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# The management of patient pathway in Onco-senology: an exploratory approach based on the shared experience of the disease on social media

*La gestion des parcours patients en Onco-sénologie :  
une approche exploratoire à partir de l'expérience partagée  
de la maladie sur les médias sociaux*

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## ABSTRACT

In a context where cancer is the leading cause of death in France, there is a real interest in identifying the perception that patients have of their care path in order to improve the perceived quality of their experience. It could ultimately help to act positively on the acceptance by the patient of a difficult situation to live and now considered as chronic. Based on an analysis of 956 speeches of breast cancer patients posted on a discussion forum, the aim of this research is to reconstruct the path experienced by patients in their experience of the disease. This

contribution explores the three key stages in the pathway of these patients. It highlights a myriad of critical touch points leading to an alteration in the perception of care on which the institutions need to pay special attention. This research also highlights two important extra-pathway stages: the pre-pathway stage and the post-pathway stage.

## Key-words

*Patient experience; Patient pathway; Health management; onco-senology; content analysis*

## RÉSUMÉ

Dans un contexte où le cancer constitue la première cause de mortalité en France, il y a un véritable intérêt à identifier la perception que les patients ont de leur parcours de soin afin d'améliorer la qualité perçue de leur expérience et finalement agir positive-

ment sur l'acceptation d'une situation difficile à vivre et désormais abordée comme chronique. À partir d'une analyse de 956 discours de patientes atteintes de cancer du sein postés sur un forum de discussion, l'objectif de cette recherche est de reconstituer le parcours vécu par les patientes dans leur expérience de la maladie. Ce travail explore les trois étapes clés du

<sup>1</sup> CR and EC were responsible for writing the article, defining the research design and conducting the literature review, EM collected the data. The 3 authors analyzed and interpreted the data. CR managed the revision process.

parcours de ces patientes, étape de découverte, étape d'examen et étape de suivi et de contrôle, et met en évidence des points de contact critiques qui sont source d'une altération de la perception de la prise en charge et auxquels les institutions de santé doivent porter une attention particulière. Cette recherche met également en évidence deux importantes étapes extra-parcours :

l'étape pré-parcours et l'étape post-parcours.

## Mots-clés

*Expérience expérience patient ; Parcours patient ; Management de la santé ; Onco-sénologie ; Analyse de contenu*

## 1. INTRODUCTION

The management of healthcare institutions is undergoing major changes. These are linked to the emergence of an increasingly competitive environment in which institutions operate. To this must be added the need to respond to patients who are increasingly demanding in terms of their cost and to involve them in the action (Sharma and Conduit, 2016). Understanding the patient's behavior and expectations is necessary for the proposal of an effective, differentiating and satisfactory charge price. It constitutes a lever for improving public action carried out within the framework of health policies. It is part of the movement that began in the 1990s to increase the participation of users and patients in the health system (Bréchat *et al.*, 2006). If this participation is acquired on the political level, it remains to be developed on the medical level (prevention, care). Indeed, to date, patient care is part of a care path dictated by the nursing staff (Berry and Bendapudi, 2007; Holman and Lorig, 2000), even if the patient is, it seems, increasingly eager to take part in defining their own path (Hibbard *et al.*, 2007; Sharma and Conduit, 2016).

The care pathway is defined by the Haute Autorité de Santé as “the right sequence and at the right time of the various professional skills directly or indirectly linked to care: consultations, technical or biological acts, medicinal and non-medicinal treatments, management of episodes. acute (decompensation, exacerbation) and other forms of care (notably medico-social, but also social)” (HAS, 2012). It refers to the stages of the health pathway focused on disease

management actions. The work relating to the care pathway deals with the role of staff and that of the patient. The role of health personnel is approached from their actions. The work studies the obligations of staff in relation to care itineraries and trajectories (Balogh *et al.*, 2011; Okun *et al.*, 2014; Weldon *et al.*, 2012; Riou and Jarno, 2000) and their contribution to improving processes care (Taplin *et al.*, 2015; Trosman *et al.*, 2016). Research on the role of patients mainly concerns their participation in the therapeutic process and decision (Batifoullier *et al.*, 2008; Ferdjaoui *et al.*, 1999). They are part of a medical approach focused on pathology. The medical pathway approach is insufficient to understand the care experiences of patients and their expectations. Thus, the purely medical care path is distinguished from the patient path. The second, unlike the first, includes the patient's representations of his care and the experience he gets from it.

To date, research on the patient pathway does not provide an in-depth understanding of the entire care experience, nor to identify the critical elements experienced by patients. However, these constitute points of attention for health professionals. The rare works which have been interested in the patient's pathway have mainly focused on the psychological effects of a diagnosis (such as that of cancer in patients with breast cancer), on the management choices or also on the quality of life (Bonnaud-Antignac *et al.*, 2015; Bourdon *et al.*, 2016; Bonnaud-Antignac and Bourdon, 2017). Although these shed light on the behavior of patients from a psychological perspective, they do not make it possible to approach the patient pathway as a whole or to identify their needs at each stage

of the pathway. The global approach to the patient is, however, one of the recommendations of the 2009-2013 cancer plan: "to make patients actors of care in the full sense" (Grünfeld, 2009, p.35). It involves a good knowledge of how the patient experiences their care pathway in order to identify the levers for increased and improved patient participation. This work is based on the observation of a lack of research on how patients experience their pathway. It is essential to understand the perception that patients have of prescribed care paths, the way they experience them and influence them in order to develop congruent and more personalized care systems. Also, the objective of this research is the springs of the patient experience and how it is constructed.

