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Experienced stigma and applied coping strategies during the COVID-19 pandemic in a high-income country - A mixed-methods study

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Experienced stigma and applied coping strategies during the COVID-19 pandemic in a high-income country

- A mixed methods study -

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Abstract

Introduction Health-related stigma is considered a social determinant of health equity and a hidden burden of disease. Regarding COVID-19, reports about patients experiencing stigma accumulate, yet studies examining the phenomenon are scarce.

Methods We conducted a mixed-methods study with sequential explanatory design in Ulm, Germany among COVID-19 survivors. Levels and dimensions of stigma were assessed by the Social Impact Scale (SIS) in 61 participants. Interviews with 14 participants were conducted to gain a deeper understanding of the experienced stigma and applied coping strategies. The questionnaire was analysed using descriptive statistics, *t*-test and ANOVA. Content analysis was used for qualitative data.

Results The SIS total score indicated an intermediate level of experienced stigma. Participants experienced stigma mainly as 'internalized shame' and 'social rejection', followed by 'social isolation'. 'Financial insecurity' played a minor role. There was no significant difference in experienced stigma regarding gender, education, occupational status, or residual symptoms. However, participants between 30 and 39 experienced higher levels of stigma than other age groups. Qualitative analysis informed a framework which stratified experienced stigma and applied coping strategies by societal layer: COVID-19-related stigma affected not only the individual, but also interpersonal and communal relations, access to institutions and social norms and values.

Conclusion The lived experience of COVID-19-related stigma is similar in different settings and was intertwined with or aggravated by socioeconomic factors. Stigma arises from misconceptions and ignorance which lead to stereotyping and discrimination. Providing accurate information and exposing misinformation on disease prevention and treatment is hence key to end COVID-19 related stigma.

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Summary box:

"What is already known about this subject?"

Health-related stigma is considered a social determinant of health equity and a hidden burden of disease. Regarding COVID-19, reports about patients experiencing stigma accumulate. So far, the few studies investigating this phenomenon were conducted in low- and middle-income countries. They indicate that stigma leads to a significant impairment of well-being in those affected, impaired access to healthcare services and hence underreporting of infections, which implies a risk for public health.

"What are the new findings?"

This study proves that COVID-19-related stigma is present in high-income countries as well and describes how socio-economic factors can enhance or mitigate stigma. We developed a comprehensive framework demonstrating how COVID-19-related stigma cuts through all societal levels: it affects the individual, interpersonal relations, life in the community, access to institutions and social norms and values. In our in-depth analysis, we do not only focus on experienced stigma as the problem, but also on applied coping strategies as possible solutions.

"How might it impact on clinical practice in the foreseeable future?"

To date, stigma as a social consequence of COVID-19 has been widely neglected and poorly addressed. With this research, we would like to give affected people a voice and sensitize clinicians, health officials and political stakeholder to the phenomenon. With joint efforts, we can provide accurate information and expose misinformation on disease prevention and treatment and ultimately end COVID-19 related stigma.

Strengths and limitations of this study

Strengths

- Mixed-methods approach to gain an in-depth understanding of COVID-19 related stigma and applied coping strategies
- Development of a comprehensive framework which might serve as a template for future research in health-related stigma
- Detailed list of quotes for every theme to increase objectivity and traceability

Limitations

- Telephone interviews instead of face-to-face interviews because of contact regulations
- Single-centre study design

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Objective

'As we combat this pandemic, we have a duty to protect people, end stigma and prevent violence.' - António Guterres (United Nations Secretary-General), on the 8th of May 2020 [1].

Health-related stigma is a social phenomenon, which implies a negative attitude towards people with a certain condition [2,3]. Stigma is often conceptualized as being perceived, enacted, internalized or structural [4]. This refers to the way an individual presumes other people's attitude towards him- or herself (perceived stigma), discriminatory behaviours (enacted stigma), a shift to a devalued self-perception (internalized stigma) and inequities embedded in policies, institutions, and social organizations (structural stigma). Regarding health, stigma is often called a hidden burden of disease [5] and described as a social determinant of health and health inequity [6]. It generates psychological stress and causes affected people to hide their condition with severe consequences for their own health, and in case of infectious diseases, for public health [7]. In the context of the COVID-19 (corona virus disease 2019) pandemic, the risk of stigmatization has been addressed early [8–10] and reports of discrimination against patients and survivors have accumulated [11]. Across the globe, people infected with or recovered from SARS-CoV-2 (Severe Acute Respiratory Syndrome Coronavirus-2) became a target of ostracism, humiliation, harassment and even violence [12–14]. As a result, people suffering from typical symptoms may refrain from seeking out testing centres or treatment to avoid respective social consequences, leading to poor health outcomes and the further spread of the virus. So far, most studies were conducted in low- and middle-income countries and little is known about the phenomenon in high-income countries. The objective of this research is to assess the level and dimensions of stigma in COVID-19 survivors during the early pandemic in a high-income country and to offer an in-depth account of stigma patterns as well as applied coping mechanisms. The results will be conceptualized in a framework and compared to those from other settings and implementations for policymakers will be discussed.

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Methods

We conducted a mixed-method study with a sequential explanatory design in the area of Ulm, Germany. The study population consisted of adult COVID-19 survivors (3-9 months *post infectionem*) who contracted SARS-CoV-2 during the first wave in 2020 and suffered from mild, moderate or severe COVID-19. The study was approved by the ethical board of the University of Ulm (No. 315/20).

Quantitative methods

Sampling, materials, data collection and potential bias

Experienced stigma was assessed using the German version of the 24-item 'Social Impact Scale' questionnaire, originally designed by Fife & Wright (2000) [15] for patients living with HIV/AIDS or cancer [16], with 8 additional COVID-19-related questions (c.f. S1). On a 4-point Likert scale, participants rate the given statements from 'I strongly agree' to 'I strongly disagree'. The questionnaire covers different dimensions of stigma, namely 'social rejection', 'internalized shame', 'social isolation' and 'financial insecurity'. A form assessing residual symptoms was added. Both were sent to 150 COVID-19 survivors. The study sample included every adult person with positive SARS-CoV-2 nasopharyngeal swab at the university testing centre by the start of the study. Since stigma is a sensitive topic, it is easily subjected to a social-desirability bias and hence bearing the risk of the respondents' inclination towards euphemized answers. To reduce this bias, absolute anonymity was ensured: Participants received the consent form and the questionnaires with a labelled and a blank envelope. The anonymously filled-in questionnaire was inserted into the blank envelope and sealed, which was placed into the labelled envelope with the signed consent form. Upon reception, the consent form was separated from the questionnaires, hence results could not be assigned to the respective respondent.

Statistical analysis

Descriptive analyses included demographic information, post-COVID-19 symptoms, the overall level of stigma and its dimensions. Results are reported in means (M) and standard deviation (SD). Univariate analyses were performed assessing differences in experienced stigma regarding gender, age groups, occupational status and number of residual symptoms using *t*-Test, ANOVA and correlation where appropriate. Missing data was handled by listwise exclusion. A significance level of $p < 0.05$ was considered significant.

Qualitative methods

Sampling and data collection

From those participants consenting to an in-depth interview, we purposefully sampled a broad range with high and low perceived stigma based on the questionnaire, different severity of disease, gender, and age group to gain diverse accounts of the phenomenon. Data analysis began after 5 interviews and data saturation was reached after the 11th. Three additional interviews were conducted to ensure no new themes emerged, resulting in a total number of 14 interviews. The interviews were held in German, being the native language of the participants and followed an interview guide (c.f. S2). However, the interview was not limited to the questions at hand, the interviewer (LP) aimed for an open discussion, allowing the interviewee to determine which topics to focus on. Due to contact regulations, the interviews were conducted by telephone and recorded.

Analysis and quality control

After transcription into German, the analysis was conducted in English. LP used content analysis to develop a preliminary coding scheme from emerging codes and themes (inductive approach). To

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ensure reliability, the coding scheme was subsequently applied to the interviews by SB and BG (deductive approach). Deviant codes were discussed within the research team and adjusted (peer-check), resulting in a refined coding scheme, which eventually informed a conceptual framework. To increase transparency, additional tables with key quotes for each code are attached (c.f. S3 and S4). Using mixed methods allows for methodological triangulation, i.e. assessing the phenomenon from different perspectives. Considerations regarding reflexivity and limitations are addressed in S5.

Patient and public involvement

The initial idea informing this research was based on patients' narratives from our post-COVID-19 outpatient department. During follow-up visits, patients moved from physical complaints to social consequences they experienced after having COVID-19, which often involved stigma. We developed the questionnaire used in the qualitative part based on those narratives. As mentioned earlier, the interview was designed as an open discussion allowing the participants to prioritise topics and report their experiences freely. However, patients were not involved in designing or recruiting. We aim to offer a lay summary in German on our website to inform participants about the results.

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Results

Quantitative results

In total, 61 questionnaires were analysed, 58% of respondents were male and the median age was 51 years (minimum = 18, maximum = 78). Regarding occupational status, 70.3% were employed, 6.3% were students or trainees and 15.6% were unemployed or received pension. Almost all participants had informed close family members (98.4%) and friends (95.3%) about their infection with SARS-CoV-2, fewer confided in acquaintances (81.3%), more distant relatives (78.1%), close colleagues (76.6%), neighbours (73.4%), superiors (71.9%) and more distant co-workers (50.0%).

Residual Symptoms:	N	%
Dyspnoea on exertion	11	20.4%
Fatigue	6	12.2%
Paraesthesia	5	10.2%
Cough	4	8.2%
Sore throat	4	8.2%
Cephalgia	4	8.2%
Palpitations	4	8.2%
Rhinorrhoea	3	6.1%
Loss of smell and taste	3	6.1%
Diarrhoea	2	4.1%
Myalgia	2	4.1%
Xerophthalmia	2	4.1%
Sleeping disorder	2	4.1%
Loss of hair	2	4.1%
Lack of attention	2	4.1%
Mucus	1	2.0%
Dyspnoea without exertion	0	0%
Fever	0	0%
Hearing loss	0	0%
Loss of vision	0	0%

Table 1: Post-COVID-19 symptoms

Table 1 demonstrates residuals symptoms participants suffered from. Dyspnoea on exertion was the leading symptom, followed by fatigue, palpitations, a sore throat, and cough.

The achievable score of the Social Impact Scale ranged from 31 (low level stigma) to 124 (high level of stigma). The achieved score in our cohort ranged from 31 to 97 with a mean of 48.1 (SD 13.1), and a median of 45.0 (c.f. fig 1).

Figure 1: Social Impact Scale, overall score

The separate questions were rated on a score from 0 (low level of stigma) to 3 (high level of stigma). The question with the highest level of experienced stigma was '*I feel others are concerned they could catch my illness.*' (*M* = 1.52), followed by '*I feel guilty, because I accidentally might have infected others.*' (*M* = 1.03), '*I feel others think I am to blame for my illness.*' (*M* = 1.0), ‚*Due to my illness others seem t* *when they are around me.*' (*M* = 0.97), ‚*When I came back to work or met friends, I was worried how they would behave towards me.*' (*M* = 0.91) and '*I feel institutions and professionals (health authority, health care workers) treated me unfair.*' (*M* = 0,81). The lowest experienced stigma resulted from the question '*I have experienced financial hardship that has affected my relationship with others.*' (*M* = 0.08), followed by '*Some family members have rejected me because of my illness.*' (*M* = 0.11) and '*My job security has been affected by my illness.*' (*M* = 0.15).

Figure 2 depicts experienced level of stigma displayed by dimension with 'internalized shame' (*M* = 1.68) and 'social rejection' (*M* = 1.58) showing the highest level, followed by 'social isolation' (*M* = 1.45). 'Financial insecurity' (*M* = 1.17) played a minor role. The overall mean was 1.55 (*SD* 0.42). Adapted to the original questionnaire [15], we calculated aggregate means. 'Social rejection' showed the highest mean (*M* = 14.22, *SD* = 4,91), followed by 'social isolation' (*M* = 10.17, *SD* = 4.16) and 'internalized shame' (*M* = 8.39, *SD* = 3.32) and, ultimately, financial insecurity (*M* = 3.51, *SD* = 1.38). The data were evenly distributed. There was no difference in experienced stigma comparing gender (*t*(59) = 0.437, *p* = 0.664), educational level (*F*(4) = 0.687, *p* =

Figure 2: Dimensions of stigma. High numbers equal high level of experienced stigma

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0.604), occupational status (*F*(3) = 0.995, *p* = 0.404) or residual symptoms (composite score of symptoms) (*r*(46) = -0.250, *p* = 0.093). There was a significant difference in age groups (*F*(6) = 2.499, *p* = 0.034), with those between 30 and 39 experienced the highest levels of stigma.

Qualitative results

During the analytical process, it became evident that COVID-19 survivors experienced stigma as a multi-layered phenomenon. Therefore, we stratified experienced stigma and applied coping strategies by societal layer, albeit knowing that these reflect a continuous spectrum rather than clearly separated domains. The respective codes and **themes** were integrated into a comprehensive framework (fig. 3). The following section will guide the reader through all strata from inner to outer layer and present the experienced stigma and the applied coping strategy for each. The number of times respective codes were applied throughout the interviews is indicated by (n). To keep this report concise, we limited ourselves to one exemplary quote for every code presented. However, we invite the reader to consult the supplementary materials S3 and S4, which offer several key quotes for both experienced stigma and applied coping strategies.

Figure 3: Comprehensive framework of experienced stigma and applied coping strategies, stratified by societal layer

Individual layer

Vulnerability was identified as key theme contributing to or resulting from internalized or perceived stigma. Different codes added to increased vulnerability:

- Fear, worries and despair (n = 11): *'I was thinking «why me???»… and «I hope this ends well…»'* (female, y/o); Most participants were worried about the outcome of their infection, yet elderly patients and those referred to the hospital were particularly in fear of death.
- Shame, guilt or remorse (n = 14): *'Of course you feel bad knowing you infected others'* (female, y/o); Although infecting others happened unwittingly in all cases, participants often felt as 'spreader', indicating an active or deliberate part in the pandemic. This left them feeling ashamed or wishing for everything to be undone.
- Loneliness and abandonment (n = 14): *'Being on my own was the hardest part.'* (male, y/o); This feeling often rose from the isolation people faced in home-quarantine or single hospital rooms, but also from the lack of information during the beginning of the pandemic regarding possible symptoms, the course of disease and treatment options.

On the other hand, **resilience** as coping strategy mitigated the experienced stigma, resulting from:

- Confidence (n = 5) *'I knew I was getting medication; I was sure that would help, otherwise they wouldn't give it to me. I wasn't worried I would die.'* (male, y/o); Elderly participants putting faith in modern medicine or young participants relying on their own immune defence were confident that they would not experience adverse outcomes.
- Self-efficacy (n = 2) *'In the beginning it was very hard for me. But as soon as I managed to structure my day, time just flew by.'* (male, y/o); Self-efficacy reflects a person's assumed control over a situation and was identified as a rare but resourceful coping strategy.

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Additionally, participants indicated different ways of **coming to terms** with the undergone infection:

- Pragmatism (n = 2): *'I had it [COVID-19], that's all there is. Now I am cured and immune.'* (female, y/o); some participants refused dwelling in the past and did not make a big deal about having had COVID-19. Interestingly, this occurred in one participant who suffered only mild symptoms but also in one that had been hospitalized for a few days.
- Delayed disclosure (n = 3): *'In the beginning, I didn't want to share with anyone. Afterwards, we talked about it.'* (female, y/o); Participants from different age groups and with different severity of disease admitted that they needed some time to process before they were able to confide in someone else, sharing what they had been through.
- Rationalization (n = 2): *'When I was there, it wasn't known to be a hotspot!'* (male, y/o); Some participants offered a rationale to justify how they got infected. They emphasized that they did not deliberately put themselves and thereby others at risk.
- Denial or fallacy (n = 1): *'Maybe I didn't have it [COVID-19]. I even know couples, where one had it and the other didn't'* (male, y/o). One participant doubted the established diagnosis.

Financial insecurity concerned comparatively few participants who were self-employed. This applied to both direct and indirect costs, the latter resulting from a loss of income:

- Direct costs (n = 2): *'If I hadn't had any savings, it would have been problematic'* (male, y/o)
- Indirect costs (n = 1): *'I have to earn my money with physical labour. When I can't work, I don't earn money…'* (male, y/o)

However, most participants were either employed or received pension and hence costs were covered by their health insurance, implying **financial security** (n = 8):

- *'I was on sick leave and got my loan as usual.'* (female, y/o)

Interpersonal layer

Used to a certain level of self-determination and a scope of action, most participants were hit hard by the **loss of autonomy**. In particular, this was reflected by a:

- Loss of independence (n = 5): *'We were all isolated, other people had to take care of us.'* (female, y/o); Quarantine or being bed-ridden meant depending on others, which was a new situation for many participants.
- Violation of privacy (n = 4): *'I live in a small village and within two hours, everyone knew about it [COVID-19]'* (female, y/o); Transgression of personal boundaries or unauthorized passing of personal information left some participants, young and elderly, feeling powerless.

Almost every participant suffered some form of **vilification** as perceived or enacted stigma:

- Blame (n = 9): *'Some people said it is my own fault that I got infected.'* (male, y/o). Some patients were made responsible for catching SARS-CoV-2 or blamed for unknowingly infecting others. This reflects a shift in perspective from passively acquiring a disease to actively spreading it. This change from victim to perpetrator was described as particularly hurtful when people had been severely ill from COVID-19.
- Disregard (n = 4): *'They [acquaintances] did not really care about what had happened to me.'* (female, y/o); Lack of concern or misconceptions about what participants were going through left some participants frustrated or angry. This was reported by patients with mild symptoms as well as those hospitalized.

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As mentioned earlier, loneliness and abandonment left participants feeling vulnerable. Additional **avoidance of personal contact** by others when participants were no longer contagious was hence particularly upsetting and by far the most frequently reported form of enacted stigma:

- (Irrational) fear of infection (n = 27) was presumably the most important driver for the reported behaviour of others: *'Many people withdrew from me for a long time…. I think they were still afraid of getting infected'* (female, 77 y/o).

Participants reported different ways in **dealing with the rejective behaviour** of others:

- Understanding (n = 10); Most participants could at least partly comprehend and therefore excuse this behaviour: *'I could totally understand their [friends] behaviour. No one knew exactly how long people can transmit COVID.'* (female, y/o)
- Reasoning (n = 2); others tended to argue: *'When they [friends] took a step back, I told them there was no reason, they could hug me, I am no longer contagious.'* (male y/o)
- Distancing (n = 2) oneself avoiding emotional involvement and further frustration: *'When I heard about what others said, I just distanced myself from that.'* (male, y/o)

Consequently, **personal contact** was much appreciated by all participants and proved one of the most powerful coping strategies, involving:

- Genuine interest and mindfulness (n = 7) regarding the participants well-being were key elements: *'It's very important that there are people who care about you and want to know how you are doing. My mum called every day to check on me, that felt good.'* (male, y/o)
- Unaltered interpersonal relationship (n = 4), i.e. discovering that 'nothing had changed' made participants feel relieved: *'With my friends, it is the same way as it has been before.'* (male, y/o).
- Comprehension (n = 4): *'I talked to a friend, and she could totally relate.'* (female, y/o). When sharing their stories induced sympathy and comprehension, participants felt that their emotions were acknowledged and legitimate.

Communal layer

The lines between the interpersonal and community layers are particularly blurry. Thus, codes and themes emerging are often similar, yet referring to a different social group. While the interpersonal layer focuses on close personal relationships, the following section refers to more distant contacts or anonymous settings.

Similar to the interpersonal layer, **social rejection** plays an important role in enacted stigma. Again, a potential driver identified was:

- (irrational) fear of infection (n = 6): *'When I did my groceries and kept a 2 to 3 meters distance, people still told me to go further away…. they even changed the side of the street when they saw me.'* (female, y/o)

Additionally, **stereotyping** as perceived stigma was indicated, mainly in younger people, suggested by:

- Perceived recklessness or carelessness (n = 4): *'Now you [referring to the interviewer] are probably going to say «how on earth could you go skiing, and how could you go there [place where she got infected]?!?», but back then it wasn't that obvious….'* (female, y/o)
- Rumours (n = 2): *'In town, everyone acted like they knew better why I was infected'* (female, y/o)

The **reaction** to experienced stigma on the communal level included:

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- Understanding (n = 3): *'I tried to understand their reaction [people at work] and asked myself, how I would have reacted in their place? And honestly, I would keep my distance too. That is probably human.'* (male, y/o)
- Reasoning (n = 2): *'I told them [people in a grocery store] I am no longer contagious and that they don't need to keep a 10-meter distance. I fact, I am less dangerous than other people.'* (female, y/o)
- Resignation (n = 3), i.e. accepting adverse behaviour without arguing: *'I didn't really bother. Couldn't change it anyway. (…) You have to take it the way it is.'* (male, y/o)

Social network and inclusion turned out as a valuable resource against experienced stigma:

- Sympathy (n = 7): *'So many people called during my absence to make sure I am okay, and they were so happy to hear from me when I called them back.'* (male, y/o). For many participants it was important, that others cared about them and felt for them.
- Solidarity and support (n = 7) from friends or neighbours helped many participants to persevere the isolation and let them rest assured that they would receive help if needed: *'Many people from our village offered help and asked if they could get us anything. I was surprised by their willingness to help.'* (female, y/o)

Institutional layer

Institutional stigma referred to the stigma participants faced in contact with health authorities, hospital staff, general practitioners, and paramedics. Actions directed towards individual participants were labelled **direct discrimination**, a form of enacted stigma. They resulted mainly from

- Unprofessional treatment (n = 4), which means inappropriate reactions from healthcare workers: *'Since I was the second patient in that other hospital, they had a lot of «respect» of me and avoided coming close to me… that was even worse for me than the [rejecting] behaviour of other people.'* (female, y/o).

In our cohort, structural stigma did not require person-to-person contact and did usually not target individuals specifically but was often based on regulations affecting the respective group. It is hence labelled as **indirect discrimination**. Two codes were identified:

- Lack of accountability (n = 10): In many participant's views, health authorities and other institutions failed to take responsibility or lacked transparency; *'They [health authorities] gave us a number where we could call, but no one ever answered the phone.'* (female, y/o)
- Inconsistency (n = 4): Due to contradictory information, participants lost trust in health officials and felt increasingly insecure*: 'They [the health authority] told me on the phone my quarantine ended on Thursday. Then I got the letter from them saying I needed to stay in quarantine for another 2 weeks'* (male, y/o)

A first, many participants' **reaction to this discriminatory behaviour** was

- Incomprehension (n = 8): *'I really felt mocked by the health authorities.'* (female, y/o).
- But eventually, in retrospect, they often reacted understandingly and forgivingly, which we labelled Leniency (n = 8): *'I guess they [the health authorities] were just overwhelmed'* (male, y/o).

Additionally, **receiving professional support** was much appreciated:

- Appreciation of health-care workers (n = 4): *'He [family doctor] called every day to make sure I was okay. That felt good.'* (female, y/o)
- Support group (n = 2): *'Is there a self-help group for COVID survivors?'* (male, y/o)

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Societal layer

This layer characterized **societal norms and values** which are partly internalized by participants.

- First, COVID-19 was seen as a non-desirable condition (n = 5) and something usually 'others' catch: *'I was surprised. I never thought* ***we*** *would get it.'* (female, y/o).
- Secondly, even if unaware of carrying an infectious virus, participants perceived themselves as a menace to others (n = 10) and public health in general. This was the most sensitive subject during the interview: Q: *'Do you happen to know if you accidentally infected somebody?'* A: *'I don't want to talk about that.'* (male, y/o)

As a reaction to the latter, people reacted in very different ways, often trying to make amendments, which we subsumed as **harm reduction**:

- Law-abiding (n=5): Participants emphasized that they stuck to the regulations and thereby avoided spreading the disease*: 'When we came back [from a hotspot] we stayed at home. So when we finally knew we had it [COVID-19], at least I didn't feel guilty, because I knew I didn't infect anyone else.'* (female, y/o)
- Social withdrawal (n = 3): Others reduced social contacts even after COVID-19 was over, often in order to avoid rejective behaviour: *'When my quarantine ended, I didn't ask people to meet. I was afraid they would react…. in a strange way.'* (female, y/o)
- Hygiene advocacy (n = 3): Others supported and propagated hygiene practices as effort to control the disease: *'I tell everyone, they should wear their face masks.'* (female, y/o)

S4 also includes participants' opinions regarding legal stipulations. However, since this is not necessarily part of experienced stigma or applied coping strategies, it will not be further discussed here.

