



**HAL**  
open science

## Social support for the chronically ill during lockdown. Qualitative research in the COVID-19 pandemic

Louise Virole, Céline Gabarro, Elise Ricadat

### ► To cite this version:

Louise Virole, Céline Gabarro, Elise Ricadat. Social support for the chronically ill during lockdown. Qualitative research in the COVID-19 pandemic. *Sociology of Health and Illness*, 2024, Online ahead of print. 10.1111/1467-9566.13845 . hal-04705462

**HAL Id: hal-04705462**

**<https://hal.science/hal-04705462v1>**

Submitted on 14 Oct 2024

**HAL** is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.



Distributed under a Creative Commons Attribution - NonCommercial - NoDerivatives 4.0  
International License

# Social support for the chronically ill during lockdown. Qualitative research in the COVID-19 pandemic

Louise Virole<sup>1</sup>  | Céline Gabarro<sup>2</sup>  | Elise Ricadat<sup>3</sup> 

<sup>1</sup>URMIS, Université Paris Cité, Paris, France

<sup>2</sup>CERIES, Université de Lille, Lille, France

<sup>3</sup>Cermes3, Institut La Personne en Médecine, Université Paris Cité, Paris, France

## Correspondence

Louise Virole, Place Paul Ricoeur, Paris 75013, France.

Email: [louise.virole@u-paris.fr](mailto:louise.virole@u-paris.fr)

## Funding information

Agence Nationale de la Recherche, Grant/Award Number: ANR-20-COV1-000

## Abstract

Chronic illness requires a web of actors, both professional and familiar, who constitute the support network of the chronically ill. This article aims to analyse how the COVID-19 pandemic has impacted on the delicate balance of these supports. Qualitative research was conducted among people with four types of chronic diseases in France: cystic fibrosis, kidney disease, haemophilia and mental disorders. Data on social support was collected using an innovative methodology combining semi-directive interviews ( $n = 54$ ) and drawings ( $n = 32$ ). During the first French lockdown (March–May 2020), the chronically ill were mainly supported by the usual support actors of their primary network: spouse and/or family. However, the COVID-19 health crisis has led to several changes in their support network; health-care professionals diversified their support roles and new supporting actors emerged, especially non-human entities and patient organisations. The chronically ill have received an interweaving of emotional, instrumental and informational, formal and informal and human and non-human support. Our study highlights the multiple

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2024 The Author(s). *Sociology of Health & Illness* published by John Wiley & Sons Ltd on behalf of Foundation for the Sociology of Health & Illness.

and dynamic ties between these types of support and argues in favour of a comprehensive approach to social support of the chronically ill, both in social science theory and in practice of care.

#### KEYWORDS

chronic disease, COVID-19, lockdown, social support, support networks

## INTRODUCTION

Chronic illness requires a web of actors, both professional and familiar, who constitute the support network of the chronically ill (Baszanger, 1986; Bury, 1982). This article aims to analyse how the COVID-19 pandemic has impacted on the delicate balance of these supports.

### **Background: The chronically ill in the context of COVID-19 in France**

To slow down the spread of COVID-19, the French government decided in March 2020 to set up a lockdown (Senik, 2022). This lockdown had many effects on the care pathways of the chronically ill. In France, care pathways for chronic patients are based on a combination of three types of medical care: hospital care, office-based practice care and community care. The lockdown had different effects on each type of care. Most hospital services closed except the emergency services, or were transformed into COVID-19 wards. The essential cure-type treatments were maintained (life-saving operations, prescriptions and medical treatments) but the so-called 'non-essential' care was put on hold.<sup>1</sup> Non-vital organ transplants and surgeries were deferred. Follow-up consultations for non-emergency care was either postponed or done by video or telephone. Among office-based practitioners, only medical professionals (general practitioners, specialists and nurses) were allowed to continue to receive patients but on a restricted basis. Paramedics (psychologists, physiotherapists and dieticians) had to stop seeing their patients, but some of them still managed to continue by telephone or video consultations. Finally, all community centres had to close during the lockdown period, but some members managed to keep in touch with chronically ill patients by phone (Auxéméry & Tarquinio, 2020).

Beyond medical care, lockdown has had a wider impact on the lives of the chronically ill (Lefève & Ricadat, 2022). During 2 months, French people were not allowed to go outside for more than 1 hour per day. Recreational stores, restaurants, museums, theatres, gyms and swimming-pools were closed. The government issued a decree forbidding interaction with people outside, or only on condition that they stayed at least two yards apart.<sup>2</sup> Within the French population, chronically ill patients were soon identified by public health authorities as a particularly at-risk group in terms of COVID-19.<sup>3</sup> At this stage of the pandemic, the list of people at risk of severe forms of coronavirus was however not set in stone. Until reliable information was available on the specific risks for each chronic condition, health authorities asked all chronically ill patients to observe strict confinement protocols to avoid contamination and infection.<sup>4</sup> Despite these measures, as early as March 2020, some chronic disease

organisations sounded the alarm about the number of deaths caused by COVID-19, for instance among kidney patients who had to leave their homes to go to a dialysis centre.<sup>5</sup> For fear of being contaminated, the vast majority of chronically ill patients followed the health instructions and experienced very strict confinement. In this article, we hypothesise that this severe lockdown greatly impacted the delicate balance of their support network.

## Sociology of chronic illness support networks

The sociology of health refers to the concept of ‘support network’ to describe the set of actors who actually help chronically ill patients (Akerman et al., 2018; Bustamante et al., 2018). The composition of these support networks is well documented: spouses, family and friends play a crucial role in accompanying and helping the chronically ill to manage their chronic illnesses (Carricaburu, 1999; Friedrich et al., 1987; Strauss & Glaser, 1975). These ‘strong links’ of private, natural and informal relationships make-up their primary network (Granovetter, 1973). Within the family, women (wives, mothers or daughters) are still the primary providers of support for the chronically ill (Cresson, 1995; Fernández-Peña et al., 2020; Gage-Bouchard et al., 2015; Toledano-Toledano & Domínguez-Guedea, 2019). Beyond the primary network, other actors intervening in an institutionalised framework are known to provide more “formal support” (Streeter & Franklin, 1992). For instance, health-care professionals and patient organisations can represent key members of the chronically ill person’s secondary network (Blois-Da Conceição et al., 2017; Huyard, 2011).

Support actors may provide different types of support. Three main categories of social support emerge from the literature (Thoits, 1995). The first type of social support is *emotional*; it refers to the set of feelings of reassurance, protection or comfort that a person can express, which includes ‘expressions of empathy, trust, affection towards the person’ (Defossez, 2021, p. 2, our translation). According to Fernández-Peña et al., ‘in the context of chronic pain, emotional support can guarantee a feeling of accompaniment, understanding and empathy for the other person’s situation, as well as constituting a coping resource, enhancing the ability to adapt to the situation and acting as a facilitator of self-management’ (Fernández-Peña et al., 2020, p. 13). The second type of social support is *instrumental* and refers to practical help such as grocery shopping, housekeeping, picking up medications, providing shelter or lending money. Instrumental support ‘is necessary in the case of the chronically ill because of deficiencies related to daily performances such as mobility, hygiene and personal care’ (Fernández-Peña et al., 2020:13). The third type of social support is *informational*. In case of chronic pain, it may take the form of ‘advice, information and help in understanding the pathology’ (Defossez, 2021, p. 2, our translation). The literature on social support often describes each actor in the support network as playing a specific role (Gage-Bouchard et al., 2015). Actors from the primary network would provide emotional and instrumental support, while secondary network actors would give mainly informational support (Thoits, 1995). However, recent studies show that emotional, instrumental and informational support are often entangled and that chronically ill patients report the most satisfactory support when emotional and instrumental support are combined (Fernández-Peña et al., 2020).

