



Physician empathy in cancer care: predictors, outcomes and perspectives

Accreditation to Supervise Research, Health Psychology

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L'empathie du médecin en oncologie: prédicteurs, issues et perspectives

Habilitation à Diriger des Recherches, Psychologie de la Santé

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You treat a disease, you win, you lose.

You treat a person, I guarantee you, you'll win, no matter what the outcome.

Hunter Doherty Adams, MD

Acknowledgments

I would like to thank warmly:

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ABSTRACT

Cancer patients face many challenges related to the disease and treatments at all phases of the disease trajectory. In the first part, using the integrative model of health psychology, I address the psychological predictors of the quality of life (QoL) of breast cancer women in the long term after the end of treatments. I also present research exploring the predictors and nature of post-traumatic growth (PTG) resulting from the disease. Having highlighted a flaw in the theoretical health-psychology models that do not integrate the impact of health professionals on patients, in the second part I focus on physician empathy, especially in cancer care. I describe and discuss the numerous definitions of the concept (e.g. compassion, accurate understanding, responses to patient cues, etc.) and ways of assessing it before addressing the predictors of various empathy concepts: physician-reported empathy, physician accuracy about patient distress and unmet needs and patient-reported empathy. I continue by exploring patient outcomes of physician empathy, both in the literature and in my research on patient QoL and survival. Physician empathy is differently related to patient QoL according to his/her emotional skills. In bad-news consultations, very high patient-perceived physician empathy hastened death but only for the listening/compassion dimension of empathy and not for the empowerment-related one. In the final part, I propose two programmes of research: one extending and enriching our work on the link between physician empathy and patient outcomes, especially in new cancer treatments such as immunotherapy; the other one on the development of physician empathy using different but complementary approaches.

RÉSUMÉ

Les patients atteints de cancer font face à de nombreux défis liés à la maladie et aux traitements et ce à toutes les étapes de la maladie. Dans la première partie, en utilisant le modèle intégratif de psychologie de la santé, j'étudie les prédicteurs psychologiques de la qualité de vie des femmes en rémission d'un cancer du sein à long terme de la fin des traitements. Je présente aussi une recherche explorant les prédicteurs et la nature du développement post-traumatique résultant parfois de la maladie. Ayant souligné une faille des modèles de psychologie de la santé qui n'intègrent pas l'impact des professionnels de santé sur les patients, dans une seconde partie, je me centre sur l'empathie des médecins, notamment en oncologie. Je décris et discute les nombreuses définitions du concept (px compassion, compréhension empathique, réponses aux opportunités empathiques, etc.) et les façons de l'évaluer avant d'étudier les prédicteurs de différents concepts empathiques : l'empathie auto-évaluée par les médecins, la précision empathique sur la détresse et les besoins non-satisfaits des patients et l'empathie des médecins évaluée par les patients eux-mêmes. Je continue en explorant les issues 'patient' de l'empathie des médecins, à la fois par une revue de littérature et à travers une de mes recherches sur la qualité de vie et la survie des patients. L'empathie du médecin est liée à la qualité de vie des patients, mais différemment selon les compétences émotionnelles de ces derniers. Dans les consultations de mauvaises nouvelles, une très haute empathie perçue par les patients accélérât la mort mais seulement pour la dimension d'écoute et de compassion de l'empathie et non pour la dimension d'empowerment. Dans une dernière partie, je propose deux programmes de recherche : l'un étendant et enrichissant notre travail sur le lien entre l'empathie médicale et les issues des patients, notamment dans les nouvelles médecines du cancer telles que l'immunothérapie, l'autre autour du développement de l'empathie des médecins par différentes approches complémentaires.

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ACRONYMS AND ABBREVIATIONS

Acronyms	Definition
ALK	Anaplastic Lymphoma Kinase
BC	Breast Cancer
BCs	Breast Cancers
CRP	C-reactive protein
EGFR	Epidermal Growth Factor Receptor
eQoL	Emotional Quality of Life
ES	Emotional skills
GP	General Practitioner
GPs	General Practitioners
HCP	Health Care Professional
HCPs	Health Care Professionals
HDR	Habilitation à Diriger des Recherches, i.e. 'Accreditation to Supervise Research'
HrQoL	Health-Related Quality of Life
IL-6	Interleukin 6
NSCL	Non-Small Cell Lung cancer
PPPE	Patient-perceived physician empathy
PTG	Post-Traumatic Growth
QoL	Quality of Life
RCT	Randomised Controlled Trial
ROS	Proto-oncogene tyrosine-protein kinase. ROS is an enzyme that in humans is encoded by the ROS1 gene.
SCL	Small Cell Lung cancer
TPE	Therapeutic Patient Education
	Interesting results or information to keep in mind

INTRODUCTION

This HDR ('Habilitation à Diriger des Recherches', i.e. 'Accreditation to Supervise Research') will mirror the main steps of my research trajectory, which can be divided into three parts. The first one relates to cancer survivorship (PhD work) and the second to doctor-patient relationships and their association with patient outcomes in cancer care (postdoctoral and tenure position work as an associate professor). The third part describes a few avenues of research for future work. This HDR will mainly focus on the second and third parts for reasons explained below.

FIRST PART. In my doctoral thesis in Nantes in the west of France, I focused on breast cancer survivors' quality of life (QoL) a long time after their diagnosis (5 to 15 years). In fact, organised screenings, the increasing efficacy of treatments as well as more personalised diagnostic and treatment approaches have considerably increased survival rates in cancer care, so that currently the number of cancer survivors exceeds the cancer patients undergoing treatment. As a result, certain types of cancer are now considered chronic diseases. Thus, data on patients' long-term quality of life, as well as a psychosocial model explaining their QoL, were needed. I tested such an integrative model to explore QoL and its associated variables in my doctoral work (Lelorain, 2009) and in a related publication (Lelorain *et al.*, 2011).

Although convenient for research purposes, the concept of quality of life does not always encompass important concepts from the patients' point of view, such as their well-being or post-traumatic growth (PTG). I thus complemented my research by exploring clinical and sociodemographic covariates of well-being (Tessier *et al.*, 2012) as well as psychological predictors of PTG (Lelorain *et al.*, 2010). I also investigated the nature of PTG: is it the result of successful coping with cancer (PTG as an outcome) or is it a cognitive way of coping with cancer (PTG as a process)? A qualitative analysis of cancer survivors' narrations was carried out to address this conundrum (Lelorain *et al.*, 2012b).

SECOND PART. Reflecting on these first three years of work, it struck me as strange that in the models studied, no variables were specified about doctor-patient relationships. Yet, in cancer settings, the attitudes and words of oncologists are of utmost importance to patients: these professionals represent a primary source of information and are responsible for crucial medical decisions involving survival. From the patients' point of view, the oncologists are the fulcrum of cancer care coordination and their attitudes are the pivotal element of care (Lelorain *et al.*, 2019b). Thereafter, I focused on doctor-patient relationships in medical settings, mostly in oncology.

Searching through the available studies on medical empathy in oncology for my postdoctoral work in Paris at the University of Paris Descartes and at the Curie Institute, I found that two elements seemed obvious and had thus never been thoroughly questioned. These were:

1) the antecedent of patient perception of physician empathy (PPPE). PPPE, by its very definition, is thought to relate to the physician's accurate understanding of the patient's needs, concerns and distress, which is supposedly the result of the physician's perspective-taking.

2) the outcomes of PPPE. Medical empathy is assumed to help patients and is therefore always advocated for their quality of life and well-being.

I set out to verify whether these two widely-held assumptions fit the reality in medical settings.

1. The antecedent of patient perception of physician empathy (PPPE)

To answer the first question, we conducted a study with advanced cancer patients. Regarding the assumption that patient perception of physician empathy depends on physician accuracy, we showed this to be true *only* under certain conditions. In particular, the capability of patients to express their emotions, i.e. one of patient ES, was one of these conditions (Lelorain *et al.*, 2015). We were also interested in the predictors of physician accuracy in the detection of patient distress. We investigated physician accuracy and predictors of accuracy for each *specific* symptom of depression (e.g. sense of failure, pessimism) (Gouveia *et al.*, 2015) and found that a higher quality of the physician-patient relationship was associated with more accuracy in the less conspicuous symptoms of depression (i.e. sense of failure, dissatisfaction, guilt and self-dislike). However, in the same data set, when focusing on accuracy in the detection of *general* patient distress, we demonstrated the pitfall of an excellent rapport with patients for an accurate detection of the general distress of patients (Lelorain *et al.*, 2014) and, once again, the important role of the patient's expression of their emotions in physician accuracy.

We further probed the determinants of physician accuracy in the detection of cancer patients' needs and concerns. A common one is the physician's ability to take the patient's perspective. In fact, an effective way to obtain an accurate picture of patients' needs and concerns is to make the effort to take their perspective (i.e. perspective-taking). Usually, perspective-taking is motivated by empathic concern, which is the emotional reaction when one feels concerned by the situation of another and are therefore willing to help him/her. In a study on general practitioners (Lelorain *et al.*, 2013), we demonstrated that a reflective activity can foster perspective-taking and make it less dependent on empathic concern. This result is interesting as empathic concern can sometimes be wearing and lead to compassion fatigue. Therefore, the possibility of reaching a high level of perspective-taking without too much empathic concern is of clinical relevance for healthcare professionals.

2. The outcomes of PPPE

To answer the second question (i.e. is medical empathy really associated with better patient outcomes?), a literature review was carried out on the relationship between medical empathy in oncology and various patient outcomes (anxiety/depression, quality of life, coping) (Lelorain *et al.*, 2012a). As this work revealed mixed results, it seemed important to look for moderating variables explaining the divergent findings. This research was undertaken in Lille, in the north of France, where I obtained a tenure position as an associate professor. One important potential moderator that emerged from the literature review was the context of the delivery of empathy. I therefore set out to study the link between physician empathy and patient outcomes according to the context of the consultation: bad-news disclosure vs. follow-up consultation without bad news.

Built on the assumption of a context-related moderator, two studies were carried out; one on patient quality of life as an outcome (Lelorain *et al.*, 2018a) and another on patient survival as an outcome (Lelorain *et al.*, 2018b). In these studies, another important moderator was taken into account: patient emotional skills (ES). It was essential to consider both sides of the doctor-patient interaction, i.e. physician empathy and how this empathy may be perceived and used by patients according to their ES. Indeed, our research has shown a strong link between patient ES on the one hand and their supportive care needs (Baudry *et al.*, 2018b) and health (Baudry *et al.*, 2018a) on the other hand. It suggests that patients with low ES may require more attention and empathy than those with high ES.

Parts I and II are depicted in Figure 1 on the next page.

THIRD PART. Finally, in the last section of this report, future research avenues resulting from our previous research will be described.

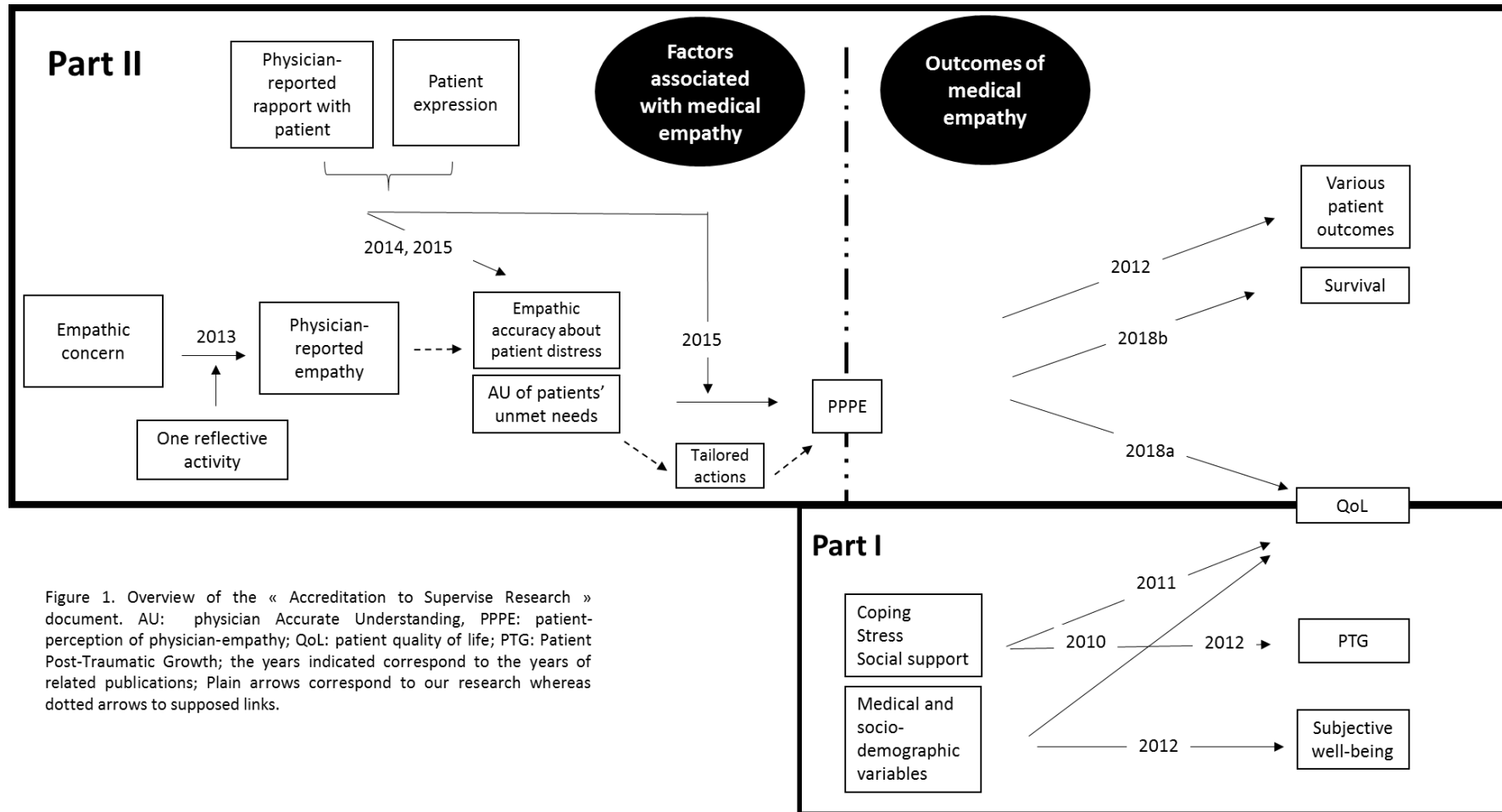


Figure 1. Overview of the « Accreditation to Supervise Research » document. AU: physician Accurate Understanding, PPPE: patient-perception of physician-empathy; QoL: patient quality of life; PTG: Patient Post-Traumatic Growth; the years indicated correspond to the years of related publications; Plain arrows correspond to our research whereas dotted arrows to supposed links.

Figure 1. Overview of the HDR.

PART 1: MENTAL QUALITY OF LIFE IN CANCER SURVIVORSHIP

1. Definition of the concept

1.1. Cancer survivorship

France is among those countries with the highest incidence of cancer worldwide (Torre *et al.*, 2015). Cancer still remains a major cause of death. However, organised screenings, the increasing efficacy of treatments as well as more personalised diagnostic and treatment approaches have considerably increased survival rates. According to French data, for all types of cancer combined, survival rates at 5 years after diagnosis vary from 51.9 to 66.1% depending on the register used (Mazeau-Woynar & Cerf, 2010). In the United Kingdom, more than 50% of all cancer patients survive for more than 10 years and this rate has doubled in the last 40 years (Retzer *et al.*, 2018). Breast cancer (BC) is one of the most prevalent cancers. About 1 in 8 women will develop BC over the course of their lifetime (Giordano & Gradishar, 2017) and with a 5-year survival rate of up to 89.1% for all stages of severity combined (Mazeau-Woynar & Cerf, 2010), BC is particularly concerned with long-term survivorship. This explains my interest in this issue. When my PhD work began in 2006, the topic had not yet been explored in France, where research had mainly focused on patients' experience during diagnosis and treatment. This is still the case (Fletcher *et al.*, 2017). Thus, limited data were available on long-term survivorship after cancer. It seemed to me that the concept of quality of life (QoL) and post-traumatic growth (PTG) could accurately describe the quality of survivorship.

Two overarching questions were of interest:

- 1) What is the quality of life (QoL) of these women 5 to 15 years after diagnosis? What is the long-term aftermath of BC and does it include some sort of personal growth due to cancer?
- 2) What psychosocial variables are associated with the long-term QoL and PTG?

First, I will describe the concepts of QoL and PTG before briefly presenting some elements of the method used to answer these questions.

1.2. The concept of Quality of Life



In their historical review of the emergence and evolution of the QoL concept in cancer care, Trudel et al. (2012) explained that there is a lack of consensus on a single definition of QoL. Instead, many definitions are given in the literature such as the widely acknowledged one of the World Health Organisation (WHO) (WHOQOL Group, 1995): ‘an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad-ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment’.

In simpler terms, it can be stated that all definitions encompass patients’ evaluation of their well-being from a physical, mental and social perspective, taking into account, as noted by Calman, ‘the difference, or the gap, at a particular period of time between the hopes and expectations of the individual and that individual's present experiences’ (Calman, 1984).

From a historical point of view (Trudel *et al.*, 2012), the concept of QoL in cancer care is relatively recent with the first official definition being given by the WHO in 1947 and the first very basic assessment designed by Karnofsky and Burchenal in 1949. This assessment, which is still widely used in cancer settings today, is the Karnofsky Scale of Performance Status. It measures in a very basic way (on a scale ranging from 0 ‘Dead’ to 100 ‘No complaints, normal life’) patients’ functional impairment, i.e. to what extent they are able to perform daily ordinary tasks alone and need assistance for their own care. Doctors, and not patients, assess patients’ functional impairment based on clinical observation and questions to patients if needed. Since 1949, many scales have been designed to assess patients’ QoL more precisely and directly from their perspective: patients fill in QoL questionnaires themselves assessing various dimensions of their lives, mainly psychological, social and physical, and in a more detailed way including, for example, their level of pain, happiness, worries about their physical appearance, etc. It is important to note the shift from the physicians’ clinical observation to patient-reported questionnaires in QoL assessment. In fact, numerous data have revealed that physicians underestimate patients’ concerns, even for the most visible or troublesome symptoms such as dyspnoea, coughing (Pakhomov *et al.*, 2008), pain (Coran *et al.*, 2013) and side effects of chemotherapy such as nausea or weight-related problems (Macquart-Moulin *et al.*, 1997). However, in one of our studies of 28 physicians and 201 metastatic cancer patients, a contrasting result was found: physicians overestimated patients’ need for psychological help (Lelorain *et al.*, 2015), probably due to normative or stereotyped reasoning leading them to think that ‘metastatic cancer patients must have psychological difficulties and therefore a high need for help’ (we will expound on this study in Part II about physician empathy). In any case, these studies converge to highlight how *distinctive*

accuracy is difficult to achieve (i.e. the accuracy based on the effort to take the perspective of another person), hence the need for patient-reported outcomes.

The rapid development of QoL assessment is a consequence of the three following interrelated points: the emergence of 1) the psycho-oncology field aimed at evaluating and reducing the impact of cancer on patients and their caregivers, 2) patient advocacy groups related to their inclusion and rights in clinical trials, and 3) the legal obligation of the regulatory agencies, such as the US Food and Drug Administration, to assess the impact of new treatments on patients' QoL.

 This rapid overview of the QoL concept illustrates that, historically, QoL is merely a way of assessing the impact of cancer and treatments on patients' lives for research purposes, that is for the development of new drugs and treatments. Most QoL measures are therefore quite basic and mainly oriented toward patients' functional impairment and cancer or treatment-related symptoms. This type of assessment is referred to as 'health-related QoL'. 

Indeed, the routine evaluation of patients' health-related QoL is still rare in clinical practice (Porter *et al.*, 2016). To the best of our knowledge, the clinical evaluation of long-term QoL is still almost non-existent in France. Within the framework of my PhD work, a hospital consultation for long-term cancer survivors was initiated by our research team for the first time in France, in Nantes (in the west of France), both for research and clinical purposes. Although attending patients were very satisfied with this new consultation, it did not last long as it was clearly not a priority for the hospital. This is regrettable as there is mounting evidence that such routine evaluation is associated with better patient-clinician communication (Howell *et al.*, 2015; Yang *et al.*, 2018a), QoL (Catania *et al.*, 2015), survival prediction (Zikos *et al.*, 2016; Ediebah *et al.*, 2018), survival (Basch *et al.*, 2017), and in a cost-effective way for a web-based procedure (Nixon *et al.*, 2018). Despite being rather basic, the routine assessment of quality of life is of interest in medical care but more specific measures are available to describe patients' experiences of disease.

Besides the basic health-related QoL measures mentioned above, others were designed in the 2000s for the more specific and psychological aspects related to cancer such as 'fear of recurrence', 'sexual issues', 'appearance-related issues' and 'post-traumatic growth (PTG) or benefit-finding (BF)' (Avis *et al.*, 2006). The latter dimension (PTG/BF) caught my attention as it is the only 'positive' QoL-dimension among the others, which basically assess limitations or impairments¹. In this respect,

¹ Incidentally, the first time I saw the expression 'benefit-finding' in the context of QoL after cancer, I did not understand it and looked it up in the dictionary thinking that it was probably another sort of limitation or impairment I did not know!

PTG/BF conveniently complements mental QoL in the study of long-term survivorship after cancer and will thus be described below.

1.3. Post-traumatic growth – Benefit finding

1.3.1. Definitions and historical perspective

Post-traumatic growth is defined as positive psychological changes experienced as a result of the struggle with highly challenging life circumstances (Tedeschi & Calhoun, 2004; Calhoun & Tedeschi, 2006a) and was first coined by Tedeschi and Calhoun in 1995. Five dimensions characterise PTG (Tedeschi & Calhoun, 1996): a greater appreciation of life, which is no longer taken for granted; a sense of personal strength; better relationships with others (e.g. more authentic and warmer); a deeper spirituality; and the emergence of new possibilities (i.e. 'because' or 'thanks to' the event people do things they would never have dared otherwise). In the case of diseases, a shift toward better health behaviours and a greater interest in health have also been reported (Sears *et al.*, 2003).

The term 'post-traumatic' is misguided in that it suggests that PTG occurs only after a trauma as defined in the DSM V (Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition) whereas it occurs after a stressful event with the same factor structure and means even if this event does not meet the criteria of trauma (Silverstein *et al.*, 2017). In fact, Tedeschi & Calhoun have themselves mentioned that they 'use the terms trauma, crises, major stressor, and related terms as essentially synonymous expressions to describe circumstances that significantly challenge or invalidate important components of the individual's assumptive world' (Calhoun & Tedeschi, 2006b). In their handbook of PTG (Calhoun & Tedeschi, 2006b), an entire chapter is dedicated to PTG in cancer, for example, even though cancer is not necessarily a traumatic experience. Some authors have even emphasised the developmental side of growth that occurs in life in relation to minor stresses, which therefore should be named stress-related growth and not PTG (Aldwin & Levenson, 2004).

Benefit-finding is very close to PTG as it means finding something good resulting from stressful events (Affleck & Tennen, 1996). The difference resides in the fact that BF can be immediate and effortless (benefits appear to be obvious) whereas PTG is a more effortful process that results from struggling during a crisis. We are interested in the effortful process of PTG.

The idea that difficult life struggles can bring about positive changes is not new. It has always been present in many religions, Greek tragedy and literature throughout the world (Calhoun & Tedeschi, 2006b). However, the concept only emerged in the scientific psychological literature in the 1990s. Since then, a burgeoning area of research has developed with, for example, only 13 articles on this topic in PubMed in 1996 (the year of the first prominent publications), 73 in 2010, 154 in 2015 and

206 in 2018. As a point of interest, the term 'PTG' was only introduced into the MeSH (Medical Subject Headings) index of PubMed in 2019. From an epistemological point of view, it is interesting to note that the emergence of PTG appeared at a time when the QoL literature had been largely developed and was ready to welcome dimensions other than impairments or limitations in the concept. The time was finally ripe for the concept to evolve.

1.3.2. Theoretical model

Calhoun & Tedeschi (2006, p. 8) proposed a comprehensive model of PTG in which, succinctly, the seismic event creates high challenges to people's beliefs and goals, narratives, and management of distress, from which ruminations, mostly automatic and intrusive, arise. Then, through self-disclosure, disengagement from previous goals, reduction of emotional distress, and models for PTG (proximate models such as a family member who experienced PTG after a stressful event or distal models such as societal themes related to PTG), people could achieve more deliberate rumination, schema change, and the development of a new narrative, from which PTG could finally arise. Their model highlights the cognitive engagement necessary for PTG, which was further confirmed in later work (Ramos *et al.*, 2018). This cognitive engagement is the processing of the traumatic event by which people reflect on what happened and on their core beliefs that might have been shaken by the stressors: their relationships with people, the controllability of life, the sense of meaning in life, their expectations for the future, their own value or worth as a person, their spiritual beliefs, etc.

Besides theories proposing how PTG emerges, the nature of PTG itself has stirred many debates (Zoellner & Maercker, 2006; e.g. Sumalla *et al.*, 2009) and is still a moot point: is PTG an effective or a dysfunctional way of coping, or a positive real outcome of functional coping? The question arises because, in longitudinal studies, PTG is often followed by better mental health (e.g. Bower *et al.*, 2005) but sometimes leads to worse patient psychological outcomes (e.g. Helgeson *et al.*, 2004) while in cross-sectional studies, mixed results are found regarding the link between PTG and mental health. In their landmark review, Zoellner and Maercker (2006) championed the idea of the two-sided nature of PTG: a functional, self-transcending, constructive side and an illusory, self-deceptive, or dysfunctional side. The constructive side is often put forward in the scientific literature, which is usually based on patient-reported questionnaires such as the PTG Inventory. Such questionnaires are purported to measure authentic PTG but only from the patient's perspective, which can be self-deceptive. Clinical interviews account better for the illusory side of PTG that emerges when patients try and develop PTG in the face of high distress whereas it is obvious to therapists that this PTG is not integrated into their lives but is rather a figment of their imagination or just a front. The illusory side of PTG echoes the cognitive adaptation theory, which proposes that people try and sustain

positive illusions when they are up against adversity in order to stave off negative emotions and distress (Taylor, 1983). What is at stake here is elucidating whether these positive illusions can be an effective way of coping or not. In clinical accounts, people are capable of reporting elements of growth that are actually not present in their life. For example, they may claim that the traumatic event made them see how important love and close relationships are whereas they do not have any close friends or family members and even devalue other people most of the time (Zoellner & Maercker, 2006). In this case, the illusion is likely to be associated with denial and therefore more distress and maladaptive coping.

Hence, clinicians should be wary of taking patient PTG-speech at face value as it may conceal suffering and dysfunctional coping, and thus backfire. An elegant way to distinguish authentic from illusory PTG is to consider both PTG and coping at the same time. PTG without joint adaptive coping points to illusory and self-deceptive PTG whereas PTG along with adaptive coping points to authentic PTG (Pat-Horenczyk *et al.*, 2015).

In a recent study in BC survivors, 56% of women reporting PTG were simultaneously using maladaptive coping (Cheng *et al.*, 2018) revealing the twofold nature of PTG: illusory, idle, and hence accompanied by maladaptive coping for some patients or else real and more likely to be associated with adaptive coping for others. Longitudinal studies following BC patients from diagnosis to long-term survivorship showed that PTG at baseline is associated with better coping and mental health in the long run (Cheng *et al.*, 2018; Hamama-Raz *et al.*, 2019). In BC settings, patient-reported PTG may thus be authentic, or at least a way of coping that helps women to pull themselves together, and thus creates positive psychological outcomes over time.

PTG has been extensively documented within a short period after BC diagnosis (e.g. Tomich *et al.*, 2005; Bellizzi & Blank, 2006), establishing that some women experience growth, especially related to a better appreciation of life and relationships with others. In contrast, long-term PTG following BC has not been widely reported. At the time of my PhD, there were only three studies on the subject at five years post-diagnosis and none of them included women beyond ten years after diagnosis. This is the reason why such research was undertaken. I shall now look at the long-term survivorship in BC patients, factoring in their QoL and possible PTG.

2. Quality of long-term survivorship in BC patients

In my doctoral work, to explore survivorship in long-term survivors of BC, I constituted a convenience sample of French women meeting the following inclusion criteria: a woman diagnosed five to 15 years earlier in the Cancer Treatment and Research Centre of Nantes (in the west of France) and without recurrence or new cancer since diagnosis. Those willing to participate (59.6%) completed questionnaires assessing their QoL, PTG and psychosocial variables. A total of 307 totally completed questionnaires without missing data were retrieved and expected to reach enough statistical power. QoL was assessed using two scales: the Medical Outcome Study Short Form-36 (MOS SF-36) (Leplège *et al.*, 2001), which is a general measure of health-related QoL applying to general and clinical populations and providing two general scores (i.e. mental and physical QoL) with sub-scores within each one (e.g. vitality within mental QoL), and the Quality of Life in Adult Cancer Survivors (QLACS) (Avis *et al.*, 2006). Participants were also asked to report the possible sequelae of their cancer.

PTG was assessed using the PTG Inventory (PTGI), which we translated into French for our purpose. In parallel, a convenience sample of 132 women without a history of cancer was constituted as a comparison group². It consisted of medical and psychology students who had to distribute the questionnaires (the same as those completed by BC women) to women seen in consultation during their internship and to personal acquaintances (family or friends). Those women were asked to refer to the most stressful event of their choice that had occurred in their life in the last twenty years. Twenty-eight BC women, selected at random from the sample, were also interviewed using open questions about the potential changes that could have occurred in the aftermath of cancer and had lasted until now.

Patient accounts were thematically analysed using Alceste© software, which also performs a descending hierarchical classification of the text and a correspondence factor analysis. The main interest of Alceste© is that it associates thematic classes with variables introduced by the researchers. For example, it can point out that a theme is more characteristic of men than of women (if the variable gender is introduced), or of approach coping than of avoidant coping (if the variable coping is introduced). The full details of the method are reported in Lelorain *et al.* (2010, 2011 and 2012b).

² I use the term 'comparison group' and not 'control group' as the latter refers to randomised controlled trials, which was not the case here.

2.1. Mental QoL and sequelae

Briefly, our BC sample was aged 62 years [36-78], lived with a partner (75%), had children (89%), was retired (73%), and had a low level of education (79% \leq school diploma). Their financial situation was perceived as difficult for 6%, correct for 60.4% and comfortable for 33.6%.

As scores of QoL with the MOS-SF36 are available for French women of the general population by different age groups (Leplège *et al.*, 2001), we compared QoL in our BC sample to these national French data. The results published in my thesis (Lelorain, 2009) revealed a *better* QoL for BC women in the physical activity dimension as well as in the ‘pain’ one (less pain in cancer women) but a worse mental QoL. In fact, mental QoL has been proven to be more likely impaired in BC cases than in other types of cancer (Le Corrolier-Soriano *et al.*, 2008).



In the national French study on cancer survivorship five years after diagnosis, 33.1% of BC women had a deteriorated mental QoL compared to 25% in the general population (INCA [French National Cancer Institute], 2018).



Our cancer sample had a better QoL than our comparison group in the physical score (less pain, fewer limitations) and in the ‘social role functioning’ sub-dimension but a worse QoL in the sexual domain assessed using the QLACS. In their study of 864 BC survivors, Ganz *et al.* found similar results regarding an impaired sexuality (Ganz *et al.*, 1998). Due to treatment-induced vaginal dryness, mastectomy, fatigue, and sometimes hair-related problems, BC plays havoc with patients’ self-confidence, body image and potentially sexuality. The same results were found in the national French study (INCA [French National Cancer Institute], 2018) performed on 4179 patients with various cancers. It revealed vaginal dryness in 45.4% of BC women, appearance-related problems in 29.1% and feeling less attractive than before cancer in 35.2%.

At first glance, it may seem surprising that, with the exception of sexuality, women who have had cancer report a better physical functioning than women without a history of cancer, but such results have been found previously (Ganz *et al.*, 1998; Bardwell *et al.*, 2004) and several explanations might apply here. First, due to their history of cancer, these women may have benefited from a rigorous medical follow-up, explaining pain control for example. However, the national French study revealed chronic pain in 71.7% of BC survivors. Second, after cancer, people sometimes change their attitude and behaviour regarding physical activity and health, which they cherish as something precious that needs to be cared for and maintained in order to move forward after cancer and prevent recurrence (Hefferon *et al.*, 2009; Corbett *et al.*, 2018). As a result, some survivors can reach a good level of physical activity and health. Finally, cancer survivors can adapt quite well to their disease and

its after-effects (Naus *et al.*, 2009) thus they assess their QoL as good whereas, objectively, it has been impaired. This phenomenon is referred to as response shift (Sprangers & Schwartz, 1999; Schwartz & Rapkin, 2004) and can account for good patient-reported QoL in spite of impairment. Finally, and most importantly, in the French national study, better or equal QoL has been found only in patients over 70 years of age. As the mean age of our sample was 62, this explanation is very plausible.

Nevertheless, impairments could be traced by cancer-related sequelae endorsed by 34.2% women of our sample as ‘somewhat troublesome’ (29.2%) or ‘very troublesome’ (5%) and were mainly of a physical nature (pain, fatigue, physical limitations). The French national study confirmed sequelae in 63.5% of their sample regardless of the type of cancer (INCa, 2018). General sequelae are mainly hearing impairments due to treatments (39.7%), and attentional and memory deficits (35.9% and 67.7%, respectively). Clinically significant fatigue was also endorsed in 48.7% of the national sample.

2.2. Post-traumatic growth

PTG items were highly endorsed in our sample as seen in Table 1, especially regarding a new ‘appreciation of life’ and ‘personal strengths’, as well as better ‘relationships with others’. In contrast, ‘spirituality’ and ‘new opportunities’ themes were not so endorsed. The same results were found in our qualitative research (Lelorain *et al.*, 2012b) and are in accordance with studies in female cancer survivors (Brix *et al.*, 2013; Wang *et al.*, 2014; Cormio *et al.*, 2017; Cheng *et al.*, 2018). The French national study on cancer survivorship also found an increase in spirituality in 25% of their sample only (INCA [French National Cancer Institute], 2018).

Table 1. Prevalence of posttraumatic growth at 5 to 15 years after breast cancer diagnosis

Item number	Item	Endorsement
1.	I changed my priorities about what is important in life	67.8%
2.	I have a greater appreciation for the value of my own life	87.0%
3.	I developed new interests	69.1%
4.	I have a greater feeling of self-reliance	63.8%
5.	I have a better understanding of spiritual matters	39.7%
6.	I more clearly see that I can count on people in times of trouble	71.3%
7.	I establish a new path for my life	55.4%
8.	I have a greater sense of closeness with others	84.4%
9.	I am more willing to express my emotions	64.8%
10.	I know better that I can handle difficulties	77.9%
11.	I am able to do better things with my life	70.4%
12.	I am better able to accept the way things work out	78.2%
13.	I can better appreciate each day	86.3%

Table 1. Continued

14.	New opportunities are available which wouldn't have been otherwise	38.1%
15.	I have more compassion for others	87.3%
16.	I put more efforts into my relationships	76.5%
17.	I am more likely to try to change things which need changing	71.7%
18.	I have a stronger religious faith	36.5%
19.	I discovered that I'm stronger than I thought I was	86.3%
20.	I learned a great deal about how wonderful people are	81.4%
21.	I better accept needing others	75.2%

Note. The percentage of endorsement refers to items endorsed from 'moderate degree' to 'very great degree'. Items in bold represent the top five most frequently reported growth experiences.

It is interesting to note that PTG was not higher in our BC sample than in our cancer-free comparison sample on any of the five PTG dimensions. In a similar study using cancer-free women identifying their own traumatic life-changing event, Brix et al. (2013) found higher levels of 'appreciation of life' and 'relating to others' dimensions of PTG in their BC sample than in their comparison one but similar results on the other three PTG dimensions. PTG may therefore unfold naturally throughout life as people grow older and encounter various difficult life-events.

A thematic class of PTG featured in our interviews with BC survivors, with typical PTG-related utterances such as: *'It has changed a lot of things in the way of thinking about things, to think that there is worse, to stand back, and to better understand people who are down too'*. Fitting with its very definition, PTG was very intertwined with suffering as perfectly illustrated here: *'This cancer is very harmful, but it also brings a lot of happiness, really a lot of happiness. As far as I'm concerned, I have suffered a lot from this cancer, but I have experienced a lot of happiness too, and I'm not going to thank this cancer because it would be out of place, but I'm going to thank life for having opened my eyes to things I maybe no longer saw'*.

Interestingly, the PTG class was not, as could logically be expected, primarily linked to our question concerning possible cancer-related changes but to the final open question that asked participants whether they would like to add something else or something they might have forgotten or something they would like to emphasise (see Figure 4, page 34).

One possible interpretation is that these positive changes were not so easily identified by women as opposed to negative changes (e.g. physical limitations, fatigue), probably because of the daily difficulty the latter involve. On the other hand, the mention of growth later in the speech revealed the demanding cognitive effort underlying the PTG, which required thinking about and processing an event, even a long time after its occurrence. In the PTG class, the presence of words like 'fight' or 'try'

associated with 'positive' showed that PTG was dependent on a cognitive effort and coping. Subjectivity indicators strongly associated with this class as revealed by Alceste© software (e.g. 'maybe', 'I think', 'I believe') confirmed the cognitive process or rumination of trying to make sense of the cancer. Therefore, the importance to PTG of the cognitive processing of the event as posited in the PTG model of Calhoun and Tedeschi (2006) previously described (page 21) received empirical support from our data. The fact that PTG was not embedded in time, as revealed by the negative association of the PTG with temporal indicators (such as words for week, days, years) in Alceste© software, also underpinned the idea that perceived changes depended less on the real historical medical facts than on the cognitive engagement by which women succeeded in distancing themselves from the stressful period of disease and treatment.

Another interpretation of the association of PTG with the final open question (and not the related-changes question) is that it is a way for women to end the interview with a positive outlook. They want to remember PTG and to communicate it as a positive conclusion. This way of pointing to growth as a conclusion could be an adaptive coping to counteract the negative aftermath of cancer, as suggested by other research (e.g. Morrill *et al.*, 2008; Park *et al.*, 2010) and in line with the finding that reported PTG is triggered by a perceived threat (McFarland & Alvaro, 2000). As patients' accounts contained difficult memories, thus eliciting potential distress and threat, PTG as a conclusion could have been a way to counter the interview-induced threat.

Finally, we found positive correlations between PTG and the three following indicators of well-being: 'happiness' assessed using a visual analogic scale and the 'vitality' and 'mental health' scores of the mental component score of the SF-36. These correlations suggest an authentic PTG in our sample of 307 long-term BC survivors, as reported in most of the 72 studies reviewed by Casellas-Grau *et al.* in BC (Casellas-Grau *et al.*, 2017). However, the question of the nature of PTG still remains.

In an original study, the authors investigated the link between PTG and the use of the Internet by BC survivors to search for information related to BC. PTG was associated with a predominant search for cancer-related psychosocial information and a decreased hope, pointing to PTG as a possible offset for hopelessness and isolation (Casellas-Grau *et al.*, 2018). However, this does not preclude that this form of PTG as a way of coping ended up in PTG as an outcome, something that was not tested in this study.

3. Factors associated with the quality of long-term survivorship in BC patients

3.1. Variables associated with mental QoL in long-term BC survivors

As mental QoL is more sensitive to psychological variables than physical QoL, we decided to focus on this and its associated psychosocial variables³ (Lelorain *et al.*, 2011).

3.1.1. The theoretical model

To explain mental QoL, we drew on the integrative model in health psychology (Bruchon-Schweitzer, 2002) (Fig. 2). Stemming from Lazarus and Folkman's transactional model of stress (Lazarus & Folkman, 1984), the model was thought to be heuristic for our purpose. Indeed, 1) it allows freedom in the choice of the explicative variables in that it specifies broad categories of variables, such as 'psychosocial antecedents', within which the choice of specific variables remains the responsibility of the researcher depending on the topic. This is why the model is more like a 'meta-model' than a model; 2) it combines variables that differ in nature (e.g. medical and psychological ones) and 3) it specifies direct and indirect effects, enabling an exploration of how the antecedents can affect the outcomes.

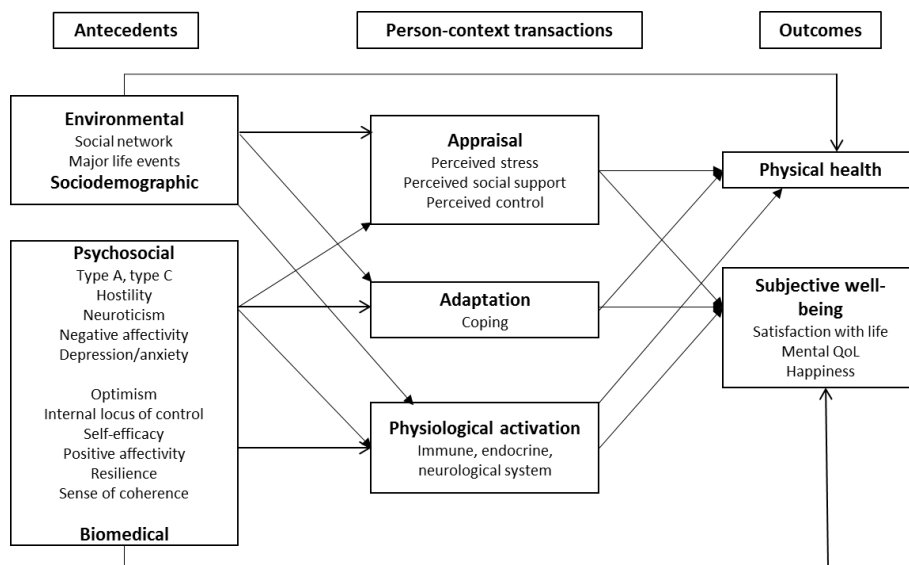


Figure 2. The integrative model in Health Psychology.

Just as a reminder, the method has already been described on page 23 in the section entitled 'Quality of long-term survivorship in BC patients'. Briefly, in a cross-sectional and retrospective design,

³ However, for interested readers, I tested an explanatory model of physical QoL in my PhD work (Lelorain *et al.*, 2009).

BC women were asked to complete validated questionnaires assessing their current QoL and various psychosocial aspects (e.g. coping using the Brief Copc that assesses 14 types of coping) referring to their reactions during cancer treatments.

Based on an examination of the literature on the variables associated with QoL in BC patients (Lelorain *et al.*, 2011), positive and negative affectivity, optimism, perceived stress, perceived social support and coping were selected.

Before testing the integrative theoretical model in a structural equation model, we first performed multiple regressions of transactional variables and treatment on mental QoL and perceived sequelae. From these preliminary analyses (data not shown), we retained only variables significantly associated with one of the outcomes: sequelae or mental QoL.

3.1.2. Psychosocial variables

Underpinned by theoretical and statistical considerations, the following model was retained (Fig. 3).

