

Experience in Healthcare Innovation

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coordinated by
Corinne Grenier

Volume 5

**Experience in
Healthcare Innovation**

Fad or New Paradigm?

Edited by

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Contents

Foreword by Vincent Dumez	xiii
Foreword by David Darmon	xv
Introduction	xvii
Luigi FLORA, Corinne GRENIER and Frédéric PONSIGNON	
Part 1. Crossed Perspectives on Experiential Knowledge	1
Introduction to Part 1	3
Corinne GRENIER, Luigi FLORA and Frédéric PONSIGNON	
Chapter 1. User Knowledge, a Key Ingredient for Health Innovation and the Sustainability of our Health Systems	11
Geneviève CYR and Marie-Pascale POMEY	
1.1. Introduction	11
1.2. Innovation	12
1.2.1. Linear innovation model	12
1.2.2. Contemporary vision	13
1.3. Towards open innovation	13
1.4. Health innovation	15
1.5. Responsible health innovation	15
1.6. Participation of patient-caregivers and citizens in innovation	18
1.6.1. Level of participation	19
1.7. Open innovation practices to bring patient-caregivers and citizens to contribute to innovations	20
1.7.1. Hackathon	20
1.7.2. Living Labs	21

1.8. Conclusion	23
1.9. References	23
Chapter 2. The Experience of Caregivers in Supporting People with Neurodegenerative Diseases	27
Anaïs CHENEAU and Valérie FARGEON	
2.1. Introduction	27
2.2. Theoretical framework	29
2.3. Data and method	32
2.4. Results	33
2.4.1. The components of care and the meaning of involvement	33
2.4.2. The dynamics of the involvement of informal caregivers and their challenges	35
2.5. Conclusion	41
2.6. References	42
Chapter 3. The Experiential Approach and Alzheimer's Disease: Including the Spiritual Dimension for a More Global Approach	45
Ruth Laure ALAMARGUY and Pauline LENESLEY	
3.1. Introduction	45
3.2. Alzheimer's disease: loss or search for meaning?	46
3.2.1. At the macrosociological level: Alzheimer's disease, a predicted loss of meaning	47
3.2.2. At the microsociological level: sick people in search of meaning	50
3.2.3. And the spiritual in all this?	52
3.3. Obstacles to taking the spiritual dimension into account in support	54
3.3.1. Institutional side: the biomedical approach, a reductive filter	55
3.3.2. The caring aspect: the relationship to spirituality guides the approach of the "patient"	56
3.4. Perspectives: ways to approach the overall lived experience	58
3.4.1. Raising awareness among professionals about their relationship to the spiritual and intimate	58
3.4.2. Initiating collective reflection	58
3.5. Conclusion	59
3.6. References	60
Chapter 4. Rethinking the Organization of SDCCs in Light of the Experience of Volunteers in a State of Great Social Precariousness	65
Corinne GRENIER	
4.1. Introduction	65
4.2. Theoretical framework: social regulation and experiential knowledge	68
4.2.1. Regulation work	68

4.2.2. Experiential knowledge	69
4.3. A situation to transform: the Boutique Solidarité de Marseille (BSM) of the Abbé Pierre Foundation	71
4.3.1. Presentation of the BSM	71
4.3.2. 2017: a problematic situation calling for work on the organization of the BSM	73
4.4. The intervention-research (IR) approach	75
4.5. The transformation of the BSM: the establishment of the Mutual Agreement Contract (MAC) as a regulation tool	76
4.5.1. The MAC	77
4.5.2. The general operation of the Boutique	78
4.5.3. The experiential knowledge of volunteers	78
4.6. Analysis of the transformation: more balanced regulations	79
4.6.1. A weak but enriched control regulation.	80
4.6.2. Autonomous regulation justified	81
4.6.3. A peaceful but “floating” joint regulation	82
4.7. Conclusion	83
4.8. Appendix	84
4.9. References	86

Chapter 5. Professional, Team and Digital Identity: The Impact on Patient Experience 89