The public health literature has shown that social support is an essential determinant of chronic disease management and is associated with good health outcomes (Frohlich, 2014). For instance, for cystic fibrosis (CF) patients, ‘increased social support is associated with decreased treatment burden and improved physical and mental health, quality of life, vitality, body image and health perception’ (Gulledge et al., 2021, p. 1). In the case of chronic kidney disease (CKD),

healthcare providers and family members ‘play a different role to help patients carry out disease management tasks’: the healthcare provider ‘is an important social support resource for patients to learn self-management behaviours’ while ‘family caregivers provide more hands-on, day-to-day care’ (Chen et al., 2018, p. 271). The same observation applies to haemophilia patients, who ‘need a wide range of social support both from their families, which help them deal with the daily complications due to their disease, and from experts, who help them manage their health’ (Ratajová et al., 2020, p. 77). These patients support network provides “practical help but also functions as an important psychological protective factor (...) in coping with haemophilia” (Ratajová et al., 2020, p. 77). Studies have shown that this beneficial effect of social support on mental health also applies to people suffering from mental health disorders, particularly depression (Gulledge et al., 2021).

## Research questions

The COVID-19 pandemic represents an interesting time to study how these different actors and categories of social support fit together. Our hypothesis is that the health crisis has disrupted the delicate balance of chronically ill patients’ support networks by cutting them off from several of their usual supporters. How has the pause in medical care and the lockdown impacted the social support that chronically ill people normally receive from health-care professionals? While the lockdown tightened marital and family relationships for certain members of the general French population (Dumont, 2021), have these actors also been a source of greater support for the chronically ill? Did they receive new forms of support during lockdown, and from whom? To what extent can the experiences of the chronically ill during lockdown provide new insights into the nature and functioning of social support?

In order to address these research questions, we conducted research with chronically ill patients. Undertaking a comprehensive sociological approach (Beaud & Weber, 2010), we decided to carry out qualitative research based on the retrospective considerations of a variety of chronically ill patients. Four pathologies were selected, representing the diversity of combination of types of care for chronically ill patients in France: cystic fibrosis (CF, kidney disease (CKD), haemophilia and mental health disorders (see methodology section). Using the collected data, this article focuses on the support networks of the chronically ill during the first lockdown between March and May 2020. In our research study, social support refers to all the helping actions or behaviours that a person receives, whether this help is subjective—the feeling of being supported—or objective—having received effective help (Cockerham et al., 2017). Our study looks at social support dynamics (Defosse, 2021), taking into account its adaptation processes according to the contexts: before, during and since the lockdown. A better understanding of the support networks of individuals with CR, CKD, haemophilia or mental disorders exposed to a health crisis may help improve chronically ill care management.

## MATERIALS AND METHODS

This article is based on data collected as part of a research initiative whose main objective is to analyse the effects of the COVID-19 pandemic on medical care and the experiences of patients with chronic diseases in France (Ricadat et al., 2021). One of the secondary objectives is to

document how the COVID-19 health crisis has impacted chronic disease support networks, particularly during the first lockdown between March and May 2020.

## Study design and participant recruitment

Four pathologies were selected, representing the diversity of combination of types of care for chronically ill patients in France: regular hospital care (CF and CKD), outpatient and hospital care with regular attendance at a centre of reference (haemophilia) or day care hospital and community care (mental health disorders) (Table 1).

We conducted a qualitative study between December 2020 and June 2021 consisting of semi-directive interviews with people suffering from chronic conditions. Several patient organisations agreed to participate in the recruitment of respondents: *Renaloo* (a CKD patient organisation), *Vaincre la Mucoviscidose* (France's primary CF patient organisation), the *Association Française des Hémophiles* (France's primary haemophilia patient organisation) and mental health organisations *Gem* (Mutual Support Groups) and *La Trame* (Community centre) (Table 2). A number of health-care professionals also agreed to assist in patient recruitment.

Respondents were recruited based on several criteria: (1). *Chronic disease*: the people recruited had to have been diagnosed with CF, CKD, haemophilia or mental disorders. For the latter, we selected only people who were under psychiatric care well before the pandemic, regardless of their mental pathology (psychosis, chronic depression, etc.). (2). *Social characteristics*: special attention was given to diversify the recruitment of respondents by gender, social class and age. All respondents were informed beforehand by letter about the purpose of the study and how it would be conducted.

TABLE 1 Types of medical care for the four selected pathologies.

	<b>Kidney disease (CKD)</b>	<b>Cystic fibrosis (CF)</b>	<b>Haemophilia</b>	<b>Mental health disorders</b>
Hospital care	<ul style="list-style-type: none"> <li>- Hospital-based services</li> <li>- Dialysis centres</li> <li>- Specialists: Nephrologist</li> </ul>	<ul style="list-style-type: none"> <li>- Hospital-based services and competence centres</li> <li>- Specialists: Pulmonologist</li> </ul>	<ul style="list-style-type: none"> <li>- Hospital-based services</li> <li>- Treatment centres for haemorrhagic diseases</li> <li>- Specialists: Haemophilologist</li> </ul>	<ul style="list-style-type: none"> <li>- Psychiatric hospitals</li> <li>- Day care hospitals</li> <li>- Specialists: Psychiatrist</li> </ul>
Office-based practice	<ul style="list-style-type: none"> <li>- Dietician</li> </ul>	<ul style="list-style-type: none"> <li>- Physiotherapist</li> <li>- Dietician</li> </ul>	<ul style="list-style-type: none"> <li>- Physiotherapist</li> </ul>	<ul style="list-style-type: none"> <li>- Psychiatrist</li> <li>- Psychologist</li> <li>- Community mental health centre</li> </ul>
Community care				<ul style="list-style-type: none"> <li>- Community centres (mutual group support)</li> </ul>

TABLE 2 Research partner organisations.

Association name	Renaloo	Vaincre la mucoviscidose	Association française des hémophiles	Gem	La trame
Chronic disease	Kidney disease	Cystic fibrosis	Haemophilia	Mental health disorders	Mental health disorders
Structure	Patient organisation	Patient organisation	Patient organisation	Community centres based on patients participative management	Community centres based on patients participative management
Role	- Advocacy - Peer support	- Research - Advocacy - Peer support	- Advocacy - Peer support	- Peer support	- Peer support

## Data collection

In order to collect data as close as possible to people's subjective experiences, we combined semi-directive interviews with chronically ill patients and drawings of their own 'egocentric network' (Smith & Christakis, 2008).

Data was then collected from three sources:

1. Oral accounts in semi-directive interviews of chronically ill patients' experiences.
2. Drawings of support networks during first lockdown, which chronically ill patients were asked to make by the end of the interviews.
3. Respondents' verbal descriptions of the elements they had drawn.

## Oral accounts of chronically ill patients' experiences during the COVID-19 pandemic

From January to July 2021, 54 in-depth interviews with patients suffering from chronic conditions were conducted. The interviews were conducted face-to-face ( $n = 20$ ) or by videoconference (on Zoom® software) ( $n = 34$ ) with those at risk of COVID-19 contamination. At the beginning of each interview, patients were reminded of the purpose of the study and asked for oral consent to participate in accordance with the ethics committee protocol. Next, patients were invited to express themselves very freely on their experience of the pandemic since the first lockdown from a broad and always identical opening instruction agreed upon by the team of researchers: 'Can you tell us how you experienced the pandemic since the first lockdown in March 2020 as a chronic patient?'. In accordance with the semi-directive interview method, the interview guide included several themes to be asked about if not spontaneously addressed. One of these themes focused on the composition of the support network that the chronically ill person was able to rely on during the first lockdown (March—May 2020). All the interviews were recorded and fully transcribed.



