



Lessons Learned From the COVID-19 Pandemic as Experienced by Older Adults Treated for COVID-19

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Abstract

Background: In order to provide the best care, the perspective of older COVID-19 patients must be involved in the development of treatment protocols. This study describes the experiences of older adults affected by COVID-19 who recovered in the hospital or at home.

Methods: Qualitative semi-structured interviews were conducted with 23 older adults affected by COVID-19. A content-based thematic analysis was conducted.

Results: Nine categories were identified as recurring topics, which were grouped into three major themes. The first theme describes experiences in the first phase of the disease when older adults fell ill. The second theme includes experiences during the illness, ranging from illness severity to participation in decision-making, communication barriers and isolation effects. The final theme covers the recovery course, residual symptoms and social aspects.

Conclusion: Older adults treated for COVID-19 experienced a feeling of being in a fast-paced whirlwind and lost total control over the situation. Extra attention should be paid to shared decision making, coordinated information provision and the instalment of a primary contract to the patient. The uncertainty of their situation, isolation measures and fears could result in psychological consequences and hinder rehabilitation in older adults.

Keywords

aging, clinical geriatrics, palliative care, rehabilitation, quality of life, nursing, institutionalisation, decision-making, communication

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Key Summary Points

Aim: This study aimed to describe the experiences of older adults affected by COVID-19 who recovered in the hospital or at home.

Findings: Older adults experienced challenges in decision-making, communication barriers and isolation effects. Recovery often took a long time with many residual symptoms and social difficulties.

Message: Proactively considering treatment preferences may reduce stress in acute situations, also isolation measures have psychological consequences and hinder rehabilitation after COVID-19.

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Introduction

The COVID-19 pandemic has disproportionately affected older adults with high rates of mortality (Bonanad et al., 2020; Grasselli et al., 2020; Karagiannidis et al., 2020; Kremer & Thurner, 2020). Frail older adults with multiple chronic conditions have an even higher risk of poor prognosis and mortality (De Smet et al., 2020; Hewitt et al., 2020; Lithander et al., 2020; Marengoni et al., 2021; Osuafor et al., 2021). The spread of COVID-19 required quick action, and treatment protocols for COVID-19 were developed at a fast pace (Derde et al., 2020; Jansen et al., 2020). However, because of the heightened sense of urgency concerning these protocols, the experiences, preferences and needs of older adults themselves could not be included.

In shared decision making (SDM), it is important to explore patients' personal preferences and to inform the patient about the risks and benefits of different treatment options (Elwyn et al., 2012; van de Pol et al., 2016). For older adults, the burden of treatment sometimes exceeds the benefits. Treatments, such as hospitalisation, intensive care admission and ventilation, often have a major impact on the well-being of older adults in terms of the loss of physical performance and independence (Aarden et al., 2021; Buurman & de Rooij, 2015; van Seben et al., 2019). Research shows that approximately 30% of older adults experience functional decline after hospital admittance (Buurman et al., 2011). Because the perception of the added value of treatment can differ between patients, it is important to discuss treatment preferences and limitations with older adults and their relatives. This is especially vital in novel crisis situations such as the COVID-19 pandemic, as uncertainty about symptoms, treatment and outcome can lead to emotional distress and negative health outcomes (Mishel, 1984).

With this backdrop, this study aims to describe the experiences of older adults treated for COVID-19 at home or in the hospital. With these insights, future COVID-19 protocols and decision aids can be adjusted or complemented with the preferences and needs of older adults. Moreover, the lessons learned may reveal additional issues that health professionals should consider when caring for older adults with COVID-19. Consequently, the findings can be used to improve SDM in the COVID-19 pandemic and possible future crisis situations.

