INCLUDING PATIENT’S EXPERIENCE IN THE ORGANISATION OF CARE: THE CASE OF DIABETES

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De Boeck Supérieur | « Journal of Innovation Economics & Management »

2019/3 n° 30 | pages 39 à 57

Article disponible en ligne à l'adresse :


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Including Patient’s Experience in the Organisation of Care: The Case of Diabetes

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ABSTRACT
Innovation is an important topic in healthcare studies with a large focus on technologies, practices and organisational arrangements. However, the increase in chronic diseases such as diabetes requires new forms of collaboration and organisation that challenge the traditional boundaries of care. Based on a qualitative study of individuals with diabetes, we describe the experiences of patients with their disease, and also the impacts on relationships with their families and friends, other health professionals, as well as with other patients. We show that including patients’ experiences in a better way stretches the traditional boundaries of healthcare pathways, which requires openness and flexibility. Results are described and then discussed.

KEYWORDS: Organisational innovation, patient’s experience, healthcare pathways, chronic disease, diabetes

JEL CODES: O350

1. Acknowledgements: We would like to thank the patients for their time. We would also like to thank the healthcare professionals at Nancy Santé Métropole and Danièle Durain, as well as the Nancy Regional University Hospital (CHRU de Nancy), especially Dr Philip Böhme and Dr Phi Linh Nguyen-thi. We thank the participants of the ‘Dynamics of Practices, Knowledge and Work in Healthcare Organisations’ at the 2017 EGOS Colloquium in Copenhagen. Finally, we are in debt to the Editor, Corinne Grenier, as well as the two reviewers for their comments. The project received support from the Grand Est Region.
Innovations, especially technological and product innovations in healthcare, have generated a considerable amount of attention in the academic literature (Damanpour, Aravind, 2012; Pauget, Wald, 2018). However, while it is important to better understand the technology itself and its impact on professional practices (Mørk et al., 2012; Nicolini, 2007), it is fundamental for both theoretical and practical purposes to have a better understanding of how the interactions and collaborations between various actors (Pénin et al., 2011) may help to foster the emergence of new ideas and innovations (Burger-Helmchen et al., 2011; Touati et al., 2016). These new forms of organisation – triggered by new public management (Hernes, 2005), the evolution of patient-physician relationships, or the increase in chronic diseases (Pauget, 2013) – require greater integration of patients in their healthcare pathways and, therefore, challenge traditional boundaries of care and of innovation (Burger-Helmchen et al., 2011).

Patients with chronic diseases challenge the organisation and boundaries of care as care also occurs outside the boundaries of hospitals and doctors’ surgeries. Indeed, patients must continue the treatment on their own, be able to adapt it, and must even be aware of signs of degradation in their diseases (Pickard, Rogers, 2012). Moreover, they face various constraints, whether these are related to the professional or private spheres, which may hinder treatment observance. Patients thus develop an experience and knowledge of their disease (Caron-Flinterman et al., 2005; Pols, 2013) that are important sources of information in relationships with healthcare professionals in order to adapt the treatment, but also to find solutions that will improve their quality of life (Epstein et al., 2010). Therefore, the challenges for healthcare organisations and for health professionals rely on finding new forms of collaboration and organisation (Pauget, Dammak, 2017; Pauget, Wald, 2018) that enable a greater involvement of patients’ experiences to improve the quality of care (Keating et al., 2013; Kitson et al., 2013). In other words, this poses a challenge to innovate in healthcare organisations by reshaping the boundaries of care and healthcare pathways (Burger-Helmchen et al., 2011) to enable new forms of collaboration (Pénin et al., 2011) and redefine the roles of the various actors involved (Jullien, Zimmermann, 2011).

If the organisational literature in healthcare provides a greater understanding of the variety of actors and their interactions which innovation in healthcare requires, they tend to lose sight of patients by focusing more on professionals (Mørk et al., 2012; Reay et al., 2017). However, studies in innovation, especially in open innovation, have highlighted the importance of integrating users in innovation processes (Hafkesbrink, Schroll, 2011; Jullien,
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Zimmermann, 2011). In healthcare, integrating patients’ experiences encourages new perspectives that cross traditional boundaries of care.

