HEALTH ENGINEERING AND SOCIETY SERIES

COMMUNICATION AND HEALTH SET

Volume 1

Patients, Caregivers and Doctors

Devices, Issues and Representations

Edited by
Laurence Corroy
Christelle Chauzal-Larguier

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coordinated by
Abdelkhalak El Hami

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First published 2023 in Great Britain and the United States by ISTE Ltd and John Wiley & Sons, Inc.

ISTE Ltd 27-37 St George's Road London SW19 4EU UK	John Wiley & Sons, Inc. 111 River Street Hoboken, NJ 07030 USA
www.iste.co.uk	www.wiley.com

Library of Congress Control Number: 2023930936

British Library Cataloguing-in-Publication Data
A CIP record for this book is available from the British Library
ISBN 978-1-78630-893-1

Preface

Chronic and long-term illnesses, because of their lasting impact over time, expose the patient, the family caregiver[1] and the professional caregiver to multiple concerns that call into question the different systems implemented, the issues and the representations linked to them. The role of these three actors and the relationships that unite them can be questioned through the prism of a wide range of methods and processes, recent or not, implemented inside the care structures (recognition of peer helpers, recourse to cohesion techniques of care teams, telemedicine, proposal of new care offers, co-design of devices with the help of "collaborating" patients) as well as outside of them (homecare, distance learning, therapeutic education, assistance to family caregivers, digital devices, narrative medicine, "edutainment" within fictional television series, etc.).

P.1. Patients, caregivers and carers at the heart of a complex relational web

This book will study the patient, the carer and the caregiver according to their status and the care relationships that unite and divide them. Today, patients, carers and caregivers are subject to a burdensome, anxiety-provoking climate, marked by a feeling of insecurity, whether material, professional or emotional, prompting them to engage in introspection that can lead to a reconsideration of their own role.

The patient is led to reflect, in particular, on their ability to maintain a positive attitude when their bruised body causes pain and questions and when the professional, social and economic environment is disrupted (Lefort and Psiuk 2019). The caregiver, trained in a form of providing medicine designed to relieve the ills of the body, rather than moral suffering, works in a tense professional context, generated by a health system on the verge of implosion (lack of staff, difficult working conditions, unattractive salaries). The degraded care sacrifices the human dimension, inflicting on the caregiver a feeling of helplessness, a loss of professional ideal (Delieutraz 2012) and a heavy emotional burden (Chahraoui et al. 2011; Petiau 2016). The latter leads to question the limits of the traditional approach of “caring” centered on the acts themselves, increasingly convinced that “care taking”, centered on the person receiving care, should be adopted instead (Hesbeen 2012). The family caregiver, little or poorly prepared (Leduc et al. 2013), prey to strong emotions (Mallon and Le Bihan-Youinou. 2017), questions their ability to reconcile their caregiving activities with professional and personal activities (Le Bihan-Youinou and Martin 2006; Fontaine 2009). An unrecognized shadow actor (Bloch 2012), they have difficulty thinking of themselves and accepting themselves as such (Bricka 2016).

Even though the knowledge and skills of the caregiver are recognized as scientific expertise, “no one today can dispute the importance of the relational attitude in care activities” (Formarier 2007, p. 33). Since patients are not satisfied with being passive (Pierron 2007) and families do not accept being left out, they all demand greater involvement in care protocols. While the dyad between the patient and the caregiver appears to be of little relevance, institutional, medical and lay discourses evoke the importance of a third category of actors, the close caregivers[2] whose important role in the care pathway is widely recognized even though the abundant literature on the subject testifies to the gray areas (Buthion and Godé 2014). The tripartite relational dimension in care is unavoidable. Patients, caregivers and carers have never so much sought, or even demanded, a more human approach to care relationships while the caregiver experiences difficulties in being able to invest in it. This triad of actors, which is part of the long term, must deal with long treatments for which the territories of understanding and the horizons of expectation of each require adjustments (Sicard 2002; Kentish-Barnes 2010; Maupetit and Fondras 2011), dialogue and assistance. Without this, the feeling of solitude felt individually by the different parties can increase (Canouï and Mauranges 1998) and cause them to sink into exhaustion, especially since the caregiver, for example, does not dare ask for help (Coudin and Gely-Nargeot 2003).