Methods

Study Design

We used a qualitative approach informed by a constructivist paradigm, meaning that reality is considered to be subjective and constructed from human experience (Guba & Lincoln, 1994). A deep exploration of older adults' perspectives was conducted using semi-structured interviews. Semi-structured in-depth interviews provide a powerful, effective and feasible research method to understand the experiences of individuals

(DeJonckheere & Vaughn, 2019). The flexible interview protocol and supplemented follow-up questions, probes and comments allow the researcher to collect open-ended data; to explore the individual's thoughts, feelings and beliefs about a given topic; and to delve deeply into personal and sometimes sensitive issues (DeJonckheere & Vaughn, 2019). Moreover, the non-verbal communication provides the researcher of additional information. Semi-structured interviews are characterised by their power to engage in deep conversation and flexibility. This flexibility is especially advantageous in studying a novel subject, such as the COVID-19 pandemic. Standards for reporting qualitative research (SRQR) guidelines have been used for transparent reporting, and a Consolidated criteria for Reporting Qualitative research (COREQ) checklist was used (O'Brien et al., 2014; Tong et al., 2007).

Setting and Participants

This study was conducted as part of the COVID-OLD project, a multicentre study that focuses on COVID-19 in older adults (Blomaard et al., 2021). We used a convenient sample. However, we aimed to recruit a diverse sample of older adults ($n = 23$), regarding whether they were admitted to the hospital, their cultural background and their living environment. Older adults who recovered from COVID-19 in a hospital were recruited by two geriatricians in the Academic Medical Center Amsterdam and the Catharina Hospital, Eindhoven. Those who recovered from COVID-19 at home were recruited in the areas of Noord-Holland, Zuid-Holland, Brabant and Utrecht through local media, several websites and a senior citizen organisation (KBO-PCOB). When potential participants were interested, the researchers sent them an information letter, and when they confirmed their willingness to participate, an appointment for the interview was made.

Inclusion and Exclusion Criteria

Because of the lack of SARS-CoV-2 PCR tests, especially during the spring of 2020 (Audit, 2020), the following inclusion criteria were used: (1) A strong suspicion of and treatment as if infected with SARS-CoV-2 (and suffering from specific symptoms, such as loss of smell or taste), (2) a general practitioner (GP) or medical specialist was involved in the treatment, (3) hospitalisation or treatment at home for COVID-19, and (4) age 70 years or older (Western background) or 60 years or older (non-Western background). As life expectancy is continuously increasing, we found it suitable to consider remaining life expectancy as an indicator of old age. Sanderson and Scherbov (2008) have suggested defining old age as beginning at ages where remaining life expectancy is 15 or less years. Therefore, we chose 70 years or older as an inclusion criterion for older adults with a Western background. The lower age inclusion threshold for older adults with a non-Western background was related to

the earlier onset of ageing symptoms in this population (Kunst, 2010). The exclusion criteria were the inability to speak Dutch and terminal illness. To our knowledge, none of the participants were diagnosed with dementia.

Data Collection

The interviews were conducted between October and December 2020 at the participants' homes ($n = 21$), or, if not possible, online through (video) calls of approximately 1 hour ($n = 2$). Two researchers, RP and DS, conducted and analysed the interviews. RP has an extensive background as a clinical nurse specialist in geriatrics and as a senior researcher on SDM with older adults. DS is a junior researcher specialising in the care of older adults. At the start of the interview, the researchers aimed to quickly build a special form of relationship by introducing themselves and the goal of the study and by listening attentively and respectfully to the participants. This was deemed important as the researchers and participants discussed personal topics. An interview guide was developed that contained questions on older adults' experiences during their illness, treatment and recovery, in the hospital or at home. A draft of this guide was established by RP, critically reviewed by the rest of the research team and adjusted according to the feedback. Example questions included the following: "What was your involvement in making treatment decisions?" or "How do you look back on recovering in the hospital/at home?" In several instances, a family member was present, and the family members were also questioned if they so wished. The data regarding relatives will be reported elsewhere. Thematic saturation was achieved, meaning that further interviews did not reveal any new themes and categories (Lowe et al., 2018).