Studies, especially in the medical and nursing literature, describe and theorise new practices that put patients at the centre of care (Charles et al., 1997; Tanenbaum, 2015). They emphasise the importance of considering the values, experiences and needs of patients in decisions about their courses of treatment (Berwick, 2009; Miles, Mezzich, 2011). These values, experiences and needs are constructed in relation to the way the patient lives with the disease (Williams, Ryan, 2017), relationships with her family and friends (Mol, 2008), with technologies (Strömberg, 2005), as well as with the different health professionals that she may encounter (Bjornsdottir, 2018). However, we still lack the empirical studies that describe these patients’ experiences in order to be able to design new forms of collaboration and organisation (Grenier, Denis, 2017; Pauget, Wald, 2018). Therefore, the focus of this study is patients’ pathways and experience in relation to their disease, family and friends, health professionals, and other patients.

This research is based on a qualitative study of patients with diabetes in the eastern region of France. Although there are different types and degrees of progression, diabetes is characterised by chronic hyperglycaemia (high blood sugar level) caused by a defect in insulin secretion, actions, or both (World Health Organization, 2016). There is no curative treatment and individuals with diabetes must learn how to be aware of their disease, the signs of evolution, pay attention to their diet, and take action when needed by injecting insulin and/or taking oral medications when prescribed. In addition, there are other constraints, such as the need to exercise, the impact of stress, outside temperatures, etc. Individuals with diabetes are, therefore, not passive in their care but play an important role in the way they manage their disease.

This study contributes to the literature by providing empirical data on patients’ experiences in diabetes. This not only involves the way patients feel about their disease, but also their relationships with family and friends, as well as with health professionals such as physicians and nurses. Considering patients’ experiences is an organisational innovation (Pauget, Dammak, 2017; Pauget, Wald, 2018) as it challenges traditional boundaries of care and healthcare pathways by including new actors (Burger-Helmchen et al., 2011). This therefore has practical implications in the design of healthcare organisations and processes, and how professionals may construct spaces to favour collaboration between complementary actors that span organisational boundaries (Hafkesbrink, Schroll, 2011; Jullien, Zimmermann, 2011). It also calls for a territorial perspective of patients’ pathways.
The next section develops what considering patients’ experiences implies in relation to different organisations of care. Then the qualitative methodology is presented within the context of diabetes. Our results are then described and discussed.

**Patient’s Experiences and Organisations of Care**

**Patient’s Experiences**

Various studies in different streams of literature show either empirically (Pickard, Rogers, 2012; Williams, Ryan, 2017) or theoretically (Berwick, 2009; Tanenbaum, 2015) the benefits of involving patients in their care. This is not only beneficial for the patient but also for practitioners and scientists (Caron-Flintermanet al., 2005; Pols, 2013). However, it is important to clarify what involving patients in their care means, in order to better understand how this may impact healthcare organisations (Grenier, Denis, 2017) and their boundaries (Burger-Helmchenet al., 2011). Indeed, several studies argue that involving patients means considering their values, preferences, choices and needs (Epstein et al., 2005; Mol, 2008) in the decisions that are made regarding the course of treatment (Miles, Mezzich, 2011; Thórarinsdóttir, Kristjánsson, 2013). This implies a focus on the patients’ experiences but also their relationships with other patients, family and friends, health professionals, and other patients that are involved in their pathways.

First, in their study of a patient with multiple chronic diseases such as diabetes and kidney failure, Pickard and Rogers (2012) show the importance of knowledge of the body. By knowing her body, the patient is able to notice subtle changes and to relate them to one of her multiple conditions. This requires constant work and adjustment as, for instance, her choices may favour a disease while increasing the risks of another one. Indeed, while keeping a low blood sugar level may limit the risk related to kidney failure, this may increase the risks of hypoglycaemia. In a similar vein, Williams and Ryan (2017) describe how patients with chronic obstructive pulmonary disease ‘feel’ in how they experience the disease. A patient describes his symptoms as “I can feel it twinge-ing” (Williams, Ryan, 2017, p. 3) while another explains that “my chest starts burning” (Williams, Ryan, 2017, p. 3). These feelings and sensations enable patients to differentiate their different symptoms, especially when they have multiple conditions, but also to understand the variations between good and bad days (Williams, Ryan, 2017). Considering
patients’ experiences with their diseases also leads to a focus on their social environments.

