

In Focus

Covid-19 Pandemic Coping Strategies in a Complex Landscape of Crisis Communication: A Participatory Study with Disability Organisations in Sweden



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INTRODUCTION

The notion of crisis communication as concerning a single message, communicated as “one voice” from official channels, speaking to the public about how to prepare for and manage crisis situations and that the problem is one of outreach (Heath, O’Hair 2020; Rowan et al. 2020; World Health Organisation 2020), is challenged. With the Covid-19 pandemic now entering its second year, it has become evident that the general public is accessing multiple channels for crisis information where the situation, the rules and knowledge are constantly changing (Lundälv et al. 2021a). Crisis information is communicated by authorities on national, regional and municipal levels, and by researchers and other so-called public experts. An array of different voices, facts, (fake) news and recommendations are channelled via public service, social media, national and international media. Most of this content is accessed and shared via digital channels, but also via communities, workplaces, and between friends and families living in the same country or abroad. Such an overload of information may result in infodemics, which makes it more difficult to identify a solution, to build trust in the responses and to increase the probability that recommendations are followed (Orso et al. 2020; World Health Organisation 2020).

Navigating through a complex crisis communication landscape has become a crisis-specific media practice that is about accessing, understanding, interpreting and evaluating crisis information, where the next step influences what coping strategies disabled people (and others) use to adapt to the crisis situation. This challenge is not only facing the public, but also public crisis communicators and other organisa-

tions that are responsible for processing and passing on messages to various communities in society. In addition, the Swedish Covid-19 strategy places an emphasis on personal responsibility and builds on recommendations and guidelines rather than strict regulations (Folkhälsomyndigheten, FHM 2021). Everyone is expected to take precautionary measures to mitigate the spread of the coronavirus, for example, by avoiding social events, keeping a safe distance from others, and staying at home in the case of symptoms (Krisinformation.se 2021). This approach requires that people, based on the (overload of) information provided, can evaluate what risks they may take in regard to their work situations, social relations and individual health, and subsequently make decisions.

This article presents insights gained from a qualitative study addressing disabled people whose everyday lives have always been characterized by extraordinary circumstances, continuously so also during the Covid-19 pandemic, and how they navigate through and manage a complex crisis communication landscape. The Swedish Agency for Participation recently reported that “there is a great risk that cross-sectoral issues of inclusion and accessibility for people with disabilities will be forgotten or not prioritized” during the Covid-19 pandemic (Swedish Agency for Participation, 2021a). To meet this challenge, a recently passed legislation was implemented during the pandemic: the Act on Accessibility to Digital Public Services (2018: 1937). Among other things, the legislation requires that all websites hosted by public actors must be made accessible to people with disabilities (Swedish Agency for Participation, 2021a: 27). In 2020, however, 34% of all authorities in Sweden failed to set any requirements

for accessibility in their procurements (Swedish Agency for Participation, 2021b: 10).

In this article, the term “disabled people” is used because the disability organisations involved in the study strive to realise social rights and to remove problems and barriers in society for people with various disabilities. As argued in critical disability studies, people with disabilities have “been made” disabled because society is not capable of accommodating their needs nor open to alternative ways of being, acting and living. When relevant support is offered to people with disabilities, they are able to act and live a fulfilling life, just as people without disabilities. It is thus important to use the term “disabled people” to highlight the problematic view of people with disabilities as being marginalised, and that the problems with accessibility and inclusion are located in the individual rather than in society (Kilman et al. 2021). Although some disabled people have been exposed to marginalization and exclusion in society, others have not experienced such exclusion. To consider all people with a disability as a homogeneous group results in a generalisation of an individual’s characteristics. Instead, we assume the concept of variation in functionality, which addresses the importance of making visible the norms in society that produce disability (Sépulchre & Lindqvist, 2016; Kilman et al. 2021).

The aim of the study is to explore crisis-specific media practices of disabled people, and in relation to that, which coping strategies they use to act and live in the times of crisis. The study takes its point of departure in the following assumptions:

- the official recommendations from public authorities are formulated based on normative assumptions of function and conditions,
- disabled people have had more difficulties in adapting to the recommendations, partly due to the normative assumptions and partly due to changed conditions for support,
- disability organisations have played a

role in bringing members’ complaints about these problems to the surface and in supporting the members.

The research questions are:

1. How have disabled people navigated through the complex landscape of crisis communication, that is, what constitutes their crisis-specific media practices?
2. What coping strategies have disabled people used to adapt to different situations during the pandemic?
3. In what ways might a complex landscape of crisis communication affect trust and recognition between authorities and disability organisations?

To answer these questions, an online workshop was organised with representatives from eight disability organisations in Sweden. The representatives are elected by the members of their disability organisations and serve as their voice in the public sphere. Their contribution to this study is based on knowledge attended from their respective members. The disability organisations work to organise their members in order to promote social rights, but also for those whose voices are not heard (Pitkin 1967; Campbell 2009). The workshop was organised by a team of researchers representing different scientific disciplines: social work and disability studies, design research, communication sciences, and sociology. Such a cross-disciplinary setting and the mix of participants representing knowledge and experiences from the disability field create conditions for knowledge sharing beyond their given contexts (Charlton 1998; Priestley et al. 2010; World Health Organization & The World Bank 2011; European Disability Forum 2020).