Stephanie BEST, Ann DADICH and Sharon WILLIAMS

5.1. Introduction	89
5.1.1. Why is identity relevant to health and social care practitioners?	89
5.1.2. How does identity relate to patient experience?	90
5.1.3. Why measure patient experience?	90
5.1.4. What is the aim of this chapter?	91
5.2. Conceptual background	91
5.2.1. Health and social care professionals’ identity	91
5.2.2. Patient experience.	92
5.3. Patient experience and health and social care professionals’ identity	93
5.3.1. Professional identity	95
5.3.2. Team identity	97
5.3.3. Digital identity	97
5.3.4. Lexical analysis	97
5.4. Implications	100
5.4.1. For researchers	100
5.4.2. For health and social care professionals and service managers	100
5.4.3. For patients and carers	101
5.5. Conclusions	101
5.6. References	102

Chapter 6. Mobilizing the Experience of People with Disabilities: A Necessity in the Transfer of Innovations	107
Éléonore SÉGARD and Philippe CHERVIN	
6.1. Introduction	107
6.2. The transfer of innovations to accelerate the transformation of services: a new approach.	109
6.3. People's experience at the heart of the development of ground innovations in the field of disability.	112
6.4. Taking into account the experience of people with disabilities in the transfer process	112
6.4.1. Evaluation	112
6.4.2. Capitalization	115
6.4.3. Transferability.	115
6.5. Implementation	116
6.6. Conclusion	117
6.7. References	118
 Part 2. Crossed Perspectives on the Impacts on Organizations and Health Systems	121
 Introduction to Part 2	123
Corinne GRENIER, Luigi FLORA and Frédéric PONSIGNON	
 Chapter 7. Reorienting Our Health System towards its Users Thanks to Design Thinking: The Experience of Kaiser Permanente	131
Inès GRAVEY	
7.1. Introduction	131
7.2. A lever for rebalancing powers between users and traditional experts	136
7.2.1. The power of empathy: from traditional experts to users in order to identify needs	136
7.2.2. The power of ideation: from managers to users in order to imagine solutions	137
7.2.3. The power of prototyping and testing: from the theoretical to empirical in bringing solutions to life	139
7.3. A lever for cultural transformation in the dual bureaucratic and health context	140
7.4. Obstacles and facilitators to integration	142
7.5. Discussion	143
7.6. Appendix: methodology.	144
7.7. References	146

Chapter 8. Patient-Centered Care at Public Hospitals: A War of the Worlds?	149
Marie-Eve LAPORTE, Patrick GILBERT and Karim ZINAÏ	
8.1. Introduction	149
8.2. Patient-centered care	150
8.2.1. Definition of patient-centered care	150
8.2.2. An international enthusiasm for patient-centered care	150
8.2.3. A counter-nature approach for the French public hospital.	151
8.3. The theory of economies of worth – a key for understanding tensions	152
8.4. Study of the orthopedics department of a Parisian hospital	153
8.4.1. War of the worlds.	154
8.4.2. Responses segmented by patient profile	155
8.4.3. The debrief room, a place for conciliation and the establishment of arrangements	158
8.5. Conclusion	159
8.6. References	159
Chapter 9. A Brief History of Changes in the Medico-Social Sector over Recent Decades. Interview with Marielle Ravot.	163
Luigi FLORA and Marielle RAVOT	
9.1. Introduction	163
9.2. Interview	164
9.3. The experience.	165
9.3.1. In terms of human resources	168
9.3.2. Concerning the reform of EHPAD pricing	169
9.3.3. About the implementation of a quality approach within EHPAD.	169
9.4. Appendix: list of acronyms	180
9.5. References	182
Chapter 10. EPoP: An Approach to Developing Peer Intervention.	183
Sabrina SINIGAGLIA	
10.1. Introduction.	183
10.2. The EPoP approach: a necessary framework for action.	189
10.3. The choice of a territorial approach.	192
10.4. The stabilization of a new function, peer-intervener and of a new mission, peer intervention representatives	199
10.5. Presentation of a panel of peer-intervener projects supported by EPoP	201
10.5.1. Presentation of Mr. B’s project.	201
10.5.2. Presentation of Mr. A’s project.	202
10.5.3. Presentation of Mrs. S’s project	203
10.5.4. Presentation of Mr. J’s project	204

10.5.5. Presentation of Mr. JB’s project	205
10.5.6. Presentation of Mrs. D’s project	206
10.6. Conclusion	207
10.7. References	208

