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Framing Body Changes in Patient-Medical Team Conversations during Treatment Trajectories in Surgical Head and Neck Oncology

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Résumé

Les personnes qui subissent une chirurgie pour un cancer de la tête et du cou sont souvent préoccupées par les changements dans l’apparence et les fonctions corporelles causés par le traitement et rapportent des problèmes d’image corporelle, des niveaux plus élevés d’anxiété et une diminution de la qualité de vie. La communication avec les professionnels de la santé peut affecter la façon dont les patients vivent avec ces changements, notamment en raison des différences dans la manière dont les patients et leur équipe médicale perçoivent le traitement et les aspects qu’ils jugent importants à discuter. Toutefois, peu d’études se sont penchées sur la communication entre les patients et leur équipe soignante autour des changements dans l’apparence et les fonctions corporelles lors de consultations cliniques. Cette étude répond à cette question en s’appuyant sur les recherches en oncologie psychosociale et sur les recherches en communication sur le *cadrage.* L’objectif est de mieux comprendre le processus de communication entre les patients et l’équipe interdisciplinaire de chirurgie cervicofaciale autour des changements dans l’apparence et les fonctions corporelles, ainsi que les impacts potentiels de cette communication sur l’expérience des patients au cours de leurs trajectoires de traitement.

Une étude empirique sur la communication entre les patients et l’équipe médicale a été menée dans une clinique d’oncologie de la tête et du cou d’un grand hôpital universitaire au Québec, Canada. Vingt patients ont participé à l’étude pendant six mois et 88 visites pré-chirurgicales et post-chirurgicales ont été observées (totalisant 54 heures de données enregistrées par audio ou vidéo). Des entrevues semi-dirigées ont été réalisées avec les patients avant et après leur chirurgie (n=45), ainsi qu’avec les membres de l’équipe médicale (n=6) à la fin de l’étude.

Tout d’abord, cette étude révèle les *patterns* d’interaction qui caractérisent les visites pré-chirurgicales : comment les changements corporels sont abordés dans les discussions en rapport avec la survie et la guérison, comment les changements corporels sont établis comme étant une préoccupation (ou non), et comment différents membres de l’équipe peuvent jouer des rôles différents pour discuter des changements corporels avec les patients. Deuxièmement, les *patterns* d’interaction qui caractérisent les visites post-chirurgicales sont décrits : comment les changements corporels sont abordés dans les discussions en rapport avec la guérison et le rétablissement physique, comment l’amélioration et le progrès sont mis en évidence dans les consultations, et comment les différences entre les points de vue des patients et des soignants sont résolues dans les interactions. Les données des entrevues complètent les analyses, montrant les impacts positifs et négatifs potentiels de ces *patterns* d’interaction sur l’expérience des patients. Plus précisément, l’analyse révèle comment les préoccupations psychosociales peuvent être mises en arrière-plan dans les interactions cliniques.

Les résultats de l’étude contribuent à la recherche sur la communication patient-soignant en permettant de comprendre comment les préoccupations émergent dans les interactions cliniques et comment les changements dans l’apparence et les fonctions corporelles sont abordés lors des consultations avec différents membres de l’équipe médicale. Ces résultats pourront être utilisés pour développer des programmes de formation pour étudiants et professionnels, afin de favoriser la prestation des soins intégrés répondant aux besoins des patients tant sur le plan physique que psychosocial.

Mots-clés : analyse des interactions, cancer de la tête et du cou, communication patient-soignant, équipes de soins en oncologie, théorie interactionnelle du cadrage.

Abstract

People who undergo surgery for head and neck cancer are often concerned about treatment-related changes in appearance and functional impairments, and report body image difficulties, higher levels of anxiety, and lower quality of life. Communication with health care professionals may impact patients' experience of body changes, notably due to the differences between how patients and their medical team view the treatment and what aspects they find important to discuss. However, relatively little is known about how patients and providers discuss changes in body appearance and functioning during clinical consultations. This study addresses this question by combining insights from psychosocial oncology research with communication research on *framing*. The aim is to better understand the process of communication between surgical patients and the interdisciplinary Head and Neck Surgery team around changes in appearance and function, as well as how patients are experiencing such communication during their treatment trajectories.

An empirical study of patient-medical team communication was conducted at the head and neck oncology outpatient clinic of a large university-affiliated hospital in the province of Quebec, Canada. Twenty patients participated in this study for a period of six months, and 88 pre-surgical and post-surgical visits were observed and audio or video recorded (54 hours of recorded data). Semi-structured interviews were conducted with patients before and after the surgery (n=45), as well as with medical team members (n=6) at the end of the study.

First, this study reveals the communication patterns that characterize pre-surgical visits: how body changes are discussed in relation to survival and cure, how body changes are established as (not) being a matter of concern, and how different team members may play different roles in discussing body changes with patients. Second, the communication patterns that characterize post-surgical visits are described: how body changes are discussed in relation to cure and physical recovery, how improvement and progress are emphasized in consultations, and how differences between patients' and providers' perspectives are resolved in interactions. Interview data complements the analyses, showing the potential positive and negative impacts of these interaction patterns on patients' experience. Specifically, the analyses reveal how psychosocial concerns can be silenced in clinical interactions.

The results of this study contribute to research on patient-health care provider communication by providing insight into how concerns emerge in clinical interactions and how changes in appearance and function are discussed in patients' visits with different medical team members. These results can be used to inform students' and professionals' training by providing guidance on integrated care addressing patients' needs in both the physical and the psychosocial domain.

Keywords: cancer care team, head and neck oncology, interaction analysis, interactional framing theory, patient-provider communication.

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List of Acronyms

The following acronyms are used in transcriptions:

DIET	Dietitian
FCG	Family member (family caregiver)
HNC	Head and neck cancer
MC	Interviewer (Maria Cherba)
NUR	Nurse navigator
PT	Patient
RAD	Radiologist
RES	Resident
SLP	Speech-language pathologist
SUR	Surgeon

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Chapter 1. Introduction

> *“Cela commence par quelques gouttes de sang au creux du mouchoir. Rien de très inquiétant. Les semaines passent. Les saignements sont de plus en plus fréquents, de plus en plus abondants. Au bout de six mois, Mathieu saigne du nez au moindre effort. C’en est devenu insupportable. Il se résigne à consulter un médecin. Déjà, il s’attend au pire; ça le frappe quand même comme une tonne de briques. Il y a bel et bien une bête qui gruge son appendice nasal. Une bête, un crabe. Le cancer. Pour l’écraser, Mathieu a le choix. Un traitement de radiothérapie à très fortes doses – un conflit nucléaire en plein visage qu’il n’a que de 60 % à 70 % de chances de gagner. Ça, ou l’amputation. […] Il opte pour la lame plutôt que pour l’atome. Mais ce n’est pas vraiment un choix. Personne ne choisit de perdre son nez. Un gouffre s’ouvre à ses pieds. Un vertige l’assaille. Il songe à en finir […] Mathieu a peur. De la souffrance et de la mort, bien sûr. Mais du regard des autres, surtout. […] Et puis, Mathieu se ressaisit. Il chasse son angoisse, sa peur et sa colère. Il est prêt pour la bataille nasale.”*

This compelling excerpt from an article recently published in the newspaper *La Presse* (Hachey, 2019) provides insight into the unique challenges that surgical head and neck cancer patients experience during their care trajectory, as they prepare to undergo lifesaving treatments that can significantly alter their appearance and cause functional impairments. “Head and neck cancer” is an umbrella term used to designate cancers starting in the head and neck region. Surgical treatment may involve total or partial removal of organs such as tongue, jaw, nose, voice box, salivary glands, as well as skin, muscles and nerves in the head and neck area. Reconstructive procedures may also be used to replace excised tissue with tissue taken from other parts of the body.

Head and neck cancers are not among the most common types of cancer. In 2016 and 2018, anti-tobacco campaigns by the *Conseil québécois sur le tabac et la santé* featuring images of patients with facial disfigurement caused by surgery for head and neck cancer were described as striking and disturbing in the media. Many people were surprised to learn that smoking causes not only lung cancer, but also cancers of the throat and mouth (CBC News, 2016; La Presse Canadienne, 2018; Radio-Canada, 2018; TVA Nouvelles, 2016, 2018). Patients diagnosed with head and neck cancer may have never heard about these conditions before, which can evoke feelings of stigma and, in Mathieu's words, *la peur du regard des autres*. This emphasizes the importance of attending to the psychological and social aspects of cancer care in this population, which has also been generally recognized in oncology.

Cancer care for the whole patient, a report published in the United States by the Institute of Medicine (2008) highlighted that the psychosocial aspects of cancer can adversely affect patients' health and well-being, and that many patients are reporting high levels of psychosocial needs that are not being met in their care. The authors of the report suggest that "attending to psychosocial needs should be an integral part of quality cancer care" (p. 9), and that health care should be organized in a way which provides psychosocial services to all patients who might need them.

In Canada, the Canadian Association of Psycho-Oncology was founded in the early 1980s with a mission of promoting the importance of psychosocial care in oncology and integrating it in clinical practice (CAPO, 2019). It is estimated that about a third of people diagnosed with cancer "express distress and require specialized psychosocial oncology or supportive care interventions to assist them to cope and manage the burden of illness and achieve improvements in quality of life" (CAPO, 2010, p. 10). These efforts are related to larger initiatives that, since the 1980s, have drawn attention to the limits of the biomedical model of care and proposed a biopsychosocial model (Beach, 2013; see also Engel, 1977; Zook, 1994), which is well summarized in this excerpt by Mol (2006, p. 405):

> [...] good care is not only, or should not only be, oriented toward the body and its physical diseases. Illness, the experience of living with a disease, is more than the disease itself and is not determined by it. Good care includes attending to the lived experience of patients. It encompasses more, and is more difficult, than sustaining health.

While there has been progress in the development of psychosocial services in oncology (for instance, psychologists are members of interdisciplinary teams for several types of cancers, including head and neck cancers), many patients report unmet supportive care needs. Specifically in head and neck oncology, high unmet needs have been identified in the psychological domain (Henry et al., 2014a). While some aspects of head and neck cancer patients' experiences are common in people with other chronic illnesses, others are distinct, particularly the treatment-related visible changes in appearance and functional impairments (Lang et al., 2013). Body image difficulties constitute a critical psychosocial issue for head and neck cancer patients, and especially for patients undergoing surgery who report, for instance, higher levels of anxiety and lower quality of life (Ellis et al., 2019; Fingeret et al., 2012, 2014, 2015; Henry et al., 2014a, 2014b; Lang et al., 2013).

Communication with the medical team is one of the elements that can contribute to head and neck cancer patients' experiences of body changes following surgery (Fingeret et al., 2015; Happ et al., 2004; Henry et al., 2014b; Lang et al., 2013; Parker et al., 2014). While patients rely on the medical team for information provision and support, identifying and responding to patients' concerns about body changes before and after surgery may be challenging, as studies have found differences between how patients and providers view treatment and consequently what they find important to discuss during pre-operative and post-operative consultations (Fang & Heckman, 2016; Fingeret et al., 2014; McNair, 2016; Roscoe et al., 2013). These differences may lead to gaps in information provision and comprehension about potential surgical outcomes (Happ et al., 2004; Parker et al., 2014), such as patients' unrealistic expectations about resuming functioning and “getting back to normal” (Henry et al., 2014b; see also Henry et al., 2016). However, relatively little is known about how patients and providers discuss changes in body appearance and functioning during clinical visits (Fingeret et al., 2014; Konradsen et al., 2009; McNair et al., 2016). More specifically, research needs to examine how medical professionals and patients highlight certain aspects of these changes during clinical consultations (McNair et al., 2016), while paying attention to patients' interactions with different members of their medical team (Arora, 2003; Ha & Longnecker, 2010). In the following section, I will explain how this study aims to answer these questions.

1.1. Study objectives

The purpose of this study is to better understand the process of communication between surgical head and neck cancer patients and their medical team around changes in appearance and functional changes resulting from head and neck cancer and surgery. Specifically, the aim is to understand how different members of the medical team and patients, in their interactions, accentuate specific aspects of changes in appearance and function in the pre-operative and post-operative periods. In addition, this study explores medical team members' perspectives on their communication with patients, as well as how patients experience this communication in the pre-surgical and in the post-surgical period, so that the study results can provide avenues to improve clinical practice.

Drawing on the literature on patient-health care provider communication, and particularly on studies of concern expression and of medical consultations informed by conversation analysis, I conducted an empirical study of patient-medical team communication in a head and neck oncology clinic. I used the concept of *framing* (see Dewulf et al., 2009) to analyze how body changes are discussed during clinical consultations, since it helps account for the emphasis put on certain elements during conversations, as well as for potential differences in the perspectives of different people involved in interactions.

The results of my analyses contribute to the scholarship in the field of patient-health care provider communication (e.g., see Barnes, 2019; Heritage & Maynard, 2006; Pino et al., 2016; Robinson, 2011) and explore avenues to enhance clinical practice. First, this study provides insight into how concerns emerge in patient-provider interactions and shows that the concept of framing can be useful to study how potential differences in patients' and team members' perspectives are manifested and resolved in interactions. Second, this study makes a contribution to research on patient-medical team communication in surgical oncology and shows how changes in appearance and function, which constitute a critical concern for patients, are discussed in medical consultations and with what potential implications for patients' experience. The results of the analyses are useful for medical students' and professionals' education, because they show how important it is to reflect on recurrent communication patterns in their conversations about body changes with patients, on the similarities and differences in how different team members discuss this topic with patients, and on potential outcomes of specific communication practices on patients' experiences. In addition, this study provides insight into how patients express their concerns during medical consultations, and thus could help medical team members to tailor their support to the needs of patients before surgery and in the postoperative and recovery period.

The present study was conducted at the head and neck oncology (surgery) outpatient clinic of a large university-affiliated hospital in the province of Quebec, Canada, between April 2017 and December 2018. Twenty patients having received various head and neck cancer diagnoses and undergoing more or less invasive surgical procedures participated in the study for a period of six months, from their pre-operative appointments at the clinic (if recruitment was possible during that time) to their post-surgical appointments up to six months after the date of the surgery. Patients came to the clinic for scheduled appointments with their surgeons. Other team members (nurse, speech-language pathologist, and dietitian) who worked at the clinic also participated in patients' care and took part in the study. Appointments were video- or audio-recorded (according to participants' preferences) and analyzed using an interactional approach inspired by conversation analysis, with a focus on how patients and providers emphasized specific aspects of body changes during their conversations, how they reacted to each other's actions, and how differences in patients' and providers' perspectives were manifested and resolved in conversations. This analysis of patient-provider interactions was complemented by interviews conducted with patients before and after the surgery, as well as by interviews with medical team members conducted at the end of the study. In the following section, I will present an overview of each of the chapters in this dissertation that follow this first introductory chapter.

1.2. Chapter overview

In Chapter 2, I present studies on the experience of head and neck cancer patients, and in particular on how changes in appearance and function following surgical procedures may affect patients' psychosocial wellbeing (e.g, see Alias & Henry, 2018; Fingeret et al., 2015). I then review the research on how patient-provider communication may impact patients' experience of body changes, focusing on the pre-surgical and post-surgical periods. Based on this literature, I highlight the need for research on patient-provider conversations about body changes, specifically regarding the following aspects: how patients express concerns and how some concerns can be silenced (e.g., see Konradsen et al., 2009; Losi et al., 2019), how patients and providers emphasize different aspects of treatment and recovery in their conversations (e.g., see McNair et al., 2016; Roscoe al., 2013), and how body changes are discussed with different members of the medical team over a longer period of time (e.g., see Arora, 2003; Thorne et al., 2014). Subsequently, I provide an overview of studies on concern expression in the broader field of patient-provider communication, focusing on the interactional perspective on concern expression during medical consultations (e.g., see Pino et al., 2016), as well as more generally on medical consultations as interactional accomplishments (e.g., see Barnes, 2019; Beach, 2015; Heritage & Maynard, 2006; Robinson, 2011).

In Chapter 3, I present the theoretical framework that guided this study. I explain how the concept of *framing*, defined from an interactional perspective (Dewulf et al., 2009), is useful to study patient-provider conversations around body changes and to show how meanings given to body changes are "continuously shaped and reshaped" in interactions (Brummans et al., 2008, p. 28, see also Cornelissen et al., 2014). To develop this framework, I also draw on the notion of *matters of concern* that has been developed by scholars studying the constitutive role of communication (Cooren et al., 2011, 2012, 2015; Vásquez et al., 2017; see also Brummans et al., 2014) to emphasize how concerns emerge in patient-provider communication, and to highlight the relevance of studying naturally occurring conversations by focusing on what participants accomplish in interactions and how they do it. I present two main elements of the concept of framing that guided the analysis of the empirical data: emphasis given to certain aspects of body changes (foregrounding/ backgrounding), and how different participants in the interaction may approach the situation from different perspectives.

In Chapter 4, I explain how I collected and analyzed the empirical data for this study. I first describe the recruitment process and the two methods of data collection (non-participant observation of recorded outpatient consultations and interviews with patients and members of the medical team). I then explain how I used these two types of data in my analysis, and how themes emerging from the analysis of the interviews and interactional patterns identified during the analysis of consultations complemented each other.

The results of the analyses are presented in Chapters 5 and 6, each dedicated to a particular period in the patients' trajectory: the pre-surgical period and the post-surgical period. It should be noted that in this dissertation the word "trajectory" is used in the common sense of the term[1] to refer to different time points in patients' interactions with their medical team, such as diagnostic investigations and diagnosis, pre-surgical period, post-surgical period, and follow-up (e.g., see Alias & Henry, 2018; Thorne et al., 2014). In Chapter 5, I present the communication patterns that characterize patient-team interactions during pre-

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[1] Rather than the concept developed by Corbin and Strauss to describe both the course of illness and the organization of all the work carried out during the course of illness (Corbin & Strauss, 1988; see also Corbin & Strauss, 1993; Grosjean et al., 2004).

surgical visits. This chapter is organized around three themes: how body changes are backgrounded or foregrounded in relation to survival and cure; how body changes are established as (not) being a matter of concern; and how team members play different roles in discussing body changes with patients.

In Chapter 6, dedicated to patient-team communication in the post-surgical period, I first show how body changes are discussed in relation to cure and physical recovery. As in the pre-surgical period, survival and cure remain important concerns for patients and providers. In addition, this chapter shows how improvement and progress are emphasized in consultations as patients are recovering from surgery. While in the pre-surgical period patients and providers anticipate changes in appearance and functional impairments, in the post-surgical period patients are living with their altered body and medical team members are helping them to recover and adjust. In this regard, my analysis shows how differences between patients' and providers' perspectives on body changes are resolved in interactions, and in particular how concerns about appearance can be foregrounded or backgrounded in patients' conversations with different team members. Throughout Chapters 5 and 6, data from patient interviews complements the analyses of interactions, in order to explore possible impacts of these interaction patterns on patient experience.

The last chapter, Chapter 7, is dedicated to the discussion of the results of this study and their implications for research and clinical practice. Specifically, I discuss how the study contributes to the literature on concern expression in medical consultations, as well as to the research on patient-medical team communication in surgical oncology, and how the theoretical framework that was developed for the study can be useful to study patient-provider communication. Furthermore, I show how in-depth analyses of patient-medical team conversations can be used to help health care professionals reflect on their practice, by providing insight into patient-team communication around body changes, a critical concern for head and neck cancer patients. To conclude, I discuss the limitations of this research and propose several avenues for future research.

Chapter 2. Literature Review

In this chapter, I will first talk about the incidence and treatment of head and neck cancer, based on recent statistics in Canada. I will then discuss the psychosocial impacts of changes in appearance and function that many patients experience as a result of treatments affecting important organs in the head and neck area. The evidence on the role of patient-provider communication in patients' experience of body changes will then be presented, highlighting how communication with the medical team can both positively and negatively affect patients' experience. In particular, I will focus on two aspects that were underlined in previous studies – expression of concerns and potential differences in patients' and providers' perspectives, as well as an area that needs further investigation – the actual conversations around body changes between patients and the members of their medical team. Finally, I will provide a general overview of the literature on concern expression and patient-provider interactions in the broader field of health communication, and explain how this literature informed the theoretical framework and the methodological approach of this study.

2.1. Head and neck cancer: Incidence, treatment, and patient experience

The term "head and neck cancer" is used in the literature and in clinical practice to refer to cancers situated in the region of the head and neck, affecting organs such as larynx, pharynx, nose, mouth, jaw, salivary glands, and tongue. Head and neck cancers are often detected in advanced stages III or IV and are considered to have a poor prognosis with five-year survival rates varying from 28% to 67% (Henry et al., 2019). According to the latest report of the Canadian Cancer Society (2019b), cancers of the oral cavity represent 3.3% of new cancer diagnoses in men (and 1.5% in women) with 3,700 (1,600 in women) projected new cases in 2019, and larynx – 0.9% (0.2%) with 980 (190) projected new cases. In addition to these most frequently occurring head and neck cancers, cancers affecting other areas (for example, nasal cavity) are rarer and statistics for them are not always reported (CCS, 2019a). There has been a reduction in laryngeal cancer incidence, likely reflecting the declining smoking rates (CCS, 2019b). In recent years, the number of HPV-associated cancer diagnoses has been increasing in Canada, the most common types of cancers being oropharyngeal and cervical. Oropharyngeal cancers represent approximately 35% of HPV-associated cancers. It is estimated that the increasing incidence of HPV-associated head and neck cancers "may have a significant impact on the health care system and resources" (CCS, 2016, p. 94).

In Canada, as in other countries where the necessary resources are available, head and neck cancers are managed by interdisciplinary teams consisting of surgeons, radiologists, nurses, dentists, dietitians, speech-language pathologists, and other professionals (CCS, 2016; see also Gilbert et al., 2009; Townsend et al., 2017). Treatment may include surgery and/or radiotherapy, with or without adjuvant chemotherapy, and many patients need multimodal treatment (Lehman & Tuinman, 2018). In recent decades, there has been progress in reconstructive surgery and radiotherapy to reduce disfigurement and functional limitations following treatments for head and neck cancer. However, treatments still have significant impacts on the appearance and function of the organs located in the head and neck area that are involved in breathing, speaking, hearing, vision, and eating (Dooks et al., 2012; Henry et al., 2014a, 2014b; Sherman & Shaw, 2018; Wainwright et al., 2007). These changes have been shown to have important impacts on patients' wellbeing and quality of life, which I will describe in the following section.

2.1.1. Psychosocial impacts of changes in appearance and function. While some of the aspects of head and neck cancer patients' experiences are common in people with other serious chronic illnesses, some aspects are distinct, such as treatment-related visible changes in appearance and functional impairments (Lang et al., 2013; Penner, 2009; Ziegler et al., 2004). The visibility and potential social implications of body changes such as changes in the appearance of the face or the altered ability to speak and eat can make them particularly significant to patients and impact their social relationships and their sense of identity (Davidson & Williams, 2019; Henry et al., 2014b; Konradsen et al., 2012; Lehman & Tuinman, 2018). Some research shows that head and neck cancer patients have an increased risk of developing anxiety, depression, and suicidal thoughts (Henry et al., 2018a, 2018b, 2019).

Body image difficulties constitute a critical psychosocial issue for head and neck cancer patients and especially for patients undergoing surgery, who report higher levels of anxiety and lower quality of life (Ellis et al., 2019; Fingeret et al., 2012, 2014, 2015; Henry et al., 2014a, 2014b; Lang et al., 2013; Rodriguez et al., 2019). Surgical procedures may include removal of parts of the jaw, tongue, nose, skin on the face and neck, as well as the lymph nodes in the head and neck area where cancer cells were found. Reconstructive procedures are commonly used to replace tissues (muscle, bone, skin) that were removed from the head and neck area with tissues taken from other parts of the body.

One of the recent developments in the scholarship on body image has been the recognition of "an obvious but oft-neglected fact that body image issues accompany changes in the appearance and functioning of the human body" (Cash & Smolak, 2011, p. 8). The concept of *body image* has been introduced in medical contexts, and in oncology in particular, to study how changes in appearance and functioning resulting from illness and its treatments can affect patients' perceptions and feelings of their bodies, and consequently patients' quality of life (Cash & Smolak, 2011; Lewin et al., 2018; White & Hood, 2011). In oncology, and specifically in head and neck cancer, changes in appearance and body function have been shown to influence patients' psychosocial wellbeing (Alias & Henry, 2018; Rhoten, 2016). Rhoten (2016, p. 1001) identified three ways in which patients' wellbeing may be affected: "(1) self-perception of a change of appearance and displeasure with the change or perceived change in appearance; (2) decline in an area of function; and (3) psychological distress regarding changes in appearance and/or function."

In the context of head and neck cancer surgery, previous studies have shown that patients may develop concerns about body changes in the pre-surgical and in the post-surgical period. In the pre-surgical period, many patients anticipate the impacts of the surgery on their body (Sherman & Shaw, 2018). In the immediate post-surgical period, patients may experience "acute body image changes" as they see and experience the changes that have occurred (Sherman & Shaw, 2018, p. 108; see also Graboyes et al., 2019). As patients continue to recover, these concerns may resolve or persist into the survivorship period after the completion of treatments, in cases where surgery leads to permanent appearance changes or functional impairments (Eades et al., 2009; Sherman & Shaw, 2018). While completing treatment and survival may be patients' primary focus after being diagnosed with a life-threatening illness, concerns such as getting back to a normal life may become more prominent in the survivorship period (Alias & Henry, 2018; Henry et al., 2014b, 2016; Konradsen et al., 2009; Molassiotis & Rogers, 2012; Newell et al., 2004; Rennie et al., 2018;

Semple et al., 2008). While the experience of body changes can vary in both valence and intensity, and while there are many factors that may contribute to it, in the following section I will present one specific component that constitutes the focus of this study – patient-health care provider communication.

2.2. The role of patient-provider communication in head and neck cancer patients' experience of body changes

There is evidence from some recent studies showing that communication with the medical team may have significant impacts on how patients experience body changes resulting from surgery for head and neck cancer. In this section, characteristics of communication during the pre-surgical and the post-surgical periods will be presented, and in particular the challenges of communication around the psychosocial aspects of care.

2.2.1. Pre-surgical period. During the pre-surgical period, studies have highlighted the gaps related to information provision and comprehension (Parker et al., 2014) and the need to enhance communication about potential surgical outcomes between medical professionals and patients/family, as they report the need for more information regarding the extent and the consequences of surgery (Happ et al., 2004; Henry et al., 2014b; see also Ziegler et al., 2004). Losi et al. (2019) showed that head and neck cancer patients tend not to discuss the impacts of surgery on appearance and function in the pre-operative period. Newell et al.'s study (2004) highlighted that patients and family members' needs vary greatly and they need tailored information and support, a need that may not always be satisfied as "patients appear to have been offered a package of information that seemed to relate exclusively to the type of surgery they were facing" (p. 408). Unmet information needs have been reported in many other oncology settings. In head and neck oncology, interventions have been developed to provide head and neck cancer patients with tailored multimedia information, resulting in positive impacts on patient satisfaction and levels of anxiety and depression (D'Souza et al., 2017; see also D'Souza et al., 2013a, 2013b, 2018).

Patient-provider communication during the pre-surgical period (as well as patient-provider communication in general, as will be discussed below) is also marked by differences in patients' and providers' perspectives (Thorne et al., 2013). For example, McNair et al.'s (2016) study of pre-operative consultations in which surgery for esophageal cancer was discussed "demonstrated a discrepancy between desired information and information provided to patients" (p. 246). While "surgeons emphasized surgical techniques and in-hospital risks," "patients wanted information about post-operative recovery, long-term quality of life and survival" (p. 260). The authors also suggest extending the study of information provision and patients' information preferences to other clinical episodes, since "it is likely that surgery was discussed at other times and with other professionals" (p. 263). This study will answer this call to gain insight into patient-medical team communication around body changes resulting from surgery.

Challenges in patient-provider communication during the pre-operative period have been studied in patients undergoing surgery for other types of cancer (e.g., see Venetis et al., 2013, 2015), but it is important to study this topic in head and neck cancer surgical patients in particular, given the visible changes in the appearance and function of critical organs located in the head and neck area that were described above. Furthermore, as surgical head and neck cancer patients report higher levels of anxiety and lower quality of life (Fingeret et al., 2014), the interactions between surgeons and patients have been linked to better adjustment to illness, better quality of life, and increased patient satisfaction (McNair et al., 2016). Specifically, as

Henry et al.'s (2014b) study of head and neck cancer patients' experience has shown, clear information and personalized support from the medical team helped patients to "feel secure in receiving treatment," while "poor communication between the patient and the staff members" and "a lack of transparency" may result in "the patient's sense of not being told the whole truth" or having unrealistic expectations about the surgery (pp. 10-12).

2.2.2. Post-surgical period. In the post-operative period, an important component of patient-provider communication is to identify and address the concerns that patients may have regarding changes in appearance and function. Konradsen et al.'s (2009) study of nurse-patient conversations during the hospital stay following facial surgery showed that disfigurement was silenced in these conversations. While patients expressed concerns about disfigurement during the interviews with the researchers, they did not bring them up with their nurses, mentioning that it was not important to them because of their male gender or older age, that survival was more important than appearance, and that their disfigurement was less apparent compared to other patients on the ward, among other reasons. Nurses also mentioned some reasons to explain this "silencing," such as perceiving disfigurement to be minor, not knowing how to address the subject, and waiting for patients to bring up the topic themselves. A thematic analysis of patient-nurse conversations revealed three ways of "silencing": "minimizing disfigurement, disfigurement is a luxurious problem and another time, another place" (Konradsen et al., 2009, p. 2409). A survey study of breast cancer patients and physicians on communication related to body image revealed similar results and barriers, as many physicians and patients did not initiate these conversations (Cohen et al., 2012). Henselmans et al.'s (2012) study on postoperative needs of esophageal cancer patients reported barriers such as "not wanting to be bothersome" and "the belief that physicians cannot provide an answer or solution anyway and […] that certain topics are not part of the physician's task" (p. 144). The authors highlight the need to find ways to address body changes in patient-provider conversations in order to help patients adjust, and identify patients who might need support. This conclusion, as Konradsen et al. (2009) suggest, may be extended to other "issues that are 'difficult to talk about'" (p. 2415), such as sexuality (e.g., see Horden & Street, 2007; Reese et al., 2017). Some possible implications of patient-provider communication in this context are helping patients develop realistic expectations about the recovery process, alleviating patients' anxieties (Henry et al., 2014b), and encouraging patients to express their concerns (Lang et al., 2013). This last point is particularly important to some authors, as many patients "minimize body image difficulties due to shame, embarrassment or guilt" (Fingeret et al., 2014, p. 635) and "do not disclose their difficulties of coping with treatment side effects to the treatment team" (Lang et al., 2013, p. 2657). In addition, concerns about body image may also be silenced in patients' everyday interactions outside of the hospital (Konradsen et al., 2012).

Lack of communication around psychosocial issues during clinical consultations in oncology has also been shown in other studies. Several studies have demonstrated that these topics are not often discussed (and when they are, they are mostly brought up by patients) and have highlighted the need for physicians to initiate these discussions to make sure that patients' psychosocial concerns are addressed (Arora et al., 2013; Baile & Aaron, 2005; Bonito et al., 2013; Fagerlind et al., 2012; Taylor et al., 2011). There is also evidence that when patients bring up such concerns, they may be "met with silence" and patients may "not offer further elaboration or information that could be useful for doctors when assessing and diagnosing patients' psychosocial history and impacts on their present conditions" (Beach, 2013, p. 9). As Lewis-Smith et al. (2018) explain, it is important to acknowledge that many cancer patients adjust to body changes and do not need psychosocial interventions. The authors thus caution against “overgeneraliz[ing] the negative experiences” (p. 71). Studies have shown that there is no direct relationship between the severity of body changes such as disfigurement and patients’ levels of associated distress. Thus, these studies emphasize the need to evaluate the support needs of all patients, even when the impact of illness and treatment on their body might be considered as ‘minor’ by their medical team (Rumsey et al., 2004; see also Henry et al., 2018c). In that respect, the need to improve patient-provider communication around psychosocial impacts, and for health care providers to be proactive about these conversations, arises in relation to assessing patients’ needs and providing support to those who might need it (Fingeret et al., 2014; Fingeret & Teo, 2018; Reich et al., 2014; Rumsey et al., 2003). Some strategies for providers as to how best approach such conversations have been developed (e.g., see Fingeret, 2010).

Studies that were summarized in this section provide insight into the important role that patient-provider communication may have in how head and neck cancer patients prepare for surgery and how they adjust to its impacts on body appearance and function. At the same time, there is a need for a better understanding of how patients and medical team members discuss this topic in actual clinical consultations, as will be explained in the following section.

2.2.3. Need for further research on patient-provider conversations about body changes.

Based on the nature of surgical treatments for head and neck cancer and the elevated risks of body image concerns in this population, it is important to develop programs to address patients’ support needs (Fingeret et al., 2015). Identifying and responding to patients’ concerns about body changes before and after surgery may be challenging as studies in head and neck oncology have found differences between how patients and providers view the treatment and consequently what they find important to discuss during pre-operative and post-operative consultations (Fang & Heckman, 2016; Fingeret et al., 2014; McNair, 2016; Roscoe et al., 2013). This conclusion is consistent with the conclusions of studies on patient-provider communication that showed that patients and providers “may have different expectations, preferences, and needs during the encounter” (Epstein & Street, 2007, p. 7) and thus privilege some topics during consultations over others (see also Carlson et al., 2005). In order to tailor support to head and neck cancer patients’ needs, studies conducted in the context of head and neck oncology clinics highlight the need for health professionals to develop a trusting relationship with patients and encourage them to voice their concerns (Lang et al., 2013). In addition, these studies have also underlined the need to provide personalized information to patients and their caregivers in a variety of formats and at different time points across the treatment trajectory (Henry et al., 2014b; Parker et al., 2014). At the same time, more research on patient-provider communication in this context is needed, as we know relatively little about the actual patient-medical team interactions around body changes during clinical consultations (Fingeret et al., 2014; Konradsen et al., 2009; McNair et al., 2016). A specific avenue for research was identified in McNair et al.’s (2016) study cited above. In this study, thematic analysis of pre-operative visits and interviews with esophageal cancer patients revealed that patients and providers might emphasize different topics during consultations. The authors suggest that an in-depth analysis of how patients and providers bring up certain topics and influence each other in their conversations will help to better understand the communication process in which certain aspects of surgery and its consequences are emphasized.

Longitudinal studies are also needed to offer insight for intervention development that reflects the process of adjustment to body changes over time (Fingeret et al., 2015; Harcourt &

Rumsey, 2011; Smolak & Cash, 2011; White & Hood, 2011). This has been highlighted in the literature on physicians' interactions with cancer patients, given that patients' needs and preferences change during the cancer care trajectory (Thorne et al., 2009, 2014) and that they meet with different members of oncology interdisciplinary teams over the periods of treatment and recovery (Arora, 2003). While there is an important body of research on communication in health care teams, it mostly covers interactions between different professionals rather than between a patient and different members of their medical team (Real & Poole, 2011), and lack of evidence regarding the latter has been reported in previous reviews (Arora, 2003; Ha & Longnecker, 2010). Arora (2003) explains that this tendency may be due to the fact that research on patient-provider communication originated in the context of primary care and covered situations that did not involve long-term relationships between patients and various professionals (important characteristics of care in the context of oncology and chronic illness). Two studies of communication between patients and different members of their medical team (colorectal cancer and chronic end-stage kidney disease) showed that consultations with different professionals covered distinct aspects of care and reflected professional boundaries (Allen et al., 2015; Carlsson et al., 2013). The authors highlight the need for more holistic care with "at least one member of a care team knowing the patient as a whole person and consistently advocating for that patient" (Allen et al., 2015, p. 53) and "an overlap of certain conversational content" (Carlsson et al., 2013, p. 824) to ensure continuity of care. Studying patients' interactions with different members of their medical team can also help account for the organizational context that "likely influences how physicians work and how they interact with patients," and thus provide insight into how the organization of care within an interdisciplinary team might “affect the process and outcomes of communication in medical consultations” (Real & Street, 2009, p. 65).

Due to evidence from studies showing that patient-provider communication may have significant impacts on how surgical patients experience body changes resulting from surgery, and the limited empirical studies on the actual patient-provider interactions in this context, it is necessary to study in more depth how patients and providers discuss body changes. A close examination of patient-provider interactions could provide insight into three areas that were described in previous studies: how patients express concerns and how some concerns can be silenced, how patients and providers may emphasize different aspects of treatment and recovery, and how body changes may be discussed with different members of the medical team over a longer period of time. Before presenting the theoretical framework that I developed to conceptualize the process of patient-provider communication in the context of pre- and post-surgical consultations in head and neck oncology, I will review some available evidence from studies of patient-provider communication in other contexts. I will focus on concern expression during medical visits, on medical visits as being constructed in patient-provider conversations, and on the impacts of patient-provider communication on patient outcomes.

2.3. Concern expression in patient-health care provider communication

The studies reviewed above have shown that patients do not always disclose their concerns about body changes to the members of their medical team who, in turn, tend not to initiate these conversations. In addition, patients often express their concerns indirectly, by providing cues for informational and emotional support to their care providers who are not always able to observe and address these cues (Beach, 2015; Beach & Dozier, 2015; Beach &

Mandelbaum, 2005; Brandes et al., 2015; Butow et al., 2002; Chapman & Beach, 2019; Levinson et al., 2000; Zimmerman et al., 2007). A review of surgeon-patient communication draws attention to this phenomenon in surgical contexts, as patients' concerns, and especially emotional concerns, are often not explored in conversations (Levinson et al., 2013; see also de Leeuw et al., 2014). Pino and Parry (2019) explain that indirect expression of concerns or "troubles" (Jefferson, 1988) is also common in everyday conversations: "People generally do not introduce their troubles abruptly into conversations; instead, they work their way towards them, or they give clues that there might be a trouble and then report it when their interlocutors ask about it" (Jefferson, 1980, 1985, cited in Pino & Parry, 2019, p. 185). Patients' indirect expression of concerns "challenges doctors to respond to issues that patients may only hint at" (Gill, 1998, cited in Beach & Dozier, 2015, p. 1250). Brandes et al.'s (2015) study investigating why cancer patients may not express their concerns during cancer consultations revealed several barriers related to providers' behavior, such as "providers not responding with empathy, providers not explicitly inviting patients to discuss their concerns and providers not providing patients with the right information to reduce concerns" (p. 320). Another important barrier was related to the organizational environment of the consultations, as patients considered that their "providers do not have time to listen to concerns" (Brandes et al., 2015, p. 320).

In the literature on patients' expressed concerns during medical visits, several definitions of concerns have been employed, ranging from those related specifically to the expression of negative emotions (sometimes referred to as "empathic opportunities") to any patient-initiated statements (including, for example, questions about illness and need for more information) that may often "hide emotional distress, which may emerge when the physician pays adequate attention to such apparently emotionally neutral contents" (Zimmerman et al., 2007, p. 448). Pino et al. (2016), in their study of end-of-life talk during palliative care consultations, showed that concerns can also be defined by looking at interactions between patients and providers. Rather than defining concerns using certain pre-established criteria (such as patient-initiated utterances or expressions of emotion), the authors suggest focusing on uptake, that is, how patients and providers respond to certain utterances by interpreting them as concerns (for example, a provider may offer help, or a patient may insist on what they were saying by repeating it). In other words, patient-initiated actions offer opportunities for further elaboration, and can be constructed as concerns (or not) in patient-provider conversations.

This perspective represents a useful avenue for research. While "there are numerous explanations for why patients' perspectives remain 'unvoiced' [...] less is known about the organization of actual moments where patients make (or attempt to make) their concerns known to doctors" (Beach, 2013, p. 8). Pino et al. (2016) also highlight the importance of considering how patient-initiated statements that are not addressed immediately may be elaborated later during the same visit. In the context of this study, where patients are being cared for by an interdisciplinary team, one can also think about how patient concerns may be addressed by different members of the medical team. I will elaborate on this definition of concerns in Chapter 3, dedicated to the theoretical framework that guided this study. In the following section, in keeping with this definition of concerns as being constructed in patient-provider conversations, I will focus on medical consultations as interactional accomplishments and give a brief overview of the literature that has examined patient-provider encounters from an interactional perspective. This approach provides an analytical framework to study the actual conversations between patients and their medical team around body changes, by focusing on what aspects of body changes are emphasized during consultations and how it is achieved in patient-provider conversations.

2.4. Medical consultations as interactional accomplishments

Since the 1970s, analysis of patient-provider interactions has been developing as a distinct research domain (Heritage & Maynard, 2006). This approach is based on earlier work that defined medical consultations as “essential unit[s] of medical practice” (Spence, 1960, cited in Barnes, 2019, p. 301) and conceptualized them as “social and relational situation[s]” (Barnes, 2019, p. 301). According to this perspective, “communication in medical care is central to both clinical treatment and relationships between professionals and patients and […] poor medical communication will be consequential for relationships and consultation outcomes” (Barnes, 2019, p. 301). Thus, the interest in studying naturally occurring patient-provider interactions recorded during clinical visits was primarily related to medical education, as these studies provided insights into specific practices and how they might be improved (Gill & Roberts, 2013; see also Duggan & Thompson, 2011). Initially developed in primary care contexts, studies of patient-provider interactions now cover multiple clinical settings, including specialty care such as oncology (Barnes, 2019; Beach & Anderson, 2004; Gill & Roberts, 2013). The development of this literature has also been related to the emergence of collaborative models of patient-provider relationships, such as shared decision-making and patient-centered care (Thoër, 2013). Following Parsons’s (1951) work that laid the foundations for a sociological perspective of health (Willis, 2015) and proposed a model based on a paternalistic relationship between a patient and a doctor, these models have been developed to account for patients' participation in their care and the collaborative process through which doctors and patients express and negotiate their perspectives and priorities (Thoër, 2013).

One particular analytic approach that has been used within the literature on patient-provider communication is conversation analysis, which emphasizes that "physician and patient, with various levels of mutual understanding, conflict, cooperation, authority and subordination, jointly construct the medical visit" (Heritage & Maynard, 2006, p. 362). In other words, according to this perspective, patient-provider encounters and their outcomes (for example, a diagnosis, a treatment recommendation, etc.) are interactional co-constructions (Gill & Roberts, 2013). The focus thus shifts from patients' and providers' individual actions and experiences to the dynamics of clinical interactions. For example, to continue with the topic of patient concerns presented above, during patient-provider consultations, "interactional possibilities are created for revealing how patients express their own conditions, and make [them] available for response" (Beach, 2018, p. 1690). Health care providers thus have "opportunities to respond and participate in actions which may or may not affiliate with patients' displayed experiences" (Beach, 2018, p. 1690). In turn, the ways in which patients present their concerns may also be responses to health care providers' actions during medical encounters. For example, White et al. (2013) showed how, in surgical consultations, patients presented their problems in the way requested by the surgeon (see also White & Cartmill, 2016). In other words, patients and providers mutually influence each other as they react and respond to each other's actions (Maynard & Heritage, 2005; Robinson, 2011).

Medical consultations are characterized, according to this approach, by recurrent patterns of interaction that can be identified through in-depth analysis of patients' and providers' conversations during medical visits, through which they "generate the sense and meaning of utterances" (Heritage & Maynard, 2006, p. 363). By focusing on "*what* is being accomplished and *how* it is achieved" (Gill & Roberts, 2013, p. 577), such analysis of patient-provider interactions can reveal distinct communication practices through which activities such as taking a medical history, establishing a diagnosis, suggesting treatment, etc. are accomplished (Heritage & Maynard, 2006, p. 364). In addition, such analysis can reveal "the contributions of all parties to the encounter" as well as "the interactional challenges and dilemmas faced by the participants and how they handle [them]" (Gill & Roberts, 2013, p. 578). For example, Ford et al.'s (2019) study of patient-provider consultations in palliative and end-of-life care showed how, in situations where there was a discrepancy between patients' and providers' perspectives (for example, when patients displayed pessimistic views about their condition), providers' displays of empathy helped bridge the gap.

Based on such qualitative studies, a number of researchers used the interaction patterns identified through in-depth analyses of conversations to conduct quantitative analyses in order to see if specific practices could be associated with specific outcomes. This quantitative approach involves systematic coding of frequencies of different actions with the subsequent evaluation of their outcomes (Heritage & Maynard, 2006; Robinson, 2011). An example of such study is Heritage et al.'s (2007) intervention that showed that primary care physicians' use of the question, "Is there something else (versus anything else) you want to address in the visit today?" had a significant impact on reducing their patients' unmet concerns. Results from such studies have been inconsistent, since the links between communication and outcomes are mostly indirect and can also be related "to the broader context of physiological, personal, and social determinants of health" (Street et al., 2009, p. 296), among other factors. Direct outcomes, according to Street et al. (2009), may be identified when patients feel reassured and comforted as a result of specific behaviors of their health care providers, such as expressions of empathy or explanations of treatment procedures. Street et al. (2009) refer to indirect outcomes to explain how outcomes such as patients' feelings of reassurance may contribute to other outcomes, such as commitment to treatment, which in turn can influence health outcomes.

Although this study adopted a qualitative approach to conversation analysis in patient-provider communication, in order to offer insight into how head and neck cancer patients and the members of their medical team discuss body changes, such quantitative studies further highlight that patient-provider communication during clinical encounters can significantly influence patient experiences. While in-depth analyses of medical encounters inspired by this conversation analysis approach do not allow for claims about the outcomes of interactions and patient satisfaction, they can offer unique insight into potential interactional consequences of particular actions. That is, they can help identify how patients and providers may respond to specific actions during the medical encounter, and thus inform clinical practice (Drew et al., 2001). Further insight into potential impacts of specific communication patterns can be gained by complementing analyses of interactions by interviews with patients (Drew et al., 2001), and I will discuss this approach in the chapter dedicated to methodology. The results from the interview-based studies on the experience of head and neck cancer patients that were presented in the previous sections also provide some insight into the role of patient-provider communication on patients' experience and further support the need to conduct an in-depth study of the actual patient-provider conversations around this topic, to identify specific communication patterns that may inform clinical practice.

2.5. Partial conclusion

In this chapter, I reviewed the literature that informed my research on patient-medical team conversations around body changes during pre- and post-surgical consultations in surgical head and neck oncology. I first presented an overview of research on the experiences of patients undergoing surgery for head and neck cancer and outlined potential impacts of patient-provider communication in this context. In particular, recent research by Fingeret and colleagues (Fingeret et al., 2014, 2015; Fingeret & Teo, 2018) reveals unmet psychosocial concerns related to body changes in this population, and the importance of developing support programs to address them. Moreover, Henry et al.'s (2014b) study provides insight into potential positive and negative impacts of patient-provider communication on patients' experience of changes in appearance and function, such as feeling secure about treatment and developing realistic expectations about the surgery and the recovery process. The work of McNair et al. (2016) and Konradsen et al. (2009) also highlights particular challenges with regard to patient-provider communication in head and neck cancer surgery, and namely possible discrepancies between how patients and providers may view the treatment and the recovery process (that leads them to emphasize different aspects of surgery in their conversations) and the silencing of conversations about body changes (as patients and providers tend not to initiate them). The need to address these challenges is further supported by evidence from studies in other oncological contexts that have drawn attention to the lack of communication around psychosocial issues (Baile & Aaron, 2005; Taylor et al., 2011) and the differences between patients' and providers' perspectives (Epstein & Street, 2007).