BACKGROUND

The workshop is part of a larger project (2020–2022) exploring crisis communication from a critical perspective (RISE n.d.), and it involves crisis communicators, civil society organisations and the public. Prior to the workshop, a national online survey

study and a preparatory workshop with crisis communicators were conducted (Lundälv et al. 2021a; Eriksson et al. 2021, 2021a). The results of these two interventions are briefly presented in the following section through reporting on the emergence of the complex crisis communication landscape and the lack of social crisis preparedness. The theoretical background chapter includes an introduction to the concepts of *coping* and *coping strategies* (Lazarus & Folkman 1984) and of *trust* and *recognition* (Habermas 1984; Honneth 2005, 2007), which are used to reflect on and mirror the results of the study. To situate our study in the research community, we also present an overview of international research on crisis communication targeting disabled people, which also address *coping strategies* and *communication and trust*, which are of special relevance to this article.

An emerging complex crisis communication landscape

In a contemporary digital society, crisis information is no longer about one message being sent via public channels speaking to the public about how to act and live in a crisis (World Health Organisation 2020). During the Covid-19 pandemic, which began in early 2020, it has become evident that the general public are accessing multiple channels and listening to multiple voices and messages sent nationally and internationally, and not seldomly pointing in different directions. Not only are the channels and messages numerous, but also the target groups that receive, interpret and act on the crisis information provided.

By analysing the experiences of crisis communicators involved in the national online survey study and the preparatory workshop, we have developed a framework to understand this new media situation (see Fig. 1). We argue that crisis communication has gone from being about “simple” communication to “complex” many-to-many communication that places new demands on both the senders of information and the receivers. The simplest way to understand communication, according to this view,

is as *one-way communication*, commonly from crisis communicators to the public, where the challenge is to design a relevant message. *One-to-many communication* occurs when communicators try to adapt messages to different target groups. *Many-to-one communication* adds the issue that a recipient, for example a citizen, receives messages from different sources and must sort and evaluate the information that reaches them as relevant or irrelevant, true or false, etc. *Complex communication* refers to the communication situation that emerged during the pandemic in Sweden and elsewhere. In such a situation, crisis communicators need to interpret rules and regulations from different authorities, including local variations, and communicate this to citizens with different messages to different target groups. The citizens, in their turn, must not only seek information from the right source and the right medium to understand which regulation applies to them, but also understand how these recommendations might impact their lives and what changes they need to make to accommodate them.

In Sweden, the digitalisation of authorities and various welfare services has become increasingly widespread. Consequently, both employees and leaders in workplaces must be given the opportunity to develop the skills and competencies needed to adapt to this reality (Wolmesjö & Fagerström 2020). As was shown by Lundälv et al. (2021a), there is a desire not only to develop new methods of promoting dialogue between authorities and the public about their needs and rights, but also for highlighting individuals' own responsibilities, capabilities and shortcomings in the event of a crisis. The study showed that non-local and non-individually adapted communication may create disengagement among target groups and plant an inability to go from information to action because they do not recognize themselves in the national messages. Aside from channelling crisis information top-down, crisis communication material and methods should also support and create guidance and

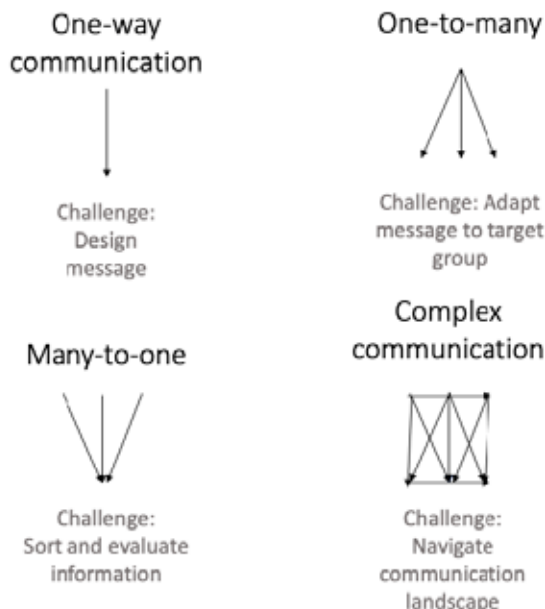


FIGURE 1. A visual overview of how crisis communication has gone from “simple” to “complex”.

initiatives for individuals to achieve better crisis preparedness using their own coping resources. This can be done by starting from their life situations, conditions and needs, based on developing individually tailored crisis plans.

Social crisis preparedness

The online survey study, the preparatory workshops with the crisis communicators, and the workshop with disability organisations, revealed a lack of social crisis preparedness (Lundälv et al. 2021a; Eriksson et al. 2021, 2021a). The disability organisations reported that some of their members have suffered from loneliness and isolation during the Covid-19 pandemic, which leads to more vulnerable situations and less independence. This applies especially to those who, in their social life, make use of various institutional support functions that run the risk of disappearing in crisis situations. In the Covid-19 pandemic, examples included the government withdrawing support functions due to the risk of infections,

support withdrawn due to staff shortages caused by illness, and the affected persons themselves withdrawing support due to the risk of being infected by support staff (Socialstyrelsen 2021).

THEORETICAL FRAMEWORK

The analytical lens used for understanding the outcome of the workshop with the eight disability organisations consists of theories on *coping* and *coping strategies* used in psychological research and in stress-related research (Aldwin 2007; Lazarus & Folkman 1984). The results are reflected upon through the notions of *trust*, which is an ambiguous concept that has interested sociologists and philosophers (Habermas 1984, Luhmann 1979), and the social philosophical concept *recognition* (Honneth 2005; 2007).

The strength of combining these three concepts is that they may be applied to create an understanding of how disabled people have felt included or excluded in the public crisis management. Moreover,

they serve to show to what extent disabled people have received recognition for their experiences and need for support and information during the pandemic. The importance of this is emphasized by Honneth (2005, 2007), who argues that a denied recognition could imply that a person is the subject of abuse and disrespect. Further is the importance of recognizing the challenges to making governmental decisions as “it is increasingly difficult to build trust that these decisions are made in the public interest” (Nohrstedt 2016:11) in a society with complex social structures. Assuming this theoretical framework allows us the following: firstly, to capture the practical strategies of disabled people and the adaptations that became necessary to cope with the pandemic; secondly, to highlight democratic issues and injustices that emerge from a lack of trust and recognition of part of the population (here, disabled people) when implementing crisis strategies, pandemic recommendations, and governmental support systems.