Data Analysis

All interviews were audio-recorded and transcribed. The analysis started with RP and DS reading each transcript to become familiarised with the data. A thematic analysis was conducted in MAXQDA 2018 to identify and to analyse patterns (or themes) within the qualitative data (Gray, 2014). The thematic analysis followed an approach that combined deductive and inductive coding. Codes and themes arose from previous research and the research question (Pel-Littel, 2020). Predefined themes included 'Falling ill from COVID-19', 'Diagnosis', 'Experiences during illness' and 'Recovery from COVID-19'. The codes were recorded in a coding framework before the start of the analysis. When a section did not fit into the predefined codes but was nevertheless deemed valuable, new codes were added to the framework. This approach was chosen because having predefined codes can help guide the analysis, while including non-predefined codes ensures that no valuable information is lost (Nowell et al., 2017). In the coding framework, all codes were accompanied by a definition, which helped to justify the inclusion of codes

and to define clearly when a code should be used (Nowell et al., 2017). Next, RP and DS coded according to the predefined coding frame while adding new codes when necessary. Next, these two researchers compared the coding of 10 interviews. Eventual disagreements between the independent coders were discussed in person to reach intercoder agreement. The disagreements found were largely related to an initial discrepancy in interpretation of predetermined codes. The researchers also reviewed the codes in relation to the themes. The themes 'Diagnosis' and 'Falling ill from COVID-19' were combined. Also, some codes were removed, and some codes were combined. The remaining transcripts were coded by DS, and RP reviewed the coding.

Results

A total of 23 older adults participated in the study (Table 1). The mean (SD) age was 75.0 (7.0) years, and 52% were female. The mean (SD) age in older adults with non-Western background was 67.6 (2.5) years and 77 (6.3) in older adults with Western background. Four in five older adults with non-Western background were female, and 8 in 18 older adults with Western background were female. On the basis of the iterative analyses, in line with the methods described above, nine categories were identified as recurring topics in most interviews. These were grouped into three major themes (Table 2). In the following sections, we describe the themes and categories that emerged from the interviews and illustrate them with quotes from the interviews.

Theme I Falling Ill from COVID-19

Signs and Symptoms not Recognised as COVID-19

When the first symptoms manifested, many older adults and their family initially thought that they were an exacerbation of chronic diseases, such as COPD or heart failure, or frequently occurring problems such as urinary tract infections or influenza:

Actually, the idea that he fainted in the bathroom and he is a heart patient, and we had the idea ... And he suffers from frequent drops in his blood pressure and then he suffers from atrial fibrillation, so actually we had the idea that this was happening again. The corona was not actually the first thing that came to mind. (partner of P6, M, 70, hospital)

Likewise, their GPs could often not directly relate the symptoms to COVID-19:

On Thursday, the fever persisted, so we asked the doctor to come, and he took a urine sample and examined it. He said, "Yes, you have a fairly serious urinary tract infection, so you can assume that that is the cause and that it is more serious than you normally have". Well then, the following Friday, the doctor came again; he

Table 1. Patient Characteristics.

Characteristics		N = 23	100%
Gender	Female	12	52.2
	Male	11	47.8
Age	64–69	4	17.4
	70–74	9	39.1
	75–79	6	26.1
	80–84	2	8.7
	85–89	0	0
	90+	2	8.7
Ethnical background	Non-Western	5	21.7
	Western	18	78.3
Living situation	Living alone	8	34.8
	Living apart together	1	4.4
	Living with partner	12	52.2
	Living with other family	2	8.7
Area of living	Urban	11	47.8
	Rural	12	52.2
Disease period ^a	First wave	21	91.3
	Second wave	2	8.7
Rated difference between health after and before COVID-19 infection (after–before)	Improved	2	8.7
	No difference	8	34.8
	Worse	13	56.5
Recovery	In the hospital	17	73.9
	At home	6	26.1
Family member present during interview	Yes	11	47.8
	No	12	52.2

^aDutch first wave Feb–May 2020, and Dutch second wave Oct–Dec 2020

Table 2. Themes and Categories.

Themes	Categories	N (%) Hospital Group that Mentioned Category	N (%) Home Group that Mentioned Category
Falling ill from COVID-19	1. Signs and symptoms not recognised as COVID-19	13 (76.5)	3 (50.0)
	2. Emotional response to the diagnosis	17 (100)	6 (100)
Experiences during illness	3. The severity of the disease	14 (82.4)	5 (83.3)
	4. Decision-making process	16 (94.1)	5 (83.3)
	5. Impact of isolation	17 (100)	6 (100)
	6. Communication	15 (88.2)	5 (83.3)
Recovery from COVID-19	7. Support	17 (100)	6 (100)
	8. Course of recovery	16 (94.1)	6 (100)
	9. Impact on social contacts	14 (82.4)	5 (83.3)

was a deputy doctor. He looked at everything and said, “I don’t think corona is very likely but let’s wait until the weekend and take the antibiotics”. (P3, M, 71, hospital)