## Drawing the support network during first lockdown: A graphic contribution

We asked the respondents to draw their support network at the end of the interview. We opted to focus the drawing on the first lockdown because it emerged as the most disorganising in terms of support networks and medical follow-up. By the end of each interview, even if this topic had been spontaneously addressed before, respondents were asked to draw their support network during the first lockdown and to comment on its composition and specificities. The following instruction was given: *'Could you please draw who played a supportive role for you during the first lockdown?'.* The interviewees were invited to draw on a blank sheet of paper or on the 'whiteboard' available via the videoconferencing software. Patients who could not access this function for technical reasons drew on a paper sheet. The drawing was either sent by email or given to the researchers immediately after the interview.

### Comments on the drawn elements

Interviewers asked patients to provide a verbal description of their drawings during the drawing process in order to gather commentaries and information on the drawn elements. While the respondents drew, we asked them: *'Could you please tell us more about what you are drawing?'.* Just after each interview, investigators created a summary sheet in which they reflected on their observations of the interview process and described respondents' emotional reactions when the drawings were suggested.

### Data analysis

We conducted a thematic analysis of the spoken responses and drawings using descriptive tables listing and characterising the drawn elements. We first compared drawings with each other to identify their commonalities and differences. Using the theoretical framework of social support, we categorised the sources of support mentioned in the drawings (primary/secondary network; formal/informal support; emotional/informational/instrumental support) and noted their frequency. We also analysed the hierarchy of social support (the most important, the most frequent, the most useful for daily life, etc.) mentioned orally or visible in the drawing design. Additionally, we analysed the elements not drawn but mentioned during interview and the ones drawn but not previously mentioned in the interview. As advised by Girard et al. (2015), we used an analysis grid that always placed the drawn elements in relation to the respondents' discourses.

### Advantages and limitations of the use of drawings

Qualitative research on the experiences of the chronically ill makes little use of the drawing technique, though the use of drawings during semi-directive interviews can greatly enrich the qualitative analysis of support networks (Virole & Ricadat, 2022). In our research study, the combined use of drawings and interviews had three major advantages. Firstly, getting adults to draw during an interview, as an unusual demand, led the respondents to emotional reactions that tend to increase adherence to and interest in the interview. Drawing seems to facilitate the expression of feelings, which gave us access to affective dimensions which are usually more



difficult to reach in traditional forms of interviewing (Catoir-Brisson & Jankeviciute, 2014). Secondly, the use of drawing encouraged respondents' reflexivity (Cohenmiller, 2018). The drawing not only illustrated what was said previously during the interview, it often changed the course of the interview. For instance, while drawing their support network, some respondents realised that certain people who they thought should have played a supportive role were missing. Combining interviews and drawings had a third advantage: it led to unexpected results (Guenette & Marshall, 2009). By comparing our three sources of data, we realised that there were contrasts between what respondents said during the interview, what was drawn, and the comments the respondents made while they were drawing. 'By changing the angle of view,' drawing revealed 'contradictory elements' (Girard et al., 2015, p. 51, our translation). Ultimately, the complementary use of drawings and narratives allowed for a more detailed and complex qualitative analysis of our research subject while remaining close to the voices of the chronically ill patients.

However, this method has limitations. First of all, out of the 54 interviewees, 22 did not draw their support network. The use of the drawing was not compulsory and we made it clear to all respondents that they had every right to decline to draw. For some patients, drawing was quite impossible due to the specific conditions of the interview's setting. For instance, we conducted interviews in a dialysis facility with CKD patients who were lying down and undergoing dialysis, which made the drawing impossible to do. In one case, researchers who conducted the interview with a mental health patient chose not to ask the respondent for a drawing because they did not wish to accentuate the patient's feeling of isolation that was been strongly reported throughout the interview. The second limitation concerns the analysis of the drawings. The respondents used various graphic elements that helped them to mind map their words and thoughts: arrows emphasised the links between the presented elements; the positioning in the sheet space and the use of visual order of magnitude contributed to a very organised description of their support network. The analysis of these graphic representations requires specific expertise in order to reduce the bias of over-interpretation or misinterpretation of the drawings (Girard et al., 2015). Regrettably, as we did not have such expertise within our research team, we have chosen to focus on the types of support represented and the order in which they appear in the drawings. Finally, the drawings gave us little insight into the dynamics of the support networks (Akerman et al., 2018). During the interviews, the respondents told us about the evolution of their experiences throughout the pandemic. However, the drawing of the support network only describes the lockdown from March to May 2020. With the exception of one of our respondents,<sup>6</sup> the drawings acted as a photograph of a moment in time without highlighting the evolution of the support network over time.

## Respondents socio-characteristics

The respondents recruited in our research have diverse socio-demographic characteristics (Table 3).

We interviewed 37 men and 17 women. We tried to recruit as many men as women to ensure a fair ratio and we were more or less successful depending on the pathologies (50% of women among the CF respondents, 47% among CKD respondents, 40% of mental disorders respondents). However, our recruitment suffered from a great gender imbalance among haemophilia respondents due to the fact that people with haemophilia are essentially a male population because of the genetic characteristics of this disease.

TABLE 3 Respondent profiles.

Social characteristics	Cystic fibrosis (CF)	Kidney disease (CKD)	Haemophilia	Mental health disorders	Total
Gender:					
Female	4	7	0	6	17
Male	4	8	16	9	37
Age:					
18–30	0	1	7	3	11
30–50	7	3	4	7	21
50+	1	11	5	5	22
Socio-professional category:					
Working class: <i>Unemployed, precarious</i>	2	2	2	13	19
Middle class: <i>Employees, students living with parents</i>	5	9	9	1	24
Upper class: <i>Executives, business owners</i>	1	4	4	1	10
Nationality:					
French	8	15	15	13	51
Other	0	0	1	2	3
Living conditions during lockdown:					
Couple cohabitation	4	11	8	1	24
Lives alone	3	3	4	7	17
Single living with family	1	1	4	6	12
Apartment sharing	0	0	0	1	1
Total	7	15	16	15	54

The average age of our respondents was 44 years. The respondents had varied socioeconomic profiles: 19 respondents were in a precarious economic situation, making up most of those with mental health disorders, 24 respondents were middle class (employees, students living in their parents' homes) and 10 were upper class (executives, business owners). The respondents were almost all of French nationality ( $n = 51$ ), with 3 respondents of foreign nationalities. Less than half of the respondents ( $n = 24$ ) spent the lockdown with their spouse, 17 respondents spent the lockdown alone at home, 12 spent the lockdown single but with family members and one respondent lived with his roommate. Of the 15 respondents with mental health disorders, only one lived with a spouse at the time of lockdown.

## RESULTS

The constraints of lockdown and the disorganisation of care services have had four main effects on the support networks of the chronically ill: 1. It led to an increase of spousal and family support; 2. It made the support of some actors more visible; 3. It changed the roles of some secondary network actors and 4. It prompted the chronically ill to seek out new actors to support them, mainly patient organisations.

### **In extraordinary times, ordinary support: The importance of relatives during lockdown**

During the lockdown, the chronically ill found support mainly from the same people they used to turn to: their families and, if they had any, their spouses. The first actors included in the drawings of support networks were almost systematically the people with whom the respondents lived on a daily basis (spouses, children, parents). The respondents living alone also tended to mention their relatives first. Spouses and family provided the chronically ill valuable instrumental and emotional support in coping with the crisis.