I then highlighted the need for further research on the actual patient-provider communication around body changes during clinical encounters (Fingeret et al., 2014;

Konradsen et al., 2009; McNair et al., 2016), and drew on previous studies to identify three particular aspects that may inform clinical practice: how patients express concerns and how some concerns can be silenced, how patients and providers may emphasize different aspects of treatment and recovery, and how body changes may be discussed with different members of the medical team over a longer period of time. I then provided an overview of studies of concern expression in the broader field of patient-provider communication, based on reviews by Zimmerman et al. (2007) and Beach (2013), and specifically highlighted the interactional definition of concerns suggested by Pino et al. (2016). Finally, I provided an overview of the literature examining patient-provider communication in clinical contexts from an interactional perspective, based on reviews by Barnes (2019), Gill and Roberts (2013), and Heritage and Maynard (2006). Based on previous studies that have shown that patients often express concerns indirectly and that it may be challenging for providers to identify and respond to them, I explained that examining how head and neck cancer patients express potential concerns that are constructed as important (or not) in their conversations with the members of their medical team can reveal specific interaction patterns that can inform clinical practice. In the following chapter, I will explain how the concept of framing and an interactional approach to analyzing matters of concern in face-to-face interactions can provide a useful theoretical framework for examining this question.

Chapter 3. Theoretical Framework: Construction of Meaning and Concern Expression in Patient-Provider Interactions as a Process of Framing

In this study, the construction of meaning given to body changes in patient-provider interactions is conceptualized as a process of framing. Drawing on Bateson's (1955) use of the term, Goffman (1974) first defined frames as certain ways of making sense of what is going on in a particular situation. For Goffman (1974), this concept is useful to shed light on "principles of organization which govern events […] and our subjective involvement in them" (p. 11), as we "fit [our] actions" to our "understandings of what it is that is going on" (p. 247). Goffman and Bateson's work on framing laid the groundwork for analyzing the construction of these understandings as "the communicative process through which people foreground and background certain aspects of experience […] to give a coherent account of what is going on that is continuously shaped and reshaped in interactions" (Brummans et al., 2008, p. 28).

In this chapter, I will first outline the various uses of the concepts of frame and framing in extant research following Dewulf et al.'s (2009) model. I will then present the communicative approach to framing in more detail and explain its utility as a theoretical framework to understand the construction of meaning given to body changes in patient-provider interactions during medical visits. More precisely, in the context of this study, the concept of framing is useful because it enables the analysis of situations where multiple actors are involved (patients/family and members of the interdisciplinary team) who may have different perspectives on the subjects that they discuss in their conversations (Dewulf et al., 2009). Several studies have shown that patients and providers may have different perspectives, goals, and needs regarding the illness and its treatment (e.g., see Fingeret et al., 2015; Happ et al., 2004; Schaepe, 2011). This attention to multiple perspectives can be useful in finding ways to improve care by focusing on the roles played by different team members, as they “approach problems and […] see the world through multiple lenses” (Dewulf et al., 2009, p. 185).

Given the scope of this study, this chapter will focus on the concept of framing as used in research in interpersonal and organizational contexts, and will not discuss the use of the concept in political sciences and media studies (see Brummans et al., 2008, p. 27). For example, a large number of framing research studies have focused on news stories, examining how some aspects of events are highlighted (while some are omitted) and made noticeable to the audience, and with what effects (e.g., see reviews by Borah, 2011; Entman, 1993). As Entman (1993) explains, “framing essentially involves *selection* and *salience,*” and has important implications as it may determine “whether most people notice and how they understand and remember a problem, as well as how they evaluate and choose to act upon it” (pp. 52-54). In the field of health communication, researchers have studied mass media coverage of health topics, including incomplete coverage, avoidance, and misrepresentation of certain topics (Kline, 2003), and various intervention studies have been conducted in health care settings to examine the effects of health-related message framing on patient outcomes such as health behaviors and psychological wellbeing (e.g., see Edwards et al., 2001; Gallagher & Updegraff, 2012).

3.1. Cognitive and interactional approaches to framing

In their review of studies of framing in conflict and negotiation research, Dewulf et al. (2009) highlight the distinction between frames as cognitive representations or knowledge structures, and framing as interactional co-construction of meaning (see also Cornelissen & Werner, 2014). In other words, they differentiate between participants' knowledge schemas or their "expectations about people, objects, events and settings in the world" and "alignments being negotiated in particular interaction" (Tannen & Wallat, 1987, p. 207). In addition, they also distinguish between different things that can be framed: issues ("the meanings attached to agenda items, events or problems in the relevant domain or context"), relationships ("the meanings about oneself and one's relationships with a counter-part"), and interactions ("the interpretations that disputants assign to their interaction process") (Dewulf et al., 2009, p. 165).

According to the cognitive-representational perspective, framing is "the way that people experience, interpret, process or represent issues, relationships and interactions" (Dewulf et al., 2009, p. 160). From the analytical point of view, this approach is focused on representation and information processing, on differences in frames between individuals, as well as on how an individual's understanding of a situation may change (p. 164).

According to the interactional perspective, framing is defined as an ongoing process of meaning construction: the meaning of issues, relationships and interactions is co-constructed and negotiated in social interaction (Dewulf et al., 2009, p. 177). The issues discussed are "not objective, a priori agenda items [...] but rather equivocal discussion topics that are named, blamed and claimed as disputants argue about them" (Felstiner et al., 1980, cited in Dewulf et al., 2009, p. 170). The focus of the analysis is on how participants bring forward specific interpretations, and how other participants adjust and react to them, receive and/or challenge them (Dewulf et al., 2009; Putnam & Holmer, 1992). In other words, “interactional framing theory focuses on whether and how framing changes over the course of interaction, as interactants react to each other’s framings” (Dewulf et al., 2009, p. 164). This analytical attention to the ways in which people react to each other (or interact with each other) is one of the principles of conversation analysis that guided the methodological approach for this study.

While previous studies have provided evidence about patients’ and providers’ perspectives on body changes following surgery for head and neck cancer, how these changes are discussed in patient-provider conversations needs further research. This study is mainly focused on the latter. As will be explained in the methods chapter, I used both observations and interviews to better understand the framing process by exploring patients’ and providers’ perspectives on their conversations around consequences of cancer surgery. By considering these two perspectives simultaneously, one can see how “individuals bring their particular cognitive frames to the interaction” and “how previous experiences enter into framing,” while showing how “the cognitive representations that we hold […] are also the result of meanings constructed in previous interactions” (Dewulf et al., 2009, p. 184).

3.2. Using the framing perspective to study face-to-face interactions

Studies of framing within the interactional paradigm have investigated how participants in the interaction jointly frame a subject in a particular way, or give it meaning. In the following paragraphs, I will discuss two defining elements of the concept of framing that can be applied to face-to-face interactions.

3.2.1. Foregrounding/backgrounding. The notion of selection and salience (Entman, 1993) is central to the definition of the concept of framing. Studies that have adopted an interactional approach and have focused on conversation and discourse have conceptualized framing as the process of "the constant oscillation between the foreground and background of a given situation" (Bergeron & Cooren, 2012, p. 123). In other words, "from a communicative perspective, framing refers to talking about a topic or issue in ways that identify a particular domain within that topic, temporarily ignoring other relevant domains" (Drake & Donohue, 1996, p. 303).

In this study, by drawing on the interactional analysis approaches developed in the field of organizational communication (Cooren et al., 2012, 2015; Vásquez et al., 2017), as well as on studies in the field of health communication that show that sometimes patients' concerns can be silenced or absent in their conversation with their health providers (Barry et al., 2001; Brandes et al., 2015; Zimmerman et al., 2007), I suggest that this dynamic between foregrounding and backgrounding also can be talked about in terms of presence/absence or "what appears to *count* or *matter* to interactants in a given situation" and "what does *not* count or matter" (Cooren et al., 2012, p. 298). More specifically, "what matters or does not matter has to do with what materializes (or does not materialize) in an interaction, whether through the form, for instance, of preoccupations, discussions, or activities" (Cooren et al., 2012, p. 299). "What matters" to people in interaction is also related to their particular roles or functions:

> […] specific *preoccupations/concerns/worries/reasons* are supposed to iteratively or repetitively animate the person who enacts [a particular] role or function. Figuratively speaking, it is in these preoccupations/concerns/worries/reasons that consequently express themselves and partly define what issues/problems/questions this person is *speaking to* in his daily activities. Furthermore, acting [in a particular role] also means that one is acting or *speaking for* a variety of principles […] (Cooren et al., 2012, p. 297)

This perspective can be helpful to study matters of concern in the context of patient/provider conversations. As was discussed in the previous chapter, concerns can be conceptualized as interactional constructions. From an interactional perspective, patients' concerns cannot always be identified using pre-defined criteria, but rather by looking at how, in their conversations, providers and patients respond to certain utterances by interpreting them as concerns. This is what Pino et al. (2016) showed in a study of end-of-life talk during palliative care consultations. They investigated "whether doctors themselves observably treat patients' in-consultation talk as containing clues relevant to end-of-life concerns" (p. 14). In other words, they studied how patients and providers engage in talk to elaborate on previously expressed "possible end-of-life considerations." By employing the term "possible considerations," the authors refer to Schegloff's (2006) reflections on "possibles," which I will cite here to further explain the idea of "possible concerns" that will be used in the analysis in this study: "possible understandings" are "accessible graspings of what another has said or done" (pp. 141-155). As participants in interaction engage in talk and pursue their conversation, they display particular understandings of their turns of talk (Schegloff, 2006). Following this perspective, in the methods chapter I will talk about patient-initiated utterances as expressions of possible concerns, and mobilize the framing perspective to show how they can be either emphasized or foregrounded, or not picked up or backgrounded during clinical consultations. The concept of framing thus helps to study how patient concerns are constructed as "important, meaningful, significant or troublesome" (Cooren et al., 2015, p. 376), as something that matters or not (and thus as requiring attention/assistance/empathy or not) in patient-provider conversations.

To finish this section, it is important to specify that the dynamic of foregrounding/ backgrounding, or what appears to matter (or not) should be seen as a continuum. For example, as mentioned previously, patients can express their concerns explicitly or implicitly, and providers can respond to them in more or less direct ways. Two studies, one not specific to health-care contexts and one on treatment recommendations, can further illustrate this idea. Kendrick & Drew (2016) studied "how help is sought and volunteered in ordinary face-to-face interactions" (p. 15) and developed a set of categories "organized as a continuum, from explicit requests, to practices that elicit offers, to anticipations of need" (p. 1). Stivers & Barnes (2018) studied treatment recommendations and showed that the strength of the physicians' endorsement of the medication can vary from strong ("the recommendation is treated as a necessary or as very important") to weak-moderate ("the recommendation is treated as ranging from likely to improve the patient's health to of only marginal value to the patient"), and patient uptake of the recommendation can vary from none, to acknowledgment, to explicit acceptance/resistance (p. 133). During the analysis, this means to pay attention to different degrees of explicitness/intensity while examining how body changes are being constructed as matters of concern (or not) in patient-provider conversations.

3.2.2. "Doing differences." As "any particular event, situation or issue can be understood and represented in very different ways, by approaching it from different perspectives," differences in framing can emerge during conversations (Dewulf & Bouwen, 2012, p. 169). To deal with these differences, interaction participants put in place different strategies of "doing differences" (Dewulf & Bouwen, 2012, p. 168), which is another element of the definition of framing from the interactional perspective. In this section, I will focus on this element specifically in the context of patient-provider communication.

Patient-provider interactions during clinical consultations are characterized by differences between the patients' and providers' roles, as well as their knowledge base and experience. As mentioned before, there is research about patients' and providers' perspectives in different contexts, and how misalignments between these perspectives can affect patient care, as patients' needs may remain unmet. Here are some examples to illustrate these misalignments and their potential impacts:

> […] when a doctor asks a patient who visits a hospital: "What brings you here?", he would like to hear about the patient's complaints. A foreign patient may, however, wrongly interpret this question as the doctor wanting to know how the patient has arrived in the hospital (e.g. by which means of transport). If a doctor recommends a patient "You might want to rest for a few days," the patient may understand this as a potential development of his condition rather than a recommendation. These instances of miscommunication are sometimes referred to as "misalignments in frames." Frame differences between participants may surface in the conversation, but they may as well pass by unnoticed. In cases where a misalignment in frames does not alter the outcome of the consultation, it may still result in protracted consultation time. (Cox & Li, 2019, p. 11)

From the interactional perspective, the focus of the analysis is on how these differences are manifested and resolved in communication. Tannen and Wallat (1987) for instance studied pediatric consultations and showed that conversations between mothers' and physicians' could be understood as resulting from different knowledge schemas. Mismatches between mothers' and physicians' perspectives (for example, on what counts as adequate reassurance) encouraged mothers to ask questions, and in response physicians switched between three interactive frames: consultation with the mother, examining the child, and managing the interaction as a social encounter (Tannen & Wallat, 1987).

A classic study that theorized the differences between the doctor's and the patient's perspectives is Mishler's (1984) analysis of patient-doctor conversations in primary care. He characterized these conversations as ongoing negotiations between what he called "the voice of medicine" and "the voice of the lifeworld," "representing, respectively, the technical-scientific assumptions of medicine and the natural attitude of everyday life" (Mishler, 1984, p. 14). Cox and Li (2019, pp. 12-13) provide a summary of Mishler's conclusions:

> […] the "voice of the lifeworld" frequently tries to interrupt the dominant "voice of medicine," for example when a patient tries to bring up additional personal concerns which may or may not be related to the problem for which he is seeing the doctor. Faced with such interruptions, doctors can react in different ways: either by opening discourse to the "voice of the lifeworld"; or by keeping discourse closed, suppressing the voice of the lifeworld, and re-establishing dominance of the "voice of medicine." Mishler felt that doctors should pay more attention to the patient's voice of the lifeworld in the medical consultation.

Subsequent studies have examined how this negotiation unfolds in patient-provider interactions and have further nuanced this model. For example, Barry et al.'s (2001) analysis of medical consultations in general practice identified four communication patterns: 1) *strictly medicine*, when both doctors' and patients' actions were situated in the medical register (this was mostly observed in consultations for acute single problems); 2) *mutual lifeworld*, where both doctors and patients used the voice of the lifeworld (this mostly occurred with patients presenting with psychological problems); 3) *lifeworld ignored* or 4) *lifeworld blocked* by doctors' use of the voice of medicine (this mostly occurred with patients presenting with chronic conditions). Barry et al. (2001) showed how doctors can change their communication strategies depending on the patient and how these four communication patterns can have an impact on the outcomes of the consultation:

> Our analysis has shown that the doctors [...] seemed to switch their communication strategy depending on whether they perceived the patient to be presenting with physical or psychological problems. Where they employed the Strictly Medicine discourse for acute physical problems this appeared to be a successful strategy. As long as there were not hidden concerns, patients did not suffer from exclusion of the lifeworld, and outcomes of the consultation were good. […] The real problems seem to lie in the consultations where patients were consulting about chronic physical problems. To patients these conditions were a lifeworld issue. However, the doctors

> seemed to see them as a physical issue requiring the voice of medicine, and the blocking or ignoring of the voice of the lifeworld as a nuisance or an inconvenience. (Barry et al., 2001, p. 504)

Similarly to Misher, the authors highlight the importance of responding to patients' "lifeworld" concerns: "if doctors could be sensitised to the importance of dealing with the concerns of the lifeworld for patients with chronic physical conditions as well as psychological conditions, it might be possible to obtain better care for patients" (Barry et al., 2001, p. 487), which is also in keeping with the conclusions of psychosocial studies in oncology that highlight the importance of assessing and addressing patients' psychosocial concerns.

Finally, the interactional approach to framing also focuses on how what is foregrounded or backgrounded may change during the course of interactions, and how the same people might define issues differently at different times, as they react and adjust to each other. According to this perspective, framing changes lie in the interaction rather than in the individual's points of view (Dewulf & Bouwen, 2012, p. 170). During the analysis of interactional data, I focused on how patients' concerns may be emphasized or backgrounded at different times during the visit, but also at different times during patients' care trajectory as they meet with different members of their medical team.

The process of "doing differences" can also be seen through the lens of legitimacy and authority, as patient-provider conversations are characterized by asymmetry. This asymmetry is an important area of study in the field of patient-provider communication (Barnes, 2019; Gill & Roberts, 2013), and can be understood in terms of the dominance of the biomedical frame in patient-provider interactions:

> […] in many instances, doctors have been found to dominate their patients – for example, by assuming and asserting rights over the management of turns and topics, or by speaking from a more technical, and so apparently superior, knowledge-base (see Drew

> and Heritage, 1992, for a recent overview). Doctors' talk has also been shown to operate within a biomedical 'frame' (in the general sense of Goffman, 1974), reflecting the institutional position from which they conventionally speak, and, again, the priorities they appear to impose on their patients during consultations. This has been contrasted with a socio-relational frame within which a broader agenda of issues, and indeed broader definitions of health and health-care, might be established. (Coupland et al., 1994, p. 90)

Adopting an interactional approach, the authors argue that this asymmetry is interactionally achieved as multiple tasks and goals are being pursued in medical encounters, and thus to understand it attention should be paid to "how interactants achieve a blending of diverse priorities" and how they "manage […] relational and medical frames" (Coupland et al., 1994, p. 92). Specifically, as Chapman and Beach (2019) observed, "interactional asymmetries" may be "enacted through the recurrent tendency of doctors not to actively align with patients' lifeworld disclosures" or to treat certain patient concerns as "not meriting further discussion" (p. 10).

Questions of legitimacy are important to consider when studying how patients express concerns during medical visits and how providers address these concerns. Patients may be ashamed of bringing up certain topics (for example, issues related to appearance and body image can be stigmatized), or feel that they might waste their providers' time by asking questions in the context of a busy clinic (Brandes et al., 2015, pp. 319-320). In the same way, as this study will show, providers may feel that it is not within their role (in the context of an interdisciplinary team) to bring up certain subjects with patients.

The general question that can be asked here is, "How do some things end up mattering more than others"? (Vásquez et al., 2017) How do some matters of concern brought up during clinical visits end up influencing the course of action (for example, in terms of decision-making, suggesting help/treatment, etc.), how do some of them become "collective concerns" (that is to say, that they become important both to the patient and to the doctor), and how are some of them being foregrounded or not taken up? In their study of strategy meetings, Vásquez et al. (2017) distinguished between "matters of concern" and "matters of authority" (that is, "authoring or dictating the course of action that will eventually be followed by the organization") (Vásquez et al., 2017, p. 419). While I did not retain this distinction for the purpose of this study focused on patient concerns, these questions helped guide my analysis by providing methodological tools to identify what is being foregrounded and backrounded in conversations. For example, my analysis will show how specific aspects of body changes are taken into account (or not) as elements of decision-making in patient-provider conversations about treatment options.

3.2.3. Empirical markers of framing. What are the empirical markers of foregrounding/backgrounding, or, in other words, how is it possible to identify matters of concern/interest and what does not count or matter in face-to-face interactions? In this section, I will summarize a number of empirical markers that were used in the studies cited in this chapter, and discuss them in the context of patient-provider communication. In the following chapter dedicated to methods, I will describe the specific markers that I identified during the analysis of patient-provider conversations recorded for this study, using the elements summarized below as a starting point.

As discussed above, one of the ways to identify patient concerns is to look at patient-initiated actions during medical encounters. Patient-initiated topics could then be further emphasized when providers (as well as patients, in subsequent turns of talk) pick up on what is said (for example, by asking further questions, by pursuing a topic), and inversely –

backgrounded when there is a lack of take up or change of topic. Repetition (Dewulf et al., 2004) is a marker that helps identify recurrent and persistent concerns.

Specific aspects of a situation can be accentuated or downplayed through specific language choices (Dewulf et al., 2004; Drake & Donohue, 1996). For example, the use of the conditional form or the definite form ("we can see if the community is interested" versus "we will concretize initiatives" [Dewulf et al., 2004, p. 187]), and labels such as "important," "pressing," etc. that participants may use while "discussing what they think should be the priority in this situation" (Bergeron & Cooren, 2012, p. 125). Another marker of foregrounding is to provide arguments, refer to important facts or principles (for example, in the context of a life-threatening illness such as cancer, one can think about survival as an important concern), or speak on behalf of one's profession (such as for example, a cancer surgeon, or a cancer patient) or organization (the treating team or the hospital) to explain or justify what is being said (Cooren et al., 2015, p. 368), to lend weight to one's position and mark the authority and legitimacy of one's viewpoint (Bergeron & Cooren, 2012, pp. 127, 134).

As mentioned above, one of the goals of framing analysis is to describe how "different parties may engage in issue framing in different ways" (Dewulf et al., 2009, p. 170) and how these differences are resolved in interactions. Differences in patients' and providers' perspectives may be revealed when they disagree, question or challenge what is being said (Dewulf et al., 2009, p. 170). Harmony of perspectives can be found in expressions of agreement, explicit or implicit; for example, patients' silence, or patients' listening to the doctor without interruptions (Tannen & Wallat, 1987, p. 211).

In addition to language use, certain aspects of a situation can also be emphasized through movement and gestures, expressed emotions, material surroundings and material objects (Cornelissen et al., 2014, see also Vásquez et al., 2017), such as specific tools and visual materials used during clinical consultations, and the physical organization of the consultation rooms. In the context of this study, the patient's body affected by illness and surgery (which can significantly alter a patient's appearance) is also important to consider. Patient concerns and the stories that patients tell during medical visits are not simply being told *about* the body and illness, but also expressed *through* the body affected by illness (Frank, 1997/2013). For example, as will be described in the following chapters, a large tumor on a patient's face can accentuate the patient's negative experience of living with illness and emphasize the urgency of extensive surgery.

3.3. Research questions

Drawing on this theoretical framework, and with the goal of using the study results to improve patient care, I investigate two research questions in this study of communication between head and neck cancer (HNC) patients and their medical team around changes in body appearance and functioning following surgery:

RQ1: How are changes in body appearance and functioning resulting from HNC and surgery framed in interactions between HNC surgical patients (and their family caregivers) and the Otolaryngology – Head and Neck Surgery interdisciplinary team (physicians, dietitian, nurse, and speech-language pathologist) during the treatment trajectory, from the pre-surgical period to the post-surgical follow-up period?

RQ2: How do these different ways of framing contribute to patients' experience of body changes resulting from HNC and surgery during the treatment trajectory?

3.4. Partial conclusion

In this chapter, I defined the concept of framing from an interactional perspective and explained its utility to study patient-provider conversations in clinical contexts. Central to the definition of framing are the notions of selection/salience, presence/absence, mattering/not mattering. Some authors commonly refer to this as a process of foregrounding/backgrounding of specific aspects of a given situation in interactions, as people bring up certain topics and react to each other's actions. In the context of patient-provider conversations, this element of framing is useful for examining how patients express potential concerns and how providers address these concerns. A second element of framing is that people involved in an interaction can foreground different aspects of the situation that matter most to them. From an interactional perspective, the focus of the analysis is on how these differences are expressed and resolved in interactions. This element of framing is helpful for investigating patient-provider communication, which is characterized by the presence of multiple goals, needs and concerns of biomedical and psycho-social order, and characterized in the context of oncology care by the fact that patients are cared for by an interdisciplinary team. Consequently, I intend to study how body changes are framed in interactions between surgical head and neck oncology patients and the members of their medical team. In the next chapter, I will describe the data collection methods and the analysis techniques that were used to answer these research questions.

Chapter 4. Methods

To gain a comprehensive understanding of how body changes were discussed during clinical consultations, I conducted a qualitative study informed by interaction analysis. In this chapter, after describing the clinical setting in which the study was conducted, I will present the recruitment process and the participant characteristics. Then, the collection and the analysis of two types of data will be described: interaction analysis of outpatient consultations and thematic analysis of the interviews with the patients and the members of the medical team. I will describe how the concept of framing was operationalized, that is, what empirical markers were identified and used during the analysis. I will also discuss how analyses of interactions and interviews complemented and informed each other, as well as the advantages and the limitations of this methodological approach. Finally, research ethics considerations will be discussed throughout the chapter. This study was approved by *le Comité d'éthique de la recherche en arts et en sciences (CÉRAS) de l'Universitué de Montréal* as well as the research ethics committee of the hospital where the study was conducted.

4.1. Description of the research setting

This study was conducted at the Head and Neck Surgery clinic of the Oncology Department of a large university-affiliated hospital in the province of Quebec, Canada. The interdisciplinary team members that are involved in weekly outpatient clinics are three surgeons, a radiologist, a nurse navigator (whose role is to coordinate patients' care), a dietitian, and a speech-language pathologist. A psychologist is also integrated in the team; she does not see patients at the outpatient clinic, but works closely with the nurse navigator to offer psychological support to patients who need it. In addition, medical students and resident physicians are involved in the clinics. In the larger context of the hospital, patients are also followed by a number of other professionals, including dentists, medical oncologists, social workers, physiotherapists, clinic coordinators and administrative support workers. In addition, a patient buddy system and a support group are in place for patients undergoing laryngectomy (removal of the voice box). Patients also have access to psychosocial support via a non-profit organization working closely with the hospital and offering various activities and support resources in the community for cancer patients and their families.

After being diagnosed with cancer, patients are scheduled for a second meeting with their surgeons to discuss treatment options. Before meeting with the patient, the members of the medical team discuss the case as a group and identify a preferred treatment option during a weekly tumor board meeting. If the patient agrees to have surgery, they sign the consent form and the clinic coordinators schedule a surgery date for the patient. Sometimes patients come in for another appointment to ask additional questions about the surgery, but usually the next time they see their surgeons is the day of the surgery. After the surgery, patients stay at the hospital (the length of the stay varies depending on the type of surgery), where they are regularly followed up by their treating team. After being discharged from the hospital, patients come for follow-ups at the outpatient clinic. The frequency of consultations depends on the surgery, but usually patients come weekly or biweekly shortly after the surgery, and then less frequently – monthly, every two months, every six months, etc. One of the important consultations after the surgery is the pathology appointment, where patients learn if their cancer was completely removed and if they need further treatment. In addition to their scheduled appointments at the Head and Neck Surgery clinic, patients who need radiation therapy or chemotherapy are also regularly coming to the hospital for their treatments, as well as for other appointments that they might need (blood tests, scans, etc.).

At the Head and Neck Surgery clinic where this study was conducted, outpatient clinics take place twice a week. Patients come in for their appointment with their surgeons at a particular time, and they are also seen by other team members (dietitian, speech-language pathologist, radiologist, nurse) if needed. The speech-language pathologist also sometimes schedules specific appointments for certain patients who need help with speaking and swallowing (for example, all the patients undergoing a laryngectomy are meeting with her prior to the surgery to learn about changes in speaking and swallowing and the different options that are available to resume these functions after the surgery). At the beginning of their appointment, patients are often seen by a resident physician (sometimes accompanied by a student) who takes the patient's history and examines the patient, and then calls the staff surgeon who conducts the consultation.

The study protocol was based on the literature review, but also discussed with three team members (nurse, surgeon, and psychologist – my second supervisor) and presented to the team during one of the weekly tumor board meetings. After the meeting, all the team members regularly involved in weekly outpatient clinics (surgeons, nurse, speech-language pathologist, dietitian) agreed to participate and signed the consent form. One physician in training did not wish to participate, and his conversations with patients were not transcribed nor used in the analyses (this person, however, gave me permission to be present in the consultation room during the meetings where he was present and to record the rest of the conversations). I approached students, residents, and other professionals who were not present during this initial meeting but were present during patient consultations on an individual basis to explain the study and obtain consent.

4.2. Data collection

To gain a comprehensive understanding of how body changes are discussed during clinical consultations, two types of qualitative data were collected for the study. With the consent of the patients having received a cancer diagnosis, their family members (if present) and the professionals involved, I observed and audio- and/or video-recorded consultations in the Head and Neck Surgery outpatient clinic. In addition, I conducted semi-structured interviews with patients and providers, and kept a fieldwork journal (Emerson et al., 1995) to record day-to-day observations, reflections, and preliminary research findings. To describe participants' profiles, patients were also asked to complete a short demographic questionnaire comprising basic information such as age, gender, and marital status. A hospital chart review was conducted to better understand patient care trajectory and collect basic information on patients' medical situation, such as the date of diagnosis, cancer type and stage, and additional treatments received. The data collection process started in April 2017 and ended in December 2018. In this section, I will first present the recruitment process and the participants' profiles, and then describe in detail how interactional and interview data was collected.

4.2.1. Recruitment process and participant profiles. Patients were eligible to participate if they (1) were diagnosed with a first occurrence, recurrence, or progression of head and neck cancer according to the TNM classification (Deschler et al., 2014); (2) the medical team identified surgery as a treatment option that will be presented to the patient; (3)

>18 years old; (4) were willing to be recorded and interviewed for the study; (5) were alert and capable of giving free and informed consent; (6) were able to read and speak English or French; (7) would be able to communicate through speech (or other audible modality compensating for voice loss) after the surgery, as evaluated by the medical team. After consultation with the Research Ethics Committee of the hospital, I decided to only approach patients who already knew their diagnosis: recruiting prior to cancer diagnosis would involve concealment of study objectives, and I could not do this without a strong rationale. A purposeful sampling strategy was used to ensure variability of gender, age, cancer site and stage, and anticipated extent of disfigurement and functional impairment, and recruitment continued until sufficient data was obtained to answer the research questions (Tracy, 2010).

Patients were not eligible to participate if (1) expected survival < 6 months according to clinical judgment and/or Karnofsky Performance Score (KPS) <60; (2) the medical team advised that the patient is not well enough physically or psychologically to participate; (3) patients are accompanied by a family member or another person who does not agree to be recorded for the study. KPS (Schag et al., 1984; Karnofsky & Burchenal, 1949) evaluates a patient's degree of functional impairment on a scale from 0 to 100, with lower scores indicating poorer functional capacity and prognosis.

Patients were recruited through the Head and Neck Surgery clinic with the help of the nurse navigator. The nurse identified patients who met the eligibility criteria during weekly tumor boards. In order to protect patients' confidentiality, the nurse first approached eligible patients. She asked them if they would agree to receive a call from me, and if they agreed, I called them to present the study in more detail, verify eligibility criteria, and schedule a face-to-face meeting to sign the consent form (usually before or after one of their scheduled appointments at the hospital).

The nurse was always the first to contact potential participants in order to preserve patients' confidentiality and avoid having patients approached by an unknown person who is not a member of their medical team. However, this could also impact patients' decision to participate in the study; as many of them told me when I first approached them, they felt very grateful to their medical team and wanted to help improve care for other patients. Out of 26 patients that were approached by the nurse, 22 agreed to take part in the study (82% participation rate). The main reason for refusal was being busy with hospital appointments and preoccupied/stressed while waiting for the surgery. The nurse was not always able to contact the patients and tell them about the study during the busy pre-surgical period, so pre-surgical appointments were not recorded for all participants. Other studies have also reported challenges of pre-operative recruitment, "as there is a narrow time window, and patients have much to consider without the burden of research participation" (McNair et al., 2016, p. 6).

One of the 22 patients enrolled in the study decided not to have surgery and thus was not included in the study. Two patients died during the course of the study, before completing the final six-month interview. One patient dropped out of the study. She explained that it was a very stressful time for her and she did not want to think about her diagnosis and surgery more than she needed to – which this study encouraged her to do. At the same time, some patients also told me that they appreciated participating in the study since it allowed them to talk about their concerns and worries with someone who was outside of their family, as well as to have some company when they were coming to the hospital for their appointments. Such potential beneficial aspects have also been reported elsewhere (e.g., see Bitzas, 2014; Dean & McClement, 2002; Pessin et al., 2008; Wright, 2012).

To ensure confidentiality, and since the analyses that will be presented in the following chapters are not linked to socio-demographic characteristics, I will describe participants' profiles as group data and I will not assign quotations to a particular participant identifier throughout the manuscript. In this way, it is not possible for a reader to identify a participant and track everything she or he said or did (Morse, 2007; Morse & Coulehan, 2015). Similarly, members of the medical team are not associated with specific participant identifiers, and their role in the team is mentioned only in instances where it is necessary to understand the data (they were informed about potential risks of being identified in the consent form).

The participant profiles of patients (n=22) are summarized in Table 1 below. For the patient who dropped out of the study after the first observation and for the patient who decided not to have surgery, only information about sex, age, and cancer site was collected.

Table 1. Participant profiles

Sex	16 men, 6 women
Age	Ranged from 30 to 89 years old, mean 65, median 65
Country of origin and language	18 participants were born in Canada, 2 immigrated to Canada 14 participants spoke French and 8 spoke English
Cancer site, stage, and treatment	Cancer sites included: larynx, jaw, hypopharynx, nose, tongue, salivary glands, floor of mouth, palate. 10 patients were diagnosed with advanced stage cancer (stages 3 and 4), 7 – with an early stage cancer (stages 1 and 2), and 3 patients had an unknown primary tumor. For 14 patients it was their first head and neck cancer diagnosis, and for 6 patients – a recurrence or a second cancer. 13 patients had radiotherapy and/or chemotherapy treatments after their surgery.
Family members	During almost all consultations, close family members accompanied patients (partner, children, sibling, or parent). One patient was coming to appointments alone. 11 patients were married, 3 were divorced, 2 were widowed and 4 were single.
Education and work status	13 participants had a high school or a CEGEP diploma, and 7 had a university degree. 14 participants were retired, 3 were working part-time, and 3 were working or studying full time.
Family income	Ranged from 20,000-39,000$ to over 100,000$ / year, median 40,000-59,000$ / year.

4.2.2. Observations and recordings of outpatient consultations. The video recordings covered patient consultations with the members of the medical team during outpatient clinics, whether they met with the patient as a team, or during separate consultations. Audio/video recording has been used to study interactions in different contexts, including patient-provider communication. While audio/video recording "is always potentially intrusive" (Chaput et al., 2011, p. 259), it is generally considered feasible and acceptable, according to previous studies in various clinical contexts such as general practice, palliative care, oncology, and chronic illness (Albrecht et al., 2009; Coleman, 2000; Parry et al., 2016; Penner et al., 2007; Pino et al., 2017; Themessl-Huber et al., 2008).

The medical team was consulted on the use of audio/video recordings, and supported video recordings to avoid bias in interpretation as much as possible, and ensure an accurate account of the consultations involving several professionals, by making it possible to verify observations (Heath & Hindmarsh, 2002). To minimize any discomfort related to the use of the recordings, patients, family members and medical professionals were informed in the consent form that they could stop the recording at any time, or choose the audio-recording option only if they were uncomfortable with the video. At any particular meeting, if at least one person preferred audio recording only, audio recording only was used. To ensure patients' and their family members' ongoing consent, I confirmed with them if they agreed for their visit to be recorded before each consultation.

A small wide-angle digital camera (Nikon KeyMission 170) was used for video-recordings. A small digital recorder (Zoom H1n) was also used to ensure a better capture of the sound. In order to facilitate patients' accommodation to the recording and not take any time from patients' visits with their medical team, the recording devices were placed in the consultation room before the patient entered the room, which was possible since patients were assigned to a specific room in the outpatient clinic by the clinic coordinator who informed me about the assigned rooms before the start of the appointment. During the consultations, I was present in the room (standing or sitting in the back of the room) and made written notes of relevant contextual information and non-verbal behavior. I took no direct part in the interaction, but answered questions in rare occasions when something was asked of me (for example, go call a team member), or a comment was made about the research project.

In keeping with this study's interactional approach, I am aware that my presence during clinical consultations affected the course of interactions to some extent, even though I was not participating in the discussions. While it was impossible to make my presence completely unnoticeable, I took some steps to minimize its impact, both for the medical team and for the patients. I had already worked as a research assistant with the medical team, and they were already familiar and comfortable with me; since the data collection continued over several months, the team got more used to my presence. In addition, several other people were already present during medical consultations, including medical students who either shadow the physician or are in training, which contributed to making my presence less exceptional. Finally, the face-to-face meetings with patients and family members to obtain consent, conducted before the start of the observations, were opportunities to create a first contact and make my presence in the consultation room less exceptional.

The recordings were reviewed to identify sequences of communication around changes in body appearance and function. Specific attention was paid to patient-initiated actions, since they could be expressions of potential concerns, as described in the previous chapter. Selected sequences of communication were transcribed verbatim and anonymized. The transcriptions took into account the content (what was said), as well as relevant non-verbal elements that helped understand how participants emphasized certain aspects during their conversations. Given that the hospital setting was bilingual, and participants (both team members and patients) sometimes communicated in their second language, I corrected some minor grammar and syntax errors during transcription to facilitate reading. For each patient, a document was created, including the patient's demographic information and sequences of communication around body changes identified in all their different visits at the clinic during the six-month study period.

Recordings started during patients' pre-surgical appointments, and continued up to six months after the surgery. The six-month study period was used to understand patient-team communication over a longer period of time, while also remaining feasible within the time frame of a Ph.D. research project. In total, 88 outpatient visits (19 during the pre-surgical period) were recorded (including 20 video-recordings), for a total of over 54 hours of recorded data. Meetings lasted 37 minutes on average (ranging from seven minutes to over two hours; median 31 minutes; mode 34 minutes); longer meetings sometimes included medical procedures (for example, changing a voice prosthesis, cleaning the wound, putting on a bandage) as well as longer waiting times between a patient's meeting with a resident physician and the arrival of a staff physician.

4.2.3. Interviews with patients and members of the medical team. To help with the interpretation of the clinical consultations, to gain insight into how foregrounding or backgrounding certain aspects of body changes contributes to patients' experience, and to identify possible ways of improving patient care, patients and team members were interviewed as part of the study. Patients' and team members' accounts helped explain what parts of interactions during clinical consultations were significant to them, or how they were "framing" and "focusing" events by emphasizing certain aspects (Gabriel, 2004, p. 66). Specifically, the goals of these interviews with patients and providers were to: identify what consultations or specific moments they considered as more or less significant regarding communication around body changes and explore in what ways they were important to them; choose sequences for interaction analysis, paying specific attention to the moments identified as significant by participants; clarify a specific moment of interaction if needed, and explore emerging themes as the analysis progresses; and collect feedback and suggestions for improvements in the area of patient-medical team communication, before the surgery and in the postoperative period.

The interview protocols were built in a way to explore the foregrounding/back-grounding process, and identify matters of concerns for patients and providers. Specifically, the patient interviews were structured around five main themes: their care trajectory at the clinic, body changes that they have been experiencing due to their illness, their perspectives on the interactions that they have had with the medical team and specifically the conversations around body changes, their experience of preparing for the surgery, and suggestions for improvement. The interviews with the members of the medical team were structured around three main themes: what they find important to discuss with their patients at different moments during the treatment trajectory, how they discuss body changes in particular, and how they see their role and the role of their colleagues in discussing these questions. The interview questions can be found in Appendix A.

Patients were interviewed before their surgery, as well as at approximately three and six months after the surgery (the dates being flexible to accommodate participants' availability and physical state). The three-month time point was chosen to allow patients to recover from the operation, and the six-month time point to allow them to further reflect on their experience over a longer period of time. Patients were free to choose a private and confidential place most convenient to them; most often the interviews took place in patients' homes, and sometimes in a private meeting room at the hospital. Two patients were hospitalized at the time of an interview, and with their permission the meeting took place in their hospital room. Interviews were conducted with patients alone, without family members present. Team members were interviewed in their offices at the hospital. All interviews were transcribed verbatim.

In total, 45 interviews with patients were conducted, for a total of over 41 hours of recorded data. Interviews lasted 56 minutes on average (ranging from 17 minutes to almost 2 hours; median 50 minutes). In addition, six interviews were replaced by a written questionnaire, in situations where patients did not feel comfortable speaking or had not recuperated their speech yet and preferred to answer in that way. Six interviews were scheduled but not conducted since participants were not feeling well enough. Interviews with the members of the medical team (three surgeons, nurse navigator, speech-language pathologist, dietitian) lasted approximately one hour each, except for one 30-minute interview.

4.3. Data analysis

In this section, I will describe how the transcripts of outpatient consultations were analyzed to identify interaction patterns, and how this analysis was combined with a thematic analysis of the interview data.

4.3.1. Identifying interaction patterns in outpatient consultations. To investigate how patients and providers were framing body changes in their conversations, I used an interaction analysis approach inspired by conversation analysis, in keeping with the interactional definition of framing that was described in the previous chapter. This analytical approach allowed me to "analyze not just what people are *up to* in a given interaction – that is, what they are trying to achieve and how they manage to do this – but also what they are reacting or responding to and how they are doing so" (Cooren, 2015, p. 35).

As mentioned in Chapter 2, conversation analysis is an approach to “the study of talk and text in social practices” that “examines the social organization of talk-in-interaction and how it enables individuals to make sense of their worlds” (Fairhurst & Cooren, 2004, p. 132). One of the central theoretical and methodological assumptions of this approach is that analyzing interactions helps understand “how social structure is locally and practically achieved” (Garfinkel, 1967, cited in Fairhurst & Cooren, 2004, p. 132), and the analytical focus is on the “situated, emergent, normative and interactional order” of social action (Fairhurst & Cooren, 2004, p. 132). In other words, to illustrate this idea in relation to patient-provider communication, in contrast to conceptualizing patient-provider conversations as a process of information transmission driven by individual characteristics, needs or preferences of patients and providers, conversation analysis examines “local and concrete moments of joint action” (Fairhurst & Cooren, 2004, p. 144) through which they “create, maintain and negotiate meaning” (Robinson, 2011, p. 502) (of diagnoses, treatment plans, etc.). This approach also highlights that patients’ and providers’ behaviors during clinical encounters are not only influenced by the above-mentioned individual characteristics, but also by specific interactional situations (Goffman, 1983, cited in Robinson, 2011, p. 502), as patients and providers mutually react and adjust to their actions. This attention to the sequential organization of conversations and the ways in which patients and providers react to each other’s actions guided the analysis of interactions.

While conversation analysis is generally known for in-depth analyses of talk in interaction, language is not the only resource “that participants mobilize to produce and understand social interaction” (Mondada, 2019), as social interactions are “multimodal” (Mondada, 2017, 2019) and include “language, gesture, gaze body postures, movements, and embodied manipulations of objects" (Mondada, 2019, p. 47). Given that not all participants agreed to video-recordings, transcripts of verbal interactions were the main focus of my analyses, but the role of multimodal resources was accounted for in certain specific situations. For example, during the analysis of pre-surgical consultations, I noticed how references to a patient's body affected by the illness contributed to foregrounding concerns about survival and cure.

Identification of empirical markers of framing. As described in the previous chapter, some empirical markers of framing were identified during the literature review, including those related to the sequential organization of conversations (for example, initiating a topic, picking up on what is said, topic change, repetition, interruptions), language choices (for example, qualifying something as being "important"), speaking on behalf of others to lend more weight to what is said (for example, speaking on behalf of the medical team), agreements/disagreements (that could point to potential differences in patients' and providers' perspectives), as well as markers that go beyond language use such as movements, expressed emotions, and references to a patient's body affected by the illness. During the analysis, I further specified these markers based on the transcripts. For example, I identified that members of the medical team, to lend more weight to what they were saying, were speaking on behalf of the team, but were also including the patient in the team (by using, for example, phrases such as "and we is all of us") and were telling stories of other patients. By comparing patient-initiated actions and the medical team members' responses within different patient consultations, I identified how the foregrounding/backrounding of body changes could be seen as a continuum: for example, patients could express potential concerns by asking vague questions, or, on the other side of the spectrum, by formulating very specific demands for assistance; patients could bring up a concern briefly at one time during one of the appointments, or, on the other side of the spectrum, bring up the same concern repeatedly over the course of a single visit and/or during several subsequent visits; surgeons could briefly mention consequences of the surgery or describe them in great detail. This constant comparison method enabled me to interpret body changes as being emphasized in some situations, and as being given less emphasis in others. In addition, by comparing team members' responses and reactions to patient-initiated topics (or, in other words, the sequential aspect of interaction highlighted by the conversation analysis approach [Cooren, 2015, p. 35]), I was able to identify certain differences in what was foregrounded by the patients and by the members of the medical team. For example, in the post-surgical visits, I noticed how surgeons tended to foreground biomedical explanations of symptoms and emphasize them as being normal (and thus not concerning) in response to patients' descriptions of their experience living with these symptoms. Finally, in order to identify what aspects of body changes were foregrounded, I also used interview data to inform the analysis of interactions: for example, I paid attention to the concerns that patients expressed during the interviews but that were not explored in detail (and thus backgrounded) during the outpatient consultations, as well as to the elements that were identified as important by patients and providers during the interviews, in addition to being emphasized during the outpatient consultations (which provided further confirmatory evidence to identify them as important concerns, such as concerns about survival and cure).

Process of data analysis. The documents assembling sequences of communication around body changes for each patient were repeatedly examined and compared to investigate how this topic was raised during visits, as I progressively moved on to focused analysis of selected sequences of interactions to explore emerging patterns (Spradley, 1980). I repeatedly returned to the initial framing markers identified in the literature in order to further specify them based on the collected data, and reviewed the transcripts several times during the process in light of the emerging empirical markers that were identified during the analysis process.

During the concurrent analysis of patient and provider interviews, I compared the themes emerging from the analysis of consultations with the themes emerging from the analysis of the interviews, which allowed me to gain more confidence about the themes and sub-themes that will be presented in the following result chapters. Given the large amount of data that was collected for the study, it is possible that more ways of framing of body changes can be identified with further analysis of the transcripts (not primarily focused on potential concerns expressed by the patients and not necessarily supported by the interview data). However, the themes identified during the data analysis process allowed me to investigate the research questions by taking into account the concerns that were important to patients and providers, as identified during the interviews, which also allowed me to identify some suggestions and opportunities for reflection that could help improve patient care. In addition, the focus on potential concerns expressed by the patients helped address one of the fundamental questions in the analysis of medical consultations, namely how doctors respond to patient-initiated actions and how these responses might influence the outcome of the consultation (Balint, 1957, cited in Barnes, 2019, p. 311).

I progressively discussed data analysis with my Ph.D. advisor (both at the initial stages of selecting relevant excerpts from the transcripts and in the later stages of in-depth conversation analysis and thematic interview analysis), and I also discussed the data collected for one patient, one video-recorded consultation, as well as themes emerging from the interview analysis with my co-advisor. In addition, a data analysis session around several selected excerpts from transcripts was organized with professors and graduate students at the Department of Communication at the *Université de Montréal*, in order to validate the empirical markers of framing that were used for the study and the interpretations of the results in light of the framing theory and the general principles of conversation analysis. All the participants in this data analysis session signed the confidentiality agreement, and patients and providers participating in the study were informed about this step in the data analysis process in the consent form.