Emotional Response to the Diagnosis

Most participants’ greatest fear was they might have infected others with the virus. Some were afraid of dying, not always

because of their own fear of death, but they felt grief for their family whom they might have to leave behind:

I was more worried because I thought, wow. And the children were here, and the grandchildren were here, could I have infected them? (P4, F, 69, hospital)

I am glad I made it for the girls. Imagine if the two of us had gone... (P14, F, 75, hospital)

Receiving a diagnosis of COVID-19 caused various emotions among older adults. A majority felt that it was an overwhelming experience, one that they just had to accept it and wait and see what happened next:

But they also asked me: “Are you afraid?” I said: “No, what should I be afraid of?” I was like that, because I didn’t know anything about the corona, I didn’t know what it did. So, I did not know that so many people were dying and so many were going to ICU and so on.” (P5, F, 66, hospital).

Those who were severely ill experienced more fear and uncertainty than those with fewer symptoms. Older adults who had previous experiences of hospitalisation had some knowledge about what to expect and felt less uncertain:

The first time I was hospitalised for COPD I was really shocked. I was not used to that. I had never been to a hospital. I was connected to all sorts of equipment and immediately put on an oxygen mask. A lot of fuss. That was much more traumatic for me than it is now. I was brought in and I knew exactly, well... but 90% I knew what was going to happen. (P8, M, 74, hospital)

Theme 2 – Experiences During Illness

The Severity of the Disease

Most participants were hospitalised, from 4 days to 6 weeks, at a special COVID-19 care unit, and some were admitted to the ICU. The most common and severe symptom described by the hospitalised participants was extreme weakness. They lacked energy to talk, to eat or even to turn their heads. Participants who did not need to be hospitalised experienced less severe symptoms:

Sometimes you think, I feel as if a lorry ran me over, you feel so miserable. You cannot even raise your hand, you cannot do anything. In addition, you cannot eat, you cannot drink because it does not work. You are not hungry, you are not thirsty, you are nothing. (P4, F, 69, hospital)

Participants who were hospitalised felt that their families were relieved of the burden of care for them and felt they could rest better in hospital than at home. Additionally, they thought that hospital isolation would prevent them from infecting others. Furthermore, they found it reassuring that medical assistance was immediately available in the hospital in case of emergency. However, there were feelings of frustration about their dependence and the uncertainty of their situation. Some older adults were very ill and realised that they could possibly die from the virus. This thought caused some of them to fear dying alone, but others described experiencing a survival instinct at that point, which encouraged them to fight for their recovery.

Especially at the moment when you think: it’s happened, I’m going to die. And also, I was like, family were not even allowed to be there. And when I’m buried, they’re not allowed to be there either. That is a trauma. (P1, M, 75, hospital)

The Decision-Making Process

None of the older adults interviewed felt that they participated in the decision-making process about whether to go to hospital. The assessment of the GP led to the decision to go to the hospital or to stay at home. Moreover, they felt so ill at that time that events more or less happened to them.

Most hospitalised older adults were asked about their wishes concerning resuscitation, intensive care admission and ventilation. Older adults who had been in hospital before were not surprised by this question and were able to give their views on it. The opinion of their own GP was often important for them in considering whether they could withstand such a drastic intervention such as hospitalisation:

Well, straight away with the GP on the phone it was, “Don’t get admitted to ICU. You won’t make it”. So, that was clear from the start, and fine by me, because I’ve always done what I wanted to do and had a great time. (P1, M, 75, hospital)

Furthermore, the media images of consequences of intensive care admission played a role. Extensive attention in the Dutch media was paid to patients on the ICU. Images and videos of admitted patients were considered alarming by respondents:

I said, “Go and fetch the priest and go on, because I’m not going to the ICU”. Then, he said to me, “How come?”, and I said, “Because I had seen it on the TV”. (P13, F, 92, hospital)