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Discussion

Comparison with international literature

In total, experienced stigma was lower in our cohort compared to people living with HIV/AIDS or cancer in the United States [15] or Germany [16] (c.f. table 2). Comparing our results to people living with cancer, 'social rejection' and 'internalized shame' were similar in both groups [15] or slightly higher [16] in people with COVID-19, while people with cancer experienced higher levels of stigma in the dimensions 'social isolation' and 'financial insecurity'. The difference to Eichhorn et al. (2015) [16] was smaller, presumably due to a similar setting, than to Fife and Wright (2000) [15].

	HIV/AIDS [15] (aggregate means)	Cancer [15] (aggregate means)	COVID-19 (aggregate means)	Cancer [16] (means)	COVID-19 (means)
Social rejection	19.95	14.87	14.22	1.42	1.58
Internalized shame	13.74	8.45	8.39	1.51	1.68
Social isolation	17.85	14.64	10.17	1.71	1.45
Financial insecurity	8.12	5.73	3.51	1.68	1.17
Total score	**59.66**	**43.69**	**36.29**	**1.59**	**1.55**

Table 2: Experienced stigma in people living with cancer, HIV/AIDS or after COVID-19

Experienced stigma across societal levels

Different individual factors, such as personality, social resources, and economic situation, can either enhance or mitigate the impact of stigma. In contrast to other, mainly low-and-middle-income countries [13,17,18], in our cohort, COVID-19-related stigma did usually not culminate in financial hardship. However, some self-employed participants had to advance money on loan for the hospital costs before they were reimbursed by their health insurance. Additionally, they suffered from a loss of income while being ill, but none reported loss of livelihood or job insecurity.

A sudden illness like COVID-19, fear of adverse outcomes and loneliness generate a feeling of vulnerability, which serves as a breeding ground for experiencing stigma. Stigma in turn increases vulnerability even further, irrespective of the setting [19]. Hence, COVID-19-related stigma leads to psychological stress and impairs the individual's wellbeing [13,19,20]. Loss of autonomy, specifically the violation of privacy, was also observed as well as in other settings [13,17,21]. Participants reported that by word of mouth, the news or rumours of someone being infected travelled quickly and confidentiality was often breached, even in healthcare facilities. This poses a serious risk for people to hide their condition and refrain from test- or healthcare-seeking, favouring the further spread of the virus [18].

If exposed, vilification including blame, social rejection and stereotyping are key themes on the communal level in our as well as in other studies examining COVID-19-related stigma: Gopichandran et al. (2021) [17] noticed an exclusion from essential services such as grocery stores and water taps. Jiang et al. (2021) [11] found that 5% of respondents lived in communities that rejected people with COVID-19. Imran et al. (2020) [13] reported social rejection of whole families if one member fell ill as well as humiliating and sarcastic behaviour of others. Amir (2020) [12] described how patients were treated as outcasts, given bad names and blamed for spreading the disease. Chew et al. (2020) [22] identified isolation, labelling, stereotyping and blame as emerging themes. International literature agrees that the underlying reason for social rejection is an (irrational) fear of infection with a perceived lethal and uncurable virus [12,13,18,21,23], correlating with experienced vulnerability among the healthy population [24].

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Stigma experienced on institutional level included both direct and indirect discrimination. The former resulted from inappropriate treatment by professionals, such as negligence of patients or compelling them to leave the hospital. Difficulties in assessing healthcare, poor services and negligence were also found in other study sites [17,19,25]. Indirect discrimination referred to a lack of accountability when health authorities were presumably too overwhelmed to take over responsibility.

On a societal level, health-related stigma is often associated with certain norms and values. People living with HIV/AIDS are often perceived as 'dirty' or 'immoral' [26] and some types of cancer are linked to a unhealthy lifestyle or risk behaviour [27]. In contrast to those conditions, COVID-19 is an airborne infection with high transmissibility. One person infects about three others [28] and health authorities made a great effort to find index patients. This induced a change of perspective from passively 'catching the virus'—as is commonly used in other viral diseases such as influenza or norovirus—to actively 'spreading the virus', even if this happened unwittingly. The change equals a shift from 'victim' to 'perpetrator' resulting in blame, which was also observed in other settings [18]. This attitude was internalized by many participants, who felt ashamed of (accidentally) infecting others.

Applied coping strategies across societal levels

On an individual level, resilience served as an effective coping strategy, either reflected by confidence in others or themselves. Gopichandran *et al.* (2021) [17] described understanding of disease characteristics, risk acceptance and self-isolation as applied coping strategies, resembling what we subsumed as 'coming to terms' with the disease. Disclosing what had happened only afterwards, which is not uncommon in traumatic experiences, rationalization to justify former behaviour and, in one case, denial were other coping strategies on the individual level.

On the interpersonal and communal level, a strong, solidary social network and sound relationships were valuable resources to cope with stigma [17,20,29]. This might work in both directions: For those not infected, COVID-19 is not reduced to a faceless, dangerous virus, but connected to a human being [30]. This can induce a comprehensive and mindful attitude which prevents stigmatization and supports those infected. 'Humanizing' COVID-19 has been insinuated as a way to end stigma, either by involving celebrities or sharing narratives from affected people [22,24,31].

On the institutional level, discrimination elicited either incomprehension or leniency in participants. From the lived experiences it becomes evident, that institutions need to be transparent [23] and give consistent instructions to preserve people's confidence and compliance.

On a societal level, coping strategies against internalized shame were diverse and ranged from social withdrawal to a strictly law-abiding or hygiene advocating behaviour, resulting from experience and hindsight to reduce (further) harm.

Intersectional stigma

As a social phenomenon, stigma can never be assessed detached from other social conditions, often mirroring power differences between groups. Most studies about COVID-19-related stigma suggest a higher prevalence among elderly people or patients with comorbidities, since they are most affected by the disease [19,23,31]. However, in our study, young to middle-**age**d participants reported the highest level of experienced stigma. This might result from the shift from 'victim' to 'perpetrator' mentioned earlier. Those participants who were seriously ill often received sympathy from their social environment and were seen as 'victims'. In contrast, young people were often asymptomatic and regarded as 'super-spreaders' [32]. They were depicted as drivers of the pandemic and hence regarded as 'perpetrators'. Reports from illegal parties despite the curfew added to a reckless and careless stereotype of young people [33]. We assume the perception of a similar stereotype caused the higher prevalence of experienced stigma in participants with travel history [34]. Those coming back from a skiing trip in a hotspot were seen as a major source of the pandemic and perceived as reckless, since they presumably valued the vacation more than their health and the health of others. Similarly, the

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patient's **origin** was also connected with COVID-19-related stigma in other settings, e.g. regarding migrant workers in Delhi, India, residing in Haryana [11,18,23,31]. However, since all our participants had the same cultural background, we were not able to assess different ethnicities in our cohort. In contrast to other studies, we did not find any difference in **gender** [13,19,23,35] or **education** [35] regarding experienced COVID-19-related stigma. Others also clearly identified an association between **poverty** [17,18] or occupational status [35] and experienced stigma, where a mutual influence can be assumed: COVID-19 is more easily spread in over-crowded, poorer areas; on the other hand, COVID-19 can lead to a loss of livelihood of those infected. We did not collect data on the economic situation, but used the occupational status as a proxy, which revealed no significant difference between the groups. However, this variable might fail to reflect more subtle socioeconomic differences between participants. Similar to Gopichandran et al. (2021) [17], our qualitative data suggested that experienced stigma differs with **residential site**: participants in more anonymous urban apartments experienced less stigma than those living in rural areas, where residents know each other and word by mouth travels quickly. On the other hand, participants from rural areas also reported more neighbourly support.

Conclusion and implications for stakeholders

Around the globe, stigma is a social phenomenon which cuts through all layers of society. It is intertwined with or aggravated by social factors and power distributions and leads to a phenomenon called 'othering' of the respective group, which is a precursor of discrimination. It leads to a limited access to healthcare and other public services and can therefore be seen as a social determinant of health equity and a hidden burden of disease. Stigma arises from misconceptions and ignorance. Information about COVID-19 in social media is often incorrect [36] and people have difficulties finding reliable sources [11] to distinguish between fake and fact. Providing accurate information and exposing misinformation on disease prevention and treatment is hence key to end COVID-19 related stigma. Information should be adapted to the respective target group and conveyed in plain and different languages. That way, stakeholders from politics, civil society or role models can join efforts to curb COVID-19 related stigma.

Reflexivity and limitations

Since the interviews were conducted by telephone, physical appearance and body language did not play a role, in contrast to face-to-face interviews. This can work in both directions: either participants appreciated the more anonymous atmosphere to share private information, or they would have preferred a more personal and intimate setting.

Talking to a medical doctor, participants are used to share physical complaints rather than social experiences such as stigma. Participants often had the impression that their narratives were inappropriate or not of interest. Therefore, continuous probing was needed, to keep participants sharing their stories. Nevertheless, an expectation bias cannot be excluded. Furthermore, a recall bias must be considered due to the retrospective character of the study.

Of note, those participants who volunteered to take part in the interview were mostly of German origin. The fact that the questionnaire required an advanced level of German, and the nature of the topic was rather sensitive could have limited the diversity of study participants. Future studies should aim to deliberately include participants with different cultural and socioeconomic backgrounds to achieve a more diverse account of the phenomenon. This would allow to assess the possible relationship between health-related stigma and racism.

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Statements

a. Contributorship

- Conceptualisation: LP, BG
- Methodology: LP
- Data acquisition: LP
- Initial analysis: LP
- Interpretation of data: LP, SB, CB, BG
- Writing - original draft: LP
- Visualization: LP
- Writing - review and editing: SB, CB, BG
- Final approval: LP, SB, CB, BG
- Accountability: LP, SB, CB, BG

b. Funding with award/grant number

There was no funding involved in this study.

c. Competing interests

The authors declare that there is no conflict of interest.

d. Data sharing statement

Data (both quantitative and original German qualitative data) are available on request.

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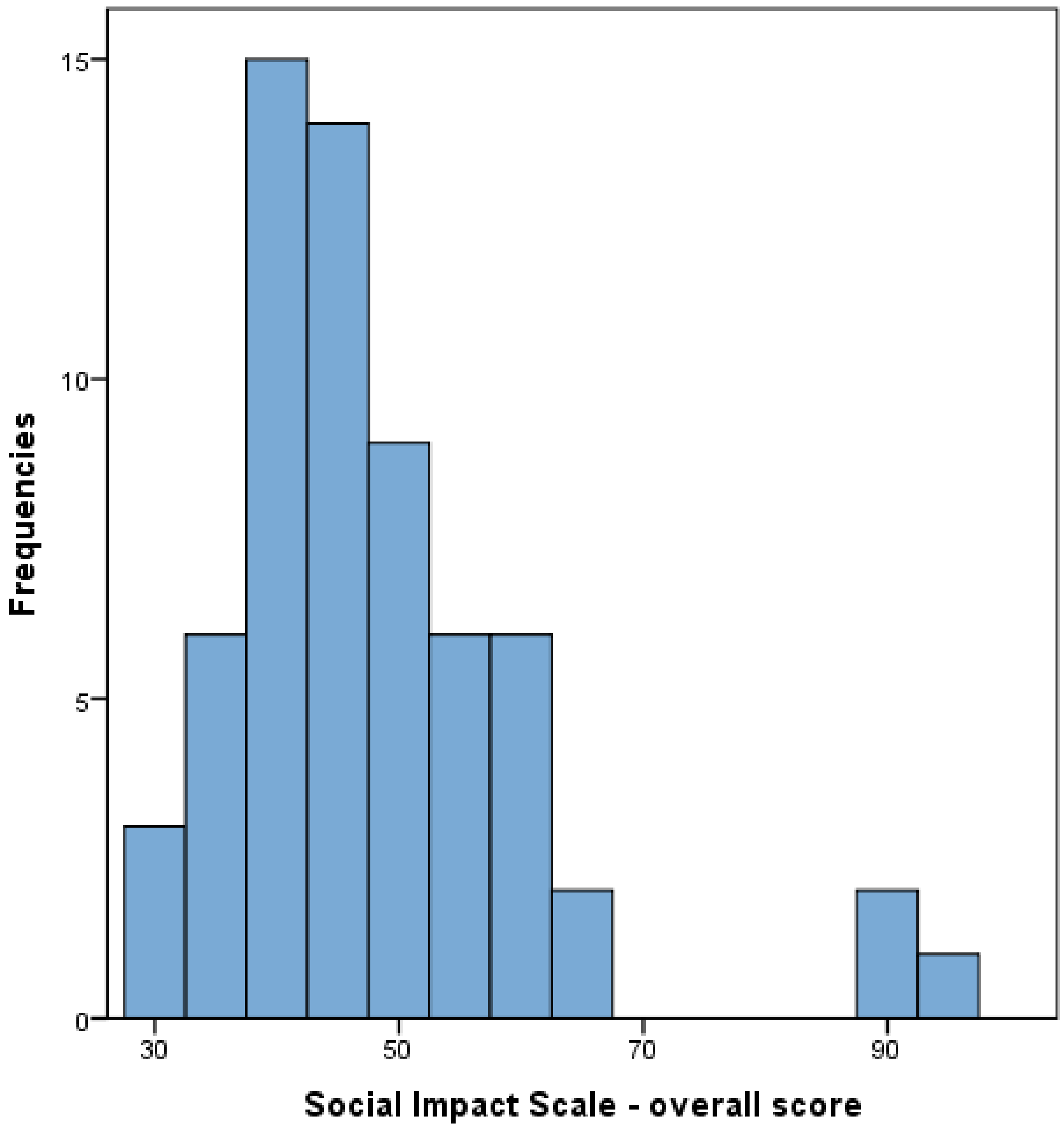
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Frequencies
30
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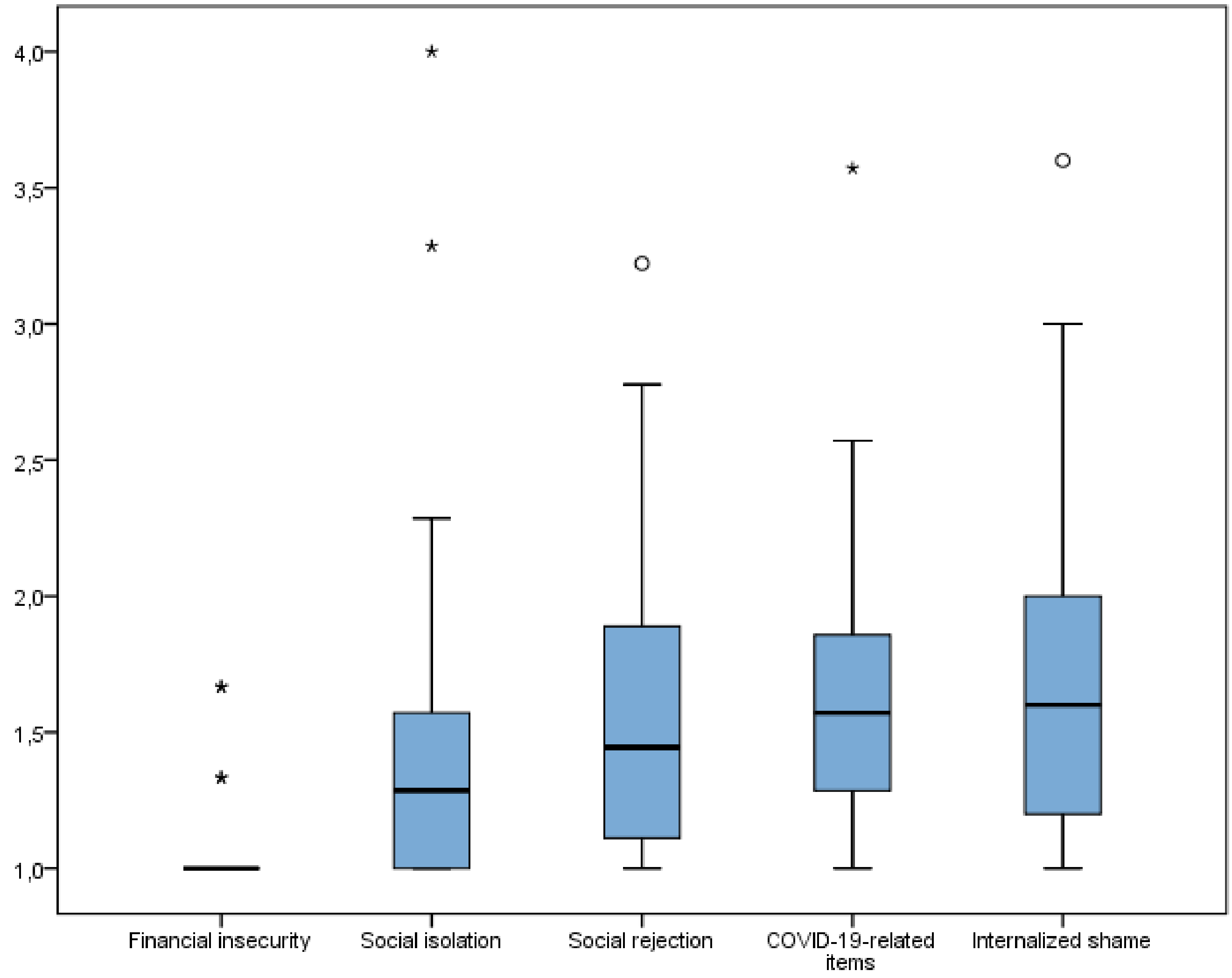
Social Impact Scale - overall score

only


4,0
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Financial insecurity
Social isolation
Social rejection
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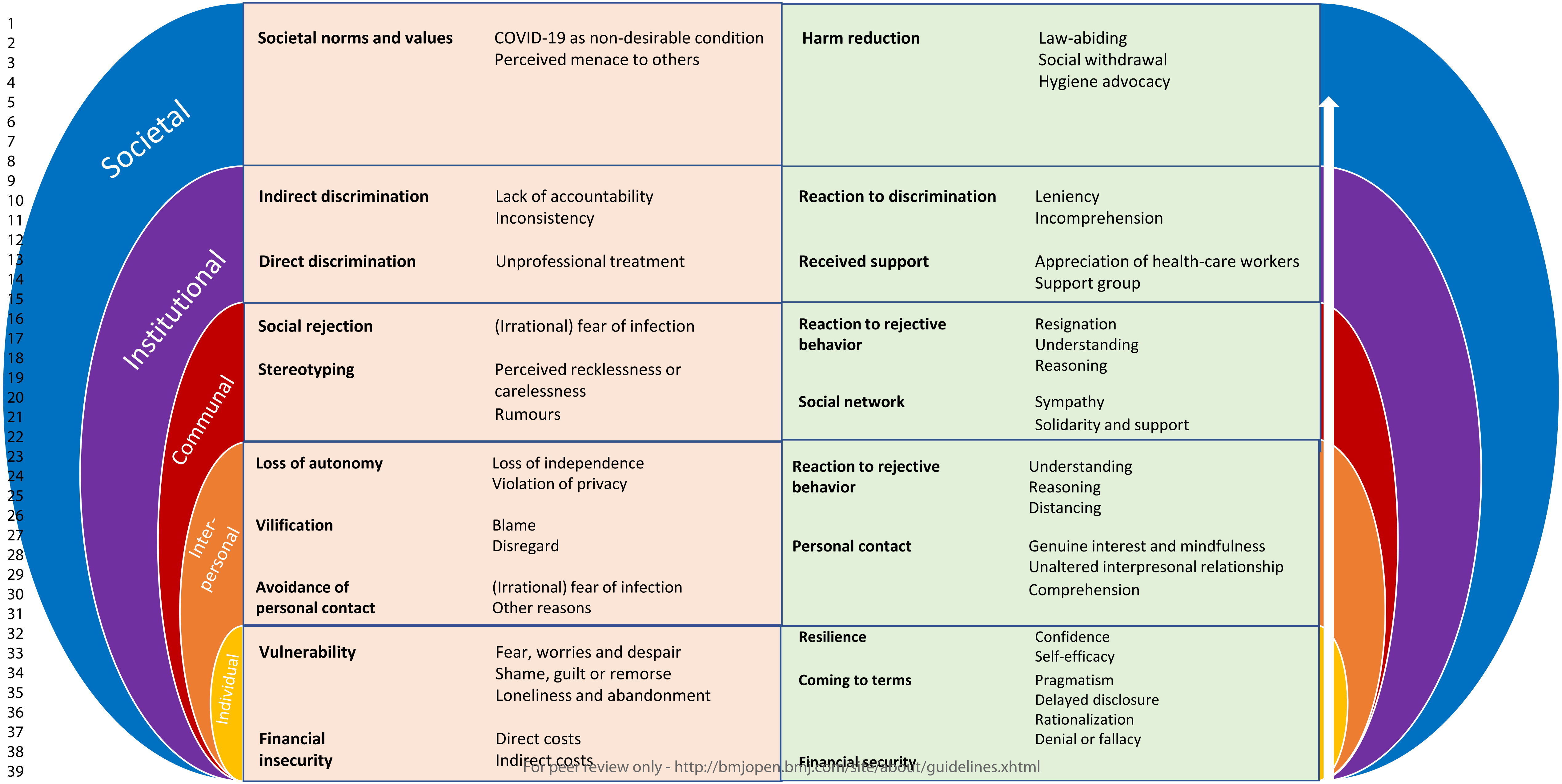

	Experienced stigma		Applied coping strategies	
Societal	**Societal norms and values**	COVID-19 as non-desirable condition Perceived menace to others	**Harm reduction**	Law-abiding Social withdrawal Hygiene advocacy
Institutional	**Indirect discrimination**	Lack of accountability Inconsistency	**Reaction to discrimination**	Leniency Incomprehension
	Direct discrimination	Unprofessional treatment	**Received support**	Appreciation of health-care workers Support group
Communal	**Social rejection**	(Irrational) fear of infection	**Reaction to rejective behavior**	Resignation Understanding Reasoning
	Stereotyping	Perceived recklessness or carelessness Rumours	**Social network**	Sympathy Solidarity and support
Inter-personal	**Loss of autonomy**	Loss of independence Violation of privacy	**Reaction to rejective behavior**	Understanding Reasoning Distancing
	Vilification	Blame Disregard	**Personal contact**	Genuine interest and mindfulness Unaltered interpresonal relationship Comprehension
	Avoidance of personal contact	(Irrational) fear of infection Other reasons		
Individual	**Vulnerability**	Fear, worries and despair Shame, guilt or remorse Loneliness and abandonment	**Resilience**	Confidence Self-efficacy
			Coming to terms	Pragmatism Delayed disclosure Rationalization Denial or fallacy
	Financial insecurity	Direct costs Indirect costs	**Financial security**	

STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1 and 2
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4
Objectives	3	State specific objectives, including any prespecified hypotheses	4
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	5
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	*5*
Bias	9	Describe any efforts to address potential sources of bias	5
Study size	10	Explain how the study size was arrived at	5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	5
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	5
		(*b*) Describe any methods used to examine subgroups and interactions	5
		(*c*) Explain how missing data were addressed	5
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy	5
		(*e*) Describe any sensitivity analyses	5

Continued on next page

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Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7
		(b) Give reasons for non-participation at each stage	(7)
		(c) Consider use of a flow diagram	n.a.
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	5
		(b) Indicate number of participants with missing data for each variable of interest	(7)
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	n.a.
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	*n.a.*
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	*n.a.*
		Cross-sectional study—Report numbers of outcome events or summary measures	*7*
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	7
		(*b*) Report category boundaries when continuous variables were categorized	n.a.
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n.a.
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	8
Discussion			
Key results	18	Summarise key results with reference to study objectives	13
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	15
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	13/14
Generalisability	21	Discuss the generalisability (external validity) of the study results	14
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	1

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Experienced stigma and applied coping strategies during the COVID-19 pandemic in Germany - A mixed-methods study

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Primary Subject Heading:	Infectious diseases
Secondary Subject Heading:	Global health, Infectious diseases, Mental health, Qualitative research, Sociology
Keywords:	COVID-19, MENTAL HEALTH, SOCIAL MEDICINE

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Experienced stigma and applied coping strategies during the COVID-19 pandemic in Germany

- A mixed methods study -

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Abstract

Objective Health-related stigma is considered a social determinant of health equity and a hidden burden of disease. This study aimed to assess the level and dimensions of stigma and respective coping mechanisms in COVID-19-survivors.

