In Conversation with a Frontline Worker in a Care Home in Sweden during the COVID-19 Pandemic

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As the world heard the historic declaration of the COVID-19 outbreak as a pandemic in March 2020 (World Health Organization 2020a), countries had to act rapidly with no previous experience to draw upon. Unlike many countries, Sweden did not impose a lockdown (Hallengren 2020) but advised its citizens on precautionary measures, including forbidding visits to care homes (Ministry of Health and Social Affairs 2020). Till date, Sweden has reported a much higher death rate (575 per million population) related to COVID-19 than its Nordic neighbours, e.g. Norway (49 per million population), Finland (60 per million population) and Denmark (107 per million population) (World Health Organization 2020b). To explore how the pandemic was experienced in the first few months by the frontline workers who found themselves in the midst of the storm, we engaged in a dialogue with one such nurse who initially approached the first author to share her experiences. This interview took place on May 15, 2020 and documents personal experience of a nurse working at a care home in Stockholm during the pandemic. She talked about how they prepared for the epidemic, directives from the municipality, personal account of interaction with residents with COVID-19 and much more. The conversation in Swedish was almost two hours long which was recorded, transcribed and translated into English, and then edited to make it concise.

Author [AUT]: *Can you please describe the place where you work?*

Frontline worker [FLW]: I work in a care home, in Stockholm, with rooms for 48 residents. Each floor houses 16 residents and divided by a glass door in two sections. Most of the residents are 80 years or older, some close to 100 years. Very few are 70–75 years. Majority (67%) of the residents have dementia, most of whom can walk and go to

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the toilet themselves. They are quite independent and not severely ill. Some use a wheelchair and are dependent for help. Every person lives in separate apartments consisting of a room and an attached bathroom. We are about 70 persons, including full time and temporary staff, who work at the care home. Most are assistant nurses. We also have registered nurses, care assistants, physiotherapist, occupational therapist, and physician. The managers, although nurses, work mainly with administrative tasks, routines, etc. and not directly with the residents.

AUT: *How did you prepare for the epidemic?*

FLW: All of March we had numerous meetings. Around mid-March, we had the first resident suspected to be infected with coronavirus. That's when we started to discuss how to do things and showed staff how to take care of this patient, but he turned out to be negative. However, we continued to outline and plan the routines. We made little stations outside each apartment. On this station, we planned to place disinfectants, gloves, personal protective equipment (PPE), everything for the staff to use if they needed to go into the room where a resident suspected to be or diagnosed with COVID-19 lived.

Ours is a privately-operated care home but financed by the municipality. On March 10th when we had the first case in Sweden, we were informed by the head of the company of the care home that they had bought a lot of protective equipment, that we should be calm. When the first person was suspected to have COVID-19, we had three face masks which we had at the care home from earlier. The company said to us if we had patient confirmed with COVID-19 then all equipment that we would need would come within three hours. They said that equipment was meant for those care homes which were affected by COVID-19. We wanted at least one set to demonstrate to our staff how to use it as it was quite complicated. We were refused. When we got confirmation about the first person with COVID-19, our manager called the head of the company for supply of PPE. They told us to go to other care homes to find protective equipment. It did not come in three hours as they had promised. Our manager went around in her car to find protective equipment. It was very difficult. We simply had one packet of three face masks.

AUT: *Did you get information from the municipality about how to prepare for the epidemic and even treatment of potential patients with COVID-19?*

FLW: Initially, we got lot of information from the Nurse Practitioner at the municipality. She sent a lot of information and asked how it was, etc. She gave a lot of support from the beginning. No one knew how it was with the disease. Many emails every day.....like a bomb.

In March, many routines were introduced from the municipality which we did not always agree with. We did not think they were good. We were told that the physician would work from home via phone and not be in place. That made it difficult for us as we needed assessments of the residents, consultation, and not only symptom management. Then around end March came directive from Region Stockholm that at care homes we would not use plastic apron with long sleeves, but use sleeveless plastic ones and short sleeved uniforms. When I saw the directive, I thought that they had made a mistake. It was impossible that we would not need long sleeved plastic aprons when we worked with confirmed patients of COVID-19 or scrubs with long sleeves to protect our arms. I really thought that they had written incorrectly and there would come a revised routine. I said this directly to my manager. I did not want to

give these routines to the staff as it was terrible. Why should we not have long sleeved protective gear!

AUT: *Did any of the residents get COVID-19? If so, how did you manage?*

FLW: COVID-19 started on the 2nd floor, not the ones where we had residents with dementia. The first staff member got sick with COVID-19 3–4 days before our first resident was infected with coronavirus.