Taking an interest in the lived experience of the routes potentially constitutes an important theoretical contribution since the routes are still under-explored. The approach usually adopted in studies and research integrates little or no (Arnaud *et al.*, 2016) the representations that patients have of this oriented care and the experiential dimension. This is however essential to decide on the best possible allocation of resources to care. To fill this gap, we are focusing on the cognitive, social, emotional and behavioral dimensions of the experience associated with the care pathway as well as on the touch points. This will make it possible to identify the points perceived as sensitive, particularly critical and potentially generating a negatively perceived experience (sources of fear, discomfort, anxieties and stress) (Duboc, 2012). Touchpoints represent all the interactions that the individual has or could have with the organization at each stage of the pathway (Homburg *et al.*, 2015; Schmitt, 2003; Lemon and Verhoef, 2016). It is on this multitude of touch points that the patient experience is built and developed. Although the patient experience is particular, it can be approached by drawing on the work developed in the field of management and marketing of services which focuses on the experience and the customer journey (Edelman and Singer, 2015; Pucinelli *et al.*, 2009; Schmitt, 1999; Verhoef *et al.*, 2009).

The advantage of an approach centered on the perception and expectations of the patient is to provide decision-making support to health professionals and managers of medical institutions. The pathway and its coordination as well as the increased participation of the patient are a subject of major interest (Bloch and Henaut, 2014) as evidenced by the many texts and documents from the health authorities (Ministry of Solidarity and Health, Regional Agencies of Health, Haute Autorité de Santé). In this context, it is a question of providing avenues for (re) thinking about adapting the care pathways and developing care processes more appropriate to the needs and expectations of patients. To do this, we are studying the case of patients with breast cancer. This type of cancer is systematically screened in France. It is one of the three most common types of cancer. The care and treatment of cancer is a national priority and a major public health issue. This disease, which presents a form of chronicization, induces a long process of care and provides the opportunity to fully study the patient pathway. The experience and the pathway lived are treated in this research from the accounts on the specialized forums of patients suffering from breast cancer<sup>1</sup>. These patients are particularly committed to sharing their experience, as shown by initiatives and studies.

In the first part, we present the theoretical framework used, which is that of the customer experience. The second sets out the methodological elements. In a third part, we present and discuss the results of the analysis of the 956 speeches collected from patients before concluding on the interest of this research and the avenues of action identified.

<sup>1</sup> We will deal with women, although breast cancer can rarely affect men.

## 2. THEORETICAL FRAMEWORK:

### The patient experience: a transposition of the framework of the customer experience

The patient experience is increasingly attracting the attention of researchers in health (Allen, 2015; Berwick *et al.*, 2008; Chhor and Mercado, 2016) and management (McColl-Kennedy *et al.*, 2012). The experience of the individual has long been discussed in the marketplace (Hirschman and Holbrook, 1982; Holbrook and Hirschman, 1982; Holbrook, 2006; Lemon and Verhoef, 2016). Understanding it is a central axis for organizations wishing to strengthen customer satisfaction. The customer experience covers the transactional exchange of products and services between the customer and the organization, but also refers to a multidimensional construct comprising cognitive, emotional, behavioral, and social aspects (Gentile, Spiller and Noci, 2007; Meyer and Schwager, 2007; Pine and Gilmore, 1998; Schmitt, 1999, 2003; Verhoef *et al.*, 2009). The health literature has shown that engaging patients in the care process helps improve their experience (Dentzer, 2013; Gruman, 2013; Okun *et al.*, 2014). In the commercial world, studies show that the behavioral dimension of the experience is inseparable from the active participation of the customer in the provision of services (Eiglier and Langeard, 1994; Eiglier *et al.*, 1997; Hibbard *et al.*, 2007; Sharma and Conduit, 2016). In the world of health, the patient also becomes progressively more active (Naja, 2009). For the "Montreal model" (Pomey *et al.*, 2015), he has a certain "expertise" due to his experiential knowledge of the disease (Pomey *et al.*, 2015). They are also "active" in their ability to change their care pathway (Batifoulier *et al.*, 2008). This approach of the patient actor (patient partner) is widely promoted in North America, in particular in Canada in the work of public health and health management, but it is little discussed in France. Patient engagement involves re-examining the traditional relational model between doctor and patient and requires a necessary adaptation of the practices of healthcare professionals (Balogh *et al.*, 2011).

