

Never far away. Those Close to the Ill: Key Players in the History of Health

ALEXANDRE KLEIN*

THE COVID-19 PANDEMIC has reminded us in a sudden and sometimes tragic way that people close to the ill are essential actors in healthcare. Whether it was husbands at the bedside of their bedridden wives, children who became informal caregivers in long-term care facilities, or neighbours carrying groceries to friends in quarantine, they were on the front lines of the disease, alongside the sick and the vulnerable. The health crisis has indeed reactivated these solidarity networks that have always been at the heart of the history of health. We tend to forget that medicine and professional care have long been secondary in the management of the disease. It is first and foremost families, parents, communities, and people nearby who, for thousands of years, have cared for, accompanied, treated, comforted sick people, entrusting them to specialists or institutions only in case of emergency or powerlessness. However, the development of modern medicine and its historiographical counterpart has made it easy to forget this centuries-old fact.

The deployment of modern medicine has been accompanied, as Jacques Léonard in France¹ and Jacques Bernier or François Guérard in Quebec² have pointed out, by a gradual medicalization of the population and the territory, and therefore by an increasingly tight network of the latter, both by the new health professionals and by a new generation of healthcare institutions. Gradually, between the last years of the nineteenth century and the first decades of the twentieth century, the doctor's office and then the hospital became the main places where health and illness were taken care of, gradually pushing the home, and the people close to the ill who lived there or not, to the side of self-medication, traditional medicine, and even practices of a quasi-charlatan nature.

It is therefore not surprising that the history of medicine, initially hagiographical and positivist, has ignored this essential part of healthcare. Focused on physicians,

* Alexandre Klein is an adjunct professor in the Faculty of Health Sciences at the University of Ottawa and coordinator of its Nursing History Research Unit. He is also the founder of the *Historien.nes de la santé* research network.

1 Jacques Léonard, *La France médicale au XIX^e siècle* (Paris: Gallimard Julliard, 1978).

2 Jacques Bernier, *La médecine au Québec. Naissance et évolution d'une profession* (Sainte-Foy: Les Presses de l'Université Laval, 1989); François Guérard, "III. La formation des grands appareils sanitaires, 1800-1945," in N. Séguin, ed., *Atlas historique du Québec. L'institution médicale* (Sainte-Foy: Les Presses de l'Université Laval, 1998), pp. 75–106.

or at best on the few other official caregivers, it has neglected people close to the ill as much as it has forgotten patients. If the social history of medicine, which has developed in the 1970s in the wake of the history of mentalities, was able to rethink the place of the ill in historiography³, it was not until Roy Porter's call for the development of a history "from below"⁴ that those close to them resurfaced, against all expectations. By exploring, as the British historian invited them to do, diaries and private correspondence, historians have indeed seen the (re)emergence of people close to the ill as vital actors of healthcare.

In their study of the correspondence of the Vaud physician Samuel-Auguste Tissot (1728–1797), Micheline Louis-Courvoisier, and Séverine Pilloud⁵ have rediscovered the multitude of roles played by people close to the ill, from the writing of the letters to their transmission to the practitioner, including the explanation of ailments, the administration of treatments, or the comforting of sorrows, but also the plurality of their relations. Tissot's people close to the ill could be, depending on the case, family members, friends, caregivers of all kinds, people from the neighbourhood, religious men or women, simple relations, or distant acquaintances; in short, all sorts of people of varying geographical and emotional proximity, present more or less constantly, and for various reasons, at the patient's side. It is for this reason that the authors speak of an "entourage." The experience of illness is always first and foremost a social experience in which the ill reveals himself or herself as a full member of a community.⁶ The contours, as well as the nature of the latter, can nevertheless be blurred and plural, and people close to the ill, which we are talking about here, diverse, if only because proximity is a relative and therefore variable notion.

The notion of Proximity

If it is first of all geographical, even topological, qualifying the short distance that separates two things or beings, the notion of proximity is also genealogical, specifying the closeness of the bonds of relationship between two people.⁷ However, and this is where it leaves the order of the only numerically quantifiable, it is also affine and dialogical, since it describes the rapprochement or the affinity that can unite or link two people at different levels (physical, psychic, intellectual, emotional, experiential, etc). The "close" (« proche ») to the ill means a person with whom one has intellectual or sentimental affinities, but also with whom one communicates

3 Jacques Revel and Jean-Pierre Peter, "Le corps : l'homme malade et son histoire," in Jacques Le Goff and Pierre Nora, *Faire de l'Histoire, vol. III : Nouveaux objets* (Paris: Gallimard, 1974), pp. 169–191.