Coping strategies

Coping is defined as the individual's own ability to master, that is, to handle different situations that appear in life (Lazarus & Folkman 1984). Coping may also be a process consisting of a variation of different coping strategies that differ from time to time. The commuting model (dual process) can be used to describe the process of an individual that combines different coping strategies by oscillating between thinking about and relating to what is difficult, and then trying to think about something else (Stroebe & Shut 1999). Through this process, individuals may get new strength and energy to handle their situation (Benkel 2011).

Two types of coping strategies are confrontational coping strategies (problem-focused coping) and avoidant coping strategies (emotion-focused coping). Problem-focused coping means that the person is striving to solve practical problems and situations. It may concern collecting and evaluating information to find alternative

solutions on their own or be about applying for help from others. Emotion-focused coping means that the person can neither deny nor reduce a stressful situation that has arisen. The person may actively seek to receive some form of emotional support from people in their immediate environment, or accept and tolerate a certain situation.

Trust and recognition

The concepts of trust and recognition are used to reflect on the situations and living conditions that vulnerable groups in society experience and the potential consequences of a lack of relevant information and support. In this study, the disability organisations report their experiences acquired from actively listening to their members and providing social support, which creates conditions for reciprocity and joint learning. When defining and acknowledging the importance of building trust and recognition between different actors in society, an emphasis is put on the importance of creating conditions for a mutual communication community where different actors' experiences and needs are acknowledged (Habermas 1984).

Trust is also relevant in the relation between different actors in society in a crisis situation. The concept of trust builds on two components, whereof one is a subjective form of trust that relates to the perceived trustworthiness of another party for a given task (Das & Teng 2004). The other is a behavioural component of trust that involves relying on another party to do something and having positive expectations of the outcome. Trust thus requires a “willingness to be vulnerable” since it involves a risk of being harmed if the trusted party is not fulfilling the expected behaviour and that it revolves around a fundamental unknowability of how the other party will act (Rousseau et al. 1998). In a crisis, a governmental authority often has the responsibility of adequately supporting citizens who have to rely on it to have their needs fulfilled. A lack of trust in such a situation means that citizens do not expect that the

government will adequately support them, and the mutual relation breaks down.

Honneth (2005, 2007) addresses the importance of recognition between two actors and how trust is built into that process. To establish trust and recognition between a disabled person and, for example, a person at an authority who provides support, communication is essential. As described by Lourens, “[d]isabled people are often silent about their actual needs in helping encounters and relationships. And, like myself, some disabled people might hide their resentment and anger when on the receiving end of unsolicited help” (Lourens 2021: 69). This may come from a lack of trust or even fear of authorities, grounded in past negative experiences with treatment from authorities or voicing concerns leading to loss of governmental support (DHR 2013). The relations of trust and distrust between authorities and citizens also relate to the concept of social trust, which in the Swedish context has been discussed and problematised by Rothstein (2003) and Trädgårdh et al. (2013). Rothstein (2003) argues that interpersonal trust arises when individuals trust the political institutions in society. That is, people trusting the authorities will have a positive effect on people’s trust in each other. A Swedish study indicates that the Covid-19 pandemic has strengthened the public’s trust in authorities (Esaïasson et al. 2020).

One of the paradoxes of trust building is that monitoring and supervising an individual’s actions seems to be able to determine whether they can be trusted or not, but it can also erode trust or show that someone is not being trusted (Baier 2013). Real trust involves a letting go of such supervising measures and trusting someone to do what is expected even when their actions risk causing harm to the trusting party. Even when accountability measures are in place, an individual must trust those measures to be functioning. Such unknowability enables complexity reduction because one party can trust in the decision taken by another party without fully knowing their reasoning or having

to monitor their actions (Luhmann 1979). With lack of trust, every interaction needs to be scrutinized and controlled, and the distrusting party cannot rely on predictable support in the future. The downside of this trust is that it makes the trusting party vulnerable when the trusted party fails to fulfil its responsibilities.

INTERNATIONAL RESEARCH ON CRISIS COMMUNICATION TARGETING DISABLED PEOPLE

Studies of more general kinds reporting on the consequences and effects of the Covid-19 pandemic on disabled people have already been conducted, whereof some have addressed *coping strategies* and *communication and trust*, which are of special relevance to this article.

Coping strategies

Most of the published research on coping and coping strategies used by people with various disabilities were conducted in the initial phase of the Covid-19 pandemic (Costabile et al. 2020; Neece et al. 2020; Saricali et al. 2020; Skapinakis et al. 2020; Umucu & Lee 2020; Buckland et al. 2021; Fluharty et al. 2021). A study involving people with multiple sclerosis showed that many had difficulty continuing their psychotherapy during the Covid-19 pandemic (Costabile et al. 2020). The group engaged in minor social activities and consumed a lot of television, which indicated that they had a great need for information, but at the same time, this was a sign of a passive attitude. A common coping strategy involved avoidance. Another study exploring the effects of the Covid-19 pandemic on people with various mental disabilities (e.g., depression) reported that the respondents that showed high levels of personal control more often used positive strategies to cope with the stress of the pandemic. The study also showed that “[d]epressive symptoms were higher in the younger, in students, in those with a stronger emotional impact, in those isolated due to symptoms” (Skapinakis et al. 2020: 1). It is also stated that an overexposure to Covid-19 related news

“was associated with a higher depressive symptomatology” (Skapinakis et al. 2020: 8). Previous research that addressed the importance of different coping strategies for the mental health of the population concluded that “[p]roblem-, avoidant- and emotion-focused coping strategies were not associated with faster improvements in mental health” (Fluharty et al. 2021: 1).