How can the relational quality of care be reconciled with a context of increased tension for the caregiver? How are the patients' relationships with doctors staged when healing medicine shows its limits? What is the place and role of the caregiver when holistic medicine, which aims to treat the person in a global way, is struggling to be developed within the hospital environment? How sustainable is the patient-caregiver-caregiver relationship model (Mitnick et al. 2010) in the event of the failure of one or more of the actors involved? Is the support of other actors (associations, private organizations, individuals, public structures and institutions) conceivable if not possible and how is it represented? These are the questions that the relationships between patients, caregivers and carers and the roles of each can raise. To answer these questions, it is essential to reflect on the representations of each person.

P.2. Representations of patients, carers and caregivers in discourse

The aim of this book is also to fill a gap in qualitative research on these issues when, as Rul and Carnevale (2014, p. 241) note, they “allow for the generation of knowledge about social processes or behaviors, or the experiences of people confronted with a situation in a given context”. While traditionally, the denomination of the patient[3] refers the patient to their condition of being consumed by suffering and devoid of knowledge, digital platforms have increased this information (Cases 2017) and the legislation[4] has recognized their right in this regard, shaking up the notion of an asymmetrical relationship between patient and caregiver. The patient has become a “knowing being” for want of a “savant” (Le Pen 2009, p. 260), an actor of their own health as envisaged by research on patient “empowerment” (Hibbard et al. 2004).

The importance of the relational dimension of care and the problems of representations raise questions about the feelings and affects that arise in the different actors (patients, caregivers, carers) in relation to chronic diseases. This requires a reflection on the researcher’s methodological approaches to study these dimensions. Phenomenological interpretive analysis allows us to discover and study in depth the experience of illness and the care process. It is increasingly used in psychological research, particularly in health and clinical psychology (Antoine and Smith 2017). The linguistic analysis of discourse, which is still underdeveloped in this field of research (Garric and Herbland 2020), allows the researcher to let these actors express themselves and recount their experiences. Speech is then a key resource that must be studied for its own sake (Rossi 2011) because it is the means of accessing a “contextualization” of the individual and/or collective experience. In this field of research, playful approaches through games can also allow actors to distance themselves from the situations of suffering experienced, both in the context of care activities and in the experience of illness, while allowing the researcher to give a participatory dimension to the studies.

The importance of the communication and information media where this discourse can be collected must also be discussed. Digital platforms allow patients to talk about their symptoms and treatments, to discuss their care pathways and their relationship with their doctors and the care team. Websites (Kinnane and Milne 2010; Dolce 2011) and forums dedicated to caregivers, with their vocation of mutual aid and exchange of advice, and also by the information and training offered, tend to break their isolation, to bring comfort (Dubreuil and Hazif-Thomas 2013) while remaining compatible with their daily lives (Nabarette 2002). Finally, testimonies can be a tool to mediate the “denial of recognition” (Charlier 2018) that one or more actors in the above-mentioned triangular relationship is/are confronted with, or to publicize the changes that have occurred, particularly in life courses (disorganization and reorganization of family ties, for example) (Dupre La Tour and Gorlero 2012; Bonnet-Llompart and Laurent 2020).

On another note, work on television series has already shown the importance in the spectatorial experience of television series and edutainment related to health (Singhal et al. 2004; Barthes 2016), whether it be prevention or apprehension of certain diseases.

Far from being anecdotal, these testimonies and stories are part of what can be defined as narrative medicine (Charon 2015; Goupy and Lejeunne 2016), which tends to develop competence and increased vigilance on the part of the patient (in the relationship they have with their own body and restores them as actors in their lives and potentially in their recovery) and of the caregiver (in the relationship that binds them to the sick loved one and repositioning them as an actor independent of the person being cared for).

Putting into words the ills experienced, distanced by language and lived experiences, far from constituting a unified whole, can also question in return the role of medical teams, the ambivalences felt, and constitute for the carers a reflexive spur on their practices while providing them with an extremely rich documentation of a multiplicity of cases. Indeed, as Dagognet (2009: 172) points out, “medicine is hermeneutics, a science of interpreting what is in front of our eyes and what we cannot see” and for which the discourses and verbal exchanges constitute indispensable methodological tools.

This book questions the devices, the stakes and the representations related to chronic and long-term illnesses by questioning the way patients define themselves, the relationships they establish with their caregivers and how the figure of the caregiver can be staged as a necessary adjuvant to the patient, whether it be testimonies on digital platforms or in fictional universes, and also in everyday life, within organizational structures (medical structures, companies, associations) and private structures (private environment of the patient and the caregiver). In order to provide elements of reflection and answers to these questions, teacher-researchers and professionals from various fields of research and competences belonging to two disciplines have collaborated in this book: information and communication sciences through the analysis of the representations of patients, care staff and carers through communication media, discourses, arguments and rhetorical figures mobilized; management sciences by studying the organizational and communicational devices of public and private companies with these targets.