4 Porter Roy, "The Patient's View: Doing Medical History from Below," *Theory and Society*, vol. 14, no. 2 (1985), pp. 175–198.

5 Micheline Louis-Courvoisier and Séverine Pilloud, "Le malade et son entourage au 18^e siècle : les médiations dans les consultations épistolaires adressées au D^r Tissot," *Revue médicale de suisse romande*, vol. 120, no. 12 (2000), pp. 939–944; Séverine Pilloud, "Mettre les maux en mots, médiations dans la consultation épistolaire au XVIII^e siècle : les malades du D^r Tissot," *Bulletin Canadien de l'histoire de la médecine*, vol. 16, no. 2 (2000), pp. 215–245; Séverine Pilloud, *Les mots du corps : expériences de la maladie dans les lettres de patients à un médecin du XVIII^e siècle : Samuel-Auguste Tissot* (Lausanne: BHMS, 2013).

6 Philippe Rieder, *Le figure du patient au XVIII^e siècle* (Genève: Droz, 2010).

7 "Proximité," *Trésor de la langue française informatisé*, <http://atilf.atilf.fr/>, accessed on September 8, 2021.

easily according to the *Trésor de la langue française*. A person close is therefore the one who is above all close to. The noun here is fully dependent on the adjective and thus on the relationship between the two entities. Again, this reminder: health, far from being primarily a medical problem, is essentially a social issue.

The development of Francophone history of health⁸, particularly in the last twenty years, has helped to (re)affirm this point. More inclusive⁹ in its approach as well as in the definition of its field of practice, this new history of health has given a central place to the laity and other lay people, including under these polemical terms the vast circle of people close to the sick. At the crossroads of family¹⁰, women¹¹ and childhood¹² history, the history of health has progressively rediscovered people as essential elements in the care of the sick and the most vulnerable, but also in the smooth running of the healthcare relationship. This was notably the case in Quebec, as in France and Belgium, with the work on asylums¹³ or on “abnormal” children¹⁴. In fact, it is with regard to the institution, mirroring its potential, its limits and its flaws, that the importance of people close to the ill is most felt. The period of psychiatric deinstitutionalization that took place throughout the West in the 1960s and 1970s was particularly revealing in this regard.¹⁵

A Discrete Historiographical Presence

If their presence was becoming more and more common and affirmed, however, people close to the ill, and in particular families, were slow to become a full-fledged historiographical subject in the field of Francophone history of health. In the introduction to a special issue of the journal *Histoire, médecine et santé* on healthcare history published in 2015, Anne Jusseaume, Paul Marquis, and Mathilde Rossigneux-Meheust recalled that: “En tant que telle, la relation de soin qui se

8 Alexandre Klein, “L’histoire de la santé : le renouveau interdisciplinaire de l’historiographie médicale francophone,” *Revue d’histoire de l’Université de Sherbrooke*, vol. 9, no. 2 (Automne 2016), <http://rhus.association.usherbrooke.ca/wp-content/articles/921.pdf>, accessed on September 8, 2021.

9 Alexandre Klein and Séverine Parayre, “Pour une histoire francophone, globale et inclusive, de la santé,” in Alexandre Klein et Séverine Parayre, eds., *Histoire de la santé (XVIII^e-XX^e siècles)*. Nouvelles recherches francophones (Québec: Presses de l’Université Laval, 2015), pp. 1–14.

10 Magda Fahrmi, *Household Politics: Montreal Families and Postwar Reconstruction* (Toronto: University of Toronto Press, 2005), In particular Chapter 3.

11 Aline Charles, *Travail d’ombre et de lumière. Le bénévolat féminin à l’Hôpital Sainte-Justine 1907-1960* (Québec: Institut québécois de recherche sur la culture, 1990), p. 191.

12 Didier Lett and Marie-France Morel, *Une histoire de l’allaitement* (Paris: Éditions de la Martinière, 2006), p. 159.

13 André Cellard and Marie-Claude Thifault, *Une toupie sur la tête. Visages de la folie à Saint-Jean-de-Dieu au tournant du siècle dernier* (Montréal: Boréal, 2007); Hervé Guillemain, *Schizophrènes au XX^e siècle. Des effets secondaires de l’histoire* (Paris: Alma, 2018); Benoît Majerus and Anne Roekens, *Vulnérables. Les patients psychiatriques en Belgique (1914-1918)* (Namur: Presses universitaires de Namur, 2018).