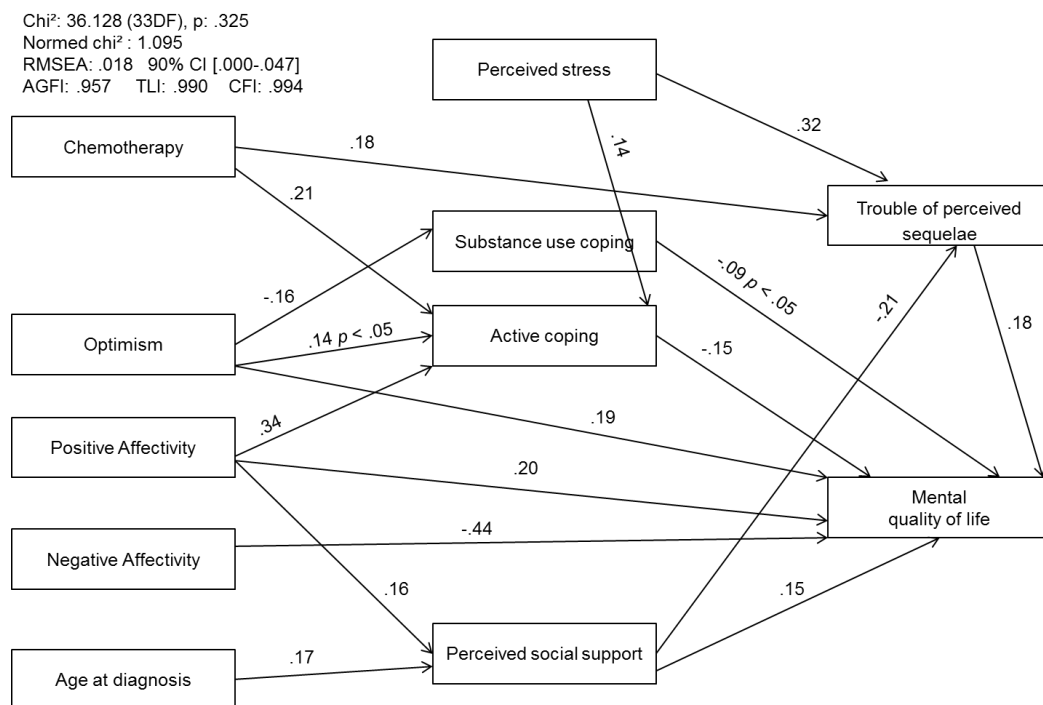


Figure 3. Retained model of mental quality of life prediction for breast cancer survivors. $R^2 = .50$ for mental quality of life and $R^2 = .18$ for sequelae. All paths shown are statistically significant at $p < .005$ unless indicated otherwise. Standardised coefficients are presented. Transactional variables (in the middle) referred to breast cancer.

The model presented an excellent fit to the data and explained a large part of the variance of the outcomes. I now discuss some of the main results of this model.

Expected results were found for personality variables that were directly linked to QoL, especially a large harmful effect of negative affectivity and a favourable effect of optimism, and positive affectivity. Since then, our results about negative affectivity and optimism have been confirmed by longitudinal studies (Brandao *et al.*, 2017; Durá - Ferrandis *et al.*, 2017). Interestingly, despite a strong correlation between optimism and positive affectivity in our sample ($r = .52, p < 0.001$), they each had their own specific role to play in mental QoL. For example, positive affectivity made it easier to perceive the environment as being supportive, as further confirmed (Den Oudsten *et al.*, 2010), probably because this personality trait makes caregivers and acquaintances want to help, whereas optimism enabled the avoidant coping of substance use to be reduced.

These results are in line with recent findings in the general population showing that greater diversity in day-to-day positive emotions is associated with lower levels of systemic inflammation (IL-6, CRP and fibrinogen) independent of mean levels of positive and negative emotions (Ong *et al.*, 2018). Basically, this means that it is beneficial for good health to experience a breadth of diverse positive emotions (e.g. both calmness and enthusiasm within the same day) and not only one single type of them.

We found a negative effect of chemotherapy through more perceived sequelae. The chemotherapy issue was confirmed in other studies (e.g. Durá - Ferrandis *et al.*, 2017). It is interesting to note that perceived sequelae were linked to social support, indicating that the way of experiencing sequelae can be alleviated by social support. The latter was expectedly linked to better mental QoL (Brandao *et al.*, 2017). Social support was higher with increasing age, highlighting a difficulty for young women to find support. Several reasons can be given. First, young women often work, as do their relatives, so that time accorded by their relatives can be reduced compared to the retired social network of older women who may have more time for support. This was confirmed by a study showing that having a job decreased satisfaction with received social support (Den Oudsten *et al.*, 2010). Second, BC at a young age may be more difficult to handle than at an older age due to the often-greater severity and aggressivity of the disease coupled with the many roles to be undertaken (worker, mother, friend, involved in the community, etc.). Hence, expectations of support are likely to be higher and the support received is more likely not to meet these expectations. Finally, cancer at an early age can frighten those around the patient, causing them to withdraw from the situation.

Of the 14 coping strategies provided by the Brief Coping questionnaire, only two were statistically associated, in a negative way, with the outcomes. As an avoidant coping, substance use was expectedly related to a lower QoL. The negative link between active coping (i.e. 'I took action to try to make the situation better' and 'I concentrated my efforts on doing something about the situation') and the outcome was less intuitive at first sight and contrary to data confirming its beneficial effect for mental health (Aguado Loi *et al.*, 2013; Elumelu *et al.*, 2015). However, a negative impact of active coping was reported in an earlier longitudinal study in long-term BC survivors (Lebel *et al.*, 2008). In our study, it should be remembered that women were asked to complete the coping questionnaire referring to how they coped with cancer at the time of the disease.

In this context, by its very nature, active coping can be an exhausting strategy in stressful events like cancer where control over the situation is far too limited during treatments for active coping to alleviate distress efficiently.



Indeed, during treatments, control is mainly in the hands of doctors and hospitals while patients are very tired. Letting go, instead of trying to make the situation better at a time where it cannot really be so, could be more helpful for patients while not giving up on acting later or within the scope of what can be done at that time.



Interestingly and confirming our reasoning, we found that positive affectivity had a harmful indirect effect on mental QoL through the mediation of active coping. However, it should be noted that our assessment of positive affectivity was actually an assessment of *high-arousal* positive affectivity using the PANAS scale (Watson *et al.*, 1988) where patients had to rate themselves on words reflecting activation such as 'excited', 'alert', 'active' and 'strong'. The same assessment with the words of high activation replaced by words of discrete positive emotions such as 'relaxed', 'at ease', and 'serene' (as used by Mikolajczak *et al.*, 2015 in Study 2) would certainly have yielded different results, such as an indirect positive effect through acceptance or positive reappraisal coping for example.

Finally, as hypothesised, cancer-related perceived stress led to lower QoL through more perceived sequelae. Interestingly, no endogenous variable was associated with perceived stress although negative affectivity, for example, was a plausible candidate in this regard. This suggests that this perception is very specific to BC and more related to the personal history or beliefs of patients than to objective medical variables such as chemotherapy or even personality.

Full reference:

Lelorain, S., Tessier, P., Florin, A., & Bonnaud-Antignac, A. (2011). Predicting mental quality of life in BC survivors using comparison participants. *Journal of Psychosocial Oncology*, 29(4), 430–449.

3.1.3. Clinical and sociodemographic variables

In specific multivariate analyses (Tessier *et al.*, 2012), we focused on the association of clinical and treatment variables, as well as sociodemographics, with a variety of patient well-being outcomes, namely mental QoL, happiness, positive affectivity and satisfaction with life. Among sociodemographics, the financial situation of patients was strikingly associated with all outcomes: feeling financially comfortable, compared to feeling comfortable but no more, was associated with more happiness, positive affectivity, and a better mental QoL. Similarly, being in financial difficulty was related to less satisfaction with life and less positive affectivity. No qualification or only primary education was also related to less positive affectivity.

These results point to BC survivors with an unfavourable socioeconomic status as a priority target for psychological and supportive care. It corroborates results that the effectiveness of psycho-oncology therapy is higher for people with a low socioeconomic level (Heron-Speirs *et al.*, 2013).

As regards clinical and treatment variables, a cancer tumour at stage 2 or 3, compared to stage 1, decreased the feeling of happiness while mastectomy expectedly decreased positive affectivity due to permanent body image damage. Finally, women who had received both chemo- and hormone therapy reported a higher score of happiness, compared to women without systemic adjuvant therapy. Although surprising at first sight, this twofold treatment, which indicates the severity of the disease, could have triggered a psychological process by which patients received a higher subjective reward from survival than women who had experienced neither of these treatments. Therefore, their feeling of gratitude for being alive was greater after such an extensive and prolonged treatment, and it is well-known that gratitude is related to happiness (e.g. consult Armenta *et al.*, 2017 for a review) even in BC patients (Ruini & Vescovelli, 2013).

These results highlight that mental QoL alone may not be a sufficient indicator to grasp the various long-lasting consequences of BC since the different outcomes studied here were not sensitive to the same predictors.

As previously presented (page 18), the concept of QoL, especially mental QoL, may not account for the whole picture of a patient's mental state. With the exception of financial issues, mental QoL, which is fundamentally a functional outcome, was not predicted by any candidate variable. The same pattern was found for satisfaction with life, which is a cognitive outcome (Shankland & Bouvard, 2012). In contrast, happiness and positive affectivity, which are emotional outcomes, were sensitive to clinical and treatment variables. Taken together, although correlations were relatively high ($> .38$) between all these outcomes, the pattern of results suggests that cognitive work may be of interest to maintain satisfaction with life in spite of clinical impairments and their emotional consequences, reminding us that PTG is theorised as a fundamentally cognitive process.

Full reference:

Tessier, P., **Lelorain, S.**, & Bonnaud-Antignac, A. (2012). A comparison of the clinical determinants of health-related quality of life and subjective well-being in long-term breast cancer survivors. *European Journal of Cancer Care*, 21(5), 692–700. <https://doi.org/10.1111/j.1365-2354.2012.01344.x>

3.2. Psychosocial variables associated with PTG in long-term BC survivors

Variables associated with PTG were determined in two ways: using Alceste© software, as it is capable of linking interviewees' characteristics to their speech as seen in Figure 4 below (Lelorain *et al.*, 2012b), and performing a multiple regression analysis on PTG with sociodemographic, medical and psychological variables as predictors (Lelorain *et al.*, 2010). The integrative model of health psychology (presented on page 28) as well as the theoretical model of Calhoun and Tedeschi (presented on page 21) guided our choice of the psychosocial variables we thought related to PTG.

As can be seen in Figure 4, the PTG class was associated with 'adaptive coping', which encompasses all the coping factors from the Brief Cope except substance use, blame and behavioural disengagement, considered non-adaptive coping. In the regression analysis performed on the total sample of the 307 survivors, we found that active, positive (i.e. positive reappraisal, humour and acceptance), relational, and religious coping were associated with PTG. We also found a trend for a positive association between denial coping and PTG ($p = .06$).

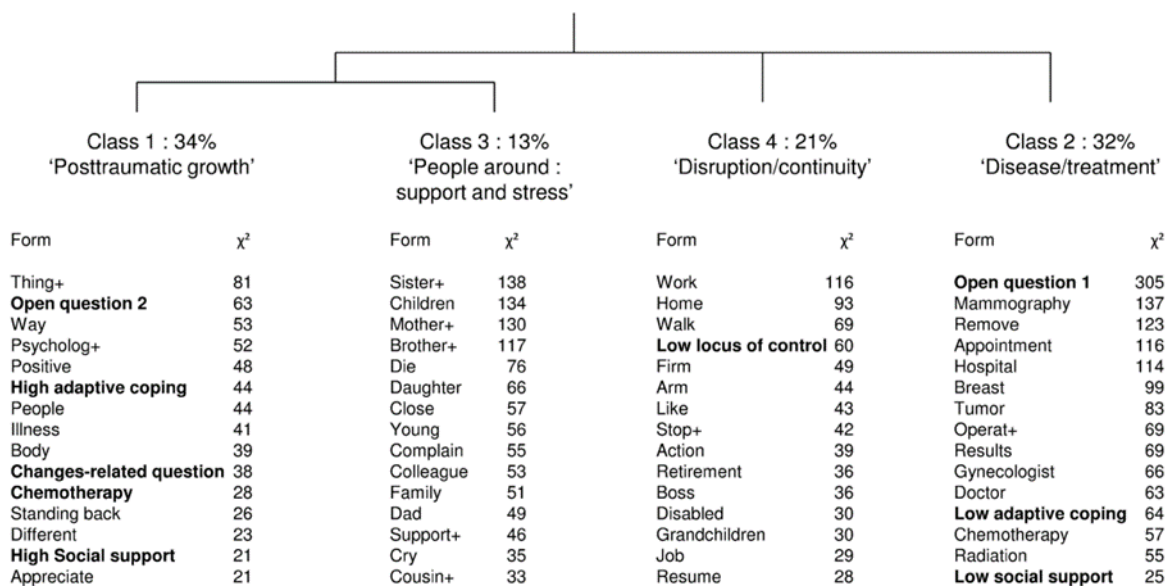


Figure 4. Descending hierarchical classification performed by Alceste© software on BC survivor interviews.

Entered variables are in bold. Only the first 15 elements most strongly associated with each class are reported. Open question 1 was: 'Could you please tell me about the way you experienced your cancer? What do you remember the most? What happened to you?'. The changes-related question bore on the possible cancer-induced changes, and open question 2 was: 'Would you like to add something else or emphasise something?'

At first sight, the latter association may seem less intuitive than the others but it matches the illusory and self-deceptive side of PTG, by which people claim PTG even though no growth is actually embedded in their life and the traumatic aftermath of cancer has not been dealt with, hence denial and likely distress. However, in line with the first data on the subject (Aldwin *et al.*, 1996), most research has since confirmed that PTG is generally associated with adaptive coping and not with non-adaptive coping (Kolokotroni *et al.*, 2014; Triplett, 2014; Danhauer *et al.*, 2015; Tomita *et al.*, 2017). We also found an association between social support and PTG, which was further confirmed (Kolokotroni *et al.*, 2014; McDonough *et al.*, 2014; Danhauer *et al.*, 2015; Cormio *et al.*, 2017; Tomita *et al.*, 2017). This result is in line with the theory proposed by Calhoun & Tedeschi (2006), which we presented on page 21, in which PTG arises through patients' self-disclosure and cognitive processing of the event. Although the authors do not explicitly mention it, these processes may be facilitated by, if not dependent on, social support.

Interestingly, opposed to the PTG class, class 2 focused on cancer and treatments, which were described in very concrete terms in the narratives.



Women characteristic of this class 2 had low adaptive coping and low social support, and were not capable of distancing themselves from the medical burden of cancer in order to gain a more meaningful overview of the situation and derive growth.



Finally, the PTG class featured chemotherapy, which is congruent with the theory that PTG derives from a stressful event, indicated here by chemotherapy treatment, which in itself is a source of stress and annoyance.

Full reference:

Lelorain, S., Tessier, P., Florin, A., & Bonnaud-Antignac, A. (2012). Posttraumatic growth in long term breast cancer survivors: relation to coping, social support and cognitive processing. *Journal of Health Psychology, 17*(5), 627–639. <https://doi.org/10.1177/1359105311427475>

In statistical regression and path analyses (Lelorain, 2009; Lelorain *et al.*, 2010), positive affectivity was associated with PTG, a result consistent with subsequent research in oncology (Kolokotroni *et al.*, 2014) and other diseases (Javed & Dawood, 2016; Satheesan & Hameed, 2017). Once again, although not explicitly mentioned in the theory of Calhoun & Tedeschi (2006), positive affectivity seems essential for the reduction of the distress induced by the event, which can in turn bring about a new perspective of the event and thus PTG. The need for positive affectivity to adopt a new and wider perspective of a difficult situation recalls the broaden-and-build theory of positive emotions (Fredrickson, 2004). The key proposition of this theory is that positive emotions broaden an individual's momentary thought-action repertoire, which in turn builds that individual's personal resources, ranging from physical and intellectual resources to social and psychological ones. This theory was verified in our data in which positive affectivity was related to adaptive coping (Lelorain, 2009), i.e. multiple ways of effective coping such as acceptance, humour, social-support eliciting, positive reappraisal, active coping, etc., which in turn was related to PTG. On the contrary, the typical patients of class 2 were stuck in a narrow view of the disease and treatment, without being able to elaborate on the experience.

Finally, among medical and sociodemographic data associated with PTG, we only found a curvilinear effect of perceived sequelae and stress on PTG (shaped as an inverse U). *Somewhat* troublesome sequelae were associated with more PTG whereas *very* troublesome sequelae were associated with less PTG; similarly, a moderate stressful-event-induced stress increased PTG whereas a high level of stress was associated with less PTG. These results are consistent with the PTG theory that posits that a situation must be stressful for PTG to emerge.



However, the curvilinear relationship suggests that, at some point, too much stress can ward off adaptive coping and efficient cognitive processing of the event, thus forestalling PTG. Further studies in cancer settings have also highlighted the curvilinear relationship between both variables (Zebrack *et al.*, 2015; Coroiu *et al.*, 2016), which could inform contentions about the nature of PTG as authentic or illusory. Patients reporting high PTG in the presence of a highly stressful event (i.e. a really traumatic event) might actually experience a self-deceptive PTG aimed at helping them in their distressing struggle whereas patients reporting PTG vis-a-vis mild or moderate stress may experience a more authentic PTG.



Full reference:

Lelorain, S., Bonnaud-Antignac, A., & Florin, A. (2010). Long Term Posttraumatic Growth After Breast Cancer: Prevalence, Predictors and Relationships with Psychological Health. *Journal of Clinical Psychology in Medical Settings*, 17(1), 14–22.

4. Take home message

The first part of this HDR was dedicated to the long-term mental QoL of women at five to ten years after a BC diagnosis, and reflected my PhD work. This research included 307 women in a cross-sectional design using patient-reported questionnaires, and 28 open interviews, as well as 132 women without BC for comparison purposes. With the exception of the sexual dimension of QoL, the physical and mental QoL of BC women on certain dimensions were equivalent to or even better than those of women without BC. In addition, BC women reported substantial levels of PTG, especially in the domains of the appreciation of life, personal strengths and better relationships with others. The exploration of factors related to mental QoL and PTG revealed the major role of affective positivity, adaptive coping, social support and perceived sequelae in the variance of these two patient outcomes. The latter two outcomes were also positively correlated in our sample, suggesting a real PTG stemming from effective coping and cognitive processing of the stressful event, and not a fake and illusory PTG as sometimes reported in research or clinical accounts. This work resulted in four publications.

5. The need to include physician empathy in our work

At this stage of my professional progression, two intertwined elements influenced the pursuit of my research theme in cancer care toward the topic of physician empathy. The first trigger factor was a dissatisfaction with the theoretical models that had underpinned my research so far, i.e. the transactional model of stress and coping and the post-traumatic growth model, as they did not capture the specificities of the cancer situation. In fact, these models were theorised for general stress and not for specific stress related to health and even less related to cancer. Yet, two factors are specific to cancer.

First, from a temporal perspective, cancer must be considered in the past, the present and the future. For patients, the past is at least the period of diagnosis and the blow that accompanies it, the present is fraught with treatments, side effects, tests and a poor quality of life, and the future is characterised by uncertainty, fear of death or of recurrence that gives the feeling of living on borrowed time, plus the aftermath of cancer in the case of survivorship.

Second, cancer care is long and depends mainly on the expertise of physicians. They are the ones who have control over the situation. In contrast, patients are often lost among medical procedures, treatments and a complex healthcare system. Against this background, patients endorse surgeons and oncologists, along with general practitioners (GPs), as their preferred professionals for the management of their cancer care (Durcinoska *et al.*, 2017). This is exactly what I witnessed in the oncological ward where I worked as a psychologist in 2009 and 2010, and which was the second trigger factor explaining my wish to orientate my research toward physician empathy. Some patients hang on the physicians' every word. Even though nurses play an increasing role in cancer care, patients do not value their opinions as much as those of physicians. Although patients fully value and adhere to nurses' advice regarding practical matters, they remain focused on physicians' words when it comes to prognosis, test results, future outlook and hope. Our clinical observation was confirmed by the health psychology master's dissertation of one of our students (Bellanger, 2018). She interviewed cancer patients about their expectations regarding healthcare professionals including nurses. In spite of her multiple reminders of the topic, patients barely spoke about nurses and kept straying onto physicians. Consequently, I am of the opinion that cancer patient representations of illness and the resulting coping cannot be studied without investigating how doctor-patient communication plays out and impacts patient outcomes. In the specific context of cancer, theoretical models such as the Common Sense Model of illness representations (Leventhal *et al.*, 1980) would thus be improved by including doctor-patient communication in their specification.

While I became convinced of the importance of physicians in cancer care, I was given the opportunity to complete a postdoctoral work on physician empathy in cancer care at Paris Descartes University and at the Curie Institute, one of the biggest cancer centres in Paris. This opportunity was the tipping point for me and I decided to move to Paris and fully focus my research on this topic.

PART 2: PHYSICIAN EMPATHY IN CANCER SETTINGS

In this part, I will first explore the definitions of empathy and related concepts such as compassion. Second, the fact that I was personally convinced of the need to integrate physician empathy into research on patient adjustment to cancer did not mean that my intuition was true. This is why I will next address the question of whether empathy is worth studying. Finally, I will describe our work on empathy in cancer care based on the two following questions: how can we explain physician empathy and what are the patient outcomes of this empathy?

From this point onward, with the exception of one study in a general medicine setting, all our work has been carried out in oncology. Therefore, by default, I will try to focus on the oncology literature, otherwise the context of non-cancer studies will be specified (e.g. general medicine, social psychology, etc.).

1. What is medical empathy?

1.1. General definitions of empathy

As Cuff et al. (2016) explain in their review of the concept, the term 'empathy' was coined in 1909 as an adaptation of the German word *Einfühlung* to describe what spectators feel in front of an artwork. In spite of more than 100 years of the use of this word, there is still no consensus on the definition of the term, which remains an elusive concept. Nevertheless, several overarching definitions of empathy have been established including (Eisenberg & Eggum, 2009):

- other-oriented perspective-taking: to take others' perspective by imagining how *they* feel and think,
- self-oriented perspective-taking: imagining how *one* would think and feel in the other's place, which is exemplified in sympathy and illustrated, for example, by the doctor who says 'I know how you feel' (Jeffrey, 2016); this process is a risk of personal distress and false assumptions.
- cognitive empathy or empathic accuracy: knowing another person's internal state, including his or her thoughts and feelings. It can be the result of perspective-taking but also of other processes such as stereotypes that I will explore later,
- emotional contagion or affective empathy: to be contaminated by the emotion of others, to feel the same emotion as another person feels,

- emotional distress: to feel distressed in the face of others' distress, which does not lead to action but to avoidance behaviour (e.g. Soodalter *et al.*, 2018 for a well-described example in palliative care) due to poor coping in the regulation of one's and others' emotions,
- and empathic concern or sympathy or compassion: to feel concerned for someone, with arguably a drive to alleviate the other's suffering.

In a non-systematic review, which does not refer to medical settings but empathy in general, 43 different definitions of empathy and eight themes closely related to the very definition of the concept were found (Cuff *et al.*, 2016).

Among the themes was, for example, the debate about the cognitive or affective nature of empathy and the distinction between empathy and related concepts like compassion or sympathy. In particular, like Batson (2009), Cuff *et al.* (2016) distinguish empathy (i.e. feeling *as* the other, feeling the same emotion) from sympathy (i.e. feeling *for* the other, feeling a different emotion that is a concern for the other person) and compassion. The latter concept is close to sympathy but implies pity and a subsequent desire to help, although in fact they are often used interchangeably (Jeffrey, 2016). After a thorough review of the different definitions, they came up with a definition that encompassed the most evidence-based consensus: 'Empathy is an emotional response (affective), dependent upon the interaction between trait capacities and state influences. Empathic processes are automatically elicited but also shaped by top-down control processes. The resulting emotion is similar to one's perception (directly experienced or imagined) and understanding (cognitive empathy) of the stimulus emotions, with recognition that the source of emotions is not one's own' (Cuff *et al.*, 2016, p. 150). Some authors also include in empathy the regulation of possible personal distress coming from the other's suffering to allow compassion and helping behaviour (Xiao *et al.*, 2016). In that sense, empathy is an emotional skill to perceive the emotions or concerns of others, to understand them, and to regulate one's emotions elicited by others in order to act on the situation to help.

1.2. Medical empathy

In medical settings, the same problem arises with the definition of empathy. In a review about empathy measures in medicine, in most retrieved articles the definition of empathy was not explicitly stated nor whether the object of empathy concerned patients' feelings only or any patients' experiences such as their supportive care needs (Pedersen, 2009).



In a more recent review about empathy in medical education research, 20% of the 109 retrieved articles even failed to define the construct of empathy and only 13% used an operationalisation that matched well the definition provided (Sulzer *et al.*, 2016).



In the retrieved definitions, empathy was mostly defined as a cognitive and behavioural element (31% as seen in Figure 5), corresponding to the seminal definition of medical empathy by Hojat as a ‘predominantly cognitive attribute that involves an understanding of the patient’s experiences, concerns, and perspectives, combined with a capacity to communicate this understanding’ (Hojat, 2007).

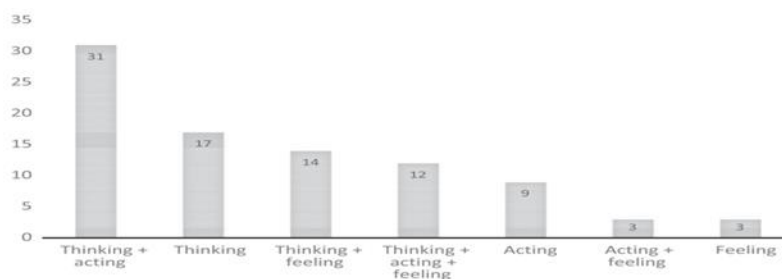


Figure 5. Frequencies of the various components in definitions of empathy in medical education research (Sulzer *et al.*, 2016).

Some authors, however, advocate the idea that medical empathy cannot be cognitive alone and that the affective component greatly serves the cognitive goal of understanding patients’ emotions (Halpern, 2003). Jeffrey (2016) also claims that, in practice, the various dimensions of empathy inevitably interact and overlap. In addition to the thinking, feeling and acting parts of empathy, some authors have mentioned a moral dimension of empathy as the internal motivation of concern for the other and a desire to relieve patients’ suffering (Morse *et al.*, 1992).

The question of the distinction between sympathy, empathy and compassion has also been addressed in medical settings. In this context, empathy ‘clearly involves imaginative involvement [...whereas] sympathy and compassion typically refer to reactive and unreflective responses whose features require no great psychological acumen to appreciate. [...] Empathy is in contrast to compassion which does not necessarily involve cognitive understanding of the others’ views’ (Jeffrey, 2016, p. 449). This distinction between empathy on one hand and compassion and sympathy on the other hand is also reported by the patients themselves when interviewed about the difference between the three concepts (Sinclair *et al.*, 2017). In this very insightful grounded theory analysis of the patients’ points of view, the authors conceptualised sympathy as a ‘shallow and superficial

emotion based on self-preservation'. Patients shun this unwanted pity-based response characterised by a lack of relational understanding and genuine concern illustrated by stereotypical utterances like 'Oh I'm sorry you're going through this'. In contrast, empathy and especially compassion are desired and deemed genuine. Empathy is defined as 'an affective response that acknowledges and attempts to understand an individual's suffering through emotional resonance'. The key words of empathy as described by patients are 'to put yourself in the patient's shoes' and recall the 'other-oriented perspective-taking' process described earlier.

Finally, compassion is motivated by love and goes beyond empathy by integrating action to relieve patients; the action part was also found in a thorough qualitative study into oncologists and patients with advanced cancer (Cameron *et al.*, 2015), as well as in a literature review in healthcare (Perez-Bret *et al.*, 2016).

In the latter, compassion is defined as a 'virtuous response that seeks to address the suffering and needs of a person through relational understanding and action'. The engagement typical of compassion is implemented by small supererogatory acts of kindness to which patients are very sensitive as they feel the genuine nature of them. Unlike Jeffrey's definition, from the patients' points of view, compassion implies a real understanding of patients' views.

In my opinion, one of the best definitions of medical empathy is that of Stewart Mercer and William Reynolds, who define empathy as an ability to: 1. Understand the patient's situation, perspective and feelings; 2. Communicate that understanding and check its accuracy; and 3. Act on that understanding with the patient in a helpful way (Mercer & Reynolds, 2002).

Although some authors claim that the acting part actually pertains to compassion and not empathy (e.g. Fernando & Consedine, 2014; Sinclair *et al.*, 2017), I would include it in medical empathy itself as in medical settings, the acting part is so critical. Medical empathy without further acting in accordance with the understood needs of patients would be a clinical nonsense as firmly advocated by authors before us (e.g. Halpern, 2003; Decety & Ickes, 2009; Jeffrey, 2016). Therefore, it is vital to maintain the third element of the definition (i.e. the acting part). However, I would merge the second and third elements of the definition into one single component. Indeed, physicians are sometimes unable to act in a helpful way because of external constraints or the patient's situation (e.g. a desire to travel, which is not possible due to poor health) but their communication of the understanding of the patient can at least be helpful in itself. Conversely, physicians committed to helping the patient with tailored actions can be perceived as empathic even though they do not explicitly communicate

their understanding and check its accuracy. Finally, I would definitely consider the internal motivation of concern for and desire to help patients as essential to the definition. Indeed, I believe that a physician could understand a patient and act on this in a helpful way without being perceived as empathic by the patient if his/her motivations were not patient-oriented. The willingness to connect with and be concerned by patients seems essential for genuine empathy.

To summarise, I propose the following definition: medical empathy is the internal motivation of concern for patients and a desire to help them that enables the identification of their emotions and the understanding of their perspective, needs and feelings and the actions resulting from this understanding, whether these be behavioural and/or verbal.

Actually, this definition is very similar to the one of compassion of Beth Lown in her model of compassion in health care (Lown, 2016).

I plan to explore empathy further by investigating its measures so as to clarify what components of empathy are at stake in clinical research.

1.3. Measures of medical empathy

1.3.1. Overview

Currently, measures of empathy in medical settings are mainly of three types (Hemmerdinger *et al.*, 2007; Pedersen, 2009; Sulzer *et al.*, 2016):

- *patient*-reported questionnaires by which patients assess the empathy of healthcare practitioners (physicians, nurses, etc.; an example will be given below),
- *practitioner*-reported or *self*-reported questionnaires by which practitioners rate themselves about their empathy with all the biases one can imagine (e.g. the Jefferson Scale of Physician Empathy, Hojat *et al.*, 2002b)
- observations of clinical encounters by external coders who code the verbal and non-verbal behaviours of healthcare professionals in interactions with patients using systematic and detailed coding systems. For example, such codes assess whether the doctor paraphrases, shows understanding and concern, back channels or legitimises the words of the patient (e.g. The Medical Interaction Process System, Ford & Hall, 2004). Assessment of physician responses to patient empathic opportunities or empathic windows or cues also falls into this category (e.g. The Empathic Communication Coding System, Bylund & Makoul, 2005). An empathic

opportunity is a verbal or non-verbal hint that suggests an underlying emotion or concern of the patient. These emotions can be positive or negative, mostly negative in cancer settings, and expressed more or less explicitly by the patient. The way the physician addresses them can be coded with different levels, from ignorance to probing with acknowledgement and further exploration.

A fourth way to assess empathy is for a caregiver to do an empathic accuracy task. The patient is asked to assess his or her distress or concerns or needs (or something else) and the caregiver is independently asked to assess the same thing but from the patient's point of view. The caregiver must 'guess' the patient's answer. The closer the caregiver is to the patient's answer, the more empathic s/he is considered.

The use of the qualitative exploration of empathy is also possible but less common (Sulzer *et al.*, 2016).

These four ways of assessing empathy – patient-reported, physician-reported, coding system, or empathic accuracy task – will be of importance throughout the rest of this work.

In his review, Pedersen (2009) found that, most frequently, empathy was studied through self-report measures probing rather general personal inclinations and attitudes towards empathy (e.g. 'I think it is important to take my patients' emotions into account') than a precise assessment of one's empathy in a precise situation with a given patient. Assessments performed by observers then followed and lastly, less frequently, patients or simulated or standardised patients were asked to rate the professionals. In addition, importantly, only 17% of the reviewed studies used more than one perspective (e.g. patient-reported and physician-reported). In 2016, Sulzer *et al.* confirmed these findings with 72% of self-reports, 26% of third-party reports and 17% of patient or standardised patient reports in empathy assessment. Here again, only 13% used more than one perspective. Contrary to these results in medicine in general, in a literature review we carried out in cancer settings (Lelorain *et al.*, 2012a, which will be featured in a subsequent part of the document), we found a majority of patient-reported assessments and coding systems and only one self-reported tool; it should also be noted that a high number of studies used bespoke tools. Finally, none of the retrieved studies evaluated empathy by using two or more different perspectives.



This lack of triangulation of perspectives is a failure of research as there is evidence that the three types of empathy assessment (i.e. patient-reported, coding systems, self-reported by physicians) are weakly correlated.



For example, patient-centred communication⁴ using a coding system was found to be very weakly correlated with patient-perceived patient-centeredness (Dong *et al.*, 2014). Self-reports of empathy are sometimes loosely correlated with actual behaviour (e.g. Colliver *et al.*, 2010; Libert *et al.*, 2017), although self-reports are associated with objective communication in medical students (Casas *et al.*, 2017; LaNoue & Roter, 2018). Furthermore, self-reports do not correlate with patient-reports (Grosseman *et al.*, 2014; Bernardo *et al.*, 2018). In one of our studies in 28 oncologists and their 201 metastatic cancer patients (Lelorain *et al.*, 2015), only one of the three dimensions of the self-report 'Jefferson Scale of Physician Empathy' (Hojat *et al.*, 2002a; Zenasni *et al.*, 2012), the 'perspective-taking' dimension, was positively related to *patient*-reported physician empathy using the CARE questionnaire (Consultation And Relational Empathy; Mercer *et al.*, 2004). The other two self-reported dimensions, 'compassionate care' and 'in the patients' shoes' did not correlate with the assessment of patients (Lelorain *et al.*, 2015).

It should be noted that the names of the three dimensions are somewhat tricky. The 'perspective-taking' dimension is the only one whose label is correct. It concerns the extent to which physicians think that it is important to understand their patients' emotions and feelings through verbal and non-verbal cues. Typical items are 'An important component of the relationship with my patients is my understanding of the emotional status of the patients and their families' and 'I try to imagine myself in my patients' shoes'. The 'in the patients' shoes' dimension actually refers to the extent to which physicians think that it is difficult to view things from the patients' perspectives. Actually, it is more a self-efficacy assessment of perspective-taking. The 'compassion' dimension refers to the extent to which physicians think that emotions have a place in care and how much they pay attention to emotions, so that it does not fit the definitions of compassion detailed previously (page 41) according to the inquiry of Jeffrey (2016) and Sinclair *et al.* (2017), in which compassion was primarily a matter of action to relieve patients' distress. In fact, the Jefferson Scale of Physician Empathy is a measure of cognitive empathy in clinical settings, which fits with the rather cognitive definition of its author, Mohammadreza Hojat (Hojat, 2007).

This fact that the different types of measures do not correlate between them is of utmost importance in the study of the outcomes of empathy as, logically, empathy has an impact on patients when it is rated by the patients themselves and not by physicians or external coders (Hollinger-Samson & Pearson, 2000; Lelorain *et al.*, 2012a), a finding confirmed in recent reviews (Street & Mazor, 2017; Elliott *et al.*, 2018).

⁴ Patient-centred communication is a larger concept than empathy, but has empathy at its core.

This is why I propose a brief focus on this type of measure.

1.3.2. A focus on patient-reported assessment

One of the most used patient-reported empathy measures is the CARE questionnaire (see the Appendix for the English and French versions of the scale). It comprises ten items and has been translated and validated in numerous languages (e.g. Aomatsu *et al.*, 2014; Bikker *et al.*, 2015, 2017; Chen *et al.*, 2015; Ahlforn *et al.*, 2017). Although some validations demonstrated the one-dimensional structure of the construct (e.g. Bikker *et al.*, 2015; Ahlforn *et al.*, 2017; van Dijk *et al.*, 2017), others found that the scale could contain two dimensions (Wirtz *et al.*, 2011; Hanževački *et al.*, 2015). Furthermore, even in papers showing one single construct (e.g. Bikker *et al.*, 2015; Ahlforn *et al.*, 2017; van Dijk *et al.*, 2017), items 9 and 10 are highly endorsed as ‘not applicable’ suggesting that these two items are not related to the rest of the scale. Indeed, these two items, - how good was the practitioner at ‘helping you to take control’ and ‘making a plan of action with you’ – pertain to the empowerment of patients, advocated by Mercer & Reynolds (2002) as an important component of medical empathy. Actually, the CARE questionnaire rigorously follows the definition of its authors in three points (Mercer & Reynolds, 2002; Fung & Mercer, 2009): 1. Understand the patient’s situation, perspective and feelings (items 1 to 4 of the scale); 2. Communicate that understanding and check its accuracy (items 5 and 6); 3. Act on that understanding with the patient in a helpful way (items 7 to 10). The CARE questionnaire follows even better the definition of empathy by Jeffrey (2016) for whom empathy comprises an emotional connection (items 1 and 6), a clinical curiosity to gain insight into patients’ concerns, feelings and distress (items 2 to 4), an another-oriented perspective with a self-other differentiation (item 5 by which physicians ask for patient feedback to check his/her understanding) and actions to help patients (items 7 to 10).

It should be noted that item 7 focuses on the positive attitude of physicians while remaining honest. Even if, at first sight, a positive attitude may not appear obvious in the empathy construct, it can be seen as a response to patients’ needs for hope and therefore considered as likely connected with empathy in medical settings (Howick *et al.*, 2015). Patients reported more compassion from physicians after watching a more optimistic video compared to a less optimistic one, while controlling for the same core content in the delivered message (Tanco *et al.*, 2015) although these results were not confirmed in a subsequent similar protocol using scripts instead of videos (Tanco *et al.*, 2018).

The issue is to clarify whether these three components are independent or not and also whether they are equally expected by and beneficial for patients according to their characteristics and the context of empathy (i.e. neutral or





emotion-laden situations). In primary care, for example, a systematic review suggested that cognitive reassurance (i.e. explanation and education, which correspond to the 'acting part' of empathy, items 7 to 10 of the CARE) was associated with better patient outcomes whereas affective reassurance (rapport and empathy, all other items of the scale) was associated with higher symptom-related burdens and less improvement at follow-up (Pincus *et al.*, 2013).



These questions will be addressed in cancer care later on in this document. Lucie Gehenne, a doctoral student under my co-supervision with Prof. Véronique Christophe, is currently working on the French validation of the scale in cancer care and on an experimental study testing the impact of two dimensions of physician empathy (i.e. affective reassurance vs. cognitive reassurance) on real cancer patients' hopelessness and perceived control over the disease. These two dimensions are displayed in videos of doctor-patient consultations played by actors (French League against Cancer funding; inclusions will start in November, 2019).

Full reference:

Gehenne, L., **Lelorain, S.**, Anota, A., Brédart, A., Dolbeault, S., Sultan, S., Piessen, G., Grynberg, D., Baudry, A-S., Christophe, V., and FREGAT Working Group. Distinction between three empathic processes in cancer care: a French validation of the CARE measure. Expected submission in November 2019 in *European Journal of Cancer care*.

2. Why is it necessary to study medical empathy?

Here, I will review three arguments to justify the need for research on empathy: 1) empathy is expected by patients, 2) however, HCP empathy may not be high, and especially 3) we do not know yet exactly in which conditions empathy may really benefit patients.

2.1. Empathy is highly expected by patients

First, medical empathy is generally expected by the general population and patients, especially as found in qualitative studies; quantitative research reports lower patient expectations (Deledda *et al.*, 2013). However, in a recent non-cancer study, 800 lay-people from four European countries were invited to assess quantitatively the importance of physicians' behaviours before, during and after consultations, in order to improve medical consultations. Five out of the six items rated as the most important during consultations related to empathy, the most important being 'the doctor knows when

to refer the patient to a medical specialist' (Mazzi *et al.*, 2016). This study confirms previous similar findings from the same authors (Mazzi *et al.*, 2013). Furthermore, empathy is an important part of patient satisfaction (Grayson-Sneed *et al.*, 2016).

In cancer care, the disclosure of bad news is frequent due to diagnosis, poor prognosis, cancer progression, recurrence, treatment failure, severe side effects, non-eligibility for surgery or clinical trials, and complications. In such cases, empathy is also generally expected (Ptacek & Ptacek, 2001; Fujimori & Uchitomi, 2009; Munoz Sastre *et al.*, 2011; Martins & Carvalho, 2013; Seifart *et al.*, 2014; Zahra Mostafavian *et al.*, 2018), at least regarding certain components such as the quality of listening, individualisation of consultations and time devoted by physicians to patients. However, patients' preferences vary on certain components such as the way to break bad news in a matter-of-fact manner or not (Fujimori *et al.*, 2007), to the extent that a minority of patients prefer a distant approach while others value an emotionally-burdened physician showing extreme compassion (Martins & Carvalho, 2013).



Therefore, there is no one-size-fits-all recipe and general guideline protocols purported to help break bad news can be called into question by empirical data (Dean & Willis, 2016).





This does not, however, alter the fact that empathy, in the sense of an accurate perception of patients' needs and tailored responses to those specific and individual needs, is always expected, mostly including a compassionate way to address those needs.

Furthermore, this expectation of empathy is not specific to bad-news disclosure and remains true throughout the cancer pathway, as we found in a cross-sectional and retrospective qualitative study about cancer care coordination (Lelorain *et al.*, 2019b). The increasing complexity of treatments and the number of healthcare professionals involved in cancer care, along with more personalised diagnostic and treatment approaches, make disjointed care more likely (Walsh *et al.*, 2011) whereas coordinated care is of utmost importance. It has many positive outcomes such as better pain management, fewer and shorter hospital visits (Dreiher *et al.*, 2012; Shin *et al.*, 2014), more patient satisfaction (Fogliano *et al.*, 2016) and quality of life (Plate *et al.*, 2017), and even less mortality (Shin *et al.*, 2014). These are the reasons why we were interested in the issue of care coordination, which had not yet been addressed in France (Fogliano *et al.*, 2016).

For this purpose, using semi-structured one-on-one interviews, we collated data from 21 cancer patients plus their family caregivers, 54 hospital healthcare professionals from both the University Hospital and the Comprehensive Cancer Centre of Lille, and 12 city doctors treating cancer

patients about their perception of the coordination of cancer care in Lille (northern France). The interviews were coded using N-Vivo 10® with a deductive approach by a predetermined coding system based on the model of Jeannie Haggerty, who had determined three dimensions of continuity: informational continuity (i.e. the transfer of appropriate information at the right time), organisational continuity (i.e. how care is organised, whether it is coherent and timely with complementary services that must not be lacking or redundant), and relational continuity (i.e. good or poor relationships, mistrust, empathy and communication).

 Strikingly, 51% of the patients' and relatives' discourses about coordination pertained to relational continuity as against only 10% for hospital healthcare professionals and 26% for city physicians. 

Relational aspects are clearly of utmost importance for patients, especially in comparison with healthcare professionals, who may not be always so relationship-oriented for reasons explained in the next section.

Full reference:

Lelorain, S., Moreaux, C., Christophe, V., Weingertner, F., & Bricout, H. (2019). Cancer care continuity: A qualitative study on the experiences of French healthcare professionals, patients and family caregivers. *International Journal of Care Coordination*, 22(2), 58–68. <https://doi.org/10.1177/2053434519856866>

Now that I have described the patients' expectations of empathy, I will present the empathy level in medical care, especially cancer care.

2.2. Empathy is arguably suboptimal

Our research into cancer care coordination illustrates the already known findings that physicians do not always fully meet patients' needs for communication and empathy (Seifart *et al.*, 2014; Dean & Willis, 2016; Sobczak *et al.*, 2018). In this regard, it seems that there is room for improvement. The problem of insufficient empathy may arise very early in the medical curriculum and career of physicians.