When we had residents who were suspected to have COVID-19 we obviously needed PPE. Those residents who were suspected to be infected, we could not go into their apartments as we needed the PPE. The first resident began to show symptoms on March 31st. She was tested on April 2nd. We had a crisis meeting. We had two registered nurses of whom one was sick....the other did not want to go into the room to take care of the patient as she was scared. A few days before that we ourselves made visors. So, we had visors but not face masks. A colleague made a face mask out of absorbent compress. When I put it over my mouth small strands of cotton started getting into my nose.....it was very unpleasant!

AUT: *What did you think about this kind of protection when you knew that it was not really any protection?*

FLW: We did not have a choice. We needed to enter the apartments. For me it was given that I would have to enter the apartment to help the resident. She was someone who was affected in the second world war, she had been through so much. When I went into her room and introduced myself, she said “do you think that I have this terrible disease?” I said, “I don’t know.” She was supposed to be tested then. She said to me she did not want to die. I said to her, “you will fight. We will fight together.”

Anyway, those who came from Region Stockholm to do the test for coronavirus had all the PPE to enter the room. They had scrubs, long sleeved plastic aprons, face mask, visor, shoe protection, cap, everything.....and I who is a nurse in the care home in the same Region Stockholm standing side by side with her, I had NOTHING. So, I thought if they could protect the nurses who came to test so that they would not get infected, why not us who worked in the care homes and had nothing? To think that we were colleagues! I requested the nurse to leave her equipment for us, the one that she had used as she would have thrown it away. She left it so we had one scrubs to go into the room.

The next day we got to know that the resident had tested positive. I was very worried. We had no PPE. My husband and I drove around many shops in Stockholm to buy raincoats to use as ‘scrubs’ at the care home. We bought two raincoats at a shop where we met a woman who bought all the other raincoats. At our care home, we found three old scrubs/coats that were made of cloth. We used those to go into the room of the resident who tested positive. We shared the tasks. I would take care of only the patients with COVID-19, only on that floor, and the other nurse of the rest of the residents on the floor.

AUT: *Did you move the others of that floor to another floor?*

FLW: No, that was not possible. A care home is not designed in a way for residents who may be contagious. It is not constructed that way. For example, we had a lot of problems with garbage. We have garbage bins in each room. We collected the contaminated garbage from each room, go through the whole floor and then take the lift down. It was a big problem. We dedicated one lift only for this floor.

As the care home consists of individual apartments for each resident, we did not have the place to move them from there. On the floor, each of the sixteen residents had own room. We did ‘cohort isolation’. We closed the whole floor. One could come in only with protected shoes. We used a lot of disinfectants, we disinfected everything all the time. We did not mix the staff. Those who worked on the 2nd floor could not work on any other floor and vice versa. We forbade visits at the care homes three weeks before the prime minister announced it. It was very difficult to make the relatives understand. Some tried to break in. Once the prime minister announced it, people began to calm down. As the first resident got infected, the staff members who worked on that floor disappeared. They got so scared that they did not come to work. Those who were in risk group disappeared too. Another one was sick although we did not know at that time since there were no tests then. So, though I normally have administrative duties, I made myself available to provide nursing on that floor, directly with patients. Me and one more. I did it also to guide them on how to take care of an infected person and what one should not do.

Within a gap of about 24 h, another resident started to show symptoms and was tested positive. She had moved in 20 days earlier. Her relative came into the apartment with her things and the next day all visits were forbidden. He could not furnish her apartment or be there for his mother. Relatives sent flowers for her every day. They left it outside and we took it up to her apartment. She had a mobile phone, a simple one. Her son called every day. I had an agreement with him that he would call at 4 pm to talk to his mother. One day he called and asked me to check on his mother as she was not answering his call. The scrubs I had, made of cloth, I had just put them in the washing machine at 90 degrees. Once we go into the rooms of the patients with COVID-19, we need to wash them at 90 degrees after we come out of their rooms. So, it should be washed before we can go into their rooms the next time. I already had those in the washing machine. He insisted that I went up to her room and checked. As I went and looked through the door, I could see that she was trying to reach for the phone but could not find it. I put on the plastic apron and face mask and went into her room and gave her the mobile phone, with gloves. She was so pleased, laughed with her son, sounded so glad and spoke so happily with him on the phone!

AUT: *You had by now two patients with COVID-19. Did you call the physician? Who did you talk to about their treatment?*

FLW: It worked like this, that we would inform the physician that a person had so and so symptoms such as fever or cough. The physician would then take the decision about testing and send a referral.