4.3.2. Thematic analysis of the interviews. Patient interview transcripts were analyzed using thematic analysis (Corbin & Strauss, 1990). First, the open coding technique was used to identify general themes in the interviews. I used QSR NVivo for this purpose. I created five broad categories in order to structure the codes in a way that could help answer the research questions and capture patients' comments and suggestions for improvement: Patients' concerns/questions/needs, Patients' perspectives on their communication with the team, Patients' suggestions for improvement, and Patients' perspectives on what works well. Within each category, I had subcategories for themes specific to the pre-surgical period, themes specific to the post-surgical period, and general themes. This initial stage of coding helped reveal common themes (for example, patients' concerns with survival that were more important in the pre-surgical period than anticipation of the consequences of the surgery), as well as differences in patients' perspectives regarding certain themes (for example, how for some patients the emphasis of doctors on long-term recovery and hope addressed their need for reassurance, and for others, also contributed to putting less emphasis on important psychosocial impacts of body changes during the post-surgical period). During the second stage of coding, I looked for relationships between themes identified in the interviews and patterns emerging from the analysis of interactions. At this stage, relevant interview excerpts were added to the documents combining excerpts from patient consultations, as interview analysis and interaction analysis continually informed each other. Excerpts from interviews where patients described their concerns with survival and cure provided additional evidence in order for me to identify survival and cure as being foregrounded during pre-surgical visits, and patients' comments on surgical procedures being presented as routine helped me identify this practice as one that contributed to establishing body changes as not being a matter of concern during pre-surgical visits. Finally, during the selective coding stage, I reviewed the interview data in light of the main categories emerging from this concurrent analysis of interviews and interactions, to further integrate these two types of data and identify the core categories around which the presentation of the results is structured in the following chapters.

Given the small number of interviews with members of the medical team (I had six transcripts), I did not use any software for the analysis, but I followed the same coding strategy as for the patient interviews. Six general themes emerged from the analysis, and were also informed by preliminary analyses of consultation transcripts and patient interviews: Discussing survival and cure; Discussing changes in appearance and function; Importance of reassurance; Discussing psychosocial concerns (including their role and the role of other team members); Providers' approach to communication around body changes; and Challenges in communicating with patients. Themes were also classified according to the period in patient trajectory (pre-surgical and post-surgical) where appropriate. The themes emerging from this analysis informed the analysis of the transcripts of the consultations and the patient interviews. For example, I noticed during the interviews that team members had a clear understanding of their roles in discussing psychosocial concerns with their patients, and among the three surgeons there were two different points of view regarding what the role of the surgeon should be. This observation made me return to the transcripts of the consultations, and helped reveal how different team members emphasized (or not) psychosocial concerns during pre-surgical and post-surgical visits, which eventually became one of the core categories presented in the results chapters. During the selective coding of the patient interviews, I also looked for patients' perspectives on this question and integrated them in the analyses. In addition, my observation of this particular theme in team members' interviews may be related to the fact that during the literature review phase for this study and my work as a research assistant for psychosocial studies with head and neck cancer patients, I was aware of the psychosocial difficulties experienced by patients that are sometimes silenced in patient-provider conversations. I then linked this idea of silencing, as well as the themes emerging from the analysis of my two different types of data, to foregrounding/backgrounding dynamics using the concept of framing as a "sensitizing concept" (Blumer, 1954; Bowen, 2006). This example illustrates the iterative process of the data analysis that was conducted for this study, as well as how patients' and providers' perspectives identified during the interviews informed the interaction analysis.

4.3.3. Considerations for combining interactional and interview data. As was noted by Pomeranz (2005), "many conversation analysts have been strongly reluctant to turn to the participants of an interaction as informants about aspects of the interaction" (p. 93). One of the reasons for this, as explained by Maynard (2003), is that "ethnographic insistence on the relevance of larger and wider institutional structures can mean a loss of data in and as the interaction, for attention shifts from actual utterances in the fullness of their detail and as embedded within a local interactional context to embrace narrative or other general accounts concerning social surroundings" (p. 72). I acknowledge, as was mentioned above, that further analysis of the transcripts could identify other foregrounding/backgrounding patterns that could not necessarily be confirmed by the interview data. However, the concurrent analysis of the observational and the interview data that was used for this study allowed me to investigate the research questions in relation to the aspects of patient-provider conversations around body changes that were important to patients and providers by paying particular attention to the potential concerns expressed by the patients, as informed by extant research on concern expression in patient-provider conversations, and given the high rates of unmet needs in this population revealed by psychosocial studies. In addition, my analysis was based on in-depth examinations of the conversation transcripts, which allowed me to identify categories emerging from interactional materials and not only from participants' views about these conversations (Beach & Anderson, 2004). In this way, combining observational and interview data "provide[d] the potential for enhancing [my] analytic claims and [...] for opening avenues for investigation that otherwise might go unnoticed" (Pomerantz, 2005, p. 93). In relation to this last point, patients' psychosocial concerns reported during the interviews but not expressed during the outpatient consultations provided further evidence to affirm that these concerns can sometimes be backgrounded in patient-provider conversations.

Pomerantz (2005) emphasizes that participant interviews are also interactional situations (between the participant and the investigator, see also Alvesson, 2003), and that "there's no simple correspondence between the matters to which the participants oriented while interacting and the matters on which participants report in their comments" (p. 101). In my fieldwork journal, I took notes about how my position within the team and my relationship with the participants might have shaped the interviews. Patients may have been reluctant to express their dissatisfaction with some aspects of their care to their medical team, as well as disclose their difficulties and concerns to me, as there is a stigma around topics related to body appearance and function. For example, subjects such as sexuality represent an important unmet need for oncology patients (Hordern & Street, 2007), but were not brought up during the interviews and the consultations. Despite these limitations, the methodological approach described in this chapter allowed me to investigate the research questions and identify foregrounding/backgrounding patterns in patient-provider conversations around body changes, similarities and differences in patients' and team members' perspectives, as well as patients' and providers' perspectives on the challenging aspects of these conversations and ways to improve care.

4.4. Partial conclusion

In this chapter, I described how I collected and analyzed two types of data for this study: recordings of outpatient consultations in the Head and Neck Surgery clinic, and interviews with patients and providers. Specifically, I described how I integrated the interaction patterns identified during the analysis of consultations with the themes identified during the analysis of the interviews. I explained how this approach helped me to identify several ways of framing body changes that will be presented in the following chapters, one chapter covering the pre-surgical period and one chapter covering the post-surgical period.

Chapter 5. Framing Body Changes during Pre-Surgical Visits

This chapter is dedicated to the presentation of framing dynamics in patient-provider conversations around body changes during pre-surgical consultations. I will present three themes that recurred during the analysis of the consultations. These themes were also deemed important during the interviews with patients and members of the medical team: (1) discussing body changes in relation to survival and cure; (2) establishing body changes as (not) being a matter of concern; and (3) medical team members' roles in discussing body changes. I will first show how patients' concerns about body changes were foregrounded or backgrounded in conversations about survival and cure. These are important concerns for patients and their care providers during the pre-surgical period. Then, I will present some specific ways in which patients and providers emphasized body changes as being concerning or not. Finally, I will show how patients' and providers' views of the roles of different team members in discussing body changes were reflected in conversations during pre-surgical visits.

This chapter is based on the analysis of 19 consultations with 15 patients. Fourteen out of 19 consultations were with surgeons, residents, and other team members when necessary. In eight consultations, the goal of the appointment was to present surgery to patients and obtain their written consent for surgery; following this appointment, one patient decided not to have surgery. Three consultations were additional meetings with surgeons requested by patients who wanted to ask more questions or receive more information about the surgery. Two visits were organized to introduce a patient to his new reconstructive surgeon (because of the change in scheduling) who re-explained her part of the procedure to the patient and asked the patient to resign the consent form. One visit was to discuss reconstructive surgery options for a patient after their first surgery.

Two out of 19 consultations were with the speech-language pathologist, specifically for patients who had to undergo a laryngectomy. Finally, three out of 19 meetings were with the nurse: the meetings with the nurse are not conducted on an appointment basis, but two patients met with her prior to or after their appointment with other team members, and they were recorded. As explained in the methods sections, pre-operative consultations were mostly dedicated to physicians or other professionals providing information about surgical procedures, and the focus of my analysis was on patient-initiated utterances and questions, and how they were discussed in the conversations that followed.

5.1. Discussing body changes in relation to survival and cure

Cancer is a life-threatening disease, and survival and cure are important concerns for patients. Specifically in head and neck cancer, which affects critical organs in the head and neck area, studies have shown that in the pre-operative period patients often experience fear of mortality and consider changes in appearance and function as a tradeoff for survival (Alias & Henry, 2018; Henry et al., 2014b; Rennie et al., 2018). During the visits at the clinic that were recorded for this study, patients often asked about the date of their surgery, and in the interviews they reported concerns about survival and a sense of urgency to remove the cancer and prevent it from spreading:

> […][1] les questions que j'ai posées la première fois que j'ai rencontré [mon chirurgien], c'est, « Je vais-tu vivre? »
>
> […] quand j'ai vu le chirurgien, c'était dans le but d'avoir un rendez-vous pour l'opération le plus vite possible. C'était clair dans mon esprit, c'est ça qu'il fallait. Parce que je vois ma situation, et ça m'angoisse, ça ne s'améliore pas, donc, c'est ça.
>
> […] one of the things I worry about is, all the time, between now and surgery day, is the cancer getting worse in there, or what does that mean, you know. I don't know how fast this cancer moves in there.
>
> […] I understand that type of cancer is… fast reaction, action, you know, it comes on and, fast-action cancer, so, the sooner the better, obviously, like most cancers.

Team members also talked about survival as being a primary concern for their patients, but also for them as health care professionals. One of the surgeons explained how he viewed survival as an important concern and the reason for doing surgery:

> […] when you are doing surgery […] first you have to remove the cancer. There's no point of making sure you swallow or you look good if you are going to leave cancer behind, there is no point of doing surgery, basically. […] so I think first and most important is removing your cancer, saving your life, and the second is your function, how you swallow, how you speak, it's important to function properly. And the last, how you look cosmetically, making sure that you look OK, you know, you look good. […] we always think of those three in a row, just making sure that you do it in that order […] I want [my patients] to understand that maybe they are not going to look so good or maybe they can't speak or swallow or whatever it is, but our goal is to remove cancer, most importantly, that's what we are here for […]

Some team members reported that communication around body changes to prepare patients for the consequences of surgery can be challenging in the pre-operative period when patients are concerned about survival:

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[1] In the transcriptions, brackets […] are used to omit certain parts of long quotes to facilitate reading. Brackets are also used to explain certain words to facilitate understanding of what is being said. The words in brackets are not a transcription of what was said in the interviews or consultations.

> […] là j’ai un monsieur […] ça fait [trois semaines] qu’il attend pour être vu ici à la clinique, qu’il sait qu’il doit perdre son œil, mais il ne savait pas à quelle intens-, qu’est-ce qu’on devait enlever, est-ce qu’il y a un bout du nez aussi qui doit partir, puis… il était tellement soulagé finalement d’apprendre qu’il pouvait avoir la chirurgie, uh, puis là tu as la famille à côté qui lui dit, ben tsé, tu vas être vivant, un œil, ce n’est rien si tu peux être en vie. Fait que, mais lui… première rencontre, ça semble être, il est juste tellement soulagé… je pense que là en ce moment il pense plus à, je veux vivre, puis tant pis si j’ai l’air d’un pirate, mais il fait des jokes avec ça, donc, c’est sa façon de coper avec ça. À quel point il est préparé? Je ne sais pas. Dans certains cas, comme je pense à cette personne-là en particulier… tu vois qu’il veut tellement vivre, fait que, bon, on va, on va continuer à se parler…
>
> […] les complications chirurgicales, des fois, ils ont toujours le choix de refuser une chirurgie, mais il n’y a pas grand monde qui vont refuser la chirurgie si c’est pour les guérir de leur cancer. Fait que ça, ils vont être prêts à faire face à ça, même une paralysie d’un nerf, ils vont dire, bon ben, c’est ça, je n’ai pas le choix, il faut qu’on y aille […]
>
> […] preoperatively [patients] are, as much as they want to hear about communication and swallowing and how they are going to talk and swallow afterwards, a lot of them couldn’t care less, they have cancer, they want to get rid of it, and this is what their goal is, their goal is to get rid of the cancer and once they get through that, then we can start focusing more on, not just getting rid of the cancer, but giving them their quality of life back.

During the analysis of patient-provider conversations in the pre-operative visits, several moments when changes in appearance and function were discussed in relation to survival and cure were identified. In this section, drawing on the empirical markers of framing identified in the previous chapters, relevant excerpts from transcribed visits will be analyzed to show how certain aspects of body changes were foregrounded or backgrounded in relation to concerns about survival and cure.

5.1.1. Foregrounding survival and cure following patients’ expression of potential concerns. As explained previously, several definitions of concerns have been used in studies of patient-provider communication. Drawing on Pino et al.’s work (2016), I use the term “possible concerns” to describe patient-initiated statements about body changes. Sometimes patients express their difficulties directly, but often, as previous studies have shown, patients’ utterances could only possibly refer to difficulties or “hide emotional distress” (Zimmerman et al., 2007, p. 448) and can be elaborated or addressed as concerns in the conversations that follow. In this section, I will analyze excerpts where survival and cure were foregrounded in response to patient-initiated topics about body changes.

In the first example, following the visit when the surgery was explained to the patient and when he signed his consent for the operation, the patient asked for another pre-operative appointment with his surgeon to ask more questions about the impacts of the operation and to reinforce his decision to choose surgery involving facial nerve sacrifice rather than radiotherapy as a treatment option. In the following excerpt, which takes place at the beginning of the meeting, the patient expresses his concern about the impacts of the surgery on his face. The surgeon responds by telling him a story of another patient who had to make a similar decision and who refused surgery because of its possible impacts on appearance, and for whom radiotherapy was not effective to remove the tumor.

Excerpt #1a

PT[1]: C’est parce que je regarde le désavantage aussi de la chirurgie.
SUR: Bonne idée.
PT: Pour la vie, je vais avoir un œil… je vais être… c’est important au niveau du visage, il va y avoir des changements.
SUR: Uh-huh, uh-huh.
PT: La chirurgie.
SUR: Uh-huh.
PT: Donc… j’essaie de balancer… Qu’est-ce qui serait mieux? C’est la chirurgie, mais il y a des conséquences plus graves…
SUR: Définitivement. Ce n’est pas une décision facile. Et-et-et… Pas pour… pas pour nécessairement vous aider à prendre une décision, mais nous avons une situation exactement comme ça avec une femme maintenant, qui a à peu près 75 [ans], je pense,

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[1] The following acronyms are used throughout the manuscript: PT (patient), FCG (family caregiver/ family member), SUR (surgeon), NUR (nurse), SLP (speech-language pathologist), DIET (dietitian), RES (resident), and RAD (radiologist). The list of acronyms is also provided on p. 11.

13 presque la même situation. Et elle a choisi la radiation avant, parce que l'opération
14 avec le sacrifice du nerf facial était trop difficile pour elle à accepter. Et la radiation, ça
15 fait seulement six-huit semaines depuis que la radiation est finie, et maintenant il y a
16 évidence très apparente de la tumeur qui reste. Hm… Et maintenant, on attend les
17 scanners maintenant, mais… Une chirurgie, c'est possible, peut-être, mais je ne sais
18 pas maintenant, je veux voir le scanner, parce que de temps en temps les cancers
19 comme ça, durant la radiation, peuvent avancer. Alors c'est possible que le scanner va
20 montrer que la tumeur est plus avancée qu'avant.
21 PT: Ah oui.
22 SUR: On va voir, il y a une… la peau est ouverte maintenant, et c'est difficile à
23 comprendre…
24 PT: Ça n'a pas été très bien.
25 SUR: Non. Mais ce n'est pas tout le monde qui est comme ça. Il y a des patients qui
26 ont de bons succès. Je pense que RAD est entré lors de la dernière visite. Est-ce qu'il a
27 parlé [avec vous]?
28 PT: Oui, oui.
29 SUR: Et il vous a donné des numéros, les probabilités de succès.
30 FCG: 50-50.
31 SUR: Oui, c'est le numéro que je veux.
32 PT: 50-50.

In this example, the story told by the physician is a way of foregrounding the chances of cure in response to the patient's expression of concern in lines 1-9 (which is also acknowledged by the physician in line 10, when he says that it is indeed not an easy choice for the patient). In response, the patient expresses his agreement by evaluating the situation described by the surgeon as "not very good" (line 24). As the conversation continues, the patient and his family member ask the surgeon specific questions and the surgeon answers: if the facial nerve absolutely has to be cut during surgery, what parts of the face will be affected by the nerve sacrifice, how big is the skin flap that will be taken from the patient's arm to replace the skin on his face, how painful is the recovery, what will be done to replace the skin on the patient's thigh that may be taken to replace the skin on his arm, when radiotherapy will start and how long it will last, how radiotherapy may affect salivary glands, how often the patient will have to put drops in his eye to prevent it from drying, how aggressive the cancer is and if the tumor is growing. The patient then goes back to his initial question about his treatment choice, as shown in the following excerpt.

Excerpt #1b

33 PT: Le cancer évolue, ou ça peut évoluer, ou c'est… psychologique?
34 SUR: Hm… Impossible pour moi à dire. Et comment mesurer l'agressivité? Ce n'est
35 pas un numéro
36 PT: On ne peut pas mesurer ça.
37 SUR: Oui. La seule chose que je peux dire, particulièrement pour les tumeurs quand il
38 y a une récidive, nous sommes agressifs. Et c'est la raison pour laquelle je
39 recommande une opération agressive. Et la radiation après, qui est agressive. Alors,
40 notre réaction est agressive.
41 PT: Donc, à vous écouter, ça ne sera pas à priori un bon choix pour moi d'aller en
42 radiothérapie au lieu de…
43 SUR: Well… La chose que nous avons bien expliquée ensemble [avec le radiologiste
44 et l'autre chirurgien] était qu'avec radiation toute seule, la meilleure situation, c'est
45 50% de contrôle de ça. Et comme j'ai expliqué aujourd'hui, une chirurgie après ça,
46 pour sauver la situation, souvent c'est tard, OK. Alors, pour avoir la meilleure chance
47 de contrôler ça à long terme, c'est une chirurgie agressive avec radiation après.
48 PT: J'ai bien compris. Même si…
49 FCG: La durée de la chirurgie, c'est combien de temps, à peu près? […]

In this conversation, the surgeon repeats what he said at the beginning of the meeting about the effectiveness of radiation (lines 44-45), and also foregrounds the aggressiveness of the cancer and the necessity to proceed with aggressive treatment, by using the word "aggressive" several times (lines 37-40). The patient responds that he understands, and does not finish his "*Même si…*" phrase (line 48) as his wife changes the subject and asks about the duration of the surgery (line 49). The rest of the discussion concerns the patient's pre-operative tests and the scheduling of the surgery, and at the end of the meeting the patient summarizes the discussion by once again going back to his initial question about his treatment choice, as shown in the following excerpt.

Excerpt#1c

PT: Mais ce que vous m'avez expliqué, je vous remercie.
SUR: Avec plaisir.
PT: Ça confirme, quand je suis rentré, je n'étais vraiment pas sûr de prendre la chirurgie ou de faire la radio avant, mais ce que vous m'avez, vous m'avez comme convaincu de prendre la chirurgie, pour avoir une meilleure vie peut-être aussi… pour les années qui me restent.
SUR: Exactement. Si votre but c'est les années, le temps, vous voulez vous donner vous-même la meilleure chance de…
PT: De vie.
SUR: De combattre, et combattre ça avec succès, de gagner cette bataille
PT: Oui
SUR: Ça c'est la meilleure façon de gagner la bataille.
PT: C'est la chirurgie
SUR: Aucun doute que ça c'est le meilleur. Il faut payer quelque chose, mais c'est la chance d'avoir…
[FCG pose plus de questions sur la chirurgie]

The excerpts above show how the patient foregrounds his concern about the consequences of the surgery by initiating the topic and pursuing it during the visit, and how the surgeon emphasizes the chances of cure in response to the patient's remarks about the choice of treatment. In addition, this excerpt also shows how, at the end of the conversation, the patient and the doctor come to a common understanding of their goal, which is to choose the treatment option that gives the patient a better chance of cure and survival. Survival and cure are thus being emphasized as a shared concern. The patient's use of the term "convincing" (*"vous m'avez comme convaincu de prendre la chirurgie,"* lines 53-54) points to a difference in the patient's and the surgeon's perspective that is resolved by persuasion and illustrates how clinical interactions may influence patients' decisions (see also Losi et al., 2019). The patient's concern about the impacts of the surgery on his face is backgrounded in this conversation: while being brought up by the patient, it is not explicitly described; while acknowledged by the physician, it is not explored in more detail. This observation has been also reported in other studies on patient-provider communication that show that many patients do not express their concerns directly in clinical visits (Zimmerman et al., 2007), but rather provide cues for support to their care providers, who are not always able to notice and address these cues (Butow et al., 2002) and do not always explicitly invite patients to express concerns (Brandes et al., 2015). In the following pages, I will analyze another excerpt where survival and cure are foregrounded following the patient's expression of concern about the impacts of the surgery.

After receiving his cancer diagnosis, the patient comes to the clinic to meet with his surgeons to discuss his treatment options. At the beginning of the visit, one of the surgeons takes off the big bandage that covers almost all of the patient's left check and side of the neck. When the surgeon takes off the bandage, a big bloody swollen lesion is revealed, covering all of the patient's cheek and going a little bit to the side of his neck. While the surgeon examines the lesion, the patient says that "it bleeds, and bleeds, and bleeds," that it hurts, that he cannot sleep in his bed because of the bleeding and has been sleeping in a chair for two weeks. The patient also tells the surgeon how the tumor has been growing for the past eight months, from a little lump to a lesion that continued to grow even after he had two surgeries to remove it (by a plastic surgeon at another hospital). The surgeon then explains to the patient that the best way to treat his cancer is to do surgery to remove the affected area, involving the nerve that controls one side of the face. The patient listens to the surgeon's explanation and says "OK," "OK," until the surgeon tells him about the effects of the paralysis on talking and smiling, and the patient expresses a possible concern by asking if there is a chance that his face will not be paralyzed:

Excerpt #2a

SUR: The chance of saving that nerve… I don't want to say zero, but it… it's very close to zero. Uh… which means you have a paralysis, mainly this part, maybe the whole half of the face that doesn't move so well, that doesn't move at all. And that would be permanent. Because you don't want to go in, sort of saving the nerve, but you leave cancer. We are there to remove cancer first.
PT: OK.
SUR: So there's a very good chance we'll have to do it. Uh... What it means is that, yeah, you're, you don't move half of your, the other half moves, it doesn't affect your speech, you can still talk, you can still swallow, what we do is we lift your lip up a bit, so that you don't, because it's going to fall down, so we lift it upwards, so we make you look like a joker, a little bit, but then with time it falls down and it makes it even.
PT: OK.
SUR: So if we look at you like this, you're going to look perfectly normal. It's when you start talking or smiling, that's when you have the effects.
PT: Is there a small chance that it won't be paralyzed?
SUR: I don't want to say zero, but it, it's… I mean, we try, but it… For a cancer like this, you don't try very long, because you want to make sure that you get the cancer out, because it's a big cancer.
PT: OK.
SUR: We want to make sure we remove it.
PT: OK.

In this example, like in the previous one, facial paralysis is presented as a necessary consequence of removing the cancer. The surgeon establishes removing the cancer as the primary concern by saying, "We are there to remove cancer first" (line 5) and "We want to make sure to remove it" (line 20). Body changes are discussed alongside solutions to make the patient "look perfectly normal," and the effects on talking and smiling are mentioned but not described in more detail (lines 13-14). As the conversation goes on, the surgeon continues to explain what can be done to reduce the impact of the facial paralysis on function, namely to lift the lip so that when the patient eats food does not come out, and to put a gold weight in the patient's eye so that it can close. "So we do little things," he says, "but that's the biggest thing that's going to affect your quality of life after the surgery, OK, that's by far the biggest," to which the patient says, "OK," and the doctor then proceeds by explaining the skin flap that will be taken from the patient's arm and the skin graft that will be taken from the patient's thigh, like in the previous example. At the end of the surgeon's explanation, the patient says, "I am anxious to get started." By saying that facial paralysis will affect the patient's quality of life, the surgeon emphasizes its impacts. However, if we take into consideration the whole conversation, these impacts are backgrounded as they are not discussed in detail while the patient and the surgeon establish removing the tumor (that is bleeding and is affecting the patient's life) as a priority and as solutions are discussed to ensure normal function.

Later during the visit, another surgeon comes in to introduce himself to the patient and tell him what he thinks about the surgery. After asking the patient about the evolution of his cancer, the surgeon explains to the patient that it has to be treated aggressively. The surgeon also foregrounds cure and the necessity to remove enough tissue to have a better chance to control the disease in response to the patient's expression of concern about the need to cut the bottom of his ear, as shown in the following excerpt.

Excerpt #2b

SUR: […] this tumor's, based on what you've told us, and what we're seeing, this tumor is behaving aggressively, it's uh, you know, it's, it's not a little benign-ish, slow growing skin cancer. This is a tumor that's growing […] We have to be radical with this thing. Because if we don't treat this aggressively, we are not going to win. OK?
PT: OK.
SUR: Uh, and we is all of us. So, we need to take this off, and, uh, we can't be shy. The, uh, we have to take your whole parotid gland and beneath, that's what underneath there, and what runs through the parotid gland is the nerve […] that moves the muscles of your face. There's no way to get that thing off, and feel like there's any sense of margin and security around it without removing the facial nerve, which runs through the heart of your parotid gland. Which means, your face on that side could be paralyzed. […] There's no way around it. […] And, and, obviously, as you know, it's so close to your ear, and that's why I was asking if you were wearing glasses, we have

to remove part of your ear with that, obviously. I would certainly try to preserve the upper third maybe of your ear, so that you, you know, you still have some, you can wear glasses and you can have that structure there, you know.
PT: You mean, the bottom of my ear is going to be, gone?
SUR: Well, it's sitting on the bottom of your ear, it's sitting, it's touching the bottom.
PT: You can't just cut that thing off, the ear has to come with it.
SUR: We need a one-centimeter margin.
PT: Yeah.
SUR: What we see, what we see there, is really, it's, you know, to use the cliché, it's the tip of the iceberg, OK. So when you see an iceberg, and you know there's lots of underneath. But… an iceberg is macroscopic, if you go scuba diving you can see the iceberg underneath. We can't see where the extensions of the tumor are, now or even when we're in there, they are microscopic. So if we don't go one and a half centimeters at least […] that margin around it, not only on the skin, but inside, we try to get it, that same distance around it, we're going to leave microscopic disease, and it's just going to grow right back. And even being that radical, neither of us can make promises to you, but we've got to do everything we can to beat this thing, and then get you to radiation as quickly as possible after the surgery.
PT: Do the best you can.

One of the markers of framing that can be observed in this example is the surgeon's use of direct language, of words such as "there is no way around it" and "obviously" (line 33) that present body changes as a necessary condition for removing the tumor. These utterances can also be qualified as "pronouncements," that is, actions by which the "physician asserts recommendations as instigator, decision maker and presents [them] as already determined," and the recommendation of doing surgery "is treated as a necessity or as very important" (Stivers & Barnes, 2018, p. 1333). The patient asks his question, "You mean, the bottom of my ear is going to be, gone?" (line 38), continues to pursue the subject by saying "You can't just cut that thing off, the ear has to come with it" (line 40), and then expresses his agreement with the surgeon by saying, "Do the best you can" (line 53). The patient's reactions to his surgeon's explanation about the extent of the surgery (lines 38, 40) are an indication of possible concerns that are not further explored in the conversation, as reacting to something is "marking the agency of what appears to matter" to the patient (Cooren et al., 2012, p. 307).

As the conversation continues, the urgency of removing the cancer is further emphasized:

Excerpt #2c

54 SUR1: It kind of sucks, but, you know what, uh…
55 FCG: Ben n'importe quoi va être plus beau que qu'est-ce que t'as là là.
56 SUR2: Ouais.
57 PT: It's true! Anything is going to be better.
58 FCG: Anything is going to be better than that! ((Looks at the patient's face.))[1]
59 PT: That's horrible.
60 SUR1: Yeah, that's horrible. That's horrible. And… You know, you, you'll adapt to it, the
61 changes and the facial paralysis, but, you have lots of people who, unfortunately, have to
62 go through this, who three or four years later, they are happy to be alive and free of tumor.
63 PT: Yep. Like I said, I'm ready. Today, tomorrow?

The surgeon acknowledges the negative impacts of the surgery by saying that "it kind of sucks" (line 54), and emphasizes survival and cure by mentioning the experience of other people (lines 61-62). The patient and his partner background the impacts of surgery in relation to the patient's present horrible condition by saying that "Anything is going to be better than that" (lines 57-58), which is also acknowledged by the surgeon ("Yeah, that's horrible," line 60). The patient then, once again, says that he is ready to do the surgery as soon as possible (line 63), which contributes to foregrounding the urgency of removing the cancer, or establishing it as a primary concern. This example also illustrates how the patient's body affected by the illness contributes to foregrounding the urgency of cure, as the patient, his partner, and the surgeons refer to it several times during the consultation, in this last excerpt by describing it as horrible. This was also observed in other appointments with patients whose

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[1] In the transcriptions, "double parentheses (( )) indicate that what is encased is a description of what is happening during the interaction. What is enclosed is not a transcription." (Cooren, 2004, p. 545, based on Jefferson's (1984) transcript notation)

appearance or bodily functions were visibly affected by the illness. Overall, this transcript illustrates how the patient briefly expresses possible concerns about the extent of the surgery and how, as the conversation unfolds, this concern is backgrounded as the patient and his surgeons establish removing the cancer as being their main and shared concern. Another way of accomplishing this can be seen in Excerpt #2b (line 27) above: by saying “and we as all of us,” the surgeon includes the patient in the team, and also communicates that the urgency of aggressive surgery is shared by both the team and the patient.

The last case that will be analyzed here to show how body changes are discussed in relation to survival and cure is a visit where a patient and her surgeons discuss surgical treatment of a tumor in the patient’s nose. The following excerpts illustrate how the patient brings up the extent of the surgery. At the beginning of her appointment, when the patient and her family members first meet with the resident, they ask about the extent of the surgery:

Excerpt #3a

PT: Do you think they are actually going to save part of the tip [of the nose]? I’m almost thinking it’s
FCG1: We’ll ask the other doctor.
PT: Yeah, we’ll ask them. I have a feeling, I just want to know what it’s like
FCG2: You think it’s up here?
RES: You want to know the extent of it.
PT: I just want to know the extent and I want to know what, what to, you know.
RES: I’ll get the doctor.
PT: Yeah, I appreciate […]

Later during the meeting, the surgeons come in and explain the procedure to the patient. They first talk about the results of the scan, on which “there is not a lot to see,” which means that the tumor is microscopic and the margins of it will be harder to define during surgery. Based on this scan and in order to ensure some margin, the surgeon explains, “[…] to remove what I feel needs to be removed […] we are looking at probably removing the middle third of your nose." They also explain that, if possible, they "would want to preserve the tip" of the nose "for cosmetic benefit," and that the margins of the removed tissues will be analyzed after the operation and if there are cancer cells present, more tissue will be resected at the time of the reconstruction of the nose. The patient and her family also ask questions about the time frame for the surgery and reconstruction, and the surgeons explain that it might vary depending on the results of the surgery and the type of reconstruction that will be done. The patient then asks if the surgeons are going to be more aggressive during the first surgery in order to get clear margins:

Excerpt #3b

PT: Are you going to be a little more aggressive to try and get clear margins the first time
SUR1: I, I, yes.
PT: Yeah.
SUR1: The answer is, this one we can answer, ((together with SUR2)), yes. Look, I
PT: But obviously I know
SUR1: I'm not, I mean, look
PT: I know you might be surprised by something, and I know you may have to take out more than you intend.
SUR1: I'm not going to go in there as a, a blade of cancer surgeon, head and neck surgeon, which is why we always say, it's better that the blade of surgeon is not also doing the recon[struction]
PT: Right
SUR1: Because then
PT: Right.
SUR1: He has conflict or she has conflict. Uh… I'm not going in there worrying about what you are going to look like after.
PT: OK.
SUR1: I shouldn't go in there worrying about that.
PT: OK, I want you to get it.
SUR1: You don't want me to think about that.
PT: OK.

In this conversation, the importance of taking the cancer out with a clear margin is established as a priority when the physicians talk about aggressive surgery with certainty ("This one we can answer, yes," line 13), and the cosmetic result ("what you are going to look like after," line 25) is described as not being a matter of concern at the moment of the first surgery. In other words, the patient's possible concern about appearance is established as not something to be worried about at the time of the discussion. While the surgeons briefly mentioned the cosmetic aspect earlier in the conversation when they explained that the tip of the nose would be preserved if possible, potential concerns about appearance are backgrounded as the surgeons are ordering concerns by priority later in the conversation: "Once we've dealt with the cancer part of it, it becomes more cosmetic-functional."

There is another example in the data where surgeons explain to the patient how they see these concerns (cancer, function, appearance) by order of importance, and this ordering is another way of backgrounding body changes in relation to survival and cure. When explaining to a patient why his facial nerve had to be removed, one surgeon specified: "When we do the surgery, we think of three things, cancer, function, and cosmetics. And we think of these three, but in that order. So we have to remove your cancer, then make sure you eat and you swallow properly, and then the last thing is that you look as normal as possible. Those are the three things, but it has to be, we can't make you look beautiful and leave the cancer, it's just all for nothing, we might as well not do the surgery." In Excerpt #3b above, it is illustrated how this ordering unfolds in patient-provider conversations.

Later during the visit introduced in Excerpt #3b, when the physicians present the consent form for the patient to sign for the procedure, the patient asks about the extent of the surgery. The excerpt below illustrates how in their response physicians emphasize the need for aggressive surgery ("Once it recurs like this, we don't go small," lines 48-50), and how the patient specifically alludes to possible concerns about appearance ("I don't know what it looks like," lines 38-40):

Excerpt #3c

SUR: ((Shows the forms to the patient)) So, this is standard consent, you've seen this before. This is just consent for general hospital stay, this is consent saying I will be performing partial rhinectomy.
PT: OK.
SUR: Removing part of the nose, as we discussed.
PT: Uh-huh.
SUR: And this is for the anesthetic. Alright?
PT: So there's a slim chance you may have to go to that side and take it off too
SUR: Well, I'm going to go a little bit over there, definitely, I am going
PT: I don't know what it looks like
SUR: I am going over to the right side, it's, it's middle third of your nose. But I'm going to do a little bit more on the left side, I think we'll go upwards towards the nasal bone
PT: Yeah.
SUR: And inferior towards the columella as we said on the septal side, based on what [another doctor] tells me. So yes, it will be both sides, but it will be more on the left.
PT: So I'm just kind of wondering, if I had come here and it's small and it didn't even reach up here
SUR: Well, we're still, again, we would have made some assurance
PT: Yeah, you need some assurance
SUR: I don't know how small it would have been. Once it recurs like this, we don't go small.
PT: Uh-huh.

At the end of the meeting, the patient asks about the extent of the surgery again and the part of the nose that will be removed:

Excerpt #3d

PT: I'm just kind of, I guess it's the bone part that I'm wondering
FCG1: She's worried about losing her nose.
PT: No, I'm ((smiles))
SUR: I told you, I said it's going to be the middle third of your nose, it's going to be middle third.
PT: Middle third, that's so weird, it's almost, yeah, very weird.
SUR: That, well, weird, but not, because we want to preserve what we can, but not leave what we shouldn't leave.
FCG2: Right. And the doctors will, they will reconstruct
PT: Yeah, they'll reconstruct.
SUR: Oh yeah, he'll reconstruct, he's done lots of them.

63 PT: ((Gives the signed papers to SUR)) I leave these with you?
64 SUR: No, I need to give these to [the receptionist and the coordinator]
65 PT: All right. Well, thank you very much.
66 SUR: We're going to see you soon.

As earlier in the visit, the surgeon answers that "we want to preserve what we can, but not leave what we shouldn't leave" (lines 58-59), which contributes to emphasize, once again, removing the cancer as a priority, while the patient's possible concern, which her family member described directly in line 53 ("She's worried about losing her nose"), is not being followed up on.

In the examples presented in this section, where the primary site of cancer was known, surgeons had some degree of certainty regarding the effectiveness of surgery as a treatment option. In the next section, I will show how body changes were discussed in situations where the primary site of cancer was not known and the effectiveness of surgery was less certain.

5.1.2. Emphasizing body changes when cure is less certain. I will present three cases in this section, one where cancer cells were found in the head and neck area but the primary cancer site was unknown, and two where surgeons were not confident that they could get the whole tumor out. In these situations, while surgery was a possible treatment option and was suggested to patients, there was less certainty about its effectiveness for removing the cancer. These examples help nuance the foregrounding/ backgrounding dynamics of discussing body changes in relation to survival and cure, and show how body changes are emphasized when cure is less certain.

In the first example, one of the surgeons presents the surgery to a patient and his family members. The surgeon has recently operated on the patient for a benign tumor on his parotid gland, and cancer cells were found in one of the lymph nodes that were removed during the operation:

Excerpt #4a

SUR: Bon, on a eu une grosse discussion dans le tumor board.
PT: Oui
SUR: Parce que comme vous savez, ce n'est pas… ce n'est pas clair exactement votre histoire, un petit peu. Uh… Comme vous savez, on a trouvé un ganglion qui avait du mélanome, mais on ne sait pas ça vient d'où. Aucune idée
PT: Aucune idée.
SUR: Toutes sortes de tests, le PET scan, il n'y a rien
PT: Rien, ma peau est correcte
SUR: C'est ça. Mais vous avez une métastase du mélanome qu'on n'aime pas d'habitude.

The surgeon then explains that a more extensive surgery will allow him to see if there are other metastases in the region, and consequently if the patient needs further treatment (like immunotherapy) to control the disease.

Excerpt #4b

SUR: Oui. Mais, l'opération, ça a l'air de quoi. Alors, c'est plus gros que t'as eu.
PT: C'est plus gros que j'ai eu
SUR: Oui, c'est la même incision qu'on continue, mais il faut descendre pour enlever, on descend dans le cou
PT: OK.
SUR: On enlève toute la glande, pas seulement la bosse, mais toute la glande parotide, alors tout le, le nerf facial
PT: Oui.
SUR: Peut être endommagé. C'est très rare, mais comme vous avez déjà eu une petite
PT: Oui-oui-oui
SUR: Mais maintenant c'est tout le nerf qui est à risque.

The surgeon then tells the patient about another option, which is regular follow-up with CT scans and PET scans.

Excerpt #4c

SUR: […] on a dit, pourquoi on fait, il y a une bonne chance qu'il n'y a rien, pourquoi on ne le suit pas juste avec un CT et un PET.
FCG: Uh-huh.
SUR: Ça c'est l'autre option. Puis ça, on a parlé de tout ça, puis il y avait un peu de, de discussion, mais à la fin on a tous décidé, parce que c'est déjà un métastase, ce n'est pas un… Si t'avais un mélanome dans la peau, qu'il n'y avait pas de métastases, on peut le suivre. Mais on sait déjà, par définition, il est métastatique, déjà c'est propagé.
FCG: It's in the lymph.
SUR: It's in the lymph nodes. So it's already moving.
FCG: It's already moving.
SUR: It makes us very uneasy to say stop and just follow, because it might pop up somewhere else. And that makes us uneasy. Parce que si on pense que c'est déjà dans le système lymphatique
PT: Le système lymphatique
SUR: Ça peut se propager. Si on continue de le suivre, ça… Ça nous inquiète un petit peu parce que ça peut continuer à propager sans qu'on puisse le savoir, puis là, pop-pop-pop, ça apparait un peu partout.
PT: Oui, oui-oui.
SUR: Alors ça, on… On veut être un peu… Quand c'est un cancer, on veut être là, avant le cancer, pas en arrière.
PT: Pas après, c'est ça.
SUR: Donc c'est ça qu'on a décidé comme le tumor board, c'est mieux de vous dire notre opinion, de tout le monde à la fin, c'est de recommander une chirurgie pour être sûr qu'il n'y a pas d'autres choses. En disant que ça se peut qu'on fait la chirurgie, qu'il n'y a rien, mais ce n'est pas pour rien, parce que c'est bon, là on sait qu'il n'y a pas de cancer du tout, là on le suit après. Là il n'y a pas d'autres traitements, on le suit. Mais s'il y en a plusieurs ganglions où il y a des petites métastases, là ça se peut que t'aies besoin d'autres traitements. Mais c'est une opération.
PT: Une autre opération.
SUR: Une autre opération.

Having explained that surgery is the preferred treatment option that the team had agreed on in lines 42-44 (which is a marker of foregrounding, as the surgeon says that he is speaking on behalf of the team), the surgeon tells the patient that he has a choice:

Excerpt #4d

51 SUR: Tu peux me dire, non, je ne veux pas d'opération, c'est correct, je sais que vous
52 recommandez et je vais prendre le, le risque de le suivre, c'est correct aussi, mais il
53 faut que vous voyiez que, comme les médecins il faut que nous vous recommandions
54 des choses
55 FCG: Être bien informé, c'est ça
56 PT: L'information.
57 SUR: Parce qu'il y a un risque. Il y a des risques des deux côtés. Il a le risque
58 d'opération, il y a des risques pour les nerfs, les vaisseaux, les cicatrices, mais il y a un
59 risque pour le suivi aussi, et avec le cancer qui revient. C'est sûr que nous comme
60 chirurgiens on pense que le risque de la chirurgie, c'est beaucoup moins que le risque
61 de, parce que quand le cancer revient, c'est le cancer, eh, et ça, c'est votre vie. Si le
62 cancer se propage, tu peux mourir de ça.
63 PT: Oui.
64 SUR: Tu ne peux pas mourir d'un nerf qui est coupé.
65 PT: Non. Coupé ou affecté
66 SUR: C'est ça que nous on pense. C'est sûr que les risques sont petits quand même, 1-
67 2% ce n'est pas gros.
68 PT: Non.
69 SUR: Mais il faut que vous compreniez qu'il y en a des risques.
70 PT: Il y en a des risques.

The surgeon foregrounds survival by saying that it is impossible to die from a damaged nerve (lines 64-66), but he also emphasizes the risk of damaging the nerve by saying that the patient needs to understand the risks (line 69). Later in the visit, the surgeon specifies the chances of finding the primary cancer with the surgery: "*On a 20% de chances qu'on trouve quelque chose et 80% qu'on ne trouve rien, à peu près*." As the conversation continues, the surgeon encourages the patient to think about the disadvantages of each choice, surgery versus surveillance:

Excerpt #4e

71 FCG1: So the surgery is more like a, more of a proactive… approach
72 SUR: Proactive, being ahead of cancer, and he's young, you know, he's healthy
73 FCG1: Yeah-yeah-yeah, of course.
74 SUR: Non, mais c'est vrai, c'est
75 PT: Je suis vieux, mais merci! ((Rit))
76 FCG2: He's very-very active
77 SUR: He's active, he's healthy, yeah. You want to be ahead of the cancer, not behind.
78 You… L'autre chose qu'il faut penser, si… Le négatif des deux. Si on fait l'opération,
79 si on ne trouve rien, mais on endommage un des nerfs qui ne bouge pas.
80 PT: Oui.
81 SUR: Comment tu te sentirais, comme ça?
82 PT: Comment je vais me sentir.
83 FCG2: Uh-huh.
84 SUR: L'autre option, si on ne fait rien, puis on fait un scan dans quatre mois puis le
85 cancer est partout. Comment tu te sentirais?
86 PT: Avec ça.
87 SUR: Ça c'est les deux négatifs des deux choix.
88 FCG1: Ouais.
89 PT: Des deux choix.
90 SUR: Les deux extrêmes.
91 PT: Deux extrêmes.
92 SUR: Il faut penser à ça un petit peu pour voir, OK, qu'est-ce que tu veux.
93 PT: Oui, qu'est-ce que tu veux
94 SUR: Mais ça, il n'y a personne qui peut répondre à ça.
95 FCG1: C'est personnel, c'est ça
96 SUR: C'est très personnel
97 PT: Ouais.
98 SUR: Mais d'habitude, on fait l'opération, on ne trouve rien et tout est beau.
99 FCG2: You're hoping
100 SUR: 80% des chances que ça va être comme ça
101 PT: Il fait soleil là, c'est beau
102 SUR: Le soleil, mais il y a des situations aussi qu'il faut que vous compreniez.

The surgeon emphasizes survival and cure by saying that the patient is young and that doing the surgery will allow him "to be ahead of the cancer, not behind" (line 77), and he also emphasizes body changes by inviting the patient to think about how he would feel if one of the nerves was damaged (lines 78-82), and by repeating once again that the patient needs to understand the consequences (line 102). At the same time, the consequences of damaging the facial nerve are not described in detail like in the previous examples, where the physicians talked about, for example, the impacts on facial movements, eating and smiling. This comparison reveals that body changes related to possible facial nerve damage are also being backgrounded in this visit. The following excerpt illustrates how the risk of damaging the facial nerve was mentioned at another time during the conversation without being described in more detail (line 116):

Excerpt #4f

103 FCG2: And the operation itself, is it considered like a big operation
104 SUR: Nooo, it's not like, it's bigger than it is, I mean, it's not, we do major surgeries,
105 14 hours, reconstructions
106 FCG2: Right.
107 SUR: You're not there, at all, you know.
108 FCG2: It's just, what's going to happen, like
109 SUR: There's going to be a scar.
110 FCG2: A bigger incision?
111 SUR: Same, we follow it, and we just continue on the neck, because we will remove
112 the neck lymph nodes, too
113 FCG2: And then that's, the healing process is
114 SUR: About the same as it was this, about the same, it takes about a week.
115 FGC1: It's just a bigger incision.
116 SUR: Just a bigger incision. The biggest risk is the nerve of the face, again
117 FCG2: And then that, by removing all that you can see
118 SUR: Right, then they check it. And they tell us.

Overall, this example illustrates how survival is being considered as the main concern and how the surgeons recommend surgery as a treatment option, while also emphasizing that the patient needs to understand the consequences (which are not specifically described).

Another example of a situation where there was less certainty that surgical intervention could remove cancer is the pre-operative meeting of a patient for whom the primary tumor site was known, "but the extent of it, the size of it, [and] what structures it's related to" were such that the surgeons did not think that they would be able to cure the patient. As one of the surgeons put it, while surgery was still on the table and discussed with the patient as a treatment option, the big question was, “Do we stand a chance of curing you?” The conversation below, which took place at the beginning of the visit, illustrates how the surgeons foreground functional changes while presenting the surgery to the patient.

Excerpt #5a

1 SUR: So the reason we wanted you to come in today is to have a really frank discussion.
2 PT: OK.
3 SUR: We did discuss in the recent past, the surgery
4 PT: Yeah.
5 SUR: OK, to take this thing out. Uh, it’s still on the table
6 PT: Uh-huh.
7 SUR: I’ve reviewed your most recent scan, we went over it with the radiologist, so I
8 can really understand, as best as we can, determine where this tumor is, the extent of it,
9 the size of it, what structures it’s related to. And it’s all critical, you know.
10 PT: Uh-huh.
11 SUR: And in the head and neck area, you’re never far from something critical.
12 PT: OK.
13 SUR: And what I conclude from doing that and from discussing your case at our tumor
14 conference with the guys in the room plus several other colleagues, I cannot tell you
15 with any measure of confidence that I can get the whole thing out.
16 PT: OK.