Indeed, although mixed results are found on the topic (Colliver *et al.*, 2010), with studies showing a stability in medical empathy during the medical curriculum, for example in Australia (Mahoney *et al.*, 2016; Hegazi *et al.*, 2017), the UK (Quince *et al.*, 2016), the USA (Teng *et al.*, 2017) and Portugal (Duarte *et al.*, 2016b), other data supported the theory of an empathy depletion in

medical students (Neumann *et al.*, 2011a; Ren *et al.*, 2016; Igde & Sahin, 2017; Han & Pappas, 2018; Hirono Ishikawa *et al.*, 2018), and nursing students too (Ward *et al.*, 2012). In fact, it depends on geosociocultural clusters. Whereas US studies predominantly show small but significant decreases in empathy, Far Eastern studies mostly show small but significant increases in empathy as undergraduates progress through the medical course (Ponnamperuma *et al.*, 2019). In 2012, one of my Master students in Paris set out to explore whether the first internship in oncology could trigger the empathy decline due to disillusion in the field. In a cross-sectional study of 50 medical students at the University of Paris Descartes, she assessed their disillusion with an *ad-hoc* questionnaire exploring the change in students' perceptions of their profession because of their internship in oncology. Notwithstanding the inherent limitations of a Master Degree work, she found a decrease in self-reported empathy after the internship and, more interestingly, an association between the change in the perception of their profession (i.e. disillusion) and the decline in empathy in a multilinear regression model controlling for their self-efficacy.



This work adds credence to other reports on the negative impact of the first clinical experiences in the field (Neumann *et al.*, 2011a; Ward *et al.*, 2012; Ren *et al.*, 2016; McFarland *et al.*, 2017; Ishikawa *et al.*, 2018; McFarland, 2019).



Interestingly, some authors have argued that the observed declines could be found more in self-reported measures, which assess rather an attitude toward empathy, than in objective observations of actual empathy (Teng *et al.*, 2017). Although this possibility cannot be entirely discounted, according to theories from social psychology (e.g. Ajzen, 2012), one could argue that, in the long run, an unfavourable attitude towards empathy will probably erode empathy eventually.

Numerous personal accounts of students or residents (e.g. Kay, 2017⁵; Chiang, 2018) are insightful to understand why empathy is curbed in medical education. Students are simply not prepared for doctor-patient relationships. Simone Chiang, a medical student, elegantly sums up the situation in the three following points (2018).

2.2.1. Little room for empathy

First, students are under educational stress and pressures with a huge amount of medical knowledge to acquire at a fast rate: there is little room for the emotional aspects of medical practice (Ahrweiler *et al.*, 2014). Indeed, workload affects empathic concern (Elayyan *et al.*, 2018; Putrino *et*

⁵ This book is a diary of an English resident in obstetrics. It is hilarious while revealing the hardship of such training. I strongly recommend reading it.

al., 2018). Furthermore, the hard working conditions of medical students in some hospitals and universities (e.g. Auslender, 2017⁶; Slavin & Chibnall, 2017; Szubert *et al.*, 2018; Vogel, 2018) could, at least in part, explain empathy falling (Ahrweiler *et al.*, 2014; Mahoney *et al.*, 2016; McFarland, 2019). This is what Beth Lown has coined the ‘hidden curriculum’ of uncaring attitudes and behaviours (Lown, 2016). It seems difficult to try to take the patients’ perspective as well as empathise with them while working in dehumanised settings that convey uncompassionate cultural norms.

2.2.2. Wrong beliefs about empathy

Second, there is a widespread belief that too much compassion and caring will lead to compassion fatigue or burnout whereas rebuttal theories and evidence exist (e.g. Tei *et al.*, 2014; Thirioux *et al.*, 2016; Hunt *et al.*, 2017; Wilkinson *et al.*, 2017; Williams *et al.*, 2017; Morice-Ramat *et al.*, 2018; von Harscher *et al.*, 2018). Residents themselves do not always agree with this proposition, some of them see the relationship in a reverse sense: burnout compromises empathy (Picard *et al.*, 2016). A recent meta-analysis could support their reasoning as it found a moderate negative correlation between compassion satisfaction and burnout ($r = -0.446$; Zhang *et al.*, 2018).

Actually, empathy leads to compassion fatigue or burnout only in professionals with low emotional awareness or unable to regulate their emotions (Eisenberg & Eggum, 2009; Gleichgerrcht & Decety, 2013; Tei *et al.*, 2014; Yu *et al.*, 2016; Hunt *et al.*, 2017; Coetzee & Laschinger, 2018), that is in professionals with low ES.

This conclusion is also suggested by an event-related brain potential study (Decety *et al.*, 2010) in which physicians, compared to control participants, did not react the same way when they were presented with visual stimuli showing physical pain. Although dispositional empathy did not differ between the two groups, the physicians, contrary to the controls, were able to regulate their emotions very early and inhibit the bottom-up processing of the perception of pain in others. In that way, physicians were able to treat patients medically and still be empathic without being affected by patients’ physical pain. Thus, it is not dispositional empathy that should be feared as being responsible for burnout but the lack of emotion regulation, which is necessary to work in the medical field.

⁶ This book is the report of a French national study based on testimonies of mental and physical abuse of medical students. Some are so shocking that I did not finish the book but since it only reveals problems, it should be kept in mind that it shows only the worst part of the situation.



Neural arguments also support this theory suggesting that compassion actually counteracts negative emotion elicited by experiencing others' suffering through positive emotion generation (Engen & Singer, 2015). Indeed, compassion is accompanied by activations in reward, affiliation and positive emotion related brain networks, which is why the authors conclude that compassion is an emotion regulation strategy (Preckel *et al.*, 2018).



This argument also fits data showing that in a general population without familial risk for hypertension, compassion is associated with less blood pressure (Saarinen, 2019). Some authors champion the idea that compassion may buffer against stress (Fernando & Consedine, 2014). In sum, compassion may even be a good thing for mental and physical health.



Furthermore, it also depends on the type of empathy referred to. Cognitive empathy, although it can be demanding, is not related to burnout or compassion fatigue whereas empathic concern can be (Gleichgerrcht & Decety, 2013; Duarte *et al.*, 2016a; Duarte & Pinto-Gouveia, 2017).

2.2.3. The problem of empathy in the curriculum

Third, empathy decline could result from the way it is taught and assessed in curriculums (if it is taught, because most medical schools in France still do not offer courses on doctor-patient relationships). While empathy would benefit from being encouraged by self-compassion, positive role models (Ahrweiler *et al.*, 2014), an emotionally safe environment and a focus on students' skills at expressing and regulating their own emotions faced with others' distress (Lown, 2016), empathy is in fact taught in a sort of one-size-fits-all manner with particular probes (e.g. 'How does it make you feel?') or specific phrasing (e.g. 'It must be hard') that students have to memorise before regurgitating them for the OSCE (Objective Structured Clinical Examination). In fact, this so-called 'empathy' recalls what was described by patients as unwanted 'sympathy' in the grounded theory described earlier on page 41 (Sinclair *et al.*, 2017). Consequently, students know how to pretend but are not truly empathic (Roper *et al.*, 2016) whereas patient satisfaction depends on a sincere display of physician emotions (Yagil & Shnapper-Cohen, 2016; Derksen *et al.*, 2017; Sinclair *et al.*, 2017).

The same problem arises in the breaking of bad news with the use of step-wise protocols such as the SPIKES (Baile *et al.*, 2000; a six-step protocol that recommends behaviours and topics to follow in order). Evidence suggests that such guidelines may not fully meet patients' needs (Salmon & Young, 2013; Seifart *et al.*, 2014; Dean & Willis, 2016) nor those of clinicians, who depart from such protocols in difficult conversations with patients because of clinical complexity (Cheng *et al.*, 2017). Furthermore, it is debatable whether it helps or hinders genuine empathic attitudes and behaviours. As genuine

empathy can be hard to achieve and distressful, young physicians sometimes prefer to avoid confrontation with patient distress by lying to them and giving them too much hope (Steven *et al.*, 2019). All these elements could explain why HCPs exhibit better communication behaviours after communication skills training while, at the same time, the training has no actual effect on patients' satisfaction, outcomes and working alliance with the HCP (Meystre *et al.*, 2013; Moore *et al.*, 2013).

 In addition, according to the model of compassion of Beth Lown (2016), communication skills are only one of the 11 elements revolving around compassion (e.g. attention, listening, recognition of emotions, perspective-taking, valuing others, self-compassion, etc.). Therefore, it is not surprising that  working on communication skills only does not improve compassion.

In contrast, an RCT including several components of the model of compassion improved patients' rating of the empathy of intervention trainees (Riess *et al.*, 2012, cited by Lown, 2016).

The three points highlighted above are in accordance with the Transactional Model of Physician Compassion stipulating that physician compassion stems from the dynamic but interrelated influences of the physician, the patient (I will expand on this later) and family, the clinical situation (I will expand on this later too), and environmental factors (Fernando & Consedine, 2014). In fact, although beyond the scope of our work, other social constructivist and organisational hypotheses, such as dramatic medicine transformations (e.g. personalised medicine), commercialisation of healthcare, evidence-based medicine, efficiency and the pharmaceutical industry's pressure on physicians, are also insightful to understand the arguably suboptimal level of empathy (Jeffrey, 2016; Hirshfield & Underman, 2017).

2.3. The beneficial effects of empathy warrant further research

The latter two claims that empathy is expected by patients and is arguably not optimal can be seriously challenged as arguments for working on empathy. In fact, patients may sometimes wish for things that could be harmful for them. Therefore, it is not because patients expect more empathy that empathy should be more developed. In the end, it must be because of its positive impact on the patient, and not only because the patient desires it.

As the positive outcomes of empathy will be extensively addressed in a later section (4. Outcomes of medical empathy), I will just mention briefly here that empathy has many positive patient outcomes *but* not in all conditions and that the conditions of its beneficial effects need further

investigation (Lelorain *et al.*, 2012a). Therefore, working on empathy is essential as it can even be detrimental to patients' health. As a physician stated:

'The more we will listen to the patient and be centred on patients' needs, the higher the risk not to do what we have to do from a biomedical point of view. We are not going to do this exam because it's complicated for the patient to accept or because that day, he/she is not ready to hear it. But, I am still a physician and if I have unpleasant things to say, I will have to say it'. (Le Rhun *et al.*, 2013, p. 44).

This quotation perfectly illustrates findings that empathy is not always favourable for patient health. For example, in an RCT in diabetes, in the experimental group, physicians were trained in the patient-centred approach. In this group, patients were more satisfied with patient communication and treatment, but their triglycerides and body mass index were *higher* than in the control group. Their knowledge level on diabetes was also *lower* than that of patients in the control group (Kinmonth *et al.*, 1998). In an RCT of active counselling vs. usual care for smokers, greater empathy of counsellors predicted a *decreased* probability of an attempt to quit smoking (Klemperer *et al.*, 2017).

In sum, research is highly needed to disentangle the conditions under which empathy can be positive for patient outcomes in the specific context of cancer care.

In the two previous chapters, I defined empathy and justified the need for working on it. In the next chapter, I will present the factors that can explain, or at least are associated with, empathy in a three-pronged approach, namely the factors associated with:

1. physician-reported empathy in GPs;
2. physicians' accurate perception of cancer patient distress (awareness of patient distress is a keystone of cancer care and empathy);
3. patient perception of physician empathy.

3. Factors associated with medical empathy

3.1. Factors associated with physician-reported clinical empathy

As developed on page 45 in the paragraph about the measures of empathy, physician-reported empathy as assessed by the Jefferson Scale of Physician Empathy is a rather cognitive empathy, which implies an attitude favourable to paying attention to patient emotions and the verbal and non-verbal cues of these emotions, but the measure does not probe the physician's own emotional reactions in response to patient situations and concerns. As this clinical cognitive empathy is expected by patients, we were interested in the factors associated with it, particularly the link between clinical empathy and empathic concern⁷. It is well known that there is an overlap between the cognitive and emotional aspects of empathy with a moderate correlation at around 0.30 (e.g. Berthoz *et al.*, 2008; Spreng *et al.*, 2009; Dehning *et al.*, 2013; Manczak *et al.*, 2016). It is logically expected that empathic concern acts as an underlying emotional motive for physicians to try and take the patient's perspective (Eisenberg & Eggum, 2009). It is not only an important element for clinical empathy but also requested by patients themselves (Sinclair *et al.*, 2017). However, too much empathic concern can become challenging and demanding, demonstrating correlations with burnout in physicians and nurses (Gleichgerricht & Decety, 2013; Duarte *et al.*, 2016a) and with systemic inflammation in parents who demonstrate empathy toward their children in the general population (Manczak *et al.*, 2016). To put it simply, empathic concern may have a psychological and physical cost. This is why we were interested in whether it was possible to maintain a good level of clinical empathy without too much empathic concern, i.e. to make clinical empathy less dependent on empathic concern (Lelorain *et al.*, 2013).

We hypothesised that any professional reflective practice resulting in stepping back and putting things into perspective could promote clinical empathy while not rendering it dependent on empathic concern. In this respect, two professional reflective practices were deemed particularly relevant: being a supervisor (i.e. a physician who supervises medical students in internships) and/or attending Balint groups. Balint groups are discussions and reflections supervised by an experienced supportive leader, which occur in a safe place, on difficult cases and feelings encountered by professionals. At the time of our study, no research into Balint groups and physician empathy was found, but as one of the aims of these groups is to improve doctors' perceptions of their patients' concerns as well as their own psychological reactions (Rabin *et al.*, 2010; Yakeley *et al.*, 2011), it seemed very plausible that Balint groups would promote clinical empathy. As regards supervisors,

⁷ As a reminder, empathic concern is the emotional concern for someone, along with a drive to alleviate the other's suffering.

although to our knowledge there is no study on empathy differences between supervisors and non-supervisors yet, at least some research has demonstrated that supervisors in general practice have clinical practices more oriented toward patients than non-supervisors do e.g. they provide more therapeutic services, more chronic care services, perform better in diabetes follow-up, seasonal flu vaccination and mammograms. This suggests a more patient-centred approach (van den Hombergh *et al.*, 2013; Letrilliart *et al.*, 2016; Devillers *et al.*, 2018), also reported in qualitative accounts of supervisors (Morrison *et al.*, 2005; Silén *et al.*, 2011). For all these reasons, we hypothesised that clinical empathy would depend on empathic concern, but to a lesser extent in physicians with a reflective activity (i.e. being a supervisor or attending a Balint group).

To test the hypothesis, GPs were asked to participate in a cross-sectional study into empathy using physician-reported questionnaires. Clinical empathy was assessed using the Jefferson Scale of Physician Empathy (see page 45 for a description) and empathic concern using the Toronto Empathy Questionnaire (Spreng *et al.*, 2009), which assesses empathic concern in general with items such as: ‘It upsets me to see someone being treated disrespectfully’ and ‘I get a strong urge to help when I see someone who is upset’. A total of 295 completed questionnaires were retrieved. As predicted, in a multivariate regression aimed at explaining clinical empathy, controlling for years of clinical experience and consultation length (the former being not associated with the outcome whereas the latter was), empathic concern interacted with the reflective activity as depicted in Figure 6.

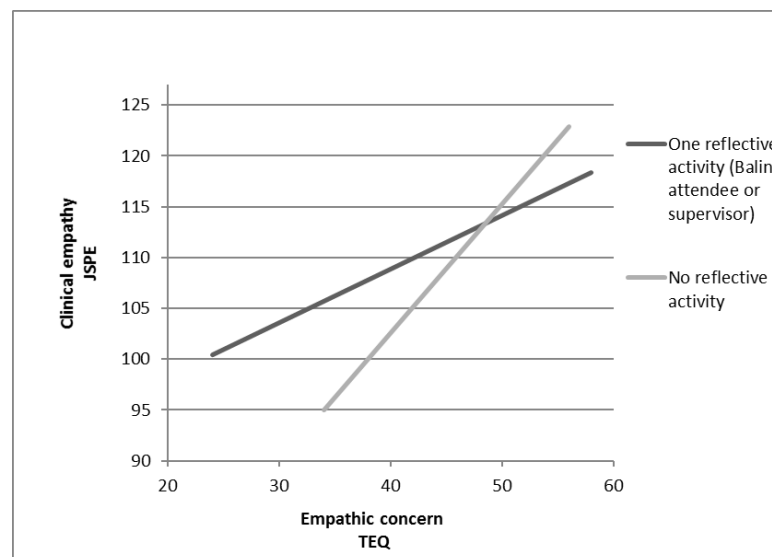


Figure 6. Moderator effect of a reflective activity on the relationship between empathic concern and clinical empathy (Lelorain *et al.*, 2013).



In physicians without a reflective activity, clinical empathy depended much more on empathic concern than in those with a reflective activity. In particular, in physicians with low empathic concern (< mean, 46), the reflective activity enabled them to reach a higher clinical empathy.



Since the study in 2013, research into the beneficial effect of Balint groups on clinical empathy has been developed with interesting results. For example, medical students who attended a Balint group, compared to a control group, increased their empathic approach at the follow-up, which was 4 months after the end of the groups (Airagnes *et al.*, 2014). In a qualitative study, family medicine residents who attended Balint seminars in their curriculum were interviewed about the way communication was taught in residency (Player *et al.*, 2018). Among the Balint-related positive themes that they brought up was the fact that those groups prevented them from becoming jaded and, on the contrary, nurtured empathy, enabling them to realise that their medical standpoint was not necessarily what their patients were experiencing and that it was important to adjust their professional role skilfully to meet the patient's psychological reasons for visiting them. Another theme was their awareness that they will not be able to help everyone; an important recognition for their well-being.

Full reference:

Lelorain, S., Sultan, S., Zenasni, F., Catu-Pinault, A., Jaury, P., Boujut, E., & Rigal, L. (2013). Empathic concern and professional characteristics associated with clinical empathy in French general practitioners. *The European Journal of General Practice*, 19(1), 23–28. <https://doi.org/10.3109/13814788.2012.709842>

As regards the impact of being a supervisor, as no study has formally established a link between the status of supervisor and empathy, we are currently conducting a study in 50 GPs and 1000 patients to assess, among other research questions, how the status of supervisor can impact patient-reported physician empathy and adherence to treatments in patients with chronic conditions. This work in progress is being undertaken with Dr Claire Pinçon, Associate Professor in Biostatistics, and Dr. Axel Descamps, GP, and with the help of four students preparing their thesis in medicine and two students in pharmacy, one of whom very recently defended his thesis on the patient-perception of pharmacist empathy by type of chronic disease (Dhelft, 2019). In his research performed on 390 patients⁸, Antoine Dhelft showed that patient-perceived pharmacist empathy was higher in patients with high ES and

⁸ To date (September 13, 2019), 44 GPs have recruited 700 patients assessing both them (i.e. their GP) and pharmacists.

better perceived health. He also found that female patients with endocrine-metabolic diseases perceived a lower level of pharmacist empathy compared with the other diseases.

3.2. Factors associated with physician accuracy concerning patient distress

As described earlier in the various definitions of empathy (page 39), one of them, called empathic accuracy, refers to knowing another person's internal state, including his or her thoughts and feelings. Among feelings, distress is particularly relevant in cancer settings so I will now present physician accuracy in detecting patient distress before studying the factors associated with accuracy.

3.2.1. Why focus on cancer patient distress?

The question of patient distress is of primary importance in cancer settings. In a recent cohort of 4664 cancer patients from 55 different American and Canadian cancer treatment centres, 46% of patients experienced significant distress on the Distress Thermometer. In this cohort, being female, aged 40-59, and having diagnoses of pancreatic or lung cancer were associated with an increased likelihood of distress (Carlson *et al.*, 2019). Distress prevalence is also particularly high in metastatic cancer patients (Sherry *et al.*, 2017; Park *et al.*, 2018). In fact, it is so high that it has been endorsed as the 6th Vital Sign by the International Psycho-Oncology Society (IPOS) (Watson & Bultz, 2010) and routine distress screening in United States oncology clinics has been mandatory since 2015. However, it is not mandatory or even routinely performed in many countries including France. In such contexts, oncologists and other HCPs are the first line to detect patients' distress and address them to psychosocial services. Unfortunately, oncologists may not consider distress screening an essential part of their job (Absolom *et al.*, 2011) and prefer to rely on their clinical acumen rather than using validated questionnaires (Mitchell *et al.*, 2008). As a result, depression is sub-detected, with for example only 34% of BC patients receiving a clinician response to their depression in a large recent cohort study (Check *et al.*, 2019). Therefore, along with a continuous effort to implement routine screening, it is critical that oncologists assess patient distress accurately by themselves in order to make the necessary referrals.

Therefore, we set out to study: 1. physician accuracy in detecting cancer patients' distress (following paragraph) and 2. factors associated with physician accuracy on general distress (Lelorain *et al.*, 2014) and on the specific symptoms of depression (Gouveia *et al.*, 2015) in the subsequent paragraph.

3.2.2. Physician accuracy concerning patient distress

Patient distress was operationalised in three ways:

1. as *general distress* using the distress thermometer (DT), which is a vertical visual scale on which patients rate their distress from 'no distress' at the bottom (0) to 'very high distress' at the top (10) (Dolbeault *et al.*, 2008). A cut-off ≥ 4 indicates that the cancer patient suffers from significant clinical distress and needs psychosocial help (Trad *et al.*, 2015; Ghazali *et al.*, 2017; Tonsing & Vungkhanching, 2018).

2. as *depression* using the score of the Beck Depression Inventory 2– Cognitive factor (Sultan *et al.*, 2010), which consists of eight items: Self-dislike, Sense of Failure, Guilt, Negative Body Image, Pessimism, Suicidal Ideation, Sadness, and Dissatisfaction with Life. The somatic factor (e.g. appetite, fatigue) was not considered because of its overlap with the impact of cancer on the patient's life. For each item, the responder chooses one of four statements of varying intensity (0-3) according to his/her present state. For the score of the Cognitive Factor, a cut-off of 3 yields the best trade-off between sensitivity and specificity when screening for depression in patients with chronic illnesses (Sultan *et al.*, 2010).

3. as each of the eight *depressive symptoms* assessed by the BDI.2-Cognitive factor. A cut-off of 1 was used to discriminate between the presence and absence of any given symptom.

A multicentric study involving two cancer centres in Paris, one in Nantes and one in Bordeaux was carried out with the help of 28 hospital physicians, mostly medical oncologists, who included 201 metastatic cancer patients in the study. Each physician was supposed to include 10 patients. After a consultation with a participant physician, the patient of the consultation completed the DT and BDI.2-SF. At the same time, independently, the physician was asked to rate the patient's emotional distress on the same instruments. Physicians were asked to give the ratings on the questionnaires (DT and BDI.2 SF) that they thought the patient had given, i.e. to take the patient's perspective.

Comparisons of ratings between physicians and patients are provided in Table 2. Patients had a mean depression score of 3.46 (3.33), which gave 51.5% of depression according to the cut-off of 3, and a mean score of 2.85 (2.54) on the DT, which gave 25.9% of significant distress according to the cut-off of 4. A different prevalence of distress was reported in a study on this issue (Schaeffeler *et al.*, 2015) pointing to a combination of instruments and the patients' subjective need for help as the best practice to identify patients in need of help. In more detail, pessimism (51.8%) and sadness (42.6%) were the most prevalent symptoms whereas guilt (14%) and suicidal ideation (17%) were the rarest although the prevalence was still relatively high, especially for suicidal ideation.

Table 2. Comparisons between physician and patient ratings on distress (Gouveia, Leloirain, ... & Sultan, 2015).

Measure	M (SD)		r	t (d)
	Patient	Oncologist		
Depression	3.46 (3.33)	3.94 (3.50)	.29***	1.67 (-.14)
A) Sadness	.54 (.72)	.70 (.73)	.31***	2.66** (-.22)
B) Pessimism	.77 (.88)	.95 (.91)	.22**	2.27* (-.20)
C) Failure	.34 (.69)	.30 (.53)	.08	-.63 (.07)
D) Dissatisfact.	.35 (.57)	.47 (.67)	.18*	2.16 (-.19)
E) Guilt	.25 (.66)	.24 (.57)	.08	-.13 (.02)
F) Self-Dislike	.21 (.47)	.17 (.42)	.09	-.95 (.09)
G) Suicidal Idea	.26 (.63)	.09 (.35)	.29***	-3.65*** (.33)
H) Body Image	.74 (.90)	1.01 (.90)	.18*	3.27** (-.30)
Distress (DT)	2.85(2.54)	4.65(2.62)	.35***	9.47*** (-.76)

* $p < .05$, ** $p < .01$, *** $p < .001$

As can be seen in Table 2, if the patients' scores are taken as the standard reference⁹, physicians *overestimated* patient distress on the DT and on three symptoms: sadness, pessimism and body image issues. Their only underestimation concerned suicidal ideas. At least three interwoven explanations are plausible as regards physician overestimation. First, the task asked of physicians could have entailed social desirability and it seems socially more desirable to overestimate patient distress than to overlook it. Second, if physicians had no idea of a patient's distress, they could have based their judgment on the following stereotype, 'all advanced cancer patients must have high distress', and rated high distress by default. Third, only 50% of the contacted physicians participated in the study. It may be that the physicians most interested in empathy were the most sensitive to patient distress and thus focused on it.

In spite of differences in absolute values of distress items between physicians and patients, small correlations were found between them on these four symptoms as well as on distress, depression, and dissatisfaction with life. This suggests that physicians may differentiate various levels of distress between patients. Accuracy was further properly assessed in the following table.

⁹ In the 'accuracy' literature in medicine, the standard reference is the patients' rating by default. We will also take this standard but this choice could be debated.

Table 3. Accuracy of physicians' ratings on patients' distress.

Measure (base rate %)	Cutoff	Agreement (%)	Se (%)	Sp (%)	κ	DOR
Depression (51.5)	≥ 3	60.7	68.9 (59.5-77.1)	52.0 (42.3-61.7)	.21 (.14-.34)	2.41 (1.35-4.28)
Depressive Symptoms	≥ 1					
A) Sadness (42.6)		41.0	32.5 (.23-.43)	47.3 (38.3-.56.5)	.19 (.08-.32)	0.43 (.24-.78)
B) Pessimism (51.8)		39.1	73.5 (64.2-81.1)	44.2 (34.6-54.2)	.18 (.05-.31)	2.20 (1.21-4.00)
C) Failure (25.0)		65.0	34.0 (22.4-47.9)	75.3 (67.9-81.6)	.09 (-.05-.24)	1.57 (.79-3.15)
D) Dissatisfaction (30.5)		62.0	49.2 (37.1-61.4)	67.6 (59.5-74.8)	.16 (.02-.30)	2.02 (1.09-3.74)
E) Guilt (14.0)		77.0	28.6 (15.3-47.1)	84.9 (78.8-89.5)	.12 (-.04-.28)	2.25 (.90-5.64)
F) Self-Dislike (19.1)		72.9	21.1 (11.1-36.4)	85.1 (78.8-89.8)	.07 (-.08-.21)	1.52 (.62-3.72)
G) Suicide Ideas (17.0)		82.0	20.6 (10.4-36.8)	94.6 (90.0-97.1)	.19 (.02-.36)	4.52 (1.55-13.20)
H) Body Image (47.5)		53.5	68.4 (58.5-76.9)	40.0 (31.1-49.6)	.08 (-.05-.21)	1.44 (.81-2.59)
Distress (25.9)	≥ 4	64.7	64.3 (45.8-79.3)	64.7 (57.4-71.5)	.17 (.05-.28)	3.31 (1.44-7.61)

Note. 95% confidence interval in parentheses; Se: Sensitivity = number of 'cases' detected by physicians/total number of cases, Sp: Specificity = number of 'non-cases' detected by physicians/total number of 'non-cases'; κ : Kappa statistic; DOR: Diagnostic Odds Ratio, is a measure of the effectiveness of a diagnostic test (here of the physician's ability to detect distress).

Row agreements (% of time that patients and physicians reached the same 'diagnosis' of distress according to the chosen cut-offs) seemed rather good. Kappa statistics, which correct for the proportion of agreement that might occur by chance, were however very low, revealing actual poor agreements; $\kappa < .20$ is considered a slight agreement (Viera & Garrett, 2005). The best agreements, but still low, were on depression, distress on the DT, sadness and pessimism, which was confirmed by higher DOR for those items with the exception of sadness. Similar results of slight agreements between patients and oncologists have been confirmed in advanced ovarian cancer patients (Rhondali *et al.*, 2015) and in cancer patients receiving radiotherapy (Mackenzie *et al.*, 2018). Fair agreements have been retrieved between patients and oncologists as regards depression of cancer patients who were admitted and referred to the consultation-liaison team (Yasugi *et al.*, 2018).

In conclusion, physician accuracy regarding patient distress was low in our sample, particularly for the less conspicuous symptoms such as guilt, self-dislike and sense of failure. These results have been confirmed in recent studies. Therefore, the exploration of the associated factors seems of critical importance.

Full reference:

Gouveia, L., Leloirain, S., Brédart, A., Dolbeault, S., Bonnaud-Antignac, A., Cousson-Gélie, F., & Sultan, S. (2015). Oncologists' perception of depressive symptoms in patients with advanced cancer: accuracy and relational correlates. *BMC Psychology*, 3(1), 1.

I will now present one of my research works, the objective of which was to explore which factors are associated with physician accuracy concerning cancer patient distress.

3.2.3. Factors associated with accuracy regarding patient distress

3.2.3.1. Overall presentation of the research

The theoretical model of Norfolk et al. (2009) presented below guided our choice of hypothesised factors.

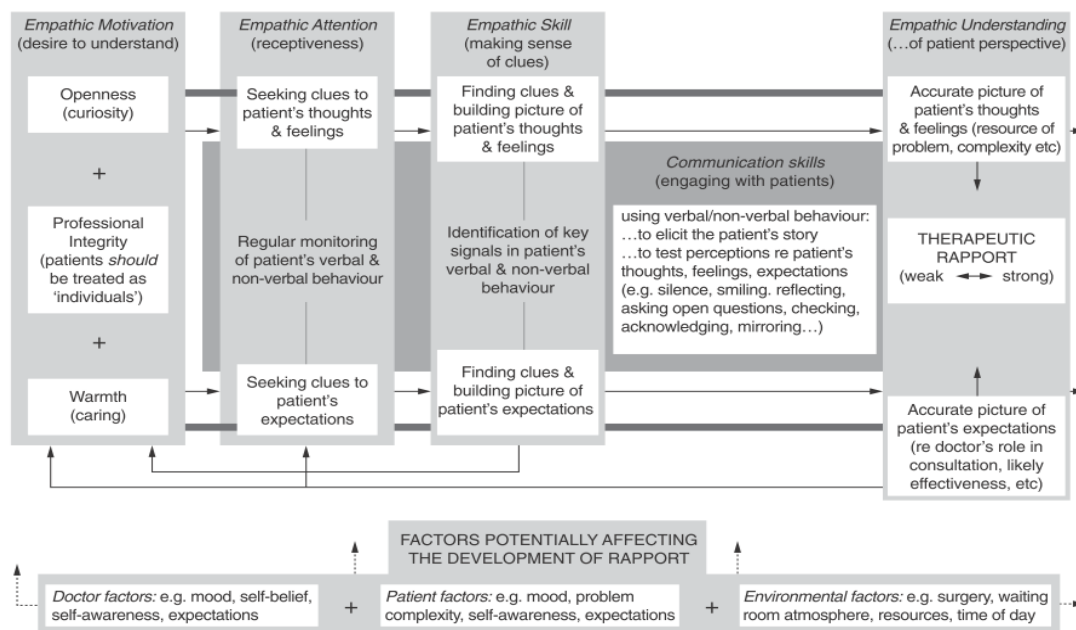


Figure 7. Theoretical model for the development of therapeutic rapport in medicine (Norfolk et al., 2009).

This theory proposes how the process of empathy plays out in a precise order to reach accuracy. Besides, factors potentially affecting the process are judiciously pointed out.

In the model, the first three blocks entitled 'empathic motivation', 'empathic attention' and 'empathic skills' are equivalent to a positive attitude towards the need to pay attention to patient emotions, i.e. to the cognitive empathy of the Jefferson Scale of Physician Empathy. It seems logical that physician empathic motivation, attention and skills leads to accuracy about the patient's emotional state. The model also specifies doctor and patient factors that potentially affect the process.

Among patient factors, we chose patient distress and patient expressive suppression. A study of advanced cancer patients showed that higher patient distress is more frequently detected by oncologists, arguably as it is more visible than moderate distress (Kennifer *et al.*, 2009). The same result was found in accuracy about pain in a non-cancer study in informal caregivers' accuracy (Suso-Ribera *et al.*, 2019). A second patient factor of interest is patient expressive suppression, i.e. the inhibition of

ongoing emotion-expressive behaviour. Experimental research supports the need for a person's verbal and non-verbal disclosure in allowing a 'perceiver' to detect accurately his/her emotions (Hall & Schmid Mast, 2007; Zaki *et al.*, 2008, 2009; Regenbogen, 2012). We assumed that the results of these experimental studies should be transferable in naturalistic clinical settings, all the more so given that the huge workload of physicians along with a lack of time and other priorities than emotion detection do not make the task easy for them. In this context, we argued that patient expressive suppression would qualify the previous hypothesised link: higher distress should lead to higher accuracy but especially in expressive patients.

Among physician factors, we retained physician self-efficacy in detecting patient distress as a possible predictor. In fact, we were interested in whether physician self-efficacy could be a reliable measure of actual accuracy.

Finally, whereas the theoretical model posits that the empathic process leads to therapeutic rapport and empathic understanding of the patient's perspective, we were of the opinion that an existing therapeutic rapport between physician and patient could also affect the empathic process and accuracy. Defined as the connection between patient and physician and their mutual commitment to the relationship, rapport is essential for effective clinical communication (Epstein & Street, 2007). A good rapport with a patient could be a motivation for physicians to pay attention to that patient's cues. We hypothesised an interaction between rapport and accuracy regarding patient distress: higher distress should lead to higher accuracy, especially in the case of a good rapport between physician and patient.

To summarise, following the model of Norfolk *et al.* (2009), the hypothesised correlates of empathic accuracy (EA) were physician-reported cognitive empathy and self-efficacy in distress detection. We also hypothesised that higher patient distress would be associated with higher EA, but that this link would be less strong in patients with high expressive *suppression* or in cases of poor rapport between physician and patient.

The study design has already been described on page 59. At the onset, physicians completed questionnaires on their empathy (Jefferson Scale of Physician Empathy) and general self-efficacy in distress detection using the ad-hoc question: "In general, I feel competent to detect my patients' emotional distress and needs'. For each included patient, physicians self-reported their perceived quality of rapport with this patient from their point of view answering the following question 'What is the quality of your relationship with this patient' from 1 'Very difficult relationship' to 7 'Very easy relationship'. Patients completed a self-reported expressive suppression questionnaire using the Emotion Regulation Questionnaire-Fr (Christophe *et al.*, 2009). As described previously, after a consultation with an included patient, physicians and patients had to rate independently patient

emotional distress on the distress thermometer. For the present purpose, the EA score was generated by calculating the absolute value of the difference between the patient's and the physician's rating, as recommended in the EA literature (Kenny & Albright, 1987; Côté *et al.*, 2011). It is therefore a measure of absolute agreement between clinicians and patients on patient distress. Multi-analyses were performed to respect the two-level hierarchical structure of patients (level 1, n = 201 patients) clustered with doctors (level 2, n = 28 doctors). Level 1 analyses look at the between-patient variations whereas level 2 analyses look at the between-physician variations by computing average scores for each physician.

3.2.3.2. Physician factors: results and discussion

Contrary to our expectations, at the physician level neither physician-reported empathy nor physician-reported self-efficacy in distress detection was associated with EA.

As we had only 28 physicians, each of whom included between three and ten patients, we cannot rule out a lack of statistical power to reveal the association. In a study of family physicians, physician-reported perspective-taking was clearly predictive of physician accuracy regarding patient distress (Yagil *et al.*, 2015). Medical students' accuracy about patients' thoughts and feelings has also been related to their favourable attitude toward psychosocial discussion (Hall *et al.*, 2015). However, the data do not always confirm the hypothesised link. For example, in non-medical settings, previous observations have revealed that people tend to overestimate their empathic skills compared to their actual ones (Kelly & Metcalfe, 2011; Sripada *et al.*, 2011).

Furthermore, in medical settings, another study with more statistical power failed to find an association between physician-reported empathy and communication performance in a decision-making encounter with a simulated advanced-stage cancer patient (Libert *et al.*, 2017). No association was also found between self-efficacy and communication performance with simulated and real patients (Gulbrandsen *et al.*, 2013; Gude *et al.*, 2017). Interestingly, in Gude's study, a negative correlation was found between self-efficacy and actual performance, suggesting that actual good communicators are aware of the difficulty whereas those who believe they are good are actually poor performers.

This poor awareness can change with training. For example, in Gulbrandsen's study, a positive correlation between self-efficacy and actual performance appeared after communication training, suggesting that such training can make physicians more aware of their true abilities.

As expected, we found a between-physician effect of physician-reported rapport on EA such that physicians with a high mean rapport with their patients demonstrated high EA on average. However, when looking at the patient-level of analyses (n = 201 patients), I will now show that a physician-reported *excellent* rapport with a given patient can be a pitfall in EA.

3.2.3.3. Patient and doctor-patient interaction factors: results and discussion

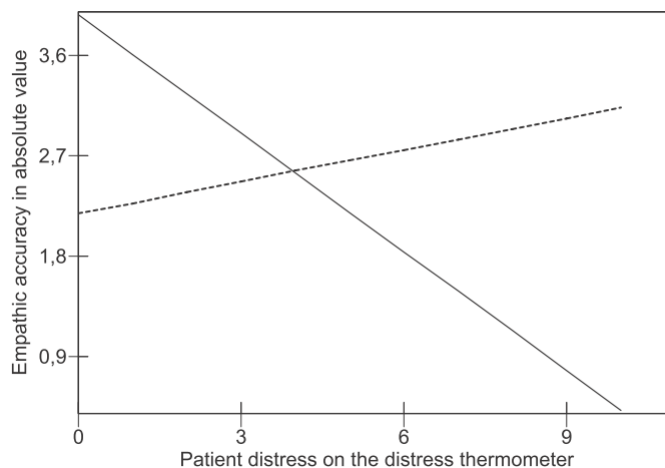


Figure 8. Interaction between patient distress and physician-perceived quality of rapport on EA. Note. Solid line: low rapport (percentile 20); dotted line: high rapport (percentile 80). Note that good accuracy is reflected by a *low* absolute value.

In the multivariable regression model, we found a significant interaction between rapport and distress on EA. As depicted in Figure 8, EA was higher when patient distress increased but, contrary to our expectations, only when physicians perceived a *poor* (and not a good) rapport with the patient. In fact, a poor rapport could be assessed by physicians faced with upset patients who notably manifest their discontent or distress. In that sense, it becomes understandable that patient distress is easier to detect. On the contrary, in the case of excellent rapport, EA was better for low patient distress but worse for high patient distress. I write *excellent* rapport as the mean of rapport was 5.7 on a scale from 1 to 7, so that rapport at percentile 80 was 7, i.e. the maximal value.

This striking finding suggests that physician-perceived excellent rapport could be a barrier and pitfall to EA for highly distressed patients. It might be that, in order to avoid placing physicians in difficulty with their emotions or to avoid disappointing them, patients withhold their distress when interacting with them (Ryan *et al.*, 2005). In advanced cancer, patients' perceptions of greater connectedness with their physician predicted fewer patient expressions of concern (Freytag *et al.*, 2018).

The low level of patient expression of concerns could be explained by no concern, but once the patient has become used to being silent, it might be more difficult to start expressing concerns when they emerge. A good rapport can therefore be tricky. It could also be that physicians perceive a very good rapport with patients for whom they have generated a representation that tends to be stable over time. Then, as demonstrated in non-clinical contexts (Gesn & Ickes, 1999; Kilpatrick *et al.*, 2002), physicians would rely much more on this pre-existing and available representation than on external cues they would have to pick up from the most recent interaction with patients to infer their mental state. The latter strategy is clearly much more demanding than the former, especially if the patient does not express himself/herself.

As hypothesised, patient expressive suppression was also explored in interaction with patient distress. This time the hypothesis was confirmed: higher distress led to better EA (lower absolute value) as high distress is easier to detect, but the effect was stronger in patients with low expressive suppression as depicted in Figure 9.

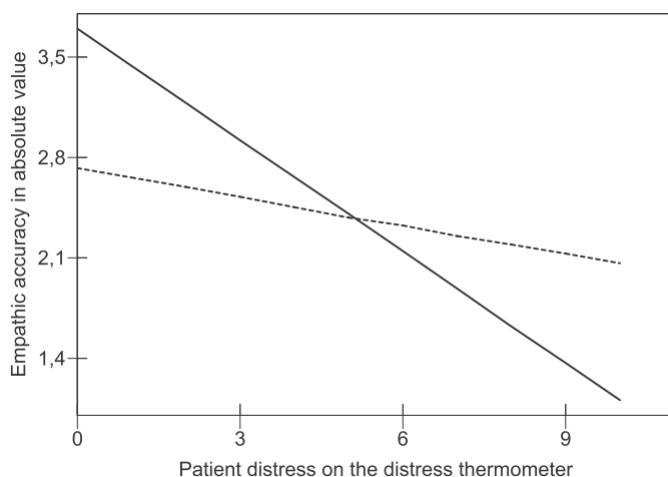


Figure 9. Interaction between patient distress and patient expressive suppression on EA.

Note. Solid line: low patient expressive suppression, i.e. patient is expressive (percentile 20); dotted line: high patient expressive suppression, i.e. patient is *not* expressive (percentile 80). Note that good accuracy is reflected by a *low* absolute value.



This result that patient expressive suppression impedes EA confirms experimental research findings about the importance of emotion disclosure for EA. This point is all the more relevant in cancer settings where many patients conceal their psychological concerns from clinicians for reasons cited above regarding the preservation of a good rapport and as they assume that emotional issues are not within the doctors' scope (Ryan *et al.*, 2005).



This assumption is logically reinforced with non-empathic doctors. In fact, an analogue study proved that a low patient-centred communication style inhibits patients' disclosure of their emotions (Adams *et al.*, 2015). This is why patient 'coaching' before consultations might be a good idea to make patients realise that they have an important role to play in consultations, and that without their active participation, physicians cannot guess their concerns and emotional state, especially since they may have other priorities. A systematic review concluded that patient-coaching enhances doctor-patient communication, including the sharing of information by patients (Alders *et al.*, 2017). Indirectly, it could then improve detection of patient distress by physicians.

Full reference:

Lelorain, S., Brédart, A., Dolbeault, S., Cano, A. Bonnaud-Antignac, A., Cousson-Gélie, F., & Sultan, S. (2014). How can we explain physician accuracy in assessing patient distress? A multilevel analysis in patients with advanced cancer. *Patient Education and Counseling*. 94(3), 322-327. doi: 10.1016/j.pec.2013.10.029

In this section and the previous one, I have tried to determine the factors associated with physician-reported empathy and empathic accuracy on patient distress. In the next section, I will focus on patient-reported physician empathy (PPPE).

3.3. Factors associated with patient perception of physician empathy (PPPE)

Among the various way to assess empathy, PPPE is of particular interest. In fact, as already stated earlier in the report, PPPE is related to patient outcomes in various settings (Lelorain *et al.*, 2012a; Street & Mazor, 2017; Elliott *et al.*, 2018) whereas *physician*-reported empathy or empathy assessed by observers is not. This is because one physician can be judged differently by different patients so that what really matters regarding a given patient's outcomes is his/her own perception of the physician. Understanding the factors associated with PPPE is thus of particular interest.

3.3.1. Sociodemographic and clinical factors

In the literature, the most commonly explored variables in this respect are sociodemographic and clinical factors of patients and physicians such as gender, physician experience and time spent in consultations.