Methods A mixed-methods study with sequential explanatory design was conducted at the University Hospital of Ulm, Germany. Stigma was assessed using the Social Impact Scale (SIS) including adult COVID-19 survivors with mild to severe disease. Subsequently, 14 participants were sampled with regard to gender, age and severity of disease for in-depth interviews to understand how stigma was experienced and coping strategies were applied. The questionnaire was analysed using descriptive statistics, *t*-test and ANOVA. Content analysis was used for qualitative data.

Results From 61 participants, 58% were male and mean age was 51 years. The quantitative analysis of the SIS indicated an intermediate level of experienced stigma. Participants experienced stigma mainly as 'social rejection' ($M = 14.22$, $SD = 4.91$), followed by 'social isolation' ($M = 10.17$, $SD = 4.16$) and 'internalized shame' ($M = 8.39$, $SD = 3.32$). There was no significant difference in experienced stigma regarding gender, education, occupational status, or residual symptoms. However, participants between 30 and 39 experienced higher levels of stigma than other age groups ($p = 0.034$). The qualitative analysis revealed how stigma seemed to arise from misconceptions creating irrational fear of infection, leading to stereotyping, vilification, discrimination, and social exclusion of COVID-19 survivors, leaving them feeling vulnerable. Stigma cut through all social levels, from the individual level at the bottom to the institutional and societal level at the top. Social networks protected from experiencing stigma.

Conclusion COVID-19-related stigma is a relevant burden in the ongoing pandemic. Providing accurate information and exposing misinformation on disease prevention and treatment seems key to end COVID-19 related stigma.

Strengths and limitations of this study

Strengths

- Mixed-methods approach to gain an in-depth understanding of COVID-19 related stigma and applied coping strategies
- Development of a comprehensive framework that might serve as a template for future research in health-related stigma
- Detailed list of quotes for every theme to increase transparency, objectivity, and traceability

Limitations

- Telephone interviews instead of face-to-face interviews because of contact regulations
- Single-centre study design
- low response rate, probably due to the sensitive nature of the topic, resulting in a comparatively low quantitative sample size
- Lack of an instrument particularly designed to assess stigma in COVID-19 survivors; Application of a questionnaire designed for people living with HIV/AIDS or cancer

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Objective

Health-related stigma is a social phenomenon, which implies a negative attitude towards people with a certain condition (1,2). Stigma occurs in different forms (3): It can result from assumed attitudes of others (perceived stigma), discriminatory behaviours (enacted stigma), a shift to a devalued self-perception (internalized stigma) and inequities embedded in policies, institutions, and social organizations (structural stigma). Regarding health, stigma is often seen as a hidden burden of disease (4) and a social determinant of health and health inequity (5). It generates psychological stress (6) and causes affected people to hide their condition with severe consequences for their own health, and in case of infectious diseases, for public health (7). In the context of the COVID-19 (coronavirus disease 2019) pandemic, the risk of stigmatization has been addressed early (8–10) and reports of discrimination against patients and survivors have accumulated (11). Across the globe, people infected with or recovered from SARS-CoV-2 (Severe Acute Respiratory Syndrome Coronavirus-2) became a target of ostracism, humiliation, harassment and even violence. Studies from Pakistan, Uganda, Malaysia, India, China, Ghana, Iran and Brazil found that COVID-19 survivors and even their families were often rejected from social life or essential services and felt humiliated (12–22). COVID-19 survivors were blamed for the disease (13,16,17) and perceived as a source of infection even after being cured (12,17,22,23), some reported finical hardship as a consequence (13,20,24). Stereotyping was common (16), especially blaming the poor, labourers and migrants (17) or people of seemingly Asian origin (25–27). Research from Malaysia, Iran and Tunisia found that affected people made efforts to hide the infection (16,21,28). Due to stigma, people with suspected COVID-19 might avoid testing or treatment facilities, leading to poor health outcomes and the further spread of the virus.

So far, most studies were conducted in low- and middle-income countries and little is known about the phenomenon in high-income countries. Labbé et al. (2022) (25) analysed editorial cartoons from Canadian newspapers and found, amongst others, a stigmatising attitude towards people from certain geographical areas with high SARS-CoV-2 incidence rates. A recent study from Spain using a survey among the general population could demonstrate that discrimination and internalised stigma increased and decreased with the dynamic of the pandemic (29). To the best of our knowledge, no study so far assessed the level and dimensions of stigma and applied coping strategies based on the experiences of COVID-19 survivors in a high-income country.

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Methods

Sampling and data collection

We conducted a sequential explanatory mixed-method study in the area of Ulm, Germany. Every adult with positive SARS-CoV-2-PCR nasopharyngeal swab was included that presented either at the hospital's outpatient COVID-19-testing centre, the hospital's emergency room or that was admitted to the hospital between March and May 2020 (n = 150). Exclusion criteria were age < 18 years and death during hospitalisation. The 'Social Impact Scale' (SIS) questionnaire (quantitative methods), a form assessing residual symptoms and socio-economic factors and a form on which participants could optionally provide a phone number for the phone interviews were sent to the COVID-19 survivors 3 to 9 months *post infectionem*. After the quantitative analysis confirmed experienced stigma in COVID-19 survivors, a phenomenological approach was employed using in-depth interviews (qualitative methods) to explore why and how stigma was experienced and to assess possible coping strategies. The study was approved by the ethical board of the University of Ulm (No. 315/20).

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Quantitative methods

The 'Social Impact Scale' questionnaire

Experienced stigma was assessed with the 24-item SIS questionnaire designed by Fife & Wright (2000) (30) for people living with HIV/AIDS or cancer and translated to German by Eichhorn et. al. (2015) with good psychometric properties (Cronbach's α = 0.81 - 0.89) (31). We added 7 additional COVID-19-related questions (c.f. Supplementary Material S1), which were evaluated separately. On a 4-point Likert scale, participants rate the given statements (items) from 'I strongly disagree' to 'I strongly agree' (1 to 4 points) resulting in an overall stigma score. These items are assigned to different dimensions of stigma, namely 'social rejection' (9 items), 'internalized shame' (5 items), 'social isolation' (7 items) and 'financial insecurity' (3 items) and are evaluated separately.

Statistical analysis

Statistical analyses were performed using IBM SPSS Statistics V23. Descriptive analyses included demographic information, post-COVID-19 symptoms, the overall level of stigma and its dimensions. Results are reported in means (M) and standard deviation (SD). Univariate analyses were performed assessing differences in experienced stigma regarding gender, age groups, education, occupational status, and residual symptoms using *t*-Test, ANOVA and correlation where appropriate. Missing data were handled by listwise exclusion. A significance level of $p < 0.05$ was considered significant.

Qualitative methods

Sampling and data collection

From those participants consenting to an in-depth interview, we purposefully sampled a broad range with high and low perceived stigma based on the questionnaire, different severity of disease, gender, age, and education to gain diverse accounts of the phenomenon (c.f. Table 1). Data were analysed using MAXQDA Plus 2020. The analysis began after the 5th interview and data saturation was reached after the 11th. Three additional interviews were conducted to ensure no new themes emerged, resulting in a total number of 14 interviews. The interviews were held in German, being the native language of the participants and followed an interview guide (c.f. Supplementary Material S2). However, the interviewer (LP) aimed for an open discussion, allowing the interviewee to determine which topics to focus on. Due to contact regulations, the interviews were conducted by phone and recorded.

Gender (N)	Male: 8	Female: 6

Age in years	Mean: 51.8	Median: 52	Min: 23	Max: 77
ISCED* 2011 level of education	Mean: 3.7	Median: 3	Min: 2	Max: 7
Severity of disease (N)**	Ambulatory mild disease: 4	Hospitalised, moderate disease: 6	Hospitalised, severe disease: 4	
Length of interview in minutes	Mean: 48	Median: 41	Min: 18	Max: 76

* International Standard Classification of Education ranging from 0 (early childhood education) to 8 (doctorate or equivalent)

**according to the WHO classification (32)

Table 1: Characteristics of interviewees and length of interviews

Analysis and trustworthiness

After transcription, the analysis was conducted in English, i.e. English codes were applied to the German transcripts. Translating the transcripts to English was avoided in order to remain close to the source data and avoid a loss of information. LP used content analysis to develop a preliminary coding scheme from emerging codes and themes (inductive 'bottom-up' approach). Coding is the first step in qualitative analysis in which phrases are linked and shapes an idea (33–35), i.e. coding implies computing meaning (36). Subsequently, the interpretation of these rather explicit and descriptive codes generates more latent and subtle subthemes that give a deeper understanding of the phenomenon (37–39). As a final step, overarching themes evolve, which allowed organising the data into a comprehensive framework. To ensure reliability, the coding scheme was subsequently applied to the interviews by SB and BG (deductive 'top-down' approach). Deviant codes were discussed within the research team and adjusted (peer-check), resulting in a refined coding scheme. To increase transparency, additional tables with key quotes for each code are attached (c.f. S3 and S4). Using mixed methods allows for methodological triangulation, i.e. assessing the phenomenon from different perspectives.

Patient and public involvement

This research was inspired by patients' narratives from our post-COVID-19 outpatient department. During follow-up visits, patients moved from physical complaints to social consequences they experienced after having COVID-19, which often involved stigma. The interview guide was informed by those narratives. As mentioned earlier, the interview was designed as an open discussion allowing the participants to prioritise topics and report their experiences freely. However, patients were not involved in designing or recruiting. We aim to offer a lay summary in German on our website to inform participants about the results.

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Results

Quantitative results

Descriptive results

In total, 61 questionnaires were analysed which equals a response rate of 41%. The socio-economic characteristics and residual symptoms are displayed in table 2.

Variable	Results (%)			Residual Symptoms	N	%
Age	M = 51 years (SD = 14.6, Min. = 18, Max. = 78)			Dyspnoea on exertion	11	20.4%
Gender	Male	58%		Fatigue	6	12.2%
	Female	42%		Paraesthesia	5	10.2%
Education	No formal education	0%		Cough	4	8.2%
	Lower secondary education, no graduation	11.5%		Sore throat	4	8.2%
	Lower secondary education, graduation	9.8%		Cephalgia	4	8.2%
	Intermediate secondary education	26.2%		Palpitations	4	8.2%
	Upper secondary education	18.8%		Rhinorrhoea	3	6.1%
	High school graduation	34.4%		Loss of smell and taste	3	6.1%
Occupation	Regularly employed	70.3%		Diarrhoea	2	4.1%
	Unemployed/ receiving pension	15.6%		Myalgia	2	4.1%
	Student/ trainee	6.3%		Xerophthalmia	2	4.1%
People informed about infection	Close family members	98.4%		Sleeping disorder	2	4.1%
	Friends	95.3%		Loss of hair	2	4.1%
	Acquaintances	81.3%		Lack of attention	2	4.1%
	Distant relatives	78.1%		Mucus	1	2.0%
	Close co-workers	76.6%		Dyspnoea without exertion	0	0%
	Neighbours	73.4%		Fever	0	0%
	Superiors	71.9%		Hearing loss	0	0%
	Distant co-workers	50.0%		Loss of vision	0	0%

Table 2: Socio-economic characteristics and residual symptoms

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The Social Impact Scale

Each of the 31 items (24 SIS items and 7 COVID-19-realted items) was rated with 1 to 4 points, resulting in a possible total score of 31 to 124. The total stigma score in our cohort ranged from 31 to 97 with a mean of 48.1 (*SD* = 13.1), and a median of 45.0 (c.f. Figure 1A). Analysing the dimensions of stigma based on the 24 SIS items, 'internalized shame' (*M* = 1.68, *SD* = 0.66) and 'social rejection' (*M* = 1.58, *SD* = 0.55) showed the highest levels of stigma, followed by 'social isolation' (*M* = 1.45, *SD* = 0.59). 'Financial insecurity' (*M* = 1.17, *SD* = 0.46) played a minor role (c.f. Figure 1B). The overall mean per item was 1.55 (*SD* = 0.42). Adapted to the original questionnaire (30), we calculated aggregate means: 'social rejection' showed the highest aggregate mean (*M* = 14.22, *SD* = 4.91), followed by 'social isolation' (*M* = 10.17, *SD* = 4.16) and 'internalized shame' (*M* = 8.39, *SD* = 3.32) and, ultimately, financial insecurity (*M* = 3.51, *SD* = 1.38). The data were evenly distributed. Items of special interest are summarised in table 3.

Figure 1. A: Social Impact Scale, overall score. B: Dimensions of stigma. High numbers equal high level of experienced stigma.

Items with the highest experienced stigma:	***M***
'I feel others are concerned they could catch my illness.'	2.52
*'I feel guilty because I accidentally might have infected others.'**	2.03
'I feel others think I am to blame for my illness.'	2.00
'Due to my illness others seem to feel awkward and tense when they are around me.'	1.97
*'I feel institutions and professionals (health authority, health care workers) treated me unfairly.'**	1.81
Items with the lowest experienced stigma:	***M***
'I have experienced financial hardship that has affected my relationship with others.'	1.08
'Some family members have rejected me because of my illness.'	1.11

'My job security has been affected by my illness.'	1.15

Table 3: Items of special interest from the questionnaire. *Additional COVID-19-related questions.

There was no difference in experienced stigma comparing gender ($t(59) = 0.437$, $p = 0.664$), educational level ($F(4) = 0.687$, $p = 0.604$), occupational status ($F(3) = 0.995$, $p = 0.404$) or residual symptoms (composite score of symptoms) ($r(46) = -0.250$, $p = 0.093$). However, there was a significant difference in age: participants between 30 and 39 experienced higher levels of stigma than other age groups ($F(6) = 2.499$, $p = 0.034$).

Qualitative results

The analytical process revealed how COVID-19 survivors experienced stigma as a multi-layered phenomenon: The descriptive codes and latent **subthemes** generated overarching **themes** that represent the societal layer in which stigma was experienced and coping strategies were applied. The following section will guide the reader through each layer, starting with the individual layer and continuing to the immediate and then wider environment. The number of times respective codes were applied throughout the interviews is indicated by (n). To keep this report concise, only one exemplary quote for every code is presented. However, we invite the reader to consult the supplementary materials S3 and S4, which offer additional quotes.

Theme 1: the individual layer

Vulnerability was identified as key subtheme contributing to or resulting from internalized or perceived stigma. Different codes added to increased vulnerability:
Fear, worries and despair (n = 11): *'I was thinking «why me???»... and «I hope this ends well...»'* (female (f), 50-59 y/o); Most participants were worried about the outcome, especially elderly patients and those referred to the hospital.
Shame, guilt or remorse (n = 14): *'Of course you feel bad knowing you infected others'* (f, 20-29 y/o); Although infecting others happened unwittingly in all cases, participants often felt as active 'spreader'. This caused feelings of shame and remorse.
Loneliness and abandonment (n = 14): *'Being on my own was the hardest part.'* (male (m), 60-69 y/o); This feeling often rose from the isolation faced in home-quarantine or single hospital rooms, but also from a perceived lack of reliable information regarding the disease.

On the other hand, **resilience** as coping strategy mitigated the experienced stigma, resulting from:
Confidence (n = 5) *'I knew I was getting medication; I was sure that would help, otherwise they wouldn't give it to me. I wasn't worried I would die.'* (m, 60-69 y/o); The elderly putting faith in modern medicine or the young relying on their body's defences felt confident they would be spared from adverse outcomes.
Self-efficacy (n = 2) *'In the beginning it was very hard for me. But as soon as I managed to structure my day, time just flew by.'* (m, 30-39 y/o); Self-efficacy reflects a person's assumed control over a situation and was identified as a rare but resourceful coping strategy.

Additionally, participants indicated different ways of **coming to terms** with the undergone infection:
Pragmatism (n = 2): *'I had it [COVID-19], that's all there is. Now I am cured and immune.'* (f, 70-79 y/o); some refused to dwell in the past and did not make a big deal about having had COVID-19. Interestingly, this also occurred in one participant that had been hospitalized for a few days.
Delayed disclosure (n = 3): *'In the beginning, I didn't want to share with anyone. Afterwards, we talked about it.'* (f, 70-79 y/o); Participants from different age groups and with different severity of disease admitted that they needed some time to process before they were able to confide in someone else.

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Rationalization (n = 2): *'When I was there, it wasn't known to be a hotspot!'* (m, 50-59 y/o); Some participants offered a rationale to justify how they got infected. They emphasized that they did not deliberately put themselves and thereby others at risk.
Denial or fallacy (n = 1): *'Maybe I didn't have it [COVID-19]. I even know couples, where one had it and the other didn't'* (m, 50-59 y/o). One participant doubted the established diagnosis.

Financial insecurity concerned comparatively few self-employed participants. This applied to both direct and indirect costs, the latter resulting from a loss of income:
Direct costs (n = 2): *'If I hadn't had any savings, it would have been problematic.'* (m, 40-49 y/o);
Indirect costs (n = 1): *'I have to earn my money with physical labour. When I can't work, I don't earn money…'* (m, 50-59 y/o);
However, most participants were either employed or received pension and hence costs were covered by their health insurance, implying **financial security** (n = 8): *'I was on sick leave and got my loan as usual.'* (f, 20-29 y/o);

Theme 2: the interpersonal layer

Used to a certain level of self-determination and a scope of action, most participants were hit hard by the **loss of autonomy**:
Loss of independence (n = 5): *'We were all isolated, other people had to take care of us.'* (f, 20-29 y/o); Quarantine or being bed-ridden meant depending on others, which was a new situation for many participants.
Violation of privacy (n = 4): *'I live in a small village and within two hours, everyone knew about it [COVID-19]'* (f, 20-29 y/o); Transgression of personal boundaries or unauthorized passing of personal information left some participants, young and elderly, feeling powerless.

Almost every participant suffered some form of **vilification** as perceived or enacted stigma:
Blame (n = 9): *'Some people said it is my own fault that I got infected.'* (m, 50-59 y/o). Some patients were made responsible for catching SARS-CoV-2 or blamed for unknowingly infecting others. This reflects a shift in perspective from passively acquiring a disease to actively spreading it. This change from victim to perpetrator was described as particularly hurtful when people had been severely ill from COVID-19.
Disregard (n = 4): *'They [acquaintances] did not really care about what had happened to me.'* (f, 20-29 y/o); Lack of concern or misconceptions about what participants were going through left some participants frustrated or angry. This was reported by patients with mild symptoms as well as those hospitalized.

As mentioned earlier, loneliness and abandonment left participants feeling vulnerable. Additional **avoidance of personal contact** by others when participants were no longer contagious was hence particularly upsetting and by far the most frequently reported form of enacted stigma:
(Irrational) fear of infection (n = 27) was presumably the most important driver for the reported behaviour of others: *'Many people withdrew from me for a long time…. I think they were still afraid of getting infected.'* (f, 70-79 y/o);

Participants reported different ways in **dealing with the rejective behaviour** of others:
Understanding (n = 10); Most participants could at least partly comprehend and therefore excuse this behaviour: *'I could totally understand their [friends] behaviour. No one knew exactly how long people can transmit COVID.'* (f, 20-29 y/o);
Reasoning (n = 2); others tended to argue: *'When they [friends] took a step back, I told them there was no reason, they could hug me, I am no longer contagious.'* (m, 50-59 y/o);

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Distancing (n = 2) oneself and avoiding emotional involvement and further frustration: *'When I heard about what others said, I just distanced myself from that.'* (m, 50-59 y/o);

Consequently, **personal contact** was much appreciated by all participants and proved one of the most powerful coping strategies:
Genuine interest and mindfulness (n = 7) regarding the participants' well-being were key elements: *'It's very important that there are people who care about you and want to know how you are doing. My mum called every day to check on me, that felt good.'* (m, 30-39 y/o);
Unaltered interpersonal relationship (n = 4), i.e. discovering that 'nothing had changed' made participants feel relieved: *'With my friends, it is the same way as it has been before.'* (m, 30-38 y/o).
Comprehension (n = 4): *'I talked to a friend, and she could totally relate.'* (f, 20-29 y/o). When sharing their stories induced sympathy and comprehension, participants felt that their emotions were acknowledged and legitimate.

Theme 3: the communal layer

The lines between the interpersonal and communal layers are particularly blurry. Thus, codes and subthemes emerging are often similar, yet referring to a different social group. While the interpersonal layer focuses on close personal relationships, the following section refers to more distant contacts or anonymous settings.

Social rejection plays an important role in enacted stigma. Again, a potential driver identified was:
(irrational) fear of infection (n = 6): *'When I did my groceries and kept a 2 to 3 meters distance, people still told me to go further away…. they even changed the side of the street when they saw me.'* (f, 20-29 y/o);
Additionally, **stereotyping** as perceived stigma was indicated by younger people:
Perceived recklessness or carelessness (n = 4): *'Now you [referring to the interviewer] are probably going to say «how on earth could you go skiing, and how could you go there [place where she got infected]?!?», but back then it wasn't that obvious….'* (f, 20-29 y/o);
Rumours (n = 2): *'In town, everyone acted like they knew better why I was infected'* (f, 20-29 y/o);

The **reaction** to experienced stigma on the communal level included:
Understanding (n = 3): *'I tried to understand their reaction [people at work] and asked myself, how I would have reacted in their place? And honestly, I would keep my distance too. That is probably human.'* (m, 30-39 y/o);
Reasoning (n = 2): *'I told them [people in a grocery store] I am no longer contagious and that they don't need to keep a 10-meter distance. I fact, I am less dangerous than other people.'* (f, 20-29 y/o);
Resignation (n = 3), i.e. accepting adverse behaviour without arguing: *'I didn't really bother. Couldn't change it anyway. (…) You have to take it the way it is.'* (m, 40-49 y/o);

Social network and inclusion turned out as a valuable resource against experienced stigma:
Sympathy (n = 7): *'So many people called during my absence to make sure I am okay, and they were so happy to hear from me when I called them back.'* (m, 60-69 y/o). For many participants, it was important that others cared about them and felt for them.
Solidarity and support (n = 7) from friends or neighbours helped many participants to persevere the isolation and let them rest assured that they would receive help if needed: *'Many people from our village offered help and asked if they could get us anything. I was surprised by their willingness to help.'* (f, 50-59 y/o);

Theme 4: the institutional layer

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Institutional stigma referred to stigma faced in contact with health authorities, hospital staff, general practitioners, and paramedics. Actions directed towards individual participants were labelled **direct discrimination**, a form of enacted stigma. They resulted mainly from
Unprofessional treatment (n = 4), which means inappropriate reactions from healthcare workers: *'Since I was the second patient in that other hospital, they had a lot of «respect» of me and avoided coming close to me… that was even worse for me than the [rejecting] behaviour of other people.'* (f, 20-29 y/o);

Structural stigma was also based on regulations affecting COVID-19 patients in general which was labelled **indirect discrimination**. Two codes were identified:
Lack of accountability (n = 10): In many participant's views, health authorities and other institutions failed to take responsibility or lacked transparency; *'They [health authorities] gave us a number where we could call, but no one ever answered the phone.'* (f, 20-29 y/o);
Inconsistency (n = 4): Due to contradictory information, participants lost trust in health officials and felt increasingly insecure*: 'They [the health authority] told me on the phone my quarantine ended on Thursday. Then I got the letter from them saying I needed to stay in quarantine for another 2 weeks.'* (m, 50-59 y/o);

A first, many participants' **reaction to this discriminatory behaviour** was
Incomprehension (n = 8): *'I really felt mocked by the health authorities.'* (f, 20-29 y/o); But eventually, in retrospect, they often reacted understandingly and forgivingly, which was labelled
Leniency (n = 8): *'I guess they [the health authorities] were just overwhelmed.'* (m, 50-59 y/o);
Additionally, **receiving professional support** was much appreciated:
Appreciation of health-care workers (n = 4): *'He [family doctor] called every day to make sure I was okay. That felt good.'* (f, 70-79 y/o);
Support group (n = 2): *'Is there a self-help group for COVID survivors?'* (m, 50-59 y/o);

Theme 5: the societal layer

This layer characterized **societal norms and values** which are partly internalized by participants.
First, COVID-19 was seen as a non-desirable condition (n = 5) and something usually 'others' catch: *'I was surprised. I never thought* ***we*** *would get it.'* (f, 50-59 y/o);
Secondly, even if unaware of carrying an infectious virus, participants perceived themselves as a menace to others (n = 10) and public health in general. This was the most sensitive subject during the interview: Q: *'Do you happen to know if you accidentally infected somebody?'* A: *'I don't want to talk about that.'* (m, 50-59 y/o);

This led to different reactions, which we subsumed as **harm reduction**:
Law-abiding (n=5): Participants emphasized that they stuck to the regulations and thereby avoided spreading the disease*: 'When we came back [from a hotspot] we stayed at home. So when we finally knew we had it [COVID-19], at least I didn't feel guilty, because I knew I didn't infect anyone else.'* (f, 20-29 y/o);
Social withdrawal (n = 3): Others reduced social contacts even after COVID-19 was over, often to avoid rejective behaviour: *'When my quarantine ended, I didn't ask people to meet. I was afraid they would react…. in a strange way.'* (f, 20-29 y/o);
Hygiene advocacy (n = 3): Others propagated hygiene practices as effort to control the disease: *'I tell everyone they should wear their face masks.'* (f, 70-79 y/o);

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Discussion

The social impact of COVID-19 in relation to other stigmatizing conditions

Regarding the quantitative results, the overall level of experienced stigma was lower in our cohort compared to people living with HIV/AIDS or cancer in the United States (30) or Germany (31) (c.f. table 4). HIV/AIDS is known as a highly stigmatising infection (40), explaining the high level of experienced stigma throughout all dimensions. Comparing our results to people with cancer, 'social rejection' and 'internalized shame' were similar (30) or slightly higher (31) in people with COVID-19. We assume that the perceived risk of infecting others with SARS-CoV-2 compared to a non-communicable disease like cancer increases feelings of shame and rejection. In contrast to chronic conditions such as HIV/AIDS and cancer, stigma towards COVID-19 survivors might decrease over time.