Second, patients’ families and friends can play important roles in the way patients experience their disease, especially spouses, parents and/or children. Indeed, Pickard and Rogers (2012) show how a patient’s son is able to identify changes, even sometimes when the patient does not. The continuous presence of family members enables them to develop an experience and knowledge about the disease and the symptoms. Moreover, family and friends are of importance in the continuity of care. Indeed, in their study of the dynamic service settings of UK mental health, Aristidou and Barrett (2018) show that family members and friends were particularly cited in the interviews as a resource to keep patients engaged in their treatments.

Third, other patients, or individuals with the same disease, can be a resource for patients. Indeed, other patients may be an important resource as, through their experiences, they understand similar issues as the patient. Therefore, their advice may be better accepted by the patients than if it had come from an expert such as a physician (Gross, 2018).

The involvement of patients in their care and consideration of a patient’s experience is of importance in improving the patient’s quality of life, co-construction of the course of treatment, and treatment observance. However, this requires an organisational innovation (Pauget, Dammak, 2017; Pauget, Wald, 2018) as it changes not only the relationships between patients and physicians but also the organisation of care and of healthcare pathways (Mol, 2008). Moreover, depending on the model of care, different tensions may arise.

**Patient’s Experiences in Different Organisations of Care**

Organisational innovations relate to changes in the way of performing, organising, and coordinating people and tasks. They impact, and are impacted by, structure, strategy, and administrative procedures (Damanpour, Aravind, 2012; Pauget, Wald, 2018). The implications of various actors leads to a reconsideration of the design of the processes and of coordination mechanisms (Hafkesbrink, Schroll, 2011). Implementing new organisations of care is difficult as it not only involves the relationship between patient and physicians, but all patients’ pathways within and across organisations (Pauget, 2013; Pauget, Wald, 2018).

This questions the roles that the various actors hold in the organisation of care (Jullien, Zimmermann, 2011). Indeed, Molleman and Van Knippenberg
(1995) describe organisations that are “product-oriented” (p. 797) where “hospitals usually create a depersonalizing environment in which patients learn that a passive role is most appropriate” (p. 797). Models such as medical paternalism or evidence-based medicine tend to favour patients’ passivity by basing care mainly on expert knowledge, and by undermining patients’ experience (Epstein, Street, 2011; Maynard, 1991). It is important to note that we do not deny that patients interact with their physicians or that they are an important source of information, but the decision on the course of treatment may, within certain models of care, be more in the hands of physicians than co-constructed with patients and other health professionals, or even with the patient’s family.

The literature describes other models of care which, to varying degrees, include the patient within co-construction of the course of treatment. Different models advocate patient involvement and consideration of patients’ experiences such as patient-centred care (Kitson et al., 2013). These models emerged in response to other models that tend to favour the authority of physicians and of medical evidence such as medical paternalism (Charles et al., 1999; Tanenbaum, 2015). Tanenbaum (2014) argues that, in certain models, the status of expert knowledge and evidence is deterministic, as they are based on medical aggregates and not on patients’ idiosyncratic experiences.

Consideration of patients’ experiences faces various challenges, especially when models that favour expert knowledge over patients’ experiences dominate. It is therefore important to describe how patients experience their disease to be able to design new forms of collaboration and of organisation (Burger-Helmchen et al., 2011; Grenier, Denis, 2017).

**Methodology**

**Research Context**

Diabetes is a chronic disease which has been increasing significantly over the past few decades, with 422 million individuals worldwide who currently live with diabetes, compared to 108 million in 1980 (World Health Organization, 2016). In 2015, 3.7 million individuals in France have had treatment for diabetes (Assurance Maladie, 2017). In this study we focus on the two main and permanent types of diabetes. Type 1 diabetes (T1D) is an autoimmune condition in which insulin-producing cells are destroyed, leading to a lack or absence of insulin production. 10% of individuals have this type of diabetes. In Type 2 diabetes (T2D), the body does not produce enough insulin, or the insulin production does not work effectively, leading
to the accumulation of glucose in the blood. 90% of people have this type of diabetes.