To answer these questions, this book presents research conducted around two closely complementary themes. The first part of the book highlights the challenges and opportunities of digital and playful devices for patients, caregivers and carers. Julie Pavillet and Aurélie Dumas are interested in a game-based device for occupational health prevention. Using a collaborative and participatory methodology, the nursing staff of a long-term geriatric care unit at the Grenoble Alpes University Hospital were asked to discuss their work in order to express their emotions and affects without violence. Through the affective and relational dynamics that the Dixit® card game creates, a team in pain manages, through individual and collective reflection on professional practices, to acquire new resources intended to facilitate the establishment of work groups that can lead to organizational changes within the hospital.

Nathalie Garric and Frédéric Pugniére-Saavedra use a situated analysis in discourse analysis combining a quantitative textometric approach and a qualitative enunciative approach to show that certain digital devices, in this case the blogs of which they are the authors, give caregivers the opportunity to provide a discourse other than the existing institutional discourse on their subject, which escapes certain normative constraints on the experience of caregiving as it is presented in media and legal discourses. Confronting this digital corpus with a corpus of individual interviews of caregivers and families, the authors conclude that this discourse does not play the role of a counter-discourse because it is constructed in and for a restricted community of people with the aim of constructing themselves and defining their role.

Ambre Davat and Fabienne Martin-Juchat detail the methodology, justify the interest and address the ethical and societal issues of the co-design project. With a group of patients, the aim was to co-design a study enabling the development of information and communication devices for future patients with chronic heart failure and equipped with connected implants. The chosen method was based on interviews allowing the collection of the experiences of the “collaborating” patients through their stories of affects related to their care path. The patients’ role was to participate in the definition of the major questioning areas of the study, to validate the hypotheses and the test method chosen. This work led to the collective and organizational dynamics involved in the follow-up of this chronic disease emerging.

Emna Cherif and Corinne Rochette look at the opportunities and challenges of highlighting healthcare offers on the websites of health institutions. This is a response to the impossibility for these organizations to communicate as commercial enterprises, to an exacerbated competition between hospital structures and to an evolution of patients’ expectations. The study of 17 institutional communication websites of hospitals (university hospitals, clinics and cancer centers) allows us to assess their patient orientation. Are patient-centric markers identifiable? How are they expressed? Being patient-centric is not present in a similar way in all the sites studied, through more or less extensive information processes and the implementation of specific resources and skills, thus highlighting cultural and behavioral approaches to this orientation.

Alexis Meyer and Christelle Chauzal-Larguier question the online marketing communication strategy pursued by seven French thermal spa establishments and one thalassotherapy center offering a mini-cure for caregivers and analyze the discourse held, in particular by using comparative analysis. Two complementary methods are mobilized: a study of the dedicated pages of the websites of these establishments and the content analysis of in-depth interviews with actors of the spa sector. Can’t the purely informative discourse evolve or even deviate towards a real commercial communication to promote some services? The caregiver then becomes not only an informative but also a commercial target. The offer so proposed constitutes a strong stake for thermalism and contributes to its repositioning.

The second part focuses more closely on the narrative and hermeneutic medicine of the patient and caregiver.

Laurence Corroy and Emilie Roche explore how the French series *Demain nous appartient,* broadcast daily by TF1 since 2017, Monday through Friday, dramatizes how a recurring character on the show faces breast cancer and how loved ones react. This ensemble show and family series offers locations that are easily identified by fans of the series: high school, police station, hospital, etc. Patients, caregivers and doctors are at the heart of hospital plots that allow, through the narrative construction of the series, the feature of several different points of view and protagonists who evolve according to the twists and turns of a specific narrative arc. The one analyzed by the two researchers corresponds to two months of broadcasting, during which the director of the hospital’s general medicine department becomes a patient with breast cancer. During this situation of personal crisis, the narrative medicine of the doctor turned patient, who evokes doubts and fears, while having expert knowledge and a supportive professional and intimate entourage, being herself of the party, intertwine. However, despite the fact that the character is familiar with the world of care, she nevertheless feels shock at the diagnosis.

From the triad of doctor to patient, carer and caregiver, preventive discourses and norms are disseminated, placing the series at the heart of a device considered to be edutainment: fans of *Demain nous appartient,* whose emotional attachment to the series and to the recurring characters is strong, receive, over the course of the episodes, preventive messages and models of valued or criticized behaviors (good care vs. bad care, the importance of screening, rapid care of patients, etc.) which emerge in the background.