The surgeon starts talking about the gravity of the surgery in terms of affecting the critical structures in the head and neck area (lines 9-11). A way of establishing the impacts of the surgery as a matter of concern, or foregrounding them, is the surgeon’s repeated use of the word “critical” in lines 9 and 11. He then explains the surgery to the patient:

Excerpt #5b

17 SUR: Uh, so, if we’re going to surgery and I want to describe to you again how we
18 would approach it, I will get everything I can, uh, it will go to, you know, your throat
19 or your pharynx, all of your soft palate, could be half of your hard palate, and good part
20 of the sinus and the maxilla, and then beyond that I would, whatever I can see and
21 access safely, remove, but I believe, given the film, that there would be microscopic
22 tumor beyond that I can get, see, appreciate. Where does that get you, if I do that, and
23 that’s what you need to understand. I need to, in good conscience, know if I’m going to
24 do this, that you understand it, OK. Uh, in terms of the morbidity of the surgery, this is
25 assuming everything goes well, there’s no complications in terms of bleeding, in terms

of free flap failing, assuming everything goes well, we remove your palate, SUR1 is good at reconstructing it, but it will not function the way your palate functions today. And the palate functions, A) to separate your mouth and your nose, and the soft palate functions to dynamically separate your mouth from your nose so that you can eat properly without regurgitation from the liquid and that you can speak properly without having what we call a nasal voice.

PT: OK.

SUR: OK, when we put a piece of tissue up there that isn't a mobile muscle, it won't do that as effectively and will cause you to regurgitate, will cause you to have a change in your voice, to some extent. Uh… So you will be recovering from a big surgery and you won't be functioning in terms of eating and swallowing and speaking as well as you are right now. Uh, so then the next point is, besides what we do negatively for you, what do we give you, do we give you anything, because I don't want to put anyone through anything like something as extensive as this, unless I'm offering you something beneficial. So… I don't, it doesn't seem like you have a lot of symptoms right now, so I will not make you feel better than you feel now, maybe we will relieve some of your pain that you were describing when you were eating, but you don't have a lot of symptoms now. Uh, are we… do we stand a chance of curing you, that's probably the big question. Given what I said, that I believe that we will unfortunately leave some tumor behind, I don't think we will be able to cure you. […] so all in all what I'm saying, is that if we do the surgery, we have the potential of giving you some more time. How much time that is, I can't say, nobody can say.

In this excerpt, the surgeon foregrounds functional changes in several ways. First, he emphasizes that he needs the patient to understand them (lines 23-24). Second, he explicitly describes the changes in function ("it will not function the way your palate functions today," line 27; "you won't be functioning in terms of eating and swallowing and speaking as well as you are right now," lines 36-37), and explains in more detail what these changes will be, in terms of changes in voice and eating (lines 31-37). And finally, he further emphasizes the extent of the surgery by saying that he does not want to "put anyone through anything like something as extensive as this" (lines 38-39). In the conversation that followed, similar ways of foregrounding body changes can be observed.

Excerpt #5c

SUR1: I'm sorry that I'm not the bearer of amazing news, it's a role I hate to play, but I have to play sometimes. But I know if I was in your position, I would want someone to be really honest with me, so I know what I'm getting into, because the way some people look at the situation is they say, well, right now I have, and you can tell me if I'm right or not, but I have some decent quality of life, we could alleviate the symptoms that you are having, you're not in hospital, you're doing what you're doing, and if we bring you in hospital and do this big operation, you're going to be in for weeks
PT: Yeah, you said a couple of weeks, that was one of my questions.
SUR1: Well, two weeks would be the best case scenario
PT: OK. And after that, it's, what's, what's recuperation part for that
SUR1: You, know, depends on how you define recuperation
PT: Yeah.
SUR1: From a kind of surgery like this, you recuperate for months, because you're adjusting to a whole new
SUR2: The biggest thing is your speech and your swallowing. So you have to almost re-learn to do it, if you want to, so the question is, we're going to put it on you, and what Dr SUR1 is leading to, what do you want
PT: Yeah.
[…]
SUR1: So I think [chemotherapy] that's another option that should be considered, that you should consider, because I think it may actually have a significant tumor effect that will not put you in the hospital for several weeks with a really anatomy-altering surgery.
PT: OK.
SUR2: Because you're not going to, you're going to look the same after the surgery, but all the inside, majorly changed
PT: I understand that
SUR2: Yes, we're going to put things back together but it doesn't function the same, so speech and swallowing, which are big things of quality of life, will be worse than you are now after surgery, there's no question about that. The question is, do you want us to go all out trying surgery and then chemotherapy or not, or you're saying, I like my quality of life for now, let's just do chemo. It's a hard decision, it's not, and even during the tumor board, we didn't necessarily agree on one or the other.
SUR1: There's no right answer, there is no one doctor who actually should or could tell you what to do.
SUR2: That's right.
SUR1: What doctors should be doing and it's what I hope we're going here, is really try to inform you as much as we can inform you, really paint a real picture for you, and then allow you to make as informed decision as, and we are here to answer any questions you have.
PT: Uh-huh, OK.
SUR2: You were not expecting all this.
PT: No, I mean… No, definitely not. […]

Surgeons are emphasizing that they want the patient to know what he is getting into (lines 49-50) and "to paint a real picture" (line 84). They directly talk about major changes in function, by mentioning that the patient will almost have to re-learn how to speak and how to swallow (lines 62-63) and that recuperation will be long ("you're going to be in [hospital] for weeks," line 54; "from a kind of surgery like this, you recuperate for months," line 60; "[the surgery will] put you in the hospital for several weeks," line 69). Changes in speech and swallowing are also being discussed as "big things of quality of life" (line 75), and the surgery is described as "really anatomy-altering" (line 69). The patient mostly listens and says that he understands (line 73), this conversation being difficult and unexpected for him, which is also recognized by the surgeon (lines 87-88).

An excerpt from another pre-surgical visit presented below is another case where the surgeons were not certain in their ability to remove the tumor and where they put emphasis on the consequences of the surgery during the consultation.

Excerpt #6a

1 SUR1: C'est 100% que, c'est 100%... Je peux dire bien-bien probable, qu'on va avoir
2 des marges positives microscopiques, juste à cause de la localisation de la tumeur. La
3 tumeur est très proche du fond de, le, orbit, eye socket
4 PT: Yeah.
5 SUR1: Alors… Au fond de ça. Alors ça veut dire que ce n'est pas loin du nerf pour
6 l'œil. Alors c'est une région qu'on va travailler proche […]
7 FCG: Est-ce qu'on peut devenir aveugle d'un œil?
8 SUR1: À cause de la proximité de la tumeur et l'œil, c'est important que vous compreniez
9 que c'est possible, on ne peut pas dire probable, mais c'est possible que tu vas avoir un
10 problème avec la vision sur le côté droit. Et c'est important que vous compreniez ça.
11 PT: Oui.
12 SUR1: C'est une chirurgie très complexe, et avec des risques, comme l'œil.
13 […]
14 SUR2: Je pense qu'il faut que vous compreniez aussi qu'on avait beaucoup de discussions.
15 PT: Uh-huh.
16 SUR2: Est-ce que ça vaut la peine de faire l'opération.
17 PT: C'est ça.

18 SUR2: On a parlé beaucoup, on a parlé beaucoup, même juste maintenant avant de
19 venir. Parce que c'est une grosse opération, et la question, est-ce que vraiment on peut
20 enlever le cancer.
21 PT: C'est ça.
22 SUR2: Puis on continue avec la radiothérapie si on laisse quelque chose. C'est sûr que
23 c'est un risque, qu'on fait tout ça et ça revient. Il y a une bonne chance, on peut dire.
24 PT: OK.
25 SUR2: Mais…
26 PT: Est-ce que ça vaut la peine?
27 SUR2: Ça c'est la question. C'est la question que seulement vous vous pouvez
28 répondre à ça. On a vraiment parlé beaucoup de tout ça, puis il y a des gens qui disent,
29 pourquoi on fait tout ça, parce que c'est vraiment dans le nerf, c'est à côté de votre
30 cerveau… C'est faisable, oui, c'est faisable, mais est-ce qu'on doit le faire.
31 PT: Ben, en fait, moi ce n'est pas une question, moi j'ai un enfant de huit ans […]

The surgeons mention the complexity of the surgery (lines 12, 19), the closeness of the tumor to the nerves and the brain (lines 3-10, 29-30) and say that it is important that the patient understands the potential consequences, such as the risks of impacting her vision (line 10). In response, the patient establishes the possibility of cure and survival as her main concern, by saying that there is no question for her of not doing the surgery since she has a young son (line 31).

5.2. Establishing body changes as (not) being a matter of concern

In the previous section, I showed how concerns about body changes were discussed in relation to survival and cure. The following pages will focus on other instances where patients brought up potential concerns about appearance and function, and I will show how they were addressed as (not) being a matter of concern in the conversations that followed.

5.2.1. Changes in appearance: From potential concerns to consideration in decision-making. In this section, two pre-surgical visits of a patient will be analyzed to show how the patient brought up changes in appearance several times during the visit, and how, in some conversations, they were not constructed as concerning, and how, in other instances, they were emphasized by being considered as an element in the decision-making process.

The patient comes to meet with his surgeon after signing his consent for his operation (removal of the nose and reconstruction) to ask more questions about the procedure. The surgeon explains to the patient that there will be a period of waiting between the surgery to remove the tumor and the surgery to reconstruct the nose, because the removed tissues will have to be analyzed to be sure that there are no cancer cells left in surgical margins. During the appointment, the patient brings up concerns about appearance. While talking about the period between the first surgery and the reconstruction, he says:

Excerpt #7a

PT: OK, donc je ne serai pas vraiment présentable, avec, sans nez, on s'entend
SUR: Ah, bon, présentable
PT: Je vais-tu avoir un gros pansement?
SUR: Bonne question. Même pas un gros pansement, eh, dans le futur, parce que tu n'as pas de nez, cette partie-là, on met un petit pansement, comme un petit triangle, que vous mettez avec, les petits auto-collants, puis
PT: OK. Puis je ne pourrais pas porter mes lunettes, ça c'est sûr.
SUR: Ah… Non.
PT: OK.
SUR: Non, parce que… Bon, je veux vous dire non, ça se peut qu'il y ait un petit peu qui reste pour le mettre, mais
PT: Ça va être douloureux puis ça va être près de la plaie, fait que
SUR: Ouais, ouais. Mais au début, non, peut-être dans…
PT: C'est correct, je me l'étais fait à l'esprit quand même.
[…]
PT: Uh… Tu m'avais dit que les résultats pour, tu dois prendre des résultats, savoir si tu en enlevais assez.
SUR: C'est ça.
PT: Tu m'as dit, deux à trois semaines.
[…]
SUR: Oui, between trois et quatre. Pour l'os.
PT: OK, ça veut dire que je vais être trois à quatre semaines sans
SUR: C'est sûr, oui
PT: Aussitôt que tu vas avoir une réponse, tu me schédules tout de suite une chirurgie?
SUR: Uh-huh, exact.

Potential concern about appearance, that is, spending some time without the nose is foregrounded when the patient brings it up as a new topic ("*je ne serai pas vraiment présentable, avec, sans nez, on s'entend,"* line 1) and repeats it later during the conversation ("*ça veut dire que je vais être trois à quatre semaines sans,"* line 22), but it does not become a matter of concern during the conversation as the patient changes the subject and the surgeon continues to answer his questions (lines 7, 24). Later during the conversation, the patient asks about scars after reconstruction in a similar manner, by bringing up the subject (lines 26, 43) and then by changing the subject (line 47):

Excerpt #7b

26 PT: Je vais avoir, à ce moment-là je vais avoir toujours une cicatrice, évidemment
27 SUR: Ouais. Uh-huh.
28 PT: Ensuite, est-ce que je vais être suivi en plastie pour me faire enlever ça?
29 SUR: Oui, est-ce que tu as déjà vu le docteur NOM?
30 PT: Non.
31 SUR: Non.
32 PT: Jamais.
33 SUR: OK. Tu ne l'as jamais eu, un rendez-vous?
34 PT: Non.
35 SUR: Ah.
36 PT: Parce qu'en fait
37 SUR: Est-ce que tu veux le voir avant ou après? Mais tu sais quoi
38 PT: Je peux le voir après.
39 SUR: Après. Parce que ça ne sert à rien, parce que, vraiment, c'est difficile à
40 PT: On ne sait pas c'est quoi le résultat.
41 SUR: Exact, donc c'est mieux après. Alors, pendant l'opération on va enlever, puis la
42 reconstruction, tu vas le voir, attends la pathologie.
43 PT: Mais est-ce que la cicatrice habituellement, elle est grosse? Ou…
44 SUR: Ça, tout dépend de ce qu'on fait
45 PT: Ça dépend de ce que, OK
46 SUR: C'est difficile à dire.
47 PT: Fait que là, il y avait, euh, pour les anti-inflammatoires, tu me disais que, il n'y a
48 pas d'autres choses […]

After his first surgery to remove the cancer, the patient came to see his surgeon, to follow up on the results of the surgery and also to discuss the next step – reconstructive surgery. The surgeon explains to the patient the surgical techniques that will be used to reconstruct the nose (using a fragment of a rib to reconstruct the bone structure) and the interior of the nose and the skin (using either the tissues near the patient's nasal cavity, or using a skin flap from the forehead or the arm). The patient asks some questions to specify and clarify as the surgeon goes on with his explanation, and at the end he asks about appearance:

Excerpt #7c

49 PT: Est-ce que tu penses, tu ne peux pas me donner, me dire que ça, si ça augure bien
50 en termes d'apparence, parce que là tu as gardé mes deux narines, en partie
51 SUR: Alors, oui, c'est ça que j'ai gardé, j'ai gardé le plus possible que je peux, parce
52 que ça, c'est le plus difficile. Ici en haut, c'est assez facile de reconstruire cette partie-là.
53 PT: OK.
54 SUR: C'est juste ici ((touche l'endroit en bas du nez et autour des narines)),
55 cosmétiquement, ça ce n'est pas facile à reconstruire.
56 PT: OK.
57 SUR: C'est pour ça qu'on essaie le plus possible qu'on peut faire, pour essayer de faire
58 juste comme ça puis ça, puis attacher ça à côté pour que ça ait l'air mieux, pour que ça
59 ait l'air, comme un nez un petit peu.
60 PT: Puis là ça va être cousu?
61 SUR: Ça va être cousu, tout va être cousu, oui
62 PT: C'est des points fondants ou des
63 SUR: À l'intérieur, ça va être fondant, à l'extérieur, c'est les points qu'il faut enlever.
64 PT: OK.
65 SUR: Parce qu'ils sont moins
66 PT: Plus résistants
67 SUR: Oui.
68 PT: OK. Ensuite, uh, je vais avoir, ben je vais voir de quoi ça a l'air, puis après ça je
69 verrai un plasticien.
70 SUR: Ou Dr NOM, c'est lui qui fait ces choses-là aussi, c'est lui qui fait la rhinoplastie
71 ou d'autres choses.
72 PT: Parfait, c'est bon. Uh, OK, c'est bon.

The surgeon answers the patient's question about appearance by explaining that some aspects of the reconstruction are not easy from the surgical point of view (lines 54-59), and that he will try as much as he can to make it look better, so that it looks “a little bit like a nose” (line 59). Later during the visit, after signing the consent form so that the team can start planning the surgery, the patient asks another question about what the reconstructed nose will look like:

Excerpt #7d

73 PT: Est-ce que ça va être, là il va toujours y avoir un côté plus profond que l’autre, j’imagine.
74 SUR: Uh, plus profond pour?
75 PT: Mais celui-là il est plus creusé, à droite.
76 SUR: Oui, mais on va faire un petit peu comme ça ((montre sur son nez)), et avec le
77 temps, mais ça se peut que ça soit un peu, mais on a toujours un peu de différence, tout le
78 monde même, chez vous, oui, ça va être, ça ne sera pas égal-égal.
79 PT: Puis est-ce que tu peux tirer pour enlever mes cernes aussi ((Tout le monde rit.))
80 FCG: Fais un lifting!
81 PT: Je veux la face de Brad Pitt!
82 SUR: Brad Pitt, oui! Donc, j’aimerais vous revoir… Vraiment après la pathologie, pour
83 discuter de la patho.
84 PT: OK.

In his response, the surgeon backgrounds appearance changes (*“ça ne sera pas égal-égal,”* line 78) by normalizing them, when he says that for everyone the two sides of the nose are not exactly the same (lines 77-78). Overall, in this visit, body changes are backgrounded or are not being constructed as a matter of concern in the conversation between the patient and the surgeon. The patient asks questions as a way to foreground potential concerns about appearance, and the surgeon, by using words such as *“on essaie le plus possible […] pour que ça ait l’air mieux”* (lines 57-58) and “*on a toujours un peu de difference, tout le monde*” (lines 77-78) talks about the changes as being not that bad and even normal, and thus expresses that he is not very concerned about them. He mentions that reconstruction is difficult from the surgical point of view (“*cosmétiquement, ça ce n’est pas facile à reconstruire,*” line 55), but does not talk about changes in appearance in more detail.

The patient's concerns about appearance were foregrounded during the next visit, when the patient told the surgeon about his hesitation regarding the outcomes of the reconstruction following his meeting with another doctor. During this visit, the surgeon explained the reconstruction procedure to the patient once again, and then said:

Excerpt #7e

85 SUR: Est-ce que ça va vous donner le nez qui était là avant? Non, ce n'est jamais le nez
86 PT: Non, je comprends.
87 SUR: Mais ça a l'air d'un nez, pas le nez qui était là avant, et c'est sûr que ça parait un
88 petit peu, c'est sûr.
89 PT: Oui.
90 SUR: C'est sûr, il faut que vous compreniez ça. Parce que l'autre option que vous avez,
91 toujours, c'est la prothèse. […] La reconstruction, ce n'est pas quelque chose qui est,
92 c'est quelque chose qui est difficile, on en fait beaucoup et on le présente, mais il y a
93 toujours l'option pour les patients comme toi de faire une prothèse […]
94 […]
95 PT: Combien d'opérations en moyenne [pour la reconstruction]?
96 SUR: Ça dépend
97 PT: Ça dépend du patient.
98 SUR: Ça dépend ce qu'il, des fois on reconstruit et les gens sont contents avec le nez, c'est bon
99 PT: Ça va être moins beau
100 SUR: Oui, c'est sûr, au début ça a l'air, c'est un petit peu gros
101 PT: Oui.
102 SUR: Puis là, ça diminue. Puis le plus difficile, vraiment, c'est cette partie-là ((touche
103 sur son visage la partie entre le nez et les lèvres)). Ça, c'est facile ((touche son nez)),
104 c'est vraiment cette partie-là, parce que chacun est un peu différent, et ça c'est le plus
105 difficile, techniquement, de refaire.
106 PT: OK

In this example, the surgeon is more direct when he is talking about appearance changes, by mentioning that the reconstructed nose will never be the same as the nose that the patient had, and that the patient needs to understand that (lines 85-90). The patient brings up appearance during the discussion about reconstruction *("ça va être moins beau,"* line 99), and then later during the visit when he asks about appearance if he decides to go with a prosthesis instead of reconstruction:

Excerpt #7f

PT: Et si je fais la prothèse, elle sera plus belle en apparence?
SUR: Ça dépend aussi, chacun est différent aussi, eh. Parce que, la couleur ça peut changer un peu, mais c'est sûr qu'une prothèse comme telle, ça a l'air plus qu'un nez normal que nous on fait, mais
PT: Tu as plus d'inconvénients parce qu'il faut que tu l'enlèves le soir, que tu le nettoies
SUR: Oui, exact.
PT: OK.
SUR: Je pense que vous avez bien compris ça.

Later during the visit, the patient summarizes his conversation with another physician to the surgeon, specifically in terms of the aesthetic aspects of the reconstruction and patients' satisfaction. In the conversation that followed, the patient and the surgeon foregrounded appearance changes by discussing them as an element in the patient's decision-making about reconstruction versus a prosthesis to replace his nose:

Excerpt #7g

PT: OK. Moi, en fait, lorsque j'ai été à [une autre clinique] voir [un autre médecin], ben, je voulais juste te résumer un petit peu comment ça s'est passé.
SUR: Oui-oui-oui.
PT: Moi j'ai, d'abord, avant qu'il ouvre mon pansement, uh, il m'a dit, écoute, une reconstruction là, ce n'est pas un succès garanti là. Il m'a dit, écoute, c'est beaucoup moins esthétique, et souvent c'est la satisfaction, et ça, on le savait un petit peu, il m'a dit, vous savez, la prothèse serait beaucoup mieux en termes d'apparence. Et puis, souvent, bon, ce n'est pas si, c'est moins complexe aussi. Évidemment, c'est moins intrusif, c'est clair.
[…]
SUR: Mais c'est bon, il faut penser à ça. Il faut que tu sois sûr que tu veux, on ne va pas, c'est quelque chose qu'il faut, tu as tellement d'options, c'est sûr
PT: Parce que ce n'est plus, c'est sûr que c'est plus intrusif et je sais que la durée
SUR: Mais c'est sûr que si t'as besoin d'une prothèse, oui, je pense que c'est mieux cosmétique un petit peu, mais il faut enlever, il faut nettoyer, c'est pour la vie
PT: Ça ne repousse pas, c'est clair.
SUR: Mais c'est bon que vous pensiez à ça, c'est important que vous pensiez à tout ça, pour être sûr que tu veux ça, eh […]

In this example, potential concerns about appearance are foregrounded as the patient is bringing up the subject several times during the course of the visit and is evoking the opinion of another physician who did not have the same perspective regarding the severity of the impacts of reconstruction on appearance (lines 118-123). Changes in appearance are foregrounded but are not constructed as a matter of concern when the patient briefly brings them up during his first visit, however, in the second visit they are foregrounded as a component that matters in the patient's decision-making about the treatment option.

5.2.2. Emphasizing long-term recovery and hope. In the interviews, the team members explained that in the context where patients are diagnosed with serious illness, are concerned about survival, and are preparing to go through extensive surgery, reassuring and motivating patients was an important role that they had to play.

> I think it's important, I think it's very important, I think they get a lot of cues from us. I think that they read our optimism or our pessimism, our positivity or negativity, I think they do, and I think they probably take a lot of cues in terms of how positive they should feel based on the way we portray things. And I think I'm aware of that […] I've seen some surgeons who are just totally-totally positive, almost to a fault, where I feel that it doesn't get the patient a realistic perspective on what their problem is, and then I've seen the opposite where the picture is painted black no matter what, even if it's not as black as being painted. So I think, being aware of that, seeing extremes, I think I try to be, I don't want to say middle of the road, but like realistic and honest. […] I'm aware that the way I portray it does affect how they are going to react to it, so when I can be very positive and it's fair and it's realistic and it's honest, then I am. When it's very negative, I don't, uh, I don't hit them over the head with it, but if they want to know if this is serious, I'll say, yes, this is serious, but it doesn't mean we can't treat it, we have hope and you have to have hope, and we do everything we can and, you know. So I think honesty is important and I think the way we present it to them is important in terms of how they are going to react to it, and then present it to their own loved ones.
>
> […] you motivate them, you are the motivator, you are the support, that's the best thing you can do, so that's I think, that's our role.
>
> […] I can't really know how much of a defect they are going to have until after they operate, so we have to be not too harsh or too negative in terms of, yeah, there will be challenges, but there will be improvements. Because time heals also, that's something

> I've learned, is that they need to be reassured that what happens right on the first day that they eat it's not what's going to happen a week or two later, things do heal and there are improvements.

Interviews with patients showed that reassurance from their medical team was important for them. They described different ways in which the team reassured them, such as information about getting back to normal appearance and functioning and positive attitude and enthusiasm:

> Helpful to me, is to know that they can do the operation and bring me back to my, the way that I eat […] And the doctor told me, 100% after your operation, you can go back to eating. Yeah.
>
> […] en fait, moi, je suis contente, parce que… Je ne me rappelle plus, je pense que c'est Dr SUR qui m'a dit, ben au bout d'un an les cicatrices vont être parties.
>
> Il faut balancer la chose […] il ne faut pas qu'ils en disent trop non plus. Mettons, je ne sais pas moi, tel handicap, telle chose, telle chose, ce sont des choses peut-être, trouver le juste milieu là-dedans. […] il faut faire attention là-dedans, en mettre un peu, mais pas trop, pour ne pas décourager. Parce qu'il faut encourager, dire, ça va bien aller […] il ne faut pas que tu dises, ah ça ne sera pas vraiment comme c'était avant, et il ne faut pas que tu dises que ça a été pire qu'on pensait. […] C'est niaiseux, mais c'est de l'encouragement que ça prend. […]
>
> Ils étaient super enthousiastes, on va te ((inaudible – guérir)), pas de trouble, alors, ça, oui, ça aide beaucoup. ((Inaudible)) qu'ils soient très positifs avant, ça a aidé, ça c'est sûr.

One of the patients explained the need for reassurance before her surgery, and the importance of meeting this need was emphasized by another patient, who identified lack of reassurance as a gap in his pre-operative conversations with his doctors:

> On n'est pas un numéro. Et ça, c'est important, continuer à faire ça. Toucher, bon, il y a des gens qui ne veulent pas être touchés, mais c'est important, toucher, la main, le genou, n'importe quoi. Juste toucher. Pour dire, oui, ça va aller, ne vous en faites pas. On a besoin de se faire dire ça. On a besoin de se faire dire ça par un médecin qui va t'opérer, vous allez voir, ça va bien aller.

> […] ça n'a pas été fait, d'après moi, de façon à… à sécuriser le patient, jamais je n'ai eu la chance de m'asseoir avec [le chirurgien], pis lui de dire, « Écoute, ça va bien aller, ne t'en fais pas ». Jamais-jamais-jamais-jamais. Jamais. Fait que ça, je trouve ça, un manque.

In this section, I will provide a number of examples to show how this reassurance, of importance to both patients and providers, was realized in patient-provider conversations during pre-surgical visits. Specifically, long-term recovery and hope were emphasized in response to potential concerns about body changes expressed by patients and their family members.

The following example, similar to the visits in Excerpts #7 and #2 presented in the previous sections, illustrates how changes in appearance are brought up by the patient after the surgeon explained the surgery to her and how, during the course of the conversation, they are not established as being a matter of concern, as the surgeon explains that the impacts on the appearance will be minimal and that with time the changes will be less apparent.

Excerpt #8a

PT: […] on a fait des blagues l'autre jour, est-ce que je vais être avec un creux dans le visage ou
SUR: Non. Non, ça c'est moi, si on fait l'opération, c'est SUR2 qui enlève la tumeur […] et c'est moi qui reconstruit.
PT: OK.
SUR: On a tous notre job, c'est moi qui le fait, puis d'habitude je prends un peu d'os de votre jambe
PT: OK
SUR: Pour reconstruire. C'est sûr qu'il faut que vous ayez un scan déjà, on va le faire, mais je pense qu'il n'y a pas de raison, ça devrait être correct.
PT: OK.
SUR: Alors non, c'est faisable, tu vas paraitre, à peu près la même chose. C'est sûr qu'un petit peu, si on regarde, mais pas vraiment, ce n'est pas une diffromité qui est très large.
PT: OK.
[…]
PT: And what about the teeth?
RAD: Vous allez perdre les dents de ce côté-là, ça sera une prothèse après.

18 PT: OK.
19 SUR: Quand tu vas être réveillée, ça va être très gonflé, et ça c'est normal, parce
20 qu'avec le temps ça dégonfle, ça diminue un petit peu.
21 PT: OK.
22 SUR: Parce qu'on ne peut pas mettre parfait, puis là ça va diminuer et ça va être un peu…
23 PT: OK.

In this example, the patient asks questions about the appearance of her face (lines 1-2) and whether she will lose her teeth (line 16), and the surgeon gives information about swelling (lines 19-20). By using words such as *"tu vas paraitre, à peu près la même chose"* (line 12), *"ce n'est pas une difformité qui est très large"* (lines 13-14), *"avec le temps ça dégonfle"* (line 20), and by offering short answers (for example, line 17), the physicians show that they are not very concerned about these changes, and the patient does not question further and expresses agreement with what her doctors are saying ("OK" in lines 11-23). Later during the same visit, the surgeon brings up the swelling as something that could be of concern, by saying that seeing the patient's swollen face in the first weeks after the surgery could be traumatizing to her child (lines 33-38 below):

Excerpt #8b

24 FCG: La convalescence, c'est combien de temps?
25 SUR: Pour ça, vous êtes à l'hôpital deux-trois semaines, puis à la maison encore après
26 quelques semaines, et quand tu vas à la maison on veut que tu sois capable de marcher, alors
27 PT: OK. Puis combien de temps avant que je puisse parler, mettons au téléphone?
28 SUR: Mais c'est même, pendant que t'es à l'hôpital tu peux parler. Après qu'on
29 l'enlève [la trachéostomie], ça prend à peu près une semaine, mais après une semaine
30 tu peux parler comme d'habitude.
31 PT: OK. Pendant une semaine je ne veux pas que [mon fils] vienne là.
32 FCG: Non, ben non
33 SUR: Une semaine et… Puis aussi il y a beaucoup de fils qui sortent, beaucoup de, tu
34 vas voir, beaucoup de choses qui… Il a quel âge?
35 FCG: On va venir le chercher.
36 SUR: Ouais. C'est mieux après quelques, une semaine
37 PT: Oui, c'est ça.
38 SUR: Parce qu'il y a beaucoup de choses et tu vas être enflée, c'est traumatisant pour

39 FCG: Ah oui, ce n’est pas une belle image pour un enfant de huit ans.
40 PT: Oui non-non, je ne veux pas qu’il vienne me voir à l’hôpital.
41 SUR: Mais après, c’est correct. C’est sûr qu’après, il peut vous voir, quand tout est
42 enlevé et tu as l’air plus comme toi, c’est correct.
43 PT: C’est ça. OK. Parfait, merci.
44 SUR: De rien. ((Serre la main de la patiente.)) S’il y a n’importe quoi, appelez NUR,
45 on est là tout le temps. ((Quitte la salle.))

While talking about the swelling as a matter of concern in the immediate post-operative period (*“il y a beaucoup de choses et tu vas être enflée,”* line 38), the surgeon also talks about it as not being a concern in longer-term recovery (*“mais après, c’est correct […] tout est enlevé et tu as l’air plus comme toi, c’est correct,”* lines 41-42).

The example that follows further illustrates how physicians, in their way of explaining potential surgical impacts to patients, describe them as being concerning or not. In this example, the patient has to undergo a total laryngectomy (removal of the vocal box), and the surgeon explains to her that it is possible, but highly unlikely, that if during the surgery they see that the cancer has spread further to her esophagus they will have to proceed with a procedure called gastric pull-up:

Excerpt #9a

1 SUR: […] Si on voit que c’est un peu plus loin qu’on a pensé, puis on ne sait jamais, là
2 on ne peut pas mettre la, le lambeau pour reconstruire, parce que c’est dans votre poitrine,
3 on ne peut pas, c’est à l’intérieur. Puis là, ce qu’on fait, c’est vraiment, on prépare pour
4 le plan Z, c’est ouvrir puis lever votre estomac en haut, ça s’appelle le gastric pull-up.
5 PT: Oufff…
6 SUR: Ça, ça devient, la chirurgie devient plus grande, puis ça, c’est le chirurgien
7 thoracique qui le fait […], mais on pense que tu n’as pas besoin de ça, c’est vraiment, on
8 se prépare trop, mais c’est toujours bien d’être trop préparé que moins.
9 PT: Que pas assez.
10 SUR: Puis on ne veut pas être là, puis on… On est là pour enlever le cancer, il faut le
11 faire, parce que comme j’ai dit, on n’a pas la radiation dans notre poche. Alors, on ne
12 va pas tricher un petit peu pour la reconstruction, on va être là pour l’enlever. Mais ce
13 qu’on voit sur, vraiment, quelques centimètres, je pense que ça va être correct, puis on

14 a fait un cas la semaine dernière qui est la même chose et ça a bien été. Mais c'est
15 toujours mieux d'être préparé-préparé […]
16 PT: Ça veut dire quoi, l'estomac qu'on
17 SUR: Alors ça, d'habitude on met, ils font avec, ils font une petite incision ici puis une
18 incision dans le thorax, puis ils libèrent tout l'œsophage et l'estomac, puis ils le
19 montent en haut. Alors, on le lève, votre estomac qui est là, il va être dans la poitrine et
20 ici ((pointe en bas de sa gorge)), et on le faut suturer dans, en haut.
21 FCG: Est-ce qu'ils sont obligés de, d'ouvrir les côtes pour faire ça?
22 SUR: Non. Dans le passé, oui, mais maintenant, on le fait par
23 FCG: Laparoscopie
24 SUR: Laparoscopie, oui.
25 PT: Avoir l'estomac dans la gorge, c'est ça l'expression.
26 SUR: Oui!
27 PT: Avoir l'estomac dans la gorge. Qu'est-ce que ça représente après?
28 SUR: Pas grand-chose pour vous. La seule chose que, le reflux gastrique, ça peut,
29 parce que l'estomac est un peu plus gros, alors des fois l'acidité peut monter un petit
30 peu plus, uh, puis la déglutition, comment ça va aller, parce que là, c'est un différent,
31 mouvement de la nourriture qui est ici, alors, mais il y a des gens qui s'habituent très
32 bien à ça et… La seule chose que, et c'est vraiment, il faut aller dans la poitrine et dans
33 l'estomac un peu pour le faire.
34 PT: Donc, si je comprends bien, je n'aurai plus de voix, et je vais avoir l'estomac dans
35 la gorge. ((Rit, FCG et SUR aussi))
36 SUR: La voix, oui, l'estomac, extrêmement improbable, mais on se prépare au cas où.

As she is listening to the surgeon's explanation of the procedure, the patient first reacts to it in line 5 ("Ouff…"), and then asks the surgeon to specify what this procedure means (lines 16, 27). It is interesting to note here that the patient's questions are not very specific: *"ça veut dire quoi," "qu'est-ce que ça représente,"* and the answers of the surgeon that follow reveal how he interprets these questions. The surgeon first answers by further specifying the surgical procedures (lines 17-20), and then later talks about functional changes. He mentions differences in swallowing and gastric reflux (lines 28-31) and describes them as not very concerning (*"pas grand-chose pour vous,"* line 28) by mentioning that there are people who adjust to these changes very well (lines 31-32). Another marker of foregrounding/ backgrounding that can be identified here is the surgeon's speech rate: when listening to the recording, one can notice that he talks fast and responds to questions without hesitation, and one of the patients (whose pre-surgical meeting was not observed) commented on this in her interview and explained how she found it reassuring in the pre-surgical period: *“[Le chirurgien], c’est une question de qu’est-ce qu’il dégage. Puis d’alléger tout ça, puis de… De la rapidité qu’il en parle, puis ben, c’est comme tellement… regarde, c’est comme ça qu’on va faire, puis… bon, tout est tellement, on sait… ben, tu lui fais confiance, ce n’est pas, il n’hésite pas […]*”

At the end of the visit, the dietitian comes in to meet with the patient to talk to her about liquid meal replacements and the possibility of using feeding tubes for nutrition during her recuperation after the surgery:

Excerpt #9b

DIET: […] Je sais que vous avez rencontré le spécialiste, Dr NOM, au cas où que l’estomac est… dans la chirurgie. Cette opération va vous déranger un peu plus que les autres, OK, parce que votre estomac va être ici
PT: Dans la gorge
DIET: Alors, les grandes, les grandes bouffes, c’est un peu plus difficile, alors on va parler de ça un peu plus, mais c’est comme, il n’y a pas d’estomac pour aider à contrôler, alors il faut manger de très petites quantités à la fois, et, on va voir. La dernière personne que j’ai vue avec cette opération a bien réussi, mieux que tous les autres avant. Ça fait quelques années maintenant, parce que c’est une opération qui n’est pas utilisée souvent. Mais je, toutes les inquiétudes que j’avais, le monsieur a été le mieux pour avaler après. Alors je peux vous, je ne veux pas vous
FCG: Décourager
DIET: Vous décourager avant, parce qu’ils ont dit que c’est très petit, le risque, alors je ne veux pas vous mettre toutes les idées négatives, parce que chaque personne est différente, et on va voir comment.

In this conversation, the dietitian informs the patient about difficulties in eating (“*il n’y a pas d’estomac pour aider à contrôler, alors il faut manger de très petites quantités à la fois,”* lines 42-43), and says that she will tell the patient more about it after the procedure, if it takes place. She also explains why she is not telling the patient more about the changes now (which is a way of backgrounding them): not to discourage her, since the risk of having a gastric pull-up is low (lines 47-51). Like the surgeon, the dietitian also mentions the example of another patient who had this type of procedure and who could eat and swallow well (lines 43-47).

As shown in the previous sections, one of the ways patients bring up concerns during clinical visits is by asking questions. After the surgeon's reply in line 36 (Excerpt #9a) above, the patient asks what her voice will be like after the procedure, and she also asks about her quality of life.

Excerpt #9c

52 PT: Mais la voix, qu'est-ce que je vais avoir comme voix.
53 SUR: Bonne question. Alors, au début, ça dépend de ce qu'on fait, ou si on voit que
54 tout est beau puis les tissus sont bons, là on met une petite prothèse, puis la voix va
55 être, presque comme vous avez maintenant. Ça se peut que ça change un petit peu,
56 mais vous pouvez toujours parler, sauf il faut mettre votre doigt comme ça ((pointe
57 vers le milieu de son cou, l'endroit où un stoma – un trou permanent dans le cou pour
58 la respiration et la voix – sera fait)).
59 PT: Oui, j'ai vu le monsieur tout à l'heure.
60 SUR: Oui!
61 PT: On entendait le monsieur.
62 SUR: Oui, exactement.
63 FCG: Il était remarquable.
64 SUR: Oui-oui, c'est ça. Alors, d'habitude les gens s'habituent, et après on peut mettre
65 quelque chose comme ça, puis les gens vivent très bien, ce n'est pas quelque chose de
66 gros.
67 PT: Qualité de vie?
68 SUR: Bonne qualité de vie avec ça. Il y a des gens qui vivent très bien, il y en a même
69 qui travaillent avec ça.
70 NUR: On va vous faire rencontrer quelqu'un aussi.
71 SUR: Mais il faut que vous vous habituiez, ça change votre vie, ça, c'est sûr et certain,
72 ça va changer votre vie. Mais je pense que vous, vous êtes préparée à ça, vous êtes
73 PT: Oui.
74 SUR: Oui, parce qu'il faut être motivé aussi pour le faire. C'est la motivation, puis je
75 pense que vous, ce que, je vous connais un petit peu, je pense que tu peux le faire.

In this excerpt, similar to the discussion that took place before, the surgeon talks about possible small changes in the voice, and says that it will be almost like the patient's voice now ("*la voix va être, presque comme vous avez maintenant,*" lines 54-55). He mentions that the patient will have to use her thumb to be able to speak (lines 56-57) and that usually people get used to it and live very well with it (lines 63-65), which is reinforced when the patient and her family member talk about the patient who had a similar surgery and who was talking (*"on entendait le monsieur […] il était remarquable,"* lines 60-63). When the patient asks about quality of life (line 66), the surgeon talks about the surgery as being life-changing (lines 70-71), which is a way of emphasizing the impacts of the changes, and adds that there are a lot of people who live well with it, who continue to work (lines 67-68), and that he thinks that the patient is prepared for it and motivated to adjust (lines 71-74). In this way, during the conversation, changes in function tend to be described by emphasizing that differences from the patient's present function will not be that big, and that people usually adjust well to these differences.

In the interviews, team members talked about the importance of developing realistic expectations while giving hope to patients, and the excerpt above illustrates how the surgeon mentions the life-changing character of the surgery while emphasizing recovery and return to function. In the next paragraphs, two examples will further illustrate how long-term recovery was emphasized in discussions about changes that took place following a patient- or a family member-initiated statement.

In the following excerpt, the patient's family member, after the surgeon explained the surgical procedures (removal of the voice box) to the patient and his family, asked about quality of life:

Excerpt #10

1 FCG: Fait que tu vas parler, tu vas avoir une bonne qualité de vie?
2 SUR: Oui. C'est une vie différente, je ne peux pas rester ici et dire, rien ne change pour
3 vous, après tout ce que j'ai expliqué, beaucoup de choses changent.
4 PT: Mais oui.
5 SUR: Mais une qualité de vie, oui, c'est bien possible. Si vous avez le bon espoir et
6 PT: Oui, faut que
7 SUR: Du support, et vous avez une attitude positive, oui. Par exemple, et nous pouvons vous
8 donner beaucoup d'exemples, vous allez rencontrer un autre patient qui a eu une chirurgie
9 comme ça, pour vous expliquer comment ça va avec ça, OK. Mais je peux dire que
10 PT: Mais quant à vous, vous avez une bonne confiance.
11 SUR: J'ai un gars, à peu près le même âge que moi, nous avons grandi dans le même
12 coin. Et ça fait 12-14 ans qu'il a eu, à 35 ans à peu près, il a eu un cancer ici. On ne peut
13 pas traiter un cancer comme ça ici, c'était donc une laryngectomie, à l'âge 35, avec des
14 petits, trois petits garçons, OK. Et il vit encore, les enfants sont [grands] comme ça,
15 une-deux fois par année il a des billets pour les Canadiens [une équipe de hockey], il
16 m'invite, on mange avant, et nous sommes dans le Bell Centre [un aréna], on parle
17 avec tout le bruit, il prend des vacances avec sa famille, une fois, deux fois par année…
18 Il va dire qu'il a une bonne qualité de vie. Mais est-ce qu'il va dire que sa vie est
19 exactement la même qu'une autre personne qui a eu une laryngectomie, non. Et il y a
20 beaucoup d'exemples comme ça.

The surgeon acknowledges that a lot of things will change after the surgery (lines 2-3), and emphasizes future recovery by telling a story of another patient who went through similar surgery with good outcomes (lines 11-18), including recovery of voice and eating function (*"une-deux fois par année il a des billets pour les Canadiens, il m'invite, on mange avant, et nous sommes dans le Bell Centre, on parle avec tout le bruit,*" lines 14-16). The patient's comment about his doctor's confidence that good quality of life is possible after the surgery (*"Mais quant à vous, vous avez une bonne confiance,"* line 10) highlights that it matters to the patient, which points to the importance of reassurance during the pre-surgical period that was described at the beginning of this section. The surgeon also mentions that hope, support and positive attitude help find quality of life after surgery (lines 5-7). Similarly, in Excerpt #9c above (lines 71-74), the surgeon says that patients need to be motivated to return to their activities after surgery, and that he feels that the patient is prepared and could have good quality of life.

These interaction patterns can also be illustrated by the following example, where the speech-language pathologist expresses her confidence that the patient will return to his activities while discussing the consequences of a laryngectomy:

Excerpt #11

1 PT: I'm very active, I bowl a lot and I golf a lot, for years and years, so I called my golf
2 ((inaudible)) the other day and I told her that maybe I'll be back in [two or three months from
3 now], and now I'm just wondering if that would be possible or not, after an operation like this.
4 SLP: It's a pretty big operation and the recuperation can take some time, for sure, and I
5 think most people usually feel that… you know, everybody's different, some people,
6 we have a patient who is a little bit younger than you, but he had his operation, and I
7 was surprised, I got an email from him, and he was already back in Cuba. And his
8 thing is scuba diving. But we are going to talk about, a little bit, he's not able to scuba
9 dive anymore, and we are going to talk about why he's not able to scuba dive. And
10 some of the limitations that, some of the things that are, that you'll be able to do after
11 the surgery. I think you're going, you know, you're a bowler, and you're a golfer, and
12 that's what you want to get back to doing, and so I think you're going to get back to
13 doing the things that you enjoy, and if you are not able to, then I think you're going to
14 find something else that you're able to do, or find an adaptive way to do it. And some
15 people say that it can take up to six months or so, to really get back to what they were
16 doing. Some people say a little bit longer, some people say a little bit less, so… But if
17 you have the drive to do it, then
18 PT: Well, I've been active all my life, so it's going to help.
19 SLP: Yeah, I think so, for sure.
20 PT: Yeah.

Following the patient's question about when he could return to sports and activities that he has been doing (lines 1-3), the speech-language pathologist mentions that the operation is "pretty big" (line 4), that recovery can take some time, up to six months (lines 4, 15-16), and that the patient may not be able to do the same things that he used to (line 13). At the same time, she says that she thinks that the patient will find a way to adapt and to do activities that he enjoys (lines 12-14), which is further emphasized by the patient's remark "I've been active all my life, so it's going to help" (line 18) and by the speech-language pathologist's answer "Yeah, I think so, for sure" (line 19).

The patient's remark in line 18 and the speech-language pathologist's response, as well as another patient's comment about his surgeon's confidence and the surgeon's response in Excerpt #10 above (lines 10-11), are examples of how recovery and hope are emphasized in conversations. While changes after the surgery are brought up by the professionals, patients in their replies comment on the recovery (Excerpt #11, line 18), and providers build on these comments to encourage and reassure them (Excerpt #10, lines 11-19; Excerpt #11, line 19), and express their confidence that patients will be able to get back to their life and activities (Excerpt #9c, lines 71-74; Excerpt #11, lines 12-17). The following excerpt from an interview with a surgeon, in addition to the interview excerpts presented at the beginning of this section, further illustrates how team members value their role of motivating and empowering patients. Here, one of the team members specifically comments on his frequent use of the expression "You are part of the team" with his patients:

> […] I think that's important, I think that I want them to be part of our, we're a team, as you know, surgeons, radiation, speech therapist, there's so many, you guys, so this is all a big team, but they have to be part of it, they have to join that team, we are not sort of fighting them against it, they have to be part of it, to try to help them. And I think those of our patients that do well, that sort of join, we are a team and they are also joining, they feel like they're battling this with us, you know, sort of thing. So they have an input, it's very important that patients feel like there's an input, you know, what they do, and hopefully they'll get better, not to give up and stuff, and to sort of butt heads, you know, so, because sometimes they don't want to do something, you know, so we have to make sure we are doing it so that you can swallow better or you need to exercise, there's a lot of exercise if people can't swallow, you need to exercise at home, so they have to be motivated to go home and exercise, they are part of that rehab, too. So that's why I try to make sure that they are, they feel empowered, too, to help themselves.

While viewing reassurance as important in the pre-surgical period, some team members explained how sometimes it does not prepare patients for the consequences of the surgery. This can be illustrated by two quotes from interviews with two professionals:

> […] on ne sait pas nécessairement qu'est-ce qu'ils vont récupérer après leur chirurgie […] on ne sait pas à quel point le patient, comment sa locution va être affectée par la chirurgie, puis il y a différents médecins qui tendent à être, qui veulent encourager le patient aussi, on ne va pas leur dire, mais là, vous ne parlerez plus, votre vie, ça va être l'enfer après, mais dans certains cas, finalement, tu as la perception que, malheureusement, leur vie, leur qualité de vie après, elle n'est pas optimale. Et qu'on ne peut pas… on n'a pas de baguette magique pour rendre la parole ou rendre la déglutition au patient… Fait que ça, c'est sûr que, c'est difficile, de voir les gens souffrir aussi, une fois la chirurgie faite […]

> […] I think just making certain that like, the doctors, we're going to take out your voice box, and we're going to put a prosthesis in and then you're going to talk. And like, it's not necessarily that simple of a thing to do. Our most recent patient, he's 82, and he is going to be able to talk, but it's going to be a long process. […] just in terms of him learning how to do it, being 82, he needs some time and some more guidance than somebody who's in their 60s who's like, got it and, so, but he'll get there.