It has been established that patients perceive physicians as more empathic when the latter are juniors compared with seniors (Pollak *et al.*, 2007; Shariat *et al.*, 2010; Kondo *et al.*, 2013) and when they spend more time in consultations (Neumann *et al.*, 2007; Hack, 2010, 2012; Johnson *et al.*, 2013). Numerous studies have shown that *physician*-reported empathy is higher in female doctors than in

male (Biswas *et al.*, 2018; see the review of Elayyan *et al.*, 2018 for references). However, data on PPPE (and not physician-reported empathy) are difficult to find. In the field, actual differences between genders could be less marked than in physician-reported questionnaires. In fact, a recent study did not find a main effect of physician gender on patient satisfaction, but did find an effect of gender concordance between physician and patient on satisfaction (Noro *et al.*, 2018), as also concluded in an earlier review (Bertakis, 2009). Female patients may also be more sensitive to physician non-empathy than male patients (Kraft-Todd *et al.*, 2017). Medical specialty is also related to empathy with people-oriented specialties being more associated with empathy than technology-oriented ones like surgery (e.g. Dehning *et al.*, 2014; Chaitoff *et al.*, 2017; Fernando & Consedine, 2017; Guilera *et al.*, 2018). Attire has also been studied. Wearing a facemask reduces PPPE (Wong *et al.*, 2013) and the white coat seems to influence PPPE, however with different results according to samples and settings. Korean patients perceive more empathy from their physicians when they wear a white coat (Chung *et al.*, 2012) whereas in a sample of 500 patients in French primary care settings, a casual outfit seemed to make patients trust the physicians more (Barbedienne, 2017). Non-verbal behaviours have also been studied with expected results; for example, a positive impact of physicians' gaze and body orientation toward patients for PPPE (Brugel *et al.*, 2015).

3.3.2. Good bearing and bedside manners

Although the previous variables are undoubtedly important, we were interested in a more fundamental question: is the seminal definition of physician empathy, presented on page 41, as a 'predominantly cognitive attribute that involves an understanding of the patient's experiences, concerns and perspectives' (Hojat, 2007) related to PPPE? The question may seem odd and unnecessary because what is defined as empathy should theoretically be judged as such by patients. However, in the field of oncology, things could be different. Good bearing and bedside manners with active listening and warmth, as well as sufficient time devoted to the patient, seem sufficient for patient satisfaction (e.g. Hack, 2010, 2012; Bayne *et al.*, 2013), which is highly correlated with PPPE ($r = .68$ in one of our databases, unpublished results).

Consistent with this idea, in a vignette study responded to by analogue patients, the latter were satisfied with the 'vignette physicians' who were able to detect the occurrence of patient emotions, even if they were wrong at determining the *nature* of the detected emotions (Blanch-Hartigan, 2013). A front empathy could be enough to be perceived as empathic in clinical settings. To fuel this reasoning, a randomised controlled trial with analogue patients watching videos of doctor-patient consultations with bad-news disclosures reported that four standardised sentences of reassurance and understanding (e.g. 'whatever happens, we will never let you down', 'I completely understand your

reluctance [...] we'll pay attention to your concerns') made analogue patients judge the physician as more empathic (Danzi *et al.*, 2018).

Thus, as some authors argue, accuracy may not be as functionally important as might a priori be thought (Epley & Caruso, 2009). This could be particularly true in medical settings and especially in oncology where patients' expectations towards physicians are first and foremost focused on medical expertise (Rudolph *et al.*, 2015) and where some patients do not even wish psychosocial issues to be addressed by physicians (Martins & Carvalho, 2013).

In a study on colorectal cancer patients' expectations towards their surgeon, some patients acknowledged that their surgeon was not a psychiatrist or a psychologist so that emotional needs should be addressed by someone else (Abelson *et al.*, 2019). Interestingly, what was emphasised as particularly valuable by some of these patients were rather acts of kindness (e.g. a surgeon put her arm around a patient who was crying; another asked to see a photo of the patient's son) than an accurate 'understanding of their experience, concern and perspectives' as mentioned in the seminal definition of empathy by Hojat (2007). The same emphasis was retrieved in a palliative setting where patients were grateful for 'all the kindness', 'greatest humanity' and 'affection and friendship' of the staff (Aparicio *et al.*, 2017) without specifically mentioning the importance of being fully understood. The sparse data available in oncology have not revealed any link between physician accuracy and concepts close to PPPE, such as patient trust in the physician (Shin *et al.*, 2011) or satisfaction with the consultation (Fröjd & Von Essen, 2006). A recent meta-analysis in dyads from the general population also confirmed only a weak correlation between accurate understanding (AU)¹⁰ and perceived empathy ($r = .134, p < .05$), which was significant only when the two people had known each other for a while (Sened *et al.*, 2017).

If it is confirmed that PPPE does not depend on physicians' accurate understanding (AU) of patients' experience, medical education could encourage physicians to show good manners rather than trying to improve their AU. It should be reminded that AU can be cognitively demanding and time-consuming. In current medical settings where physicians have so much to handle, it would be a shame to add a cognitive load on them if AU was not necessary. On the other hand, as described below, compelling arguments also support the need for AU for PPPE.

¹⁰ I will use 'accurate understanding' to describe the accuracy with which a physician perceives the needs and concerns of a specific patient.

3.3.3. The role of accurate understanding

First, some patients want their physicians to truly understand their concerns and needs, especially at the time of their cancer diagnosis and when they are undergoing treatment (Shim *et al.*, 2016). AU thus seems essential to PPPE, as supported by a study performed with couples that demonstrated that the perception of empathy from the partner depends on his/her AU in interaction with his/her empathic concern (Winczewski *et al.*, 2016). AU is thus necessary to the perception of empathy.

Second, an AU of patient needs is logically required by physicians for them to address those needs and thus be perceived as empathic. Findings that patients' unmet information needs are strongly related to low PPPE support this line of reasoning (Nambisan, 2011; Neumann *et al.*, 2011b; Brédart *et al.*, 2013).

This is why the lack of a statistically significant relationship between AU and PPPE in oncology (Fröjd & Von Essen, 2006; Shin *et al.*, 2011) can be questioned. I think that these studies failed to demonstrate the link between AU and PPPE because of the following two methodological drawbacks: first, previous studies assumed a direct link between AU and PPPE, whereas we think that AU is actually a *moderator* of the link between patients' unmet needs and PPPE; second, previous studies did not explore the type of AU whereas there are different types with different clinical implications. I will now develop these two points.

3.3.3.1. AU as a moderator

Rather than influencing PPPE directly, AU could interact with patient unmet needs to explain PPPE. As previously stated, there is a strong link between patient unmet needs and low PPPE, a fact confirmed by recent studies (Walling *et al.*, 2016). However, somewhat surprisingly, PPPE depends on elements that go beyond the physicians' scope of action, such as the hospital's organisation of care (Neumann *et al.*, 2007; Kowalski *et al.*, 2009; Ansmann *et al.*, 2012). Dysfunctional hospital organisation can create patient unmet supportive care needs, for which physicians are not responsible, but which still impact PPPE. Yet, it could be expected that, although physicians are not responsible for and perhaps unable to meet these patient needs, their accurate awareness of these concerns could at least lessen the strong negative impact of unmet needs on PPPE. We thus expected a moderating effect of AU on the link between patient unmet needs and PPPE. Although there was no empirical study at the time of our research to support this hypothesis, from a theoretical point of view, it was conceivable that AU, as an acknowledgement of patient suffering, could buffer the negative impact of unmet needs on PPPE. Nevertheless, as developed in the following two paragraphs, the moderating effect could be possible only under a particular type of AU.

3.3.3.2. The type of AU

According to some authors, perspective-taking (i.e. adopting another's perspective by putting oneself in the other's shoes) (Epley & Caruso, 2009; Myers & Hodges, 2009) and getting another person's perspective directly, through conversation and questions (Eyal *et al.*, 2018), could be two ways, among others, to achieve good AU.

AU can also be achieved by the projections of one's own emotions on another person, or by knowledge of the other, or by stereotypes. Therefore, it might be that previous studies did not assess the AU stemming from physician perspective-taking and perspective-getting, which recall the *distinctive* accuracy of social psychology, but rather assessed a *normative* or *stereotype* accuracy resulting from physician heuristics to obtain an idea of the patient's situation rapidly and effortlessly. These heuristics are automatic and typically come from: projections (a sad physician will be prone to perceive sadness in others) (Clark *et al.*, 2017), stereotypes (e.g. 'All advanced cancer patients must have a lot of unmet needs') or egocentric perspectives (e.g. 'If, as a physician, I have done everything that can be done for a patient, (s)he should not have unmet needs') (Epley & Caruso, 2009; Myers & Hodges, 2009; Zaki & Ochsner, 2011). If, for example, a physician assumes that cancer patients always have numerous unmet needs, s/he will be accurate with all patients that do have many unmet needs. However, although this *stereotype* AU can be high, since it is not based on a sound knowledge of a specific patient by taking and getting his/her perspective, it should not be related to PPPE. We therefore propose that AU could have the speculated moderating effect (i.e. AU moderates the negative impact of unmet needs on PPPE) but only for a *distinctive* AU.

To help with this complex notion of AU, we propose the following summary.

Distinctive accuracy = the physician is accurate about his/her patient because the physician has made the effort to try to understand this given patient by taking and getting his/her perspective. The physician is truly interested in a given patient. For example, the physician says that the patient is distressed (good accuracy) because s/he paid attention to the patient and clearly asked him/her about distress.

Normative or stereotype accuracy = the physician is accurate about his/her patient thanks to automatic, rapid and effortless processes such as stereotypes, which do not imply a specific knowledge of a given patient. The physician is probably not interested in his/her patient. For example, the physician says that the patient is distressed (good accuracy) because s/he thinks that patients are often distressed. Accordingly, s/he thinks that this given patient is probably distressed too. This accuracy does not come from an interest in the patient.

We hypothesise that AU could have a moderating effect (i.e. AU moderates the negative impact of unmet needs on PPPE) only for a *distinctive* AU.

3.3.3.3. When does distinctive AU occur?

Because of physician external constraints, such as lack of time, and since perspective-taking and perspective-getting are energy-consuming and demanding tasks, it can be assumed that, by default, physicians do not take patient perspectives but use heuristics instead. This hypothesis was confirmed in medical students (Maxfield *et al.*, 2011). Accordingly, a distinctive AU ought to occur if physicians have a good reason to engage actively in the interaction with patients and take their perspectives. Among other motivations, perspective-taking/getting are triggered in difficult situations to cope with relationship threats (Smith *et al.*, 2011b), lack of personal control (Waytz *et al.*, 2010) and when people expect rewards from good accuracy (Hess *et al.*, 2017). This may explain why medical students elicit more patient perspectives in the case of an unclear diagnosis, which can be challenging for the doctor-patient relationship, compared to a clear diagnosis (Maxfield *et al.*, 2011). Therefore, although it may not seem intuitive at first sight, we assumed that distinctive AU would be more likely with patients for whom physicians perceive *poor* rapport rather than with 'easy' patients. Moreover, distinctive AU can only occur with patients who disclose information/cues on which physicians can draw in order to understand them accurately. The importance of a target's expression for perceiver accuracy has been demonstrated in numerous studies (Hall & Schmid Mast, 2007; Zaki *et al.*, 2009; Leloirain *et al.*, 2014). Without clear available information, physicians have no other choice but to use heuristics, and even perspective-taking is not effective (Eyal *et al.*, 2018).

Overall, distinctive AU is assumed when physicians experience poor rapport with patients or when patients are expressive.



To summarise, we decided to investigate the unresolved issue of how AU could contribute to PPPE in ecological cancer settings. Clarifying this issue is vital to demonstrate the importance of AU in the doctor-patient relationship. If AU is not an important component of PPPE, one should avoid additional strain on doctors caused by trying to understand their patients accurately. It should be recalled that AU can be cognitively demanding and time-consuming.



Based on a theoretical reasoning, we proposed a new model in which AU would buffer the negative impact of unmet patient needs on PPPE, but only for an assumed *distinctive* AU, which, in this study, is either with expressive patients providing diagnostic information about their needs and emotions, or when physicians have poor rapport with a patient. High patient expressiveness and poor rapport were used as 'proxies' for an assumed distinctive AU. In addition, we controlled for the classic covariates of PPPE, i.e. physician self-reported empathy, length of consultations, and physician experience in oncology.

3.3.4. Test of a new model

The proposed model was tested with the study described on page 59 in which 28 physicians rated 201 advanced cancer patients' distress and unmet supportive care needs after a consultation trying to take the patient's perspective and thus obtain an AU of the patient's needs. At the same time, the patient was asked to independently rate his/her unmet needs.

Patient unmet supportive care needs were assessed using an ad-hoc adaptation of the Supportive Care Needs Survey-Short Form 34 (Brédart *et al.*, 2012) which yielded two factors: psychological and staff-related unmet needs. Physician AU of patient unmet needs was generated by summing the physician's accurate items for each of the two dimensions (psychological and staff-related needs). For each item, the physician was considered accurate if (s)he gave the same rating as the patient to within one point. Rapport with the patient was reported by physicians using the following single question: 'What is the quality of your relationship with this patient?'. Patient expressiveness was assessed with the expressive suppression dimension of the Emotion Regulation Questionnaire (Christophe *et al.*, 2009), PPPE with the CARE questionnaire (Mercer *et al.*, 2004) and physician-reported empathy with the JSPPE (Hojat *et al.*, 2002a; Zenasni *et al.*, 2012).

To respect the two-level hierarchical structure of patients nested within doctors, multilevel analyses were performed with MLwiN software. Our hypotheses were tested using two three-way interactions: patient unmet staff-related needs * AU * rapport, and patient unmet psychological needs * AU * patient expressiveness. To avoid type I error, we chose these two interactions only. Patient expressiveness concerns the expression of emotions and was thus deemed particularly relevant to psychological needs whereas a poor rapport with the physician was deemed to be more relevant to staff-related needs as it probably reflects the patient's dissatisfaction with information and staff care.

3.3.4.1. Agreement between patients and physicians on patient needs

The results of physicians' rating of patients' needs are presented in Table 4.

Table 4. Patient unmet needs as rated by patients and physicians.

Dimension/item	Patient's rating		Physician's rating		Difference [†]	AU [‡]	ICC
	Mean	SD	Mean	SD			
Psychological dimension							
Lack of energy, tiredness	3.32	1.92	4.09	1.73	0.77***	49	0.37***
Uncertainty about the future	3.64	2.11	4.11	1.78	0.48**	43	0.25*
Keeping a positive outlook	3.11	2.05	3.91	1.66	0.79***	43	0.36***
Feelings about death and dying	3.08	2.17	3.89	1.68	0.81***	42	0.34***
Being informed about things you can do to help yourself to get well	3.83	2.24	3.42	1.55	-0.41 [†]	41	0.17
Dimension score	3.40	1.69	3.89	1.39	0.49***	2.17 (1.47)	0.29***
Staff-related dimension							
Being given explanations of those tests for which you would like explanations	3.05	2.05	3.03	1.50	-0.02	43	0.01
Being informed about your test results as soon as feasible	3.44	2.27	3.31	1.67	-0.13	43	0.24 [‡]
Hospital staff attending promptly to your physical needs	2.43	1.85	3.25	1.61	0.82***	51	0.36***
Reassurance by medical staff that the way you feel is normal	3.02	2.08	3.68	1.66	0.66***	48	0.30***
Being treated like a person not just another case	2.60	2.07	2.44	1.41	-0.16	57	0.20 [‡]
Being adequately informed about the benefits and side effects of treatments before you choose to have them	3.38	2.24	3.19	1.59	-0.19	42	0.17
Dimension score	2.99	1.73	3.15	1.27	0.16	2.83 (1.85)	0.24***

Note. For each item, AU is the percentage of physicians who were accurate on this item (i.e. same rating as the patient to within one point). For each dimension, AU is the mean score of accurate items per physician, with standard deviation in brackets; ICC = Intra Class Correlation Coefficient. ICC < .40 reflects poor agreement. *** $p < .001$, ** $p < .01$, * $p < .05$, † Difference was tested using paired t test, ‡ AU: Accurate understanding of patient's unmet needs.

Physicians poorly assessed their patients' unmet needs (all ICC < .40). If we consider patients as the reference, physicians overestimated or equivalently rated all needs except for the one about 'being informed about things you can do to help yourself to get well' for which they underestimated the needs of patients.



It is interesting to note that physicians underestimated the need of patients to take control over the situation by self-management.



It recalls the issue of therapeutic patient education, which is not well invested in by physicians in France. With two students, one studying for a Master's degree in Health Psychology in Lille and the other for a Therapeutic Patient Education degree in Lille, we thematically investigated the attitude of physicians and medical staff toward patient education (Rey *et al.*, 2016; Lelorain *et al.*, 2017). Although numerous meta-analyses have demonstrated the effectiveness of patient education regarding various patient outcomes such as better emotional well-being (Matsuda *et al.*, 2014) and even higher survival rates (Oh *et al.*, 2016), some physicians do not see its usefulness and consider it a waste of time. Furthermore, some are reluctant to give knowledge and tips to nurses and other staff members, as well as to patients, as they easily feel dispossessed of their medical power (Rey *et al.*, 2016; Lelorain *et al.*, 2017). The same result was found in a recent German study in cancer care (Steven *et al.*, 2019). More information on the topic can be found at:

Rey, C., Verdier, E., Fontaine, P., & Lelorain, S. (2016). Fostering hospital physicians' involvement in therapeutic patient education: avenues for continuing training and team support. *Éducation Thérapeutique Du Patient - Therapeutic Patient Education*, 8(1), 10105. <https://doi.org/10.1051/tpe/2016005>

Lelorain, S., Bachelet, A., Bertin, N., & Bourgoin, M. (2017). French healthcare professionals' perceived barriers to and motivation for therapeutic patient education: A qualitative study. *Nursing & Health Sciences*, 19(3), 331–339. <https://doi.org/10.1111/nhs.12350>

3.3.4.2. AU moderates the 'unmet staff-related needs->PPPE' link

As expected, we found a significant interaction, which is plotted in Figure 10.

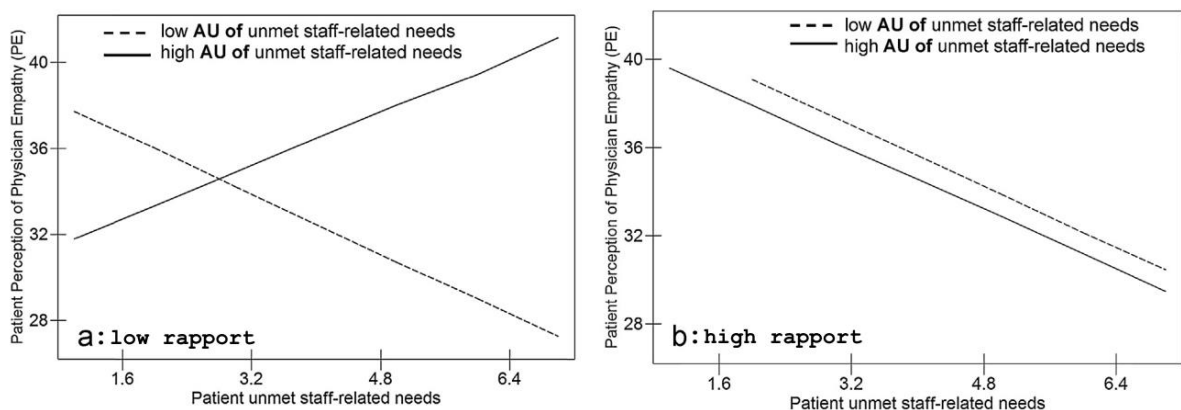


Figure 10. Three-way interaction between unmet staff-related needs, AU, and rapport.

- (a) Interaction plot between patient unmet staff-related needs and PPPE for a low rapport with the patient (left side).
- (b) Interaction plot between patient unmet staff-related needs and PPPE for a high rapport with the patient (right side).

AU = accurate understanding; Due to the negative skewed distribution of rapport, low rapport was plotted with a value of 3 and high rapport with the maximal value of 7 on a 7-point Likert scale.



When the physician reported an excellent rapport with the patient (right side of figure), whatever their AU, patient unmet staff-related needs were associated with less perceived empathy. Even a high AU was unable to counter the negative effect of unmet needs on PPPE, probably because this apparent high AU may be a heuristic such as a stereotype, projection or ego-perspective. On the contrary, when rapport was low, patient unmet needs were associated with higher PPPE but only for high AU.





Interestingly, a recent study in couples, carried out in an ecological setting, confirmed our results: on conflict days (which recall a low rapport), a high AU of the partner made him/her perceived as more empathic in spite of the conflict (Lazarus *et al.*, 2018). Therefore, this AU probably reflects distinctive AU stemming from an effort to take or obtain the patient's perspective.



Informal feedback from physicians at the end of the study added credence to our argument that, by default, physicians use heuristics to work routinely with patients. In the debriefing interviews following the research, the physicians told us that the AU was difficult and that they sometimes felt they had performed it randomly. Consistent with previous findings (Fagerlind *et al.*, 2008), physicians reported that they rarely questioned themselves about their patients' care needs in their usual routine. From a lay point of view, this may be surprising, but the heavy workload of physicians explains, at least in part, this lack of perspective-taking on patients' supportive care needs. However, an encounter with a difficult patient may trigger perspective-taking.

In fact, the prevalent terminology for poor rapport between physicians and patients is 'difficult patient encounters' or 'difficult patients' defined by a physician as 'those who make us feel frustrated, uncomfortable, or 'ineffective' and 'present' some type of threat: they can reject us or harm us' (Duxbury (2000) cited by Robiner & Petrik, 2017). Little is written in the scientific literature about this topic and the few existing articles are often more based on reflexion and ethics than on empirical data. However, empirical data are insightful, revealing that more than 90% of physicians have encountered difficult patients (Acar & Buldukoglu, 2016; Sandikci *et al.*, 2017) and that 17.8% of patients are rated as difficult by their providers of internal medicine (Hinchey & Jackson (2011) cited by Robiner & Petrik, 2017).

A recent review (Robiner & Petrik, 2017) classified the factors associated with difficult patient encounters at three levels: the patient, the physician and the system.

1) At the patient level, patients with more than five physical symptoms, functional disorders such as headaches, life-threatening illnesses, mental disorders (67% of difficult patients against 25% of non-difficult patients), and depression and anxiety during the week preceding the clinic visit were good candidates for categorisation as difficult patients. Cancer patients are therefore highly likely to become difficult patients.

2) At the physician level, long daily working hours, a large number of patients and little experience increase the likelihood of difficult encounters, as also confirmed by recent data (Sandikci *et al.*, 2017). Physicians' perfectionism, difficulty in accepting failure, high expectations toward patients, low emotional skills (ES) and low interest in the psychosocial aspects of care were further risk

factors for difficult encounters. Remarkably, we found the same risk factors in healthcare providers of therapeutic patient education (TPE) vis-à-vis their experience of patient encounters in this context and thus their motivation for patient education (Lelorain *et al.*, 2017, 2019a). HCP emotional skills explain their motivation for TPE (Lelorain *et al.*, 2019a). Interviewed about their experience of TPE, the HCPs with a low interest in the psychosocial aspects of TPE (i.e. focusing on disease and treatment only) were the most disappointed by it (Lelorain *et al.*, 2017). In their discourse, anger against and conflictual situations with patients could be guessed as illustrated by the following quote of a nurse (p. 4): 'I had hope in TPE, I thought it would work but in fact it depends on the patients. I thought patients would be very motivated as [...] we have time for TPE, we have TPE dedicated nurses. I thought the TPE results would be better but in, the end, patients come back and we have the feeling that everything they have been told is gone and forgotten'.

More information in:

Lelorain, S., Bachelet, A., Bertin, N., & Bourgoin, M. (2017). French healthcare professionals' perceived barriers to and motivation for therapeutic patient education: A qualitative study. *Nursing & Health Sciences*, 19(3), 331–339. <https://doi.org/10.1111/nhs.12350>

Lelorain, S., Bachelet, A., Goncalves, V., Wortel, E., Billes, M., Seillier, M., ... Bourgoin, M. (2019). Nurses' and nursing assistants' emotional skills: a major determinant of motivation for patient education. *Journal of Advanced Nursing*. <https://doi.org/10.1111/jan.14033>

3) Finally, at the system level, the sense of depersonalisation experienced by inpatients due to the large number of providers they had met, some of whom did not even introduce themselves, the generic hospital gown, their identity reduced to a room number, and the uncontrollability of care, can trigger anger and fear and cause difficult encounters with physicians. The latter, in turn, suffer from an ultra-competitive, demanding and fast-paced health system, which places great pressure on them to perform more tasks in less time with a focus on cost reduction. Surgical departments are especially at risk of difficult patient encounters (Sandikci *et al.*, 2017).

It is thus important to keep in mind that poor rapport can be of different types, be it either at one level (e.g. patient level) or, most likely, at different ones (patient and system levels). One limitation of our study is that it did not explore the sources of poor rapport.

However, in the light of the three-level analysis of rapport, physicians who reported low rapport but at the same time achieved high AU were probably dealing with a poor rapport mainly due to patient factors (e.g. multiple physical symptoms, life-threatening cancer, anxiety) and system

factors, rather than to their own factors. In fact, it can be assumed that, thanks to their ES and interest in the psychosocial aspects of care, they were able to achieve high AU and were thus perceived as empathic by patients. In contrast, physicians who reported low rapport and performed badly on AU might rather have experienced a poor rapport mainly due to their own 'flaws' (e.g. little attention to patients' needs, a defensive posture faced with patient suffering, low ES), explaining the low PPPE.

Finally, it should be noted that among the controlled variables inserted into our model for the prediction of PPPE, only the length of consultations remained significantly associated with PPPE. Experience in oncology and physician-reported perspective-taking, which were correlated with PPPE in bivariate analyses, were no longer significant in the multivariate model.

3.3.4.3. AU moderates the 'unmet psychological needs->PPPE' link

As expected, we found a significant interaction, which is plotted in Figure 11.

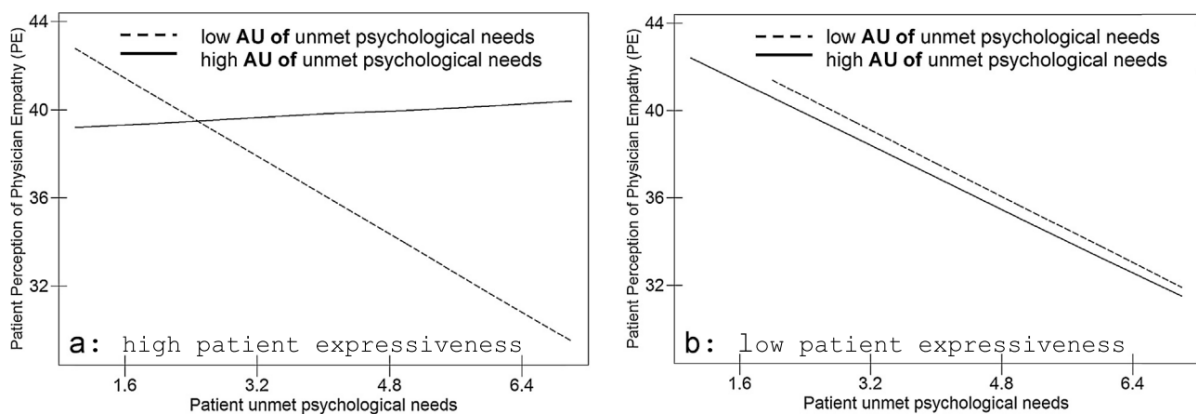


Figure 11. Interaction between unmet psychological needs, AU, and patient expressiveness.

- (a) Interaction plot between patient unmet psychological needs and PPPE in highly expressive patients (left side).
- (b) Interaction plot between patient unmet psychological needs and PPPE in low expressive patients (right side).

AU = accurate understanding

Percentiles 20 and 80 of expressiveness were chosen to plot the interaction.

When patients were not expressive (right side of figure), whatever the physician AU, patient unmet psychological needs were associated with less perceived empathy. Even a high AU was unable to counter the negative effect of unmet needs on PPPE, probably because it was a heuristic such as a stereotype, a projection or an ego-perspective. In any case, it seems very unlikely that this AU came from patients' spontaneous words since those patients were not expressive. On the contrary, when patients were expressive, patient unmet needs were no longer associated with PPPE in the case of a high AU. Therefore, here, the AU probably reflected a distinctive AU stemming from an effort to take



or obtain the patient's perspective, which made the patient perceive high empathy in spite of unmet needs.

These results support the contention that PPPE is not only dependent on physicians but also on patients. Patient expressiveness enables physician AU, which is associated with high PPPE even for patients with high unmet needs. Patients' clear and explicit expression of their emotions and concerns is thus extremely important.

Congruent with this idea, physicians explore patients' disease and illness more when interacting with high participation patients than with low participation patients (Cegala & Post, 2009). It should be noted that this participation has to be clear and explicit, with clear sentences. In the lay population, there is a widespread misbelief that non-verbal communication is more important than verbal communication. It is often said that '70% of communication is carried out through non-verbal communication'. Although non-verbal communication is important, this common belief is false (e.g. Kraus, 2017; Eyal *et al.*, 2018). This is why communication training is dedicated to cancer patients to enhance their communication skills in order to express emotions and concerns and ask for help from their physicians (e.g. Porter *et al.*, 2015). Such interventions also aim to increase patients' expectations that communicating during consultations is necessary and helpful for their quality of life. In fact, due to age or cultural embedded attitudes towards physicians, some patients are still reluctant to express their feelings and needs to physicians. They do not see the point. Yet, an interesting study proved that BC patients' quality of life was more related to the patients' communication skills than to physicians' communication skills (Trudel *et al.*, 2014). However, evidence of the impact of patients' communication on their health, psychosocial well-being or treatment outcomes is still lacking as concluded by a recent review (D'Agostino *et al.*, 2017). At least, this review showed that patient participation increased with training and that patients thus received more information during visits. This is a good point as oncologists underestimate patients' needs for explanations and participation in their treatment plan (Goldzweig *et al.*, 2015). Patient question-prompt lists given to them before consultations are therefore useful. They give patients the legitimacy to ask questions whatever the taboo or the sensitive issue of the question (sexuality domain or prognostic-related questions) and are thus a good way to encourage patient expression (Heyn *et al.*, 2013; Alders *et al.*, 2017; Amundsen *et al.*, 2018).



Again, among the controlled variables, only the length of consultations remained significantly associated with PPPE.

3.3.4.4. Conclusion

 This study is one of very few that elucidate how AU contributes to PPPE in naturalistic cancer settings. It showed that, under conditions that are thought to maximise perspective-taking and thus distinctive AU, e.g. low rapport with patients or when patients are expressive, AU buffers the adverse effect of patient unmet needs on PPPE. 

A promising perspective would be to clarify explicitly with physicians on what they base their reasoning to try to take the patients' perspective. In this way, we could formally assess whether AU was distinctive or stereotypic.

Another avenue of research would be to include data on physician behaviour during consultations. This would enable us to determine whether AU alone or AU coupled with empathic behaviour is the source of PPPE. A recent study answered this question by showing that medical students' emotion recognition ability led to patients' positive evaluation only in extrovert students (Schreckenbach *et al.*, 2018). Interestingly, the main effects of emotion recognition or extraversion were not sufficient to yield similar effects.

 This study thus bolsters the idea that PPPE depends on both AU and good bearing/bedside manner and that to pay patients lip service does not render physicians empathic to patients. The good bearing/bedside manner needs to be tailored to the patient's needs and preferences. 

Fortunately, it seems that AU goes along with further actions that take into account the information provided by AU. For example, medical students with high AU behave in a more engaged way with patients than their counterparts with low AU (Hall *et al.*, 2015); female physicians, but not male physicians, with high AU show more verbal and non-verbal behavioural adaptability to meet their patients' preferences in terms of communication (Carrard *et al.*, 2018). In an experimental study on leadership, women with higher interpersonal accuracy adapted their behaviour more to the needs and preferences of their subordinates (Palese & Schmid Mast, 2017, cited by Schmid Mast & Hall, 2018). Although gender seems important to consider, AU may, at least in women, lead to more tailored behaviours, which are logically associated with better patient satisfaction (Carrard *et al.*, 2016). To sum up, AU would lead to tailored actions, which in turn would increase PPPE.

Full reference associated with the heading '3.3. Factors associated with patient perception of physician empathy (PPPE)':

Lelorain, S., Brédart, A., Dolbeault, S., Cano, A., Bonnaud-Antignac, A., Cousson-Gélie, F., & Sultan, S. (2015). How does a physician's accurate understanding of a cancer patient's unmet needs contribute to patient perception of physician empathy? *Patient Education and Counseling*, 98(6), 734–741. <https://doi.org/10.1016/j.pec.2015.03.002>

In this section 3, I described the factors associated with empathy, whether it was self-reported empathy by physicians, physician accuracy regarding patient distress or perceived empathy by patients. I showed that:

- physician-reported empathy depends on empathic concern, especially for those without a reflective activity (part 3.1);
- physician accuracy regarding patient distress is rather low. However, it can be high for highly distressed patients, except in the case of excellent doctor-patient rapport, which can therefore be a pitfall in distress detection, and in the case of inexpressive patients who make distress detection harder for physicians (part 3.2);
- physician AU of patient unmet needs buffers the adverse effect of patient unmet needs on PPPE, but only under conditions that are thought to lead to distinctive AU, i.e. in the case of low rapport with patients or when patients are expressive (part 3.3).

In the next section, I will focus on the outcomes of empathy. First, I will rapidly present a theoretical model of the positive outcomes of medical empathy. Then, I will describe a literature review I carried out in 2012, which confirms the model. This review points to several limitations of the research into empathy outcomes that we addressed in an important international study. This work will be the opportunity to discuss the pitfalls of empathy.

4. Outcomes of medical empathy

4.1. Theoretical assumptions about the benefits of empathy

By default, medical empathy is thought to be positive for patients. This idea is so pervasive that the seminal theory of Melanie Neumann (Neumann *et al.*, 2009) presented in Figure 12 expounds only positive effects of empathic communication.

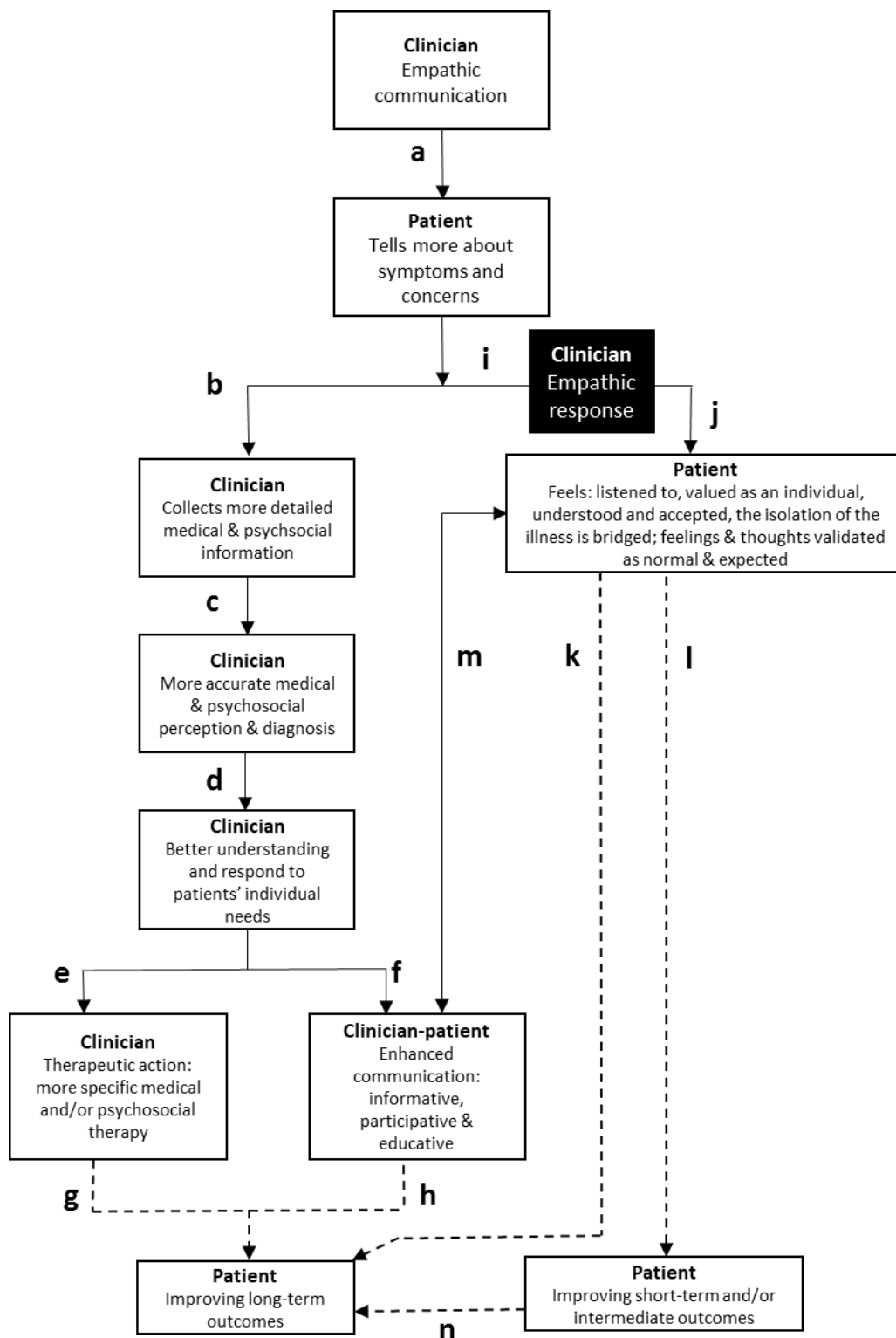


Figure 12. Effect model of empathic communication in the clinical encounter, from Melanie Neumann (2009).

Solid arrays translate already proven links whereas dotted ones assume links that were not empirically established at the time of the model (2009). I have added the black square, which was not in the model of Neumann, and letters to name each path easily.

In the left 'cascade' of the model, clinical empathy would make patients prompt to express symptoms and concerns (path a), which in turn would facilitate AU (paths b and c), leading to tailored therapeutic actions (d and e) and enhanced communication (f). Therefore, on this side of the model, in spite of appearing linear, the model is rather circular as empathic communication eventually leads to enhanced communication, which seems very close to empathic communication. Long-term positive outcomes are then assumed.

One part of the model fits our previous findings that expressive patients lead to distinctive AU which leads to 'clinician-patient: enhanced communication' and thus arguably to perceived empathy by the patient. The model also specifies that clinician accuracy leads to a better understanding and response to patients' individual needs (path d), a theoretical path supported by the results of Carrard et al. (2018) previously presented (i.e. female physicians with high AU showed more behavioural adaptability to meet their patients' preferences in terms of communication).

Furthermore, at the top, the model specifies that empathic communication triggers patient expression (path a), the latter hinting at the concept of 'cues' or 'empathic opportunities'. As a reminder, an empathic opportunity or a patient cue is a verbal or non-verbal patient hint that suggests an underlying emotion or concern in the patient. A recent study in early-stage BC patients confirmed that oncologists' patient-centred communication (i.e. investigating patient's worries, emotional needs and the psychosocial impact of the illness) was associated with a higher number of expressed concerns by patients during the interviews (Del Piccolo *et al.*, 2019).

The link between empathic communication and patients' expression of symptoms and concerns could also be thought of in the reverse sense. It would even be more logical for the right side of the model. In fact, patients certainly do not feel understood because they express concerns, as specified in the model (original path i), but because their expressed concerns are empathically responded to by clinicians (paths i and j). Theories of social sharing of emotions provide proof for this contention. Contrary to the widespread common-sense belief, research into social sharing has demonstrated that expressing one's emotions does not alleviate those emotions (Rimé, 2009; Nils & Rimé, 2012). Instead, it is the response of the 'perceiver' of emotions that helps to assuage the emotions of the target (Nils & Rimé, 2012). This is why I added a black square between the patient expression of symptoms and concerns and his/her feeling of being listened to, understood and accepted.

4.2. Empirical evidence: a systematic literature review in 2012

As the model of Neumann was published in 2009 and contained hypothesised paths (in dotted lines), in 2012, we set out to verify these paths by performing a systematic literature review. Studies were selected if they met the following inclusion criteria: to be quantitative, in adult cancer care, to have a measure of empathy according to the definition of Hojat (2007; see page predominantly cognitive for the definition) or in accordance with one of the elements of the Consultation and Relational Empathy (CARE) questionnaire (e.g. warmth, positive attitude, understanding of the patients' emotion), and to study the link between clinicians' empathy and patient outcomes whatever the outcomes. We defined patient outcomes as observable or self-reported consequences of a medical encounter or relationship. Outcomes are often categorised by a temporal criterion (de Haes & Bensing, 2009) which was deemed relevant for the presentation of the results:

- within the consultation (e.g. patient participation),
- proximal (within one month of the consultation; e.g. immediate satisfaction or recall of information),
- intermediate (e.g. adherence to treatment until up to one year after the consultation),
- distal (e.g. quality of life or survival after more than one year of the consultation).

Our goals were to (i) give an overview of measures related to empathy in cancer research as well as investigating patient outcomes; (ii) study the associations between physicians' or nurses' empathy and patient outcomes; (iii) make assumptions about the conditions in which these associations can be stronger or weaker.

4.2.1. Overview of the results

Thirty-nine studies were retrieved. Most of the outcomes were proximal and related to patient satisfaction with clinicians/medical encounters or to patient psychological adjustment. Among the 14 intermediate or distal outcome studies, only five were prospective, the others being retrospective. In most samples, patients were assessed at the beginning of or during treatment. Only six studies included patients with advanced cancer or in palliative treatment. Professionals were nurses in nine studies and physicians in the other 30. Empathy was mainly evaluated using patient-reported measures or coding systems. None of the 39 retrieved studies evaluated empathy by using two different approaches (e.g. patient-reported measure and coding system).

For clarity, I will not exhaustively address the 39 studies but give the main results and important discussion points. I will also mention important studies published since 2012 on the same topics.

4.2.2. In-consultation outcomes

Within consultations, the oncologist's partnership building, supportive talk and facilitative communication (e.g. asking for understanding and patient's opinion), assessed using coding systems, were associated with active patient participation in the consultation (Maguire *et al.*, 1996; Ishikawa, 2002; Street *et al.*, 2005), including about taboo topics such as complementary and alternative medicine (Roter *et al.*, 2016). A reverse result was only found in chemotherapy education sessions performed by nurses. Against this background, nurses who provided space for patient emotions and concerns, also assessed using external coding, *reduced* the expression of patient cues and concerns in those sessions (Oguchi *et al.*, 2011). This surprising result might be due to the educational context in which patients expect information and thus are capable of turning back swiftly to informational exchanges once their distress has been addressed with empathic responses. In this particular context, the empathic response would be enough for patients to feel recognised and thus to return to the educational focus of the session without developing their concerns further.

Overall, with the exception of one study in a specific educational context, these studies seemed to support the 'path a' of Melanie Neumann's theory (2009).

4.2.3. Proximal outcomes after the clinical encounter

Once again, most of these outcomes pertained to patient satisfaction with the clinician or the visit. PPPE was related to higher patient satisfaction (Takayama *et al.*, 2001; Zachariae *et al.*, 2003; Dong *et al.*, 2014) but only in early cancer stage patients in one study (Rutter *et al.*, 1996). With coding systems assessing empathy, nurses' empathy was also associated with higher patient satisfaction (Uitterhoeve *et al.*, 2009).

Interestingly, in a radiotherapy education session, PPPE was related to trust in the radiation therapist and to patient authentic self-representation, i.e. the extent to which patients express truly what they feel about cancer (Dong *et al.*, 2014). This study confirms the path (a) of the theoretical model of Melanie Neuman (2009) presented page 82.

Psychosocial exchange, assessed using a coding system, was related to higher patient satisfaction during the counselling phase of the consultation but to *lower* satisfaction during the physical examination phase of the consultation (Eide, 2003).