First of all, because of their fear of the risk of COVID-19 contamination, most respondents with haemophilia, CF and CKD, especially those with kidney transplants, did not leave their homes at all during the lockdown, even for authorised reasons such as food shopping and collecting medication. As a result, these respondents sought instrumental support from those around them, notably the people they lived with on a daily basis. Relatives of chronically ill patients helped them by shopping for them or collecting their medicine from the pharmacy. Robert, a CKD 65-year-old male respondent told us that he had ‘a wonderful wife who does the shopping’ while he stayed confined. Roseline’s son went on looking for her ‘plethora of medications.’ This kind of support was very important for the chronically ill as it allowed them to live as normally as possible. Secondly, our respondents also received emotional support that helped them reduce their feelings of isolation, particularly for those living alone. Some of them decided to go live with their families so as to not be alone. Ryme, a CKD 35-year-old woman, went to live with her family. In her drawing, she put her family first (Figure 1); she said it was ‘the most important pole’ because she was able to see them ‘for real’ and not ‘virtually.’

These forms of support are not new to the patients; in their view, spouses and family members provided them emotional and instrumental support long before the COVID-19 pandemic. However, some of the usual supporters of the chronically ill such as friends, colleagues and health-care professionals became distant during the lockdown while others became closer. Spousal and family support was therefore intensified during the lockdown. Paradoxically, respondents often minimised or took this support for granted. Half of the respondents who agreed to draw their support network spent the lockdown living with their spouse, female ( $n = 10$ ) or male ( $n = 7$ ). Among these respondents, most men and women systematically stated that their partner did help them during the interview and drew them in first or second position in their drawings. However, we found a gender gap in the commentaries on the drawings. While female respondents commented on their drawings by valorising the support roles of their companions, male respondents were more likely to minimise the support of their spouse or mother, especially their instrumental support. For instance, on one hand, Rachel, a CKD 27-year-old woman living with her partner stressed

that she ‘needed’ her spouse on a daily basis to carry her peritoneal dialysis bags. In her drawing, Rachel included her partner first while valuing his instrumental support role by her side: ‘he is my caregiver’. On the other hand, Reginald, a CKD 80-year-old man living with his wife told us that he did not consider his wife as a support because it was ‘normal’ within the context of marriage: ‘Helping is not the word eh! We are married. Of course, we help each other.’ Another example is that of Renaud, a CKD 52-year-old man who told us during his interview that his wife and daughter went shopping for him because he could not go out for fear of COVID-19 contamination. But at the time of the drawing, he included his nurse first, then in second place his wife and daughter. While Renaud was writing ‘Companion and daughter,’ he nuanced their support role: ‘in fact it was rather me who played a support role for my wife, because she was depressed during the first lockdown.’ Renaud minimised his wife’s instrumental support role while emphasising the moral support he gave her. Finally, Hugolin, a 19-year-old male respondent with haemophilia and living in his parents’ apartment, told us that his mother went for his medication at the hospital’s pharmacy during lockdown because he himself would not go out due to his illness. However, at the time of the drawing Hugolin did not include his mother or almost any human beings (see below Figure 2).

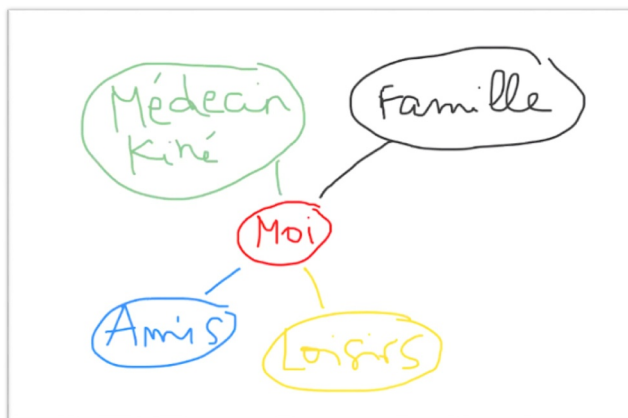


FIGURE 1 Ryme, 35 years old woman with kidney transplant. Captions: 1. ‘Famille’ = Family, 2. ‘Médecin Kiné’ = Doctor and physiotherapist, 3. ‘Amis’ = Friends, 4. ‘Loisirs’ = Hobbies.



FIGURE 2 Hugolin, 19 years old man with haemophilia. Captions: 1. Drawing of a cannabis joint, 2. ‘TV FIFA’ = TV Football video game, 3. ‘YTB’ = Youtube, 4. ‘AFH TS’ = French Association of Haemophilia and initials of a member.

## **In time of crisis, visibility of ‘new’ sources of support: ‘Non-human’ support**

Indeed, our results show that chronically ill patients feel that non-human entities played an important supportive role for them during lockdown. Of the 32 drawings collected, 10 included non-human entities. We collected drawings with pets, TV shows, food, restaurants, drugs, medication, books, nature and more. These entities provided mostly emotional support and, to a lesser extent, these non-human entities also provided informational support. For instance, Hakim, a 26-year-old man with haemophilia, included a continuous news channel even though the support it provided was ambivalent: ‘Yes, I watch a lot of news channels. Especially at that time... So, I wouldn’t say it made me feel better, sometimes it’s more stressful, but it does shed light on the epidemic, on the evolution, and everything.’

In most cases, the non-human entities were mentioned last, after a hesitation. Some even asked us for permission. After drawing her boyfriend, Manon, a CF 32-year-old woman asked us: ‘Can I put virtual people or not? I mean, that I know?’ After receiving permission, Manon added a famous YouTuber, her cat, a few restaurants and a chocolatier. The non-human entities arrived in first and second place in only three drawings collected: the ones from Stephane, Samuel and Hugolin, as mentioned above. Samuel, a 30-year-old man with mental disorders drew first his mother in whose home he lives, and then drugs (‘Coke, beer and benzodiazepine’) which provided, as he put it, ‘chemical emotional support’ during the lockdown. Hugolin, for his part, drew mainly non-human entities (Figure 2). He drew first a cannabis joint in his mouth. He told us that it was his first source of support during the lockdown: ‘what sustained me during the lockdown... the cigarette, you could say. Let’s say it’s a cigarette that makes you feel good.’ He then included video games, which provided emotional support, and YouTube videos about the COVID-19 pandemic, a source of informational support. He finished with a representation of a member of the haemophilia patient organisation that contacted him during the lockdown to see how he was doing.

## **Old actors, new roles: When new forms of support appear from health-care professionals during lockdown**

Although support from relatives increased during lockdown, its form has not changed radically. However, our study reveals that the COVID-19 health crisis had the effect of transforming the role of some health-care professionals, such as doctors, nurses or community pharmacists, who were already present in the secondary network of the chronically ill. While the support they gave before the crisis was mainly informational, they also began providing emotional and instrumental support to the chronically ill during the lockdown. These changes were nonetheless only possible if they had good relationships with the respondents that dated long before the crisis.

Some chronically ill patients highlighted that their doctors provided them with emotional support during the lockdown, whereas they usually limited themselves to medical advice centred on informational support. Not surprisingly, the emotional support role of health-care professionals is nevertheless more common among mental health professionals. Most respondents with mental health conditions acknowledged that the closure of health care facilities

affected them greatly. They received emotional support from their psychologists, typically at a distance, and from other health-care professionals who did not usually do so, for instance the nurses. This was the case for Sandra, a 28-year-old woman suffering from eating disorders who used to go to a daytime hospital every day. The closure of the hospital during the lockdown greatly impacted her as she lost the emotional support she usually received from her interactions with other patients. When her eating disorders got out of control, Sandra decided to move back in with her parents 2 weeks after the beginning of the lockdown. On her drawing (Figure 3), Sandra first indicated her mother as her main source of support during the lockdown and then, in a second and third circle of health professionals, the daytime hospital nurse and the medical-psychological centre psychologist. Sandra's nurse called her every week during lockdown to find out how she was doing. Even though Sandra did not answer each time because she felt stressed about answering the phone, she said that she felt reassured that he kept calling her.