A study examined the type of coping strategy used by families with children with intellectual disabilities during the Covid-19 pandemic (Neece et al. 2020). The three most common strategies used by families were to use their routines and schedules. They also tried to find fun things to do and meditated and engaged in various exercises (Neece et al. 2020: 745). Another study examining coping strategies of people with disabilities showed that strategies such as “acceptance” and “self-distraction” were the most used (Umucu & Lee 2020). The results indicate that “perceived stress was associated with both maladaptive (i.e., denial, substance use, behavioural disengagement, venting, self-distraction, and self-blame) and adaptive (i.e., planning and religion) coping strategies in our participants” (Umucu & Lee 2020: 196).

A literature review published by The Swedish Public Health Agency (2020) reports that there are three main forms of coping strategies that clearly reduce Covid-19 related stress in the population: distraction, active coping and emotional support (emotion-focused coping strategies). These strategies can increase the mental well-being of people with various disabilities, which could also be observed in international studies on the importance of coping (Park et al. 2020; Umucu & Lee 2020). Several studies have also examined the situation during the Covid-19 pandemic for people with visual impairments and have found an increased risk of loneliness, social isolation and vulnerability (Gombas & Csakvari 2021; Halpern et al. 2021; Jondani 2021; Kim & Sutharson 2021; Lundälv et al. 2021a; Rosenblum 2020).

Communication and trust

Previous research reports the importance of providing relevant information, guidance and support from consumer advocacy organisations to people with intellectual and developmental disabilities during the Covid-19 pandemic (Ervin Hobson-Garcia 2020). Several studies focused on trust and the important connection between trust and communication (Goggin & Ellis 2020; Helsingen et al. 2020). One study claims that people with disabilities suffer a higher risk of communication shortcomings between themselves and the health care system; thus, they advocate the potential of using telemedicine in healthcare to create improved conditions for communication (Jumreornvong et al. 2020). An emphasis is put on the importance of using multimodal communication strategies (e-mail, radio, television, and text) and disability organisations being involved in developing the information targeting people with disabilities. Thus, people with disabilities should be included in planning for preparedness against future pandemics (Sabatello et al. 2020).

Social media has been important in disseminating information on disability issues concerning risks and support during the Covid-19 pandemic (Thelwall & Levitt 2020). A study explored levels of trust in the information sources about health recommendations among people with disabilities and concluded, “[t]rust in information sources is associated with action. It is important to provide clear, consistent and non-polarizing messages during public health emergencies to promote widespread community action” (Ipsen et al. 2021: 1).

In Sweden, the media coverage of the Covid-19 pandemic has largely not drawn attention to the situation of particularly vulnerable groups in society. The question of possible risk groups, such as disabled people, has been sparsely reported (Ghergetti & Odén 2021), with the exception of the elderly, who have been referred to as a vulnerable group in need of special protection. International research has drawn attention to how vulnerable social groups

can receive the authorities' messages and information through public education such as crisis management (Rahm 2021). As stated, "citizen education becomes a way to manage the crisis, by relaying governmental information to target groups that would otherwise be hard to reach, but also that the crisis becomes a way to initiate educational efforts both broadly and specifically, within the organisation as well as towards its target groups" (Rahm 2021: 59). The results of these studies indicate that the Covid-19 pandemic highlights the vulnerability of people with disabilities during crises and that their crisis preparedness needs to be strengthened.

METHODS

The study presented in this paper assumes a qualitative and participatory research approach (Ham et al. 2004; Wermeling & Nydahl 2011) by involving the disability organisations in all phases: from preparation to implementation of the workshop. In addition, written questions were distributed to the disability organisations that could not partake in the workshop. Such an inclusive and participatory approach is in line with previous initiatives that also place an emphasis on the importance of involving disability organisations and their knowledge and experiences in research (Charlton 1998; Priestley et al. 2010; World Health Organisation & The World Bank 2011; Burke & Byrne 2020; European Disability Forum 2020).

Literature search

A literature search in various databases for international research studies was carried out using several different international databases and the keywords: Covid-19, Coronavirus Disease 2019, pandemic, disability, disability movement, disability organisations, crisis communication, communication, coping strategies, and coping. The period included in the search was articles published between January 2020 and May 2021.

Workshop setting and activities

The workshop with the disability organisations was conducted using a video conferencing platform and a joint digital whiteboard for visual materials and notes. The workshop lasted for two hours, including a brief introduction to the project, the agenda, and the digital whiteboard. Two types of rooms were used: a main room and breakout rooms, where the representatives from the disability organisations, from now on referred to as "participants", were allowed to interact with each other in smaller groups. Three activities of 20 minutes each were organised.

Activity 1: Crisis communication

The participants were asked to reflect on how the members of the disability organisations have handled the complex landscape of crisis communication in terms of the following: accessing, sorting, evaluating, understanding, and acting upon the information.

Activity 2: Social crisis preparedness part I

The participants were asked to create fictional characters representing typical members of the disability organisations and create a timeline of activities performed by their characters during a day (pre-Covid-19).

Activity 3: Social crisis preparedness part II

The participants were asked to reflect on their characters' lives during the pandemic in relation to life pre-Covid-19.

