

SHARING IS CARING

Shared decision-making in complex surgical oncology using animated videos

Song L. L. Duimel

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“Victory belongs to the most tenacious”

- Phillip Chatrier court at the French Open Roland Garros -

A PhD trajectory feels like a tennis match - a total mind game. You have to pivot constantly, stay on your toes, and adjust your strategy point after point. You wipe away sweat and sometimes some tears, and in certain moments you are forced to even transcend yourself. You learn to focus on the next point, not the last mistake. You move from game to game, from set to set, knowing that momentum can shift at any time. And you also learn when to look toward your box to lean on your coaches and cheerleaders because no one wins a long match alone.

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PROPOSITIONS

Accompanying the dissertation of Song L.L. Duimel

SHARING IS CARING

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1. In complex surgical oncology, such as oral cancer, shared decision-making is often claimed but rarely really realized in practice. – *This dissertation*
2. Patients cannot be expected to independently identify, reflect on, and articulate their values, goals, and preferences; they rather require guidance and support from clinicians to facilitate this process. – *This dissertation*
3. Improving shared decision-making in complex surgical oncology requires not only the provision of verbal information by clinicians but also a shared communicative responsibility between clinicians and patients, supported by additional informational resources. – *This dissertation*
4. Audiovisual materials, such as 2D and 3D animated videos, have the potential to support clinicians' communication in routine oncology care, yet their development is complex and challenging. – *This dissertation*
5. A one-size-fits-all approach to introducing audiovisual materials, such as animated videos, into the patient journey does not meaningfully support shared decision-making in complex surgical oncology. – *This dissertation*
6. More attention should be given to training and supporting clinicians in using tools that help patients reflect on, articulate, and integrate their values, goals, and preferences into treatment decisions. – *This dissertation*
7. The best support in life sometimes comes at unexpected moments and from different corners of the world.
8. From time to time, you must "pull a Felipe[1]" to counter procrastination and finish work just before a deadline.
9. A PhD dissertation is finished through critical feedback, just enough enjoyment to keep going, and the illusion that the end is near – all of which are strategically maintained by good supervisors until everyone agrees it is time to stop.
10. Positioning yourself as a healthcare communication specialist at the intersection of communication science and clinical practice is valuable because it bridges these two "worlds" and provides insights that cannot be gained from being embedded in either alone.
11. Sleeping is always the best medicine – *Mother of Song*

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1 An informal reference to my dear friend Felipe who was often found to be working till late, sometimes even past midnight; a relatable phenomenon experienced by many PhD candidates.

PROLOGUE




Where it all started...

PROLOGUE

Since I was young, I knew I wanted to work in oncology. For years, I watched my dad juggle work and family life, while caring for my mother. I saw them driving back and forth to the hospital countless times, and trying to navigate the maze we call the health care system. Although these hospital visits were anything but pleasant – I understood exactly what was going on – the hospital itself felt oddly comforting to me, familiar, and in some way, like a second "home". To this day, I sometimes tell people that I grew up in the hospital.

One of the healthcare providers who left a lasting impression on me during those years was my mother's oncologist. He was warm, compassionate, and deeply considerate. He made it a priority to truly listen to his patients, creating a space for both the patient and their loved ones in every step of the decision-making process. Looking back now, I realize he was an early role model for colleagues: knowledgeable yet patient, comprehensive yet kind. He showed that medicine was not only about treatment plans and test results, but also about people.

When I was eight or nine, that quiet desire to become a doctor grew stronger when a kind nurse, named Alwies, had the idea to dress me in a white coat during one of our routine visits to the hospital's oncology clinic. Together, we made our "rounds", stopping by and checking in on all patients that came in that day. At some point, one patient looked at me and even said: "They are just getting younger and younger." Whether she truly believed I worked there or not, I must have looked very young and small in that oversized coat, I felt proud. That moment sealed my ambition of becoming a doctor.

Though, years later, I chose a different path. Instead of pursuing medicine, I stepped into a field that would allow me to support patients in another meaningful way. This led me first to Wageningen University, where I studied Health and Society, and later to the University of Amsterdam, where I specialized in Persuasive Communication, including health communication. Somewhere along the way, the childhood ambition of working in oncology faded into the background. It quietly resurfaced during my master thesis, when I joined a research project under the supervision of Annemiek, investigating online health information-seeking behavior of oncology patients. It was through this project that something clicked. Research, particularly oncology-related research, felt right, purposeful, and as the next step in my life.

After finishing my master thesis, Julia encouraged me to attend one of her coffee meetings to discuss my aspirations, or so I thought the aim of this meeting would be. Little did I know that this meeting would change the direction of my life and would be the start of my journey to where I am today. That Monday afternoon, I met Fons and Rob for the first time.

They introduced me to the world of head and neck surgical oncology and to the Virtual Therapy project. This ambitious project aimed to create patient-specific, virtual medically simulated audiovisual models to predict functional impairments after oral cancer surgery. The goal was to improve patient care, strengthen patient-physician communication, and support treatment decision-making. They needed someone with a background in health communication.

I started as a research assistant and it gradually evolved into my PhD trajectory. Almost five years of collaboration, discoveries, setbacks, professional and personal growth, and lots of questions and meeting. Who could have thought that I would find my way back to oncology? That a single Monday afternoon meeting could lead to a five-year journey focused on improving patient counseling in head and neck surgical oncology? That patient-physician communication in oncology would become the work I feel most passionate about?

In many ways, life has come full circle, bringing me back to where I first envisioned myself. Working to improve the experiences of oncology patients and their loved ones. Just as I had once imagined as a little kid in that white coat that was way too big for me. Maybe that little girl knew all along….

CHAPTER 1

General introduction

GENERAL INTRODUCTION

"It hit me out of the blue. I was lying there in the operating room while they were preparing me for surgery. And yes, at some point I did ask, 'What are we going to do? How will this proceed?' And of course, I never really had any idea. I was afraid that all my teeth would have to be removed. And then at some point, I was faced with the choice of whether or not to have radiation treatment and what the possibilities or impossibilities were. But it all happened so terribly fast that I didn't think about it. I would have liked to have known a little more, but again, that's in hindsight".

(Patient who underwent oral cancer surgery[1])

A cancer diagnosis turns the lives of patients and their loved ones upside down. From that moment on, they usually embark on an emotionally charged and overwhelming journey, navigating numerous medical consultations with often complex and extensive information, and confronting decisions that would profoundly shape their future. Advances in cancer care have led to the availability of multiple treatment options, each with its own potential side effects, outcomes, and impact on daily life [1,2]. Because of this, treatment decisions often involve complex trade-offs requiring patients and clinicians to weigh the potential effectiveness of a treatment option against its possible impact on daily functioning and quality of life (QoL). Consequently, consultations in which patients must decide on their treatment are particularly complex and challenging, especially when these decisions are highly preference-sensitive and associated with long-term implications. In such consultations, active patient involvement through shared decision-making (SDM) is essential to identify the course of action that best aligns with their values, goals, and preferences [3–6]. To ensure that SDM is effective and leads to decisions that best fit the patient's situation, the clinician, patient, and, if present, informal caregiver(s) must actively work together. In this process, patients must be adequately informed and equipped to understand the potential benefits, risks, and uncertainties of each possible treatment option, so they can critically evaluate and discuss these with their clinician and family members and align them with their values, goals, and preferences [3–5,7]. Thus, SDM focuses on the process of arriving at a decision rather than on who makes the actual decision.

Despite its clear value in surgical oncology, implementing SDM in clinical practice remains particularly challenging[8,9]. Many patients struggle to identify and articulate what matters most to them, to evaluate available options in light of their personal values, goals, and preferences, or to fully comprehend the implications of different treatments [10]. Moreover,

1 Illustrative quote from one of the patient participants in our focus group study (Chapter 5) about the rollercoaster journey patients embark on when being diagnosed with cancer.

the emotionally charged and cognitively demanding setting of oncology further complicates implementing SDM [11] as well as the perceived decisional complexity and suboptimal clinician communication [10,12–14]. The SDM process can be further complicated by a perceived lack of choice, the unpredictability of treatment outcomes, the complexity of (medical) information, and the characteristics of the patient population, such as older age, lack of medical expertise (e.g., limited health literacy), and communication difficulties [14–18]. Consequently, patients may feel, and in fact be, uncertain, unprepared, and inadequately supported to participate meaningfully in the SDM process [19,20].

To improve decision-making in cancer care, numerous interventions have been developed, ranging from decision aids, educational (group) meetings, and coaching, to web-based tools, educational materials, feedback sessions, or patient-mediated interventions, targeting either healthcare professionals, patients, or both. Although many of these approaches have shown promise, their overall effectiveness continues to be inconclusive, with studies reporting mixed results and limited empirical support [21–25]. The interventions have in common that they primarily focus on verbal communication, either in auditory or in written form. Still, verbal communication alone may not sufficiently support patients' comprehension or engagement in decision-making, especially in an emotionally charged, cognitively demanding context such as oncology [16,26–28]. Instead, patients may benefit from multimodal interventions that facilitate patient understanding and (more) involvement in decision-making. By presenting information in both auditory and visual formats, audiovisual materials can simplify complex medical concepts and reduce cognitive load, making it easier for patients to process and recall information [29–31]. Nevertheless, despite their potential and increasing use, evidence on how audiovisual materials can best support information provision and SDM in surgical oncology remains scarce [32–34].

This dissertation, therefore, aims to explore whether and how SDM in complex surgical oncology can be improved. Specifically, it focuses on oral cancer, a subtype of head and neck cancer (HNC), which involves highly preference-sensitive treatment decisions. Patients with oral cancer are often required to carefully weigh the potential benefits and risks of different treatment options, since aggressive multimodal treatments, including surgery, radiotherapy, and chemotherapy, are frequently necessary. Each of these treatments can have substantial consequences for a patient's QoL, as they may impair vital oral functions such as speech, swallowing, eating, and breathing. Consequently, these patients need to balance treatment effectiveness (i.e., survival) against functional impairments that can profoundly affect daily life [35–38]. Although interest in SDM within head and neck surgical oncology is steadily increasing, progress in both empirical research and practical implementation continues to lag behind [39]. As a result, a significant opportunity for improving the communication and information provision practices is being missed. This is particularly concerning since many patients with HNC, including those with oral

cancer, frequently report unmet needs, particularly in terms of information related to treatment side-effects and outcomes, after care, and coping [40–42]. Moreover, many of them experience decisional conflict and regret [43–45], indicating they feel unsure about which choice to make or feel disappointed, unsatisfied, or distressed once a decision has been made [20,46], even when initially being satisfied with the treatment decision [47].

The development of the concept of shared decision-making over time

In modern medicine, SDM is increasingly being encouraged as the preferred approach to delivering high-quality care [48]. Today's oncology patients are becoming increasingly involved in the decisions about their care [49]. However, this level of participation has not always been the norm. Tracing back to the Hippocratic Oath, clinicians were seen as wise authority figures, much like kings or priests, whose role was to restore the patient's health. Patients were viewed as passive individuals with little responsibility or decision-making power over their treatments and health [50,51], and this historical perspective largely shaped medical decision-making [51,52]. Patients received only the information that clinicians deemed necessary to secure consent for treatments or interventions they believed were in the patient's best interest [53]. In this paternalistic model, patients' input in medical decision-making was minimal, and decisions were based on the clinician's professional judgment rather than on patients' preferences. This was commonly justified by the concept of "benevolent deception", meaning that withholding information was acceptable to protect the patient from harm [51,52]. As such, healthcare decisions were frequently made on the patient's behalf without ensuring their full understanding, valuing their input, or even obtaining their full consent [51,52].

In the mid-20th century, medical decision-making underwent a significant transformation [54]. This key milestone was driven by the World Medical Association's adoption of the Declaration of Helsinki in 1964, which laid the groundwork for modern standards in medicine [54–56]. Around the same time, scholars began to challenge the idea that illness could only be understood from a biological perspective. In response to this, Dr. George Engel advanced this shift by introducing a revolutionary perspective: the biopsychosocial model. This model assumed that clinicians should not only consider the physiological side of illness but also its psychological and social aspects [57–60]. This approach challenged the traditional paternalistic model that reduced patients to their disease, and instead promoted a more empathic, patient-centered form of care that valued the patient-clinician relationship. Over the decades that followed, Engel's ideas helped medicine to move away from the dominant paternalistic model toward more informative models of care. In these models, patients increasingly came to be seen as individuals with rights and active roles

in their care rather than passive recipients. Clinicians offered patients support to help them understand their situation and reach an agreement on the recommended course of action [53,54]. Yet, it was not until the 1970s that the concept of SDM was first mentioned in print [61], and in the 1990s that SDM appeared in the research literature [62,63]. Patients gained greater autonomy and became more actively involved in medical decision-making [52,54,64]. Accordingly, SDM attracted increasing interest in clinical practice, (medical) research, and literature [52,54,64]. Specifically, since the beginning of the 21st century, SDM has received substantially more attention, with numerous studies seeking to define it, develop an SDM model, and/or explain its components [65].

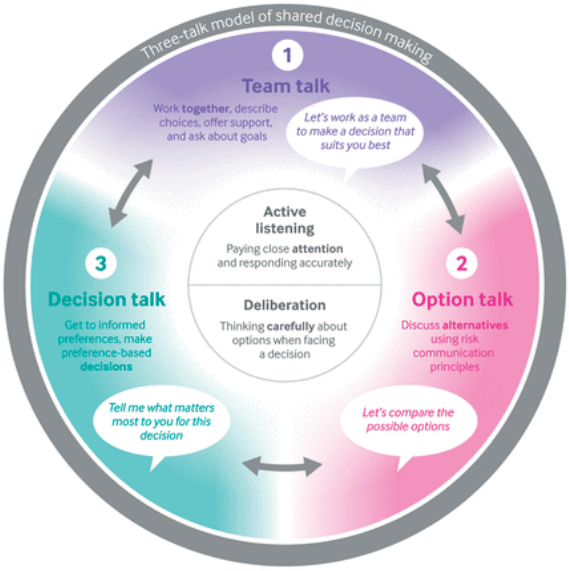


Figure 1. The three-talk model of shared decision-making [4].

Today, while its exact definition is still under debate [65–68], SDM is generally understood as a dynamic, collaborative conversation with the clinician in which patients, along with informational caregivers, when present, actively engage in evaluating available care options [3–5]. Over the years, several theoretical models have been developed to illustrate the process of SDM, of which the three-talk model may be the best known (Figure 1) [4]. The model describes the three conversational stages that occur between the patient and the clinician during a consultation. During the first stage, 'team talk', the patient and clinician establish a partnership, working together as a team to discuss the choices to be made and to identify the patient's goals in terms of their care. Following this, during the 'option talk' stage, they discuss and compare the possible alternative care options. In the last stage, 'decision talk', the patient and clinician make preference-based decisions after carefully weighing each option against the patient's preferences. However, the successful

implementation of these various stages depends on more than a patient and clinician following a checklist in which each stage is checked during consultation [69]. Equally important is the continuous, active listing and careful deliberation between the patient and clinician, working together to understand one another through mutual respect, empathy, compassion, and integrity throughout these stages [3–5]. In this sense, both patients and clinicians should become aware of and aim to improve their communication by adopting a personal and respectful approach [70,71]. SDM is thus not merely a stepwise process following various stages; it also entails a person-centered communication style [72].

Beyond the recognition in (clinical) practice and research, SDM is also further protected by legislation in many countries [73–75]. Legal frameworks safeguard patients' fundamental rights, including the right to informed consent and the principle of patient autonomy. Moreover, this legislation reinforces the principles of SDM and helps ensure that actively involving patients in decisions about their care is a priority. In the Netherlands, for example, Article 448 of the Dutch Medical Treatment Contracts Act (WGBO) obliges clinicians to inform patients about the purpose of a proposed treatment or research, the available alternatives, the potential consequences and risks, and to provide space for questions so that decisions can be made together [76]. This should indicate an important role for the clinician to adapt their communication in order to facilitate SDM.

Online information-seeking to facilitate shared decision-making and improve patient care

Even though much of the SDM process typically unfolds within the consultation room, decision-making is not always confined to the patient-clinician encounter. In practice, while clinicians remain the primary source of information, patients often continue to reflect on decisions outside the clinical setting [3,77–79]. This support may come from various resources, such as peer patients, written and printed materials, and the internet [27,28,77,80]. In particular, the use of the internet among patients with cancer has grown substantially [81,82]. In the Netherlands, for instance, online platforms have increasingly become popular venues for patients seeking both informational and emotional support [83,84]. Many patients turn to the internet to become more involved and actively engage in the decision-making process during consultations [85,86]. In doing so, they may seek information online to understand and collaborate with the clinician (e.g., prepare for consultation) or to gain (more) control in the decision-making about their care (e.g., validate or challenge what has been said) [8,86–89]. Potentially, such online support may help patients feel less uncertain, more empowered, and more reassured when making decisions about their care [90]. In this way, the internet can serve a supportive, stimulating, and mediating role in the SDM process [91].

Knowledge of why patients search online and what type of informational and/or emotional support they are seeking can be an adequate indicator of what matters to the patient. Although such understanding can be used as a springboard to explore patients' needs and preferences, little is known about the motives of patients with cancer for online information-seeking. For this reason, understanding why patients seek informational and/or emotional support online can enhance communication and help clinicians tailor their information provision to the individual patient, and ensure that patients receive and are referred to accurate, reliable, and personally relevant information. In addition, since we also know little about individual differences in patients' online information-seeking behavior, it is worthwhile to explore not only patients' motives for seeking informational and emotional support online, but also how these motives may vary across individuals.

Why shared decision-making matters in oral surgical oncology

As illustrated above, person-centered communication and engaging in SDM are always key to delivering high-quality cancer care. However, they become especially crucial in life-altering and preference-sensitive situations, such as in the context of HNC, where the complexity and long-term consequences of treatment decisions require careful deliberation between patients and clinicians (e.g., head and neck surgeons[2]). These decisions not only determine survival but also the patient's QoL. HNC includes malignancies of the skin (i.e., cutaneous), oral cavity, larynx, oropharynx, hypopharynx, nasopharynx, nasal cavity, palatum durum, lips, paranasal sinuses, salivary glands, and neck nodes of unknown primary origin (Figure 2) [92–95]. With approximately half of all HNC cases, oral cancer is one of the most common subtypes of HNC [96,97]. Globally, it ranks as the 16th most common malignancy [98], with incidence rates still rising [96,99,100]. Although oral cancers are increasingly diagnosed in younger populations (≤ 45 years), they mainly affect older adults who are often frailer and more likely to have comorbidities [101–104]. At the same time, environmental pollution, socioeconomic status, and lifestyle-related factors, such as poor dietary intake, inadequate oral hygiene, use of smokeless and smoked tobacco, betel leaf chewing, alcohol consumption [95,105–107], cannabis use [108], and other recreational drug use [109–111] remain important contributors to the development of oral cancer. Although oral cancer can manifest itself in several areas of the cavity (Figure 3), tongue cancer (i.e., tongue squamous cell carcinoma) is the most common subtype, accounting for 25% to 40% of oral cancer cases in the Western world, followed by cancers of the floor of the mouth, which represent 15% to 20% of all cases [112]. Although oral cancer remains relatively

2 In the Netherlands, treatment decision-making conversations are typically conducted by the head and neck surgeon, though this is not formally defined, and international practices vary substantially. Shared decision-making most of all requires that the clinician involved is able to discuss all reasonable treatment options with the patient and, when involved, their informal caregiver(s).

rare in the Netherlands compared to other parts of the world [113–115], approximately 920 individuals are diagnosed each year[116]. This trend is worrisome, as tumors in this location can be lethal, but also when cured can profoundly compromise the oral cavity function, which plays an essential role in everyday life activities, from chewing, swallowing, speaking, breathing [117,118], and to intimate and social interactions [119,120].

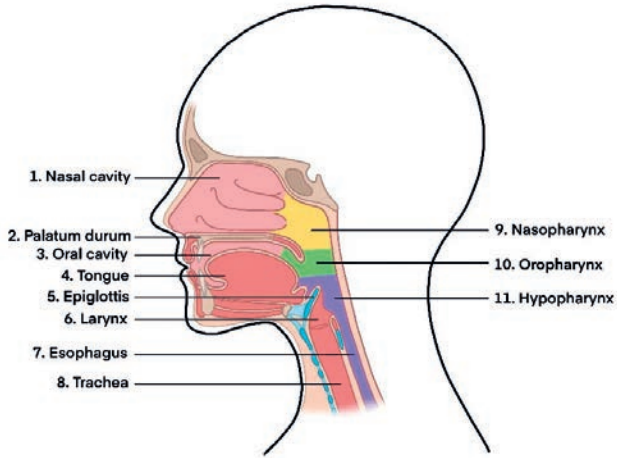


Figure 2. Anatomy of the head and neck area.

Note: (1) Nasal cavity refers to the inside of the nose, behind the nostrils, (2) Palatum durum refers to the front, bony part of the roof of the mouth, (3) Oral cavity, (4) Tongue, (5) Epiglottis refers to the leaf-shaped flap in the throat that prevents food and water from entering the windpipe and lungs, (6) Larynx is commonly known as the throat or voice box that contains the vocal cords, (7) Esophagus is commonly known as the food pipe to transfers food from the throat to the stomach, (8) Trachea is commonly known as the windpipe, (9) Nasopharynx refers to the upper part of the throat located directly behind the nose, (10) Oropharynx refers to the middle part of the throat, located directly behind the mouth, (11) Hypopharynx refers to the lowest part of the throat. The paranasal sinuses are a group of four paired air-filled spaces that surround the nasal cavity, which are not displayed. Salivary glands are small organs that produce saliva, which are located in pairs in front of the ears, under the jaw, and under the tongue.

Advances in diagnosis, staging, and treatment over the years have considerably improved treatment outcomes for patients with oral cancer [121]. Today, multiple treatment modalities are available, including surgery, radiotherapy, chemotherapy, immunotherapy, and combinations of these modalities [122]. Yet, for most advanced oral cancer cases, a multimodal approach is required, whereby surgery remains recommended as the primary and gold-standard curative treatment option [122,123]. This usually involves removal of the primary tumor and neck lymph nodes, combined with reconstruction of the tongue and/or mandible, typically followed by postoperative (chemo)radiotherapy [122]. The extent of surgical removal depends on the tumor's location, size, and depth (Figure 4) [122,124]. While this combination of treatments can be life-saving, they have a significant and lasting impact on a patient's daily functioning and QoL [125,126]. Surgical treatment can alter a patient's facial appearance, affect their body image, and substantially compromise vital functions.

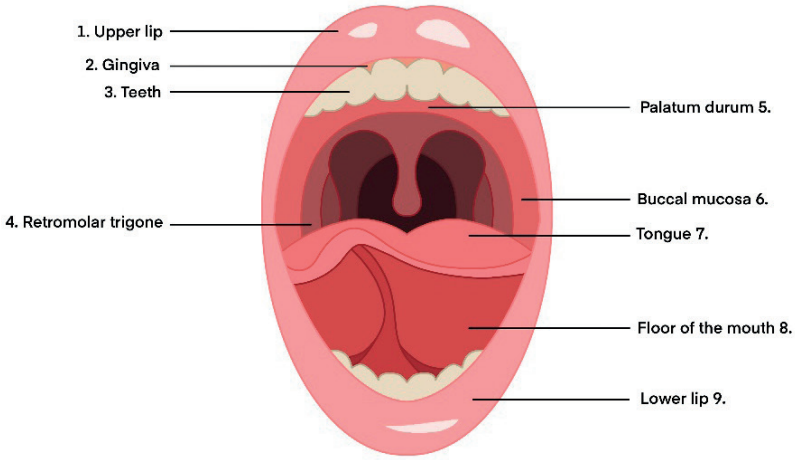


Figure 3. Key locations of oral cancers.

Note: (1) Upper lip, (2) Gingiva refers to the tissue surrounding the teeth, known as gum, (3) Teeth, (4) Buccal mucosa refers to the inner lining of the cheeks, (5) Retromolar trigone is the small, triangular-shaped area of gum tissue located directly behind the last molar teeth on the lower jaw, (6) Palatum durum refers to the front, bony part of the roof of the mouth, (7) Tongue, (8) Floor of the mouth, (9) Lower lip.

It can affect the anatomical tissue needed for effective chewing and swallowing of food and liquids (Figure 5) [127–129]. For this reason, many patients report persistent problems with speaking clearly, eating, drinking, tasting, breathing [130,131], as well as problems with intimacy and social relationships [132], leading to a reduced QoL [35,36]. Moreover, apart from surgery, postoperative radiotherapy is often needed, which can also induce significant morbidity. In advanced tumors, chemo radiation therapy can be an alternative to avoid surgery; however, even these treatment modalities come with significant toxicity and morbidity and reduce the chance of survival [122]. This makes oral cancer care a clear example of why SDM is essential in complex preference-sensitive treatment decision-making, specifically when treatment decisions go beyond merely discussing medical facts and include patients' values, goals, and preferences.

In the context of oral cancer, it might be even more important to strengthen the patient-clinician relationship and apply SDM. At the communication and relational levels, SDM fosters trust [134,135], which is essential when navigating the complex and emotional decisions surrounding oral cancer treatment. Moreover, patients who engage in SDM understand their treatment options better, tend to rate both their interaction with the clinician and their overall service experience more positively [136]. On the patient level, SDM can also help patients with oral cancer, reduce feelings of conflict and uncertainty, and increase treatment adherence [134–137]. Potentially, SDM can thus help shape how patients experience their patient journey. In the context of oral cancer, where surgery is considered

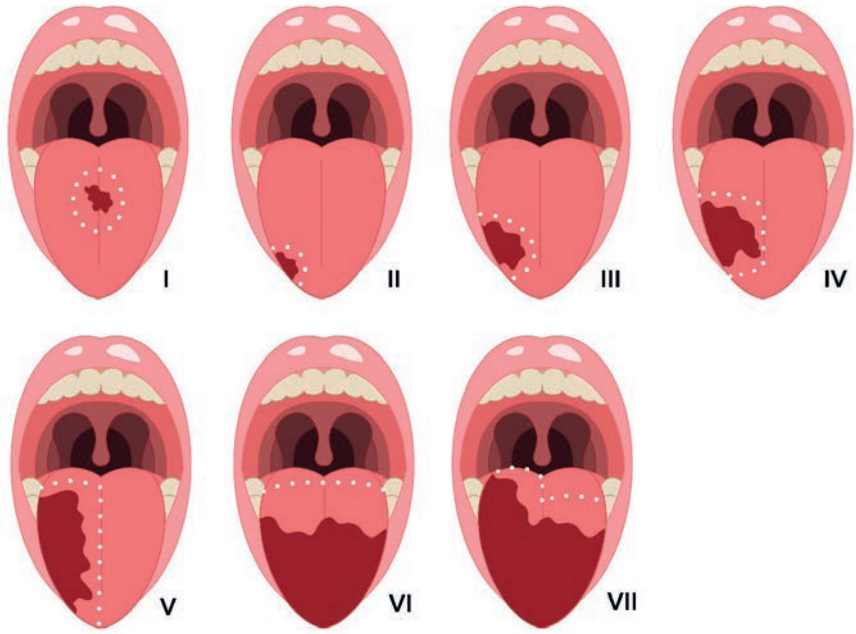


Figure 4. Variety of possible surgical removals of tongue tumors [124].

Note: A variety of surgical interventions exist to remove different types of tongue tumors. Depicted are a few examples of the removal of a tumor on the tongue, an organ composed of several muscles. The white dotted lines indicate surgical incisions, with removal margins ranging from 0.5 to 1.5 centimeters, to ensure safe removal of the entire tumor. (I) and (II): Tumors that are limited to the tongue surface. (III): Tumors that infiltrate superficially into muscle tissue, or infiltrate less than 10 millimeters deep into the tongue. (IV): Tumors that infiltrate almost into the entire depth of muscle tissue, or infiltration is larger than 10 millimeters deep at one side of the tongue. (V): The majority of the tongue is involved, but the mobile portion remains intact.

the primary treatment, SDM becomes especially beneficial as it can facilitate discussions of possible alternatives [39,138], such as induction immunotherapy or concomitant chemoradiotherapy, which are more experimental and less invasive treatment options. Some patients may ultimately not wish to undergo extensive surgery. In these instances, best supportive and/or palliative care options should also be discussed [139,140]. Despite these advantages, it remains unclear to what extent SDM is currently practiced in oral cancer care. Gaining insights into the actual implementation of SDM is crucial for identifying where improvements are necessary, so that patients receive the support required to make informed decisions that align with their values, goals, and preferences.

The complexity of shared decision-making in oral surgical oncology

Although SDM is essential to support patients in making treatment decisions in oral cancer care, putting it into practice can be particularly difficult. Many patients



Figure 5. Psychosocial consequences of head and neck cancer treatment [133].

Note: "Make sense campaign" (2022) focused on showcasing the psychosocial consequences of head and neck cancer treatment. The images show the potential impact on a patient's appearance, breathing, intimacy and sexuality, eating, and speaking. The images are used with permission from the Dutch patient association head and neck (PVHH).

enter a "survival mode" after diagnosis, focusing mostly on curation and prioritizing survival[141–143]. This often limits careful consideration of a possible alternative, less invasive treatment options, or of their own values, goals, and preferences, even when the expected functional consequences of the recommended treatment are severe [144]. Additionally, population characteristics, as well as personal characteristics such as health literacy, anxiety, education, and age, may further influence participation in SDM and perceived SDM [145]. Despite growing attention, SDM is often underrepresented in medical education, leaving clinicians insufficiently trained to apply it in clinical practice effectively[69]. Even experienced clinicians struggle to navigate patients with oral cancer in SDM. Predicting post-treatment functional impairments and QoL is challenging because anatomy, recovery, and coping vary widely across patients. As a result, clinicians often rely on their own clinical experience and retrospective clinical data when counseling patients. However, these estimates can be inaccurate and may unintentionally bias decisions toward more invasive treatments [146]. In addition, some clinicians perceive SDM as less appropriate when surgery is considered the gold-standard curative option [147]. This can narrow discussions to a choice between curative surgery and less curative options, as well as best supportive care, rather than a true exploration of all possible treatment options. One of the greatest challenges, therefore, lies in how information about treatment and its consequences is communicated. Treatment decision-making consultations in oral cancer care often involve discussions of complex jargon about multimodal treatment approaches [148] and carry significant consequences for daily life, as explained above. Such consultations are even more difficult for patients to fully understand and recall than less invasive treatments in other contexts. Most often, clinicians primarily rely on verbal explanations to describe the possible outcomes of oral cancer treatment, making it difficult for patients to visualize these functional impairments and their consequences for daily life and QoL. Nevertheless, many patients with HNC, including those with oral cancer, express a wish to be actively involved in decision-making [149]. However, patients often feel unable to participate meaningfully because the information they receive is too difficult, abstract, or inaccessible [10,19].

In an effort to address these challenges and improve SDM, researchers at the Netherlands Cancer Institute developed biomedical "virtual surgery" models that simulate the removal of human tongue tissue (virtual surgery) to predict functional impairments (Figure 6) [150–152]. Before these models were introduced, no objective tools existed to show patients the possible functional outcomes of surgery. In the meantime, newer versions of the models have been developed to predict tongue movement and functional consequences for each patient after surgery [153]. These personalized audiovisual representations, also called "Digital twins", are designed not only to inform multidisciplinary treatment board discussions but also to help patients better envision the potential impact of oral cancer surgery during consultation (Figure 6). This step is essential to determine whether or not these consequences are acceptable. As considerations of patients' QoL have become increasingly important, these models might support clinicians in explaining diagnosis, surgery, and possible consequences while also enabling patients to participate meaningfully in SDM [154,155]. However, the complexity of these tools poses a new challenge, as patients may struggle to interpret them and may require high levels of health literacy to understand them. It is therefore crucial to explore alternativ simplified forms of visual presentations to ensure that patients can envision and fully nderstand what different choices, such as surgery, might mean for their daily lives. Des| :e the anticipated limited patient comprehension when evaluating virtual surgery mode and confronting a digital virtual twin, a virtual personalized representation of the expecte functional consequences may support the medical multidisciplinary decision-making p cess (Figure 7).

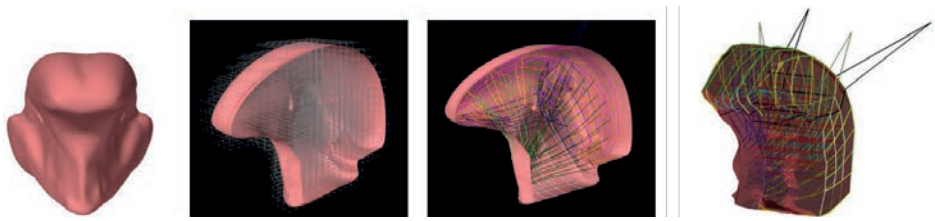


Figure 6. Biomechanical models [150,151,153].

Note: Visual representation of the virtual tongue model, showing the surface of the tongue, its "building blocks", and the different mucles in a variaty of colors.

Animated videos in support of the shared decision-making process

One promising strategy to improve patients' ability to participate in SDM by facilitating information processing is the use of audiovisual materials, such as videos and animations [156–158]. According to the cognitive theory of multimedia learning, people process information more effectively when it is delivered through auditory/verbal and visual/pictorial information-processing channels simultaneously [159]. This dual-channel processing may help reduce cognitive load [29–31], as each of these separate information-

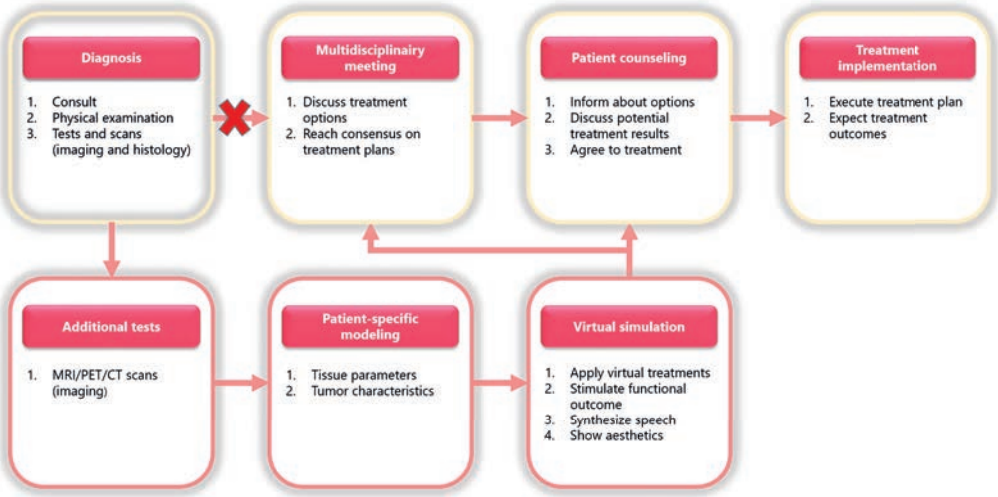


Figure 7. Hypothesized workflow of multidisciplinary tumor board meetings using the digital virtual twin model.

Note: In blue is shown the current workflow: the patient is diagnosed, the individual patient case is discussed during multidisciplinary tumor board meeting, and the treatment decision-making consultation that leads to the treatment the patient undergoes. In yellow is shown the idea for addition to the future workflow: after diagnosis, via additional tests, a patient-specific digital twin model is made, undergoing virtual simulation to depict potential functional consequences of treatment. This depiction of the consequences can be used as input for the multidisciplinary tumor board meeting and during the treatment decision-making consultation with the patient.

processing systems only has limited cognitive processing capacity [31]. Audiovisual materials can therefore make it easier for patients with oral cancer to understand and retain complex medical information [156,158]. Audiovisual materials can offer a scalable, cost-effective way to address high healthcare demand, allowing healthcare organizations to provide patients with consistent, high-quality information without overburdening their healthcare professionals [160–163]. Additionally, audiovisual materials can be adapted to fit the preferences and needs of diverse patient populations, including those with limited (health) literacy [158,164] or language proficiency. They can be accessed multiple times, allowing patients to process information at their own pace and supporting decision-making outside the clinical setting. Despite these advantages, knowledge on the overall effectiveness of audiovisuals for providing pre-treatment information to patients with cancer is lacking. However, such insights are crucial to determine whether audiovisual materials can serve as an additional, reliable way to inform patients with oral cancer in the SDM process.

Among audiovisual materials, animated videos in particular may present complex information in a less cognitively demanding manner [34,165,166]. Unlike live-action or recorded videos, animated videos feature a series of moving images that are drawn or simulated[167].

One benefit of animated videos is that they can present information in a simplified, less confrontational format [34]. Patients who potentially undergo oral cancer surgery are often asked to quickly process complex medical information during emotionally charged consultations [168]. In these cases, animated videos, including two-dimensional (2D) and three-dimensional (3D) formats, may be especially effective in explaining the pathways, surgical techniques, and outcomes in complex surgical oncology treatments [34,169–171]. Despite the promise such animated videos may hold for the SDM process, the development and implementation of these materials in oral cancer surgery communication remain in their infancy. More insights into the content, design, and implementation requirements are needed to guide developers in creating such animated videos and to accelerate their uptake in this oncology field.

Outline and aims of this dissertation

This dissertation aims to explore whether and how SDM in complex surgical oncology can be improved. To achieve this, the dissertation is divided into two main parts, each addressing an approach to advance communication practices in complex surgical oncology. **Part I: Support-seeking practices and shared decision-making** explores the support-seeking behaviors and communication practices of patients and clinicians, before and during clinical encounters that may influence patient involvement in SDM. It aims to gain insight into how patients' and clinicians' behaviors contribute to treatment communication and SDM. Following this exploration of patients' preparatory behavior, we explore the state of SDM in the complex context of oral cancer by investigating whether and how SDM is currently applied by head and neck surgeons. In addition, we study how the perceived levels of SDM relate to the observed levels of SDM. In this part, the following research questions are addressed, which correspond to the individual chapters in this dissertation:

Chapter 2: Which patient profiles can be identified among cancer patients based on their motives for seeking informational and/or emotional support online? And how do these patient profiles based on patients' motives for seeking informational and/or emotional support online differ in terms of their psychological and background characteristics, and patients' perceptions of health care services?

Chapter 3: To what extent do head and neck oncology surgeons employ shared decision-making in daily practice? And how does the perceived level of shared decision-making by head and neck oncology surgeons and patients relate to the observed level?

Part II: **Supportive audiovisual materials** of this dissertation focuses on the role of audiovisuals as a means of mediated patient education in complex surgical oncology. Here, I move beyond traditional modes of information provision, where healthcare professionals primarily rely on verbal communication. Rather, I explore the potential of audiovisuals to improve SDM in complex surgical oncology. Specifically, part II aims to investigate the potential of these materials to support patients and their informal caregiver(s) in understanding treatment options and consequences, promoting SDM in oral oncology. In this part, we address the following research questions, which correspond to the individual chapters in this dissertation:

Chapter 4: What is the effect of using audiovisuals to provide pre-treatment information to patients with cancer on immediate, intermediate, and long-term outcomes?

Chapter 5: What are the needs and preferences of patients, their caregivers, and healthcare professionals for the content, design, and adoption requirements of animated videos in complex surgical oncology communication?

Based on these aims and research questions, this dissertation is outlined as follows. **Chapter 2** takes a broader perspective, investigating how patients with cancer use the internet to seek informational and emotional support in preparation for and as a follow-up to clinical encounters. By examining their underlying motives for going online, we aim to identify distinct patient profiles based on their online support-seeking behaviors. **Chapter 3** narrows the focus to the context of complex surgical oncology, specifically head and neck cancer. We aim to explore the state of shared decision-making in head and neck oncology by quantitatively assessing current communication dynamics between patients, head and neck surgeons, and informal caregivers. **Chapter 4** presents a systematic review to explore the effectiveness of audiovisuals in oncology. Through an in-depth analysis of existing literature, we aim to evaluate the immediate, intermediate, and long-term outcomes of using audiovisual materials to deliver pre-treatment information to patients with cancer. **Chapter 5** builds on these findings by exploring the perspectives of key end-users of educational animated videos, including healthcare professionals, patients, and informal caregivers. We aim to identify their needs and preferences regarding the development and implementation of animated videos to support communication about oral cancer treatment in surgical oncology. Finally, this dissertation ends with a summary of the results, general discussion, methodological considerations, and pointers for the future in **Chapters 6 and 7**.

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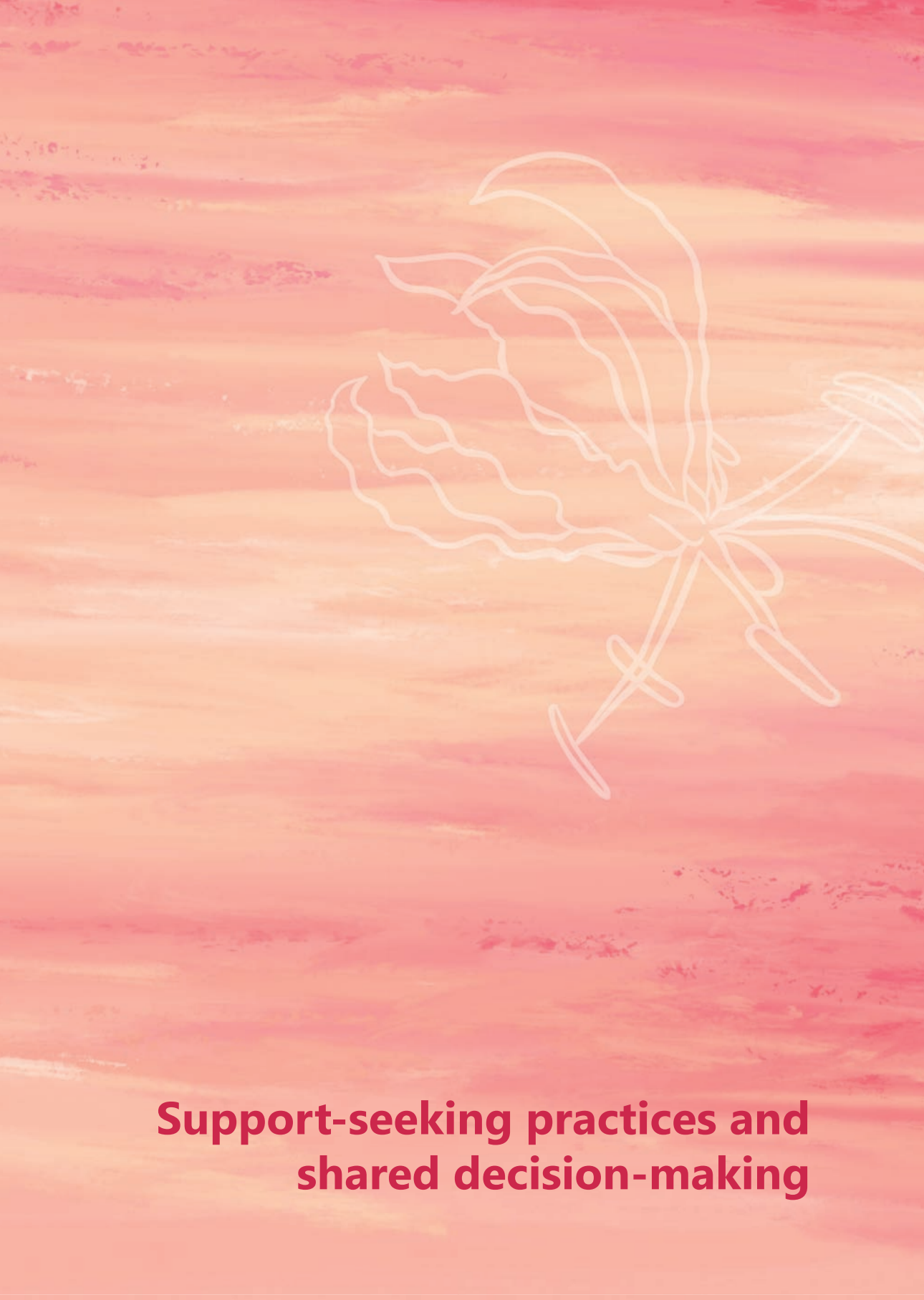
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PART I





Support-seeking practices and shared decision-making

CHAPTER 2

Profiling cancer patients based on their motives for seeking informational and emotional support online

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ABSTRACT

Understanding why patients seek informational and/or emotional support online is fundamental to providing patients with accurate and reliable support that is tailored to their needs, preferences, and personal situation. Based on the stress and coping theory and uses and gratifications theory (UGT), this study aimed to identify theoretically founded profiles of cancer patients differing in their motives for seeking informational and/or emotional support online, and to compare the profiles in terms of patients' psychological and background characteristics, and perception of health care services. Hierarchical cluster analysis was conducted, using questionnaire data of patients visiting a large Dutch health website (N = 181). This revealed three distinctive profiles, i.e., overall seekers (n = 83, 46.0 %), occasional information seekers (n = 83, 46.0 %), and contact exchangers (n = 15, 8.0%). Patients across these profiles differed in their eHealth literacy, with the contact exchangers being more eHealth literate than the overall seekers and occasional information seekers. The results can be used to create awareness among health care providers, web designers, and patient organizations on different types of cancer patients with different motives for seeking informational and/or emotional support online, and help them to tailor recommendations to and development of (online) sources that fit patients' needs. Future research could further investigate the integration of stress and coping theory with UGT by acknowledging the interplay of different coping strategies and different gratifications.

INTRODUCTION

The internet is an important source of information and support for many patients [1,2], often in combination with a health care provider consultation [3,4]. By engaging in so-called "convergence", patients have become more active in managing their health[5,6]. According to Kreps[7], convergence is a process in which patients sequentially use multiple sources of information to fulfill their information and support needs. Patients can either use "information accessed through digital mass media and its subsequent discussion in interpersonal encounters" (type 1 convergence, p. 519) or "conduct interpersonal and peer discussions about health-related issues in virtual discussion spaces of various kinds" (type 2 convergence, p. 521). There are many reasons why patients engage in convergence. Generally, they use the internet for additional information to prepare for consultation or seek information beyond the consultation with their providers, to deal with conflicting information, or to connect with peers and receive and/or give emotional support on online platforms [5,6,8–11].

Cancer patients differ in the information and support they need and prefer [12–15], and accordingly, in their information and support-seeking behavior [16–19]. Research has indicated that cancer patients visit different online platforms to find different content which suggests they go online for different reasons (i.e., motives) to satisfy their needs [5,20,21]. Some patients seem predominantly to seek informational support to cope with their illness, while others seem mainly to seek emotional support [3,8,10,11]. An explanation for this variation can be found in the stress and coping theory which posits that individual factors influence how a person evaluates a stressor (e.g., cancer diagnosis) and coping possibilities (e.g., motives to use the internet), ultimately influencing what coping strategy they employ [22,23].

Earlier studies provided valuable insights into the motives for internet use among cancer patients in general [5,6,10,24], but did not account for individual differences in patients' motives for seeking different types of informational and/or emotional support online. When accounting for individual differences, previous research focused on how patients' psychological and background characteristics, and perception of health care services relate to the individual differences in support needs [12,15,25–28] and internet use [5,6,16,29,30]. To the best of our knowledge, no previous research has accounted for individual differences by exploring typical patient groups (or clusters). Therefore, information is lacking on whether there are individual differences in motives of cancer patients for seeking informational and/or emotional support online, and if so, what factors relate to these differences in motives. Consequently, instead of taking a variable-oriented approach by looking at population-based correlations, this study looks at the response patterns of individual people. Understanding different patient groups based on the motives that cancer patients

may have to go online is essential to provide patients with accurate and reliable (online) informational and emotional support [29,31,32] that is tailored to their personal situation, needs, and preferences. Tailoring [33] (i.e., individualized communication) to the specific individual support needs of patients may improve the provision of (online) information and subsequently enhance coping with the illness by reducing patients' distress [34–36]. This study, therefore, focuses on (1) identifying typical patient profiles based on their motives for seeking informational and/or emotional support online, and (2) comparing these profiles in terms of patients' psychological and background characteristics, and perception of health care services.

Motives for using the internet

The uses and gratification theory (UGT) can be used to understand why people use the internet. According to this theory, people actively choose a medium based on its appropriateness to satisfy their needs [37]. There are three general types of gratifications that are unique to internet use: process, content, and social gratifications. Process gratifications concern the actual use of the medium[38] and refer to the satisfaction people experience from purposefully navigating online[37]. However, process gratifications can only partially explain why cancer patients use the internet because of the emphasis on the experience [37,39,40].

Before discussing how the internet fulfills patients' content and social gratifications, it is important to understand the needs of patients. Research has shown that informational and emotional support are the two types of support most commonly sought and used by individuals coping with illness [21,41,42]. According to the optimal matching model, patients need the proper type of support (informational and/or emotional support) that matches their needs to reduce stress and enhance coping with their illness [34–36,43]. This means that patients actively seek out and choose communication channels they believe are appropriate to find the proper kind of support to fulfill their needs. Thus, content gratifications can explain why patients use the internet, namely to gratify their need for informational support. Studies have shown that patients may search online to enhance the quality of the consultation and collaboration with their provider [3,5,11]. Patients use the information to prepare questions for their provider and to better understand their symptoms and worries, and medical jargon [11,44]. Consequently, patients may use the internet to search for informational support to complement the consultation and to understand what will or has been said [3,11]. Moreover, patients have been found to use the internet for a "second opinion" [3,5]. For instance, when they are in doubt about the quality or accuracy of the information given by the provider during the consultation [3,44,45].

Next to gratifying their need for informational support (i.e. content gratifications), patients can use the internet to gain social gratifications by seeking emotional support [37]. Patients try to lessen negative emotions caused by, for example, the diagnosis or implications of treatment by seeking emotional support from others [23,46,47]. Many believe that only a fellow patient could understand their suffering, and consider online peer support, such as reading and sharing experiences, to be valuable, especially after diagnosis [3,10,11,47,48]. Considering the many different motives for seeking online, our first aim is to investigate typical patient profiles based on their motives for seeking informational and/or emotional support online. We propose the following research question (RQ):

RQ1*: Which patient profiles can be identified among cancer patients based on their motives for seeking informational and/or emotional support online?*

Differences in cancer patients and their motives for using the internet

The stress and coping theory explains why cancer patients differ in their motives for seeking informational and/or emotional support online [22,23]. According to this theory, individual factors can influence patients' cognitive appraisal, i.e., the individual's judgment of a stressor, such as their diagnosis with cancer (i.e., primary appraisal), and the available coping options (i.e., secondary appraisal) which result in different patient coping strategies. Coping refers to the constantly changing cognitive and behavioral efforts of a person to deal with a stressful situation and is generally divided into problem-focused and emotion-focused coping [23]. Problem-focused coping is directed at solving or managing the stressful situation and includes seeking informational support [23,49], which implies that a patient may use the internet to satisfy their needs through content gratifications [37]. Emotion-focused coping is directed at controlling or minimizing the emotions associated with the stressful event and includes the expression of emotions or seeking emotional support [49,22,23], which implies that a patient may seek to satisfy their needs through social gratifications [37].

Subgroups of cancer patients that seek informational and/or emotional support online may differ based on various individual characteristics. However, to the best of our knowledge, empirical evidence is lacking on how individual characteristics may vary across different patient subgroups that seek support online. In their review, Thomsen et al. [50] found that differences in coping styles (problem-focused and emotion-focused coping) among cancer patients may be related to several factors, such as uncertainty, emotions, and control. Additionally, Franks and Roesch's [51] meta-analysis indicated that moderator variables, such as age, may influence the relationship between an individual's

appraisal of a stressor and their coping strategy. Indeed, patients' psychological (e.g., psychological distress, coping style) and background characteristics (e.g., age, gender, educational level, eHealth literacy), as well as patient's perception of health care services (e.g., trust in the physician) play a role in the behavior of patients seeking support online [29,44,52–56]. Although the results of these previous studies are ambiguous, we expect that individual characteristics will vary across types of patients that seek support online.

Psychological factors

Whether patients seek informational and/or emotional support online may depend on an individual's level of psychological distress and coping style. There is evidence that higher levels of anxiety and stress relate to a higher need for information [44,52,57–59]. Consequently, a patient who searches for informational support online may demonstrate greater levels of distress (e.g., anxiety, cancer worry).

In contrast, seeking emotional support online can also be done to reduce higher cancer-related distress levels. Some studies, for instance, found that higher levels of distress are associated with the need for emotional support [60–62]. In terms of coping style, relationships with a so-called monitoring (i.e., information seeking) coping style are inconclusive, with findings of associations between a monitoring coping style and either informational [57,59,63], emotional support [64,65], or both [66,67].

Background characteristics

The use of the internet for informational and/or emotional support may also be explained by several background characteristics. In general, studies show informational support to be more likely sought online by younger patients than by older patients, as older patients seem to need, and desire, less (detailed) information than younger patients. However, it has also been suggested that receiving emotional support online is valued more by younger patients than by older patients [61,68–70].

