rylee has been using this new diary app that occasionally asks her what she's doing throughout the day. It asks her about her work, and at the end of the week, it gives the entries back to her so she can review and think about her work.

- **Rylee:** I guess I'll write about picking up Sam.

- **Narrator:** At the end of the week at home, the app prompts Rylee to review her diary entries from the week. There are notes about chores and pictures of meals that Rylee's cooked. There's a couple posts about her errands to pick up Sam.

- **Narrator:** The app asks Rylee some questions to help her think back on her work that week. "What is your biggest concern or challenge this week?" the app asks.

- **Rylee:** Mrs. Davis keeps asking me to do these errands that aren't in my job description. I don't mind doing a little cleaning here and there, but telling me to pick up her grandson isn't right!

- **Narrator:** The app asks her a follow up question to try to get Rylee to think about her problem. "Why is this a problem?" the app asks.

- **Rylee:** It's not really my job, and it feels disrespectful to me. I'm supposed to take care of Mrs. Davis's health. What if something happens to her while I'm gone?

- **Narrator:** The app asks her where the problem is and how she might solve it.

- **Rylee:** I could ask Mrs. Davis to not send me to pick up Sam, but she's always grumpy. I'm afraid I'll lose my job.

- **Narrator:** The app asks if there are other ways for Rylee to solve the problem.

- **Rylee:** Well, I guess the problem is that I have to be with Mrs. Davis. If I'm with Mrs. Davis, it would be okay. Maybe I could convince her to come with me while picking up Sam and make it into an outing. He only needs to be picked up on Tuesdays, and Mrs. Davis needs to get out at least once a week anyway.

- **Narrator:** "Who do you have to talk to and what should you say to them?" the app asks.

- **Rylee:** I have to tell Mrs. Davis that I can go with her to pick up her grandkids, but she can't be alone for her own health.

- **Narrator:** The diary entries are automatically deleted after a couple weeks for patient privacy, but Rylee can make separate reminders for herself. The app asks Rylee to make some notes about things she could try to solve her problem. They might not work, but at least Rylee feels like there's a way forward.

C.3 Week 4: Video Calls for Remote Mentorship

- **Narrator:** It's late in the evening on a Thursday, and Imani is at home. It's almost dinner time, but first, she needs to make a phone call. It's been almost 8 months since she became a home care worker. At the end of the onboarding training, her agency had offered her to have a mentor assigned to her. It seemed like a good way to build a stronger relationship with someone more experienced, so Imani had accepted.

- **Narrator:** Imani grabs her phone and clicks the icon she had saved earlier to start the video call. The call connects faster than she expected.

- **Imani:** Oh, hey, Sofia. Let me get somewhere quiet.

- **Narrator:** The screen shows a glimpse of a busy kitchen as Imani gets up from the dining table.

- **Sofia:** Hello, Imani. What cooking is your mom doing tonight?

- **Narrator:** Imani smiles as she describes the chicken and lentil stew that Mama's cooking in the kitchen. Sofia usually asks about her dinner. Imani thinks it's because Sofia's also a mom and cooks a lot, though Sofia's Columbian food is a lot different. Most of the time, this is how their calls go: talking about random things or sometimes complaining about their week. This week, though, something was worrying Imani that she wanted to bring up with Sofia.

- **Imani:** Actually, I have a question about this letter I got.

- **Narrator:** Imani grabs the letter she received from the agency and holds it up so the camera can see it.

- **Sofia:** Oh that, on the COVID policy? The new one?

- **Imani:** Yes, it says that now we have to wear a new mask for inside with our client and a different one out on the street? That's crazy. I'll be going through my masks twice as fast!

- **Sofia:** Yes. I think they're worried about complaints from clients. But you should be getting masks from the agency. A few days ago, I heard that they're giving everyone a fabric mask for outside.

- **Imani:** What, I haven't heard this! Am I supposed to go into the office? I don't really want to travel more than I have to.

- **Sofia:** Yes, but if you call your coordinator, they can mail them to you. You can probably ask for more than one fabric mask too. I asked for two.

- **Imani:** Huh, okay. Thanks so much for the information. I'll call tomorrow.

C.4   Week 5: E-Petitions for Collective Needs and Mobilization

- **Narrator:** Virginia is finally back home after her first day on the job with a new client. First days are always a bit touchy because you never know what to expect. She really wants to talk about it, so she decides to call up Alexis, another home care worker that she met a couple years ago when they shared a client. These days, they work for different agencies, but they're still friends, and Alexis is often available to chat.

- **Alexis:** Hey, Virginia, what's up?

- **Virginia:** Oh hey, Alexis. Listen, I just got back from my first day with my new client.

- **Alexis:** Oh okay, how did it go?