	HIV/AIDS (30) (aggregate means)	**Cancer** (30) (aggregate means)	**COVID-19** (aggregate means)		**Cancer** (31) (means)	**COVID-19** (means)
Social rejection	19.95	14.87	14.22		1.42	1.58
Internalized shame	13.74	8.45	8.39		1.51	1.68
Social isolation	17.85	14.64	10.17		1.71	1.45
Financial insecurity	8.12	5.73	3.51		1.68	1.17
Total score	**59.66**	**43.69**	**36.29**		**1.59**	**1.55**

Table 4: Experienced stigma in people living with cancer, HIV/AIDS or after COVID-19

Experienced stigma and applied coping strategies from the inner to the outer societal level

On an individual level, factors such as personality, social resources, and economic situation, can either enhance or mitigate the impact of stigma. In our cohort, COVID-19-related stigma did usually not culminate in financial hardship, in contrast to other, mainly low-and-middle-income countries (13,17,41). Some participants suffered from a loss of income while being ill, but none reported loss of livelihood or job insecurity.

A sudden illness like COVID-19 resulting in fear of death or infecting others, loneliness, and shame generates a feeling of vulnerability, which serves as a breeding ground for experiencing stigma. Vice versa, stigma seems to increase vulnerability, both in this and other studies (6,22,42,43). Hence, COVID-19-related stigma leads to psychological stress and adds to the burden of disease (13,24,42). Loss of autonomy, specifically the violation of privacy, was also observed in other settings (13,41,44). Participants reported that rumours of someone being infected travelled quickly and confidentiality was often breached, even in healthcare facilities. This poses a serious risk for people to hide their condition and refrain from test- or healthcare-seeking, favouring the further spread of the virus (17). In contrast, the individual's resilience was a valuable source for coping, reflected either by self-confidence or trust in others. In other studies, faith in God strengthened the resilience in COVID-19 survivors (24,45). 'Coming to terms with the disease' was described as a way of accepting and adapting, which was similarly found by Gopichandran *et al.* (2021) using the terms 'understanding disease characteristics, risk acceptance and self-isolation' (41) and by Bhandari et al. (2021) as 'accepting reality' (45). Sharing experiences, often delayed, which is not uncommon after trauma, rationalization to justify former behaviour and, in one case, denial were other coping strategies observed, similarly to the 'rationalisation and sharing problems' Bhandari *et al.* (2021) described (45).

On an interpersonal or communal level, stigma was often experienced as vilification including blame, social rejection, and stereotyping. Similarly, Gopichandran et al. (2021) (41) noticed an exclusion from essential services such as grocery stores and water taps. Jiang et al. (2021) (11) found that 5% of

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respondents lived in communities that rejected people with COVID-19. Imran et al. (2020) (13) reported social rejection of whole families if one member fell ill. Amir (2020) (12) described how patients were treated as outcasts, given bad names and blamed for spreading the disease. Our data suggests that triggers for discriminating of COVID-19 survivors were a general fear of getting infected and noticing presumably irresponsible behaviour of others, often based on misconceptions regarding modes of transmission. Since the virus was perceived as lethal, social rejection seemed reasonable to keep supposedly infectious people at a distance (12,13,17,26,44). In some studies, stigmatizing attitudes were linked to experienced vulnerability, poor education and conflicting information in the media (14,18,23,25), pointing out the necessity of careful communication and precise information about COVID-19 (29). On the other hand, a strong, solidary social network and sound relationships were valuable resources to cope with stigma (24,41,45,46). This might work in both directions: For those not infected, COVID-19 is not reduced to a faceless, dangerous virus, but connected to a human being (47). This can induce a comprehensive and mindful attitude that prevents stigmatization and supports those infected. 'Humanizing' COVID-19 has been insinuated as a way to end stigma, either by involving celebrities or sharing narratives from affected people (16,18,48).

Stigma experienced on an institutional level included both direct and indirect discrimination. The former resulted from inappropriate treatment by professionals, such as negligence of patients or compelling them to leave the hospital. Difficulties in accessing healthcare, poor services and negligence were also found in other settings (19,41,42). Indirect discrimination referred to a lack of accountability when health authorities were presumably too overwhelmed to take over responsibility. These experiences elicited either incomprehension or leniency in participants and show the necessity for institutions to be transparent (26) and give consistent instructions to preserve people's confidence and compliance.

On a societal level, health-related stigma is often associated with certain norms and values. For example, people living with HIV/AIDS are often perceived as 'dirty' or 'immoral' (49) and some types of cancer are linked to an unhealthy lifestyle or risk behaviour (50). In contrast to those conditions, COVID-19 is an airborne infection with high transmissibility, meaning that one person infects about three others (51). We noticed that COVID-19 survivors often felt like a source of infection, i.e. a menace to others and were ashamed and eager to reduce further harm. The findings indicate a change of perspective from passively 'catching the virus'—as is commonly used in other infections—to actively 'spreading the virus', even if this happened unwittingly. The change equals an unprecedented shift within social norms from 'victim' to 'perpetrator'. This public attitude is also reflected in editorial cartoons blaming certain groups or behaviour for the transmission of COVID-19 (25), which does not only add to the psychological stress in affected people, but also to a polarization within society. As a coping strategy, participants reacted with social withdrawal, a strictly law-abiding or hygiene advocating behaviour.

The experienced stigma and applied coping strategies within the respective social layer are depicted as comprehensive framework in figure 2. Stigma experienced at the individual level is shown at the bottom of the framework, followed by the interpersonal, communal, institutional, and finally the societal level.

Figure 2: Comprehensive framework of experienced stigma and applied coping strategies, stratified by societal layer

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Intersectional stigma

As a social phenomenon, stigma can never be assessed detached from other social conditions, often mirroring power differences between groups. Most studies about COVID-19-related stigma suggest a higher prevalence among the elderly or patients with comorbidities, since they are most affected by the disease (26,42,48). However, in our study, young to middle-**age**d participants reported the highest level of experienced stigma. This might result from the shift from 'victim' to 'perpetrator' mentioned earlier. Those participants who were seriously ill often received sympathy from their social environment and were seen as 'victims'. In contrast, young people were often asymptomatic and regarded as 'super-spreaders' (52), i.e. drivers of the pandemic. Similarly, a recent study from Israel found negative age-related stereotypes associated with younger people (54). Reports from illegal parties despite the curfew added to a reckless and careless stereotype of young people (53). We assume stereotyping also caused experienced stigma in participants with travel history (55): Those coming back from a skiing trip in a hotspot were seen as a major source of the pandemic and perceived as reckless, putting fun above health. Similarly, the patient's **origin** was also connected with stigma in other settings, e.g. regarding migrant workers in Delhi, India, residing in Haryana (11,17,26,48). However, since all our participants had the same cultural background, we were not able to assess different ethnicities in our cohort. In contrast to other studies, we did not find any difference in **gender** (13,26,42,56,57) or **education** (56–58) regarding experienced stigma. Previous research identified an association between **poverty** (17,41) or occupational status (56) and experienced stigma, assuming a mutual influence: COVID-19 is more easily spread in over-crowded, poorer areas; on the other hand, COVID-19 can lead to a loss of livelihood of those infected. We did not collect data on the economic situation, but used the occupational status as a proxy, which revealed no significant difference between the groups. However, this variable might fail to reflect more subtle socioeconomic differences between participants. Similar to Gopichandran et al. (2021) (41), our qualitative data suggested that experienced stigma differs with **residential site**: participants in more anonymous urban apartments experienced less stigma than those living in rural areas, where residents know each other and word by mouth travels quickly. On the other hand, participants from rural areas also reported more neighbourly support.

Reflexivity and possible bias

The interviews were conducted by phone, so physical appearance and body language did not influence the data, in contrast to face-to-face interviews. This can work in both directions: either participants appreciated the more anonymous atmosphere to share private information, or they would have preferred a more personal and intimate setting.

Talking to a medical doctor (LP), participants are used to sharing physical complaints rather than social experiences such as stigma. Participants often had the impression that their narratives were inappropriate or not of interest. Although participants were encouraged to share their stories, an expectation bias cannot be excluded. Since stigma is a sensitive topic, it is easily subjected to a social-desirability bias and hence bearing the risk of the respondents' inclination towards euphemized answers. Furthermore, a recall bias must be considered due to the retrospective character of the study. Ultimately, those participants who volunteered to be interviewed were mostly of German origin. The requirement of an advanced level of German might have limited the diversity of study participants and caused a selection bias, since the sample is unlikely to represent all cultural groups and ethnicities living in Germany.

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Conclusion and implications for stakeholders

Around the globe, stigma is a social phenomenon that cuts through all layers of society. It is intertwined with or aggravated by social factors that can lead to 'othering' and discrimination. It can limit access to healthcare and other public services and can therefore be seen as a social determinant of health equity and a hidden burden of disease. Stigma arises from perceived careless behaviour and irrational fear of infection, which emerge from misconceptions about the disease. Information about COVID-19 in social media is often incorrect (59) or biased (25) and people have difficulties finding reliable sources (11) to distinguish between fake and fact. In line with previous research (29), we emphasize the need of providing accurate information and exposing misinformation on disease prevention and treatment to end COVID-19 related stigma.

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Figure legends

Figure 1: A) Social Impact Scale, overall score. B) Dimensions of stigma. High numbers equal high level of experienced stigma.

Figure 2: Comprehensive framework of experienced stigma and applied coping strategies, stratified by societal layer

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Statements

a. Contributorship

- Conceptualisation: LP, BG
- Methodology: LP
- Data acquisition: LP
- Initial analysis: LP
- Interpretation of data: LP, SB, CB, BG
- Writing - original draft: LP
- Visualization: LP
- Writing - review and editing: SB, CB, BG
- Final approval: LP, SB, CB, BG
- Accountability: LP, SB, CB, BG

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c. Competing interests

The authors declare that there is no conflict of interest.

d. Data sharing statement

Data (both quantitative and original German qualitative data) are available on request.

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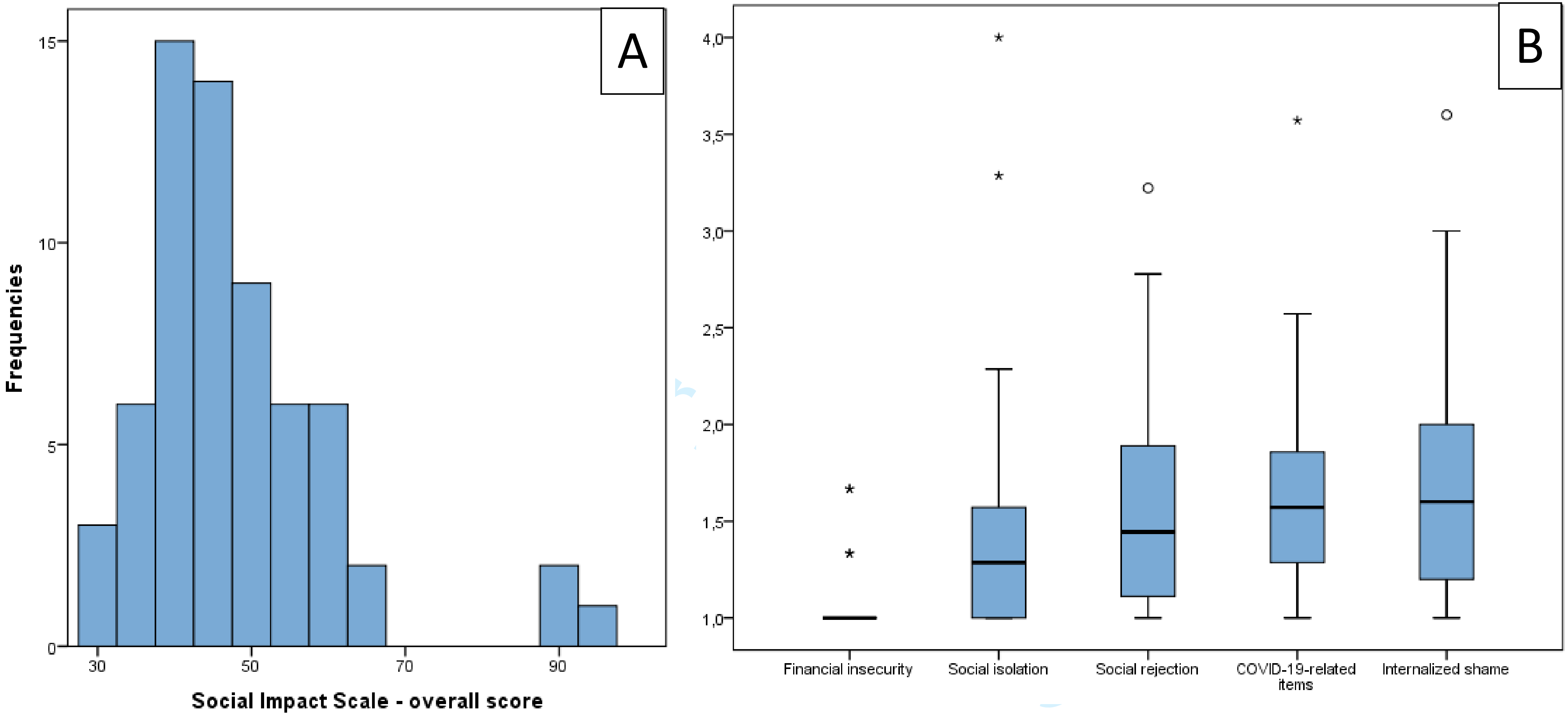
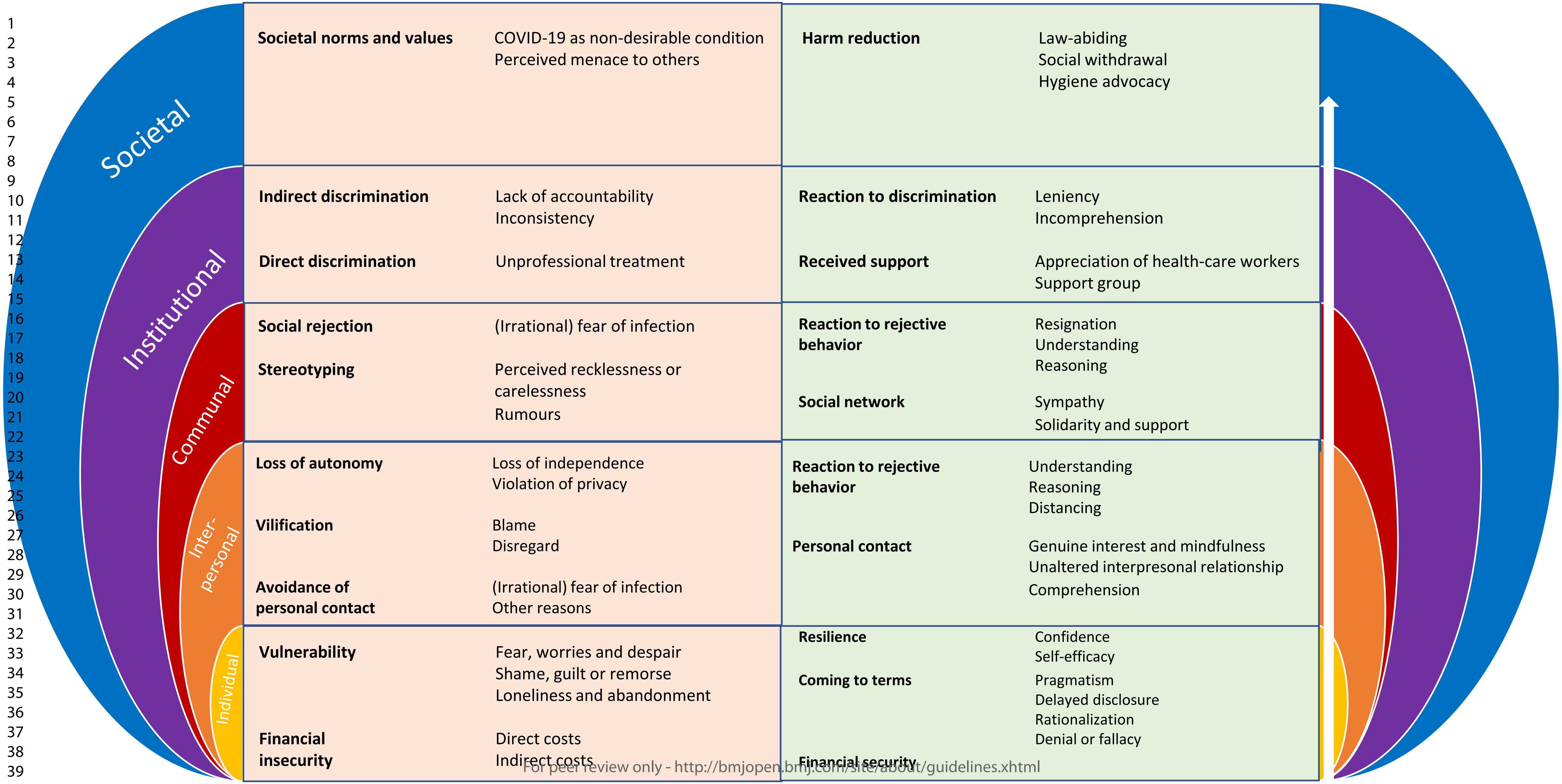

A
Frequencies
15
10
5
0
30
50
70
90
Social Impact Scale - overall score
B
4,0
3,5
3,0
2,5
2,0
1,5
1,0
Financial insecurity
Social isolation
Social rejection
COVID-19-related items
Internalized shame



	Experienced stigma		Applied coping strategies	
Societal	**Societal norms and values**	COVID-19 as non-desirable condition Perceived menace to others	**Harm reduction**	Law-abiding Social withdrawal Hygiene advocacy
Institutional	**Indirect discrimination**	Lack of accountability Inconsistency	**Reaction to discrimination**	Leniency Incomprehension
	Direct discrimination	Unprofessional treatment	**Received support**	Appreciation of health-care workers Support group
Communal	**Social rejection**	(Irrational) fear of infection	**Reaction to rejective behavior**	Resignation Understanding Reasoning
	Stereotyping	Perceived recklessness or carelessness Rumours	**Social network**	Sympathy Solidarity and support
Inter-personal	**Loss of autonomy**	Loss of independence Violation of privacy	**Reaction to rejective behavior**	Understanding Reasoning Distancing
	Vilification	Blame Disregard	**Personal contact**	Genuine interest and mindfulness Unaltered interpresonal relationship Comprehension
	Avoidance of personal contact	(Irrational) fear of infection Other reasons		
Individual	**Vulnerability**	Fear, worries and despair Shame, guilt or remorse Loneliness and abandonment	**Resilience**	Confidence Self-efficacy
			Coming to terms	Pragmatism Delayed disclosure Rationalization Denial or fallacy
	Financial insecurity	Direct costs Indirect costs	**Financial security**	

Supplementary material

S1) COVID-19-related questions added to the Social Impact Scale

S2) Interview guide

S3) Table with quotes for experienced stigma

S4) Table with quotes for applied coping strategies

S1) Additional COVID-19-related questions (additional to the Social Impact Scale)

1. Ich hatte die Befürchtung, dass andere aufgrund meiner längeren Abwesenheit meine Erkrankung erahnen konnten.

1. I was worried that others might suspect my illness due to my long absence.

2. Ich habe mich schuldig gefühlt, dass ich (eventuell) andere angesteckt habe, auch wenn dies unwissentlich geschah.

2. I feel guilty because I accidentally might have infected others.

3. Als ich auf meine krankheitsbedingte Abwesenheit angesprochen wurde, habe ich offen gesagt, dass ich an COVID19 erkrankt war.

3. When I was asked about my absence, I admitted that I had COVID-19.

4. Als ich nach meiner Erkrankung zurück in die Arbeit kam oder mich mit Freunden getroffen habe, hatte ich Sorge, wie meine Kollegen/Freunde wohl auf mich reagieren würden.

4. When I met colleagues or friends after being ill, I was worried how they would react towards me.

5. Wenn jemand mit mir über meine Erkrankung spricht, ist mir das unangenehm.

5. It makes me feel uncomfortable if someone alludes to my illness

6. Ich wünschte, es hätten weniger Leute von meiner Erkrankung erfahren.

6. I wish less people had known about my illness.

7. Ich habe das Gefühl, durch Institutionen (z.B. Gesundheitsamt, Arztpraxis, Rettungsdienst etc.) ungerecht oder nachteilig behandelt worden zu sein.

7. I feel that I have been treated unfairly or adversely by institutions (health authority, family doctor, paramedics)

S2) Interview guide

Alter / Geschlecht/ höchster Bildungsabschluss/ Schwere der COVID-19-Erkrankung
Age/ Gender/ highest level of education/ severity of COVID-19

1. Was ging Ihnen durch den Kopf, als Sie erfuhren, dass der Test positiv ausgefallen war?

1. What was going through your mind when you received the positive COVID-19 test result?

2. Wie hat sich ihr Leben verändert, seitdem Sie an COVID19 erkrankt waren?

2. Did your life change since you had COVID-19? If yes, how did change?

3. Haben Sie jetzt noch gesundheitliche Beschwerden, auch wenn die Erkrankung als ausgeheilt gilt?

3. Do you still have any symptoms, even if the infection is cured?

4. Wie haben Sie die Zeit in Quarantäne erlebt?

4. How did you experience the time in quarantine?

   a. Wie sah ein typischer Alltag in der Isolation aus?

   a. How did your everyday routine in quarantine look like?

   b. Was war besonders schwierig in dieser Zeit?

   b. What was particularly difficult during that time?

5. Mit wem konnten Sie offen über Ihre Erkrankung sprechen?

5. Who could you talk to about your condition?

6. Gab es Situationen, in denen Sie gezögert haben, offen über Ihre Erkrankung zu sprechen?

6. Have you experienced a situation where you hesitated to talk freely about your infection?

7. Wie fielen die Reaktionen der Mitmenschen auf die Erkrankung aus?

7. How did people react to your infection?

8. Haben Sie das Gefühl, dass andere Sie anders behandeln, als vor Ihrer Erkrankung?

8. Do you have the feeling, that others treat you differently since you had COVID-19?

   a. Inwiefern?

   a. How so?

   b. Beispiel?

   b. Example?

   c. Wie sind sie damit umgegangen?

   c. How did you cope with/ handle the situation?