In addition, patients' online support-seeking behavior is related to an individual's education level. Patients who seek informational support online tend to have a higher level of education [59,71,72], as they seem to prefer more information compared to individuals with lower levels of education [61,70]. Nevertheless, one study has shown that seeking informational support online is rather correlated with lower levels of educational attainment instead of higher levels, with less educated patients having higher needs for information [73]. However, other research suggests that seeking emotional support online is more likely done by patients with higher education levels [61].

eHealth literacy is also another background characteristic that seems to be related to seeking informational and/or emotional support online. eHealth literacy refers to "the

ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem" [74] (pe9). Patients seeking informational support on the internet seem to have higher (e)Health literacy than those not seeking informational support [44,54,75]. However, empirical evidence of a relation between eHealth literacy and emotional support seeking online is lacking.

Finally, informational support is suggested to be more likely sought by male patients than by women [70,76–78]. Numerous studies have shown that patients who seek emotional support online are more likely to be female [61,68,78–81], because women tend to seek emotional support more proactively [48,76,77].

Patients' perception of health care services

In addition to psychological and background factors, differences across different subgroups may also relate to patients' perception of health care services, such as trust in their physician. Many patients consider health care providers to be the most important source of informational support [2,82–84]. Both seeking informational and emotional support are sought when patients are dissatisfied with, or mistrust the health care provider [25]. Compared to trusting patients, dissatisfied and mistrusting patients seem to seek informational support rather than emotional support [44,52,85].

Consequently, evidence of the influence of the different psychological and background characteristics, and patients' perception of health care services, is inconsistent. Therefore, the second aim of this study is to investigate whether cancer patients who seek informational and/or emotional support online vary across different profiles based on individual characteristics. Figure 1 shows our conceptual model. We formulate the following RQ:

RQ2*: How do the patient profiles based on patients' motives for seeking informational and/or emotional support online differ in terms of their psychological and background characteristic, and patients' perception of health care services?*

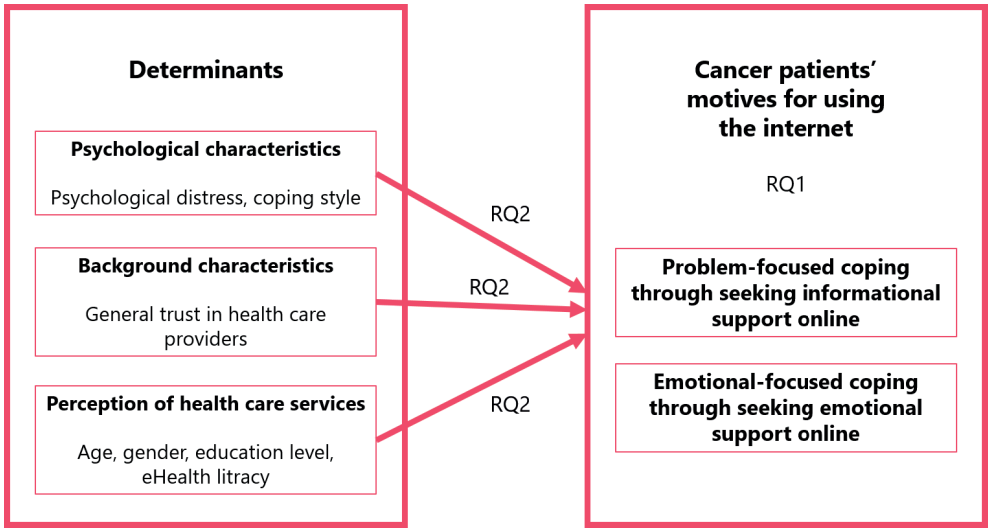


Figure 1. Conceptual model of cancer patients' motives for using the internet.

MATERIALS AND METHODS

Participants and procedure

As a leader in Europe with the highest percentage of people that use the internet for health information-seeking, this study specifically focuses on the Netherlands [86]. The Dutch website Kanker.nl is one of the largest and best-known for cancer-related information, and offers both peer- (e.g., blogs, discussion groups) and expert-generated platforms (e.g., medical library, expert questions). The number of visits to the website is increasing, with 6,589,396 unique visitors in 2020 compared to 5,807,878 the year before [87]. Between December 2019 and January 2020, a survey and informed consent were sent by Kanker.nl via e-mail to 1475 users of the website's online panel who consented to research on their user profile. To be eligible for the study, participants had to be either a current patient or cancer survivor, at least eighteen years old, and have sufficient command of the Dutch language. This study was approved by the Ethics Committee of the University of Amsterdam (reference number: 2019-PC-11494).

Motives for using the internet

Based on the results of the previous studies [3,5,6,10,11,88], we created twenty-two items to examine patients' motives for seeking informational and emotional support online, e.g.,

"Would you visit Kanker.nl if you have any questions after your conversation with your health care provider?", "Would you visit Kanker.nl if you want the experiences and advice from others?". To not overburden participants, items could be answered with dichotomous responses (yes or no). Based on our review of the literature, we grouped the items into three categories, ending up with six items in the "informational support: looking for complementary information" category, seven items in the "informational support: dealing with conflicting information" category, and nine items in the "emotional support: giving and/or receiving emotional support" category. Kucher Richardson Formula 20 (KR-20) was used to measure how consistent the reliability of the dichotomous scores on the motives was. One item (i.e., "Would you visit Kanker.nl if you want information about alternative treatments") decreased the reliability of the "looking for complementary information" category and was therefore deleted from the category for further analyses. A total score was calculated for each of the motive categories, resulting in "informational support: looking for complementary information" category (range 0-5), "informational support: dealing with conflicting information" category (range 0-7), and "emotional support: giving and/or receiving emotional support" category (range 0-9). This indicated that the higher the score, the more relevant the motive for a patient. Table 1 offers an overview of all items in the categories, including the Kuder Richardson-20 α measures.

Measures of factors associated with motives for using the internet

Psychological factors

Cancer-related psychological distress was measured with three concepts. First, to examine how patients react during dramatic life-changing events, such as the diagnosis of cancer, intrusive thinking was measured with the 7-item Impact of Events Scale (IES) [89], e.g., "I thought about the disease when I didn't mean to" assessed on a 4-point scale (0 = "not at all", 1 = "rarely", 2 = "sometimes" to 4 = "often", Cronbach's α = .87). Second, worries about the disease were measured with an adapted 6-item Cancer Worry Scale (CWS; Custers et al., 2014), e.g., "During the last month, how often have you thought about your chances of getting cancer (again) or further expansion of the cancer?", with the same 4-point scale used (Cronbach's α = .90). The higher the score, the higher patients' distress. Last, a shortened Dutch version of the Intolerance of Uncertainty Scale (IUS) was used to assess patients' feelings of uncertainty, e.g., "Unforeseen events seriously upset me", using a 5-point scale (ranging from 1 = "strongly disagree" to 5 = "strongly agree", Cronbach's α = .88).

To measure patients' coping style, an adapted version of the shortened Threatening Medical Situation Inventory (TMSI) [66,91]. Participants indicated the extent to which statements applied to them after diagnosis with cancer, e.g., "I intended to read about

Table 1. Motives for seeking informational and emotional support online.

Category	Motives (Would you visit Kanker.nl if you …)
Informational support: Looking for complementary information (KR-20 α = .76)	…want to better understand what the health provider has told you? …received too little information from your health provider? …have any questions after your conversation with your health provider? …want to reduce your uncertainties (e.g., about treatment, the future)? …want to prepare for your conversation with your health provider?
Informational support: Dealing with conflicting information (KR-20 α = .76)	…have received conflicting information from different health providers? …want to put the information that the health provider has told you into perspective? … come across conflicting information on the internet? …have received conflicting information from your family and/or friends? …want to check the information from the health provider? …have received information that goes against your own opinion? …want information that you did not want to discuss with your health provider during the conversation?
Emotional support: Receiving and/or giving emotional support (KR-20 α = .82)	…want to feel understood by others? …want to have contact with fellow cancer patients? …want information about the possibilities for contact with fellow cancer patients? …want to share your current situation? …want emotional support? …want to share the information you have received from your health provider with others? …want the experiences and advice of other patients? …want to share your experience(s) with others (e.g., about treatment, consequences for your work?) …want to participate in group conversations/group discussions?

Note. Reported Kuder Richardson-20 α concern reliability for each motive category after deleting the item "… want information about alternative treatments."

my/the disease", with each item measured on a 5-point scale (1 = "not applicable at all", 5 = "very applicable", Cronbach's α = .88). The higher the score, the more actively a patient searches for information to deal with their disease.

Background characteristics

Patients' background information was asked in terms of age, gender, education level, and eHealth literacy. Three categories were made for education level: low (i.e., primary education, lower vocational education, preparatory secondary vocational education, secondary general education), middle (i.e., higher secondary general education, pre-university education secondary vocational education), and high (i.e., higher vocational education, university).

Finally, eHealth literacy was measured with an adapted and shortened ten-item version of the Dutch Digital Health Instrument[92]. Measures included information-seeking skills (e.g., "When searching for information about the disease cancer on Kanker.nl, how difficult do you find it to choose from the information you find?"), information assessing skills (e.g., "When searching for information about the disease cancer on Kanker.nl, how difficult do you find it to determine the reliability of the information?"), information application skills (e.g., "When searching for information about the disease cancer on Kanker.nl, how difficult do you find it to determine whether the information found applies to you?"), and participants' navigation skills (e.g., "When searching for information about cancer on Kanker.nl, how often does it occur that you get confused on the website?"). Each of these skills was measured, using a 4-point scale (1 = "very easy", 4 = "very difficult", Cronbach's α = .87) where higher scores indicated better digital health literacy skills.

Patients' perception of health care services

For patients' trust in health care providers, an adapted version of the Patient Trust in a Physician Scale was used[93], e.g., "Sometimes physicians place their interest above the medical interest of a patient". For each of the five items participants indicated the extent to which it applied to them on a 5-point Likert scale (e.g., 1 = "strongly disagree", 5 = "strongly agree", Cronbach's α = .86). Higher scores indicated a higher trust in physicians.

Statistical analysis

First, descriptive statistics were conducted to determine the characteristics of the sample. Agglomerative hierarchical cluster analysis was used to identify distinctive patient profiles with the motives for seeking informational and emotional support online as a clustering variable. The statistical method allows clustering of group cases in a way that all individuals within one cluster are similar to each other based on specific variables but significantly distinct from individuals in other clusters [94–96]. Hierarchical cluster analysis is explorative, allowing the researcher to explore possible cluster solutions rather than having to pre-specify the number of clusters to determine the clustering of the data (e.g., *k*-means cluster analysis) [97–100]. Consequently, patients' motives were first standardized into z-scores to balance out the influence that uneven values of the motives categories could have on the clustering of the data [101–103]. Different amounts of individual motive items in each motive category could affect the cluster analysis and act as a weight when determining how to cluster the data (i.e., clustering algorithms such as Wards' Euclidean distances). Ward's clustering algorithm with squared Euclidean distance was used to join individuals into clusters to minimize variance within each cluster [94,95,104]. Investigation of inversed scree plots, three random subsamples, and dendrograms led to a three- and four-cluster solution. Each profile was then scored on the three motive categories in

comparison to the other clusters (i.e., high, moderate, low). Noteworthy is that this does not mean that a certain profile has a high, moderate, or low motivation in general, but that these scores are relative compared to the other clusters. To determine the appropriate cluster solution, both solutions were (visually) inspected for interpretability by looking at their representation. Finally, one-way analyses of variance (ANOVAs) with Welch and Games-Howell post hoc comparisons were conducted to compare the cluster solutions on the psychological, and background characteristic, and patients' perceptions of health care services. To analyze all data IBM's SPSS software version 26 was used with a significance set at *p*-level .05[105].

RESULTS

Sample characteristics

A total of 211 participants responded to the invitation, of which 181 (85.8%) current (*n* = 90, 49.7%) and ex-patients (*n* = 91, 50.3%) completed the online survey. More than half of the participants were female (*n* = 94, 51.9%) and reported to have completed a high level of education (*n* = 97, 53.6%). Age ranged from 20 to 88 (*M* = 60.46, *SD* = 9.28). Breast cancer (*n* = 41, 22.7%) and urological cancers (*n* = 22.7%, 22.7%) were the most common cancer diagnoses. Time since diagnosis ranged from two months to 331 months (*M* = 68.68, *SD* = 60.93). Of the 87 patients who still received treatment, 35 (40.2%) underwent curative treatment and 45 (51.7%) underwent palliative care (i.e., life extension and/or relief of pain). Characteristics of this sample are presented in Table 2.

Patient profiles according to motives

The hierarchical cluster analysis identified a three-cluster solution as the best theoretical fit. All clusters significantly differed from each other concerning the main motives for using Kanker.nl ($p < .001$; Table 3). We called the most active type of patients the *overall seekers* (*n* = 83). These patients reported a high motivation to use the internet to look for complementary information (*M* = 4.25, *SD* = 1.10), to deal with conflicting information (*M* = 5.57, *SD* =1.53), and to give and/or receive emotional support (*M* = 7.37, *SD* = 1.50). The second cluster is best referred to as the *occasional information seekers* (*n* = 83). Patients within this cluster were characterized by a moderate motivation to use Kanker.nl to look for complementary information (*M* = 3.36, *SD* = 1.43) as well as a moderate motivation to use the internet to deal with conflicting information (*M* = 3.93, *SD* = 1.60). This cluster had a low motivation to visit Kanker.nl to give and/or receive emotional support (*M* = 2.57, *SD* = 1.56). The *contact exchangers* (*n* = 15) were the least motivated to use Kanker.nl to find

Table 2. Sample characteristics

Variable	Current patients and cancer survivors *N* = 181
Age (at time of survey), *M* (*SD*), range	60.46 (9.28), 20-88
<50 years, *n* (%)	25 (13.8)
51-60	60 (33.1)
61-70	75 (41.4)
>71	21 (11.6)
Gender, *n* (%)	
Female	94 (51.9)
Male	87 (48.1)
Education, *n* (%)	
Low education level	23 (12.7)
Middle education level	61 (33.7)
High education level	97 (53.6)
Living situation, *n* (%)	
Alone	40 (22.1)
With Partner	105 (58.0)
With Partner and child(ren)	31(17.1)
With Child(ren)	2 (1.1)
With Other family members (e.g., parent, brother/sister)	1 (0.6)
Other	2 (1.1)
Type of cancer diagnosis, *n* (%)	
Breast cancer	41 (22.7)
Stomach, liver or colon cancer, incl. esophageal, rectum, pancreatic, and	25 (12.8)
thyroid cancer	13 (13.8)
Lung cancer	9 (5.0)
Gynecological cancer (e.g., cervical, ovarian, and vulva cancer)	15 (8.3)
Blood or lymph node cancer (e.g., Hodgkin's disease, non-Hodgkin,	41 (22.7)
leukemia)	11 (6.1)
Urological cancer (e.g., kidney, prostate, bladder, testicular cancer)	6 (3.3)
Head and neck cancer, brain cancer (e.g., mouth or throat, retinal cancer)	7 (3.9)
Skin cancer (e.g., melanoma)	28 (15.5)
Bone cancer, incl. multiple myeloma, Waldenstrom's disease	
Other	
Ongoing treatment, *n* (%)	
Yes	87 (48.1)
Goal of ongoing treatment, *n* (%)	
Curing	35 (40.2)
Sedative and/or palliative	45 (51.7)
I don't know	7 (8.0)
Time since diagnosis (at time of survey), *M* (*SD*), range[a]	68.68 (60.93), 2-331
0-12 months, *n* (%)	17 (9.4)
13-24 months	22 (12.2)
24-36 months	19 (10.5)
37-48 months	12 (6.6)
49-60 months	14 (7.7)
More than 61 months	64 (35.4)

Note. [a] Missing data for 33 participants

complementary information (*M* = 0.47, *SD* = 0.52) and deal with conflicting information (*M* = 0.33, *SD* = 0.49). In contrast to the other clusters, this group was reasonably motivated to give and/or receive emotional support on Kanker.nl (*M* = 5.60, *SD* = 1.76). A visualization of the three patient profiles is provided in Figure 2 and a comparison of the cluster composition based on the main motives is presented in Table 3.

To gain more insight into the profiles, we examined differences between the clusters on the item level of the motives. Several differences between clusters are considered noteworthy. Compared to the contact exchangers, the overall seekers and the occasional information seekers reported relatively higher motivation to visit Kanker.nl to better understand what the provider has told (respectively $p < .001$, mean diff. = .69; $p = .001$, mean diff. = .79), and when they received too little (respectively $p < .001$, mean diff. = .66; $p < .001$, mean diff. = .74) or conflicting information from the provider (respectively $p < .001$, mean diff. = .73; $p < .001$, mean diff. = .78). Moreover, in comparison to the occasional information seekers and the contact exchangers, the overall seekers also indicated to be relatively higher motivated to visit the website when they had uncertainties (respectively $p < .001$, mean diff. = .27; $p < .001$, mean diff. = .52), questions after consultation (respectively $p = .001$, mean diff. = .24, $p < .001$, mean diff. = .57), encountered information conflicting with their own opinion (respectively $p = .001$, mean diff. = .24; $p < .001$, mean diff. = .56), wanted to share their current situation (respectively $p < .001$; mean diff. = .74, $p = .002$, mean diff. = .47). In addition, compared to the overall seekers, the occasional information seekers and contact exchangers were relatively more motivated to visit Kanker.nl for contact with peers (respectively $p < .001$, mean diff. = .51; $p < .001$, mean diff. = .54), with the contact exchangers being the most motivated to engage in contact with peers. Finally, in comparison with the occasional information seekers and contact exchangers the only cluster that appeared to be relatively highly motivated to visit Kanker.nl to share their experience(s) with others were the overall seekers (respectively $p < .001$; mean diff. = .65, $p = .022$, mean diff. = .29). The differences among the clusters based on the items can be found in Table 4.

Differences across the patient profiles

Apart from the significant differences found in the different motives for online information and/or emotional support-seeking, the clusters only significantly differed in their eHealth literacy, $F(2, 178) = 11.77$, $p < .001$. Considering the overall sample's average (*M* = 1.99, *SD* = 0.43), the overall seekers (*M* = 1.98, *SD* = 0.35) scored about average for eHealth literacy. They appeared to be slightly more eHealth literate than the occasional information seekers (*M* = 1.91, *SD* = 0.38) but less eHealth literate than the contact exchangers (*M* = 2.47, *SD* = 0.75). Post hoc analysis revealed a significant difference between the overall seekers and

contact exchangers ($p < .001$, mean diff. = 0.49) but no significant difference between the overall seekers and the occasional information seekers ($p = .524$, mean diff. = 0.07). Yet, the occasional information seekers differed significantly in their eHealth literacy from the contact exchangers ($p < .001$, mean diff. = 0.56). Comparisons between the clusters based on characteristics are presented in Table 5.

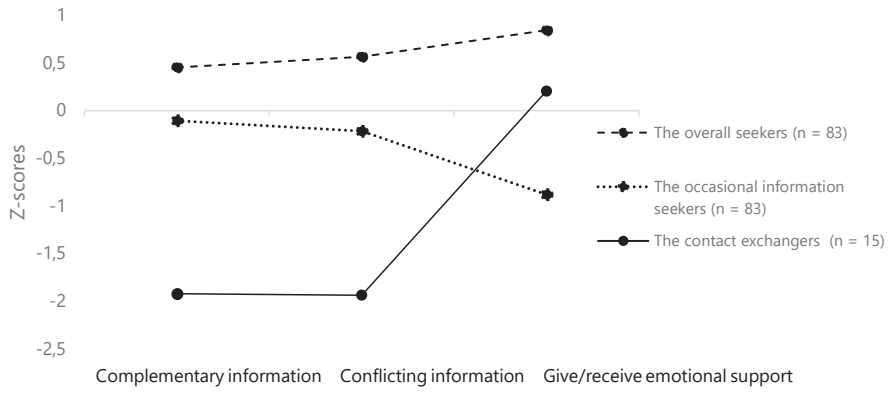


Figure 2. Hierarchical cluster analysis revealed a three-cluster solution.

Table 3. Scoring of the three clusters on the three motive categories.

Motive category	Cluster 1 (*n* = 83) The overall seekers	Cluster 2 (*n* = 83) The occasional information seekers	Cluster 3 (*n* = 15) The contact exchangers	*F*(df), *p*-value
Informational support: Looking for complementary information, (*M*, *SD),* range	High (*M* = 4.25, *SD* =1.10), 0-5	Moderate (*M* = 3.36, *SD* = 1.43), 0-5	Low (*M* = 0.47, *SD* = 0.52), 0-5	61.35 (2, 178), *p* < .001
Informational support: Dealing with conflicting information, (*M, SD*), range	High (*M* = 5.57, *SD* = 1.53), 0-7	Moderate (*M* = 3.93, *SD* = 1.60), 0-7	Low (*M* = 0.33, *SD* = 0.49), 0-7	83.32 (2, 178), *p* < .001
Emotional support: Giving and/ or receiving emotional support, (*M*, *SD*), range	High (*M* = 7.37, *SD* = 1.50), 0-9	Low (*M* = 2.57, *SD* = 1.56), 0-9	Moderate (*M* = 5.60, *SD* = 1.76), 0-9	199.91 (2, 178), *p* < .001

Note. Significant difference for the one-way ANOVA was set at 5%

Table 4. Representation of the three clusters based on the three motive categories

Category	Motives (Would you visit Kanker.nl if you …)	The overall seekers (*n* = 83), *n* (%)	The occasional information seekers (*n* = 83), *n* (%)	The contact exchangers (*n* = 15), *n* (%)
Informational support: Looking for complementary information	…want to better understand what the health provider has told you?	77 (92.8) [a]	68 (81.9) [a***]	2 (13.3) [b***]
	…received too little information from your health provider?	78 (94.0) [a]	71 (85.5) [a***]	3 (20.0) [b***]
	…have any questions after your conversation with your health provider?	67 (80.7) [a**]	47 (56.6) [c***]	0 (0.0) [b***]
	…want to reduce your uncertainties (e.g., about treatment, the future)?	71 (85.5) [a***]	49 (59.0) [c***]	1 (6.7) [b***]
	…want to prepare for you conversation with your health provider?	60 (72.3) [a*]	44 (53.0) [c**]	1 (6.7) [b**]
Informational support: Dealing with conflicting information	…have received conflicting information from different health providers?	81 (97.6) [a]	77 (92.8) [a***]	3 (20.0) [b***]
	…want to put the information that the health provider has told you into perspective?	63 (75.9) [a***]	40 (48.19) [c**]	0 (0.0) [b***]
	…came across conflicting information on the internet?	71 (85.5) [a]	60 (72.3) [a***]	1 (6.7) [b***]
	…have received conflicting information from your family and/or friends?	52 (62.7) [a***]	23 (27.7) [b]	0 (0.0) [b***]
	…want to check the information from the health provider?	65 (78.3) [a***]	39 (47.0) [c**]	0 (0.0) [b***]
	…have received information that goes against your own opinion?	72 (86.7) [a**]	52 (62.7) [c***]	1 (6.7) [b***]
	…want information that you did not want to discuss with your health provider during the conversation?	58 (69.9) [a***]	35 (42.2) [c*]	0 (0.0) [b***]

Emotional support: Giving and/or receiving emotional support	…want to feel understood by others?	58 (69.9) ^{a***}	17 (20.5) ^{ab}	6 (40.0) ^{a}
	…want to have contact with fellow cancer patients?	38 (45.8) ^{a***}	80 (96.4) ^{a}	15 (100.0) ^{b***}
	…want information about the possibilities for contact with fellow cancer patients?	77 (92.8) ^{a***}	32 (38.6) ^{b***}	13 (86.7) ^{a}
	…want to share your current situation?	72 (86.7) ^{a***}	11 (13.3) ^{c***}	9 (60.0) ^{b*}
	…want emotional support?	45 (54.2) ^{a***}	6 (7.2) ^{b}	3 (20.0) ^{ab}
	…want to share the information you have received from your health provider with others?	61 (73.5) ^{a***}	12 (14.5) ^{b}	4 (26.7) ^{b***}
	…want the experiences and advice of other patients?	81 (97.6) ^{a***}	55 (66.3) ^{b}	12 (80.0) ^{ab}
	…want to share your experience(s) with others (e.g., about treatment, consequences for your work?)	74 (89.2) ^{a***}	20 (24.1) ^{c*}	8 (53.3) ^{b*}
	…want to participate in group conversations/group discussions?	64 (77.1) ^{a***}	22 (26.5) ^{b***}	14 (93.3) ^{a}

Note. Differing superscripts (a, b, c) indicate significantly different mean scores within a row; comparisons were made between clusters in order of 1 to 2, 3 to 1, and 2 to 3 and provided with level of significance in the same order * $p < .05$; ** $p < .01$; *** $p < .001$.

Table 5. Comparison of the three clusters based on psychological, perception of health care services, and background characteristics.

Variable	The overall seekers (*n* = 83; 45.9%)	The occasional information seekers (*n* = 83; 45.9%)	The contact exchangers (*n* = 15; 8.3%)	*F*-test (df)	Welch and Games-Howell post hoc pattern
Cancer-related psychological distress, *M* (*SD*)	2.82; 0.73	2.72; 0.65	2.63; 0.77	0.75 (2, 178), $p = .475$	ns
Intrusive thinking	2.04; 0.71	1.91; 0.65	2.10; 0.78	0.97 (2, 178), $p = .381$	
Cancer Worry	2.42; 0.71	2.20; 0.64	2.39; 0.77	2.27 (2, 178), $p = .107$	
Intolerance for uncertainty					
Coping style, *M* (*SD*)	4.05; 1.01	4.01; 1.02	3.60; 1.02	1.37 (2, 178), $p = .256$	ns
Trust in doctors, *M* (*SD*)	3.85; 0.83	4.13; 0.70	4.00; 0.92	2.67 (2, 178), $p = .072$	ns
Age, *M* (*SD*)	60.66; 7.63	60.93; 10.77	56.80; 8.43	1.30 (2, 178), $p = .276$	ns
Gender, *n* (%)				1.61 (2, 178), $p = .203$	ns
Male	40 (48.2)	43 (51.8)	4 (26.7)		
Female	43 (51.8)	40 (48.2)	11 (73.3)		
Educational level, *n* (%)				1.19 (2, 178), $p = .307$	ns
Low education level	10 (12.0)	10 (12.0)	3 (20.0)		
Middle education level	36 (43.4)	22 (26.5)	3 (20.0)		
High education level	37 (44.6)	51 (61.4)	9 (60.0)		
eHealth literacy, *M* (*SD*) [a]	1.98; 0.35	1.91; 0.38	2.47; 0.75	11.77 (2, 178), $p < .001$	$1<3^{***}$; $2<3^{***}$

Note. One-way ANOVAs with Welch and Games-Howell post hoc tests for violation of the assumption of homogeneity variance. [a] = significant difference among all profiles (global level), for the one-way ANOVA, significant difference among all profiles was set at 5%.

* $p < .05$; ** $p < .01$; *** $p < .001$; ns = non-significant

DISCUSSION

In this study, we identified three online support-seeking profiles based on their motives for using the internet to seek informational and/or emotional support: the overall seekers, the occasional information seekers, and the contact exchangers. The overall seekers represented almost half of the sample and appeared to be the most motivated to use the website Kanker.nl for three main motives: looking for complementary information, dealing with conflicting information, and giving and/or receiving emotional support. The second largest group, the occasional information seekers, appeared to be almost equally moderately motivated to use the internet for seeking complementary information and dealing with conflicting information, but the least motivated to use the internet to give and/or receive emotional support. The smallest group, the contact exchangers, noticeably differed from the others in being the least motivated to seek informational support and more motivated than the other two groups to give and/or use emotional support. These results are in line with existing research, showing that cancer patients primarily go online to seek informational support, but seek emotional support to a less extent [2,6,10,88].

We found the three profiles not only vary in motive but also differ in their level of eHealth literacy, with the contact exchangers being more eHealth literate than the overall seekers and the occasional information seekers. This seems to contradict our expectations of patients with higher levels of eHealth literacy being more likely to seek informational support online than less eHealth literate patients [75]. One explanation for this result can be that patients with higher eHealth literacy may be in need of more detailed medical information than provided by a general health website like Kanker.nl, and instead use other sources, such as online medical journals or databases (e.g., PubMed), to fulfill their information needs [44,106]. The higher eHealth literate contact exchangers in our study mainly seemed to use the studied website to contact peers. This suggests that general health websites like Kanker.nl are best able to fulfill the information needs of lower eHealth literate groups. Therefore, referrals to use such general health websites might be most beneficial to them [75]. In contrast, higher eHealth literate patients might benefit more from accessible academic literature. To pinpoint which platforms or websites are particularly beneficial for patients with higher or lower eHealth literacy levels, it would be worthwhile to examine different types of patient groups visiting various platforms and websites in future studies, especially since the results and assumptions of this study are based on one specific online group of patients visiting one particular general health website.

Theoretical implications

This study contributes to a better understanding of the individual differences in patients' online support-seeking behavior. Using the UGT and stress and coping theory provided a firm theoretical basis for our profiles: The UGT proved tenable for understanding patients' motives for online support-seeking and understanding that the internet mainly serves two primary functions for patients coping with an illness such as cancer, i.e., fulfilling content and social gratifications [21,37,41,42]. Our results showed that in search of different gratifications some patients mainly use the internet to seek specific content (i.e., informational support), while others use the medium to mainly seek contact with peers (i.e., emotional support). In turn, the stress and coping theory showed the importance of patients' differences in coping which led to its use as a theoretical basis for examining differences between typical patient profiles. Our findings are in line with the theoretical assumption that people actively seek to fulfill their needs through finding the proper type of support [34,35,43], as we found patients to employ problem-focused coping through seeking informational support online and/or emotion-focused coping through seeking emotional support online. This presence of seeking informational and/or emotional support online within both the UGT and stress and coping theory suggests that the two theories complement each other and show novel insights into the continuous interaction between content and social gratifications. In other words, the two coping strategies derived from stress and coping theory (problem-focused coping and/or emotion-focused coping) seem to lead to the need for content gratifications and/or social gratifications, resulting in seeking informational and/or emotional support online. Indeed, informational and emotional support have previously been associated with problem- and emotion-focused coping [49]. As informational and emotional support-seeking are accounted for in both theories, it would be worthwhile to test in future research how the UGT and stress and coping theory can be combined into a truly integrated model for online information seeking. Based on previous research in the offline setting (i.e., patient-provider communication), suggesting that patients' need for emotional support consists of both instrumental and affective needs [107], there seems to be no straightforward relation between problem-focused coping and content gratifications respectively emotion-focused coping and social gratifications. This indicates an interplay between these two coping strategies and the two types of gratifications (content and social gratifications). For example, a patient may express problem-focused coping by searching for information on treatment online (e.g., to look for complementary or to deal with conflicting information), or by connecting with peers on an online forum (i.e., receive and/or give peer support). On the other hand, if a patient feels distressed, they could express emotion-focused coping by connecting with peers online to deal with their emotions, or by searching for online factual information. As such, future research needs to take into account how the stress and coping theory could be

extended by integrating the UGT while also acknowledging this interplay of the different coping strategies and gratifications of the UGT.

Practical implications

Our study contributes to improving health care providers' information provision and suggests some useful directions for clinical practice. The findings can be used to create awareness among providers that there are three different types of cancer patients' that differ in their motives for seeking informational and/or emotional support online. Oncology health care providers can use this knowledge to know which patients may be more in need of (online) informational and/or emotional support. Importantly, it can support them in finding the proper type of support that match patients' individual support needs. These insights are needed to tailor the referrals to further (online) sources. Therefore, we advise providers to find out what type of patient they are encountering and whether the patient prefers additional online and/or offline support. In case a patient prefers to use the internet after the consultation and receive recommendations for accurate and reliable websites, providers should determine the amount of confidence one has in their internet use and whether they have used it prior to the medical encounter (i.e., eHealth literacy). For example, they could ask patients questions regarding motives for seeking informational support and/or emotional support. In particular, questions that relate to the biggest differences across the three patient profiles in our study could be used to determine which sort of websites or online platforms are the best suited for the patient (e.g., "Would you prefer to visit the internet to check the information that is discussed during this consultation?"). In addition, similar motive-related questions could be used in cases where a patient (also) wishes to receive support offline and/or feels less confident in their use of the internet. While doing so, each of the three different patient profiles can serve as a persona to tailor the referrals to online platforms or websites that fit the patient's individual needs [108]. A persona in this case is essentially an explicit description of a particular patient that represents one of the subgroups of patients that seek support online [109]. For instance, our results could inform providers whether a patient would prefer recommendations for a more general health website, such as Kanker.nl, would prefer support finding (and interpreting) more detailed information, as found in medical journals, or, for "contact exchangers", they might recommend an online support group. This way, providers will act as moderators by guiding patients' internet use [29]. This is important because more and more patients appear to request online recommendations from providers [10,29,110].

The awareness of different patient profiles can help providers to tailor recommendations not only to accurate and reliable websites or platforms, such as Kanker.nl, but also

which type of offline sources of support (e.g., patient organization, nurse practitioner, psychologist, social worker) that fit patients' individual needs would benefit the patient. For example, when providers encounter a patient who could be an "overall seeker" they could refer to a nurse practitioner for more informational support and to a psychologist or patient organization for emotional support from peers. Finally, our results may also be useful for web designers and patient organizations in developing informational and emotional support options for patients with cancer. This means that they should take different patient profiles (i.e., personas) and different levels of eHealth literacy into account when creating layout, content, and materials [111]. Consequently, future research on interventions should investigate whether the three patient profiles provide sufficient foundation for supporting health care providers in tailoring recommendations to further (online) sources. Additionally, future studies should examine if the patient profiles can serve as personas for patient organizations and web designers to develop informational support for patients with cancer.

Limitations and future directions

This study has some limitations. To which profile a patient has been assigned in our cluster analysis may have been determined by how the participants interpreted the motives as well as by our categorization of the motives. As previous research showed an interplay between cancer patients' need for informational support and need for emotional support, implying that some emotional support motives (emotion-focused coping) may be interpreted as informational support motives (problem-focused coping), and vice versa [107], participants' individual characteristics and their personal situation may have affected their interpretation of the motives. Future research could investigate this interplay by, for instance, combining quantitative methods with more in-depth qualitative methods examining which specific online content cancer patients end up searching, depending on their needs and motives for seeking informational and/or emotional support online.

Whether other factors distinguish the profiles besides the motives and eHealth literacy is yet still unknown, as our results only showed validation for this characteristic. There may be several reasons for this. First, our sample consisted of patients already active online which may have given a biased view of patients' motives to seek informational and/or emotional support online since actively participating in an online community (i.e., online panel) requires certain skills in itself [112]. We recommend future research to examine which other relevant factors may relate to the motives for seeking informational and/or emotional support online. For example, theories and theoretical models such as social determination theory (SDT), Longo's expanded model of health information-seeking behaviors, and Johnson's comprehensive model of information seeking may

provide additional insights into possible factors that might distinguish the different profiles[4,53,56]. According to SDT, someone's level of autonomy, relatedness and competence are important drivers for the development of motivation. Additionally, Longo's and Johnson's model may provide other personal characteristics that might be better suited to examine the differences between clusters, for example, culture, attitudes, cognitive abilities, salience, and beliefs [113,114]. Other research also suggests personality traits (e.g., neuroticism, agreeableness, openness to experience, conscientiousness, and/or extraversion) as influential factors [44,115,116]. Second, needs and motives may be considered as distinct variables, such that needs generate the tendency to go online (i.e., initial stimuli) and that motives are the actual reasons for patients' continued internet use [11]. This may imply that differences between the clusters are better explained by needs than by patients' individual characteristics. Third, our sample (the online panel from Kanker.nl) may have been homogenous in nature and too small which might have influenced the results regarding the individual characteristics. Van Eenbergen et al. [117], for instance, have shown that there are differences in internet use between a population-based sample and an online cancer community (e.g., an online panel), meaning that the latter might not be representative of the group of cancer survivors in general. Moreover, studies have shown that patients with higher educational attainment are more likely to search online [59,71,84]. Our sample mainly consisted of patients with mid to high levels of education which might be the reason why we found no difference between the profiles in terms of educational level. In addition, traditional notions of statistical power of the sample size seem to apply only partially to cluster analysis, indicating that a greater sample does not necessarily improve the results [118]. Recent research that uses cluster analysis has proven its usefulness and appropriateness, some including small samples as well [57,119–121]. Fourth, there may have been a recall bias at the time of completing the survey because patients' time since diagnosis varied from two months to more than five years after diagnosis. Emotions, such as anxiety, and with that the need for information and/or emotional support change over time, indicating that the timing of the survey might have mattered [6,28]. Therefore, we encourage future studies to examine patients' motives for going online real-life, i.e., simultaneously with the actual online seeking behavior than retrospectively. Finally, since this study focused on including several user-oriented motives that originated from the need for problem-focused coping and content gratifications, and the need for emotion-focused coping and social gratification, we suggest future studies to also include motives, such as using the internet for its anonymous character, from a media-oriented perspective based on the UGT expectation that patients also use the internet because of process gratifications [37].

CONCLUSION

Using the UGT and stress and coping theory in this study resulted in theoretically-founded profiles of cancer patients in terms of their motives to seek informational and/or emotional support online. This study is the first to explore individual differences across groups of cancer patients that seek support online. Health care providers should be aware that cancer patients not only vary in their motives for seeking informational and/or emotional support but that patients also differ in their level of eHealth literacy. The three patient profiles (the overall seeker, the occasional information seekers, and the contact exchangers) found could serve as a description of a particular patient representative (i.e., persona) for providers, web designers, and patient organizations to tailor to individual patients. Furthermore, based on the results of this study we suggest future research to investigate extending the stress and coping theory by acknowledging the interplay of different coping strategies and different gratifications. Many studies have examined health-related (online) support-seeking behavior, using similar and different theories and/or models concentrating on a few factors which complicates a comprehensive understanding of the behavior. Therefore, the need for future research to develop theories and/or models capable of addressing their extension and integration continues to grow.

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CHAPTER 3

Exploring the state of shared decision-making in head and neck oncology: Assessment of treatment communication

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ABSTRACT

Objective. To explore the state of shared decision-making (SDM) in head and neck (HN) oncology by investigating the extent to which SDM is currently employed by HN surgeons and how the perceived levels of SDM relate to the observed levels of SDM. Additionally, surgeon and patient perspectives on patient involvement in SDM and potential associations with observed levels of SDM were explored.

Methods. Perceived level of SDM and patient involvement were measured by SDM-Q-9/ SDM-Q-Doc resp. Control Preference Scale. Observed SDM was measured by analyzing audiotaped consultations (N = 42) using the OPTION^{MCC+} instrument. Univariate linear analyses were conducted to identify possible associations with surgeon-observed SDM.

Results. Median perceived SDM scores of surgeons (74.4 %) and patients (71.1 %) were relatively high, whereas observed median OPTION-scores were moderate (surgeons 48 %, patients 42 %, caregivers 24 %). Consultation time and patient OPTION-score were positively associated with surgeon OPTION-score.

Conclusion. Surgeons and patients seem to overestimate the extent of SDM compared to the observed reality. Patients' goals, values and preferences need to be addressed more during consultations.

Practice Implications. The findings can be used to raise awareness of SDM among surgeons to improve their skills. Routine training in medical education can benefit from effective integration of SDM principles during consultations.



INTRODUCTION

The dynamic, collaborative process of shared decision-making (SDM) allows patients, and when present, informal caregivers (hereafter: caregivers), to be involved during consultations [1–4]. Particularly important in applying SDM is the prioritization of the patient's needs, values, goals of care, and preferences. When it comes to health- or treatment-related decisions, SDM has demonstrated several benefits, such as reducing the likelihood of decisional regret, higher patient satisfaction, lower healthcare costs, and ultimately, potentially higher quality of life (QoL) [5–10]. As a result of SDM, patients are generally better informed about benefits and risks, enabling healthcare providers and patients to choose treatment options that best suit patient needs [1–4].

In recent years, there has been a significant drive towards SDM in oncology healthcare. Patients are increasingly being viewed as partners, rather than passive recipients of treatment [11]. However, the implementation of SDM often proves to be challenging due to several factors, such as consultation time [12], uncertainty or lack of consensus regarding the preferred treatment choice [13], or healthcare providers' limited communication skills [13,14]. In addition, patients' preferences for involvement in the decision-making process may differ significantly from the healthcare provider's view of these preferences. Previous research has shown that patients' preferences and perceptions of their involvement in decision-making vary [15]. Some patients prefer active involvement, while others opt for a more passive role [15,16]. The application of SDM should acknowledge these potential differences by requiring healthcare providers to step in as mediators in order to collaboratively make treatment decisions [17,18]. Nevertheless, healthcare providers often find it difficult to involve patients in decision-making [12,19]. Meanwhile, patients and their caregivers may encounter barriers that hinder their participation in the decision-making process, including limited knowledge as well as underestimating their own expertise relative to that of healthcare providers [20,21]. Patients' belief in the "doctor knows best" concept might pose significant hurdles in making collaborative treatment decisions [22–24]. Consequently, weighing the potential benefits of treatment against the potential impact on their QoL is often very complex.

In the context of head and neck cancer (HNC), a delicate consideration of the potential advantages and drawbacks of each treatment option remains crucial, as comprehensive aggressive treatments, including surgery, radiation therapy, and chemotherapy, are frequently required [25]. These treatment modalities can have a major impact on patients' QoL by potentially causing significant functional impairments related to speaking, swallowing, eating, or breathing [26–28]. Moreover, patients may experience pain, fatigue, and emotional distress, which can further affect their overall well-being [29]. The overarching goal of most treatments is to cure patients from their malignancy, but there is often a

delicate balance between extending survival and preserving QoL [27,30]. Consequently, in these situations, the implementation of SDM is important to value the patients' personal values, goals of care, needs, and preferences.

Despite the fact that SDM is particularly suitable for HNC, its implementation remains insufficiently explored. This represents an essential knowledge gap, as it has been documented that HNC patients experience clinically significant decisional conflict and regret [31–35], despite initially being satisfied with the treatment decision [36]. This lack of research is especially concerning given that SDM has already been shown to be employed only to a limited extent in less invasive medical contexts, such as rheumatoid arthritis [37], vascular surgery [38,39], (medical) oncology [39], anesthesiology [40], a mixture of diverse medical specialties [41,42], and different types of decisions. Studies in these areas have reported relatively low OPTION-scores, ranging from 3.8 to 39.3, indicating that healthcare providers are not fully applying SDM in practice. As such, we need to clarify two issues. First, information is lacking on the extent to which healthcare providers within HNC presently apply SDM. Second, it remains unknown to what extent head and neck (HN) healthcare providers and patients perceive SDM being employed during consultation, and how these observed and perceived levels of SDM relate to each other. As far as we are aware, only a few studies exist that have assessed SDM implementation and have taken into account the perceived level of SDM of healthcare providers and patients while also investigating the observed level of SDM [38,40]. Accordingly, with this study, we aim to explore SDM in HN oncology by (1) investigating the extent to which surgeons employ SDM in daily practice, and (2) by gaining insight into how the perceived level of SDM by surgeons and patients relates to observed SDM. Additionally, we examine patient preferences for SDM and the extent to which surgeons can properly assess them.

METHODS

This prospective cross-sectional study was conducted according to the principles of the Declaration of Helsinki at the Department of Head and Neck Oncology and Surgery at a Dutch tertiary hospital [43]. The ethical review committee approved the study (registration number IRBd21-078). The research design, data collection process, and anticipated analyses were preregistered on the Open Science Framework (OSF; https://osf.io/248fu/).

Participants and procedure

We recruited five out of ten experienced HN surgeons based on age and gender to form a representative group within the Head and Neck department. Inclusion criteria were:

1) performing clinical work for more than three days per week; 2) having a permanent position as an HN surgeon; and 3) having treatment decision-making consultations with non-cutaneous carcinoma HNC patients. Surgeons involved in the study setup were excluded as potential participants (RD, MvdB). To be eligible for the study, patients had to 1) be diagnosed with a primary non-cutaneous HNC; 2) be eighteen years or older; 3) have sufficient command of the Dutch language, and 4) be without cognitive impairments (e.g., Korsakov syndrome). Patients were screened by the multidisciplinary tumor board, and then contacted by one of the researchers (AH or SD) to be informed about the study. Interested patients were seen before consultation for a face-to-face explanation of the study and the opportunity to ask questions, after which they signed informed consent.

Between May 2021 and October 2022, consultations between surgeons, patients, and if present, their informal caregivers (hereafter: caregivers) were recorded with a Roland Ediroll R-07 [44]. During these consultations, diagnosis and advice for treatment from the multidisciplinary tumor board were discussed. Following up on previous studies [37–42,45], we aimed to obtain at least five recordings per surgeon.

Measures

Patients' age, gender, and diagnosis were collected from their electronic health record. Other characteristics, such as marital status, living situation, education level, employment status, and presence of an informal caregiver, were obtained after consultation via a study specific questionnaire that included the Dutch version of the SDM-Q-9 for patients and the Control Preference Scale (CPS) [46]. Likewise, after consultation, HN surgeons completed a similar study specific questionnaire, including questions about their work experience in HN oncology (in years), training in SDM (none, minimal= attended at least one course/ training, some= attended > 2 courses/trainings), the SDM-Q-Doc for healthcare providers, and an adjusted CPS to fit surgeons' perspective.

The Dutch versions of the SDM-Q-9 and SDM-Q-Doc (Appendix A) have previously been shown to be reliable instruments for investigating how SDM is perceived [47–49]. Both are nine-item, validated questionnaires that measure patients' and surgeons' perceived level of SDM on a six-point Likert scale, ranging from 0 (completely disagree) to 5 (completely agree). Scores can be summed up, averaged, and then rescaled into a percentage range from 0 (no perceived SDM) to 100 (highest level of perceived SDM). In addition, the validated Control Preference Scale (CPS) was used to assess patients' preference for and perceived involvement in the decision-making process. The scale contains five decision-making related statements, with two describing an active role of the patient (patient-led), one a shared role (collaborative), and two a passive role of the patient (physician-led),

which we reduced into three categories for analysis [46,50]. We developed two customized CPS measures alongside Degner's original: one to assess surgeons' perception of patients' preferences and another to measure their own preference for patient involvement in decision-making.

For objective assessment of the level of SDM, the validated Observing Patient Involvement (OPTION) scale was used. The original OPTION[5] manual [51], which assesses only healthcare providers, does not incorporate patient behavior, making it insufficiently specific as SDM should also allow the patient and their caregivers to actively participate in conversation [52]. For this reason, we used the OPTION[MCC] manual [53] and adapted it for our study, the OPTION[MCC+] (Appendix B). Instead of scoring patients and caregivers from 0 (passive participation) to 2 (active participation), they were assessed similarly to the surgeons on a 5-point scale. The seven OPTION items were scored based on the general description in the manual wherein scores for surgeons range from 0 (no effort) to 4 (exemplary effort) and scores for patients and caregivers from 0 (passive participation) to 4 (very active participation). Before actual assessment of the consultations, two raters (SD and RT) performed a calibration session. Each scored ten randomly chosen consultations independently, spread over three calibration phases, to discuss any discrepancies in OPTION-scores and to reach consensus. Subsequently, the remaining consultations were independently scored in batches off five to give room to discuss any doubts. A third assessor (AH) was consulted in case any doubts or disagreements could not be solved. The OPTION-scores (0-28) of both raters were summed, averaged and then rescaled into a percentage total score between zero and hundred [53]. There are no officially defined cutoff values to interpret the observed level of SDM, but some studies have used three categories [37,40]: low (0-33.3%), moderate (33.3-66.6%), and high (66.6-100%), which we adopted.

Statistical analysis

Statistical analyses were performed using IBM SPSS Statistics 27 [54], with a significance level set at $p < 0.05$. Only consultations with both surgeon's and patient's questionnaires were included for analysis. Descriptive data were employed in accordance with the normal distribution of the data. Before analysis of the data, the two-way mixed inter-rater reliability, single measurement intra-class correlations coefficients (ICC) with a consistency agreement and 95% confidence interval (CI) were calculated [55]. Following the OPTION manual, an ICC score of > 0.6 was deemed to be acceptable to continue independent scoring by the two raters [51]. When ICC was ≤ 0.6, calibration between the raters was continued until ICC > 0.6 was achieved.

A Bland-Altman plot was created to examine the consistency between the SDM-Q-9 and SDM-Q-Doc questionnaires, thereby providing insight into potential systematic discrepancies and the extent of the differences in scores. To investigate any potential associations with surgeons' OPTION-scores, univariate linear regression analyses were conducted for the variables: consultation duration, patients' age, gender, education level, tumor stage, tumor location, SDM-Q-9 score, SDM-Q-Doc score, CPS, the presence of a caregiver, and patients' and caregivers' OPTION-score. All independent variables were carefully considered in relation to the dependent variable (surgeons' OPTION-scores) to determine inclusion and exclusion in case of minimum variation to avoid skewed distribution, as this could limit statistical power and lead to potentially misleading results from the regression analysis. Hence, multivariate linear regression was not performed due to the lack of statistical power.

RESULTS

Five surgeons conducted 42 audiotaped consultations. Six consultations were excluded because questionnaires were not returned, leaving 36 consultations for analysis (Figure 1). The median duration of the consultations was 20 minutes (range 10-43 minutes). Most patients were male (25/36), and the mean age was 67.8 years (SD 2.0). Sixteen patients were diagnosed with an early stage of disease (stage I and II), and the predominant types of carcinoma were oral (10/36) and oropharyngeal (10/36). Most of the HN surgeons were male (4 out of 5), and their working experience ranged from 15 to 40 years. Only one surgeon had followed multiple courses on SDM (the only female) and two others had completed an SDM-related course, whilst the remaining two had no experience or training in SDM. Table 1 presents a full overview of characteristics.

Observed levels of SDM

Inter-rater reliability

Reliability calculations, including the ten calibration consultations, resulted in a good level of agreement with ICCs of 0.767 (surgeons) 0.762 (patients) and 0.809 (caregivers).

OPTION-scores

The median total OPTION-score for all surgeons was 48.0 %, and ranged between 9.0 and 95.0 percent. OPTION-scores varied widely between the five surgeons. Three surgeons scored substantially lower for observed SDM level than perceived based on the SDM-Q-Doc and SDM-Q-9 (Appendix C). When looking at the item level (Table 2), surgeons scored moderate on all items, except for item 4 'option talk' on which they scored high.

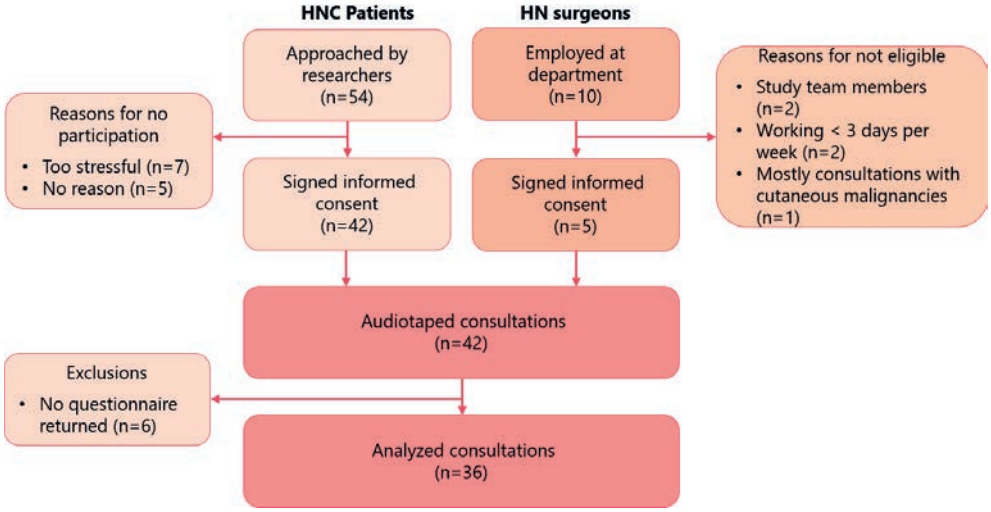


Figure 1. Flowchart of study inclusions

The median total OPTION-score for patients was 42 % (range 0-91 %). Patients scored low on item 2 'alternative option talk', and moderate on all other items. The median total OPTION-score for caregivers was 24 % (range 0-64), with no median scores above 37.5 % on all seven items. Appendices D and E provide a visual representation of the OPTION-scores per individual group and per item.

Perceived levels of SDM

The surgeons gave themselves a median SDM-Q-Doc score of 71.1 %, with a wide range (26.7-91%). None of them rated themselves the maximum 100 % score (Appendix F). The highest median score was observed for item 9 'agreement' with a score of five points, while items 7 'weighing' and 8 'decision' had the lowest median scores of three points. Similarly, patients had a median SDM-Q-9 score of 74.4 % (range 8.9-100 %). A quarter of the patients (9/36) rated the consultation with the maximum SDM-Q-9 score (100%). Item 5 'understanding' received the highest median score of five points, while items 6 'preference' and 7 'weighing' scored the lowest with a median of 3.5 points. Appendix G presents the scoring on the SDM-Q-Doc and SDM-Q-9 per item.

When comparing scores for the perceived level of SDM, a Bland-Altman analysis showed that the SDM-Q-9 scores were significantly higher than the SDM-Q-Doc scores, with a small mean difference of 2.5 %. However, also several opposing scores were observed. The plot can be found in Appendix H.

Table 1. Baseline characteristics of patients and surgeons.