Moreover, our study reveals that some health-care professionals who were only playing an informational role before the pandemic started to play an instrumental support role during the lockdown. Some respondents stressed the instrumental support of their community pharmacists who delivered their medication, in particular the ones with whom they had a good relationship for a long time. Manon included her pharmacist in her support network drawing, 'because they're great, I've been going to the same pharmacy for 10 years, they delivered it to me, down the street from my house, so I wouldn't have to come.'

Not all healthcare professionals have diversified their support role; some kept their usual role or even withdrew. It is interesting to note, however, that by staying in their usual roles they tend not be included in the chronically ill's drawings. For instance, Honoré, a 74-year-old male respondent with haemophilia, didn't designate healthcare professionals as supports during lockdown because he felt that they did 'what they usually do.' Mathieu, a CF 33-year-old man told us that his follow-up centre 'has been there but as they are all the time.' As they didn't provide 'a particular support,' Mathieu didn't include them in his drawing. In the end, healthcare professionals were included in over half of the drawings.

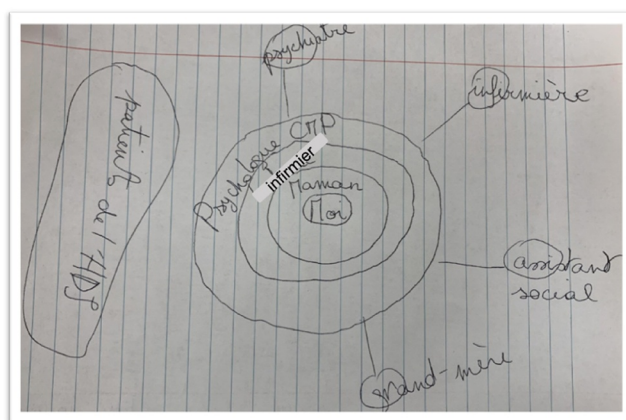


FIGURE 3 Sandra, 28 years old woman with mental disorders. Captions: 1. « Maman »: Mother; 2. « Infirmier »\*: Male Nurse; 3. « Psychologue CMP »: Psychologist from Medical-psychological Centre; 4. « Psychiatre »: Psychiatrist; 5. « Infirmière »: Female Nurse; 6. « Assistant social »: Social Worker; 7. « Grand-mère »: Grandmother; 8. « Patients de l'HDJ »: Patients from the Day Hospital.



## Seeking new support: The emergence of chronic disease organisations in support networks

For many of the chronically ill interviewed, a new support actor has emerged during the lockdown: chronic patient organisations. The respondents who already knew about these organisations stated that they played an enhanced role and presence in their daily lives, while those who discovered the organisations because of the crisis found that they could be a precious resource. These organisations provided them with a great deal of informational and emotional support and, to a lesser extent, instrumental support.

One of the main challenges for respondents with haemophilia, CF and CKD during the lockdown was to find reliable and clear medical information that could help them understand the risk they faced with COVID-19 and how to minimise it. As the list of people at risk was continuously modified throughout the lockdown, the chronically ill had to deal with vague and sometimes contradictory information. At first, most of the respondents turned to their usual contacts: their practitioners. While respondents with haemophilia were quickly reassured by the information they received from the health-care professionals at the beginning of the lockdown, people with CF and CKD were confronted with the lack of knowledge from their doctor who struggled to give them answers. They had no choice but to look for information on their own and turned to chronic disease organisations, some of them for the first time. Regine, a 57-year-old woman followed the kidney disease association *Renaloo* on social media for years but never contacted them or participated in events before the lockdown. As soon as the lockdown was announced, she realised that her nephrologist ‘knew less than *Renaloo*.’ ‘I said to myself at that time that my information centre was *Renaloo*. My database was *Renaloo* and if I had to look for information, I would look elsewhere. I looked, but every time, *Renaloo* was the better one.’ Roseline, a 56-year-old female respondent and kidney transplant recipient also highlighted the important informational support role played by this organisation. On the drawing of her support network (Figure 4), Roseline first included her hospital nephrologist, then *Renaloo*, then Simone, a friend and member of *Renaloo*, and in fourth place her children. Roseline used the talking groups organised by *Renaloo* to ask questions about the risks she faced as a transplant recipient and told us that she found a lot of information on this specific issue through the organisation.



FIGURE 4 Roseline, 56 years old woman with kidney transplant. Captions: 1. « *Nephrologue Necker* »: Nephrologist in Parisian hospital; 2. « *Association Renaloo* »: Association of kidney disease patients; 3. « *Simone* »\*: Friend member of *Renaloo* association; 4. « *Mes enfants* »: My children.



The support given by patient organisations was not only informative but also emotional. Roseline added that the talking groups provided an emotional type of support and that these forums helped her a lot because they allowed her to 'free' her 'fears' by sharing them with people 'who were going through the same questioning.' 'It was our space where we could free our questions, our fears. They didn't necessarily have the answers... (...) We have experiences that intersect at one time or another, so it is important to exchange with people who are going through the same questions, the same interrogations, the same fears.' Most respondents who participated in talking groups organised by chronic disease organisations reported that they appreciated being able to share their concerns with people who share the same medical conditions and that they felt less lonely and anxious afterwards. 'I think it helped us a lot, psychologically and morally, to have these Skype® aperitifs [with the haemophilia patient organisation] in the evening. I think it did us good. For me personally, at least.' (Horace, 57 years old man with haemophilia).

Finally, although to a lesser extent than informational and emotional support, the respondents told us that patient organisations provided them with instrumental support. While at the start of lockdown France was experiencing a shortage of masks, haemophilia, CF and CKD patient organisations distributed free masks to the chronically ill while lobbying so that they could have priority access to masks reimbursed by social security.<sup>7</sup> Thanks to patient organisations, the chronically ill received masks much more quickly than if they had waited for the institutional responses, which took several weeks. Some patient organisations also delivered meals to the homes of the chronically ill. Simone, a 59-year-old woman with psychiatric illness who was very concerned about COVID-19 contamination and refused to leave her house told us that the mental health patient association *La Trame*, where she went from time to time, delivered her meals throughout the lockdown. Ultimately, our results show that patient organisations were very responsive to the pandemic and played a decisive support role for the chronically ill.

## DISCUSSION

Our study in times of pandemic does highlight the importance of the support network of the chronically ill in their daily lives. These results, anchored in 'exceptional' times, should be discussed in the light of the literature on social support for the chronically ill during regular times.

### The health crisis as magnifying glass

The pandemic had a magnifying glass effect on the tangle of 'care' that any chronic disease requires (Mol, 2010), going far beyond medical treatment alone.