In the merchant world, the relationships that the customer develops with other customers have a

strong social dimension and contribute to the service experience (Carù and Cova, 2003; Capelli and Sabadie, 2007). In the medical world, some reflections are emerging in France around the sharing of patient experience (Akrich and Méadel, 2009), the "expert" patient (Chauvin, 2013; Gross, 2014) or patient communities (Kivits *et al.*, 2010; Silber, 2009). They gradually make it possible to better decode the way in which patients experience their pathway. Building the most positive experience possible is an indisputable marker of "living better with the disease". Experience and emotion are inseparable.

The emotional dimension has been addressed in the psychology work on the acceptance of illness, although the latter have not conceptualized it from a purely experiential angle. Thus, it has been demonstrated by Bourdon *et al.* (2016) that breast cancer patients recognize an altered quality of life following diagnosis, but this could be improved over time with emotional (psychological and personal) support. The authors show that the trying experience, directly linked to heavy and painful treatments, can modify the choice of some patients, for example in the case of outpatient surgery. Reducing the time spent in the hospital, thanks to an adaptation of the treatment protocols, "positively" modifies the perception of the disease but implies good preparation of the patient and his strong involvement (Bonnaud-Antignac *et al.*, 2015; Bourdon *et al.*, 2016; Bonnaud-Antignac and Bourdon, 2017). This work allows us to understand the key role of the spatio-temporal dimension of the experience in the patient pathway, in particular for chronic diseases for which the management is spread over a long time.

In the medical world, experiential analysis of the patient pathway is emerging. On the other hand, in the commercial universe, it has given rise to a rich and dense stream of research since the end of the 1990s (Pine and Gilmore, 1998; Schmitt, 1999). In the early 2000s, this movement focused on the experience that the customer gets from his journey (Pucinelli *et al.*, 2009; Verhoef *et al.*, 2009; Edelman and Singer, 2015) around the three key stages (pre-purchase, purchase, post-purchase). More specifically, it explores the interactions that can exist between customers and the company in a servuction system



(Lemon and Verhoef, 2016; Eiglier and Langeard, 1987). Each touch point with staff, other customers, physical support gives rise to a more or less positively perceived experience (Gronroos, 1990; Stein and Ramaseshan, 2016). The customer experience is built through four main categories of touchpoints (Edelman and Singer, 2015):

- those linked to the brand, these are naturally the product, service, advertising, etc.,
- those related to partners, these are interactions with the customer controlled by the organization (for example resellers),
- those related to the customer himself, the co-creation of value falls under this category,
- external, social ones refer to the influence (requested or experienced) exerted by other customers and peers at each stage (pre-purchase, purchase, post-purchase) of the experience<sup>2</sup>.

As highlighted by the results of the work, the identification and modeling of the steps followed by consumers and the determination of critical touch points in the customer journey allow the development of an offer more suited to customer expectations (Trénival, 2013).

The touch points between the patient and the medical servuction system are numerous and varied and constitute critical elements on the basis of which part of the quality of care is built. Research by Vennik *et al.* (2016) in the Netherlands, those of Côté *et al.* (2017), Carman *et al.* (2013) or also by Pomey *et al.* (2015) in Canada show the variety of touch points with medical personnel, caregivers, other patients, information and technical supports that can be modeled as a continuum. The patient experience can be seen as relating only to the care experienced as a medical technique, but this would ignore how the peripheral services offered in hospitals can help to change the perception of the medical experience.

Services such as socio-aesthetics, artistic expression workshops that enrich the service offer of hospitals are akin to hedonistic "consumption" by the patient. They clearly contribute, through specific touch points, to transforming the experience.

Our research falls within this perspective, it focuses on understanding the patient pathway, identifying its stages and the various touch points on which the patient experience is built.

The objective of this research is to model the pathway of patients taking into account their lived experience of the disease. From there it is a question of identifying the way in which the care is experienced, that is to say the care service and finally to assess the capacity of the health services to best fulfill their mission towards users.

### 3. METHODOLOGY

To meet the research objectives, we referred to a specialized forum for patients with breast cancer. The topic of the Internet and health has been a subject of attention and concern for several years now. The work carried out on this topic mainly deals with the information made available to patients. The wealth of information and the lack of control over content is a concern of professionals (Eysenbach *et al.*, 2002). However, the Internet has helped to develop a "public health space" (Akrich and Méadel, 2009), of exchanges and debates, freely open and widely visited. It is a source of rich material for the researcher interested in patient behavior.

#### 3.1. Data collection

"Les Impatientes"<sup>3</sup> is the reference forum for all patients who are looking for support and who wish to be informed and have feedback from other patients who have had similar experiences. The choice of this

<sup>2</sup> For more details, see the article of Edelman, D. C. & Singer, M. (2015). "Competing on customer journeys", *Harvard Business Review*, 93 (11), pp. 88-100.