9. Gab es Reaktionen von Mitmenschen als diese von Ihrer Erkrankung gehört haben, die Sie überrascht haben? (positiv und negativ), und wenn ja, inwiefern?

9. Did you experience reactions of others when they heard about you having COVID-19 which surprised you, either in a good or in a bad way?

10. Das Gesundheitsamt muss alle Kontaktpersonen informieren bzw. Sie mussten die Kontaktpersonen angeben – wie war das für Sie?

10. The health authority was obliged to inform every person you had been in contact with when you were diagnosed with COVID-19 – how did you feel about that?

11. Wie war das in der Arbeit, wie reagierten Kollegen auf Sie, als Sie zurückkamen?

11. At work, how did colleagues react when you came back?

12. Es besteht immer das Risiko, unbewusst andere Personen anzustecken. Wie ging es Ihnen damit und wie sind Sie damit umgegangen?

12. There is always a risk to infect others, unknowingly. How did you feel about this and how did you cope with it?

13. Im Nachhinein ist man immer schlauer. Denken Sie manchmal, dass Sie hätten verhindern können, dass Sie sich angesteckt haben?

13. In hindsight, do you think you could have prevented catching COVID-19?

14. Angenommen ein guter Freund von Ihnen würde jetzt an COVID19 erkranken – wie würden Sie sich verhalten? (Vignette)

14. Assuming a close friend of yours would catch COVID-19, how would you react? (vignette)

15. Hatten Sie aufgrund der Erkrankung finanzielle Sorgen?

15. Did you have financial problems because of having had COVID-19?

S3) Experienced stigma by societal level

Theme	*Type of stigma*	Code (n*)	Quotes
Individual level			
Vulnerability	-	Fear, worries and despair (n = 11)	‘I was thinking «why me?»… and «I hope this ends well…»’ (female, 50-59 y/o) ‘I was thinking about death, about becoming even sicker and needing assisted ventilation… This was in the back of my head all the time. I really hope I don’t catch it [SARS-CoV-2] again….’ (female, 70-79 y/o) ‘It got worse and worse, I couldn’t talk, I couldn’t breathe…. I was on my own and…[stops speaking and starts to cry]’ (female, 70-79 y/o) ‘When I woke up again, I knew I would survive…. but still, I was having these panic attacks’ (male, 60-69 y/o) ‘I was afraid I could die. I saw it happen to other patients. It was frightening. The whole situation was frightening.’ (male, 40-49 y/o) ‘You have this feeling that there is nothing to look forward to….’ (male, 30-39 y/o)
	Internalised stigma / Perceived stigma	Shame, guilt or remorse (n = 14)	‘Of course you feel bad knowing you infected others’ (female, 20-29 y/o) ‘I talked to the people who went into quarantine because of me to make sure they are okay’ (male, 60-69 y/o) ‘I took the wrong decision to go there [place where he was infected]. I had this gut feeling that there is something wrong, that I shouldn’t go there. But my friends told me to come with them…. I should have listened to my gut feeling.’ (male, 50-59 y/o) ‘I really don’t want to talk about it’ (male, 50-59 y/o, sounding distressed), as response to the question, if he accidentally infected others.
		Loneliness and abandonment (n = 14)	‘We all felt left alone. We didn’t have any kind of support, neither by a doctor nor the public health authority. No one contacted us for days in a row and we started feeling afraid if all of that [referring to the COVID-19 symptoms] were still normal. Somehow, we felt left alone.’ (female, 50-59 y/o) ‘People didn’t want to have contact with me. This was especially hard for me, since I had been abroad before for two months, this really got to me.’ (female, 20-29 y/o) ‘You feel that your social network isn’t there, the ones you need most aren’t with you.’ (female 50-59 y/o) ‘Being on my own was the hardest part.’ (male, 60-69 y/o) ‘You feel lonely. There was no one to talk to.’ (female, 70-79 y/o) ‘You learn very quickly who stands by your side in these difficult times and who lets you down…’ (male, 50-59 y/o)
Financial insecurity	-	Direct costs (n = 2)	‘That [not having COVID-19] would have saved me a great deal. Luckily, my health insurance covered most of the expenditures, but since my deductible is rather high, this disease caused a great financial loss for me.’ (male, 50-59 y/o) ‘If I hadn’t had any savings, it would have been problematic….’ (male, 40-49 y/o)

		Loss of income / indirect costs (n = 1)	‘I have to earn my money with physical labour. When I can’t work, I don’t earn money…’ (male, 50-59 y/o)
Interpersonal level			
Loss of autonomy	*Perceived stigma / (Enacted stigma)*	Loss of independence (n = 5)	‘As we were all in quarantine, we relied on others to supply us with food’ (female, 50-59 y/o) ‘We were all isolated, other people had to take care of us.’ (female, 20-29 y/o)
		Violation of privacy (n = 4)	‘When I was gone and they knew about it [COVID-19], they turned my whole workplace upside down’ (male, 50-59 y/o) ‘I live in a small village and within two hours, everyone knew about it [COVID-19]’ (female, 20-29 y/o)
Vilification		Blame (n = 9)	‘Some people said it is my own fault that I got infected.’ (male, 50-59 y/o) ‘They didn’t talk bad in front of me…. but behind my back, I could sense that they thought it’s my own fault’ (male, 50-59 y/o) ‘They [family members] were very angry with us that we didn’t tell them about our infection. But we didn’t know ourselves at that time and didn’t have any symptoms! How should we know that we were ill?’ (female, 50-59 y/o) ‘She [a niece] was at our place before [we knew we had COVID-19] and it took a long time until she was able to get a test. She is still holding a grudge until today….’ (female, 50-59 y/o)
		Disregard (n = 4)	‘People didn’t understand what I was going through. They said «it’s like a flu», but for me, it didn’t feel just like a flu. No one said «this sounds really bad»’ (female, 50-59 y/o) ‘They [acquaintances] did not really care about what had happened to me.’ (female, 20-29 y/o) ‘My sister said, as long as you don’t need invasive ventilation, it’s not that bad. But for me, just needing oxygen was already more than enough….’ (female, 50-59 y/o)
Avoidance of personal contact	*Enacted stigma*	(Irrational) fear of infection (n = 27)	‘In the beginning it felt like people were really scared of me.’ (female, 20-29 y/o) ‘Meeting people in person [in contrast to talking in the phone] was different. People become…. very careful’ (male, 30-39 y/o). ‘My aunt living next door kept her distance for weeks after my quarantine had ended, as if I were still contagious.’ (female, 20-29 y/o) ‘I noticed some people take a step back when I told them [about the COVID-19-infection]’ (male, 50-59 y/o) ‘Everyone you tell that you had COVID flinches and takes a step back’ (male, 50-59 y/o) ‘Many people withdrew from me for a long time…. I think they were still afraid of getting infected’ (female, 70-79 y/o)
		Other reasons (n = 2)	‘She distanced herself from me. I don’t know why, she doesn’t even believe in COVID.’ (female, 50-59 y/o)
Community level			
Social rejection	*Enacted stigma*	(Irrational) fear of infection (n = 6)	‘When I did my groceries and kept a 2 to 3 meters distance, people still told me to go further away…. they even changed the side of the street when they saw me.’ (female, 20-29 y/o) ‘When I went back to the office, some colleagues told me straight to the face they didn’t like having me there. We are working in shifts and they would change shifts so they didn’t have to work with me.’ (male, 30-39 y/o)

			‘When I went to the hairdresser, I told them I really needed a haircut since I had had COVID 3 months ago. First, they refused to cut my hair, they were afraid of getting infected.’ (male, 40-49 y/o)
Stereotyping	*Perceived stigma*	Perceived recklessness or carelessness (n = 4)	‘Now you [meaning the interviewer] are probably going to say «how on earth could you go skiing, and how could you go there [place where she got infected]?!?», but back then it wasn’t that obvious….’ (female, 20-29 y/o) ‘People asked, why did go there, when it was a hotspot.’ (male, 50-59 y/o) ‘If a friend of mine had COVID, I would support him and say it’s not his fault that he got it. We didn’t choose for this either. I’d say it’s okay. I wouldn’t treat him any different and just act normal’ (female, 50-59 y/o)
		Rumours (n = 2)	‘In town, everyone acted like they knew better why I was infected’ (female, 20-29 y/o)
Institutional level			
Indirect discrimination	*Structural and enacted stigma*	Lack of accountability (n = 10)	‘They [health authorities] gave us a number where we could call, but no one ever answered the phone.’ (female, 20-29 y/o) ‘When I should be discharged from the hospital, and I was still contagious, they [the hospital staff] told me there was no transport to get me home, of course I wasn’t allowed to use the public transport and a family member should pick me up. But they were all in quarantine. I tried to contact the public health authority all day long to get a permission for my mother to pick me up, that was very distressing for me. Then they [the hospital staff] came all of the sudden and said I had to go now.’ (female, 20-29 y/o). ‘After we knew we had been in a hotspot, we tried to get a test. When finally someone answered the phone, they told us we couldn’t get a test since the place wasn’t officially declared a hotspot yet.’ (female, 20-29 y/o) ‘Even when I felt bad, it was impossible to find a doctor to talk to… so in the end I called 112 [national emergency number]’ (female, 50-59 y/o) ‘The worst thing was to get to the hospital in the first place…. So I dialled that number, but ended up in an endless waiting loop. In the other clinic it was exactly the same. I called my general practitioner; he wrote me a sick note for a week. But I didn’t need that, I told him I need help… but all he did was writing a second sick note for another week…. Either you are rejected right away or you end up in an endless waiting loop on the phone.’ (male, 50-59 y/o) ‘When I came back home [from a hotspot] my friend who was with me tested positive. The health authority didn’t contact me for days. Then I called them, and they said they were not responsible, another authority is responsible for my case. So I called them, but they said, the first authority was responsible….’ (male 50-59 y/o)
		Inconsistency (n = 4)	‘First, they [public health authority] sent us to a testing centre because we had been to an endemic area. But later they were upset that we went there, since we were supposed to stay at home in quarantine….’ (female, 20-29 y/o) ‘First they told me I have to stay in quarantine for another 2 weeks after I was discharged from the hospital. On the last day of my quarantine, my son got a letter that he needs to stay in quarantine for another 2 weeks, in case he got infected on my last day in quarantine. But my wife and daughter didn’t have to stay in quarantine any longer, but we were all members of the same household. That didn’t make any sense.’ (male, 50-59 y/o) ‘They [the health authority] told me on the phone my quarantine ended on Thursday. Then I got the letter from them saying I needed to stay in quarantine for another 2 weeks’ (male, 50-59 y/o)

Direct discrimination		Unprofessional treatment (n = 4)	'Since I was the second patient in that other hospital, they had a lot of «respect» of me and avoided coming close to me… that was even worse for me than the [rejecting] behaviour of other people.' (female, 20-29 y/o) 'After I was discharged from the hospital, I wanted to go to the general practitioner for a prescription but they told me I wasn't allowed there, even though I wasn't in quarantine anymore. Then 12 weeks later, I needed a letter of transferral, but even then, my sister had to get it for me…' (male, 60-69 y/o) 'When he [a friend] stayed at home because one of our group tested positive, his boss counted that as vacation, because the health authority hadn't called yet.' (male 50-59 y/o) 'I was feeling so bad, but in that other hospital they [staff] told me to leave immediately, they threw me out…. so I was crying in front of the hospital until my daughter came to get me. A few days later, I collapsed, and I was brought in here and needed oxygen' (female, 70-79 y/o)
Societal level			
Societal norms and values	*Perceived and internalized values and stigma*	COVID-19 as non-desirable condition (n = 5)	'When I got the positive test, I was utterly shocked' (female, 20-29 y/o) 'I was surprised. I never thought *we* would get it.' (female, 50-59 y/o) 'I was just feeling ill and coughing. Maybe it wasn't COVID after all. They [the doctors] said the CT-scan confirmed it, but my test was negative.' (male, 50-59 y/o, denying he had COVID-19)
		Perceived menace to others (n = 10)	'I didn't want to bother people. Maybe they would have thought I am still contagious.' (female, 70-79 y/o)** 'None of my family members got ill, I didn't infect anyone.' (male, 30-39 y/o)** 'We all paid a lot of attention. We didn't infect others.' (male 50-59 y/o)** Q: 'Do you happen to know if you accidentally infected somebody?' A: 'I don't want to talk about that.' (male, 50-59 y/o)

* n = the number how many times this code was applied throughout the interviews

** The assurance of not having infected others reflects the perceived stigma as menace to others and the public health on one hand and efforts to contain the disease as coping with this perception on the other hand.

S4) Applied coping strategies by societal level

Theme	Code (n*)	Quotes
Individual level		
Resilience	Confidence (n = 5)	'I knew I was getting medication; I was sure that would help, otherwise they wouldn't give them to me. I wasn't worried I would die.' (male, 60-69 y/o) 'I felt in good hands.' (male, 50-59 y/o) 'None of us felt that sick that we needed to go to the hospital.' (female, 50-59 y/o)
	Self-efficacy (n = 2)	'In the beginning it was very hard for me. But as soon as I managed to structure my day, time just flew by.' (male, 30-39 y/o)
Coming to terms	Pragmatism (n = 2)	'I had it [COVID-19], that's all there is. Now I am cured and immune.' (female, 70-79 y/o)
	Delayed disclosure (n = 3)	'Back then, I told them [friends and family] I had it [COVID-19]. But I didn't tell them any details. Now I would, but back then, I just didn't want to.' (male, 40-49 y/o) 'In the beginning, I didn't want to share with anyone. Afterwards, we talked about it.' (female, 70-79 y/o) 'I would not go around and tell everyone deliberately that I had it [COVID-19]. But now it is over, if anyone asked, I would answer honestly that I had it.' (male, 30-39 y/o)
	Rationalisation (n = 2)	'We checked the incidence before we went, and it looked fine, so we didn't see any danger in going there [to a hotspot]' (female, 20-29 y/o) 'When I was there, it wasn't known to be a hotspot' (male, 50-59 y/o)
	Denial or fallacy (n = 1)	'Maybe I didn't have it [COVID-19]. I even know couples, where one had it and the other didn't' (male, 50-59 y/o)
Financial security	Financial security (n = 8)	'I didn't face any financial problems, my salary just continued.' (male, 40-49 y/o) 'I was on sick leave and got my loan as usual.' (female, 20-29 y/o) 'I am retired, so I didn't have any financial problems.' (female, 70-79 y/o)
Interpersonal level		
Reaction to rejective behaviour	Understanding (n = 10)	'I could totally understand their [friends] behaviour. No one knew exactly how long people can transmit COVID' (female, 20-29 y/o) 'I could understand that, I didn't blame anyone.' (female 70-79 y/o)
	Reasoning (n = 2)	'I tried to explain, I argued with them [family members]…. but with some people, you just can't reason at all.' (female, 50-59 y/o) 'When they [friends] took a step back, I told them there was no reason, they could hug me, I am no longer contagious.' (male 50-59 y/o)
	Distancing (n = 2)	'When heard about what others said, I just distanced myself from that.' (male, 50-59 y/o)

Personal contact	Genuine interest and mindfulness (n = 7)	‘In a way, we were lucky, that the whole family was in quarantine, so we had each other’ (female, 20-29 y/o) ‘It is very important, that there are people who care about you and want to know how you are doing. My mum called every day to check on me, that felt good.’ (male, 30-39 y/o) ‘I would call and make sure he [friend from vignette] is okay. I would tell him, everything is going to be fine, since he is young.’ (female, 20-29 y/o) ‘Some people just want to know more about it from people who had it [COVID-19] and are very interested in what I experienced.’ (male, 30-39 y/o)
	Unaltered interpersonal relationship (n = 4)	‘With my friends, it is same way as it has been before. No distance, not too many questions.’ (male, 30-39 y/o) ‘I infected my boyfriend, but he remained relaxed.’ (female, 20-29 y/o) ‘When I came home from the hospital, everyone was just so happy to see me, that was very touching.’ (male, 50-59 y/o)
	Comprehension (n = 4)	‘I talked to a friend in a similar situation, and she could totally relate.’ (female, 20-29 y/o) ‘People told me it’s a miracle I got through all of this without serious psychological damage. When we talked about it, it became clear, that others were frightened of being alone in such a situation as well’ (female, 70-79 y/o) ‘If a friend of mine had COVID, I would support him and say it’s not his fault that he got it. We didn’t choose for this either.’ (female, 50-59 y/o)
Community level		
Reaction to rejective behaviour	Resignation (n = 3)	‘I can live with it [people avoiding him]. I take it with humour.’ (male, 50-59 y/o) ‘I didn’t really bother. Couldn’t change it anyway. (…) You have to take it the way it is.’ (male, 40-49 y/o)
	Understanding (n = 3)	‘That was a new situation, people probably didn’t know better.’ (female, 20-29 y/o) ‘I tried to understand their reaction [people at work] and asked myself, how I would have reacted. And honestly, I would keep my distance too. That is probably human.’ (male, 30-39 y/o)
	Reasoning (n = 2)	‘I told them [people in a grocery store] I am no longer contagious and that they don’t need to keep a 10-meter distance. I fact, I am less dangerous than other people.’ (female, 20-29 y/o)
Social network and inclusion	Sympathy (n = 7)	‘So many people called during my absence to make sure I am okay, and they were so happy to hear from me when I called them back.’ (male, 60-69 y/o) ‘I received so much sympathy, from friends and relatives, but also from the whole community, where I am active in different associations. They all felt for me and asked «Hey, how are doing?». I got a lot of positive signals. They just wanted me to recover soon.’ (male, 60-69 y/o)
	Solidarity and support (n = 7)	‘From time to time, a neighbour would leave something for me at my door.’ (female, 20-29 y/o) ‘Many people from our village offered help and asked if they could get us anything. I was surprised by their willingness to help.’ (female, 50-59 y/o) ‘Some neighbours made food and left it at the door for us. They really cared about us’ (male, 50-59 y/o)
Institutional level		
Reaction to discrimination	Leniency (n = 8)	‘I guess they [the health authorities] were just overwhelmed’ (male, 50-59 y/o) ‘I hope by now, it is more organised’ (female, 50-59 y/o) ‘Those people refusing the regulations don’t carry the responsibility. Everyone with that kind of responsibility supports a lockdown.’ (male, 50-59 y/o)

	Incomprehension (n = 8)	'I was feeling sick and I couldn't get through [by telephone] to any doctor or health authority for days to get a test. That really bothered me.' (female, 20-29 y/o) 'I really felt mocked by the health authorities.' (female, 20-29 y/o) 'For me, it was extremely hard. (…) That is why I didn't tell the health authority I also had contact with my parents. I didn't want to do this to them' (male, 30-39 y/o)
Received support	Appreciation of health-care workers (n = 4)	'He [family doctor] called every day to make sure I was okay. That felt good.' (female, 70-79 y/o) 'I remember a doctor who was looking for possible treatment options all day long and called another university hospital. In the end, the treatment saved me' (male, 50-59 y/o) 'The hospital staff was very caring and always very kind' (male, 60-69 y/o)
	Support group (n = 2)	'Is there a self-help group for COVID survivors?' (male, 50-59 y/o)
Societal level		
Harm reduction	Law-abiding (n=5)	'I kept my distance, I stuck to the rules, I didn't infect anyone.' (female, 70-79 y/o)** 'When we came back [from a hotspot] we stayed at home. So when we finally knew we had it [COVID-19], at least I didn't feel guilty, because I knew I didn't infect anyone else.' (female, 20-29 y/o) 'I was scared to infect anyone. We barely had contact, I wore a mask when I went to the bathroom, I did my laundry separately, just like the health authority told me to. In the end, none of my family members got ill, I didn't infect anyone.' (male, 30-39 y/o)** 'We all paid a lot of attention. We didn't infect others.' (male 50-59 y/o)**
	Social withdrawal (n = 3)	'I didn't want to bother people. Maybe they would have thought I am still contagious.' (female, 70-79 y/o) 'When my quarantine ended, I didn't ask people to meet. I was afraid they would react…. in a strange way.' (female, 20-29 y/o) 'I am only on contact with my closes relatives.' (male, 50-59 y/o)
	Hygiene advocacy (n = 3)	'I tell everyone, they should wear their face masks.' (female, 70-79 y/o) 'No matter where we go, with all our friends, we have this discussion [about the need for regulations and hygiene practices], it is the only way. When people say «It is only a flu.», I tell them, it is not. It is a whole different affair.' (male 60-69 y/o)

* n = the number how many times this code was applied throughout the interviews

** The assurance of not having infected others reflects the perceived stigma as menace to others and the public health on one hand and efforts to contain the disease as coping with this perception on the other hand.

Perception of legal stipulations (measures of containment, mandatory face mask, curfew)	Support (n = 5)	‘I tell everyone, they should wear their face masks, if they got it [COVID-19], it’s to late.’ (female, 73 y/o) ‘I wish people would pull themselves together. (…) If you are unlucky, you are gone.’ (male, 69 y/o)
	Acceptance (in spite of struggle) (n = 6)	‘I longed to go out for a walk….but I stayed inside’ (female, 25 y/o) ‘We were all cramped together. After some time, it is normal you go on each other’s nerve…. Then you need to withdraw to have your own space’ (female 23 y/o)
	Confusion (n = 6)	‘I think the whole topic is very confusing, I am missing a clear line. The regulations are different in different places, that confuses people.’ (female, 51 y/o) ‘Sometimes, the regulations seem a bit random.’ (male, 38 y/o) ‘Of course we need certain restrictions, but sometimes it feels like those in charge didn’t really think that through.’ (female, 25 y/o)
	Doubt and refuse (n = 3)	‘For me, it was extremely hard. (…) That is why I didn’t tell the health authority I also had contact with my parents. I didn’t want to do this to them’ (male, 38 y/o) ‘I am not sure, if wearing these masks is really the solution for this problem.’ (male, 53 y/o) ‘I am not supporting these masks…. It is hard to breathe.’ (male 55 y/o)
	Hope (n = 2)	‘Maybe we can all go back to normal soon.’ (male, 38 y/o)

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Title and abstract

	Page/line no(s).
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	p 1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	p 1

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	p2
Purpose or research question - Purpose of the study and specific objectives or questions	p2

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	p4
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	p14
Context - Setting/site and salient contextual factors; rationale**	
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	p4
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	p4
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	p4-5

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Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	p4 (S2)
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	p4-5 and table 1
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	p4-5
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	p5
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	p5

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	p7-11 (and figure 3 as model)
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	p7-p11 (and more quotes and notes in S3, S4)

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	p12-14
Limitations - Trustworthiness and limitations of findings	p14

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	p15
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	p15

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014 DOI: 10.1097/ACM.0000000000000388

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STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1 and 2
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4
Objectives	3	State specific objectives, including any prespecified hypotheses	4
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	5
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	*5*
Bias	9	Describe any efforts to address potential sources of bias	5
Study size	10	Explain how the study size was arrived at	5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	5
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	5
		(*b*) Describe any methods used to examine subgroups and interactions	5
		(*c*) Explain how missing data were addressed	5
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy	5
		(*e*) Describe any sensitivity analyses	5

Continued on next page

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Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7
		(b) Give reasons for non-participation at each stage	(7)
		(c) Consider use of a flow diagram	n.a.
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	5
		(b) Indicate number of participants with missing data for each variable of interest	(7)
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	n.a.
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	*n.a.*
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	*n.a.*
		Cross-sectional study—Report numbers of outcome events or summary measures	*7*
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	7
		(*b*) Report category boundaries when continuous variables were categorized	n.a.
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n.a.
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	8
Discussion			
Key results	18	Summarise key results with reference to study objectives	13
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	15
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	13/14
Generalisability	21	Discuss the generalisability (external validity) of the study results	14
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	1

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Experienced stigma and applied coping strategies during the COVID-19 pandemic in Germany

- A mixed methods study -

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Abstract

Objective Health-related stigma is considered a social determinant of health equity and a hidden burden of disease. This study aimed to assess the level and dimensions of stigma and respective coping mechanisms in COVID-19-survivors.