Respondents

An invitation to participate in the study was distributed to the 49 disability organisations included in the umbrella organisation the Swedish Disability Rights Federation (Funktionsrätt Sverige 2017; Lundälv et al. 2021b; Lundälv et al. 2021c). As stated, "The basis for all work at the Swedish Disability Rights Federation is the principle of equal value of all people and everybody's right to self-determination and full participation in society" (Funktionsrätt Sverige 2017). Eight disability organizations volunteered

to partake in the study: The Swedish Association of the Visually Impaired (SRF), The Swedish Association of Hard of Hearing People (HRF), The Swedish Association for Survivors of Polio, Accident and Injury (RTP), The Autism and Asperger Association, The Swedish Stroke Association, Organization for People With Impaired Mobility (DHR), Association of Young People with Reduced Mobility, and The Swedish Association for Disabled Children and Young People (RBU). The selection of organisations should not be seen as a representative selection of the disability organisations that exist in Sweden, but a selection based on the interests and availability of the organisations. The representatives who participated in the workshop had different roles in the various organisations they were representing, such as chairperson, ombudsperson, business developer or member.

Ten participants (6 women and 4 men) attended the workshop, coming from disability organisations primarily representing people with motor impairments, visual impairments, hearing impairments, neuropsychiatric disabilities, traffic injured

people (e.g., Traumatic Brain Injury) and people who have had a stroke. Two participants, representing a hearing-impaired association, contributed with written answers after the workshop.

Data gathering and analysis

The methods for data collection during the workshop were notes that were first kept in the joint digital whiteboard and then copied to a text document for analysis. The discussions were also audio recorded and transcribed.

The data collected in Activity 1: Crisis Communication

The participants were asked to describe how the members of the disability organisations access, interpret, evaluate the crisis information, and take subsequent action based on this. The data was categorized under four themes, which were analysed, creating the basis of the description that contributed to answering the first research question. **Figure 2** illustrates how the notes were visually captured.



FIGURE 2. Notes added to the joint digital whiteboard from the discussions about crisis information (the notes are in Swedish).

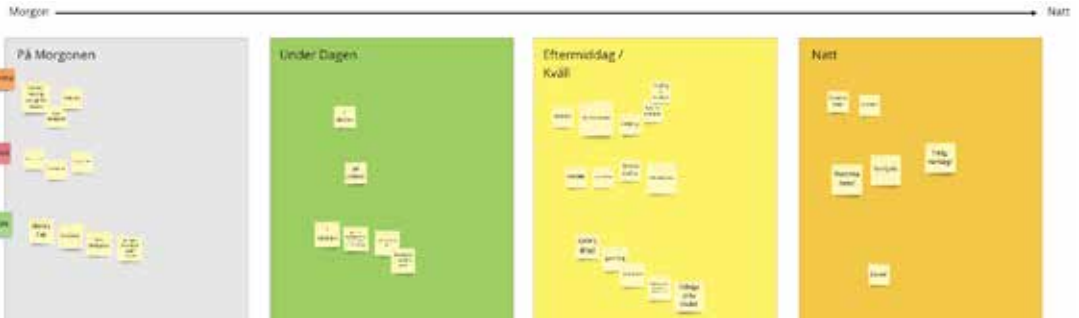


FIGURE 3. An example of a timeline indicating the activities performed by their characters (the notes are in Swedish).

**The data collected in Activity 2:
Social Preparedness Part I**

The participants created characters that represented typical members of the disability organisations and timelines of their daily activities. The data were analysed through theories of coping and coping strategies, which contributed to answering the second research question. **Figure 3** illustrates how the notes were visually captured.

**The data collected in Activity 3:
Social Preparedness Part II**

The participants were asked to reflect on their characters' lives during the Covid-19 pandemic. The data were analysed through a SWOT analysis (Strengths/Weaknesses/Opportunities/Threats) (Jackson et al. 2003). The answers were sorted under the four factors, which then created categories of insights that contributed to answering the second and third research questions. **Figure 4** illustrates how the notes were visually captured.



FIGURE 3. Documentation of the three groups' reflection on their characters' lives during the pandemic (notes in Swedish).

ETHICAL CONSIDERATIONS

Specific research ethics considerations and awareness are required when conducting research involving people with disabilities (Beauchamp & Childress 2013; Swedish Research Council 2017).

Prior to the workshop, the participants were informed about the purpose of the present study, and its approach and methods for handling data. An oral informed consent was achieved; in addition, the participants were asked to fill in a digital consent form. The present study did not gather any individual data since the workshop participants were representing the members of the disability organisations and thus participated on a general level (organisational level). Individual conditions were not directly studied, and the results presented address concerns on the societal and aggregate levels. Previous studies in Sweden involving disability organisations have assumed a similar ethical stance (Lundälv et al. 2015; Bahner 2017). Therefore, we determined we did not have to apply for the traditional ethical approval, and the present study has not undergone an ethical review.

RESULTS

The result section provides answers to the three research questions by presenting and analysing the workshop outcome.

RQ1: How have disabled people navigated through the complex landscape of crisis communication, that is, what constitutes their crisis-specific media practices?

The question is answered by describing disabled people's practices used for accessing, understanding, interpreting, evaluating, and acting upon crisis information. This is done by summarising their answers in four themes.

Accessing channels providing crisis information

As is the norm for people in general, disabled people turn to general news channels and feeds for accessing crisis information, but also to channels with accessibility-

adapted information (if available), addressing accessibility issues such as visual (e.g., colour blindness), auditory (hearing difficulties), and learning/cognitive (e.g., dyslexia). They also get access to information via second-hand sources, such as family members, assistants or group housing staff, thereby becoming dependent upon their sources' abilities to interpret and pass on the information. Some of the disability organisations offer the service of adapting general crisis information to target groups and individuals by, for example, offering contact with hospital social workers, who provide information that is relevant to specific target groups.