AUT: *Once the residents were tested positive, was there any treatment?*

FLW: No. Our physician said in the beginning that all those residents who tested positive would be given palliative care and not curative treatment. My manager and I were very upset by this. This was an absurd situation. Just because a resident tested positive didn’t mean she had to die!

AUT: *Those others who were suspected, were they on the same floor?*

FLW: Yes. There were eight patients on one side and eight on another side. The residents on the other side did not have any symptoms. Some felt that they had symptoms, but they all tested negative in the beginning. By now, we had six residents and only two scrubs. We started working with those who were not infected or suspected

for COVID-19 and moved on to those who were infected.

AUT: *What happened to those who died?*

FLW: The care transport had come to take the first patient but by then the second patient had died. The first patient passed away on Tuesday night and the second on Wednesday afternoon. The transport had so many persons to collect that they needed time and could not come earlier. When they came, we had arranged her so well in clothes that she liked. This is something we do for all. Those who came to take her said “no, don’t do anything. Just leave the patient as it is, you don’t need to do anything.” I thought like this.....we were near them when they lived, even if we could get infected, but now we were to leave them alone just because she died! It was the routines which stated that the bodies to be put in a plastic bag and marked with the person’s identity. That day I thought it was the worst day I had experienced in my professional life. I took off my PPE, went down from that floor, just sat and cried. Although we knew that we were not supposed to hug each other, my manager hugged me and we hugged each other for a few minutes. It was very, very difficult.

AUT: *Did any other resident get infected?*

FLW: We had many who were suspected to be infected and we began with the same routine with isolation. It was difficult. For example, when we feed a resident, we take the tray into the room. In case of suspected infection, after the meal, we would come out of the room of the resident with the tray, but could not put down the tray anywhere as it would infect other things in the room. So, we had another person to take the tray with gloves on. Just for you to get an understanding what we do to avoid getting infected in a care home. Everything we touch on this floor can get contaminated. There is always a person who is always cleaning with disinfectants. For example, the disinfectant that would come, you know the ones that you can pump, it never came. We had only those with cap on. This meant that we had to take hold of the bottle and pour out the disinfectant. This contaminated the bottle every time we had to use disinfectant. We would go home and keep thinking of every step we took at the care home. We could not sleep well as everything we did had a risk of contamination. It is very difficult to NOT contaminate. I worked on Thursday. I could not sleep that night. I had terrible diarrhoea and felt feverish. All the organs inside me was burning. I felt now I have the disease. All those who worked on that floor became infected.

AUT: *How many?*

FLW: I don’t remember the exact number. I think 22 of the staff members were infected.

AUT: *Were the staff tested?*

FLW: We were all tested. The week I became sick, the week after Easter, the municipality offered to test all staff members who worked at the care home. I was the first person to be tested.

AUT: *How many of the residents became infected?*

FLW: By this date, five residents had died, six infected and survived, and five were never infected on the 2nd floor. In the beginning, eight residents on one side got infected but eight others on the other side on the same floor were not infected. When I returned after my illness, residents even on the other side of the floor became infected. All of these residents but one survived. There was another resident by whom I was really touched. She was blind. She was infected. She talked a lot with her children on the phone. As I went into her room, she told her children that she would hang up as I had

gone into the room. I asked her if she wanted me to put on the radio so that she could listen to some music. She said, “no....I have spoken with my children. They had said such beautiful things and I don’t want to forget them. I will not listen to anything else. I will have their words in my head.”

Around the end of April, the physician declared via telephone all the other residents as healthy since they did not have any symptoms of COVID-19. One resident had cough for a long time. He was tested twice for COVID-19 and came out negative. Suddenly, he started to cough blood. I called the physician and she texted that she would order a test for him. I told the physician that he was not a patient of COVID-19. She said he had symptoms. I said, “no, he had been coughing for two weeks, he is 97 years old. If he had COVID-19 at the age of 97 years and coughed so much he would not have lived.” I wanted to take a blood test and put him on antibiotics as he probably had pneumonia or something else. The physician refused. She said he had COVID-19 and had to be tested. It is so difficult that we need to fight for a physician to listen to us! She would not even come to the care home to see the patients. So, it is I who had to report to her about everything! We had two patients with pneumonia whom she wanted to test for COVID-19 and put on palliative care immediately. But they were not in a palliative care situation, they were not dying! They were suffering from a different disease. It is very difficult to fight with the physician every time like that. The first thing she said to us, when the epidemic started, was that all patients who tested positive would be put on palliative care. We did not accept it right away but tried to engage in a discussion with the physician to reconsider her decision.