Chapter 11. The Potential for Digital Health to Reframe the Role of Compassion in Patient Experience Innovation 211

Lester LEVY, Ann DADICH and Kevin LOWE

11.1. Introduction	211
11.2. Definitions	213
11.2.1. Compassion	213
11.2.2. Digital health.	214
11.3. Compassion in digital health	214
11.4. Deconstructing patient experience	216
11.4.1. Patient one	216
11.4.2. Patient two	217
11.4.3. Patient three	218
11.5. Blending digital health with the human touch for positive patient experiences	219
11.6. Conclusion	220
11.7. References	221

Chapter 12. Help with Prescribing Mobile Health Applications: A Partnership Design 227

Luigi FLORA, David DARMON, Stephen DARMONI, Julien GROSJEAN, Christian SIMON, Parina HASSANALY and Jean-Charles DUFOUR

12.1. Introduction	227
12.2. ApiAppS research, a response adapted to the times?	230
12.3. Design carried out with the participation of citizens	231
12.4. Categorization choices and their development during this research	232
12.5. A dynamic mobilizing cross-perspectives between patients and doctors	233
12.6. Conclusion	235
12.7. References	236

Chapter 13. Beyond the Testimony: Patient Partners and Ongoing Education Program 239

Yves COUTURIER, Marie-Eve POITRAS, Marie-Dominique POIRIER and Anaëlle MORIN

13.1. Introduction	239
13.2. Train-the-trainer program an effective strategy for professional development in primary care.	239

13.3. Innovation in the train-the-trainer approach through increased patient participation. 241

13.4. Study context 242

13.5. Theoretical framework. 243

13.6. Intervention 245

13.7. Methodology 246

13.8. Results. 246

13.9. Favorable conditions for full recognition of trainer status for patients in the context of ongoing training 247

13.10. An enrichment proposal for the Montreal model. 248

13.11. Conclusion. 250

13.12. References. 250

Chapter 14. The Care Partnership: Challenges and Perspectives for Healthcare Systems 253

Philippe ANHORN

14.1. Introduction 253

14.2. Context and definitions 254

 14.2.1. The Réseau Santé Région Lausanne (RSRL) 254

 14.2.2. The care partnership. 255

 14.2.3. The anticipated care plan (ProSA) 257

14.3. Theoretical foundations of the research 259

14.4. Methodology 260

14.5. Main research results. 260

 14.5.1. The importance of the care partnership 260

 14.5.2. The need for an action plan. 261

 14.5.3. On the need to remove or alleviate structural obstacles 262

 14.5.4. The opportunity to act in a favorable temporal context 263

14.6. Conclusion 264

 14.6.1. Conclusion and managerial recommendations 265

14.7. References 268

List of Authors 271

Index. 275

Foreword by Vincent Dumez

This book proposes an international kaleidoscope of the current deployment of the notion of patient experience and consequently that of patient partnership through the combined perspectives of patients and health professionals. Each of the experiments presented here constitutes an invaluable source of innovation through the engagement mechanisms developed as much as through the results observed on the strategic, tactical and operational levels. They also cut across the major missions of our health systems, namely care, teaching and research, showing that we are undoubtedly in the midst of large-scale systemic organizational and cultural change with multiple impacts.

At the heart of these experiments is the fundamental question of the mobilization of patient knowledge in different forms and by different means. This knowledge, still poorly known, underestimated and consequently underused, is nevertheless the main “fuel” of the innovation driven by this movement of change that we discover in this work through the achievements of actors from extremely varied horizons. From the engagement initiative of a large private health organization like Kaiser Permanente, to the pioneering initiative of a living laboratory in the clinical context of a public university hospital, to advocacy in the context of Alzheimer’s disease, “patient” knowledge is highlighted again and again as a lever for innovation at the very heart of patient experience.

To support this critical effort to mobilize patient knowledge, an organizational transformation must of course be supported by inspired leadership and a vision of humanist care. Our health institutions have most of the time been structured above all to support the practices of health professionals putting the experience of patients and their families second. The reversal of this logic to aim for a better balance requires us to rethink certain hitherto unshakable fundamental operational pillars. Several avenues of innovation are proposed for this purpose in this work, particularly in terms of supporting the most vulnerable populations which are too

often on the margins of our systems, as well as in terms of profound and necessary change in the philosophy of care or even the digital revolution, an irresistible and radical lever for modifying the practices of all health stakeholders including patients and their families. Through these structuring innovations, the patient experience is therefore lastingly transformed, inviting an in-depth questioning of institutional modes of operation and the way in which we orchestrate communication and collaboration and therefore, consequently, the sharing of knowledge and power.