Patients	**N=36**
Age in years (mean, SD)	67.8 (2.0)
Gender	
Male	25 (70%)
Female	11 (30%)
Educational level	
Low	15 (42%)
Middle	10 (28%)
High	11 (30%)
Tumor stage	
I	9 (25%)
II	7 (19%)
III	11 (31%)
IV	9 (25%)
Tumor location	
Hypopharynx	2 (6%)
Larynx	4 (11%)
Oral cavity	10 (28%)
Oropharynx	10 (28%)
CUP	3 (8%)
Nasopharynx	2 (6%)
Parotic gland	2 (6%)
Vestibulum nasi*	3 (8%)
Treatment undergone	
Surgery	17 (48%)
(+ PORT)	*4*
Chemo-radiation	7 (19%)
Radiation therapy	9 (25%)
None	3 (8%)
Intention chosen treatment	
Curative	33 (92%)
Palliative	3 (8%)
Treatment according to protocol	
Yes	35 (97%)
No	1 (3%)
Reason	Patient's wish
Duration of consultation in minutes (median, range)	20,15 (10,05 – 43,23)
Visiting primary physician	
Yes	9 (25%)
No	27 (75%)

Brought to consultation	
Came alone	7 (19%)
Partner	16 (44%)
Child(ren)	6 (17%)
Friend	2 (6%)
Sibling	1 (3%)
Partner and child(ren)	1 (3%)
Other**	3 (8%)
Head-and-Neck Surgeons	**N=5**
Age in years (median, range)	54 (39 – 63)
Gender	
Male	4 (80%)
Female	1 (20%)
Work experience in years (median, range)	24 (15 – 40)
Training in SDM	
None	2 (40%)
Minimal	2 (40%)
Some	1 (20%)

Note: *Of which one had a mucosal melanoma; **Others were daughter in law, partner's cousin, child, and sibling; CUP = Carcinoma of an unknown primary tumor; SDM = shared decision-making; PORT = postoperative radiation treatment

Patient involvement in SDM process and surgeon's perspective (CPS)

Based on the CPS scored, most patients (n=17, 47.2 %) expressed a preference for a collaborative treatment choice, followed by a physician-controlled choice (n=11, 30.6 %). Surgeons also predominantly favored a collaborated choice (n=16, 44.4 %), with a patient-controlled choice (n=13, 36.1 %) being the next most common option (Table 3).

In twenty-three cases (63.9%), the surgeon's assumptions aligned with patient preferences for involvement, but in thirteen cases (36.1%), there was a mismatch. Among cases where surgeons assumed a patient-controlled approach (n=13), one patient actually preferred collaboration, while five patients favored a physician-controlled approach. Conversely, in cases where surgeons assumed a collaborative approach (n=15), one patient desired a patient-controlled approach, and two preferred a physician-controlled one. Additionally, when surgeons assumed patients preferred physician-controlled decision-making (n=7), four patients preferred a collaborative decision-making process.

In nine of 42 consultations (21.4 %), the way in which the consultation had taken place did not match the patient's preferences. Seventeen of 42 (40.5 %) patients preferred a

Table 2. OPTION-scores per item

Item	Behavior description	Surgeons Median (range)	Patients Median (range)	Relatives Median (range)
1	Goal talk: identify patient values and goals of care	37.5% (0-75.0%)	50.0%, (0-100%)	25.0% (0-75.0%)
2	Alternative option talk: discussion of alternate options	50.0% (0-100%)	25.0% (0-100%)	25.0% (0-75.0%)
3	Team talk: forming a partnership	62.5% (12.5-100%)	50.0% (0-100%)	37.5% (0-75.0%)
4	Option talk: information about options	75.0% (12.5-100%)	50.0% (0-100%)	37.5% (0-75.0%)
5	Decision talk: eliciting patient's preferences	50.0% (0-100%)	50.0% (0-100%)	37.5% (0-87.5.0%)
6	Integrative decision talk: integrating patient's preferences	43.8% (0-100%)	43.8% (0-100%)	25.0% (0-75.0%)
7	Evaluation talk: check satisfaction with choice and SDM process	37.5% (0-100%)	37.5% (0-100%)	25.0% (0-75.0%)

Note: The categories are indicated in colors: low score is white (score between 0% and 33.3%), moderate score is light grey (score between 33.3% and 66.6%), and high score is dark grey (score between 66.6% and 100%).

collaborative approach to decision-making, but for five of 42 (11.9 %) patients it felt like a patient-controlled choice, and for four it felt like a physician-controlled one.

Table 3. CPS: Patient's preferred and perceived involvement in SDM and concordance with surgeon's perspective

CPS items	Preference of the patient	How it went according to the patient	What the surgeon thinks the patient prefers	What the surgeon prefers
	N=36	N=34*	N=36	N=36
Patient-controlled	8 (22.2%)	13 (38.2%)	13 (36.1%)	13 (36.1%)
Collaborative	17 (47.2%)	8 (23.6%)	15 (41.7%)	16 (44.4%)
Physician-controlled	11 (30.6%)	13 (38.2%)	8 (22.2%)	7 (19.5%)

Note: *Missing data of two patients

Associations with HN surgeons' observed level of SDM

Consultation time (β0.019, 95 % CI 0.004 – 0.034, p=0.013), and a higher OPTION-score of patients were positively correlated (β0.606, 95 % CI 0.34 – 0.87, p<0.001) with HN surgeons' observed level of SDM. No other significant associations were found. Additionally, no characteristics of surgeons were included in the univariate linear regression analysis due to the small number of participating surgeons (Table 4).

Table 4. Associations with HN surgeons' observed level of SDM

	Univariate linear regression analysis		
Variable	B	95 % CI	*p*-value
Patient age	0.126	-0.506 – 0.758	0.688
Patient gender	12.469	-3.620 – 28.558	0.125
Patient educational level			
Low	Reference		
Middle	4.950	-12.457 – 22.358	0.567
High	-10.823	-24.928 – 3.282	0.128
Tumor stage	1.903	-5.454 – 9.259	0.603
Tumor location			
Parotic gland	Reference		
Hypopharynx	-2.264	-23.058 – 18.531	0.825
Larynx	1.473	-33.300 – 36.245	0.932
Oral cavity	-2.409	-12.392-7.573	0.625
Oropharynx	-2.275	-6.554 – 2.003	0.286
CUP & MUP	0.195	-8.123 – 8.512	0.962
Nasopharynx	2.096	-3.614 – 7.805	0.459
Duration consultation	0.019	0.004 – 0.034	0.013
The presence of a caregiver			
No	Reference		
Yes	4.212	-15.130 – 23.554	0.661
SDM-Q-9 score	0.141	-0.143 – 0.426	0.319
SDM-Q- Doc	0.363	-0.177 – 0.902	0.181
OPTION patient	0.606	0.338 – 0.874	*0.000*
OPTION caregiver	0.246	-0.129 – 0.620	0.191
CPS patient – What would you prefer?			
Collaborative decision-making	Reference		
Patient-led decision-making	29.611	-15.441 – 74.663	0.190
Physician-led decision-making	-10.507	-25.337 – 4.324	0.159
CPS patient – How was the choice made?			
Collaborative decision-making	Reference		
Patient-led decision-making	-4.720	-33.174 – 23.734	0.738
Physician-led decision-making	-4.845	-23.762 – 14.072	0.606

CPS HN surgeon – What would the patient prefer?	Reference		
Collaborative decision-making	17.762	-3.315 – 38.840	0.096
Patient-led decision-making	-13.571	-28.356 – 1.214	0.071
Physician-led decision-making			
CPS HN surgeon – What would you prefer?			
Collaborative decision-making	Reference		
Patient-led decision-making	18.579	-28.915 – 66.073	0.432
Physician-led decision-making	-1.546	-17.253 – 14.161	0.843

Note: All significant p-values (<0.05) are displayed in italics; *including nasal vestibule and mucosal melanoma; CPS = Control Preference Scale for patient involvement; CUP = Carcinoma of an unknown primary tumor; MUP = metastasis SDM = shared decision-making

DISCUSSION AND CONCLUSION

Discussion

Main findings

This study explored the current state of SDM in the complex setting of HN oncology. Although both surgeons and patients perceived a relatively high level of SDM, participation in SDM during consultation was observed to be lower than reported. Moreover, when looking at patient involvement, we found that both patients and surgeons mostly preferred a collaborative approach to the decision-making process. In almost two-thirds of the cases, surgeons' assumptions aligned with patients' preference for involvement. However, the mismatch in the remaining cases and the nine consultations that had not taken place as preferred by the patient demonstrate that discordance in surgeons' and patients' perceptions of decision-making roles is still commonly present. Furthermore, the duration of the consultation and patient OPTION-score were correlated with the observed SDM level of surgeons. No other associations were found.

Interpretations and comparing studies

Overall, surgeons in our study were observed to apply SDM moderately, with a median total OPTION-score of 48.0 %. This finding was somewhat contrary to our expectations, as it indicates a somewhat higher level of SDM compared to what has been reported in other studies [37–41,56]. One explanation for this higher OPTION-score may be that treatments for HNCs are extensive and have a significant impact on patients' functioning and OoL, requiring a trade-off between survival and organ preservation through elaborate discussion [27,57,58]. Notably, the relatively higher scores were primarily driven by surgeons' performance on specific aspects of SDM, particularly their ability to effectively discuss the recommended treatment options (OPTION item 4). While this indicates strength in presenting information and guiding patients, it may not necessarily imply equally strong performance across all dimensions of SDM, such as eliciting patient preferences or exploring their values and concerns. Secondly, patients in our study showed relatively active engagement during consultations (mean total OPTION-score of 42 %), which appeared to positively correlate with the surgeons' SDM performance. While it remains unclear whether this is a reciprocal relationship – where active patients prompt more engagement from physicians and vice versa – or if one behavior inherently strengthens the other, these dynamics may have encouraged surgeons to adopt practices that possibly resulted in higher OPTION-scores. Thirdly, the study setting – a specialized center with a strong emphasis on patient-centered care – might have contributed to the higher scores. However, even if physicians express support for SDM, their tendency to predominantly discuss treatment options, and not other aspects of SDM, still reflects a commonly observed behavior that hinders the full implementation of SDM [59]. Additionally, important

to note is that the surgeons performed less well on the OPTION items that specifically address SDM behavior (i.e., item 1 'goals talk', item 5 'decision talk', item 6 'integrative decision talk', and item 7 'evaluation talk'). Consequently, our findings suggest that while SDM is being moderately applied in this context, there is still room for improvement, particularly in ensuring a more balanced approach across all elements of SDM. Future research could explore the variability in scores among different physicians and settings, and investigate how specific training interventions can enhance SDM practices in HNC care.

Similar to surgeons, patients were observed to participate moderately in the decision-making process (median total OPTION-score 42 %), scoring low on asking about alternative treatment options (OPTION item 2) but moderate on all other items. On the other hand, caregivers participated considerably less during consultations (median 24 %), with median score indicating low participation across all OPTION items. While our primary focus was on the performance of surgeons and patients as key actors in the decision-making process, caregivers are often involved in patients' care. Although we did not delve further into caregivers' contributions in this study, exploring the dynamics of the relationship between the patient and caregiver could provide valuable insights. There was considerable variation in who was included as a caregiver – ranging from partners and children to extended family members or neighbors – making it difficult to draw firm conclusions about their overall influence. Exploring this relationship could enhance our understanding of patient involvement, and future research could incorporate qualitative study designs to explore this aspect further [60].

When exploring both levels of SDM, a discrepancy appears to exist between surgeons' and patients' perception of SDM and the extent to which we observed SDM being employed. As expected, both surgeons and patients perceived SDM to be adequately implemented during consultation, which is consistent with previous research [37,38,40,41,45,56], indicating that surgeons and patients tend to overestimate the extent of SDM in their consultations. This discrepancy between perception and observation may stem from a lack of complete understanding of what SDM truly involves, leading surgeons and patients to believe that SDM has occurred [59,61]. Consequently, they might have misinterpreted aspects of counseling as SDM, whereas objective scoring may indicate otherwise. Additionally, they might have mistaken the mere inclusion of some SDM-related components, such as discussing patients' goals, values, and preferences, for quality discussion of the components. Another explanation for this discrepancy may be that surgeons and patients reported on their overall satisfaction with the consultation rather than on the perceived level of SDM. However, given the complexity and potential impact of the treatment decisions, it is important to improve the decision-making process with HNC patients, especially since SDM has been shown to be beneficial for various patient and healthcare-

related outcomes [5–10]. As such, given the overall satisfaction of surgeons and patients with the current state of the decision-making process in HN oncology, we recommend future research to explore these considerations.

Furthermore, patients' preferences for involvement in decision-making vary widely, and discrepancies between the preferred and perceived level of involvement are often observed [15,22,38,41]. In our study, the surgeons almost never explicitly asked the patient to what extent they wished to be involved in the decision-making. Similarly, we found this discordance in surgeons' assumptions of patients' preference for involvement in decision-making and patients' actual preference, with surgeons overestimating patients' preferences eight times and underestimating them five times. This highlights the need for more attention to patients' involvement preferences by HN surgeons, especially since discordance between preferred and actual involvement has been reported to substantially affect diverse patient outcomes, such as patient satisfaction, patients' understanding of information, fulfillment of information needs [62], and both physical and emotional QoL [63].

Lastly, longer consultation time and an active patient during SDM are two known correlates [37,38,45]. However, further implementation and improvement of SDM into HNC decision-making does not necessarily have to lead to prolonged duration of the consultation [64,65]. Although, consultation time may initially increase while healthcare providers are still in training and learning to apply SDM in their consultations, the duration of the consultations may decrease once they have acquired adequate SDM skills [66]. While we hypothesized that being an older patient and lower literacy would relate to a lower OPTION-score, as suggested in qualitative research [67], we found no significant correlations for any patient and tumor characteristic.

Limitations

We acknowledge that this study has some limitations. First, due to the exploratory nature of the study, only five surgeons from one hospital were included. Nevertheless, an attempt was made to assemble a reality-based group, with different ages and only one female surgeon (out of 2 employed). Multivariate analysis was not possible due to limited power, which highlights the need for further research on SDM in HN oncology. This limitation prevented us from exploring the potential influence of several important variables on SDM practices. For example, factors such as gender of the surgeon, prior SDM training, years of clinical experience, and specific institutional characteristics could not be included in our analysis. These variables might play a critical role in shaping how SDM is implemented in clinical practice and could provide valuable insights into strategies for improving patient-centered care [68]. Future (international) multicenter studies involving larger sample sizes are needed to allow for more robust statistical modeling, such as multivariate analysis, to investigate these factors comprehensively. This would allow us

to identify key determinants of SDM performance and tailor interventions to address gaps more effectively. Although this expansion of research is crucial for advancing the implementation of SDM and optimizing decision-making process in HN oncology, obtaining a larger, diverse dataset may present challenges, including differences in incidence rates [69,70] and distribution of HN surgical oncology workforce [71–73]. .

Second, despite our efforts to ensure the reliability of the scoring process, raters may have influenced the OPTION-scores. We implemented thorough calibration, inter-rater reliability assessment, and third reviewer for discrepancies, but bias remains a possibility, potentially limiting generalizability. Factors such as raters' familiarity with SDM principles or subjective interpretations of certain consultation behaviors may have led to higher scores. Nonetheless, we believe our calibration process ensured that both raters were sufficiently aligned before proceeding to independent scoring (ICC score of >0.6). Still, future research could enhance objectivity by further standardizing coding guidelines (e.g., extension of scoring examples), involving external raters, and assessing intra-rater reliability alongside inter-rater reliability. This is especially important when there are limited calibration opportunities due to a high volume of recordings or extended gaps between analyses, preventing double coding of all consultations.

Third, consultations were only audio recorded, whereas videos could have provided more insight into the communication process through nonverbal communication [74]. Fourth, surgeons' effort to apply SDM may have been stimulated by our study, as they were aware of being audiotaped. However, effect of the presence of an audio recorder during consultation has been reported to be negligible [75]. Fifth, the proposed treatment modality may have influenced the duration of consultations. For instance, HN may spend less time explaining radiotherapy treatment plans in detail compared to surgical procedures. This suggests that rather than the consultation length itself being directly related to SDM, the type of treatment proposed might influence the length of the consultation. Sixth, the SDM-Q9 and SDM-Doc questionnaires seem to be overly generic instruments for measuring perceived SDM levels. They lack detailed elaboration of each item, which is necessary to fully appreciate the quality of SDM. Lastly, although the OPTION^{MCC+} instrument reflects the three-talk model of SDM, it cannot be directly compared with the SDM-Q-9 and SDM-Q-DOC questionnaires due to the difference in items. For example, OPTION items 1 'goal talk', 3 'team talk', 6 'integrative decision talk', and 7 'evaluation talk' do not appear to be exactly included in the SDM-Q questionnaires. No statistical correlation exists between all items of both measures that assess the same part of the SDM process [76]. Measuring SDM thus far remains challenging, further emphasizing the need for future research using measures with the exact same, comparable items. Ultimately, by addressing these limitations, we can better understand the determinants of SDM performance and develop tailored interventions to improve SDM in HN oncology.

CONCLUSION

This exploratory study revealed that SDM in HN oncology of a tertiary hospital in the Netherlands is being applied to a moderate extent. However, a significant gap exists in the discussion of patients' values, goals, and preferences, indicating that more attention and involvement from healthcare providers is required. It is therefore essential to raise awareness about what SDM truly entails, especially considering the high prevalence of decisional conflict and regret. Both surgeons and patients tend to overestimate the extent of SDM compared to objective observations, and different perceptions of patient involvement exist. Moving forward, future research in the context of HN oncology should delve deeper into investigating the duration of consultation and patient OPTION-score, as they appear to be associated with a higher objective physician SDM-score. Specifically, exploring how SDM can be implemented without extending the consultation time may contribute to facilitating SDM uptake. Additionally, it is important to explore methods for effectively assessing both observed and perceived SDM levels in clinical practice. Enhancing SDM in HN oncology could lead to better patient and health care-related outcomes. As such, addressing the identified gaps in SDM practice is needed for improving patient care and health care delivery in this setting.

PRACTICE IMPLICATIONS

Our study offers insight to SDM in HN oncology and presents opportunities for improvement. Although it appears that the majority of patients and surgeons prefer to make the final treatment decision together, we believe that it is the healthcare provider's responsibility to take the lead in supporting the patient in decision-making, particularly in such stressful situations such as HN oncology. This involves assessing the patients' values, needs, and preferences, taking into account the most relevant clinical evidence available, before making a joint decision about the course of action. Therefore, we suggest that healthcare providers ask as many open (follow-up) questions when discussing patient's values, needs, and preferences and listen carefully to gain more insight into their patients' lives, what is important to them, and what doubts, concerns, and fears they may have. This is important, as patients' goals, values, and preferences regarding different treatment options, as well as rounding off the decision-making process during consultations, appeared to require improvement.

Furthermore, education and awareness campaigns have recently been launched that highlight the importance and benefits of SDM [77]. Nevertheless, whilst the concept of SDM has increasingly found its way into medicine and is also included in the vision document for Dutch medical specialists [78], HN surgeons tend to overestimate how skilled they are at

applying it. We therefore recommend for communication skills training in medical (follow-up) training programs in SDM [79]. This training should be part of the Continuous Medical Education (CME) program to keep the SDM skills of surgeons up-to-date [80–84]. Moreover, while the implementation of SDM has made progress through the use of training and tools [79], challenges such as the potential prolongation of consultation time remain. To address this, integrating SDM preparation into the electronic patient record system could be an effective strategy [85–87]**.** By allowing patients to complete pre-consultation questionnaires or indicate their treatment preferences at home, physicians can review this information in advance and focus on more critical discussions during the consultation. This approach will likely not only streamline the SDM process and reduce time pressure during face-to-face interactions but also foster an environment that encourages patient participation.

Additionally, the use of decision aids, audiovisuals, and written resources remains crucial. These tools allow patients to process information at their own pace and come prepared for consultation. By combining these resources with pre-consultation inputs, we can optimize SDM implementation while maintaining manageable consultation times [88,89]. In conclusion, both patients and healthcare providers can benefit from prioritizing patient engagement and employing approaches that facilitate SDM.

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APPENDICES

Appendix A. SDM-Q-9 and SDM-Q-Doc items

Item	Description	Referred to in the text
Item 1	Clarifying a decision needs to be made	'clarification'
Item 2	Eliciting the patients' preferred involvement	'involvement'
Item 3	Stating there is more than one way to deal with the problem	'alternatives'
Item 4	Explaining the pros and cons of treatment options	'options'
Item 5	Investigating if the patient has understood all the information	'understanding'
Item 6	Identifying the patients' preferred treatment option	'preference'
Item 7	Weighing the treatment options	'weighing'
Item 8	Making a shared decision	'decision'
Item 9	Agreement on follow-up arrangements	'agreement'

Appendix B. OPTION^{MCC+} items and measure scoring guide

Item	Behavior description
1	Goal talk: identify patient values and goals of care
2	Alternative option talk: discussion of alternate options
3	Team talk: forming a partnership
4	Option talk: information about options
5	Decision talk: eliciting patient's preferences
6	Integrative decision talk: integrating patient's preferences
7	Evaluation talk: check satisfaction with choice and SDM process

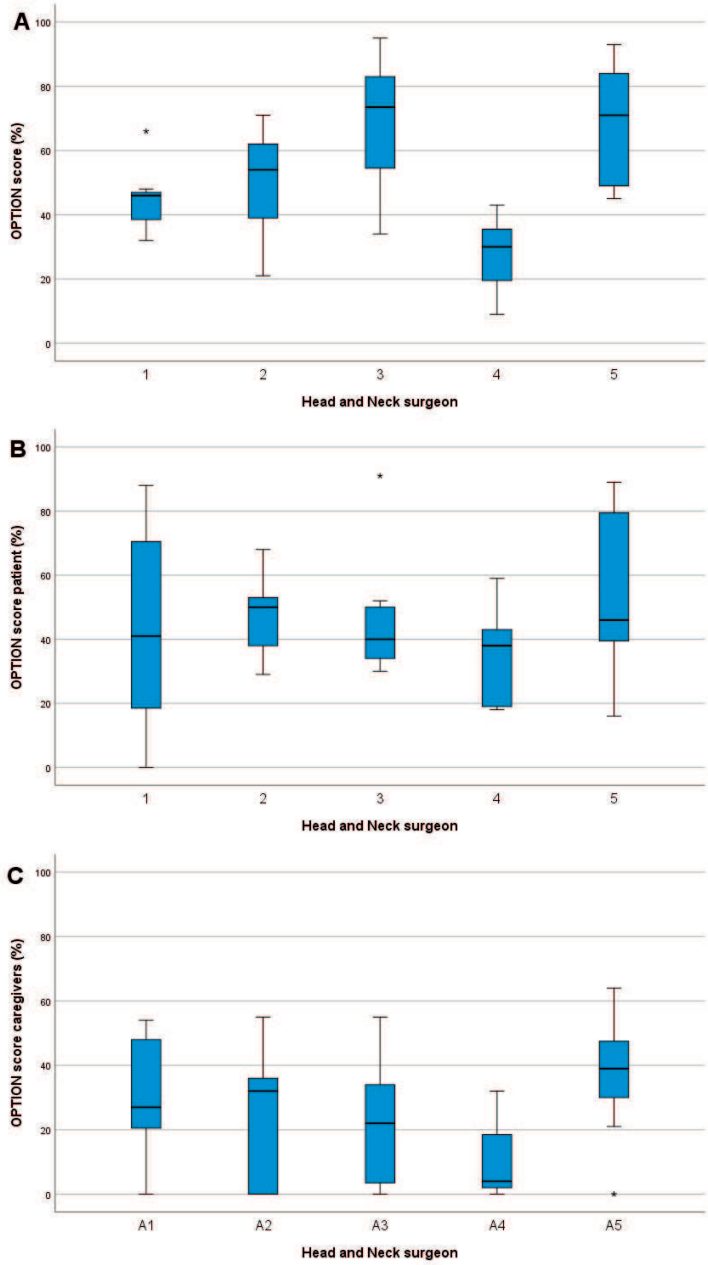
Score for physicians	Description (based on the OPTION^{MCC})
0 = no effort	Zero effort was observed. The behavior is not observed.
1 = minimal effort	Efforts to communicate could be implied or interpreted. A minimal attempt is made to exhibit the behavior.
2 = moderate effort	Basic phrases or sentences used. The behavior is exhibited to a good standard.
3 = skilled effort	Substantive phrases or sentences are used. The behavior is exhibited to a good standard.
4 = exemplary effort	Clear, accurate communication methods are used. The behavior is executed to a very high standard.

Score for patients and relatives	Description (adapted based on OPTION^{MCC} manual)
0 = passive	No, or minimal participation (e.g., only "yes", "no" or "uhu"
1 = responsive	Answers concisely on questions (short/one sentence answers, or short responses to the doctor, e.g., 'What?')
2 = very responsive	Answers in detail on questions (multiple or long sentences as answers or questions in response to the doctor, e.g., 'So you mean that X?'
3 = active	Answers and asks questions (more than one question(s) that add new information to what is already discussed)
4 = very active	Answers and asks questions, brings in own ideas, and shares perceptions

Appendix C. Observed and perceived level of SDM per head and neck surgeon

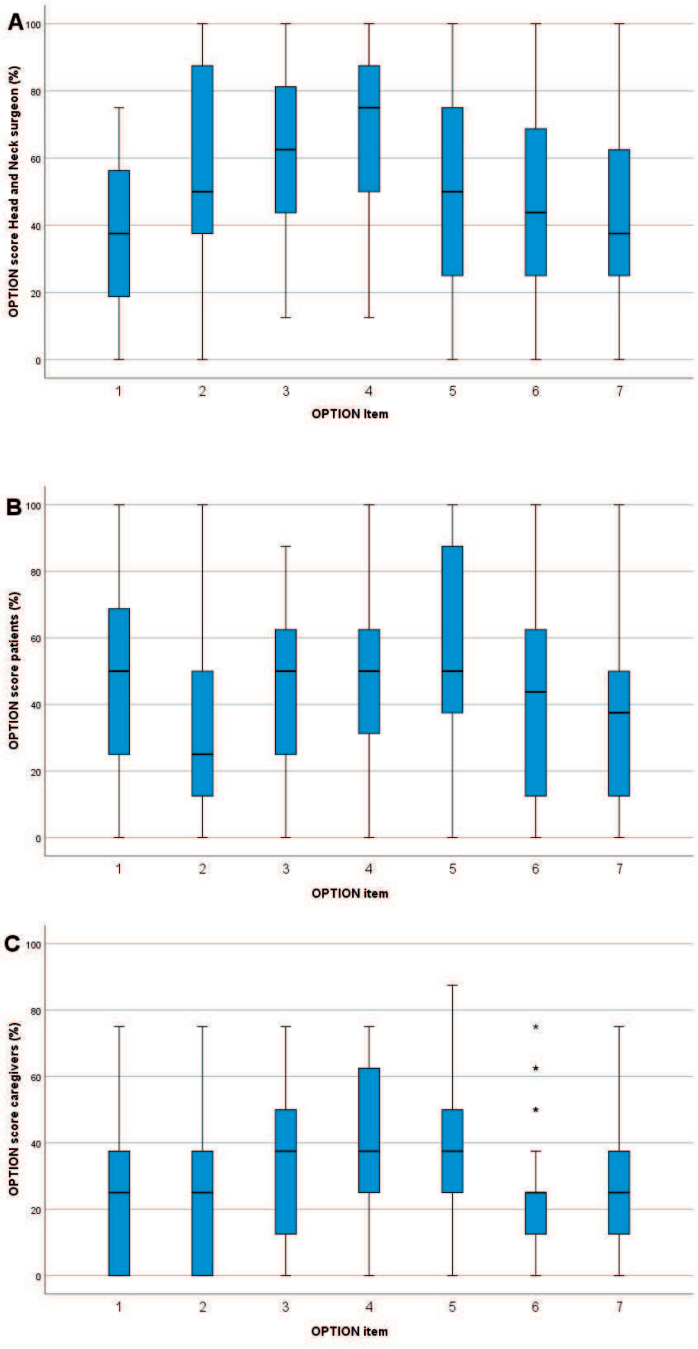
Surgeon	OPTION-score Median (range)	SDM-Q-Doc Median (range)	SDM-Q-9 Median (range)
1	46.0% (32.0-66.0%)	57.8% (46.7-91.1%)	93.3% (55.6-100.0%)
2	54.0% (21.0-71.0%)	80.0% (26.7-84.4%)	51.1% (11.1-100.0%)
3	73,5% (34.0-95.0%)	72.2% (55.6-80.0%)	80.0% (37.8-95.6%)
4	30.0% (9.0-43.0%)	82.2% (66.7-86.7%)	77.8% (20.0-100.0%)
5	71.05% (45.0-93.0%)	71.1% (57.8-80.0%)	68.9% (8.9-100.0%)

Appendix D. OPTION^{MCC+} scores per head and neck surgeon



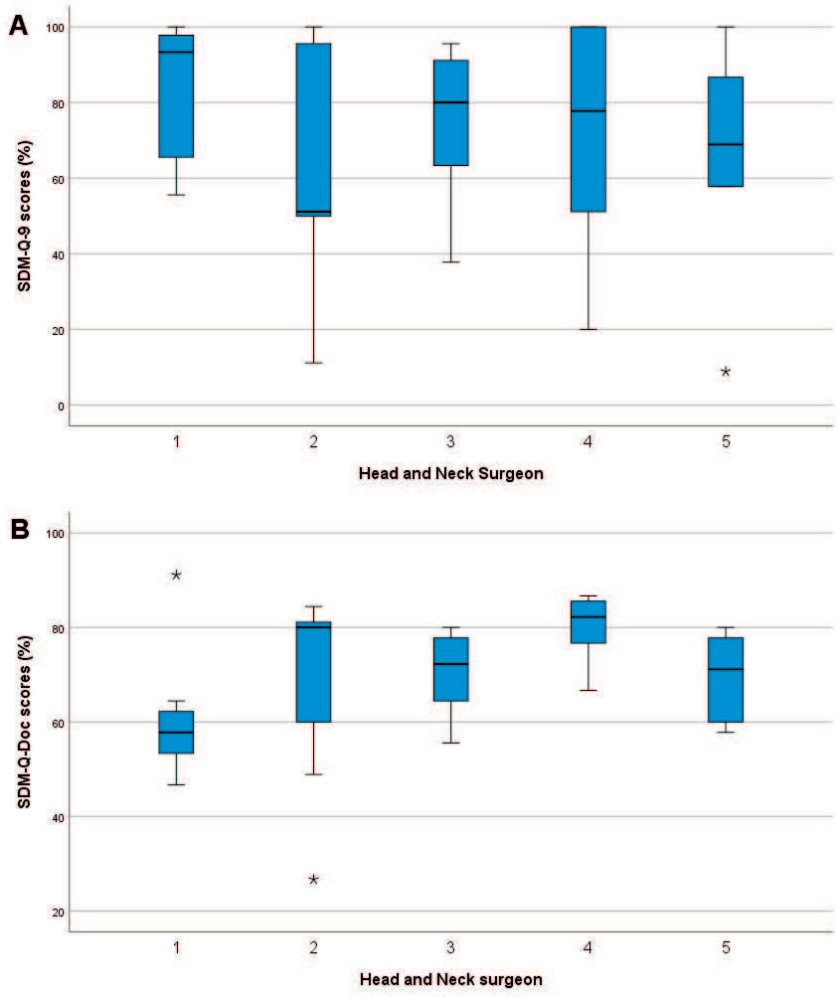
Note: (A) Rescaled total OPTION score physician per head and neck surgeon. (B) Rescaled total OPTION score patients per head and neck surgeon. (C) Rescaled OPTION score relatives per head and neck surgeon. Boxes represent values between the 25th and 75th percentiles, whiskers the upper and lower adjacent values, and the horizontal lines represent the median values. Outliers are displayed as asterisks.

Appendix E. OPTION-scores per item



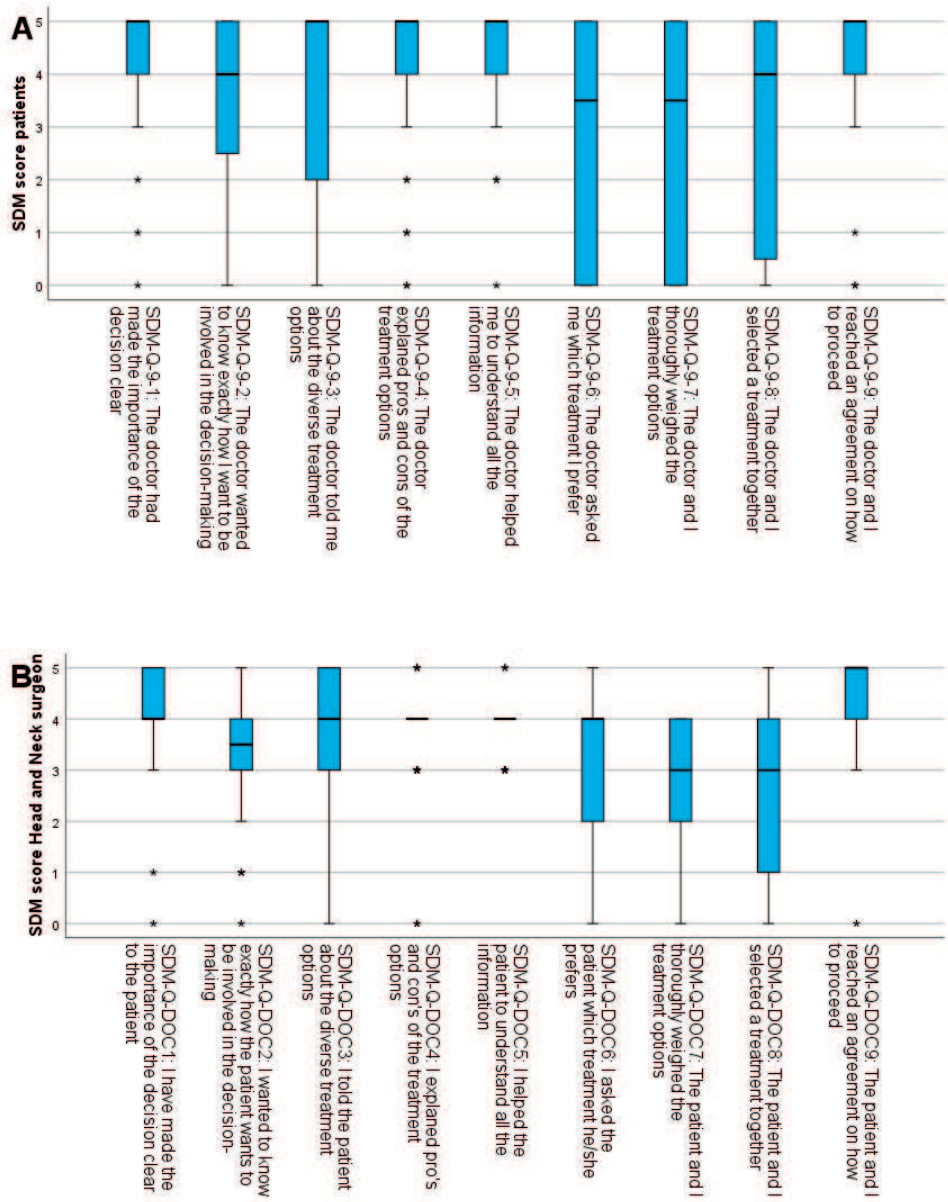
Note: (A) Physicians' OPTION scores for each of the 7 items. (B) Patients' OPTION scores for each of the 7 items. (C) Relatives' OPTION scores for each of the 7 items. Boxes represent values betweent he 25th and 75th percentiles, whiskers the upper and lower adjacent values, and the horizontal lines represent the median values. Outliers are displayed as astrisks.

Appendix F. SDM-Q-9 scores and SDM-Q-Doc scores per head and neck surgeon.



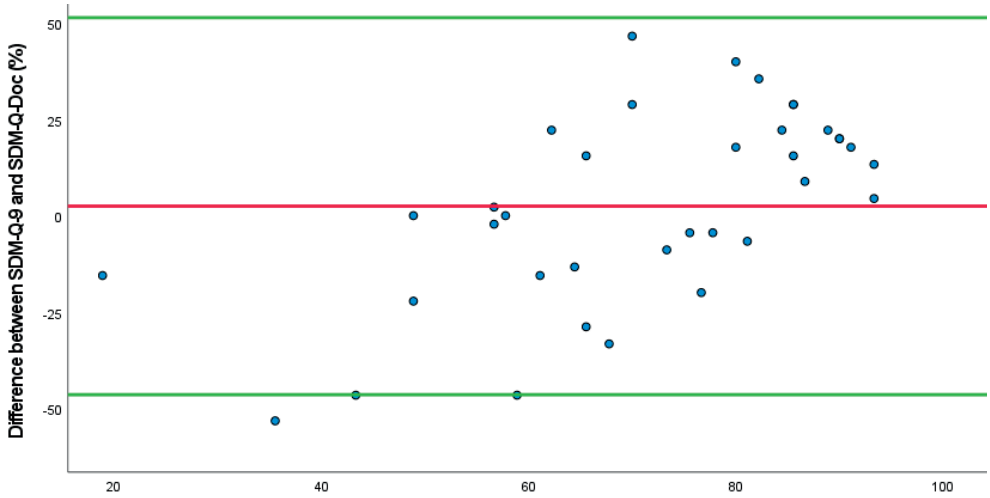
Note. (A) SDM-Q-9 scores (patient) per head and neck surgeon. (B) SDM-Q-Doc scores per head and neck surgeon. Boxes represent values between the 25th and 75th percentiles, whiskers the upper and lower adjacent values, and the horizontal lines represent the median values. Outliers are displayed as asterisks.

Appendix G. SDM-Q-9 and SDM-Q-Doc scores per item



Note. (A) SDM-Q-9 scores (patient) per head and neck surgeon. (B) SDM-Q-Doc scores per head and neck surgeon. Boxes represent values between the 25th and 75th percentiles, whiskers the upper and lower adjacent values, and the horizontal lines represent the median values. Outliers are displayed as asterisks.

Appendix H. Bland-Altman plot for SDM-Q-9 and SDM-Q-Doc scores



Note: Bland-Altman plot of the differences between SDM-Q-9 (patient) and SDM-Q-Doc (surgeons) scores. The green horizontal line indicates the mean difference, and the red horizontal line the 95% limits of agreement ($p < 0.05$).

PART II

Supportive audiovisual materials

CHAPTER 4

The immediate, intermediate, and long-term effectiveness of audiovisuals for providing pre-treatment information to patient with cancer: A systematic review

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ABSTRACT

Objective: To assess the effectiveness of audiovisuals in providing pre-treatment information to patients with cancer. Following the Six Function Model of Medical Communication, we distinguish between immediate, intermediate, and long-term outcomes.

Methods: A systematic search was performed in five electronic databases for quantitative studies comparing the addition of audiovisuals with standard care or alternative interventions. Quality was assessed using Cochrane's Risk of Bias 2.

Results: After abstract (n = 10,179) and full-text (n = 85) screening, 37 articles were included. Audiovisuals positively impacted patients' anxiety, knowledge, understanding, and physiological responses shortly after the consultation, particularly when video was compared with standard verbal care without audiovisual. Only five studies measured long-term outcomes, leaving the long-term effectiveness of audiovisuals unexplored. Majority of studies showed 'high risk of bias' (n = 34).

Conclusion: Although caution is warranted because of the variability in study design and quality, the results suggest potential benefits of using audiovisuals alongside interpersonal communication.

Practical implications: More high-quality and longitudinal research is needed with emphasis on comparing counseling with and without usage of audiovisual tools. Healthcare providers can improve the short-term impact of information provision by using audiovisuals alongside standard care, but should carefully consider content, for whom, how, and timing.



INTRODUCTION

As the landscape of cancer therapies advances, more treatment options become available [1,2], thereby intensifying the complexity of treatment decision-making. Patients and healthcare providers often navigate through the various benefits, disadvantages, and goals of reasonable treatment options to decide which treatment is most suitable. Effective decision-making necessitates adequately informed and engaged patients during consultation [3,4]. Nevertheless, when confronted with the cancer diagnosis, patients often experience elevated anxiety during the diagnostic and treatment planning phase [5], which may have a serious impact on their information processing [6–8] and patient outcomes, such as recall, knowledge, and (health-related) quality of life [8–13] . Consequently, engaging in shared decision-making may be challenging for patients with cancer [14]. Traditionally, most information regarding diagnosis, various treatment options, and prognosis is communicated verbally. Nonetheless, it is hypothesized that the provision of information could be enhanced by supporting it with other sources of information for instance to improve patient understanding [15]. Over the past years, various types of educational materials for oncology patients have been developed to improve pre-treatment information provision and patient outcomes, including printed and written materials, decision aids, mobile apps, videotapes, and interactive computer-based multimedia resources with different media modalities [16–20]. Previous research on the effects of using such (mediated) patient education has indicated promising results, such as decreased anxiety, increased knowledge, and higher satisfaction [18,21–26]**.** Particularly**,** audiovisual materials could play a pivotal role in providing patients with information. According to the Cognitive Theory of Multimedia Learning (CTML) [27,28], people process information best when it is presented simultaneously visually and auditorily, facilitating dual-channel processing and reducing cognitive load [27,29]. Additionally, audiovisuals offer a simple means to deliver high-quality counseling that can be accessed repeatedly.

While the CTML suggests the potential usefulness of audiovisuals in the field of oncology, there is no recent comprehensive and systematic synthesis of the scientific evidence on the effectiveness of using audiovisuals in pre-treatment oncology counseling. Although previous reviews have attempted to present an overview of patient education within the field of oncology, including audiovisuals, they have yet fallen short in addressing this literature gap. Two reviews explored interactive multimedia, of which one dates back to over seventeen years ago [18] and another exclusively investigated it in relation to surgery [23]. In addition, five other reviews did not specify the patient education intervention studied, leading to results that encompassed all different formats, such as written or verbal information, videotapes, and teaching programs. Moreover, of these five reviews, three focused on either chemotherapy and radiotherapy [30] or surgery [22,26], one on patients with gynecologic cancer [24], and one on oncologic patients in low- and middle-income countries[17].

Notably, three of these five reviews were conducted nearly ten years ago [24,26,30]. As such, three issues require our attention. First, because of fast developments in technology and oncology counseling, previous reviews are outdated. Second, none of these previous reviews investigated a single format of patient education, such as audiovisuals, making it difficult to understand which results belong to which patient education format. Third, the focus on specific treatments or patient groups in these reviews limits our understanding of the use of audiovisuals for patients with cancer in general.

Furthermore, to better understand the effectiveness of audiovisual communication for patients with cancer, it is essential to consider the different types of effects these audiovisuals might have. In their Six Function Model of Medical Communication (SFMMC) for effective interpersonal medical communication, De Haes and Bensing (2009) propose that medical communication outcomes can be classified into three temporal categories: Immediate outcomes pertain to effects occurring within the medical encounter, intermediate outcomes involve the effects shortly after the encounter, while long-term outcomes refer to effects occurring after an extended period has passed [31]. Although this framework was originally designed for interpersonal communication, this classification can also be applied to mediated communication [32].

Accordingly, with this review, we aim to systematically assess the effectiveness of using audiovisuals as mediated patient education for adult oncology patients, seeking to answer the research question: "What is the effect of using audiovisuals to provide pre-treatment information to patients with cancer on immediate, intermediate, and long-term outcomes?" In doing so, we categorize the evidence of quantitative research into immediate, intermediate, and long-term outcomes. Insights into these effects of patient educational audiovisuals can raise awareness among healthcare providers regarding the use of these materials and provide guidance for future research, contributing to advancing the development of audiovisual resources for patients with cancer.

METHOD

Before the start of this study, a protocol was written and registered (PROSPERO CRD42022351122).

Search strategy

We conducted two systematic searches on April 20th, 2022, and August 11th, 2023, with the help of two specialized librarians (SvdM, SG), utilizing the electronic databases Medline

(Ovid), PsycINFO (Ovid), Embase (embase.com), CINHAL (Ebsco), and Communication & Mass Media Complete (CMMC; Ebsco). The search strategy in Medline served as a basis for the other searches, following the Population-Intervention-Comparison-Outcome-Study design (PICOS) framework for systematic reviews [33]. Table 1 presents the conceptualization and operationalization of the main variables. We used search terms for the title, abstract and keywords, and thesaurus terms (e.g., MeSH terms) where appropriate, related to cancer, patients, audiovisuals, cancer therapies, and numerous possible immediate, intermediate and long-term patient outcomes of using audiovisuals. Part of the search terms for the outcome were based on the search by Bolle et al. in 2015 [32]. Appendix A presents the final search strings. We did not impose any restrictions with regard to language, country, time period, or study design in order to find all possible papers and to ensure a comprehensive review [34–36]. Conference abstracts from the Embase database were removed based on the publication type tag. Only the second search limited the publication date to records from 2022 onward. Reference checking was done on March 7th, 2023 and February 27th, 2024 for all eligible studies to check for additional citations (i.e., snowballing) using citationchaser [37].

Study eligibility

Our selection of eligible studies adhered to the PICOS criteria. Eligible full-text studies had to be written in English and published within peer-reviewed academic journals. Only quantitative intervention study designs comparing an intervention group (IG) with a control group (CG), such as randomized controlled trials (RCTs), controlled clinical trials (CCTs) or quasi-experiments, were included to explore evidence of any effects of audiovisual material. Participants in the studies had to be 18 years or older, diagnosed with cancer, and exposed to an audiovisual aimed at providing information or education pretreatment. Studies were excluded if the audiovisuals aimed to increase preventative or screening behavior, or enrollment for clinical trials. Additionally, studies were excluded if the intervention entailed a decision aid, interactive multimedia platform, game, or an analysis of the audiovisual content.

Study selection

Two reviewers (SD, RvS) independently assessed all titles and abstracts for compliance with the inclusion criteria using Rayyan [39]. Any doubts were resolved through discussion, and a third reviewer (JvW) was available for unresolved disagreements. Eligible studies underwent full-texts review against the inclusion criteria by the first author (SD), in consultation with the third reviewer. From the identified relevant full-text studies,

Table 1. Overview of conceptual and operational definitions of main review variables.

PICOS Variable	Conceptual definition	Operationalized definition
Population: Patients with cancer	Adult patients or survivors diagnosed with cancer.	Adults diagnosed with cancer or within the oncology diagnostic phase older than 18 years of age.
Intervention: Treatment information presented prior to treatment via audiovisual material	The simultaneous presentation of pre-treatment information through both the visual and auditory channel in the human information-processing system [27].	Audiovisuals were defined as the simultaneous presentation of visual and auditory elements within one medium of communication, which may include, for instance, animation videos, film, videotapes that could be shown via different types of channels such as television, tablets, smartphones, computers or laptops. Audiovisuals can be watched before or after a treatment decision-making consultation in preparation for this consultation or treatment.
Comparison: Provision of information following hospital protocol	Standard care without audiovisuals, or standard care with alternative mediated interventions.	The non-simultaneous presentation of information via audio-only (e.g., speech) or visual-only (e.g., written, static images), or a combination of these comparators in different patient education format
Outcomes: Immediate outcome	The endpoints that are relevant during medical consultation between patient and healthcare provider [31].	The measurement of a patient outcome related to the evaluation of audiovisual material itself, or a patient outcome measured during or within 24 hours after exposure to the audiovisual materials.
Outcomes: Intermediate outcome	The endpoints that are relevant shortly after medical consultation between patient and healthcare provider [31].	A patient outcome related to the evaluation of audiovisual material measured shortly (i.e., from 24 hours to three weeks) after exposure to the audiovisual material.
Outcomes: Long-term outcome	The ultimate aim of maximizing doctor-patient communication to better patients' health [31].	A patient outcome related to the evaluation of audiovisual material measured after an extended period (i.e., more than three weeks) after being exposed to the audiovisual material.
Study Design: Quantitative Research	A search method for collecting and analyzing numerical data through systematic observation of variables, for instance, created using surveys and/or manipulation of specific variables [38].	Randomized controlled trials (RCTs), controlled clinical trials (CCTs), or quasi-experiments

study characteristics (i.e., study design, sample, intervention and its characteristics, comparison group), study methodology (i.e., time points of measurement, measures, patient outcomes, intervention development), and study results were extracted by the first reviewer using a Microsoft Excel file. In doing so, the first author determined for each outcome whether the included studies measured it as an immediate, intermediate, or long-term outcome. The corresponding authors of 28 articles were contacted for missing or unclear data. If the authors did not respond, the data were considered as not reported.

Risk of bias assessment

All final included studies underwent a methodological analysis using a modified version of Cochrane's RoB-2 tool version 2 for randomized controlled trials [40], which can also be used for non-randomized studies. This tool facilitated evaluation of the overall risk of bias per study, considering domains such as randomization procedure, allocation concealment, missing data, measurement of outcomes, and reporting of outcomes. Each domain was assessed by the second author (RvS) as 'low risk', 'some concerns', or 'high risk', by answering several signaling questions.

RESULTS

Search results

A total of 15,138 records were retrieved from the five databases, with 13,264 from the first search and 1874 from the second round. After removing 4959 duplicates, 10,179 remained for title and abstract examination, resulting in 85 full-texts for thorough screening against the inclusion criteria. This selection process led to 35 potentially eligible papers. Snowballing after the first search yielded two additional full-texts which led to a total of 37 papers (comprising 36 unique studies) (Figure 1). Table 2 provides a summarized overview of the characteristics of the included studies, demonstrating great variety in study methodology, the type of intervention (e.g., communication formats), and characteristics and content of the audiovisuals. A list of all excluded studies can be found in Appendix B.

Comparison group

Fifteen studies compared the addition of audiovisual(s) presented to the intervention group (IG) with interpersonal information provided as standard care (SC) in the control group (CG) [41–55]. In eighteen (19 papers) of the 36 unique studies the CG also received written printed material (WPM) [56–72], nurse education, or psychological support, WPM, and a placebo video about gardening [73], or WPM and a general information video on the

risks, benefits, alternatives and procedural information of treatment [74] in addition to SC. Additionally, three studies involved a second comparison group that received either WPM [75], a public health video [76], or a psychosocial information manual along with professional support for six weeks [77] in addition to SC.

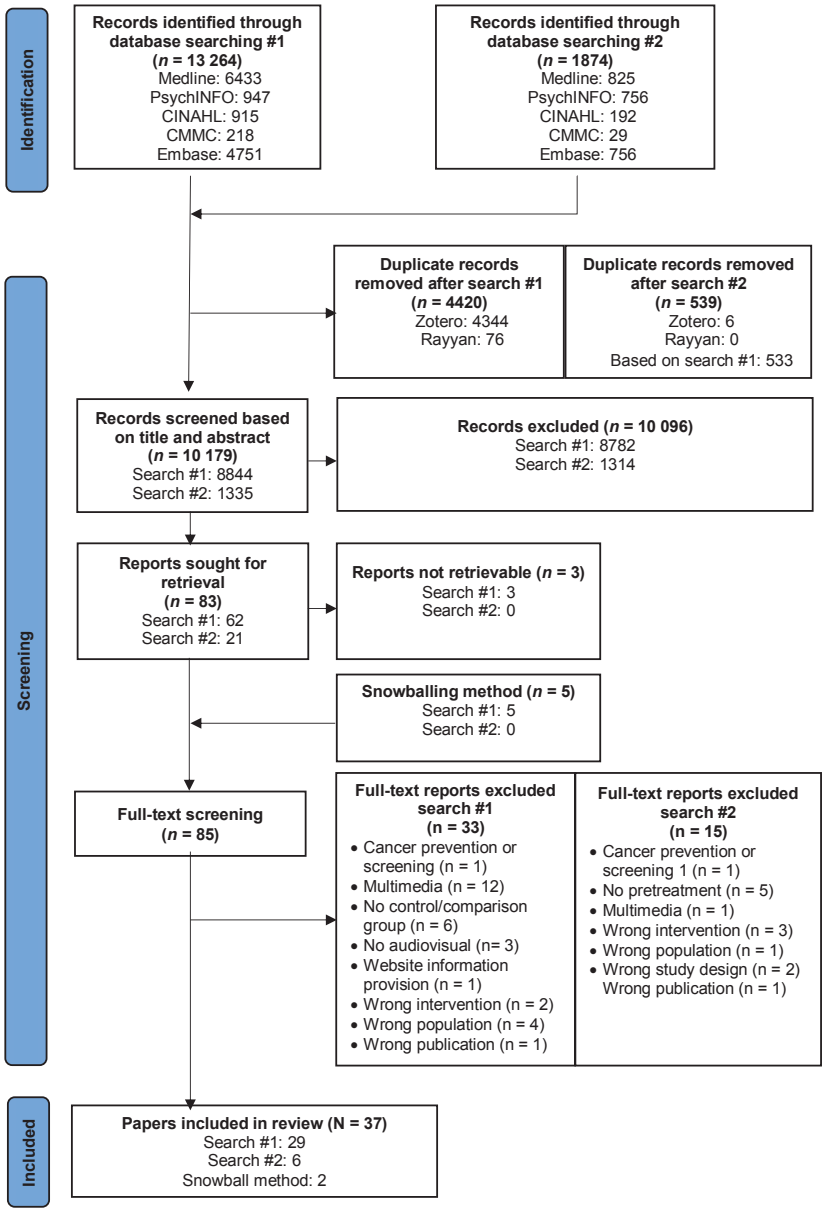


Figure 1. PRISMA flowchart of selection process.