14 Lucia Ferretti, “De l’internement à l’intégration sociale : l’Hôpital Sainte-Anne de Baie-Saint-Paul et l’émergence d’un nouveau paradigme en déficience intellectuelle, 1964-1975,” *Revue d’histoire de l’Amérique française*, vol. 65, no. 2–3 (automne 2011-hiver 2012), pp. 331–361; Anatole Le Bras, *Un enfant à l’asile. Vie de Paul Taesch (1874-1914)* (Paris: CNRS Éditions, 2018); Susanne Commend, *Vulnérables, tolérés, exclus. Histoire des enfants handicapés au Québec, 1920-1990* (Montréal: Presses de l’Université de Montréal, 2021).

15 Alexandre Klein, Hervé Guillemain and Marie-Claude Thifault, eds., *La fin de l’asile? Histoire de la déshospitalisation psychiatrique dans l’espace francophone au XX^e siècle* (Rennes: Presses universitaires de Rennes, 2018).

noue entre malades, soignants et famille n'a [...] été que peu adoptée comme angle problématique par les historiens français"¹⁶ (As such, the healthcare relationship that develops between patients, caregivers, and family has [...] been little adopted as a problematic angle by French historians). To fill this void, these historians actually set up or participated in a seminar on "Liens familiaux et institutions disciplinaires"¹⁷ (Family Ties and Disciplinary Institutions) held under the auspices of the Groupe de recherche sur les institutions disciplinaires (GRID) beginning in 2018.¹⁸

In parallel, and as early as 2016, the *Historien.nes de la santé network*¹⁹, created in 2012 to try to join Francophone researchers in this field, also tackled the issue by organizing a first symposium in Montréal on "Les relations de santé."²⁰ The majority of the presentations focused on people close to the ill as key players in these healthcare relationships, indicating once again the need to question this theme more precisely, for its own sake, and in particular outside the sole family perspective.²¹ For this reason, the network has decided to organize a symposium on "Les malades et leurs proches"²² in May 2019, also in Montréal. The aim was to bring together researchers in history of health (or working from a historical perspective, or on historical objects) who are interested, regardless of their approach, the period, or geographical area of their study, in the shared experience of illness and health by the ill and people close to them (in all senses of this expression). This event aimed to open a space for exchange and debate around the experiences of these "lay people," their role in the history of healthcare, and their place in its current historiography. The various presentations, which dealt with the representations of health and illness held by people close to the ill, their relationships with patients and healthcare professionals, and the sources of this history of proximity in healthcare, showed the diversity, but also the importance of this rich transversal research theme. A part of the presentations of this symposium forms the present thematic section.

A Contemporary Francophone History of Proximity

We wanted to collect articles that are diverse, both in their approach and in their subject matter, in order to show the richness and multiplicity of the issue of people

16 Anne Jusseaume, Paul Marquis and Mathilde Rossigneux-Meheust, "Le soin comme relation sociale : bilan historiographique et nouvelles perspectives," *Histoire, médecine et santé : Revue d'histoire sociale et culturelle de la médecine, de la santé et du corps*, no. 7 (printemps 2015), <http://journals.openedition.org/hms/765>, accessed on September 9, 2021. There was no article in the file that directly addressed the issue of people close to the ill.

17 The program of the seminar can be viewed here: <https://grid.hypotheses.org/programme-2019-2020>

18 They are also preparing a special issue of the journal *Mouvement social*, which will include some of the presentations of the following parties: Elsa Génard, Anatole Le Bras, Paul Marquis, Mathieu Marly, Mathilde Rossigneux-Méheust, and Lola Zappi, eds., "Les liens familiaux à l'épreuve des institutions disciplinaires," *Mouvement social* (in preparation).

19 The *Historien.nes de la santé network* is mainly organized around a blog that is updated daily <http://histoiresante.blogspot.com/> and a Facebook page that posts the announcements.

20 The program of this event is available here: <https://histoiresante.blogspot.com/2016/04/histoire-des-relations-de-sante-aux.html>.

21 The subject is still dominant, as evidenced by the recent symposium "Families and Health: Historical Perspectives," organized by the University of Wolverhampton on November 9: <https://familiesandhealthconference.wordpress.com/>.