Methods A mixed-methods study with sequential explanatory design was conducted at the University Hospital of Ulm, Germany. Stigma was assessed using the Social Impact Scale (SIS) including adult COVID-19 survivors with mild to severe disease. Subsequently, 14 participants were sampled with regard to gender, age and severity of disease for in-depth interviews to understand how stigma was experienced and coping strategies were applied. The questionnaire was analysed using descriptive statistics, *t*-test and ANOVA. Content analysis was used for qualitative data.

Results From 61 participants, 58% were male and mean age was 51 years. The quantitative analysis of the SIS indicated an intermediate level of experienced stigma. Participants experienced stigma mainly as 'social rejection' ($M = 14.22$, $SD = 4.91$), followed by 'social isolation' ($M = 10.17$, $SD = 4.16$) and 'internalized shame' ($M = 8.39$, $SD = 3.32$). There was no significant difference in experienced stigma regarding gender, education, occupational status, or residual symptoms. However, participants between 30 and 39 experienced higher levels of stigma than other age groups ($p = 0.034$). The qualitative analysis revealed how stigma seemed to arise from misconceptions creating irrational fear of infection, leading to stereotyping, vilification, discrimination, and social exclusion of COVID-19 survivors, leaving them feeling vulnerable. Stigma cut through all social levels, from the individual level at the bottom to the institutional and societal level at the top. Social networks protected from experiencing stigma.

Conclusion COVID-19-related stigma is a relevant burden in the ongoing pandemic. Providing accurate information and exposing misinformation on disease prevention and treatment seems key to end COVID-19 related stigma.

Strengths and limitations of this study

Strengths

- Mixed-methods approach to gain an in-depth understanding of COVID-19 related stigma and applied coping strategies
- Detailed list of quotes for every theme to increase transparency, objectivity, and traceability

Limitations

- Telephone interviews instead of face-to-face interviews because of contact regulations
- Single-centre study design
- Lack of a validated instrument particularly designed to assess stigma in COVID-19 survivors

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Introduction

Health-related stigma is a social phenomenon, which implies a negative attitude towards people with a certain condition (1,2). Stigma occurs in different forms (3): It can result from assumed attitudes of others (perceived stigma), discriminatory behaviours (enacted stigma), a shift to a devalued self-perception (internalized stigma) and inequities embedded in policies, institutions, and social organizations (structural stigma). Regarding health, stigma is often seen as a hidden burden of disease (4) and a social determinant of health and health inequity (5). It generates psychological stress (6) and causes affected people to hide their condition with severe consequences for their own health, and in case of infectious diseases, for public health (7). In the context of the COVID-19 (coronavirus disease 2019) pandemic, the risk of stigmatization has been addressed early (8–10) and reports of discrimination against patients and survivors have accumulated (11). Across the globe, people infected with or recovered from SARS-CoV-2 (Severe Acute Respiratory Syndrome Coronavirus-2) became a target of ostracism, humiliation, harassment and even violence. Studies from Pakistan, Uganda, Malaysia, India, China, Ghana, Iran and Brazil found that COVID-19 survivors and even their families were often rejected from social life or essential services and felt humiliated (12–21). COVID-19 survivors were blamed for the disease (13,15,16) and perceived as a source of infection even after being cured (12,16,21,22), some reported finical hardship as a consequence (13,19,23). Stereotyping was common (15), especially blaming the poor, labourers and migrants (16) or people of seemingly Asian origin (24–26). Research from Malaysia, Iran and Tunisia found that affected people made efforts to hide the infection (15,20,27). Due to stigma, people with suspected COVID-19 might avoid testing or treatment facilities, leading to poor health outcomes and the further spread of the virus.

So far, most studies were conducted in low- and middle-income countries and little is known about the phenomenon in high-income countries. Labbé et al. (2022) (24) analysed editorial cartoons from Canadian newspapers and found, amongst others, a stigmatising attitude towards people from certain geographical areas with high SARS-CoV-2 incidence rates. A recent study from Spain using a survey among the general population could demonstrate that discrimination and internalised stigma increased and decreased with the dynamic of the pandemic (28). To the best of our knowledge, no study so far assessed COVID-19 related stigma in survivors from high-income countries. Therefore, our objective was to evaluate the level and dimensions of experienced stigma and applied coping strategies in COVID-19 survivors during the early pandemic in a high-income setting.

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Methods

Sampling and data collection

We conducted a sequential explanatory mixed-method study in the area of Ulm, Germany. Every adult with positive SARS-CoV-2-PCR nasopharyngeal swab was included that presented either at the hospital's outpatient COVID-19-testing centre, the hospital's emergency room or that was admitted to the hospital between March and May 2020 (n = 150). Exclusion criteria were age < 18 years and death during hospitalisation. The 'Social Impact Scale' (SIS) questionnaire (quantitative methods), a form assessing residual symptoms and socio-economic factors and a form on which participants could optionally provide a phone number for the phone interviews were sent to the COVID-19 survivors 3 to 9 months *post infectionem*. After the quantitative analysis confirmed experienced stigma in COVID-19 survivors, a phenomenological approach was employed using in-depth interviews (qualitative methods) to explore why and how stigma was experienced and to assess possible coping strategies. The study was approved by the ethical board of the University of Ulm (No. 315/20).

Quantitative methods

The 'Social Impact Scale' questionnaire

Experienced stigma was assessed with the 24-item SIS questionnaire designed by Fife & Wright (2000) (29) for people living with HIV/AIDS or cancer and translated to German by Eichhorn et. al. (2015) with good psychometric properties (Cronbach's α = 0.81 - 0.89) (30). We added 7 additional COVID-19-related questions (c.f. supplementary material 1), which were evaluated separately. On a 4-point Likert scale, participants rate the given statements (items) from 'I strongly disagree' to 'I strongly agree' (1 to 4 points) resulting in an overall stigma score. These items are assigned to different dimensions of stigma, namely 'social rejection' (9 items), 'internalized shame' (5 items), 'social isolation' (7 items) and 'financial insecurity' (3 items) and are evaluated separately.

Statistical analysis

Statistical analyses were performed using IBM SPSS Statistics V23. Descriptive analyses included demographic information, post-COVID-19 symptoms, the overall level of stigma and its dimensions. Results are reported in means (M) and standard deviation (SD). Univariate analyses were performed assessing differences in experienced stigma regarding gender, age groups, education, occupational status, and residual symptoms using *t*-Test, ANOVA and correlation where appropriate. Missing data were handled by listwise exclusion. A significance level of $p < 0.05$ was considered significant.

Qualitative methods

Sampling and data collection

From those participants consenting to an in-depth interview, we purposefully sampled a broad range with high and low perceived stigma based on the questionnaire, different severity of disease, gender, age, and education to gain diverse accounts of the phenomenon. Data were analysed using MAXQDA Plus 2020. The analysis began after the 5th interview and data saturation was reached after the 11th. Three additional interviews were conducted to ensure no new themes emerged, resulting in a total number of 14 interviews. The interviews were held in German, being the native language of the participants and followed an interview guide (c.f. supplementary material 2). However, the interviewer (LP) aimed for an open discussion, allowing the interviewee to determine which topics to focus on. Due to contact regulations, the interviews were conducted by phone and recorded.

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Analysis and trustworthiness

After transcription, the analysis was conducted in English, i.e. English codes were applied to the German transcripts. Translating the transcripts to English was avoided in order to remain close to the source data and avoid a loss of information. LP used content analysis to develop a preliminary coding scheme from emerging codes and themes (inductive 'bottom-up' approach). Coding is the first step in qualitative analysis in which phrases are linked and shapes an idea (31–33), i.e. coding implies computing meaning (34). Subsequently, the interpretation of these rather explicit and descriptive codes generates more latent and subtle subthemes that give a deeper understanding of the phenomenon (35–37). As a final step, overarching themes evolve, which allowed organising the data into a comprehensive framework. To ensure reliability, the coding scheme was subsequently applied to the interviews by SB and BG (deductive 'top-down' approach). Deviant codes were discussed within the research team and adjusted (peer-check), resulting in a refined coding scheme. To increase transparency, additional tables with key quotes for each code are attached (c.f. supplementary material 3 and 4). Using mixed methods allows for methodological triangulation, i.e. assessing the phenomenon from different perspectives.

Patient and public involvement

This research was inspired by patients' narratives from our post-COVID-19 outpatient department. During follow-up visits, patients moved from physical complaints to social consequences they experienced after having COVID-19, which often involved stigma. The interview guide was informed by those narratives. As mentioned earlier, the interview was designed as an open discussion allowing the participants to prioritise topics and report their experiences freely. However, patients were not involved in designing or recruiting. We aim to offer a lay summary in German on our website to inform participants about the results.

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Results

Quantitative results

Descriptive results

In total, 61 questionnaires were analysed which equals a response rate of 41%. The socio-economic characteristics and residual symptoms are displayed in table 1.

Variable	**Results (%)**		**Residual Symptoms**	**N**	**%**
Age	M = 51 years (SD = 14.6, Min. = 18, Max. = 78)		Dyspnoea on exertion	11	20.4%
Gender	Male	58%	Fatigue	6	12.2%
	Female	42%	Paraesthesia	5	10.2%
Education	No formal education	0%	Cough	4	8.2%
	Lower secondary education, no graduation	11.5%	Sore throat	4	8.2%
	Lower secondary education, graduation	9.8%	Cephalgia	4	8.2%
	Intermediate secondary education	26.2%	Palpitations	4	8.2%
	Upper secondary education	18.8%	Rhinorrhoea	3	6.1%
	High school graduation	34.4%	Loss of smell and taste	3	6.1%
Occupation	Regularly employed	70.3%	Diarrhoea	2	4.1%
	Unemployed/ receiving pension	15.6%	Myalgia	2	4.1%
	Student/ trainee	6.3%	Xerophthalmia	2	4.1%
People informed about infection	Close family members	98.4%	Sleeping disorder	2	4.1%
	Friends	95.3%	Loss of hair	2	4.1%
	Acquaintances	81.3%	Lack of attention	2	4.1%
	Distant relatives	78.1%	Mucus	1	2.0%
	Close co-workers	76.6%	Dyspnoea without exertion	0	0%
	Neighbours	73.4%	Fever	0	0%
	Superiors	71.9%	Hearing loss	0	0%
	Distant co-workers	50.0%	Loss of vision	0	0%

Table 1: Socio-economic characteristics and residual symptoms

The Social Impact Scale

Each of the 31 items (24 SIS items and 7 COVID-19-realted items) was rated with 1 to 4 points, resulting in a possible total score of 31 to 124. The total stigma score in our cohort ranged from 31 to 97 with a mean of 48.1 (*SD* = 13.1), and a median of 45.0 (c.f. Figure 1A). Analysing the dimensions of stigma based on the 24 SIS items, 'internalized shame' (*M* = 1.68, *SD* = 0.66) and 'social rejection' (*M* = 1.58, *SD* = 0.55) showed the highest levels of stigma, followed by 'social isolation' (*M* = 1.45, *SD* = 0.59). 'Financial insecurity' (*M* = 1.17, *SD* = 0.46) played a minor role (c.f. Figure 1B). The overall mean per item was 1.55 (*SD* = 0.42). Adapted to the original questionnaire (29), we calculated aggregate means: 'social rejection' showed the highest aggregate mean (*M* = 14.22, *SD* = 4.91), followed by 'social isolation' (*M* = 10.17, *SD* = 4.16) and 'internalized shame' (*M* = 8.39, *SD* = 3.32) and, ultimately, financial insecurity (*M* = 3.51, *SD* = 1.38). The data were evenly distributed. Items of special interest are summarised in table 2.

Figure 1. A: Social Impact Scale, overall score. B: Dimensions of stigma. High numbers equal high level of experienced stigma.

Items with the highest experienced stigma:	***M***
'I feel others are concerned they could catch my illness.'	2.52
*'I feel guilty because I accidentally might have infected others.'**	2.03
'I feel others think I am to blame for my illness.'	2.00
'Due to my illness others seem to feel awkward and tense when they are around me.'	1.97
*'I feel institutions and professionals (health authority, health care workers) treated me unfairly.'**	1.81
Items with the lowest experienced stigma:	***M***
'I have experienced financial hardship that has affected my relationship with others.'	1.08
'Some family members have rejected me because of my illness.'	1.11

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'My job security has been affected by my illness.'	1.15

Table 2: Items of special interest from the questionnaire. *Additional COVID-19-related questions.

There was no difference in experienced stigma comparing gender ($t(59) = 0.437$, $p = 0.664$), educational level ($F(4) = 0.687$, $p = 0.604$), occupational status ($F(3) = 0.995$, $p = 0.404$) or residual symptoms (composite score of symptoms) ($r(46) = -0.250$, $p = 0.093$). However, there was a significant difference in age: participants between 30 and 39 experienced higher levels of stigma than other age groups ($F(6) = 2.499$, $p = 0.034$).

Qualitative results

Before conducting the interviews, participants were selected to balance gender, age groups, educational background, and severity of disease (c.f. table 3). Gender distribution and mean age were equivalent to the quantitative results. Participants from the ends of the age range, with different educational level and severity of disease were purposefully sampled.

The analytical process revealed how COVID-19 survivors experienced stigma as a multi-layered phenomenon: The descriptive codes and latent **subthemes** generated overarching **themes** that represent the societal layer in which stigma was experienced and coping strategies were applied. The following section will guide the reader through each layer, starting with the individual layer and continuing to the immediate and then wider environment. The number of times respective codes were applied throughout the interviews is indicated by (n). To keep this report concise, only one exemplary quote for every code is presented. However, we invite the reader to consult the supplementary materials S3 and S4, which offer additional quotes.

Gender (N)	Male: 8	Female: 6		
Age in years	Mean: 51.8	Median: 52	Min: 23	Max: 77
ISCED* 2011 level of education	Mean: 3.7	Median: 3	Min: 2	Max: 7
Severity of disease (N)**	Ambulatory mild disease: 4	Hospitalised, moderate disease: 6	Hospitalised, severe disease: 4	
Length of interview in minutes	Mean: 48	Median: 41	Min: 18	Max: 76

* International Standard Classification of Education ranging from 0 (early childhood education) to 8 (doctorate or equivalent)
**according to the WHO classification (38)

Table 3: Characteristics of interviewees and length of interviews

Theme 1: the individual layer

Vulnerability was identified as key subtheme contributing to or resulting from internalized or perceived stigma. Different codes added to increased vulnerability:

Fear, worries and despair (n = 11): *'I was thinking «why me???»… and «I hope this ends well…»'* (female (f), 50-59 y/o); Most participants were worried about the outcome, especially elderly patients and those referred to the hospital.

Shame, guilt or remorse (n = 14): *'Of course you feel bad knowing you infected others'* (f, 20-29 y/o); Although infecting others happened unwittingly in all cases, participants often felt as active 'spreader'. This caused feelings of shame and remorse.

Loneliness and abandonment (n = 14): *'Being on my own was the hardest part.'* (male (m), 60-69 y/o); This feeling often rose from the isolation faced in home-quarantine or single hospital rooms, but also from a perceived lack of reliable information regarding the disease.

On the other hand, **resilience** as coping strategy mitigated the experienced stigma, resulting from:

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Confidence (n = 5) *'I knew I was getting medication; I was sure that would help, otherwise they wouldn't give it to me. I wasn't worried I would die.'* (m, 60-69 y/o); The elderly putting faith in modern medicine or the young relying on their body's defences felt confident they would be spared from adverse outcomes.
Self-efficacy (n = 2) *'In the beginning it was very hard for me. But as soon as I managed to structure my day, time just flew by.'* (m, 30-39 y/o); Self-efficacy reflects a person's assumed control over a situation and was identified as a rare but resourceful coping strategy.

Additionally, participants indicated different ways of **coming to terms** with the undergone infection:
Pragmatism (n = 2): *'I had it [COVID-19], that's all there is. Now I am cured and immune.'* (f, 70-79 y/o); some refused to dwell in the past and did not make a big deal about having had COVID-19. Interestingly, this also occurred in one participant that had been hospitalized for a few days.
Delayed disclosure (n = 3): *'In the beginning, I didn't want to share with anyone. Afterwards, we talked about it.'* (f, 70-79 y/o); Participants from different age groups and with different severity of disease admitted that they needed some time to process before they were able to confide in someone else.
Rationalization (n = 2): *'When I was there, it wasn't known to be a hotspot!'* (m, 50-59 y/o); Some participants offered a rationale to justify how they got infected. They emphasized that they did not deliberately put themselves and thereby others at risk.
Denial or fallacy (n = 1): *'Maybe I didn't have it [COVID-19]. I even know couples, where one had it and the other didn't'* (m, 50-59 y/o). One participant doubted the established diagnosis.

Financial insecurity concerned comparatively few self-employed participants. This applied to both direct and indirect costs, the latter resulting from a loss of income:
Direct costs (n = 2): *'If I hadn't had any savings, it would have been problematic.'* (m, 40-49 y/o);
Indirect costs (n = 1): *'I have to earn my money with physical labour. When I can't work, I don't earn money…'* (m, 50-59 y/o);
However, most participants were either employed or received pension and hence costs were covered by their health insurance, implying **financial security** (n = 8): *'I was on sick leave and got my loan as usual.'* (f, 20-29 y/o);

Theme 2: the interpersonal layer

Used to a certain level of self-determination and a scope of action, most participants were hit hard by the **loss of autonomy**:
Loss of independence (n = 5): *'We were all isolated, other people had to take care of us.'* (f, 20-29 y/o); Quarantine or being bed-ridden meant depending on others, which was a new situation for many participants.
Violation of privacy (n = 4): *'I live in a small village and within two hours, everyone knew about it [COVID-19]'* (f, 20-29 y/o); Transgression of personal boundaries or unauthorized passing of personal information left some participants, young and elderly, feeling powerless.

Almost every participant suffered some form of **vilification** as perceived or enacted stigma:
Blame (n = 9): *'Some people said it is my own fault that I got infected.'* (m, 50-59 y/o). Some patients were made responsible for catching SARS-CoV-2 or blamed for unknowingly infecting others. This reflects a shift in perspective from passively acquiring a disease to actively spreading it. This change from victim to perpetrator was described as particularly hurtful when people had been severely ill from COVID-19.
Disregard (n = 4): *'They [acquaintances] did not really care about what had happened to me.'* (f, 20-29 y/o); Lack of concern or misconceptions about what participants were going through left some participants frustrated or angry. This was reported by patients with mild symptoms as well as those hospitalized.

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As mentioned earlier, loneliness and abandonment left participants feeling vulnerable. Additional **avoidance of personal contact** by others when participants were no longer contagious was hence particularly upsetting and by far the most frequently reported form of enacted stigma:
(Irrational) fear of infection (n = 27) was presumably the most important driver for the reported behaviour of others: *'Many people withdrew from me for a long time…. I think they were still afraid of getting infected.'* (f, 70-79 y/o);

Participants reported different ways in **dealing with the rejective behaviour** of others:
Understanding (n = 10); Most participants could at least partly comprehend and therefore excuse this behaviour: *'I could totally understand their [friends] behaviour. No one knew exactly how long people can transmit COVID.'* (f, 20-29 y/o);
Reasoning (n = 2); others tended to argue: *'When they [friends] took a step back, I told them there was no reason, they could hug me, I am no longer contagious.'* (m, 50-59 y/o);
Distancing (n = 2) oneself and avoiding emotional involvement and further frustration: *'When I heard about what others said, I just distanced myself from that.'* (m, 50-59 y/o);

Consequently, **personal contact** was much appreciated by all participants and proved one of the most powerful coping strategies:
Genuine interest and mindfulness (n = 7) regarding the participants' well-being were key elements: *'It's very important that there are people who care about you and want to know how you are doing. My mum called every day to check on me, that felt good.'* (m, 30-39 y/o);
Unaltered interpersonal relationship (n = 4), i.e. discovering that 'nothing had changed' made participants feel relieved: *'With my friends, it is the same way as it has been before.'* (m, 30-38 y/o).
Comprehension (n = 4): *'I talked to a friend, and she could totally relate.'* (f, 20-29 y/o). When sharing their stories induced sympathy and comprehension, participants felt that their emotions were acknowledged and legitimate.

Theme 3: the communal layer

The lines between the interpersonal and communal layers are particularly blurry. Thus, codes and subthemes emerging are often similar, yet referring to a different social group. While the interpersonal layer focuses on close personal relationships, the following section refers to more distant contacts or anonymous settings.

Social rejection plays an important role in enacted stigma. Again, a potential driver identified was:
(irrational) fear of infection (n = 6): *'When I did my groceries and kept a 2 to 3 meters distance, people still told me to go further away…. they even changed the side of the street when they saw me.'* (f, 20-29 y/o);
Additionally, **stereotyping** as perceived stigma was indicated by younger people:
Perceived recklessness or carelessness (n = 4): *'Now you [referring to the interviewer] are probably going to say «how on earth could you go skiing, and how could you go there [place where she got infected]?!?», but back then it wasn't that obvious….'* (f, 20-29 y/o);
Rumours (n = 2): *'In town, everyone acted like they knew better why I was infected'* (f, 20-29 y/o);

The **reaction** to experienced stigma on the communal level included:
Understanding (n = 3): *'I tried to understand their reaction [people at work] and asked myself, how I would have reacted in their place? And honestly, I would keep my distance too. That is probably human.'* (m, 30-39 y/o);
Reasoning (n = 2): *'I told them [people in a grocery store] I am no longer contagious and that they don't need to keep a 10-meter distance. I fact, I am less dangerous than other people.'* (f, 20-29 y/o);

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<u>Resignation</u> (n = 3), i.e. accepting adverse behaviour without arguing: *'I didn't really bother. Couldn't change it anyway. (…) You have to take it the way it is.'* (m, 40-49 y/o);

Social network and inclusion turned out as a valuable resource against experienced stigma:
<u>Sympathy</u> (n = 7): *'So many people called during my absence to make sure I am okay, and they were so happy to hear from me when I called them back.'* (m, 60-69 y/o). For many participants, it was important that others cared about them and felt for them.
<u>Solidarity and support</u> (n = 7) from friends or neighbours helped many participants to persevere the isolation and let them rest assured that they would receive help if needed: *'Many people from our village offered help and asked if they could get us anything. I was surprised by their willingness to help.'* (f, 50-59 y/o);

<u>Theme 4: the institutional layer</u>

Institutional stigma referred to stigma faced in contact with health authorities, hospital staff, general practitioners, and paramedics. Actions directed towards individual participants were labelled **direct discrimination**, a form of enacted stigma. They resulted mainly from
<u>Unprofessional treatment</u> (n = 4), which means inappropriate reactions from healthcare workers: *'Since I was the second patient in that other hospital, they had a lot of «respect» of me and avoided coming close to me… that was even worse for me than the [rejecting] behaviour of other people.'* (f, 20-29 y/o);

Structural stigma was also based on regulations affecting COVID-19 patients in general which was labelled **indirect discrimination**. Two codes were identified:
<u>Lack of accountability</u> (n = 10): In many participant's views, health authorities and other institutions failed to take responsibility or lacked transparency; *'They [health authorities] gave us a number where we could call, but no one ever answered the phone.'* (f, 20-29 y/o);
<u>Inconsistency</u> (n = 4): Due to contradictory information, participants lost trust in health officials and felt increasingly insecure*: 'They [the health authority] told me on the phone my quarantine ended on Thursday. Then I got the letter from them saying I needed to stay in quarantine for another 2 weeks.'* (m, 50-59 y/o);

A first, many participants' **reaction to this discriminatory behaviour** was
<u>Incomprehension</u> (n = 8): *'I really felt mocked by the health authorities.'* (f, 20-29 y/o); But eventually, in retrospect, they often reacted understandingly and forgivingly, which was labelled
<u>Leniency</u> (n = 8): *'I guess they [the health authorities] were just overwhelmed.'* (m, 50-59 y/o);
Additionally, **receiving professional support** was much appreciated:
<u>Appreciation of health-care workers</u> (n = 4): *'He [family doctor] called every day to make sure I was okay. That felt good.'* (f, 70-79 y/o);
<u>Support group</u> (n = 2): *'Is there a self-help group for COVID survivors?'* (m, 50-59 y/o);

<u>Theme 5: the societal layer</u>

This layer characterized **societal norms and values** which are partly internalized by participants.
First, COVID-19 was seen as a <u>non-desirable condition</u> (n = 5) and something usually 'others' catch: *'I was surprised. I never thought **we** would get it.'* (f, 50-59 y/o);
Secondly, even if unaware of carrying an infectious virus, participants perceived themselves as a <u>menace to others</u> (n = 10) and public health in general. This was the most sensitive subject during the interview: Q: *'Do you happen to know if you accidentally infected somebody?'* A: *'I don't want to talk about that.'* (m, 50-59 y/o);

This led to different reactions, which we subsumed as **harm reduction**:

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Law-abiding (n=5): Participants emphasized that they stuck to the regulations and thereby avoided spreading the disease: *'When we came back [from a hotspot] we stayed at home. So when we finally knew we had it [COVID-19], at least I didn't feel guilty, because I knew I didn't infect anyone else.'* (f, 20-29 y/o);

Social withdrawal (n = 3): Others reduced social contacts even after COVID-19 was over, often to avoid rejective behaviour: *'When my quarantine ended, I didn't ask people to meet. I was afraid they would react…. in a strange way.'* (f, 20-29 y/o);

Hygiene advocacy (n = 3): Others propagated hygiene practices as effort to control the disease: *'I tell everyone they should wear their face masks.'* (f, 70-79 y/o);

Discussion

The social impact of COVID-19 in relation to other stigmatizing conditions

Regarding the quantitative results, the overall level of experienced stigma was lower in our cohort compared to people living with HIV/AIDS or cancer in the United States (29) or Germany (30) (c.f. table 4). HIV/AIDS is known as a highly stigmatising infection (39), explaining the high level of experienced stigma throughout all dimensions. Comparing our results to people with cancer, 'social rejection' and 'internalized shame' were similar (29) or slightly higher (30) in people with COVID-19. We assume that the perceived risk of infecting others with SARS-CoV-2 compared to a non-communicable disease like cancer increases feelings of shame and rejection. In contrast to chronic conditions such as HIV/AIDS and cancer, stigma towards COVID-19 survivors might decrease over time.