Older adults who were well informed about intensive care admission experienced more peace of mind and felt that this knowledge enabled them to make a well-informed choice between being admitted to ICU or not. For older adults and family members who were asked this question for the first time, the shock was great. Because their situation was often serious at the time, they felt that the reason for discussing it was that such an intervention might actually be needed in the short-term:

And then on Thursday afternoon they called me and asked me, “If he has to go into the intensive care unit, do you still want to do that? Do we still have to do that?” Well, I was stunned. I thought, what are we talking about? So bluntly from.... (partner of P15, M, 76, hospital)

The extent to which people had ever discussed these issues with their relatives or with their GP varied greatly. Some ($N=6$) had discussed and recorded everything, some had never wanted to talk about it or thought that it would never happen

to them ($N = 5$). There was also a group that had ‘discussed the topic at one time or another’ or they assumed that the next of kin would be able to decide in accordance with their wishes if they were no longer able to express their wishes themselves ($N = 10$). Others felt that they should actually start discussing this issue because after COVID-19, they now knew better what they would like at such a time. Additionally, after COVID-19, sometimes, the children insisted on discussing it and recording it for the future.

A number of older adults felt they were not properly involved in the discharge policy. As a result, there was much uncertainty and a lack of clarity about what would happen to them after hospitalisation:

But my son thinks I should also put down on paper what I want when I start suffering from dementia... Yes, if you have to say: do you want to die or do we have to, you know, because maybe at that moment they see that I’m actually a vegetable, but they keep keeping me alive. So, I have to put down on paper what I want. I didn’t do it, though. (P7, F, 69, hospital)

Communication

The hospitalised participants had to deal with many health professionals, who were often completely wrapped up in protective clothing, which made it difficult to distinguish among them. Many older adults experienced difficulties receiving information from too many people, especially when the information was sometimes contradictory:

But if you ask that, you get all these political answers, [yes, the nurses are lovely, fine, some better than others, that’s with everything in life], they can’t tell you anything”. “The doctor is coming soon”. Well, you have a different doctor every day. (P2, M, 73, hospital)

This issue led to frustration and confusion. There was a need for someone who had an overview and could coordinate the information:

At first, it hit me quite hard that they sent me home straight away because I had had a fight with a doctor. He came to tell me that I was going home the next day. I said, “I don’t think so, I am going to rehabilitation”. Because they had told me “You can’t go home yet. So, we are looking for a rehabilitation centre for you”. But then the doctor came and told me “No, you’re going home tomorrow”. I said, “No, I am not going home. I am going to rehabilitation”. That was a bit of a setback. Yes, at that moment when he said it, the doctor, I was really stubborn and angry. I can say that honestly. I didn’t look at him anymore. (P12, M, 77, hospital)

Miscommunication sometimes led to distressing situations: because of the local increase in COVID-19 patients in hospitals, patients were transferred to another department or

even another hospital without informing the family. Older adults sometimes experienced that health professionals were under so much pressure that they had little time to explain things properly and that hearing impairments, language barriers or memory problems were not considered. However, there were also experiences that everything was discussed in detail and explained clearly.

The Impact of Isolation

Because of mandatory isolation regulations, contact was limited or sometimes only digital. Contact with family members, especially grandchildren, gave people courage. Some patients could not distinguish between health professionals and family because of all the protective clothing:

So, then there were two nurses, as far as I was aware, because she obviously had a face mask and glasses. And she was in hospital clothes. Then, one of them left, and my daughter-in-law said, “Do you know who I am?” I said, “I don’t know anything about it”. I didn’t see it either. Then, she said, “I am M.” and then I saw her hair. (P12, M, 77, hospital)

It was understood that isolation was necessary, but people felt very uncomfortable underneath, as if they had done something wrong:

The hardest thing for me was feeling like a leper. That everyone avoids you. You’re careful yourself, even with my own daughter. Bedding was often washed separately. Family that didn’t come to visit. I don’t blame them, but you feel like a leper. So, yes. So that’s the terrible feeling of the corona. (P22, F, 64, hospital)

Because I thought it was terrible. I felt like a criminal... that the children didn’t go to the parents anymore and then they would stand at the door waving and looking through the window and it was as if you had done something terrible. (P11, F, 90, hospital)