22 The program of this event is available here: <http://histoiresante.blogspot.com/2019/04/les-malades-et-leurs-proches.html>.

close to the ill, but also to consider, beyond the multiplicity of fields and periods, the existence of possible lines of force that would characterize the place and role of people close to the ill in health issues in the modern era. Unlike the presentations of the symposium that originated it, all articles in this thematic section concern only the contemporary period, from the first decades of the seventeenth century to those of the twenty first century. It must be said that this period, which marks the gradual professionalization of doctors, but also their monopolization of the field of care and illness, questions in a unique way the place of people close to the ill in healthcare.

What can be their prerogatives, their singular contributions in the face of a medical power so omnipotent and invasive that it has made all exteriority its own?²³ How can we reorganize the field of healthcare as doctors, and other official health professionals, impose themselves as the only possible, legal, and even effective recourse? How does the caregiver role of people close to the ill continue under these conditions? What readjustments, transformations, or adaptations are needed?

These questions, all the more important since the issue of people close to the ill is once again being raised in the healthcare network, particularly through the increasingly recognized status of “informal caregivers”; we wanted to raise these questions in the French-speaking world, in the tradition of our *Historien.nes de la santé* network, which promotes research in French in this field. Of course, the texts you are about to read are only interested in a small (but important) part of the latter, since their authors, as well as their research fields, are either Quebecers, Franco-Ontarians, or French. Very far, therefore, from being exhaustive, this thematic section aims above all to present unique analyses of particular cases showing, from two living hearts of the French-speaking world, the singularity of the relationships between the ill and persons close to them. The thematic section also includes the transformations that may (or may not) have taken place over the last three centuries in the role, and the place and participation of these full-fledged actors in healthcare. Moreover, it provides through these studies, various tools to approach these relationships of proximity in healthcare, of which it often presents unexpected, even unprecedented forms. The thematic section intends to contribute to the reintegration of people close to the ill in the Francophone historiography of health in order to open up the necessary research on proximity and thus promote the development of new work throughout the French-speaking world.

Composition of the Thematic Section

At the beginning of this thematic section, Isabelle Robin reminds us of the multiple roles that people close to the ill could play in the Age of Enlightenment, at a time when doctors had not yet acquired a monopoly on healthcare. Based on the medical correspondence of the French physician Étienne François Geoffroy (1672-1731), she traces the different ways in which those around the patient intervene and the effects of their presence and actions. It thus highlights the central role of people close to the ill in their accompaniment, whether for the writing or the transmission of the

23 « *La médecine n'a aujourd'hui plus de champ extérieur* » (Medicine today no longer has an external field), observed Michel Foucault in 1976 in a lecture entitled “*Crise de la médecine ou crise de l'antimédecine*” in *Dits et écrits II. 1975-1988* (Paris: Quarto/Gallimard, 2001), pp. 40–58; the quote appears on page 53.

missives to the Parisian doctor or for taking charge of injuries and sufferings. She also emphasizes the complementary nature of the physician-those close to the ill combo in assisting the patient(s), rather than a possible competition or opposition.

Fleur Beauvieux's study of social relations in Marseille during the plague of 1720 confirms this analysis. Using judicial archives and private archive sources to bring to light what was happening within the walls of the quarantined city of Marseille, she reveals the practices of mutual aid and solidarity that were established by those close to the ill, such as families, of course, but also neighbours and acquaintances. Many fled the city, and thus their loved ones, before the doors were closed, including caregivers. But the cases remain rare and therefore not very representative of the relationships that were established in the plague-stricken city. On the contrary, we saw the maintenance and even the development of relationships of care between the confined inhabitants, despite the distance imposed by the disease and the fear it engendered, confirming once again the essential role of those close to the ill in the management of healthcare, but also for end-of-life assistance.

Using patient files from three French psychiatric asylums, Anatole Le Bras analyzes how disease tears families apart. The internment of a loved one is indeed an opportunity to see (re)appear the fracture lines underlying the relationships between brothers and sisters, children and parents, wives or husbands and families-in-law. Postures and reactions are diverse, but the admission of a loved one into an institution never leaves anyone indifferent. It is the understanding and sometimes the very definition of the disease as well as of the family that are then at stake. While the institution comes to replace the family to welcome a patient, the family questions and redefines itself, sometimes dividing or on the contrary uniting to face adversity. The cards of proximity are then often reshuffled, and with them the family and care relationships that prevailed until now. This article is a fine reminder that people close to the ill are not a homogeneous group and that their very definition can be the subject of lively discussions in which the doctor's opinion plays an important role, particularly in the case of psychiatric internment.