With the discovery of insulin in 1922, physicians working on the treatment of diabetes have been pioneers in involving patients in their care (Grimaldi, 2017). Starting from an authoritarian position on the part of health professionals, and a passive position on the part of patients, this changed in the 1970s towards a more humanist pedagogy and an active role by patients (Grimaldi, 2017). This has evolved towards a competence and management by objectives approach since the 2000s. Patient involvement relies on considering all patient aspects (biological, psychological and social) in order to help them – based on their beliefs, understanding of their disease, constraints, needs, and resources – to improve their knowledge, but also their quality of life (Golay et al., 2008).

Data Collection

Data collection encompassed two main steps. The first step of data collection consisted in interviewing 16 individuals with diabetes, both from a local network, and a university hospital. Some of the interviewees are T1D and others, the majority, T2D (see Table 1). Our data also consisted in interviewing six diabetologists, three nurses, a dietician, two expert patients and the coordinator of a local network. All the interviews were conducted between December 2016 and December 2018 and lasted from 20 to 110 minutes. Some health professionals were interviewed several times. The majority of interviews were recorded and taped. When they were not, extensive notes, even quotes, were taken during the interviews and were completed either the same day or, at the latest, the following day.

Second, this dataset was completed with documents from the World Health Organization, the French medical association, the patient association and the local network. This dataset has been enriched by several informal discussions with people with diabetes, diabetologists and nurses. The first round with individuals with diabetes provided knowledge about the daily practices of each individual, how they manage their disease and integrate it in their lives, the devices they use (glycaemia readers, pens, insulin pumps, and so on), as well as the interactions they have with the different actors, and what these actors bring in the management of their diabetes. Interviews with diabetologists and the coordinator of the local network provided information about their role in the treatment and management of diabetes, and how they perceive the roles of other actors.
Data analysis

To analyse this set of interviews, we followed an iterative process, going back and forth between the data, literature, and an emerging structure of theoretical arguments. We primarily focus on patients’ experiences with the disease as well as their relationships with family and friends, and health professionals, as well as with other patients. This led us to narrow our focus and to better consider the construction of patients’ experiences. We went back and forth to construct our analysis between the dataset and the literature to better understand patients’ experiences (Pickard, Rogers, 2012; Williams, Ryan, 2017).

Findings

Patients’ Experiences with Diabetes

Diabetes is a complex and evolving disease where the patient’s experience of the disease is of key importance to improve the quality of life, but also to slow down the evolution of the disease. Sensations and experience are also very important in order to avoid risk, such as hypoglycaemia. While in some rare cases in our study some patients do not feel hypoglycaemia, others do: “we feel it coming, we are sweaty and shaky” (Patient 14, T2D). To avoid this, individuals with diabetes have to control what they eat, their physical activity, and their level of stress. These different elements may have different impacts on the individual and the way she lives and experiences diabetes. For example, while some patients are “sad” and “feel restricted” (Patient 1, T2D), or even “punished” (Patient 6, T2D), some explain that diabetes is more

<table>
<thead>
<tr>
<th>Reference</th>
<th>Type of diabetes</th>
<th>Length of interview</th>
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<tbody>
<tr>
<td>Local network</td>
<td></td>
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</tr>
<tr>
<td>Patient 1</td>
<td>T2D</td>
<td>0h45</td>
</tr>
<tr>
<td>Patient 2</td>
<td>T1D</td>
<td>1h50</td>
</tr>
<tr>
<td>Patient 3</td>
<td>T2D</td>
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<td>Patient 4</td>
<td>T1D</td>
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<tr>
<td>Patient 5</td>
<td>T1D</td>
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<tr>
<td>Patient 6</td>
<td>T2D</td>
<td>0h35</td>
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<td>Hospital</td>
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<tr>
<td>Patient 7</td>
<td>T2D</td>
<td>0h40</td>
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<tr>
<td>Patient 8</td>
<td>T2D</td>
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<td>Patient 9</td>
<td>T2D</td>
<td>0h20</td>
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<td>Patient 10</td>
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<td>Patient 11</td>
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<td>Patient 12</td>
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<tr>
<td>Patient 13</td>
<td>T2D</td>
<td>0h35</td>
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<tr>
<td>Patient 14</td>
<td>T2D</td>
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<tr>
<td>Patient 15</td>
<td>T2D</td>
<td>0h35</td>
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<tr>
<td>Patient 16</td>
<td>T2D</td>
<td>0h25</td>
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</tbody>
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accepted in their lives; one interviewee explained that he takes his treatment in the morning and in the evening and “the rest of the day I am like anyone else” (Patient 9, T2D). This must be nuanced with the evolution of the disease and the different types of treatment that can be more constraining, such as insulin injections. These treatments and constraints also affect the person’s social life.

