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COVID health crisis and chronic illness: Protocol for a qualitative study

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COVID health crisis and chronic illness: Protocol for a qualitative study

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Abstract

Background: The acute nature of COVID-19 epidemic puts a strain on the health resources usually dedicated to chronic illness. Induced changes of care practices and networks had major repercussions on the experience of chronically ill people. This paper presents the research protocol PARCOURS-COVID, and aims to study the effects of such a reorganization on their usual care network which fosters and qualify its quality and continuum.

Objective: Our first objective is to document chronically ill people experience through its transformations and adaptations, both in its practical dimension – daily life and care – and subjective dimension (psychosocial experience of illness and relationship to the health system). The second objective of the study is to identify and reconstruct these reorganizations during the lockdown and the post-lockdown period, in order to grasp their repercussions chronologically and structurally. The last objective is to produce recommendations for adapting the healthcare system to future crises by better acknowledging the experience of chronic patients, their involvement and consultation in the preparation and management of a health crisis.

Methods: The PARCOURS-COVID study is a qualitative and participatory research involving patient organizations as research partners and members of patient organizations as part of the research team. Three group of chronic diseases have been selected regarding the specificities of the care network they mobilise: cystic fibrosis and kidney disease, haemophilia and mental disorders. Four consecutive phases will be conducted: i) preparatory interviews; ii) in-depth individual interviews with patients of each pathology will be analysed using a qualitative method of thematic analysis; iii) results of these both latter will be triangulated through interviews with members of each patient's care ecosystem; iv) focus-groups will be organized to discuss the results with research participants ie. representatives of chronic disease associations, patients, actors of the medical, psycho-social and family care network in a research-action frame.

Results: The protocol study has undergone a peer-review by the French National Research Agency's scientific committee and has been approved by the Research Ethical Committee of the Université de Paris (registration number: IRB 00012020-59 June 28th, 2020). The project was funded from July 2020 through March 2021. Expected results will be disseminated in 2021 and 2022.

Conclusions: Our findings will better inform the stakes of the current health crisis on the management of the chronically ill and, more broadly, any future crisis for a population deemed to be at risk. They will improve health democracy by supporting a better transferability of knowledge between the scientific and citizen communities.

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Background

Since the 1970s and 1980s, the rise of chronic disease has contributed to the construction and promotion of a paradigm leading to a broader definition of medicine around the notion of "care" - a notion developed in medicine as well as in the social sciences and moral philosophy. Faced with living with chronic disease, medicine cannot be defined by its curative and therapeutic aim only. In order to potentiate its effects in terms of patient's quality of life, care needs to be deployed in a multiplicity of relationships and practices combining medical, psychological, ethical and social approaches (1–3). What is then sought is less to repair an organism or a function than to support a person living with a chronic disease (4).

The management of a chronic disease requires the daily intervention and cooperation of many different actors, which define an ecosystem of care. Such an ecosystem is based on a network of actors and institutions, medical or not, that combines diverse approaches and practices and requires constant collaborations and negotiations (5). From healthcare professionals' point of view, this approach should aim at providing a form of care that focuses on the sick person, in a perspective that articulates individual needs and public health policy requirements to make the patient a real partner in care (6). This ecosystem of care is determined by the pathology and the specificities of its medical follow-up, but it is also highly dependent on the patient's background and social environment, resources and living conditions. It entails patient's empowerment and active participation in their care support (7–10).

The measures that resulted from the COVID-19 epidemic led to prioritize acute care, placing particular strain on the resources usually dedicated to the management of chronic pathologies. In France, as soon as March 2020, the High Authority of Health (HAS) and the Ministry of Health's scientific council published recommendations[1] reasserting the need to maintain care for the chronically ill. Simultaneously, patient organizations attested to the difficulties that patients encountered in their usual follow-up. The gap progressively increased between health policies recommendations and the experience of individuals with chronic illness.