There are members of the disability organisations that are excluded from accessing crisis information online because they cannot take part in digital media due to their low levels of digital skills. In comparison to the elderly, younger members that were born with, for example, visual impairments have high levels of digital skills as they have grown up with digital media. On the other hand, as pointed out by the participants in the workshop, it can be an advantage to avoid accessing numerous news channels, social media etc., and only go to a few perceived, reliable sources.

Source criticism

News provided by public service and government information sources are considered reliable, even if the information often points in different directions and can be difficult to understand and interpret for the members. For example, one thing can be said at press conferences and something else at the municipal level or on social media platforms, which creates uncertainty. As communicated by one of the workshop participants, one must rely on and make decisions based on one's "gut feeling". This approach, however, demands a lot from the individual and his/her capacity to make decisions based on an overload of rather scattered information.

Understanding and interpreting crisis information

It is difficult for some members of the disability organisations to sort the information and understand what exactly applies to them, partly due to the lack of coherent information. At the beginning of the Covid-19 pandemic, there was an overload of information written about the situation, which was difficult for the members to relate to due to various reasons, such as cognitive disabilities and fatigue. The continued large flow of information caused some concern. As expressed by one of the participants in the workshop, new information has recently been published about the major risks of obesity linked to the Covid-19 pandemic, but how should members interpret the information and how concerned should they be?

Members of the disability organisations lose their independence when they need to ask for help, and they become dependent upon the skills and knowledge of second-hand sources. Many have turned to their organisations to ask how to respond to the recommendations given by the authorities, which, consequently, places high demands on the organisations and their own abilities and competencies to interpret and adapt to new information that is presented on a continuous basis. Adding to the confusion, some organisations refrain from communicating their own positions. Instead, they serve as a forum for discussion about the situation and deal with particular questions raised by members. Other organisations interpret the information and then share it via their social media platforms, such as Facebook.

Management – going from knowledge to action

The members of the disability organisations take action based on the crisis information provided and follow the general recommendations, although they can be interpreted in different ways and contain conflicting messages. Members are dependent upon the public to do the same, that is, distance themselves and take responsibility. For

example, visually impaired people cannot see whether they are keeping their distance or not and are thus dependent upon others to ensure that the recommendations are followed. When this dependency is not met, frustration and tensions occur.

At the workshop, it became clear that the members, like the rest of the population, are tired of the situation and long for the return of social life. The longer the Covid-19 pandemic lasts the sense of information fatigue increases, and people choose to opt out of news feeds.

During the Covid-19 pandemic, some organisations have developed new strategies for communicating with members. The change to digital meetings has proven important in counteracting loneliness and isolation.

RQ2: What coping strategies do disabled people use to adapt to different situations during the pandemic?

The question is answered in two steps. Firstly, a brief description of the coping strategies (pre-Covid-19) of the fictional characters was created by the workshop participants. This facilitated a reference point for the second step: a description of the members' lives during the pandemic and how they have adapted to the crisis situation. Their actions and coping strategies are, among other things, influenced by their crisis-specific media practices used for managing and acting upon the crisis information provided.

Coping strategies used by the fictional characters

The fictional characters and timelines were analysed qualitatively and described by examining which coping strategies could be traced in their activities throughout one day. The characters' activities were sorted under problem-focused coping and emotion-focused coping.

Problem-focused coping

Problem-focused coping strategies are used by individuals seeking to solve practical problems and situations on their own

through taking action or applying for help. The characters Anna and Max are both youths in special needs education and attend school daily. They require school support for inaccessibility and are provided with transport to and from school. The school environment has been adapted so they can circulate without major assistance. However, some disabled people are completely or partially dependent on personal assistance. For them, the school environment is not always available. The character Linus is an adult who is transported to his employment daily. He prefers not to rely too much upon others but to solve issues on his own. Another character, Berta, is 60 years old and finds it difficult to handle computers and digital media, which prevents her from accessing information and communicating with her family. To manage the situation, she applies several coping strategies and actively seeks help regarding how the new technology works. She also applies similar strategies for coping with situations and tasks that she is unable to do on her own. For example, she asks the home care staff for concrete help. The character Björn was also described as coping with problems in everyday life by asking not only home care staff and assistance staff but also relatives for practical and social support.

Emotion-focused coping

The emotion-focused coping strategy is used by individuals that deny and/or cannot reduce a stressful situation that has arisen and thus actively seek emotional support from others. However, emotion-focused coping strategies must be interpreted with caution here. When the workshop participants revealed that social isolation has increased among many members, it can be difficult for them as representatives to become aware of such sensitive areas, if members deny problems and vulnerability (Farhang et al 2021).

Two other characters created at the workshop, Anna and Max, use emotion-focused coping strategies when they participate in extracurricular activities, such

as wheelchair dancing, horseback riding or hanging out with friends. Both receive support from relatives to be able to travel to leisure activities. Some people with disabilities can be very emotionally driven, which means that they do not want to feel lonely or isolated. Meeting others in a similar situation or spending time with friends can be a way to break the silence and loneliness. The character Gustav is a teenager who finds school very stressful and is not given enough support. To cope with the stress of a difficult school day, he sometimes uses video games and online interaction. The character Berta has a low income and thus cannot afford to acquire the technology that enables her to communicate digitally in society. Having accepted her situation, she uses emotion-focused coping by asking friends for help. The character Björn feels isolated in his everyday life. He uses an emotional-focused coping strategy by talking about his feelings, not only to the home care staff and assistance staff but also to his family members, thereby receiving some form of emotional support from people around him.

Coping strategies used to adapt to the situation during the pandemic

The workshop participants were asked to reflect on their members' lives during the Covid-19 pandemic and describe how they have adapted to the crisis situation. Their answers formed categorised actions employed for coping with the pandemic's effects.