Diabetes has consequences for the patients’ social lives in relation to their family and friends. A patient explains that other people “think for us” (Patient 2, T1D) in terms of what they can eat. For example, a host who prepares a specific dessert for the diabetic person, without asking or considering whether the person with diabetes could have eaten the dessert. Diabetes can also force itself into a couple’s life:

“[My partner] used to be embarrassed to be able to eat something sweet next to someone for whom sugar is completely forbidden. Yes, you are embarrassed but I had to say, shit, don’t worry, I am used to it. She doesn’t do it anymore but at the beginning of our relationship she was saying I can’t eat something like that. I can’t say that’s a nice cake whereas you’re just nearby and can’t eat it.” (Patient 4, T1D)

Moreover, considering the patient’s experience also leads one to understand the autonomy of the person with diabetes. Indeed, while some patients describe their daily lives as very independent in the way they manage their meals, what they eat, how much, and when; others are more dependent on their partner. For example, a patient explains that he is dependent on his wife for meals, therefore, when she is not home, it is easier from him to order a pizza. His wife and daughter also help him to control his glycaemia. The way diabetes impacts both the person who has diabetes and the partner is well illustrated by a wife, whose husband has diabetes, talking about the diabetologist: “that’s him, who is taking care of us for the diabetes” (Patient 12, T2D, emphasis added). This “us” illustrates that diabetes and the way it is lived by individuals has an impact on the social relationships, in particular with the patient’s partner and children. The different experiences with the disease and relationships with family and friends may affect relationships with health professionals.

**Relationships with Health Professionals**

Individuals with diabetes encounter various health professionals, such as general practitioners, diabetologists, nurses, and dieticians. Various organisations of care co-exist and some professionals may be resistant, more by
training, to involve the patient in their course of treatment, including their experiences: “I think that there is a defensive position from the medical profession. […] We are in a system more of prescribers than a person accompanying another one.” (diabetologist 1)

General practitioners are central actors in the treatment of diabetes as the large majority of individuals with diabetes are affected by T2D which in most cases requires oral drugs and a regular surveillance evolution. General practitioners provide patients with mainly medical knowledge and advice about how to manage diabetes in terms of diet and physical activity. Next, diabetologists essentially treat individuals affected by T1D and T2D for whom the disease is more advanced. This requires more thorough knowledge about the treatment that patients require in relation to their jobs and physical activities, as well as the types of device that they might need. Although central in terms of medical knowledge, diabetologists are assisted by other health professionals.

Outside hospitals, nurses play an important role in the management of diabetes. First, for some patients, nurses are the actors that they meet with regularly. For those who have recently needed insulin injections or those who cannot inject insulin themselves, district nurses come every day, sometimes several times a day, to inject insulin, as a patient describes: “The nurse comes to do the injections twice a day, before, three times a day. She controls the glycaemia, in the morning before lunch and in the evening before dinner. She also does the calculation of the doses.” (Patient 12, T2D) Within the hospital, some nurses are in charge of patient education. They meet with the patient to understand their life projects and to find solutions to deal with diabetes while not jeopardising their projects. They also train patients to use the different instruments such as pens, readers, and pumps and help them to choose the one that best fits their constraints and lifestyle.