The emergence of the COVID-19 pandemics in France has been characterised by a highly centralized reorganization of the health system as a response to the epidemic, without considering regional nuances. This reorganization focused on taking care almost only of COVID infected patients. In the media or social networks, health professionals denounced these difficulties, adding the issue of infected patients triage (12).The lockdown measures seem to have disrupted the ecosystem of care for the chronically ill on two levels. Firstly, medical appointments were postponed or suspended, leading to self-medication practices without medical follow-up or storage of medicines essential to the control of the chronic condition (11). Moreover, the quality of life of chronically ill people was directly affected, as concerns rose about their health status and their risks to be infected by the COVID-19 and as usual interactions with caregivers and health professionals were limited or modified, particularly through the use of systematic teleconsultation. In the case of mental disorders, psychiatric care facilities' closure led to stop some therapeutic activities, though essential for some patients whose trouble are very sensitive to the environment and social interactions. Secondly, in many instances, care was reduced to chemical treatments, sometimes even intensified to compensate for the lack of psychosocial care, even though they produce side effects that increase the risk of COVID-19 infection (13). It seems that prescribed care was doubly restricted: firstly, only vital surgical operations were maintained and, secondly, care was deprived of several of its dimensions: psycho-social, pain control, support, etc.

Moreover, life with a chronic illness requires personal capacity to mobilize its own knowledge based on experiences and brings together medical, psychological, social vulnerabilities. Individuals rely on the support of network of care to limit the effects of these vulnerabilities, yet the resulting quality of life rests on a delicate

[1] https://www.has-sante.fr/jcms/p_3178526/fr/maladies-chroniques-dans-le-cadre-du-covid-19, consulté le 20 mars 2020 ; https://solidarites-sante.gouv.fr/soins-et-maladies/maladies/maladies-infectieuses/coronavirus/professionnels-de-sante/article/en-ambulatoire-recommandations-covid-19-et-prise-en-charge, consulté le 22 mars 2020.

balance which is constantly co-constructed and renewed. The experience of being autonomous or dependent does not come solely from the fact of having or not having support; it is rather a singular combination of material and human, family and professional support (14). The occurrence of a health crisis can deeply compromise this balance, which is already tangled in ordinary times, and increase the vulnerability of people living with a chronic disease.

Conversely, research has shown that living with a chronic disorder also leads individuals to develop specific strategies and skills. Experiencing chronic disease requires the mobilization and acquisition of an important knowledge, know-how and resources, especially regarding the management of uncertainty and risk in the health field (15). Associative or targeted information networks of users and patients participate in structuring and disseminating this expertise related to the experience of chronic disease (16,17,18). This experience makes the chronically ill particularly sensitive to public health and solidarity issues. It is therefore likely that the individual or collective experience of chronic disease has been not only a factor of vulnerability but also a factor of resources, inventions and adaptation in the current crisis. These experiences, that involve both the individuals with chronic illness and the actors participating in their support network, should therefore be documented and valued.

Hence, we hypothesize that the COVID-19 health crisis created an unbalance in the ecosystem of care of the chronically ill. Along with the instability of the situation of individuals with chronic diseases, the crisis also revealed their strength and their know-how in managing uncertainty as well as health and solidarity imperatives. Consequently, there is a dire need to document the experiences of chronic patients and their caregivers.

This paper presents the research protocol PARCOURS-COVID, funded by the National Research Agency (ANR). In order to prepare this protocol, we organized a focus group with a panel of patients' organizations stakeholders, in order to identify their concerns and research needs. Several issues emerged from the focus groups. First of all, they acknowledged the COVID-19 public health measures' inadequacy with the experience of patients and actors, professionals or carers, involved in the management of a chronic disease. Secondly, they asked for a better recognition of their experiential knowledge. Finally, they reported that the COVID crisis profoundly altered care relationships and pratices.
Hence, the focus group confirmed the importance of developing a research considering their experiences and knowledge, along with providing a first set of hypotheses. PARCOURS-COVID research protocol was therefore designed to address these issues, using a qualitative and participative methodology.