<sup>3</sup> [URL: <http://www.lesimpatientes.com/>], as this blurb says, this is "the premier network of women with breast cancer. For those who no longer want to undergo medicine by being simple patients, for those who want to take charge of their health, for those who think that life does not wait: it is here and now".

discussion forum is motivated by the very nature of the subject. This is very sensitive to discuss in individual interviews. In addition, the anonymity of the patients (guaranteed by the forum) allows participants to comfort and gain confidence without the discomfort caused by a face-to-face interview. The forum provides access to the various testimonials of patients, their experiences and their pathway, without having to travel. The forum has 10,634 members (May 2018). The 45-55 age group is the most represented (32%). Next come those of 55-65 (29%), 35-45 (18%) and 65 and over (15%). The under 35 category is the least represented (6%)<sup>4</sup>. This representation is consistent with the latest statistics published by the League against Cancer showing that 75% of breast cancers occur after 50 years<sup>5</sup>. The forum does not publish statistics on the geographical residence of the patients, but an in-depth analysis of the profiles of those registered reveals an over-representativeness of French cities.

We have chosen to analyze the comments posted over a period of one year (July 15, 2015 - July 15, 2016). A total of 956 comments<sup>6</sup> from 221 patients were collected.

### 3.2. Data analysis

A thematic content analysis was performed. This followed two stages.

The first consisted of vertical and horizontal treatment to identify the general structure of the patient pathway. Vertical processing updates what is said by the same person for each of the stages of the path followed. The horizontal one shows how each step is experienced by all people. At the end of this double treatment we identified isolated comments that did not allow us to follow the pathway and the experience over time. These were not subsequently exploited because they referred to patient "observers" (18 out of 221) who intervened in a very ad hoc manner on the forum.

The second step was that of coding the data around the three main stages of the pathway (before treatment, treatment, post-treatment) and the critical touch points that we were able to identify in the speech of the 203 patients (221-18). The content analysis also revealed a pre- pathway phase, before the onset of the disease, and a post- pathway phase, after the end of follow-up and checks. The content analysis is also based on the four dimensions of the experience:

- the cognitive dimension (for example knowledge is approached from "I know" and non-knowledge from "I don't know"),
- the emotional dimension (controlled / rationalized, uncontrolled reactions),
- the social dimension (engagement in the forum and relationship to others),
- the behavioral dimension (for example "I changed hospitals").

## 4. RESULTS AND DISCUSSION

The different pathways are built on the basis of the stages followed and the places frequented by the patients before, during and after the treatments. The pathways necessarily have a medical angle but are mainly approached from the patient experience lived throughout the care process. Patient psychology plays an important role in how they experience their situation and cope with the disease. The content analyzes carried out make it possible to identify the elements sought by patients in medical support. They can be seen as critical touch points in the pathway of these patients.

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<sup>4</sup> [URL: <http://www.lesimpatientes.com/membersearch.asp>] (20 May 2018).

<sup>5</sup> [URL: <https://www.ligue-cancer.net/localisation/sein/>] (30 March 2020).

<sup>6</sup> A posted comment has an average of 50 words. For each impatient, the number of comments posted varies greatly from 1 to 16 depending on the person for the period studied.

## The stages of the pathway experience

The experience of the medical pathway as it is presented through the discourse of patients can be schematized around three stages (1. Discovery of the disease, 2. Examination, confirmation of the diagnosis and treatment, 3. Follow-up and control). These steps, presented in Figure 1, are modeled on those of the customer experience process (pre-purchase, purchase, post-purchase) (Lemon and Verohéf, 2016). The modeling of the patient pathway results from a prescribed treatment path. It is understood according to the different phases of anxiety experienced by patients during their experience of the disease. These phases constitute here critical touch points that health-care institutions must take into account for better patient care.

**1. The discovery stage** turns out to be a particularly sensitive phase in terms of the patient / doctor relationship. The discovery constitutes a first phase of concern (fig. 1). The incomprehension of what the disease can be on the one hand and on the other hand the relational difficulties with the doctors which some report constitute sensitive points and this especially since the first interlocutor is the general practitioner or specialist.

*“On September 5 a biopsy, on the 10th the lab sends the results to the radiologist, on the 17th having no news, I called the radiologist's office the secretary told me there was a quack with the mail we are sending it to you today, in fact they had not sent anything. I call my GP, he asks for a copy of the lab report.... The next day I receive the letter from the radiologist who puts in ‘questionable cells’ and ‘I insist that you contact your doctor’. I call my doctor back, it's September 18th and he's telling me it's cancer. No good phone! It's Friday, the weekend is going to be awesome. On Monday he receives me, just tells me carcinoma, no more details.” (Ancolie).*

*“I see a pitt bull tumbling down bearing the name of a radiologist who yells at me, telling me that a breast like that was not normal etc. etc. he echoes me and text me*

*madam, you have breast cancer, the sky is falling on my head.” (Arum).*

All adopt the same attitude of shock and incomprehension followed by an intensive request for information on the various treatments, the meaning of medical terms or even the cure rates. Patients use the discussion forum in this discovery phase to find the information they lack and supplement the explanations provided by the medical world which they believe to be insufficient. They want to feel supported and especially reassured by patients who have had similar experiences.