In relation to this last observation, one of the patients who had a voice prosthesis made a similar comment in her postoperative interviews. She experienced problems with her voice prosthesis, and felt that patients should be informed about potential difficulties:

> J'aurais aimé en savoir plus sur le processus du retour de la voix et comprendre mieux les différents objets utilisés pour les problèmes liés à la prothèse de voix. Regarder plus tôt l'état de la prothèse et plus régulièrement avant le départ. Mieux comprendre les conséquences éventuelles des problèmes liés à la prothèse et la cicatrisation des tissus internes. Je sais que j'ai vécu, et vis encore, des choses un peu inusitées qui ont mis l'équipe (médecin et ortho) dans des situations difficiles à évaluer. […] Prévenir que même si la prothèse de voix est installée lors de l'opération, il peut y avoir des problèmes et qu'il faille faire différentes interventions.

Thus, while encouragement from the medical team may have a positive impact on patients' experiences, as I described at the beginning of this section, it can also have a negative impact by backgrounding potential negative outcomes and not helping patients to prepare for the consequences of surgery.

5.2.3. Presenting surgical procedures as routine. Another way of establishing body changes after the surgery as not concerning that was observed during the meetings were mentions of routine surgical procedures and the team's experience with performing such procedures. This can be illustrated by the following example where the surgeon explains how he is going to reconstruct an area on the patient's neck to replace the tissue that will be taken out during surgery:

Excerpt #12

SUR: […] To reconstruct that area, because it's going to be quite wide, we have to take tissue from other places. Uh, so we usually take it from your arm. We take a, a skin, it's called the free flap, we take skin from your vessels, with some vessels ((shows on his left arm)), and we take this and put it there to reconstruct that area and to provide some bulk to it.
PT: OK.
SUR: And we connect these little vessels to the neck, to make sure there's blood supply. There's always a risk, which is very low, about 2%, that the flap doesn't survive, that there's a rejection. And then we have other plans, well, plans, the chance of that is very low, 98% chance you'll be fine, and most people are fine, you're healthy, you're fine, there should be no reason why your vessels are not good. Uh… but there's always a bit of a risk to that. Uh, and then for this, usually we try to close this, but I have a feeling with your size, we actually take a little skin graft from here ((touches his thigh)) and we put it there ((touches his arm)). ((PT laughs)) The reason why we don't take this to there- ((Noticing FCG's facial expression)) Oh, I know
FCG: Aïe! ((Laughs))
SUR: The reason is, the reason why we, this is just a skin graft, it's very thin
FCG: Yeah.
SUR: And it wouldn't fill the defect. Whereas, here, you can easily fill it, so it's like a… It's a little bit of patchwork
FCG: Uh-huh.
SUR: But that's… We do this once a week here, so. It's called the free flap surgery.
PT: I'm anxious to get started.

In this example, the patient reacts to the surgeon's explanation with laughter (line 14), and his partner says "Aïe" and laughs as well (line 16). In response to these reactions that could express possible concerns, the surgeon explains why the procedure has to be done in that particular way (lines 17-20) and says that he does it weekly (line 22), thus establishing the procedure as not being a matter of concern, which is further consolidated by the patient who changes the subject by mentioning that he is anxious to get started (line 23).

The following excerpt illustrates how the surgeon presents the surgical procedure as routine in response to a patient's family members' question about the impacts on function of removing lymph nodes in the patient's neck:

Excerpt #13

1 FCG1: And how many lymph nodes would you remove?
2 SUR: We remove all… It's… Everybody's different, probably about 20 or 30, roughly
3 FCG1: What are like, the long-term side effects of not having the lymph nodes in that area?
4 SUR: Nothing, nothing. We do this all the time, we do neck dissections, we
5 FCG2: Like it doesn't do anything
6 FCG1: They are obviously there for a reason, right? ((Smiles))
7 SUR: Your immune system, you have so many in your body that if I remove 20 or 30,
8 it's not going to be any difference in your life.

The surgeon responds to FCG1's question, "What are […] the long-term side effects of not having the lymph nodes in that area?" (line 3) by saying that he does this procedure all the time (line 4). By paraphrasing and asking a follow-up question (lines 5-6), the family members show that the surgeon's response is not enough, and the surgeon then further explains why they should not be concerned about the removal of the lymph nodes (lines 7-8).

These two examples also illustrate how patients' concerns about surgical procedures can be expressed vaguely, as in the first example, or in the form of specific questions, as in the second example. They also show how the surgeon's mention of routine procedures is accepted as a satisfactory response by the patient and his partner in the first example (they do not ask any further questions), and how in the second example potential impacts of the surgery are further emphasized when the family members ask additional questions, and are re-established as not concerning by the surgeon who offers further explanations.

Two patients whose pre-surgical meetings were not recorded talked about their surgeons presenting procedures as routine, which offers further evidence to identify this theme as a particular way of framing. These patients described how presenting surgical procedures as routine during pre-surgical meetings influenced their experience. One of the patients, for example, said that it was reassuring for him:

> J'avais les deux, ils m'ont expliqué ce qu'ils allaient faire… Uh, en me disant, me rassurant qu'il y avait toutes chances de succès, que c'était rendu presqu'une routine, chirurgie routine, ce qui m'a… rassuré.

One patient commented on a particular expression that his surgeons used, *"routine sérieuse"*:

> […] j'ai beaucoup aimé aussi, il m'a dit que c'était une opération qui est de routine, mais qui est sérieuse. Autrement dit, on le fait souvent, mais c'est délicat. Il dit, on en fait deux-trois fois par semaine, mais il faut être très méticuleux pareil. J'ai beaucoup aimé la définition qu'il a donnée à la gravité de l'opération, les termes qu'il a utilisés. […] j'ai trouvé ça très rassurant qu'il avait de l'expérience là-dedans, que ce n'était rien de nouveau pour lui, mais, par contre, c'est délicat. J'ai beaucoup apprécié ces deux termes. Délicat, je me doute parce que, dans ce coin-là, il y a beaucoup de vaisseaux sanguins, des nerfs, il y a des dents, il y a… Il y a beaucoup de choses. Fait que, c'est peut-être pour ça qu'il a dit que c'était très délicat, ça ne serait pas comme travailler sur un fémur, mettons. Ici il y a beaucoup de nerfs, il faut qu'ils fassent attention pour ne pas couper les bons nerfs, il faut être très délicat. […] On prend notre temps puis on fait un bon travail même si on sait qu'on l'a déjà fait plusieurs fois, oui.

Another patient also noticed that his surgeon mentioned that he does the procedure often, but in his case, he felt that it didn't give him a clear picture, since he received a different opinion from another physician:

> […] lorsque tu en rencontres un puis qu'il te donne une version des faits puis tu rencontres l'autre puis qu'il te donne un point de vue qui est différent, là tu remets en question, par rapport au Dr NOM que j'avais rencontré versus Dr SUR qui dit, oui, il n'y a aucun problème, je fais ça fréquemment, ça va très bien aller, le pronostic est super bon. Bon, c'est sûr qu'il tient compte de mon âge, de ma condition, de l'état de mon diagnostic, et cetera, et Dr NOM qui lui m'a dit, mon dieu, vous savez monsieur PT, êtes-vous sûr que vous voulez une reconstruction, savez-vous dans quoi vous vous embarquez, vous savez qu'il y a beaucoup de, beaucoup de patients, le taux de satisfaction n'est pas très élevé par rapport à ça […] ça me fait penser, quand tu as le petit ange puis le petit diable, mais à un moment donné, donne-moi l'heure juste, ou essaie de me donner une meilleure idée.

Once again, these excerpts illustrate how the same communication pattern (i.e., presenting surgical procedures as routine) may affect patients' experience both positively and negatively. The potential negative impacts, as shown in this excerpt, consist in backgrounding body changes, which may not allow patients to fully understand the impacts of the surgery.

Having presented recurrent communication patterns during the pre-surgical visits and their potential impacts, I will now discuss how patients and providers perceive the roles of different team members in discussing body changes, and how these roles may manifest in clinical interactions.

5.3. Team members' roles in discussing body changes

In the context of an interdisciplinary team, different team members (surgeons, speech-language pathologist, dietitian, and nurse) have different roles in patient care. In this section, I will focus on one specific theme that was identified during patients' and providers' interviews: medical team members' roles in discussing patients' concerns and psychosocial concerns in particular.

5.3.1. Assessing and addressing psychosocial concerns. The interviews that were conducted with patients and providers for this study, as well as other research on interactions and framing that was reviewed in the previous chapters (see Dewulf et al., 2009; see also Cooren et al., 2012), indicate that participants' perceptions of their roles in a particular situation shape what issues they will bring up (or foreground) in conversations, and what issues they will not bring up (or background). In this section, I will show how team members and patients view their role in expressing and addressing psychosocial concerns during pre-surgical consultations. This aspect of patient-provider communication was identified as a distinct theme in this study following the observation that some of the concerns that patients shared with me during the interviews were not brought up during their visits. Patients explained why they did not bring up certain subjects, and team members made similar observations in their interviews. Four examples of conversations during pre-surgical visits were identified to illustrate how patients' and providers' perceptions of their roles in addressing psychosocial concerns are reflected in patient-provider conversations (which, in turn, might contribute to shaping patients' perceptions).

It has been suggested in previous studies that health professionals might find it difficult to assess and address patients' psychosocial concerns, for example concerns about appearance, because of the time restrictions in the context of busy clinics, or the uncertainty as to how to best address the topic with their patients (Lewis-Smith et al., 2018, p. 73). In the interviews, two surgeons made similar observations:

> […] we only have X amount of time, right, we're dealing with complex situations, complex health care problems, complex cancer, complex psychosocial issues […] So I won't deceive myself in thinking that I can assess and have our 45-minute [diagnostic] consultation and then maybe another half-hour visit where we discuss surgery and then

> go to the OR [operating room], that's a total of one hour, I will not deceive myself and say, oh we understand everything that this patient needs, clear cut, and we've addressed them all. The truth is that we probably don't understand their needs and we have not addressed them all. But I think that's the reality of trying to practice health care in a setting that we work in and I think that we also rely a lot, we're lucky that we have [our] infirmière pivot […] social workers and our psychologist who help assess and recognize and address some of their needs beyond the direct immediate cancer care. So I think we do better than we used to because of the team that we have around us. But even with that, you don't necessarily define correctly all their needs and address them. And I think that a lot of the research actually […] is revealing that.

> […] quand on parle de la chirurgie et surtout pour les grosses opérations, effectivement, les patients sont comme muets, ils écoutent puis on le voit qu'à un moment donné il y en a trop qu'ils ont à intégrer puis à gérer […] c'est comme si à un moment donné leur tête est tellement submergée qu'il ne peut plus y avoir de questions qu'ils sont capables de poser, puis souvent c'est NUR qui va finalement répondre aux questions […] Nous, souvent, on ne reverra pas les patients après ça, on va les voir, on va tout expliquer, et finalement on va les voir la journée de l'opération. C'est rare que les patients vont finalement revenir nous voir pour qu'on ait le temps de faire ça. Souvent ça va être NUR qui va se ramasser à faire ce travail-là ou à faire ce trait d'union entre notre rencontre pour tout expliquer puis le fait que le patient a pris quelques jours ou une semaine, peu importe, pour arriver à digérer toute cette information-là, puis que les questions finissent par être soulevées dans leur tête, puis qu'ils soient capables même de les formuler, parce qu'au début j'imagine c'est tellement de choses que, exactement, tu ne sais plus quoi poser comme question. Tu sais qu'il devrait y avoir plein de questions que tu devrais avoir, mais […] tu te sens submergé par tout ça, puis les questions vont venir, mais après. Mais là, tu n'es plus dans le bureau quand c'est le moment.

In these excerpts, health care providers recognize the difficulty of discussing psychosocial concerns with patients and highlight the importance of other team members (the nurse navigator and the psychologist) in assessing and addressing their patients' psychosocial needs. One of the surgeons also mentioned that many of her patients are not always able to ask for psychosocial support during meetings, and that the nurse pivot played an important role in reaching out to these patients and helping them with these needs:

> […] il y en a qui vont être très bons à formuler ou même ils vont dire, j'ai besoin de quelqu'un à qui parler, est-ce qu'il y a un psychologue que je pourrais voir, par exemple, il y en a qui vont d'entrée de jeu le dire. Il y en a d'autres qui sont

> évidemment super fermés à l'idée, ils ne parlent pas, ils ne posent pas de questions, ils vivent ça à leur manière, mais la majorité des patients se situe un petit peu au milieu, ben, tant mieux pour ceux qui sont capables de le formuler puis de dire qu'ils ont besoin d'aide, mais c'est quand même une très petite portion des patients ou au moins, les patients ne sont pas tous à l'autre extrême non plus. Et puis ils arrivent à un moment donné à, puis une chance qu'il y a comme un peu des filets, comme NUR qui peut un peu récupérer ces patients-là pour les aider puis répondre aux questions qu'elle est généralement capable de répondre.

In her interview, the nurse talked about her role in similar terms, and she explained how she tries to bring up psychosocial issues with patients that she knows are not frequently addressed in their meetings with other team members. As an example, she talked about patients' potential concerns and support needs around sexuality:

> Ce n'est vraiment pas quelque chose qu'on aborde ou que les médecins vont aborder, fait que là j'essaie […] mettons un patient va se faire enlever un œil, tu ne penses pas à le dire, mais vous savez, ça va peut-être changer votre relation avec votre conjointe […] c'est sûr que c'est quelque chose à quoi ils vont penser aussi, bon, les enfants comment ils vont me regarder, mais ce n'est pas quelque chose qu'on pose naturellement, en général c'est même tabou. Et tout le monde va dire, c'est à quelqu'un d'autre de le faire, et là, je fais un exercice d'en parler, vraiment, parce que ce n'est pas quelque chose qu'on va aborder. On parle de, OK, on va vous sauver la vie, mais il y a comme une vie après, et elle n'est pas la même, donc, oui, j'essaie de penser aux autres petites choses à côté.

This understating of different team members' roles was also reflected in patient interviews. Patients said that they did not share their concerns with their surgeons because they did not perceive it as being the surgeons' role, and they saw how busy they were at the clinic. Patients also mentioned that they had other resources available to them, including the nurse, for example:

> […] on a des ressources autres, mais ce n'est pas avec [les chirurgiens], ils ne sont pas là pour un échange là, sur nos émotions, puis c'est correct, comme je disais. Eux-autres, c'est médical, puis… Ils arrivent à peine, ils sont toujours débordés, comme tous les autres.

> Eux c’est des super-techniciens qui règlent un problème très précis. […] Moi ce qui m’importe le plus avec l’équipe chirurgicale, c’est de savoir qu’ils faisaient la meilleure job possible, que c’étaient les meilleurs. […] pour ça, ils ont fait leur job, ils ont rencontré mes attentes.

Let us now see how these views about team members’ roles are reflected in conversations during pre-surgical visits where potential psychosocial concerns brought up by patients are backgrounded through not being explored in more detail by the providers. The first example is from the pre-operative meeting of a patient who had a tumor in her nose. After the patient asked about how long she may have to wait between the first surgery to reconstruct her nose and the corrective surgery to improve the way the reconstructed nose looks, her family member said that she might have difficulty going out during that period:

Excerpt #14

PT: And when you do reconstruction, let’s say a month later, within the month later, and let’s say it’s a one shot, the first shot of reconstruction, there might be another one, how much time frame am I looking out, how many months out?
SUR: Oh, it varies depending on what we do, it’s hard to know. You know, if we do this, or if we do just a forehead flap, it’s… You’re basically talking a good six months, for sure, you know, all in all.
PT: OK. It’s just that
FCG: She might not be able to go out with her nose
SUR: Well, we’re going to, if we do a forehead flap, which is a flap, you flip it, you’re going to look very funny for a good month.
PT: I know, it looks horrid, it looks horrid.
SUR: Because we leave it connected, it looks terrible for a good month.
PT: Yeah.
SUR: You do, yeah, I can’t go on and
PT: Yeah.
SUR: […] it’s a shock, you know. But after that, when you cut that little bridge and it starts looking more like a nose, it starts looking better. But it takes a long time to actually go down and to heal, and even after 6 months you might need a little procedure after, to fix the skin.
PT: This is just, it’s important but it’s not as important as my this ((points to her nose)), my plan this year was to have [talks about another health problem that she has] […]

Following FCG's remark "She might not be able to go out with her nose" (line 8), the surgeon validates it by saying that it will look "very funny" (line 10), to which the patient responds, "I know, it looks horrid, it looks horrid" (line 11), further expressing her potential concern about appearance. The surgeon continues to explain that it will look terrible at first (line 12), that it will be a shock (line 16) and that recovery can take a long time, and in response the patient explains that she is asking about the time frame because of another health condition (lines 20-21).

The second example is an excerpt from a meeting of another patient who had a tumor in his nose, which was referred to in the previous sections, in Excerpt #7. This conversation took place after the patient told his surgeon about his meeting with another physician that made him question his choice of surgical reconstruction and consider a prosthesis to replace his nose. The surgeon asked the patient:

Excerpt #15

SUR: Qu'est-ce que tu en penses, je veux savoir, qu'est-ce que t'en penses maintenant?
PT: Moi je pense que, je pense que je vais honnêtement, je pense que je vais y aller vers la prothèse.
SUR: Prothèse?
PT: Mais je vais me donner quelques heures là
SUR: Mais c'est pour ça que je vous demande un petit peu, pour savoir.
PT: C'est sûr que tu vas m'enlever le septum, il faut enlever les narines, je vais me faire faire une prothèse, je crois.
SUR: OK.
PT: Uh… Je vais essayer de voir, je vais avoir mes traitements de radio, je vais voir comment- D'abord, le plus important pour moi, c'est de voir que le cancer est disparu, ça c'est sûr, et c'est normal. Et la deuxième chose, uh, c'est que je sois à l'aise pour sortir à l'extérieur, mais je veux dire, j'ai été, je sors avec mon pansement présentement, je vais dans des, l'anniversaire de mon frère il y a une semaine, c'est correct, mais c'est sûr que le regard des gens n'est pas le même
SUR: C'est sûr, non
PT: C'est évident là
SUR: Oui.

19 PT: Mais en même temps, bon, ce n’est pas si
20 SUR: Mais n’importe quoi tu décides, ça va être ça, eh, prothèse ou pas de prothèse
21 PT: Mais je comprends, mais je veux dire, ce n’est pas que je n’ai pas confiance pour
22 la reconstruction là
23 SUR: Non-non
24 PT: Ce n’est pas la, mais je regarde le pour et le contre, et je me dis, ouais, moi ma
25 blonde je pense qu’elle va accepter le choix que je prends, puis ma famille est au
26 courant de toutes les décisions puis des choix. Ce qui est important, c’est que j’espère
27 que je vais garder une bonne qualité de vie pendant plusieurs années, je l’espère, je le
28 souhaite, puis être capable de vivre, même si j’ai cet handicap-là, mais c’est correct, il
29 y en a qui en ont des, bien pire que moi, puis c’est correct, je veux dire.
30 SUR: L’autre positif pour faire la prothèse, c’est plus facile pour nous de suivre le
31 cancer, aussi.
32 PT: Ah oui, c’est sûr.
33 SUR: Parce que, on va se revoir beaucoup, eh, on va se revoir pour au moins cinq ans,
34 puis quand on l’enlève, on regarde, puis c’est très facile à voir s’il y a des traces. Si on
35 fait la reconstruction, on regarde avec la caméra, mais ce n’est pas la même chose. Puis
36 on fait un CT scan d’habitude pour être sûr qu’il n’y a pas d’autres choses.
37 PT: Puis l’avantage que j’ai aussi, c’est que, si je me fais faire une prothèse, ben,
38 exemple, j’ai un catalogue de nez puis je peux choisir celui que je veux
39 SUR: ((Rit.)) Oui!
40 PT: Donc, mais là dans le fond, ça c’est, je pense que ça va être ça, mais je vais
41 [réfléchir], jusqu’à maximum demain matin
42 SUR: Oui.
43 PT: Puis la dernière chose, mais là je vais voir Dr RAD pour la radio. […]

The patient tells the surgeon that it is important to him to be able to go outside, and that he noticed that people did not look at him in the same way (lines 12-15), and the surgeon expresses acknowledgment in response (lines 16-18). When the patient continues to talk about his concerns *“Ce qui est important, c’est que j’espère que je vais garder une bonne qualité de vie pendant plusieurs années, je l’espère, je le souhaite, puis être capable de vivre, même si j’ai ce handicap-là”* (lines 26-28), the surgeon responds by talking about the advantages of the prosthesis, in terms of post-operative follow-up (lines 30-36).

The third example is from a pre-operative meeting with the speech-language pathologist. The patient has laryngeal cancer that affects his voice quality, and the speech-language pathologist tells him about supports that are available so that the patient can speak louder:

Excerpt #16

1 SLP: […] how long has your voice been
2 PT: My voice changed this year.
3 SLP: OK.
4 FCG: Over the holidays.
5 SLP: OK.
6 PT: We went to breakfast in March with some good friends of ours, every Saturday and
7 Thursday, and my voice was getting lower and lower. And they told me, keep your
8 mouth shut, because we don't know what you're saying.
9 SLP: Because they can't hear you.
10 PT: That's it.
11 SLP: There's something I could do in the interim, between now and your surgery, is to
12 order a voice amplifier for you, if that's something that you would be interested in using.
13 It's something that goes just around your head, kind of a microphone here, and then
14 there's a little amplifier that you can carry around with you, you can put it on your
15 buckle and you can turn up the volume of your voice that way. So if you're at a
16 restaurant, or if you're in a more noisy setting, it's going to carry your voice more. The
17 quality will be the same, but it's going to be louder.
18 PT: I think I'm going to be so embarrassed, I don't think I want to do that.
19 SLP: There's also, the side mike as well, so you could just put it on the side of your
20 shirt here. People don't say that it works as well as the one that goes around your head
21 that's a little bit more intrusive, but it's something that you could think about using for
22 the next couple of weeks or so.
23 FCG: Well right now he has like a little electronic writing board.
24 SLP: OK, yeah. And you use that?
25 PT: Yeah.
26 SLP: That's something that you definitely want to bring to the hospital with you, OK.
27 PT: Yeah, it's very nice.

When the patient expresses potential concern about using a microphone (line 18), the speech-language pathologist tells him about a less visible device, without exploring his concern in more detail (lines 19-20). The patient also mentioned possible embarrassments related to speaking with others to the nurse, when he saw her just before his appointment with the speech-language pathologist, to discuss pre-surgical preparation and the visits and tests that he had to do to make sure that he was ready for surgery. In the following excerpt, the patient brings up his concern in response to a solicitation by the nurse, which reflects her role in assessing psychosocial needs that was discussed in the interviews with providers mentioned above. At the end of the meeting, the nurse looks at the patient, sees that he looks sad and asks him:

Excerpt #17

1 NUR: But how do you feel about it? You look…
2 PT: Well, I guess it… I made up my mind, I said, look, something has to be done, and
3 I'm going to do it. I know there's going to be a lot of… Embarrassments for me,
4 because I know a lot of people, I do a lot of things with people, so I don't know how
5 this thing is going to work. Some people say they don't hear, and then the voice could
6 be much different.
7 NUR: Yeah. There are different devices, and this is something you can look at with
8 SLP. But then also you'll meet with a patient who had it, you can have a better idea.
9 PT: Oh yeah, right.
10 NUR: And also, I don't know if she mentioned it to you, but there's a support group,
11 monthly, and you meet many other people who went through laryngectomy, so you can
12 share your experience also.
13 PT: But then, to me, I will be busy with everything…
14 NUR: Yeah, you want to go back to your bowling and
15 PT: Yeah, look, to me, my golf is, I've been playing golf for many years, I was always
16 a member of a club, different clubs. So, to me, it's part of my life.
17 NUR: Yeah.
18 PT: But now, I don't know, when I go back…
19 [The nurse tells him how long his hospital stay will last]

As in the previous excerpt, the nurse tells the patient about available devices (lines 7-8). In addition, she mentions that there is a support group where the patient can share his experience (lines 10-12). The nurse inquires about the patient's thoughts (line 1), and the patient shared his concern about embarrassments with her, concern that he also shared with the speech-language pathologist. The nurse responds by suggesting several support resources to the patient, thus recognizing that the patient's remarks about embarrassments could potentially represent a need for support. In other words, by doing so, the nurse recognizes the patient's remarks as a matter of concern, as something that has to be attended to.

These excerpts, along with the previous examples, illustrate how potential psychosocial concerns expressed by patients or family members may not be explored (or backgrounded) by health care providers during clinical appointments, and illustrate the importance of addressing this topic and the role of the nurse who brings it up with the patients. As one of the patients explained in her interview:

> Les changements d'apparence, quand c'est au niveau du visage, je pense que les gens devraient être mieux préparés puis peut-être de voir, de faire un genre de test psychologique avant l'opération pour voir l'importance que ça l'a dans la vie de quelqu'un, de préparer avant les faits, plutôt que d'être devant les faits accomplis puis de plus avoir le choix. […] moi, c'est énorme, c'est très, je ne suis pas capable de passer au travers, je ne suis même pas capable d'aller ailleurs qu'au dépanneur, je ne vois plus personne dans ma vie, je ne veux pas que personne me voie comme ça, je me trouve laide, je n'ai plus d'amoureux dans ma vie parce que je ne m'aime pas, je m'haïs. […] Et on ne m'a pas préparée à ça du tout.

The need to assess the importance of appearance in a patient's life described by this patient was also brought up by another patient and highlighted by the nurse:

> Puis là, tu te remets en question, parce que tout ce qui [est] question d'esthétique, je me suis dit, je refuse d'être si superficielle. Mais, est-ce que c'est être si superficielle? Ou c'est juste normal que, eille, je vais ressortir comment là, avec toute cette histoire-là? Je vais-tu avoir des bandages pendant trois mois? Je vais-tu…
>
> […] j'ai des patients qui me disaient ça, justement, j'étais convaincue que je me fichais du physique, mais là je trouve que j'ai l'air d'un monstre. Parce que ça change aussi ta perception de ce qui est important. Quand on, on a comme une balance, tu te dis, j'ai le choix entre vivre ou mourir, OK, ben là, je vis, mais finalement j'ai l'air d'un monstre puis je, je n'aime pas ça, finalement. Je pensais que je m'en fichais de l'apparence, mais non, je ne m'en fiche pas.

One more patient in the study said in his post-surgical interviews that he would have liked to be more prepared to deal with the impact of the surgery on the psychosocial level. He specifically commented on how these impacts can be overlooked in the context where patients look for reassurance in the face of life-threatening illness, and physicians present treatment in reassuring ways (as discussed in the sections above):

> Lorsque tu es le sujet d'un problème comme celui que j'ai, puis que c'est abordé de façon légère, ça peut avoir tendance à dédramatiser la chose et à rassurer le patient, c'est ce que je comprends parfaitement, parce que, oui, comme je disais, il y a une grande part de stress là-dedans. Mais en même temps […] ça ne prépare pas psychologiquement à ce qui t'attend. Donc, finalement, c'est un mal pour un bien. […] le lendemain lorsque tu réalises l'impact que ça a, et souvent tu ne le réalises même pas sur le coup, tu le réalises très progressivement, moi je le réalise, je le réalise, l'impact que ça a, la différence sur ma qualité de vie, uh, elle existe, elle est là, je sais que je suis capable, comme d'autres l'ont fait avant moi, de vivre avec ça, mais je trouve que ça, c'est un mal pour un bien.
>
> Les questions que je me posais […] touchaient souvent le long terme, mais […] ici au niveau médical, ce qui compte c'est aujourd'hui et maintenant, et puis demain, comme demain matin, qu'est-ce qu'on fait, mais dans six mois-un an, ouf, cinq ans, c'est… J'ai, j'ai vraiment, honnêtement je n'ai pas eu beaucoup de renseignements là-dessus, fait que c'est une source d'incertitude pour le patient, je pense, puis je crois que ça devrait être abordé. Les aspects sociaux, psychologiques, fonctionnels, mais oui, je comprends que, quand tu es dans une situation d'urgence, tu commences par patcher la fuite d'eau qu'il y a chez vous, puis après ça tu penses peut-être à refaire la plomberie au complet. […] oui, il y a une situation d'urgence puis on est là pour y répondre, t'appelles les pompiers, tu n'as pas le temps de penser à la couleur que tu vas peinturer ton salon, dans un an, six mois, mais oui, si tu as déjà ta réponse, ben, ou peut-être le lendemain de l'incendie, mettons, déjà ça peut t'aider à te faire une idée de ce qui t'attend. Fait que, oui, ça serait positif.

Even though these conversations only represent a small part of patients' care trajectory and their communication with the team, they reflect the conclusions of studies in psychosocial oncology that have highlighted the importance of assessing the gravity of potential psychosocial concerns. Many patients may underestimate their psychosocial needs, and stigma related to seeking psychosocial help constitutes an important obstacle for seeking care (Cohen et al., 2018). The analyses above help identify moments in patient-provider conversations where patients' concerns could be foregrounded by exploring them in more detail, and offering help if needed.

5.3.2. Discussing the impacts of the surgery on daily life and functioning. This theme came up during patient interviews, when some patients talked about the subjects that would have been helpful for them to discuss before the operation. An excerpt from a pre-surgical consultation will first be analyzed to show how certain aspects of body changes were emphasized by the surgeon as being the topic of his conversation with the patient, and others were backgrounded as the surgeon explained that other team members will discuss them with the patient.

In this example, the patient asked for a second appointment with his surgeon before the operation to learn more about the surgery. As he explained to his physician, he did not have any specific questions and wanted to hear what the surgery would entail: *"J'aimerais que vous m'expliquiez plus ce que vous allez me faire. C'est quoi qui va m'arriver?"* As the surgeon was explaining the surgical procedures, the patient asked about daily maintenance of his stoma (a permanent surgically made tracheostomy in the neck), and the surgeon explained that the patient would meet with the speech-language pathologist who will give him more details about that.

Excerpt #18

SUR: OK? Pour respirer et parler, ça c'est les deux choses qui vont changer pour vous le plus, vous allez respirer par un trou ici ((pointe vers son cou)), ça va être un trou…
((À NUR)) Est-ce que monsieur a rencontré…
NUR: Il a rencontré SLP là, mais il n'a pas encore vu le patient.
SUR: On va arranger ça?
NUR: Oui.

7 SUR: Vous allez
8 PT: J'ai déjà vu quelqu'un avec ça [avec une laryngectomie].
9 SUR: Ah oui? OK. Alors ça va prendre du travail pour juste comprendre, prendre soin
10 de ça, mais avec un peu de pratique, ça va aller.
11 PT: Et ça, il va falloir nettoyer à tous les jours?
12 SUR: Ils vont vous expliquer ça, tous les détails, oui.
13 PT: OK.
14 FCG: C'est beaucoup d'entretien, oui?
15 SUR: NUR va expliquer, et SLP va expliquer, je vais juste finir, comme ça
16 FGC: OK.
17 PT: Oui-oui.
18 SUR: Je ne veux pas oublier les points importants.
19 PT: Oui-oui.
20 SUR: Et je vais répondre aux questions. Alors, ça c'est la façon de respirer. Pour
21 parler, hmm, vous allez parler par la bouche […]

The patient and his wife emphasize the question about daily maintenance and cleaning by repeating it ("*Et ça, il va falloir nettoyer à tous les jours?",* line 11; "*C'est beaucoup d'entretien, oui?"*, line 14), and the surgeon backgrounds these potential concerns by explaining that the nurse and the speech-language pathologist will talk about these things with the patient (lines 12-15). In the interviews, some patients said that there was a lack of information regarding daily care after the surgery as well as impacts on function, and, as one patient explained, this role was not necessarily their surgeons' role:

> […] on devrait, sans que ce soit nécessairement le médecin, que ce soit l'infirmière pivot par exemple ou un médecin résident, qu'ils puissent te dire, ben, écoute, oui, tu vas avoir, ça va affecter tel tel tel aspect de ta vie, dans le fond, c'est un travail d'ergothérapeute, peut-être aussi, je ne sais pas, mais à quelque part, c'est de dire, regarde, oui, au niveau fonctionnel, au niveau psychologique, au niveau, surtout les aspects qu'on connait de l'être humain, dans le fond, au niveau psychologique, moral, physique, au niveau du travail, au niveau des soins quotidiens, des choses comme ça […] ça peut paraitre banal, mais je veux dire, ça devient à un moment donné, c'est juste, de faire un pansement, c'est niaiseux, mais de faire un pansement, de nettoyer la plaie, de s'assurer d'avoir une procédure stérile, et après ça de dire, oui, écoute, comment tu vas faire pour te brosser les dents […]

> Tu lui parles d’une reconstruction [au patient], mais il veut savoir c’est quoi les étapes, puis est-ce que ça va faire mal, puis quelle apparence je vais avoir, puis, est-ce que ça va être fonctionnel dans ma vie de tous les jours après ce type d’intervention-là. Donc, résultat, uh, c’est ça, c’est ça qui manque.
>
> […] juste des fois il y a des questions que j’ai oublié de lui demander [au chirurgien], s’il y avait un impact après l’opération, en enlevant les ganglions. […] Je vais-tu être malade, je vais-tu […] Les ganglions, si vraiment ça va affecter mon corps après, ou il va pouvoir fonctionner pareil, je ne sais pas là… Ça va-tu agir sur mon métabolisme, ça va-tu… je ne sais pas. C’est ça. Vu que je suis une personne… Uh, active, très active, oui, je suis une personne active à 62 ans, c’est sûr qu’il y en a, il y en a qui ne sont pas actifs, peut-être, je ne sais pas, moi je suis actif, je bouge, je fais du bicycle, je joue au hockey, ça veut dire que, ça va-tu vraiment, il va-tu avoir un impact sur moi, je ne sais pas là, c’est pour ça que j’aurais aimé savoir. […] Si je me fais opérer dans six ou sept semaines, je suis comme dans l’inconnu, je ne sais pas… qu’est-ce qui va se passer après, c’est sûr… Toi je ne sais pas si tu le sais, mais moi, je ne le sais pas. C’est comme inconnu pour moi […] c’est important pour moi, de continuer à vivre normalement après. Oui, c’est important. Oui, parce que j’ai des petits enfants, je bouge beaucoup, puis j’aimerais ça continuer ça.
>
> […] il y a le sujet qu’on n’a pas discuté, c’est la question de la chirurgie. D’abord, ils vont ouvrir ici, ils vont enlever la peau ((montre verticalement sur sa joue)). Uh, par après, est-ce qu’il va y avoir des problèmes de rasage? Ou si je veux me faire pousser une barbe? C’est un détail, mais quand même, c’est des choses qu’on pourrait discuter éventuellement.

Some patients also shared that it was difficult to bring up these subjects during their pre-surgical appointments:

> […] Mettons, je te dis que ta paupière ne ferme plus, ça va être quoi ta réaction? Mais ça prend-tu des gouttes? Ça prend-tu, je ne sais pas moi? Et ça, ils n’ont pas… Et quand il te dit, ta paupière ne fermera plus, c’est banal, mais ce n’est pas banal! Pour eux autres, je comprends que c’est banal, ils en font, je ne sais pas combien dans l’année, comme ça. Mais le patient? Ta paupière, elle ne fermera plus. Ils n’ont pas dit, « Bon, conséquemment, ce que tu devrais faire, c’est des gouttes, le port de lunettes… » Moi, je dis ça, mais je ne sais pas si ça va être ça. Je sais que ma paupière ne fermera plus, c’est ce qu’ils m’ont dit. […] Puis nous autres, parce que tu peux bien dire, « Mais là, tu aurais pu poser la question! » Mais le patient il est tellement abasourdi quand il apprend ça, dans le cerveau il n’y a pas de place pour, pour être logique comme ça. Parce qu’on lui apprend que là, ça ne fermera plus. Parce qu’ils vont couper le nerf.

> PT: […] ce qui arrive avec moi, c'est la deuxième fois [le patient a déjà eu une chirurgie pour son cancer], comment je vais m'en sortir de là, quelle sorte de figure je vais avoir. Ça, c'est un problème ça ((pointe vers sa mâchoire)), j'ai un problème ici, mais j'essaie de ne pas trop regarder dans le miroir. La deuxième fois, comment ça va se passer, ouf… Je vais être défiguré encore au complet. Quand ils t'ouvrent là, et ici, puis… pas évident, eh? Puis après ça, ben, il y a des journées où j'articule moins, parce qu'ils ont fait la reconstruction à l'intérieur de la bouche, c'est sûr qu'on articule moins. Il y a des mots maintenant que je ne suis pas capable de prononcer correctement, parce que la langue, elle ne sort pas, alors c'est, malheureusement… Alors, la deuxième fois, ça va être quoi, je ne sais pas.
> MC: Et de ça, en avez-vous discuté avec les médecins, de cette question?
> PT: Ben, on a discuté un peu, mais ils ont trop d'ouvrage, eh. C'est dûr, discuter au complet, d'un bout à l'autre, quand il y en a d'autres qui attendent en arrière de moi, tu ne peux pas prendre deux heures de leur temps, oublie ça. Peut-être si on a un contact plus long pour parler de la chose qu'ils vont faire, qu'ils vont intervenir, pour cette maladie-là, je ne sais pas, peut-être, une rencontre un peu plus prolongée, ouais.

One of the ways of backgrounding the impacts of surgery on functioning is, as was shown in the previous sections, when patients briefly bring up potential concerns that are not explored in more detail in the conversation that follows. While the reasons that patients do not ask questions during medical visits are beyond the scope of the study (some of the reasons mentioned during patient interviews were: shock following a cancer diagnosis, confidence in the team, avoiding potentially stressful information, awareness that physicians are busy and need to see other patients in the clinic, and knowing that it is difficult to foresee the outcomes of the surgery), I will give one example from a pre-surgical interview to show why it may be important for the team to explore potential concerns in more detail to address patients' worries. This patient explained that he was worried about the impacts of the operation on his speech, vision, and hearing, but did not bring up these questions (during his appointment that was previously cited in Excerpt #2) assuming that the doctors would tell him if they anticipated any changes in these areas:

> I just want to be able to talk. If my sight is not hurt, nothing done to it, my hearing nothing done to it, I can get through the rest. […] I didn’t ask any questions. I mean, I’m assuming, if they are going to cut that and I can’t talk, they would have told me, you know. They didn’t say, you can’t see, and you won’t be able to hear, so I’m assuming, paralyzed, the cheek, fine, but I’m assuming my hearing, my eyes, you know, hearing, eyes and mouth, it’s still going to work, you know. […] as long as I can see, and I can hear, and I can talk, I’ll manage the rest. […] when they said, they are doing to cut, they are going to, my face will be paralyzed, well, imagine if I was going to the eye, and the ear, and the nose, or mouth, they would have told me. If they didn’t say, look, maybe your eye, maybe your ear, maybe your mouth, they didn’t mention those. They just said, your face is going to be paralyzed, well, this is my face ((points to his cheek)), this is not my face ((points to his mouth, ear, and eye)), this is not my face, my mouth is not my face, to me. That’s what I think. To me, if they didn’t mention those things, it’s because it’s good. […] I just hope I’ll be able to talk the way I’m talking to you now when it’s finished. That’s the thing that worries me the most, you know. Hearing, seeing, and talking. Scar, I can live with the scar. As long as I can do those things, and I can work on them to improve them, you know. I mean, if my lip is hanging and there’s no feeling, it’s not going to sound the same, but I can still communicate […] When I’m done, first day […] if I can see and I can hear and I’m alive, then I’m happy.

A similar example can be found in another patient’s pre-operative interview, when she expressed her worries about spending some time without her teeth, which only took the form of a short question in her conversations with her doctors (“*And what about the teeth?”,* Excerpt #8a, line 16):

> […] parce qu’ils vont me mettre un nouveau palais dans la bouche, combien de temps que je vais être pas de dents, euh… Ouff…[…] parce que s’ils me disaient que j’allais être trois mois pas de dents, mais c’est trois mois sans voir mes enfants et sans voir personne, surtout je ne veux pas que personne me voie de même.

These examples show how visibly “unproblematic alignments” (Dewulf et al., 2009, p. 162) of the patient’s and the doctor’s perspectives may be seen differently in light of the patient’s interview. In fact, patients’ brief questions and remarks during clinical visits may be expressions of important concerns that were revealed during the interviews but did not become apparent during clinical visits.

5.4. Partial conclusion

Analyses of medical consultations before surgery that were presented in this chapter, complemented by the analyses of interviews with patients and team members, show how body changes were framed during the pre-surgical period (and contribute to answering the first research question). First, I showed how body changes were foregrounded or backgrounded as patients and providers discussed survival and cure, which represent an important concern for both patients and providers according to the literature (and was also supported by the interview data). Specifically, my analyses revealed how patients' concerns were expressed and addressed in conversations at different levels of 'intensity' (or on the continuum between what appears to matter or not that was discussed in Chapter 2). Thus, I showed how patients brought up potential concerns in more or less direct ways, and how providers backgrounded them as not being of concern or, on the other side of the spectrum, as being important elements in patients' decisions about the treatment option. In addition, I explained that an important contextual element to understand these conversations was the perceived effectiveness of the surgery to remove the cancer.

Second, I showed how body changes were discussed as (not) being a matter of concern in conversations that did not involve considerations about survival and cure, by highlighting once again the different ways in which certain topics were emphasized in more or less direct ways. In this context, the role of backgrounding body changes by emphasizing long-term recovery and the routine nature of surgical procedures in reassuring patients was discussed. This analysis offered elements of answers to the second research question about the impacts of different ways of framing on patients' experience.

Finally, I talked about the team members' roles in discussing particular aspects of body changes. My analysis showed that psychosocial concerns and impacts of the surgery on everyday life and functioning can be backgrounded in patients' conversations with their surgeons, thus highlighting the important role played by the nurse and other team members. My analysis of the patient interviews revealed what was backgrounded in certain conversations, when potential concerns expressed by patients very briefly during consultations were described as important preoccupations during the interviews. This analysis offered further evidence to answer the second research question and highlighted the importance of assessing patients' support needs.

In the following chapter, I will show how body changes were framed during post-surgical visits.

Chapter 6. Framing Body Changes during Post-Surgical Visits

In this chapter, I will present three themes that were recurrent during the analysis of the consultations, and that were also described as being of importance to patients and providers during the interviews: discussing body changes in relation to cure and physical recovery, resolving differences in patients' and providers' perspectives, and foregrounding and backgrounding concerns about appearance. As in the pre-surgical period, survival and cure remained important concerns for patients and providers. Since patients were recuperating from surgery, consultations were also focused on wound healing and function recovery. I will first show how body changes were discussed in this context. I will then focus the analysis on another aspect that patients and providers described as being characteristic of their conversations during the post-surgical period, namely the differences in how they perceived body changes. I will show how these differences were manifested and resolved in interactions. Finally, in the last section of this chapter, I will explore in more detail the conversations around one specific topic where differences in patients' and providers' perspectives were especially apparent: changes in appearance following surgery.

As in the previous chapter, the consultations analyzed in this chapter were mostly with surgeons and residents. In addition, appointments with the speech-language pathologist and the dietitian were more frequent during the post-operative period, as patients needed support to recover their speaking and eating function after the surgery. Patients' conversations with the nurse were recorded when the nurse was present during scheduled appointments at the clinic. As described in the methods chapter, patients' unscheduled visits with the nurse were not recorded as part of this study. However, analysis of several recorded consultations where the nurse was present, combined with the data collected during patient and provider interviews, allowed me to discuss her role in the team specifically with regard to assessing and addressing patients' psychosocial concerns during the post-surgical period.

6.1. Discussing body changes in relation to cure and physical recovery

Pursuing treatment and managing symptoms have been identified as important concerns for head and neck cancer patients, especially during the first year following their diagnosis (Molassiotis & Rogers, 2012). In the present study, when patients came to the outpatient clinic after their hospital stay, one of their main concerns, as well as of the members of their medical team, was physical recovery and cure. Especially in the first weeks after the surgery, patients were recovering from major operations often involving reconstructive procedures, and were waiting for the results of pathology tests to know if their tumor was completely removed during surgery or if they needed further treatment. Many patients had radiotherapy or chemotherapy after their surgery, and were also dealing with the side effects of these treatments. During outpatient visits, the team members often told patients that it usually takes up to a year for the body to recover, and both appearance and functional outcomes can improve during this period of time. Here is how some team members described what mattered to them and to the patients during the post-operative period:

> […] when we see them in the post-op period, we're dealing with wound issues, we're dealing with functional issues, we're dealing with healing, we're dealing with cancer management, what's our next treatment, what's our next step, is there a next step, how we are going to do our surveillance, so we are really looking at the real kind of black

> and white things in terms of, to make sure they are healing properly, to make sure cancer's controlled, to make sure they don't need any further radiation or chemotherapy or further surgery.
>
> […] une raison pour laquelle ils viennent nous voir, soit que c'est le suivi à deux mois pour s'assurer que le cancer n'est pas là, ou ils ont un suivi post-scan […] fait que, finalement, bonnes nouvelles, il n'y a pas de récidive, ça va bien, ou oh, malheur, il y a quelque chose, il faut faire d'autres investigations.
>
> […] they've usually lost weight post-op, so first it's trying to deal with stopping the weight loss, did they get everything that they needed, in terms or nutritional supplements and their education, and then where are they in terms of their diet when they left the hospital and when we see them and what's the next step. Can we progress the diet textures, what recommendations can we make to get them one step further ahead. If they are on a tube feeding, because some of them go home on a tube feeding, it's a matter of looking at the plan of what are we doing in terms of swallow rehab or reevaluation of swallow, and reevaluating that, do they have everything they need for tube feeding, is everything going OK, so it's the following-up of the care they got and seeing the progression that we can implement. So sometimes it's just giving them suggestions that will help them move along, but it's always trying to get the calories and the protein, and that has to be always, and making sure that weight is stable, and depending on what the next phase of their treatment is, because often it's radiation and chemo, so it's a matter of getting them OK, better, on the upswing, when they come to the next phase.
>
> […] a lot of [patients] tell me they can't sleep before they see us, a lot of patients tell us. Even five years after their treatment, the day that they see us, the day before they can't sleep. They are worried, what if we find cancer, you know, so as soon as you tell them, there's no cancer, it's like, and you can see it in a lot of them, they are like, thank God.

Within this context, I identified two particular ways of framing body changes by emphasizing recovery and cure that will be discussed in the following sections: ordering concerns by priority and emphasizing improvement and progress in function recovery.

6.1.1. Ordering concerns about body changes by priority. In this section, three cases will be presented to show how patients and providers, in their conversations during outpatient meetings after the surgery, established an order of priority as they discussed body changes. The analysis will show the different ways this was accomplished, which could vary by complexity and directness.