Methods/Design

The objective of the PARCOURS-COVID study is to document and highlight the experience of people with chronic diseases confronted to the health crisis by focusing on the changes occurred in their daily practices and ecosystem of care. It is led by the Institute the Person in Medicine, where social science researchers (history, philosophy and ethics, psychology, psychoanalysis, sociology, anthropology), physicians, caregivers and patient representatives collaborate to produce scientific knowledge in the medical humanities from a multidisciplinary approach developed over several years. The choice of adopting a qualitative approach by participatory research carried out with and among users, professionals and caregivers, supported by a strong involvement of chronic disease associations in the design and conduct of the project, has three goals:

1/ to value the lived experience – i.e. both psychic and social, existential and practical, and the representations – i.e. the ways in which chronic illness, COVID-19 and broadly, the health crisis are thought about and made explicit in the discourse of the chronically ill. Semi-directive individual interviews with patients will be conducted to that effect.

2/ to document changes in the practices and organisation of the chronic care ecosystem in order to identify factors that are adaptive or, on the contrary, deleterious to maintaining its balance. Interviews with players in

the medical, family or caregiver network designated by patients will be conducted regarding this goal.

3/ to produce and disseminate recommendations for a better adaptation of the health system for chronic patients in the case of another health crisis, to ensure that the preparation and management this crisis will respect patients' rights by promoting participation and involvement of patients and chronic patients' organizations. Workshops with stakeholders in the health system will help transform and disseminate results in organizations and communities.

Study design and participant recruitment

The PARCOURS-COVID research has been funded by the ANR for 9 months, from August 2020 to April 2021. The work program was developed in order to conciliate the project's feasibility requirements with the achievement of its scientific and operational objectives in a short time frame. Thus, we opted for a rapid qualitative approach and a participatory research including patient participants and associations' members as research partners, an approached validated in the literature (19). The methodology is based on listening to the interviews, then synthetizing them according to themes predefined by the research team, while allowing new themes to emerge if necessary. Rapid qualitative methods are therefore partly deductive, while retaining their inductive component.

Three groups of chronic pathologies were identified regarding the care networks' specificities they mobilize:

Group 1: Cystic fibrosis - a disease with a respiratory component and therefore a high risk of complication in the case of COVID-19, and kidney disease, both of which require a combination of hospital and non-hospital care (regular interventions by physiotherapists or home care nurses). Two main patients' organizations (Renaloo and Overcoming Cystic Fibrosis - *Vaincre la mucoviscidose*) agreed to participate in the recruitment of patients, as well as to the other stages of the research.

Group 2: Haemophilia, a case that will raise the issues of a pathology that is most often self-managed with intravenous self-treatment (2 or 3 days per week) whose day-to-day management is essentially based on a close relationship with healthcare professionals, mainly hospital doctor and nurse from rare disease expertise centre, but less frequently general practitioner. The French Association for Haemophiliacs agreed to assist in patient recruitment and to participate in the research process.

Group 3: Mental disorders, a case that will help understand the specific impact of the health crisis for people suffering from disorders that are very sensitive to the environment and to social interactions, both of which were particularly disrupted during lockdown. Patients suffering from mental disorders require forms of care that are essentially based on relations, through consultations but also through day hospitals, peer groups, etc. A variety of professional partners agreed to assist in patient recruitment and participation in research. Previous collaborations have also been initiated with healthcare professionals in the psychiatric sector.

Research process

Four consecutive phases are scheduled: 1) Preparatory interviews with medical or associative actors of each pathology's field; 2) semi-directive interviews with patients out of these three groups, their results being then 3) triangulated through semi-directive interviews with members of the patient's care ecosystem, in order to cross perspectives and gain a deeper understanding of the situation, through an analysis that will be carried out in close collaboration between social science researchers from several disciplines, patient associations and caregivers; 4) focus-groups to discuss the results with research participants.

1 Phase 1: exploratory interviews

We will diversify entries in the field through our partnership with patient organizations. A series of preparatory interviews with key informants for each pathology will help identify specific situations and difficulties encountered during the crisis, including regarding medical care, as well as the organization's involvement. This phase will therefore include 16 interviews: with each organization leader and health

professionals, a doctor and a first-line professional per pathology. One or two researchers from the team will carry them out by phone or videoconference or in person if the situation allows it.