*“I have the impression of arriving on a path where a lot of women may be walking at different stages, but I am not the only one on the road.” (Bleuet).*

*“If I can have opinions on people who are in the same case.” (Capucine).*

These results converge with those of research on the announcement of the diagnosis. All of them underline the state of shock of the patients and the importance of this act, which must seal the pact of confidence between the doctor and the patient (Reich *et al.*, 2008). The announcement of the diagnosis leads to a whole series of psychological reactions in the patient (Baillet and Pélicier, 1998) also, it must be prepared and adapted to each patient. Studies highlight the educational dimension of the advertisement (Reich *et al.*, 2008) for certain chronic diseases such as diabetes. This educational dimension was not reflected in our results, probably because the patient is relatively powerless in the face of the evolution of the disease, cancer, over which he has no control. The cognitive dimension of the announcement has also been addressed in research by highlighting the need (Legrand and Reich, 2003) to provide information on medical decisions based on the patient's representations of his disease and treatments, all by focusing on developing desirable attitudes and appropriate behavior in the patient.

**2. The examination and treatment stage** gives rise to questions about the types of examinations and the results, as well as the treatments and their effects. The exchanges are of more technical content on:



- **The nature of the examinations and the interpretation of the results** (many are those who provide explanations on figures, rates, etc.).

*“Anatomical pathology, also called pathological anatomy, is the medical discipline that is part of the study of disease. It studies damage and structural changes to organs and tissues caused by disease (disease reaction).” (Jasmin)*

*“Your tumor is less than 2cm, it can be operated on immediately, the pet-scan is ok and no echo lymphadenopathy.” (Iris).*

*“Infiltrating ductal carcinoma (3 3 2 = high grade), and the proliferation marker (ki67 to 80% = very high rate of the mitotic index). The very high ki67 means that the tumor is very aggressive. As for the ‘Sarco contingent...’, normally unknown to the ‘battalion’ of breast tumor cells, I think these are the very undifferentiated cells (normal breast cells are differentiated) typical of triple-negative breast cancer.” (Rose).*

- **Treatments and their effects.**

*“It may be your ki67 that explains your chemo (E.C. and 3 Taxotère) compared to mine (3 F.E.C. and 3 Taxotère).” (Rose).*

*“Nausea, insomnia and morale at half mast for 4 days after the 4th injection of granulocytes. The oncologist prescribed 7 injections for me from D + 6.” (Jacinthe).*

*“The oral chemo protocol is as follows: Endoxan 50 mg tab 1 tab / day + methotrexate 2.5 mg tab 1 tab morning & evening Monday, Thursday 1 tab morning and evening + IV herceptin. I started on October 14, 2015 and I admit that it's blah, blah not great ... Side effects: headaches (==> IRM CEREBRAL November 09, 2015), toothache, jaws, sinuses the face, fatigue +++++, joint pain everywhere (cervical, shoulder, back, pelvis, elbow, wrists...) and nausea +++++.” (Jonquille).*

They are in a way looking for evidence to develop confidence in all the professionals involved in the care.

*“Your priority: first, choose the right hospital and the right caregivers.” (Coquelicot).*

Most project themselves into “how to live with”.

*“I am interested in knowing the % of recurrences under tamoxifen on a % of overall recurrences ... indeed X% of patients recur but 13% of these X%: what percentage does it give on arrival? And what a quality of life...” (Hortensia).*

These results highlight the importance of patient adherence to her treatment. This implies a perfect understanding of the nature and purpose of the examinations she undergoes as well as the treatment prescribed or administered to her (Regnier-Denois *et al.*, 2009; Marie *et al.*, 2010). Most patients describe the treatment they are taking without questioning the rationale. While we can identify through the experience of these patients a questioning of the variability of medical practices (examinations or treatments) for the same disease, they clearly perceive the need to adapt examinations and treatments to each case.

**3. Survivorship and follow up stage** stresses the need for patients to be able to assess the quality of follow-up generally associated with the quantitative importance of the examinations performed.

*“At the end of the treatments, I had no radiological examination to confirm that the treatment had worked well or not. So I did what I wanted. I asked my onco gynecologist to give me a prescription ... at my expense but at least I was reassured. The results were good. My onco was probably right to wait 6 months but one more exam is good for morale...” (Edelweiss).*

They largely question **the reliability of the diagnosis**. They kind of need guarantees. This need is strongly linked to the experience lived during the previous stages of the pathway and also to the personal search for information.

*“I did have my appointment with an oncologist and I asked him the question of the follow-up after the treatments ... And he confirmed that mammo + echo control after 6 months after stopping the rays: that's a long time I think! I told him and he replied that it was the protocols ... I told him that I could never wait 6 months, resume my activity without knowing if all the treatments were effective ... he told me said we'll see at that time! Since I will be on Herceptin for a year (HER +++), he told me I was covered (except I read cases where even on Herceptin some people relapsed or metastasized). But I am not losing hope ...! I will see with my surgeon or my doctor to see what we can do if he does not want to give in!” (Dahlia).*

This third step shows an eagerness on the part of the patients to get out of the uncertainty by obtaining closer follow-up. Here again, providing information on monitoring protocols and their reasons would reduce the psychological tension experienced by patients. For some researchers (Mallinger *et al.*, 2005), the adoption of a “patient-centered” attitude by doctors and nursing staff implies quality and appropriate communication which reinforces patient satisfaction with their care.