Avoiding media and information flows

Members of disability organisations have had great difficulties in absorbing information and sorting the different messages given by the authorities, among others. Some members with certain disabilities found it difficult to watch evening news broadcasts on television as they simultaneously had home care service. Others lacked the strength to partake of crisis information due to fatigue and pain caused by their disabilities. Limited capacity and concentration difficulties curtailed their accessing

information even if it was freely available via various channels, such as radio, television or the Internet. Such circumstances lessened their ability to assume a problem-focused coping strategy. Therefore, some members had no choice other than to avoid taking part in the information flows because they became so tired of the amount of information circulated. "Information fatigue" in this case is not only caused by an overload of information, but also by their individual conditions for partaking.

Less special assistance and escort assistance

The general recommendation given by the authorities call for limited personal contact. Thus members of disability organisations who live with assistance as part of their everyday lives have strived not to engage with new staff due to the fear of being infected. In addition, their regular assistants have, to a higher degree, been on sick leave during the pandemic, thus leaving many of the members with less assistance or being alone. Asking for support comes with the risk of being infected, which has led members to refuse help and instead rely on relatives. Other members have simply learned to live with the situation, opting to stay at home and not ask to be accompanied to activities outside their home.

Increased independence

In contrast, other members use positive strategies to cope with the stress of the pandemic. Consequently, the situation has resulted in an increased independence. An example is the case of home schooling, which they experience as sometimes being organised on more equal terms in comparison to schooling on campus. In terms of accessibility, some (not for e.g., deaf people) find it easier to have digital meetings. Social gatherings are easier to attend online than in a physical setting due to transportation issues or physical barriers, etc. Moreover, it has been related that digital meetings can even reduce stress for participants. Not having to move back and forth to different places may result in a slower pace of life and

reduced social stress. It was also pointed out that an increased use of digital services such as online food purchases, which many members have been motivated to learn to use, also increases opportunities for independence.

Less active leisure time and social life

There are members that experience poorer social lives because many leisure activities, such as social events or sport activities, have been cancelled, which influences their routines and schedules. Both the activities themselves and the opportunities to be transported to the actual physical site have deteriorated. As pointed out at the workshop, travelling and transportation services have become more difficult as they involve risk. A commonly used strategy by members to solve the problem is to cancel participation.

Loneliness and isolation

A major effect of the pandemic for all is reduced contact and social interaction, thus leading to loneliness. Due to the issues put forward in the sections above, members have not been able to socialise with others, which has led to isolation exposure. Many of the members find it difficult to take the initiatives to engage in social activities and to resume contact with people. In other cases, members have developed strategies for dealing with stress and social isolation. For example, some had used chat groups and social media to talk to others in the same situation and to seek emotional support.

Higher level of social crisis preparedness

An observation put forward is that people with various forms of disabilities often possess a higher level of social crisis preparedness than the general public since they are more used to being isolated and finding alternative solutions in everyday life. Even before the pandemic, many of the members' only social contacts were immediate family, personal assistants, or home care staff. Consequently, they were unused to large gatherings and intensive contact with many people. Instead, they built a tight network of people

to socialise with; hence, their lives during the pandemic were not much different.

Easier to attend member meetings

During the pandemic, many of the disability organisations have been able to arrange more member meetings and have learned more about how to organise such meetings. For some members, participating in online meetings is easier as there is no need to be transported to a physical location. Consequently, digital meetings encourage more participation, improve accessibility and promote inclusion, and issues such as geographical distance, transportation and mobilities become less important. As noted, this is an opportunity that has been largely neglected pre-Covid-19 but will play an important role post-Covid-19.

Improved relationships and extended contact with disability organisations

As a result of the pandemic and subsequent crisis situation, the participants in the workshop found that they had established closer contact with the members of the disability organisations and found new and different ways to offer support. As many members do not have any relatives, they have been forced to solve problems by themselves or ask the disability organisations for assistance. One participant recounted how the organisation telephoned their members and was met with stories about a need for social and psychosocial support. Evidently, the members had found new opportunities to compensate for shortcomings in society.

RQ3: In what ways might a complex landscape of crisis communication affect trust and recognition between authorities and disability organisations?

As illustrated, disabled people use different coping resources and abilities to achieve welfare and well-being. Listening to their experiences and practical knowledge of, for example, coping strategies is a matter of both trust and recognition (Habermas 1984; Honneth 2005, 2007). The results presented

in the previous sections are here reflected upon to see how a complex landscape of crisis communication might affect matters of trust and recognition between authorities and disability organisations.

For disabled people in need of professional care on a daily basis, there is already some form of trust (although it may be a tarnished trust) established in the definition of Das and Teng (2004), where a person relies on and expects the provision of these services in their everyday life. The Covid-19 pandemic has imposed a renegotiation of these relations of trust and has forced people to make their own assessments of who or what they can trust and what care they can expect to receive. Significantly, this has occurred in a complex communication situation with many messages from multiple sources that they need to interpret and adapt to their own changing life situations in accordance with government recommendations (FHM 2020). If there is no sense of mutual recognition between the provider of care and the person in need of care, this becomes a cognitively and physically taxing effort of constantly making sure one's needs are taken care of and getting the recognition one deserves. Failure of such mutual recognition of changing circumstances due to the pandemic not only risks negative physical or social impacts but also what Honneth (2007) calls a moral injury – where in a severe societal crisis a certain group's well-being and life circumstances have been ignored or overlooked in crisis communication and strategies that address a more normative understanding of the population.