Finally, in this proliferation of innovations characteristic of major emerging transformation movements, it remains essential to implement mechanisms to fully understand their nature, their systemic ramifications, their impacts in fine on health and possibly also, their limits. We must therefore evaluate initiatives as systematically as possible and produce research to develop the science of patient experience and partnership with a view to the “intelligent” scaling of innovations. This work also offers some significant avenues for reflection on this very critical question, on how this science can help us to transfer and scale innovations in a precise and adapted way, as well as on what it teaches us in terms of the evolution of roles, the development of capacities or of an organizational model.

Happy reading!

Vincent DUMEZ
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Partner patient
Co-director of the Center of Excellence on
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Foreword by David Darmon

The care partnership with the patient is considered an important social innovation because it strengthens patients' engagement and responsibility in their own care. This can improve health outcomes, patient satisfaction and quality of life. Care partnerships are based on transparent communication and active collaboration between patients and healthcare professionals, allowing care plans to be personalized and taking into account patients' unique preferences and needs. It can also reduce healthcare costs by minimizing medical errors and unnecessary hospitalizations. Technological innovations are also important, but the care partnership emphasizes the human connection and collaboration to achieve optimal health outcomes.

In a world where new techniques and technologies have taken a prominent place in our lives, it is increasingly important to understand how they can be used to improve the quality of medical care. This book examines the importance of patient participation in care using, among other things, innovations to facilitate communication, collaboration and decision-making. It demonstrates how patients can become active partners in their own care by using the digital tools available to them to collect and share information, monitor their health and better understand treatment options. Perspectives from healthcare professionals, patients and technology experts are explored to provide a comprehensive picture of the use of new technologies in medical care. This book is a valuable guide for those seeking to understand how new technologies can help improve care for partner patients. The example of mobile health applications is an illustration of this in that they can enable the autonomy of patients, when and if they wish, by giving them access to information on their state of health and advice on how to manage their illness, as well as allowing them to monitor their progress and communicate with their doctor and other health and medico-social professionals. It also values their experiential knowledge by giving them an active role in managing their health and recognizing their expertise with regard to their own body and its symptoms.

Corinne Grenier, through her systemic vision, and Luigi Flora, as a patient researcher and pioneer of the vision of partnership (with whom I have the pleasure of directing the Center for Innovation in Partnership with Patients and the Public at the University of Côte d'Azur), offer through this collective work a reflection on the evolution of care and on what there is to come as well as a desirable future.

Once you have taken the path of partnership, it is difficult to turn back, as you will notice when reading this book.

Introduction

This book, entitled *Experience in Healthcare Innovation: Fad or New Paradigm?*, follows the international conference held in June 2021 on health innovation through shared perspectives, and even experiences combining the knowledge of each person. Through this book, the opportunity is given to contributors (who may or may not have participated in the conference) to, shed light on the subjects covered. In-depth studies can, for some, take up questions asked during the discussions following the communications presented during the 2021 conference.

The 2021 conference was the result of an initiative born in 2008. The KEDGE Business School health conferences are organized by Corinne Grenier¹ in partnership with the social work research institutes (IRTS) of Provence-Alpes-Côte d’Azur-Corsica and Nouvelle Aquitaine, with the support of the ARAMOS association. They question actors, organizations and public authorities in the health and social action sectors using a multidisciplinary approach to better understand their dynamics. In 2021, after the brand new Center for Innovation in Partnership with Patients and the Public (CI3P) of the Faculty of Medicine of Côte d’Azur University (Flora et al. 2020) proposed two communications at the previous conference², the 2021 conference pursues the ambition of questioning innovation by partnering with the CI3P, an innovation center co-directed by a doctor–patient tandem, through the perspective of *the experience of stakeholders: new perspectives on health innovation*.

Introduction written by Luigi FLORA, Corinne GRENIER and Frédéric PONSIGNON.