The following excerpt illustrates how a patient talked about his desire to go back to eating and talking during his appointment which took place three months after his surgery and five weeks post-radiation, and how the medical team emphasized the need for the patient to recover from radiotherapy first, all while acknowledging the patient's concerns. This patient underwent a laryngectomy – his voice box was removed, and his esophagus and trachea were separated so that he would breathe through a stoma (a surgically made permanent hole in the neck) and eventually eat through the mouth. At the time of this meeting, the patient was recovering from his radiotherapy treatments and could not speak or eat yet.

Excerpt #19a

SUR: How are you doing?
PT: ((Articulates with his lips and gesticulates))
SUR: Not bad?
PT: ((Articulates with his lips and gesticulates))
SUR: You want to talk?
PT: ((Articulates with his lips and gesticulates))
RAD: You want to eat.
SUR: You want to eat. You want to talk and eat.
RAD: That's important.
SUR: Yeah. Let's just close the door. I want you to eat, too!
PT: ((Articulates with his lips and gesticulates))
SUR: You are asking me something?
PT: ((Articulates with his lips and gesticulates))
RES: When can he talk.
FCG: When can he talk.
SUR: Oh, we have to put in the
RES: Prosthesis.
SUR: Yeah, the speech prosthesis. But, let me look at things, yeah I think you are still healing, it may be a little early to jump on that. ((Examines the patient.))
[The surgeon then aks the patient several questions, about the swelling and the wound healing process, as well as tells him about the follow-up to make sure that his stoma does not shrink.]

23 SUR: […] And we are going to measure the stoma, I want to make sure the opening is
24 not shrinking and I want to see you back in two weeks. While you are healing, I don't,
25 well that's raw in the middle, we've got to let you heal before we even think about
26 putting in a speech prosthesis.
27 PT: ((Articulates with his lips and gesticulates))
28 SUR: You want to eat. Well, swelling has to go down. […]

The patient foregrounds his concerns about going back to eating and talking by bringing them up three times (lines 4-8, 11-15, 27-28). As this appointment was not video-recorded, the exact gestures of the patient cannot be described, but his concerns are voiced by the surgeon, the radiologist, the resident, and his wife: "You want to talk and eat" (line 8), "When can he talk" (line 14), "You want to eat" (line 28). The surgeon and the radiologist acknowledge these concerns and emphasize them by saying that they are important ("That's important," line 9) and that they share them ("I want you to eat, too!", line 10). At the same time, the concern about speaking is backgrounded as not requiring any action at the present moment, as the healing of the stoma takes priority. The surgeon articulates this order as he explains: "I think you are still healing, it may be a little early to jump on that" (lines 18-19), "we've got to let you heal before we even think about putting in a speech prosthesis" (lines 25-26). In other words, in this interaction, the difference in the concerns that are given priority (Bergeron & Cooren, 2015, p. 125) (the patient's preoccupation with getting back to speaking versus the surgeon's concern about the physical healing process and making sure that the stoma stays open) is resolved as the surgeon clearly establishes the order of priorities, and as the patient and his wife do not bring up their concerns again. While the physicians acknowledge the patient's concerns, they do not discuss them in the same level of detail as concerns about healing; for example, while the surgeon explains the follow-up process to the patient (lines 23-26), he does not directly answer the patient's question about how long it will take before he can talk (lines 13-18).

Later during the meeting, the radiologist brings up the topic of eating again, and asks the patient if he has tried eating anything:

Excerpt #19b

29 RAD: Have you tried eating anything?
30 PT: ((Articulates with his lips and gesticulates))
31 RAD: You try all the time and it doesn't go through.
32 PT: ((Articulates with his lips and gesticulates))
33 RAD: Nothing goes through, OK.
34 SUR: Well we'll see what the barium swallow [test] shows and then maybe we can have it
35 FCG: Actually last week you had some juice, some coffee and stuff, and part of it did go down.
36 DIET: Keep trying.
37 FCG: Sometimes part goes down.
38 DIET: Keep trying every day, OK. Just little sips, little sips, yeah. Not so much coffee
39 because that will dry you out, but, because even last time, I saw you on the Monday,
40 nothing, and I saw you later in the week and you were swallowing. So just keep at it
41 […] [She asks the patient to try and drink some water, but it doesn't work.]
42 DIET: Yeah, there's secretions, still.
43 SUR: Yeah.
44 FCG: There's a lot.
45 SUR: But we're still, we're only at five weeks since the radiation.
46 RAD: Yeah, you have to give it time.
47 SUR: There's still swelling and radiation and everything.
48 DIET: But once you clear up all that secretions, there may be an opening, like if you've
49 got a lot of that blocking through, that's going to block your passage away.
50 RAD: Give it some time.
51 SUR: So, SLP is going to come, RES is going to come in and measure the stoma, and then
52 take an appointment to see us in two weeks, because we want to keep an eye on that, OK.
53 And we'll order a barium swallow, we'll get that, maybe before your next visit. All right?

In this conversation, the patient's concern about eating is foregrounded as the radiologist's question and the patient and his partner's responses that follow explore it more detail and specify what is going on ("You try all the time and it doesn't go through," line 31; "last week […] part of it did go down," line 35), and as the dietitian engages in the conversation by encouraging the patient to keep trying ("Keep trying […] Keep trying every day […] just keep at it," lines 36-40) and by talking about the progress that she has noticed since she saw the patient last time (lines 39-40). In this way, the patient's difficulty swallowing is being foregrounded as a concern that can be addressed through a specific recommendation (to keep trying to swallow) and the assessment that is done by the dietitian (as she asks the patient to try to swallow some water). This shows how "what matters" in this conversation is related to health providers' roles on the team (Cooren et al., 2012, p. 297), and also gives an example of how the dietitian and the physician work together as members of an interdisciplinary team. At the end of this conversation, as the patient is not able to swallow water, the surgeon and the radiologist acknowledge the patient's difficulty and emphasize that the patient needs to heal first ("we're only at five weeks since the radiation," "You have to give it time," lines 45-46), as in the previous excerpt.

The recovery process was long for this patient as his tissues were very fragile after radiotherapy treatments, and six months after his surgery he was still not able to speak and eat and he was relying on a feeding tube that was inserted in his stomach. His appointments at the clinic were mostly focused on physical care and trying to stretch his esophagus so that there is an opening large enough for food to go down. The patient was very tired during this time, and answered some of the interview questions very briefly in writing. In his questionnaire at six months post-surgery, he wrote that he expected to be eating and drinking by now, but that he was still on tube feeding: "3x2hrs feedings a day really make me weak and not functional. Social life is 0." He wrote that he had no suggestions for the team: "They seem to do what they can," "they are clear but sometimes I guess there are complications." In this patient's case, while the primary concern of the physicians was mostly a biomedical one, the patient's concerns were also acknowledged in conversations, and as illustrated in the excerpts above these acknowledgments are a way of resolving the differences in the concerns expressed by the patient and the team members. During the patient's visit to the clinic at five months after surgery, I identified similar interaction patterns. While the surgeon emphasized the healing of the tissues as being the main concern, he acknowledged that the patient was looking forward to recover his function:

Excerpt #19c

54 SUR: What happens when you drink now?
55 PT: ((Articulates with his lips and gesticulates))
56 SUR: Nothing, are you sure? 100%? Nothing goes down.
57 FCG: Nothing.
58 SUR: OK. It's very swollen, it may open up ((inaudible)), but it's a little bit premature,
59 because it's very fragile, the tissue. ((Inaudible.)) We'll get it open. Every time we've
60 had this, it's not the first time, we'll be able to get it open one way or the other.
61 Sometimes what we're able to do is get you to do the stretching after we stretch it once,
62 and SLP will teach you how, she's an expert… But I'd sit tight, how long since, when
63 did he finish [radiation]? October? I would wait until at least four-five months and then
64 when everything's settled down. You look after your stoma, that's important, that's
65 really important. Because that inflammation, when it goes down, it may open up and
66 then you may be able to swallow, and then if you need a little popping up, we'll stretch
67 it, you'd be fine at that point.

In this excerpt, as in the previous excerpts, the surgeon explicitly says that what is really important at this point is for the patient to look after his stoma (lines 63-64), and that they need to wait for the tissues to heal (lines 65-66), but his way of acknowledging the patient's concerns is different, as he also reassures the patient that the situation will improve ("We'll get it open," line 59; "We'll be able to get it open one way or the other," line 60; "we'll stretch it, you'd be fine at that point," lines 66-67) and that the patient is in good hands

("Every time we've had this, it's not the first time," lines 59-60; "SLP will teach you how, she's an expert," line 62). This also echoes the team members' perspectives on their role as their patients' motivators and support, which were discussed in section 5.2.2., and on which I will also elaborate in the following section.

The first post-operative visit of another patient further illustrates how surgeons acknowledge patients' concerns while emphasizing curing cancer as the most important concern. The patient came to the clinic one month after her operation. As a result of the surgery, the patient lost her upper teeth, and her face was still very swollen. The same morning, the patient had an appointment in the radiotherapy clinic, as she had to go through radiation and chemotherapy as additional treatment. At the beginning of the meeting, the patient meets with a resident physician who examines her and then calls in the staff surgeon. The surgeon examines the patient, and they then discuss her upcoming radiotherapy, as well as other subjects such as pain control and wound care. The excerpt that will be analyzed here starts when the patient asks the surgeon about her teeth.

Excerpt #20a

1 PT: After, what happens with my teeth?
2 SUR: Yeah, so, we'll see. So after, we'll see, when everything clears, there's no more
3 cancer, after the radiation we'll get a scan
4 PT: Yeah.
5 SUR: And then we check, we check what it looks like, and then we plan for something,
6 sometimes we can put a prosthesis, sometimes we can put different things, there's
7 many different things that we can do when it comes to that time.
8 PT: OK-OK.
9 SUR: We will send you to a dentist, one of our dentists. How much do we have left?
10 ((Examines the patient's mouth.))
11 PT: On this side, down
12 SUR: No down is not a problem, up, it's this area, so.
13 PT: Yeah.

14 SUR: We’ll see, you are not there yet, so we’ll have to see. Sometimes you can put a
15 prosthesis on top of that, sometimes we have to do certain things
16 PT: OK. I know I’m not there yet.
17 SUR: You’re not there yet.
18 PT: Because when I look at my face, I’m so depressed. ((Laughs a bit))
19 SUR: I know. It’s going to change some more, you know.
20 FCG: She’s laughing, but
21 SUR: I know, I know, it’s not, I know. No, you are not there at all, you are still swollen, so
22 it’s just, which we wanted to, remember, I told you, I’m going to make you, I told you
23 PT: OK.
24 FCG: She’s not happy about it now.
25 SUR: I know, I know.
26 PT: I just, I thought I would have a lot of scars, but, nothing like this
27 SUR: Like this, yeah, the swelling.
28 PT: Yeah.
29 SUR: But this is going to, you’ll see, wait.
30 PT: OK.
31 SUR: You’re not there yet. Most important is to get rid of the cancer. And we’re still
32 worried about that.
33 PT: Yeah, I know.

The patient expresses a specific concern – that she is depressed when she looks at her face (line 18), which is further emphasized by the family member (lines 20, 24). The surgeon is also very direct in his description of what constitutes the most important concern as this time – “to get rid of the cancer” (lines 31-32). At the same time, he repeatedly acknowledges the patient’s concern about appearance (“I know, I know,” lines 19-25), and he offers reassurance as to the improvements that the patient will see over time (“It’s going to change some more,” line 19; “you’ll see, wait,” line 29), similar to the surgeon’s reassuring statements in Excerpt #19c above. As was described in the chapter on pre-surgical appointments, reassuring, motivating and encouraging patients was an important role for the medical team, and statements of reassurance and encouragment were very frequent during the post-operative appointments as well. In order to illustrate one more time how the medical team acknowleged patients' concerns and offered reassurance to patients during moments where curing cancer was an important concern, here is how a resident closed this appointment, as she saw the patient crying:

Excerpt #20b

PT: ((Recommence à pleurer.)) C'est long.
RES: Je sais que c'est long.
PT: Je ne travaille pas.
RES: Je sais, je sais qu'il y a beaucoup d'autre stress qui vient avec ça, OK, je sais. Mais vous avez de la famille, vous avez du monde qui vous aide, puis nous on est ici pour vous. Vous allez vous en sortir, madame PT, OK? Nous, on a confiance que vous allez vous en sortir. Vous, vous ne le voyez peut-être pas maintenant, mais nous, on a confiance. OK?
PT: OK.

To further show how concerns about body changes were discussed in relation to the priority of curing cancer, I will analyze a case involving another patient who had a laryngectomy and who, prior to his meeting with his surgeons, told the resident that he was not able to talk. The patient was at two months after his surgery. This excerpt shows how the patient's potential concern about not being able to talk is backgrounded in relation to getting the cancer out, as the topic of the conversation changes:

Excerpt #21

RES: How do you feel?
PT: ((Shakes his head, and says "not good" with his lips, that he cannot talk.))
RES: Not good? You cannot talk. Cancer is out, that's the most important part.
FCG: But he's getting more radiation though, so, is that because the cancer can come back?
RES: No, it's just because of the close margin. I'm going to call RAD and he will tell you more info about it. [They talk about radiation a little more]
RES: RAD will be planning the radiation, and he will tell you more about it, but, yeah… Otherwise, eating well? PEG [feeding tube] or mouth?
FCG: Oh, mouth.
RES: By mouth?
FCG: Oh yeah-yeah.

RES: You still have the PEG in?
FCG: Oh, he never had one.
RES: Oh, never had one, just making sure. OK, good. And other than this… ((Inaudible.)) So you're gaining more weight now, OK, that's good, perfect. And who's doing the dressing for your left arm?
FCG: CLSC.
RES: CLSC? Anything else that I should know about?
FCG: Uh, actually he's done so well.
RES: Yeah, that's great.
FCG: I can't believe that he's doing so well. Good genes or something…
RES: And he's always smiling! ((PT smiles, and everyone else, too.))
[During the meeting with the surgeon that followed, the conversation was mainly about the patient's radiation treatments that were going to start soon. It was explained to the patient that everything will have to heal before he could practice speaking.]

In this excerpt, the patient's statement that he is not feeling good (line 2) is backgrounded in three ways. First, the resident explains that the cancer is out and that is "the most important part" (line 3). Then, the family member changes the subject and asks about radiation, and the resident pursues this topic (lines 4-8). And, finally, the family member and the resident emphasize that the patient is doing well (lines 19-22). I would like to stress again here that the goal of this analysis is not to evaluate health care providers' behaviors, but rather to see how patients bring forward potential concerns and how they may be backgrounded or foregrounded in the conversation that follows. Analysis of conversations does not provide any conclusions regarding the impacts of these conversations on patient outcomes, but the interview data helps support the interpretation of patient-initiated utterances, like the one in line 2 in the excerpt above, as important concerns that were acknowledged but not explored during clinical visits. These potential concerns that patients briefly expressed during the visits, without constituting explicit demands for help, provide health providers "opportunities to recognize and validate" (Beach, 2018, p. 1688) patients' descriptions of their experience (and eventually explore and address specific concerns), especially given that recuperation from radiation may be long and patients can wait several months before recovering function. This was illustrated in Excerpt #19 above, and also in a post-operative interview that a patient completed in writing three months after his surgery, because he was still not able to speak: "The biggest challenge in my body is the inability to speak. Hopefully this will change for the better, but with much effort. […] Even that the doctors indicated this would be a life-changing operation, I still did not realize how much it would be not being able to communicate with family and friends."

In the post-operative interviews, some patients explained that in the immediate post-surgical period their concerns with the results of the pathology and the success of the surgery were at that time most important during consultations with their medical team, and questions about recovery and return to normal function were not always discussed during clinical visits. For example, a patient who had surgery for a cancer of unknown primary source explained that in the context of the limited time that she had with her surgeon during post-operative consultations, she did not have answers to all her questions about body changes:

> […] je suis revenue [de mon rendez-vous à la clinique] puis je n'avais pas plus de réponses. Il y a mon mari qui m'a dit, « Puis, pour le goût, c'est-tu normal », ben là, finalement, on a tu tout abordé au fond? On a tu vraiment eu le temps d'en discuter? Ça va vite, ça va vite, puis t'es là, puis… ça n'a pas vraiment répondu, mais je me suis dit, bon, ça prendra le temps que ça prendra. Et de toute façon, j'ai recommencé à manger correctement, bon, puis c'est moi-même qui verrai l'évolution de tout ça. Mais c'est vrai que, pour l'instant, l'évolution de tout ça, il n'y a rien, ça n'a pas changé, je suis gelée de la même façon qu'après l'opération, puis là, c'est trois mois, tu te dis, peut-être je devrais sentir un petit changement, mais il n'y a pas beaucoup de changement. […] effectivement, tu reviens [d'un rendez-vous à la clinique], tu as toujours des interrogations […] Dans le fond, maintenant, la communication [avec mon chirurgien], ce n'est pas, je vais venir te parler, ça fait trois mois… non-non, là c'est, OK, le scan, as-tu vu quelque chose, t'as rien vu, ben, merci, salut, je m'en vais, c'est tout ce que je veux savoir. Le reste, je me débrouille, je suis rendue à cette étape-là. […] je pense que

> là j'en arrive à un degré de communication qui est juste sur un côté, ce n'est plus moi, là je ne te parle plus, je m'en viens t'écouter. Puis il n'y aura rien d'autre, tout ce que je veux, c'est une réponse par rapport à la source [de mon cancer], puis par rapport à, est-ce que j'ai bien fait de ne pas faire de radiothérapie.

Later in the interview, the patient explained that she knew she could always contact her medical team if she wanted to get answers to certain questions, but she also explained that her surgeon's answers to her questions led her to think that her concerns were not important:

> PT: Mais c'est drôle, si tu as posé une question au médecin et il n'a pas plus répondu, ça veut dire que ce n'est pas important, cette histoire-là. Tu sais, le goût, ah, regarde, ça va revenir, OK, bon parfait. Mais tu ne m'as pas dit quand ça va revenir. Fait que, tu as l'impression, de par l'attitude du médecin que, dans le fond, c'était une question qui était… c'était une préoccupation qui n'avait pas lieu d'être. Tu te préoccupes, mais ne t'inquiète pas avec ça, regarde, ce n'est pas, OK. Mais moi, quand tu me dis, n'inquiète-toi pas, c'est exactement ce que je fais. OK, je n'ai pas à m'inquiéter là-dessus, parfait, merci, c'est tout ce que je veux entendre. […] De voir que c'est aussi banal pour lui, dans le fond, j'ai posé une question, mais il n'y avait même pas lieu d'inquiétude, ce n'était tellement pas un sujet que tu devrais t'inquiéter que
> MC: Fait que ça vous a permis de
> PT: Ben justement, dans le fond, de dire, au fond, le goût, c'est-tu vraiment quelque chose d'important? Si j'avais juste ça dans la vie, si j'étais un gros mangeur, mais non, j'ai d'autres choses, fait que, si ça ne goute pas, ça ne goute pas. […]

This excerpt shows how this patient interpreted and adapted to what her surgeon communicated to her during the visits. While the patient said that she was not worried about changes in her ability to taste food after hearing her surgeon's reaction ("moi, quand tu me dis, n'inquiète-toi pas, c'est exactement ce que je fais"), she also shared the questions and the uncertainties that she had about her rehabilitation with me during the interview, which indicates that they were backgrounded or "silenced" (and thus not explored) during her post-operative visits. It is also notable how this preoccupation and the ordering of body changes in relation to cure is reflected in this patient's perception about her relationship with her surgeon and their interactions during the outpatient visits, or what could also be referred to as relationship framing and interaction framing (Dewulf et al., 2009). She sees these visits not as a two-way conversation between her and her surgeon, but rather as a one-way exchange where the surgeon gives her important information about the success of the surgery in controlling the cancer: "*Je pense que là j'en arrive à un degré de communication qui est juste sur un côté, ce n'est plus moi, là je ne te parle plus, je m'en viens t'écouter*."

Another case that shows how concerns about body changes are ordered by priority is the one-month post-surgical visit of a patient who had a large tumor on one side of his face. To remove the tumor, the surgeons had to remove his facial nerve, and one side of his face was not moving. He still had a bandage that he had to change regularly, and his partner was helping him to change it at home. At the beginning of the meeting, the patient and his partner meet with a resident who asks the patient how he is feeling, answers the patient's questions about weight loss and the soreness in his shoulder; talks with him about the care of his eye (since the eyelid is not moving on one side, it is important to be careful and take care not to scratch it), his upcoming radiotherapy treatments and eye surgery (so that he can close his eyelid); advises on wound care, and examines and cleans the wounds on the patient's face, neck and arm (a skin flap was taken from his forearm to replace some of the skin that was removed from the head and neck area during the surgery). The resident then says that the patient looks like he is doing great (to which the patient agrees) and that she is impressed, and encourages him to keep it up. She then leaves the room to bring in one of the staff surgeons. The surgeon also examines the patient's neck and arm and says that everything is healing nicely, and tells him that he will soon start his radiation treatments. The patient then says he has a couple of questions for the surgeon, and asks him if the side of this face is getting better (the surgeon says that it is healing great), if the corner of his mouth on the paralyzed side will move up or down (the surgeon explains that it was surgically moved up a little bit to make sure that food does not come down when the patient eats) and if his mouth opening was going to change because it is small (as a result of the surgery) and it is hard for him to get food in it (the surgeon explains that it will not change, but that the patient can keep trying to open it as much as he can to stretch the muscles). In response, the patient points to the left side of his mouth and asks if it is going to move:

Excerpt #22

1 PT: But is this going to move? ((Points to the left side of his face))
2 SUR: That's not going to change.
3 PT: That's not
4 SUR: No, that's not going to change, no. Keep on doing that, open as much as you can.
5 PT: So I'll keep doing it to stretch this.
6 SUR: Yeah, stretch it, yeah, absolutely.
7 PT: OK.
8 SUR: The more you stretch, the better it'll be.
9 PT: But I'm never going to look like before. ((Laughs a bit))
10 SUR: You'll never look like before, no, that's 100% ((Laughs a bit, too))
11 PT: I'm so happy just to be alive!
12 SUR: That's right, well that's exactly right
13 PT: You know
14 SUR: That's why you need the radiation now, you know
15 PT: Yeah.
16 SUR: To make sure that gets rid of all the [cancer] cells that might have stayed behind.

By continuing to ask questions about body changes ("But is this going to move?", line 1), the patient foregrounds them and expresses a potential concern about the permanent character of the changes by stating "I'm never going to look like before" (line 9), followed by an acknowledgment and reinforcement from the surgeon ("You'll never look like before, no, that's 100%," line 10). In line 11, however, the patient says, "I'm so happy just to be alive!" emphasizing his concern about survival, which is also confirmed by the surgeon ("That's right, well that's exactly right," line 12), as he explains that the patient needs radiation therapy "to make sure that gets rid of all the [cancer] cells that might have stayed behind" (line 17). The patient's potential concerns about facial paralysis (line 9) are acknowledged by the surgeon (line 10), but not emphasized in the same way as the concern about survival, that is to say, by offering a specific solution and reassurance to address it (the surgeon's mention of radiation in lines 14-16). The patient's statement "I'm so happy just to be alive" following his mention of the various changes that he has been living with since his operation can also be interpreted as a way of backgrounding potential concerns that was highlighted in previous studies. For example, Beach (2018, p. 1688) explains that patients can, "in the midst of troubles," emphasize their wellness and display resilience. Beach (2018, p. 1688) further interprets such patients' statements of wellness in light of the existing literature on communication in medical care:

> The outset of a cancer diagnosis is replete with stressors, but also filled with powerful resources for remaining hopeful when faced with potentially despairing circumstances (Beach, 2014). The juxtaposition of stressful experiences with a "bright side" (Holt, 1993) of hopeful conduct reflects the co-presence and delicate balance of "bad" and "good" news in everyday living (Maynard, 2003; Maynard & Frankel, 2006).

Encouraging and motivating patients during their recovery emerged as an important theme both from the interview data and the interactional data that was analyzed for this study. Emphasizing hope and reassurance was important for both patients and providers in the pre-surgical period, as well as during the post-surgical period, as I will show in the following section. At the same time, as I will explain shortly, reassuring patients while backgrounding their concerns (that is to say, by not exploring them in more detail) can be problematic as it does not allow the members of the medical team to understand and address the difficulties that patients experience (this was also highlighted in the literature; e.g., see Ford et al., 2019, Henry et al., 2018c).

6.1.2. Emphasizing improvement and progress in function recovery. As in the pre-operative period, in the post-operative period the members of the team explained that they had an important role in motivating and encouraging patients as they were recovering from surgery. Patients also said in the interviews that this was one of the aspects of their communication with the team that they particularly appreciated. In this section, I will show how improvement and progress in function recovery were emphasized in interactions during clinical visits by analyzing excerpts from patients' appointments with the speech-language pathologist and the dietitian. These team members spent a lot of time with some patients during the post-operative period to help them recover eating and speaking functions. Specifically, the three excerpts below will illustrate interaction patterns that were identified during the analysis as emphasizing improvement and progress in function recovery: comparing the patient's situation to his/her earlier situation, and reinforcing the patient's statements about improvements.

The first excerpt is from the first post-operative visit of a patient who had surgery for a cancer in his jaw, and who had difficulties with closing his mouth and swallowing, particularly because of the swelling that was still present. At the beginning of the meeting with the speech-language pathologist and the dietitian, the patient's wife explained that the patient tried eating at home, but was not able to swallow. The speech-language pathologist and the dietitian encouraged him to keep practicing:

#Excerpt 23a

1 SLP: […] si ça c'est quelque chose que vous voulez faire, de retourner à manger, de
2 retourner à boire, si ça c'est un de vos buts, c'est important que vous pratiquiez, c'est
3 ça, OK. Je suis heureuse que vous faites des exercices pour les lèvres, pour essayer de
4 mieux les fermer, mais aussi c'est vraiment, si vous choisissez un des exercices, c'est
5 d'avaler, OK.
6 DIET: Avec force! ((Tout le monde rit)) Avec force. C'est encore enflé, certain, c'est enflé.
7 PT: Oui.
8 FCG: Ah oui-oui.
9 DIET: C'est très enflé, et chaque semaine, chaque jour, vous allez voir une amélioration,
10 OK, je suis certaine que c'est mieux maintenant que c'était il y a trois semaines
11 PT: Ah oui.
12 DIET: OK, alors, vous allez [voir], c'est le temps. Dans mes 36 ans ((tout le monde rit
13 un peu)), je vais vous dire, c'est le temps qui aide l'enflure à se baisser, mais avec
14 exercices, avec essais, OK. Alors, une ou deux cuillères à la fois et plusieurs fois. Et
15 une ou deux gorgées d'eau, et plusieurs fois, OK. Quand j'avais brisé ma cheville, ils
16 m'avaient dit de faire un exercice comme ça avec une serviette, j'ai dit, ils sont fous,
17 j'étais là avec la serviette ((tout le monde rit)), rien ne bougeait, et finalement, ça a
18 bougé, mes doigts ont commencé à bouger et tout.
19 FCG: Oui.
20 DIET: Alors, c'est la même chose avec ça, on ne voit pas d'améliorations tout de suite,
21 c'est aussi, si ça ne bouge pas, on essaie, et avec le temps ça va commencer, les nerfs
22 se guérissent, il y a moins d'enflure, et ça commence à bouger.
23 FCG: Oui, oui.

In this excerpt, the dietitian emphasizes progress as she is comparing the patient's present situation to the time when the patient was hospitalized (line 10), which is also recognized by the patient, as he expresses his agreement in line 11. At the same time, the dietitian acknowledges the patient's physical challenge ("*C'est encore enflé, certain, c'est enflé,"* line 6), and further emphasizes improvements by invoking knowledge from her 36 years of experience: that the situation will improve (lines 12-14). As the visit continued, the dietitian and the speech-language pathologist helped the patient practice swallowing, and at the end of the meeting, the speech-language pathologist emphasized progress and encouraged the patient to practice again:

#Excerpt 23b

24 SLP: […] je veux que vous pratiquiez.
25 FCG: Ah oui.
26 SLP: C’est ça. Parce que même aujourd’hui, vous avez pratiqué quelques gorgées,
27 quelques bouchées, ça a amélioré aujourd’hui parce que vous avez pratiqué.
28 PT: Uh-huh.
29 SLP: Ça a amélioré depuis que vous étiez
30 FCG: À l’hôpital.
31 SLP: Oui, OK.
32 FCG: ((Au patient)) Donc on fait ça tous les jours là ((tout le monde rit un peu))
33 SLP: C’est ça. OK? ((PT fait un signe d’accord avec ses pouces et sourit.))
34 FCG: On fait ça tous les jours.

In this excerpt, the speech-language pathologist emphasizes improvement not only by comparing the patient’s situation to his situation when he was at the hospital (lines 29-31), but also by mentioning the progress that she observed during the consultation (lines 26-27). The patient and his wife further emphasize this by saying that they will keep practicing at home (lines 32-34). Another patient’s meeting with the speech-language pathologist in the post-operative period further illustrates how improvements are emphasized as the speech-language pathologist and the patient discuss how the patient’s situation has progressed since his surgery:

Excerpt #24

1 SLP: […] in terms of swallowing, my colleague will be following you to give you
2 some exercises.
3 PT: OK.
4 SLP: But yeah, in terms of, because it’s difficult to chew, do you find that you have a
5 lot of purees left in your mouth after you’ve eaten? ((Looks into the patient’s mouth))
6 Or they mostly go down?
7 PT: They mostly go down.
8 SLP: OK. Yeah, so softer things, you can try and see how they go, if you want to, if
9 they go well, you continue with them. It might not be an entire meal of soft items, it

might be that, you’ve got one and you try, it’s one item on your entire tray, give it a try. It might be hard, if it’s hard, if it’s too hard, try it again in a week.
PT: OK.
SLP: If it’s just a little bit hard, it is going to be a bit hard, because remember when you started eating and drinking in the hospital, it was hard
PT: Yeah.
SLP: It was tiring.
PT: Yes.
SLP: And you had to do it, you had to work through it.
PT: Yeah.
SLP: It’s like an exercise.
PT: You wouldn’t leave me alone! ((Laughs))
SLP: It’s like an exercise that you’ve got there, it’s a little bit more challenging than what you’re doing now.
PT: OK.
SLP: OK?
PT: Yeah.
SLP: Good?
PT: Yeah.

The excerpts presented above show how the speech-language pathologist and the dietitian emphasized improvements and progress as they encouraged patients to keep practicing, which was essential for them in order to regain function. In this way, they also showed that “the conversation between professionals and patients is a crucial element of the treatment itself” (Mol, 2006, p. 412).

Another interaction pattern that contributed to emphasizing progress during the post-surgical period was reinforcing patient-initiated statements about improvements. In the examples above, medical team members initiated discussions about improvements, but patients also often talked to the team about their progress and the team members pursued these conversations, which contributed to reinforcing patients’ statements. The excerpts below illustrate how the speech-language pathologist pursued the topic of function improvement initiated by patients:

Excerpt #25

1 PT: Pour la parole, ça va quand même bien pour parler.
2 SLP: Oui, oui-oui-oui, ça va vraiment bien pour parler. [PT explique qu'elle ne peut
3 pas avoir accès à un SLP dans sa région, mais ça va très bien.]
4 FCG: Non, ta parole, ça va très bien, tu as fait beaucoup-beaucoup de progrès.
5 SLP: Oui-oui-oui, oui, je me souviens de la première journée qu'on s'est rencontrés à
6 l'hôpital
7 PT: Oui.
8 SLP: Je pense que ça faisait vraiment seulement, vous étiez capable de prendre des
9 liquides seulement, et vous deviez comme, pencher votre corps un peu en arrière pour
10 être capable de prendre de l'eau.
11 PT: Ah oui, oui-oui, c'était, ah oui.
12 SLP: Vous avez travaillé fort.
13 PT: En tout cas [Change de sujet]

Excerpt #26

1 PT: I feel much better, it's [my speech] improving.
2 SLP: And it's going to continue to improve like that, it is.
3 PT: Great.
4 SLP: Yeah, yeah-yeah-yeah, so just like anything, it's still only been two months, same
5 thing with eating and drinking, you're going to find that that's going to get easier,
6 you've probably already, did I give you purees when you were at the hospital
7 PT: Yeah, so
8 SLP: And then now you are taking ((inaudible)), right
9 PT: Yeah.
10 SLP: And what are you eating now?
11 PT: Just normal, like, my mom cooks normally, she doesn't have to cook it softer, just
12 everything normally.
13 SLP: OK.

In these excerpts, the speech-language pathologist reinforces the patients' statements about speech improvement (Excerpt #25, lines 2-3, 5-6, 12; Excerpt #26, lines 2-4) and pursues the conversation by bringing up improvements in eating and drinking (Excerpt #26, lines 4-6). These examples illustrate how motivating and encouraging patients, which patients described during interviews as one of the aspects in their communication with the team that they appreciated, was accomplished during post-surgical visits. To finish this section, I will provide some examples from the interviews with patients and team members that highlight the importance of the conversations illustrated in the excerpts above:

> […] ils étaient toujours en train de me motiver à faire quelque chose pour revenir, pour être en forme. Et la façon dont ils le disaient, ils me motivaient. Et des fois je disais, non, je ne veux pas faire telle affaire, ou je ne voulais plus venir à mes rendez-vous, non-non, il faut que vous continuiez, puis on continue à vous suivre. Puis ils étaient motivés eux aussi, fait que, juste voir leur motivation à eux autres, puis ils étaient contents aussi de la réussite de mon opération, eux-mêmes, ils étaient très contents.
>
> Ça aide parce qu'on dirait, ça aide un peu à être… c'est psychologique, eh, si le médecin te dit, ça va bien aller, c'est bien, tu fais des progrès, c'est sûr que c'est encourageant, c'est encourageant. Et même ma femme le dit.
>
> […] ils ne lâchent pas, puis ils veulent que ça soit bien fait, puis j'essaie de faire ce qu'ils me disent tout le temps, puis… Mais c'est ça, c'est toute une équipe qui pousse vers la guérison. Et à mon âge, SUR m'a souvent dit, à mon âge, j'ai de l'air en forme, même si j'étais un peu gras, mais j'ai de l'air en forme, puis il m'a dit, je vais être capable de passer à travers, fait que, ça aide à être positif dans tout ça. Et d'être positif, c'est important, je pense, pour continuer puis pour avoir de meilleurs résultats. C'est ça qu'on espère tout le temps, mais je pense que tout le monde, j'ai toujours senti que tout le monde était là pour que ça aide, pour que ça aille mieux.
>
> […] they reassure me that after the whole treatment, I will be able to eat & talk. It is helpful in a way, they gave me hope, but at the moment I find it difficult to swallow & talk.

These excerpts show how foregrounding improvements and progress made a difference in patients' experience by motivating them to keep practicing and by giving them hope during the period of time when they were in the process of recovery. The team members particularly talked about the importance of reassurance in the post-operative period, when patients are learning to live with the body changes that may be difficult for them to envision in the pre-surgical period. For example, one of the surgeons explained it in this way:

> […] some patients, even though they think they understand what they are going to face afterwards, they can't possibly understand or prepare themselves for. So that's when the art of medicine, and the hand-holding and engaging, again, our team, to help them get through it, that's when it comes into play.

In this way, specifically in relation to the recovery of eating and speaking functions, regular follow-ups with the speech-language pathologist and the dietitian were not only instrumental in terms of providing hands-on care and teaching patients about specific techniques and exercises, but also played an important role in terms of, as the surgeon described it, "the hand-holding and engaging." The dietitian and the speech-language pathologist also talked about this during their interviews:

> […] we're here for you, yeah, really, I think that the line of like, I'm here for you, we're all here for you, I know it's a lot of information, it doesn't matter, you don't need to take it, you know, take what you can with you, but we are here every single step of the way […] we will continue to follow you […] you continue to be followed and seen by the whole team, so…. by just going in there and just reassuring them that all of that, and what they are doing is great and good and they just have to keep going and doing that, that is a huge, a huge part of my job. And it's funny because it's something that I didn't really understand when I first took on this role and I was like, that's not my job, it's not like technical speech pathology, but it's become something that… has so much power to it in terms of just empowering the patient. You don't feel like you're doing much of anything, but when the patients go in and see the doctors and the doctors tell you, oh my God, you saw this patient, they are so much better, and it's like, I didn't do anything, but it's, I guess, you've changed some amount of their, how they are thinking about the difficulties that they are having.

> […] psychological component is very big, very big in this population, very big. In any patient population, you want to be reassured, but this patient population […] these patients need to feel normal. So [when they are in the hospital] you want them out of bed, you want them shaved, you want them dressed, you want them groomed, and not tied down to their beds, so that they can feel improvement, that they can feel that things are normal. So that was always the philosophy that I started my career in ENT [Ear Nose, and Throat], is try as much as possible make them feel that things will be good and that they will not be handicapped […] we're always trying to, whenever they have another bad day we're trying to be upbeat and positive […] and then there's also situations where there's nothing that could be done, so you can only be positive up to a certain point. So, you have to be realistic and temper a little bit the enthusiasm, the

> encouragment […] So that's, yeah, it's a matter of giving them hope, giving them information, giving them hope in a realistic [way], yeah.

These excerpts show that members of the medical team value motivating and encouraging patients as an important component of their role in the post-operative period. In the data that was collected for this study, "situations where there's nothing that could be done" described by the dietitian were not identified, as within the six-month period following the surgery the patients were still in active recovery. Such conversations may be studied in the longer term post-operative period, and a framing analysis perspective that reveals how patients bring up their concerns and identifies possible differences in patients' and providers' perspectives may be useful, as will be discussed in the last chapter. In the next section, I will continue the analysis by presenting the second theme that reveals how body changes were framed in patient-team conversations during post-surgical visits: how differences between patients' and providers' concerns were manifested and resolved in conversations.

6.2. Resolving differences between patients' and providers' perspectives

During the interviews, patients and medical team members explained that differences in how they see body changes were an important component of their communication during clinical consultations. During the analysis of interactional data, I identified two specific interaction patterns that illustrate how these differences are manifested and resolved in interactions: foregrounding biomedical explanations in response to patients' descriptions of symptom experiences, and emphasizing surgical wound healing in the immediate post-treatment period.

Before presenting each of these themes in this section, I will show how, during the interviews, patients and providers commented on the fact that they did not have the same perspective on body changes following surgery. For example, here is how one of the surgeons talked about these differences, as well as about his way of managing them in his conversations with patients:

> I remember […] we had a very young woman, she was probably in her thirties or her forties, with oral tongue cancer, she was a teacher, and she had small to medium size oral tongue cancer, and we had to resect and reconstruct with a flap […] And the two of the principal things that can be affected after you do a partial glossectomy [removal of part of the tongue] and reconstruction are speech and swallowing. And we did the surgery, it went very well, we were very happy with the pathology, the reconstruction was perfect, SUR did a beautiful job, and it takes a little time to heal, and now she's four-five-six months down the road, she's gone back to teaching. Our perspective is her speech was excellent, it was like, a home run, it was really one of the better speech outcomes. To the point that, for sure, for any of us in the clinic, if we didn't know she had a partial glossectomy with reconstruction, we wouldn't even – and we're attuned to hear, right, the typical speech of someone – we would not have known she had the operation. And she was so disappointed […] she was a French teacher and she took her teaching very seriously, and she explained to us that you have certain French words that have to be articulated in a certain very precise way and it wasn't quite right and… I'm not saying she was complaining, but she was bringing out this observation from her perspective, and certainly it bothered her. [And] we just said, look, you'll continue to work with the speech therapist and it will get better with time. And anyway, I didn't hear it get better because I didn't hear anywhere for it to go quite frankly, it was this good to me, but then again I'm not mother tongue French. So, anyway, it got to the point, after a year, 18 months, she was extremely happy, and now everything is perfect and great. But there was a period of time where our assessment of the deficit was not her assessment of the deficit, there was a disconnect there. But she just tried to, I mean, you have to acknowledge the patient's perception of, and I don't say perception meaning it's just a perception, I mean their observations, we have to acknowledge what their concerns are and address it and if it's something that's rectifiable or something that we can change, then we use every tool, but if there's nothing we can do we just have to acknowledge it and recognize it and empathize and support them.

In this excerpt, the surgeon gives an example of a situation where differences in perspectives were apparent, and when there was "a disconnect" between his assessment of body changes and his patient's assessment. He also talks about his strategies, which will be also illustrated in the interactional data below: to acknowledge the patient's perspective, to inform patients about available support and solutions, and to remind them that there will be improvements with time. In the cases that will be analyzed below, I will illustrate how this happens through interaction.

Another interview with a patient conducted for this study indicates that patients' awareness of these differences in perspective may lead them to suppress their differing perspectives during consultations. During his last interview at six months after the surgery, a patient told me about his concerns about going back to work as a speaker/presenter given that he still had difficulty speaking, and I asked him if that was something that he discussed with his doctors:

> Pour moi, c'est ma vie personnelle, ça ne regarde pas. […] Non, je n'en ai pas parlé à SUR, d'après moi c'est, c'est juste, ça ne regarde pas, puis, il n'y a aucune contrainte… […] La contrainte, c'est moi qui me l'impose, de dire, j'ai de la misère encore dans l'élocution, il ne peut rien faire, puis il va dire, « Mais vous, vous pouvez y aller, voyons donc, il n'y a pas de problème! » Moi c'est l'image, je ne me sens pas à l'aise de… d'affronter, ils sont quand même, il y a toujours 15 à 20 personnes… Ça ne m'intéresse pas d'aller… c'est vrai, c'est la première fois que ça m'arrive, mais ça ne m'intéresse pas de le faire, de me mettre en face, puis de les entretenir pendant une heure de temps.

This quote further illustrates how potential psychosocial concerns (here, specifically, about getting back to work and speaking in public) can be silenced in consultations, especially with the surgeons, and highlights the importance of other team members, such as the nurse and the psychologist, to whom patients can express such concerns, as was also shown in the first results chapter. At the same time, as I will show in Section 6.3.2, during the interviews with team members, the possibility for all team members, including the surgeons, to play a more active role in addressing patient's psychosocial concerns was discussed. This echoes researchers and practitioners in the field of psychosocial oncology who are advocating for a better integration of psychosocial care to reduce stigma and guide patients towards support resources (Holland et al., 2010, 2011; Jacobsen et al., 2012).

Before proceeding with this analysis of interaction excerpts, I will cite another story that was recounted to me by one of the surgeons, to further illustrate the differences between the patients' and the providers' perspectives in the particular context of head and neck surgical oncology:

> […] il y a un patient que j'ai vu, [il avait] une greffe faite [sur le cuir chevelu], mettons, un bon huit-dix mois auparavant, fait que là, c'état beau, à notre sens à nous, c'était super beau, ça avait bien guéri, la greffe, tout ça, c'était propre, mais il n'avait toujours pas de cheveux sur sa greffe. Et là il dit, "Ça va-tu rester comme ça?" Et moi au début, je ne comprenais pas, j'ai dit, "Ben oui, ça va pas mal rester comme ça, […], mais là c'est très beau, ça a tout bien guéri, il n'y a plus de croute, ce n'est pas rose, toute la greffe a prise, c'est très bien." Et il dit, "Oui, mais […] je n'ai pas de cheveux là." Et là j'ai compris ce qu'il voulait dire par "Ça va-tu rester comme ça" […] des fois c'est peut-être de porter un peu attention quand le patient nous pose certaines questions, nous on va avoir tendance à, à répondre vraiment d'un côté médical, alors que le patient […] sa question "Ça va-tu rester comme ça" ce n'est pas tout à fait ça à quoi on répond, on ne répond pas à sa question à lui. Fait que, oui, je pense qu'en post-opératoire on pourrait améliorer ce volet-là, moi je pense que oui. Soit en écoutant un petit peu plus ou des fois en posant une ou deux questions de plus, pour répondre à la question plus précisément du patient.

In this excerpt, the surgeon gives another example of challenges that she encounters in her conversations with patients related to the differences between, as she says, the patients' and the providers' points of view. She reflects on possible strategies to make sure that she answers her patients' questions by taking into account their perspective. A way of focusing on the patient's perspective (or foregrounding it) suggested by this surgeon is to explore the patient's concerns with follow-up questions to better understand them, and this will be specifically illustrated in Excerpt #33 later in the text. In the analysis that follows, I will show

how differences in patients' and providers' perspectives were manifested and resolved in conversations.

6.2.1. Foregrounding biomedical explanations in response to patients' descriptions of symptom experiences. In this section, I will analyze three excerpts where biomedical explanations of symptoms were foregrounded in response to patient-initiated descriptions of how they experienced these symptoms. These excerpts are taken from the case narrative of one patient, as they illustrate this framing dynamic in relation to the surgeons' reflections about the roles of different team members that were described in the first chapter, and as the patient's post-operative interview provides insight into how conversations during clinical consultations may impact patients' experience.

The first excerpt is the patient's first post-operative visit, two weeks after his surgery for salivary gland cancer. At the beginning of his conversation with his surgeon, the patient tells him that his tongue feels thick and crooked to him:

#Excerpt 27a

SUR: Bonjour!
PT: Bonjour docteur.
SUR: Comment ça va vous?
PT: Ça va pas pire.
((SUR examine le patient.))
SUR: It's good, it's healing well.
PT: La langue, pour moi, me semble très épaisse.
SUR: Oui, parce que la sen-
PT: Et croche
SUR: Non, c'est parce que la sensation a changé, parce que le cancer était dans le nerf, puis on a coupé le nerf qui cause la sensation, c'est à cause de ça que vous sentez que c'est gros, mais ce n'est pas gros.
PT: OK.
SUR: Puis l'autre chose que, c'est un nerf qui cause le mouvement de la langue, ça aussi il fallait le couper, ce nerf, c'est à cause de ça que la langue est un peu croche.
PT: Oui.

17 SUR: Alors, les deux choses que vous sentez, que c'est large et que c'est croche, parce
18 que les sensations ont changé. C'est à cause de ça que vous le sentez comme ça.
19 PT: Ici, il y a de l'inflammation […] [Change de sujet]

In this conversation, the difference between the patient's and the surgeon's perspectives first manifests as the patient brings up his sensation of his tongue (lines 7-9) in response to the surgeon's assessment that it is healing well (line 6). It then further unfolds as the surgeon explains to the patient that even if he feels that his tongue is thick, it is not thick, and specifies why the patient feels that way (lines 10-12). He also explains why the patient feels that his tongue is crooked (lines 14-15), and reinforces his explanation by summarizing it in lines 17-18. The patient's potential concern expressed in lines 7-9 ("*La langue, pour moi, me semble très épaisse […] et croche*") is backgrounded in this conversation, as the patient responds "OK" to the explanations provided by the surgeon (lines 13, 16), and does not pursue the topic further by changing the subject in line 19.

In his next postoperative visit, ten days later, the patient brings up the same concern about his tongue again, and further specifies why it is concerning to him – because it is more difficult for him to eat. By comparing this conversation with the conversation above, it is also possible to say that the patient's concern is backgrounded in Excerpt #27a above, since the reason why it was of a concern to the patient is not evoked in the conversation.