These three phases cover critical touch points to which health institutions must pay more attention in order to be able to develop care that is better perceived and, above all, better experienced by patients.

## 5. THE STAGES BEFORE AND AFTER CANCER

The analysis allows for a “before cancer” step and an “after cancer” step. These two steps complete the three steps of discovery, treatment and follow-up. The introduction of these phases in the patient pathway approach is part of the demand for a more comprehensive care model. This responds to the needs identified in 1998 during the general meetings of cancer patients which constitute one of the foundations of the INCA (National Cancer

Institute) project and which is expressed in the orientations of the cancer plan (2009-2013 and 2014- 2019). In the words of the patients analyzed, the social dimension linked to “reintegration” constitutes a particularly present element. While for some the return to work is going well, this is not the case for all.

*“I went back to work at the beginning of September full time and I'm doing pretty well. I continue my sports activities which do me the greatest good physically and morally.” (Campanule).*

*“Today I am going to tell you my story and tell you how the hope of a job quickly made me regain control of my life!” (Clématite).*

Other women point out the difficulty in returning to their former life, especially at the professional level. They highlight the insufficient consideration by employers of their situation and the lack of awareness of the effects linked to the experience of the disease on professional (re) positioning.

*“Back to work at the end of 2011. But now I saw the occupational doctor but could not react. Inability to work and after the nightmare the human resources manager who does not know what to do with you and where to put you or rather find a leader who wants you well in her group. I feel helpless in the face of so much incomprehension. I sank into a serious depression (I do not specify due to the disease) but rather to the professional environment with vexatious remarks, the devaluation, the malice of this environment which advocates performance.” (Pétunia)*

We can identify an intermediate stage between the end of the disease and the return to a social and professional life that patients want closest to that before the disease. This intermediate stage can take the form of taking care of oneself, a time to rebuild a little. The offer of certain services makes it possible to “repair” the body a little from the traces of the disease and the treatment, but they do not repair a certain socio-professional fragility detectable in the post-cancer phase.