Leaving the world of fiction, Anne Vega and Ibtissem Ben Dridi shed light on the way in which relatives are progressively led to take charge of and support their family members suffering from cancer. The announcement of the disease is experienced as a trauma, a shockwave that must be gradually absorbed – the help of family members is therefore crucial. In addition to psychological difficulties, patients may also be in a precarious financial and family situation. While patients from well-to-do or even very well-to-do social categories may feel more at ease with the medical profession and are better able to discuss and negotiate treatment protocols, those from working-class backgrounds are more apprehensive about making their point of view heard. The two authors show to what extent, in this case, the help of relatives, extended to colleagues, neighbors and other patients encountered who form a supportive entourage, can be decisive. A diversified support network allows patients to acquire empowerment with regard to their illness and also with regard to the medical profession, partially freeing them from the asymmetrical positions between “knowers” and patients and from injunctions that may be impossible to follow to the latter. The caregiver can also, in socially disadvantaged family contexts, develop skills similar to those of a home care worker.

The field study conducted by Aicha Benabed in the Algerian context shows how caregivers are led to develop the medical know-how which is extremely important for the very longevity of the patient they care for. This “medical work” (Strauss 1992) is illustrated by the family trajectories that the researcher was able to identify and present. The testimonies demonstrate the scope and diversity of the tasks performed. Learning to assess the weak signs of the disease in order to evaluate the condition of the sick family member and understand their symptoms makes it possible to anticipate their daily needs. This watchfulness places the caregiver in a state of extreme vigilance, which proves to be exhausting in the long run and a source of anxiety. Help does not only develop in the family context; the caregivers interviewed show that when their loved ones were hospitalized, their care work continued, as hospitals are understaffed. It is the women on whom all care work rests. The author thus notes a gendered and asymmetrical division of care in the Algerian context, which weighs heavily on female caregivers, whose well-being is undermined.

Managing emotions, ambivalent feelings and even guilt can be difficult and even painful for caregivers. If caregivers develop hermeneutics of the patient they are caring for, hermeneutics of the self is just as fundamental. Digital platforms, allowing relative anonymity and a wider circulation of caregivers’ dilemmas and difficulties, often appear to be an easy way to speak out and testify. However, is the platformization of relationships and communications without impact on the type of discourse delivered and the emotions expressed? Abdelhadi Bellachhab, Olga Galatanu and Valérie Rochaix provide enlightening answers by comparing two communicational devices and two corpora – the first corresponding to 10 discussions from a digital platform where caregivers of Alzheimer’s patients express themselves and the second to 10 semi-directive biographical interviews conducted as part of a scientific project. The results show that the modalities of emotional expression, as well as the emotions themselves, depend on the communication devices observed. If guilt, for example, is experienced and discussed on the online discussion forum, it hardly appears during the discussions conducted with the researchers. It seems, therefore, that addressing peers who share common experiential experiences on a digital platform is viewed quite differently compared to testifying with researchers. It would be hasty to conclude, however, that emotions are not expressed in front of scientists, some of them are on the contrary strongly evoked, notably the caregivers' constant fear of doing wrong.

The difficulty of taking care of someone who gives their time, love and energy to a close family member, finally led the DanaeCare team to propose a co-construction of a territory that facilitates assistance. André Simonnet, Julia Gudefin and Maya Chabane indeed emphasize a problem often underestimated by caregivers concerning the impact of territorial networking on their daily life. The fact that the public authorities have thought of care as primarily intended for the elderly and the loss of autonomy is not without consequences. However, assistance is diverse, transgenerational and concerns multiple pathologies. They do not fit easily into the categories conceived by public policies. The project led by the authors, DanaeCare, is therefore part of a territorial logic, that of the department of Saint-Etienne and adopts a concerted approach. In the tripartite relationship between caregiver, carer and patient, it is important that each actor be recognized, especially the carers who ensure a crucial coordination for the patient. The lengthening of patients' lives, and hence the chronicity of illnesses and treatments, are profoundly transforming this tripartite relationship, where the patient can gradually become an expert on their illness and the caregiver a fine interpreter of the loved one to whom they provide support, while developing multiple skills. The DanaeCare project highlights the importance of co-constructing adapted solutions within a given territory.

The experiences and disciplines brought together in this book shed light on the complexity and interest of paying close attention to the relationships that develop between patients, care staff and family members. The dualities between those who know and those who do not seem less and less operational. Thinking about the actors in interaction, respecting the patient’s word as well as the caregiver’s role in order to provide the most appropriate solutions will undoubtedly improve the quality of care, and also the care relationships.

February 2023

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