Nevertheless, isolation also had its good sides, especially for those who were still very ill and valued their peace and quiet as they did not have the energy for social contacts. There were also many restrictions at home such as a long isolation period of 14 days. For some, this isolation hampered rehabilitation because going somewhere or seeing someone was not possible. Family members came to wave in the garden, which was nice on the one hand, but it felt clumsy and annoying that this was the only possibility to meet one another:

We didn’t let anyone into the house, so we didn’t really have anyone in the house for six weeks. The children stood here in front of the window, and we stood here waving in our pyjamas; it was horrible. (P18, F, 82, home)

Theme 3-Recovery from COVID-19

Support

For older adults, social support was extremely important to keep going. Both in hospital and at home, their children in particular were seen as great support; however, some older adults did not want to burden their children with their own fears. Then, it was helpful if they could share their concerns with the nurses:

Look, if there were visitors, just when M. came or the children, I handled myself well. I didn't let on that I was depressed. Absolutely not. But if I did, it was nice to have them (nurses) hold your hand or sit on your bed for a while. Really had time for a chat. (P12, M, 77, hospital)

The personal attention of nurses often made the older adults feel tremendously good. In particular, they paid attention to who they were as a person instead of a patient. Sometimes the nurses had time for this, but often not, because everyone was in a hurry:

We talked about this and that. It was, I thought, a pleasant conversation afterwards. Very strange. I was back in the outside world, so to speak. She had walked the Santiago de Compostela. She talked about her hobbies and such. I found that quite nice. (P8, M, 74, hospital)

To maintain contact with the home front while in hospital, many older adults learned to make video calls for the first time from their children. Additionally, the many postcards received by patients in hospital were seen as real support. Likewise, when older adults recovered at home, they often experienced much (practical) support, sometimes overwhelming. This support varied from grocery shopping, food in front of the door, books and flowers to mowing the lawn. People looked for ways to help in a safe way. Mental support was provided too; a trusted person whom you could always call if you felt bad or listening to music together with someone (at a distance) and then discussing it on the phone. People also felt supported by their faith and by the fact that they were prayed for:

Well, there is one thing: almost every day, at least every other day, we got something delivered to the door. They would call to say, "We'll bring you a box of strawberries or some flowers". Or a niece of ours came to sing a song with a drawing. Or she would send an app. She had sung at home, and she would send a video of her singing. That is the best medicine of all. (P9, M, 72, hospital)

Course of Recovery

Recovery from the virus sometimes took months for older adults. Most older adults rated their current health considerably lower than their health before their illness. After the acute course of the virus in the hospital, people continued to recover in a rehabilitation centre or at home. Participants noticed that they were doing better by getting their sense of humour back, their appetite and taste improved, their condition was restored, and they were able to do more activities. Their recovery went in ups and downs, and many older adults were uncertain whether they would ever fully recover. A number of older adults mentioned residual symptoms that they did not know were part of COVID-19, such as being more emotional and forgetful and having more headaches, nightmares and panic attacks:

I don't know if you really recover from corona. It's a rollercoaster, it goes up and down. Sometimes you're fine, I already mentioned those panic attacks, sometimes you can stand up and then you think: wow. That you almost collapse or that your legs don't want to. (P4, F, 69, hospital)

Impact on Social Contacts

Older COVID-19 survivors returned to a changed world of social distancing and limited opportunities for activity. They were more housebound, partly because of their poor condition but also because of limitations put forth by the government. Important aspects of rehabilitation, such as engaging in social contacts and activities, were more difficult to achieve:

We have a walking club together, and then you (=partner) can be very enthusiastic about it. Yes, and then I say to myself, yes, I should have gone with him, but I'm not able to do that yet either. I'm actually a burden. (P18, F, 82, home)

Some older adults experienced that other people avoided them, crossed the street when they approached or refrained from visiting. Although they understood the fear of the virus better than anyone, former patients found it difficult to feel rejected after such a period of loneliness and isolation, even though they were supposedly no longer contagious. Likewise, they felt aggrieved by people who denied the seriousness of the virus:

In the beginning, it was when they met you in the hallway, or they saw you coming and went straight back inside. Most of them have parents who are also vulnerable. So, I can understand that. (P22, F, 64, hospital)

Discussion

Main Findings

This study identified the experiences and perceived needs of older COVID-19 survivors during the disease process and recovery phases, particularly regarding their emotions, participation in decision making, communication and support. The majority of the participants (21/23) became infected with the virus during the first wave of COVID-19 in the Netherlands (March-May 2020). It is plausible that experiences of older adults during later waves differed from this group, as more information became available and treatment was constantly improving. However, as only two participants became infected in a later wave, we cannot state this for certain.