#Excerpt 27b

20 PT: OK. La sensibilité de ma langue, en arrière ici, je la sens toujours épaisse, et je ne
21 mange pas de ce côté-là ((Inaudible))
22 SUR: Sortez la langue pour moi ((Examine la langue.)) Alors, le nerf qui bouge la
23 langue, quand tu sors la langue, ça tourne vers la droite
24 PT: Oui, je le sens.
25 SUR: OK, parce que le nerf qui contrôle le mouvement du côté droit de la langue,
26 c'était affecté par la tumeur, c'était enveloppé, alors c'était nécessaire d'enlever ça

27 pour enlever la tumeur. Alors, à cause de ça, c’est des changements pour vous pour la
28 langue, l’articulation, manger, et ça c’est la raison que vous avez l’impression que c’est
29 bien gonflé.
30 PT: Oui.
31 SUR: Uh… We didn’t do any flap ((Inaudible, briefly speaks to RES)) So, c’est une
32 impression, vraiment, la langue, ce n’est pas tellement gonflé, ce n’est pas gonflé du tout
33 PT: Ah non.
34 SUR: C’est l’impression à cause de, et ça c’est, tu vas t’habituer.
35 PT: Ah oui, OK, parce qu’ici, c’est encore dur et très ((touche son cou))
36 SUR: Ah ça c’est le, la guérison et la cicatrisation dans le cou, mais dans la langue,
37 c’est l’explication.
38 PT: OK. Fait que ça, ça va devenir plus mou, je présume, avec le temps, oui?
39 SUR: Avec le temps, oui.
40 PT: OK, je souhaite que ça peut-être, que ma langue devienne moins, ou plus sensible,
41 moins épaisse
42 SUR: Avec le temps, ((to SLP)) you are working with him a little bit, speech?
43 SLP: Yeah.
44 SUR: Because that ((inaudible)) that’s permanent, I had to resect it [the nerve].
45 SLP: Yes, yeah, he’ll be working with [my colleague] when he starts his radiation.
46 PT: OK. Puis, l’autre chose [Change de sujet.]

As in the previous excerpt, when the patient describes how his changed body feels to him (“*La sensibilité de ma langue, en arrière ici, je la sens toujours épaisse,*” line 20), the surgeon explains to the patient the surgical procedures that caused this sensation of thickness (lines 25-29), and further emphasizes that this sensation is an impression that the patient has because one of the nerves had to be taken out during the surgery, as the patient’s tongue is not really swollen (“*Vous avez l’impression que c’est bien gonflé […] c’est une impression, vraiment, la langue, ce n’est pas […] gonflé du tout,*” lines 28-32). The patient’s difficulty eating expressed at the beginning of this conversation is backgrounded as this topic is not pursued further. In line 38, the patient emphasizes his concern about the way his tongue feels by bringing up the topic once again: “[…] *je souhaite que ça peut-être, que ma langue devienne moins, ou plus sensible, moins épaisse*.” The surgeon does not directly address it, but confirms with the speech-language pathologist that she is working with the patient on his speech. In this situation, the brief exchange between the surgeon and the speech-language pathologist (lines 42-45) can be seen as a different way of foregrounding the patient's concerns, given the limited amount of time that surgeons can spend with their patients in the context of a busy clinic. Another way of accomplishing this is for the surgeons to encourage patients to discuss their concerns with other members of the team, like in this example from the patient's post-operative meeting with his surgeon:

Excerpt #27c

47 FCG: Tu voulais savoir pourquoi que l'eau te sortait par le nez, quand tu bois de l'eau,
48 de temps en temps.
49 PT: Quand je bois de l'eau, à un moment donné, ça coule par le nez.
50 SUR: C'est vrai? ((À RES)) We didn't go that far
51 FCG: De temps en temps.
52 SUR: ((À RES, en regardant aussi l'écran de l'ordinateur)) Oh, maybe the sensation is
53 different
54 PT: Mais je pense que
55 SUR: Je pense que c'est, parce qu'on n'est pas allé assez loin, ça veut dire que le palais
56 ne bouge pas puis ça ne bloque pas complètement, et c'est à cause de ça que quand
57 vous buvez, ça revient.
58 FCG: Oui.
59 SUR: Ça se peut que c'est à cause de ce nerf-là qui était coupé, la sensation est différente,
60 vous ne le sentez pas puis ça ne referme pas, puis ça sort un petit peu, ça se peut.
61 PT: OK. J'avale un peu différemment depuis l'opération.
62 SUR: Oui, c'est sûr.
63 RES: C'est normal.
64 PT: Et si je pousse un peu ma langue vers le haut, c'est là que ça sort.
65 SUR: Oui-oui, oui, ça se peut que là vous poussez un petit peu, c'est en arrière.
66 PT: Oui, en tout cas.
67 SUR: Parlez de tout ça avec l'orthophoniste, c'est important.
68 FCG: Oui, OK.
69 PT: Oui, on va tout voir ça. Merci docteur, je pense que vous avez répondu à toutes nos
70 questions.
71 SUR: Alors, je pense que pour nous, on n'a pas besoin de vous voir, parce que c'est
72 vraiment RAD qui va prendre soin de vous maintenant. [Parle un peu plus du suivi en
73 radiothérapie pour la suite.]

As the patient is about to change the topic of the conversation in line 66, the surgeon encourages him to talk about his difficulties eating with the speech-language pathologists, and emphasizes that it is important (line 67). These examples show how patients' concerns that are not discussed in detail (and, in this way, are backgrounded) during the appointments with the surgeons are at the same time being framed as important when surgeons make sure that other team members follow up with the patient and encourage the patient to discuss their concerns with other team members. The post-operative interview with the patient indicates, as has also been shown in other examples, that the concerns that patients briefly express during their meetings with their medical team at the clinic can be further elaborated when patients have a greater opportunity to express them. This excerpt once again highlights the importance of other team members, such as the nurse and the psychologist, who can assess and address these concerns. As the patient needed radiation after his surgery, at three months after his operation he was still in recovery; in response to his questions about improvements with eating and speaking, as in the examples that were presented in section 6.1.1, the team members explained that he was still in recovery. In his post-operative interview, the patient told me about his concerns about eating and speaking that, beyond the physiological aspect, involved social aspects as well:

> Qu'est-ce qui m'a le plus dérangé c'est, je n'avale plus comme avant, ((inaudible)), et puis […] ça ils ne m'ont pas prévenu tellement de ça, je m'en suis rendu compte moi-même. Et puis… Encore aujourd'hui, je ne suis pas capable de boire de l'eau. […] Boire du vin, oublie ça, ça brûle, ça chauffe, ça… uh… la nourriture, il faut faire attention. ((Inaudible, transcription à partir des notes: « Manger est difficile »)) C'était ça mon gros handicap, et c'est encore ça. Ensuite, parler, c'est assez facile de s'en rendre compte, ma langue est gelée de ce côté-ci, en permanence, ça c'est plate. […] Comme, manger, est-ce que je vais manger un peu plus normal, parler un peu plus normal, est-ce que je vais avoir plus de force? ((Inaudible.)) Et ça, ça me préoccupe, parce que c'est du quotidien. Je n'ai pas été dans un restaurant encore, j'ai peur. Parce

> que tu veux boire, mettons, du liquide, mais je peux m'étouffer. ((Inaudible.)) Quand je mange, j'ai un chum qui vient, et je n'ai même pas été capable de placer un mot ((dans la conversation)), parce que, lui, il ne réalise même pas mon problème. ((Inaudible))

The patient also commented on the brief exchanges that he had with his surgeons around his difficulties with eating and speaking. He said that he understood that they could not give him exact information as to when he would recover function, but also expressed his preference for the surgeons to take more time for these discussions during the post-operative period:

> SUR il m'a dit, pour la déglutition, il dit, ça peut prendre six mois comme ça peut prendre dix mois. Il dit, il n'y a pas une personne pareille. Puis c'est sûr qu'à 67 ans, je ne guéris pas aussi vite qu'un gars de 20 ans, et ça, ça compte aussi. ((Inaudible.)) […] Quand nous on les rencontre, on comprend aussi qu'ils n'ont pas les réponses à tout. […] Moi, SUR, je l'ai vu une fois avant l'opération, et après ça je ne l'ai même pas vu. Une fois, une seconde. Mais des fois si ton médecin, ton chirurgien, t'expliquerait, mettons, un peu avant, puis probablement un peu moins, parce qu'il ne sait pas des fois ce qu'il va découvrir. Mais par contre, après l'opération, il peut prendre un peu de temps. ((Inaudible, transcription à partir des notes: « Prendre le temps de s'asseoir proche du patient, lui expliquer, ça ferait une différence. »)) La confiance que ça donnerait. Mais là tu as l'impression d'être un morceau de viande qui a été mis sur une planche et qu'il faut arranger. C'est vraiment l'impression que j'ai, un morceau de viande. Fait que ça, ça ne change rien dans la vie d'un médecin, mais l'impression que ça donne au patient, c'est ((inaudible.)) […]

This excerpt again illustrates how the patient's support needs, expressed in the interview, were not apparent during the clinical visit. In addition, this excerpt indicates how foregrounding biomedical explanations in response to patients' concerns may impact patient experience. The patient's need for more attention from his surgeons (and one can also say more empathy as the patient talks about the need "to take the time to sit closer to the patient") suggests that the absence of empathetic responses to the patient's descriptions of negative experience (in Excerpts 27a, 27b, and 27c above) can also be seen as an empirical marker of backgrounding of potential concerns. It is important to note here that this theme was explicitly mentioned during interviews with three patients, who reflected specifically on these aspects of their interactions with the team (see also patients' comments in section 5.3.2, on how in pre-surgical meetings the consequences of the surgery can be presented as common or "*banals*"). My goal here, again, is not to evaluate the medical team's actions, but rather to show how patients may see specific interaction patterns that were identified during post-operative consultations, with particular attention to the aspects that were identified as helpful or as problematic by the patients, so that the results of the study can inform practice. Here is how another patient talked about this when he reflected on his communication with his surgeons six months after his surgery for nasal cancer, which involved the removal of his nose:

> [...] je ne remets pas en question l'empathie là, je sais que mon médecin traitant, particulièrement, était très-très empathique, c'est quelqu'un qui avait, qui était très de bonne humeur, et je l'ai apprécié énormément [...] Mais pour eux, tout est banal, tout est banal, des patients comme toi, ils en voient à la longueur de la journée. Fait que, quand tu vas le voir, tu dis, ben, regarde, j'ai de la difficulté à manger, j'ai si, – "Ah ouais, c'est normal." Ouais, c'est normal, mais tu comprends-tu que toi tu manges trois fois par jour et moi j'ai de la difficulté à en manger deux, tu comprends-tu? Uh, oui, c'est normal, mais qu'est-ce que je peux faire maintenant? Est-ce que tu as une solution à mon problème? Et c'est sûr qu'il y a toujours une solution, c'est sûr qu'ils peuvent t'organiser ça autrement, il n'y a aucun problème, mais ne dites-moi pas que c'est banal. Il n'y a rien de banal là-dedans, il n'y a rien de banal à se faire amputer le nez, rien de banal à avoir de la difficulté à manger dur, il n'y a rien… ce n'est pas… ce n'est pas banal.

This patient, like all the patients in this study, indicated that he was generally satisfied with the care that he received, and the quote above illustrates specific aspects of his care that he appreciated: the empathy and the good humor of his surgeon, and the fact that there were always solutions to his problems. However, he also points out the differences in the patients' and the doctors' perspectives, by bringing up the need to recognize patients' subjective experiences, even if they can seem very common to the doctors: "[…] ne dites-moi pas que c'est banal. Il n'y a rien de banal là-dedans." These comments are consistent with the conclusions that were made in the studies examining the question of empathy in patient-provider interactions. As Ford et al. (2019, p. 31) noted, "reassurance can present a problem, however, because simply telling patients that their symptoms are not serious from a medical perspective does nothing to address the impact that these symptoms have on their lives" (see also Henry et al., 2018c).

6.2.2. Emphasizing surgical wound healing in the immediate post-surgical period. One particular discussion topic that was identified in conversation transcripts and that illustrates the differences in patients' and providers' perspectives are surgeons' assessments of the surgical site as "beautiful" during post-operative visits that took place shortly after the surgery. In this section, I will analyze post-operative consultations with two patients to show how patients' assessments of their appearance were backgrounded in these situations. I will also present patients' reflections from post-operative interviews to show how this way of framing may contribute to patients' experiences.

The first case consists of the first two post-operative meetings of a patient who had a tumor resected on one side of his neck. A skin flap was detached from his shoulder and attached to his neck to repair missing tissues. One side of the flap remained attached to the shoulder, so that it stayed connected to the blood vessels. After one month, when the resection on the neck was healed, the surgical team removed the flap and reattached it to the shoulder. The patient spent one month with the flap, which was covered with a big bandage. At the beginning of his first post-operative appointment, the patient meets with a resident who, while she is examining the patient, says:

Excerpt #28a

1 RES: Your wound looks healthy and the flap is taking so nicely, it’s so beautiful.
2 PT: Yeah?
3 RES: Yeah, it looks good! ((Continues to examine the wound.)) Let me see here what
4 we can do…
5 PT: I, I glanced at it in a mirror and it didn’t look so good to me.
6 RES: Well, because, you’re still
7 PT: Of course I know the doctor is
8 RES: No, it’s taken, the flap really well. Show me your teeth? Good. Close your eye.
9 You don’t have eye symptoms or anything, no.
10 PT: No.
11 RES: OK, perfect, OK. I’m just going to get some ((Goes to the counter to get a pair of
12 scissors. Goes back to the patient and continues to examine the wound.)) It’s so
13 beautiful, it’s perfect! So you said, six more days of antibiotics?
14 PT: Yeah.
15 RES: Perfect. Let me speak to SUR and I’ll be right back.
16 PT: OK.

In response to the resident physician’s assessments of the wound and flap in lines 1 and 3 (“the flap is taking so nicely, it’s so beautiful,” “it looks good”), the patient expresses a potential concern about appearance in line 5 (“I glanced at it in a mirror and it didn’t look so good to me”). Initiating a new topic is a marker of foregrounding here, and can be further supported by the interview data, as several patients described how they were surprised and sometimes shocked when they saw their wounds after the surgery. In lines 6-8, as in the excerpts presented in the previous section, the physician offers an explanation as to why it did not look good, and the patient acknowledges this difference in perspectives (“Of course I know the doctor is,” line 7). The physician further emphasizes that the flap is healing well as she continues examining the patient (“it’s taken, the flap really well,” line 8; “it’s so beautiful, it’s perfect,” lines 12-13). When the resident comes back with a staff surgeon, the staff surgeon describes the wound in the following way after examining it:

Excerpt #28b

17 SUR: […] Well, it looks good but it's… I mean, it looks bad but it is good.
18 PT: Yeah, that's what I said.
19 SUR: It looks bad, but it is good. ((To RES)) What did you guys put in there? Nothing?
20 ((Continues to examine the wound with RES.))

The surgeon acknowledges the difference between the way that the wound looks and the way that it heals ("it looks bad but it is good," line 19), and the patient's potential concern about the way that it looks is not explored in the conversation that followed, which was mainly focused on caring for the patient's wound and dressing it. In his next post-operative meeting, a similar conversation took place:

Excerpt #28c

21 SUR1: ((Examines the wound.)) Beautiful, wow!
22 PT: Yeah, I know, everybody says that
23 SUR1: Well it's something relatively new, it's not, the concept is not new, but… The
24 actual flap itself is pretty unusual.
25 PT: Yeah.
26 SUR1: That's good, it works beautifully for you, great.
27 ((SUR2 enters the room.))
28 SUR2: Hey! ((Looks at the wound)) That looks great!
29 PT: There you go, you're going to tell me, it's beautiful too. To me, it's not beautiful!
30 ((Laughs, everyone else laughs, too))
31 SUR2: It will be! Wait, we'll see what it's going to look like in a couple of weeks!

At the end of this exchange, when SUR2 says, "It will be [beautiful]" (line 31), he acknowledges what was previously said by the patient ("To me, it's not beautiful!", line 29), and offers reassurance that it will get better. Overall, in the three excerpts above, the patient's possible concern about appearance is backgrounded, as it is not explored by the physicians, and as the patient does not pursue the topic further while the conversation is focused on wound healing. In the interview at three months after his surgery, the patient explained his perspective on these conversations:

> I look at it [the wound and the flap] in the mirror sometimes and it's hard for me to see ((the bandage is on the side of his neck)), I just want to see how it's coming along, so when he said it was beautiful, I said, I looked in the mirror and it didn't look beautiful to me ((laughs)), you know, it's not that I, you know, beautiful, that's not the words to use, they could say, it's coming along well, it's going to be OK, it's progressing, but beautiful ((laughs)), but that's OK. […] I just got a joke out of it, that's all.

During the interview, the patient also talked about his appearance and that he did not like the way he looked, and he also explained that he had found his own way to handle it and was not expecting any support in this regard from his medical team: "They are doctors and they are doing the best they can […] they do what they have to do and that's it, you know. I don't expect going there and get moral support."

A similar interaction pattern can be observed in another patient's first post-operative appointment, which took place two weeks after he had surgery to remove a tumor in his jaw. One side of the patient's face was very swollen, and his speech was different because of the swelling. At the beginning of the appointment, a resident physician examined the patient before calling in a staff surgeon:

Excerpt #29a

PT: It's [the wound] closing up?
RES: Yeah, this is closing up. Just the skin is still a little bit open, but that usually takes a little bit of time.
PT: OK.
RES: The, the other one, is an opening in the wound, on the lateral part of it
PT: OK.
RES: There's a little bit of secretions and I think you might need antibiotics, OK
PT: OK.
RES: But I'll show it to SUR, too. And the other thing is, we're going to have a look inside your mouth. ((Examines the patient)) Beautiful. All nice… this is also good… OK, inside the mouth, it looks perfect.

12 PT: From the outside it looks like hell. ((Laughs a little)).
13 RES: ((Laughs a little, too)) Oh well, it's healing.
14 PT: I'm scaring little kids!
15 RES: The swelling, this was bigger, now it's a lot smaller
16 SLP: Yeah, the swelling has gone down
17 RES: Yeah-yeah.
18 PT: OK.
19 RES: OK, so, we'll have SUR come in, have a look at you, examine you, make sure
20 everything's OK.

As in the previous excerpt, the patient briefly mentions his negative perception of his appearance in line 12 ("From the outside it looks like hell"), and in response the resident comments on the healing and the swelling that is going down (lines 13-17). When the staff surgeon comes in later, he tells the patient that he is looking good as soon as he sees him:

Excerpt #29b

21 SUR: Hey! How are you doing? You're looking good!
22 PT: ((Smiles, with gestures and by moving his head from side to side: "so-so," "not so good"))
23 SUR: Sort of!
24 PT: Sweet doctor! ((Everyone laughs))
25 SUR: You look perfect!
26 PT: Yeah-yeah.
27 ((SUR starts examining the wound.))

In his interview three months after the surgery, the patient spoke about such interactions with his surgeons:

> […] SUR, la dernière fois que je l'ai vu, il a dit, Oh, ça parait bien! Je l'ai traité de sweet-talker. J'ai trouvé ça bien drôle. Mais c'était pour être drôle aussi, oui. Parce que je savais que lui, il parlait de, de la guérison, de la greffe et puis tout ça, comme ça, je savais que la réaction de l'équipe médicale, c'était purement, la guérison. […] ils regardaient ça d'un autre point de vue, purement médical. Tu es en train de guérir, notre chirurgie a bien marché, on a fait une bonne job.
> MC: Et pour vous, cette approche, c'était
> PT: Ils faisaient leur job, oui, c'était professionnel. Et puis… C'était rassurant qu'ils étaient contents de ce qu'ils avaient fait. S'ils rentraient puis ils regardaient ça, puis ils

> disaient, merde, là ((Rit)), mais là, gros sourire, continue, ça marche bien… Ça me disait, OK, c'était rassurant.

For this patient, as well as for the patient in Excerpt #28, the emphasis put on wound healing was reassuring, and he explained that he understood his physicians' perspective was different. He also talked about his experience of living with his altered appearance and speech:

> PT: Je n'aime pas sortir en public, uh… J'ai appris qu'il y a des gens, des amis qui réagissent mieux que d'autres à ça. J'en ai un qui est très bien, et l'autre ami, je le connais même plus longtemps, il ne peut pas dealer avec ça. Même mes frères, ils ont de la difficulté à me regarder dans la face. Même si je leur dis, ce n'est pas pénible, c'est difficile, ils ont de la misère avec ça. Comme ça, OK, je vais patienter quelques mois et puis ça va descendre. Uh… C'est difficile d'être en public, même [à l'hôpital], les gens me regardent. Ce n'est pas facile.
> MC: C'est sûr.
> PT: Mais, OK. Il n'y a pas grand-chose que je peux faire. Je pensais porter un niqab à un moment donné, puis ((Rit)). Mais non, je ne peux pas. Mais je peux comprendre les gens qui sont inquiets des cicatrices. Tu te fais remarquer.
> MC: Et de tout ça, avez-vous discuté avec votre équipe médicale?
> PT: Oh oui, mais eux-autres, ils savent qu'avec le temps, ça va… ça va réduire, c'est normal, ils me disent. OK. En ce moment il y a deux réactions. Celle médicale, de l'équipe, et puis le grand public qui voit ça pour la première fois, c'est… Je ne peux pas dire que je m'habitue. Mais je me sens rassuré par le personnel médical. OK, éventuellement, ça va réduire et tu vas être capable de parler comme du monde. Parce que, pour l'instant, mes lèvres ne se rencontrent pas, alors quand elles vont pouvoir se rencontrer, je vais être capable de manger en public. Mais pour l'instant, je ne peux pas, oui.

This excerpt is another example of how patients' concerns that were not expressed during consultations were made visible during the interviews. In the consultations with surgeons, patients' brief mentions of potential concerns about appearance were backgrounded or not pursued, as patients did not see it as their surgeons' role to discuss such concerns. The difference between the patient's perception of the appearance of the wounds and the physician's perspective of the way in which the wounds were healing manifested during consultations, as patients and providers acknowledged them (for example, "Of course I know the doctor is," Excerpt #28a, line 7; "it looks bad but it is good," Excerpt #28b, line 19). This difference was resolved as patients' remarks about appearance were not constructed as concerning (or, in other words, requiring further exploration or discussion) and as the conversations focused on surgical wound healing. In the following section, the analysis will show how patients' potential concerns about appearance were backgrounded in other situations, as well as how, in some instances, they were foregrounded.

Before concluding this section, it is worth mentioning that another study conducted with head and neck cancer patients to explore their experiences of disfigurement can provide further insight into possible impacts of backrounding patients' negative assessments during post-operative consultations that emphasize the wound healing process. This interview study was conducted in the same hospital department as the present study, and a perceived lack of empathy was described by some participants as characteristic of a negative relationship with health care professionals. Similarly to the interaction patterns identified in the excerpts above, patients in the study commented on "a lack of empathy, such as when a physician seemed more focused on patient survival and what they considered to be surgical success than the patient's struggle to cope with disfigurement" (Henry et al., 2014b, p. 12).

6.3. Foregrounding and backgrounding concerns about appearance

In the previous sections, excerpts where patients expressed potential concerns about appearance were analyzed, with emphasis on a particular difference in patients' and providers' perspectives, namely patients' negative assessments of their appearance and providers' positive assessments of the physical healing process. In this section, other ways of backgrounding potential concerns about appearance will be presented, as well as situations where these concerns were emphasized as concerning. This theme was identified as an important one during the analysis based on patients' descriptions of their concerns about appearance during the interviews and the fact that they tended to be silenced during clinical consultations, also reflecting the results of some previous research (Cohen et al., 2012; Konradsen et al., 2009; Losi et al., 2019).

6.3.1. Establishing changes in appearance as not being a matter of concern. In this section, I will analyze three cases that show how patients brought up potential concerns about appearance and how they were not constructed as being concerning in the conversations that followed. These three cases were chosen to show the dynamics of foregrounding/ backgrounding as a continuum, from a topic brought up by a patient not being pursued, to acknowledgments of patients' perspectives and explanations as to why appearance is not concerning.

The first excerpt is from a patient's appointment with the speech-language pathologist at three months after he had surgery for a cancer in his mouth. During the surgery, a significant part of the patient's lower lip was removed. This patient also had surgery for cancer in the same region ten years previously, which affected the appearance of his chin. The patient described these changes in these words in one of the interviews: "C'est sûr que des fois quand je me regarde la figure dans le miroir, ben, la lèvre n'est plus là, le menton n'est plus là… Des fois c'est un choc regarder dans le miroir, ((inaudible)), mais bon, je vis encore." During his follow-up appointment at the clinic, the patient told the medical team that he was having difficulty with eating and drinking, as his two lips were not closing. The speech-language pathologist met with the patient to help him with closing his mouth and swallowing.

Excerpt #30

((SLP donne un verre d'eau au patient pour qu'il puisse essayer de boire. SLP lui donne des conseils, de prendre de plus petites gorgées, de continuer à avaler. Elle tient le miroir devant le patient pour qu'il puisse voir sa bouche.))
SLP: Est-ce que ça aide, d'être devant le miroir?
PT: Je n'aime pas ça, le miroir, parce que je ne suis pas beau ((Rit un peu, SLP aussi.))
SLP: Prenez une petite gorgée… ((Continue à donner des conseils au patient, de serrer les lèvres)). Mais ça va mieux que la dernière fois qu'on s'est vus.
PT: Mais oui. ((PT continue de boire, SLP surveille et donne des conseils.))

During the appointment, the speech language pathologist focused on encouraging the patient to practice and on giving him advice, which included highlighting specific strategies that patient had already developed for eating and drinking and motivating the patient to continue using them. Patient's potential concern about appearance ("Je n'aime pas ça, le miroir, parce que je ne suis pas beau," line 5) is backgrounded as it is not pursued in the conversation; the speech-language pathologist does not seek further elaboration, and the patient does not elaborate on it either, and does not bring it up during subsequent visits.

The next excerpt is from a post-operative visit that took place five months after a patient's surgery. At the end of the meeting, the patient tells the surgeon that his shoulders looked different since the operation:

Excerpt #31

PT: I have a question for you.
SUR: Yeah.
PT: This shoulder, since the operation, it's not the same as this shoulder.
SUR: Yeah, let me see, lift up your hand
PT: Well now I'm able to lift, because the gym, I told you, I started back, before it was like this ((lifts just a little bit))
SUR: Yeah, yeah.
PT: But if I take my shirt off and you

9 SUR: Yeah, you see, it is lower
10 PT: It’s lower.
11 SUR: Because all the muscles, we removed a lot of the muscles in there, and a lot of
12 the nerves
13 PT: OK.
14 SUR: So your main nerve is OK still, there’s probably little branches that make it go
15 down a little bit.
16 PT: OK.
17 SUR: So, and you’re, you’re a kind of guy that works out so you notice more than
18 probably a normal, well normal, any usual person
19 PT: Yeah, to me it just looks funny.
20 SUR: Because you’re so built on the other side, you know
21 PT: No but I lift it better, it still hurts, but when I look, I go, gee, maybe it’s dislocated
22 or something.
23 SUR: No-no, it’s just the way it looks because of the surgery.
24 PT: OK.
25 SUR: But keep on exercising
26 PT: Yeah-yeah
27 SUR: Because the more, it’s like physio.
28 PT: Yeah, I go six days a week.
29 SUR: Perfect, really?
30 PT: Yes, six days a week, I didn’t go today, but I’m going to go this afternoon.
31 SUR: Yeah, yeah, definitely, keep on, it’s like physiotherapy for you, but it will, it will
32 never be the same as this.
33 PT: Ah OK.
34 SUR: But it’s normal, yeah.
35 PT: OK, as long as I know.
36 SUR: And probably most people wouldn’t notice it so much, but because you exercise,
37 so you build this muscle up, and this muscle is down
38 PT: Oh me I noticed because I look, but I mean, nobody else notices.
39 SUR: Yeah, exactly. But that’s fine, I think you’re good, I think we’ll get the PET scan
40 […]

As the patient started to ask his question in line 3 (“This shoulder, since the operation, it’s not the same as this shoulder”), the surgeon first interprets it as a question about the movement of the shoulder, as he asks the patient to lift up his hand (line 4). The patient then specifies that he is asking about the way his shoulder looks (“if I take my shirt off…”, line 8; “to me it just looks funny,” line 19), and in the responses offered by the surgeon appearance is not constructed as concerning, as the surgeon explains the surgical procedures and says that “it’s just the way it looks because of the surgery” (line 23). The surgeon encourages the patient to keep exercising (line 25), which contributes to emphasizing the uneven appearance as a condition that can be improved. At the same time, the surgeon tells the patient that his shoulders will never be the same, which is again framed as not concerning through being described as normal (line 34) and as something that “probably most people wouldn’t notice so much” (line 36). The patient’s agreement in line 38 (“Oh me I noticed because I look, but I mean, nobody else notices”), followed by the surgeon’s positive evaluation in line 39 (“Yeah, exactly. But that’s fine, I think you’re good”), further establish appearance as not being a matter of concern in this situation. In the interview, the patient explained that he asked the question because he didn’t know that his surgery would involve resection in his shoulder: “[…] me I thought it was just here ((points to his face and neck)), like I didn’t know it was going into here ((points to his shoulder)), but it’s minor, if I was 25 years old, maybe it would bother me, but at my age, it doesn’t bother me. Like, see, what bothers me, is this freaking eye…” In the following example, on the contrary, potential concerns about appearance expressed by the patient during the consultations were also described as being of importance to the patient during the interview (see also examples presented in section 6.2).

This patient had a partial glossectomy: part of her tongue was removed and replaced with tissues taken from her forearm. In her first post-operative visit at the clinic, she asked the surgeon about the appearance of her tongue:

Excerpt #32a

1 PT: From what I see, you cut off half of the tongue, or just the tumor, just the back, I
2 don't know
3 SUR: Well, we removed the tumor with a surrounding portion of tongue.
4 PT: Yeah.
5 SUR: Uh
6 PT: Like, what I see right now, it's like, almost a half
7 SUR: Well, at the front it is
8 PT: Uh-huh.
9 SUR: And then as you go towards the back, because the tongue is, the tongue is much
10 bigger than what you see.
11 PT: Oh, OK.
12 SUR: So by, by volume, it's nowhere close to a half, nowhere close.
13 PT: OK.
14 SUR: But in terms of the front of the tongue, yeah, we went down the midline and then
15 as we went further back where the tumor got more to the side and then we, from the
16 midline
17 PT: So, what I see is what was removed, right
18 SUR: Well, anything that is flap
19 PT: Uh-huh.
20 SUR: Is replacing tongue that was.
21 PT: Oh, OK. So where I see the flap is, my original tongue
22 SUR: Your original tongue is the pink, on this side, and anything that looks more like
23 skin color is flap replacing original tongue.
24 PT: OK, OK.

In this conversation, the patient brings up the topic of the extent of the surgery, by mentioning that from her perspective, from what she sees, half of the tongue was cut (line 1, line 6). The surgeon then explains that from the surgical perspective, "it's nowhere close to a half" (line 12), while also acknowledging what was just described by the patient: "But in terms of the front of the tongue, yeah, we went down the midline" (line 14). The patient then asks the surgeon about possible changes in the way her tongue looks as she continues to recover from the operation:

Excerpt#32b

25 PT: So after it’s going to be, how it’s going to be like, after the swelling is gone?
26 SUR: After the swelling is gone, your speech will be almost normal if not normal.
27 PT: But I’ll still see, like a
28 SUR: No you’ll, again, you’ll see the color differential
29 PT: Uh-huh.
30 SUR: It’s never going to take on the color of mouth lining called mucosa, because it’s
31 not mucosa, it’s skin.
32 PT: Uh-huh.
33 SUR: It’s always going to look more like skin then mucosa, because that’s what it is.
34 But that will be just an appearance thing, because I expect that your articulation and
35 your swallowing will be essentially normal.
36 PT: Uh-huh. And also, I’ll lose the taste from this side, right. […]

Similarly to Excerpt #31 above, when the patient asks her question in line 25 (“how it’s going to be like, after the swelling is gone?”, the surgeon answers from the physical function perspective (“your speech will be almost normal if not normal,” line 26), and in response the patient emphasizes the appearance aspect (“but I’ll still see, like a,” line 27). The surgeon answers the patient’s questions and finishes by describing changes in the way the patient’s tongue looks as not concerning: “But that will be just an appearance thing, because I expect that your articulation and your swallowing will be essentially normal” (lines 34-35). This also echoes one of the themes presented earlier, namely the ordering of concerns about body changes by priority. The patient expresses her agreement and does not pursue the discussion further by changing the subject in line 36. This way of presenting concerns about appearance as secondary to other more important concerns can also be observed in another appointment with this patient which took place four months after her operation. The surgeon tells the patient that the scars on her arm and neck are taking longer to recover, and is thinking about possible solutions to help with scar healing.

Excerpt #32c

37 SUR: […] the question is, how can we make your scars a bit better, you know.
38 PT: OK.
39 SUR: So I would try this first, we'll try all the stuff that we know, at the end if it
40 doesn't, if you still have red, we might send you to a dermatologist to see if they can
41 PT: Yeah, because I think, my skin type is quite like, scarry
42 SUR: You do, you scarred, yeah, because by now it shouldn't be this red.
43 PT: You see, like, all these scars
44 SUR: Yeah, you just scar
45 PT: It takes a long time to go, I know that, like, even just a mosquito bite, it takes a
46 long time.
47 SUR: Yeah, eh, yeah. So the good news there's no cancer, the bad-, well
48 PT: OK ((Laughs))
49 SUR: The question is, how can we make you better with the scarring now, that's the
50 only thing
51 PT: OK
52 SUR: Which is a good thing, if we're talking about scarring, that's a good thing!
53 PT: Yeah, yeah-yeah.

In this conversation, the issue of scarring is being emphasized as the patient and the physician pursue the topic in lines 37-46, and as the surgeon mentions possible solutions to address the problem: "we'll try all the stuff that we know, at the end if it doesn't […] we might send you to a dermatologist" (lines 39-40). At the same time, the surgeon specifies that overall the issue with scarring is not "bad" (line 47), and presents scarring as a concern that is secondary to the main concern – making sure there is no cancer (lines 47, 52) – a statement with which the patient agrees (line 53). Further evidence of potential concerns about appearance being backgrounded in these conversations can be found in this patient's interview three months after her operation when she commented on my observation that her questions about appearance were sometimes not emphasized as concerning by the surgeons:

> […] for me, I think it is both, it [appearance] is as important as function, too, especially for a girl, for a female, I think, I'm definitely concerned about appearance, and so, yeah, I worry about it a lot, and I also asked questions about appearance, how it can go after, and that's definitely something I'm concerned a lot about, yeah. For their

> response, it doesn’t make me feel anything, good or bad, uh… Yeah, because I know, it’s something that I have to check out by myself, they cannot really give you any surgeon answer about that.

Like other patients in the study, this patient shared her concerns about appearance while also explaining that surgeons do not necessarily have a role to play in discussing these concerns with patients, as there is not “any surgeon answer about that.”

6.3.2. Patients’ role in emphasizing changes in appearance as a matter of concern.

Analysis of the data from the recorded consultations indicates that the topic of appearance changes was often brought up by the patients. In situations where the physicians responded by reassuring patients and explaining why they were not concerned about appearance, patients often agreed with the explanations provided and did not pursue the topic further. In this section, I will analyze two cases where patients were more assertive in bringing up their dissatisfaction with their appearance. Throughout this section, several interaction patterns that were presented in the previous sections will be illustrated again, providing further evidence to identify these patterns as significant.

The first case is from the case narrative of a patient who underwent surgery for a tumor in her jaw. In her pre-operative interview, she explained that her main concern was recovering from the operation and getting back to her activities, like exercising, driving, gardening and maintaining the house (she was living alone, but was very active and able to take care of herself). She said that the medical team reassured her that if she kept active, kept on eating well and exercising, she would get back in shape. She also said that she was concerned about appearance:

> […] j’aimerais en sortir avec toutes mes capacités que j’avais, puis le même visage que j’avais, puis… une nouvelle gencive, quoi. […] [Pendant mes consultations pré-chirurgicales], j’ai questionné [les médecins] sur l’opération, si ça changerait le profil de mon visage – ils ont dit non, s’ils couperaient la peau dans mon visage – puis ils m’ont dit non, non plus, maintenant ils font ça juste à l’intérieur de la bouche, je pense. Mais ils vont reconstruire mes gencives, fait que… C’est là-dessus que je questionnais beaucoup là.

In her post-operative visits within three months following the surgery, she briefly brought up the appearance of her mouth that was altered as a result of the surgery. Similarly to some of the excerpts that were analyzed above, recovery and good surgical outcomes were emphasized in the conversations: the medical team was very happy about the result of the surgery, the patient was recovering well and did not need radiotherapy, her functional outcomes (eating, speaking) were steadily improving, and appearance was discussed as possibly improving during the months to come as the patient was recovering and as she was waiting for a new dental prosthesis to be made for her. During her second interview, the patient said that she had not been expecting her mouth to be affected during the operation, but that she was reassured by her surgeons and was confident in her medical team:

> […] moi, mon visage, c’est très, très important. Là il y a mes lèvres qui ne sont pas tout à fait placées, mais elles se replacent tranquillement. […] Ça faisait une semaine et demie [depuis l’opération], puis je ne voulais pas me regarder dans le miroir. […] Et à un moment donné je n’y ai pas pensé, et je me suis levée de la toilette avec le grand miroir en face, et là j’ai trouvé ça effrayant, et j’ai dit, non, ça ne se peut pas. C’était surtout ma bouche qui était déplacée, et puis l’enflure aussi. Mais, en tout cas, les médecins m’ont rassurée là-dessus, ils m’ont dit, ça va tout se replacer, puis après ça, l’enflure aussi, ils ont dit, ça va tout se replacer. Et maintenant, il ne reste pas grand-chose, c’est pas mal tout replacé, et avec encore un peu de temps, tout va être rentré dans l’ordre. […] [Les chirurgiens] m’ont rassurée beaucoup là-dessus, puis je me rends compte que c’est une question de temps, parce que ma bouche était croche un peu, et là maintenant elle est à peu près toute replacée […] pour la bouche, je ne pensais pas, ils ne m’avaient pas dit comment ça serait […] je n’étais pas vraiment préparée à ça, mais ça n’a pas été trop difficile quand même, je l’ai accepté […] je me disais, si c’est comme ça, c’est parce qu’il fallait qu’ils le fassent comme ça, il n’y avait pas d’autres solutions […] Moi je pense que, parce qu’ils ne savent pas comment

> ça va se passer aussi. Là ça s'est passé comme ça, mais pour une autre personne, ça ne se passerait peut-être pas comme ça. Puis je pense qu'il y a des choses, ce qu'ils ne m'ont pas dit, je me dis c'est parce qu'ils étaient mieux de ne pas me le dire. Moi, c'était ma bouche qui m'a frappée le plus, mais ils étaient mieux de ne pas me le dire que j'allais avoir la bouche défaite, parce que je, je ne sais pas, je n'aurais pas été aussi enthousiaste, je n'aurais pas, je ne sais pas si je l'aurais fait. […] Et je fais confiance à l'équipe beaucoup, c'est une équipe extraordinaire, je pense, oui, c'est une équipe qui sont sérieux, humains… j'ai trouvé qu'ils étaient très humains, ils voulaient vraiment le bien de la personne, le bien-être.

During the last appointment that was recorded for the study after more time had passed since the operation, the patient was still not completely satisfied with the way that her face looked, and she brought it up with her surgeon.

Excerpt #33

SUR: Ça va bien?
PT: Oui.
SUR: La bouche et tout ça.
PT: Mais je trouve que ma, le côté où j'ai été opérée, il descend, je n'aime pas ça.
SUR: OK. Vous voulez dire comme, esthétiquement ou fonctionnellement quand vous mangez?
PT: Les deux là, les deux. Parce que ma prothèse, c'est comme si elle ne me fait plus. Puis je sens ici, regardez, je vais faire ça ((remonte la peau de sa joue un peu et la tient proche de son oreille)). Ma fille ça faisait longtemps qu'elle ne m'a as vue, et elle a dit, là, ça baisse ici. Puis ça change ma physionomie du visage.
SUR: OK, tout à fait, tout à fait.
PT: Fait que ça, je me demandais s'il n'y avait pas moyen de, mettre une pince ((rit un peu))
SUR: Ça, ça serait le fun, non, ce n'est pas aussi simple que ça, malheureusement.
PT: Non, non, mais je n'aime pas ça, parce que là, je ne veux pas que ça me fasse tout le visage de travers là
SUR: Ouais.
PT: S'il n'y a pas, un petit quelque chose, uh
SUR: Ça, malheureusement, c'est dans la lignée des face lifts là, des redrapages du visage ça. […] ça va en chirurgie esthétique […]
PT: Mais c'est à cause de l'opération que c'est comme ça là.
SUR: Ben, vous avez bien raison, sauf que, comment, je ne sais pas comment trop l'exprimer, dans le sens que, vous avez raison, c'est parce qu'il y a eu la grosse chirurgie, parce que vous aviez eu un cancer et tout ça, mais le côté de raffinement de l'esthétique, ça ce n'est pas couvert par [l'assurance], c'est
PT: Si on est défiguré, il faut l'endurer.

SUR: Mais là, vous n'êtes pas défigurée là, madame PT4, quand même, je peux vous amener voir du monde qui ont, on pourrait dire que là, c'est plus défiguré ((SUR et PT rient un peu)) Là ce que vous me pointez là, je ne veux pas être pas fine avec vous, mais ça, ce n'est pas être défigurée, quand même, quand on vous regarde […] de notre côté, je vais vous examiner, habituellement quand même on ne recommande pas trop de changements pour deux ans.
PT: Ah oui, deux ans.
SUR: Parce que, deux ans, c'est là où il y a quand même, on parle quand même à la base d'un cancer, vous n'avez même pas franchi encore un an, ça a l'air d'aller super bien là
PT: Oui, oui
SUR: Au point de vue de ce côté-là, mais habituellement on se dit, un bon deux ans, parce que c'est là qu'il y a le maximum de récidives qui peuvent se produire. Alors, si vous alliez faire n'importe quel travail esthétique, habituellement on dit, attendez au moins qu'on franchisse ces deux années
PT: Oui, oui. Et est-ce qu'il y a un exercice à faire?
SUR: On pourrait voir avec les physiothérapeutes, on pourrait voir avec les physiothérapeutes, peut-être aussi, avec le dentiste, celui qui avait fait les prothèses dentaires, s'il est capable de les ajuster un petit peu pour que vous puissiez aussi mastiquer des deux côtés, parce que des fois il peut y avoir un peu d'atrophie musculaire en dessous de ça, ce qui crée une asymétrie.
FCG: Ça je trouve que c'est bien de dire ça, parce que le fait que tu manges d'un côté seulement, ça empêche tes muscles de travailler ici.
SUR: Voilà. En tout cas, ça va être asymétrique, comme si on a une jambe dans un plâtre, quand on enlève le plâtre, la jambe fond, eh, c'est comme de la glace au soleil.
FCG: Oui, ça, ça fait du sens.
SUR: En tout cas, ça pourrait, vous n'avez pas tort avec ce que vous dites, probablement un combo entre physiothérapie et aussi avec le denturologiste s'il peut essayer d'ajuster un petit peu la prothèse pour qu'il y ait un meilleur, un meilleur appui partout sur la mâchoire
PT: Oui.
SUR: Pour que, exactement, vous soyez capable de plus mastiquer des deux côtés.
[Elles parlent un peu plus de sa prothèse.]
PT: Avant de toucher à
SUR: Oui, et de toute façon, d'habitude on ne recommande pas de faire quoi que ce soit comme travail esthétique, à moins que ça soit des choses d'infiltration ou des choses qui s'en vont au bout de quelques mois, mais on va recommander d'attendre parce que, si jamais, on ne l'espère pas, les chances sont faibles, mais s'il y a une récidive, mais là on risque de tout défaire le travail qui aura été fait.
PT: Ah oui, oui.
FCG: Absolument. Pas d'esthétique pour le moment, c'est sûr.
SUR: Non, moi j'attendrais.
FCG: Parce que tu n'es pas encore sortie du côté médical

68 SUR: C’est ça, exactement, puis il ne faut pas s’engager quand même, c’est une
69 chirurgie aussi, si vous allez vers quelque chose comme le redrapage du visage, c’est
70 quand même une chirurgie, c’est une opération qui comporte ses risques aussi
71 PT: Oui.
72 SUR: Alors vous ne voudrez pas faire ça pour que, on ne l’espère pas là, mais que
73 PT: Oui
74 SUR: Qu’il y a quelque chose
75 PT: On est mieux d’attendre, oui.
76 SUR: C’est ça, exactement, de reporter un petit peu plus.
77 PT: Et puis, mais c’est ça, à part de tout ça on avait d’autres questions. [Change de sujet.]

As the patient brings up her concern in line 4 (“*je trouve que ma, le côté où j’ai été opérée, il descend, je n’aime pas ça*”), the surgeon asks a follow-up question to clarify whether the patient’s concern is about function or about appearance (“*Vous voulez dire comme, esthétiquement ou fonctionnellement quand vous mangez?*”, lines 5-6). In the conversation that follows, the patient emphasizes her dissatisfaction with the way her face looks by bringing it up several times: “*ça change ma physionomie de visage*” (line 10), “*Je n’aime pas ça*” (line 14), “*Si on est défiguré, il faut l’endurer*” (line 25). The surgeon responds by acknowledging the patient's concern (“*tout à fait, tout à fait*” in line 11, “*vous avez bien raison […] vous avez raison*” in lines 21-22), by recognizing the difference between her own and the patient’s assessment of the patient’s appearance (“*je peux vous amener voir du monde qui ont, on pourrait dire que là, c’est plus défiguré [...] ce que vous me pointez là, je ne veux pas être pas fine avec vous, mais ça, ce n’est pas être défigurée, quand même,*” lines 26-29) and by prioritizing the need for making sure there is no cancer recurrence during the two years following surgery (lines 30-31, 38-39). Thus, the surgeon is ordering concerns about recurrence and concerns about appearance by priority. This ordering is further established in the conversation, as the patient's daughter and the patient express their agreement (“*Pas* *d'esthétique pour le moment, c'est sûr [...] Parce que tu n'es pas encore sortie du côté medical,*" lines 65-67; "*On est mieux d'attendre, oui,*" line 75) and as the patient moves on to another topic (line 77). When the patient asks if there is an exercise that she can do (line 40), appearance is foregrounded as a concern requiring attention and specific actions that could improve the outcome (physiotherapy and adjustment of the dental prosthesis, lines 51-54). This excerpt illustrates how the patient, by pursuing the topic of appearance throughout the conversation, contributes to establishing appearance as a matter of concern. Thus, assertive statements by patients, in which they express their perspectives on their appearance, disagree with their health care provider's perspectives, and especially keep pursuing the topic, constitute one of the ways in which concerns about appearance can be foregrounded in conversations during post-operative, as well as pre-operative consultations (as was shown in Excerpt #7 in section 5.2.1).

This can be further illustrated in the first post-operative visit of another patient. An excerpt from this appointment was previously analyzed in section 6.1.1. (Excerpt #20a), specifically a moment when the patient and her daughter brought up that the patient was concerned about her appearance. "[…] when I look at my face, I'm so depressed," the patient said, and the surgeon responded by reassuring the patient and establishing "getting rid of the cancer" as the main concern. The conversation continued as follows, as the patient pursues the topic that she had brought up:

Excerpt #20c

1 SUR: You're not there yet. Most important, is to get rid of the cancer. And we're still
2 worried about that.
3 PT: Yeah, I know.
4 SUR: Remember, it was aggressive, it was going deep, and now you need that radiation.