Note: A study was considered 'wrong' when it did not adhere to the inclusion criteria following the PICOS method.

Table 2. Summarized overview of included studies (N=37).

Authors, year, country	Study design	Sample	Setting / Type of audiovisual / Visual / Audio / Access	Theory & Involved stakeholders in development	Intervention group & Control group(s)	Outcomes & Instruments
Behboudifar, et al[a] (2018), Iran [57]	Multicenter RCT Pre-posttest	60 participants, IG: 30; CG: 30 Cancer diagnosis: Head and neck Gender (female): IG: 13, CG: 11 Age (mean): IG: 52.2, CG: 50.6 Education (> HS): IG: 6, CG: 1	Home / Video Visual: Film, images, texts Audio: Voice-over, music Access: *NR*	Theory: *NR* **IS:** Researchers and several experts, including oncologist and medical education experts	**IG**: Video on DVD (20 min) in addition to SC **CG:** SC and 3 pamphlets with same content as the video **FE:** After treatment decision-making consultation **VC:** Explanation of disease and treatment modalities, radiotherapy, and side-effects and self-management **TOF:** RT	**Anxiety:** STAI* **Self-care:** Self-Care Diary*
Behboudifar et al[a] (2018), Iran [56]	Multicenter RCT Pre-posttest	66 participants, IG: 33, CG: 33 Cancer diagnosis: Head and neck Gender (female): IG: 16, CG: 9 Age (mean): IG: 52.66, CG: 50.51 Education (> HS): IG: 8, CG: 2	Home / Video Visual: Film, images, texts Audio: Voice-over, music Access: *NR*	Theory: *NR* **IS:** Researchers and several experts, including oncologist and medical education experts	**IG:** Video on DVD (20 min) in addition to SC **CG:** SC and 3 pamphlets with same content as the video **FE:** After treatment decision-making consultation **VC:** Explanation of disease, radiotherapy, preparation for treatment, essential tips during treatment session **TOF:** RT	**Anxiety:** STAI*
Bouton et al. (2012), USA [41]	Monocenter quasi-experiment Pre-posttest	81 participants, IG: 40, CG: 41 Cancer diagnosis: Breast Gender: All female Age (mean): IG: 50.4, CG: 50.6 Education (> HS): IG: 15, CG: 7	Family Learning Center/ Video Visual: *NR* Audio: *NR* Access: *NR*	Theory: *NR* **IS:** Researchers and a Spanish interpreter	**IG:** Video (8 min) in addition to SC **CG:** SC **FE:** After treatment decision-making consultation **VC:** Basic concepts about breast cancer and the management of breast cancer **TOF:** S	**Understanding:** Self-developed 11 question multiple choice questionnaire

Table 2 (*continued*)

Authors, year, country	Study design	Sample	Setting / Type of audiovisual / Visual / Audio / Access	Theory & Involved stakeholders in development	Intervention group & Control group(s)	Outcomes & Instruments
Chien et al. (2020), Taiwan [77]	Multicenter quasi-experiment with randomized assignment Pre-posttest	103 participants, IG: 28, CG: 50, CG2: 25 Cancer diagnosis: Prostate Gender: All male Age (mean): Education (> HS): IG: 17, CG: 11, CG2: 19	Home / Videos Visual: Film, images, animation, actual patients and their partners, demonstrations Audio: Spoken language, sounds, music Access: *NR*	Theory: Folkman's Theory **IS:** Principal investigator, with feedback from case manager, nurse, urologist , and psychology professional	**IG:** Six videos on smartphone (*NA* min) in addition to SC, psychosocial information manual and professional telephone support for 6 weeks **CG:** SC **CG2:** SC and psychosocial information manual and telephone support for 6 weeks **FE:** After treatment decision-making consultation **VC:** Most common symptoms as well as difficulties, care problems, healthy diet, sports, stress management experienced by couples who face prostate cancer **TOF:** Couple-based psychosocial intervention when receiving radical prostatectomy	**Disease appeals:** CAHS* **Anxiety:** MAX-PC* **Positive and negative affect**: PANAS* **Relationship satisfaction:** Dyadic satisfaction subscale of DAS* **Health-related quality of life:** Medical Outcomes Study 12-item short form health survey*
Dawdy et al. (2018), Canada [62]	Monocenter RCT Posttest only	58 participants, IG: 29, CG: 29 Cancer diagnosis: Prostate Gender: All male Age (mean): 69.2 Education: *NR*	Hospital or home / Video Visual: Film, text, images, healthcare providers, patient actor, consultation room, mock delivery of RT, CT scans Audio: Spoken language, voice-over Access: *NR*	Theory: *NR* **IS:** Researcher, patient education specialists, and tested by and feedback from patients, interprofessional team of radiation therapists, professionals from Sunnybrook Office of Patient Experience	**IG:** Video on YouTube (5 min) in addition to SC and WPM **CG:** SC and WPM **FE:** After treatment decision-making consultation , before treatment planning appointment **VC:** Preparation instructions for prostate CT and RT planning **TOF:** Preparation for CT scans before RT	**Patient satisfaction with information received:** Self-developed questionnaire **Patient preparedness:** Self-developed questionnaire **Rescanning rate:** Number of patients needing to be rescanned

Table 2 (*continued*)

Authors, year, country	Study design	Sample	Setting / Type of audiovisual / Visual / Audio / Access	Theory & Involved stakeholders in development	Intervention group & Control group(s)	Outcomes & Instruments
De Lorenzo et al. (2004), Italy [75]	Multicenter RCT Pre-posttest	300 participants, IG1: 99, CG: 99, CG2: 102 Diagnosis: Breast, colon and/or rectum, lung, ovary, lymphomas, other Gender (female): IG: 64, CG: 59, CG2: 55 Age (median): IG: 56, CG: 58, CG2: 58	Home / Video Visual: Film, text, actual patients receiving treatment Audio: Spoken language Access: Unlimited	Theory: *NR* **IS:** Researchers, patients, relatives, doctors, nurses, radiographers, and pharmacists	**IG:** Video on video tape (20 min) in addition to SC and booklets **CG:** SC **CG2**: SC and booklets about type of tumor and CT **FE:** After treatment decision-making consultation **VC:** Explanation about CT, RT, and side-effects **TOF:** RT and CT	**Level of psychological distress**: PDI* **Quality of Life, perceived severity of disease, and degree of anxiety:** VAS* with 100mm long ruler
Delcambre et al. (2020), USA [74]	Monocenter RCT Posttest only	231 participants, IG: 120, CG: 111 Cancer diagnosis: Basal cell carcinoma, squamous cell carcinoma, and/or melanoma in situ Gender (female): IG: 34, CG: 35 Age (mean): IG: 67.96, CG: 67.83 Education (>HS): IG: 103, CG: 90	Hospital / Video Visual: Film, text, images, actual treatment Audio: Voice-over Access: *NR*	Theory: *NR* **IS:** *NR*	**IG:** Video on tablet (1.40 min) in addition to SC, a longer comprehensive video, and WPM **CG:** SC, a longer comprehensive video, and WPM **FE:** After treatment decision-making consultation on same day of treatment **VC:** The longer video contained an explanation of the benefits, risks, alternatives, and basic procedural information of Mohs micrographic surgery. The shorter condensed video was developed for the preoperative period and highlighted the benefits, risks and alternatives of Mohs micrographic surgery. **TOF:** Mohs surgery	**Anxiety:** STAI* **Patient satisfaction:** Self-developed questionnaire **Knowledge:** Self-developed questionnaire

Table 2 (*continued*)

Authors, year, country	Study design	Sample	Setting / Type of audiovisual / Visual / Audio / Access	Theory & Involved stakeholders in development	Intervention group & Control group(s)	Outcomes & Instruments
Dunn et al. (2004), Australia [61]	Multicenter longitudinal quasi-experiment Pre-posttest	92 participants, IG: 48, CG: 44 Cancer diagnosis: Breast, head and neck Gender: NA Age (mean): Breast IG: 57.1, CG: 56.0; head and neck IG: 57.3, CG: 59.8 Education (> HS): IG: 7, CG: 2	Clinic or home / Video Visual: Film Audio: Spoken language Access: Unlimited	Theory: *NR* **IS:** Researchers, division of oncology, patients and their families (consultations)	**IG:** Video on video player (25 min) in addition to SC **CG:** SC + booklet **FE:** After treatment decision-making consultation **VC:** Explanation of RT treatment, how to prepare, and clarification of misconceptions about RT **TOF:** RT	**Knowledge:** Self-developed 12-item knowledge of radiation therapy scale **Psychological distress:** PAIS-SR* **Cognitive judgment aspect of psychological distress:** CMS* **Physical well-being:** SF36 physical functioning subscale **Coping with side-effects self-efficacy:** CBI-L*
Esen et al. (2023), Turkey [52]	Monocenter RCT Pre-posttest	40 participants, IG: 20, CG: 20 Cancer diagnosis: Lung, choroidal melanoma. Metastasis in brain or bone Gender (female): IG: 10, CG: 9 Age (mean): 57 Education: *NR*	*NA* / Videos Visual: Film, people Audio: *NR* Access: *NR*	Theory: *NR* **IS:** Researchers, senior radiation oncologist and radiation oncology resident	**IG:** Two videos (2-3 min) in addition to SC **CG:** SC **FE:** After treatment decision-making consultation **VC:** Radiation simulation process with explanations about reasons for immobilizers usage and how the patients will experience them, treatment areas, movements of the RT device, and brief moments of treatment were shown **TOF:** RT	**Anxiety:** STAI* and VFAS*

Table 2 (*continued*)

Authors, year, country	Study design	Sample	Setting / Type of audiovisual / Visual / Audio / Access	Theory & Involved stakeholders in development	Intervention group & Control group(s)	Outcomes & Instruments
Fernandes et al. (2020), Brazil [68]	Monocenter longitudinal RCT Pre-posttest	130 participants, IG: 65, CG: 65 Cancer diagnosis: Head and neck Gender (female): IG: 10, CG: 4 Age (mean): IG: 59.1, CG: 59.1 Education (> HS): IG: 3, CG: 7	Hospital / Video Visual: Film, text, images, treatment room, healthcare providers, actual patients Audio: Voice-over Access: *NR*	Theory: *NR* **IS:** Researchers and multidisciplinary oncology team	**IG:** Video on 21-inch monitor with speaker (10 min) in addition to SC and WPM **CG:** SC and WPM **FE:** After treatment decision-making consultation **VC:** Explanation of RT, why a CT scan is needed and the confection and use of the mask and intraoral stent. Also, reinforcement of the need for dental evaluation before starting treatment and examples of all the possible toxicities, and recommendations about oral hygiene, suspension of bad habits, general care, and proper diet **TOF:** RT	**Anxiety and depression symptoms:** HADS* **Quality of Life:** UW-QOLv4* **Understanding:** Initial radiotherapy understanding and Post-Radiotherapy understanding questionnaires
Gao et al. (2022), China [42]	Monocenter RCT Pre-posttest	60 participants, IG: 30, CG: 30 Cancer diagnosis: Lung, breast, esophageal, and other cancers Gender (female): IG: 13, CG: 11 Age groups: IG <40: 7, 40-49: 6, 50--59: 9, 60-69: 7, >70: 1; CG <40: 5, 40-49: 9, 50-59: 9, 60-69: 5, >70: 2 Education (> HS): IG: 1, CG: 3	Hospital / Video Visual: Film, virtual patient in demonstration of treatment Audio: Sound of radiation machine Access: *NR*	Theory: *NR* **IS:** Researchers	**IG:** Video through VR glasses (30 min) in addition to SC **CG:** SC **FE:** After treatment decision-making consultation **VC:** Entire RT process, display of an actual RT equipment model, how the linear accelerator works and moves, virtual patient demonstrations with radiation beam during treatment, and RT positioning and simulation **TOF:** RT	**RT comprehension:** Self-developed questionnaire **Anxiety:** STAI* **Fear:** VAS* **Physiological data:** Heart rate, respiration rate, systolic blood pressure, diastolic blood pressure

Table 2 (*continued*)

Authors, year, country	Study design	Sample	Setting / Type of audiovisual / Visual / Audio / Access	Theory & Involved stakeholders in development	Intervention group & Control group(s)	Outcomes & Instruments
Geller et al. (2010), USA [73]	Multicenter RCT Pre-posttest	59 participants, IG: 30, CG: 29 Cancer diagnosis: Ovarian Gender: All female Age (mean): IG: 62.63, CG: 58 Education (>HS): IG: 8, CG: 15	Hospital / Video Visual: Film, healthcare providers Audio: Spoken language, voice-over Access: *NR*	Theory: *NR* **IS:** Researcher, patients, and, healthcare providers	**IG:** Video on DVD (25 min) in addition to SC, psychological support, and WPM **CG:** SC, psychological support, and WPM **FE:** Before treatment decision-making consultation **VC:** In the intervention video gynecologic oncology staff explained to patients and families frequently asked questions and treatment regimes. Also, information was provided information, explanation about anticipating fears and clarification of misconceptions of were given. The placebo video discussed topics about gardening. **TOF:** Mixed	**Knowledge:** Self-developed questionnaire **Distress:** STAI*, DT*, IES* **Cancer learning attitudes:** Self-developed measure
González-Arriagada et al. (2013), Brazil [43]	Monocenter longitudinal CCT Pre-posttest	38 participants, IG: 19, CG: 19 (Pre-RT) 24 participants, IG: 12, CG: 12 (Post-RT) Cancer diagnosis: Head and neck Gender (female): Pre-RT IG: 3, CG: 4; Post-RT IG: 1, CG: 3 Age (mean): Pre-RT IG: 59.7, CG: 57.9; Post-RT IG: 56.7, CG: 58.9 Education (> HS): Pre-RT IG: 0, CG: 1; Post-RT: 0, CG: 0	Hospital / Video Visual: *NR* Audio: *NR* Access: *NR*	Theory: *NR* **IS:** Researchers and multidisciplinary oncology team	**IG:** Video on laptop with speakers (6 min) in addition to SC **CG:** SC **FE:** *NR* **VC:** Radiotherapy side effects and an emphasis on cooperation of patients to prevent these complications **TOF:** RT	Self-developed pre-radiotherapy questionnaire: **Understanding, doubts about treatment, and anxiety** Self-developed post-radiotherapy questionnaire: **Understanding, satisfaction of the information received, and fear**

Table 2 (*continued*)

Authors, year, country	Study design	Sample	Setting / Type of audiovisual / Visual / Audio / Access	Theory & Involved stakeholders in development	Intervention group & Control group(s)	Outcomes & Instruments
Harrison et al. (2001), UK [63]	Monocenter RCT Pre-posttest	274 participants, IG: 141, CG: 133 Cancer diagnosis: Head and neck, bladder/prostate Gender (female): IG: 19, CG: 15 Age (mean): IG: 66, CG: 66 Education: *NR*	NA / Video Visual: Film, healthcare providers, actual patients Audio: Spoken language Access: *NR*	Theory: *NA* **IS:** *NA*	**IG:** Video on video player (*NR* min) in addition to SC, booklet, and leaflet **CG:** SC, booklet, and leaflet **FE:** *NR* **VC:** Information on planning and treatment, interviews with patients who were already treated talking about their experiences, and interviews with clinicians about the side-effects of RT **TOF:** RT	**Anxiety:** HADS* **Worry:** Questionnaire
Isikli et al. (2023), Turkey [44]	Monocenter RCT Pre-posttest	84 participants, IG: 42, CG: 42 Cancer diagnosis: Colorectal, lung, gastric, breast, pancreatic, thyroid, liver, nasopharyngeal, and other cancers Gender (female): IG: 17, CG: 21 Age (mean): IG: 63.71, CG: 59.4 Education (HS or university): IG: 7, CG: 15	Hospital / Video Visual: Film, images, healthcare providers, actual patients Audio: Voice-over Access: *NR*	Theory: *NA* **IS:** Researchers and two faculty members from the department of surgical diseases nursing	**IG:** Video on YouTube (10 min) in addition to SC **CG:** SC **FE:** After treatment decision-making consultation, on same day before undergoing treatment **VC:** The stages before, during and after the surgery for implantable port catheters **TOF:** Surgery to implement portable catheter to be used for CT	**Fear of pain:** Fear of Pain Questionnaire-III* **Pain levels:** VAS*
Kasai et al. (2023), Japan [45]	Monocenter RCT Posttest only	30 participants, IG: 17, CG: 13 Cancer diagnosis: Rectal Gender (female): IG: 5. CG: 4 Age (mean): IG: 64.00, CG: 61.00 Education: *NR*	Clinic / Video Visual: *NA* Audio: *NA* Access: *NR*	Theory: *NA* **IS:** *NA*	**IG:** Video on iPad (20 min) in addition to SC **CG:** SC **FE:** On same day before treatment decision-making consultation **VC:** Explanation of rectal cancer, surgical procedures and approaches, specifically the robotic surgery. Also complications were shown and quality of life after hospitalization **TOF:** Robotic surgery	**Anxiety:** Self-developed questionnaire **Comprehension:** Self-developed questionnaire **Patient satisfaction:** Self-developed questionnaire



Table 2 (*continued*)

Authors, year, country	Study design	Sample	Setting / Type of audiovisual / Visual / Audio / Access	Theory & Involved stakeholders in development	Intervention group & Control group(s)	Outcomes & Instruments
Kinnane et al. (2008), Australia [64]	Monocenter RCT Pre-posttest	60 participants, IG: 31, CG: 29 Cancer diagnosis: Colorectal, breast Gender (female): IG: 26. CG: 22 Age (mean): IG: 54.8, CG: 49.0 Education (> HS): IG: 6, CG: 5	Clinic / Video Visual: Film Audio: Voice-over Access: Once	Theory: *NR* **IS:** Researchers, The Cancer Council Victoria, Cancer Nurses Society of Australia, Chemotherapy Special Interest Group, Southern Health Oncology, and the Medical Haematology Focus Group	**IG:** Video (10 min 30 sec) in addition to SC **CG:** SC and WPM **FE:** After treatment decision-making consultation, on same day before undergoing treatment **VC:** Most important 'take-home' information of dealing with nausea and vomiting and taking anti-emetic medications. Explanations were given on monitoring for and reporting signs of infection, low platelet count and anemia, and mouth care. Patients also received advice concerning eating well and drinking. fluids, Prevention and control of constipation and prevention and control of diarrhea **TOF:** CT	**Patient recall:** Self-developed questionnaire **Telephone calls to outpatient clinic:** Number and content of phone calls from patients reporting symptoms or recorded phone calls for general advice
Koth et al. (2021), USA [66]	Monocenter RCT Pre-posttest	78 participants, IG: 39, CG: 39 Cancer diagnosis: Head and neck Gender (female): IG: 8, CG: 6 Age (mean): IG: 62.3, CG: 63.1 Education: *NR*	Hospital / Video Visual: Film, patient actor, mock delivery of treatment Audio: Spoken language Access: *NR*	Theory: *NR* **IS:** *NR*	**IG:** Video in Virtual Environment Radiotherapy Training system (5 min) in addition to SC and WPM **CG:** SC and WPM **FE:** After treatment decision-making consultation **VC:** Video portrayed the creation of a thermoplastic mask, CT simulation, radiation planning, and the delivery of radiation treatments, as well as a mock delivery **TOF:** RT	**Anxiety:** STAI*

Table 2 (*continued*)

Authors, year, country	Study design	Sample	Setting / Type of audiovisual / Visual / Audio / Access	Theory & Involved stakeholders in development	Intervention group & Control group(s)	Outcomes & Instruments
Kotha et al. (2023), USA [65]	Monocenter RCT Pre-posttest	57 participants, IG: 29, CG: 28 Cancer diagnosis: Cervix, Uterine, Vagina Gender: All female Age (mean): IG: 60.0, CG: 58.0 Education: *NA*	Home / Video Visual: Film, images, text, healthcare providers, treatment rooms, treatment machines and instruments Audio: Spoken language Access: *NR*	Theory: *NR* **IS:** Researchers and radiation oncology physicians	**IG:** Video on computer/laptop (16 min) in addition to SC and handouts **CG:** SC and handouts **FE:** After treatment decision-making consultation **VC:** Explanation of gynecologic brachytherapy's general principles, risks and benefits, potential side effects, and treatment team **TOF:** Brachytherapy	**Distress:** National Comprehensive Network DT* **Treatment-related satisfaction:** Self-developed questionnaire*
Kumar et al. (2021), USA [46]	Monocenter RCT Posttest only	107 participants, IG: 58, CG: 49 Cancer diagnosis: Breast Gender (female): IG: 58, CG: 48 Age (mean): IG: 53.9, CG: 56.4 Education (> HS): IG: 55, CG: 41	Home / Videos (2) Visual: Film, healthcare providers, waiting, consult and treatment rooms, treatment machines Audio: Spoken language, voice-over Access: *NR*	Theory: *NR* **IS:** Researchers, senior breast radiation oncology attending physician, radiation oncology resident physician, breast radiation oncology nurse, administrative director Health education department, radiation oncology research assistants, past patients, other consultants such as with expertise in patient education	**IG:** Two videos on computer/laptop (7-8 min) in addition to SC **CG:** SC **FE:** After treatment decision-making consultation, before treatment planning consultation **VC:** The general overview video discussed treatment, simulation and treatment, side-effects, and after treatment follow-up broadly, while the detailed video went into more detail on the same topics specifically to treatment of breast cancer **TOF:** RT	**Knowledge, fear, anxiety, satisfaction:** Self-developed pre-consult survey and post-consult survey
Lakshman et al. (2022), India [53]	Monocenter RCT Pre-posttest	200 participants, IG: 100, CG: 100 Cancer diagnosis: *NA* Gender (female): IG: 53, CG: 54 Age (mean): IC: 41.53, CG: 42.92 Education: *NR*	Hospital / Video Visual: *NR* Audio: *NR* Access: Once or twice	Theory: *NR* **IS:** *NR*	**IG:** Video on laptop (6 min) in addition to SC **CG:** SC **FE:** After treatment decision-making consultation, on say day before undergoing treatment **VC:** Explanation of spinal anesthesia/ subarachnoid block (SAB) method **TOF:** S	**Anxiety**: VAS* **Hemodynamic parameters:** Heart rate, systolic blood pressure, diastolic blood pressure, mean arterial pressure



Table 2 (*continued*)

Authors, year, country	Study design	Sample	Setting / Type of audiovisual / Visual / Audio / Access	Theory & Involved stakeholders in development	Intervention group & Control group(s)	Outcomes & Instruments
Liu et al. (2021), China [47]	Multicenter RCT Pre-posttest	128 participants, IG: 64, CG: 64 Cancer diagnosis: Gastric Gender (female): IG: 26, CG: 30 Age (mean): IG < 60: 18, ≥ 60: 46, CG < 60: 15, ≥ 60: 49 Education (> 9 years): IG: 8, CG: 8	Hospital / Video Visual: Film, healthcare providers, waiting room, operating room, recovery room Audio: *NR* Access: *NR*	Theory: *NR* **IS:** *NR*	**IG:** Video (20 min) **CG:** SC **FE:** After treatment decision-making consultation, 24 hours before undergoing treatment **VC:** Explanation of the benefits of minimally invasive gastrectomy versus open surgery, team members, anesthesia, fluid intake, and postoperative care **TOF:** S	**Anxiety:** HADS* **Depression:** HADS* **Psychological response:** Blood samples and recordings of vital signs
Love et al. (2016), USA [48]	Multicenter RCT Pre-posttest	32 participants, IG: 16, CG: 16 Cancer diagnosis: Basal cell carcinoma Gender (female): IG: 4. CG: 5 Age (mean): IG: 64.70, CG: 62.90 Education: *NR*	Clinic / Video Visual: Film, images, text, healthcare provider Audio: Spoken language Access: *NR*	Theory: *NR* **IS:** Researchers and Cancer Quest (a cancer education and outreach program)	**IG:** Video on iPad (9 min) in addition to SC **CG:** SC **FE:** On same day before treatment consultation **VC:** Three treatment options with visuals of each procedure (cure rates, scar appearance, healing time, post procedural care), ending with a summary comparing procedures **TOF:** Three treatment options	**Knowledge:** Self-developed questionnaire **Patient satisfaction:** Self-developed questionnaire

Table 2 (*continued*)

Authors, year, country	Study design	Sample	Setting / Type of audiovisual / Visual / Audio / Access	Theory & Involved stakeholders in development	Intervention group & Control group(s)	Outcomes & Instruments
Moysés et al. (2022), Brazil [76]	Monocenter RCT Pre-posttest	39 participants, IG: 14, CG1: 13. CG: 12 Cancer diagnosis: Cervical Gender: All female Age (mean): IG: 48.0, CG1: 51.15, CG2: 44.75 Education: 28.2% of women were illiterate	Hospital / Video Visual: Film, actors Audio: Spoken language, music Access: *NR*	Theory: The Self-Regulatory Model of Illness Perceptions **IS:** Researchers in the areas of public health, psychology, nursing and medicine	**IG:** Video on tablet (7 min 54 sec) in addition to SC **CG1:** SC and placebo video **CG2:** SC **FE:** On same day before undergoing treatment **VC:** The intervention considered the cultural, social and health literacy characteristics of Amazonian women, and tells the story of a young woman talking about the information from the pamphlet with her sister, making her decide to carry out the preventive exam for Cervical Cancer. Together they seek the health unit to carry out the preventive examination and during medical consultation, they receive guidance on cervical cancer considering the five dimensions of Leventhal's Self-Regulation Model. The placebo video entailed a public video from the Ministry of Health of Brazil addressing health habits. **TOF:** RT and CT	**Illness perceptions:** Brief IPQ-R* **Knowledge:** Self-developed questionnaire
Mumtaz et al. (2022), Indonesia [58]	Monocenter quasi-experiment Pre-posttest	80 participants, IG: 40, CG: 40 Cancer diagnosis: Breast, colon, pancreas, malignant lymphoma, and other cancers Gender (female): IG: 28, CG: 30 Age (mean): IG: 50.68, CG: 50.85 Education (> HS): IG: 3, CG: 5	Hospital / Video Visual: Animation, text Audio: Voice-over Access: *NR*	Theory: *NR* **IS:** *NR*	**IG:** Video on laptop (10 min 53 sec) in addition to SC **CG:** SC and booklet **FE:** On same day before undergoing treatment **VC:** Explanation of chemotherapy, the side effects of chemotherapy, the warning signs after chemotherapy, and tips for dealing with side effects **TOF:** CT	**Self-efficacy of symptom management:** The self-efficacy of symptom management instrument*

Table 2 (*continued*)

Authors, year, country	Study design	Sample	Setting / Type of audiovisual / Visual / Audio / Access	Theory & Involved stakeholders in development	Intervention group & Control group(s)	Outcomes & Instruments
Orringer et al. (2005), USA [54]	Monocenter RCT Pre-posttest	217 participants, IG: 112 (109 completed knowledge questionnaire, 104 completed anxiety questionnaire), CG: 105 (100 completed knowledge questionnaire, 99 completed anxiety questionnaire) Cancer diagnosis: Melanoma Gender: *NR* Age: *NR* Education: *NR*	Home / Video Visual: Film, images, diagrams, professional actors Audio: Spoken language Access: *NR*	Theory: *NR* **IS:** Researchers, multidisciplinary team consisting of dermatologists, surgeons, oncologists, psychiatrists, psychologists, nurses, social workers, lay people, a survey and marketing expert, producer	**IG:** Video on videotape (10 min 55 sec) in addition to SC **CG:** SC **FE:** Before treatment consultation **VC:** Basic educational information important for any patient newly diagnosed with melanoma (overview of melanoma), including incidence of melanoma, the risk factors for melanoma, its clinical presentation, how melanoma may metastasize, types of treatment available, and concept of creating a multidisciplinary treatment plan was emphasized **TOF:** Different treatment options	**Anxiety:** STAI* **Emotional distress:** Distress Thermometer* **Knowledge:** Self-developed questionnaire
Schofield et al. (2008), Australia [72]	Monocenter quasi-experiment Pre-posttest	100 participants, IG: 50, CG: 50 Cancer diagnosis: Breast, gastrointestinal, gynecological, head and neck, lung, prostate/ testicular, and other cancers Gender (female): Curative IG: 20, CG: 12; palliative: IG: 5, CG: 11 Age (mean): Curative IG: 57.40, CG: 57.50; palliative IG: 56.5, CG: 56.88 Education (> HS): Curative IG: 18, CG: 13; palliative IG: 6, CG: 8	Home / Video Visual: Film, healthcare providers, cancer survivors Audio: Spoken language Access: *NR*	Theory: *NR* **IS:** Researchers and stakeholder consultation involving ongoing feedback from consumers and healthcare professionals	**IG:** Video on DVD (25 min) in addition to SC and nurse education **CG:** SC and nurse education **FE:** After treatment consultation **VC:** Cancer survivor discussing experiences when having CT, side effects, and self-care strategies they used to manage these side effects **TOF:** CT	**Patient satisfaction with information:** Self-developed questionnaire **Anxiety:** HADS* **Depression:** HADS* **Self-efficacy:** CBI* **Perceived needs of patients:** SCNS* short form

Table 2 (*continued*)

Authors, year, country	Study design	Sample	Setting / Type of audiovisual / Visual / Audio / Access	Theory & Involved stakeholders in development	Intervention group & Control group(s)	Outcomes & Instruments
Tan et al. (2018), Singapore [59]	Monocenter quasi-experiment Pre-posttest	62 participants, IG: 30, CG: 32 Cancer diagnosis: Breast Gender: All female Age (mean): IG: 53.0, CG: 54.0 Education (> secondary): IG: 17, CG: 15	Home / Video Visual: Film, breast cancer survivors Audio: Spoken language Access: *NR*	Theory: *NR* **IS:** Researchers, suggestions from patients with breast cancer, and breast oncology experts' contributions	**IG:** Video on DVD (30 min) in addition to SC and booklet, brochures **CG:** SC and booklets, brochures **FE:** After treatment consultation **VC:** The various medical treatments of breast surgery, including RT, CT, hormonal therapy, and targeted therapy. Personal stories from 5 breast cancer survivors of different ethnic groups (Chinese, Malay, and Indian) regarding their life experiences and testimonies of going through the treatment process **TOF:** Different treatment options	**Knowledge:** Modified version of Knowledge of Breast Cancer questionnaire* **Anxiety:** STAI* **Satisfaction with decision-making:** SWD tool*
Thomas et al. (2000), UK [69]	Multicenter RCT Pre-posttest	220 participants, IG: 113, CG: 107 Cancer diagnosis: Breast, intestinal, malignant lymphoma, and other cancers Gender (female): IG: 73, CG: 55 Age (mean): IG: 59.0, CG: 63.0 Education: *NR*	Home / Video Visual: Film, actual patients Audio: Spoken language, voice-over Access: Unlimiteds	Theory: *NR* **IS:** Researchers held six focus group meetings with three doctors, five nurses, one pharmacist, two radiographers, ten patients and their relatives	**IG:** Video on cassette (20 min) in addition to SC and booklet **CG:** SC and booklet **FE:** After treatment consultation **VC:** A comprehensive description of chemotherapy and radiotherapy, including a clear indication of the associated risks. Patients describing their own experiences, side effects, and the methods used to alleviate them **TOF:** RT, CT	**Anxiety:** HADS* **Depression:** HADS* **Patient satisfaction with information received:** Self-developed questionnaire

Table 2 (*continued*)

Authors, year, country	Study design	Sample	Setting / Type of audiovisual / Visual / Audio / Access	Theory & Involved stakeholders in development	Intervention group & Control group(s)	Outcomes & Instruments
Tucker et al. (2022), USA [49]	Monocenter RCT Pre-posttest	75 participants, IG: 37, CG: 38 Cancer diagnosis: Endometrial Gender: All female Age: IG 30-39: 2, 40-49: 2, 50-59: 12, 60-69: 12, 70-70: 9; CG 30-39: 0. 40-49: 3, 50-59: 14, 60-69: 15, 70-79: 5 Education (> HS): IG: 32, CG: 23	Hospital / Video Visual: Animation, text Audio: Voice-over Access: *NR*	Theory: *NR* **IS:** Researchers with feedback from division faculty and staff	**IG:** Two videos on iPad (5 min) in addition to SC **CG:** SC **FE:** On same day before treatment consultation **VC:** One video showed minimally invasive staging surgery for endometrial cancer, emphasizing sentinel lymph node mapping and biopsy. It provided details on the procedure's execution and associated risks. The second video covered perioperative instructions and expectations, outlining what patients should expect during their hospital stay and postoperative recovery **TOF:** Staging surgery	**Patient satisfaction:** CSQ-8, global satisfaction question **Comprehension:** Self-developed questionnaire
Turkdogan et al. (2022), Canada [50]	Monocenter RCT Pre-posttest	100 participants, IG: 50, CG: 50 Cancer diagnosis: Head and neck Gender (female): IG: 33, CG: 30 Age: IG 18-39: 6, 40-59: 23, 60-79: 22, ≥ 80: 9; CG: 18-39: 5, 40-59: 23, 60-79: 26, ≥ 80: 7 Education: IG high school/ college: 30, university: 30; CG high school/college: 28, university: 33	Hospital or home / Video(s) Visual: Animation, text Audio: Voice-over Access: Unlimited	Theory: *NR* **IS:** Researchers took a multidisciplinary approach, whereby content reviewed by participating otolaryngologists, ancillary health care clinicians, respiratory therapist, physiotherapist, oncology focused psychologist and radiation oncologist	**IG:** Video(s) (ranges between 10 min 15 sec to 15 min 11 sec) in addition to SC **CG:** SC **FE:** After treatment consultation **VC:** Medical and surgical information concerning the diagnosis and treatment, as well as psychosocial elements, such as mental health and family life, in the recovery process. Explanation of the details of their diagnosis, how to adequately prepare for their upcoming surgery, what to expect during their hospital stay, and what steps they can take to help the recovery process at the hospital and on discharge home **TOF:** S	**Patient satisfaction with surgery and recovery:** Self-developed questionnaire, EORTC QLQ-INFO25*

Table 2 (*continued*)

Authors, year, country	Study design	Sample	Setting / Type of audiovisual / Visual / Audio / Access	Theory & Involved stakeholders in development	Intervention group & Control group(s)	Outcomes & Instruments
Ünal Toprak et al.(2021), Turkey [55]	Monocenter quasi-experiment Pre-posttest	30 participants, IG: 15, CG: 15 Cancer diagnosis: Breast Gender: All female Age (mean): IG: 52.26, CG: 52.0 Education (> HS): IG: 2, CG: 3	Home / Video Visual: Animation, text Audio: Voice-over Access: *NR*	Theory: *NR* **IS:** Researchers interviewed patients with breast cancer receiving chemotherapy	**IG:** Video on CD (*NR* min) in addition to SC and nurse education **CG:** SC and nurse education **FE:** After treatment consultation **VC:** Information about cancer and symptom management **TOF:** CT	**Quality of Life:** EORTC QLQ-C30*, EORTC QLQ-BR23 scale*
Walker & Podbilewicz-Schuller (2005), USA [70]	Multicenter RCT Pre-posttest	79 participants, IG: 42, CG: 37 Cancer diagnosis: Breast Gender: All female Age (mean): IG: 52.4, CG: 58.1 Education (years, mean): IG: 14.1, CG: 14.5	Clinic / Video Visual: Film, real-life settings, healthcare providers, patient actors Audio: Spoken language Access: *NR*	Theory: Social Learning Theory **IS:** *NR*	**IG:** Video (19 min) in addition to SC and WPM **CG:** SC and pamphlet **FE:** On same day before treatment consultation **VC:** Typical sequence of events during the clinic appointment and introduction of healthcare professionals in each of the various disciplines the patient is likely to see. Video normalizes psychosocial evaluation with a psychologist and depicts this as routine care. Viewers receive specific advice about how to make the most of the appointment and are provided with basic questions that they may wish to ask their doctors **TOF:** Other, namely typical sequence of events and preparation for clinic appointment	**Patient satisfaction:** Self-developed questionnaire **Distress (depression, anxiety helplessness):** STAI*, CESD*, Helpless/hopeless subscale* **Quality of Life:** FACT-G* **Satisfaction with multidisciplinary appointment, satisfaction with the orientation (videotape versus pamphlet), informational preparedness, and participation in treatment decision-making**: Self-developed questionnaire

Table 2 (*continued*)

Authors, year, country	Study design	Sample	Setting / Type of audiovisual / Visual / Audio / Access	Theory & Involved stakeholders in development	Intervention group & Control group(s)	Outcomes & Instruments
Wilkins et al. (2006), USA [71]	Monocenter CCT Pre-posttest	101 participants, IG: 52, CG: 49 Cancer diagnosis: Breast Gender: All female Age (mean): 54.9 Education: 68% of the total sample had at least some college education	Clinic / Video Visual: Film, graphs, actual patients, cancer survivors Audio: Spoken language, voice-over Access: *NR*	Theory: *NR* **IS:** Researchers held patient focus groups and used surveys of physician experts	**IG:** Video on videocassette player and monitor (approx.. 60 min) in addition to SC and WPM **CG:** SC and WPM **FE:** On same day before treatment consultation **VC:** Explanation of breast cancer, analysis of mastectomy and breast conservation as the primary treatment options, including relative risks and benefits of the treatment choices. Interviews with current and former patients who chose the various options are also included. **TOF:** Three treatment options	**Knowledge about breast cancer, self-efficacy to communicate with physician/manage disease, perceived involvement in care, satisfaction with treatment decision, autonomy and information-seeking preferences**: CES-D Scale*, Global Health Status/Quality Life Scale of the EORTC QLQ-C30 questionnaire*, and 5 functional scales of the EORTC QLQ-C30*: **Anxiety:** STAI*
Wirawan et al. (2022), Indonesia [60]	Monocenter quasi-experiment Pre-posttest	82 participants, IG: 41, CG: 41 Cancer diagnosis: Breast, colorectal, lymphoma, head and neck, malignant lymphoma, and other cancers Gender (female): IG: 24, CG: 31 Age (mean): IG: 49.85, CG: 50.63 Education (> HS): IG: 15, CG: 5	Clinic / Video Visual: Animation Audio: Voice-over Access: *NR*	Theory: *NR* **IS:** Researchers and review by one oncologist, two nursing lecturers with doctoral education, and one clinical nurse in oncology	**IG:** Video (approx.. 11 min) in addition to SC and booklet **CG:** SC and booklet **FE:** On same day before undergoing treatment **VC:** The video content included the definition of CT, the reason for giving chemotherapy, how CT drugs work, how to administer CT, the cycle of CT, the steps of CT, the risks that can occur during CT, the side effects of CT that can occur, the evaluation of emergency conditions that are required to contact health services, and proper hand washing techniques **TOF:** CT	**Distress:** Distress thermometer*

Table 2 (*continued*)

Authors, year, country	Study design	Sample	Setting / Type of audiovisual / Visual / Audio / Access	Theory & Involved stakeholders in development	Intervention group & Control group(s)	Outcomes & Instruments
Wysocki et al. (2012), Poland [51]	Monocenter RCT Pre-posttest	58 participants, IG: 29, CG: 29 Cancer diagnosis: Breast Gender: All female Age (mean): IG: 60.0, CG: 55.0 Education: *NR*	Hospital / Video Visual: Film, text, cancer survivor Audio: Spoken language Access: *NR*	Theory: *NR* **IS:** *NR*	**IG:** Video (12 min) in addition to SC **CG:** SC **FE:** After treatment consultation on afternoon before surgery **VC:** Important health- and culturally related issues **TOF:** S	**Anxiety:** VAS* (100mm) **Knowledge:** VAS* (subjective measurement), self-developed questionnaire
Yang et al. (2023), Taiwan [67]	Monocenter RCT Posttest only	110 participants, IG: 55, CG: 55 Cancer diagnosis: Breast Gender: All female Age (mean): IG: 53.78, CG: 56.16 Education (> HS): IG: 28, CG: 21	Hospital / Video Visual: *NR* Audio: *NR* Access: *NR*	Theory: *NR*[b] **IS:** Researchers and colleagues	**IG:** Video (*NR* min) in addition to SC and nurse education **CG:** SC, leaflet, and nurse education **FE:** *NA* **VC:** Radiotherapy instructions, common side effects, and principles of self-care **TOF:** RT	**Patient satisfaction with the intervention material, patient satisfaction with leaflet, understanding of basic information, patient satisfaction with education from nurses, self-care assessment, and understanding of basic information:** Self-developed questionnaire

Note: [a] = Same sample and study, but different patient outcomes; [b] = The Self-Regulatory Model of Illness Perceptions was mentioned in the introduction but not in the description of the audiovisual development; Brief IPQ-R = Brief Illness Perception Questionnaire; CAHS = Cognitive Appraisal of Health Scale, CBI = The Cancer Behaviour Inventory; CCT = controlled clinical trial; CES-D = The Center for Epidemiologic Studies Depression Scale; CG = control group; CG2 = second comparator group; CMS = Constructed Meaning Scale; CT = chemotherapy; DAS = Dyadic Adjustment Scale; DT = Distress thermometer; EORTC = The European Organization for Research and Treatment of Cancer; FACT-G = Functional Assessment of Cancer Therapy; FE = first moment of exposure to audiovisual; HADS = Hospital Anxiety Depression Survey; HS = high school; IES = Impact of Event Scale; IG = intervention group; IS = Involved Stakeholders during development of audiovisual; MAX-PC = Memorial Anxiety Scale for prostate cancer; *NR* = not reported; PAIS-SR = Psychological distress subscale of Psychosocial adjustment to Illness Scale; PDI = Psychological Distress Inventory; PANAS = Positive and Negative Affect Schedules; RCT = randomized controlled trial; RT = radiotherapy; S = surgery; SC = standard care consisting verbal information; SCNS = The Supportive Care Needs Survey; STAI = State Trait Anxiety Inventory; SWD = Satisfaction with Decision tool; TOF = treatment of focus; VC = video content; *NA* = not applicable/not reported; VAS = Visual Analogue Scale; VFAS = Visual Facial Anxiety Scale; WPM = written, printed material; * = validated instrument

Intervention effects

Timing of the assessment of outcomes varied greatly, ranging from immediately to weeks or even months after exposure to the audiovisual(s). In five studies, assessments took place at several time points, leading to certain outcomes being categorized in more than one temporal category [47,51,57,62,64]. Additionally, many different instruments were used to assess the various patient outcomes (Table 2). In this review, we consider results relevant if at least two or more studies reported on a certain patient outcome. Additional details of the study findings can be found in Appendices C, D, and E.

Immediate outcomes

Based on the studies' description of the measurement time points, we categorized eight studies as having measured outcomes within 24h after exposure to the audiovisual or outcomes related to the audiovisual itself [44,45,47,48,54,66,70,74]. Table 3 provides a summarized overview of the findings across studies in this category.

Immediate anxiety. In five studies, the level of anxiety was measured immediately after exposure to the audiovisual. Among them, three compared the addition of an audiovisual to SC with SC alone, with one study reporting significantly less anxiety in the IG [47], another reporting equal anxiety levels in the IG and CG [45], and the third reporting significantly less anxiety in CG [54]. In two other studies, where both the IG and CG received additional WPM [66], or additional WPM and a general informational video, no significant difference in favor of the audiovisual was observed when compared to SC [74].

Immediate knowledge and understanding. Four studies evaluated knowledge and understanding immediately following audiovisual exposure. Three of these studies compared the addition of an audiovisual to SC with SC alone. Two reported significantly increased knowledge from baseline in the IG than in the CG [48,54], while the third study found no significant difference [45]. In the remaining study, no significant difference was found comparing audiovisual to SC when both the IG and CG also received additional WPM and a general information video [74].

Patient satisfaction with consultation. Two studies assessed how satisfied patients were with the information received by comparing SC alone with SC plus audiovisual; however, both found no significant effect favoring the IG [45,48].

Other outcomes. Other outcomes were measured in only one study and found significant effectiveness of the audiovisual on IG patients' satisfaction with the information material [70], depression [47], and physiological response (heart rate, blood pressure, cortisol) [47]. One

study found significant effect on distress in favor of the CG [54]. No effectiveness was found for patient's fear of pain and pain levels [44].

Intermediate outcomes

We categorized 27 studies (comprising 28 papers) as having assessed 'intermediate outcomes', i.e., measured between 24h and three weeks after exposure to the audiovisual material [41–43,46,47,49,51–54,56–65,67–73,75]. A summarized overview of all findings in this category is presented in Table 4.

Intermediate anxiety. Of fifteen papers (comprising fourteen studies) reporting on anxiety, seven studies compared the addition of an audiovisual to SC with SC alone. Four reported significantly less anxiety in the IG [42,47,52,53], while three found no significant difference between the IG and CG [46,51,72]. Another three papers (comprising two studies) compared an audiovisual against WPM, with one reporting no significant difference [59], and the other revealing significantly lower anxiety in the CG [56,57]. Four studies compared audiovisual to SC, with both groups receiving additional WPM. One of these significantly favored the IG [69], while the other three showed no significant difference [63,68,71]. The remaining study found no significant effect when comparing the addition of audiovisual to SC with a second comparison group receiving WPM in addition to SC [75].

Intermediate knowledge and understanding. Of thirteen studies on knowledge and understanding, four compared an audiovisual to SC. Four reported significantly more knowledge in the IG [41,42,46,54], while another three showed no significant effect [43,49,51]. Three studies in which an audiovisual was compared to WPM found no significant differences favoring the IG [59,61,67]. In two studies where both IG and CG received WPM when comparing the audiovisual to SC, no significant difference was observed [68,71]. Knowledge significantly increased in the IG of a study comparing the intervention audiovisual to a public health video, with both groups receiving additional WPM and psychological support [73].

Intermediate satisfaction with consultation. The satisfaction of patients with the consultation, as measured after 24 hours to three weeks, was assessed in seven studies. Among the three studies comparing audiovisual to SC, two found no effect [46,72], while the other found patients in the CG to be more satisfied [49]. Similarly, two studies reported that the audiovisual did not significantly impact patients' satisfaction when compared to WPM [59,70]. Of two studies comparing audiovisual to SC, where both IG and CG received additional WPM, one reported a significant benefit of providing the audiovisual [69], while the other found no effect [71].

Psychological distress. Two of five studies assessing patients' distress compared audiovisual to WPM and reported that watching the audiovisual did not significantly

Table 3. Overview of the immediate outcomes found in the included studies (n=8)[a].

Immediate outcome	Intervention	In favor of IG Sig. diff.	In favor of CG Sig. diff.	Equal in IG & CG *ns*
Anxiety (n=5)	Video vs. SC	1 [47]	1 [54]	1 [45]
	Video + WPM vs. WPM			1 [66]
	Video + WPM vs. WPM + general video			1 [74]
Knowledge / understanding (n=4)	Video vs. SC	2 [48,54]		1 [45]
	Video + WPM vs. WPM + general video			1 [74]
Patient satisfaction with information material (n=2)	Video vs. SC			2 [45,48]
Patient satisfaction with consultation (n=1)	Video + WPM vs. WPM	1 [70]		
Emotional distress (n=1)	Video vs. SC		1 [54]	
Depression (n=1)	Video vs. SC	1 [47]		
Physiological response (n=1)	Video vs. SC	1 [47]		
Fear of pain (n=1)	Video vs. SC			1 [44]
Pain levels (n=1)	Video vs. SC			1 [44]

Note: [a] Table only contains studies that have tested for significance between IG and CG; CG = control group; IG = intervention group; SC = standard care consisting of verbal information; WPM = written, printed material

reduce distress more than receiving SC alone [61,70]. Two other studies compared the audiovisual to SC while both groups also received WPM; one found no benefit of the audiovisual [65], whereas the other showed a significantly greater decrease in distress in the CG [60]. The fifth study compared an audiovisual against a public health video and provided

both study arms with additional WPM and psychological support alongside SC, and found significantly less distress in the CG [73].

Self-efficacy. Five studies assessed patient's self-efficacy, of which one reported that patients who watched the audiovisual felt significantly more confident in coping with cancer than those receiving SC alone [72]. Of two studies comparing audiovisual to WPM, one significantly favored the IG [58], whereas the other found no effect [61]. The remaining two studies reported no significant difference when comparing audiovisual to SC with both study arms also receiving WPM [71] or comparing audiovisual to a public health video with additional WPM and psychological support [73].

Intermediate depression. Depression was assessed in four studies. Two revealed the audiovisual's significant negative effect on depression when comparing to SC [47] or to WPM [69]. However, two other studies found no significant difference between IG and CG when comparing audiovisual to SC [72] or when both IG and CG received additional WPM [68].

Intermediate physiological response. In three of the four studies comparing audiovisual to SC, watching the audiovisual resulted in more benefits than receiving SC alone on patients' physiological response. Heart rates, blood pressures, and respiratory rates were significantly lower in the IG than in the CG [42,47,53]. However, when comparing audiovisual to WPM no significant differences were found between IG's and CG's physiological responses in terms of physical functioning [61].

Intermediate fear. Three studies measured patients' fear by comparing audiovisual to SC alone. One study significantly favored the IG [42], whereas in another study patients in the CG experienced significantly less fear than the IG [43]. The third study found no significant difference between the IG and CG [46].

Intermediate quality of life. Three studies assessed patients' well-being. No significant differences were found in studies comparing audiovisual to WPM [70] or audiovisual to SC when both study arms received additional WPM [68]. However, the audiovisual did have a positive significant effect in one study where it was compared to SC and a second group also receiving WPM [75].

Other outcomes. Fifteen studies assessed patient outcomes that were only measured in one study. Among them, five studies found a significant impact of the audiovisual on IG patients' doubts before therapy [43], self-care behavior [67], preparedness for appointment [70], number of telephone calls to outpatient clinic [64], and participation in treatment decision-making [70]. No effectiveness of the audiovisual was found on patients' perceived needs, satisfaction with treatment, autonomy and information-seeking preference, information

recall, perceived involvement in care of the physician, CT rescanning rates, psychological distress (cognitive judgement aspect), worry, and perceived severity and curability of the disease. One study found the CG to hold a more favorable attitude towards learning about cancer than the IG [73].

Table 4. Overview of the intermediate outcomes found in the included studies (n=27)[a]

Intermediate outcomes	**Intervention**	**In favor of IG**	**In favor of CG**	**Equal in IG & CG**
		Sig. diff.	**Sig. diff.**	***ns***
Anxiety (n=14*)	Video vs. SC	4 [42,47,52,53]		3 [46,51,72]
	Video vs. WPM		1 [56,57]	1 [59]
	Video + WPM vs. WPM	1 [69]		3 [63,68,71]
	Video + WPM vs. WPM vs. SC			1 [75]
Knowledge / understanding (n=13)	Video vs. SC	4 [41,42,46,54]		3 [43,49,51]
	Video vs. WPM			3 [59,61,67]
	Video + WPM vs. WPM			2 [68,71]
	Video + WPM + psych. support vs. placebo video + WPM	1 [73]		
Patient satisfaction with consultation [b] (n=7)	Video vs. SC		1 [49]	2 [46,72]
	Video vs. WPM			2 [59,70]
	Video + WPM vs. WPM	1 [69]		1 [71]
Psychological distress (n=5)	Video vs. WPM			2 [61,70]
	Video + WPM vs. WPM		1 [60]	1 [65]
	Video + WPM + psych. support vs. placebo video + WPM		1 [73]	
Self-efficacy (n=5)	Video vs. SC	1 [72]		
	Video vs. WPM	1 [58]		1 [61]
	Video + WPM vs. WPM			1 [71]
	Video + WPM + psych. support vs. placebo video + WPM			1 [73]

Depression (n=4)	Video vs. SC	1 [47]		1 [72]
	Video vs. WPM	1 [69]		
	Video + WPM vs. WPM			1 [68]
Physiological response (n=4)	Video vs. SC	3 [42,47,53]		1 [61]
Fear (n=3)	Video vs. SC	1 [42]	1 [43]	1 [46]
Quality of life (n=3)	Video vs. WPM			1 [70]
	Video + WPM vs. WPM			1 [68]
	Video vs. WPM vs. SC	1 [75]		
Patient satisfaction with treatment (n=1)	Video + WPM vs. WPM			1 [65]
Perceived needs of patients (n=1)	Video vs. SC			1 [72]
Doubts before the therapy (n=1)	Video vs. SC	1 [43]		
Autonomy and information-seeking preferences (n=1)	Video + WPM vs. WPM			1 [71]
Recall (n=1)	Video + WPM vs. WPM			1 [64]
Perceived involvement in care (n=1)	Video + WPM vs. WPM			1 [71]
Self-care assessment (n=1)	Video vs. WPM	1 [67]		
Rescanning rate (n=1)	Video vs. WPM			1 [62]

Table 4. *(Continued)*

Intermediate outcomes	Intervention	In favor of IG Sig. diff.	In favor of CG Sig. diff.	Equal in IG & CG *ns*
Participation in treatment decision-making (n=1)	Video + WPM vs. WPM	1 [70]		
Cognitive judgmental aspect of patients' psychological distress (n=1)	Video vs. WPM			1 [61]
Cancer learning attitudes (n=1)	Video + WPM + psych. support vs. placebo video + WPM		1 [73]	
Worry (n=1)	Video + WPM vs. WPM			1 [63]
Perceived severity and curability of the disease (n=1)	Video vs. WPM vs. SC			1 [75]

Note: [a] Table only contains studies that have tested for significance between IG and CG; [b] = including satisfaction with information and satisfaction with decision-making; *** =** comprising of 15 papers; CG = control group; IG = intervention group; SC = standard care consisting of verbal information; WPM = written, printed material.