This enlightening result is a reminder that in cancer care, patient priorities still revolve around medical issues. There may be a specific time for empathy to be appreciated by patients.



Cultural issues could also be at stake. In a Japanese study, physician empathy was correlated to *less* patient satisfaction (Ishikawa *et al.*, 2002). Some studies failed to reach statistical significance between physician empathy and patient satisfaction, whether empathy was assessed by coding (Butow *et al.*, 1995, 2002) or by a perspective-taking task (Fröjd & Von Essen, 2006).

However, in another perspective-taking task, nurses' underestimation of patients' depressive symptoms was associated with less patient satisfaction (Mårtensson *et al.*, 2010), supporting the contention that clinicians' acknowledgement of patient suffering is of primary importance with respect to patient satisfaction and possibly to well-being. In fact, PPPE was associated with reduced distress (Zachariae *et al.*, 2003) and less anxiety in the case of bad test results but not for good results (Takayama *et al.*, 2001). As good test results should not cause anxiety, the latter finding is expected. From a methodological point of view, it suggests that the link between empathy and anxiety should be preferably studied in anxiety-inducing situations, or that the emotional load should at least be considered when studying empathy.

Interestingly, opposite results on anxiety were found in recently diagnosed cancer patients attending a treatment-options consultation (Smith *et al.*, 2011a). Empathy was assessed using the Response to Emotional Cues and Concerns (RECC) coding system. This comprises four levels of responses to patient cues and concerns from ignorance or rejection (level 0) to adequate responses to patient emotions and an invitation to elaborate further (level 4, e.g. 'I can see you are worried, can you tell me a bit more about what scares you?'). Higher empathy at the RECC led to *more* patient anxiety two weeks after the encounter. As pre- and post- patient anxiety levels were highly correlated in this study, one cannot preclude that high empathy actually reflected high patient anxiety that could not be quelled by physicians during the consultation in spite of their empathic engagement. Furthermore, the authors claim that short-term anxiety should not necessarily be perceived as an adverse outcome. Considering the complexity of information given and discussed in a highly emotion-laden atmosphere, anxiety, however uncomfortable, might also reflect a thorough but critical discussion of the pros and cons of various treatment options. As counter-intuitive as this may seem, I also wonder whether too much room given to emotions in these treatment-oriented consultations could feed into patient anxiety. I will return to this topic later. Furthermore, in this study nothing was assessed about how patients regulated their emotions after physicians' empathic answers nor about physicians' intentions when answering to patients: did they wish to receive more information about the patient's perception of the various treatment options or to explore compassionately the patient's emotions or something else?

Two studies examined the link between empathy and patient recall of information given during the consultation. One revealed a positive link between nurses' encouragements (using a coding

system) and patient recall whereas nurses' distancing attitude reduced patients' recall (Jansen *et al.*, 2010). The other study, carried out with physicians, did not reach statistical significance (Butow *et al.*, 1995).

One study assessed patient preferences, before the consultation, about their desired level of participation during treatment decision-making. Then, the patient's actual perceived role was assessed after the consultation. Interestingly, irrespective of the declared preferred role before the consultation, patients who reported an actual shared role in decision-making, even if this was not their declared preference, were most satisfied with 1) the consultation 2) the information about treatment, and 3) the emotional support received from physicians (Gattellari *et al.*, 2001). The same results have been found with patient satisfaction about decisions made about surgery and chemotherapy (Martinez *et al.*, 2016).



These results point to the issue of taking patients' opinion at face value and as stable over time.



For example, it may challenge procedures in which patients are interviewed about their will, such as living wills. Indeed, patients may declare preferences that may evolve with time and clinical experiences or may remain stable but not meet basic human psychological needs. In the two cited studies (Gattellari *et al.*, 2001; Martinez *et al.*, 2016), the basic psychological need for control and autonomy (Ryan & Deci, 2000; Deci & Ryan, 2008) could arguably explain the power of shared decision-making, even for those who a priori thought they would prefer another way of interacting.

4.2.4. Intermediate outcomes

When the outcome was assessed weeks or months after the consultation but within one year of the encounter, empathy was associated with fewer information needs (Neumann *et al.*, 2011b; Walling *et al.*, 2016), higher patient satisfaction (Ptacek & Ptacek, 2001; Schofield *et al.*, 2003; Walker *et al.*, 2003; Mandelblatt *et al.*, 2006; Smith *et al.*, 2010; Sikavi & Weseley, 2017) and higher patient-perceived quality of surgical care (Ejaz *et al.*, 2016). However, in one study based on 55 consultations about treatment options (Smith *et al.*, 2011a), although not statistically significantly ($p = 0.29$), empathy *decreased* patient satisfaction (standardised $B = -0.20$)¹¹. Similarly, in an initial consultation

¹¹ It may seem strange to highlight a non-significant effect, but it should be remembered that p values depend a great deal on sample sizes. This is why it is recommended to look at the *effect sizes* regardless of the p values.

with an oncologist where the goal was to discuss possible treatments, the oncologist's empathy assessed with an external coding (i.e. cluster of 'showing agreement/understanding/empathy, paraphrasing, checking and legitimising') was related to *less* patient satisfaction three months after the consultation (Ong *et al.*, 2000). Patients were already aware of their cancer diagnosis before the consultation. The two latter results may be due to the specific nature of the consultations oriented toward treatments. If this assumption is true, once again, it would support the need to take the context of empathy into account when examining its effect on patients. There may be a time for dealing with emotions and another time for cognitions when discussing treatment plans or during physician examination.

Regarding psychological adjustment, patient-reported surgeon empathy at diagnosis disclosure was associated with less anxiety eight months after the consultation in a prospective study (Schofield *et al.*, 2003) confirming previous similar results in a breast-cancer retrospective study (Roberts *et al.*, 1994). A recent prospective study confirmed again these findings: over a period of eight months after surgery, BC women who perceived support from their doctor had acute psychiatric co-morbidity less frequently (Singer *et al.*, 2016). In a recent retrospective study, patient-perceived physician emotional support was also related to patient hope (Cao *et al.*, 2017).



On the contrary, in a cross-sectional study in BCs, patient-perceived empathy from the surgeon was not associated with any of the outcomes studied, which were patient BC knowledge, coping, QoL and breast conserving surgery (Maly *et al.*, 2008). However, in the same study, physician participatory style (i.e. the degree to which the surgeon had provided the women with information about BC and encouraged them to participate in their own treatment decision-making process) was associated with positive coping and more BC knowledge. Therefore, when empathy and participatory style are in competition (i.e. entered simultaneously in the same statistical model), physician participatory style may be more powerful than emotional empathy to improve patient outcomes. This is also what has been found in a longitudinal study in BC patients followed during six months after cancer-related rehabilitation. Even after comprehensive adjustment for sociodemographic, medical, psychological variables, and rehabilitation centre effects, physician participatory style was a statistically and clinically relevant predictor of HrQoL (Farin & Nagl, 2013).

Finally, in BC women with persistent pain, physician participatory style was associated with better patient pain management but not with a better QoL or a lower level of pain (Smith *et al.*, 2010).

4.2.5. Distal outcomes

Four cross-sectional retrospective studies were retrieved in which patients were asked to look back on their diagnostic consultation (Omne-Pontén *et al.*, 1994; Mager & Andrykowski, 2002), encounters with the surgeon (Thind *et al.*, 2009), and hospital stay (Neumann *et al.*, 2007).

PPPE was related to a lesser need for medical information (Neumann *et al.*, 2007), higher intention to follow physician recommendation regarding treatment in prostate cancer patients who choose active surveillance instead of definitive therapy (Orom *et al.*, 2014), less psychological distress (Mager & Andrykowski, 2002; Neumann *et al.*, 2007), better psychosocial adjustment (Omne-Pontén *et al.*, 1994), and better socioemotional and cognitive functioning (Neumann *et al.*, 2007). The effect of empathy on psychological distress was mediated by less desire for more information about cancer diagnosis/progress and treatment options (Neumann *et al.*, 2007), but not by desire for more information about side effects and medication or about social questions and health promotion.

 A prospective study following during a 3-year period prostate cancer patients who underwent radical prostatectomy revealed significant associations between patient-provider communication in terms of devotion, support and shared-decision making, and functional aspects of HrQoL (Ernstmann *et al.*, 2017). 

4.2.6. Outcomes related to the overall relationship with physicians

In these studies, patients were asked to assess their physician in general instead of referring to a particular encounter or time point in the disease trajectory. In patients with advanced cancer, PPPE was associated with the absence of anxiety disorders (Spencer *et al.*, 2010), greater psychological well-being (Mack *et al.*, 2009), less suicidal ideation and greater willingness to adhere to treatment in young adults (aged from 20 to 40) with incurable cancer (Trevino *et al.*, 2013, 2014). In a longitudinal study, PPPE assessed at 18 months after diagnosis also predicted adherence to hormone therapy at 36 months post-diagnosis in a low-income population of BC women (Liu *et al.*, 2013). Patient-reported nurses' empathy correlated to greater satisfaction with care (Galbraith, 1995). Finally, PPPE was negatively related to 'Internet as a preferred source of information' (Tustin, 2010) and positively to 'the oncologist as the most preferred source of information'. In a sample of 2746 colorectal and lung cancer patients, PPPE was statistically related to a lower level of patient pain but without reaching the minimal clinically important difference (Martinez *et al.*, 2015).

4.2.7. Conclusion and perspectives: a forthcoming meta-analysis

This review highlighted the potential benefits of physician and nurse empathy for cancer patients. Positive outcomes were indicated and, in non-significant studies, the effect sizes went in the expected direction. However, studies with a significant adverse effect of empathy were also revealed.

It could be tempting to draw further conclusions based on a count of the studies with significant and non-significant p values but this would be a mistake. In fact, many studies on the same topic may not be significant due to poor precision of estimations and small sample sizes whereas the computation of a summary effect size of those studies by meta-analytic procedures could give a significant effect (Borenstein *et al.*, 2011b; Cooper, 2016a). Conversely, a significant effect in most or all studies may only reflect a publication bias and not a true effect (Borenstein *et al.*, 2011a; Cooper, 2016b).

To offset these limitations, we are currently performing a meta-analysis with a doctoral student under my co-supervision, Lucie Gehenne (co-supervision with Prof. Véronique Christophe), and a colleague of mine, Dr. Christelle Duprez. This work focuses on physicians only. The meta-analysis process has many advantages over a systematic review. First, it will provide a summary overall effect of the link between physician empathy and patient outcomes, and a prediction interval characterising the range of the distribution of the effect sizes. A summary effect will also be provided by type of outcome (e.g. patient satisfaction, quality of life). Second, it will take into account the scientific quality of each retrieved study using checklists such as the AXIS tool (Downes *et al.*, 2016). The quality of studies will be used as a moderator of the empathy-outcome link. Third, it will enable us to test other possible moderators that could explain the different effects of empathy on patient outcomes (no effect, positive or adverse effects). Finally, references will be updated from 2012 to now.

Our review suggests several moderators. In studies focusing on treatments, high empathy seemed unnecessary (Oguchi *et al.*, 2011) or even not welcomed (Ong *et al.*, 2000; Smith *et al.*, 2011a). Interestingly, in these three studies, empathy was assessed using coding systems that represent clinicians' answers to patient emotions and room given to those emotions. In this context, this 'emotional empathy' may be used parsimoniously. As the length of consultations is limited in cancer care (from 15 minutes in standard consultations to 30 minutes for bad-news disclosure in most hospitals), too much time given to patients' emotions may be at the expense of information about the disease and treatment options, so important for patients' feeling of control and thus well-being. The

mediation result that empathy decreases patients' need for information about the disease and treatments, which in turn decreases psychological distress (Neumann *et al.*, 2007), supports this idea. Congruent with this, the studies using the CARE questionnaire, which contains an empowerment part (e.g. the physician explained things clearly, helped you to take control) in addition to the emotional one (e.g. the physicians seemed genuinely concerned), showed a positive effect of empathy.

Therefore, the nature (i.e. emotion- vs. empowerment-oriented vs. both) and context of empathy (i.e. type of consultation) will be tested as moderators if statistically possible. For example, in standard consultations where patients' health is checked to be sure that chemotherapy can be administered, empathy should not be especially expected and therefore not especially beneficial to patients. Conversely, in bad-news or treatment-options consultations that can induce more anxiety, the effect could be higher; however, the reverse hypothesis is also possible: as bad-news and treatment discussions entail more distress and anxiety, empathy may not be effective in reducing patient distress in this case.

Finally, two methodological moderators will also be tested in addition to the quality of the studies: prospective vs. cross-sectional designs and coded vs. patient-reported vs. physician-reported empathy.

Full references:

Lelorain, S., Brédart, A., Dolbeault, S., & Sultan, S. (2012). A systematic review of the associations between empathy measures and patient outcomes in cancer care. *Psycho-Oncology*, 21(12), 1255–1264. <https://doi.org/10.1002/pon.2115>

Gehenne, L., Duprez, C., Christophe, V. & **Lelorain, S.** Physician empathy and cancer patient outcomes: a meta-analysis. In preparation (expected submission in January 2020); PROSPERO 2018 CRD42018112729
https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=112729

Having suggested some moderators to take into account in the empathy-patient outcome link, I will now present recent research integrating some of these propositions (Lelorain *et al.*, 2018a).

4.3. The role of the type of consultation and patient emotional skills

When inconsistent links are found between two variables, such as between PPPE and patient outcomes in our case, potential moderators may be tested. We were interested in two potential moderators that could explain under which conditions PPPE may impact patient outcomes: the type of consultation and patient ES.

4.3.1. The type of consultation

As stated above, we think that the link between empathy and patient outcome should be tested according to the emotional load of the consultation (i.e. the type of consultation). As suggested by previous results (Takayama *et al.*, 2001; Yagil & Shnapper-Cohen, 2016), we believe that in bad-news consultations, compared to follow-up consultations, the effect of empathy should be stronger since empathy becomes highly expected and important in this type of consultation.

4.3.2. Patient emotional skills

Another element that seems critical to consider when studying the effect of physician empathy on patient outcomes is the *patient* to whom empathy is directed. Strikingly, no study in our literature review considered the patient (Lelorain *et al.*, 2012a). In all retrieved and presented studies, the positive hypothesised effect of empathy was implicitly conceptualised as depending on the physician only. However, physician empathy is oriented toward a given patient. It may be that empathy is beneficial for certain types of patients and not for others. We hypothesised that patient ES would be a variable able to differentiate patients for whom empathy could be beneficial or not. ES refer to their ability to address and process emotional information. People with high ES are adept at identifying, understanding, expressing and regulating their emotions and those of others (Brasseur *et al.*, 2013).

Social support has demonstrated a positive effect only in the receivers of support who express their emotions (Tamagawa *et al.*, 2012), correctly process the supportive message (Bodie *et al.*, 2011) and regulate their emotions (Lakey & Orehek, 2011). In the same way, patients may benefit from physician empathy, which is a kind of support, only if they have these same ES. This pattern of results has also been found in BC patients receiving emotional support on the Internet. The supportive messages received online had positive effects only in women with high ES (Yoo *et al.*, 2014).



If patients do not possess the ES to process physician empathy as a supportive resource fostering positive coping, it may be useless or even wrongly perceived.



In this respect, a focus-group study showing videos of bad-news consultations to lay people was very insightful. It revealed that the same physician's question - 'Is there someone you can call or talk with' (about a cancer diagnosis) - was interpreted as very caring by some people but 'impressively uncaring' (sic) by others (Quirk *et al.*, 2008). The same variability is described in another article where the authors, two physicians in palliative care, described four different scenarios they often encounter when they answer empathically to the hopeless question of their patients 'Isn't there anything more you can do?'. They explain that most of the time their empathic answer (i.e. 'I can see this isn't what

you were hoping for') make difficult conversations flow better but that it also does not work sometimes or even worsen the situation (Back & Arnold, 2013).

These results demonstrate strong patient variability in the processing of the same message. Some patients with low ES may not only overlook empathy in the physician's question but also even be angry toward the doctor as they misunderstand the intention behind the question. Indeed, in the study of Quirk et al. (2008), one person thought that the doctor did not want to talk about the cancer diagnosis with the patient therefore putting the responsibility on someone else by asking the question. Patients with low ES would probably keep their anger to themselves without expressing anything of it to the doctor, then distrust him/her (with all the negative consequences of this) and ruminate on their cancer diagnosis and the way it had been 'awfully disclosed'. On the contrary, a patient with high ES may perceive empathy in the question, understand the intention behind it, thus feel supported and helped, then trust the doctor (with all the positive consequences of this) and finally think whom they could call to talk with and share a comforting moment. Those patients will therefore also benefit from social support from friend or family while the benefit of social support has been largely proven even with regard to 'hard' outcomes such as survival (Lutgendorf *et al.*, 2012; Pantell, 2013).

Our second hypothesis was therefore that physician empathy would improve patient outcomes for patients with high emotional skills, as these would enable them to process this empathy and benefit from it as illustrated in the previous example. This effect should be found in bad-news consultations only.

4.3.3. Method of the study

To test our hypotheses, we performed a study on 296 thoracic (63.5% of the sample) and digestive (36.5%) cancer patients recruited by 22 physicians from the University Hospital of Lille (France) and from the University Cancer Centre of Leipzig (Germany). These cancer types were chosen because of their poor prognosis implying many bad news consultations and room for physician empathy. In fact, due to their poor prognosis and heavy treatment, these cancers often entail psychological distress (e.g. Hellstadius *et al.*, 2017; Kim *et al.*, 2017; Sato *et al.*, 2018) and great fatigue (e.g. Chen *et al.*, 2018). Distress and fatigue hinder patients' QoL, especially *emotional* QoL (Inoue *et al.*, 2016; Lee *et al.*, 2019). Furthermore, in two longitudinal studies, patient emotional QoL was sensitive to physician support (Singer *et al.*, 2016; Ernstmann *et al.*, 2017). This is the reason why patient emotional QoL (eQoL) was chosen as an 'outcome'¹².

¹² I write outcome in quotation marks due to the cross-sectional design of the study

Physicians proposed this cross-sectional study at the end of a consultation. Upon acceptance, patients had one week to complete questionnaires on their emotional skills using the Short-Profile of Emotional Competence scale (Mikolajczak *et al.*, 2014) and on their perception of physician-empathy during the consultation using the CARE questionnaire already presented on page 46 and in the Appendix (Mercer *et al.*, 2004). At the same time, patients assessed their eQoL using the emotional dimension of the Functional Assessment of Cancer Therapy-General (Conroy *et al.*, 2004; Costet *et al.*, 2005). Examples of items are 'I feel sad', 'nervous', 'I worry about dying' and 'I am losing hope in the fight against my illness'. The type of consultation was reported by the physician at the end of the consultation according to the following rule: if the patient was informed of cancer recurrence (4% in our sample) or a change in therapy due to cancer progression (88%) or the end of active treatment (8%), this was considered a 'bad-news consultation', otherwise it was a 'follow-up consultation'. Patient sociodemographic data were self-reported whereas medical data were reported by the clinical research associate. Patients in follow-up and bad-news consultations were different patients.

4.3.4. Results and discussion

Controlling for medical (type and stage of cancer, time since diagnosis, metastases, treatment and type of consultation) and sociodemographic (age, gender, marital status, education, financial situation, professional status) variables, we found a significant interaction between patient-perceived physician empathy (PPPE), patient emotional skills and the type of consultation, as depicted in Figure 13.

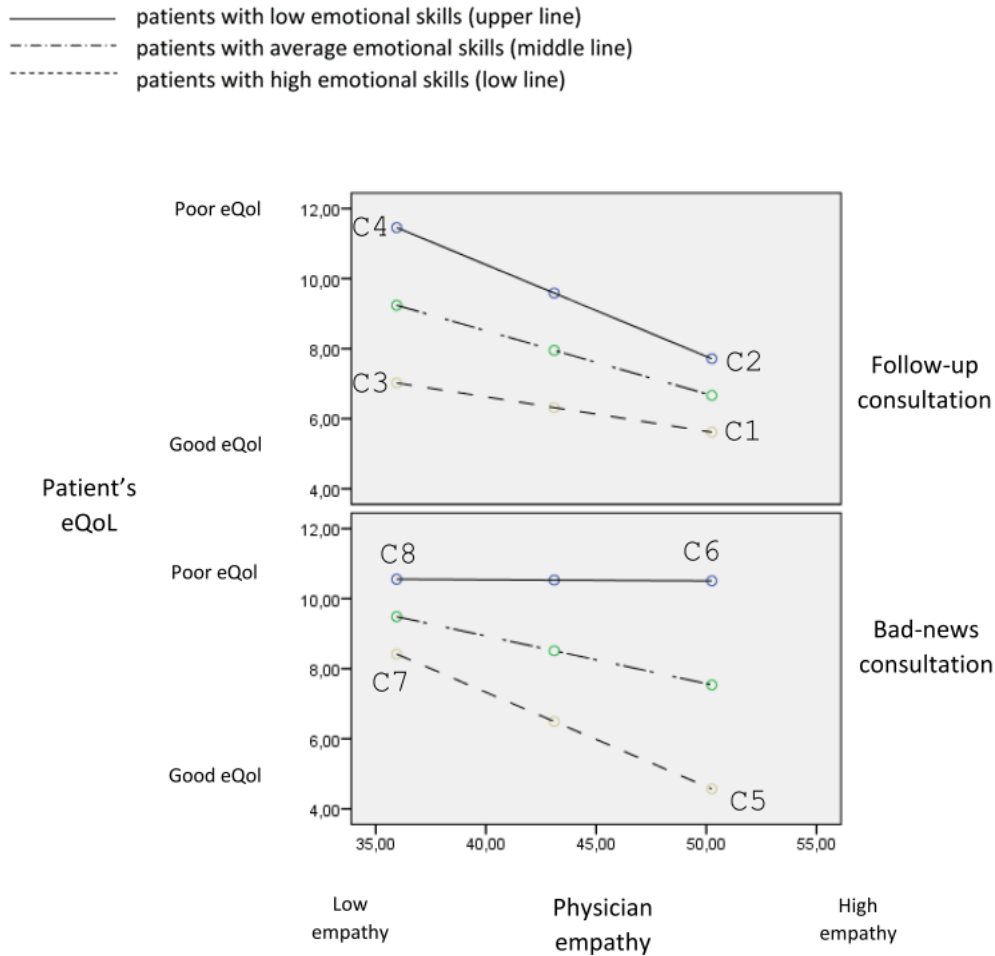




Figure 13. Interaction plot of physician empathy, patient emotional skills and type of consultation. Patient emotional skills are plotted using mean \pm one standard deviation. eQoL = emotional quality of life. C1 = Case 1, C2 = Case 2, etc.



Contrary to our first hypothesis, in follow-up consultations, PPPE was significantly associated with a better eQoL for some patients. These patients had low or average ES and represented 72% of patients in this type of consultation in our sample. Patients with high ES (28% in our sample) did not benefit from PPPE¹³. However, the latter had a rather good eQoL regardless of the empathy level. This confirms previous data showing that ES are associated with better health in the general population (Mikolajczak *et al.*, 2015; Baudry *et al.*, 2018a) as well as in cancer patients (Rey *et al.*, 2013). This is why when the consultation does not bring bad news, as in follow-up consultations, these patients have enough personal resources (i.e. good ES) to cope with cancer. However, contrary to our expectation, 72% of patients benefited from empathy in this type of consultation. This suggests that even if we consider consultations as ‘follow-up’ consultations from a medical point of view, patients view them differently. They remain situations with a great deal of uncertainty and QoL issues to cope with that

¹³ For readability reasons, statistical details are presented in the published article only.

necessitate physician empathy for most patients. However, as these situations are not hopeless, we can assume that, in spite of low/average emotional skills, patients are still able to process physician empathy correctly and thus benefit from it.

Data found in non-cancer settings support the idea that in situations that are not too emotionally laden, patients with low emotional skills benefit from the support of others. For example, in the general population, the social support of the significant other enabled high positive affect in people with low emotional skills only (Gallagher & Vella-Brodrick, 2008). People with high emotional skills did not benefit from social support. However, the latter had high positive affect regardless of the social support level. This pattern of results exactly fits our data. In the same way, participants treated for an alcohol use disorder by psychotherapy did not benefit equivalently from the therapeutic alliance with the therapist (Connors *et al.*, 2016). Patients who significantly reduced their drinking before treatment, who may have high emotional skills, had good therapy outcomes (i.e. low consumption) regardless of the therapeutic alliance. In contrast, people who did not succeed in reducing their drinking before treatment, who may have low emotional skills, benefited from the therapeutic alliance to reduce their drinking. Once again, this pattern of results is similar to our data. Another study in advanced cancer patients confirmed the pattern: optimistic patients were not anxious regardless of their social support whereas patients with low optimism were sensitive to social support (Applebaum *et al.*, 2014). It should be noted that in spite of their advanced cancers, these patients were not assessed at bad-news disclosure.

 In short, in situations that are not too emotionally laden, patients with low ES benefit from the support of others whereas people with high ES perform well regardless of the perceived support. 

 As regards bad-news consultations, our hypothesis was confirmed: PPPE was not associated with eQoL in patients with low emotional skills whereas it was in patients with average and high emotional skills, who represented 46% of patients in this type of consultation in our sample. Patients with low emotional skills did not benefit from empathy and had a bad eQoL regardless of empathy. 

Associations have been established between poor emotion regulation, an important component of emotional skills, and dissociation (Powers *et al.*, 2015). Dissociation involves disruptions in the usually integrated functions of memory, identification, and perception of self and environment.

Therefore, patients with low emotional skills may be likely to experience dissociation in bad-news consultations and thus at risk of ‘missing’ the consultation in spite of their physical presence. They could rate the physician as empathic due to a general feeling that the physician did his/her best, but without having concretely perceived and processed the empathic statements and explanations of the physician because of their dissociative state.

In contrast, patients with average/high emotional skills were sensitive to empathy: the more empathetic they perceived their physician, the better their eQoL was. In our sample, 88% of the bad news related to cancer progression requiring a change of treatments. This implies a cognitive load to understand the medical situation, the available treatment options and maybe deal with shared decision-making with the physician. Participation in an RCT is also sometimes proposed, which is a difficult choice to make due to the complexity of options and the uncertainty inherent in each option. We think that the cognitive load of bad-news consultations could help those patients. Indeed, in healthy controls (i.e. people with average/high emotional skills) under threat, experimental studies have demonstrated that a cognitive task may successfully direct attention away from anxiety and facilitates work memory (Iida *et al.*, 2011; Vytal *et al.*, 2012, 2013). Interestingly, this does not apply to patients with anxiety disorders (Vytal *et al.*, 2016), who are likely to have poor emotional skills. Under threat, the latter’s memory is impaired even with a cognitive task to perform. Therefore, patients with high emotional skills can probably switch from the emotional load of the consultation to paying attention to the medical information given by the physician. Accordingly, they could benefit from physician support and clear explanations, thus maintaining a correct eQoL thanks to a good memory of the empathetic consultation. In contrast, patients with low emotional skills are probably trapped in their attempts to regulate their emotions, which prevent them from remembering and benefiting from physician empathy.

To explain the different patterns of results between bad-news and follow-up consultations, we propose the following model. We can consider the type of consultation, patient emotional skills and PPPE as three possible resources. The first is related to the context, the second to the patient and the third is mainly related to the physician, although it should be remembered that it is the perception of the patient and thus also related to the patient. In our model, for example, a follow-up consultation is a contextual resource and high PPPE is a physician-related resource.



As illustrated in Table 5, our data suggest that at least two resources must be present to maintain a correct eQoL (e.g. follow-up and high PPPE).





Table 5. Modelling of the interaction between three resources on patient eQoL.

Case number	Context: type of consultation	Physician: PPPE	Patient: emotional skills	Outcome: patient eQoL
1	Follow-up +	High +	High +	Correct
2	Follow-up +	High +	High -	Correct
3	Follow-up +	Low -	High +	Correct
4	Follow-up +	Low -	High -	Poor
5	Bad-news -	High +	High +	Correct
6	Bad-news -	High +	High -	Poor
7	Bad-news -	Low -	High +	Poor
8	Bad-news -	Low -	High -	Poor



Note. The case numbers refer to one specific situation that can be visualised in Figure 13 presented earlier on page 95.

4.3.5. Practical implications

If our results were confirmed by further studies, at least three implications could be drawn from them.



 First, as already said, clinicians should keep in mind that in ‘follow-up’ consultations, in spite of low challenges from a medical point of view, their empathy is still beneficial for the majority of patients. The importance of a ‘follow-up’ consultation from the patient point of view should not be underestimated. 

The same problem arises with survivorship after the end of successful treatments. From a medical point of view, a follow-up after the end of treatments is enough. However, from the patients’ perspective, the end of treatments is a challenging time when they need help to cope with the aftermath of cancer (e.g. Sterba *et al.*, 2015; Powers *et al.*, 2016; Jacobs & Shulman, 2017).

 Second, physicians would gain from being aware that in bad-news consultations, even a high level of empathy is not enough to alleviate some patients’ distress (i.e. those with low ES). 

This awareness could prevent physicians from blaming themselves for failing to relieve patients or from overestimating their power. Furthermore, as patients with low ES can benefit from physician empathy in a less emotionally loaded context, once they have processed the bad news, they could benefit from physician empathy again. Therefore, for these patients, the consultation following the

bad news should be prioritised and, if necessary, they could still be referred to supportive care. This brings us to the third implication.

Third, patient emotional skills should be addressed. There is mounting  evidence that emotional skills can be increased by training (Nelis *et al.*, 2009; Smyth & Arigo, 2009; Kotsou *et al.*, 2011). 

This is why, two years ago, with my colleague Marie-Mai Nguyen, we set up an RCT aimed at increasing pulmonary and oesogastric cancer patient emotional skills. These cancers were chosen because of their poor prognosis that requires a high level of emotional skills. The intervention consists of three group sessions for each patient. In the experimental arm, patients are trained in identifying and understanding (session 1), expressing (session 2) and regulating (session 3) emotions. The control group undergoes three sessions of relaxation. The study suffered numerous setbacks in its implementation in the field that we analysed and corrected in order to propose a new multicentric study for which we have just received further funding (90,000 euros from the Regional Council of Northern France).

Full reference of the empathy study:

Lelorain, S., Cattan, S., Lordick, F., Mehnert, A., Mariette, C., Christophe, V., & Cortot, A. (2018). In which context is physician empathy associated with cancer patient quality of life? *Patient Education and Counseling*, 101(7), 1216–1222. <https://doi.org/10.1016/j.pec.2018.01.023>

In this section, I have described results demonstrating the association between PPPE and patient eQoL, according to the context and patient ES. In spite of the interest of such results, two weaknesses of the study need to be addressed: the cross-sectional design, which precludes making causal inferences, and the psychological nature of the outcome, which is not of interest to many physicians. To counteract these two drawbacks, we set out to explore the link between physician empathy and patient *survival*, as described in the next section.

4.4. Patient survival and the pitfalls of empathy

4.4.1. Rationale for patient survival as an outcome

Although survival can be seen as an ambitious outcome to relate to physician empathy, three arguments oriented us toward this hypothesis.

First, a landmark meta-analysis demonstrated that patient psychological factors such as depression or coping predicted cancer patient survival (Chida *et al.*, 2008). Therefore, a relational factor such as PPPE might also predict such an outcome. Indeed, in other chronic conditions, PPPE has been longitudinally associated with important biological patient outcomes such as HbA1C or cholesterol in diabetic patients (Hojat *et al.*, 2011). A recent prospective cohort study of type 2 diabetes patients even revealed that HCP empathy assessed by patients in the year after diagnosis was associated with a lower risk of all-cause mortality in the 10-year follow-up time (Dambha-Miller *et al.*, 2019).

Second, medical empathy can be considered close to social support and the role of social support in survival, including cancer survival, has been established (Holt-Lunstad *et al.*, 2010; Lutgendorf *et al.*, 2012). As a major source of support for cancer patients, physician empathy might impact survival, as suggested by patients themselves (Frenkel *et al.*, 2016). In the latter work, 29 exceptional patients, i.e. those who unexpectedly survived a cancer with a very poor prognosis, mainly attributed their survival to their physician's compassion, availability, sense of calmness and honesty coupled with giving hope. Therefore, in bad-news consultations, how physicians present to patients the progress of the disease and its treatment could play a major role in counteracting the potential helplessness/hopelessness of patients (Cao *et al.*, 2017), which are associated with less fighting coping (Miyashita *et al.*, 2015) and poor prognosis (Watson *et al.*, 2005; Price *et al.*, 2016).

Third, biologically, empathy is related to the hormone oxytocin (Hubble *et al.*, 2017), which has anti-proliferative, anti-metastatic and anti-angiogenic effects in some cancers (Ji *et al.*, 2018).

For these three reasons, patient survival was deemed a relevant outcome in relation to physician empathy and we hypothesised that physician empathy would increase patient survival. Based on our previous results (Lelorain *et al.*, 2018a), we also tested the impact of the emotional context of empathy, namely follow-up versus bad-news consultations, on the link between PPPE and patient outcome (interaction hypothesis).

To verify our hypotheses, we carried out an extension of the previous study (Lelorain *et al.*, 2018a), using a subset of data on thoracic cancers (n = 179) that we complemented with specific medical information retrieved from patient medical records and known for its prognostic role in cancer

survival: type and severity of cancer (NSCL-SCL stage I, II, III versus NSCL-SCL stage IV or mesothelioma¹⁴), smoking status, the Charlson index of comorbidities¹⁵, performance status with the Karnofsky index (West & Jin, 2015), treatments *after* the study (treatments before the study had already been retrieved in the primary study) and the genetic mutation EGFR or ALK or ROS versus none of these. All these variables except smoking status (too many missing data) and treatments (too high correlations with other medical data) were included in the analyses. Patient emotional skills and eQoL were also included as covariates. The primary study ran from January 2015 to July 2016 while in the extended study, patients were followed until 1 April 2018, the date of censoring.

Cox proportional hazard regression models were performed. I conducted these analyses as part of my University Degree dissertation in Applied Statistics that I carried out in 2017-2018 under the supervision of Dr. Claire Pinçon, Associate Professor in Statistics at the Pharmacy Faculty of Lille.

4.4.2. Empirical results

The median follow-up was estimated at 3.1 years, 95% CI (2.92-3.09). Eighty-three patients (46.4%) were still alive at the time of censoring, 1 April 2018. Briefly, patients were mostly older men with a relatively low level of education, NSCL cancers at stage I, II or III, and a performance status indicating correct functional status. Forty-three percent of patients were included in the study after the disclosure of bad news, consisting overwhelmingly of a change in treatment due to treatment failure.

The two subsamples by type of consultation differed only in expected variables such as the presence of metastases and the number of deaths at the study censoring. Importantly however, PPPE did not differ between bad news and follow-up consultations. Patients were also similar in ES. The two subsamples by PPPE (i.e. when PPPE was dichotomised by a median split) were also identical with the exception of three variables: in the low empathy group, there were more men, a poorer eQoL and lower ES. Although the two latter variables can be expected to relate to less PPPE, to our knowledge no previous data have revealed less PPPE in male patients compared to females.

Multivariate Cox regressions are presented in Table 6.

¹⁴ There are different types of lung cancer: NSCL (the most common) and SCL within the lung itself, and mesothelioma which affects the lining of the lung (Selby, 2019). Severity of cancer is assessed through 4 stages, the higher the stage, the worse the situation.

¹⁵ The Charlson Comorbidity Index combines all the comorbidities of one patient into a single score with higher scores indicating greater comorbidity.

Table 6. Adjusted Cox Proportional Hazard Model for overall survival.

Variable	Hazard ratio	95% CI	p value
Age	1.04	1.00-1.07	0.029
Woman	0.48	0.26-0.89	0.019
Patient-reported Education			
No diploma (reference)			
High school	0.42	0.22-0.81	0.009
Bachelor degree	0.41	0.16-1.06	0.07
>Bachelor	0.50	0.14-1.70	0.26
Patient-reported Financial situation			
Not at all or not very comfortable (reference)			
Moderately comfortable	1.42	0.58-3.45	0.44
Rather or very comfortable	1.27	0.46-3.57	0.65
Type and severity of cancer			
Stage I, II or III (NSCL or SCL) (reference category)			
Stage IV (NSCL or SCL)	3.14	1.22-8.09	0.018
Mesothelioma (no stage assigned)	3.30	1.22-8.91	0.018
PS 60-70 (compared to >70)	2.53	0.84-7.59	0.10
Time since diagnosis and inclusion in the study	0.98	0.84-1.14	0.75
Charlson index of comorbidities	1.02	0.88-1.17	0.80
Mutation (ALK, EGFR, ROS <i>vs.</i> none of them)	1.40	0.64-3.06	0.40
Metastases	0.92	0.38-2.25	0.85
Patient eQoL	1.06	1.01-1.12	0.03
Patient emotional skills	1.57	0.87-2.85	0.14
Patient-perceived physician empathy	-	-	-
Type of consultation (bad-news <i>vs.</i> follow-up)	-	-	-
Empathy*type-of-consultation			0.022
Empathy in bad-news consultations	1.06	1.01-1.12	0.024
Empathy in follow-up consultations	0.96	0.90-1.03	0.24

NSCL: Non-small cell lung cancer; SCL: Small cell lung cancer; n = 143 (due to missing data in some variables); -2 Log Likelihood (-2LL) = 587.8; Akaike Information Criterion (AIC) = 625.8; Schwarz Bayesian Criterion (SBC) = 668.8; eQoL: emotional quality of life; EGFR: Epidermal Growth Factor Receptor; ALK: Anaplastic Lymphoma Kinase; ROS: ROS proto-oncogene 1, receptor tyrosine kinase.

Among the confounders, age, stage IV or mesothelioma and cancer-related distress increased the risk of death. On the contrary, being a woman and having a high school diploma (compared to no diploma) were protective factors for survival. Controlling for all available confounders, we found a significant interaction between the type of consultation and empathy but not between empathy, the type of consultation and patient ES (data not shown). Due to the inclusion of thoracic cancers only for this extension of the study and due to missing data, the regression was performed on 143 patients only. As a three-term interaction requires a great deal of statistical power, it might be a power issue.

Strikingly, the two-term interaction found was in the opposite direction of our hypothesis as pictured in Figure 14.

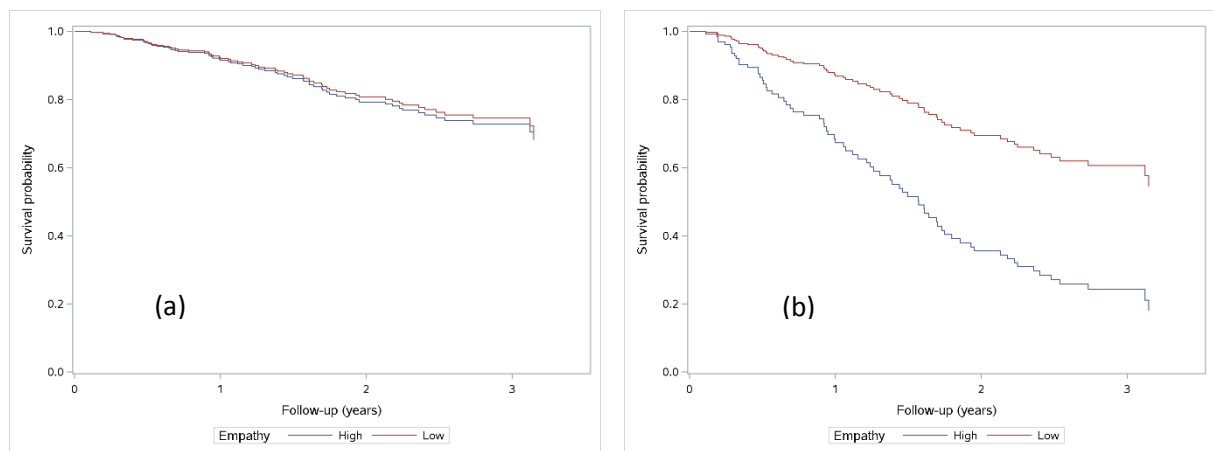


Figure 14. Kaplan-Meier curves for survival probability for patients with high PPPE (> 45) versus low PPPE (< 45) by median split.

(a) Follow-up consultations: adjusted Cox regressions showed no differences by empathy ($p = 0.24$). (b) Bad-news consultations: adjusted Cox regressions showed differences by empathy ($p = 0.024$). PPPE: patient-perceived physician empathy.



While, as hypothesised, empathy was not related to survival in follow-up consultations, HR = 0.96 by point of empathy score, 95% CI (0.90-1.03) (Fig. 14, part a), it unexpectedly increased the risk of death by 6%, 95% CI (1.01-1.12) in bad-news consultations (Fig. 14, part b). Thus, a one-point increase in the empathy questionnaire, which went from 20 to 50 points in our sample, increased the risk of death by 6% in patients receiving bad news.



We were so surprised that we decided to try and explain this puzzling result.

Based upon our analysis of the different components of the empathy scale (as described on page 46), we explored whether our result was true for two different dimensions of empathy: a passive empathy of listening, understanding the patient and showing him/her care and compassion (items 1 to 6, in Appendix) and an active and positive empathy whereby the physician tries to give control and options to patients (items 7 to 10). Interestingly, the interaction only remained significant with the empathy of listening and compassion. This type of empathy was associated with an increased risk of death in the bad-news condition, HR = 1.13 by point of empathy, 95% CI [1.03-1.23], $p = 0.008$, but not in the follow-up condition, HR = 0.94 by point of score, 95% CI [0.86-1.05], $p = 0.30$. In contrast, active and positive empathy did not interact with the type of consultation, ($p = 0.07$). Regardless of the type of consultation, active/positive empathy was not associated with survival. The passive listening/compassion part of empathy was thus responsible for the harmful effect of empathy on

patient survival. Of particular note, both models detailing a specific type of empathy had a better statistical fit (SBC of 556.3 for listening/compassion and 649.5 for active/positive empathy) than the model with general empathy (SBC of 668.8), demonstrating the relevance of specifying the type of empathy.

Full reference:

Lelorain, S., Cortot, A., Christophe, V., Pinçon, C., & Gidron, Y. (2018). Physician Empathy Interacts with Breaking Bad News in Predicting Lung Cancer and Pleural Mesothelioma Patient Survival: Timing May Be Crucial. *Journal of Clinical Medicine*, 7(10), 364. <https://doi.org/10.3390/jcm7100364>

The analyses of this publication were the subject of my University Diploma dissertation in Applied Statistics.

4.4.3. Pitfalls of empathy and clinical implications

To our knowledge, this is the first time that PPPE was examined in relation to cancer patients' survival. Unexpectedly, in the bad-news consultations, PPPE was associated with a higher risk of death. Although we controlled for all available medical, psychological and sociodemographic data, these results must be considered with caution, as the study was not initially designed to study survival. Consequently, the study must be replicated using a prospective design and more survival predictors, such as biomarkers and treatments, in a more detailed way.

Nevertheless, previous literature is in line with our results. In a quantitative study on 169 colon patients at their initial clinical interview, very high PPPE was associated with a *lower* reduction of fear of recurrence after the consultation, compared with poor PPPE (Groß *et al.*, 2015). These results may be illuminated by a qualitative study on GP empathy in which some patients declared that a high level of physician empathy was worrying as it conveyed the message that the situation was really bad (Derksen *et al.*, 2017).



In the two latter examples, empathy actually reinforced what it was supposed to alleviate: fear of recurrence and awareness of the severity of the bad news, respectively.



This awareness could have serious physical implications. In fact, according to Leventhal's Common-Sense Model of illness representation (e.g. Leventhal *et al.*, 1980, 1998), patients' representation of their illness in terms of beliefs and expectations impacts their coping with the illness. Furthermore, in an integrated bio-behavioural model, patient psychological state, including appraisal

and coping, was related to cancer-related processes (e.g. tumour growth) through neuroendocrine and immune pathways (Antoni *et al.*, 2006). In sum, according to these models, patient beliefs, perceptions and expectations might influence cancer progression. These theoretical assumptions have been validated by empirical data.