Although all older adults had heard about the virus through television or newspapers, atypical signs and symptoms sometimes led in some cases to a late diagnosis of COVID-19. Most participants were hospitalised, but few were involved in admission or treatment decisions. Many older adults described feeling miserable and weak during their hospital stay, which made their self-care and communication with others difficult. Although everyone was aware of the need for isolation measures, these requirements caused great feelings of loneliness and fear. Older adults perceived person-centred communication with health professionals to be very supportive. All participants in our study recovered more or less from the virus, in contrast to many who died from COVID-19. Especially for those who had been severely ill, recovery could take a long time, and many were still suffering from residual complaints. While health professionals were puzzled about finding proper treatment for the virus, for many older adults, family turned out to be a very important medicine, both during hospitalisation and at home.

Comparison with Existing Literature

Several case reports confirm atypical symptoms of COVID-19 in older adults (Isaia et al., 2020; Norman et al., 2020; Singhanian et al., 2020; Tay & Harwood, 2020). Our study findings were consistent with these previous results. Therefore, it is important that older adults, their families and healthcare professionals are aware of atypical symptoms in older adults. In line with Osuafor et al. (2021), we recommend that health professionals maintain a low threshold for COVID-19 testing in frail older patients, as rapid diagnosis helps to plan adequate care and treatment (Osuafor et al., 2021).

Our results showed that the need for the coordination of information for older adults in hospitals is not unique for COVID-19 and has been addressed in many other studies (Bauer et al., 2009; Ekdahl et al., 2010; Forsman & Svensson, 2019). However, COVID-19 caused particular challenges because of a high workload among health professionals, high levels of uncertainty about the prognosis of COVID-19,

communication barriers that were due to face masks and protective clothing, and limited possibilities to involve older adults' relatives.

Several studies emphasised the importance of SDM in relation to COVID-19; however, the older adults in our study experienced little involvement in decision making (Cardona et al., 2020; Köther et al., 2021; Paladino et al., 2021; Simpson et al., 2020). This study confirms that when older adults are in acute poor condition, it is difficult to participate in SDM (Dyrstad et al., 2015; Ekdahl et al., 2010, 2011; Gauthier, 2005). Therefore, it is important to encourage older adults to think proactively about treatment preferences or limitations and share this with their families (Coleman et al., 2020). A structured approach can help to guide discussions about the diagnosis, expected course and care of persons with COVID-19 in hospitals, and communication tools have been developed in several countries to promote this approach (Gaur et al., 2020; Paladino et al., 2021).

The psychological burden of isolation among older adults in our study reported during their recovery from COVID-19 was significant. In particular, our participants mentioned the fear of dying alone. These results are in line with previous findings, which underline an association between quarantine measures or social exclusion and negative psychosocial outcomes, including depressive symptoms, anxiety, cognitive impairment and loneliness (Krendl & Perry, 2021; Plagg et al., 2020; Röhr et al., 2020; van Tilburg et al., 2021). To ensure that an unaccompanied palliative situation does not occur, (Galbadage et al. 2020) recommend outlining 'an integrative approach to address the unique and holistic needs of critically ill patients dying with COVID-19. These include intentional and increased coordination with trained palliative care staff, early and frequent goals of care including a discussion of end-of-life plans, broader use of technology to improve connectedness, and SDM with patients' families'. (Galbadage et al., 2020)

Social isolation limited the rehabilitation of the participants in our study. Many of them needed several months to return to the level of functioning they had before COVID-19, and most have not yet reached this level. This outcome is consistent with research showing that isolation decreases physical activity levels and is a well-acknowledged risk factor for morbidity and mortality (Cacioppo et al., 2014; Kobayashi & Steptoe, 2018; Peçanha et al., 2020; Plagg et al., 2020). Specialised rehabilitation care in a specialised facility or at home should be optimised to support older adults recovering from COVID-19 (De Biase et al., 2020; Grund et al., 2021; Iannaccone et al., 2020; Peçanha et al., 2020).