Long-term outcomes

We categorized five studies as addressing 'long-term outcomes', being measured later than three weeks after exposure to the audiovisual. Both of the two studies assessing knowledge and understanding found no effect in favor of the IG when comparing the addition of an audiovisual to SC with SC alone [43,51]. However, the remaining patient outcomes within this category were measured in only one study, of which two found a significant positive effect of the audiovisual on patients' self-care behavior [57] and patients' satisfaction with surgery and the recovery process [50]. A summarized overview of the findings within this category is presented in Table 5.

Table 5. Overview of the long-term outcomes found in the included studies (n=5)[a].

Long term outcomes	Intervention	In favor of IG Sig. diff.	In favor of CG Sig. diff	Equal in IG & CG *ns*
Knowledge/ understanding (n=2)	Video vs. SC			2 [43,51]
Anxiety (n=1)	Video vs. prof. support + WPM vs. SC			1 [77]
Self-care (n=1)	Video vs. WPM	1 [57]		
Disease appeals (n=1)	Video vs. prof. support + WPM vs. SC			1 [77]
Positive and negative affect (n=1)	Video vs. prof. support + WPM vs. SC			1 [77]
Relationship satisfaction (n=1)	Video vs. prof. support + WPM vs. SC			1 [77]
Health-related quality of life (n=1)	Video vs. prof. support + WPM vs. SC			1 [77]
Patient satisfaction with surgery and recovery process (n=1)	Video vs. SC	1 [50]		
Fear (n=1)	Video vs. SC			1 [43]
Patient satisfaction with consultation (n=1)	Video vs. SC			1 [43]

Note: [a] Table only contains studies that have tested for significance between IG and CG; CG = control group; IG = intervention group; SC = standard care consisting of verbal information; WPM = written, printed material.

Quality of the included studies

In total, 34 studies (comprising 35 papers) had an overall high risk of bias judgment. The primary concerns across these studies were the lack of blinding of patients, healthcare providers and researchers, as well as the lack of blinding of the outcome assessment. Consequently, most of the high risk is contained in the fourth domain ‘blinding of

outcome assessment'. In addition, allocation sequence of patients to either the IG or CG was not always concealed and both patients and researchers were aware of patients' assignment to the intervention. Furthermore, one study raised some concerns [62] for risk of bias, while another was found to be of low risk [64]. Figure 2 and Appendix F show the risk of bias judgments across studies.

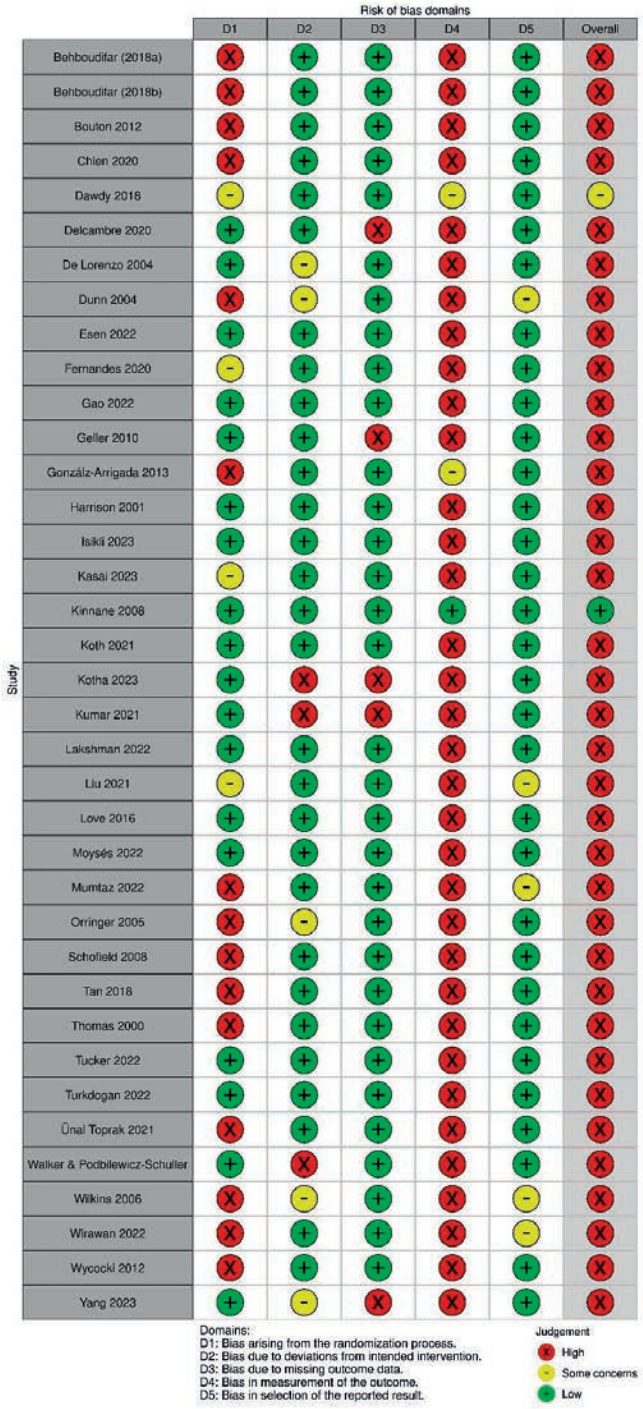


Figure 2. Risk of Bias of the included studies.

DISCUSSION AND CONCLUSION

Discussion

Principal findings

This systematic review assessed the effectiveness of using audiovisuals in delivering pre-treatment information to adult patients with cancer. By categorizing outcomes into 'immediate', 'intermediate', and long-term', we aimed to deepen our understanding of the effectiveness of using audiovisuals to achieve the goals established by the Six Function Model of Medical Communication [31]. Our review suggests that using audiovisuals for patient education in oncology holds promise for improving specific short-term outcomes. The most positive effects of using audiovisuals were found on patients' immediate knowledge and on the intermediate outcomes of knowledge, understanding, anxiety, and physiological responses (i.e., heart rate, blood pressure, respiratory rate), particularly when comparing the addition of an audiovisual to SC with SC alone (i.e., verbal information from the healthcare provider). No other overall benefits of using audiovisuals were found when, for instance, both the IG and CG received supplementary education material. Additionally, few studies found opposite effects in favor of the CG, such as a positive effect on intermediate anxiety and distress after being exposed in favor of WPM as compared to a video [56,57,60,73]. The majority of all the patient outcomes were measured between 24 hours and three weeks after exposure to the audiovisual (categorized as 'intermediate outcomes'). Long-term outcomes, if measured at all, were primarily measured in only one study, which involved the continued measurement of an outcome over several time points. Only five studies measured the impact of using an audiovisual over an extended period, confirming the scarcity of longitudinal evidence [78], with no overall effect in favor of the IG receiving an audiovisual.

Heterogeneity among studies

Our results should be interpreted with caution as we observed not only a large variation in study methodology (e.g., study design, type of measurements, time points of measurements, patient populations), but also in the type of intervention (e.g., communication formats), and the characteristics and content of the audiovisuals, reflecting the heterogeneity in study findings and the difficulty of comparing and interpreting them. For instance, we found that twenty studies tested their intervention using randomization within a single center [42,44–46,49–54,62–68,74,76,77], while seven (comprising 8 papers) did so across multiple centers [47,48,56,57,69,70,73,75] and nine did not employ randomization by including a CG and IG sequentially [41,43,55,58–61,72]. There was often a lack of clear explanations for when and why certain outcomes were measured, with several studies using self-developed or different instruments to measure the same outcomes. None of the included studies

provided justification for their selection of measured time points, and not all assessed patient outcomes were substantiated. In addition, a wide variety of different patient outcomes were measured across the three time categories, showing inconsistencies in prioritization among studies. Yet, it is important to prioritize outcomes and measure them at set time points, not only to provide a basis for evidence-building in the field, but also to further clarify the actual effectiveness of medical communication [31], including the added value of using audiovisuals for oncology patients. Scholars should thus first consider their priorities while developing future studies. Furthermore, while eleven studies included study populations that consisted of patients with different cancer diagnoses [42,52,58,60,61,63–65,69,72,75] and showed that study findings applied to all types, five studies only included patients with sex-specific malignancies [49,62,73,76,77]. Fifteen studies compared using audiovisuals in addition to SC with SC alone [41–55], while nine provided both IG and CG with an alternative, additional educational intervention such as WPM, a general information video, nurse education, or psychosocial support [59,63,64,66,68,71–73,77]. Nine studies (comprising ten papers) provided the CG with WPM as alternative intervention in addition to SC [56–58,60–62,65,67,69,70]. Additionally, nine papers did not report on how the audiovisuals were created [45,47,51,53,58,63,66,70,74], whereas the remaining 27 (comprising 28 papers) studies used a co-creation approach for this. Stakeholder involvement during development was sometimes limited to the researchers themselves, with only a few cases involving a range of experts from different backgrounds were engaged, of which nine included patients [46,55,59,61,62,69,71,73,75]. Only three studies clearly indicated the use of theory in developing their audiovisual [70,76,77], showing a lack of guidance during development. Moreover, our assessment of the methodological quality resulted in an overall high risk of bias in the majority of the studies (n = 34), particularly due to patients' potential awareness of the intervention and lack of blinding to patients' allocation in either IG or CG. Although these two shortcomings could affect interpretation and validity of the results, they are inherent challenges in research involving exposure to stimulus materials such as audiovisual material. Consequently, no meta-analysis was conducted because of the high methodological heterogeneity and many studies having a high risk of bias.

In addition to the wide variety of study methods and types of interventions, we found that the characteristics of the audiovisuals varied, with several studies failing to report on the content and form of the visuals, audio, or frequency of access to the audiovisuals (Table 2). Most commonly, videos were recorded in the form of film, often supplemented with additional text, images, photos, and/or graphs. Six studies chose to include animated elements in their videos or to use an entirely animated video format as an intervention, something we predominantly observed in recent studies [49,50,55,58,60,77]. Diverse topics were discussed in all the different videos, including disease, treatment, side effects, self-management, preparation instructions, frequently asked questions, misconceptions, and previous experiences. Additionally, some videos showed real patients and healthcare

providers, whereas other showed actors on screen, accompanied by voice-over or speech spoken by the person(s) in frame. Besides variation in content and topics, there was also great variety in the delivery of the audiovisual. Patients watched it at home, on-site, or could choose their preferred viewing location, which seemed to determine how often they could watch it. A final variation we found was related to the types of technology used in the studies, with more recent studies using updated and advanced methods, such as VR [42], to provide the audiovisual(s) (Table 2).

Eventually, when we systematically compared studies that found a significant effect of the audiovisual to those that did not, we did not identify any consistent patterns predicting these outcomes, except that the addition of an audiovisual, such as video, to SC resulted in positive effects compared to SC alone. No other consistencies were found in terms of study methodology, type of intervention, or characteristics of the audiovisuals that could shed light on the conditions under which audiovisuals are specifically effective. As a result, we are unable to provide a specific explanation for when audiovisuals are effective.

Interpreting and comparing to other studies

While our systematic review found no consistent support for using audiovisuals to deliver pre-treatment information to oncology patients, previous non-clinical experimental studies have suggested their potential benefits, including increasing patients' information recall [79–82], satisfaction [79,83], informed decision-making [79], and reducing cognitive load and decisional conflict [83]. Non-clinical experiments allow researchers to investigate the true effectiveness of an intervention in a controlled environment, whereas clinical experiments may be interfered with by other possible confounding factors that could significantly influence study findings, for example, patients not watching the full-length of a video [65]. It is possible that environmental or situational conditions may have potentially influenced the results of the included studies. Another explanation for studies not finding more significant positive effects may be related to the type of intervention or the quality of the audiovisual, as other educational modalities might have also been effective in delivering pre-treatment information, not necessarily only the audiovisual(s). This may have resulted in improved patient outcomes in both study arms, with only marginal additional improvements from viewing the interventional audiovisual. In fact, we often found that studies did not report significant differences in favor of audiovisuals when patients in both groups received additional education alongside SC.

Despite the aforementioned considerations, audiovisuals as supplementary material to SC may be particularly beneficial for some specific groups of patients. Previous research has shown that audiovisuals are more effective than WPM to educate people with limited health literacy, while this difference was not found in people with high health literacy [82]. However, none of the studies we included in this review did subgroup analyses for people

with different health literacy or educational levels. Moreover, prior studies have shown that tailoring the delivery mode (i.e., mode tailoring) of educational material can be an effective way to enhance the effectiveness of medical communication. To illustrate, an online experiment showed that modalities were significantly more effective in terms of information recall and intention to perform breast self-examination when people were exposed to their preferred modality [84]. This could be explained by the fact that people have different learning styles and different preferences for how they prefer to receive patient education, sometimes due to sensory limitations [85,86]. Similarly, other experimental studies have shown that people benefit from information delivered in a mode-tailored manner, with audiovisuals significantly outperforming other modalities, such as text, although this was not the case in all studies [79–81,87–89]. Hence, audiovisuals could be mostly beneficial for those who prefer and learn best from auditory and visual input. In particular the provision of additional information through patient education materials by itself may results in patient benefits compared to standard verbal care alone. Consequently, it would be worthwhile for future experimental clinical research to further investigate the possibilities of mode-tailoring and to distinguish between different patient groups (e.g., health literacy, cancer types, learning style).

Limitations

Our review has some limitations. First, utilizing de Haes' and Bensing's Six Functions Model of Medical Communication [31], designed for interpersonal communication, in the context of audiovisuals as mediated patient education presented challenges regarding the categorization of study results into 'immediate', 'intermediate', or 'long-term' outcomes. The model does not provide any specifications for temporal cut-offs, prompting us to create the three temporal categories to distinguish the several diverse patient outcomes. Additionally, only one of the two reviewers (SD) determined whether a patient outcome belonged to the immediate, intermediate, or long-term outcome category, which made the categorization of the outcomes solely dependent on a single judgment. Nevertheless, while it is possible that some findings could have been categorized elsewhere, the framework contributed to disentangling the many diverse patient outcomes. Third, we did not include qualitative research and conference papers, which could have provided a deeper understanding of the effectiveness of audiovisuals. Finally, it may be possible that our review lacks studies that did not report on any significant effect due to publication bias. Despite these limitations, this review offers an insightful overview of the current body of research and shows the complexity of providing audiovisual medical communication within oncology.

CONCLUSION

This systematic review offers a comprehensive summary of the current evidence regarding the use of audiovisuals in educating adult patients with cancer. Our findings suggest that audiovisuals can potentially benefit oncology patients' knowledge, understanding, anxiety, and physiological responses in the short term, particularly when compared to standard care consisting of verbal information alone. Nevertheless, the large heterogeneity in the design and quality of the studies made it challenging to understand the various results and to find any specific explanations for the effectiveness of audiovisuals. As a consequence, this forces us to interpret our findings with caution, while also providing recommendations for future research to improve study design and quality.

PRACTICAL IMPLICATIONS

Overall, in principle healthcare providers can enhance the delivery of information provision by integrating audiovisuals into standard care. The patient-provider interaction remains critical to the decision-making process. Although standard care typically relies on verbal interpersonal communication, integrating audiovisuals can enable tailoring the delivery of information to better suit patients' needs and preferences. This implies that personalizing the delivery mode of mediated patient education is essential to achieving the best patient outcomes, something medical education scholars should consider incorporating in their shared decision-making education for healthcare providers. Healthcare providers should be able to determine the most effective way to inform their patients, by considering who, how, and when to use supplementary audiovisuals as some patients could potentially benefit more from its usage than others. This tailoring approach should contribute to delivering higher-quality patient-centered care. However, there is still room for improvement, and with our review, we revealed some essential opportunities for future research. For instance, more high-quality and longitudinal research, such as RCTs examining patient outcomes over longer periods, are needed with an emphasis on comparing standard care counseling with and without the use of audiovisual resources, investigating the same patient outcomes measured at similar time points and with the same measurement instruments. Additionally, future studies should explore which types of audiovisuals (i.e., characteristics) are the most effective for which patients (i.e., health literacy, education, learning style, cancer type), as well as investigate the moment and methods they should be integrated into daily clinical practice. Therefore, ultimately, we recommend future studies to be more thoughtful when making decisions during study development, specifically related to study methodology to avoid publication bias, the types of intervention (e.g., audiovisuals versus alternative modalities), the characteristics of audiovisuals (i.e., visuals, audio), the use of guiding theory, and the involvement of

various stakeholders (e.g., health care providers, patients, and health communication experts) in the process of development of audiovisual material.

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APPENDICES

Appendix A. Search strategy

Medline via Ovid

#	Query
1	exp neoplasms/ or neoplas*.ti,ab,kf. or cancer*.ti,ab,kf. or tumor*.ti,ab,kf. or tumour*.ti,ab,kf. or maligna*.ti,ab,kf. or metasta*.ti,ab,kf. or blastoma*.ti,ab,kf. or carcinoma*.ti,ab,kf. or leukemi*.ti,ab,kf. or lymphoma*.ti,ab,kf. or melanoma*.ti,ab,kf. or sarcoma*.ti,ab,kf. or oncolog*.ti,ab,kf.
2	"Patient Simulation"/ or ((actor or analogue or healthy or naive or placebo or simulated or standardized or standardised) adj1 patient*).ti,ab,kf. or ((healthy or lay or naive or simulated) adj1 (participant* or person* or subject*)).ti,ab,kf.
3	radiotherapy/ or radiotherap*.ti,ab,kf. or "radiation therap*".ti,ab,kf. or brachytherap*.ti,ab,kf. or chemoradiotherap*.ti,ab,kf. or radiochemotherap*.ti,ab,kf.
4	Neoplasms/dt or ("drug therapy"/ and exp neoplasms/) or chemotherap*.ti,ab,kf.
5	exp immunotherapy/ or immunotherap*.ti,ab,kf. or "immune therap*".ti,ab,kf. or radioimmunotherap*.ti,ab,kf. or immunoradiotherap*.ti,ab,kf.
6	or/1-5 [cancer OR simulated patient OR radiotherapy OR chemotherapy OR immunotherapy]
7	"Audiovisual Aids"/ or exp multimedia/ or exp Gamification/ or exp "video recording"/ or animat*.ti,ab,kf. or audiovisual.ti,ab,kf. or avm.ti,ab,kf. or "digital educational material*".ti,ab,kf. or "digital media".ti,ab,kf. or film*.ti,ab,kf. or gamification.ti,ab,kf. or multimedia.ti,ab,kf. or video.ti,ab,kf. or videos.ti,ab,kf. or videorecording*.ti,ab,kf. or Youtube.ti,ab,kf.
8	exp "Patient Education as Topic"/ or exp "Health Literacy"/ or "decision making"/ or ((patient or patients) adj5 (educat* or instruct* or inform* or understand* or knowledge or empowerment)).ti,ab,kf. or "health literacy".ti,ab,kf. or "health education".ti,ab,kf. or "informed decision making".ti,ab,kf.
9	(satisfaction or "client attitude*" or "patient attitude*").ti,ab,kf. or exp "Patient Satisfaction"/ or usability.ti,ab,kf. or usefulness.ti,ab,kf. or exp "Quality of Life"/ or "quality of life".ti,ab,kf. or qol.ti,ab,kf. or hrqol.ti,ab,kf. or ((behavior or behaviour) adj5 (change* or changing)).ti,ab,kf. or ((lifestyle or "life style") adj5 (change* or changing)).ti,ab,kf. or exp "Health Behavior"/ or "health behavior*".ti,ab,kf. or "health behaviour*".ti,ab,kf. or "self efficac*".ti,ab,kf. or exp "Self Efficacy"/ or "self management".ti,ab,kf. or "self care".ti,ab,kf. or exp "Self Care"/ or exp "Independent Living"/ or "independent living".ti,ab,kf. or "living independent*".ti,ab,kf. or "self administration".ti,ab,kf. or "self medicati*".ti,ab,kf. or (treatment adj5 (compliance or "non compliance" or noncompliance or adherence or "non adherence" or nonadherence)).ti,ab,kf. or (medication adj5 (compliance or "non compliance" or noncompliance or adherence or "non adherence" or nonadherence)).ti,ab,kf. or exp "Medication Adherence"/ or anxiety.ti,ab,kf. or exp "Anxiety"/ or exp "Stress, Psychological"/ or (stress adj5 (emotional or psychological)).ti,ab,kf. or uncertainty/ or uncertainty.ti,ab,kf. or recall.ti,ab,kf. or knowledge.ti,ab,kf. or exp "Knowledge"/ or exp "Comprehension"/ or comprehension.ti,ab,kf. or comprehending.ti,ab,kf. or understanding.ti,ab,kf. or "patient participation".ti,ab,kf. or exp "Patient Participation"/ or "patient empowerment".ti,ab,kf. or "decision making".ti,ab,kf. or exp "Patient-Centered Care"/ or "patient centered".ti,ab,kf.

10 or/8-9 [patient education OR outcomes Bolle, 2015]

11 6 and 7 and 10 [population AND audiovisuals AND outcomes]

Embase via embase.com

#	Query
1	'neoplasms'/exp OR neoplas*:ti,ab,kw OR cancer*:ti,ab,kw OR tumor*:ti,ab,kw OR tumour*:ti,ab,kw OR maligna*:ti,ab,kw OR metasta*:ti,ab,kw OR blastoma*:ti,ab,kw OR carcinoma*:ti,ab,kw OR leukemi*:ti,ab,kw OR lymphoma*:ti,ab,kw OR melanoma*:ti,ab,kw OR sarcoma*:ti,ab,kw OR oncolog*:ti,ab,kw
2	'patient simulation'/exp OR (((actor OR analogue OR healthy OR naive OR placebo OR simulated OR standardized OR standardised) NEAR/1 patient*):ti,ab,kw) OR (((healthy OR lay OR naive OR simulated) NEAR/1 (participant* OR person* OR subject*)):ti,ab,kw)
3	'radiotherapy'/exp OR radiotherap*:ti,ab,kw OR 'radiation therap*':ti,ab,kw OR brachytherap*:ti,ab,kw OR chemoradiotherap*:ti,ab,kw OR radiochemotherap*:ti,ab,kw
4	'chemotherapy'/exp OR chemotherap*:ti,ab,kw
5	'immunotherapy'/exp OR immunotherap*:ti,ab,kw OR 'immune therap*':ti,ab,kw OR radioimmunotherap*:ti,ab,kw OR immunoradiotherap*:ti,ab,kw
6	#1 OR #2 OR #3 OR #4 OR #5
7	'audiovisual aid'/exp OR 'audiovisual equipment'/de OR 'multimedia'/exp OR 'videotape'/exp OR 'gamification'/exp OR animat*:ti,ab,kw OR audiovisual:ti,ab,kw OR avm:ti,ab,kw OR 'digital educational material*':ti,ab,kw OR 'digital media':ti,ab,kw OR film*:ti,ab,kw OR gamification:ti,ab,kw OR multimedia:ti,ab,kw OR video:ti,ab,kw OR videos:ti,ab,kw OR videorecording*:ti,ab,kw OR youtube:ti,ab,kw
8	'patient education'/exp OR 'health literacy'/exp OR 'decision making'/exp OR (((patient OR patients) NEAR/5 (educat* OR instruct* OR inform* OR understand* OR knowledge OR empowerment)):ti,ab,kw) OR 'health literacy':ti,ab,kw OR 'health education':ti,ab,kw OR 'informed decision making':ti,ab,kw
9	satisfaction:ti,ab,kw OR 'client attitude*':ti,ab,kw OR 'patient attitude*':ti,ab,kw OR 'patient satisfaction'/exp OR 'usability':ti,ab,kw OR usefulness:ti,ab,kw OR 'quality of life'/exp OR 'quality of life':ti,ab,kw OR qol:ti,ab,kw OR hrqol:ti,ab,kw OR (((behavior OR behaviour) NEAR/5 (change* OR changing)):ti,ab,kw) OR (((lifestyle OR 'life style') NEAR/5 (change* OR changing)):ti,ab,kw) OR 'health behavior'/exp OR 'health behavior*':ti,ab,kw OR 'health behaviour*':ti,ab,kw OR 'self efficac*':ti,ab,kw OR 'self concept'/exp OR 'self management':ti,ab,kw OR 'self care':ti,ab,kw OR 'self care'/exp OR 'independent living'/exp OR 'independent living':ti,ab,kw OR 'living independent*':ti,ab,kw OR 'self administration':ti,ab,kw OR 'self medicati*':ti,ab,kw OR ((treatment NEAR/5 (compliance OR 'non compliance' OR noncompliance OR adherence OR 'non adherence' OR nonadherence)):ti,ab,kw) OR ((medication NEAR/5 (compliance OR 'non compliance' OR noncompliance OR adherence OR 'non adherence' OR nonadherence)):ti,ab,kw) OR 'medication compliance'/exp OR anxiety:ti,ab,kw OR 'anxiety'/exp OR 'mental stress'/exp OR ((stress NEAR/5 (emotional OR psychological)):ti,ab,kw) OR 'uncertainty'/exp OR uncertainty:ti,ab,kw OR recall:ti,ab,kw OR knowledge:ti,ab,kw OR 'knowledge'/de OR 'comprehension'/exp OR comprehension:ti,ab,kw OR understanding:ti,ab,kw OR 'patient participation':ti,ab,kw OR 'patient participation'/exp OR 'patient empowerment':ti,ab,kw OR 'decision making':ti,ab,kw OR 'patient centered':ti,ab,kw
10	#8 OR #9
11	#6 AND #7 AND #10
12	#6 AND #7 AND #10 AND [embase]/lim
13	#12 NOT ('conference abstract'/it OR 'conference paper'/it OR 'conference review'/it)

PsycINFO via Ovid

#	Query
1a	cancer*.ti,ab,id. OR exp neoplasms/ OR neoplasm*.ti,ab,id. OR tumor*.ti,ab,id. OR tumour*.ti,ab,id. OR maligna*.ti,ab,id. OR metasta*.ti,ab,id. OR blastoma*.ti,ab,id. OR carcinoma*.ti,ab,id. OR leukemi*.ti,ab,id. OR lymphoma*.ti,ab,id. OR melanoma*.ti,ab,id. OR sarcoma*.ti,ab,id. OR oncology/ OR oncolog*.ti,ab,id.
1b	patient simulation.ti,ab,id. OR ((actor or analogue or healthy or naive or placebo or simulated or standardized or standardised) adj1 patient*).ti,ab,id. OR ((healthy or lay or naive or simulated) adj1 (participant* or person* or subject*)).ti,ab,id.
1c	radiation therapy/ OR radiotherap*.ti,ab,id. OR radiation therap*.ti,ab,id. OR brachytherap*.ti,ab,id. OR chemoradiotherap*.ti,ab,id. OR radiochemotherap*.ti,ab,id. OR
1d	(drug therapy/ AND exp neoplasms/) OR chemotherap*.ti,ab,id.
1e	exp Immunotherapy/ OR immunotherap*.ti,ab,id. OR immune therap*.ti,ab,id. OR radioimmunotherap*.ti,ab,id. OR immunoradiotherap*.ti,ab,id. OR
2	Animation.ti,ab,id. OR Animation/ OR Audiovisual.ti,ab,id. OR Audiovisual Communications Media/ OR avm.ti,ab,id. Digital educational material.ti,ab,id. OR Digital intervention/ OR Digital media/ OR Digital media.ti,ab,id. OR Digital video/ OR Educational audiovisual aids/ OR film*.ti,ab,id. OR films/ OR Gamification.ti,ab,id. OR multimedia/ OR Multimedia.ti,ab,id. OR Televised instruction/ OR Video.ti,ab,id. OR Videos.ti,ab,id. OR videorecording*.ti,ab,id. OR videotapes/ OR youtube/
3a	exp Client Education/ OR exp Health Literacy/ OR exp Decision Making/ OR decision making.ti,ab,id. OR ((patient or patients) adj5 (educat* or instruct* or inform* or understand* or knowledge or empowerment)).ti,ab,ti. OR health literacy.ti,ab,id. OR health education.ti,ab,id. OR exp Health Education/ OR informed decision making.ti,ab,id.
3b	satisfaction.ti,ab,id. OR Patient attitude*.ti,ab,id. OR client attitude*.ti,ab,id. OR Exp Client attitudes/ OR exp client satisfaction/ OR usability.ti,ab,id. OR usefulness.ti,ab,id. OR exp "Quality of Life"/ OR Quality of life.ti,ab,id. OR qol.ti,ab,id. OR Hrqol.ti,ab,id. OR “Health related quality of life”/ OR ((behavior OR behaviour).ti,ab,id. ADJ5 (change* OR changing).ti,ab,id.) OR Exp Behavior change/ OR ((lifestyle OR life style).ti,ab,id. ADJ5 (change* OR changing).ti,ab,id.) OR exp Health Behavior/ OR health behavior*.ti,ab,id. OR health behaviour*.ti,ab,id. OR self efficac*.ti,ab,id. OR exp Self Efficacy/ OR self management.ti,ab,id. OR Exp self-management/ OR self care.ti,ab,id. OR exp Self Care/ OR exp Self-care skills/ OR independent living.ti,ab,id. OR living independent*.ti,ab,id. OR self administration.ti,ab,id. OR self medicat*.ti,ab,id. OR Exp self-medication/ OR (treatment.ti,ab,id. ADJ5 (compliance OR non compliance OR noncompliance OR adherence OR non adherence OR nonadherence).ti,ab,id.) OR (medication.ti,ab,id. ADJ5 (compliance OR non compliance OR noncompliance OR adherence OR non adherence OR nonadherence).ti,ab,id.) OR medication adherence.ti,ab,id. OR anxiety.ti,ab,id. OR exp Anxiety/ OR exp Psychological stress/ OR (stress.ti,ab,id. ADJ5 (emotional OR psychological).ti,ab,id.) OR uncertainty/ OR Uncertainty.ti,ab,id. OR recall.ti,ab,id. OR Exp “Recall (learning)”/ OR knowledge.ti,ab,id. OR exp Health Knowledge/ OR exp Comprehension/ OR comprehension.ti,ab,id. OR Comprehending.ti,ab,id. OR understanding.ti,ab,id. OR patient participation.ti,ab,id. OR exp Client Participation/ OR patient empowerment.ti,ab,id. OR exp Patient Centered Care/ OR patient centered.ti,ab,id.

CINHAL via Ebsco

#	Query
1a	(MH “Neoplasms+”) OR (MH “Leukemia+”) OR (MH “Lymphoma+”) OR (MH “Oncology+”) OR TI (neoplas* OR cancer* OR tumor* OR tumour* OR maligna* OR metasta* OR blastoma* OR carcinoma* OR leukemi* OR lymphoma* OR melanoma* OR sarcoma* OR oncolog*) OR AB (neoplas* OR cancer* OR tumor* OR tumour* OR maligna* OR metasta* OR blastoma* OR carcinoma* OR leukemi* OR lymphoma* OR melanoma* OR sarcoma* OR oncolog*)
1b	(MH “Patient Simulation”) OR TI ((actor OR analogue OR healthy OR naive OR placebo OR simulated OR standardized OR standardised) N1 (patient*)) OR AB ((actor OR analogue OR healthy OR naive OR placebo OR simulated OR standardized OR standardised) N1 (patient*)) OR TI ((healthy OR lay OR naive OR simulated) N1 (participant* OR person* OR subject*)) OR AB ((healthy OR lay OR naive OR simulated) N1 (participant* OR person* OR subject*))
1c	(MH “radiotherapy+”) OR (MH “brachytherapy”) OR (MH “Chemoradiotherapy+”) OR TI (radiotherap* OR “radiation therap*” OR brachytherap* OR chemoradiotherap* OR radiochemotherap*) OR AB (radiotherap* OR “radiation therap*” OR brachytherap* OR chemoradiotherap* OR radiochemotherap*)
1d	((MH “Drug Therapy+”) AND (MH “Neoplasms+”)) OR (MH “Chemotherapy, Cancer+”) OR TI chemotherap* OR AB chemotherap*
1e	(MH “Immunotherapy+”) OR (MH “Radioimmunotherapy”) OR TI (immunotherap* OR “immune therap*” OR radioimmunotherap* OR immunoradiotherap*) OR AB (immunotherap* OR “immune therap*” OR radioimmunotherap* OR immunoradiotherap*)
2	(MH “Audiovisuals”) OR (MH “Multimedia+”) OR (MH “Gamification+”) OR (MH “Videorecording+”) OR TI (animat* OR audiovisual* OR avm OR “digital educational material*” OR “digital media” OR film* OR gamification OR multimedia OR video OR videos OR videorecording* OR Youtube) OR AB (animat* OR audiovisual* OR avm OR “digital educational material*” OR “digital media” OR film* OR gamification OR multimedia OR video OR videos OR videorecording* OR Youtube)
3a	(MH “Patient Education+”) OR (MH “Health Literacy”) OR (MH “Decision Making, Patient+”) OR (MH “Health Education+”) OR TI (((patient OR patients) N5 (educat* OR instruct* OR inform* OR understand* OR knowledge OR empowerment))) OR AB (((patient OR patients) N5 (educat* OR instruct* OR inform* OR understand* OR knowledge OR empowerment))) OR TI (“health literacy” OR “health education” OR “informed decision making”) OR AB (“health literacy” OR “health education” OR “informed decision making”)

3b	(MH “Patient Satisfaction+”) OR (MH “Consumer Attitudes”) OR (MH “Patient Attitudes”) OR (MH “Quality of Life+”) OR (MH “Health Behavior+”) OR (MH “Self-Efficacy”) OR (MH “Self-Management”) OR (MH “Self Care+”) OR (MH “Self Administration+”) OR (MH “Self Medication”) OR (MH “Medication Compliance”) OR (MH “Anxiety+”) OR (MH “Stress, Physiological+”) OR (MH “Uncertainty”) OR (MH “Knowledge+”) OR (MH “Consumer Participation”) OR (MH “Patient Centered Care”) OR TI (satisfaction OR “client attitude*” OR “patient attitude*” OR “usability” OR usefulness OR “quality of life” OR qol OR hrqol OR “health behavior*” OR “health behaviour*” OR “self efficac*” OR “self management” OR “self care” OR “Independent Living” OR “living independent*” OR “self administration” OR “self medicat*” OR anxiety OR uncertainty OR recall OR knowledge OR comprehension OR comprehending OR understanding OR “patient participation” OR “patient empowerment” OR “decision making” OR “patient centered”) OR AB (satisfaction OR “client attitude*” OR “patient attitude*” OR “usability” OR usefulness OR “quality of life” OR qol OR hrqol OR “health behavior*” OR “health behaviour*” OR “self efficac*” OR “self management” OR “self care” OR “Independent Living” OR “living independent*” OR “self administration” OR “self medicat*” OR anxiety OR uncertainty OR recall OR knowledge OR comprehension OR comprehending OR understanding OR “patient participation” OR “patient empowerment” OR “decision making” OR “patient centered”) OR TI (((behavior OR behaviour) N5 (change* OR changing)) OR AB (((behavior OR behaviour) N5 (change* OR changing) OR TI (((lifestyle OR life style) N5 (change* OR changing)) OR AB (((lifestyle OR life style) N5 (change* OR changing)) OR TI ((treatment N5 (compliance OR non compliance OR noncompliance OR adherence OR non adherence OR nonadherence))) OR AB ((treatment N5 (compliance OR non compliance OR noncompliance OR adherence OR non adherence OR nonadherence))) OR TI ((medication N5 (compliance OR non compliance OR noncompliance OR adherence OR non adherence OR nonadherence))) OR AB ((medication N5 (compliance OR non compliance OR noncompliance OR adherence OR non adherence OR nonadherence))) OR TI ((stress N5 (emotional OR psychological))) OR AB ((stress N5 (emotional OR psychological)))

Communication & Mass Media Complete (CMMC) via Ebsco

#	Query
1a	TI (cancer* OR neoplasm* OR tumor* OR tumour* OR maligna* OR metasta* OR blastoma* OR carcinoma* OR leukemi* OR lymphoma* OR melanoma* OR sarcoma* OR oncolog*) OR SU (cancer* OR neoplasm* OR tumor* OR tumour* OR maligna* OR metasta* OR blastoma* OR carcinoma* OR leukemi* OR lymphoma* OR melanoma* OR sarcoma* OR oncolog*) OR AB (cancer* OR neoplasm* OR tumor* OR tumour* OR maligna* OR metasta* OR blastoma* OR carcinoma* OR leukemi* OR lymphoma* OR melanoma* OR sarcoma* OR oncolog*) OR KW (cancer* OR neoplasm* OR tumor* OR tumour* OR maligna* OR metasta* OR blastoma* OR carcinoma* OR leukemi* OR lymphoma* OR melanoma* OR sarcoma* OR oncolog*)
1b	TI (“patient simulation” OR ((actor or analogue or healthy or naive or placebo or simulated or standardized or standardised) N1 patient*) OR ((healthy or lay or naive or simulated) N1 (participant* or person* or subject*))) OR SU (“patient simulation” OR ((actor or analogue or healthy or naive or placebo or simulated or standardized or standardised) N1 patient*) OR ((healthy or lay or naive or simulated) N1 (participant* or person* or subject*))) OR AB (“patient simulation” OR ((actor or analogue or healthy or naive or placebo or simulated or standardized or standardised) N1 patient*) OR ((healthy or lay or naive or simulated) N1 (participant* or person* or subject*))) OR KW (“patient simulation” OR ((actor or analogue or healthy or naive or placebo or simulated or standardized or standardised) N1 patient*) OR ((healthy or lay or naive or simulated) N1 (participant* or person* or subject*)))
1cde	TI (radiotherap* OR “radiation therap*” OR brachytherap* OR chemoradiotherap* OR radiochemotherap* OR chemotherap* OR immunotherap* OR immune therap* OR radioimmunotherap* OR immunoradiotherap*) OR SU (radiotherap* OR “radiation therap*” OR brachytherap* OR chemoradiotherap* OR radiochemotherap* OR chemotherap* OR immunotherap* OR immune therap* OR radioimmunotherap* OR immunoradiotherap*) OR AB (radiotherap* OR “radiation therap*” OR brachytherap* OR chemoradiotherap* OR radiochemotherap* OR chemotherap* OR immunotherap* OR immune therap* OR radioimmunotherap* OR immunoradiotherap*) OR KW (radiotherap* OR “radiation therap*” OR brachytherap* OR chemoradiotherap* OR radiochemotherap* OR chemotherap* OR immunotherap* OR immune therap* OR radioimmunotherap* OR immunoradiotherap*)
2	TI (Animat* OR Audiovisual* OR avm OR digital N3 education* OR digital N3 intervention* OR “digital media” OR film* OR gamification OR Multimedia OR televis* N3 instruction* OR Video OR Videos OR videorecording* OR videotape* OR youtube) OR SU (Animat* OR Audiovisual* OR avm OR digital N3 education* OR digital N3 intervention* OR “digital media” OR film* OR gamification OR Multimedia OR televis* N3 instruction* OR Video OR Videos OR videorecording* OR videotape* OR youtube) OR AB (Animat* OR Audiovisual* OR avm OR digital N3 education* OR digital N3 intervention* OR “digital media” OR film* OR gamification OR Multimedia OR televis* N3 instruction* OR Video OR Videos OR videorecording* OR videotape* OR youtube) OR KW (Animat* OR Audiovisual* OR avm OR digital N3 education* OR digital N3 intervention* OR “digital media” OR film* OR gamification OR Multimedia OR televis* N3 instruction* OR Video OR Videos OR videorecording* OR videotape* OR youtube)

Note: #3a OR #3b not needed due to scope of database, and therefore limited number of hits

Appendix B. Excluded studies based on full-text review

Reason for exclusion	Author (year) – Search No. 1	Author (year) – Search No. 2
Cancer prevention/ screening	Ferris (2015),	Hecken (2023)
Interactive multimedia	Benson (2022), Diefenbach (2012), Diefenbach (2018), D'Souza (2013a, 2013b), Enzinger (2020), Huber (2013), Maslin (1998), Olver (2009), Peipert (2021), Street (1995), Sun (2017)	Marziliano (2023),
No control/ comparison group	Dharmarajan (2019), Gadler (2016), Islam (2021), McGregor (2003), Onel (1998), Pérez (2020)	
No full-text retrievable	Balazy (2019), Szumacher (2016), Vanchieri (1991)	
No pre-treatment		Amanian (2022), Baralo (2022), Neubert (2023), Ko (2023), Yan (2023)
Wrong intervention	Bol (2013), Gyomber (2010), Hansen (2018), Newsom (2018), Nguyen (2019), Rainey (1985)	Abouzian (2022), Ilie (2023), Yeo (2023)
Wrong population	Bader & Stickman (2003), Beach (2016), Mayilvaganan (2018), Munigala (2018)	Molher (2022)
Wrong publication type	Clarke (2019)	Gaitan-Herrera (2022), Leiter. (2023),
Wrong study design		Khandpur (2022), Schulz (2023)

Appendix C. Summary of findings of the immediate patient outcomes

Variable	Authors (year)	Study findings	Overall outcome
Anxiety (n=5)	Liu et al. (2021)	Significant lower anxiety score in IG than CG at T2 (p=0.018) Significant less patients anxious in IG than CG at T2 (p=0.037) NO significant difference in anxiety severity between CG and IG at T2 (p=0.574)	Sig. diff. in favor of IG
	Orringer et al. (2016)	Significant decrease in anxiety in IG and CG (p<.001) Significantly more decrease anxiety in CG than IG (p<.001)	Sig. diff in favor of CG
	Kasai et al. (2023)	NO significant difference between IG and CG (p=0.475)	Equal (ns)
	Koth et al. (2021)	NO significant improvement in IG in overall mean anxiety (p=0.118) Significantly less worry in IG than CG (p=0.038) Significantly more in IG than in CG felt steady (p=0.018) Significantly more 'never smokers' in IG than in CG had less anxiety than 'active/former smokers' (p=0.021) Significantly more patients 'with more time since diagnosis' in IG than in CG had less anxiety (p=0.008) Significantly less anxiety in married IG than in married CG (p=0.047)	Equal (ns)
	Delcambre et al. (2020)	IG had lower average anxiety score than CG (17.1, 5.73; 17,48, 5.43) out of 40 NO significant difference in average anxiety between IG and CG (p=0.626)	Equal (ns)

Knowledge / understanding (n=4)	Love et al. (2016)	NO significant difference in IG and CG in baseline knowledge Patients in IG reported increase in knowledge about treatment (92.3%) Significant larger gain in knowledge of IG (M=9, SD=3.6) (p=.0048) than in CG (M=2.9, SD=2.2)	Sig. diff. in favor of IG
	Orringer et al. (2005)	Significant increase in knowledge in IG (p<.001) Significant increase in knowledge of the control group (p<.001) NO significant difference in mean baseline melanoma knowledge between CG and IG. Significantly more knowledge increase in IG than in CG (p<.001)	Sig. diff. in favor of IG
	Kasai et al. (2023)	NO significant difference between IG and CG (p=0.168)	Equal (ns)
	Delcambre et al. (2020)	NO significant difference in overall knowledge scores between IG and CG (p=0.131) IG (7.97 out of 10) had more knowledge than CG (7.55 out of 10) Significant more knowledge in IG (p<0.001), felt more informed about risks and benefits (p=0.049)	Equal (ns)
Patient satisfaction with information (n=1)	Love et al. (2016)	NO significant difference in patient satisfaction between CG and IG in both centers (p=0.0064; p=0.0065) Patients reported higher average satisfaction (4.9±0.3) than physicians (4.3±0.7) with video Patients in IG reported ability to make informed decision (84.6%), efficiency of their clinic visit (100%), and would recommend video to friend and want videos in future (92.3%)	Equal (ns)
	Kasai et al. (2023)	NO significant difference between IG (20) and CG (21) (p=0.099)	Equal (ns)
Patient satisfaction with information material (n=1)	Walker & Podbilewicz-Schuller (2005)	Significantly more satisfaction in IG with video than in CG with pamphlet (p=.049)	Sig diff. in favor of IG
Emotional distress	Orringer et al. (2005)	Significant decline in emotional distress in IG (p<.001) Significant decline in emotional distress in CG (p<.001) Significantly more decrease in emotional distress in CG than IG (p<.001)	Sig. diff in favor of CG

Depression	Liu et al. (2021)	Significant lower depression score in IG than in CG at T2 (p=0.001) Significant less patients depressive in IG than in CG at T2 (p=0.007) NO significant difference in depression severity between CG and IG at T2 (p=0.461)	Sig. diff. in favor of IG
Physiological response	Liu et al. (2021)	Significant lower systolic blood pressure, diastolic blood pressure, and heart rate in IG than in CG at T2 (p=0.016; p=0.004; p=0.020) Significant lower cortisol in IG than CG at T2 (p=0.005)	Sig. diff. in favor of IG
Fear of pain	Isikli et al. (2023)	NO significant difference between the total scale scores (p=0.158) and the fear of mild pain (p=0.439) and the fear of medical pain (p=0.967) mean scores of the IG and CG groups Significant higher mean score of the fear of severe pain subdimension (29.79, SD 9.86) in CG than IG (24.67, SD 8.01) (p=0.011)	Equal (ns)
Pain levels	Isikli et al. (2023)	NO significant difference between IG and CG preoperative (T0) (p=0.170) NO significant difference between IG and CG postoperative (T1) (p=0.194) Significant increase in pain in CG (p=0.014) NO significant increase in pain in IG between the 2 time points (p=0.098)	Equal (ns)

Appendix D. Summary of findings of the intermediate patient outcomes

Variable	Authors (year)	Study findings	Overall outcome
Anxiety (n=14*)	Esen et al. (2023)	Significant more VFAS anxiety reduction in IG (p<0.001) Significant anxiety (STAI) reduction IG over all time points (p<.001) Significantly lower anxiety in IG than CG after video (p<0.001) and after treatment (p=0.001)	Sig. diff. in favor of IG
	Kumar et al. (2021)	NO significant differences in anxiety between CG and IG (p=.550) 46.8% of IG said video decreased anxiety either “a little” or “very much”	Equal (ns)
	Lakshman et al. (2022)	Reduction in CG and IG Significant greater reduction in IG than in CG at T2 (p=.014) and T3 (p<.001)	Sig. diff. in favor of IG
	Liu et al. (2021)	Significant lower anxiety score in IG than CG at T3 (p=0.026) Significant less patients with anxiety in IG than CG at T3 (p=0.017) NO significant difference in anxiety severity between CG and IG at T3 (p=0.292)	Sig. diff. in favor of IG
	Schofield et al. (2008)	NO significant differences between CG and IG, also not when curative/palliative patients	Equal (ns)
	Wysocki et al. (2012)	NO significant differences between CG and IG over all time-points (p=0.41, p=.3201, p=.4567, p=.6416)	Equal (ns)
	Gao et al. (2022)	Significantly lower anxiety in IG than CG (p<0.05)	Sig. diff. in favor of IG
	Behboudifar et al. Heshmati Nabavi, Heidarian Miri et al. (2018)	Significant lower anxiety in CG than IG (p=0.009)	Sig diff. in favor of CG
	Behboudifar, Heshmati Navabi, Anvari et al. (2018)	Significant lower anxiety in CG than IG (p=0.009)	Sig diff. in favor of CG
	Tan et al. (2018)	Significantly less anxiety in CG and IG over time (p<.001) NO significant difference between CG and IG (p=.403)	Equal (ns)
	De Lorenzo et al. (2004)	NO significant difference between CG, IG1, IG2	Equal (ns)
	Harrison et al. (2001)	NO significant change in anxiety in CG and IG over all three assessment points (p=.34) NO significant reduction in worry levels IG and CG from baseline (p=0.53, p=0.44) NO significant difference in reduction in worry levels between IG and CG (p=0.94) Only decrease in anxiety on last day treatment and maintained in IG	Equal (ns)

Variable	Authors (year)	Study findings	Overall outcome
	Thomas et al. (2000)	Significantly less anxiety in IG than CG during treatment (p=.001) Significant decrease in anxiety between T0 > T1 for IG (p<.001), not in CG (this even increased) (p=.104) Significantly less people with anxiety in IG than CG (p=0.001)	Sig. diff. in favor of IG
	Wilkins et al. (2006)	NO significant difference between CG and IG (p=.20)	Equal (ns)
	Fernandes et al. (2020)	NO significant difference for anxiety (p=.1832) and depression (p=.2641) between CG and IG NO significant difference for UW-QOLv4 scores between CG and IG (p=.5148) Significantly more reported being less scared and less anxious in IG and CG at T1 (P=0.0018; p<0.0001)	Equal (ns)
Knowledge / understanding (n=13)	Kumar et al. (2021)	More knowledge of RT in IG (p=0.009) Significantly more patients in IG than CG reported confidence in knowledge of RT side effects (p=0.012), RT process (p=0.008)	Sig. diff. in favor of IG
	Bouton et al. (2012)	Significantly more correct answers from IG than CG (p=0.0007)	Sig. diff in favor of IG
	Gao et al. (2022)	Significantly more comprehension in IG than CG (p<0.05)	Sig. diff in favor of IG
	Orringer et al. (2005)	Significant increase in knowledge in IG (p<.001) Significant increase in knowledge in CG (p<.001) NO significant difference in mean baseline melanoma knowledge between CG and IG. Significantly more knowledge increase IG than CG (p<.001)	Sig. diff. in favor of IG
	Gonzales-Arriagada et al (2013)	At Pre-RT - Better in IG than CG At Pre-RT - Significant question only #8 “loss of food taste due to RT” (p=.0318) At Pre-RT - Significant increase in IG with fundamental education level (p=0.0095) At Post -RT - NO significant difference between CG and IG	Equal (ns)
	Tucker et al. (2022)	NO significant difference in comprehension over time in both IG and CG (p=0.84) or between IG and CG (p=0.23)	Equal (ns)
	Wysocki et al. (2012)	NO significant differences between CG and IG (p=.0101, p=.0367, p=.4509) in knowledge (subjective), but lower in IG Paradoxically the subjective knowledge level was lower in the intervention group at all time points; however, the difference between the groups became smaller over time NO significant differences in knowledge (objective) were observed between CG and IG at all time-points.	Equal (ns)

Variable	Authors (year)	Study findings	Overall outcome
	Dunn et al. (2004)	NO significant effect of videotape (p=0.07; p=0.19) Knowledge improved in IG and CG	Equal (ns)
	Yang et al. (2023)	Significantly more understanding of what radiotherapy is in CG than CG (p=0.0001)	Sig. diff. in favor of CG
	Tan et al. (2018)	Significant interaction effect of group and time (p=.008) NO significant difference between CG and IG (p=.126) Significantly more knowledge in CG and IG (p=.001) over time, but more in IG	Equal (ns)
	Wilkins et al. (2006)	NO significant difference between CG and IG (p=.89)	Equal (ns)
	Fernandes et al. (2020)	Better understanding of IG in all phases Significant better understanding in IG only at T2 (p=.0024) Significant better understanding IG for question #3 “need for dental evaluation” (p≤.0001) Significant improvement understanding at T1 for CG and IG NO significant difference at T3 between CG and IG (p>.05) Significant effect of educational level at T3 (less educated better understanding; more in IG) (p=0.0245) NO significant difference between IG and CG overall (p>0.05)	Equal (ns)
	Geller et al. (2010)	No increase in cancer knowledge of placebo group, but attitudes about learning about cancer nearly unanimously more favorable Significantly more answers correct by IG than CG (p=.0004)	Sig. diff. in favor of IG

Satisfaction with consultation (n=7)	Kumar et al. (2021)	NO significant difference between IG and CG, but all satisfied with consult (p=.457) The majority in CG and IG were extremely satisfied with their visit (p=.459)	Equal (ns)
	Schofield et al. (2008)	Significantly more satisfied palliative patients in IG than CG (p=.026). NO significant differences for curative patients between IC and CG	Equal (ns)
	Tucker et al. (2022)	Significant more satisfaction in CG than in IG ($p<0.01$ & $p=0.04$)	Sig. diff. in favor of CG
	Walker-Podbilewicz-Schuller (2005)	NO significant main effect of IG Significantly more satisfaction among minorities in IG than minorities in CG (p=.007)	Equal (ns)
	Tan et al. (2018)	NO significant difference between CG and IG (p=.29) Both groups generally satisfied with the nature of surgery decision	Equal (ns)
	Wilkins et al. (2006)	NO significant difference between CG and IG (p=0.24)	Equal (ns)