1 Coordinator of the “*Innovation, Healthcare and Inclusive Society*” Lab.

2 Two communications which resulted in publication (Flora 2021).

According to the book *Terminologie de la pratique collaborative et du partenariat patient en santé et services sociaux* (Direction collaboration et partenariat patient (DCPP-CIO, UdeM 2016)), the patient experience is defined as:

The overall knowledge drawn from situations experienced living with the disease which have an impact on the patient, as much on their ways of taking care of themselves, of interacting with those involved, as on their way of using health services and social services (Ibid., p. 17).

The place and role of the people concerned (patients, people with disabilities and caregivers) in their relationship to the experience of living with illness or a disability situation have attracted the interest of the human and social sciences since the 1950s, in particular with regard to the first works focusing on relationships between health professionals and patients in order to explain care trajectories and the organizational and managerial structuring allowing for the delivery of care (Strauss 1992). Anthropology (Laplantine 1986) has also been concerned with the way in which patients experience their illness by emphasizing the social and cultural elements, which permeate their experience of their illness and their recovery. It was firstly with the emergence of pathologies such as AIDS (Epstein 1996) in the third sector health environment and the perspective of community health, for example, that the experience was questioned in its collective dynamics. This was, however, a societal movement, which was made broader with the birth of popular epidemiology in the 1970s, through population reactions to attacks on health due to local pollution in the USA, and which has since spread across the planet as populations gradually sense or perceive risks to their health, which are factors of public health problems (Brown 1987, 1997).

To better understand what has become a social fact in the 20th century, the following have appeared or been recovered (Flora 2012; Flora et al. 2014; Jouet 2014) in the sense given to them by the father of sociology Emile Durkheim (1894), concepts such as *empowerment or recovery* and capability (Le Gales and Bungener 2015), coming *from* the field of North American psychiatry and taken up by French researchers (Greacen and Cadeau 2012) which now irrigate the work on experience (Troisoeufs 2020). Other *concepts* come from the political sciences and evoke the question of *citizen participation*. Multiple user participation and professionalization initiatives exist, such as the *Montreal model* (Vanier et al. 2014; Pomey et al. 2015), the expert patient program in England (Rogers et al. 2008) or the model of *narrative medicine* (Charon 2015).

Many terms have come to enrich the roles that patients can endorse in the health system: the expert user (Jouet et al. 2010); the trainer-patient (Flora 2010); the resource-patient developed by the French Association of Hemophiliacs since the beginning of the century³; the researcher-patient (Godrie 2017); the health mediator-peer (Roelandt et al. 2016); the expert-patient (Tourette-Turgis 2015); the teacher-patient (Gross and Gagnayre 2017); the partner-patient (Pomey et al. 2015); and the tracer-patient (HAS 2014).

At the international level, multiple initiatives for the participation and professionalization of patients, relatives and health users have existed for several years. For example, in France, experiences of peer health mediators supported by the WHO can be identified (see the report from the World Health Organization Collaborating Center (WHOC) (Roelandt et al. 2015)). More broadly, we finally talk about the professionalization of patients/users to configure participatory health systems.

This trend, the social fact of recognizing patients' knowledge, is thus carried by patients and relayed by international (Consortium APPS 2020) and national (HAS 2020) agencies as well as by major Evidence Based Medicine journals (EBM) (Richards et al. 2013). These different models are based on a renewed partnership between patients and professionals. The latter are challenged on two counts: a) because their practices are questioned by what patients, beneficiaries and citizens tell them; b) as well as because the experience of professionals counts just as much and their lived experience of their work needs to be integrated into innovation approaches.

Thus, the chapters issued from the 2021 conference consider the experience of patients, relatives and/or segments of the population just as much as the experience of professionals to address the question of innovation in health. This perspective thus adopts the point of view of the organization or its representatives and would be the primary cause of the power to act.

As a result, it is possible through the insights offered throughout the chapters to apprehend and understand how *experience* is now reinvested when each of the parties is interested in innovation approaches and in the capacity of health organizations and the health system to innovate in partnership with patients, relatives and citizens. The relationship appears a priori to be virtuous: taking into account the lived experience of the people concerned (patients, beneficiaries, caregivers, professionals, volunteers, citizens, etc.) so as to imagine, design and deploy interventions, organizations or services that are more appropriate and

3 See: <https://afh.asso.fr/je-me-forme/education-therapeutique-des-patients/patientsparents-ressources/programme-patients-parents-ressources/>.

appropriable by these actors. The recognition of experience, and of citizen participation in the creation and deployment of public policies, raises complex questions, some of which the chapters proposed in this work shed light on.