① Patient beliefs about cancer curability or awareness of their terminal status has been related to all-cause mortality in several studies (Soler-Vila *et al.*, 2005; Soler-Vilá *et al.*, 2009; Kim *et al.*, 2013; Greer *et al.*, 2014; de Rooij *et al.*, 2018). The same result was found between patient perception of consequences (i.e. my cancer affects my life) and emotions (i.e. my cancer affects me emotionally) and all-cause mortality (Thong *et al.*, 2016). Naturally and very importantly, the latter studies controlled for sociodemographic and biomedical variables known for their link to cancer survival. ①

As physician empathy comprises items on information and hope given to patients, it arguably may affect patient beliefs and expectations and therefore cancer survival. A puzzling study even showed that the perception of the GP of the palliative status of his/her cancer patient impacted cancer patient survival: cancer patients who were not perceived as ‘palliative’ by their GPs survived longer than patients of an aware GP (Farquhar *et al.*, 2002).

This does not mean that physician empathy should equate with lying about cancer prognosis. However, prognosis disclosure would gain by being informed by these studies. As poor prognosis disclosure can cause anxiety and accelerate death, it should be done only if there is a good reason, i.e. 1) the patient explicitly asks for it *and* is psychologically able to receive the news or 2) the family needs patient awareness to discuss practical or emotional issues related to the impending death. A longitudinal study in palliative care over six months revealed that prognostic awareness was detrimental to patient well-being whereas awareness *coupled with a high acceptance* of prognosis significantly reduced psychological symptoms and was associated with a better QoL (Tang *et al.*, 2016).

The fact that patient awareness of prognosis in palliative care is higher in patients at peace with life (Fisher *et al.*, 2015) and that patient preferences for prognostic information are greater among those with lower distress (Ellis & Varner, 2018) corroborates the need for psychological resources in patients to face awareness of near death. Therefore, in bad-news consultations in which the issue of prognosis can quickly be raised by the patient or the next of kin or the physician, physician accuracy about the patient’s desire to know, psychological distress and acceptance or not of poor prognosis is absolutely vital. In fact, the way of presenting the bad news will largely depend on these factors,

regarding both patient and family. To disclose bad news with a poor prognosis when patients or family do not have the psychological resources to cope with it can be harmful, even if the news is delivered in a highly compassionate way.

Unfortunately, as our study was based on post-hoc analyses, information about whether the issue of prognosis had been addressed in consultations, notwithstanding the bad news, was not available, nor about the psychological resources of the patient regarding his/her future and possible death. This is an avenue for future research on physician empathy in cancer survival.

Finally, 88% of the bad news concerned a change of treatment due to treatment failure, with the rest being recurrence or entry into palliative care. Consequently, our results are particular to this precise kind of bad news and specific research is also needed on cancer relapse.

In Part 2, I described my past work on medical empathy. In the final part, I will present two research programmes for the future, one that will enrich and extend my past fundamental research on ‘physician empathy and patient outcomes’ and an interventional one on empathy training.

PART 3: PROPOSED AVENUES FOR FUTURE RESEARCH

Programme 1. Physician empathy and patient outcomes

This programme is composed of two parts.

The first part aims to test the impact of medical empathy with far-reaching outcomes. Indeed, now that the impact of medical empathy on patient-reported outcomes has been well-established, the *medical* outcomes, such as inflammatory markers and survival, must now be considered. Furthermore, in order to reveal the impact of physician empathy, it must be studied *ecologically*, that is in a way that fits the clinical reality of the patient, as I will develop below.

The second part deals with the challenges posed by an emerging new treatment, immunotherapy, which leaves much room for physician empathy and thus its outcomes. I will explain why immunotherapy is a golden opportunity for empathy studies.

1. An ecological study with far-reaching outcomes

This research continues our previous work on survival but takes into account its flaws and includes more far-reaching outcomes: inflammation markers and survival.

1.1. An ecological way to consider empathy

1.1.1. The need to consider several physicians

A flaw of empathy research is that empathy is very often assessed in one professional only (i.e. a physician in 90% of studies) and at a single time point, such as one given consultation, or in a general assessment (i.e. how is your physician in general).



An ecological way of studying empathy must consider all the important physicians gravitating around the patients and different critical stages of the disease.



In cancer care, patients encounter many doctors: e.g. their GP, the surgeon, the radiotherapist, the oncologists and the residents. I write oncologists and residents in plural as, due to staff turnover, a patient is very likely to meet several oncologists and residents throughout the cancer pathway. Furthermore, in specific cases such as immunotherapy, more doctors are encountered due to immunotherapy-induced diseases, which requires patients to consult specialists of these diseases.

In one study in a cancer rehabilitation context, empathy was assessed as a global score for an entire team (Quaschnig *et al.*, 2013), which is better than focusing on one single doctor but still not relevant as the average score for an entire team does not reveal discrepancies between physicians. This is why assessing several physicians is important as I assume interactions between empathy from various physicians on patient outcomes. For instance, a non-empathic surgeon can lessen the impact of the empathy of the oncologist or vice-versa. This idea comes from clinical observations where I have seen some patients affected by a bad remark from one particular physician. I remember a radiologist saying abruptly to a patient 'If you have surgery, in any case, it will not be possible to remove the entire tumour'. After that, the patient was less sensitive to the positive and empathic words of the surgeon, who was also more optimistic about the outcome of possible surgery. Sometimes patients bring up things that were said two years ago and have been completely forgotten by the physicians.

This is why I am going to perform a longitudinal research in cancer care in which several physicians will be assessed on their empathy by patients in the first year of diagnosis and treatment (T1). The first year has been chosen as a critical time of adjustment to the disease. Follow-up time will be defined according to the survival mean of the chosen cancer (T2). Another important time of assessment will be at cancer recurrence (T3) when specific patient needs are known to arise, such as strong support from the physician (Thorne *et al.*, 2014), help in maintaining a sense of control in life and in dealing with the unpredictability of the future and spiritual issues (McIllmurray *et al.*, 2001).

The targeted physicians will be the GP, the surgeon if appropriate, and the most seen oncologists. The GP will be included as a likely well-known physician of the patient and often the first contact in cancer history. Furthermore, it should be remembered that his/her beliefs may impact patient survival (Farquhar *et al.*, 2002) so that his/her consequent empathy is of interest. Oncologists have regular meetings with patients and are therefore important physicians for them. Lastly, the surgeon plays a significant role, with surgery remaining the major treatment in cancer care, and should therefore be included too. However, to make it simpler, surgeons will be assessed overall by the patients after the first year of cancer, and not at different time points, as they intervene for a short period often at the beginning of the disease.



To the best of our knowledge, no study has yet examined longitudinally the impact of different physicians throughout the cancer trajectory.



1.1.2. Methodological issues

Statistical analyses will explore how the collected empathy measures best predict patient outcomes: I do not assume that a mean of all empathy measures of the various HCPs (i.e. all measures combined in a single average score) will be a good predictor due to interactions between them and different impacts depending on the type of patient. For instance, the worst perceived-empathy may be the most influential in patients with low ES, likely to be highly affected by bad attitudes or words, whereas the highest perceived-empathy may be the most influential in patients with high ES who will be able to focus on it more.

Statistical analyses will also take into account three possible sources of variability: empathy differences between physicians (level 1: on average, some physicians may be perceived more empathic than others), differences in empathy perception between patients of the same physician (level 2), and differences in perceived empathy for the same physician by the same patient but at different times of evaluation (level 3: e.g. empathy at diagnosis, during treatments and at cancer recurrence).

The longitudinal design (level 3) will be crucial to see the evolution of PPPE with the same physician and its link to outcomes. To our knowledge, with the exception of one study in localised prostate cancer patients undergoing a radical prostatectomy (Ernstmann *et al.*, 2017), this research issue has never been explored. In Ernstmann's study, very slight variations were observed in PPPE over the course of treatment during a three-year follow-up, but radical prostatectomy is a very hopeful situation from an oncological point of view. The question of empathy evolution merits further exploration in cancers with possible poor evolutions. For example, if a not-very-empathic oncologist at the first assessment becomes more empathic at cancer recurrence, although valuable, this may strongly convey the idea that something is really wrong and thus have counterproductive effects as discussed above. However, positive effects of the increase of empathy are also possible.





In order to gain a good understanding of PPPE, a mixed-method will be used.



In addition to the questionnaire on empathy filled by patients, a short interview of 5 to 10 minutes will be carried out with the patients after each of their three assessments of the empathy of the oncologist. These interviews will review with the patient why s/he assessed the oncologist that way and ask for examples of what s/he considered empathic or not in the consultation. This procedure

will shed light on the empathy score. For instance, a maximal level of perceived empathy could be due to the concern and warmth felt by the patient or because the physician gave them hope. Some patients may even score their physician at the same level at each time of assessment because they want to give an overall assessment instead of focusing on one precise consultation, even if this was not the best empathic one. Beyond descriptive information about the reasons for the perceived empathy, the nature of these empathy scores revealed by interviews will be included in statistical analyses.



1.2. Objective patient outcomes

 In order to have an impact on physicians who are not sensitive to patient-reported outcomes, the outcomes of the study will be objective: overall mortality and inflammation indexes. 

Inflammation indexes such as CRP or IL-6 have both been shown to play a role in sickness symptoms (Reed *et al.*, 2016), postoperative morbidity (Szczepanik *et al.*, 2011) or even cancer progression (Voronov *et al.*, 2014; Leuzzi *et al.*, 2016). As such, they are ideal potential mediators between PPPE and patient outcomes, including survival. However, with the exception of one study showing an indirect association between physician empathy and prostate cancer NK subset via less patient anxiety, stigma feeling and more self-efficacy (Yang *et al.*, 2018b), to our knowledge, physician empathy has never been studied in relation to cancer patient inflammation and survival.

1.3. Controlled variables

Controlled variables will be extremely important with regard to such an outcome. This is why the study must be conducted in one cancer only, for example a precise type of lung cancer, NSCL, in order to control precisely the known genetic, medical and treatment variables related to this specific cancer survival. Cancers with a poor prognosis, which are not so much studied in psycho-social oncology, should be prioritised, e.g. lung or colorectal cancers. Patient variables known for their link to cancer survival will also be included.

 Depression and poor-coping style will be inevitable candidates (Chida *et al.*, 2008; Prinsloo *et al.*, 2015; Feller *et al.*, 2019). Social support and integration will also be controlled for as they have been related to overall survival in colorectal cancers (Hsu *et al.*, 2017; Sarma *et al.*, 2018). 

Furthermore, I assume an interaction between patient social support and physician empathy so that patients with low social support, known to be more sensitive to other resources (Gallagher & Vella-Brodrick, 2008), are likely to be more sensitive to physician empathy.

Two other important variables to take into account will be the gender of physicians and patients. In the literature about empathy and patient outcomes, this variable is rarely considered, whereas evidence exists regarding the role of physician gender at least. A summary article on the topic concluded that male physicians make patients feel more satisfied when verbally expressing patient-centeredness while female physicians make them more satisfied when they adapt their nonverbal communication to the different needs of their patients, i.e. the degree of patient preferences for patient-centred behaviours (Schmid Mast & Kadji, 2018).

Finally, as suggested by our previous work, the type of empathy (listening/compassion vs. active/positive) will be addressed with regard to patient outcomes. If possible, we will compare three theoretical categories (i.e. high level of both types of empathy, high level of listening/compassion only, high level of active/positive only) to the reference one: low levels of both types.

The second part of Programme 1 addresses the issue of empathy in the new context of immunotherapy.

2. The psychological challenges of new treatments: immunotherapy

2.1. The context

There have been rapid changes in oncological treatments in recent years: for example, personalised medicine or precision medicine is an emerging therapy. While classic treatments are similar for all patients with the same condition at the same stage, personalised medicine searches for specific treatments for one given patient according to his/her condition coupled with his/her genetic makeup and changes responsible for cancer growth. Targeted treatments (as they are also called) thus target the specific elements responsible for cancer growth in one precise individual instead of attacking the whole body (i.e. cancer and non-cancer cells) as previously (National Cancer Institute, 2019).

Immunotherapy is another emerging cancer treatment. Targeted therapies and immunotherapy are often presented as two separate treatments but targeted therapy induces immune changes in the long run so both are actually related (Mortier, 2019). The aim of immunotherapy is to trigger the immune system to fight cancer, regardless of histology or genetic status. It is a complete revolution in oncological settings as its effect can be sometimes 'miraculous' (sic; Prof. Alexis Cortot, 2017, medical oncologist, personal communication) leading to prolonged

survival in cases where near-death was the most likely result before this treatment (e.g. Robert *et al.*, 2015; Reck *et al.*, 2016). For example, most patients with metastatic melanoma, for whom median survival was eight months in 2010, are now treated for four years with immunotherapy and can thereafter live without treatment (Mortier, 2019). Some patients are happy to stop treatment, considering they are cured, while others do not want to stop because of a fear of recurrence, which is rare but possible.

However, the effects of immunotherapy can be dramatic with precipitated death or severe side effects characterised by the development of mild to severe immunotherapy-induced diseases (Barber, 2018 for a list of common side effects), which can even last after the end of immunotherapy treatment. Consequently, patients are sometimes reluctant to take up or continue immunotherapy after the initial response due to the potential severity of side effects (McMullen *et al.*, 2019), not to mention that immunotherapy cannot be stopped so easily; once the immune system has been bolstered, it is difficult to stop it.

The major issue is that immunotherapy is an all-or-nothing response, especially in fragile patients. To date, physicians are unable to predict the outcome of immunotherapy in terms of both induced toxicity and survival, e.g. in ear-nose-throat cancers, hyper-progression of the disease due to the treatment occurs in 5 to 15-20% of patients (Clatot, 2019). This leaves patients faced with a difficult uncertainty.

Furthermore, because these treatments are recent, little knowledge is available about patients' QoL when undergoing them, although a recent review concluded that the available quantitative data were in favour of a good HrQoL for patients with NSCL cancer (Chouaid *et al.*, 2018).

Therefore, the aims of this line of research will be twofold:

1. To evaluate qualitatively the psychological impact of immunotherapy and its toxicity on patients and family caregivers. Although some HrQoL assessments have been made using the usual standardised questionnaires, to the best of our knowledge (i.e. using a search on Web of Science, Scopus and Science-Direct databases), only one Australian study has explored the *experiences* of cancer patients with metastatic melanoma concerning immunotherapy using an interpretative phenomenological analysis (Levy *et al.*, 2019).

This study revealed patients' difficulty in dealing with uncertainty related to immunotherapy treatment, disease trajectory, family relationships, and decision-making. More investigation is required in other cancers, such as NSCL, and in other countries. In

addition, to the best of our knowledge, nothing is known about patients for whom the therapy has been completely successful: what impact on their representation of medicine as completely powerful, if they blame themselves for being alive whereas other patients have died following the same treatment or if they consider that life has given them a unique opportunity, thus placing on them the responsibility of leading an exemplary life. Having confronted probable death may also have profoundly changed these patients, leading to difficulties in resuming life as previously and in interacting with other people who have not faced death.

2. To test longitudinally the impact of three psychological factors – i.e. PPPE, patient ES and beliefs and expectations about immunotherapy – on the patient outcomes of the effectiveness and toxicity of immunotherapy. These three candidates for possible predictors of the toxicity and effectiveness of immunotherapy are further developed below.

2.2. Possible psychological predictors of immunotherapy outcomes

2.2.1. Patient emotional skills



Patient emotional skills (i.e. the way patients process and regulate their emotions and those of others) seem a very promising variable in the context of immunity.





In fact, in a study in men with prostate cancer, emotion regulation significantly predicted lower IL-6, sTNF-RII, and CRP (Hoyt *et al.*, 2013). Similar findings were observed in women with BC whose high positive affectivity, a marker of high emotion regulation, assessed at the end of treatment predicted lower CRP one year later (Moreno *et al.*, 2016). Again in women with BC, emotional acceptance, one of the markers of emotion regulation, attenuated the association of proinflammatory cytokines IL-8 and TNF- α with sickness symptoms, reducing the latter in women with high emotional acceptance (Reed *et al.*, 2016).

The revised and shortened 13-item version of ES validated in French in our laboratory will be used (Baudry *et al.*, 2019).

2.2.2. Patients' expectations

Another psychological variable to target is *patients' expectations regarding treatment outcomes and toxicities*. One meta-analysis of 21 prospective studies showed that pre-surgery

patients' expectations predicted post-surgery quality of life (Auer *et al.*, 2016). In cancer settings, data have established a strong and robust association between patients' expectations and post-chemotherapy nausea (the meta-analysis of Colagiuri & Zachariae, 2010), as well as between expectations and other post-chemotherapy side effects (Olver *et al.*, 2005). Such results have recently been confirmed in another meta-analysis showing medium effect size correlations between expectations of side effects and actual side effects experienced in cancer patients (Fletcher *et al.*, 2018). Furthermore, as already stated, patient beliefs about the curability and consequences of cancer are related to all-cause mortality in several studies (Soler-Vila *et al.*, 2005; Soler-Vilá *et al.*, 2009; Thong *et al.*, 2016; de Rooij *et al.*, 2018) so that it can be assumed that beliefs about the efficacy of immunotherapy may have a long-term impact on its effectiveness and toxicity.

 Interestingly, a longitudinal study of 798 women with advanced ovarian cancer revealed that higher patient optimism, minimisation and lower helplessness/hopelessness were associated with longer overall survival when assessed prior to the first cancer progression but not when assessed after cancer progression (Price *et al.*, 2016). Therefore, patient psychological predictors should be assessed early in the cancer trajectory. 

The Brief Illness Perception Questionnaire (BIPQ) will be used. It assesses patient beliefs about the identity of the illness (name and symptoms), the causes of the illness, the consequences (impact on life domains), the timeline (i.e. how long patients think the illness will last) and whether the illness can be cured or controlled. A recent meta-analysis on this tool revealed correlations between the BIPQ and various outcomes and a sensitivity to change after interventions on patients' beliefs (Broadbent *et al.*, 2015). In particular, patient personal control is the most sensitive to change, which is good news for psychologists and HCPs as one of their goals is to empower patients so that they feel better able to cope with the disease and its related uncertainty.

2.2.3. Patient perceived physician empathy

Finally, PPPE will be assessed using the CARE questionnaire. I assume that PPPE, at least its active/positive part (items 7 to 10 of the CARE scale, presented in Appendix), will explain patients' expectations of the treatments and outcomes, which in turn will explain in part the efficiency and side effects of the treatments. Thus, a mediation effect is assumed: PPPE -> patients' expectations -> outcomes. Surprisingly, not many studies have addressed the physician's role in placebo effects (Blasini *et al.*, 2018) so that there is room for the topic, especially in therapeutic treatments with uncertainty issues such as immunotherapy.

However, the available data from an experimental study are in favour of the importance of patient-perceived physician warmth and competence.



Without these features, even if the physician conveyed positive expectations to patients, the placebo effect did not work (Howe *et al.*, 2017). This is why, once again, it will be very important to study the different dimensions of empathy (i.e. affective vs. cognitive) as described on page 46.



Programme 2. Empathy training: interventional research

The aim of this programme is to develop clinical empathy, both for physicians (sections 1 and 2) and students in psychology (section 3). As regards physicians, I first propose a study to reveal the most influential physician factors on PPPE among the known candidates. The retained factors will be targeted as a priority in the proposed training. Then I will move on to three projects of empathy training according to the context (initial or continuous education) and the mental state of physicians.

1. What contributes most to patient perception of physician empathy?

As I developed fully in 'Part 2, section 4', PPPE is beneficial for many patient outcomes including medical ones, as will be further explored in Programme 1. Therefore, it is of utmost importance to know the predictor variables of PPPE, as these must be targeted in any strategy to improve PPPE. As I presented on page 67 and thereafter, some clinical and sociodemographic variables are known to be related to PPPE.



However, to our knowledge, no study has yet sought to make these known variables compete in a single mathematical model in order to rank them from the most to the least influential. This prioritisation is vital so that educational actions can be targeted toward the most influential components of PPPE.



Based on previous research, the candidate variables will be:

- Physician *distinctive* accuracy about patient distress and the main domains of HrQoL. A short questionnaire will be independently answered by the physician and patient after a consultation. To examine the distinctive nature or not of accuracy, physicians will also be asked to note whether they have answered by chance or because they think they know the patient's answer.
- The extent to which the physician likes and has sympathy for the patient.
- Physician basic non-verbal behaviours such as eye contact, leaning posture, and mimicry (e.g. Gorawara-Bhat *et al.*, 2017; Wu *et al.*, 2018).
- Physician basic verbal behaviours such as asking questions, responding to patient emotional cues and whether the physician encourages the patient or not.

The choice of the variables will be further specified according to the most convincing research on the best verbal and non-verbal predictors of PPPE.

The above variables will be tested as predictors of PPPE controlling for other variables known for their impact on PPPE such as patient ES (a small correlation of .24 was found in one of our databases), patient helplessness/hopelessness regarding his/her cancer, patient QoL, and patient and physician gender. The whole picture is depicted in Figure 15.

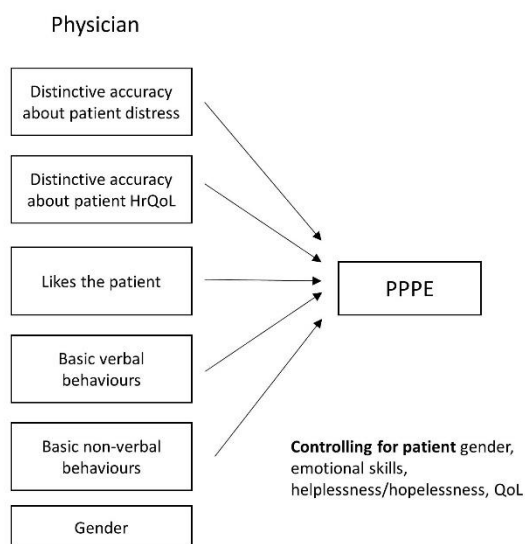


Figure 15. Competitive predictors of PPPE.

PPPE = patient perceived physician empathy; QoL = Quality of Life

In practice, consultations will be videotaped. Just after the consultation, the physician will answer the accuracy test and the 'liking question' while the patient will rate the perception of physician

empathy. In addition, a short interview with patients will help to explore the reasons for their rating of the physician. Using the videos, researchers will code the selected verbal and non-verbal behaviours.

The results will enable us to give some guidance to physicians who ask for only quick tips to be empathic, either because they do not have time to develop the whole 'empathy package' but are willing to test some things or because they are not interested in the topic but are still curious to have some cues about it. They will also provide a very important basis to target the interventions proposed below aimed at developing physician empathy in the field.

In the following section, I will describe four projects on the development of empathy according to the context and emotional state of the physician. The projects are evidence-based medical training aimed at developing physician empathy:

1. in initial education,
2. in continuing education if the physician is in emotional distress, with both a multidisciplinary reorganisation of work and an increase in physician ES, which I assume will lead to greater well-being and empathy,
3. in continuing education if the physician is comfortable with motivational interviewing,
4. in continuing education using physician drawings as a medium in consultations if the physician is not interested in motivational interviewing.

In Figure 16, a decisional tree presents the various contexts and adapted actions. The goal is to reach as many doctors as possible and not only the most motivated and volunteers.

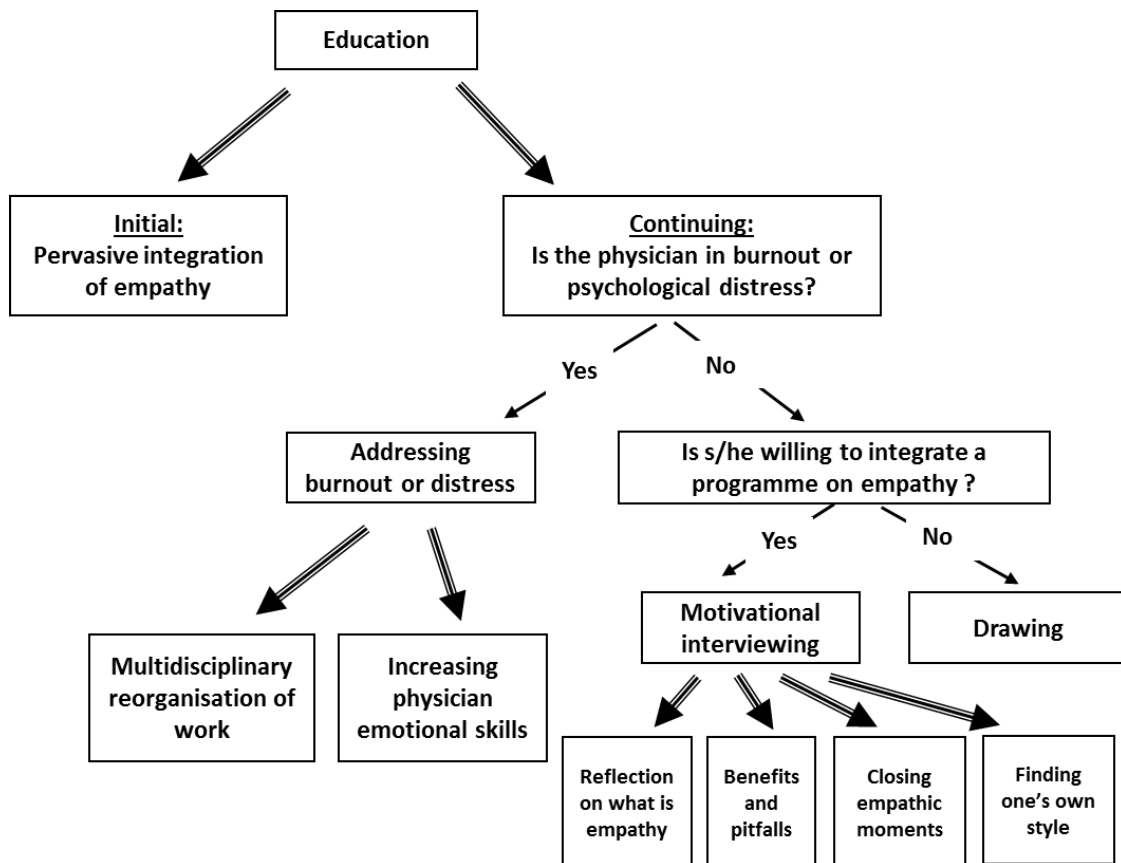


Figure 16. Decisional tree related to empathy training according to the context. Full arrows describe the subcomponents of one box.

2. How can physicians be reached?

2.1. Pervasive integration of empathy in initial medical education

The first avenue of research concerns medical education about empathy. Currently, as I stated previously, medical education rarely addresses doctor-patient communication, including empathy issues. However, in France, some universities provide teaching on the topic but, as already mentioned, students may cram the course for the exam only. Consequently, the teaching is poorly integrated into their practice. Furthermore, teaching empathy in this way separates relational issues from the other parts of medicine, as if it was an option only for those interested in it. Instead, a little of the patient-centred approach will be integrated into each part of medicine related to chronic diseases and even, to a lesser extent, acute medicine.



The aim of the research will be to test how the pervasive integration of the patient-centred approach will impact students' attitude and behaviours in actual practice compared to training without those elements.



For example, some firms create digital clinical cases to train students (e.g. <https://www.youtube.com/watch?v=MfShSlyvLZc> or <https://simforhealth.fr/en/virtual-clinical-cases-to-provide-better-health-care-for-cancer-pain/> or search for 'simforhealth clinical cases' on Google and look at the proposed videos). These cases are created by health professionals. Students have to choose from many suggestions what to do or ask the patient at each step of the consultation and can even write what they would ask or say to the patient. To our knowledge, such cases are mostly technical and do not include many psychosocial issues. The following ones will therefore be included.

- Patients' worries (i.e. empathic opportunities) will be included to see whether or how it is dealt with by students.
- In cases, depressed patients will consult for a technical issue and I will test whether students will detect a depressive mood and refer them or not to psychosocial support.
- According to the theoretical model presented on page 82, medical communication impacts patient disclosure of important information for the physician to reach an accurate diagnosis.

Therefore, I will design cases so that a missing answer to a patient



empathic opportunity will prevent patient disclosure of important information, without which either diagnosis will be inaccurate or the patient will refuse to follow the physician's proposed treatment.



Students will receive feedback and notes for each clinical case. These elements will also take communication skills into account.

As well as the integration of empathy into ordinary training, empathy-related courses could be proposed but, as I have just developed, new ways of teaching would be welcome. Furthermore, I think that a prerequisite to increasing empathy, regardless of the trigger of the increase, is ensuring that physicians are not in psychological distress. Clearly, it is difficult to be other-centred while being in need of psychological help oneself. Thus, before any empathy-related intervention, physicians should be screened for psychological distress and if positive, their distress should first be addressed with an original programme such as the one developed below.

2.2. To reduce physician burnout: comprehensive interventions

At one root of lack of physician empathy is burnout or, more broadly, emotional distress (Damiano *et al.*, 2017; Murali & Banerjee, 2018) so a logical way to improve empathy is to address physicians' mental state and burnout.



This will be a far-reaching measure as burnout concerns between 42 and 50% of physicians according to several large American and recent cohorts (Yates, 2019).



However, the way to address their distress should not target physicians only (West *et al.*, 2016; Murali & Banerjee, 2018). In fact, physician burnout has mainly been explained by a lack of acknowledgement of their contributions to the department (Duke *et al.*, 2019), long working hours, a lack of respect from colleagues, insufficient compensation, a lack of clinical autonomy and increasing computerisation of practice (Murali & Banerjee, 2018; Nicholls, 2019, cited by Yates, 2019).



This is why an effective intervention should target both working conditions/environment and individual psychological factors such as ES (West *et al.*, 2016, 2018; Lindeman *et al.*, 2017).



Indeed, by definition, ES increase empathy since they allow an identification and understanding of the emotions of patients and make patients more comfortable in expressing their emotions. Physician ES also enable physicians to stay calm and helpful when faced with distressed patients, thus helping them regulate their emotions.

For clarity reasons, I present below the two facets separately but, in the field, they may not be so separate.



2.2.1. Multidisciplinary reorganisation of work

Working conditions/environment will be addressed with the help of colleagues in occupational psychology and ergonomists. Consultants adept at organisational change management will also review the functioning of medical departments in order to gain efficacy and thus time and energy for physicians to be with their patients. Individual psychological factors to target should also be considered within the specific features of the medical context. For example, oncologists want evidence-based training on how to manage emotion-oriented communication *while using the computer* during consultations (Visser *et al.*, 2018).

In my opinion, one major issue of some interventions aimed at developing empathy in cancer care is that they have mainly been designed by psychologists who have transmitted what they know and practice about empathy as psychologists to physicians in cancer care.



However, the contexts are so different in many ways – e.g. physicians have little time, a high cognitive load, a priority for medical issues also expected by patients, heavy environmental constraints, such as a computer between them and patients – that interventions should be thought of totally

differently, that is grounded in, and customised for, the specific medical context of each type of physician (oncologists, surgeons, radiotherapists, etc.). Actually, even in medical contexts, the interventions should be completely tailored to a specific environment such as ‘this department of this hospital of that city’, otherwise they may even be harmful. This is what happened when a successful wellness programme for emergency *nurses* was delivered to emergency *medicine residents*: for 72% of them, the programme *worsened* their burnout (Hart *et al.*, 2019). Feedback by attendees pointed to the instructors’ poor understanding of residency stressors and work, resulting in a lack of relevance. On the contrary, tailored interventions such as one comprehensive wellness curriculum based on very pragmatic help and advice (e.g. 24-hour access to complimentary bottled water and sports drinks in the residents’ lounge, new monthly music playlists for exercise or study, access to income tax software) delivered by both the faculty and residents themselves to other residents significantly improved residents’ wellness (Lefebvre *et al.*, 2019).

 This is why before addressing physicians’ individual factors, such as their ES as developed below, psychologists should stay in the targeted setting for a few days in order to think of ways of adapting their knowledge creatively to the specific setting of one department and one profession. 

2.2.2. Physician emotional skills

While taking the specific context of each type of physician practice into account, physician ES seem of particular interest. ES, i.e. the way people perceive, understand, express and regulate their emotions and those of others, have been associated with less burnout (Lin *et al.*, 2016; Lindeman *et al.*, 2017; Cofer *et al.*, 2018; Beierle *et al.*, 2019) and higher job satisfaction (Hollis *et al.*, 2017) in surgical residents, reduced fatigue and burnout in nursing care (Beauvais *et al.*, 2017) and greater well-being in junior physicians working in emergency medicine (Mache *et al.*, 2018) among other examples.

 The most recent systematic review investigating the role of emotion regulation in physician burnout confirmed, from the 14 retrieved studies, the relationship between the two variables (Jackson-Koku & Grime, 2019). 

An analysis of a fictional but typical case of a physician intending to discuss palliative care with a patient whose cancer has progressed gives an insightful illustration of the role of ES in burnout and empathy (Soodalter *et al.*, 2018). The case describes how low physician ES led to an anticipation of negative feelings and attentional bias toward threat before the encounter, to emotional contagion when faced with the emotional outburst and anger of the patient receiving the bad news, and ended

up with physician cognitive freezing and avoidance of the discussion by proposing a new undesirable and unintended chemotherapy. Post-consultation time may thus be characterised by rumination on the missteps, conflict feelings about the performance and avoidance of such situations in the future, all elements leading to physician emotional exhaustion and burnout.

As revealed by a recent review (Erdman *et al.*, 2017), there is a growing interest in ES within surgical education but this mainly revolves around a quantitative assessment of ES, whereas further research is warranted on integrating ES into surgical education and their effect on patient outcomes. This is why I think that training targeting physician ES will be relevant as suggested by the few interventions already designed and implemented.

For example, a two-hour training course led to an increase in ES in emergency medicine residents from T1 (before the intervention) to T3 (six months after the intervention) (Gorgas *et al.*, 2015). The course was based on a TED-Talk lecture delivered by Daniel Goleman and on active reflections on case analyses discussed in small groups with a final debriefing.

Interestingly, the change in ES was not observed immediately after the course but six months later. This suggests that participants need time to process and apply the learned skills in the field.

It should be noted that the course targeted ‘compassion’ and ‘perspective-taking’ as ES. In fact, perspective-taking implies perceiving and understanding the emotions and perspectives of others and thus fits two dimensions of ES. Compassion involves an additional desire to help, which translates into the regulation of others’ emotions, thus engaging another dimension of ES (i.e. regulation). ‘Perspective-taking’ and ‘compassion’, which recalls ‘empathy’, are therefore a part of ES, explaining the correlations between ES and empathy (e.g. Sommaruga *et al.*, 2017; Nightingale *et al.*, 2018). Furthermore, perspective-taking and compassion may be highly correlated (Pekaar *et al.*, 2018). Training in perspective-taking is therefore likely to trigger compassion.

Another study in surgical residents demonstrated the efficacy of training designed to improve resident ES, which were still higher one year after the end of the course (Riall *et al.*, 2018). The same positive result was found in a pre-post assessment of a four-hour training workshop delivered to paediatric residents (Shahid *et al.*, 2018).

The goal of the research will be to test the efficacy of an intervention aimed at increasing physician ES. It is expected that the intervention will increase ES, which in turn will increase well-being and empathy.

2.2.3. Method

As available research suggests that short interventions are successful in increasing ES, these will be preferred given the heavy schedule of physicians. As briefly described on page 99, with my psychologist colleague, Marie-Mai Nguyen, we have already designed a three-session programme to increase cancer patient ES. In the context of an electronic-personalised programme for obesity in pregnancy to improve delivery (Hospital Clinical Research Programme, 2014, 'Programme Hospitalier de Recherche Clinique', PHRC in French), I have also designed the psychological part of an educational tool to improve the ES of those obese women. The psychological content was based on cognitive and behavioural exercises related to affect-regulation training (Berking & Lukas, 2015) and clinical positive psychology (Magyar-Moe, 2009); the whole programme also contained medical, nutritional and physical-activity-related advice (Deruelle *et al.*, 2020).

All the work carried out in these two previous research projects will be used to design the intervention for physicians.

The study will be an RCT with a control group undertaking a sham intervention: a discussion group on the topic of well-being. Outcomes will be ES, well-being and PPPE assessed at pre- and post-intervention times and at follow-up (i.e. 3 and 6 months). Physicians should be blind to the goal of the study (and thus to the latter outcome, PPPE), which is ultimately to increase PPPE, to ensure that an increase in PPPE will be the result of the increase in ES and well-being and not an expectation effect. PPPE is actually the main outcome so that such a study will meet the need for interventional studies on both burnout *and its effects* (West *et al.*, 2018). To blind PPPE as the outcome to physicians may also help in recruiting physicians less interested in the topic.



The way of presenting the intervention and its goals to doctors will be carefully thought through without emphasising the psychological aspects of the intervention, which are so off-putting for some physicians. A preliminary study will test different ways of presenting the intervention to physicians with the intention to participate as the outcome.



Finally, should ES increase but not empathy (i.e. a disconfirmation of my hypothesis), then the study would at least provide the knowledge that well-being might be necessary but not sufficient to increase empathy. If this were the case, 1) moderators should be explored to know whether this conclusion is true for everybody or specific to some physicians according to their gender, age, medical specialty, etc., 2) beyond ES and well-being, empathy should be addressed specifically with an innovative and supportive programme such as the one I propose below.

2.3. Motivational interviewing and self-determination intervention

As I described earlier in the document, there is a pervasive idea that empathy is absolutely necessary in medicine and that non-empathic physicians are wrong and should be trained to empathise. I think that this implicit assumption is a poor basis for reaching and engaging the least motivated physicians. Therefore, I would propose a course including a motivational interviewing on empathy, following this structure: 1. Definitions of empathy, 2. Benefits of empathy, 3. Pitfalls of empathy, 4. Knowing how to close an empathic opportunity, 5. Finding one's own empathic style.

The research goal will be to test how 'motivational interviewing' on empathy will impact students' attitudes and behaviours in actual practice compared to the current training using a pre-post intervention design. Furthermore, empathy will also be assessed by patients of attendees, before and after the intervention, to ensure that the effect of such reflections will reach the patients. Indeed, if the physician changes his/her behaviours but without any impact from the patient's perspective, all this would be useless.

2.3.1. Definitions of empathy

First, there will be a brain-storming of the definitions of empathy, intertwined with important key messages on the topic: the concept of empathic opportunities and possible responses, the two sub-dimensions of empathy (compassion/listening and active/positive), the notion of hope while being honest if the patient can cope with a poor prognosis.

2.3.2. Benefits of empathy

Second, the benefits of empathy will be sought by participants and supported by both our literature review of 2012 and forthcoming meta-analysis. Since physicians are not always sensitive to subjective patient-reported outcomes, such as QoL or well-being, an emphasis will be placed on objective outcomes such as inflammation, cancer biomarkers or survival. For example, in general medicine, physician empathy rated as perfect (maximal score on the CARE scale) by patients has been related to a more significant change in IL-8 and neutrophil count after a common cold compared to physicians being perceived as less empathic (Rakel *et al.*, 2011). In cancer care, a recent study has shown a significant link between physician-reported empathy and advanced prostate cancer patients' NK (Natural Killer) cells (Yang *et al.*, 2018b).

Another value of empathy, which will be advantageous for participants to find, will be the benefit to the physicians themselves. Indeed, research has often demonstrated a link between empathy and physician well-being.



Knowing that an oncologist will impart 20,000 pieces of bad news on average to patients in his/her career (Schmid Mast *et al.*, 2005), that is to say 20,000 empathy-triggering situations, it is clearly worth the effort to reflect on empathy.



2.3.3. Pitfalls of empathy

Third, in order to engage physicians who are not very interested in psychosocial issues and to warn those who rely too much on empathy, a discussion about its pitfalls will be necessary. In fact, empathy and, more broadly, a patient-centred approach are not always desirable as demonstrated in the following points.

2.3.3.1. Empathy: not with all patients

Although patients would like individualised and comprehensive care provided by experts of whom they can ask questions, empathic communication is not desired by all patients (e.g. Back & Arnold, 2013; Martins & Carvalho, 2013; Rudolph *et al.*, 2015). Furthermore, as already said, empathy can be worrying for some patients in certain contexts such as bad-news disclosure with a poor prognosis.

2.3.3.2. The cost of empathy

The effort to take a given patient's perspective while at the same time dealing with the medical and administrative sides of the consultation can deplete the cognitive and attentional resources of the physician, leaving less available empathy for the next consultations (Eisenberg & Eggum, 2009; Robieux *et al.*, 2018). In addition, the empathy of parents toward their children (Manczak *et al.*, 2016) and of family caregivers toward a relative with cancer (Rohleder *et al.*, 2009) is associated with higher inflammation rates of CRP and Il-6 in parents and caregivers.

2.3.3.3. Empathy: not all the time

As a physician declared: 'the more we listen to and focus on patients' needs, the higher is the risk that we will not do what we have to do in biomedical terms. We won't do that exam because it is complicated for the patient to accept or because that day s/he is not able to hear it. However, I remain an HCP and if I have unpleasant things to say, I will have to say them anyway' (Le Rhun *et al.*, 2013, p. 44).

The physician was right. In diabetes care, an RCT comparing usual care to care by HCPs (nurses and physicians) trained in the patient-centred approach showed unexpected results. In the group of trained HCPs, patients were more satisfied with their treatment and the HCP and also felt better *but* reported higher BMI and triglyceride concentrations and less knowledge about the disease.

Furthermore, both groups were equivalent for glycaemic control and lifestyle (Kinmonth *et al.*, 1998). In summary, this intervention was a medical failure. Another striking result was found in a telephone intervention study aimed at helping patients to quit smoking: controlling for the agreement between patient and counsellor on the goals and tasks of the intervention, patient-reported counsellor empathy *decreased* the number of patient attempts to quit smoking (Klemperer *et al.*, 2017). Once again, empathy does not help in all contexts. Surgical students facing painful patients also feared that an empathic response to pain would prevent them from continuing their work (Kopecky *et al.*, 2018).

2.3.4. Closing patient empathic opportunities

At this stage of the course, attendees will be aware that empathy can help patients but also that there are probably times and contexts to be empathic. With that in mind, theoretically they should be interested in engaging in empathy behaviours to some extent. However, a worry often encountered is well illustrated by the words of a female dietician: 'I have found that it can be dangerous [to leave room for patients' emotions, experiences and difficulties] as it allows obstacles to emerge that we cannot always resolve' (Le Rhun *et al.*, 2013 p. 45). The same issue has been noted regarding depression and anxiety screening: HCPs do not do it because they do not know how to deal with potential patient distress (Hudson, 2019). Although this fear is entirely legitimate, the problem is that it is often resolved by HCPs with a cold attitude that leaves no room for emotions and empathy.

This is why HCPs will be trained to close empathic opportunities once they have answered them enough according to the available time, the remaining tasks of the consultations and their emotional availability.





If professionals had the assurance that they could close emotional moments when they wished, they would more easily allow themselves to open up to patient emotions.



This argument is supported by an anaesthetist when he highlights the need 'for striking this balance between 'unemotional' factual action and empathy for the critically ill patient and relatives' (Quintel, 2017 p. 1723). Furthermore, in my experience, cancer patients are generally very understanding of the fact that HCPs, especially doctors, cannot spend too much time dealing with their emotions. Very often, patients even apologise for their depressed or anxious reactions. Therefore, in this part of the training, HCPs will themselves find ways to close emotional moments before uncontrollable outbursts of tears. They will be asked to suggest sentences and non-verbal behaviours that might stop patients' emotional reactions and these sentences will be discussed with the other professionals and psychologists. For example, a stop could be formulated like this: 'Mr or Ms XXX, I'm

sorry to interrupt you [i.e. HCPs should be trained to interrupt patients]. I'm listening carefully to you because I can see your fear/emotion/anxiety/whatever-emotion-is-detected and I empathise with you, but right now I need your attention/calmness/what-is-needed to go on with the consultation/the exam/whatever-is-going-on'.