Variable	Authors (year)	Study findings	Overall outcome
	Thomas et al. (2000)	Significantly more people in IG found video helpful than not (p<0.001) Significantly more satisfaction with the information in IG than CG (p <.001)	Sig. more in IG
Psychological distress (n=5)	Walker & Podbilewicz-Schuller (2005)	Distress at follow-up was very strongly predicted by baseline distress NO significant difference between CG and IG NO significance, but less distress in unmarried IG than unmarried in CG	Equal (ns)
	Dunn et al (2004)	NO significant effect of videotape (p=0.61; p=0.70) Reduction of distress in IG and CG	Equal (ns)
	Kotha et al. (2023)	NO significant difference in baseline distress (first analysis) between IG and CG (p=0.65) NO significant difference between IG and CG in distress (first analysis) from T0>T1 (p=0.60) or from T1>T2 (p=0.73) NO significant difference in baseline distress (video completely watched) between IG and CG (p=0.41) NO significant difference between IG and CG in distress (video completely watched) from T0>T1 (p=0.33) or from T1>T2 (p=0.75)	Equal (ns)
	Wirawan et al. (2022)	Significant difference in baseline distress between IG and CG (p <0.05) Significant differences in distress from T0 > T1 in IG (p=0.000) and CG (p=0.004) Significantly more decrease in distress in CG than IG (p=0.037)	Sig. diff. in favor of CG
	Geller et al. (2010)	Significantly more distress in IG when negative learning attitude (p=0.046) No association between gaining knowledge and increased self-efficacy or reduced distress/anxiety	Sig. diff. in favor of CG

Self-efficacy (n=5)	Schofield et al. (2008)	Significantly more confidence in curative IG than CG (p=0.044) NO significant differences for self-perceived palliative patients between CG and IG	Sig. diff in favor in IG
	Dunn et al. (2004)	NO significant effect of videotape (p=0.89; p=0.85) Improvement in IG and CG	Equal (ns)
	Mumtaz et al. (2022)	Significant difference from T0 > T1 in mean self-efficacy based on CG and IG's characteristics (p<.05), but highest change in IG Significant difference in self-efficacy from T0 > T1 in IG (p=.000) and CG (p=0.010) Significantly more self-efficacy in IG than CG from T0 > T1 (p<.05)	Sig diff. in favor of IG
	Wilkins et al. (2006)	NO significant difference between CG and IG (p=.75)	Equal (ns)
	Geller et al. (2010)	NO significant difference in self-efficacy between CG and CG before or after the intervention or between women who changed their attitudes in a more or less favorable direction	Equal (ns)
Depression (n=4)	Liu et al. (2021)	Significant lower depression score in IG than in CG at T3 (p<0.001) Significant less patients depressive in IG than in CG at T3 (p=0.014) NO significant difference in depression severity between CG and IG at T3 (p=0.555)	Sig. diff in favor of IG
	Schofield et al. (2008)	NO significant differences between CG and IG, also not when curative/palliative patients	Equal (ns)
	Thomas et al. (2000)	Significantly less depression in IG than CG (p=.001) Significantly less people with depression in IG than in CG (p=0.001) Significant decrease in depression between T0 > T1 in IG (p<.001), and a significant increase IG (p<.001)	Sig. diff in favor of IG
	Fernandes et al. (2020)	NO significant difference for anxiety (p=.1832) and depression (p=.2641) between CG and IG	Equal (ns)

Physiological response (n=4)	Lakshman et al. (2022)	Significant increase in HR in CG and IG at T2 (less in video group) (p=0.209) Significant higher mean HR in CG at T3 (p=0.589), T4 (p=0.098), T5 (p=0.088), T6 (p=0.016) Significant more increase blood pressure in CG than IG from T1 >T3 (p<.001) after intubation blood pressure were higher in CG than IG Significant higher mean SDP (blood pressure) in control group at T3, T4, T5, T6 (all p<0.001) Significant higher mean DBP (blood pressure) in CG at T3, T4, T5, T6 (all p<0.001) Significant higher MAP (blood pressure) in CG at T3, T4, T5, T6 (all p<0.001)	Sig. diff. in favor of IG
	Liu et al. (2021)	Significant lower SBP, DBP, HR in IG than CG at T3 (p=0.009; p=0.010; p<0.001) Significant lower cortisol in IG than CG at T3 (p=0.006)	Sig. diff in favor of IG
	Gao et al. (2022)	Significantly lower Heart rate in IG than in CG (p<0.05)	Sig. diff. in favor of IG
	Dunn et al. (2004)	NO significant effect of videotape (p=0.06; p=0.86) Maintained in IG and CG	Equal (ns)
Fear	Gonzales-Arriagada et al. (2013)	NO significant difference between CG and IG, but more patients in IG reported worried about taking care of their oral health during RT	No sig diff. but in favor of CG
	Kumar et al. (2021)	NO significant difference in fear between CG and IG (p=0.203) 66% of IG said video made feel “a little more” or “much more” comfortable coming to consult	Equal (ns), but in favor of IG
	Gao et al. (2022)	Significantly lower fear in IG than CG (p<0.05)	Sig. diff. in favor of IG
Quality of life	Walker & Podbilewicz-Schuller (2005)	Significant Interaction of IG and history of mental health treatment in predicting overall QoL (p=.048) NO significance, but higher QoL in IG with history mental health than in CG with history mental health (p=.084)	Equal (ns), but in favor of IG
	Fernandes et al. (2020)	NO significant difference for UW-QOLv4 scores between CG and IG (p=.5148)	Equal (ns)
	De Lorenzo et al. (2004)	Significant more QoL improvement in IG2 than CG and IG1 (p<.019)	Sig diff in favor of IG

Satisfaction with treatment	Kotha et al. (2023)	NO significant difference in satisfaction (first analysis) between IG and CG (p=0.64) NO significant difference between IG and CG in satisfaction (first analysis) from T0>T1 (p=0.82) or from T1>T2 (p=0.94) NO significant difference in satisfaction (video completely watched) between IG and CG (p=0.21) NO significant difference between IG and CG in satisfaction (video completely watched) from T0>T1 (p=0.40) or from T1>T2 (p=0.49)	Equal (ns)
Perceived needs of patients	Schofield et al. (2008)	NO significant differences for either self-perceived curative or palliative patients between CG and IG	Equal (ns)
Doubts before the therapy	González-Arriagada et al. (2022)	Significantly less doubt in IG than CG (p=.0422)	Sig. diff. in favor of IG
Autonomy and information-seeking preference	Wilkins et al. (2006)	NO significant difference between CG and IG (p=0.55)	Equal (ns)
Recall	Kinnane et al. (2008)	NO significance difference between CG and IG, but IG higher recall in mouth problems, symptoms of low red cell count, prevention of constipation	Equal (ns)
Perceived involvement in care	Wilkins et al. (2006)	NO significant difference between CG and IG (Doctor facilitation p=0.83; patient information p=0.29; patient decision-making p=0.06)	Equal (ns)
Telephone calls to outpatient clinic	Kinnane et al. (2008)	27/60 patients called 52x from T1 to T2, mostly women (27 CG vs. 25 IG) Majority calls (80%) from IG about medical problems from video. Significantly more general calls from CG (44.4% vs. 26%; p=0.06)	Sig. diff. in favor of IG
Self-care assessment	Yang et al. (2023)	Significant difference in increase in patient comprehension in IG (24.8% to 98.5%) compared to CG (10.9% to 79.1%) (p<0.001)	Sig. diff. in favor of IG
Rescanning rate	Dawdy et al. (2018)	NO significant difference in number of patients needing CT rescans between CG and IG	Equal (ns)
Informational preparedness	Walker & Podbilewicz-Schuller (2005)	Significantly feeling more prepared for appointment in IG than in CG (p=0.050)	Sig. diff. in favor of IG
Participation in treatment decision-making	Walker & Podbilewickz-Schuller (2005)	Significantly feeling more prepared to ask questions during appointment in IG than in CG (p=0.050)	Sig. diff. in favor of IG

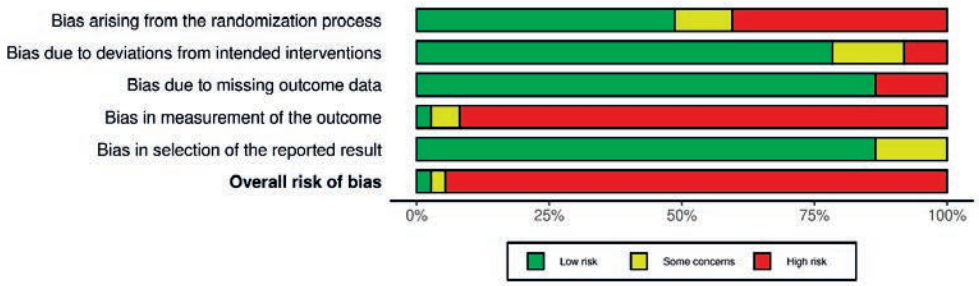
Variable	Authors (year)	Study findings	Overall outcome
Cognitive judgmental aspect of patients' psychological distress	Dunn et al. (2004)	NO significant effect of videotape (p=0.31; p=0.20) Maintained in IG and CG	Equal (ns)
Cancer learning attitudes	Geller et al. (2010)	Significant decrease in attitude about learning about cancer in 42% of IG (p=0.037) Significant association of increased negative attitudes with more intrusive thoughts (IES-intrusion) about ovarian cancer (p=0.046) CG became more favorable attitude	Sig. diff. in favor of CG
Worry	Harrison et al. (2001	NO significant reduction from T0 > T1 in IG (p=0.53) or CG (p=0.44) NO significant reduction between IG and CG (p=0.94) Significant more worries in IG about "hair loss" from T0>T1 (p=0.02)	Equal (ns)
Perceived severity and curability of the disease	De Lorenzo et al. (2004)	NO significant difference between CG, IG1, IG2	Equal (ns)

Appendix E. Summary of findings of the long-term patient outcomes

Variable	Authors (year)	Study findings	Overall outcome
Knowledge/ understanding (n=2)	Wysocki et al. (2012)	NO significant differences between CG and IG (p=0.0101, p=0.0367, p=0.4509) in knowledge (subjective), but lower in IG Paradoxically the subjective knowledge level was lower in the intervention group at all time points; however, the difference between the groups became smaller over time NO significant differences in knowledge (objective) were observed between CG and IG at all time-points.	Equal (ns)
	Gonzales-Arriagada et al (2013)	At Pre-RT – Better knowledge in IG than CG At Pre-RT - Significant question only #8 “loss of food taste due to RT” (p=.0318) At Pre-RT - Significant increase in IG with fundamental education level (p=0.0095) At Post -RT - NO significant difference between CG and IG	Equal (ns)
Self-care (n=1)	Behboudifar, Heshmati Nabavi, Anvari et al. (2018)	Significant more effect of IG on self-care behavior (p=0.003; p=0.01; p=<0.001)	Sig. diff. in favor of IG
Disease appeals (n=1)	Chien et al. (2020)	At T0 - Significant higher challenge scores of PIP group (1.84) (p=0.021) and MPI group (1.57) (p=0.020) than CG At T4 - Significant lower challenge scores of PIP group (-2.69) (p<0.001) and MPI group (-1.51) (p=0.030) than CG From T1-T3 - NO significant differences in challenge scores between CG, PIP group, and MPI group	Equal (ns)
Positive and negative affect (n=1)	Chien et al. (2020)	At T0 - Significant higher positive affect score of MPI group (4.42) than of CG (p=.007) At T1 & T4 - Significant lower positive affect score of MPI group (-4.77, -3.97) (p=0.038) than of CG At T2-T3 - NO significant differences between CG, PIP group, and MPI group for positive affect scores From T0-T4 - NO significant difference between CG, PIP group, and MPI group for scores for negative affect and anxiety specific to prostate cancer	Equal (ns)
Anxiety	Chien et al. (2020)	From T0-T4 - NO significant difference between CG, PIP group, MPI group for scores for negative affect and anxiety specific to prostate cancer	Equal (ns)

Relationship satisfaction (n=1)	Chien et al. (2020)	From T0-T4 - NO significant difference in satisfaction with relation between PIP group, MPI group, and CG	Equal (ns)
Health-related quality of life (n=1)	Chien et al. (2020)	From T0-T4 - NO significant difference in physical and mental scores between PIP group, MPI group, and CG At T0 - NO significant difference in mental score between MPI group and CG From T1-T4 - NO significant difference in physical score between MPI group, PIP group, and CG	Equal (ns)
Patient satisfaction with surgery and recovery process (n=1)	Turkdogan et al. (2022)	IG and CG felt adequately informed, but the IG was more satisfied with 11.3-point mean difference. Effect sizes (η^2): 0.89, 0.67, 0.44, 0.35, 0.91, 0.80 100% of patients claimed that videos were easy to understand, were appropriate in length, and would recommend the video to family or friends who have a similar diagnosis. No characteristics found to influence dissatisfaction IG were positive about video	Sig. diff. in favor of IG

Appendix F. Summary plot of Risk of Bias assessment



CHAPTER 5

Exploring the needs and preferences for animated videos in complex surgical oncology communication: A focus group study with patients, informal caregivers, and healthcare providers

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ABSTRACT

Audiovisuals, like animated videos, can support the growing demand for patient-centred education in oncology. However, optimal design for adoption, usability, and implementation remains unclear. This study explores the needs and preferences of diverse key end-users for the content, design, and adoption requirements of animated videos in complex surgical oncology communication, focusing on oral cancer treatment. Using a reflexive thematic approach, we analysed six focus group sessions and two individual interviews with patients (*n*=17), informal caregivers (*n*=2), and healthcare providers (HCPs) (*n*=13). While shared needs and preferences emerged, notable differences and concerns were identified. Patients need practical information about treatment and daily life impact, whereas caregivers and HCPs prioritized clinical accuracy and integration into HCP workflows and the patient journey. Some caregivers and HCPs questioned the suitability of (animated) videos, citing the unpredictability of treatment and its consequences. They expressed concerns about inducing distress or creating unrealistic expectations. These diverging perspectives present a challenge for video developers aiming to promote patient-centred education while acknowledging emotional impacts and treatment uncertainty. Based on our findings, we offer recommendations for designing and implementing animated videos that complement standard communication and promote patient-centred care in surgical oncology, while addressing the differing perspectives of key end-users.



INTRODUCTION

The rising cancer incidence [1] and the growing strain on healthcare systems [2] are increasing the demand for patient-centered care. Effective patient-centered communication not only improves the quality and involvement in shared decision-making (SDM) [3] but also enhances patient satisfaction [4], understanding of the consequences of disease and treatment, and sense of control [5], and reduces decisional regret [6,7], eventually leading to a better quality of life (QoL) [8,9]. However, several factors may hinder patients' ability to engage in patient-centered communication. These challenges include the emotional stress of a diagnosis, the complexity of the treatment decision, the clarity of communication from healthcare providers (HCPs) [10,11], and patient-specific factors such as age [12], educational background [13], and health literacy [14].

This may be especially true for patients undergoing oral cancer treatment, as the information is often complicated due to the intricate anatomical sites and multimodal treatments involved [15]. Surgery is the primary treatment for this form of head and neck (HN) cancer, frequently combined with reconstruction of the tongue and/or mandible and removal of the neck lymph nodes, typically followed by postoperative (chemo) radiotherapy [16]. Although this treatment combination has proven effective, it can significantly impact a patient's functioning and QoL [17–19]. For example, treatment can result in appearance changes and substantial consequences in vital functions such as speech, swallowing, chewing, tasting, or breathing [20,21]. Even after successful treatment, patients might continue experiencing reduced QoL due to these persistent functional challenges [19,22]. The severity of these consequences varies widely and is difficult to predict, making it challenging to counsel the patient appropriately.

Audiovisual materials offer innovative digital solutions to meet the growing demand for patient-centered communication in oncology [23,24]. These materials have shown to be promising tools to support HCPs in conveying information to patients with cancer [25]. According to the cognitive theory of multimedia learning, people process information more effectively when presented simultaneously through visual and auditory channels [26]. This dual-channel processing may help reduce cognitive load [27] and empower patients to participate actively in patient-centered communication. In particular, animated videos, which feature a series of moving images that are drawn or simulated [28], have the potential to present complex information in a simplified manner, avoiding cognitive overload, and emotional and verbal communication barriers [29–31].

Animated videos, particularly three-dimensional (3D) formats, may be especially effective in explaining the pathways, surgical techniques, and outcomes in complex surgical oncology treatments [31–34]. While previous research has demonstrated the potential of

animated videos in oncology [25,29,31], prior studies reporting video characteristics have shown considerable variability in format, content, design, and implementation [25]. Consequently, there is no consensus and little evidence on how to optimally develop and implement videos that meet the needs and preferences of its key end-users, including patients, informal caregivers (hereafter: caregivers), and HCPs. To address this gap, this study explores the needs and preferences of patients, their caregivers, and HCPs for the content, design, and adoption requirements of animated videos in complex surgical oncology communication by focusing on oral cancer treatment. For this study, we focus on oral cancer surgery because of the considerable challenges in information provision and decision-making [35–37]. Ultimately, by generating insights into patients', caregivers', and HCPs' needs and preferences, we seek to sophisticate the future development of animated videos in complex surgical oncology patient-provider communication using a user-centered design approach [38,39].

METHOD

Study design and participants

Based on Eason's categorization for user types, we considered patients as primary users who directly engage with the videos, their caregivers as secondary users who access the videos through patients, and HCPs as tertiary users who influence how the videos are integrated into their consultation [40]. To explore these diverse perspectives, we chose a focus group design to encourage participants to share, build upon, and compare each other's responses and opinions, which can lead to a more comprehensive understanding [41–43]. In addition, two individual interviews, one with a patient with oral cancer and one with an HN surgeon, were conducted because they could not attend the focus groups.

Participants were recruited at the HN department of a tertiary cancer center in the Netherlands. A total of fifty HCPs, primarily relevant to the patient journey of patients with oral cancer, were approached for participation, including HN surgeons (*n*=9) and paramedics such as speech therapists (*n*=7), nurse practitioners (*n*=4), and specialized HN nurses (*n*=30). Recruitment of patients was based on HCPs' invitation and by sending out social media posts, newsletters, and emails via the HN Patient Association, PanelCom, Kanker.nl, our center's internal patient panel, and the respective networks of the authors. Through a combination of purposeful and theoretical sampling [44], we applied distinct inclusion and exclusion criteria per focus group session (Table 1). Patients were considered eligible if they had sufficient command of the Dutch language and no cognitive impairments. To represent newly diagnosed patients, we also included analog disease-

naive patients without prior knowledge of oral cancer surgery [45]. Individuals willing to participate were sent an information letter via email or post, including an informed consent form, before participation.

Animated videos as discussion facilitators

We created various animated video prototypes to fuel discussion on participants' needs and preferences. To develop the prototypes, we formed a team that included one 3D artist, two animators, one video editor, and two researchers in health communication. Several steps were undertaken in preparation for the prototypes' development, including informal meetings with HN surgeons, paramedics, and patients, observations during consultations and surgeries, and examinations of diagnostic scans and speech/swallowing videos. Details on the development and examples of the prototypes are presented in Supplementary material A. The animated video prototypes were made available in a PowerPoint and can be found via: URL.

Data collection

Two moderators (SD with SÖ and/or AL) conducted four focus group sessions, and three focus groups were conducted by a single moderator (SD). One interviewer (SD) and an observer (SÖ) carried out the two individual interviews. For practical reasons, the focus group with HN surgeons and the individual interview with an HN surgeon took place on-site, while the remaining were held online via Microsoft Teams. We developed a semi-structured interview guide for the focus group with HN surgeons and one for the focus group with patients (Supplementary material B). Minor adjustments were made iteratively to ensure its applicability to different subsequent sessions with the analog disease-naïve patients and paramedics. Participants were sent a short questionnaire before the focus groups or interviews, including questions about demographic and clinical characteristics, where applicable. Each session started with participants introducing themselves and elaborating on their experience with HCPs' information delivery. Succeeding interview topics were introduced by the leading moderator, followed by a presentation of our animated video prototypes. We scheduled each focus group with 3-8 participants per session to balance interaction and manageability [42,46]. The composition of participants differed across these sessions (Table 1). Our research team regularly met to review preliminary findings and evaluate when enough conceptual richness (i.e., saturation) was reached [47]. The interviews were conducted between February 2023 and June 2024 [48].

Table 1. Participants interviewed per focus group.

Participants	Eligibility criteria
1. Head and neck surgeons (*n*=6[a])	• Physicians conducting treatment decision-making consultations with patients diagnosed with oral cancer. • Having a permanent position as head and neck surgeon at our hospital's HN department.
2. Patients with oral cancer (*n*=5[b])	• Patients or cancer survivors who have. undergone curative surgical treatment for a primary malignancy in the oral cavity (the tongue, floor of the mouth, and/or mandible) • Speech was sufficiently understandable to participate.
3. Head and neck surgeons (*n*=2), patients with oral cancer (*n*=2), caregivers (*n*=2)	• Caregivers had to be closely involved with the care of a patient or a cancer survivor
4. Analog patients with a previous cancer diagnosis outside of the head and neck area (*n*=7)	• Patients or cancer survivors who are considered an "expert" on receiving a cancer diagnosis but who are unfamiliar with (information on) head and neck oncology [45].
5. Analog disease-naïve patients (*n*=3)	• Individuals with no cancer history who serve as actor patients or naïve patients to simulate newly diagnosed patients with oral cancer, pre-treatment at the start of their care path [45]. • Lack experience with and are unfamiliar with head and neck oncology
6. Speech therapists (*n*=2), nurse practitioners (*n*=2), specialized head and neck nurse (*n*=1)	• Healthcare providers closely involved in the care path of patients with oral cancer, pre-, peri-, and/or postoperative

Note: In case the eligibility criteria of end-users have already been mentioned before, repetition of mentioning was avoided, [a] including one interview with an HN surgeon, [b] including one interview with a patient diagnosed with oral cancer.

Data analysis

We analyzed the verbatim anonymized transcripts of the recorded focus groups and interviews using Braun and Clarke's reflexive thematic approach [49,50]. This analysis was conducted with the assistance of IBM's CAQDAS software ATLAS.ti (Windows version 23.1.1) [51] and Microsoft Excel. After familiarization with each transcript, two coders (SD with alternating SÖ and AL) independently double-coded and discussed five transcripts at different time points in the analysis phase. A combination of deductive, based on the four

interview topics, and inductive coding, involving data-derived and researcher-derived codes, was applied. Subsequently, all transcripts were coded in a reflexive manner by the first author (SD) [49,50]. This iterative coding and cross-checking allowed for patterns and themes to emerge. Doubts or disagreements between the coders were resolved through discussion.

Research team and reflexivity

The study team members varied in age, gender, expertise, and experience. Three female health communication researchers (JvW, AL, SD), all trained and experienced in qualitative research, were part of the team, including the principal investigator (SD), who led the interviews with support from a female research assistant (SÖ) trained in qualitative methods but new to oncology communication research. Additionally, two male HN surgeons (MvdB, AB) and a male phonetician with extensive experience in HN surgical oncology and limited qualitative research experience provided valuable outsider perspectives during data analysis.

Ethical considerations

This prospective study was conducted according to the principles of the Declaration of Helsinki [52] and preregistered on the Open Science Framework (OSF; osf.io/jz7xc). The Institutional Review Board at our hospital approved the study (registration no: IRBd23-051), and all participants provided written informed consent prior to enrollment in the study, including publication of the study results.

RESULTS

A total of 58 individuals showed interest in our study, of which 32 participated in seven focus group sessions, lasting 51.32 – 113.41 minutes, and two individual interviews, lasting 27.59 – 68.53 minutes. One patient dropped out of the study at the start of a focus group session because they felt overwhelmed. Patient (*n*=17), caregiver (*n*=2), and HCP (*n*=13) characteristics are presented in Table 2. Figures 1 to 4 contain visual representations of the results per topic. Quotes from patients, caregivers, and HCPs are referred to as “Q” in text, numbered, and presented in Table 3.

Table 2. Participant characteristics.

Patients and informal caregivers	**N = 19**
Type of participant	
Oral cancer survivor	7 (36.8%)
Analog patients with a cancer diagnosis outside of the head and neck area	7 (36.8%)
Analog disease-naïve patients	3 (15.8%)
Informal caregiver	2 (10.5%)
Gender	
Male	6 (31.6%)
Female	13 (68.4%)
Age at participation in years (median, range)	62 (51-84)
Education	
Low education level	0 (0%)
Middle education level	4 (21.1%)
High education level	15 (78.9%)
Marital status	
Single	4 (21.1%)
In relationship	1 (5.3%)
Married	11 (57.9%)
Living together	2 (10.5%)
Divorced	0 (0%)
Widow(ed)	1 (5.3%)
Living situation	
Alone	6 (31.6%)
With partner	11 (57.9%)
With partner and child(ren)	2 (10.5%)
With family member(s)	0 (0%)
Tumor location*	
Oral cavity	7 (50%)
Melanoma	1 (7.1%)
Breast	2 (14.3%)
Lung	2 (14.3%)
Prostate	1 (7.1%)
Bladder	1 (7.1%)
Time since first diagnosis at the time of study participation in months	
0-12	3 (21.4%)
13-24	1 (7.1%)
25-36	1 (7.1%)
37-48	2 (14.3%)
>48	7 (50%)

Treatment modality*	
Surgery	6 (42.9%)
Surgery + (Neo) Adjuvant chemotherapy	1 (7.1%)
Surgery + (Neo) Adjuvant radiation therapy	
Surgery + (Neo) Adjuvant chemoradiation therapy	2 (14.3%)
	5 (35.7%)
Healthcare providers	**N = 13**
Type of medical profession	
Head and Neck surgeon	8 (61.5%)
Speech therapist	2 (15.4%)
Nurse practitioner	2 (15.4%)
Specialized Head and Neck nurse	1 (7.7%)
Gender	
Male	7 (53.8%)
Female	6 (46.2%)
Age at study participation in years (median, range)	49 (26-63)
Specialization in head and neck surgical oncology in years	
0-5	0 (0%)
6-10	2 (25%)
11-15	0 (0%)
16-20	1 (20%)
> 20	2 (25%)
Experience working as a paramedic with surgical head and neck oncology patients in years	
0-5	3 (60%)
6-10	0 (0%)
11-15	1 (20%)
16-20	1 (20%)
> 20	0 (0%)

Note: *minus three simulated patients and two informal caregivers.

Current communication practices

Information (re)sources

While most patients, caregivers, and HCPs indicated that information was primarily provided verbally by the *healthcare provider* during counseling, a few patients noted that specific information needs prompted them to seek additional information on the *Internet*. A few patients reported receiving *self-created material*, such as drawings, flyers, or *diagnostic results*, with one patient recalling being shown a *video* by a nurse specialist. Not all patients and caregivers opted to use additional information sources, as they had adopted a “let it all happen” approach, meaning that survival had been their priority (Q1).

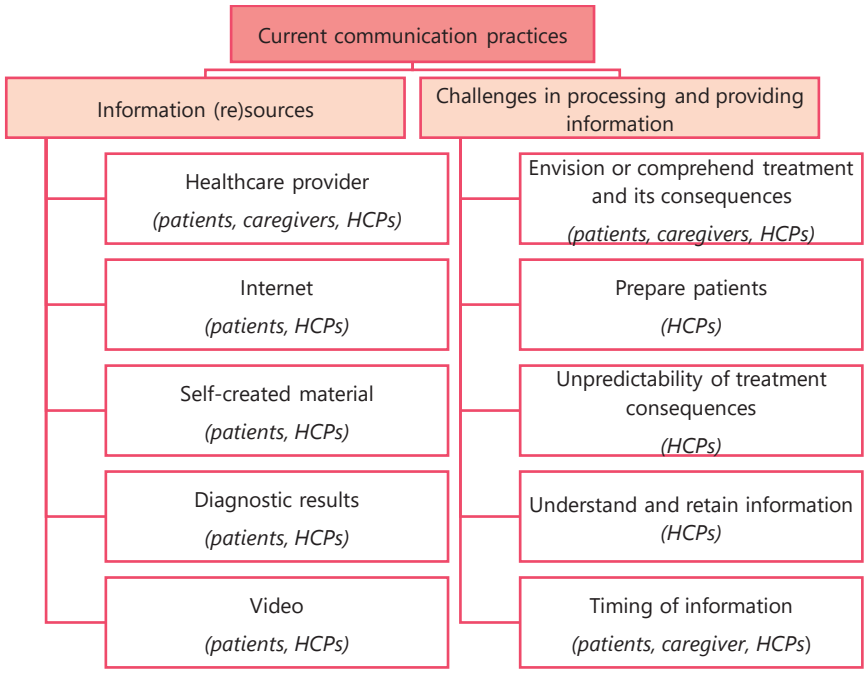


Figure 1. Visual representation of the 'Current communication practices' topic.

HCPs mentioned usually supporting their explanations with drawings, (online) images, or scan results, with a few providing flyers or directing patients to websites. Additionally, two HCPs reported regularly using videos during their consultations (Q2, Q3), whereas some HCPs only offer supplementary information upon request or when they believe it would benefit the patient specifically. One surgeon additionally clarified that the use of supplementary resources during the consultation tends to decrease when HCP workloads increase (Q4).

Challenges in processing and providing information

Most patients, caregivers, and HCPs elaborated on the challenges experienced when receiving or providing information. Nearly half of them indicated that they had struggled or seen patients struggling to *envision or comprehend* their treatment and its potential consequences (Q5, Q6). For example, some patients reported that their pre-treatment expectations differed from their actual experiences (Q7, Q8), and two HCPs disclosed having seen patients who were frustrated after treatment because their expectations were not met (Q9).

Alternatively, several HCPs found it challenging to *prepare patients* for what lies ahead due to the *unpredictability of treatment consequences* for daily life (Q10). Several patients, caregivers, and HCPs acknowledged that this may be further complicated by the diversity in patients' (information) needs and coping styles. Another challenge is the substantial amount of information discussed during consultations. This leads to information overload and makes it challenging for patients to *understand and retain the information* provided (Q11). Due to this, the *timing* thereof seems to be important. For example, one patient, one caregiver, and four HCPs noted that some information might be given too early in the patient journey. Some patients and HCPs suggested strategies to address these challenges, for instance, by prioritizing patients' needs, ensuring they receive all necessary information at the right time, and dosing and tailoring information delivery.

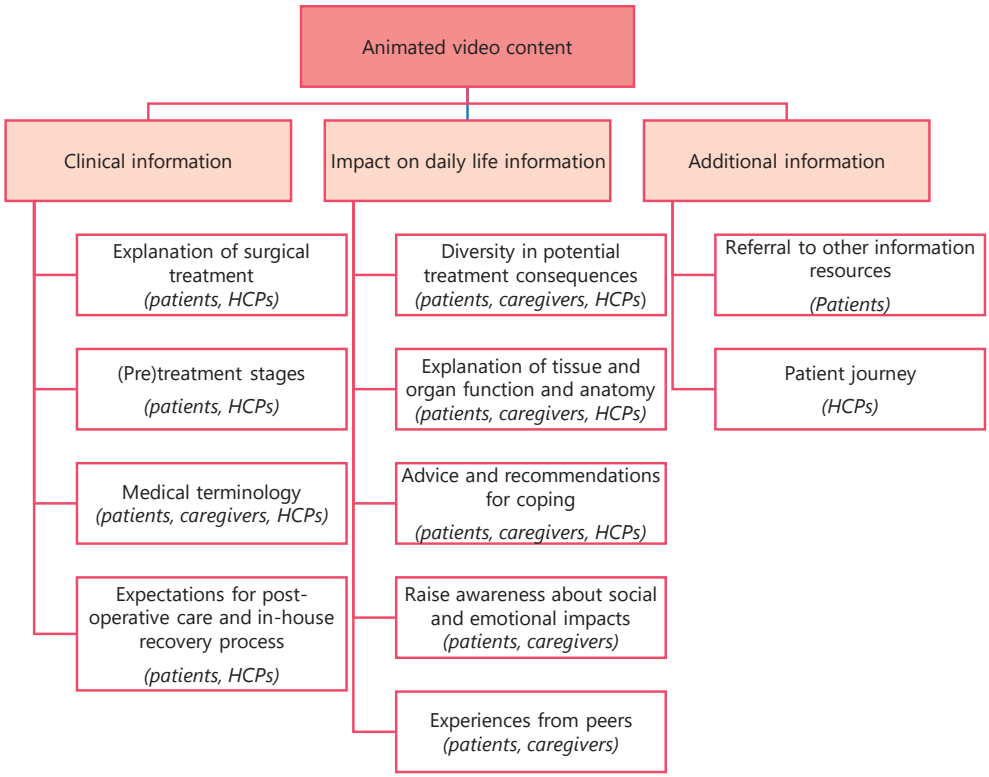


Figure 2. Visual representation of the 'Animated video content' topic.

Animated video content

Clinical information

Most patients, caregivers, and HCPs prefer videos explaining the medical and technical aspects of treatment and postoperative care. For example, some patients and HCPs suggested that videos can *explain surgical treatment itself*, such as the potential surgical procedures (Q12, Q13) and reconstruction techniques (Q14), while a few others also proposed videos to address (*pre)treatment stages*, including diagnostic workup (Q15) and indications for any additional treatment (Q16). Although many patients preferred detailed videos covering various aspects of treatment (Q17, Q18), some patients, but all caregivers and HCPs, were more hesitant (Q19). They believed that the emphasis in developing such videos should be on avoiding unrealistic expectations (Q20). Personalized videos could potentially solve this, but are considered unfeasible, making them question the added value of treatment videos overall (Q21). Some patients, caregivers, and the majority of HCPs believed that videos could prepare patients better for treatment by helping them understand the *medical terminology* used by HCPs (Q22). Additionally, some patients and HCPs suggested showing what to *expect for the post-operative care and in-house recovery process* (Q23, Q24).

Impact on daily life information

Most patients, caregivers, and HCPs felt it was important to address the impact of surgery on daily life, although opinions differed on the detail and extent of this. A majority of patients, caregivers, and paramedics indicated that videos should address *diversity in potential treatment consequences* (Q25). Patients predominantly preferred that videos should elaborate on the consequences for daily functioning, whereas caregivers and HCPs suggested that videos should *explain the functionality and anatomy of the tissues and organs* involved in surgery to help patients understand how this might result in functional impairments (Q26, Q27). This because they expressed concerns about the presentation of surgical outcomes, primarily because of the unpredictability of treatment consequences. Almost a third of patients, caregivers, and HCPs recommended that videos should provide *advice and recommendations for coping* with treatment consequences in daily life (Q28, Q29, Q30), for example, by sharing first-hand experiences from other patients and caregivers. About half of the patients and caregivers, along with one HCP, felt that incorporating stories of peers would make the video more informative (Q31). In addition, about a quarter of the patients and caregivers believed that the primary purpose of the videos should be to *raise awareness about the social and emotional impacts* of treatment, with several patients suggesting that simply acknowledging the existence of these potential consequences could already benefit new patients (Q32, Q33). Some patients, caregivers, and HCPs also questioned the added value of videos showing treatment consequences, noting that depicting actual functional treatment consequences could be

irresponsible (Q34). In contrast, others wondered about the feasibility of the videos and how they should be explained in depth.

Additional information

Some patients and HCPs also proposed additional ideas to make videos more informative. Several patients and one HCP suggested that it would be helpful for patients if videos also included *referral information* on where they could find additional scientific articles and videos (Q35), professional help (Q36), or where they could connect with peers (Q37). Another suggestion made by a few HCPs was to have a video with an overview of the *patient journey*, from entering the hospital to diagnostics and treatment (Q38).

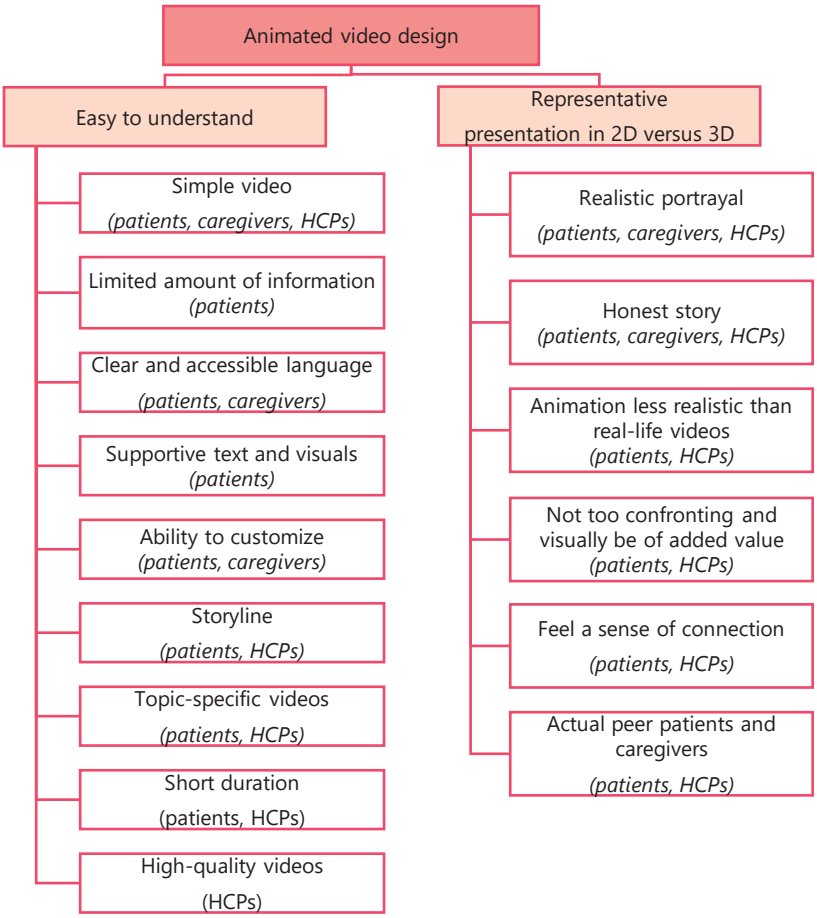


Figure 3. Visual representation of the 'Animated video design topic.

Animated video design

Easy to understand

At least half of the patients, caregivers, and HCPs emphasized that the design of the videos should be *simple,* using *clear and accessible language* (Q39), with some suggesting a *limited amount of information* (Q40), *clear and accessible language* (Q41), and *supportive text and visuals* (Q42). Additionally, a video should be *customizable* by providing options to adjust the level of information details and video content (Q43). To make the videos easy to follow, a few patients and HCPs recommended sticking as much as possible to a *storyline* (Q44) and for each video to focus on a *separate topic*. One of the most important recommendations given by many patients and nearly all HCPs was to keep videos *short*, with a duration of 2-3 minutes (Q45). Last, while some patients and paramedics found animated videos a suitable video format, most surgeons stressed the importance of *high-quality videos* (Q46).

Representative presentation in 2D versus 3D

For many patients, caregivers, and HCPs, it was important that videos show representative content. Videos should give a *realistic portrayal* and an *honest story* (Q47). However, a few patients and HCPs felt that (3D) animated videos would, while potentially less confronting, be *less realistic than real-life videos* (Q48, Q49). Other patients and HCPs reported being satisfied with the 3D animated videos we presented during the focus group, indicating they found them realistic and visually engaging. However, the videos should *not be too confronting and visually be of added value* for patients. Some patients and a few HCPs perceived the 3D animated videos to be intense and sometimes confronting (Q50, Q51), increasing anxiety because of the heavy information given. Other patients preferred verbal communication or 2D animated videos over 3D ones, as some reported finding the 3D animated videos too plastic and medical-looking. Furthermore, several patients and HCPs emphasized that patients should *feel a sense of connection* to the information shown in the videos to perceive it as relevant (Q52). Subsequently, no consensus was reached about the appearance of the patient. Another suggestion given by some patients and HCPs was to show *actual peer patients* and possibly also *peer caregivers* who share their experiences (Q53).

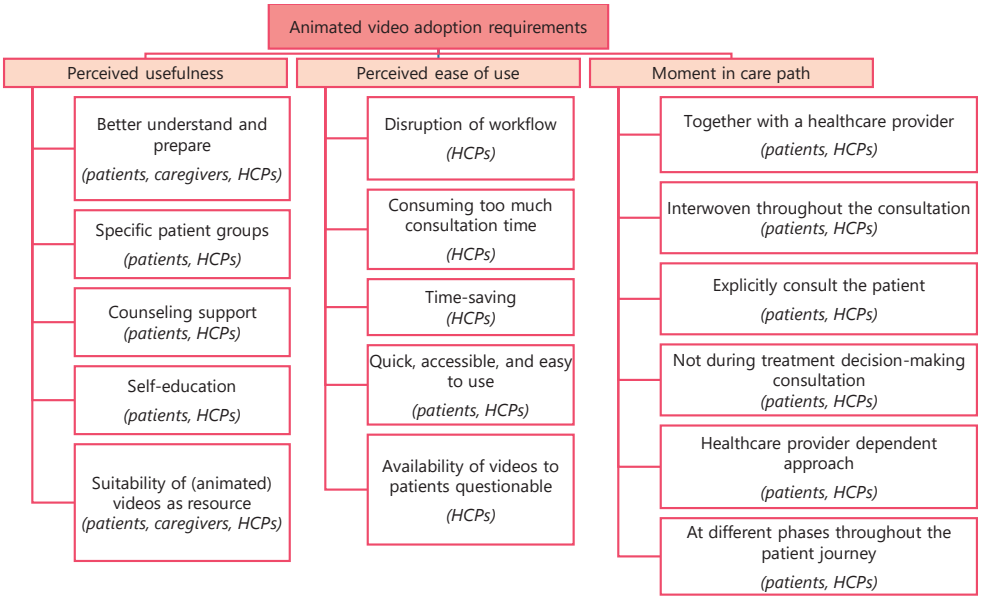


Figure 4. Visual representation of the 'Animated video adoption requirements' topic

Animated video adoption requirements

Perceived usefulness

Almost three-quarters of all patients and caregivers, along with half of the HCPs, perceived videos as a valuable resource, at least to some extent, for helping patients *better understand and prepare* for treatment, the postoperative period, or potential treatment consequences, with usefulness often depending on the content (Q54, Q55, Q56). This might be especially for *specific patient groups*, such as those with a different language background or lower health literacy (Q57). While some patients and a few HCPs felt that videos could offer *counseling support* to HCPs in explaining complex information (Q58), videos were also perceived valuable for use outside of the hospital for *self-education* at home, allowing patients to watch them with family and friends (Q59) or to recall what was discussed with the HCP (Q60).

However, some patients, caregivers, and HCPs questioned the *suitability of (animated) videos as a resource* providing supplementary information (Q61) as they had not missed audiovisual support for understanding HCP's verbal information. Caregivers argued that resources other than videos might be more helpful (Q62). A few HCPs, therefore, preferred static images or drawings (Q63). Nonetheless, as one caregiver indicated,

videos on treatment consequences may be relevant when patients have a choice between equivalent treatments with different implications (Q64).

Perceived ease of use

According to surgeons, video showing should not *disrupt their workflow*, for instance, by reducing their ability to control its flow (Q65). In addition, one patient and half of all surgeons anticipated that showing of a video would *consume too much consultation time* with the patient (Q66). In contrast, one specialized HN nurse and a nurse practitioner believed that videos could be *time-saving,* enabling HCPs to tailor the following information to the individual patient (Q67).

Furthermore, more than one-third of patients and HCPs indicated that videos should be *quick*, *accessible, and easy to use*. In doing so, several suggested that videos should easily be shown on the computer or laptop by the HCPs. This would also allow for videos to be watched online (Q68). Alternatively, a specialized HN nurse preferred that patients watch videos on a tablet in the waiting room to prepare for consultation (Q69). Three HCPs *questioned making the videos available to patients*, for instance, by using the hospital's patient portal, as they observed that patients are already receiving much information and were concerned that some patients do not possess a computer or the skills for it (Q70).

Moment in patient journey

Almost all patients and HCPs felt that how the videos are presented during the patient journey is important. More than a third supported using videos during the consultation. In doing so, some patients and paramedics emphasized that patients should watch the videos *together with an HCP* to answer questions or tackle misinterpretations (Q71, Q72). Although a few surgeons mentioned preferring videos to be watched at home, they later acknowledged that a short video could also be shown at the end of their consultation (Q73). Alternatively, a few patients and paramedics envisioned the videos *interwoven throughout the consultation* (Q74). Some patients and HCPs felt it was important to *explicitly consult the patient* about their video viewing preferences (Q75).

However, not all types of consultations were considered suitable for showing videos. Some patients and a few paramedics noted not to *show videos during a treatment decision-making consultation* since this could overload and distress patients (Q76). Instead, they recommended that videos should, for instance, be shown during a second consultation with the surgeon. However, two other paramedics pointed out that certain videos, such as those on surgical techniques, may best be shown by surgeons or later in the patient journey by other HCPs (Q77). More than a quarter of patients and HCPs indicated that speech therapists, nurse practitioners, and specialized HN nurses could show videos to patients. Mostly, paramedics proposed this healthcare provider-dependent *approach*,

explaining that each HCP could provide the most relevant information to their discipline (Q78). In this way, patients would gradually receive information *at different phases throughout the patient journey* (Q79).

Table 3. Quotes per theme of patients, caregivers, and healthcare providers.

Themes	Quotes	Quote no.
Current information practices		
Information (re)sources	*"You only hope for one thing, which is to stay alive. And everything else is not important at that moment."* – Patient with OC	Q1
	"I really like those videos, at least for the swallowing for which I use them. It really gives much insight, so I use it quite often." – Speech therapist	Q2
	"I often show a video too, because it gives people an even better idea of what to expect more or less." – Nurse	Q3
	"I find that the busier I get, the less I use materials. What I do is I give them a card that has all the addresses on it. They watch it at home themselves, like 'Here, that is your homework.'" – Surgeon	Q4
Challenging provision of information	*"When I heard it [surgery plan], I was glad he was going to draw because I was like 'What do I imagine with that?'"* – Patient with OC	Q5
	"[…] but sometimes I think that you actually cannot tell or explain to the patient all that is going to happen to them, because it is actually not understandable if you have never experienced anything like that." – Surgeon	Q6
	"There is so much skin in my mouth from my leg, I cannot close my mouth. […]. And that I did not expect from the information given." – Patient with OC	Q7
	"I never knew that at some point after surgery, a piece from my arm was attached to my tongue." – Patient with OC	Q8
	"I sometimes have the idea that if people had known in hindsight that there would be so much loss of functionality after a commando surgery, they would have thought about it a little better, or sometimes, in some cases, they regret it [choosing surgery]." – Nurse	Q9

	"But when you are talking about function loss after surgery, I personally find that very difficult to describe. Also, because it is, of course, very individual how patients experience it." – Nurse	Q10
	"[…] it runs out the side just as fast. It does not stick." – HN surgeon	Q11
Animated video content		
Clinical information	*"Yes, I would have liked a 3D image of the lower jaw to see what would be removed from it. I would have liked to have seen that beforehand, but I also realize that the decision as to what will be removed is often made during surgery. […]. But in general, if I had known that beforehand, I could have prepared better, I think."* – Patient with OC	Q12
	"I do find it insightful that you [the patients] think 'oh so you get a chunk out of our neck or out of your tongue and there is also a bite out of your thigh and that goes in there then." – Speech therapists	Q13
	"Indicating that there are more options for harvesting a skin graft." – Patient with OC	Q14
	"I was suddenly told, when I made an appointment for the CT scan, that there should also be a PET scan. [...]. So I was not told why there had to be a PET scan. So that trajectory that's good to bring into focus, and that then surgery will take place." – Patient with cancer diagnosis outside HN area	Q15
	"Maybe that [additional treatment] should already be mentioned at some point, that that is a possibility, and then also show how that goes." – Nurse	Q16
	"[...] that so with a cheese slicer you get a very thin layer and that is, say, needed to seal your wound." – Patient with OC	Q17
	"[…] that piece just stays is really a square piece, say on your thigh, and that just stays a color difference. It is quite a big piece, so that is shown, really well explained." – Patient with OC	Q18
	"I also think that it is quite intense. Honestly, I do not know if I would want to see that." – Patient with OC	Q19

	"If I had seen this beforehand, I would think 'Okay, so a two-centimeter incision and then I would visit in the evening, and it is a fifteen-centimeter incision and then think oh God in the animation it only said two centimeters, what is going on?'." - Caregiver	Q20
	"I am sure there are standard surgeries. If you make a video of that, that is fine, but do you need to know all those side roads? I do not know if that is helpful and if that can be done." - Caregiver	Q21
	"We sometimes talk about terms that are not clear to patients. So I think that in advance, certain images or animation might help in the patient's understanding of certain terms?" – Surgeon	Q22
	"People often find the cuff cannula scary, while it is there for safety. But that is what people do not understand. – Nurse	Q23
	"Because you wake up and then think, 'My arm in a cast?' […]. But that absolutely does not slide like that, and it will heal well. – Patient with OC	Q24
Impact on daily life information	*"[…] difficulty eating, drinking, and speaking, but how and to what extent? That is what you want to know."* – Patient with OC	Q25
	"Instead of just portraying really difficult speaking people, maybe you could throw it more on the function of the tongue for speaking, and that that changes." – Speech therapist	Q26
	"So that you explain more about how it works physiologically, and then you can open up the conversation, for example, 'what does that mean for you.'" – Nurse practitioner	Q27
	"That could perhaps be made clear in an instructional video, how to get that food and drink inside." – Patient with OC	Q28
	"It is more indeed how do you deal with that and how do you inform your environment of that?" – Patient with OC	Q29
	"And what do you look like, and how do you deal with that? These are things you do not think about when they tell you that you have cancer. But that does have a huge impact on the process after surgery." - Caregiver	Q30

	"Maybe you can show from peers what it can look like afterwards. […]. If I had had a better image in advance of what the outline would be like, I would have been prepared a little better on that part." – Patient with OC	Q31
	"So I like how you can see that you think 'oh that is going to happen'. Well, I think that can already be helpful." – Speech therapist	Q32
	"Well, exactly that bit of awareness, yes." – Patient with OC	Q33
	"Look for an explanation of certain surgery that's fine with me, but how that is going to function after surgery, I do not agree with what you see." – Surgeon	Q34
Additional information	*"The reference to articles can also be included, as long as it is not too much. You should not overwhelm people with it either."* – Patient with cancer diagnosis outside HN area	Q35
	"And maybe with phone numbers, including whether you can already get mental health counseling?" – Patient with diagnosis outside HN area	Q36
	"Referring to the patient association, Canker.nl, or a Facebook group is always possible. Especially if you offer these videos to be listened to and seen at home at a later stage, it has additional value." – Patient with OC	Q37
	"I do think there are some very insecure patients who find it very exciting. If there were some broader video, it would be nice to have it with information about the whole process in the hospital." Speech therapist	Q38
Animated video design		
Easy to understand	*"Keep it very basic, very simple, and then give room for the doctor to explain."* – Surgeon	Q39
	"You have to be careful not to give people too much information." - Patient with cancer diagnosis outside HN area	Q40
	"Easy understandable language might also be possible." - Caregiver	Q41
	"Well, maybe a few key words support the visual." Patient with OC	Q42

	"Maybe to do a design, like you have on YouTube, with videos where you then have different links underneath. [...], so that you also create a few categories in which those who need more information can find their way more easily, so to speak, and can easily click through, and those who do not need it, well, they leave it." – Patient with cancer diagnosis outside HN area	Q43
	"It should be that simple, right? And that is a storyline." – Surgeon	Q44
	"I think short, clear videos will suffice. At most a sentence under a video or a title with it. And leave the rest to the treating physician for explanation." – Patient with OC	Q45
	"And when you create a video, you just do it all in quality, you just want to see it back properly because that is what a patient expects." – HN surgeon	Q46
Representative presentation	*"Well, for me, it may look realistic. It does not have to be prettier than it is. [...] honesty is, I think, an important point in showing what could be consequences."* - Patient with OC	Q47
	"[...] but sometimes it is also very difficult for a patient to identify with that other person. Also very confronting, so in that respect, animations are better for that, but if you are going to talk about what it really looks like, then an animation is just not the same as a real person. And somewhere in between, I think, is the preference, but that is complicated." – Nurse practitioner	Q48
	"[...] because some people want to see many details, and you can also show all the horrible things. Some people do not want to see at all and everything in between, and an animation, well, I doubt it really gives a real picture." – Surgeon	Q49
	"I thought these [points to 3D animated video prototype] did come across pretty harsh, at least intense. I thought, wow, I mean, we have all been ill and through it all, but these visuals really hit you." – Patient with cancer diagnosis outside HN area	Q50
	"Uh, instead of having an actual someone, uh, that is pretty intense, I think to see that talking will become really difficult or to hear that." – Speech therapist	Q51

	"Conveying something that you are in the middle of or have experienced yourself is often much more authentic and, I think, hits home better with someone who is in the same boat." – Patient with cancer diagnosis outside HN area	Q52
	"Well, maybe you can show fellow patients what it can look like afterwards. It is not always pretty […]. If I had had a better idea what the outcome would be like beforehand, I would have been prepared a little better on that part." – Patient with OC	Q53
Animated video adoption requirements		
Perceived usefulness	*"When you come into the consultation room and do not know anything, I think it is nice to see it quietly at home. At least what is going to happen, how it is going to happen, what the impact is, especially after a while."* - Caregiver	Q54
	"We do not really talk about the scars and everything like that with the patients. But I can imagine that [points at video prototype] gives quite a good idea of what to expect. – Speech therapist	Q55
	"I then required an air opening, a cannula. You have an image and a picture, but a video would also be instructive. Because that thing that gets removed and at some point has to be cleaned regularly. [...] And that can be made clear in a video, I think." – Patient with OC	Q56
	"I would like to think that it could be an addition for a very large part and then maybe anyway for non-native speakers and low literacy." – Speech therapist	Q57
	"What I do like is that when you like to watch it together, you can immediately intervene on the questions that a patient has." – Nurse practitioner	Q58
	"During the time I had my surgery, I had to deal with little children hanging around, and to include them in the whole process of what is going to happen to Mom, it would have been very useful for me to be able to show animations. [...]. So I really do see added value from this kind of communication tool." – Patient with OC	Q59
	"So that when you are sitting at home recovering from the news and think 'Gosh, what did he actually say?', that you can then look back at things like that [animated videos]." – Patient with cancer diagnosis outside HN area	Q60

	"You would have to make it per person, then, per patient, or per person, does not seem feasible. Because everybody has a different level of education. [...]. Sometimes, if you are not careful, it gets taken the wrong way by the patient. That is why I am not really in favor of making the videos, frankly." – Surgeon	Q61
	"But you are then overloaded with information from someone you trust, whom you put your fate in their hands. And then being distracted by a video, you have to wonder if that is helpful." – Caregiver	Q62
	"Also, here [points at animated video prototype], I think it can just be a static drawing where you point to something yourself. You can make it much more personal than when it is a moving animation." – Surgeon	Q63
	"Now if you have to choose between two or three equivalent options, in the end, the image [in the video] can then be decisive as far as I am concerned." – Caregiver	Q64
Perceived ease of use	*"I prefer to keep what I tell the patient in my hands and to what depth. And not only dependent on my own [experience] but also depending on what the patient wants to know."* – Surgeon	Q65
	"But the thing is, if you are going to supervise those videos in the consulting room, we do not have time for that. Because then it really quickly becomes three-quarters of an hour." – Surgeon	Q66
	"[…] that we can go into that interview or information session better prepared, which leaves you, well, also just more time to go deeper." – Nurse	Q67
	"I think more people own a computer than a tablet. [...]. But yes, if it is on your computer, you are going to see it on your tablet or your phone can too." – Patient with OC	Q68
	"Maybe between appointments, because usually they come to us after the outcome interview, but then in that interim, you can put them in the waiting room with an iPad." – Nurse	Q69
	"I think, given the patient category, they are not so likely to watch a video at home about the surgery. A lot of patients cannot even get into their patient portal. They do not have a computer." – Nurse	Q70

Moment in care path	*"If you show a patient this in advance at home, [...] leads to a lot of ambiguity and questions. [...]. You have to physically show and explain these things together."* – Nurse practitioner	Q71
	"But I do not really agree with letting people watch that at home, because it can cause panic [...]. Somebody has to be there, it does not necessarily have to be the physician, but then let the patient view that with the nurse." – Patient with cancer diagnosis outside HN area	Q72
	"I then also think, you tell the story and then you say, 'Look, this is the video, and then we will discuss it some more'. In the meantime, I enter my data and the patient watches the video [...]. Then you say, 'You understand more or less what is said there? Do I need to explain anything?" - Surgeon	Q73
	"You know what you have in-house, and you just choose from that when it comes up. Every consultation is so different. Sometimes you do have a certain structure, but, no, I think you really have to choose that for yourself when it is needed." – Speech therapist	Q74
	"So I think it is also occasionally just those supervisory questions of "Do you still find that somewhat pleasing to see?' – Patient with OC	Q75
	"I cannot imagine showing those videos in your first conversation. You have to deal with it yourself when you hear you have cancer. Then that video does, well, come in, I guess, I think that is too much." – Nurse practitioner	Q76
	"All visual, audio, and images related to diagnostics, I can show during my clinic. Uhm, surgical things, I think that would be a good time for the head and neck surgeon. But then, they can ask the head neck nurse about the possible side effects, consequences, etc. Some deeper questions, because indeed they have already seen the videos. So I think you should not wait too long for that. – Nurse practitioner	Q77
	"The role of the nurse practitioner is also an extension of the physician. They have more time to go into it. [...]. So I can imagine that the speech therapist is there for talking, eating, swallowing, but surgically, the wounds, it would be very nice if the nurse practitioner could do a lot in that." – Speech therapist	Q78

	"Of course, you have to give information, but you also have to dose it for people." – Nurse practitioner	Q79

Note: Quotes were translated from Dutch to English and made understandable; HN = head and neck; OC = oral cancer

DISCUSSION

This study explored the needs and preferences of patients, their caregivers, and HCPs for the content, design, and adoption requirements of animated videos in complex surgical oncology communication by focusing on oral cancer treatment. While we identified some common ground among the groups of end-users, several key differences and concerns emerged, specifically regarding which information the videos should provide, how information should be presented, and when the videos should be integrated into HCP workflows and the patient journey. Developing and implementing animated videos in the context of complex surgical oncology communication is thus not easy. The differences in needs, preferences, and concerns pose a significant challenge for video developers to create videos that inform and empower patients while minimizing distress and managing expectations realistically. Our findings highlight key features that should be considered to ensure these videos effectively complement the standard verbal communication provided by HCPs.