The announcement of the lockdown prompted the chronically ill respondents to activate their support network at once. While sociological literature shows that the ability to activate their support network is socially situated (Gage-Bouchard et al., 2015), our results show that chronically ill respondents from all social background managed to mobilise the actors of their support network and to articulate different types of support to meet their specific needs faced with the crisis. The disorganisation of medical care induced by the pandemic had the effect of making the chronically ill rely on the people they could easily call on for help: mainly their

'significant others' (Gage-Bouchard et al., 2015) with whom they lived. The lockdown seems to have tightened marital and family relationships, as demonstrated by a qualitative study carried out among the general French population (Dumont, 2021). Complementing the care provided by relatives, patient organisations have played a crucial support role for the chronically ill. During the health crisis, they adapted by creating new discussion groups or by making their groups accessible at a distance. Many of our respondents participated for the first time in their lives in these exchange groups during the lockdown, and testified to having received emotional and informational support. The literature has emphasised the importance of peer support in managing chronic disease on a daily basis (Huyard, 2011). Because of their 'experiential homophily', peers are often more helpful than any 'well-intentioned advice or empathy' given by 'significant others' (Gage-Bouchard et al., 2015, p. 64). This peer support is increasingly found in the online environment (Colineau & Paris, 2010). By reaching out for resources during the lockdown, many chronically ill patients have enriched their support network by activating new connections with other chronically ill people. Our results corroborate the studies carried out on long COVID-19 disease, which show how, in the face of the crisis, patients have collectively connected with other people suffering from the same symptoms and have been able to support each other (Callard & Perego, 2021). In accordance with the literature (Fernández-Peña et al., 2020), our research study shows that relationships with both kin and individuals who share the same illness experience are complementary in the balance of the support networks of the chronically ill.

## The interweaving of social support categories

The chronically ill were able to benefit from an interweaving of emotional, instrumental and informational, formal and informal and human and non-human support. These results highlight the multiple and dynamic ties between these categories used in the literature to describe social support.

First of all, our results show that emotional, informational and instrumental support go hand in hand. In our study, informational support and emotional support received by respondents are strongly combined. In the context of COVID-19, information is key. At the time of the lockdown, chronically ill patients found themselves in a situation of unprecedented uncertainty when faced with COVID-19 (Giry, 2020). Our results show that access to accurate and reliable information on the risks of COVID-19 as a chronic patient have been a great source of reassurance. Emotional support can thus be found through access to information. However, this finding needs to be tempered. For some of our respondents, knowing about the high risks incurred as a chronic patient has been a source of anxiety or even despair.<sup>8</sup> To a lesser extent, our results show that emotional and instrumental support can also be interwoven. Some of our respondents who lived alone asked their families to take them in, which can be classified as instrumental support since it refers to practical help. However, the reasons for these requests refer more so to emotional support. Indeed, people sought shelter because they were anxious about being left alone in their own homes. This practical help was experienced as a strong emotional support. These results call to move beyond rigid separation between these three types of support and to further study the links between these categories and how these ties evolve in different contexts.

Secondly, when asked to draw their support network, more than half the respondents included the members of their primary network but also health-care professionals and patient

organisations. These last two actors provide what Streeter and Franklin call 'formal support' (Streeter & Franklin, 1992). However, 'in most of the work on the subject, social support refers only to the help provided by family, friends or more distant circles of acquaintances and does not concern the help produced by institutional actors' (Defossez, 2021, p. 7, our translation). On the contrary, our study shows the importance of the support of these institutional actors as well as the connections between formal and informal support. Many of our respondents became friends with members of their peer organisation and are referred to by their first names on their drawing.<sup>9</sup> This was less the case for health-care professionals, who were always named by their family name or by their profession, even if some acknowledge their unusual solicitude towards them. The support provided, both formal and informal, invites relativising this distinction. By revealing the role of not-so-weak 'weak ties' (Granovetter, 1973) during the lockdown, these results encourage researchers to include both informal and formal support in their description of support networks. In addition, new research perspectives emerge to analyse how context can lead to changes in the support actor's status, from formal to informal, or position, from secondary network to primary network, within support networks.

Thirdly, triangulation of the data from the narratives and the network drawings prompted us to broaden our definition of a supporting actor. Respondents spontaneously included not only human but also non-human supports in their drawings. Drugs, animals, media or food were identified as full members of their support networks. Yet the literature about social support tends to focus only on human support (Fernández-Peña et al., 2020). As the sociology of the actor-network argues (Callon & Law, 1997), in order to describe 'the very nature of societies' one shouldn't 'limit oneself to human individual actors, but extend the word actor, or actant, to non-human, non-individual entities' (Latour, 1996, p. 369). Our research shows that chronic disease patients feel that a variety of entities constitute their support network and that non-human entities can sometimes be more supportive than humans... particularly in a context where physical contact between humans is restricted. Setting them aside would be to remove much of the support that people receive. These findings suggest that the boundaries for what researchers mean by supporting actor would benefit to be expanded to include non-human entities.

## The need for a comprehensive approach to social support

This study was able to reveal the strong connections between social support categories through a comprehensive approach to social support that not only pays attention to chronically ill patients' subjectivity but also to the nature and type of social support provided.

According to Defossez (2021), there are two sociological approaches to social support: the comprehensive approach of individual experience used by the sociology of chronic illness and the 'reticular approach to support' used by the sociology of networks. The sociology of chronic illness has incorporated the question of social support during interviews with the chronically ill but 'tend not to care what this support actually entails' (Defossez, 2021, p. 6, our translation). On the other hand, the sociology of networks provides precise quantitative data on the social support of the chronically ill but give little insight into the personal experiences of the respondents. Our study set out to counter these shortcomings by developing a comprehensive approach that takes into account not only the 'objective support' received by patients, but also their perceived support, known as 'subjective support' (Blois-Da Conceição et al., 2017; House & Kahn, 1985). The same form of concrete help can be perceived as support by one patient or, on

the contrary, as conventional and expected, therefore not defined as support by another. In this respect, the case of women's support is particularly instructive. Our research study reveals the mechanism of minimising women's support, typically as spouse or mother, in male respondents' discourses even though they have been particularly helpful to them. Indeed, the contrast between 'objective support,' or the help actually given by women, and 'subjective support' as felt by the male respondents is a good indicator of the gendered division of support for the chronically ill (Fernández-Peña et al., 2020). Even if the 'caregiver burden' is still mainly carried by women (Toledano-Toledano & Domínguez-Guedea, 2019), their care tends to be considered as 'natural' and hence not labelled as support, especially within the framework of the heterosexual couple and family (Cresson, 1995; Tronto, 1987). Ultimately, our results highlight the need to develop comprehensive approach of social support as aligned as possible to the subjectivity of individuals.

## CONCLUSION AND PRACTICAL IMPLICATIONS

The lockdown highlighted the essential roles and adaptability of support networks for the chronically ill in dealing with the upheaval of the health crisis. Chronically ill patients have been able to both rely on their usual supporters and engage new supporters in order to cope with the disorganisation of medical care and the isolation induced by the lockdown. Our study shows that during this 3-month period, support from close relatives increased, some health-care professionals diversified the nature of their support and new support from patient organisations was activated. Moreover, our results highlight the important supporting role of non-human entities. This research study, conducted during a period of health crisis, gave new insights on the nature and functioning of social support in more ordinary times. The experience of the chronically ill during lockdown highlighted the multiple and dynamic connections between emotional, informational and instrumental support, formal and informal support or human and non-human support. These results pave the way for new research perspectives on the sociology of chronic illness, as well as on the sociology of networks.

From a public health perspective, our findings have also many practical implications for the management of chronically ill patients. First of all, as Chen and al. (2018) show in their study with haemophilia patients, in order to improve the care of chronically ill patients, care protocols should shift from an individual self-management enhancement programs to a systemic approach that help patients strengthen their supportive environment. Our study argues in favour of setting up care programs that can improve the social support of chronically ill patients by relying on the key support actors identified by the patients themselves. These may be 'traditional' actors (spouse, family), but also less common supporters such as friends, members of patient organisations, community pharmacists or... non-human entities. Finally, our results argue in favour of chronic care programs that can connect these actors and facilitate their collaboration – especially between doctors and patient organisations –, thereby creating a community of support around the patient.