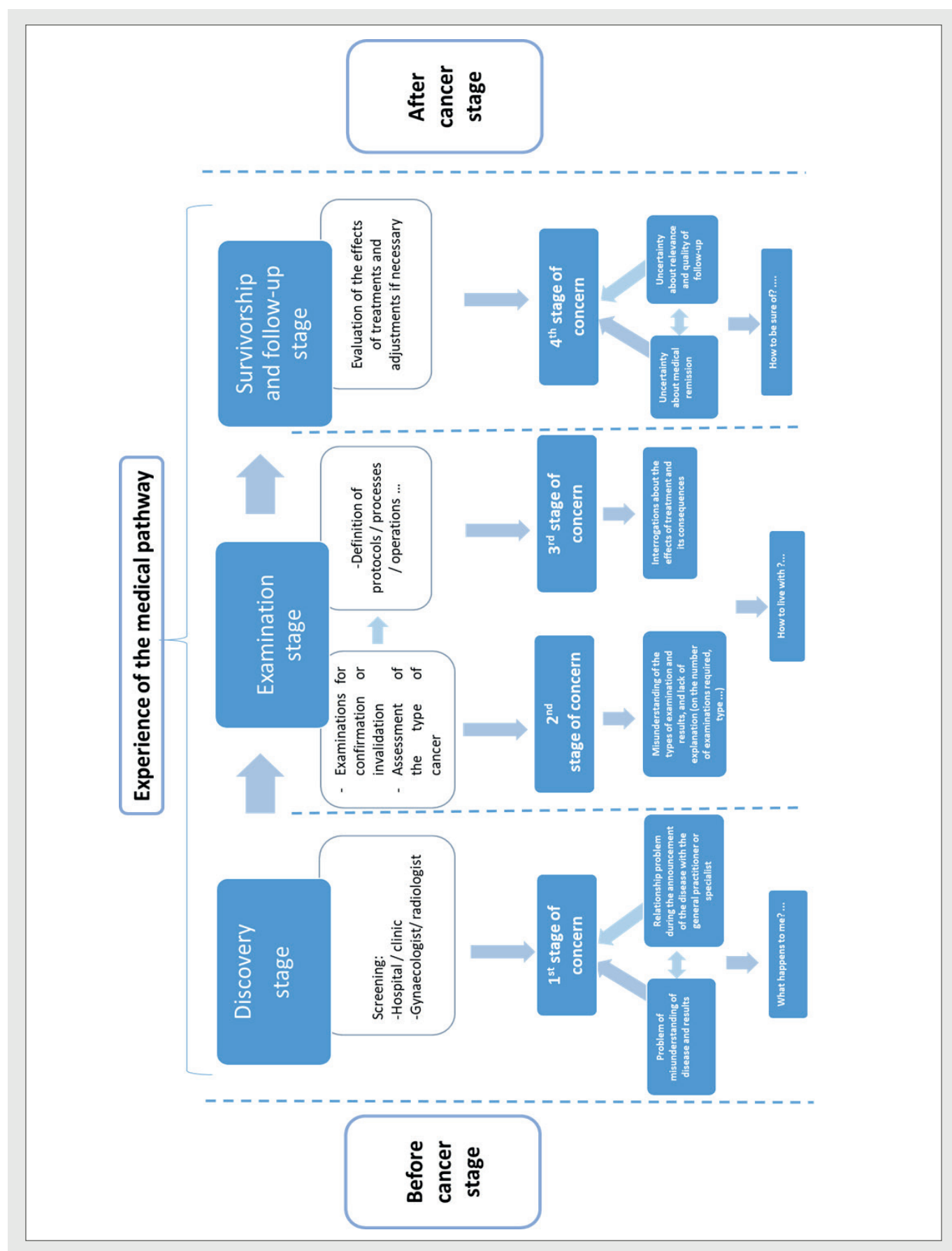


Figure 1 – Modelling the experience of the patient pathway

Source: authors

*“La Roche Posay is a makeover as much for the skin, scars as for morale. When I got home I was no longer the same and I slowly resumed fishing and the joy of living. If you still have the possibility to do it this year do not hesitate.” (Lilas).*

Finally, the stage before the disease is not clearly identifiable in the comments: the attitude towards prevention, the ability to comply with the recommendations of screening campaigns. However, these are more and more aspects of the health authorities really wanting to integrate into the pathway.

## 6. CONCLUSION:

### Theoretical and practical contributions limits and research perspectives

This exploratory research brings a non-medical approach to the patient pathway, using the patient's experience, which until then little explored, as a key to understanding. The analysis of the results here makes it possible to model the patient pathway based on the framework of the customer journey (Lemon and Verhoef, 2016; Pucinelli *et al.*, 2009; Verhoef *et al.*, 2009; Edelman and Singer, 2015). It confirms the existence of critical points at the three main stages inseparable from the experience of the disease: the discovery stage, the examination and treatment stage, and the follow-up and control stage. The results shed light on the elements poorly experienced by patients during their pathway. These require special attention in order to improve patient satisfaction. The results highlight relational and informational concerns throughout the stages of the pathway. Overall, patients follow the recommendations of their attending physicians or gynecologists who refer them to oncologists and surgeons in public hospitals or dedicated and private centers. Whatever the care structure, the patients' comments show an equivalence of examinations and treatments (similar medical protocols). While the pathways are perceived quite similar from a medical perspective, they are experienced very differently from an experiential angle. The way of qualifying the experience develops around the critical touch

points. Two main dimensions stand out: the informational dimension (cognitive) and the relational dimension (emotional and social). Most patients seek support first, which they seem to not always find from the medical and health care team. They need to feel surrounded and supported by people who understand their anxieties and distress. The patients deplore a significant lack of information and highlight problems of misunderstanding at all stages of the pathway, partly linked to a dialogue and insufficient listening. They will therefore try to find the information sought outside the medical framework. Thus, the medical dimension (professionalism, expertise) is only one component in determining a patient's pathway, just like informational (request and transmission of information) and relational (empathy, support).

The identification of touch points allowed us to confirm the existence of a patient pathway, which captures the experience and expectations of patients in a more complete way than the only medical pathway that it completes.

To conclude, this research presents an original proposal for modeling the patient pathway beyond the medical pathway and from the patient's experience. By focusing on the vision of users of health services, our work complements the more institutional vision of a user who is an actor in their health that public policies in their implementation work to disseminate.

On the theoretical level, the post-pathway phase constitutes a first contribution to document for future research more precisely. Likewise, it would be interesting to understand why the upstream phase (pre- pathway) is little mentioned but also to succeed in identifying whether there are particular pre- pathway trajectories that could impact the experience of the disease such as having been confirmed / confronted. to illness in a loved one before being so yourself.

On a more managerial level, this research emphasizes the need to assess the quality of the care offered by hospitals and specialized centers in a different way. Based on this exploratory analysis of the experiences of patients with breast cancer, it appears that hospitals and specialized centers



must pay particular attention to the relational and informational dimensions of the follow-up of their patients and in particular to look into information sharing. The space represented by online communities allows for collective ownership of medical information. It probably contributes to the constitution of a form of expertise (Akrich and Méadel, 2009) that it can be beneficial to integrate for health organizations. This last point raises the question of the role that hospitals could possibly play towards these online communities of patients in order to guarantee valid information. It also questions the nature of the resources that could be injected into this process, including human resources.