First, we found that patients, caregivers, and HCPs prefer a video to educate patients about the medical and technical aspects of treatment and postoperative care, as well as the impact of treatment on daily life. Some also suggested including links to help patients find extra resources. While we expected each group of end-users to favor detailed descriptions of diagnostic pathways and surgical treatment [53–55], predominantly patients express a strong desire for comprehensive information about all aspects of their care journey. In contrast, HCPs and caregivers are more cautious, fearing that too much detail could create unrealistic expectations. Instead, they prefer videos that focus on promoting patient autonomy, providing coping strategies, and addressing the emotional impact of treatment. Relatedly, several patients, caregivers, and HCPs emphasized the importance of presenting information honestly without making information on treatment, postoperative period, and treatment consequences appear more beautiful than they might be. While some patients and HCPs found animation, including the 3D animations used in this study, less confronting and more abstract than real-life video recordings, others found the 3D animated videos fear-provoking due to their realistic animation style and the detail of information conveyed. Consequently, such realistic 3D animated videos may be too confrontational for newly diagnosed patients, who are already experiencing high levels of anxiety and distress [56].

Second, there seemed to be a consensus regarding the design of the video. All users prefer videos that are simple, easy to follow, and accurately convey information. They recommended short videos with a maximum duration of 2-3 minutes using clear and accessible language, supportive text and visuals, a structured storyline, and a focus on a single topic. Incorporating these features can help reduce cognitive overload [27] and make

information more accessible, particularly for those with lower health literacy [57] or language barriers (Hyatt et al., 2017; Shaw et al., 2015). The versatility of animation allows for various stylistic choices, such as different animation techniques, art styles, sound, music, visuals, and verbal and textual elements, which may mitigate this emotional distress [60]. As such, one way to make information less confronting may be through metaphors, for which animation is particularly well-suited [60]. Additionally, several patients and HCPs suggested using peer patients and caregivers as an alternative to animation. Research has shown that patients consider support from fellow patients beneficial [61]. Incorporating peer patients in videos may thus enhance relatability and foster a sense of connection, and possibly contribute to feelings of empowerment [62].

While our study extends existing research on the information needs of patients with head and neck cancer by providing insight into how clinical information and the impact of treatment on daily life can effectively be addressed in animated videos [54,61], it remains relatively unclear how best to depict them in the animated videos visually. Participants only provided limited concrete suggestions for their visual presentation. Future research should compare different animation and presentation styles (e.g., 2D animation, 3D animation, live-action, metaphors) to determine their effectiveness and how they affect patient outcomes, such as emotional response. Additionally, building on our findings, video developers should collaborate closely with patients, caregivers, and HCPs to ensure that video development finds the appropriate balance between empowering patients and accommodating the concerns of caregivers and HCPs [38,39].

Third, we found that patients, caregivers, and HCPs differed in their opinions on the adoption requirements for the videos. While most patients, caregivers, and HCPs saw (animated) videos as valuable resources, caregivers and some HCPs questioned their suitability as supplementary information resources. Instead, they reasoned for other non-digital alternatives, such as static images and drawings, as more effective tools. Perceptions of ease of use also varied between HCPs. Surgeons were more concerned that integrating the videos into consultations could disrupt their workflow and take up too much time. In contrast, several paramedics believed that using videos could actually improve efficiency, saving time by allowing them to tailor subsequent information provision to individual patient needs. On the other hand, patients were more concerned with the accessibility of the videos. They suggested that videos should be easy for HCPs to display during consults and compatible with diverse technical devices at home. Nevertheless, some HCPs are worried about the potential challenges patients might face in accessing videos from home, pointing out issues such as information overload or the lack of technical devices and skills. To tackle this, patients and HCPs emphasized that having an HCP present is important to address potential questions or prevent misinterpretation of information by patients. For example, through an HCP-dependent approach, where multiple HCPs

show videos relevant to their field at different stages of the patient journey. This would allow patients to absorb information gradually. However, a concern with this approach is whether patients would still receive enough information in time to make an informed treatment decision. Withholding videos during the decision-making period defeats their purpose of adequately informing patients and empowering them to participate actively in patient-centered communication and, thus, in SDM. Some patients and HCPs, therefore, suggested scheduling a second consult with a surgeon to ensure patients have adequate time to process the information before deciding.

Ultimately, this study highlights the challenge of adequately preparing patients for treatment. Finding the right balance between providing sufficient information and avoiding information overload during a highly stressful period, in which patients must make important decisions within a limited timeframe, proves particularly difficult. Preferences regarding the content of educational videos and the optimal timing of presenting these videos within the patient journey appear to vary between user groups. However, a recent review has shown the potential of showing audiovisuals pre-treatment to oncology patients, including when they were shown prior to the treatment decision-making consultation, without causing any additional anxiety amongst the intervention group compared to the control group [25]. Future research should explore the optimal timing for implementing videos, including the video content, in the patient journey through journey mapping. At the same time, video developers should adopt a user-centered design approach, including the various end-users, to incorporate these users' various needs and preferences at various moments of the patient journey.

Strengths and limitations

A key strength of this study is that it provides more in-depth insights into the design requirements needed to develop further (animated) videos for use in complex oncology counseling. By focusing on the context of oral cancer counseling, where patient-provider communication appears particularly challenging, we identified several specific needs and preferences that can guide the creation of effective educational tools for oncology patients. In doing so, we included diverse perspectives of potential key end-users, including patients, caregivers, and various HCPs, such as surgeons, speech therapists, and specialized nurses. Another notable strength of our study lies in the simulation of the perspectives of future patients, which we aimed to represent by including analog patients who were diagnosed with a cancer type outside the head and neck area or who have no prior experience with cancer. Furthermore, our study findings go beyond considerations of the video content and design by also addressing the crucial factor of the adoption and implementation of videos. This highlighted that the acceptance and usability of videos

heavily depend on when they are introduced in the patient journey and which key end-user delivers or adopts them.

However, several limitations exist despite these contributions to developing (animated) videos. First, while the inclusion of eight surgeons provided valuable insights, there was a limited representation of other HCPs that are important in the disease trajectory of head and neck patients, such as speech therapists, specialized nurse practitioners, and specialized nurses, which may have affected our comprehension of their needs and preferences. Furthermore, most patients in this study had a higher educational level (78.9%), resulting in an overrepresentation of this demographic and an apparent underrepresentation of patients for whom animated videos may be particularly beneficial, such as those with lower health literacy, lower socioeconomic status, or differing language backgrounds. Last, due to ethical concerns, we did not include newly diagnosed patients, resulting in a lack of insight into the actual perspective of this group, specifically considering that the information needs between diagnosed patients and surgically treated patients with oral cancer differ [63]. Nevertheless, our inclusion of analog patients should have accommodated this somewhat.

CONCLUSION

Our study provides valuable insights into the needs and preferences of patients, their caregivers, and HCPs for the content, design, and adoption requirements of animated videos in complex surgical oncology communication by focusing on oral cancer treatment. While the end-users shared some common needs and preferences, notable differences and concerns emerged in their views on the use of videos during consultations. These mainly revolved around which information about treatment and its impact on daily life the videos should provide, how this information should be presented, and the ways in which the videos should be integrated into clinical pathways and the patient journey. The involvement of patients, caregivers, and HCPs in developing and implementing animated videos is thus fundamental to maximizing their adoption, usability, and implementation. Ultimately, video developers should carefully consider these diverse perspectives outlined in this study, as a key challenge lies in creating videos that accurately inform patients which allows them to actively engage in patient-centered communication while also minimizing unnecessary distress and avoiding unrealistic expectations. Our findings not only contribute to the development of animated videos in complex surgical oncology communication, such as oral cancer treatment, but may also be relevant to other video formats and other complex medical contexts, both within and beyond the field of oncology.

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SUPPLEMENTAL MATERIALS

Supplementary material A: Topic guide used for semi-structured focus groups and individual interviews.

In between, adjustments and revisions were made to make each interview guide suitable for the particular focus group.

Interview Guide

Focus group round 1: Head and neck surgeons (60-75 minutes), including a break of 5-10 min

Checklist for the researcher(s):

- Check whether all PowerPoints with the prototypes/examples of animations are open for the session. Have all PowerPoints been sent to all participants of the focus group?
- Start recording the (Zoom) meeting
- Check if we have all informed consent statements. This is done as a second check. If not, this must still be requested (online) verbally from the participants. After completion, these must still be sent.

Aim of the interview: To understand the needs and preferences of head and neck surgeons with regard to animation videos that discuss surgical treatment, the postoperative period, and possible functional consequences.

Interview guide legend

- [indication for the interviewer/researcher]
- [action to be performed for interviewer/researcher]
- *italics* = examples regarding direction/type of answers that are being sought

Introduction round
[Consent check] Before we really start, have you read and signed the consent form? If not, could you send/return it back as soon as possible? Is everything clear? Introduction: As you know, we have already conducted a previous study that showed that the use of audiovisual material is necessary in practice. We are curious about the opinions within this group.
1 Can you briefly tell us something about your experiences with audiovisual material?
2 What do you think are the advantages of audiovisual material? And why do you think this is an advantage? What do you think are the disadvantages of audiovisual material? And why is this a disadvantage for you? How could this (material) be improved? How can this be used better?

Topic 1: Video Content
Goal: To find out what kind of information doctors want in the animation videos related to the surgery, postoperative period and functional outcomes.
Introduction: In order to find out how the videos can best support you, it is important for us to find out what your needs and preferences are with regard to the content. This is one of the two big topics, besides design. During the following questions you will always see some examples so that you can indicate a preference and feedback. You can also see the examples in the PowerPoint, which we just emailed, if you like.
3 What information about treatment would you like to see in the video(s) to be able to discuss this clearly with the patient and loved one(s)? *→ See if there is an answer in the direction of something similar to: trans oral excision, command procedure, sentinel node procedure, incisions, reconstructions (FFRF, ALT, Pectoralis major), mandibular reconstruction* • How/in what way would you like to see this information in the video(s)?   o Why? • **[show slide nr ... until...]** What is your first impression of the examples we are showing you now?   o Why?   o What do you think the videos should look like?   o On which

4 What information about the postoperative period would you like to see in the video(s) in order to be able to discuss this clearly with the patient and any loved one(s)?

→ E.g.: Tracheotomy (cannula), Tube feeding, Drains

- How/in what way would you like to see this information in the video(s)?
    - Why?
- **[show slide nr ... until...]** What is your first impression of the examples we are showing you now?

5 What information about functional consequences of the operation would you like to see in the video(s) in order to be able to discuss this clearly with the patient and any relative(s)?

→ E.g.: Daily life, Eating (chewing), Drinking (swallowing), Speech (articulation), (tongue) Mobility, Intimacy, Appearance (aesthetic), Social matters, etc.

- Which functional consequences should be addressed in particular in the video(s)?
- How/in what way would you like to see this information covered in the video(s)? Why?

  → E.g.: Acting out by fellow sufferer/other patient, statistical figures/numbers, percentages, graphs, tables, pie charts, bar charts, icons/figures

- **[show slide no ... until...]** What is your first impression of the examples we are showing you now?

Topic 2: Video Design/Lay-out

Goal: To find out what doctors prefer as a design for the animation videos.

Introduction: It is very important to us that you also think about the design of the videos, so how they should look visually. The videos will have two different animation styles, a 3D part in which dimension/depth can be seen from a different angle and a 2D part with flat images without depth. We also focus on components such as colors, backgrounds, texts, and so on. We will show you a few examples so that you can indicate a preference. You can also see them in the PowerPoint, which we just emailed, if you like. Take your time to go through them.

6 What do you think the person/patient shown in the 3D part of the videos should look like?

- [show slide nr ... until...] How realistic or detailed?
- [show slide nr ... until...] Which gender? Or would you rather have a neutral gender shown?
    - Why?

  → E.g.: alternation for inclusivity, neutral
- [show slide nr ... until...] What skin color?
    - Why specifically that skin tone type?

      → E.g.: alternation for inclusivity

7 What do you think the person/patient shown in the 2D part of the videos should look like?

- **[show slide nr ... until...]** Which style / way of animation appeals to you the most?
- **[show slide nr ... until...]** Which gender?
    - Or would you rather have a neutral gender shown?
    - Why?

      → E.g.: alternation for inclusivity, neutral
- Around what age or age range?
- **[show slide nr ... until...]** What skin color?
    - Why?

→ E.g.: alternation for inclusivity

8 Who should tell the information in the videos?

- **[show slide nr ... until...]** By which person or persons?

  → E.g.: Doctor (factual medical information, functional consequences), Patient / fellow sufferer (medical information, functional consequences: narrative / from own experience, anecdotal)

- Do certain topics have to be discussed by a specific character?

  - To what extent could patients and loved ones benefit from seeing the experiences of other fellow sufferers?

    → E.g.: Doctor (factual medical information, functional consequences), Patient / fellow sufferer / patient models (medical information, functional consequences: narrative / from own experience, anecdotal - can help to learn to deal with it)

- To what extent could background noise or music be used for this?

9 **Introduction**: We want to take all kinds of patients into account as much as possible and we also want the videos to be understandable for everyone.

- Do you have any suggestions for this?

- How should this be done in the videos?

- **[show slide nr ... until...]** Suppose we can also show this as text in the video, which example do you prefer?

10 Which color(s) do you prefer in the following examples?

- **[show slide nr ... until...]** Background in the videos?

- **[show slide nr ... until...]** Introduction and conclusion of the videos?

Topic 3: Medium, Channel, and Implementation

Goal: (1) to find out what doctors need to use the animation videos during consultations and (2) how doctors want to show the animation videos.

Introduction: Finally, we are curious about how the videos can best be implemented and offered so that they may become part of your information provision in the future. We also have the idea of making the videos available to patients and relatives after the consultation.

11 How and when can these videos best be implemented in your consultation?

- What is the maximum length of the different videos?
- On which device would you like to show the videos to the patient and loved one(s) during the consultation?

  → *E.g.: Computer, Laptop, Tablet*

- Where or in what environment would you like to be able to find the videos during the consultation?

  → *E.g.: Head and neck website, YouTube, via shared file folder, new page/website, YouTube video on Head and neck website, other (online) environment, etc.*

12 To what extent should patients and loved ones(s) be able to see the videos at home after the consultation?

- How would you like to pass on the videos to the patient and loved one(s)?

  → *E.g.: Message via MijnAVL, E-mail, Physical paper, etc.*

- Through where or which environment would you like to make the videos available to the patient and loved one(s) at home?

  → *E.g.: Head and neck website, YouTube, via shared file folder, new page/website, YouTube video on Head and neck website, other (online) environment, etc.*

Wrap up

We now have enough feedback and input from you to further design the animation videos according to your needs and preferences. Before we really wrap up:

- Do you want to say anything about the development of the animation videos before we end the focus group? Or are there any questions?
- I would like to thank you for your time and participation! If you have any questions, you can email us at: XXX

Interview Guide

Focus group round 2: (Ex) patients and caregivers (60-75 minutes), including a break of 5-10 min

Checklist for the researcher(s):

- Check whether all PowerPoints with the prototypes/examples of animations are open for the session. Have all PowerPoints been sent to all participants of the focus group?
- Start recording the (Zoom) meeting
- Check if we have all informed consent statements. This is done as a second check. If not, this must still be requested (online) verbally from the participants. After completion, these must still be sent.

Aim of the interview: To understand the needs and preferences of patients and caregivers with regard to animation videos that discuss surgical treatment, the postoperative period, and possible functional consequences.

Interview guide legend

- [indication for the interviewer/researcher]
- [action to be performed for interviewer/researcher]
- *italics* = examples regarding direction/type of answers that are being sought

General welcome
[Welcome] Welcome everyone and thank you for your time and for participating in this focus group (briefly introduced by both researchers). **[Duration]** The interview will last about 60-75 minutes including the break. To ensure that we do not take up more of your time, we may have to interrupt you from time to time. After the interview, there is of course always time to talk further outside the investigation. **[Survey]** Furthermore, we have sent you a short questionnaire prior to this interview so that we get an extra good idea of who we spoke to today. **[Consent check]** And then finally, before we really start, have you read and signed the consent form? If not, could you send/return it as soon as possible? Is everything clear? If so, then we are really going to start now

Introduction round
Introduction: First of all, I would like to do a short round of introductions, then we can really start
1 Who are you?
2 Could you share with us when you or your loved one was first told the diagnosis of a malignant tumour in the mouth?
3 What treatment(s) did you or your loved one undergo for this?

Topic 1: Earlier experiences with information
Goal: To find out what was the previous experience of patients and loved ones with the physician's provision of information
Introduction: We understand that hearing the diagnosis of a tumour in the mouth brings fear and stress. Your whole life is turned upside down as a result. You will also receive all kinds of information from the doctor during the outcome interview in which the diagnosis and advice for treatment are discussed. With the following questions, we would like to ask you to think back, in particular, to this consultation in which the diagnosis and treatment recommendations were discussed.
4 Besides hearing the diagnosis, what information from the doctor during the outcome interview stuck with you? • What did you think of the information the doctor gave? • What did you think of the way this information was given by the doctor? • Did you understand the information the doctor told you? • What parts of information were most important to you? • Were you missing any information? What would you have liked to know more about? o To what extent could this missing information have helped you? o To what extent did the doctor prepare you for the consequences of the surgery: how the surgery would change your daily life? ← Were you expecting it?

5 Did you look up any additional/additional information besides the conversation with the doctor?

- If yes, why did you do so?
    - What kind of information did you look up?
    - Where did you look up this information?
    - Did you understand this information?
    - What did you like about this information?
    - Did the doctor advise you to look up this additional/additional information?
    - Were you able to find this information?
- If no, why not?

6 Did the doctor use tools to give you more information in addition to what he/she was already telling you?

→ *For example: flyers, pictures, drawings, or videos*

- **[used supplementary]** What additional way was used or could you give an example?
    - Before this, had you experienced a doctor using supplemental materials before?
        - ← If yes, what previous experience?
        - ← If no, how did you experience this complementary way?
- **[no additional]** Would you have liked it more if the doctor did use additional/supplementary material to give information to you in addition to the information he/she told you?
    - In what ways would you have liked to have been given more information in addition to the information the doctor told you?
        - ← Why?

Topic 2: Video Content

Goal: To find out what kind of information patients and loved ones want in the animation videos related to surgery, postoperative period and functional outcomes.

Introduction: As we indicated earlier, we are currently developing animated videos. These videos could then be used during a rash discussion by the physician in addition to the information he/she is telling. It is very important in this development that we take into account what patients and loved ones want and need when it comes to such videos. Indeed, in this way they will be more useful. In the following questions, we would like to ask you again to think back to the outcome interview where the diagnosis and the recommendation for treatment was discussed. Only imagine here that the doctor also used animated videos during the interview, which you could then watch back at home. Furthermore, from time to time we will also show you some examples so that you can indicate what you would have preferred to see in those videos. You can also see the examples in the PowerPoint, which we just emailed, if you like. Please take your time to go through them.

7 What information about the surgery would you have liked to see in the videos?

- How / in what way would you have liked to see this information in the videos?
  - Why?
- [show slide no. ...until...] What is your first impression of the examples we show you now?

8 What information about the period immediately after surgery would you have liked to see in the videos?

→ *E.g: Tracheotomy (cannula), Tube feeding, Drains*

- How / in what way would you have liked to see this information in the videos?
  - Why?
- **[show slide no. ...until...]** What is your first impression of the examples we show you now?

9 What information about the consequences of surgery would you have liked to see in the videos?

→ *E.g: Everyday life, Eating (chewing), Drinking (swallowing), Speech (articulation), (tongue) Mobility, Intimacy, Appearance (aesthetic), Social issues, etc.*

- How/how would you have liked to see this information in the video/videos?
  - Why?

→ *E.g: Portrayal by fellow sufferer/other patient, statistical figures/numbers, percentages, graphs, tables, pie charts, bar graphs, icons/puppets*

- **[show slide no. ...until...]** What is your first impression of the examples we show you now?

Topic 3: Video Design/Lay-out

Goal: To find out what patients and loved ones prefer as design for the animated videos

Introduction: It is very important for us that you also think about the design of the videos, that is, how they should look visually. The videos will have two different animation styles, a 3D part where dimension/depth or seeing it from a different angle and a 2D part with flat images without depth. Furthermore, we will focus on such elements as colors, backgrounds, texts and so on. We will show you a few examples each time so you can indicate a preference. You can also see them in the PowerPoint we just emailed you if you like. Please take your time to go through them.

10 What do you think the person/patient seen in the 3D part of the videos should look like?

- **[show slide nr ...until...]** How realistic/real or how much detail?
- **[show slide nr ...until...]** What gender? Or would you prefer a neutral gender to be shown?

→ *E.g: alternate for inclusivity, neutral*

  - Why?

- **[show slide nr ...until...]** What skin color?

→ *E.g: alternate for inclusivity*

  - Why?

11 What do you think the person/patient seen in the 2D part of the videos should look like?

- **[show slide nr ... until...]** Which style/mode of animation do you most like/dislike to see?

- **[show slide nr ... until...]** Which gender? Or would you prefer a neutral gender to be shown?

  → *E.g: variety for inclusivity, neutral*

  - Why?

- Around what age or age range?

- **[show slide no ... until...]** What skin color?

  → E.g: alternate for inclusivity

  - Why?

12 By whom do you think the information should best be told in the videos?

- [show slide no. ...to/...] By which person(s)?

→ E.g: Physician (factual medical information, functional consequences), Patient / fellow sufferer (medical information, functional consequences: narrative / from own experience, anecdotal)

- To what extent should there be any difference in what exactly is told by whom?

- To what extent could it help patients and loved ones after you to see the experiences of other fellow sufferers?

→ E.g: Physician (factual medical information, functional consequences), Patient / fellow sufferer / patient models (medical information, functional consequences: narrative / from own experience, anecdotal - could help to learn to cope)

- To what extent could background noise or music be used in this process?

13 **Introduction**: We want to take all kinds of patients into account as much as possible, and in addition, we also want the videos to be understandable for everyone.

- Do you have any suggestions for this?
- In what way should this be done in the videos?
- **[show slide no. ...until...]** Suppose we could also show this as text in the video, which example would you prefer?

14 What color(s) do you most like to see in the following examples we are showing you now?

- **[show slide nr ...until...]** Background in the videos?
- **[show slide nr ...until...]** Introduction and conclusion of the videos?

Topic 4: Medium, Channel, and Implementation

Goal: To find out in what ways patients and loved ones want to see the animation videos (1) during the consultation with the doctor (2) and at home.

Introduction: Finally, we are curious about how the videos can best be implemented and offered so that possibly in the future the videos can actually become part of your information services. Furthermore, we have the idea of making the videos available to patients and loved ones after the consultation.

15 How do the videos fit best?

- What should be the maximum length of the different videos?
- On which device would you like to see the videos during the conversation with the doctor?

  → *E.g: Computer, Laptop, Tablet*

16 To what extent would you like to have the opportunity to watch the videos at home after the consultation?

- How would you like to take the videos) with you?

  → *E.g: Message via MijnAVL, E-mail, Physical paper, etc.*

- In what way would you like to receive the videos to take home?

  → *E.g: via email, via MijnAVL, via note from doctor on sheet, via leaflet*

- Through where or what environment would you like to receive the videos sent home?

  → *E.g: Main Neck website, YouTube, new page/website, YouTube video on Main Neck website, other (online) environment, etc.*

Wrap up

We now have enough feedback and input from you to further design the animation videos according to your needs and preferences. Before we really wrap up:

- Do you want to say anything about the development of the animation videos before we end the focus group? Or are there any questions?
- I would like to thank you for your time and participation! If you have any questions, you can email us at: XXX

Supplementary material B: Development of animated videos

The creation of an animated 3D visualization of a surgical procedure is a complex task in multiple phases that often requires a team. For this project, the team was formed by one 3D modeller, one video editor, and one 3D animator. Generally, we took a total of eight steps to complete this task: (1) reference, (2) storyboarding, (3) sculpting, (4) retopology, (5) rigging, (6) texturing, (7) animation, and (8) video editing.

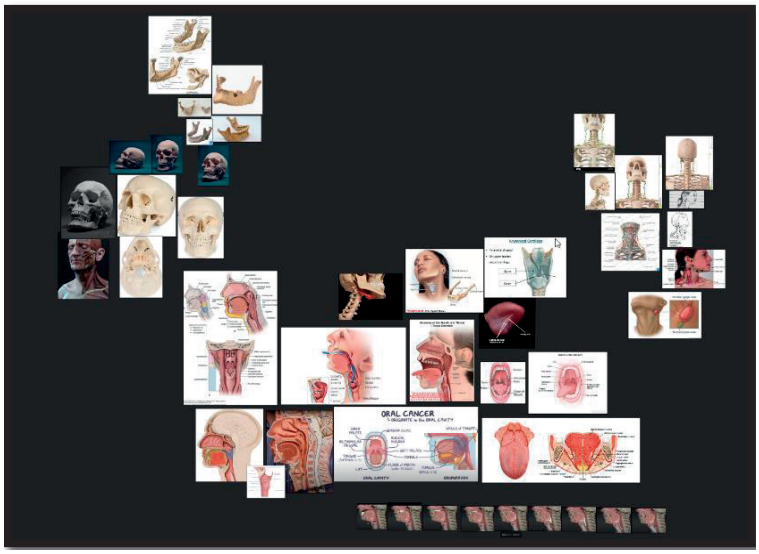


Figure 1. A collection of images to be used as a reference when creating the 3D

1. Reference: The process started with gathering references (Figure 1). This is required for the artist who creates these videos so that they have a strong foundation in understanding the purpose of the project, the correct anatomy of the parts that are involved, and the style in which the final product should be shown. In this case, reference constituted of pictures gathered from the internet depicting neck and head anatomy, screenshots of similar educational videos for the look and feel, sketches of how the tumours affect patients created during talks with medical professionals from the Netherlands Cancer Institute-Antoni van Leeuwenhoek, and 3D scans of patients, including imaging.

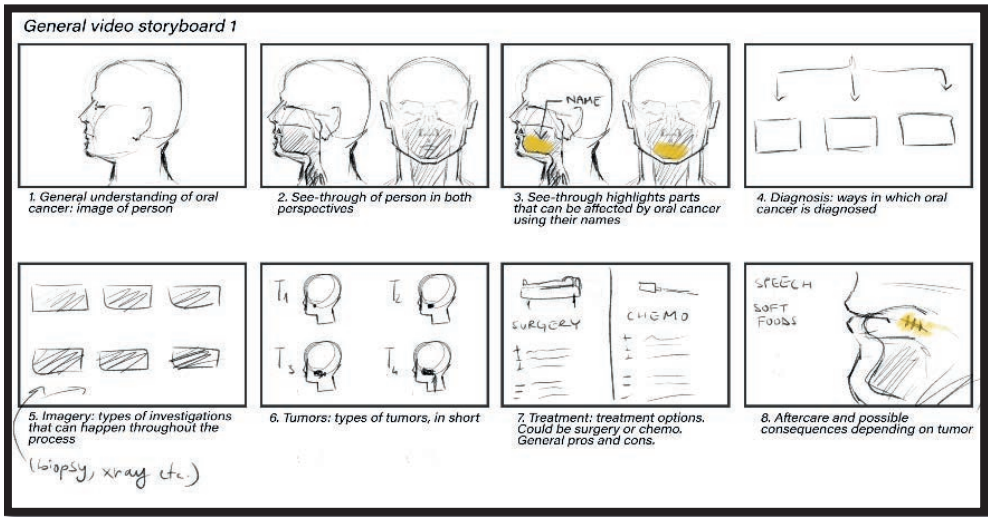


Figure 2. Storyboard showing the main ideas, subjects, and camera movements to be used as a guide when creating

2. Storyboarding: The videos need to follow a logical timeline to convey information in the clearest way possible (Figure 2). As such, we created a storyboard, which can be compared to the scripts used for movies, except that storyboards are a collection of sketches that depict what the video should look like. They are created by an artist and are an easy way to present the idea of the final product to the entire team. Each frame of the storyboard pictures a frame that should be shown in the final product, in order, from the start of the video to the end, and it is useful for details like shot angles and transitions. In this case, multiple storyboards were created, ranging from the ones that show how tumours look like and how they are removed to the daily impact of surgical treatment.

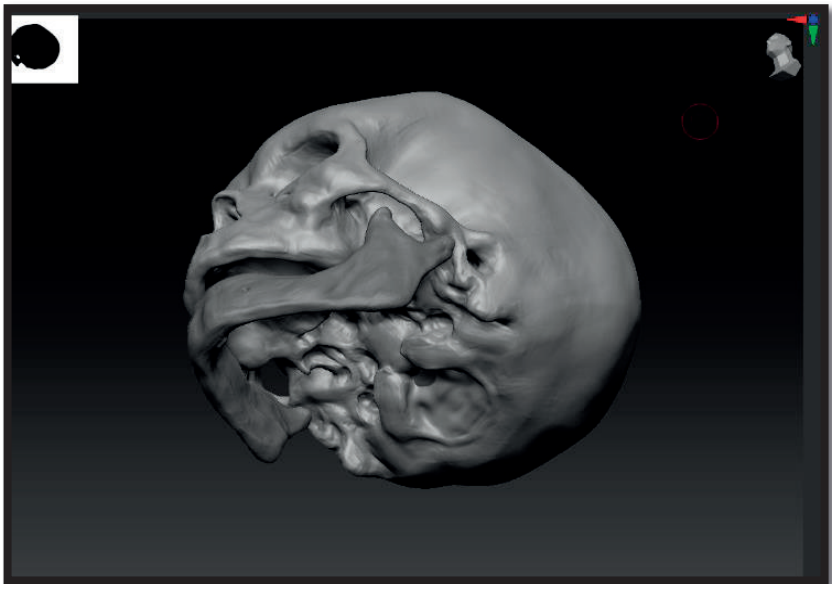


Figure 3. Digital sculpture of a skull, unfinished

3. Sculpting: With the reference and storyboards done, the 3D model creation can start (Figure 3). The most common way of creating detailed models, such as realistic skulls, is sculpting. We created the necessary 3D models in software that replicates traditional clay sculpting: the artist pushes, pulls, cuts, and adds to the digital piece of clay until it reaches the desired shape. For this project, everything from the skull and spine to the larynx and tumours was created using digital sculpting.

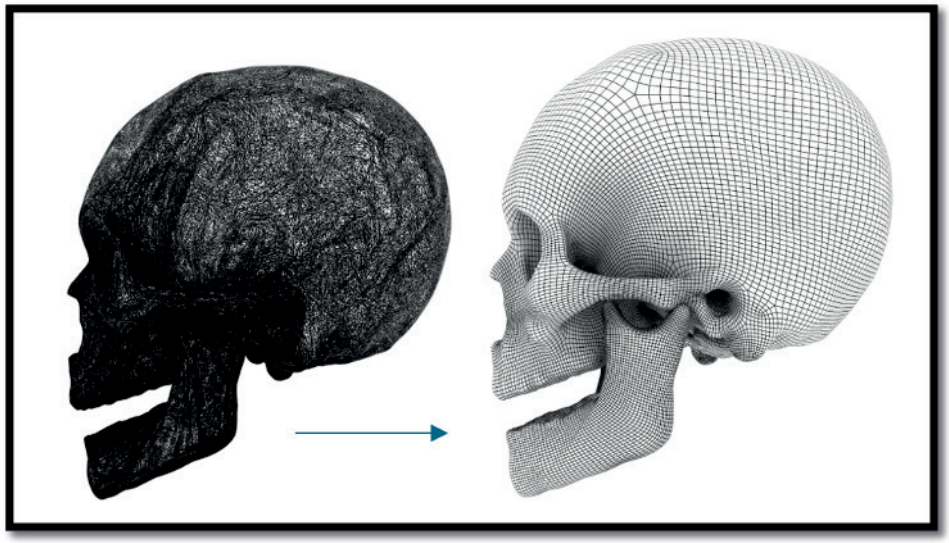


Figure 4. The sculpted skull is made out of polygons, arranged randomly by the computer. These polygons are rearranged manually during the process called “retopology”.

4. Retopology: A sculpt is made from millions of little square planes which the computer needs to process in order to create an image or animation (Figure 4). These planes are called polygons, and they are heavy on the machine in large numbers. The number of polygons needs to be manually reduced to endure a smooth animation process later, in a process called “retopology”. This means wrapping the sculpts in as little polygons as possible, without affecting the initial shape too much. Having fewer polygons in a detailed area might cause it to look blocky due to the fact that the individual polygons might become visible, resulting in a serrated look rather than a smooth curve.

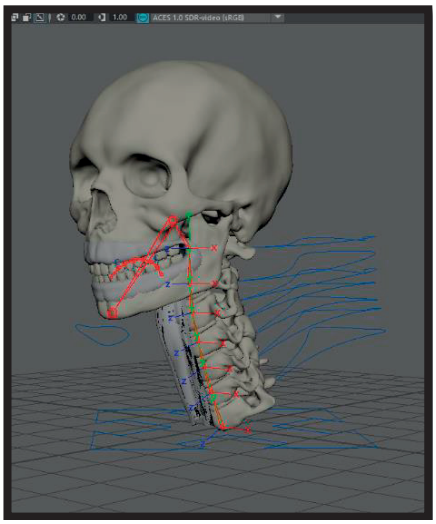


Figure 5. Screenshot of a rig. The red lines represent the digital bones, while the blue lines are the controls that move the bones.

5. Rigging: Models, much like puppets, require a "skeleton" to move (Figure 5). In the digital world, adding this skeleton is called "rigging," and it facilitates every type of movement, from jaw rotation to tongue volume deformation based on its position. It works by adding bones to the models, which are constrained to limit movement or controlled by functions for complex deformation. Additionally, just like a puppet, these bones are moved by a controller, except that instead of a wooden cross, the digital controls are colorful shapes that are tied to each relevant bone or bone sequence.

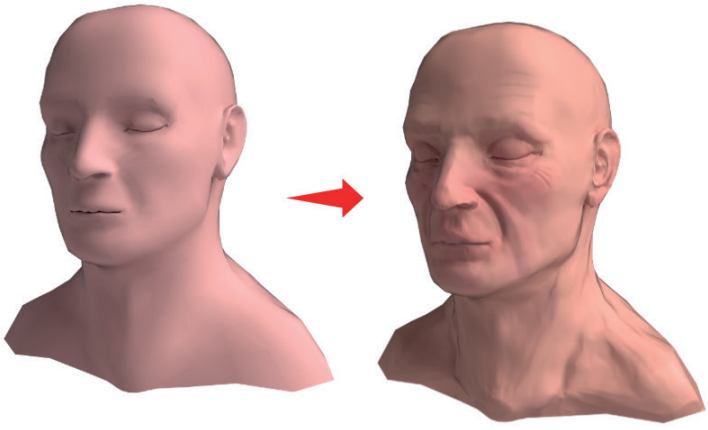


Figure 6. The head model with a very simple texture can be transformed into a more realistic version by adding multiple colors and details, such as wrinkles.

6. Texturing: 3D models receive their look and feel through texturing, which is the process of applying color and other surface information to a model (Figure 6). The color can be painted on, and the model can become glossy, matte, metallic, or a mix between these. Small details, such as scratches or skin spots, are also painted on in this process.

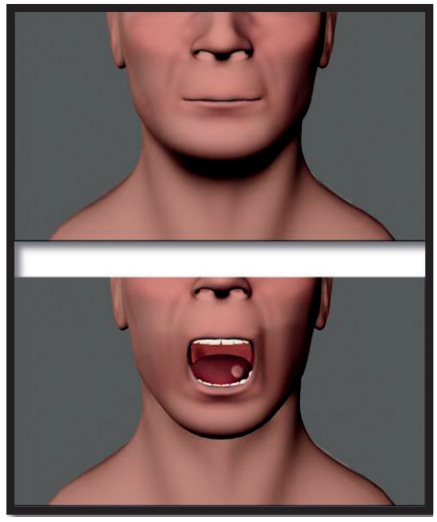


Figure 7. The mouth can be animated to

7. Animation: The model is now painted and ready to move (Figure 7). Our animator did this based on the storyboards. They established angles, manipulated the controllers to achieve movement: closing or opening the mouth, moving the tongue, or even changing the color and size of an inflamed lymph node. Once we were happy with the shots, they were processed by the computer, a process which is called “rendering”. Rendering can take a long time because the computer has a lot of calculations to do, such as the way the light reflects on the model, how the materials react to it, and which parts of the model move.

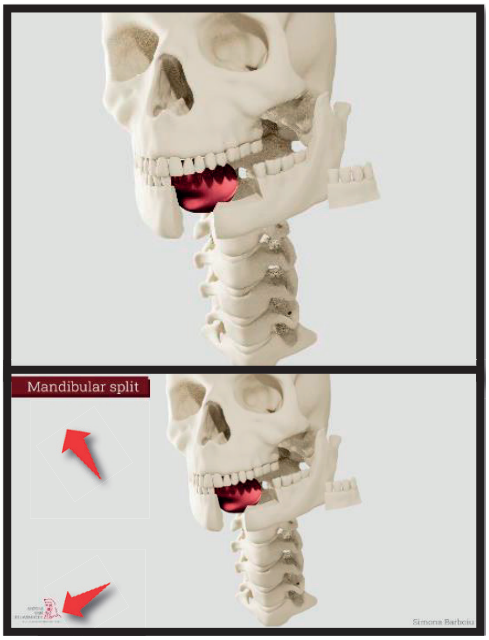


Figure 8. During video editing, design elements such as text or the hospital logo were added.

8. Video editing: Once all the previous steps are done, the product is a few short videos or pictures. These were put together in a video by the video editor, who decides, based on the storyboard, the sequence of the shots, their length, and whether they need to be modified in terms of contrast or color. During video editing, subtitles, transitions and sound are added.

CHAPTER 6

Summary of the results

SUMMARY OF THE RESULTS

SHARING IS CARING: Shared decision-making in complex surgical oncology communication using animated videos

Treatment decision-making in complex surgical oncology is challenging, as patients often face choices that weigh survival against long-term implications and quality of life (QoL). These decisions are medically complex, emotionally charged, and highly sensitive to individual preferences. In such contexts, a strong and collaborative shared decision-making (SDM) process between patients and clinicians, and when present, informal caregivers, is essential to arrive at treatment choices that reflect the patient's values, goals, and preferences [1–3]. This is particularly true for head and neck cancer (HNC), where patients frequently undergo invasive treatment that can profoundly affect their daily functioning and QoL [4–7]. Effective communication and information provision in this context are critical for delivering high-quality care, especially since many patients with HNC experience decisional conflict and regret [8–10]. Despite the clear relevance of SDM in this context, both research and practical implementation of SDM in head and neck oncology remain limited [11]. This dissertation, therefore, explored whether and how SDM in complex surgical oncology can be improved by focusing on oral cancer surgery. Specifically, it consists of two parts.

We first explored how support-seeking behaviors and communication practices can influence patient involvement in decision-making before and during the clinical encounter. We aimed to gain insight into how the actions of both patients and clinicians contribute to treatment communication and SDM (Part I: Support-seeking practices and shared decision-making). Accordingly, we conducted two quantitative studies: one focusing on the online support-seeking behavior of patients with cancer (Chapter 2) and the other investigating the current perceived and observed SDM levels in head and neck oncology (Chapter 3). Next, we explored the role of audiovisual materials as a means of mediated patient education, examining their potential to improve communication and SDM among patients, clinicians, and informal caregivers in complex surgical oncology (Part II: Supportive audiovisual materials). For this reason, we systematically reviewed the literature on audiovisuals (Chapter 4) and explored the perspectives of patients, clinicians, and informal caregivers as potential end-users of (2D/3D) animated videos (Chapter 5).

Part I: Support-seeking practices and shared decision-making

In **Chapter 2**, we first adopted a broader perspective on patients' support-seeking behavior to gain an understanding of why patients with cancer seek informational and/or emotional support online. This knowledge is fundamental to understanding how patients might prepare for or complement conversations with their clinician (e.g., head and neck surgeon), including consultations in which a (complex) decision has to be taken. Building on this, we aimed to profile patients based on their motives for seeking informational and/or emotional support online and to explore how these profiles differed in terms of psychological and background characteristics, as well as in patients' perceptions of health care services. Patients and cancer survivors were sent a survey via email by Kanker.nl that asked about their motives for seeking informational and/or emotional support online. Additionally, measures for their distress, coping style, eHealth literacy, and perception of health care services were included in the survey, alongside questions about their demographic and medical characteristics. In total, 181 participants completed the survey. An exploratory hierarchical cluster analysis was conducted to identify distinct patient profiles, and additional analyses, such as one-way ANOVA and Chi-square, were conducted to investigate how these patient profiles differed.

Three patient profiles were identified, each differing in their online support-seeking behavior. The most active type of patients were the "overall seekers". Compared to the other two groups, patients in this group were the most motivated to use Kanker.nl, to seek informational support, complement information from healthcare professionals, and address conflicting information. Moreover, they appeared to be the most motivated to give and/or receive emotional support online. The "occasional seeker" was the second largest group of patients identified. This group was moderately motivated to use Kanker.nl to find complementary information and to deal with conflicting information, and the least motivated to give and/or receive peer support. The third type of patients, the "contact exchangers", were the least motivated to use Kanker.nl to find information that complements that of healthcare professionals or to deal with conflicting information. However, they were motivated to use the website for peer contact. Furthermore, these patient profiles varied not only in their motives for going online but also in their level of eHealth literacy. Interestingly, the contact exchangers were the most eHealth-literate of the three patient groups. The findings of this study suggest that, beyond relying on clinicians as their primary resource, patients may have different motives to seek additional informational and/or emotional support. These insights can help clinicians deliver accurate, reliable (online) support that is tailored to each patient's needs, preferences, and personal circumstances as part of the SDM process.

To determine whether SDM needs improvement in complex surgical oncology decision-making, such as in oral cancer, it was important to gain insight into current communication and information-provision practices in this field. In **Chapter 3**, we explored the uptake of SDM in daily practice in head and neck oncology. A total of 42 treatment decision-making consultations were audio-recorded amongst five head and neck surgeons (range 5 to 7 consultations per surgeon) at an outpatient clinic. Each of the 36 recordings was carefully analyzed by two independent assessors, who scored the occurrence of SDM on all seven items of the OPTION^{MCC+} instrument to assess the objective SDM level. In addition, perceived SDM level and preferences for patient involvement were examined using a survey comprising the SDM-Q-Doc/SDM-Q-9 questionnaires and the Control Preference Scale. Both surgeons and patients filled out the survey after consultation.

The results showed that SDM is only moderately applied in current treatment decision-making in head and neck oncology. Surgeons' efforts to apply SDM were particularly short in those elements most central to the process, with higher OPTION-scores reflecting discussion of treatment options rather than the elicitation and integration of patient values, goals, and preferences. Conversely, both surgeons and patients perceived a relatively high level of SDM practices during consultation. While both surgeons and patients mostly preferred a collaborative approach to decision-making, in almost two-thirds of cases, the surgeons' assumptions about patients' preferences for involvement were correct. In thirteen cases, the surgeon's assumptions did not align with the actual preference of the patient. The duration of the consultation and patient OPTION-score were correlated with the observed SDM level of surgeons. We found no other associations with surgeons' observed SDM level. Our analyses in this study thus indicate that both information provision and SDM in oral surgical oncology require improvement, as patients' values, goals, and preferences are often only limitedly elicited and integrated when deliberating treatment options.

Part II: Supportive audiovisual materials

To better grasp how SDM in the context of complex surgical oncology can be improved, we aimed to explore whether audiovisual materials could have potential for information provision as part of the SDM process. Following this, in **Chapter 4**, we systematically reviewed the literature to assess the effectiveness of audiovisual materials providing pre-treatment information in oncology on patient outcomes. After retrieval of 15,138 records from five different electronic databases and screening against the inclusion criteria, 37 full-text articles were found to be eligible for inclusion. From each study, the results and multiple study and intervention characteristics were extracted. Results were categorized

into immediate, intermediate, and long-term outcomes of the audiovisual intervention, drawing on the Six Function Model of Medical Communication [12].

The results suggest that audiovisual materials in oncology patient education hold promise for improving specific immediate outcomes, such as knowledge, particularly when standard verbal care is compared with standard care complemented with a recorded video or health animation. Slightly longer after exposure, the audiovisuals also led to positive effects on patients' knowledge, understanding, anxiety, and physiological responses, including heart rate, blood pressure, and respiratory rate. However, results indicated no overall benefits of using audiovisual materials, for example, when both the intervention and control groups received supplementary educational materials. Finally, no long-term outcomes, if measured at all, were found to be significantly in favor of the intervention group receiving an audiovisual. Ultimately, our review suggests that audiovisual materials, such as (animated) videos, can support the SDM process between surgical oncology patients and clinicians by improving patient knowledge and understanding, albeit mainly in the short term and when provided alongside standard verbal care.

As a first step in developing audiovisual materials to support the SDM process, **Chapter 5** aimed to provide insight into the most effective approaches to designing and implementing animated videos for complex treatment decision-making in the context of oral surgical oncology. To gain this knowledge, we explored the needs and preferences of patients, their caregivers, and clinicians regarding the content, design, and adoption requirements of (2D/3D) animated videos for complex surgical oncology communication focused on oral cancer. Six focus group sessions and two individual interviews with patients (n = 17), informal caregivers (n = 2), and clinicians (n = 13) were analyzed using a reflexive thematic approach. In total, eleven themes emerged from the analysis regarding current communication practices and the content, design, and adoption requirements of animated videos. Importantly, although some common ground was identified among the various end-user groups, several group-specific differences and concerns also emerged, particularly regarding the content, design, and integration into clinicians' workflows and the patient journey.

Patients, informal caregivers, and clinicians preferred animated videos that included information on the medical and technical aspects of treatment and postoperative care, as well as their impact on daily life. However, patients strongly favored including information about all aspects of the care journey. We also found that patients preferred comprehensive information, whereas clinicians and informal caregivers expressed concern that providing too much detail might create unrealistic expectations. Clinicians and informal caregivers further indicated that videos should promote patient autonomy, provide coping strategies, and address the emotional impact of treatment. Most patients and clinicians favored

animated formats because they were considered less confronting than real-life video recordings. However, the 3D-animated videos were reported to be fear-provoking because of how realistically and in detail they portrayed the information. Regarding the videos' design, all end-users appeared to share a similar perspective. A video should be simple, easy to follow, and accurately convey a single topic. Finally, we identified substantial differences among patients, informal caregivers, and clinicians regarding perceived usefulness and ease of use, as well as the best moment to implement a video in the patient journey. Although most participants perceive (3D animated) videos as valuable, informal caregivers and some clinicians questioned their suitability as supplementary resources. Surgeons expressed concerns about workflow disruption and consultation time, whereas several paramedics perceived efficiency and time-related benefits when patients viewed the videos with a clinician before or during consultations. Paramedics suggest discipline-specific videos, so patients can gradually absorb the information throughout their patient journey. Overall, this study suggests that developing and implementing animated videos in complex surgical oncology, such as oral cancer surgery, is challenging. Differences in end-users' needs, preferences, and concerns complicate the development of animated videos that inform and empower patients while minimizing distress and managing expectations realistically.

This dissertation contributes to the healthcare communication field in several ways. First, it adds to the limited existing research on SDM about treatment decisions in complex surgical oncology, specifically oral cancer. Second, the mixed-methods approach provides a comprehensive understanding of the communication processes and support-seeking practices that influence patient involvement in decision-making and offers insight into the steps needed to improve SDM in complex surgical oncology. Third, it shows that additional information resources, such as audiovisual materials, alongside the standard care patients in oral surgical oncology receive, are promising, especially in light of the projected increase in oral cancer incidence and the corresponding need for greater digitalization in healthcare. Fourth, treatment decision-making in surgical oral oncology does not necessarily require intricate visual tools, such as the virtual biomedical twin models discussed in the introduction, to effectively inform patients with oral cancer. Potentially, “simpler” visuals, such as health animations, could be a solution to improve patient outcomes. In line with this, this dissertation highlights how challenging SDM in oral cancer treatment and the development of audiovisual material already are. Finally, it underscores the importance of interdisciplinary collaboration when conducting communication research in a complex medical setting.

CHAPTER 7

General discussion

GENERAL DISCUSSION

Insights and recommendations for practice

As this dissertation focuses on whether and how SDM can be improved in surgical oncology, specifically in oral cancer, the following section synthesizes key insights from the research process and translates them into short-term, actionable recommendations for clinical practice. Although SDM is inherently a collaborative process that requires active input from both patients and clinicians, I believe that clinicians specifically hold responsibility in initiating and facilitating patient engagement in the decision-making, particularly in emotionally demanding and complex contexts such as oral oncology. Given the knowledge asymmetry between the two, clinicians may be the best positioned to structure the decision-making process.