2 Phase 2: in-depth patient interviews

We will combine the recruitment of chronically ill individuals through the partner organizations with the recruitment of patients through the health professionals we met during phase 1. This will allow us to interview patients that are at varying distance from patient organizations. Seven to ten adult patients per disease group – as identified above – will be interviewed. Patient recruitment in the first group will be equally divided between the two diseases. The participants' situations will be diversified with regard to their socio-economic characteristics and to ensure a balanced ratio of gender, a variety of ages and of geographical location, between Paris and the Regions or between COVID so called red and green zones. We will also discuss with the partner organization and health professionals the pertinence of adding some pathology-specific criteria – such as type of treatments or access to care. This phase will therefore include around thirty interviews of chronically ill people, conducted by phone by members of the research team (only researchers or organizations leaders that are part of the team).

3 Phase 3: in-depth caregivers or healthcare network member interviews

Caregivers or members of the person's healthcare network will be recruited with the cooperation and consent of phase 2 patients, who will be asked to name the two most important persons involved in the day-to-day management of their chronic disease. At the rate of 1 to 2 actors identified per patient, the number of interviews can therefore be estimated between thirty and sixty. The interviews will be conducted by members of the research team (only researchers or association leaders of the team).

4 Phase 4: focus-group for feedback and dissemination

Focus groups will be organized in order to provide feedback to the participants and to discuss the results with them. Results from phase 2 and 3 will provide the basis for public policy recommendations. Participants of the focus group will include phase 2 interviewees on a voluntary basis. The focus groups will be led by the promoters of the present project, including the post-doctoral student (LV) who will be responsible for the organisation and follow-up. Each focus-group will discuss the main hypotheses and categories elaborated in by the research team, and help deepen and validate them. The discussions will be recorded and transcribed, then linked to the empirical data gathered in phases 1 to 3. Focus-groups data collected will be analysed to produce recommendations and outcomes. This participatory research process aims to improve their transferability to medical populations, citizens and health authorities (20). It will thus help raise awareness, as well as produce recommendations concerning the monitoring and care of chronically ill patients in the event of a health crisis, for different audiences: health authorities, scientific and professional networks, but also service users and citizens. A specific website and a social network outreach strategy will be deployed for this phase.

Data analysis

Data analysis will take place continuously throughout the project and will begin in phase 1, with the production of summary sheets at the end of each interview. This process will help organize the data according to the various themes and perspectives that relate to the disciplines represented in the project. Emerging new themes will be included to feed conceptual categories. Return to the transcribed document will be possible, in order to find the exact verbatim of a statement identified in a sheet, to quote but also to identify the context. We will use the iterative process which is characteristic of qualitative methodologies (21). Our approach aims at building hypotheses through linking categories to empirical data.

During the descriptive phase of each case (phases 2 and 3), a summary sheet will be produced for each interview, including a one-page summary of the interview from the interviewee's point of view, as well as a brief paragraph on the interview's relevance to the research issue. An account of the interviews and contacts made (synthetic field diary) will also be produced by the researcher investigating the situation of each person

within his or her healthcare network. The structure of these sheets will be discussed by all the researchers so that all the questions of interest to the various disciplines and user representatives can be considered. The results will be discussed and produced collectively through a series of working sessions in two formats, alternating between general meetings involving all the research team members, and smaller analysis workshops involving each time researchers of two disciplines and a member or an association or a professional.

By associating phases 2 and 3, we aim to cross-reference the points of view of the different actors around the same situation and thus to point to the role of some of them, which may remain hidden after a single interview (22). This method will help reveal important but generally invisible players (pharmacist, medical secretary, etc.), as well as adaptations of the forms of support between relatives that have been reconfigured by the containment measures. Comparing points of view also makes it possible to understand the plurality of definitions of the situation, an important dimension to be considered in the context of the health crisis, which is modifying everyone's expectations and requires continuous adaptation and negotiation. Finally, triangulating these two sources of data aims to capture the concrete and organisational reconfigurations of the healthcare ecosystems that are affected by the reorganisation of healthcare resources, as well as their effects on the quality of medical and psychosocial care. Phases 2 and 3 will document more precisely objectives 1 and 2 defined above.