Psychologists may also be present, for example for recently diagnosed individuals, as the first step to accepting living with diabetes is to “mourn over good health” (coordinator of the local network). In the same way as mourning a close family member or friend, individuals with diabetes must realize that they will never be in good health again and, therefore, they must learn to live with their disease. This is particularly illustrative of the necessary consideration that individuals with diabetes must have toward their disease. An important step when considering individuals with diabetes is that accepting the chronic disease is often difficult: “accepting is something very difficult, most people are in denial. For them, it is a failure. Having diabetes would be nothing but having to cure themselves it’s terrible.” (coordinator of the network) This is shared by diabetologists who argue that they have to get patient’s adhesion
to get results. Unlike an acute disease, where a patient can be passive and not involved in the treatment and still get better, here daily treatment is required. For example, an individual with T1D eats every day at the same hour, measures his portions, knows the equivalent, injects insulin daily, and checks glycaemia regularly:

“Sorry for the expression but that’s a pain in the arse. You spend your life controlling your glycaemia, injecting insulin, looking at the time you ate, what you ate, what you’re going to do during the day, if it’s not too late, if it’s not too cold, if it’s not too warm, if you don’t have something unexpected. That’s the everyday life of diabetics.” (Patient 4, T1D)

For health professionals, adhesion is crucial and is emphasised by different professionals and diabetics themselves. This implies considering diabetics as people and not patients – as it impacts the next stages of the treatment. A general instance echoed by the coordinator of the local network and diabetologists is that general practitioners are the first health professionals that people with diabetes meet. However, diabetes is one disease among many that general practitioners treat, but they are not always appropriately trained to manage the relationship with the patient, especially concerning how to announce the diagnosis. Therefore, they sometimes announce T2D as ‘light diabetes’ which may lead people to not consider their disease seriously. This lack of training from general practitioners is also felt by individuals who have been diabetic for a long time: “The general practitioner, you see him 20 minutes, twice a year […] If you don’t tell him exactly what you need and if you’re not well… You really have to tell him the symptoms.” (Patient 5, T1D) For general practitioners, care practices are perceived as mainly based on expert knowledge through lack of training regarding chronic diseases. Moreover, the time spent with general practitioners is rather short and a lot of information must be transmitted, as one interviewee puts it: “the problem is, he speaks so fast. He overwhelms me with information. But sometimes, I don’t dare to ask him to repeat.” (Patient 14, T2D)

In addition, diabetologists’ practices have drastically evolved in the past decades, especially regarding the consideration of patients as individuals and not only as an object of care. They must endorse a particular role: “we must help the patient to live with her disease while keeping the best overall health” (diabetologist 4). This was illustrated by several people who have been diabetic for a long time and have therefore witnessed the evolution of the caring system. The consequences of bad management were emphasised, such as showing images of individuals who have had a foot or a leg amputated. Even in the daily practice of checking glycaemia bad consequences were clearly stated: “They tell you directly, when you do your glycaemia, you don’t use the thumb or...”
index finger. Ok, why? In case of blindness because you know, a lot of diabetics become blind.” (Patient 2, T1D) This illustrates the change with today’s practices where knowledge, even medical, has a different status:

“The health professional has knowledge of the disease but the patient is not only a patient. She has her experiential knowledge, as we say now in therapeutic education. She has her own knowledge, her own expertise of her life with the disease while the health professional, the doctor especially, has an expertise of the disease, scientific knowledge. That’s the confrontation of the two types of expertise.” (diabetologist 1)

This confrontation, and consideration of the patient first as a person, enables the translation of expert knowledge into practice for individuals with diabetes. This approach to patients appeared to be helpful with recently-diagnosed individuals. This was illustrated by the dietician who explained that “I always start with the patient” (dietician). However, even though increasing a patient’s adhesion to the management of the disease, individuals who have had diabetes for a long time have the expert knowledge they need, mostly about their own type of diabetes, and therefore tend to see consultation as not very useful in terms of living with diabetes: “Some of the diabetologists are younger than me, they told me: you know better than us. Do you realise psychologically how it is?” (Patient 4, T1D)

Among health professionals, nurses are very present for patients. Their role is not to transmit expert knowledge but to provide patients with practical knowledge. This translation of expert knowledge – how to prick – is made possible by spending time with a patient: “This was the most horrible adventure of my life, I had to prick myself. I swear, to me, it was horrible. Thank God, I had a nurse who showed diplomacy, psychology, patience, kindness and all that. She stayed for 45 minutes beside me before I pricked myself.” (Patient 6, T2D) This is more difficult to attain from either general practitioners or diabetologists as in the current organisation of care, medical encounters tend to be more limited in time.