- **Virginia:** Eh, I don't know. He seems like a nice guy. Quiet, mostly keeps to himself. And I took the case because it's close to where I live.

- **Alexis:** You don't sound super happy, though.

- **Virginia:** Mmhmm.... Yeah, it's just that he's overweight and needs help getting up out of his bed and chair to do just about anything. He's way too heavy for me to lift!

- **Alexis:** Oh wow. How heavy are we talking about here?

- **Virginia:** I'm sore everywhere! My arms hurt, and I'm getting old. I don't think I can do this!

- **Alexis:** Yeah, you shouldn't push yourself like that. Are you going to ask them to change your case?

- **Virginia:** I guess so. I just feel bad about it. The client, he's a nice guy, and the location is convenient. It's a hassle for everyone. I just wish they would have told me that I'd have to be lifting the client.

- **Alexis:** Well why don't you ask your agency to tell you these things?

- **Virginia:** Are you kidding? There's all these agency policies. They're not going to tell me.

- **Alexis:** Sure, but they really shouldn't be giving you clients that you can't take care of. And if lots of aides are having the same problem, maybe that will encourage the agency to change their policy.

- **Virginia:** How am I supposed to get a bunch of aides together?

- **Alexis:** You know, there's this online website for workers to make petitions. Let me send it to you. I think if you write something, and get other aides to sign it,

that will get agencies to pay attention. You could probably even ask your union rep to help get the word out.

- **Narrator:** Later that night, Virginia clicks on the link that Alexis texted her. To create a petition, it asks her what agency she works with and to briefly describe what she wants the agency to do.

- **Virginia:** "I want my agency to tell me if a case requires me to lift the patient because I'm not strong enough to lift patients."

- **Narrator:** The petition site allows home care workers to sign petitions by writing their name, email, and selecting their agency. The site assures Virginia that names and contact information are not shared, only aggregated information by each agency. Virginia spends some time browsing through some petitions by other home care workers and signs a couple.

- **Narrator:** A few weeks later Virginia's petition has a few hundred signatures. The site allows other aides to make comments on Virginia's petition, and these comments can also be signed by other aides who agree.

- **Narrator:** The top comments on Virginia's petition talk about other important types of information that aides should get about potential cases, such as whether the client lives with family or is diagnosed with or at risk of COVID-19. The union might use Virginia's petition to make the case for changing the policies at her agency.

Appendix D

Ground Rules for the HCW Peer Support Program

1. Voluntary Participation

    - Participation is a voluntary act of bravery.

    - You don't have to talk about things.

    - We encourage you to speak as openly as you feel comfortable.

2. Mutual Respect

    - All responses are valid. There are no right or wrong answers.

    - Please respect others even if you don't agree with them.

    - Don't attack others.

3. Confidentiality of Clients and Other HCWs

- Anything said here is confidential.

- Don't reveal names and other identifying information about your clients.

- Protect the privacy of other members by not revealing their names and other identifying information outside of this group.

4. Fairness in Participation

   (a) Sharing Circles

   - Allow each other equal opportunities to speak.

   - Make sure the previous person has finished speaking.

   - The facilitator may call on names or decide the speaking order if multiple people wish to speak.

   - The facilitator may cut someone short if we're running low on time to allow others to speak.

   (b) Social Networking Group

   - Allow each other equal space to create posts about their own experiences.

   - The moderators may promote someone's post to give it more attention.

   - The moderators may remove spam posts.

Appendix E

Weekly Topics in the HCW Peer Support Program

Week 1 – *Why did you choose to join the home care profession? What do you wish you had known when you first started?*

Week 2 – *Tell us about a time when a client made you angry or treated you unfairly. How did you handle the situation?*

Week 3 – *Tell us about a time a doctor or nurse recognized your contributions to your clients' health.*

Week 4 – *Tell us about a time you helped a coworker do a better job or encouraged them to feel more motivated.*

Week 5 – *When was the last time you had to have a long discussion with your coordinator? What was that about and how did you handle it?*

Week 6 –   *What makes you happy to come to work? Tell us about a special time that you were looking forward to going to work.*

Week 7 –   *Do you feel safe while working with a client or traveling to and from a client? Tell us about a time you felt you had to protect yourself.*

Week 8 –   *Tell us about something that you and your client did together to have fun or pass the time. How did you come across this activity?*

Week 9 –   *At your agency, what are problems that home care workers don't discuss with coordinators? How do different agencies handle these problems?*

Week 10 – *Think back to your last new client or your first client. What advice would you give to a new home care worker or substitute?*

Week 11 – *Tell us about a time when you were proud of the work you did or felt you did a good job as a home care worker.*

Week 12 – *Tell us about a time where you had a long discussion with a client's family member. How do you deal with clients' family members?*

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