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PART 1

Crossed Perspectives
on Experiential Knowledge

Introduction to Part 1

The first part of the book *Experience in Healthcare Innovation: Fad or New Paradigm?* is made up of six chapters combining different views, perspectives and areas in order to deepen the notion of experience.

Geneviève Cyr and **Marie-Pascale Pomey** offer us the first chapter entitled “User Knowledge, a Key Ingredient for Health Innovation and the Sustainability of our Health Systems”.

Here, it is the patients and caregivers who are at the heart of the authors’ chapter, developing experiential knowledge related to their health condition and the use of both health and medico-social services. This knowledge is considered to be an important resource in health innovation approaches; their active engagement is recognized as an essential element of a learning health system and as one of the necessary conditions for redesigning the health system (Carman et al. 2013). With the description of a few concrete cases, the authors deepen the distinction between patient participation (and that of their caregivers) and citizen participation in the evolution of the health system, all of this according to different levels of participation, allowing new ways to create value for the system.

Open innovation is defined with regard to three complementary perspectives: centered on users and the response to their needs, centered on the organization and the creation of value through the search for new market opportunities, and centered on the ecosystem, looking at spaces and places for generating new ideas. This form of innovation is necessarily collaborative, participatory and very often emergent. In the field of health, the search for value takes on particular meanings such as: improving the efficiency, effectiveness, quality, safety and/or affordability of health care (WHO 2023). It is about improving or transforming treatment, diagnosis,

education, awareness, prevention, research quality and delivery, and access to health care (Kimble and Massoud 2017).

The authors look with interest at a particular case of innovation, so-called responsible innovation (RIH, responsible innovation in health), defined as a collaborative approach by which stakeholders commit themselves to clarify and implement a set of principles and values as well as ethical, economic, social and environmental requirements in order to respond to the challenges and needs of health systems in a sustainable manner (Silva et al. 2018). RIH targets five areas of value: for the population, for the health system, the economy, the organization and the environment. The objectives are all the more achieved when the participation of individuals is strong. Cyr and Pomey then rely on the typology of Arnstein (1969), which defines the degree of citizen participation in eight levels (manipulation, education, information, consultation, involvement, partnership, delegation of powers and control of citizens) to propose a similar scale for the participation of patients and health users. The authors also rely on Kaulio's model (1998) to understand the modalities of user involvement in innovation processes.

These methodological approaches for working with patients and caregivers' voices and making them heard are illustrated by different examples of spaces such as hackathons and "living laboratories" (Niitamo and Leminen 2011), those of the LIO (research laboratory in imaging and orthopedics, CHU Montreal, Canada) and of the Living Lab LUSAGE (Broca Hospital, Paris, France), for example.

Anaïs Cheneau and **Valérie Fargeon** focus on caregivers of the elderly in the second chapter entitled "The Experience of Caregivers in Supporting People with Neurodegenerative Diseases", wondering if their particular position (neither patients nor professionals) does not make their experiences and their forms of involvement and participation specific. The authors study the cases of caregivers of people with Parkinson's disease or amyotrophic lateral sclerosis (ALS).

This work is a continuation of initial work on the production of care by caregivers (Bungener 1987), particularly through the capabilities approach (Le Galès et al. 2015), which allows us to understand what they do, for what reasons and the conditions for carrying out their activities. It aims to understand the particular case of the participation of relatives and caregivers, with regard to the modalities of patient involvement and participation in care, and, for example: on an information–consultation–collaboration–partnership continuum (Pomey et al. 2015) for the micro level of care and the clinical relationship, or with regard to the work of Scholl et al. (2014) for a more global approach, focusing on access to care, its coordination and continuity, as well as teamwork.