From my experience, this part of the training will also be the opportunity to discuss the cases of patients who need to be referred to a psychologist and/or psychiatrist.

 It is important to detect such cases as otherwise HCPs may have the impression that they cannot alleviate these patients' distress nor stop their complaints or aggressive behaviours to resume the course of the consultation.  Sometimes, physicians have to delineate boundaries to contain patients' outbursts (Back & Arnold, 2013).

2.3.5. Finding one's own empathic style



It is known that lectures or modelling (i.e. showing what to do using videos) are not effective for improving physicians' communication skills (Berkhof *et al.*, 2011). According to this systematic review, what worked was small-group discussions and role-playing with feedback. So, in a humanistic perspective, I think that all physicians have their own inner resources to find how they can be empathic with patients. Courses on empathy should therefore be replaced by sessions in which physicians can choose and test their own strategies. This method has many advantages.

First, according to the self-determination theory (Ryan & Deci, 2000; Deci & Ryan, 2008), motivation and well-being are enhanced 1) when people feel they can make their own choices and decide freely how to do things and 2) when they feel competent in what they do. Thus, even if physicians' choices may not be the best ways to be empathic from a theoretical point of view, at least they will be their ideas and choices. Therefore, they are more likely to adhere to them and apply them in the field with a feeling of competence than if they apply, only in the short term, something they have not chosen and with which they are not at ease.

 A strong link ($B = .50$) has been found between medical students' self-reported empathy and their self-esteem (del Carmen Perez-Fuentes *et al.*, 2019; Huang *et al.*, 2019). Therefore, it is important to give physicians confidence in their abilities to support patients and it cannot be done with a top-down lecture  in which psychologists place themselves as experts against non-competent physicians. On the contrary, physicians need to be supported to become aware of their inner resources and value.



Second, it will solve the French problem of medical hierarchy. In France, this hierarchy is strong and psychologists are considered to be at a lower level than physicians. This sometimes creates defensive reactions toward training by psychologists. A colleague of mine told me that at the beginning of a training session about delivering bad news, a doctor once said sarcastically 'Oh OK! This is a psychologist who has never given bad news to a patient who is going to teach us this!'. Such conflicts may be defused by explaining that we are not going to tell physicians how to do their jobs, but instead help them to reflect on the way they could deal with distressed patients while maintaining their well-being and consultation schedule. Physicians will propose their own strategies, which will be discussed with other attendees, and a positive feedback will be given by the psychologist based on his/her expertise. For example, if a physician says that s/he is at ease being silent faced with a patient's distress, this proposition could be validated by the fact that physicians' silences help patients recognise the information given during the consultation (Visser *et al.*, 2019). I also think that such training will be better welcomed and accepted if it is jointly facilitated by the psychologist and a physician of the department. The impetus should come first from someone in the department, ideally high in the hierarchy. It is well-known that the attitude of those at a high level is a potent driver for the rest of the department. This will require the physician and the psychologist to work together before facilitating the training.

I am also of the opinion that physicians should be encouraged to empathise, *but at the minimum*. In fact, studies have shown that a few seconds of empathy are enough to reduce patient anxiety (40 seconds in Fogarty *et al.*, 1999; 38 seconds in Sep *et al.*, 2014).

 It is important for physicians to understand that little things can make a difference so they are not discouraged by misconceptions about medical empathy. 

The idea is not to become a psychologist, which could be off-putting for a physician not interested in psychosocial issues, but to explore ways of doing something at the minimum toward patient emotions and perspectives.

From a research point of view, one may argue that such a research design will be problematic as it will not be reproducible due to the fact that each physician will have to find his/her own way of being empathic. This is true.

 Therefore, physicians' decisions about their way of being empathic should be informed by the doctors themselves during the training and after consultations/encounters with patients. 

The psychologist will meet each doctor individually after two weeks to ask whether s/he has changed something in his/her communication or behaviour or way of regulating his/her emotions or anything else, and if yes, the nature of the change. If needed, a readjustment will be considered during this first meeting. A second meeting will be scheduled after additional time for the same purpose. This procedure will reveal what kind of change had an impact on PPPE.

2.3.6. Medical settings

This training will be carried out in various medical settings such as cancer care or general medicine. However, having talked with HCPs from various settings, I realised that some medical specialities, such as emergency medicine and ICU, may be particularly in need of help with doctor-patient communication and empathy (personal communication with Isabelle Gustin and HCPs in the emergency department of a hospital in northern France). A quick search on the 'Web of Science' databases confirmed the paucity of empathy research in these specialities: 457 hits for 'physician empathy AND cancer' within the last five years against 49 hits for the same research in emergency medicine. Yet, in such a stressful context, empathy could be of utmost importance, both for the patients *and families*, a topic never addressed to the best of my knowledge. In fact, I have never seen a study on the impact of physician empathy on family caregivers' outcomes. Yet, in an emergency setting, the way of delivering bad news, often related to a traumatic experience (e.g. accident, stroke, etc.), is likely to impact caregivers greatly. This is why the trauma literature, knowledge and theories will be taken into account in such research.

In this section, I have proposed a full intervention directly targeting empathy. However, some physicians will never attend such training and, if it was mandatory, they could still be fixed in the earliest stages of the change process. Furthermore, the personality traits of 'agreeableness' and 'openness to experience' are associated with physician empathy (Guilera *et al.*, 2019; O'Tuathaigh *et al.*, 2019), especially in technology-oriented specialities (Guilera *et al.*, 2019). For example, in surgery and radiology, physicians with low agreeableness have a low self-reported empathy (Guilera *et al.*, 2019). Therefore, in answer to a question I am often asked, namely, 'Can we really increase everyone's empathy, is it not a question of personality?', I would say that for some physicians, empathy and a person-centred approach will never be their priority. This is why I now propose, especially for these physicians, the exploration of a medium between physicians and patients, i.e. drawing, as a means of facilitating doctor-patient communication and PPPE.

2.4. To explore drawing as a medium between physicians and patients

2.4.1. Rationale

In consultations, some physicians spontaneously sketch a disease and how treatments work to explain them clearly to patients who take the drawing home. If, at first sight, a drawing may appear insignificant, arguments contradict this point of view.

Multiple studies have reviewed the link between patients' drawings of their disease and their outcomes (Broadbent *et al.*, 2018) and, according to the Common Sense Model of Self-Regulation, patients' representations of their illness in terms of identity, control, causes, consequences and timeline impact patient outcomes.

These representations can be explored through patients' drawings as shown by the work of Elisabeth Broadbent in various pathologies such as headache, heart failure, blood disorder, mild traumatic brain injury or myocardial infarction among others (e.g. Broadbent *et al.*, 2004, 2006, 2009; Reynolds *et al.*, 2007; Ramondt *et al.*, 2016; Jones *et al.*, 2019). For example, in patients with blood disorders, the number of blood cells drawn was negatively correlated with personal control (Ramondt *et al.*, 2016). A recent literature review retrieved 101 studies on the topic covering 27 disease categories (Broadbent *et al.*, 2018). Patients' drawings reflected all the domains of illness representations, especially symptoms, anatomy and emotional representations, with more organ damage drawn and a larger drawing size associated with worse perceptions and health outcomes.

Therefore, I assume that physicians' drawings will impact patients' representations and thus outcomes. In addition, I assume that with drawings in consultations, patients will feel more at ease to ask questions through this medium, which may facilitate a better rapport with the physician.

The theoretical framework and experiences within the field of health education support these assumptions (Laholt *et al.*, 2017; Garista *et al.*, 2019), such as the use of pictures (i.e. 'photo-language' in French) in patient education to open up discussions about a disease, its treatments and the emotional issues patients would not dare to bring up without the pictures (CHU de Nantes [Teaching hospital of Nantes], 2006).

The aim of this research will be to explore differences in patient outcomes both during and after consultations according to whether or not the physician had used a drawing, in a cancer setting.

2.4.2. Method

The study will be proposed to physicians as a study on patient understanding of medical information. Ideally, physicians should be blind to the empathy outcome so as to reach a wide range of physicians and not only those interested in doctor-patient issues.

A convenience sample of volunteer physicians will be tested in two phases: a 1st phase with consecutive patients without drawing (the number of required patients will be determined with the usual statistical procedure according to the expected effect size and available data) and a 2nd phase with consecutive consultations with drawing. Consultations will be recorded. Outcomes will be:

- during the consultations: patient communication (i.e. number of questions asked and of concerns expressed) and physician behaviours (i.e. basic non-verbal and verbal empathic behaviours)
- after the consultations: PPPE and patient satisfaction with the consultation and illness perceptions. Coding will be used to classify their overall perception as realistic, negatively unrealistic or positively unrealistic.

In addition to the experimental conditions (i.e. drawing or not) as a predictor, important features of the drawings, such as disease- and/or treatment-oriented, integrating or not psychosocial issues, etc., will be taken into account. PPPE in the 1st phase of the non-drawing condition will probably be an important moderator of the impact of drawing: physicians with low PPPE without drawing may be those whose patients would benefit most from the drawings. Patient emotional distress before the consultation and socioeconomic status will also be controlled for. A collaboration with expert researchers in drawing will be undertaken.

3. Educational projects in health and psychopathology fields

Since 2010, the University of Lille has offered a Master's degree in Psychopathology and Health Psychology, in which I give many courses to Health Psychology students in TPE, oncological, supportive and palliative care. As in many universities, most courses are usually lectures with a PowerPoint presentation and discussions with students about the content according to their questions and remarks. However, other methods are required by attendees in continuing education: role-playing and videos (Taylor *et al.*, 2019). In the last year of their Master's degree, our students have made the same request and it is a good idea. Given that it has been shown that only role-playing and small group discussions improve physician communication skills (Berkhof *et al.*, 2011), it may be assumed that Psychology students will progress better through role-playing rather than lectures. Because in the Health Psychology option, there is a small group of 15 to 17 students, who already have significant

experience from their internship in the last year of the Master’s degree, I decided to begin role-playing with them. I listed a series of common clinical cases or situations in the studied disciplines (see Table 7 for some examples), suggested one to them and asked some students to play the patient (and family sometimes) and one student to play the psychologist. The other students were asked to observe the role-playing carefully and give supportive and constructive feedback to the actors. Before the role-play, I briefed the false patient and family on their roles and circumstances. Students could also suggest clinical cases they had encountered in their internships.

Table 7. Examples of clinical cases used for role-playing with Psychology students.

Discipline	Clinical case
Psycho-oncology	A female cancer patient is very stressed because she has heard that it is vital to be positive to heal from cancer whereas she is completely depressed.
Palliative care	The wife of a patient at end-of-life is in psychological distress because of her husband’s ‘denial’ of near death.
Therapeutic patient education	A male obese patient is really motivated to change his eating habits and life style but does not know what to do and where to start.

At first, I thought that role-playing would be an interesting activity but had no idea of the extent to which it would be so informative. It made me realise the gap between what students think they know and what they actually do. For example, they think they are empathic but miss patient empathic opportunities or answer them inappropriately, or they tell their teachers that they have had enough courses on motivational interviewing but find themselves at a loss in an encounter with a ‘fictional’ patient whom they are trying to convince. Students are also surprised themselves by such gaps: when they train in patient-education group sessions, they experience the huge cognitive loads they have in remembering the story, the questions and remarks of all the participants while at the same time handling the group and its outliers without losing their educational goals in the given timing of the session.

Each year I ask them for feedback on our role-playing and the majority are really enthusiastic in spite of their fear of exposing themselves in these activities. They say that they learn a great deal about themselves from the experience and also from watching the other students. I believe that this role-playing increases their self-efficacy and helps them to link theoretical constructs to clinical practice. However, I have two concerns about it. First, in spite of positive feedback from students, I have no formal assessment of the activity outcomes and second, I have always thought that it would be better if the students could train with actors instead of their peers whom they know rather well and with whom they feel quite confident.



Regarding the first point, there is actually a strong need for an evidence-based approach to determine what constitutes quality training in psychologists (Callahan & Watkins, 2018).



Regarding the second, I was contacted by a colleague of the University of Lille, Ariane Martinez, Associate Professor in Theatre Studies, who was looking for a collaboration between our two disciplines as she was interested in the medical field. After a discussion, we came up with the idea that her students could play the patients in our psychological role-playing. In that way, her students would train to act correctly while mine would be in a more ecological situation: with someone they do not know and who could act the given scenario very well.

We therefore answered a call for proposals from the University of Lille entitled 'Transformations pédagogiques [Educational Transformations]' and were successful. The project will be pilot-tested this academic year 2019-2020 with the help of 30 hours given to each of us for its preparation and implementation. In practical terms, Ariane will first meet my students to give them some tips in verbal and non-verbal behaviours (e.g. space handling) and to understand better our field of Health Psychology. I will do the same with Ariane's students. Then, our students will come together for the role-playing, which will be filmed by Ariane's crew. The two of us will review the performance of each student solely with the student but not with the whole group. This is a pilot study whose aim is to design the activity, try the implementation in the field and assess student satisfaction, self-efficacy and feedback about the experience.

CONCLUSION

Thanks to the incredible progress of medicine, people now live longer but with multiple chronic conditions for approximately one in three adults (Hajat & Stein, 2018). Cancer is among the four most prevalent chronic conditions with cardiovascular and chronic lung diseases and diabetes. In this context, health psychology has consistently grown for 30 years, trying to explain the link between patients' emotions, behaviours, thoughts, and their health, in order to preserve their QoL in spite of chronic diseases, including cancer (as studied in Part I of this report). Informal and professional caregivers are also now carefully considered for their role in the patient's health as well as for the challenges they face (as studied in Part II related to physician empathy).

Specifically, in Part I, I demonstrated the usefulness of the integrative model of health psychology in the explanation of mental QoL in BC survivors. The crucial role of psychological variables, such as the negative impact of negative affectivity and the high positive impact of social support, were confirmed. Puzzling results were also described and debated, such as the negative link between active coping and mental QoL, showing the benefits of letting go in hospital settings where patients have little control over the situation. The question of PTG as an interesting cognitive coping method was also addressed.

In Part II, I detailed the numerous definitions hidden by the term 'empathy'. Then, I showed the many benefits of physician empathy for patient outcomes, also highlighting the prerequisites and pitfalls of empathy. In order to have accuracy about patient distress, physicians need expressive patients and should be cautious about patients with whom they have an excellent rapport; physician empathy perceived by patients with low ES is not enough to improve their QoL after bad-news consultations, whereas patients with high ES benefit from it. The clinical implications are important. I also questioned the very definition of empathy, asking whether physician accuracy was related to PPPE. Indeed, distinctive accuracy is a protector factor for PPPE. Lastly and unexpectedly, I revealed a negative association between PPPE and patient survival, showing the need to consider the *exact* nature of empathy as our results concerned only one facet of empathy: listening/compassion.

In part III, I proposed two avenues of research that meet the need for convincing research about the role of empathy in patient health and evidence-based training to develop empathy in as many physicians as possible. Medicine is at a turning-point: medical revolutions due to therapeutic breakthroughs imply new organisations of care and different roles for physicians and patients (e.g. multiple physicians around one patient, a growing involvement of patients in decision-making, constant demanding tasks for physicians, etc.). All these changes are a great opportunity for health

psychology to play a major role in the preservation of everyone's well-being: patients, caregivers and HCPs. In order to grasp this opportunity, health psychologists have a great deal to do. They need good clinical knowledge of the studied topics, many exchanges with clinicians and patients in order to understand them well and a cutting-edge methodological expertise to convince them with RCTs and robust findings. They must also have the required communication skills for the valorisation and promotion of their findings, so important in changing practices.

In the midst of the reorganisation and restructuring of research and health, researchers should also take care not to deviate too much from what they think is really needed. Current political pressures in the health domain, such as RCTs being seen as the unique valuable methodology or many publications being needed for one researcher per year, may be a risk for science. Longitudinal and large time-demanding studies are also required despite their lower cost-effectiveness in terms of publication rates, and phenomenological studies are needed too. The experiences of the different stakeholders should not be overlooked.

To conclude, an open-minded approach is needed: Galileo was condemned for his theory although he was right, quantum physics has revealed what was previously considered impossible (e.g. the observer has an impact on the observed element), and theories about the nature of consciousness as a product of the brain are currently being challenged by the worldwide reports of near-death experiences. At our level, even this HDR revealed some unexpected and counter-intuitive results (e.g. active coping being negatively related to mental QoL, excellent doctor-patient rapport compromising physician accuracy, and empathy hastening death). An open mind is thus needed to integrate and process correctly such results that challenge our basic assumptions without ever losing sight of the ultimate objective of all this research: the well-being of those concerned, namely patients, relatives and HCPs.

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Appendix: The Consultation and Relational Empathy (CARE) questionnaire

CARE Patient Feedback Measure for

*** Type name of Practitioner here ***

Please write today's date here:

/ /

D D
M M
Y Y

Please rate the following statements about today's consultation.

Please mark the box like this with a ball point pen. If you change your mind just cross out your old response and make your new choice. Please answer every statement.

How good was the practitioner at...	Poor	Fair	Good	Very Good	Excellent	Does not apply
1) Making you feel at ease <small>(introducing him/herself, explaining his/her position, being friendly and warm towards you, treating you with respect; not cold or abrupt)</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2) Letting you tell your "story" <small>(giving you time to fully describe your condition in your own words; not interrupting, rushing or diverting you)</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3) Really listening <small>(paying close attention to what you were saying; not looking at the notes or computer as you were talking)</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4) Being interested in you as a whole person <small>(asking/knowing relevant details about your life, your situation; not treating you as "just a number")</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5) Fully understanding your concerns <small>(communicating that he/she had accurately understood your concerns and anxieties; not overlooking or dismissing anything)</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6) Showing care and compassion <small>(seeming genuinely concerned, connecting with you on a human level; not being indifferent or "detached")</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7) Being positive <small>(having a positive approach and a positive attitude; being honest but not negative about your problems)</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8) Explaining things clearly <small>(fully answering your questions; explaining clearly, giving you adequate information; not being vague)</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9) Helping you to take control <small>(exploring with you what you can do to improve your health yourself; encouraging rather than "lecturing" you)</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10) Making a plan of action with you <small>(discussing the options, involving you in decisions as much as you want to be involved; not ignoring your views)</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Comments: If you would like to add further comments on this consultation, please do so here. 						

Curriculum Vitae (en français)

Sophie Lelorain, Ph.D.

Enseignante-chercheuse en Psychologie de la Santé,
Laboratoire SCALab, Sciences Cognitives & Affectives,
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Aperçu rapide

Chronologique : formations et activités professionnelles

<u>Depuis sept. 2012</u>	Maître de conférences (MCU) en psychologie de la Santé SCALab UMR CNRS 9193, Université de Lille
Sept. 2014 – août 2016	Chargée de recherche (en plus du poste de MCU) Unité Transversale d'Education du Patient, CHRU Lille
2010-2012	Postdoctorat en psychologie de la santé Institut Curie/Université Paris Descartes
2009-2010	Attachée temporaire d'enseignement et de recherche à temps plein (ATER) Département de psychologie, Université de Nantes Psychologue à temps partiel (20%) Service d'oncologie médicale digestive et thoracique, CHU de Nantes
2006-2009	Doctorat en psychologie de la santé Université de Nantes/Maison des Sciences de l'Homme de Nantes
2005-2006	Master 2 Recherche Département de psychologie, Université de Nantes
1999-2004	Master Professionnel à l'École de Psychologues Praticiens de Paris, EPP

Intérêts professionnels : l'essentiel

- Impact de **l'empathie médicale** sur l'ajustement des patients au **cancer**/soins palliatifs et à la **maladie chronique**
- Rôle des **compétences émotionnelles** des patients et des soignants dans l'ajustement des patients au cancer
- Facteurs prédictifs de l'adhésion des patients à **l'éducation thérapeutique**

I. RECHERCHE

Mes recherches s'inscrivent dans le champ de **la psychologie de la santé en oncologie et dans les pathologies somatiques chroniques**. L'objectif est de comprendre les processus d'adaptation des patients à la maladie, avec un intérêt particulier pour les relations soignants-soignés comme facteur clef de cette adaptation.

Projets de recherche

- 2019- en cours** **Empathie des Médecins et des Pharmaciens, adhésion thérapeutique et indicateurs d'état de santé (EMPATHIE)**
Sur fonds propres ; début des inclusions en mars 2019.
Co-responsable scientifique avec le Dr Claire Pinçon, MCU Laboratoire de Biomathématiques, Faculté de Pharmacie de Lille et le Dr Axel Descamps, CCU, Faculté de Médecine, Université de Lille.
- 2018- en cours** **Vers une nouvelle conceptualisation de l'empathie : Impact sur les issues de santé du patient. (COMETE)**
Financement de la Ligue contre le Cancer (65 785 €).
Porteur et co-responsable scientifique avec le Pr V. Christophe. Cette étude fait partie de la thèse de Lucie Gehenne dirigée par le Pr V. Christophe et dont j'assure le co-encadrement.
- 2016-en cours** **Efficacité d'une intervention éducative visant à augmenter les Compétences Emotionnelles des patients en rémission d'un cancer œsogastrique ou broncho-pulmonaire : étude pilote randomisée, multicentrique, contrôlée (ÉmoVie-K)**
Financement OncoLille (44 400 €), Santélys (15 000 €) & La Région Hauts-de-France (AAP Recherche clinique dans les établissements de santé, 90 000 euros).
Porteur et responsable scientifique
Investigateur principal : Pr Alexis Cortot, CHRU de Lille
- 2016-en cours** **Participation initiale des patients à un programme d'éducation thérapeutique du patient**
Financement PHRIP 2016 (190 000 €).
Responsable scientifique
Investigatrice principale : Mme Maryline Bourgoïn, CHRU de Lille

- 2016-en cours** **Obésité et Grossesse : Etude des facteurs influençant la participation à un programme associant Activité physique adaptée et conseils Nutritionnels – OGAN**
Financement Conseil Régional et Chercheurs citoyens (93 743,80 euros).
Coordinateur et investigateur principal : Pr Philippe Deruelle, CHRU Lille.
Impliquée dans l'évaluation des aspects psychologiques.
- 2015-en cours** **Programme personnalisé utilisant les nouvelles technologies pour la prise en charge de l'obésité au cours de la grossesse afin d'améliorer les conditions de l'accouchement – ePPOP-ID**
Financement PHRC 2014 (586 619 €).
Coordinateur et investigateur principal : Pr Philippe Deruelle (CHRU Lille).
Créatrice du contenu du site web pour la partie « psychologie » et responsable de l'évaluation des aspects psychologiques
- 2014-2016** **Modérateurs du lien entre empathie médicale et issues positives pour le patient en oncologie – EMP+ SIRIC ONCO Lille - CHRU de Lille – Université de Lille – Université de Leipzig, Allemagne**
Financement SIRIC ONCOLille (10 000 €).
Porteur et responsable scientifique du projet.
- 2013-2015** **Freins et leviers de la coordination et continuité du parcours de santé en cancérologie**
Centre de Référence Régional en Cancérologie C2RC – Université de Lille
Financement de la région et SIRIC ONCOLille.
Responsable scientifique du projet.
- 2010-2012** **Perception par les médecins des besoins et de l'état émotionnel des patients atteints de cancer métastatique**
Postdoctorat – Institut Curie/Université Paris Descartes
Financement INCA SHS 2009.
Sous la direction du Pr Serge Sultan, du Pr Anne Brédart et du Dr Sylvie Dolbeault.
- 2006-2009** **Qualité de vie et développement post-traumatique à long terme d'un cancer du sein.**
Doctorat – Université de Nantes
Financement : allocataire-monitrice
Sous la direction du Pr Agnès Florin et le co-encadrement du Pr Angélique Bonnaud-Antignac ; Mention très honorable avec les Félicitations du Jury.

Publications

Revues à comité de lecture

Le classement indiqué est celui par quartile de Scimago (uniquement pour les revues internationales)

1. Amiri, C., **Lelorain, S.**, Herzog, D., & Gidron, Y. (2019). Daily Hassles, Coping and Well-Being: The Moderating Role of Hemispheric Lateralization. *Neuropsychiatry*, 9(2), 2269–2278. <https://doi.org/10.4172/Neuropsychiatry.1000574>
Q3 in Medicine/Psychiatry and Mental Health
2. **Lelorain, S.**, Moreaux, C., Christophe, V., Weingertner, F., & Bricout H. (2019). Cancer care continuity: a qualitative study on the experiences of healthcare professionals compared to those of patients and family caregivers. *International Journal of Care Coordination*, 22(2), 58-68.
3.Q2 in Medicine/Health Policy
3. **Lelorain, S.**, Bachelet, A., Goncalves, V., Wortel, E., Billes, M., Seillier, M., Bertin, N., Bourgoin, M. Nurses' emotional skills: a major determinant of motivation for patient education. In press in *Journal of Advanced nursing*.
Q1 in Nursing/miscellaneous
4. Untas, A., **Lelorain, S.**, Dany, L., & Koleck, M. Psychologie de la santé et éducation thérapeutique : état des lieux et perspectives. Sous presse dans *Pratiques Psychologiques*.
5. **Lelorain, S.**, Cortot, A., Christophe, V., Pinçon, C., & Gidron, A. (2018). Physician empathy interacts with breaking bad news in predicting lung cancer and pleural mesothelioma patient survival: timing may be crucial. *Journal of Clinical Medicine*, 7(10): 364. <https://doi.org/10.3390/jcm7100364>
Q1 in Medicine/miscellaneous
6. **Lelorain, S.**, Cattan, S., Lordick, F., Mehnert, A., Mariette, C., Christophe, V., & Cortot, A. (2018). In which context is physician empathy associated with cancer patient quality of life? *Patient Education and Counseling*, 101(7):1216-1222. <https://doi.org/10.1016/j.pec.2018.01.023>
Q1 in Medicine/miscellaneous
7. Baudry, A.S., Grynberg, D., Dassonneville, C., **Lelorain, S.**, & Christophe, V. (2018). Sub-dimensions of trait emotional intelligence and health: a critical and systematic review of the literature. *Scandinavian Journal of Psychology*, 59(2) :206-222. DOI: 10.1111/sjop.12424
Q2 in Medicine/miscellaneous
8. Baudry, A., **Lelorain, S.**, Mahieuxe, M., & Christophe, V. (2018). Impact of emotional competence on supportive care needs, anxiety and depression symptoms of cancer patients: a multiple mediation model. *Supportive Care In*

Cancer: Official Journal Of The Multinational Association Of Supportive Care In Cancer, 26(1), 223-230. doi:10.1007/s00520-017-3838-x

Q2 in Oncology

9. **Lelorain, S.**, Bachelet, A., Bertin, N., & Bourgoin, M. (2017). French healthcare professionals' perceived barriers to and motivation for therapeutic patient education: A qualitative study. *Nurs Health Sci.* 19(3):331–339. doi:10.1111/nhs.12350.

Q1 in Nursing/miscellaneous

10. Rey, C., Verdier, E., Fontaine, P. & **Lelorain, S.** (2016). Renforcer l'implication des médecins hospitaliers en éducation thérapeutique : piste pour la formation continue et l'accompagnement d'équipe. *Éducation Thérapeutique du Patient/Therapeutic Patient Education*, 8(1) :10105
DOI: <http://dx.doi.org/10.1051/tpe/2016005>

11. **Lelorain, S.**, Brédart, A., Dolbeault, S., Cano, A. Bonnaud-Antignac, A., Cousson-Gélie, F., & Sultan, S. (2015). How does a physician's accurate understanding of a cancer patient's unmet needs contribute to patient perception of physician empathy? *Patient Education and Counseling.* 98(6):724-41. doi:10.1016/j.pec.2015.03.002

Q1 in Medicine/miscellaneous

12. Gouveia, L., **Lelorain, S.**, Brédart, A., Dolbeault, S., Bonnaud-Antignac, A., Cousson-Gélie, F., & Sultan, S. (2015). Oncologists' perception of depressive symptoms in patients with advanced cancer: accuracy and relational correlates. *BMC Cancer.* 3(1):6. doi: 10.1186/s40359-015-0063-6. eCollection 2015

Q1 in Oncology

13. **Lelorain, S.**, Brédart, A., Dolbeault, S., Cano, A. Bonnaud-Antignac, A., Cousson-Gélie, F., & Sultan, S. (2014). How can we explain physician accuracy in assessing patient distress? A multilevel analysis in patients with advanced cancer. *Patient Education and Counseling.* 94(3), 322-327. doi: 10.1016/j.pec.2013.10.029

Q1 in Medicine/miscellaneous

14. **Lelorain, S.**, Sultan, S., Zenasni, F., Catu-Pinault, A., Jaury, P., Boujut, E., Rigal, L. (2013). Empathic concern and professional characteristics associated with clinical empathy in French general practitioners. *European Journal of General Practice.* 19 (1), 23-8. doi:10.3109/13814788.2012.709842

Q1 in Medicine/Family Practice

15. **Lelorain, S.**, Brédart, A., Dolbeault, S., & Sultan, S. (2012). A systematic review of the associations between empathy measures and patient outcomes in cancer care. *Psycho-Oncology.* 21(12), 1255-64. Doi: 10.1002/pon.2115

Q1 in Oncology

16. Tessier, P., **Lelorain, S.**, & Bonnaud-Antignac, A. (2012). A comparison of the clinical determinants of health-related quality of life and subjective well-being in long term

breast cancer survivors. *European Journal of Cancer Care*, 21(5) :692-700. doi: 10.1111/j.1365-2354.2012.01344

Q2 in Oncology

17. **Lelorain, S.**, Tessier, P., Florin, A., & Bonnaud-Antignac, A. (2012). Posttraumatic growth in long term breast cancer survivors: relation to coping, social support and cognitive processing. *Journal of Health Psychology*, 17(5), 627-639. doi: 10.1177/1359105311427475

Q2 in Applied Psychology

18. **Lelorain, S.**, Tessier, P., Florin, A., & Bonnaud-Antignac, A. (2011). Predicting Mental Quality of Life in Breast Cancer Survivors Using Comparison Participants. *Journal of Psychosocial Oncology*, 29(4), 430-449. Doi: 10.1080/07347332.2011.582635

Q2 in Applied Psychology

19. **Lelorain, S.**, Bonnaud-Antignac, A., & Florin, A. (2010). Long Term Posttraumatic Growth after Breast Cancer: Prevalence, Predictors and Relationships with Psychological Health. *Journal of Clinical Psychology in Medical Settings*, 17(1), 14-22. doi: 10.1007/s10880-009-9183-6

Q2 in Clinical Psychology

Chapitres de livres

1. Deruelle, P., **Lelorain, S.**, & Couturier, E. (à paraître). Les bons réflexes. In P. Deruelle (Ed), *Alimentation de la femme enceinte*. Montrouge : Parresia.
2. **Lelorain, S.**, & Garnier, P-H. (2016). Gestalt-thérapie, Chapitre 6. In A. Untas, C. Bungener et C. Flahault (Eds.), *Interventions psychothérapeutiques dans les maladies chroniques*. Louvain-la-Neuve : De Boeck.
3. **Lelorain, S.**, & Sultan, S. (2012). La communication dans la relation de soin : rôle du psychologue, Chapitre 8. In S. Sultan et I. Varescon (Eds.), *Psychologie de la santé*. Paris : PUF
4. Sultan, S., Christophe, V. & **Lelorain, S.** (2012). Régulation des émotions, stress et maladie, Chapitre 26. In M. Mikolajczak et M. Desseilles (Eds.), *Traité de régulation émotionnelle*. Bruxelles : De Boeck

Conférences invitées scientifiques

Lelorain, S. (Novembre, 2017). Co-construire l'alliance thérapeutique. Conférence plénière présentée au 34^{ème} congrès de la Société Française de Psycho-Oncologie, Cité des Sciences et de l'Industrie, Paris, France.

Lelorain, S. (2012, Octobre). *L'empathie en oncologie*. Conférence invitée pour la 3^{ème} édition du colloque Sciences humaines et Cancérologie, Besançon, France.

Présentations scientifiques avec comités de pairs - colloques internationaux
(uniquement depuis l'après thèse, 2010)

Gidron, Y. & **Lelorain, S.** (2019). Synergism between physicians' empathy, bad news and cancer death: The role of hopelessness and inflammation. **Oral** communication presented at the 33rd European Health Psychology Society (EHPS) conference, Dubrovnik, Croatia.

Lelorain, S., Wilu Wilu, A., d'Almeida, G., Alsberghe, L., Bertin, N., & Bourgoïn, M. (2019, September). Medical empathy and patient health beliefs explain patients' intention to uptake patient education. **Poster** presented at the 33rd European Health Psychology Society (EHPS) conference, Dubrovnik, Croatia.

Gehenne, L., **Lelorain, S.**, FREGAT Working Group, & Christophe, V. (2019). Predicting the severity of surgical complications in oesogastric cancers: what if psychological factors mattered? **Oral** communication presented at the 33rd European Health Psychology Society (EHPS) conference, Dubrovnik, Croatia.

Lelorain, S., Cortot, A., Cattan, S., Lordick, F., Mehnert, A., Marriette, C., Christophe, V. (2017, August). When and for which patients does physician empathy improve cancer patient emotional quality of life? **Oral** communication presented at the 19th world congress of Psycho-Oncology and Psychosocial Academy (IPOS), Berlin, Germany.

Lelorain, S., Cortot, A., Cattan, S., Lordick, F., Mehnert, A., Marriette, C., Christophe, V. (2016, August). How does physician empathy interact with patient emotional skills to predict patient quality of life? **Oral** communication presented at the 30th European Health Psychology Society (EHPS) conference, Aberdeen, Scotland.

Lelorain, S., Pigeyre, M., Couturier, E., Guilbert, E., Deghilage, S., Deruelle, P. (2016, August). Investigation of the health benefits of an internet Personalized Program in Obese Pregnant women. **Poster** presented at the 30th European Health Psychology Society (EHPS) conference, Aberdeen, Scotland.

Pigeyre, M., **Lelorain, S.**, Couturier, E., Guilbert, E., Deghilage, S., Deruelle, P. (2016, May). Electronic-Personalized Program for Obesity During Pregnancy (ePPOP). **Poster** communication presented at the 13th International Congress on Obesity (ICO), Vancouver, Canada.

Lelorain, S., Brédart, A., Dolbeault, S., & Sultan, S. (2014, August). What factors contribute the most to patient-reported physician empathy (PRPE) in advanced cancer patients? **Oral** communication given at the 28th European Health Psychology Society (EHPS) conference, Innsbruck, Austria.

- Lelorain, S.**, Brédart, A., Dolbeault, S., & Sultan, S. (2013, July). Predictors of physicians' empathic accuracy on advanced cancer patients' distress. Interactive **poster** presented at the 27th European Health Psychology Society (EHPS) conference, Bordeaux, France.
- Lelorain, S.**, Brédart, A., Dolbeault, S., & Sultan, S. (2012, August). *Is oncologists' perception of patients' needs related to patient-reported physicians' empathy?* Interactive **poster** presented at the 26th European Health Psychology Society (EHPS) conference, Prague, Czech Republic.
- Lelorain, S.**, Brédart, A., Dolbeault, S., & Sultan, S. (2011, October). *The Ability of Oncologists to Infer the Emotional Distress and Needs of their Advanced Cancer Patients.* **Oral** communication given at the 13th World Congress of the International Psycho-Oncology Society, Antalya, Turkey.
- Lelorain, S.**, Cano, A., Brédart, A., Dolbeault, S., & Sultan, S. (2011, October). *Needs, Priorities, and Concerns of Terminally Ill Cancer Patients: a Literature Review.* **Poster** presented to the 13th World Congress of the International Psycho-Oncology Society, Antalya, Turkey.
- Lelorain, S.**, Florin, A., Tessier, P., & Bonnaud-Antignac, A. (2011, July). *Dimensions and determinants of posttraumatic growth in French women.* **Poster** presented to the 12th European Congress of Psychology, Istanbul, Turkey.
- Lelorain, S.**, Brédart, A., Dolbeault, S., & Sultan, S. (2011, July). *Outcomes of empathy in oncological settings: a review of the literature.* **Poster** presented to the 12th European Congress of Psychology, Istanbul, Turkey.
- Lelorain, S.**, Sultan, S., Rigal, L., Jaury, P., Falcoff, H., Catu-Pinault, A., Boujut, E., & Zenasni, F. (2011, March). *Empathie, sympathie et confusion émotionnelle chez les médecins de famille.* **Poster** présenté au 33^{ème} congrès de la Société Québécoise pour la Recherche en Psychologie, Quebec City, Qc, Canada.

Actes de colloques internationaux (uniquement depuis 2010)

- S. Lelorain**, A. Cortot, F. Lordick, A. Mehnert, S. Cattan, V. Christophe, When and for which patients does physician empathy improve cancer patient emotional quality of life? *Psycho-Oncology*. 26 (2017) 6–6.
- L. Gouveia, **S. Lelorain**, A. Bredart, S. Dolbeault, S. Sultan, W. Burns, Oncologists' Recognition of Depressive Symptoms in Advanced Cancer Patients: What Symptoms do they Accurately Detect and How?, *Psycho-Oncology*. 22 (2013) 222–223.
- L. Gouveia, **S. Lelorain**, A. Bredart, S. Dolbeault, S. Sultan, Oncologists' recognition of depression in advanced cancer patients: What symptoms do they detect and how?, *Psychology & Health*. 28 (2013) 223–223.

S. Lelorain, A. Bredart, S. Dolbeault, S. Sultan, Predictors of physicians' empathic accuracy (EA) on advanced cancer patients' distress, *Psychology & Health*. 28 (2013) 251–251.

S. Lelorain, A. Bredart, S. Dolbeault, S. Sultan, Is oncologists' perception of patients' needs related to perceived empathy?, *Psychology & Health*. 27 (2012) 261–261.

Présentations scientifiques avec comités de pairs - colloques nationaux (uniquement depuis 2010)

Gidron, Y., **Lelorain, S.**, Christophe, V., Lartigau, E., & Cortot, A. (Juin 2018). L'espoir, un modérateur du rôle pronostic de l'inflammation dans le cancer du poumon. Communication orale au 10^{ème} congrès de l'AFPSA (Association Francophone de Psychologie de la Santé), Université de Metz, Metz, France.

Lelorain, S., Bertin, N. & Bourgoïn, M. (Juin 2018). Par quels processus les compétences émotionnelles des soignants impactent-elles leur motivation à l'éducation thérapeutique ? Communication affichée au 10^{ème} congrès de l'AFPSA (Association Francophone de Psychologie de la Santé), Université de Metz, Metz, France.

Lelorain, S. (Décembre 2014). Quelle place pour l'empathie du soignant et l'alliance thérapeutique dans l'éducation thérapeutique du patient ? Communication orale présentée au symposium « L'apport de la psychologie à l'éducation thérapeutique » du 7^{ème} congrès de l'AFPSA (Association Francophone de Psychologie de la Santé), Université de Liège, Liège, Belgique.

Lelorain, S., Brédart, A., Dolbeault, S., & Sultan, S. (Décembre 2012). Modèle prédictif multiniveau du repérage de la détresse des patients en oncologie. Communication affichée au 7^{ème} congrès de l'AFPSA (Association Francophone de Psychologie de la Santé), Université de Lille 3, Lille, France.

Lelorain, S., Bonnaud-Antignac, A., & Florin, A. (Juin 2010). *Le développement post-traumatique à long terme d'un cancer du sein : étude qualitative*. Communication orale présentée au Colloque Sciences humaines et Cancérologie, Université de Franche Comté, Besançon, France.

Lelorain, S., Bonnaud-Antignac, A., Tessier, P., & Florin, A. (Juin 2010). *Etude prédictive de la qualité de vie mentale à long terme d'un cancer du sein*. Communication orale présentée à la Troisième journée doctorale en psychologie de la santé, Université Paul Verlaine, Metz, France.

Valorisation scientifique et ateliers délivrés (depuis 2010)

Les communications liées à des **ateliers** délivrés (communications plus pratiques que théoriques) sont inscrites en gras et soulignées

Lelorain, S. (Septembre, 2019). Qualité de vie : impact du cancer sur le vécu des patients sous immunothérapie. Table rond avec Chloé Prod'Homme et Laurence Vanlemmens lors des 2èmes journées d'Immuno-Oncologie du Nord-Ouest organisées sous l'égide du Cancéropôle Nord-Ouest, Le Touquet, France.

Lelorain, S. (May 2019). How to synthesize research using patient-reported measures in cancer care: meta-analyses principles and issues. **Inserm workshop 255** – Recent Developments in the analysis of patient-reported outcomes and psychometric data in health, Bordeaux, France.

Lelorain, S. & Bourgoin, M. (Avril 2019). Facteurs déterminants de la participation des patients à un programme d'éducation thérapeutique. Journée de Neurologie de Langue Française, Palais des Congrès, Lille Grand Palais, France.

Lelorain, S. (Mars 2019). Impact de l'empathie des soignants sur les patients : données scientifiques. La semaine du cerveau – société des neurosciences, La Plaine Image, Tourcoing, France.

Lelorain, S. (Septembre 2018). Rôles des émotions et des relations soignants-soignés en oncologie. Journée de l'axe 5 du Cancéropôle Nord-Ouest, CHU d'Amiens, Amiens, France.

Lelorain, S. (Décembre 2017). Comment motiver une femme enceinte au changement. Table ronde de la journée scientifique « 1000 jours qui comptent pour la santé », Lille Grand Palais, France.

Lelorain, S., Cortot, A., Cattan, S., Lordick, F., Mehnert, A., Marriette, C., Christophe, V. (Juin 2017). Un autre regard : Empathie et cancer. Communication orale présentée à la journée de Pneumo-Cancérologie des Hauts de France, Ennevelin, France.

Lelorain, S., Cortot, A., Cattan, S., Lordick, F., Mehnert, A., Marriette, C., Christophe, V. (Janvier 2017). Stratégies de régulation émotionnelle en cancérologie : patient & soignant. Communication orale présentée à la 17ème journée lilloise de cancérologie digestive, Lille, France.

Lelorain, S. (Septembre 2016). Statistiques textuelles par Alceste ou Iramuteq. **Atelier délivré au 4ème workshop de la Plateforme Qualité de vie et Cancer** : « Les méthodes qualitatives pour la qualité de vie en oncologie », Maison Européenne des Sciences de l'Homme et de la Société, Lille, France.

Bredart, A., Lemogne, C., & **Lelorain, S.** (Novembre 2015). *Recherche en psycho-oncologie, entre qualitatif et quantitatif*. **Atelier délivré lors du 32ème congrès de la Société Française de Psycho-Oncologie**, Lille Grand Palais, Lille, France.