	HIV/AIDS (29) (aggregate means)	**Cancer** (29) (aggregate means)	**COVID-19** (aggregate means)	**Cancer** (30) (means)	**COVID-19** (means)
Social rejection	19.95	14.87	14.22	1.42	1.58
Internalized shame	13.74	8.45	8.39	1.51	1.68
Social isolation	17.85	14.64	10.17	1.71	1.45
Financial insecurity	8.12	5.73	3.51	1.68	1.17
Total score	**59.66**	**43.69**	**36.29**	**1.59**	**1.55**

Table 4: Experienced stigma in people living with cancer, HIV/AIDS or after COVID-19

Experienced stigma and applied coping strategies from the inner to the outer societal level

On an individual level, factors such as personality, social resources, and economic situation, can either enhance or mitigate the impact of stigma. In our cohort, COVID-19-related stigma did usually not culminate in financial hardship, in contrast to other, mainly low-and-middle-income countries (13,16,40). Some participants suffered from a loss of income while being ill, but none reported loss of livelihood or job insecurity.

A sudden illness like COVID-19 resulting in fear of death or infecting others, loneliness, and shame generates a feeling of vulnerability, which serves as a breeding ground for experiencing stigma. Vice versa, stigma seems to increase vulnerability, both in this and other studies (6,21,41,42). Hence, COVID-19-related stigma leads to psychological stress and adds to the burden of disease (13,23,41). Loss of autonomy, specifically the violation of privacy, was also observed in other settings (13,40,43). Participants reported that rumours of someone being infected travelled quickly and confidentiality was often breached, even in healthcare facilities. This poses a serious risk for people to hide their condition and refrain from test- or healthcare-seeking, favouring the further spread of the virus (16). In contrast, the individual's resilience was a valuable source for coping, reflected either by self-confidence or trust

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in others. In other studies, faith in God strengthened the resilience in COVID-19 survivors (23,44). ‘Coming to terms with the disease’ was described as a way of accepting and adapting, which was similarly found by Gopichandran *et al.* (2021) using the terms ‘understanding disease characteristics, risk acceptance and self-isolation’ (40) and by Bhandari et al. (2021) as ‘accepting reality’ (44). Sharing experiences, often delayed, which is not uncommon after trauma, rationalization to justify former behaviour and, in one case, denial were other coping strategies observed, similarly to the ‘rationalisation and sharing problems’ Bhandari *et al*. (2021) described (44).

On an interpersonal or communal level, stigma was often experienced as vilification including blame, social rejection, and stereotyping. Similarly, Gopichandran et al. (2021) (40) noticed an exclusion from essential services such as grocery stores and water taps. Jiang et al. (2021) (11) found that 5% of respondents lived in communities that rejected people with COVID-19. Imran et al. (2020) (13) reported social rejection of whole families if one member fell ill. Amir (2020) (12) described how patients were treated as outcasts, given bad names and blamed for spreading the disease. Our data suggests that triggers for discriminating of COVID-19 survivors were a general fear of getting infected and noticing presumably irresponsible behaviour of others, often based on misconceptions regarding modes of transmission. Since the virus was perceived as lethal, social rejection seemed reasonable to keep supposedly infectious people at a distance (12,13,16,25,43). In some studies, stigmatizing attitudes were linked to experienced vulnerability, poor education and conflicting information in the media (17,22,24,45), pointing out the necessity of careful communication and precise information about COVID-19 (28). On the other hand, a strong, solidary social network and sound relationships were valuable resources to cope with stigma (23,40,44,46). This might work in both directions: For those not infected, COVID-19 is not reduced to a faceless, dangerous virus, but connected to a human being (47). This can induce a comprehensive and mindful attitude that prevents stigmatization and supports those infected. ‘Humanizing’ COVID-19 has been insinuated as a way to end stigma, either by involving celebrities or sharing narratives from affected people (15,17,48).

Stigma experienced on an institutional level included both direct and indirect discrimination. The former resulted from inappropriate treatment by professionals, such as negligence of patients or compelling them to leave the hospital. Difficulties in accessing healthcare, poor services and negligence were also found in other settings (18,40,41). Indirect discrimination referred to a lack of accountability when health authorities were presumably too overwhelmed to take over responsibility. These experiences elicited either incomprehension or leniency in participants and show the necessity for institutions to be transparent (25) and give consistent instructions to preserve people’s confidence and compliance.

On a societal level, health-related stigma is often associated with certain norms and values. For example, people living with HIV/AIDS are often perceived as ‘dirty’ or ‘immoral’ (49) and some types of cancer are linked to an unhealthy lifestyle or risk behaviour (50). In contrast to those conditions, COVID-19 is an airborne infection with high transmissibility, meaning that one person infects about three others (51). We noticed that COVID-19 survivors often felt like a source of infection, i.e. a menace to others and were ashamed and eager to reduce further harm. The findings indicate a change of perspective from passively ‘catching the virus’—as is commonly used in other infections—to actively ‘spreading the virus’, even if this happened unwittingly. The change equals an unprecedented shift within social norms from ‘victim’ to ‘perpetrator’. This public attitude is also reflected in editorial cartoons blaming certain groups or behaviour for the transmission of COVID-19 (24), which does not only add to the psychological stress in affected people, but also to a polarization within society. As a coping strategy, participants reacted with social withdrawal, a strictly law-abiding or hygiene advocating behaviour.

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The experienced stigma and applied coping strategies within the respective social layer are depicted as comprehensive framework in figure 2. Stigma experienced at the individual level is shown at the bottom of the framework, followed by the interpersonal, communal, institutional, and finally the societal level.

Figure 2: Comprehensive framework of experienced stigma and applied coping strategies, stratified by societal layer

Intersectional stigma

As a social phenomenon, stigma can never be assessed detached from other social conditions, often mirroring power differences between groups. Most studies about COVID-19-related stigma suggest a higher prevalence among the elderly or patients with comorbidities, since they are most affected by the disease (25,41,48). However, in our study, young to middle-**age**d participants reported the highest level of experienced stigma. This might result from the shift from 'victim' to 'perpetrator' mentioned earlier. Those participants who were seriously ill often received sympathy from their social environment and were seen as 'victims'. In contrast, young people were often asymptomatic and regarded as 'super-spreaders' (52), i.e. drivers of the pandemic. Similarly, a recent study from Israel found negative age-related stereotypes associated with younger people (53). Reports from illegal parties despite the curfew added to a reckless and careless stereotype of young people (54). We assume stereotyping also caused experienced stigma in participants with travel history (55): Those coming back from a skiing trip in a hotspot were seen as a major source of the pandemic and perceived as reckless, putting fun above health. Similarly, the patient's **origin** was also connected with stigma in other settings, e.g. regarding migrant workers in Delhi, India, residing in Haryana (11,16,25,48). However, since all our participants had the same cultural background, we were not able to assess different ethnicities in our cohort. In contrast to other studies, we did not find any difference in **gender** (13,25,41,56,57) or **education** (56–58) regarding experienced stigma. Previous research identified an association between **poverty** (16,40) or occupational status (56) and experienced stigma, assuming a mutual influence: COVID-19 is more easily spread in over-crowded, poorer areas; on the other hand, COVID-19 can lead to a loss of livelihood of those infected. We did not collect data on the economic situation, but used the occupational status as a proxy, which revealed no significant difference between the groups. However, this variable might fail to reflect more subtle socioeconomic differences between participants. Similar to Gopichandran et al. (2021) (40), our qualitative data suggested that experienced stigma differs with **residential site**: participants in more anonymous urban apartments experienced less stigma than those living in rural areas, where residents know each other and word by mouth travels quickly. On the other hand, participants from rural areas also reported more neighbourly support.

Limitations, reflexivity, and possible bias

Regarding the quantitative part, a questionnaire designed for people living with HIV/AIDS or cancer was applied in the absence of one specifically designed for experienced stigma in COVID-19 survivors. Since these conditions differ in many ways, the questionnaire used might fail to reflect certain dimensions of COVID-19 related stigma. Moreover, the response rate to the questionnaire was low, probably due to the sensitive nature of the study and the single-centre study design, resulting in a comparatively low quantitative sample size.

Regarding the qualitative part, the interviews were conducted by phone, so physical appearance and body language did not influence the data, in contrast to face-to-face interviews. This can work in both

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directions: either participants appreciated the more anonymous atmosphere to share private information, or they would have preferred a more personal and intimate setting. Talking to a medical doctor (LP), participants are used to sharing physical complaints rather than social experiences such as stigma. Participants often had the impression that their narratives were inappropriate or not of interest. Although participants were encouraged to share their stories, an expectation bias cannot be excluded. Since stigma is a sensitive topic, it is easily subjected to a social-desirability bias and hence bearing the risk of the respondents' inclination towards euphemized answers. Furthermore, a recall bias must be considered due to the retrospective character of the study.

Ultimately, those participants who volunteered to be interviewed were mostly of German origin. The requirement of an advanced level of German and the single-centre study design might have limited the diversity of study participants and caused a selection bias, since the sample is unlikely to represent all cultural groups and ethnicities living in Germany.

Conclusion and implications for stakeholders

Around the globe, stigma is a social phenomenon that cuts through all layers of society. It is intertwined with or aggravated by social factors that can lead to 'othering' and discrimination. It can limit access to healthcare and other public services and can therefore be seen as a social determinant of health equity and a hidden burden of disease. Stigma arises from perceived careless behaviour and irrational fear of infection, which emerge from misconceptions about the disease. Information about COVID-19 in social media is often incorrect (59) or biased (24) and people have difficulties finding reliable sources (11) to distinguish between fake and fact. In line with previous research (28), we emphasize the need of providing accurate information and exposing misinformation on disease prevention and treatment to end COVID-19 related stigma.

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Statements

a. Contributorship

- Conceptualisation: LP, BG
- Methodology: LP
- Data acquisition: LP
- Initial analysis: LP
- Interpretation of data: LP, SB, CB, BG
- Writing - original draft: LP
- Visualization: LP
- Writing - review and editing: SB, CB, BG
- Final approval: LP, SB, CB, BG
- Accountability: LP, SB, CB, BG

b. Funding with award/grant number

There was no funding involved in this study.

c. Competing interests

The authors declare that there is no conflict of interest.

d. Data sharing statement

Data (both quantitative and original German qualitative data) are available on request.

e. Ethical approval

The study was approved by the ethical board of the University of Ulm (No. 315/20). Prior to inclusion, an informed consent was obtained from all participants.

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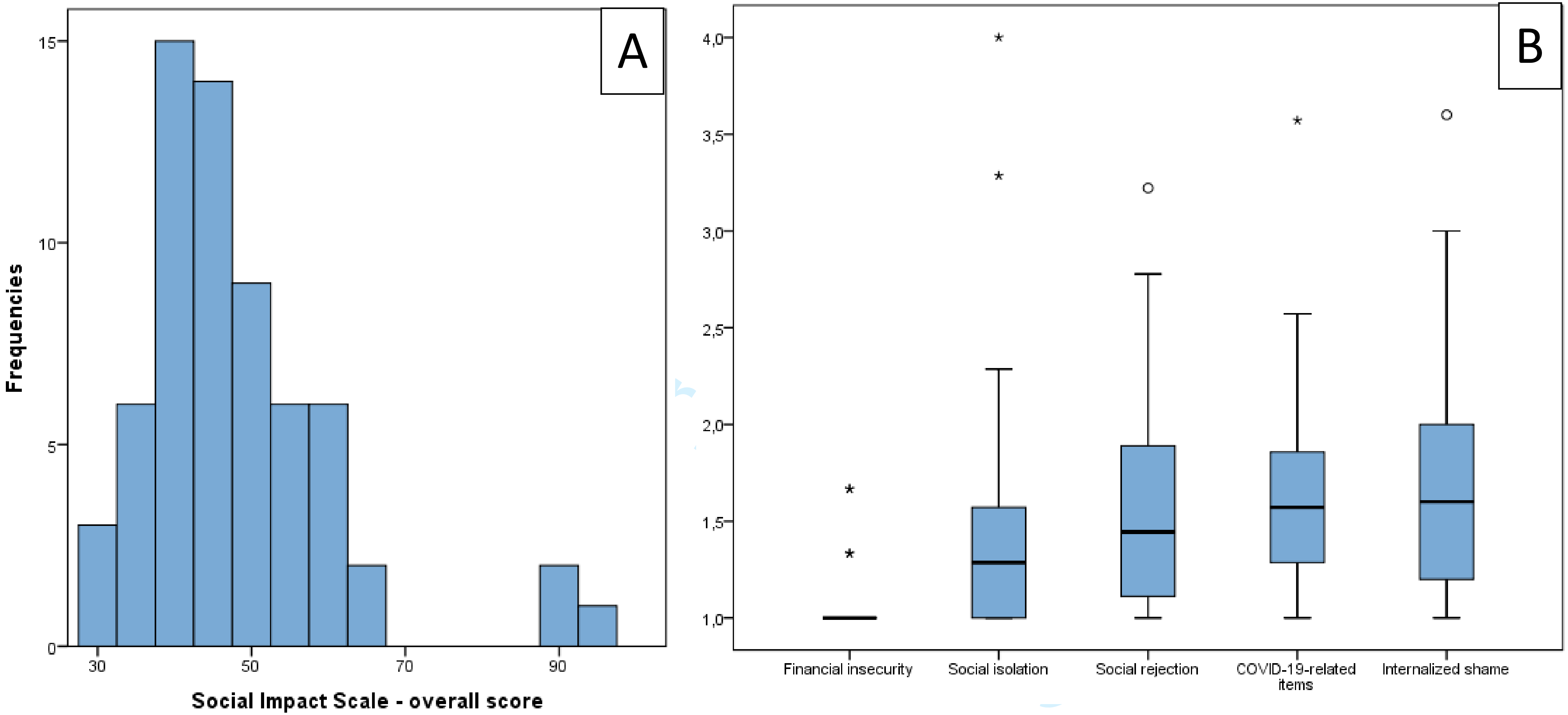
A
Frequencies
15
10
5
0
30
50
70
90
Social Impact Scale - overall score
B
4,0
3,5
3,0
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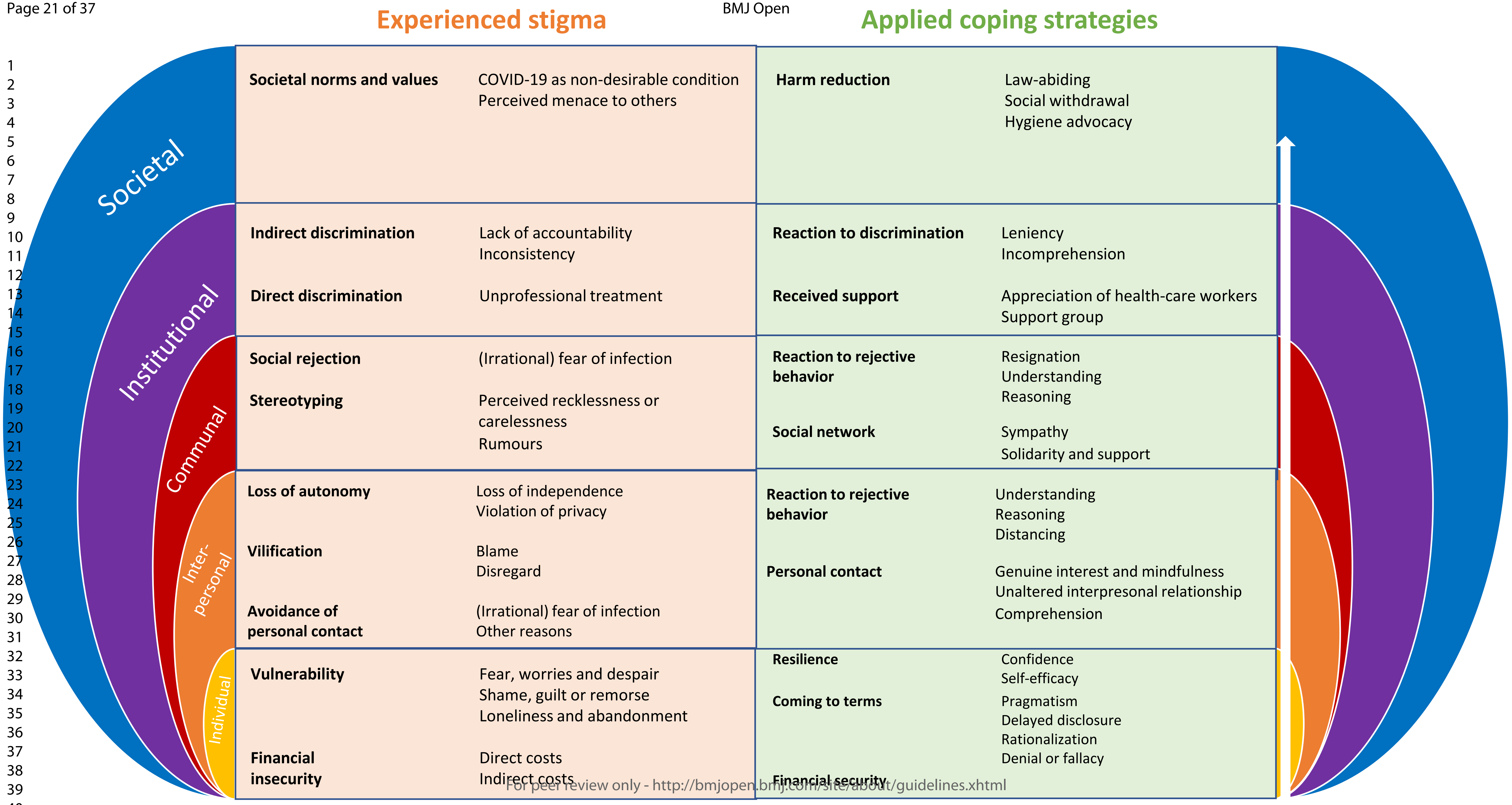
Financial insecurity
Social isolation
Social rejection
COVID-19-related items
Internalized shame



	Experienced stigma		Applied coping strategies	
Societal	**Societal norms and values**	COVID-19 as non-desirable condition Perceived menace to others	**Harm reduction**	Law-abiding Social withdrawal Hygiene advocacy
Institutional	**Indirect discrimination**	Lack of accountability Inconsistency	**Reaction to discrimination**	Leniency Incomprehension
	Direct discrimination	Unprofessional treatment	**Received support**	Appreciation of health-care workers Support group
Communal	**Social rejection**	(Irrational) fear of infection	**Reaction to rejective behavior**	Resignation Understanding Reasoning
	Stereotyping	Perceived recklessness or carelessness Rumours	**Social network**	Sympathy Solidarity and support
Inter-personal	**Loss of autonomy**	Loss of independence Violation of privacy	**Reaction to rejective behavior**	Understanding Reasoning Distancing
	Vilification	Blame Disregard	**Personal contact**	Genuine interest and mindfulness Unaltered interpresonal relationship Comprehension
	Avoidance of personal contact	(Irrational) fear of infection Other reasons		
Individual	**Vulnerability**	Fear, worries and despair Shame, guilt or remorse Loneliness and abandonment	**Resilience**	Confidence Self-efficacy
			Coming to terms	Pragmatism Delayed disclosure Rationalization Denial or fallacy
	Financial insecurity	Direct costs Indirect costs	**Financial security**	

Supplementary material

S1) COVID-19-related questions added to the Social Impact Scale

S2) Interview guide

S3) Table with quotes for experienced stigma

S4) Table with quotes for applied coping strategies

S1) Additional COVID-19-related questions (additional to the Social Impact Scale)

1. Ich hatte die Befürchtung, dass andere aufgrund meiner längeren Abwesenheit meine Erkrankung erahnen konnten.

1. I was worried that others might suspect my illness due to my long absence.

2. Ich habe mich schuldig gefühlt, dass ich (eventuell) andere angesteckt habe, auch wenn dies unwissentlich geschah.

2. I feel guilty because I accidentally might have infected others.

3. Als ich auf meine krankheitsbedingte Abwesenheit angesprochen wurde, habe ich offen gesagt, dass ich an COVID19 erkrankt war.

3. When I was asked about my absence, I admitted that I had COVID-19.

4. Als ich nach meiner Erkrankung zurück in die Arbeit kam oder mich mit Freunden getroffen habe, hatte ich Sorge, wie meine Kollegen/Freunde wohl auf mich reagieren würden.

4. When I met colleagues or friends after being ill, I was worried how they would react towards me.

5. Wenn jemand mit mir über meine Erkrankung spricht, ist mir das unangenehm.

5. It makes me feel uncomfortable if someone alludes to my illness

6. Ich wünschte, es hätten weniger Leute von meiner Erkrankung erfahren.

6. I wish less people had known about my illness.

7. Ich habe das Gefühl, durch Institutionen (z.B. Gesundheitsamt, Arztpraxis, Rettungsdienst etc.) ungerecht oder nachteilig behandelt worden zu sein.

7. I feel that I have been treated unfairly or adversely by institutions (health authority, family doctor, paramedics)

S2) Interview guide

Alter / Geschlecht/ höchster Bildungsabschluss/ Schwere der COVID-19-Erkrankung
Age/ Gender/ highest level of education/ severity of COVID-19

1. Was ging Ihnen durch den Kopf, als Sie erfuhren, dass der Test positiv ausgefallen war?

1. What was going through your mind when you received the positive COVID-19 test result?

2. Wie hat sich ihr Leben verändert, seitdem Sie an COVID19 erkrankt waren?

2. Did your life change since you had COVID-19? If yes, how did change?

3. Haben Sie jetzt noch gesundheitliche Beschwerden, auch wenn die Erkrankung als ausgeheilt gilt?

3. Do you still have any symptoms, even if the infection is cured?

4. Wie haben Sie die Zeit in Quarantäne erlebt?

4. How did you experience the time in quarantine?

    a. Wie sah ein typischer Alltag in der Isolation aus?

    a. How did your everyday routine in quarantine look like?

    b. Was war besonders schwierig in dieser Zeit?

    b. What was particularly difficult during that time?