Susanne Commend's article on the families of disabled children in Quebec also questions the complexity of the relationship between caregivers and people close to the ill. The article highlights the submission of families to the medical discourse, through an internalization of its norms, and the resulting sacrifice of people close to the ill. But it also points out the strategies of resistance or adaptation developed by these same families in order to reappropriate part of the norms of healthcare and their life story. Between victimization and adaptation, dependence and resistance, families maintain sometimes tense relations with doctors, but find in other healthcare actors, in particular social workers, relays and supports for the affirmation of a proper family care for their children. The creation of parents' associations also contributes to the existence of these alternative care pathways (because they are based on representations of disability not shared with the medical profession), and to the recognition of the rights of children and their close caregivers.

This acceptance/opposition dynamic between people close to the ill, especially families, and the medical profession is also at the heart of Dannick Rivest and Julien Prud'homme's study. On the issue of the body in the history of autism, the two

authors retrace the history of the role of parents in understanding and defining the disorder of their child or children, but also in the adoption of therapeutic strategies to mitigate its effects. They propose the hypothesis of an “eclipse of the body” in the “expansion of autism” that marked the period 1980–2010 by showing how it affects the position and the discourses of parents about the disorders of their children. They remind us that the role of people close to the ill in healthcare is also determined in an evolving dialogue with the medical profession, as well as with the society in which they are integrated, which, in turn, has concrete effects on the management of those they take care of.

Marie-Claude Thifault, Sandra Harrisson, and Andrée-Anne Sabourin turn the perspective around by questioning the experiences of mothers diagnosed with schizophrenia in their article. Using patient records from the Department of Psychiatry at the Montfort Hospital in Ottawa, they examine the troubled lives of women with schizoid disorders in the second half of the twentieth century at three important points in parenthood: motherhood and birth, the age of parenthood, and entry into old age. Each time, they highlight the difficulties experienced by these women with regard to their loved ones as well as their illness, but also the impact of their disorders on these same loved ones. The authors thus give voice to rarely heard persons, who speak of the suffering of knowing they are ill, with all the weight of care and concern (in the double sense of worry and solicitude) that they place on those they love, but also the stability and hope that the family represents for those whose vulnerability increases with age.

Finally, Benoît Carini-Belloni also approaches the question of proximity in healthcare from an original angle, through his study of the relations between mutualist doctors in the Bouches-du-Rhône region of France and their working-class patients or people close to them. By tracing the portrait of these idealistic caregivers and their unique institutional achievements, he questions the existence of a social, cultural, political, and sometimes friendly proximity between these full-fledged caregivers and their working-class patients. He thus opens an unexpected dimension to the study of people close to the ill in the field of healthcare by drawing the figure of the doctor as close, and this proximity as the condition of the possibility of establishing a fairer health system, without ignoring the limits of this proximity as well as of the experimentation carried out by these activist doctors.

For a Socio-Cultural History of Proximity in Health

Thus, through this series of inspiring studies, which testify to a particularly dynamic Francophone history of health, a portrait emerges of a research project rich in lessons for the history of health, but more widely for contemporary social history. Indeed, the prism of health and illness, which brings together these different cases, acts as a magnifying glass on relationships, sometimes strained, that go far beyond the framework of healthcare. It is the very conditions of social relations that are at stake in these singular, sometimes extreme, situations of illness and care. Therefore, by highlighting the social interactions that take place between people close to the ill around a pathology, a disorder or a therapeutic intervention, the history of proximity in health offers a new and original window to social history to grasp the

way in which social groups are constituted, transformed, and interact in the face of sometimes dramatic situations. Moreover, through its approaches stemming from “history from below,” microhistory, or the history of sensibilities, it invites social history to vary the scales and to multiply the perspectives in order to understand its intent in its cultural complexity and diversity. This singular perspective, which is the question of proximity, finally reminds us that the history of health, beyond a simple history of knowledge, sciences, and techniques, is first and foremost a social and cultural history of interpersonal relations and representations at stake in a given society at a given moment, when illness strikes and healthcare is required. It is a history of individual and collective experiences of health and illness, as well as of its representations, discourses and practices. In short, a history that is created first and foremost from person to person.