Strengths and Limitations

Even though the strength of this study is the diversity among the participants in terms of age, cultural background, living environment and hospitalisation versus recovery at home, the sample size was too small to analyse between-subgroup

differences. Considering previous findings, we would expect to see different experiences dependent on cultural background. Cultural background seems to affect SDM as barriers relating to language, different values or expectations and prejudices might be more common in an intercultural context (Suurmond & Seeleman, 2006). Furthermore, it is possible that feelings of fear or feeling alone were influenced by the quality of the social network of the older adult.

As our research suggests that prior experiences with hospitalisation and knowing what to expect had an effect on the extent to which older adults felt secure, it is possible that prior knowledge reduces anxiety in older adults when needing medical assistance. This could have been a potential barrier to some older adults when seeking medical help for COVID-19. Nevertheless, as this was not specifically studied, we cannot state this for certain.

We acknowledge the limitation that this study recruited older COVID-19 survivors, and future research may be needed to add the perspective of informal caregivers regarding deceased older relatives. Although our study provides an in-depth insight into the experiences of older adults, it is merely a selection of older adults and cannot be generalised for all older adults, especially since a convenient sample was used. Furthermore, not all discussed topics may be applicable in all cultures, countries and sociodemographic strata, as norms, values and contextual factors may differ. Nevertheless, we believe that thematic saturation was achieved and that additional interviews would not reveal any new themes and categories. While knowledge about the treatment of COVID-19 in older adults is developing rapidly, we believe that the insights provided by this study remain valuable not only with respect to COVID-19 but also for possible new unknown diseases in the future or situations in which rapid response is crucial.

Implications for Research and Practice

Our study provides indications for current practice. GPs, district nurses and senior organisations could raise awareness of atypical symptoms that may indicate COVID-19, such as drowsiness and falling (Norman et al., 2020; Tay & Harwood, 2020). They should also encourage older adults to think proactively about preferences and wishes for treatment and care and to discuss this with their families. This process will assist in decision making when older adults are in acute poor condition. In addition, the particular challenges of COVID-19 related to social distance and isolation measures emphasised the need for better coordination of information for patients and families within the hospital, especially with regard to discharge planning. The person-centred communication skills of health professionals become even more important when 'live' family support is limited. Family support is an important medicine for older adults, and digital solutions are very important when 'live' visits are not possible. Rehabilitation care should be optimised to help older adults regain the

best possible functional level after COVID-19. The findings from this study have been translated into practical recommendations for older adults, family caregivers and healthcare professionals and are distributed via the online channels of Vilans, the national Centre of Expertise for Long-term Care in the Netherlands and senior citizen organisations (KBO-PCOB) (Suppl. File 1–3).

Conclusion

Older adults treated for COVID-19 experienced a feeling of being in a fast-paced whirlwind in which they have lost total control over the situation. The main lessons learned from the COVID-19 pandemic as experienced by older adults treated for COVID-19 are to pay extra attention to shared decision making, unambiguous and coordinated information provision, and the instalment of one healthcare professional that serves as a primary contact to the patient. The uncertainty of their situation, isolation measures and fears for what was to come could result in psychological consequences and could hinder rehabilitation in older adults. It is important to be aware of these experiences. Our findings and lessons learned may enrich current guidelines and protocols for COVID-19 from the perspective of older adults and can aid in securing that even in times of crisis, the patient is still at the heart of the provision of care.

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Authors' Contributions

Study concept and design: RP, DS, HW, JF and CL. Acquisition of data: RP and DS. Analysis and interpretation of data: RP and DS. Preparation and critical revision of the manuscript: RP, DS, HW, JF, SJ and CL. All authors have read and approved the manuscript.

Declaration of Conflicting Interests

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Ethics Approval and Consent to Participate

The requirement to obtain approval for this study was waived by the Institutional Review Boards of the Amsterdam University Medical Center, location AMC (W20_443#20.486), and the Catharina Hospital Eindhoven (W.20.226). All participants provided informed consent to participate in the study.

Availability of Data and Materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

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