Changing life circumstances and added difficulties due to a crisis characterized by complex communication highlight the importance of reciprocity and the need to establish spaces – a mutual communication community (Habermas 1984) creating conditions for dialogue and joint learning. In such a mutual communication community, reciprocity can emerge, needs can be recognized, and trust established, despite often occurring power asymmetries between receivers and providers of care,

and the impersonal character of complex crisis information that is often difficult to navigate. In addition, an individual's own responsibilities, capabilities and shortcomings in the event of a crisis can be highlighted. Establishing these trusted relations takes time and effort, and changes in circumstances during a crisis risk undermine these, all of which should be taken in consideration when communicating with vulnerable groups in society.

DISCUSSION

As indicated by the results, the members of the disability organisations not only face the risk of infodemics (Orso et al. 2020; World Health Organisation 2020), thus making it more difficult to make informed decisions, but they also actively choose to avoid information, which is a coping strategy also identified in other studies (Costabile et al. 2020). Due to their individual situations, some members are forced to shut down and avoid accessing crisis information, even if it is available. For them, the concept of "information fatigue" is not only related to an overload of information but to a de facto mental "fatigue" that prevents them from partaking. Other members do not access crisis information due to low levels of digital skills and lack of access to technology. However, accessing but a few reliable sources can actually become an advantage, as previous research indicates that an overexposure to Covid-19-related news is linked to higher depressive symptoms (Skapinakis et al. 2020).

Some of the coping strategies presented follow a dual process, where the members combine different coping strategies for handling both the positives and the negatives effects of the pandemic. In comparison to the general public, the lives of disabled people are always characterized by special circumstances. When these "special circumstances" are suddenly shared by the general public, through being restricted by a pandemic, new openings for mutual learning and development appear. Two examples of this are the members' experiences of an increased independence

and that online settings for various events (school teaching, meetings etc) result in participation on more equal terms. It was also put forward that disabled people may possess a higher level of social crisis preparedness than the general public because they are more used to being isolated and to finding alternative solutions for everyday life.

In contrast, and as also shown in other studies (Costabile et al. 2020; Rosenblum 2020; Halpern et al. 2021; Kim & Sutharson 2021), many members experienced loneliness and isolation during the pandemic. As a consequence of the recommendations to observe social distancing, members have actively limited their number of contacts, including assistance and other kinds of support, such as transportation to activities outside home. Some members have accepted the situation and have chosen to tolerate it. Others have strategized different ways of coping with stress and social isolation, e.g., using various digital communication means seeking emotional support, which are active and emotion-focused coping strategies that have been proven to reduce Covid-19 related stress (FHM 2020; Park et al. 2020; Umucu & Lee 2020).

The study also showed that the disability organisations have acted and implemented concrete measures to support and to facilitate the members during the pandemic, which confirms both curiosity and creativity on the part of the organisations. They have improved the relationships with many of their members and found alternative ways to offer support. They have also gained experiences of how online meetings can be organised in fruitful ways, which will become a part of their activities post-Covid-19.

It takes time and effort to establish a mutual communication community (Habermas 1984) that builds on relationships between authorities and disability organisations characterised by trust, recognition and mutual understanding. The Covid-19 pandemic and the challenges of navigating through a complex crisis communication landscape presenting an overload of information make it more difficult to build trust

(World Health Organisation 2020) and risk undermining these relationships. In such infodemic situations, disabled people are forced to make their own assessments of who or what they can trust and what care they can expect to receive. Their strategies for coping with the crisis situation are in part based on their crisis-species media practices and their abilities to evaluate what risks they may take regarding their individual situation, but also the recognition of their situation by the authorities. When no such recognition is established, due to lack of communication between the parties, we risk causing a moral injury (Honneth 2007), where certain vulnerable groups' well-being risk being neglected. The disability organisations and other civil society organisations play an important role in creating conditions for such reciprocity, where needs can be recognized and where trust can be established. This results in better crisis preparedness among both authorities and members of disability organisations.

Limitations of the study

Due to practical reasons, a limited number of all disability organisations in Sweden participated in the workshop, which makes it difficult to draw any general conclusions on disabled people's situations during the pandemic. The study only includes the representatives of the disability organisations' experiences and knowledge of the members' situations during the Covid-19 pandemic and does not include the direct experiences of the members, or their relatives and families. The data generated at the workshop did not allow us to analyse specific coping strategies, but only strategies in more general terms. In order to conduct such an analysis, we would need to have data that can be related to different coping scales or a COPE questionnaire (Coping Orientation to Problems Experienced) to investigate "how individuals' coping strategies were related to changes in mental health over time" (Fluharty et al. 2021: 1).

CONCLUSION

The aim of this study was to gain an understanding of disabled people's crisis-specific media practices and their ways of coping with situations caused by the Covid-19 pandemic. The theoretical concepts of trust and recognition were used to elaborate in what ways the contemporary complex landscape of crisis communication might affect the relation between authorities and the disability organisations, and potential consequences, especially for disabled people in vulnerable situations, whose lives are dependent on various forms of institutional support. The results of this study show how disabled people in Sweden have used a variation of coping strategies to handle situations caused by the Covid-19 pandemic. Their actions are influenced by their crisis-specific media practices used for handling the overload of crisis information provided in the current complex crisis communication.

The study should be read in the light of the Swedish Covid-19 strategy, which has put a strong emphasis on the individual's responsibility and that every citizen is expected to follow the recommendations and take precautionary measures to limit the spread of the virus. This approach requires that both public agencies and citizens are capable of handling and navigating the emerging complex crisis communication landscape of today, and based on them, make responsible decisions and take relevant measures. The results presented address some of the challenges of building such a mutually communicative community, in which disabled people's needs are recognized, and trust is established. The study also presents opportunities for renewal and areas of potential development, as well as opportunities for mutual learning. By creating conditions for dialogues between disability organisations, authorities and the general public, we can go beyond a normative view of what constitutes crisis communication and preparedness and explore what we can learn from (dis)abled people, whose everyday lives have always been characterized by extraordinary circumstances.

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