Cheneau and Fargeon conclude their study by showing that the participation of loved ones, ranging from dialogue with professionals to co-production in care actions, varies depending on the loved ones and the components of support during the care process. This variability reflects situations where involvement or noninvolvement is sometimes desired, sometimes constrained, in particular to overcome the difficulties of access to professionals or of hospital organization. It also reveals the weakness of the psychosocial approach in the health system. The involvement and participation of loved ones are the expression of two non-convergent logics: an institutional logic of cost reduction and a logic where loved ones seek to strengthen their capacity to act.

Ruth-Laure Alamarguy and **Pauline Lenesley** deepen the experience of people with Alzheimer's disease by focusing on the spiritual dimension of this experience. Their chapter is entitled: "The Experiential Approach and Alzheimer's Disease: Including the Spiritual Dimension for a More Global Approach". It is here a multidimensional approach to the sick person is considered, since "spirituality fundamentally responds to the need to find meaning and reason for the events of life (Jobin 2012)" (quoted by Gaillard Desmedt and Shaha (2013, p. 1)). This is frequently defined as "an aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connection to the moment, to themselves, to others, to nature, and to the signifier or the sacred" (Appleby et al. 2018).

However, several studies show that the spiritual dimension of support and care is little taken into account due to the lack of time or to the discomfort of distinguishing between spirituality and religion. From then on, Alamarguy and Lenesley wonder how to reconcile this issue of quality of care with the embarrassment caused by the evocation of the spiritual; and how to understand the spiritual dimension in a healthcare situation, beyond the strong influence of a biomedical vision of disorders. The first meta-analysis (Edward et al. 2010) has already revealed that it is above all the relationship that is decisive in taking spiritual needs into account.

Based on ethnographic research in EHPADs¹, the authors first highlight the important role of the establishment's commitment to taking the spiritual experience of residents into account when supporting professionals. However, they engage in it in three proactive ways, at the explicit request of the resident, some more in the background; positions depending on the way in which the professional views their own spirituality. They conclude their work by proposing some recommendations.

¹ EHPAD: accommodation establishment for dependent elderly people (or medicalized nursing home) specific to France.

In the fourth chapter “Rethinking the Organization of SDCCs in Light of the Experience of Volunteers in a State of Great Social Precariousness”, **Corinne Grenier** analyzes the regulatory work within an *accueil de jour* (ADJ), or day center, started by a team of around 10 social workers to ease tensions, support the quality of the work and allow those welcomed to truly find a haven of peace and comfort. This day center, called Boutique Solidarité, is managed by the Abbé Pierre Foundation and is located in one of the districts of Marseille (France) known as one of the poorest in Europe. Those welcomed are people in great social and economic precariousness. This organization is mainly defined by its welcoming mission “in unconditionality” and as a space of relationship and expression which is open to all and where people create meaning and commonality together; it is intentionally a place of very weak control regulation (Martinez-Perez 2013). However, the multiplicity of incidents, sometimes serious, was putting more and more strain on the team and those welcomed, including the volunteers, who, support the salaried team in their activity for around two mornings per week. The bet is that this work can contribute to their recovery process.

The author conducted action research at the request of the foundation in order to rethink the framework of the action, thus asking the research question by mobilizing the theory of regulation (Reynaud 1997) and the notion of experiential knowledge: “to what extent does the experiential knowledge of volunteers contribute to the regulatory work within a day center?”. This articulation was observed around the establishment of a new system, the Mutual Agreement Contract (MAC), which defines the framework for action of volunteers with those welcomed and with the team. We have also defined the method of management of the MAC (signature, discussion time to take focus in on volunteers and their activities) as well as a better organization of the activity of the Boutique in general. For the Boutique, the MAC had to be a tool that participates in the volunteer’s recovery process, by supporting their behavior, as well as their experiential knowledge. This knowledge is built in the experience of being welcomed at the Boutique, in being with others, identifying or analyzing situations or more generally in knowing what to do and what to say in certain circumstances.

The process of implementing the MAC has made it possible to bring about a “peaceful” joint regulation, wherein volunteers and teams interact more to know how to act in the face of any situation. The capacity of volunteers to put forward their knowledge and the attention paid by employees were possible thanks to the establishment of several regulatory spaces, allowing a “long and repeated practice of an activity which allows the emergence of the experienced individual” (Demailly and Garnoussi, 2015, p. 58). This being said, this joint regulation still proves to be unstable, in particular because the team has not managed to support a space specific to volunteers, and still remains uncertain about the reason to support and use the