**Relationships with Other Patients**

Experience is provided by other individuals with diabetes and cannot be provided by other actors. This can, for example, be experiences regarding meals, how to manage diabetes during celebrations, while travelling, the role of relatives, etc. This sharing is of importance for people with diabetes, as beyond the oral drugs or insulin injections and checking glycaemia, it is the impact on personal and intimate aspects of life, such as food, habits, and
social life, that may make diabetes more difficult to manage. Indeed, living with diabetes is different than knowing about the disease. For example, as the coordinator of the local network, who is not diabetic, talking about hypoglycaemia put it: “we can’t explain what it is, we don’t know. I know that it exists but I don’t know what it is”.

During their pathways, patients may also meet expert patients who are either individuals who are diabetic, or who have been meeting with diabetics for a long time. They facilitate discussion groups in order to improve the sharing of experience. This enables people with diabetes to feel that they are not alone and, therefore, they learn how to better manage their disease from others’ experiences: “I’m going all the time because if I feel low, it helps to buck me up. You must always be full of energy, going out to walk two or three kilometres. That’s what puts fuel in the engine.” (Patient 5, T1D)

Discussion

Based on our qualitative research, we describe how individuals with diabetes live with their disease, also in relation to their family and friends, health professionals, and other individuals with diabetes. This allows us to have a better understanding of patients’ experiences and what are the impacts on the design of new forms of collaboration and of organisation (Grenier, Denis, 2017; Hafkesbrink, Schroll, 2011; Jullien, Zimmermann, 2011). This study aims to make two contributions: 1) to provide an empirical description of the experience of people with diabetes, and 2) to describe the extent to which a patient’s experience presents a strong interest for the design of new forms of collaborations and of organisation.

First, we provide an empirical description of patients’ experiences with a chronic disease, diabetes, and the different elements that this involves. Care in chronic diseases greatly benefits from involving patients in the decision on the course of treatment, which implies different elements, such as her own experience, relationships with family and friends, as well as with health professionals and other patients. These new forms of collaboration (Pauget, Dammak, 2017; Pauget, Wald, 2018) in the construction of care challenge the ‘traditional’ boundaries of care by fostering new types of collaboration and organisation, especially healthcare pathways (Pauget, 2013; Pénin et al., 2011), although this has evolved over the past decades. Beyond the new postures that healthcare professionals must adopt – as described in the medical literature (Tanenbaum, 2015; Wyer et al., 2014) – the consideration of patients’ experiences presents an important challenge for the organisation of care in chronic diseases. Indeed, we saw that patients can have very different
levels of acceptance of the disease, which can be an important element in the decision about the course of treatment. Moreover, this may involve the patient's partner and/or children, as they too are impacted by the disease and the related constraints, but most of all, because they are – or at least can be – a resource in terms of observance and control.

This specific construction of the experience of care stretches the boundaries of how care (Burger-Helmchen et al., 2011; Mørk et al., 2012) is considered in studies dealing with management and innovation in healthcare. Indeed, care cannot be reduced to a distribution of expert knowledge from health professionals to patients, as a patient's experience is of core importance in the management of chronic diseases. Furthermore, care in chronic diseases occurs in different places where not only expert knowledge matters. This new form of collaboration, which places patients at the centre, is made possible by the consideration, although challenged, of experience as a source of information which is complementary to expert knowledge. Therefore, collaborations (Grenier, Denis, 2017; Pauget, Dammak, 2017) for a greater implementation of innovation should go beyond communities of practice and professionals (Mørk et al., 2010; Touati et al., 2016) to be extended to actors who have been identified through patients' pathways. Adopting a patient-care perspective in our studies may bring new insights on how innovative practices, and therefore innovative forms of organisations (Pauget, Wald, 2018; Pénin et al., 2011), may be implemented, and whether innovations are technology-based (Mørk et al., 2010), process-based (Sørensen, Torfing, 2011), or are organisational arrangements (Reay et al., 2017).