PT: But getting rid of the cancer looking like that?
SUR: I know.
PT: I can't go out. Is that better?
SUR: Yep. I know. Wait, we're not, radiation, you'll see, it's another hit.
PT: OK.
SUR: We hit you once, and now the radiation is going to hit you again, it's not
PT: Oh.
SUR: No, it's true.
PT: OK.
SUR: It's not easy, it's not easy to go through all this. And you're in the middle of it still.
PT: OK.
SUR: It's like a tornado, you're still in the middle of it, and then at some point in time, we're going to say, OK, this is going to be your new you, and then, how can we fix things, you know, what can we do.
PT: But you promised me I was going to look good after. ((Starts to cry))
SUR: You are not going to look normal, you're not going to look normal. You are not going to look like you did way back when, before. But you are going to look as normal as possible.
PT: OK.
SUR: OK? But we're not, we're still in many ways away. There's always stuff we can do afterwards, but first of all, we have to make sure the cancer is, to get it
PT: OK.
SUR: That's number one right now. So we did all this, now we have to get you to radiation, try to get rid of that, and then we'll get another scan, probably a couple of months after that, and then, that's the big one, and then, you know, we'll see. ((Looks at PT crying.)) I know, you've gone through a lot. And you still have a lot to go through.
PT: A friend of mine said… ((Inaudible, crying))
SUR: And she knew you before, too, right
PT: Yeah.
SUR: When somebody knows you before, obviously, it's different.
PT: And the way I speak.
SUR: Yeah. But it's still big, it's still swollen inside, you can see it, it's still there.
PT: Yeah.
SUR: So wait, it's still, you're not
PT: Wait how long?
SUR: Uh? Oh, the radiation, you'll see the changes, everybody's a little different, but after the radiation we'll see how much it changes after the radiation, and we'll know, too.
PT: OK.
SUR: And then, usually, like I say, after the radiation finishes, we get a scan three months out.
PT: OK.
SUR: And that's when we know. But this ((points to the swollen part of the patient's face)), a lot of this changes even after a year after we're done. So a lot of the times we wait for about a year until we do anything. And the reason is, because we don't want to do it too early, because there's still change even after a year.

PT: OK.

SUR: So, you know, this is going to change still, but a lot of times usually we don’t do anything for a good year, one is to make sure there’s no cancer, that it’s gone, and two, is to know how everything heals, so then we can, we know what we have to work with.

PT: So I won’t have teeth for a year?

SUR: There’s a chance, there’s a chance, yeah. Usually, after the radiation, we’ll get you to see a dentist.

PT: OK.

SUR: And see. Some patients, there’s some prosthesis they can attach to those, and that’s why I was asking how many [teeth] you have left, and some, we had to remove what we had to remove for the cancer, the question is, can you attach anything to this. It’s hard to know, but there’s a chance that they might not be able to attach anything to this, you know.

PT: OK. ((Continues to cry))

FCG: Mais, mom, tu vas peut-être être capable de mieux parler parce que ça va déjà désenfler.

SUR: Ça va, oui, ça, c’est sûr que ça va, ça, ça va changer.

PT: Mais pas de dents… ((Continues crying))

SUR: ((To RES)) Est-ce qu’elle a vu DR NOM? C’est sûr qu’avant la radiothérapie elle va voir quelqu’un, un dentiste. ((To PT)) Et là tu peux parler un petit peu avec eux autres, mais c’est sûr que, ça, c’est juste avant la radio, mais c’est vraiment après qu’ils décident qu’est-ce qu’on peut faire pour les dents. Mais ça, on n’est pas là encore. ((To RES)) Do you want to take out some stitches? ((To PT)) RES va enlever tout ça, alors, tu n’as pas besoin de nous, parce que c’est vraiment, c’est la radiothérapie qui est la prochaine étape.

PT: Oui.

SUR: Alors c’est Dr RAD qui va s’occuper de vous

PT: OK.

SUR: Puis après que tout est fini, vous revenez à notre clinique.

PT: OK.

SUR: Mais entre temps, s’il y a n’importe quoi, vous appelez soit NUR, la porte est toujours ouverte, s’il y a n’importe quoi. Mais vraiment, c’est Dr RAD qui prend soin de vous maintenant, et vous revenez après ça. ((NUR entre dans la salle.))

PT: OK.

SUR: OK? Essayez de garder, garder la force. OK, bye madame. ((Touche l’épaule de la patiente et quitte la salle.))

RES: Ce n’est pas facile, eh? Est-ce que vous vous rappelez quand on s’est rencontrés au début? Qu’on vous a dit que ça va être difficile, la première semaine? Je ne sais pas si vous vous en rappelez. Peut-être pas. On a dit que ça allait être difficile, mais ça allait aller mieux.

PT: Oui.

RES: Et ça s’est mieux passé après. Même chose, OK.

PT: Oui. Mais c’est long, tabarouette.

RES: Je sais que c’est long.

PT: Je ne m’attendais pas à ce que ce soit si long que ça, je ne peux pas être un an sans dents, sans pouvoir pratiquer mon métier, mon travail ((Continue à pleurer.))

RES: ((S’approche de la patiente, touche son épaule, reste proche.)) Oui, je comprends.

Considering this longer excerpt in its entirety helps to show how the patient continues expressing her concerns throughout the conversation: “But getting rid of the cancer looking like that? [...] I can’t go out. Is that better?” (lines 5-7), “But you promised me I was going to look good after” (line 19), “So I won’t have teeth for a year” (line 53), etc. The patient’s negative experience of living with her altered body is further emphasized by feelings of sadness and the patient’s crying. As the surgeon responds to these statements, he acknowledges the patient’s concerns (for example, “I know,” line 8; “I know, you’ve gone through a lot,” line 29), but also offers the patient information as to what she can expect during the upcoming year (lines 45-48). The fact that at the time of the appointment the patient was at only one month after her operation was also brought up by the surgeon several times to emphasize that concerns about appearance will be addressed later in the patient’s care trajectory (for example, “we’re still in many ways away,” line 23), and that curing cancer was the priority at the present time (“first of all, we have to make sure [...] to get it [...] that’s number one right now,” lines 24-26). At the same time, as the patient pursued the topic during the conversation and as the physicians acknowledged it and offered empathy, the patient’s concerns about appearance were also emphasized in this conversation.

The observation that changes in appearance were mostly brought up by the patients is supported by some of the reflections that the surgeons shared with me during the interviews. As was also shown in the previous chapter covering the pre-surgical period, surgeons explained that they relied a lot on other members of the team to address patients’ needs beyond the immediate cancer care, especially given the limited amount of time that they had in the context of a busy clinic. A surgeon also explained that while the medical team took a proactive approach to assess potential concerns regarding recovering physical function, when it came to concerns about appearance, they tended to wait until the patient brought up the subject:

> […] on va les faire voir en orthophonie si c'est quelque chose de fonctionnel pour avaler […] on va être quand même plutôt proactifs pour que ça s'améliore le plus possible. Fait que, des fois peut-être qu'on va au-delà de ce que le patient pourrait dire, fait que peut-être certains patients aussi finissent, en parlent plus ou moins de ce volet-là parce qu'aussi, très rapidement après l'opération, c'est comme, ils font avec l'orthophoniste leur genre de physiothérapie, fait que, ça devient partie intégrante de leur routine de vie puis quotidienne pratiquement. Le côté esthétique, c'est différent. Ça, c'est souvent, je pense qu'on attend que le patient en parle. Puis des fois les patients n'en parlent juste pas parce que ça allait avec le fait de traiter le cancer. En tout cas, à nous, ils ne nous en parlent pas, j'aimerais dire, parce que je ne suis pas sure qu'ils n'en parlent pas, ils doivent en parler à quelqu'un certainement, que ça, qu'ils ne trouvent pas ça facile, je suis sure. Mais à nous, c'est rare qu'ils vont nous, qu'ils vont s'ouvrir sur ce volet-là. Puis c'est vrai qu'on ne le demande pas nécessairement, on ne va pas leur demander, comment vous vivez avec votre nouvelle apparence, c'est rare qu'on va poser cette question-là. […] on n'y pense pas, je pense qu'on n'y pense pas. On focusse beaucoup sur, ils vont toujours venir nous revoir puis il y a toujours une raison pour laquelle ils viennent nous voir […] il n'y a pas de récidive, ça va bien, ou oh, malheur, il y a quelque chose, il faut faire d'autres investigations. Fait que je pense qu'on n'y pense pas, on va y penser après, mais on n'y pensera pas sur le coup quand on voit le patient parce qu'on est en train de donner des résultats de scans ou d'autre chose, puis en espérant toujours qu'on a des bonnes nouvelles à leur donner, puis sinon, ben arriver à trouver un plan pour traiter ce qui se passe. Fait que je pense qu'on, c'est comme si on survolait ce volet-là sans l'aborder, puis pas parce qu'on, en tout cas, en ce qui me concerne, pas parce que je ne veux pas, je pense que je l'oublie. C'est comme si, on sait que ça allait être ça, c'est comme si je le prenais pour acquis, dans le fond.

The nurse, in her interview, acknowledged her role in addressing such concerns with patients, and explained how she tried to be proactive and bring up certain topics with the patients that she knows may not be addressed by other team members, such as topics about appearance. She explained why this was important to her:

> […] autant il faut se préparer à la chirurgie, mais il faut être là après aussi, parce qu'on ne peut pas se préparer, peu importe ce qu'on aura fait avant, uh, c'est peut-être autre chose qui va nous déranger, qu'on n'aura même pas abordée ou… oui. Puis les gens nous disent, ah, j'ai plein de gens comme ça, ils me disent, je m'en fous de l'apparence, enlevez-moi un œil, enlevez-moi une oreille, il n'y a pas de problème, puis finalement, quand tu ne l'as plus, ton oreille, ben tu te rends compte qu'elle était importante, qu'elle tenait tes lunettes ou, tu sais, il y a des choses comme ça qu'on ne pense pas, c'est ça […] On en parle, tout simplement, OK, la perception, comment les gens vont me voir, est-ce qu'il y a des stratégies finalement pour aider cette personne-là à s'adapter avec ce niveau, oui, c'est quelque chose qu'on aborde, tout le temps, oui.

The following excerpt illustrates how the nurse initiated these conversations with one of her patients. This example is from the first post-operative visit of a patient who had his nose removed during surgery, and was still waiting for the results of the pathology report to see if he needed further treatment. While he was waiting, a bandage in the middle of his face was covering his exposed septum and nasal cavity. The nurse asked the patient how he was feeling:

Excerpt #34a

1 NUR: Sinon, vous, le moral, comment ça va?
2 PT: Ça va.
3 NUR: Ouais.
4 PT: Ah non, ça va, je n'ai pas, je n'ai pas à me plaindre. C'est sûr que c'est inconfortable, la
5 douleur ((Inaudible)) Peut-être éventuellement je vais avoir besoin de soutien, mais
6 pour le moment ((Inaudible)) J'ai vu la plaie, je sais de quoi ça a de l'air
7 NUR: Oui, et puis
8 PT: C'est sûr, mais pour ça je savais que ça allait ressembler à ça.
9 NUR: OK, vous étiez bien préparé.
10 PT: Oui. Là j'ai un sinus ici qui est décongestionné, de gauche, mais de droite il est
11 resté partiellement bouché [Continue de parler de ce symptôme.]

In this brief exchange, the patient takes the opportunity offered by the nurse's question in line 1 to tell her that he saw his wound, he knew what it looked like (line 6), but that he was prepared for that (lines 8-10). As the patient moves on to another topic (lines 10-11), potential concern about appearance ("*J'ai vu la plaie*") is not further emphasized. Later during the conversation, the nurse brings up the topic of appearance again, by asking the patient about his social interactions:

Excerpt #34b

12 NUR: Avez-vous vu d’autres personnes que votre conjointe?
13 PT: Non. Ma famille, mes parents, ma conjointe, c’est tout.
14 NUR: Pour le moment
15 PT: Ça ne me tente pas, je n’ai pas envie de me faire voir comme ça, je ne me sens pas
16 à l’aise. Je ne parle pas psychologiquement, mais je parle physiquement, ce n’est pas le
17 fun. ((Inaudible)) Je sais que ce qui m’attend, c’est une très grosse opération.
18 NUR: Oui.
19 PT: Moi je suis toujours dans un état où, je suis dans un état où j’attends, j’anticipe
20 toujours quelque chose qui va être important, quand ça va être reconstruit, si tout se
21 passe bien, en tout cas, on le souhaite, je le souhaite de tout cœur, si la pathologie
22 d’abord dit qu’ils ont réussi à enlever le cancer, si on dit, OK, tu n’as pas besoin de
23 radio, ça serait formidable, puis là on va reconstruire. Mais je réussis à dormir puis je
24 mange bien.
25 NUR: OK, c’est bon.
26 PT: C’est bon.
27 NUR: Mais je peux déjà vous donner les coordonnées de notre psychologue, comme ça
28 vous l’aurez
29 PT: Oui, ça serait gentil.
30 NUR: Puis, elle, elle peut vous voir, mettons vous avez un rendez-vous, elle peut
31 essayer d’arranger que ça soit [le même jour]
32 PT: Je te dirais qu’après ma reconstruction peut-être que, plus
33 NUR: Mais je vais quand même
34 PT: Actuellement je suis comme dans un état de, même avant la chirurgie, je veux dire,
35 je suis dans un état d’alerte
36 NUR: OK. Mais je vais vous le laisser.
37 PT: Parfait

In this conversation, as the patient explains that his main concern at this time is his pathology report and his upcoming surgery (lines 19-23, 34-35), and that he is not comfortable seeing other people as “*physiquement, ce n’est pas le fun*” (lines 16-17), the nurse initiates a conversation about psychosocial support that is available at the clinic (lines 27-28), and thus emphasizes potential concerns about appearance as concerns that the patient can get help with.

During her interview, one of the surgeons reflected on the possibility for the surgeons to play a more proactive role in initiating conversations around appearance:

> […] Ça ne veut pas dire que nous on va être capable de, d'accompagner le patient là-dedans, mais je pense que […] poser juste une question, peut-être qu'elle pourrait être aussi simple que, comment ça va, comment vous gérez […] la nouvelle apparence […] est-ce que vous trouvez ça difficile […] ça peut se faire en probablement deux-trois phrases, je ne pense pas que ça a besoin d'être une discussion d'une demi-heure, le patient va surement nous dire, "ben, ce n'est pas facile," fait qu'on pourrait dire, "pensez-vous que vous aimeriez ça en discuter avec quelqu'un d'autre" […] moi je pense que oui, on pourrait améliorer ça.
> MC: Dans le rôle du chirurgien.
> SUR4: Oui, mais oui, sinon, je ne sais pas qui. Parce que c'est, à moins que tout le monde appelle NUR, mais […] je pense qu'on pourrait faire un effort pour la poser cette question-là. […] des fois mes collègues vont dire, on passe déjà beaucoup de temps, mais on demande s'ils ont de la douleur, je veux dire, dans le fond, on pourrait juste poser une question en supplément pour savoir s'il y a besoin de ce volet-là. On les envoie en clinique de la douleur quand on n'est pas capable de soulager leur douleur, c'est la même chose au fond, c'est juste que c'est un autre volet. […] ça fait partie de tout le côté des soins intégratifs puis d'avoir des équipes multidisciplinaires.

Excerpts 34a and 34b above illustrate how, as this surgeon explained, patients' potential concerns about appearance can be assessed during conversations that do not take a lot of time. This surgeon explained that "opening the door" was especially important for patients who are not explicitly expressing concerns in consultations (as the analysis of several excerpts in the previous sections has shown). She also explained that the specific role that could be played by the surgeons is not only to offer opportunities for concern expression, but also emphasize appearance and, more generally, other psychosocial concerns, as important and valid concerns, to the same extent as concerns about curing cancer:

> […] on a […] un rôle à jouer là-dedans […] de dire, écoutez, si vous en avez besoin, c'est important, c'est tout aussi important que le côté physique, contrôle des cellules tumorales et tout ça. Fait que des fois, ça fait en sorte que les patients se disent, ah OK. Et quand le service est offert aussi, on a [une psychologue] qui fait partie de l'équipe, on a une équipe qui s'occupe de ça, ça finit par être, ça fait partie des soins.

This surgeon's comments also reflect the position of some authors who have studied uptake of psychosocial concerns in patient-provider communication and who have criticized providers' tendency to "distend or ignore the psychosocial aspects of clients' medical concerns" (Robinson & Nussbaum, 2004, cited in Robinson, 2011, pp. 507-508). This has also been highlighted in studies in the field of psychooncology: while patients' care needs relate to both the management of cancer and attention to psychosocial aspects, there is evidence that physicians "pay minimal attention to patients' psychosocial and health-related quality of life concerns" (Hack et al., 2005, p. 837). In this context, researchers have called for a better integration of the psychosocial component in routine care and for developing training programs to enhance physicians' communication skills and in particular their ability to address patients' psychosocial needs (Hack et al., 2005; see also Holland et al., 2010, 2011; Jacobsen et al., 2012). The results of this study show how psychosocial concerns can be addressed by different members of the medical team, and thus can nuance such critiques. However, in light of these reflections, one can also ask if the fact that concerns about appearance were mostly foregrounded when patients were assertive about them may contribute to patients' perceptions of psychosocial needs as being not as important as the needs related to the immediate cancer care, and may thus influence patients' utilization of psychosocial services. A recent study conducted in the same head and neck oncology clinic showed that many patients were unaware of social support services, up to 50% patients with clinical levels of psychological distress did not use them, and barriers to utilization included stigma towards seeking help and emphasis on disease and symptom burden (Cohen et al., 2018). This will be further discussed in the conclusion chapter.

6.4. Partial conclusion

In this chapter, I first showed how body changes were discussed in relation to cure and physical recovery, which remained important concerns for patients and providers in the post-surgical period. Two ways of framing were described: (1) ordering concerns about body changes by priority and (2) emphasizing improvements in function recovery (RQ1). Specifically, I showed how establishing cure as being the most important concern may align with patients' perspectives, and at the same time may leave patients' potential concerns unexplored. In addition, the interview data showed how emphasizing improvements and progress in function during consultations may contribute to reassuring and motivating patients during the period of active recovery. At the same time, it may contribute to the silencing of patients' concerns (RQ2).

Second, the analysis focused on the ways of resolving differences in patients' and providers' perspectives that manifested during consultations. Two particular interaction situations where differences in patients' and providers' perspectives were manifested were presented: (1) foregrounding biomedical explanations in response to patients' descriptions of symptom experience and (2) emphasizing surgical wound healing in the immediate post-treatment period (RQ1). My analysis of the interview data showed that while such ways of framing may reassure patients that their physical recovery is going well, it may also contribute to patients' concerns not being expressed or explored during consultations, and communicate lack of empathy to patients (RQ2).

Finally, my analysis showed how concerns about appearance were foregrounded and backgrounded in consultations. More specifically, I showed how patients tended to briefly bring up potential concerns about appearance and how the subsequent conversations tended not to pursue these concerns. In addition, I analyzed two cases where patients were more assertive in describing their concerns to show that patient assertiveness constituted a specific way of foregrounding body changes (RQ1). Different team members' roles in assessing and addressing concerns about appearance were then discussed based on the analysis of interview data and a patient-nurse conversation. I also highlighted that some patients did not perceive the lack of uptake of appearance concerns by surgeons as problematic, because they did not see it as being the surgeons' role. In relation to this observation, discussion on the impacts of this interaction pattern on patients (RQ2) and on the role of surgeons in addressing such concerns was opened, based on the reflections of one of the surgeons. I will continue this discussion in the final chapter.

Chapter 7. Conclusion

In this final chapter, I will first summarize the results of the analyses by going back to the research questions. Specifically, I will explain how changes in body appearance and function were framed in patient-medical team interactions during pre- and post-operative consultations (RQ1) and how these different ways of framing might contribute to patients' experience (RQ2). I will summarize the main findings in relation to the pre- and post-operative period, as well as some overarching considerations and their contributions to the literature. I will then discuss the implications for research and practice of my empirical findings as well as of the theoretical framework that I developed. Finally, I will talk about the limitations of this study and propose several directions for future research.

7.1. Summary responses to the research questions

First, the analyses of patient-provider conversations showed how body changes were discussed in relation to other important concerns for patients and providers, namely survival and cure. While previous studies have shown that fear of mortality may be prominent during the pre-surgical period and patients may consider body changes as a tradeoff for survival (Alias & Henry, 2018; Henry et al., 2014b; Rennie et al., 2018), this study empirically demonstrated how body changes were foregrounded or backgrounded in relation to survival and cure in actual patient-provider conversations, and how patients and providers emphasized survival and cure as a shared concern. In the post-surgical period, as patients and team members were concerned about the results of the surgery and the possible need for further treatment (radiotherapy or chemotherapy), my analyses revealed how patients and providers established an order of priority as they discussed body changes in relation to survival and cure, as well as in relation to wound healing.

Second, while patients and team members explained in the interviews that reassurance about long-term recovery was important for patients both in the pre-surgical and in the post-surgical period, my analyses showed how team members emphasized long-term recovery, hope, and improvements in function recovery in their conversations with patients. Patient interviews revealed how these conversations positively contributed to their experience, since patients did not only require information about potential surgical outcomes from their team but also reassurance about their ability to go back to their normal life.

Third, my analyses revealed a number of recurring framing markers, or specific actions accomplished by patients and providers during consultations that established certain aspects of body changes as being important. As the analyses focused on patient-provider conversations initiated by a patient's expression of potential concern, this study showed that bringing up a new topic and either pursuing or not pursuing it contributed considerably to constructing changes in function and appearance as a matter of concern (and thus requiring acknowledgment, specific care recommendations, etc.) or not. Specifically, the analyses revealed how patient-initiated potential concerns about appearance and the impacts of surgery on daily life and functioning tended to be backgrounded in patient-provider conversations if patients did not pursue the topic. As literature has shown, psychosocial concerns can be silenced in patient-provider conversations (Arora et al., 2013; Baile & Aaron, 2005; Bonito et al., 2013; Fagerlind et al., 2008, 2012; Konradsen et al., 2009; Taylor et al., 2011). In this dissertation, I have identified specific interaction patterns that may contribute to this "silencing." Data from patient interviews indicated how emphasizing body changes as not concerning contributed to feelings of reassurance for some patients and how, for some, it also conveyed a downplaying of patients' difficulties and of the important impacts that these changes had on their lives.

Moreover, my analyses showed how differences in patients' and team members' perceptions of body changes, highlighted by previous studies (e.g., see McNair et al., 2016), were manifested and resolved in conversations. This was especially apparent in situations where patients expressed potential concerns about appearance. Specifically, this study revealed how biomedical explanations were foregrounded in relation to patients' descriptions of symptom experiences, and how surgical wound healing was emphasized in relation to patients' negative evaluations of their appearance. The analyses also showed how team members acknowledged patients' concerns about appearance while emphasizing curing cancer and wound healing as the most important concerns (see also Ford et al., 2019). Patient interviews showed that while patients were concerned about their appearance, they often did not pursue this topic in their conversations with their medical team (these concerns can also be referred to as "unvoiced" [Barry et al., 2000]). Furthermore, interviews with patients and team members revealed that patients and team members were aware of the differences in their perspectives regarding changes in appearance, as well as regarding the social aspects of changes in function (for example, going back to work, eating with others, speaking in public, etc.). While some patients explained that they did not expect their team members (and surgeons in particular) to engage in such conversations with them, some patients expressed a need for more support during the interviews.

Finally, this study showed how different team members emphasized different aspects of body changes in their conversations with patients. While patients' unscheduled meetings with the nurse were not recorded during this study (which constitutes a limitation that I will discuss below), patient-nurse conversations that were analyzed showed the role played by the nurse in addressing patients' psychosocial needs. Specifically, psychosocial concerns that tended to be silenced in patients' conversations with physicians (as patients tended to briefly bring them up and as team members tended not to elaborate on them) were foregrounded in patients' conversations with the nurse, who pursued potential concerns initiated by patients and proactively initiated conversations in this area. Interviews with team members showed that they were aware of their different roles in this regard and of the lack of integrated care. In addition, an interview with one of the surgeons revealed how this organization of care may influence patients' experience, as I will discuss in the next section.

7.2. Contributions to scholarship and clinical practice

7.2.1. Contributions to research on patient-provider communication. This dissertation makes several contributions to the literature on patient-provider communication. First, this study adds to research on concern expression by analyzing moments from naturally occurring clinical consultations "where patients make (or attempt to make) their concerns known to doctors" (Beach, 2013, p. 8). In line with previous research adopting an interactional perspective on the expression of matters of concern in non-medical contexts (see Cooren et al., 2012; Pino et al., 2016; Vásquez et al., 2017), this study demonstrated how concerns emerge in patient-provider conversations. This study provided further support for research that has shown that patients often express concerns indirectly and that some concerns are unvoiced during consultations (Beach, 2013; Beach & Dozier, 2015; Brandes et al., 2015; Zimmerman et al., 2007). In addition, the concept of framing that guided this study allowed me to show how, in situations where patients expressed their concerns explicitly and were assertive about them, they were backgrounded when patients and providers gave priority to different aspects of patients' care. For example, while previous research has demonstrated that initiating conversations about body changes may be challenging because patients and their medical team members are concerned about survival and cure (Alias & Henry, 2018), this study showed how body changes were backgrounded as patients and the medical team members overwhelmingly emphasized survival and cure during clinical visits. While the need for health professionals to proactively initiate conversations around body changes and their impacts with head and neck cancer patients has been highlighted by other researchers (Lewis-Smith et al., 2018), this study indicates that patient-provider communication in this context is challenging not only because of silenced or unvoiced concerns, but also because patients and providers discuss these issues in relation to other important concerns (such as concerns about survival and cure) that may become emphasized in their conversations. In this way, this study suggests a conceptual model that could inform future research on patient-provider communication by focusing on how potential concerns expressed by patients may or may not be accentuated in conversations during clinical visits.

Second, the study responds to the need identified in the literature on patient-provider communication to investigate how the larger organizational context may shape communication during specific medical consultations (Real & Street, 2009) and how patients interact with different professionals involved in their care (Arora, 2003; Ha & Longnecker, 2010). Specifically, this study highlighted how different members of an interdisciplinary oncology team see their respective roles and how these roles are reflected (and one can also say, reinforced) in their conversations with patients. In particular, this study showed how psychosocial concerns tended to be backgrounded in patients' conversations with surgeons and foregrounded in patients' conversations with the nurse. In line with previous studies showing that consultations with different professionals cover distinct aspects of care and reflect professional boundaries (Allen et al., 2015; Carlsson et al., 2013), this study showed how important it is for professionals such as nurse navigators to ensure that patients receive holistic care and that their needs beyond their immediate cancer treatments are addressed (Allen et al., 2015; see also Fillion et al., 2009; Henry et al., 2018c).

Finally, this study makes an important contribution to research on patient-team communication in surgical oncology by showing how changes in appearance and function, which constitute important concerns for patients, are discussed during clinical consultations. The results of this study provide evidence to support previous studies that have found that concerns about body changes may be silenced in relation to survival and cure (e.g., see Alias & Henry, 2018), that they may not be discussed as patients and providers tend not to initiate these conversations (e.g., see Losi et al., 2019), and that patients and providers may prioritize different aspects of body changes (McNair et al., 2016). This study makes a contribution to this literature by demonstrating how patient-provider conversations during clinical consultations reflect (and contribute to) these practices. That is to say, how patients and providers, as they bring up certain topics during consultations and react to each other's actions, may focus on physical recovery and give less emphasis to psychosocial aspects, to the detriment of rehabilitation in line with current multidimensional models of function (WHO, 2001). Analysis of patient-provider conversations revealed how patients tended to agree with their provider's perspective, and how in some situations there were discrepancies between what was emphasized by patients and what was emphasized by the members of the medical team. While the analysis of interactional data allowed me to identify these discrepancies in situations where patients explicitly expressed potential concerns, the analysis of patient interviews also helped reveal concerns that were not apparent in interactions, as well as potential negative impacts of some communication patterns. The lack of emphasis on body changes may lead to patients' concerns being unacknowledged (or disenfranchised [see Doka, 1989]) and limit patients' opportunities to express their difficulties as they are adjusting to their altered bodies and to receive support. Thus, this dissertation provides insight into the actual patient-medical team interactions around body changes during clinical consultations, which is needed to inform clinical practice and develop supportive interventions for head and neck cancer patients who undergo treatments impacting appearance and function (Fingeret et al., 2014; Konradsen et al., 2009; McNair et al., 2016). In the following section, I will discuss in more detail how the study findings could be used to inform clinical practice.

7.2.2. Potential contributions to clinical practice. As mentioned earlier, research focused on close examinations of patient-provider conversations and on the ways in which patients and providers mutually influence each other cannot "*prov[e]* practices right – or wrong," but rather can help identify certain interaction patterns that may "contribute to *improving* them" (Mol, 2006, p. 411). My analyses of clinical consultations informed by interview data showed how the same interaction patterns may have different impacts on patients' experiences. For example, emphasizing that body changes are of little concern may contribute to feelings of reassurance for some patients, while it may convey a lack of empathy for other patients and result in a lack of preparedness for the consequences of the surgery. While previous studies have identified the need for providers to inform patients about the impacts of head and neck cancer surgery (on different levels, including impacts on appearance, function, and psychosocial well-being) (e.g., see Ziegler et al., 2004), in this dissertation I also demonstrated the importance of paying attention to interaction dynamics, that is, how clinicians and patients in their conversations give more or less importance to certain impacts of the surgery. Thus, the kinds of transcripts I analyzed for this study could be used to create case studies and simulation scenarios to teach communication skills to medical students and staff. A close examination of patient-provider conversations could consequently encourage "a better understanding of [providers'] interactional dynamics [with patients] and/or expand their repertoire of ways to handle difficult situations" (Pomerantz et al., 2018, p. 114; see also Barnes, 2005, 2019). A particular illustration of such difficult situations that was mentioned during the interviews with team members are conversations about changes in appearance and, more generally, about the psychosocial impacts of body changes. In addition, health care providers could be invited to reflect on potential "interactional consequences" (Drew et al., 2001, p. 66) of their actions. For example, how, by pursuing or not pursuing certain topics brought up by patients, they may contribute to foregrounding or backgrounding patients' concerns about body changes.

The theoretical framework that was developed for this study, focusing on how patients bring up potential concerns and how they can be foregrounded or backgrounded in patient-provider conversations, could also help provide patient-centred care. While there are many definitions of this term (Street, 2017), one of the key aspects of patient-centred care that has been identified in the literature is the tailoring of information provision and support to patients' needs (Epstein & Street, 2007; Lussier & Richard, 2008; Stewart, 2001; Zucca et al., 2017; see also Rodin et al., 2009). By staying mindful of concerns that are important to patients as they emerge in clinical consultations (when patients initiate topics in more or less direct and explicit ways), health care providers "might best attend to what patients treat as meaningful for their lives and treatment" (Beach, 2018, p. 1694), and thus enhance the provision of personalized care tailored to patients' needs. My analyses showed that patients' potential concerns about body changes are not always explored in their conversations with medical team members. When patients bring up such concerns briefly (or do not bring them up at all), providers typically do not explore them in depth, and patients and providers tend to orient the discussion towards other aspects of care. In line with previous research on patient-centered care, clinicians could reflect on such "missed opportunities" and ask whether "creating space" for conversations around body changes during outpatient visits could help patients express their concerns and help clinicians provide tailored information and support (Cortez et al., 2019; Maynard et al., 2016; see also Robinson, 2003). It is also important to note that the patient-clinician encounter is one of the patients' first exposures to the social realm after surgery, and that silencing changes in appearance and function may impede full integration of this new reality and institutionally perpetuate stigma related to a visible difference (Rao et al., 2019).

In addition, some authors have highlighted that insights from research on concern expression in medical consultations could also be used to help patients prepare for their consultations with their health care providers (Linn et al., 2019). For example, Beach and Mandelbaum (2005) suggest that the results of the analyses of interactions around psychosocial issues during clinical consultations can have implications for both patients ("in terms of how they present issues that have relevance to their health, but which [health care providers] may not ask about") and health care providers ("in terms of pursuing psychosocial matters that may have health relevance, even if they are raised only tangentially") (p. 345). Because it may be difficult for health care providers to identify and address concerns that patients may express briefly or indirectly (Beach & Dozier, 2015), using tools such as concern prompt lists during consultations has been suggested in some studies to help patients identify topics that they would like to discuss with their team. Such "patient concern inventories" have been developed specifically for head and neck cancer patients, taking into account the particular concerns that they might have regarding changes in appearance and function (e.g., see Flexen et al., 2012; Jacobs et al., 2018; Rogers et al. 2009). As Vásquez et al. (2017) have suggested, using such supports could contribute to emphasizing or foregrounding patients' concerns, through their inscription on a concern prompt list, in addition to voicing them. At the same time, the results of this study show that medical team members have a stronger influence in terms of orienting conversations and focusing them on specific aspects of patients' care. In this context, patients may not bring up their concerns or may not be assertive about them during clinical visits (when compared with the concerns expressed in much more detail during the interviews).

Moreover, recent studies on body image in oncology, including in head and neck cancer patients, highlight factors that may impact patient-provider communication beyond the immediate interactional context, and particularly the stigma attached to cancer-related disfigurement and functional difficulties, as well as to other psychosocial concerns (Cohen et al., 2018; Sherman & Shaw, 2018). Because patients might not bring up stigmatized issues during consultations (Epstein & Street, 2007), and because health care providers might not initiate these conversations, there is a risk of patients' support needs remaining unaddressed (Lewis-Smith et al., 2018). In light of the results of my analyses, clinicians could consider whether the interaction patterns that were identified in this study (including patients' and providers' actions that establish changes in appearance as not being a matter of concern) might contribute to patients' feelings of stigma. The interview data shows that patients identified certain concerns (such as concerns about going back to work, concerns about appearance) as not being appropriate to be discussed with surgeons, and that team members relied on the nurse to discuss these important concerns with patients. Considering that psychosocial concerns may be backgrounded in relation to survival and cure, future studies could explore whether integration of these topics in patients' conversations with physicians could contribute to establishing them as important and valid, to the same extent as the concerns about curing cancer, as one of the surgeons explained in her interview. Specifically, as I will discuss in the next section, future research could investigate whether such an approach could reduce barriers to psychosocial services utilization, which include stigma around seeking help and emphasis on disease and symptom burden (Cohen et al., 2018).

7.3. Limitations and directions for future research

While this study was designed to account for patients' care trajectories over six months and include different members of their team, the data that was collected does not reflect all interactional situations where body changes can be discussed. First, as participants were recruited after having received a cancer diagnosis, discussions about treatment options occurring during the meetings where patients received their diagnosis were not included. Based on the results of this research, studying patient-team communication in the context of cancer diagnosis could further demonstrate how consequences of surgery are discussed in relation to survival and cure. Second, the recruitment was more challenging during the pre-surgical phase. While the analysis of available interactional data combined with interview data allowed me to answer the research questions, future studies could provide further insight into patient-provider conversations around body changes during this period. Finally, patients' unscheduled conversations with team members were not considered. As was discussed in the previous chapters, the study mainly accounted for patients' scheduled meetings with surgeons and less for patients' conversations with the nurse navigator. Focusing on patient-nurse conversations in the context where this study took place – where the nurse has a distinct role to play in assessing and addressing patients' psychosocial concerns – could provide further insight into specific communication practices that contribute to establishing these concerns as important in patient-nurse interactions.

Furthermore, several limitations should be considered while interpreting the results of the study. First, since patients had to be physically well enough to participate in the study, the analyses did not reflect the experiences of patients who were very unwell (see also Morse, 2000). For these patients, communication with their team might be more challenging. Moreover, because not all participants accepted video recordings, analyses of framing markers that go beyond verbal interactions were limited in this study. To address these limitations, future studies could employ research methods that go beyond verbal communication and use other strategies to understand interactions during clinical visits and its impacts on patient experience. For example, arts-based methods could provide participants with an opportunity to describe their experiences of illness in a different way (e.g., see Morse, 2000; Fancourt & Finn, 2019; Ellingson, 2019). In addition, future research could focus on how material and embodied dimensions of patient-provider interactions (e.g., see Caronia, 2018; Cornelissen et al., 2014; Mondada, 2017, 2018, 2019; Vásquez et al., 2017) may contribute to give more or less emphasis to changes in appearance and function during clinical consultations.

Second, because the study objectives were disclosed to the participants, patients who did not feel comfortable discussing body changes were excluded. Full disclosure was important to ensure informed consent. In this context, while interpreting the results of this study, it is important to recognize that they may not reflect the experiences of patients for whom discussing and reflecting on this topic may be especially uncomfortable or difficult.

Third, since patients were approached by the nurse and knew that the results of the study would be communicated to the medical team, they may have avoided discussing the negative aspects of their communication with the team and may have focused more on the positive aspects. Indeed, in situations where participants are interviewed about their communication practices, asking them to “interpret their own and others’ behavior elicits attitudes and beliefs that may be reported in a more favorable light” (Koenig & Robinson, 2014, p. 132). In addition, establishing potential impacts of certain communication practices on patients’ experience may be challenging, because patients’ satisfaction with their care is often related to their interactions with the whole health care system during their treatment trajectories (Street et al., 2009). This is especially relevant in the context of cancer diagnosis and treatment, since patients meet with multiple professionals in multiple contexts. One of the medical team members who was interviewed for this study explained this in the following way:

> It’s not just the operation, the effects of that operation, it’s those ten days to three-week period or longer if there are complications, that whole process of being in the hospital that has an impact on how patients feel about and how their experience through that is. […] if the whole, that they didn’t have to wait for their treatment, that they were treated with respect, that they were taken care of, they come back and they say, even if they had six weeks or two months of hell, if their patient experience was good, that, they remember. They remember that the staff was wonderful and that we got them through it. […] I find that the hospitalization has a big impact on how they respond to their experience with the surgery. […] the surgery may have gone well, but it’s like, they want to get out of here […] they can’t sleep, and their pain is not responded to […] the food is terrible or whatever, so the patient experience in the hospital, the whole scenario, will have an impact on how they react to their surgery.

Fourth, as within six months after their surgery patients were still in the process of recovery and were told by the medical team that their outcomes might improve during the first year, studying patient-provider interactions in the longer term postoperative period could reveal how patients and providers discuss body changes that may not improve.

Finally, this study was conducted in a setting where patients were cared for by an interdisciplinary team, members of which recognized the importance of attending to patients’ psychosocial concerns. Thus, the results of this study may not reflect the experiences of patients in settings with more limited resources and less integrated psychosocial services.

Having discussed the limitations of this study and how future research could address some of them, I will now conclude by identifying three specific research directions that could add to our understanding of patient-medical team communication around body changes.

Beyond patients' interactions with different team members, future research could also consider how communication between team members without patients' presence may impact patient-provider conversations around body changes. For instance, studies of interprofessional communication during oncology "tumor boards" (team meetings to discuss patient cases and decide on a preferred treatment option) have shown that these meetings are usually medically focused and led by physicians, while other health care disciplines (e.g. nurses, psycho-oncologists) are rarely given space to participate in discussions, which could explain why patient preferences and psychosocial concerns are not emphasized as often as biomedical information (Lamb et al., 2013; Rosell et al., 2018; see also Wittenberg-Lyles et al., 2009). Studying these team meetings in head and neck oncology could help further explore "how different perspectives of the patient's situation are made relevant and meaningful in team talk" (Fox & Brummans, 2019, p. 260) or, in other words, how they emphasize different aspects of what is important in a patient's care, based on their respective roles in the team.

Specifically in relation to the results of this study, one aspect of patient-team communication around body changes and psychosocial concerns more generally could be investigated in future research. Because the role of assessing and addressing patients' psychosocial concerns was mainly assumed by the nurse, future studies could further explore potential reasons for this organization of care and investigate how integration of these conversations in patients' consultations with other team members could influence patients' experience. In particular, future studies could ask if surgeons' more active role in pursuing these conversations could help reduce barriers to utilization of psychosocial services, such as patients not thinking that their distress is serious enough, stigma towards seeking help, lack of integration in routine care, and emphasis on disease symptom burden (Cohen et al., 2018).

Finally, future research on patient-provider communication could investigate the usefulness and the limitations of the theoretical framework that I developed for this project to study conversations around psychosocial concerns in other clinical contexts. While studies in different clinical settings continue to report that patients' psychosocial concerns are less likely to be addressed in medical consultations compared with medical concerns (see Santo et al., 2019; Steven et al., 2019), such research could help identify how patient-provider communication can be enhanced and tailored to patients' needs. Specifically, such an approach could help reveal opportunities to support patients' rehabilitation both in the physical and in the psychosocial domain (Penner, 2009) and contribute to the current efforts to ensure that psychosocial support becomes an integral part of quality care (Institute of Medicine, 2008).

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Appendix A – Interview Questions

Interviews with patients

1st Interview (before the surgery)

Thank you for taking the time to talk with me today. The goal of this interview is to explore your experience during the consultations with your medical team that you have had so far. In particular, we are interested in your conversations with the team about the changes in your body resulting from cancer and surgery. We also want to know what was most or least helpful to you while coping with your diagnosis and preparing for the surgery. This will help us analyze the video recordings while taking into account your experience, so that the results of the study can be used to tailor the care to the needs of people followed at the Head and Neck Surgery clinic.

A. To start, I would like to learn more about your care trajectory at the Head and Neck Surgery clinic so far.
    - How were you referred to the clinic? How were you diagnosed? How were you presented with surgery as a treatment option, and how did you decide to have surgery? How are you preparing for the surgery?

B. Now, let's talk more about the changes in your body you have been experiencing due to your diagnosis.
    - How would you describe the changes you have noticed in the appearance or the functioning of your body before you were diagnosed? Have they changed since? And what are you experiencing now?
    - What helps you to cope with these changes? Has the medical team played a role in helping you to cope with these changes?

C. I am also interested in knowing more about the interactions with the medical team you've had so far.
    - During the consultations that you've had, what were for you the important things that you wanted to discuss with the team? Do you feel like you had an opportunity to bring up these subjects and ask the questions that you had? Express the concerns that you had?
    - How would you describe your conversations with the team about changes in the appearance and functioning of your body related to your diagnosis? And the possible effects of the surgery on your body?
    - What information did you receive from the medical team about the possible effects of the illness and surgery on your body? If you haven't received any information, what would you like to know?
    - And did you ever feel like you needed more information or support?

D. Now I would like to ask you about your experience of preparing for the surgery.
   - What are your expectations? What are your concerns? Have you talked about your concerns with the team? And how helpful/unhelpful were these conversations?

E. To conclude,
   - Based on your experience, what suggestions would you have for the team to help people followed at the clinic in terms of adjusting to body changes due to the illness?
   - Based on your experience, what suggestions would you have for the team to help people followed at the clinic prepare for the surgery?
   - Would you like to add anything to what we have talked about today? Did we leave anything out that seems important to you? Anything that we hadn't discussed that you wanted to touch on?

Thank you for your participation in this study. We greatly appreciate your input.

Interviews with patients

2nd and 3rd Interviews (3 and 6 months after the surgery)

Thank you for taking the time to talk with me today. The goal of this interview is to explore your experience during the consultations with your medical team that you have had so far. In particular, we are interested in your conversations with the team about the changes in your body resulting from cancer and surgery. We also want to know what was most or least helpful to you while coping with your diagnosis and recovering from surgery. This will help us analyze the video recordings while taking into account your experience, so that the results of the study can be used to tailor the care to the needs of people followed at the Head and Neck Surgery clinic.

A. To start, I would like to learn more about (how your surgery went and [2nd interview only]) how you have been recovering.
   - Can you tell me about your hospital stay? What were the changes in your body that you noticed? Has the medical team played a role in helping you to cope with these changes? What was helpful/not helpful?
   - And over the last [two] months, when you were discharged from the hospital and recuperating at home, what changes in your body have you been experiencing as a result of the surgery? How have you been adjusting to these changes? Has the medical team played a role in helping you to cope with these changes?
   - Now that you've had the surgery, do you feel that there is anything that you would have found helpful to know before the surgery? Anything that surprised you or that you were not prepared to?

B. Now, I would like to know more about the interactions with the medical team you've had since your surgery.
    - During the consultations that you've had, what were for you the important things that you wanted to discuss with the team? Do you feel like you had an opportunity to bring up these subjects and ask the questions that you had? Express the concerns that you had?
    - How would you describe your conversations with the team about the process of recovery from surgery? What information did you receive from the team? Did you ever feel like you needed more information or support?

C. Now I would like to ask you some more questions about your recovery from the surgery.
    - What are your expectations? What are your concerns? Have you talked about your concerns with the team? And how helpful/unhelpful were these conversations?

D. To conclude,
    - Based on your experience, what suggestions would you have for the team to help people followed at the clinic in terms of adjusting to body changes due to the illness and surgery?
    - Based on your experience, what suggestions would you have for the team to help people followed at the clinic to recover from surgery?
    - Would you like to add anything to what we have talked about today? Did we leave anything out that seems important to you? Anything that we hadn't discussed that you wanted to touch on?

Thank you for your participation in this study. We greatly appreciate your input.

Interviews with members of the medical team

Thank you for taking the time to talk with me today. The goal of this interview is to explore your perspective on your communication with surgical head and neck oncology patients, to inform my ongoing analyses of patient interviews and observations of outpatient appointments at the clinic. I am particularly interested in your interactions with patients around appearance and functional changes following surgery, both during the pre-surgical and the post-surgical period. I would like to better understand how you perceive this communication, what aspects you find challenging, and also what works well.

A. To start, I would like to better understand the trajectory that patient goes through with you, before and after surgery. Starting from the first time when you meet with the patient, and then up to several years after the surgery, you have several conversations, and I am interested, specifically in terms of communication, what you find important to discuss with your patients at different time points in their trajectory.

- During pre-surgical consultations, what is your approach to communicating around body changes? What are the important things that you want to discuss with your patients? What subjects or areas do you usually cover? To what degree does this vary dependent on certain characteristics of the patient?
- What, according to you, are the most important subjects or areas for the patient? To what extent do you think they are similar to the things that you find important to discuss as a physician? How do you manage discrepancies, if any?
- During post-surgical consultations, what are the most important things that you want to discuss with your patients? What subjects or areas do you usually cover? To what degree does this vary dependent on certain characteristics of the patient?

B. Now, let's talk more about your communication with patients specifically around body changes, the process of recovery from surgery and adjustment to body changes.

- How do you address body changes following surgery and the process of recovery and adjustment in your pre-surgical consultations?
- How do you address body changes following surgery and the process of recovery and adjustment in your post-surgical consultations?
- How do you see your role, as well as other team members' roles in helping patients to prepare and adjust to body changes following surgery?
- How would you describe "good" communication? From your experience, what works well in terms of preparing patients to the surgery and supporting them as they recover?
- And what would you say are your communication challenges with your patients around the consequences of the surgery and the recovery process? And how do you think these challenges might be addressed?

C. Would you like to add anything to what we have talked about today? Did you leave anything out that seems important to you?