- Lelorain, S.,** Cortot, A., Cattan, S., & Christophe, V. (Juin 2015). *EMP+ résultats préliminaires*. Communication orale présentée lors de la journée scientifique de l'axe 1, résistance tumorale, du SIRIC ONCOLille, CHRU de Lille, Lille, France.
- Lelorain, S.** (Mars 2015). *L'empathie dans la prise en charge en oncologie*. Communication orale présentée lors du premier forum de cancérologie de la Fédération de Cancérologie du CRHU de Lille, CHRU de Lille, Lille, France.
- Lelorain, S.** (Septembre 2014). *La qualité de vie en psychologie de la santé : état des lieux de la recherche*. Communication orale présentée au second séminaire de formation de la plateforme nationale « Qualité de vie et Cancer » sur « l'Apport de la psychologie et de l'économie de la santé », Faculté des Sciences Pharmaceutiques, Nantes, France.
- Collet, F., Bertin, N., & **Lelorain, S.** (Mars 2014). *Partager nos connaissances, respecter nos compétences*. Communication orale présentée au forum d'échanges de l'Unité de Transversalité en Education du Patient du CHRU de Lille. CHRU de Lille, Lille, France.
- Lelorain, S.,** & Christophe, V. (Novembre 2013). Stratégies de régulation émotionnelle en cancérologie : patients et soignants. Communication orale au cours intensif de cancérologie digestive – FFCD –PRODIGE – BGDO. Lille, France.
- Lelorain, S.,** Brédart, A., Dolbeault, S., & Sultan, S. (Juin 2013). L'empathie en oncologie : modèles multiniveaux. Communication orale au 4^{ème} atelier du groupe de travail Modevaiia (MODélisation de la VARIabilité Intra et inter-individuelle). Camaret sur mer, France.
- Lelorain, S.,** Brédart, A., Dolbeault, S., Cousson-Gélie, F., Bonnaud-Antignac, A., Cano, A., & Sultan, S. (Décembre 2012). Perception des besoins et émotions par les patients atteints de cancers métastatiques et leurs oncologues. Communication orale présentée au séminaire « Mesures subjectives en santé et recherche en psycho-oncologie » du Cancéropôle Ile-de-France, Espace Laroche foucauld, Paris, France.
- Lelorain, S.,** Brédart, A., Dolbeault, S., Cousson-Gélie, F., Bonnaud-Antignac, A., & Sultan, S. (Décembre 2011). *Perception des besoins et émotions des patients atteints de cancers métastatiques et leur oncologue*. Communication orale présentée au Séminaire conjoint Institut Curie – Institut Gustave Roussy – Université Paris Descartes, « Mesures subjectives en santé et recherche en psycho-oncologie », Maison des Associations de Solidarité, Paris, France.
- Lelorain, S.** (Juin 2011). *Coping, qualité de vie et développement post-traumatique. Etude transversale rétrospective à long terme d'un cancer du sein*. Communication orale présentée à la Journée scientifique du Laboratoire de Psychopathologie et Processus de Santé, EA 4057, Université Paris Descartes, Paris, France.
- Lelorain, S.,** Brédart, A., Dolbeault, S., & Sultan, S. (Décembre 2010). *Perception par les oncologues des besoins et de la détresse émotionnelle des patients atteints de cancer avancé*. Communication orale présentée au Séminaire conjoint Institut

Curie – Institut Gustave Roussy - Université Paris Descartes, « Mesures subjectives en santé et recherche en psycho-oncologie », Institut Curie, Paris, France.

II. ENSEIGNEMENT-PEDAGOGIE

Depuis 2012. MCF en psychologie de la santé, Université de Lille.

- Service à temps complet : 192h de cours par an en psychologie de la santé, incluant des enseignements dans le DUEP (Diplôme Universitaire en Education du Patient, voir ci-dessous), à la faculté de médecine de Lille, et dans la Licence professionnelle en Qualité de vie-vieillessement, Qua2vie.
- 2019-2020 : obtention d'une réponse favorable, avec Dr Ariane Martinez, à l'AAP « Transformation Pédagogique » 2019 de l'université de Lille pour la mise en place innovante de jeux de rôles mutualisés entre les étudiants du Master PePS (parcours psychologie de la santé) et les étudiants du Master Arts.
- Encadrements **de 106 étudiants** depuis le début de ma carrière de la Licence au Master.
- Co-encadrement, avec le Pr V. Christophe, de la thèse de Lucie Gehenne depuis octobre 2017 (financement Institut National du Cancer)
- Co-responsable, avec Mélanie Seillier, du DUEP (Diplôme Universitaire en Education du Patient) de la CARSAT Nord-Picardie/Universités de Lille 1, 2, 3, de 2012 à 2018.
- Responsables des UEs suivantes à l'UFR de psychologie : L3 Psychologie de la santé (option mineure), M1 Psychologie de la santé (Champ disciplinaire majeur), M1 Séminaire pré-professionnalisant en santé, M2 Psycho-oncologie, M2 Education Thérapeutique du patient, M2 Soins de support.
- Responsable de l'UE « Dimension psychologique de l'expérience de la maladie » du DUEP (Diplôme Universitaire en Education du Patient) de 2012 à 2018.

III. EXPERIENCES CLINIQUES EN PSYCHOLOGIE DE LA SANTE

2015-2017 Co-animation, au CHRU de Lille, de groupes de patients atteints de diabète (avec Marie-Mai Nguyen, psychologue) et de cancer (avec Gildas d'Almeida, psychologue) pour la mise en place de la recherche EMOVIE.

Depuis mai 2014 Co-animations d'ateliers pratiques de jeux de rôles sur l'alliance thérapeutique et la communication médicale pour des professionnels de santé en oncologie (essentiellement internes et infirmières).

- Avec Sarah Dauchy pour la SFPO (Société Française de Psycho-Oncology) et le laboratoire Lilly (Lille, mai 2014 & juin 2015)
- Avec Anne-Laure Taksin, Didier Mayeur, et la compagnie Arcalande, pour le laboratoire Celgène, (Le Chesnay, novembre 2015).
- Avec le Dr Yannick Le Corre pour le laboratoire Novartis (Angers, décembre 2015).

2009-2010 Psychologue clinicienne en oncologie

Hôpital Nord Laënnec, Service d'oncologie médicale digestive et thoracique – hospitalisation conventionnelle et hôpital de jour, lits identifiés soins palliatifs.

- Soutien psychologique aux patients et familles, et à l'équipe
- Suivi à long terme de patients en rémission
- Travail de liaison avec l'unité mobile et l'unité fixe de soins palliatifs, d'intervision avec les psychologues de ces services.
- Passation de questionnaires de qualité de vie (e.g. SF-36), coping (e.g. Brief Cope), et entretiens cliniques d'évaluation de la dépression (MADRS) à des fins d'aides au diagnostic et de suivi d'évolution des patients.

IV. Formations continues suivies

En statistiques

- **Meta-analysis workshop**
 - 3 jours de formation aux méta-analyses avec le logiciel CMA (Comprehensive Meta-Analysis) délivrée par le Pr Michael Borenstein, du groupe BIOSTAT, Hilton London Kensington, Londres, 7-9 mai 2018.
- **Diplôme Universitaire de Statistique Appliquée sous SAS University Edition de la faculté des Sciences Pharmaceutiques et Biologiques de l'Université de Lille**
 - DU dirigé par le Dr Claire Pinçon, de Novembre 2017 à Mai 2018, Université de Lille, Lille

- Tests d'hypothèses ; modèles de régression avec critère continu, binaire, censuré ; initiation aux analyses longitudinales ; calculs du nombre de sujets nécessaires. Mémoire réalisé sur la prédiction de la survie des patients en oncologie thoracique avec le modèle de Cox : mention TB.
- **Testing for Mediation and Moderation using SPSS PROCESS**
 - Une journée de formation délivrée par le Dr Chris Stride du groupe Falcon Training in conjunction with Figure It Out Training Courses, Birkbeck College, London, le 6 janvier 2017
- **Initiation aux modèles mixtes, de l'ANOVA vers les modèles mixtes**
 - 3 jours de formation délivrés par le Pr Myriam Maumy-Bertrand du groupe Arkésys, Université de Lille, les 5, 6 et 7 décembre 2016
- **Analyse de la variance & régressions**
 - 3 jours de formation CNRS délivrés par le Pr Thierry Anthouard du groupe Arkésys, Université de Lille, le 1^{er}, 2 et 15 octobre 2015
- **Ateliers statistiques Modevaia (MODélisation de la VARIabilité Intra et inter-individuelle)**
 - 3 jours de communications et d'échanges, animés par les Pr Jean-Luc Kop et Yvonnice Noël, Camaret-sur-Mer, 23-25 juin 2013
- **Modèles en équations structurales**
 - Une journée de formation aux modèles en équations structurales avec AMOS, délivrée par le Pr Pierre Vrignaud, à SPSS, La Défense, Paris, le 22 juin 2009

En analyse de données textuelles

- **Alceste**
 - Formation de deux jours, délivrée par la Société Image, Carcassonne, le 26 et 27 septembre 2016
- **NVivo 10**
 - Formation de deux jours au logiciel Nvivo 10 délivrée par Marie-Hélène Paré de la société QSR International Nvivo, Lille, les 18 et 19 décembre 2013
- **NVivo 10**
 - Formation d'une journée au logiciel Nvivo 10 délivrée par Véronique Gosselain de la société RITME formation, Lille, le 27 juin 2013

Autres

- **Formation à l'éducation thérapeutique du patient**

- Formation certifiante de 42h délivrée par l'Unité Transversale d'Education du Patient du CHRU de Lille, Lille, octobre et novembre 2014
- **Anglais : atelier d'écriture ou d'expression orale à l'Université de Lille**
 - 15 heures : mai-juin 2017, « écriture » par Chad Langford
 - 21 heures : mai-juin 2016, « écriture » Chad Langford
 - 17 heures : mai-juin 2014, « oral » par Eva Donohoe
 - 17 heures : mai-juin 2014, « écriture » par Chad Langford

V. RESPONSABILITES COLLECTIVES

- **Depuis septembre 2018, Référente Handicap de l'UFR de psychologie de l'Université de Lille**
- **Depuis septembre 2018, membre du Conseil de l'UFR de psychologie de l'Université de Lille**
- **Depuis juin 2015, membre du Comité d'Expertise Scientifique « Recherche en Sciences Humaines et Sociales » de la Ligue Nationale Contre le Cancer**
- **Membre de la European Health Psychology Society (EHPS) et du CA de l'association Francophone de Psychologie de la Santé (AFPSA)**
- **Réalizations régulières de reviews pour différents journaux et institutions:**
 Journaux (entre autres) : *Psycho-oncology, Patient Education and Counseling, Clinical Psychology & Psychotherapy, Journal of Health Psychology, International Journal of Medical Education, etc. ;*
 Institutions (entre autres) : Institut National du Cancer, Ligue Contre le Cancer, Fonds d'Intégration en Psycho-Oncologie de la Fondation CHU Sainte-Justine au Canada
- **Membre du Comité d'Organisation** du 7^{ème} congrès de l'Association Française de Psychologie de la Santé (AFPSA) de décembre 2012 à Lille
- **Membre du Comité Scientifique** du 10^{ème} congrès de l'AFPSA de juin 2018 à Metz
- **Membre du Jury de thèse** de la Thèse en Sciences de l'Education d'Emilie Ghysens sur la durée de vie des psychologues en soins palliatifs soutenue à Nantes en Janvier 2019
- **Membre de Jury de Comité de Sélection MCF** en psychologie, section 16, à Lille : année 2014 (Poste de Mohamad El Haj), 2015 (Poste de Delphine Grynberg)

- **Membre du Comité de Suivi de Thèse** de la thèse d'Anne-Sophie Baudry (Direction de thèse Pr Véronique Christophe) et de la thèse de Laura Caton (Direction Pr Yori Gidron)

VI. Remerciements

Grâce à leur confiance et leurs compétences, j'ai pu avancer et continue d'avancer sur divers projets, je les en remercie chaleureusement.



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Curriculum Vitae (English)

Sophie Lelorain, Ph.D.

Lecturer-researcher in Health Psychology
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Last updated: 17 April 2020

Quick overview

In chronological order: education and positions

<u>Since 2012</u>	Associate Professor in Health Psychology SCALab UMR CNRS 9193, University of Lille
Sept. 2014 – August 2016	Researcher (50%, in addition to the Associate Professor position) Cross-sectoral Unit of Patient Education, University Hospital of Lille
2010-2012	Postdoctoral Researcher Curie Institute and Paris Descartes University
2009-2010	University Teacher and Research Assistant (full time) Department of Psychology, University of Nantes Clinical psychologist (part time: 20%) Department of digestive and thoracic medical oncology University Hospital of Nantes
2006-2009	PhD in Health Psychology University of Nantes/ French Scientific Group of Nantes called 'La Maison des Sciences de l'Homme'.
2005-2006	Master Degree in Research Department of Psychology, University of Nantes
1999-2004	Master Degree at the Paris School of Clinical Psychologists

Main research topics

- The impact of medical empathy on patients in cancer/palliative care and chronic diseases.
- The role of patients' and professionals' emotional skills in psychological adjustment.
- Predictors of patient uptake of patient education programmes.

I. RESEARCH

My research is related to health psychology in cancer care and chronic diseases. The common goal is to understand how patients cope with the illness, with a focus on doctor-patient relationships as a key factor of patient adjustment.

Research projects

- 2019- in progress** **Physician and pharmacist empathy, treatment adherence and health indicators (EMPATHIE)**
Equity funding; Patient inclusions started in March 2019
Co-scientific director with Dr Claire Pinçon, Associate Professor in Biomathematics laboratory, Lille Faculty of Pharmacy and Dr Axel Descamps, Medical Faculty, University of Lille.
- 2018- in progress** **A new conception of empathy: impact on health patient outcomes (COMETE)**
Funding from the French League Against Cancer (65,785 €).
Co-scientific director with Pr V. Christophe. This study is a part of the PhD work of Lucie Gehenne, supervised by Pr V. Christophe and me.
- 2016-in progress** **Efficacy of an intervention at increasing emotional skills of oesogastric and thoracic cancer patients after treatments: a multicentric randomised controlled pilot study (ÉmoVie-K)**
OncoLille (44,400 €), Santélyls (15,000 €) & Northern France Region Funding (90 000 euros)
Scientific director and co-leader of the project with Dr C. Duprez
Principal Investigator: Pr Alexis Cortot, University Hospital of Lille
- 2016-in progress** **Patient uptake of patient education programmes**
Hospital Programme of Nursing and Paramedical Research (190,000 €)
Scientific director
Principal investigator: Maryline Bourgoïn, University Hospital of Lille
- 2016-in progress** **Obesity and Pregnancy: Predictors of patient participation in a programme combining adapted physical activity and food advices. OGAN**

	<p>Regional Council Funding (93,743 €) Principal investigator and leader: Pr Philippe Deruelle, University Hospital of Lille <u>Scientific director of the assessment of psychological predictors</u></p>
2015-in progress	<p>Electronic-Personalized Program for Obesity in Pregnancy to Improve Delivery, (ePPOP-ID) Hospital Clinical Research Program (586,619 €) Principal investigator and leader: Pr Philippe Deruelle, University Hospital of Lille <u>Author of the Web content for the psychological part designed for patients and director of the assessment of psychological variables.</u></p>
2014-2016	<p>Moderator variables between medical empathy and cancer patient outcomes – EMP+ University of Lille & University of Leipzig Funding from the Integrated Cancer Research Site of Lille (10,000 €) <u>Leader and scientific director</u></p>
2013-2015	<p>Barriers to and development of cancer care continuity Regional Cancer Reference Centre Funding from the Northern Region and the Integrated Cancer Research Site of Lille <u>Scientific director</u></p>
2010-2012	<p>Physician perception of metastatic cancer patients’ needs and emotional state <u>Postdoctoral researcher –Curie Institute and Paris Descartes University</u> Funding from French National Cancer Institute Supervised by Pr Serge Sultan, Pr Anne Brédart and Dr Sylvie Dolbeault</p>
2006-2009	<p>Quality of Life and post-traumatic growth in women long term after the end of treatments <u>PhD researcher – University of Nantes</u> Ministry of Higher Education and Research funding Supervised by Pr Agnès Florin and Pr Angélique Bonnaud-Antignac</p>

Publications

Peer-reviewed journals

Journal ranking is indicated according to Scimago quartiles (indicated for international journals only)

20. Amiri, C., **Lelorain, S.**, Herzog, D., & Gidron, Y. (2019). Daily Hassles, Coping and Well-Being: The Moderating Role of Hemispheric Lateralization. *Neuropsychiatry*, 9(2), 2269–2278. <https://doi.org/10.4172/Neuropsychiatry.1000574>
Q3 in Medicine/Psychiatry and Mental Health
21. **Lelorain, S.**, Moreaux, C., Christophe, V., Weingertner, F., & Bricout H. (2019). Cancer care continuity: a qualitative study on the experiences of healthcare professionals compared to those of patients and family caregivers. *International Journal of Care Coordination*, 22(2), 58-68.
Q2 in Medicine/Health Policy
22. **Lelorain, S.**, Bachelet, A., Goncalves, V., Wortel, E., Billes, M., Seillier, M., Bertin, N., Bourgoin, M. Nurses' emotional skills: a major determinant of motivation for patient education. In press in *Journal of Advanced nursing*.
Q1 in Nursing/miscellaneous
23. Untas, A., **Lelorain, S.**, Dany, L., & Koleck, M. Psychologie de la santé et éducation thérapeutique : état des lieux et perspectives. Sous presse dans *Pratiques Psychologiques*.
24. **Lelorain, S.**, Cortot, A., Christophe, V., Pinçon, C., & Gidron, A. (2018). Physician empathy interacts with breaking bad news in predicting lung cancer and pleural mesothelioma patient survival: timing may be crucial. *Journal of Clinical Medicine*, 7(10): 364. <https://doi.org/10.3390/jcm7100364>
Q1 in Medicine/miscellaneous
25. **Lelorain, S.**, Cattan, S., Lordick, F., Mehnert, A., Mariette, C., Christophe, V., & Cortot, A. (2018). In which context is physician empathy associated with cancer patient quality of life? *Patient Education and Counseling*, 101(7):1216-1222. <https://doi.org/10.1016/j.pec.2018.01.023>
Q1 in Medicine/miscellaneous
26. Baudry, A.S., Grynberg, D., Dassonneville, C., **Lelorain, S.**, & Christophe, V. (2018). Sub-dimensions of trait emotional intelligence and health: a critical and systematic review of the literature. *Scandinavian Journal of Psychology*, 59(2) :206-222. DOI: 10.1111/sjop.12424
Q2 in Medicine/miscellaneous
27. Baudry, A., **Lelorain, S.**, Mahieux, M., & Christophe, V. (2018). Impact of emotional competence on supportive care needs, anxiety and depression symptoms of cancer patients: a multiple mediation model. *Supportive Care In*

Cancer: Official Journal Of The Multinational Association Of Supportive Care In Cancer, 26(1), 223-230. doi:10.1007/s00520-017-3838-x

Q2 in Oncology

28. **Lelorain, S.**, Bachelet, A., Bertin, N., & Bourgoïn, M. (2017). French healthcare professionals' perceived barriers to and motivation for therapeutic patient education: A qualitative study. *Nurs Health Sci.* 19(3):331–339. doi:10.1111/nhs.12350.

Q1 in Nursing/miscellaneous

29. Rey, C., Verdier, E., Fontaine, P. & **Lelorain, S.** (2016). Renforcer l'implication des médecins hospitaliers en éducation thérapeutique : piste pour la formation continue et l'accompagnement d'équipe. *Éducation Thérapeutique du Patient/Therapeutic Patient Education*, 8(1) :10105
DOI: <http://dx.doi.org/10.1051/tpe/2016005>

30. **Lelorain, S.**, Brédart, A., Dolbeault, S., Cano, A. Bonnaud-Antignac, A., Cousson-Gélie, F., & Sultan, S. (2015). How does a physician's accurate understanding of a cancer patient's unmet needs contribute to patient perception of physician empathy? *Patient Education and Counseling.* 98(6):724-41. doi:10.1016/j.pec.2015.03.002

Q1 in Medicine/miscellaneous

31. Gouveia, L., **Lelorain, S.**, Brédart, A., Dolbeault, S., Bonnaud-Antignac, A., Cousson-Gélie, F., & Sultan, S. (2015). Oncologists' perception of depressive symptoms in patients with advanced cancer: accuracy and relational correlates. *BMC Cancer.* 3(1):6. doi: 10.1186/s40359-015-0063-6. eCollection 2015

Q1 in Oncology

32. **Lelorain, S.**, Brédart, A., Dolbeault, S., Cano, A. Bonnaud-Antignac, A., Cousson-Gélie, F., & Sultan, S. (2014). How can we explain physician accuracy in assessing patient distress? A multilevel analysis in patients with advanced cancer. *Patient Education and Counseling.* 94(3), 322-327. doi: 10.1016/j.pec.2013.10.029

Q1 in Medicine/miscellaneous

33. **Lelorain, S.**, Sultan, S., Zenasni, F., Catu-Pinault, A., Jaury, P., Boujut, E., Rigal, L. (2013). Empathic concern and professional characteristics associated with clinical empathy in French general practitioners. *European Journal of General Practice.* 19 (1), 23-8. doi:10.3109/13814788.2012.709842

Q1 in Medicine/Family Practice

34. **Lelorain, S.**, Brédart, A., Dolbeault, S., & Sultan, S. (2012). A systematic review of the associations between empathy measures and patient outcomes in cancer care. *Psycho-Oncology.* 21(12), 1255-64. Doi: 10.1002/pon.2115

Q1 in Oncology

35. Tessier, P., **Lelorain, S.**, & Bonnaud-Antignac, A. (2012). A comparison of the clinical determinants of health-related quality of life and subjective well-being in long term

breast cancer survivors. *European Journal of Cancer Care*, 21(5) :692-700. doi: 10.1111/j.1365-2354.2012.01344

Q2 in Oncology

36. **Lelorain, S.**, Tessier, P., Florin, A., & Bonnaud-Antignac, A. (2012). Posttraumatic growth in long term breast cancer survivors: relation to coping, social support and cognitive processing. *Journal of Health Psychology*, 17(5), 627-639. doi: 10.1177/1359105311427475

Q2 in Applied Psychology

37. **Lelorain, S.**, Tessier, P., Florin, A., & Bonnaud-Antignac, A. (2011). Predicting Mental Quality of Life in Breast Cancer Survivors Using Comparison Participants. *Journal of Psychosocial Oncology*, 29(4), 430-449. Doi: 10.1080/07347332.2011.582635

Q2 in Applied Psychology

38. **Lelorain, S.**, Bonnaud-Antignac, A., & Florin, A. (2010). Long Term Posttraumatic Growth after Breast Cancer: Prevalence, Predictors and Relationships with Psychological Health. *Journal of Clinical Psychology in Medical Settings*, 17(1), 14-22. doi: 10.1007/s10880-009-9183-6

Q2 in Clinical Psychology

Book Chapters

1. Deruelle, P., **Lelorain, S.**, & Couturier, E. (upcoming book). Les bons réflexes [The good strategies]. In P. Deruelle (Ed), *Alimentation de la femme enceinte [Pregnant women dietary habits]*. Montrouge : Parresia.
2. **Lelorain, S.**, & Garnier, P-H. (2016). Gestalt-thérapie [Gastalt therapy], Chapitre 6. In A. Untas, C. Bungener et C. Flahault (Eds.), *Interventions psychothérapeutiques dans les maladies chroniques [Psychotherapeutic interventions in chronic diseases]*. Louvain-la-Neuve : De Boeck.
3. **Lelorain, S.**, & Sultan, S. (2012). La communication dans la relation de soin : rôle du psychologue [Communication in medical care: the role of the psychologist], Chapitre 8. In S. Sultan et I. Varescon (Eds.), *Psychologie de la santé [Health Psychology]*. Paris : PUF
4. Sultan, S., Christophe, V. & **Lelorain, S.** (2012). Régulation des émotions, stress et maladie [Emotion regulation, stress and diseases], Chapitre 26. In M. Mikolajczak et M. Desseilles (Eds.), *Traité de régulation émotionnelle [Emotion regulation handbook]*. Bruxelles : De Boeck

Invited seminars

Lelorain, S. (November, 2017). Co-construire l'alliance thérapeutique. Conférence plénière présentée au 34^{ème} congrès de la Société Française de Psycho-Oncologie, Cité des Sciences et de l'Industrie, Paris, France.

Lelorain, S. (2012, October). *L'empathie en oncologie*. Conférence invitée pour la 3^{ème} édition du colloque Sciences humaines et Cancérologie, Besançon, France.

Communications in international conferences (since the end of my PhD work in 2010)

Gidron, Y. & **Lelorain, S.** (2019). Synergism between physicians' empathy, bad news and cancer death: The role of hopelessness and inflammation. **Oral** communication presented at the 33rd European Health Psychology Society (EHPS) conference, Dubrovnik, Croatia.

Lelorain, S., Wilu Wilu, A., d'Almeida, G., Alsberghe, L., Bertin, N., & Bourgoin, M. (2019, September). Medical empathy and patient health beliefs explain patients' intention to uptake patient education. **Poster** presented at the 33rd European Health Psychology Society (EHPS) conference, Dubrovnik, Croatia.

Gehenne, L., **Lelorain, S.**, FREGAT Working Group, & Christophe, V. (2019). Predicting the severity of surgical complications in oesogastric cancers: what if psychological factors mattered? **Oral** communication presented at the 33rd European Health Psychology Society (EHPS) conference, Dubrovnik, Croatia.

Lelorain, S., Cortot, A., Cattan, S., Lordick, F., Mehnert, A., Marriette, C., Christophe, V. (2017, August). When and for which patients does physician empathy improve cancer patient emotional quality of life? **Oral** communication presented at the 19th world congress of Psycho-Oncology and Psychosocial Academy (IPOS), Berlin, Germany.

Lelorain, S., Cortot, A., Cattan, S., Lordick, F., Mehnert, A., Marriette, C., Christophe, V. (2016, August). How does physician empathy interact with patient emotional skills to predict patient quality of life? **Oral** communication presented at the 30th European Health Psychology Society (EHPS) conference, Aberdeen, Scotland.

Lelorain, S., Pigeyre, M., Couturier, E., Guilbert, E., Deghilage, S., Deruelle, P. (2016, August). Investigation of the health benefits of an internet Personalized Program in Obese Pregnant women. **Poster** presented at the 30th European Health Psychology Society (EHPS) conference, Aberdeen, Scotland.

Pigeyre, M., **Lelorain, S.**, Couturier, E., Guilbert, E., Deghilage, S., Deruelle, P. (2016, May). Electronic-Personalized Program for Obesity During Pregnancy (ePPOP). **Poster**

communication presented at the 13th International Congress on Obesity (ICO), Vancouver, Canada.

Lelorain, S., Brédart, A., Dolbeault, S., & Sultan, S. (2014, August). What factors contribute the most to patient-reported physician empathy (PRPE) in advanced cancer patients? **Oral** communication given at the 28th European Health Psychology Society (EHPS) conference, Innsbruck, Austria.

Lelorain, S., Brédart, A., Dolbeault, S., & Sultan, S. (2013, July). Predictors of physicians' empathic accuracy on advanced cancer patients' distress. Interactive **poster** presented at the 27th European Health Psychology Society (EHPS) conference, Bordeaux, France.

Lelorain, S., Brédart, A., Dolbeault, S., & Sultan, S. (2012, August). *Is oncologists' perception of patients' needs related to patient-reported physicians' empathy?* Interactive **poster** presented at the 26th European Health Psychology Society (EHPS) conference, Prague, Czech Republic.

Lelorain, S., Brédart, A., Dolbeault, S., & Sultan, S. (2011, October). *The Ability of Oncologists to Infer the Emotional Distress and Needs of their Advanced Cancer Patients.* **Oral** communication given at the 13th World Congress of the International Psycho-Oncology Society, Antalya, Turkey.

Lelorain, S., Cano, A., Brédart, A., Dolbeault, S., & Sultan, S. (2011, October). *Needs, Priorities, and Concerns of Terminally Ill Cancer Patients: a Literature Review.* **Poster** presented to the 13th World Congress of the International Psycho-Oncology Society, Antalya, Turkey.

Lelorain, S., Florin, A., Tessier, P., & Bonnaud-Antignac, A. (2011, July). *Dimensions and determinants of posttraumatic growth in French women.* **Poster** presented to the 12th European Congress of Psychology, Istanbul, Turkey.

Lelorain, S., Brédart, A., Dolbeault, S., & Sultan, S. (2011, July). *Outcomes of empathy in oncological settings: a review of the literature.* **Poster** presented to the 12th European Congress of Psychology, Istanbul, Turkey.

Lelorain, S., Sultan, S., Rigal, L., Jaury, P., Falcoff, H., Catu-Pinault, A., Boujut, E., & Zenasni, F. (2011, March). *Empathie, sympathie et confusion émotionnelle chez les médecins de famille.* **Poster** présenté au 33^{ème} congrès de la Société Québécoise pour la Recherche en Psychologie, Quebec City, Qc, Canada.

Conference proceedings (since 2010)

S. Lelorain, A. Cortot, F. Lordick, A. Mehnert, S. Cattan, V. Christophe, When and for which patients does physician empathy improve cancer patient emotional quality of life? *Psycho-Oncology*. 26 (2017) 6–6.

- L. Gouveia, **S. Lelorain**, A. Bredart, S. Dolbeault, S. Sultan, W. Burns, Oncologists' Recognition of Depressive Symptoms in Advanced Cancer Patients: What Symptoms do they Accurately Detect and How?, *Psycho-Oncology*. 22 (2013) 222–223.
- L. Gouveia, **S. Lelorain**, A. Bredart, S. Dolbeault, S. Sultan, Oncologists' recognition of depression in advanced cancer patients: What symptoms do they detect and how?, *Psychology & Health*. 28 (2013) 223–223.
- S. Lelorain**, A. Bredart, S. Dolbeault, S. Sultan, Predictors of physicians' empathic accuracy (EA) on advanced cancer patients' distress, *Psychology & Health*. 28 (2013) 251–251.
- S. Lelorain**, A. Bredart, S. Dolbeault, S. Sultan, Is oncologists' perception of patients' needs related to perceived empathy?, *Psychology & Health*. 27 (2012) 261–261.

Communication in French conferences (since 2010)

- Gidron, Y., **Lelorain, S.**, Christophe, V., Lartigau, E., & Cortot, A. (Juin 2018). L'espoir, un modérateur du rôle pronostic de l'inflammation dans le cancer du poumon. Communication orale au 10ème congrès de l'AFPSA (Association Francophone de Psychologie de la Santé), Université de Metz, Metz, France.
- Lelorain, S.**, Bertin, N. & Bourgoïn, M. (Juin 2018). Par quels processus les compétences émotionnelles des soignants impactent-elles leur motivation à l'éducation thérapeutique ? Communication affichée au 10ème congrès de l'AFPSA (Association Francophone de Psychologie de la Santé), Université de Metz, Metz, France.
- Lelorain, S.** (Décembre 2014). Quelle place pour l'empathie du soignant et l'alliance thérapeutique dans l'éducation thérapeutique du patient ? Communication orale présentée au symposium « L'apport de la psychologie à l'éducation thérapeutique » du 7ème congrès de l'AFPSA (Association Francophone de Psychologie de la Santé), Université de Liège, Liège, Belgique.
- Lelorain, S.**, Brédart, A., Dolbeault, S., & Sultan, S. (Décembre 2012). Modèle prédictif multiniveau du repérage de la détresse des patients en oncologie. Communication affichée au 7ème congrès de l'AFPSA (Association Francophone de Psychologie de la Santé), Université de Lille 3, Lille, France.
- Lelorain, S.**, Bonnaud-Antignac, A., & Florin, A. (Juin 2010). *Le développement post-traumatique à long terme d'un cancer du sein : étude qualitative*. Communication orale présentée au Colloque Sciences humaines et Cancérologie, Université de Franche Comté, Besançon, France.

Lelorain, S., Bonnaud-Antignac, A., Tessier, P., & Florin, A. (Juin 2010). *Etude prédictive de la qualité de vie mentale à long terme d'un cancer du sein*. Communication orale présentée à la Troisième journée doctorale en psychologie de la santé, Université Paul Verlaine, Metz, France.

Scientific promotions and facilitated workshops (since 2010)

Workshops are in bold and underlined.

Lelorain, S. (Septembre, 2019). Qualité de vie : impact du cancer sur le vécu des patients sous immunothérapie. Table ronde avec Chloé Prod'Homme et Laurence Vanlemmens lors des 2èmes journées d'Immuno-Oncologie du Nord-Ouest organisées sous l'égide du Cancéropôle Nord-Ouest, Le Touquet, France.

Lelorain, S. (May 2019). How to synthesize research using patient-reported measures in cancer care: meta-analyses principles and issues. **Inserm workshop 255** – Recent Developments in the analysis of patient-reported outcomes and psychometric data in health, Bordeaux, France.

Lelorain, S. & Bourgoïn, M. (Avril 2019). Facteurs déterminants de la participation des patients à un programme d'éducation thérapeutique. Journée de Neurologie de Langue Française, Palais des Congrès, Lille Grand Palais, France.

Lelorain, S. (Mars 2019). Impact de l'empathie des soignants sur les patients : données scientifiques. La semaine du cerveau – société des neurosciences, La Plaine Image, Tourcoing, France.

Lelorain, S. (Septembre 2018). Rôles des émotions et des relations soignants-soignés en oncologie. Journée de l'axe 5 du Cancéropôle Nord-Ouest, CHU d'Amiens, Amiens, France.

Lelorain, S. (Décembre 2017). Comment motiver une femme enceinte au changement. Table ronde de la journée scientifique « 1000 jours qui comptent pour la santé », Lille Grand Palais, France.

Lelorain, S., Cortot, A., Cattan, S., Lordick, F., Mehnert, A., Marriette, C., Christophe, V. (Juin 2017). Un autre regard : Empathie et cancer. Communication orale présentée à la journée de Pneumo-Cancérologie des Hauts de France, Ennevelin, France.

Lelorain, S., Cortot, A., Cattan, S., Lordick, F., Mehnert, A., Marriette, C., Christophe, V. (Janvier 2017). Stratégies de régulation émotionnelle en cancérologie : patient & soignant. Communication orale présentée à la 17ème journée lilloise de cancérologie digestive, Lille, France.

Lelorain, S. (Septembre 2016). Statistiques textuelles par Alceste ou Iramuteq. **Atelier délivré au 4^{ème} workshop de la Plateforme Qualité de vie et Cancer** : « Les

méthodes qualitatives pour la qualité de vie en oncologie », Maison Européenne des Sciences de l'Homme et de la Société, Lille, France.

Brédart, A., Lemogne, C., & **Lelorain, S.** (Novembre 2015). *Recherche en psycho-oncologie, entre qualitatif et quantitatif. Atelier déliovré lors du 32^{ème} congrès de la Société Française de Psycho-Oncologie*, Lille Grand Palais, Lille, France.

Lelorain, S., Cortot, A., Cattan, S., & Christophe, V. (Juin 2015). *EMP+ résultats préliminaires*. Communication orale présentée lors de la journée scientifique de l'axe 1, résistance tumorale, du SIRIC ONCOLille, CHRU de Lille, Lille, France.

Lelorain, S. (Mars 2015). *L'empathie dans la prise en charge en oncologie*. Communication orale présentée lors du premier forum de cancérologie de la Fédération de Cancérologie du CRHU de Lille, CHRU de Lille, Lille, France.

Lelorain, S. (Septembre 2014). *La qualité de vie en psychologie de la santé : état des lieux de la recherche*. Communication orale présentée au second séminaire de formation de la plateforme nationale « Qualité de vie et Cancer » sur « l'Apport de la psychologie et de l'économie de la santé », Faculté des Sciences Pharmaceutiques, Nantes, France.

Collet, F., Bertin, N., & **Lelorain, S.** (Mars 2014). *Partager nos connaissances, respecter nos compétences*. Communication orale présentée au forum d'échanges de l'Unité de Transversalité en Education du Patient du CHRU de Lille. CHRU de Lille, Lille, France.

Lelorain, S., & Christophe, V. (Novembre 2013). *Stratégies de régulation émotionnelle en cancérologie : patients et soignants*. Communication orale au cours intensif de cancérologie digestive – FFCD –PRODIGE – BGDO. Lille, France.

Lelorain, S., Brédart, A., Dolbeault, S., & Sultan, S. (Juin 2013). *L'empathie en oncologie : modèles multiniveaux*. Communication orale au 4^{ème} atelier du groupe de travail Modevaia (MODélisation de la VAriabilité IntrA et inter-individuelle). Camaret sur mer, France.

Lelorain, S., Brédart, A., Dolbeault, S., Cousson-Gélie, F., Bonnaud-Antignac, A., Cano, A., & Sultan, S. (Décembre 2012). *Perception des besoins et émotions par les patients atteints de cancers métastatiques et leurs oncologues*. Communication orale présentée au séminaire « Mesures subjectives en santé et recherche en psycho-oncologie » du Cancéropôle Ile-de-France, Espace Laroche foucauld, Paris, France.

Lelorain, S., Brédart, A., Dolbeault, S., Cousson-Gélie, F., Bonnaud-Antignac, A., & Sultan, S. (Décembre 2011). *Perception des besoins et émotions des patients atteints de cancers métastatiques et leur oncologue*. Communication orale présentée au Séminaire conjoint Institut Curie – Institut Gustave Roussy – Université Paris Descartes, « Mesures subjectives en santé et recherche en psycho-oncologie », Maison des Associations de Solidarité, Paris, France.

Lelorain, S. (Juin 2011). *Coping, qualité de vie et développement post-traumatique. Etude transversale rétrospective à long terme d'un cancer du sein*. Communication orale

présentée à la Journée scientifique du Laboratoire de Psychopathologie et Processus de Santé, EA 4057, Université Paris Descartes, Paris, France.

Lelorain, S., Brédart, A., Dolbeault, S., & Sultan, S. (Décembre 2010). *Perception par les oncologues des besoins et de la détresse émotionnelle des patients atteints de cancer avancé*. Communication orale présentée au Séminaire conjoint Institut Curie – Institut Gustave Roussy - Université Paris Descartes, « Mesures subjectives en santé et recherche en psycho-oncologie », Institut Curie, Paris, France.

II. TEACHING AND PEDAGOGICAL MANAGEMENT

Since 2012: Associate Professor in Health Psychology, University of Lille

- 192 hours of teaching per year in health psychology (e.g. psycho-oncology, palliative care, patient education, health psychology models, supportive care), including courses in The University Degree of Patient Education, in the medical Faculty of Lille and in a Bachelor Degree of aging-related Quality of Life.
- 2019-2020: In partnership with Dr Ariane Martinez, winning project of the call for proposals entitled 'Pedagogical transformations' of the University of Lille. Our project is an innovative training for students both in psychology and in drama. The whole project is detailed in the part III of the HDR.
- Supervisor of **106 students** at Bachelor and Master level.
- Co-supervisor, with Pr V. Christophe, of a PhD student, Lucie Gehenne, since October 2017 (National Cancer Institute funding).
- Co-director, with Mélanie Seillier, of Patient Education Degree of the University of Lille, from 2012 to 2018.

III. CLINICAL EXPERIENCES IN HEALTH PSYCHOLOGY

2015-2017 **Co-facilitator of diabetic and cancer patient groups** with Marie-Mai Nguyen and Gildas d'Almeida, for EMOVIE research on patient emotional skills.

Since May 2014 **Co-facilitator of medical role-playing sessions for healthcare professionals in cancer care (mostly internists and nurses).**

- With Sarah Dauchy for the French Psycho-Oncology Society and Lilly Laboratory (Lille, May 2014 & June 2015).
- With Anne-Laure Taksin, Didier Mayeur, et Arcalande Society, for Celgène Laboratory, (Le Chesnay, November 2015).
- With Dr Yannick Le Corre for Novartis Laboratory (Angers, December 2015).

2009-2010

Clinical psychologist in cancer care

Department of digestive and thoracic medical oncology, University Hospital of Nantes. In and outpatients, palliative care.

- Psychological support to patients, formal and informal caregivers.
- Long term follow-up of patients after treatments.
- Co-working with the hospital mobile palliative care team and the department of inpatient palliative care.
- Assessment of patient quality of life (e.g. SF-36), coping (e.g. Brief Cope), and psychological distress (MADRS) in order to help diagnoses and to follow-up patients.

IV. Advanced training

In statistics

- **Meta-analysis workshop**
 - 3 days using CMA software (Comprehensive Meta-Analysis), provided by Pr Michael Borenstein, BIOSTAT, Hilton London Kensington, London, May 7-9, 2018.
- **University Degree in Applied Statistics at the Pharmacy Faculty of Lille.**
 - Direction: Dr Claire Pinçon; November 2017 to May 2018, University of Lille.
 - Regressions with continuous, binary and censored outcomes; introduction to longitudinal analyses; computation for the number of required observations. Dissertation on survival prediction of thoracic cancer patients using Cox regressions.
- **Testing for Mediation and Moderation using SPSS PROCESS**
 - One day, provided by Dr Chris Stride, Falcon Training in conjunction with Figure It Out Training Courses, Birkbeck College, London, January 6, 2017.
- **Introduction to mixed models**
 - 3 days, provided by Pr Myriam Maumy-Bertrand, Arkésys, University of Lille; December 5, 6, 7, 2016.
- **Variance analysis and regressions**
 - 3 days, provided by Pr Thierry Anthouard, Arkésys, University of Lille, October 1, 2, 15, 2015.

- **Statistical workshops by 'Modevaiaa' (Inter et intra variability analysis)**
 - 3 days of presentations and exchanges, facilitated by Pr Jean-Luc Kop and Yvonnice Noël, Camaret-sur-Mer, June 23-25, 2013.
- **Structural equation modeling**
 - One day using AMOS software, provided by Pr Pierre Vrignaud, SPSS, La Défense, Paris, June 22, 2009.

In text analysis softwares

- **Alceste**
 - Two days, provided by 'Image' society, Carcassonne, 26 and 27 September, 2016.
- **NVivo 10**
 - Two days, provided by Marie-Hélène Paré, QSR International Nvivo society, Lille, 18, 19 December, 2013.
- **NVivo 10**
 - One day, provided by Véronique Gosselain, RITME society, Lille, 27 June, 2013.

Miscellaneous

- **Patient Education Training**
 - 42 hours, certified training required to legally perform Patient Education in France, provided by the University Hospital of Lille, October & November 2014
- **English: workshop delivered by the University of Lille for writing or oral expression**
 - 15 hours: May-June 2017, « writing » by Chad Langford
 - 21 hours: May-June 2016, « writing » by Chad Langford
 - 17 hours: May-June 2014, « oral » by Eva Donohoe
 - 17 hours: May-June 2014, « writing » par Chad Langford

V. COLLECTIVE RESPONSIBILITIES

- **Since September 2018, point of contact for disabled students in psychology at the University of Lille.**
- **Since 2018, Member of council of department of psychology of the University of Lille**

- **Since June 2015, Member of the human and social sciences research Scientific Committee of the French League Against Cancer.**
- **Member of the European Health Psychology Society (EHPS) and Board Member of the French health-psychology society.**
- **Regular review for various journals and institutions:**
 Journals (among others): *Psycho-oncology*, *Patient Education and Counseling*, *Clinical Psychology & Psychotherapy*, *Journal of Health Psychology*, *International Journal of Medical Education*, etc. ;
 Institutions (among others): French National Cancer Institute, French League Against Cancer, Integration funding in psycho-oncology of the Sainte-Justine University Hospital, Canada.
- **Member of the Organizational Committee for the 7th congress of the French health-psychology Society, December 2012, Lille.**
- **Member of the Organizational Committee for the 10th congress of the French health-psychology Society, June 2018, Metz.**
- **Member of the PhD panel** for the dissertation of Emilie Ghysens on the experiences and challenges of psychologists in palliative settings, Nantes, January 2019.
- **Member of Assistant Professor Committees in psychology** in Lille: 2014 (selected person: Mohamad El Haj), 2015 (Selected person: Delphine Grynberg).
- **Member of PhD monitoring committees** for the PhD of Anne-Sophie Baudry (Supervised by Pr Véronique Christophe) and of Laura Caton (Supervised by Pr Yori Gidron). This committees ensures that the work is well under progress and that there is no problem in the student-director relationships.

VI. Acknowledgements

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Curie Institute, Paris



Pierre-Henri Garnier
University Hospital of Nantes



Véronique Christophe
University of Lille



Pr Alexis Cortot
University Hospital of Lille



Pr Christophe Mariette†
University Hospital of Lille



Pr Florian Lordick
Leipzig Center for cancer
diagnosis, treatment and
research, Germany



Maryline Bourgoïn
University Hospital of Lille