Second, patients' experiences present a strong interest for the design of new forms of collaborations and organisation. There should be better consideration of different types of knowledge and practices in the design of new forms of organisations of care, in order to develop innovative practices. Care may differ from one person to another as one person does not necessarily have the same values and lifestyles (Golay et al., 2008). Therefore, forms of collaboration which imply that physicians have the knowledge about the treatment, and that patients must follow these recommendations, may be limited to understanding chronic diseases. Indeed, adhesion may take time but it also differs from one patient to another, especially as the disease evolves and patients learn more and more about how to manage their disease. Therefore, their relationships with the different actors change along with their need for support.

Greater autonomy enabled by patients’ experiences and practices also improves care, as individuals with diabetes become less and less dependent on other actors. Evolution of the diabetics' understanding of their own disease
and, most of all, their bodies and lives, changes relationships with the different actors as time spent with the different actors may decrease over time. Innovative practices, whether they are situated within a defined space (Reay et al., 2017), an initiative (Touati et al., 2016), or challenged by technologies (Nicolini, 2006, 2007), should be open to better consideration of patients’ experience and their environment, in order to improve their adaptation and appropriation. This is of particular importance with the increase of chronic diseases such as diabetes, which represents a challenge for healthcare and its organisation.

**Managerial Implications**

Focusing on patients’ experiences challenges the boundaries of healthcare organisations and calls for a new organisation and processes of care and, therefore, of managerial work (Damanpour, Aravind, 2012; Hafkesbrink, Schroll, 2011; Pénin et al., 2011). We move from a system where physicians are at the centre of care to new forms of relationships where the complementarity of different actors – patients, physicians, and nurses – must be considered and organised. Organisational innovations have an impact on structure and processes. Managers must, therefore, focus on how patients can be integrated at the different stages of their healthcare pathways, and how processes are flexible enough to be adapted to the needs of the different patients and to the inclusion of other actors such as the patients’ family and friends. If healthcare organisations are already flexible and can adapt to patients’ needs to a certain extent, Reay et al. describes certain conditions that can be mobilised and adapted in order to create spaces where learning can occur: assembling the right people, developing positive social relationships, focusing the conversation, and managing setbacks and frustrations (2017, p. 82). Although this study has focused on professionals, this can be extended to collaboration between different actors of care involved in the patient’s pathway. This questions the specific spatial arrangements (Reay et al., 2017) and processes (Grenier, Denis, 2017) that favour the involvement, not only of patients but also, when required and/or possible, their families and friends (Berwick, 2009), as well as the healthcare team, and even, when needed, social workers (Bjornsdottir, 2018). This requires a reconceptualisation of organisational processes (Pauget, Wald, 2018) towards more organic forms of collaboration (Pauget, Dammak, 2017; Pénin et al., 2011).

Another managerial implication of this study is in the design of the processes related to patients’ pathways. If processes must be open enough to include different types of actors, they must also be flexible enough to adapt to the patient and the stage of the disease. Indeed, one aspect of adhesion
to manage the disease is time. From our observation, with the only diabetic who accepted her diabetes rather easily, at least in her discourse, this was due to the fact that her mother was diabetic and therefore she already knew what the consequences of the disease were. The others, even one who had had diabetes for 25 years, still felt different emotions, such as anger or sadness, regarding diabetes. As emphasised by different doctors, acceptance and adhesion takes time. While some programmes enable health professionals to spend more time with patients regarding their needs, complementary spaces may be considered in order to adapt to the way patients manage their disease.

**Limitations and Further Research**

We identified two main limitations to our study. First, we focused on diabetes, which implies specific patients’ experiences as well as specific health professionals. Considering the increase in chronic diseases (Pauget, 2013), it would be interesting to research patients’ experiences in other chronic diseases in order to highlight other forms of collaboration and organisation.

Second, the focus of this study was patients’ experiences with diabetes. Therefore, we did not study particular spaces where experiments of new forms of collaboration and of organisation are taking place. Moreover, if the changes in the relationships between patients and physicians are well documented (Greenhalgh et al., 2015; Tanenbaum, 2015), how to include patients is still overlooked. The medical literature describes evaluation tools (Cox et al., 2014; Fiallo-Scharer et al., 2017) that include not only medical items but also others that enable the evaluation of the healthcare team, family, and interactions with other patients. Further research could look at spaces that experiment with the strong integration of patients into their care.

**REFERENCES**


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