Discussion

As the exploratory phase of the research is being finalized, several operational issues emerged that foster discussion. The health crisis made it more complex to access the field, requiring adaptation from the research team. We encountered difficulties to access patients with mental illness. This situation was largely caused by a heightened variety of patients relationships to health care services, along with the fact that mental health organizations are loosely structured and scattered (23).

Realizing that the heterogeneity of chronic disease management requires a differentiated approach to each disease, we decided to adapt our recruitment to the specificities of each field. We changed our strategy to find other sources of entry into the field of mental health. We have varied our entry points in the field, by diversifying the interlocutors: psychiatrists, psychologists, associations (the French National Union of Families and Friends of Mentally Ill People – *UNAFAM*), mutual self-help groups, patients' homes (*Clubhouse*). We integrated a new specialized researcher into the research team, Ana Marques, who helped us enter into a psychiatric hospital in the department of Seine-Saint-Denis, where COVID has had significant repercussions in terms of overloading structures, forcing hospitals to reorganize strongly (24). These adjustments allowed us to diversify the profile of recruited patients, as we gained accessed to them through various care structures (psychiatric hospital, medical-psychological center...).

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To conclude, the preparatory interviews were essential to inform the specificities of each field of chronic disease and allowed us to adapt our patient recruitment strategy to begin phase 2 of the research. At the end of our research, our findings will better inform the stakes of the current health crisis on the management of the chronically ill and, more broadly, any future crisis for a population deemed to be at risk. They will improve health democracy by supporting a better transferability of knowledge between the scientific and citizen communities.

Declarations

Abbreviations
ANR : Agence Nationale de la Recherche (National Agency of Research)
HAS: High Authority of Health

Ethics approval and consent to participate
Two separate interview guides have been co-constructed with the research team, based on the exploratory focus group: one is dedicated to "patient" interviews for phase 2, the other to "professionals/helpers/professionals" for phase 3. They are the result of a multidisciplinary approach, since researchers and representatives of patient associations suggested themes using their respective epistemological or experiential references.

The interviews will be conducted in compliance with health regulations by phone or videoconference. They will all be recorded with the oral consent of the individuals, fully transcribed and anonymized, and made available to all the members of the research team. The protection of the data collected will be specified in an information letter given to each person asked to participate in the research.
Having a consent form signed multiplies the documents with the identity of the persons. This is why we have not opted for this procedure, in favour of an oral recording of the consent before starting the interview which, in our opinion, better guarantees anonymity. This consent is subsequently recorded in writing in the transcript of the interview. Furthermore, having someone sign a consent form when working in SHS can significantly alter the relationship between the respondent and the interviewer before starting the discussion. Plus, in the context of the health crisis and protective measures to which we are all currently subject, we will not find ourselves physically face-to-face with the respondent. Getting him/her to sign will be even more difficult and will be done electronically, which is less protected and protectable.
The ethics committee approved this procedure (interview guides and consent).

CER U-Paris : Comité d'Éthique de la Recherche (Research Ethics Committee of the University of Paris)
Trial registration: IRB n° 00012020-59 (June, 28th, 2020)

Consent for publication
Not applicable.

Availability of data and materials

Data will be stored in encrypted form on a secure server in the University of Paris cloud, accessible only to authorized researchers. The data processing implemented for the needs of this research will be done in compliance with MR 004 and declared to the DPO registry of the University of Paris.
If there is a need to transfer data, as to share it among researchers for example to a laptop or USB key, the use of "7-zip" is envisaged. This software allows an encryption key to be put in to encrypt the data and avoids the risk of confidentiality problems in case of loss or theft of the computer.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

All co-authors except LV designed the research protocol, ER and LV wrote this paper and all co-authors participated in reviewing and approving the final text.

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