## AUTHOR CONTRIBUTIONS

**Louise Virole:** Conceptualisation (lead); formal analysis (lead); investigation (equal); methodology (equal); writing - original draft (lead); writing - review & editing (lead). **Céline Gabarro:** Conceptualisation (equal); formal analysis (equal); investigation (equal); methodology (equal); writing - review & editing (equal). **Elise Ricadat:** Conceptualisation (equal); data curation (lead);

formal analysis (equal); funding acquisition (lead); investigation (equal); methodology (lead); project administration (lead); supervision (lead); writing - review & editing (equal).

## ACKNOWLEDGEMENT

The authors would like to thank the 'Fondation de France' and the 'Agence Nationale de la Recherche' (the French National Research Agency (ANR-20-COV1-000) which founded the PARCOURS-COVID research at the Institute 'La Personne en Médecine' (ANR-18-IDEX-0001), University de Paris Cité. We thank the research team who wrote the PARCOURS-COVID protocol: Ricadat É (dir), Béliard A, Citrini M, Craus Y, Gabarro C, Mamzer M, Marques A, Sannié T, Teixeira M, Velpry L, Villa F, Virole L, Lefève C. We want also to thank health professionals and patients' organisations which helped us to recruit patients: *Association Française des Hémophiles*, *Renaloo*, *Vaincre la Mucoviscidose*, *Groupes d'Entraide Mutuelle* and *La Trame*. We thank all the respondents who took the time to answer our questions and draw their support network.

## CONFLICT OF INTEREST STATEMENT

The authors declare no Conflict of interest.

## DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

## ETHICS STATEMENT

The research protocol received ethical approval from the *Comité d'Éthique de la Recherche* (Research Ethics Committee) of the University of Paris Cité, France.

## ORCID

Louise Virole  <https://orcid.org/0000-0002-3782-181X>

Céline Gabarro  <https://orcid.org/0000-0002-9312-2060>

Elise Ricadat  <https://orcid.org/0000-0001-8202-1523>

## ENDNOTES

- <sup>1</sup> Bibliothèque Nationale de France. (2021). L'épidémie de COVID-19 et le premier confinement. Un parcours guidé dans les archives de l'Internet. <http://archivesinternet.bnf.fr/20200419093928/http://www.lepoint.fr/societe/petit-abecedaire-des-mots-qui-nous->
- <sup>2</sup> Vie Publique, 2020. 'Coronavirus: Les mesures de confinement', 17 March 2020: <https://www.vie-publique.fr/en-bref/273932-coronavirus-les-mesures-de-confinement>
- <sup>3</sup> Haut Conseil de Santé Publique, 2020. « Coronavirus SARS-CoV-2 prise en charge des personnes à risque de formes graves ». 4 Avril 2020. <https://www.hcsp.fr/explore.cgi/avisrapportsdomaine?clefr=790>
- <sup>4</sup> Haute Autorité de Santé, 2020. « Faire face à la maladie chronique pendant le confinement », March 2020. [https://www.has-sante.fr/jcms/p\\_3178865/fr/faire-face-a-une-maladie-chronique-pendant-le-confinement](https://www.has-sante.fr/jcms/p_3178865/fr/faire-face-a-une-maladie-chronique-pendant-le-confinement)
- <sup>5</sup> Renaloo, 2020. « 300 patients dialysés atteints de COVID-19 en France au 30 Mars 2020 ». 31 March 2020. <https://renaloo.com/300-patients-dialyses-atteints-de-covid-19-en-france-au-30-mars-2020/>
- <sup>6</sup> Samia, a 60-year-old woman with mental disease, drew her entire social network and mentioned people who have since died, including a friend who died in a retiring home during lockdown. As she inscribed family members on her drawing, Samia stopped to tell us more about the conflicting ties she has had with her family for decades.

- <sup>7</sup> For instance, in June 2020, the organisation *Vaincre la Mucoviscidose* provided thousands of free cloth masks and surgical masks to cystic fibrosis patients and their families. Source: VLM's 2020 report: [https://www.vaincrelamuco.org/sites/default/files/20210922\\_-\\_vaincre\\_ra\\_2020\\_-\\_hd\\_pap.pdf](https://www.vaincrelamuco.org/sites/default/files/20210922_-_vaincre_ra_2020_-_hd_pap.pdf)
- <sup>8</sup> For instance, in May 2020, at the end of the lockdown, *Renaloo* released its first figures on the number of deaths among transplant recipients. Rachel told us that hearing at a *Renaloo* café that 20% of transplant recipients with COVID-19 had died during the first lockdown so 'depressed' her that she never attended another café.
- <sup>9</sup> The first and last names of the people included in the drawings have been anonymised. The first names have been replaced by other first names: for example, Roseline wrote the first name of a friend in her drawing who is a member of the *Renaloo* organisation, and we have changed it to 'Simone' (drawing n° 4). In the case of health-care professionals, we have replaced their last name with their status: for instance, Sandra wrote her nurse's last name in her drawing, and we have replaced it with the term 'nurse' (drawing n°3).

## REFERENCES

- Akerman, G., Barthe, J.-F., Defosse, A. (2018). Dynamique des réseaux personnels à l'épreuve des maladies graves et de longue durée. *Temporalités. Revue de Sciences Sociales et Humaines*, 27, 1–17. <https://doi.org/10.4000/temporalites.4016>
- Auxéméry, Y., Tarquinio, C. (2020). General sanitary containment during the Coronavirus epidemic: Medico-psychological consequences in general population, caregivers, and subjects suffering previously from mental disorders (Retrospective on the repercussions of lethal mass risks, scientific models of collective confinement, first clinical observations, implementation of countermeasures and innovative therapeutic strategies. *Annales Medico-Psychologiques*, 178(7), 699–710. <https://doi.org/10.1016/j.amp.2020.06.001>
- Baszanger, I. (1986). Les maladies chroniques et leur ordre négocié. *Revue Française de Sociologie*, 27(1), 3–27. <https://doi.org/10.2307/3321642>
- Beaud, S., & Weber, F. (2010). *Guide de l'enquête de terrain: produire et analyser des données ethnographiques*. Éditions la Découverte.
- Blois-Da Conceição, S., Galiano, A. R., Sagne, A., & Poussin, M. (2017). Données actuelles et perspectives futures dans l'étude des liens entre soutien social et santé: vers une prise en compte des attitudes à l'égard du réseau de soutien en psychologie de la santé. *Psychologie Française*, 62, 135–162. <https://doi.org/10.1016/j.psfr.2016.06.002>
- Bury, M. (1982). Chronic illness as a biographical disruption. *Sociology of Health & Illness*, 4(2), 167–182. <https://doi.org/10.1111/1467-9566.ep11339939>
- Bustamante, A. V., Vilar-Compte, M., & Ochoa Lagunas, A. (2018). Social support and chronic disease management among older adults of Mexican heritage: A U.S.-Mexico perspective. *Social Science & Medicine*, 216, 107–113. <https://doi.org/10.1016/j.socscimed.2018.09.025>
- Callard, F., & Perego, E. (2021). How and why patients made Long Covid. *Social Science & Medicine*, 268, 113426. <https://doi.org/10.1016/j.socscimed.2020.113426>
- Callon, M., & Law, J. (1997). L'irruption des non-humains dans les sciences humaines: quelques leçons tirées de la sociologie des sciences et des techniques. *Les limites la Rationalité, Tome, 2*, 99–118. <https://doi.org/10.3917/dec.reyna.1997.01.0099>
- Carricaburu, D. (1999). Les hommes hémophiles face à la médecine: Mise en acte d'une recherche. *Socio-Anthropologie*, 0–8(5). <https://doi.org/10.4000/socio-anthropologie.55>
- Catoir-Brisson, M.-J., & Jankeviciute, L. (2014). Interview and visual methods: A creative research approach in information and communication sciences. *Sciences de la Société*, 92, 111–127. <https://doi.org/10.4000/sds.1130>
- Chen, Y. C., Chang, L. C., Liu, C. Y., Ho, Y. F., Weng, S. C., & Tsai, T. I. (2018). The roles of social support and health literacy in self-management among patients with chronic kidney disease. *Journal of Nursing Scholarship*, 50(3), 265–275. <https://doi.org/10.1111/jnu.12377>
- Cockerham, W. C., Hamby, B. W., & Oates, G. R. (2017). The social determinants of chronic disease. *American Journal of Preventive Medicine*, 52(1), S5–S12. <https://doi.org/10.1016/j.amepre.2016.09.010>
- Cohenmiller, A. S. (2018). Visual arts as a tool for phenomenology. *Forum Qualitative Sozialforschung*, 19(1). <https://doi.org/10.17169/fqs-19.1.2912>