AUT: *How did your experience help you to adjust your own routines? Now you have managed to get rid of the virus from your care home. What is it that you did so that it is free of infection?*

FLW: We have done a combination of things. First, we clean to an extreme level on the 2nd floor. People know that they must wear PPE. We did cohort isolation and separated the wings but not the residents as we could not do that. Even those who did not have any symptoms, they remained in their own apartments all the time. They could not meet anyone else. It was very important that we did not mix the staff between the different floors. Usually, all staff members have the same changing room. However, now all those who worked on the 2nd floor changed first into clean clothes to go down and out. The staff used a lot of gloves. They used less disinfectant and more gloves. Even on those floors where there was no infection, even they used a lot of gloves, they were really scared. So, there was an over consumption of gloves. It was very difficult to have gloves for all. The Nurse Practitioner at the municipality helped us quite a lot. Every week we had meeting via Skype with her and the head of our company. After the initial period we had a steady supply of PPE, either from the municipality or the company. But long-sleeved plastic aprons never came. We used the three scrubs we had, made of cloth. One of the staff members’ mother made four more. We use all these all the time.

AUT: *Did you get any education from Region Stockholm about how to manage the infection, to stop the spread, the routines, etc.?*

FLW: All the training came from Karolinska Institute, via Region Stockholm such as, films on the web on hand hygiene, how to use PPE. We did everything ourselves, adjusted our work to take care of the residents. They should have prioritised us because we worked with older people. Now we can manage things well, but it was very difficult in the beginning. Recently (end of April) a report came from the National Board of

Health and Social Affairs about how to manage COVID-19 among persons with dementia (Socialstyrelsen 2020). It is not possible to protect those who have severe dementia. They wander about. We cannot close their doors. If the infection comes into the floors where there are persons with dementia, it will not be possible to protect them from one another.

AUT. *How did your family react to the situation? Were they afraid for you?*

FLW: Those days that were heaviest, when so many people died, I did not want to go home after work. I could not tell my family what had happened, all the bad things that happened at the care home. I wandered around in Stockholm after work. I talked to a friend who was a priest, about the things that happened. She listened a lot and helped me. I could not relax, could not let go. Later it became better. One must constantly think of what to do next. Could we give oxygen? I started to think ... I myself did not have problem with breathing, only once I felt that it was difficult to breathe. Then we discovered that many did not have good oxygen saturation even though they did not have difficulty with breathing. They die in silence. That's when we started to use the pulse oximeter much more at the care home and began to think why we weren't allowed to administer oxygen. I have heard that oxygen was administered at care homes before.

AUT: *The guidelines say that those requiring surgical care should get it. Is it happening in practice?*

FLW: One of the first information that came from the company, where our physician was employed, that no one was to be sent to the hospital, not even for a fracture. We had a resident who had broken her arm and we tried to send her to the hospital, but no one accepted her. I don't know what will happen if a resident gets stroke. It is so diffused... we don't know what to do or not to do if things happen. It is terrible to be without the physician, to have to assess these situations alone, and not be able to send to the hospital or having to beg "please take this person, she is bleeding so much".

AUT: *Thank you for sharing your experience with us.*

Authors' Note Several issues arise from the account of the frontline worker of a care home in Sweden, the most poignant and ethically significant being: Could some of the deaths have been avoided if residents who tested positive for COVID-19 were given more active treatment instead of directly being placed in palliative care? Did the "one size fits all" approach of the physician in treating all sick residents as patients with COVID-19 prior to testing, hence placing them in palliative care and refusing treatment contribute to high death rate in care homes in Sweden? This was not an isolated case as the same approach by physicians at care homes has been reported in the national news in the country. Could another reason of the excess mortality be the refusal to send residents with illnesses other than COVID-19 to hospitals? Structural limits inhibiting care workers' autonomy and lack of horizontal communication among staff members prevent care workers from performing tasks to their abilities and professional ethics thus resulting in physical and mental distress with emotional consequences (Banerjee et al. 2012). Lack of trust among health care professionals has taken its toll on intra- and inter-professional collaboration which may take many years to re-build.

Although some of the makeshift measures by the staff at this specific care home did not meet with the quality standard of PPE as would be required in clinical settings, their spontaneous efforts exemplify how care providers across the country filled in the supply gaps of PPE. Sweden has woken up to the urgency of re-vamping care homes to be better prepared

for managing contagious disease. This not only requires adapting administrative and clinical routines but even in terms of physical structure of the care homes. Finally, a long-term aftermath of the pandemic is the traumatic experience of frontline workers while selflessly responding to the crisis, a challenge that needs to be prioritised by the health care system (Gordon et al. 2020; Holmes et al. 2020; Shanafelt et al. 2020).

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

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