5. Mit wem konnten Sie offen über Ihre Erkrankung sprechen?

5. Who could you talk to about your condition?

6. Gab es Situationen, in denen Sie gezögert haben, offen über Ihre Erkrankung zu sprechen?

6. Have you experienced a situation where you hesitated to talk freely about your infection?

7. Wie fielen die Reaktionen der Mitmenschen auf die Erkrankung aus?

7. How did people react to your infection?

8. Haben Sie das Gefühl, dass andere Sie anders behandeln, als vor Ihrer Erkrankung?

8. Do you have the feeling, that others treat you differently since you had COVID-19?

    a. Inwiefern?

    a. How so?

   b. Beispiel?

   b. Example?

   c. Wie sind sie damit umgegangen?

   c. How did you cope with/ handle the situation?

9. Gab es Reaktionen von Mitmenschen als diese von Ihrer Erkrankung gehört haben, die Sie überrascht haben? (positiv und negativ), und wenn ja, inwiefern?

9. Did you experience reactions of others when they heard about you having COVID-19 which surprised you, either in a good or in a bad way?

10. Das Gesundheitsamt muss alle Kontaktpersonen informieren bzw. Sie mussten die Kontaktpersonen angeben – wie war das für Sie?

10. The health authority was obliged to inform every person you had been in contact with when you were diagnosed with COVID-19 – how did you feel about that?

11. Wie war das in der Arbeit, wie reagierten Kollegen auf Sie, als Sie zurückkamen?

11. At work, how did colleagues react when you came back?

12. Es besteht immer das Risiko, unbewusst andere Personen anzustecken. Wie ging es Ihnen damit und wie sind Sie damit umgegangen?

12. There is always a risk to infect others, unknowingly. How did you feel about this and how did you cope with it?

13. Im Nachhinein ist man immer schlauer. Denken Sie manchmal, dass Sie hätten verhindern können, dass Sie sich angesteckt haben?

13. In hindsight, do you think you could have prevented catching COVID-19?

14. Angenommen ein guter Freund von Ihnen würde jetzt an COVID19 erkranken – wie würden Sie sich verhalten? (Vignette)

14. Assuming a close friend of yours would catch COVID-19, how would you react? (vignette)

15. Hatten Sie aufgrund der Erkrankung finanzielle Sorgen?

15. Did you have financial problems because of having had COVID-19?

S3) Experienced stigma by societal level

Theme	*Type of stigma*	Code (n*)	Quotes
Individual level			
Vulnerability	-	Fear, worries and despair (n = 11)	'I was thinking «why me?»… and «I hope this ends well…»' (female, 50-59 y/o) 'I was thinking about death, about becoming even sicker and needing assisted ventilation… This was in the back of my head all the time. I really hope I don't catch it [SARS-CoV-2] again….' (female, 70-79 y/o) 'It got worse and worse, I couldn't talk, I couldn't breathe…. I was on my own and…[stops speaking and starts to cry]' (female, 70-79 y/o) 'When I woke up again, I knew I would survive…. but still, I was having these panic attacks' (male, 60-69 y/o) 'I was afraid I could die. I saw it happen to other patients. It was frightening. The whole situation was frightening.' (male, 40-49 y/o) 'You have this feeling that there is nothing to look forward to….' (male, 30-39 y/o)
	Internalised stigma / Perceived stigma	Shame, guilt or remorse (n = 14)	'Of course you feel bad knowing you infected others' (female, 20-29 y/o) 'I talked to the people who went into quarantine because of me to make sure they are okay' (male, 60-69 y/o) 'I took the wrong decision to go there [place where he was infected]. I had this gut feeling that there is something wrong, that I shouldn't go there. But my friends told me to come with them…. I should have listened to my gut feeling.' (male, 50-59 y/o) 'I really don't want to talk about it' (male, 50-59 y/o, sounding distressed), as response to the question, if he accidentally infected others.
		Loneliness and abandonment (n = 14)	'We all felt left alone. We didn't have any kind of support, neither by a doctor nor the public health authority. No one contacted us for days in a row and we started feeling afraid if all of that [referring to the COVID-19 symptoms] were still normal. Somehow, we felt left alone.' (female, 50-59 y/o) 'People didn't want to have contact with me. This was especially hard for me, since I had been abroad before for two months, this really got to me.' (female, 20-29 y/o) 'You feel that your social network isn't there, the ones you need most aren't with you.' (female 50-59 y/o) 'Being on my own was the hardest part.' (male, 60-69 y/o) 'You feel lonely. There was no one to talk to.' (female, 70-79 y/o) 'You learn very quickly who stands by your side in these difficult times and who lets you down…' (male, 50-59 y/o)
Financial insecurity	-	Direct costs (n = 2)	'That [not having COVID-19] would have saved me a great deal. Luckily, my health insurance covered most of the expenditures, but since my deductible is rather high, this disease caused a great financial loss for me.' (male, 50-59 y/o) 'If I hadn't had any savings, it would have been problematic….' (male, 40-49 y/o)

		Loss of income / indirect costs (n = 1)	'I have to earn my money with physical labour. When I can't work, I don't earn money…' (male, 50-59 y/o)
Interpersonal level			
Loss of autonomy	*Perceived stigma / (Enacted stigma)*	Loss of independence (n = 5)	'As we were all in quarantine, we relied on others to supply us with food' (female, 50-59 y/o) 'We were all isolated, other people had to take care of us.' (female, 20-29 y/o)
		Violation of privacy (n = 4)	'When I was gone and they knew about it [COVID-19], they turned my whole workplace upside down' (male, 50-59 y/o) 'I live in a small village and within two hours, everyone knew about it [COVID-19]' (female, 20-29 y/o)
Vilification		Blame (n = 9)	'Some people said it is my own fault that I got infected.' (male, 50-59 y/o) 'They didn't talk bad in front of me…. but behind my back, I could sense that they thought it's my own fault' (male, 50-59 y/o) 'They [family members] were very angry with us that we didn't tell them about our infection. But we didn't know ourselves at that time and didn't have any symptoms! How should we know that we were ill?' (female, 50-59 y/o) 'She [a niece] was at our place before [we knew we had COVID-19] and it took a long time until she was able to get a test. She is still holding a grudge until today….' (female, 50-59 y/o)
		Disregard (n = 4)	'People didn't understand what I was going through. They said «it's like a flu», but for me, it didn't feel just like a flu. No one said «this sounds really bad»' (female, 50-59 y/o) 'They [acquaintances] did not really care about what had happened to me.' (female, 20-29 y/o) 'My sister said, as long as you don't need invasive ventilation, it's not that bad. But for me, just needing oxygen was already more than enough….' (female, 50-59 y/o)
Avoidance of personal contact	*Enacted stigma*	(Irrational) fear of infection (n = 27)	'In the beginning it felt like people were really scared of me.' (female, 20-29 y/o) 'Meeting people in person [in contrast to talking in the phone] was different. People become…. very careful' (male, 30-39 y/o). 'My aunt living next door kept her distance for weeks after my quarantine had ended, as if I were still contagious.' (female, 20-29 y/o) 'I noticed some people take a step back when I told them [about the COVID-19-infection]' (male, 50-59 y/o) 'Everyone you tell that you had COVID flinches and takes a step back' (male, 50-59 y/o) 'Many people withdrew from me for a long time…. I think they were still afraid of getting infected' (female, 70-79 y/o)
		Other reasons (n = 2)	'She distanced herself from me. I don't know why, she doesn't even believe in COVID.' (female, 50-59 y/o)
Community level			
Social rejection	*Enacted stigma*	(Irrational) fear of infection (n = 6)	'When I did my groceries and kept a 2 to 3 meters distance, people still told me to go further away…. they even changed the side of the street when they saw me.' (female, 20-29 y/o) 'When I went back to the office, some colleagues told me straight to the face they didn't like having me there. We are working in shifts and they would change shifts so they didn't have to work with me.' (male, 30-39 y/o)

			‘When I went to the hairdresser, I told them I really needed a haircut since I had had COVID 3 months ago. First, they refused to cut my hair, they were afraid of getting infected.’ (male, 40-49 y/o)
Stereotyping	*Perceived stigma*	Perceived recklessness or carelessness (n = 4)	‘Now you [meaning the interviewer] are probably going to say «how on earth could you go skiing, and how could you go there [place where she got infected]?!?», but back then it wasn’t that obvious….’ (female, 20-29 y/o) ‘People asked, why did go there, when it was a hotspot.’ (male, 50-59 y/o) ‘If a friend of mine had COVID, I would support him and say it’s not his fault that he got it. We didn’t choose for this either. I’d say it’s okay. I wouldn’t treat him any different and just act normal’ (female, 50-59 y/o)
		Rumours (n = 2)	‘In town, everyone acted like they knew better why I was infected’ (female, 20-29 y/o)
Institutional level			
Indirect discrimination	*Structural and enacted stigma*	Lack of accountability (n = 10)	‘They [health authorities] gave us a number where we could call, but no one ever answered the phone.’ (female, 20-29 y/o) ‘When I should be discharged from the hospital, and I was still contagious, they [the hospital staff] told me there was no transport to get me home, of course I wasn’t allowed to use the public transport and a family member should pick me up. But they were all in quarantine. I tried to contact the public health authority all day long to get a permission for my mother to pick me up, that was very distressing for me. Then they [the hospital staff] came all of the sudden and said I had to go now.’ (female, 20-29 y/o). ‘After we knew we had been in a hotspot, we tried to get a test. When finally someone answered the phone, they told us we couldn’t get a test since the place wasn’t officially declared a hotspot yet.’ (female, 20-29 y/o) ‘Even when I felt bad, it was impossible to find a doctor to talk to… so in the end I called 112 [national emergency number]’ (female, 50-59 y/o) ‘The worst thing was to get to the hospital in the first place…. So I dialled that number, but ended up in an endless waiting loop. In the other clinic it was exactly the same. I called my general practitioner; he wrote me a sick note for a week. But I didn’t need that, I told him I need help… but all he did was writing a second sick note for another week…. Either you are rejected right away or you end up in an endless waiting loop on the phone.’ (male, 50-59 y/o) ‘When I came back home [from a hotspot] my friend who was with me tested positive. The health authority didn’t contact me for days. Then I called them, and they said they were not responsible, another authority is responsible for my case. So I called them, but they said, the first authority was responsible….’ (male 50-59 y/o)
		Inconsistency (n = 4)	‘First, they [public health authority] sent us to a testing centre because we had been to an endemic area. But later they were upset that we went there, since we were supposed to stay at home in quarantine….’ (female, 20-29 y/o) ‘First they told me I have to stay in quarantine for another 2 weeks after I was discharged from the hospital. On the last day of my quarantine, my son got a letter that he needs to stay in quarantine for another 2 weeks, in case he got infected on my last day in quarantine. But my wife and daughter didn’t have to stay in quarantine any longer, but we were all members of the same household. That didn’t make any sense.’ (male, 50-59 y/o) ‘They [the health authority] told me on the phone my quarantine ended on Thursday. Then I got the letter from them saying I needed to stay in quarantine for another 2 weeks’ (male, 50-59 y/o)

Direct discrimination		Unprofessional treatment (n = 4)	'Since I was the second patient in that other hospital, they had a lot of «respect» of me and avoided coming close to me… that was even worse for me than the [rejecting] behaviour of other people.' (female, 20-29 y/o) 'After I was discharged from the hospital, I wanted to go to the general practitioner for a prescription but they told me I wasn't allowed there, even though I wasn't in quarantine anymore. Then 12 weeks later, I needed a letter of transferral, but even then, my sister had to get it for me…' (male, 60-69 y/o) 'When he [a friend] stayed at home because one of our group tested positive, his boss counted that as vacation, because the health authority hadn't called yet.' (male 50-59 y/o) 'I was feeling so bad, but in that other hospital they [staff] told me to leave immediately, they threw me out…. so I was crying in front of the hospital until my daughter came to get me. A few days later, I collapsed, and I was brought in here and needed oxygen' (female, 70-79 y/o)
Societal level			
Societal norms and values	*Perceived and internalized values and stigma*	COVID-19 as non-desirable condition (n = 5)	'When I got the positive test, I was utterly shocked' (female, 20-29 y/o) 'I was surprised. I never thought *we* would get it.' (female, 50-59 y/o) 'I was just feeling ill and coughing. Maybe it wasn't COVID after all. They [the doctors] said the CT-scan confirmed it, but my test was negative.' (male, 50-59 y/o, denying he had COVID-19)
		Perceived menace to others (n = 10)	'I didn't want to bother people. Maybe they would have thought I am still contagious.' (female, 70-79 y/o)** 'None of my family members got ill, I didn't infect anyone.' (male, 30-39 y/o)** 'We all paid a lot of attention. We didn't infect others.' (male 50-59 y/o)** Q: 'Do you happen to know if you accidentally infected somebody?' A: 'I don't want to talk about that.' (male, 50-59 y/o)

* n = the number how many times this code was applied throughout the interviews

** The assurance of not having infected others reflects the perceived stigma as menace to others and the public health on one hand and efforts to contain the disease as coping with this perception on the other hand.

S4) Applied coping strategies by societal level

Theme	Code (n*)	Quotes
Individual level		
Resilience	Confidence (n = 5)	'I knew I was getting medication; I was sure that would help, otherwise they wouldn't give them to me. I wasn't worried I would die.' (male, 60-69 y/o) 'I felt in good hands.' (male, 50-59 y/o) 'None of us felt that sick that we needed to go to the hospital.' (female, 50-59 y/o)
	Self-efficacy (n = 2)	'In the beginning it was very hard for me. But as soon as I managed to structure my day, time just flew by.' (male, 30-39 y/o)
Coming to terms	Pragmatism (n = 2)	'I had it [COVID-19], that's all there is. Now I am cured and immune.' (female, 70-79 y/o)
	Delayed disclosure (n = 3)	'Back then, I told them [friends and family] I had it [COVID-19]. But I didn't tell them any details. Now I would, but back then, I just didn't want to.' (male, 40-49 y/o) 'In the beginning, I didn't want to share with anyone. Afterwards, we talked about it.' (female, 70-79 y/o) 'I would not go around and tell everyone deliberately that I had it [COVID-19]. But now it is over, if anyone asked, I would answer honestly that I had it.' (male, 30-39 y/o)
	Rationalisation (n = 2)	'We checked the incidence before we went, and it looked fine, so we didn't see any danger in going there [to a hotspot]' (female, 20-29 y/o) 'When I was there, it wasn't known to be a hotspot' (male, 50-59 y/o)
	Denial or fallacy (n = 1)	'Maybe I didn't have it [COVID-19]. I even know couples, where one had it and the other didn't' (male, 50-59 y/o)
Financial security	Financial security (n = 8)	'I didn't face any financial problems, my salary just continued.' (male, 40-49 y/o) 'I was on sick leave and got my loan as usual.' (female, 20-29 y/o) 'I am retired, so I didn't have any financial problems.' (female, 70-79 y/o)
Interpersonal level		
Reaction to rejective behaviour	Understanding (n = 10)	'I could totally understand their [friends] behaviour. No one knew exactly how long people can transmit COVID' (female, 20-29 y/o) 'I could understand that, I didn't blame anyone.' (female 70-79 y/o)
	Reasoning (n = 2)	'I tried to explain, I argued with them [family members]…. but with some people, you just can't reason at all.' (female, 50-59 y/o) 'When they [friends] took a step back, I told them there was no reason, they could hug me, I am no longer contagious.' (male 50-59 y/o)
	Distancing (n = 2)	'When heard about what others said, I just distanced myself from that.' (male, 50-59 y/o)

Personal contact	Genuine interest and mindfulness (n = 7)	‘In a way, we were lucky, that the whole family was in quarantine, so we had each other’ (female, 20-29 y/o) ‘It is very important, that there are people who care about you and want to know how you are doing. My mum called every day to check on me, that felt good.’ (male, 30-39 y/o) ‘I would call and make sure he [friend from vignette] is okay. I would tell him, everything is going to be fine, since he is young.’ (female, 20-29 y/o) ‘Some people just want to know more about it from people who had it [COVID-19] and are very interested in what I experienced.’ (male, 30-39 y/o)
	Unaltered interpersonal relationship (n = 4)	‘With my friends, it is same way as it has been before. No distance, not too many questions.’ (male, 30-39 y/o) ‘I infected my boyfriend, but he remained relaxed.’ (female, 20-29 y/o) ‘When I came home from the hospital, everyone was just so happy to see me, that was very touching.’ (male, 50-59 y/o)
	Comprehension (n = 4)	‘I talked to a friend in a similar situation, and she could totally relate.’ (female, 20-29 y/o) ‘People told me it’s a miracle I got through all of this without serious psychological damage. When we talked about it, it became clear, that others were frightened of being alone in such a situation as well’ (female, 70-79 y/o) ‘If a friend of mine had COVID, I would support him and say it’s not his fault that he got it. We didn’t choose for this either.’ (female, 50-59 y/o)
Community level		
Reaction to rejective behaviour	Resignation (n = 3)	‘I can live with it [people avoiding him]. I take it with humour.’ (male, 50-59 y/o) ‘I didn’t really bother. Couldn’t change it anyway. (…) You have to take it the way it is.’ (male, 40-49 y/o)
	Understanding (n = 3)	‘That was a new situation, people probably didn’t know better.’ (female, 20-29 y/o) ‘I tried to understand their reaction [people at work] and asked myself, how I would have reacted. And honestly, I would keep my distance too. That is probably human.’ (male, 30-39 y/o)
	Reasoning (n = 2)	‘I told them [people in a grocery store] I am no longer contagious and that they don’t need to keep a 10-meter distance. I fact, I am less dangerous than other people.’ (female, 20-29 y/o)
Social network and inclusion	Sympathy (n = 7)	‘So many people called during my absence to make sure I am okay, and they were so happy to hear from me when I called them back.’ (male, 60-69 y/o) ‘I received so much sympathy, from friends and relatives, but also from the whole community, where I am active in different associations. They all felt for me and asked «Hey, how are doing?». I got a lot of positive signals. They just wanted me to recover soon.’ (male, 60-69 y/o)
	Solidarity and support (n = 7)	‘From time to time, a neighbour would leave something for me at my door.’ (female, 20-29 y/o) ‘Many people from our village offered help and asked if they could get us anything. I was surprised by their willingness to help.’ (female, 50-59 y/o) ‘Some neighbours made food and left it at the door for us. They really cared about us’ (male, 50-59 y/o)
Institutional level		
Reaction to discrimination	Leniency (n = 8)	‘I guess they [the health authorities] were just overwhelmed’ (male, 50-59 y/o) ‘I hope by now, it is more organised’ (female, 50-59 y/o) ‘Those people refusing the regulations don’t carry the responsibility. Everyone with that kind of responsibility supports a lockdown.’ (male, 50-59 y/o)

	Incomprehension (n = 8)	‘I was feeling sick and I couldn’t get through [by telephone] to any doctor or health authority for days to get a test. That really bothered me.’ (female, 20-29 y/o) ‘I really felt mocked by the health authorities.’ (female, 20-29 y/o) ‘For me, it was extremely hard. (…) That is why I didn’t tell the health authority I also had contact with my parents. I didn’t want to do this to them’ (male, 30-39 y/o)
Received support	Appreciation of health-care workers (n = 4)	‘He [family doctor] called every day to make sure I was okay. That felt good.’ (female, 70-79 y/o) ‘I remember a doctor who was looking for possible treatment options all day long and called another university hospital. In the end, the treatment saved me’ (male, 50-59 y/o) ‘The hospital staff was very caring and always very kind’ (male, 60-69 y/o)
	Support group (n = 2)	‘Is there a self-help group for COVID survivors?’ (male, 50-59 y/o)
Societal level		
Harm reduction	Law-abiding (n=5)	‘I kept my distance, I stuck to the rules, I didn’t infect anyone.’ (female, 70-79 y/o)** ‘When we came back [from a hotspot] we stayed at home. So when we finally knew we had it [COVID-19], at least I didn’t feel guilty, because I knew I didn’t infect anyone else.’ (female, 20-29 y/o) ‘I was scared to infect anyone. We barely had contact, I wore a mask when I went to the bathroom, I did my laundry separately, just like the health authority told me to. In the end, none of my family members got ill, I didn’t infect anyone.’ (male, 30-39 y/o)** ‘We all paid a lot of attention. We didn’t infect others.’ (male 50-59 y/o)**
	Social withdrawal (n = 3)	‘I didn’t want to bother people. Maybe they would have thought I am still contagious.’ (female, 70-79 y/o) ‘When my quarantine ended, I didn’t ask people to meet. I was afraid they would react…. in a strange way.’ (female, 20-29 y/o) ‘I am only on contact with my closes relatives.’ (male, 50-59 y/o)
	Hygiene advocacy (n = 3)	‘I tell everyone, they should wear their face masks.’ (female, 70-79 y/o) ‘No matter where we go, with all our friends, we have this discussion [about the need for regulations and hygiene practices], it is the only way. When people say «It is only a flu.», I tell them, it is not. It is a whole different affair.’ (male 60-69 y/o)

* n = the number how many times this code was applied throughout the interviews

** The assurance of not having infected others reflects the perceived stigma as menace to others and the public health on one hand and efforts to contain the disease as coping with this perception on the other hand.

Perception of legal stipulations (measures of containment, mandatory face mask, curfew)	Support (n = 5)	‘I tell everyone, they should wear their face masks, if they got it [COVID-19], it’s to late.’ (female, 73 y/o) ‘I wish people would pull themselves together. (…) If you are unlucky, you are gone.’ (male, 69 y/o)
	Acceptance (in spite of struggle) (n = 6)	‘I longed to go out for a walk….but I stayed inside’ (female, 25 y/o) ‘We were all cramped together. After some time, it is normal you go on each other’s nerve…. Then you need to withdraw to have your own space’ (female 23 y/o)
	Confusion (n = 6)	‘I think the whole topic is very confusing, I am missing a clear line. The regulations are different in different places, that confuses people.’ (female, 51 y/o) ‘Sometimes, the regulations seem a bit random.’ (male, 38 y/o) ‘Of course we need certain restrictions, but sometimes it feels like those in charge didn’t really think that through.’ (female, 25 y/o)
	Doubt and refuse (n = 3)	‘For me, it was extremely hard. (…) That is why I didn’t tell the health authority I also had contact with my parents. I didn’t want to do this to them’ (male, 38 y/o) ‘I am not sure, if wearing these masks is really the solution for this problem.’ (male, 53 y/o) ‘I am not supporting these masks…. It is hard to breathe.’ (male 55 y/o)
	Hope (n = 2)	‘Maybe we can all go back to normal soon.’ (male, 38 y/o)

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Page/line no(s).

Title and abstract

Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	p 1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	p 1

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	p2
Purpose or research question - Purpose of the study and specific objectives or questions	p2

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	p4
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	p14
Context - Setting/site and salient contextual factors; rationale**	
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	p4
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	p4
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	p4-5

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Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	p4 (S2)
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	p4-5 and table 1
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	p4-5
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	p5
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	p5

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	p7-11 (and figure 3 as model)
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	p7-p11 (and more quotes and notes in S3, S4)

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	p12-14
Limitations - Trustworthiness and limitations of findings	p14

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	p15
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	p15

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014 DOI: 10.1097/ACM.0000000000000388

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STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1 and 2
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4
Objectives	3	State specific objectives, including any prespecified hypotheses	4
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	5
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	*5*
Bias	9	Describe any efforts to address potential sources of bias	5
Study size	10	Explain how the study size was arrived at	5
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	5
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	5
		(*b*) Describe any methods used to examine subgroups and interactions	5
		(*c*) Explain how missing data were addressed	5
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy	5
		(*e*) Describe any sensitivity analyses	5

Continued on next page

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Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7
		(b) Give reasons for non-participation at each stage	(7)
		(c) Consider use of a flow diagram	n.a.
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	5
		(b) Indicate number of participants with missing data for each variable of interest	(7)
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	n.a.
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	*n.a.*
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	*n.a.*
		Cross-sectional study—Report numbers of outcome events or summary measures	*7*
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	7
		(*b*) Report category boundaries when continuous variables were categorized	n.a.
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n.a.
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	8
Discussion			
Key results	18	Summarise key results with reference to study objectives	13
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	15
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	13/14
Generalisability	21	Discuss the generalisability (external validity) of the study results	14
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	1

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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