- Colineau, N., & Paris, C. (2010). Talking about your health to strangers: Understanding the use of online social networks by patients. *New Review in Hypermedia and Multimedia*, 16(1/2), 141–160. <https://doi.org/10.1080/13614568.2010.496131>
- Cresson, G. (1995). *Le travail domestique de santé*. L'Harmattan.
- Defossez, A. (2021). Comment étudier le soutien apporté aux malades. *Emulations - Revue de Sciences Sociales*, 0–17. <https://doi.org/10.14428/emulations.varia.034>
- Dumont, C. (2021). *Collectif d'Analyse des Familles en Confinement, Familles confinées. Le cours anormal des choses, Lectures*. <https://doi.org/10.4000/lectures.51290>
- Fernández-Peña, R., Molina, J. L., & Valero, O. (2020). Satisfaction with social support received from social relationships in cases of chronic pain: The influence of personal network characteristics in terms of structure, composition and functional content. *International Journal of Environmental Research and Public Health*, 17(8), 2706. <https://doi.org/10.3390/ijerph17082706>
- Friedrich, H., Ziegeler, G., & Denecke, P. (1987). Faire face à une maladie chronique: conditions psychosociales et familiales. *Sciences Sociales et Santé*, 5(2), 31–44. <https://doi.org/10.3406/sosan.1987.1056>
- Frohlich, D. O. (2014). The social support model for people with chronic health conditions: A proposal for future research. *Social Theory & Health*, 12(2), 218–234. <https://doi.org/10.1057/sth.2014.3>
- Gage-Bouchard, E. A., LaValley, S., Panagakis, C., & Shelton, R. C. (2015). The architecture of support: The activation of preexisting ties and formation of new ties for tailored support. *Social Science & Medicine*, 134, 59–65. <https://doi.org/10.1016/j.socscimed.2015.04.003>
- Girard, S., Rolland, L., & Rivière-Honegger, A. (2015). Saisir la territorialité par le dessin. Retours méthodologiques. *Sciences de la Société*, 96, 47–67. <https://doi.org/10.4000/sds.3286>
- Giry, J. (2020). *Les fake news comme concept de sciences sociales. Essai de cadrage à partir de notions connexes: rumeurs, théories du complot, propagande et désinformation* (pp. 371–394). Questions de Communication.
- Granovetter, M. (1973). Strength of weak ties. *American Journal of Sociology*, 78(6), 1360–1380. <https://doi.org/10.1086/225469>
- Guenette, F., & Marshall, A. (2009). Time line drawings: Enhancing participant voice in narrative interviews on sensitive topics. *International Journal of Qualitative Methods*, 8(1), 85–92. <https://doi.org/10.1177/160940690900800108>
- Gulledge, A., Miller, S., & Mueller, M. (2021). Social support and social isolation in adults with cystic fibrosis: An integrative review. *Journal of Psychosomatic research*, Vol. 150, 110607, Elsevier Inc. <https://doi.org/10.1016/j.jpsychores.2021.110607>
- House, J. S., & Kahn, R. L. (1985). Measures and concepts of social support. In S. Cohen & S. L. Syme (Eds.), *Social Support and health*. FL (pp. 83–108). Academic Press.
- Huyard, C. (2011). Why come together in an association? Four motives for forming or joining rare disease associations. *Revue Française de Sociologie*, 52, 719–745. <https://doi.org/10.3917/rfs.524.0719>
- Latour, B. (1996). On actor-network theory: A few clarifications. *Soziale Welt*, 47, 369–381.
- Lefève, C., & Ricadat, É. (2022). Les malades chroniques à l'épreuve de la pandémie de Covid-19, entre inventivité et vulnérabilités. In *Soigner et tenir dans la pandémie*. PUF.
- Mol, A.-M. (2010). *Care in practice: On Tinkering in Clinics*. Homes and Farms.
- Ratajová, K., Blatný, J., Poláčková Šolcová, I., Meier, Z., Hornáková, T., Brnka, R., & Tavel, P. (2020). Social support and resilience in persons with severe haemophilia: An interpretative phenomenological analysis. *Haemophilia*, 26(3), e74–e80. <https://doi.org/10.1111/hae.13999>
- Ricadat, É., Béliard, A., Citrini, M., Craus, Y., Gabarro, C., Mamzer, M. F., Marques, A., Sannié, T., Teixeira, M., Tocilovac, M., Velpy, L., Villa, F., Virole, L., & Lefève, C. (2021). COVID-19 health crisis and chronic illness: Protocol for a qualitative study. *JMIR Research Protocols*, 10(9), 1–7. <https://doi.org/10.2196/28728>
- Senik, C. (2022). *Pandémies: nos sociétés à l'épreuve*. Éditions la Découverte. Fondation pour les sciences sociales.
- Smith, K. P., & Christakis, N. A. (2008). Social networks and health. *Annual Review of Sociology*, 34(1), 4015–4418. <https://doi.org/10.4067/S0716-10182018000600629>
- Strauss, A., & Glaser, B. (1975). *Chronic illness and the quality of life*. C.V. Mosby Co.
- Streeter, C. L., & Franklin, C. (1992). Defining and measuring social support: Guidelines for social work practitioners. *Research on Social Work Practice*, 2(1), 81–98. <https://doi.org/10.1177/104973159200200107>
- Thoits, P. (1995). Stress, coping, and social support processes: Where are We? What Next. *Journal of Health and Social Behavior*, 35, 53–79. <https://doi.org/10.2307/2626957>



- Toledano-Toledano, F., & Domínguez-Guedea, M. T. (2019). Psychosocial factors related with caregiver burden among families of children with chronic conditions. *BioPsychoSocial Medicine*, 13, 1–9. <https://doi.org/10.1186/s13030-019-0147-2>
- Tronto, J. C. (1987). (Vol. 12, pp. 644–663). *Beyond gender difference to a theory of CareSigns: Journal of women in Culture and society*. University of Chicago Press. <https://doi.org/10.1086/494360>
- Virole, L., and Ricadat, E. (2022). Combining interviews and drawings: Methodological considerations. In *New Trends in qualitative research (NTQR) - qualitative research: Practices and challenges*, 11, e545, <https://doi.org/10.36367/ntqr.11.2022.e545>

**How to cite this article:** Virole, L., Gabarro, C., & Ricadat, E. (2024). Social support for the chronically ill during lockdown. *Qualitative research in the COVID-19 pandemic. Sociology of Health & Illness*, 1–22. <https://doi.org/10.1111/1467-9566.13845>