Our research highlights the key role of touchpoints in building a patient experience, which in this case turns out to be quite negative. It shows the interest that health structures have in paying particular attention to it in order to develop actions likely to contribute to a more positive experience of the stages of the pathway. Our recommendations go in this direction and are formulated according to the categorization of touch points proposed by Lemon and Verhoef (2016):

**1.** The first category of customer experience touchpoints (here patient) is the brand. We can see that this constitutes a touch point that is not neutral. Thus, CHUs, centers for the fight against cancer (CLCC), care structures designated by their name (“Gustave Roussy”, “Georges Pompidou” for example) constitute brands in their own right. They generally carry a positive perception associated with their expertise. On the other hand, some large healthcare establishments lose the benefit of the institutional brand (CHU or CLCC) because they are perceived as “dehumanized medical factories”. The “human” aspect of centers and hospitals is just as important to patients as the treatments they receive. Indeed, many patients plan to change hospital, center or oncologist if they feel neglected by the medical profession. The patients seek empathy and the availability of the medical profession. The establishment of charters of commitments around the attention paid, the ability of doctors and staff to take the time to listen and respond to patients' concerns is a tool that can be mobilized, as is the assignment of a referring to the follow-up of each patient in the stages

of his pathway, like “case managers”. It appears necessary, despite a context marked by strong constraints, in particular on human resources, to train and dedicate staff to the management of patient pathways so that they feel better supported but also to strengthen coordination between all actors (attending physician, oncologist, radiologist, etc.). A point that appears in the decree of July 2018 on advanced nursing practices. This is, moreover, one of the elements exposed in the Institut Gustave Roussy establishment project: “improving the management of the care pathway by developing new professions (such as that of nurse clinicians) intended to improve everything, along the patient pathway, their care in all its dimensions and at each stage of the disease, but also useful and innovative services such as the web portal and the mobile application offering a personal digital space ‘MonGustaveRoussy’”. It could thus be envisaged to use digital tools more extensively for closer personalized remote monitoring and thus strengthen relational proximity. These tools would allow (after patient consent) the collection of behavioral information useful for refining patient knowledge and adapting management or, in some cases, the offer of additional services to treatment. This is an axis on which French hospitals seem to be committed, as evidenced for example by the digital projects of the cancer centers of the Unicancer federation presented in June 2018 on the occasion of the E- day. Health.

**2.** The second category concerns the touch points associated with partners and / or over which the entity (medical structure) exercises some control. It appears that there is still significant work to be done in terms of identification and coordination of health actors (CLCC, town doctors, therapeutic education associations, etc.). Cooperation between health actors does exist, but it is often of an inter-individual nature (attending physician, radiologist, oncologist) and requires, to be more efficient, to think up cooperation networks, or innovative and open organizations built around care pathways or even even a fitness trail. This requires evolving information systems for true sharing of medical information, the shared medical record is still underutilized. Coordinated health stakeholder networks, such as oncology networks, must be an axis of progress for hospital organizations.



3. The third category of touch points relating to the customer himself is not properly identifiable. We can hypothesize that the absence or near absence (this would need to be confirmed by future research<sup>7</sup>) of these touch points constitutes a strong characteristic of the universe of oncology care. The patient does not a priori have the initiative and control over the pathway of medical care or in a very exceptional way. However, this could evolve with the spread of a culture of prevention and emerging self-diagnostic practices. The development of predictive medicine based on advances in oncogenetics could help. The patient more and more eager to take control over health, in the near future, could contribute to the development of a real “pre-diagnosis market” and thus be at the initiative of the first contact with the structures intervening in the field the universe of oncology.

4. Finally, the fourth category concerns the social and external touch points which provide an overall very positive experience here. In fact, the influence of other patients and peers is a major influence on the perception of the care and care pathway. These other patients are a real resource to be activated in a supervised manner. The sharing of experience, both with other patients and with the medical profession, is a particularly important marker for these patients having an emotionally strong and painful experience. This research underlines, in the case studied, an absence of experience sharing with the medical profession. Also, it is ultimately up to health organizations to develop a stronger presence of health professionals via digital tools and technologies and thus help strengthen the quality of the relationship while co-building a more efficient health system.

Information and communication technologies are a useful medium for the dissemination of rapid information from healthcare organizations to patients and between healthcare professionals themselves. These tools open up new avenues for developing relationships. They can be used to facilitate the feedback of information from the patient. Mobile applications, patient portals, online communities contribute to a form of patient education about the

world of health, the process of care and the disease. It is necessary to think about how to participate in the animation of patient communities to contribute to the circulation of reliable and quality information. To do this, it might be appropriate to rely on the leaders of online communities to enrich discussions with healthcare professionals and support these leaders in their reflective process for better reporting of their experience to other patients. It could be a way to counterbalance the movement around a gradual digitization of part of the touch points as part of redesigned processes. The development of a hospital seen as a platform producing technical medical acts where the patient is passing through contributes to the distension of the relationship in these more psychological and social dimensions. These inseparable dimensions of comprehensive care could be invested more heavily by other actors (communities, associations, etc.).

Despite the theoretical and managerial contributions presented by this research, certain limitations should be emphasized. They constitute avenues of research for the future. Our study focused only on the case of French patients with breast cancer. It would therefore be appropriate to extend the study to other types of pathologies in order to increase the validity of the results. In addition, it covered a period of one year which does not allow us to reconstruct the pathway of each patient in its entirety (from diagnosis to remission). It would be opportune to establish a typology of patients based on a modeling of their profiles and to investigate in more detail the post- pathway experiences but also the pre-pathway.

<sup>7</sup> The request for genetic analyzes on the daughters of mothers or grandmothers affected or having been affected could represent a point of contact relating to the client himself.

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