In addition, while the healthcare system comprises multiple stakeholders and SDM can occur at various points along the patient journey, the recommendations presented in this part of the discussion are deliberately confined to the treatment decision-making consultation, in line with the primary focus of this dissertation. Ultimately, through these insights and recommendations for practice, I seek to contribute directly to the field of SDM. Accordingly, the findings in this dissertation suggest the need for better support for surgical oncology patients, informal caregivers, and clinicians in implementing SDM, particularly through health communication interventions, such as audiovisual materials. Table 1 provides an overview of the two main parts of this dissertation and connects the four insights with the findings in the corresponding chapters.

Table 1. Four insights and their corresponding chapters are aligned with the aims of this two-part dissertation.

	Chapter 2 Patient profiles based on their motives for seeking informational and/or emotional support online	**Chapter 3** Exploration of SDM in head and neck oncology	**Chapter 4** Systematic review of audiovisual materials in pre-treatment oncology	**Chapter 5** Needs and preferences for animated videos of diverse end-users in oral surgical oncology
Part 1: Exploring the support-seeking behaviors and communication practices of patients and clinicians, before and during clinical encounters that influence patient involvement in SDM.				
Insight 1 - Clinician verbal information during treatment decision-making consultations is often insufficient to help patients engage meaningfully in SDM in complex surgical oncology.	X	X		X
Insight 2 - Clinicians often insufficiently explore and integrate patient values, goals, and preferences during treatment decision-making encounters in complex surgical oncology.		X	X	X
Part 2: Investigating the potential of audiovisual materials to support patients and their informal caregiver(s) in understanding treatment options and consequences, promoting SDM in complex surgical oncology.				
Insight 3 - No one-size-fits-all approach to introducing audiovisual materials, such as animated videos, into the patient journey exists to support SDM in complex surgical oncology meaningfully.			X	X
Insight 4 - There is a tension between patients' need for transparent, comprehensive audiovisual information and clinicians' concerns about creating unrealistic expectations given the unpredictability of treatment outcomes.				X



Information provision and SDM between patients and clinicians in complex surgical oncology

Insight 1: *Clinician verbal information during treatment decision-making consultations is often insufficient to help patients engage meaningfully in SDM in complex surgical oncology.*

The findings of this dissertation suggest that patient information does not adequately meet patients' needs and requires improvement. Across **Chapters 2, 3, and 5**, we consistently found that the standard care is insufficient to enable patients to become optimally involved in their care. For example, **Chapter 2** showed that patients actively sought informational support via Kanker.nl both before and after consultations, using it to prepare for the consultation as well as to complement or validate the information provided by clinicians. However, because this was not examined within the context of SDM consultations, it remains unclear at what stage in the care trajectory this behavior occurs: prior to SDM, between consultations, or after SDM has already taken place. This distinction is critical. If patients predominantly seek information prior to SDM, this behavior should not be interpreted as compensatory for inadequate clinical communication, but rather as indicative of what patients themselves consider relevant for decision-making. In this case, online information-seeking provides a meaningful window into patients' needs, concerns, preferences, and informational priorities. Consequently, it should be regarded as complementary to clinical communication and explicitly incorporated into the SDM process, for instance by clinicians actively exploring what patients have sought and why. Conversely, if patients predominantly seek information after SDM, this cannot be straightforwardly be attributed to insufficient information provision by clinicians. While it may in part reflect unmet information needs [13–17], it may equally point to additional needs such as peer support that fall outside of the scope of clinical consultations. As this chapter did not specifically examine patients' online information-seeking behavior in complex surgical oncology, further research is needed to determine how, when, and why patients engage with online resources, and how this relates to the SDM process, particularly among patients with HNC, including oral cancer.

The study in **Chapter 5** further illustrates that patients in complex surgical oncology struggle to envision and comprehend their treatment and its potential consequences. At the same time, clinicians acknowledged the difficulty of adequately preparing patients for these procedures due to the unpredictability of treatment outcomes. While some clinicians used visuals to complement the verbal information, their dominant form of information provision is verbal. Importantly, the majority of patients and clinicians in our study expressed a preference for integrating animated videos into the patient journey and believed that these can enhance patient understanding. This indicates a need to integrate

this form of audiovisual materials into clinicians' workflows, which is also suggested by previous research [18].

Despite this evidence of the need to improve current information provision, contradictory indications also emerged, with patients and clinicians alike reporting that adequate information has been provided during treatment decision-making consultations. For instance, in **Chapter 3**, we saw that both patients and head and neck surgeons reported that SDM had occurred satisfactorily during consultations. We also learned in **Chapter 5** that some patients and their informal caregivers felt they had already received sufficient verbal information from clinicians. They had not sought additional information on the internet, nor had they opted to use additional information resources. This contradicts prior research showing that patients with HNC experience unmet information needs [18–23], as well as decisional conflict and regret [8–10]. The satisfaction with information in **Chapters 3 and 5**, therefore, casts doubt on whether this satisfaction genuinely reflects patients' experience of SDM or just merely acceptance of the treatment information provided by the head and neck surgeon. Specifically because **Chapter 3** shows that head and neck surgeons primarily discussed the treatment option recommended based on the multidisciplinary tumor board meeting, which confirmed our preexisting assumption that clinicians predominantly focus on medical, technical information [24–26]. As a result, it remains unclear where this inconsistency comes from and where the problem is. It raises the question of whether these unmet needs reflect a limitation of the SDM process itself, or rather indicate ongoing informational needs beyond treatment decision-making. For example, patients may have felt sufficiently informed to participate in the decision, yet still desired more information afterward. Alternatively, some information needs may not be expressed during treatment decision-making because patients perceive their questions as irrelevant to the treatment decision, hesitate to inquire, or prefer not to ask the clinician.

Recommendation for practice 1: *Enabling meaningful engagement in SDM requires clinicians to routinely incorporate and actively discuss and use supplementary information resources, such as online and/or audiovisual materials, to complement their verbal information provision and support patients' ability to process, retain, and reflect on information.*

Building on the findings discussed above, it appears that patients in complex surgical oncology may require additional information beyond that provided by their clinician to participate meaningfully in SDM. Many patients prefer to be involved in decisions about their cancer treatment [24,27,28] and increasingly demonstrate a willingness to take a more assertive role [29]. A clear majority of participants in **Chapter 3** expressed a preference for a collaborative decision-making style, indicating a desire to engage in SDM together with

the head and neck surgeon. While patients in this population perceive the information to be sufficient and feel adequately involved in SDM, our findings also imply concerns about the current, predominantly verbal mode of information delivery and point to a need for complementary formats, such as online resources and audiovisual materials. Previous research indicates that the internet has become a key resource for patients seeking health information [30–33]. Nevertheless, its use and integration into complex surgical oncology communication also come with several challenges. Today, substantial misinformation and disinformation about cancer exist online [34–36], which requires patients to distinguish between reliable and unreliable sources [37,38]. However, many older adults with cancer and their informal caregivers struggle with this [39]. Additionally, the limited use and integration of discussing online health information in consultations can be attributed to factors related to patients (e.g., patients' sociodemographic characteristics) [40], clinicians (e.g., communication and integration of online information difficulties) [41,42], and the system (e.g., time, complexity of navigating websites, poorly organized webpages) [32,43]. Consequently, to mitigate these communication challenges, such as the amount of information patients need to recall from the information provided during consultation, additional strategies are needed to reduce the patients' cognitive load.

Notably, visual cues [44], such as graphical health information, and audiovisual formats [45,46], such as recorded videos [47] and health animations [48,49], can play a valuable role in improving patient outcomes, including information recall and processing. According to the cognitive multimedia learning theory, individuals process information more effectively when it is simultaneously presented through visual and auditory channels [50]. Therefore, in the context of complex surgical oncology consultations, verbal communication alone may be insufficient to ensure adequate understanding and, consequently, meaningful participation in SDM. Accordingly, clinicians are encouraged to use supplementary information resources such as webpages and/or (animated) videos that are, for instance, carefully curated by the head and neck patient association and the Dutch head and neck tumor work board in close collaboration with communication scientists.

Insight 2: *Clinicians often insufficiently explore and integrate patient values, goals, and preferences during treatment decision-making encounters in complex surgical oncology.*

Both **Chapters 3 and 5** show that discussions among patients, clinicians, and informal caregivers in complex surgical oncology rarely address patients' goals, values, and preferences, particularly regarding daily life and QoL. This finding is consistent with previous SDM research [51], including studies in oncology [52–54]. However, studies analyzing how SDM in surgical oncology consultations is discussed remain scarce. The study in **Chapter 3** provides novel insight into this discussion, showing that head and neck

surgeons only moderately explored and integrated patient values, goals, and preferences into the decision-making process. Relatedly, we observed that patients' discussions of their values, goals, and preferences were modest. Instead, consultations often centered on treatment options, particularly those recommended by the medical team, which is consistent with prior findings [24–26] and supports the notion that clinicians often underestimate patients' information values and goals [14,55,56]. Nonetheless, this does not necessarily imply that clinicians do not tailor their consultations, as previous research shows that they do intend to modify information but rather often base this on their impressions of patients' characteristics and behaviors [57]. Furthermore, both patients and surgeons expressed a preference for collaborative decision-making. However, this preference did not consistently translate into substantive discussions of patient values, goals, and preferences. In fact, in nearly one-third of the cases, a mismatch occurred between surgeons' assumptions and patients' preferences for involvement. These findings build on previous research showing that preferred roles for SDM are still applied only to a limited extent in everyday clinical practice [24,27,58,59], including in head and neck cancer [60]. It is thus possible that even when clinicians favor SDM, their beliefs hinder the exploration of patients' values, goals, and preferences [61,62].

In addition, in **Chapter 5**, we observed limited evidence of explicit discussions of patient values, goals, and preferences. Some patients described adopting a "let it all happen" approach, indicating that they frequently went along with surgeons' recommendations, assuming the clinician knew best how to achieve a cure [62–64]. In this context, patients are overwhelmed by fear, anxiety, and uncertainty during the diagnosis and decision-making phase, which may constrain their ability to become aware and reflect on their own values, goals, and preferences regarding a treatment decision [65,66]. Instead, they tend to prioritize survival, which may have overshadowed opportunities for further deliberation, including reflection on what different treatment options would mean for their daily lives and QoL [67] or on their own supportive care needs [68]. Despite this "let it all happen" approach, some patients reported that treatment outcomes and (long-term) consequences were more impactful than initially anticipated, which suggests that professionals should explicitly address these values, goals, and preferences to prevent anticipated decisional regret.

The lack of incorporation of patient values, goals, and preferences was also evident in the included studies in **Chapter 4**, which showed that most video interventions primarily explained treatments and side effects. Thus, although audiovisual materials are increasingly used to support the provision of patient information, they rarely address the elements needed to help patients translate clinical information into their own values, goals, and preferences. Moreover, none of the included studies examined outcomes related to improvements in the discussion or integration of patient values, goals, and preferences, nor did they evaluate whether such discussions enhanced SDM. This

represents a missed opportunity, as audiovisual materials provided prior to treatment decision may be particularly well suited to supporting patients in clarifying their values, goals, and preferences.

Recommendation for practice 2: *Clinicians should be trained and supported to use tools that help patients reflect on, articulate, and integrate their values, goals, and preferences into treatment decisions.*

Although deliberation of patients' values, goals, and preferences is central to person-centered care, the complexity of surgical oncology treatment, and in particular the prioritization of surgery as the only curative option in oral cancer, may have led consultations to primarily focus on medical information [62]. Despite the benefits for patients [69,70] and clinicians [71], both patients and clinicians seem to struggle to incorporate values, goals, and preferences into their treatment decisions. Importantly, patients need to be able to foresee and compare the potential consequences of different treatment options in order to deliberate meaningfully [72]. Nevertheless, they may struggle to recognize the relevance of sharing personal information for the decision-making process [63] or may find it difficult to express their questions, thoughts, and concerns to their clinician [73]. Additionally, patients seem to have a misunderstanding of what incorporating values, goals, and preferences actually entails, which may have resulted in their misinterpreting the clarity and length of surgeons' explanations and answers to questions with the feeling of being involved [74–76]. This implies that patients cannot be expected to independently identify, reflect on, and articulate their values, goals, and preferences, but rather require guidance and support from clinicians to facilitate this process. One way to enable this is to involve nurse practitioners (more) in the SDM process. Nurse practitioners, in particular, often already engage in more in-depth conversations with patients and their informal caregivers [77], yet they rarely take an active role in the decision-making process [78–80]. While they document most of the psychosocial information in patients' electronic health records following social anamnesis (social history), including patients' living situation, lifestyle, social support system, occupation, daily routines, and psychological well-being, they can meaningfully inform clinicians when preparing for treatment decision-making. Consequently, nurse practitioners could explain the SDM process during preparatory consultations with the patient and informal caregiver, and explore patients' values, goals, and preferences, as well as their (health) literacy and information-seeking behavior. This may help clinicians become better prepared and make SDM conversations more efficient.

Clinicians also experience difficulties eliciting and integrating patients' values, goals, and preferences into their consultations [81–83]. For example, in the context of oral surgical oncology, surgeons may assume that incorporating values, goals, and preferences is not always possible, particularly when treatment options are perceived as unequal

and surgery is viewed as the only curative option. Additionally, clinicians believe that eliciting and integrating patient values, goals, and preferences necessarily requires more consultation time [63,82,84,85], yet this does not always have to be true [54,86,87]. Moreover, clinicians often appear to equate successful SDM with providing medical information and reaching mutual agreement, rather than with actively exploring and integrating patients' values, goals, and needs [24,88]. This suggests that clinicians often believe they are sufficiently involving patients, whereas in reality they are not [24,89,90]. As a result, these misperceptions make it a challenge to incorporate these values, goals, and preferences into the consultation.

Therefore, building on insight 2 and the above-described implications, I argue for systematically addressing the misunderstandings and misperceptions that clinicians may hold about incorporating values, goals, and preferences into their consultations through communication skills training [62]. Investments in SDM training have been shown to result in favorable changes in clinicians' communication behaviors and practices [91–95]. Central to this training should be helping clinicians to learn how to avoid misjudging or misdiagnosing patients' values, goals, and preferences, which are often driven by implicit assumptions or "natural instincts" rather than by explicit exploration [77]. From this perspective, eliciting and integrating patient values, goals, and preferences should not be viewed as an additional task for clinicians, but rather as a fundamental method of care [96] and thus as an investment in person-centered care [97]. Importantly, clinicians should be taught throughout their clinical practice, as SDM requires them to develop, nurture, and sustain a diverse set of competencies and professional qualities, including curiosity about patients' lived experiences and what matters most to them [98]. Ultimately, comprehensive and well-structured SDM training should be taught by professional SDM communication specialists and embedded in undergraduate medical education to ensure that (future) clinicians are adequately prepared, especially since the core SDM competencies of eliciting and integrating patients' values, goals, and preferences seem to be currently infrequently and inconsistently taught by supervisors who are often not specifically trained in SDM themselves [99].

Furthermore, trainings should also focus on teaching clinicians how to create opportunities within consultation to gain insight into what matters most to each patient, ensuring they use their time with the patient wisely, for example, by asking more targeted questions, allowing reflective silences, and explicitly linking treatment options to patients' daily lives and QoL [100]. Such careful allocation of time may subsequently lead to discussions about patient values, goals, and preferences, therewith contributing to effective SDM and person-centered care [1,98,101–103]. Moreover, even prior to meeting the patient, clinicians can already draw on existing psychosocial information, for instance, in patients' electronic health records, to prepare for SDM conversations, allowing them to form a provisional

diagnosis of their patient's values, goals, and preferences. However, based on my observations of multidisciplinary tumor board meetings at the head and neck oncology and surgery department, much of this psychosocial information frequently gets lost during discussion of a patient's individual case and the notes of these meetings, used by clinicians to prepare for treatment decision-making consultations, typically only contain medical information and lack patients' contextual circumstances [104].

In addition to teaching core SDM principles and communication strategies that promote patient involvement and patient self-advocacy, training should also include structured self-reflection. For example, I would encourage clinicians to assess their own, and perhaps even their colleagues' consultations, using validated instruments such as the OPTION^{MCC}, Decision Support Analysis Tool, Four Habits Coding Scheme, or Mapping'SDM [105], as we have done in **Chapter 3**. Comparing consultations before and after training may help clinicians gain insight into their communication practices, identify misperceptions, and identify concrete opportunities for improvement. Additionally, beyond these formal training moments, clinicians may benefit from continued on-the-job learning by regularly reflecting on their practices after trying new approaches or implementing changes [106,107]. These reflections could also be brought back as input in subsequent training sessions, allowing SDM training efforts to build on one another over time.

Embedding SDM communication training within Continuing Medical Education (CME) programs may provide a sustainable way to support clinicians in developing and maintaining these competencies [108], as well as offering accreditation credits to encourage further clinicians' attendance at such training and education sessions. For example, in the Netherlands, medical specialists are required to participate in ongoing professional development activities to maintain their RGS-registration (Registratiecommisie Geneeskundig Specialisten) [109]. This means that they need to ensure continued expertise in their own field, quality of care, and patient safety to maintain and protect their specialist title legally. In line with this, I would encourage clinicians to make use of the training resources available online, such as e-learning [110,111], and even to complement their SDM communication training with events focused on healthcare communication and SDM, such as the International Shared Decision Making (ISDM) conference and International Conferences on Communication in Healthcare (ICCH) conference. Participation in such events not only facilitates knowledge exchange but also enables clinicians to build professional networks that can support continued learning and reflection on SDM practices, including, for instance, how best to identify, elicit, and integrate patients' values, goals, and preferences.

Lastly, in addition to the above, I encourage clinicians to consider using an SDM tool to empower and improve patients' communication during treatment decision-making

encounters. Some of these well-known interventions are the "Ask 3 Questions" approach [112–114], decision aids [115–118], and question prompt lists (QPLs) [73,119–121], that patients can use before, during, or after the clinical encounter. Even more recently, an Online Value Clarification Tool (OnVaCT) [54,122] and the Goings-On application [123,124] have been developed to help patients clarify their values and goals. Additionally, more SDM-supporting instruments exist. In 2025, the "Federation of Medical Specialists published an overview of all instruments available in the Netherlands to support the SDM process, including description, objectives, their characteristics, and when they can be used [125]. Still, while such tools may boost patients' self-advocacy during decision-making, their effectiveness largely depends on clinicians' competence in successfully discussing these during SDM communication [73,126–128].

Insight 3: *No one-size-fits-all approach to introducing audiovisual materials, such as animated videos, into the patient journey exists to support SDM in complex surgical oncology meaningfully.*

Both **Chapters 4 and 5** indicate that implementing audiovisual materials, such as animated videos, into routine, complex surgical oncology practice may be challenging and cannot be achieved overnight. Although beyond the scope of this dissertation, findings from our study, presented in **Chapter 5**, suggest that concerns about, and resistance to, innovation and change may be among the factors complicating the effective implementation of *animated videos* in oncology decision-making [129,130]. This finding is consistent with previous research showing that established workflows may hinder or limit the uptake of new practices [131]. Not all patients, clinicians, and informal caregivers perceived *animated videos* as a valuable or suitable addition to standard care. Some informal caregivers and clinicians expressed a preference for alternative resources that clinicians are already comfortable showing to patients, such as static images and drawings [132]. Additionally, some patients and surgeons raised concerns about potential disruptions to the clinical workflow and the anticipated time investment required to show and discuss videos during consultation. As a result, no consensus emerged regarding an optimal moment to introduce animated videos within the patient journal in complex surgical oncology. These concerns may reflect broader apprehensions about losing control over the consultation, uncertainty about how to meaningfully incorporate videos into verbal information provision, or fears of inefficient use of already limited consultation time [133]. Notwithstanding that the use of new tools requires an initial time investment, such concerns may become less prominent once clinicians are adequately trained and supported [54,91–94,134].

Another important consideration in determining how *animated videos* can be integrated into the patient journey is the timing of patients' first exposure to these materials.

Although our review presented in **Chapter 4** did not explicitly focus on timing, a closer examination of the included studies reveals a remarkable inconsistency. Across the 37 included studies, patients were exposed to audiovisual materials at varying moments pre-treatment. In many cases, patients had seen the video after the treatment decision-making consultation, sometimes even on the day of treatment or right before treatment planning. However, it remains unclear whether these videos were intended to facilitate SDM, as none of the included studies justified their choice of the timing of patients' first exposure to the audiovisual intervention, aligning with the findings of a previous review [49]. It is therefore safe to say that the potential effects of when patients can access supporting audiovisual materials remain largely underrecognized, despite evidence that the timing and frequency of educational interventions influence SDM and communication practices [135–137].

Recommendation for practice 3: *Clinicians should develop competencies that enable them to critically assess, discuss, and tailor the use of audiovisual materials to individual patients' needs.*

Healthcare systems are increasingly moving toward a model in which both clinicians and patients are envisioned as equal partners in care. In response to growing healthcare demands and the rising prevalence of cancer among older adults [138], international and national initiatives have increasingly placed increasing emphasis on SDM and the use of supportive tools. In the Netherlands, for example, these ambitions are explicitly reflected in the vision documents "Medical Specialist 2025" and "Samen Beslissen" of the "Federation of Medical Specialists" [139,140]. However, our studies raise important concerns about the extent to which audiovisual materials can meaningfully support SDM when they are primarily introduced after treatment decisions have already been made. When used only post-treatment decisions, these tools risk shifting from genuinely supporting deliberation of values, goals, and preferences to merely informing patients, thereby limiting their potential to contribute to the SDM process. This concern is particularly relevant given that high levels of decisional conflict and regret among patients with HNC remain common [8–10], even when patients were initially satisfied with their treatment decision [141].

Importantly, opportunities to introduce animated videos in head and neck oncology are constrained by the time-sensitive nature of the disease and treatment. Timely initiation of treatment is essential to safeguard survival, oncological, functional, and psychological outcomes [142,143]. In the Netherlands, national quality standards prescribe that primary treatment should begin within 30 calendar days from a patient's first outpatient clinic consultation [144,145], leaving a relatively narrow window for deliberation of patient values, goals, and preferences and decision-making. Consequently, this limits the feasibility of lengthy reflection periods and requires careful consideration of when SDM-supportive

tools, such as animated videos, can realistically be introduced. This emphasizes the need to deliberately identify critical moments within the patient journey where additional information and decision support are most needed and most impactful, rather than assuming that SDM-supportive interventions can be flexibly added at any point. These structural constraints further complicate the identification of an appropriate moment for SDM-supportive interventions.

Given the current lack of explicit guidance and training on integrating audiovisual materials, such as animated videos, into SDM, I argue that strengthening clinicians' competencies in effectively combining patient–clinician communication with audiovisuals is essential. Importantly, this goes beyond learning how to use such materials. Clinicians also need to develop the skills to determine whether audiovisual materials are appropriate for a particular patient and to explicitly discuss their potential use and content with patients as part of the SDM process. This comprises exploring patients' preferences for supplementary information, their emotional readiness, and their ability to engage with the material to determine an appropriate course of action. I recommend, for instance, explicitly framing audiovisual materials as optional resources, discussing their potential added value, and inviting patients to express their preferences regarding when and how they would like to use them. Such dialogue can be considered part of SDM, recognizing that patients' values depend on their informational and/or emotional support needs, emotional readiness, and desired level of support.

Furthermore, to operationalize the use of animated videos in complex surgical oncology, I believe several interrelated considerations should be addressed. The use of animated videos requires that patients be given sufficient opportunity not only to view the materials but also to ask questions and reflect on their meaning [146]. Findings from **Chapter 5** indicate that both patients and paramedics preferred watching videos with a healthcare professional rather than independently, particularly to allow immediate clarification and reduce the risk of misinterpretation. Therefore, I argue that paramedics, such as nurse practitioners and nurses, can play a vital role by sitting with patients during video viewing, offering follow-up consultations or (video)calls in which questions can be addressed or even final treatment decisions can be confirmed [77–80]. At a minimum, patients should be given time to reflect on how the information presented relates to their own values, goals, and preferences before final treatment decisions are confirmed, even if certain preparatory arrangements for treatment have already been made.

At the same time, creating such opportunities for patients to consider and reflect on treatment options considering their values, goals, and preferences poses challenges not only regarding clinicians' workflow but also regarding the Dutch guideline-driven standard to initiate primary cancer treatment within 30 days of the first outpatient consultation

[144,145]. Even though these structural constraints further complicate identifying suitable moments for SDM-supportive tools, room can and should be created within the patient journey for these materials to contribute to SDM meaningfully. Rather than restricting their use to a single consultation, such as the treatment decision-making consultation, their use may be better distributed across clinicians and presented at carefully selected moments in the patient journey, where information is most relevant and needed. One promising approach to identifying such moments is the use of methods such as Metro Mapping [147,148]. This method supports the (re)design of care trajectories in oncology by visualizing both clinical processes and parallel information streams, thereby identifying opportunities to embed SDM better. Metro Mapping is currently applied within the European 4D Picture research project, which aims to improve the patient journey by developing and evaluating solutions (i.e., design-based data-driven decision-support tools and redesigning care paths) that enhance awareness and integration of patient values, goals, and preferences in light of treatment options [149,150]. Based on this project, I recommend that clinicians reflect on their clinical workflows and provide insight into feasibility constraints and opportunities for the use of audiovisual materials, such as animated videos, within the patient journey. In the meantime, although further research is needed to investigate how these supplementary resources can optimally fit within clinical workflows, I encourage clinicians to ask their peers who already have experience in discussing online health information and/or showing audiovisual materials during consultation for tips and recommendations, or to attend one of their consultations to observe [151,152]. Considering that clinicians are lifelong learners, some of these peers may have refined their skills through informal learning in clinical practice [106,107].

Insight 4: *There is a tension between patients' need for transparent, comprehensive audiovisual information and clinicians' concerns about creating unrealistic expectations given the unpredictability of treatment outcomes.*

In our focus group study in **Chapter 5**, many patients expressed a clear preference for detailed clinical and procedural information, seeking to understand exactly what surgical procedures, including tissue reconstruction, and (pre)treatment stages might involve. Newly diagnosed surgical oncology patients regularly seek information related to cancer treatment, alternative therapies, and surgery [153]. Additionally, a majority of patients with HNC indicate wanting to receive as much detail as possible about their cancer and treatment [18,23]. In contrast, clinicians and informal caregivers expressed concerns, cautioning that videos with detailed clinical information could create unrealistic expectations due to the unpredictability of treatment and its outcomes [154–156]. A similar pattern emerged regarding psychosocial information, in which patients also predominantly preferred animated videos to elaborate on the impact of treatment on daily life, thereby highlighting the diversity of potential consequences. However, informal caregivers and clinicians again

expressed their reservations. Earlier research revealed that patients feel underprepared for the impact of treatment on their lifestyle regarding possible physical and psychological consequences, despite clinicians' explanations [18–23,157]. At the same time, clinicians' hesitations about providing too much detailed information on clinical and impact on daily life could also indicate a broader struggle with them communicating uncertainty in the context of variable and probabilistic outcomes [158–160]. Discussing treatment risks, outcome variability, and the limits of prediction thereof is already fundamentally difficult, but potentially even more so when audiovisuals influence patients' expectations. Moreover, clinicians' reservations may similarly point out their underlying concern about causing patients more distress or fostering unrealistic expectations. Nevertheless, patients in our focus group study reported preferring an honest and realistic portrayal of information, which may suggest that patients prefer clinicians communicating about uncertainty [161], even if this is shocking and discouraging, since this could help patients to assess the potential impact of their disease and treatment [162]. It therefore appears that the diverging perspectives are less a disagreement over the quantity of information than a matter of differences in psychological and practical purpose. While patients seemed to reflect on video content from an emotional perspective, clinicians predominantly perceived the animated videos as a medium for informing patients and informal caregivers.

Recommendation for practice 4: *To support SDM, clinicians should wisely use a combination of audiovisual materials, online sources, and verbal communication to mitigate the difference in information preferences among patients.*

The recent technological developments in maxillofacial and reconstructive surgery, as described in the introductory **Chapter 1** of this dissertation, complicate the discussion of effective animated videos to involve patients in SDM in head and neck surgical oncology. These advantages in virtual surgical planning have made it possible to develop detailed 3D models for tongue tumor resections, which might be helpful in the future to predict postoperative functional outcomes to enable well-founded decisions by the tumor board on functional inoperability [163–165]. Nonetheless, the findings in this dissertation clearly suggest that the earlier assumption made by our colleagues warrants critical consideration. That is, based on the discoveries made, this assumption that realistic visualizations can serve as opportunities to actively involve patients in SDM by visually guiding them through highly technical, surgical treatment processes may have become irrelevant. Rather than expressing a desire to engage deeply with complex technical information about treatment, many patients in our studies across **Chapters 2, 3, and 5** appeared primarily concerned with treatment possibilities for survival and, in several cases, with the impact of treatment on daily functioning and QoL. Initial ambitions to translate highly complex, technical virtual models directly into person-centered support tools may therefore be overly ambitious and insufficiently aligned with patients' needs

and capacities. In fact, it became clear that there is a need for a simpler way of presenting the information. I therefore strongly believe that supplementing clinicians' verbal communication requires deliberately conveying the uncertainty and unpredictability of surgical outcomes to support patients' deliberation in SDM.

To genuinely support SDM, audiovisual materials, such as animated videos, must be able to communicate the uncertainty and unpredictability of treatment outcomes in ways that are explicit yet sensitive. For example, this can be achieved by presenting outcome ranges rather than single-point estimates, using clear visualizations (e.g., icon arrays or probability scales), providing plain language explanations of risks and limitations, and explicitly acknowledging what is unknown or variable. At the same time, information should be framed with supportive language and accompanied by opportunities for patients to ask questions or discuss concerns with their clinician. Moreover, in line with the concerns and worries expressed in **Chapter 5**, I recommend that animated video content provide treatment information in a more explanatory manner, leaving room for clinicians to personalize it during SDM conversations. For example, instead of showing a specific tumor resection, as if it were already decided, animated videos could explain that surgical decisions, such as the extent of resection, reconstruction type, or donor skin, depend on findings during surgery and therefore cannot be fully predicted in advance. Similarly, the videos may lend themselves well to explaining what tumor staging entails, in which category the patient's tumor falls, why surgical resection margins are needed, and why reconstructions with donor tissue may be necessary. Meanwhile, animated videos focusing on the psychosocial perspective of treatment could, for example, clarify the clinical, physical, psychological, social, and contextual factors that generally determine treatment (functional) consequences. They can also explain what aftercare involves. As a result, the burden of managing expectations does not rest entirely on clinicians or the patient-clinician encounter. However, it is supported by the design of the videos and can be tailored to the patient's information needs. In doing so, informational transparency can be balanced with attention to emotional well-being, thereby enabling patients' meaningful involvement in SDM. Ultimately, design choices are no longer merely aesthetic decisions but ethical ones, as they may directly influence how patients interpret potential treatment outcomes and subsequently deliberate about treatment options.

When unpredictability and uncertainty are not sufficiently defined or explained, patients may struggle to distinguish among various outcomes. As **Chapter 5** suggests, the added value of animated videos will eventually not depend solely on their format, but rather on how clearly they communicate complex information, variability, unpredictability, and the uncertainties of treatment outcomes to remain accessible and comprehensible to patients. However, developing audiovisual materials that can clearly and responsibly convey the unpredictability and uncertainty of treatment outcomes poses not only considerable

content challenges but also design challenges. As illustrated in this chapter, patients and clinicians differed substantially in how they perceived and experienced the information provided in these animated videos. As such, it is important to carefully consider how best to design and use audiovisual materials, such as animated videos, with respect to explicit depictions of treatment, its outcomes, and (functional) consequences, since this may influence patients' interpretation of the certainty and predictability of those outcomes. Given the many divergent perspectives of patients, clinicians, and informal caregivers, I believe that no single optimal way to use tools that support SDM in complex surgical oncology exists. Rather than striving for one fixed design, animated videos should enable adaptability. This would allow clinicians to use the materials in a tailored, deliberate manner that explicitly addresses the inherent uncertainty and unpredictability of treatment and its outcomes, while also accounting for the variety in information needs [166].

Lastly, based on previous research [167], interactive and modifiable 3D-animated videos may offer additional possibilities for tailoring information provision, for instance by adjusting viewing perspectives or annotating elements in the video using a digital pen and a tablet during consultation. Additionally, patients would be able to take home personalized videos, preventing misinterpretation of uncertainties and unpredictability surrounding treatment and outcomes. Ultimately, however, it is that such a tool should remain supporting clinicians' verbal communication about the uncertainty and unpredictability of treatment and its outcomes.

Methodological considerations

This dissertation, to the best of our knowledge, is the first to thoroughly explore whether and how SDM in complex surgical oncology can be improved, using oral cancer as a context. By adopting a multiperspective and interdisciplinary approach, we integrated expertise from health(care) communication, head and neck surgery, and phonetics to develop a holistic understanding of the research problem. Despite these strengths in collaboration [168,169], several methodological considerations warrant reflection beyond the limitations discussed in each chapter.

In **Chapter 3**, our OPTION^{MCC+} proved to be a valuable instrument for assessing the objective level of SDM in head and neck oncology. The OPTION^{MCC} instrument was originally developed to examine SDM in decision-making among older adults with multiple chronic conditions [170,171], and was adapted for the setting of this project. The instrument is relevant in head and neck oncology, as patients with HNC, including oral cancer, are predominantly older and often experience comorbidity [172]. Although other instruments to assess objective SDM exist, the OPTION instruments are frequently recognized as one of the most suitable [173,174].

A key strength of the more recent OPTION^{MCC} is that it assesses all elements of the SDM process, including the explicit scoring of the elicitation and integration of patient values, goals, and preferences. As collaboration and discussion around patient values, goals, and preferences lie at the core of SDM [1,2,175], this represents a notable advantage. In addition, the instrument enables the assessment of triatic SDM by accounting for the participation of patients and informal caregivers alongside that of the clinician [170,171]. Despite the considerable number of coding systems available to systematically assess the interaction among patients, clinicians, and informal caregivers, a recent review found that only one other system, the PaeD-TrICS, includes triadic communication behaviors, focusing on preventive dental consultations with preschool-aged patients and their families [105]. Taking note of the triadic intent of the SDM process, the OPTION^{MCC} therewith surpasses many coding systems, as well as its predecessors, the OPTION^{5} and OPTION^{12}, by also taking into account the communicative behaviors of patients and informal caregivers.

However, the OPTION^{MCC} does not allow evaluation of the precise content or quality of the discussion, nor of the bi-directional interaction among patients, clinicians, and informal caregivers. For example, more active elicitation by a clinician may lead to greater patient involvement, and vice versa, potentially resulting in higher OPTION scores for either the clinician or the patient. Nevertheless, the OPTION^{MCC}, in which each SDM dimension is scored on a Likert scale for the clinician, patient, and informal caregiver separately, is too limited to capture these dynamic, reciprocal processes in detail. A more fine-grained approach, with greater attention to interactional nuances, for instance through qualitative research methods such as conversation analysis or in-depth observational studies, could provide richer insight into how specific communicative behaviors influence patient involvement throughout the decision-making process. Moreover, the OPTION^{MCC} itself would benefit from further development, particularly with respect to scoring precision, explicitly paying attention to clinicians' conscious or unconscious steering (i.e., implicit persuasion) [176], and identification of missed opportunities to facilitate SDM [83,177]. Although the original scoring manual provides some guidance on scoring per OPTION-item, clarifications are rather limited, with only a few clinician examples provided and even fewer descriptions of what patients' and caregivers' participation could entail [178]. In particular, the items related to eliciting and integrating patient values and preferences (items 5 and 6, respectively) are given limited guidance in the OPTION^{MCC} manual. Notably, all OPTION^{MCC} items are weighted equally, with each item scored from 0 (passive) to 4 (active), despite discussion of patient goals having a high priority in SDM and the fact that the tool draws heavily from and integrates core principles of the three-talk model and goal-based model [2,103,179]. Future research would therefore benefit from more detailed analyses of individual SDM instrument items to gain deeper insight into patients', clinicians', and informal caregivers' performance in eliciting and integrating values, goals, and preferences. Moreover, further investigation into how, when, and by whom deliberation about values, goals, and

preferences is initiated and integrated into treatment discussions would help clarify the mechanisms underlying value-based decision-making and inform the development of interventions to support meaningful patient involvement in these contexts better.

In addition, the OPTION^{MCC} would benefit from guidance on interpreting the objective level of SDM. Now, similar to the earlier-developed OPTION^{5} instrument guide, scores for each individual OPTION^{MCC} item (0 to 4) are summed to create a total score, followed by conversion to a relative score between 0 and 100. Without any clear-cut-off indications for these scores, it is currently difficult to interpret this overall score. In our SDM study presented in **Chapter 3**, we treated the scoring as having three levels (low, moderate, high). Future developments could use this three-level interpretation of the objective SDM level as inspiration, but should preferably also include some description per level to assist its users in what these scores could entail in terms of patients', clinicians', and informal caregivers' decision-making behavior, what this overall score implies, and what could be recommended to improve in that instance.

In **Chapter 3**, we also assessed the subjective level of SDM as perceived by head and neck surgeons and patients. We used the SDM-Q-DOC/9-questionnaires [180–182], which are widely applied across clinical contexts, including cardiovascular diseases [183,184], dermatology [185], anesthesiology [26], mental illnesses [186–188], otolaryngology [189], traumatology [190], and oncology [191–193]. Additionally, since their development in 2009, they have been translated into many languages [194–199]. The questionnaires provided insight into the perspectives of the clinician and patient (i.e., dyadic SDM) and enabled comparison between the two, revealing inconsistencies in perceived SDM. However, the questionnaires assess only the extent to which specific behaviors occurred (0= completely disagree, 5 = completely agree). They do not specify how these behaviors should be performed, nor do they provide clear scoring criteria, for instance, on how "strongly agree" meaningfully differs from "somewhat agree". As a result, patient responses on the SDM-Q-9 may partially resemble their overall satisfaction with the clinician rather than what he/she did or said during consultation. Consequently, we should interpret the findings from these questionnaires with caution.

While both SDM assessment tools were useful to gain insight into the objective and perceived SDM, the SDM-Q-DOC/9-questionnaires and OPTION^{MCC} cannot be directly compared. Although the latter reflects the three-talk model of SDM, its items cannot be directly equated with those of the SDM-Q-9 and SDM-Q-DOC questionnaires' items. For example, OPTION^{MCC} items 1 ('goal talk'), 3 ('team talk'), 6 ('integrative decision talk'), and 7 ('evaluation talk') are not included in the SDM-Q questionnaires. Previous research has likewise found no statistical correlation between items from both measures that assess similar aspects of the SDM process [200]. To enhance comparability and conceptual

coherence, future research would benefit from aligning questionnaire items more closely with the observational instrument, ensuring that similar constructs and phases of the SDM process are assessed across methods. Furthermore, we only measured SDM exclusively during the treatment decision-making consultation, representing one single time point. This consultation was deliberately selected because it is typically the phase when most information is exchanged between patients and clinicians, and treatment decisions are made. However, as mentioned in **Chapter 1**, SDM is not confined to this moment and may unfold well before and after this encounter [1,97]. We did not include questions assessing whether patients had spoken with other clinicians prior to the recorded consultation, either to receive information or to express their preferences. Additionally, no questions addressed whether patients had sought informational or emotional support from other resources, such as online platforms, peer patients, family members, friends, acquaintances, written or printed materials, or their electronic patient portal [1,201–203]. It therefore remains unknown to what extent SDM occurs throughout the patient journey. Recent developments have addressed these limitations, such as the oncology-specific 15-item iSHAREphysician and iSHAREpatient questionnaires [204,205]. However, we were unable to consider these questionnaires because our study had started (May 2021) before they were tested and validated (May 2022) [205].

Another important methodological consideration concerns the application of a user-centered design (UCD) approach in the development of health communication interventions such as the animated videos described in **Chapter 5**. UCD emphasizes the active involvement of key end-users throughout all stages of intervention development [206–208]. Applying this approach can help ensure that the intervention meets the needs and preferences of end-users and can increase the (continued) acceptability of health interventions, such as animated videos. In our study, patients, informal caregivers, and clinicians were considered the primary, secondary, and tertiary end-users of the animated videos [209] and recruited to participate in our focus groups. Unfortunately, not all potential end-users of this type of video were well represented. For instance, participation by informal caregivers, nurses, nurse practitioners, and speech therapists was relatively low, and patient participants were predominantly highly educated and female. This contrasts with the broader head and neck patient population, in which patients diagnosed with HNC are predominantly male, of lower socioeconomic status, and older [172,210,211]. Consequently, this raises questions about whether enough input from these various potential end-users was collected in this study. Nevertheless, the combination of patients, surgeons, and informal caregivers in a single focus group session proved worthwhile. Although the overall attitude of this group appeared to be less favorable to the use of (animated) videos in surgical oncology counseling than in the focus groups with patients only, bringing them together added value through the group dynamics that emerged. These dynamics differed from those observed in the separate patient and healthcare professional focus

group sessions, specifically the one with only surgeons. It would have been interesting to include a broader mix of key end-users in joint sessions to explore how different group dynamics might have stimulated thought-provoking discussions and generated additional insights. However, conducting separate focus groups may have ensured that participants felt sufficiently comfortable to express honest opinions and views, without experiencing social pressure to provide socially desirable responses in each other's presence.

Looking ahead

Now that I have reflected on my own dissertation's insights and outlined their practical implications and recommendations, it is time to look beyond this project and consider the future. In the next section, I present my philosophies on what could come next after conducting this research, as it has inspired ideas on how to continue, both in terms of multidisciplinary collaboration and potential research studies beyond those discussed earlier in this dissertation.

Broadening interdisciplinary teamwork

One overall lesson from this project is that transdisciplinary teamwork is necessary for studying, developing, and optimizing patient counseling in the context of complex surgical oncology [212]. While the research project in this dissertation could not have progressed without the support and input from academic colleagues working both inside and outside head and neck oncology, such as health(care) communication experts, medical technicians, phonetics expert, speech therapists, nurse practitioners, and head and neck surgeons, the scale and complexity of the project described in this dissertation could have benefitted from further holistically broadening this expertise. In other words, bringing science, clinical practice, and industry together may have led to greater progress, as many healthcare communication interventions often stagnate in the end phase, facing difficulties in implementation in daily clinical practice or in maintaining their success once they have left the research context. Therefore, I recommend that future projects expand the variety of experts involved, including not only clinicians such as nurse practitioners, nurses, and speech therapists, but also professionals in the areas of patients' QoL, implementation strategy or consultancy, eHealth, animation development, video editing, healthcare law, policy, quality, and insurance. Especially, patients can provide fundamental experimental knowledge relevant to all stages of health and social care research, from development through implementation, and can help identify sources of distress, miscommunication, or unrealistic expectations that researchers may have missed initially [213,214]. While involving additional stakeholders may initially introduce logistical and methodological difficulties, future projects will be substantially stronger and less likely to stagnate in the implementation phase [215]. At the same time, it is also

important to ensure that not too many stakeholders are closely involved in every phase of such a project. Therefore, I would recommend working primarily with a core research team that is closely embedded within the larger team. This would allow us to work and meet in smaller teams, sometimes alternating with larger group meetings. Depending on the research phase and the input needed, different experts may be involved. Ultimately, it is crucial to coordinate everyone's involvement and contribution to the research project and to have a clear view of everyone's responsibilities.

Collaborating to achieve a shared objective

Although much emphasis in this dissertation is placed on clinicians' performance in SDM and person-centered care, I also believe that the healthcare ecosystem as a whole should bear responsibility for guiding and supporting patients in decision-making. This not only includes clinicians and policymakers, but also third-party stakeholders, medical educators, the government, researchers, and patients themselves. In light of this, recent developments are increasingly made to improve SDM in the Netherlands, especially since the arrival of the Dutch Integrative Care Agreement (IZA) [216]. This agreement has been brought to life by several Dutch parties, including the Ministry of Health, Well-being, and Sports (VWS), the Federation of University Medical Centers (NFU), the Association of Hospitals (NVZ), and the Federation of Medical Specialists (FMS). Herein, plans were made to ensure that healthcare remains of quality, accessible, and available to all. This includes focusing on ensuring that care remains appropriate by providing information that matches the patient's abilities, delivered through a cooperative decision-making process centered on the patient. Accordingly, the adoption of the agreement makes the research, development, and implementation of audiovisual patient education materials an even greater priority in the near future.

Future research directions

Beyond transdisciplinary collaboration, successful complex healthcare communication interventions require a systematic, methodologically rigorous approach to their development, implementation, and evaluation, grounded in solid scientific evidence [217–219]. Guidance from the UK Medical Research Council (MRC) frames this process as a continuous progression through four research phases: the development or identification of the intervention, feasibility testing, implementation, and evaluation [220]. Taking the MRC framework into account, I recommend the following future studies to build on this dissertation and develop evidence-based, implementable healthcare communication interventions.

To deepen our understanding of how SDM is employed in complex surgical oncology, particularly in head and neck, it is essential to conduct qualitative analyses to further investigate the clinical interactions among patients, clinicians, and informal caregivers.

Although **Chapter 3** reports qualitative findings regarding SDM from one single center, data collection for this study was deliberately multicenter to enrich the data for future studies. Two of these studies are currently ongoing, with the audiotaped consultations from both centers being transcribed and analyzed for implicit steering and missed opportunities. Moreover, additional follow-up focus group sessions were held at both institutes in which head and neck surgeons reflected on the combined results of all three related studies. These complementary data sources may provide more in-depth empirical evidence and offer insights into where and how clinicians' communication efforts fall short. Such insights are not only valuable for identifying gaps in current practices but also for guiding the development of healthcare communication interventions. More importantly, by making these shortcomings visible, they may raise awareness among clinicians on their SDM skills, thereby motivating them to engage in training and to adopt supportive interventions such as animated videos. In that way, animated videos could be positioned as practical tools that may not only facilitate patient understanding but also help bridge communication gaps.

It would also be advisable to initiate a Delphi study (Barrett & Heale, 2020), ideally conducted across multiple centers, to further develop the animated videos for head and neck oncology, specifically oral cancer treatment. Delphi studies are fundamental to reaching expert consensus on the development of interventions such as 2D and 3D animated videos, as they involve multiple rounds in which experts are asked questions and/or to provide feedback [221]. An additional benefit of this approach is that participants can see the results of previous rounds and thus respond to their own or others' views accordingly. Part of this Delphi study should be an in-depth exploration of the timing of these animated videos. In addition, think-aloud studies are useful for developing digital health interventions, as they provide insights into users' thought processes and help identify usability issues and areas for improvement [222,223].

Based on our systematic review in **Chapter 4**, we concluded that few studies adopted a randomized controlled trial (RCT) with a longitudinal design or assessed long-term outcomes. Additionally, in none of the studies were audiovisual materials used during treatment decision-making consultations. In light of this gap, I propose an RCT to investigate the effectiveness of the animated videos, with two study arms to be compared. The first arm would consist of standard verbal care without any intervention, and the second arm would involve the implementation of animated videos within the patient journey, after clinicians have participated in a communication training focused on integrating these materials into their workflow and consultations. Additionally, it would be recommendable to conduct this study over a longer period whereby patient outcomes are measured at several points in time, for instance before, during, shortly after, over a certain period, and a longer period. Additionally, it would be important to include patient

outcomes that might relate to the effectiveness of audiovisuals on facilitating SDM, such as patient involvement in decision-making, patient readiness for SDM, decisional conflict and regret, and patient satisfaction. In addition to short-term effects, long-term outcomes, such as QoL, should also be assessed to determine the intervention's sustained impact. Moreover, outcomes related to clinicians and the consultation itself are important to consider if we aim to understand better the effects of using audiovisual materials, such as animated videos. It would therefore be valuable to complement quantitative findings with qualitative findings. In doing so, consultations in both study arms will have to be video-recorded before and after the introduction of the animated videos. This is not only to conduct qualitative content analyses to investigate how SDM has been employed, but also to conduct a qualitative self-assessment (i.e., a within-subject comparison). For this, clinicians would have to review several of their own consultations to assess their SDM performance. After this, they could also assess several of their colleagues' consultations before and after the implementation of animated videos. This could potentially increase their awareness of the quality of SDM before and after the implementation of the audiovisuals.

Finally, in exploring the use of animated videos to facilitate SDM in complex surgical oncology settings, future research should consider the potential role of Artificial Intelligence (AI) in developing such videos. The overarching project, from which this dissertation originated, initially envisioned personalized audiovisual representations of head and neck treatment outcomes, initially by creating personalized virtual surgical models (i.e., "Digital Twin") that could present outcomes for an individual patient. Ideally, these models could both inform multidisciplinary tumor board meetings and treatment decision-making consultations. Although creation of a personalized Digital Twin is challenging, usage thereof is gradually expanding within healthcare [224]. Looking ahead, the continued progress in biomedical modeling, together with the growing capabilities of AI, are likely to substantially improve the sensitivity of predictions of functional impairments [225]. As such, AI (i.e., machine learning) may enable more accurate modeling of surgical details, improving the development of personalized Digital Twins. Nevertheless, as also mentioned above, the initial ambitions to use these highly complex, technical virtual models during treatment decision-making consultations may be overly ambitious and insufficiently aligned with patients' needs and capacities. Instead, to improve SDM during treatment decision-making consultations, it would be interesting to explore the potential of AI in assisting in the development of tailored animated videos that are based upon these personalized Digital Twins.

Concluding thoughts

Despite its growing popularity over the past two decades, it has become increasingly clear that SDM is a more complex intervention than initially assumed. This dissertation shows that improving SDM in complex surgical oncology requires more than good intentions. It calls for structurally strengthening information provision, explicitly integrating patients' values, goals, and preferences, and thoughtfully embedding supportive tools such as audiovisual materials into clinical practice. Only through deliberate communication, transdisciplinary collaboration, and sustained attention to patients' lived experiences can SDM move from principle to practice in surgical oncology. Still, while this dissertation's findings have shed light on current communication and information provision practices and laid the groundwork for developing and implementing audiovisual materials in complex settings, such as oral surgical oncology and beyond, many important questions remain.

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APPENDICES

List of abbreviations

Nederlandse samenvatting

Author contributions per chapter

PhD portfolio

List of publications

Acknowledgements

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LIST OF ABBREVIATIONS

AI	Artificial Intelligence
ANOVA	Analysis of Variance test
AVL	Antoni van Leeuwenhoek
CCT	Controlled Clinical Trial
CG	Control Group
CI	Confidence Interval
CME	Continues Medical Education program
CPS	Control Preference Scale
CTML	Cognitive Theory of Multimedia Learning
CWS	Cancer Worry Scale
FMS	Federation of Medical Specialists
HCP	Healthcare provider
HN	Head and Neck
HNC	Head and Neck Cancer
ICC	Intra-class Correlations Coefficients
ICCH	International Conference on Communication in Healthcare
IES	Impact of Events Scale
IG	Intervention Group
IUS	Intolerance of Uncertainty Scale
ISDM	International Shared Decision Making conference
IZA	Integrative Care Agreement
MRC	UK Medical Research Council
NFU	Dutch Federation of University Medical Centers
NKI	Netherlands Cancer Institute
NVZ	Dutch Association of Hospitals
OnVaCT	Online Clarification Tool
OPTION	Observer Patient Involvement in Decision-Making instrument
OSF	Open Science Framework
PVHH	Dutch Patient Association Head and Neck
QoL	Quality of Life
RCT	Randomized Controlled Trial
SC	Standard Care
SDM	Shared Decision-Making
SDT	Social Determination Theory
SFMMC	Six Function Model of Medical Communication framework
TMSI	Threatening Medical Situation Inventory
UGT	Uses and Gratification Theory
UCD	User-Centered Design

VWS	Dutch Ministry of Health, Well-Being, and Sports
WGBO	Dutch Medical Treatment Contracts
WPM	Written Printed Material

NEDERLANDSE SAMENVATTING

Samenvatting van de resultaten

SHARING IS CARING: gezamenlijke besluitvorming binnen complexe chirurgisch oncologische communicatie met behulp van animatie video's

Het besluitvormingsproces binnen chirurgische oncologie is uitdagend, omdat patiënten vaak moeten kiezen tussen enerzijds overleving en anderzijds de langetermijngevolgen en hun kwaliteit van leven. Deze keuzes zijn niet alleen medisch ingewikkeld, maar ook emotioneel belastend voor de patiënt en sterk afhankelijk van persoonlijke voorkeuren. In zulke situaties is gezamenlijke besluitvorming tussen de patiënt en diens zorgverlener (en mogelijk de informele zorgverlener) belangrijk om tot een behandelkeuze te komen die de waarden, doelen en voorkeuren van de patiënt reflecteren. Dit geldt in het bijzonder voor de context van hoofd-hals oncologie, waarbij patiënten vaak ingrijpende behandelingen moeten ondergaan die hun dagelijks functioneren en kwaliteit van leven sterk beïnvloeden. Omdat veel patiënten met hoofd-halskanker moeite hebben met het nemen van beslissingen en achteraf spijt hebben van hun behandelkeuze, zijn effectieve communicatie en duidelijke informatievoorziening cruciaal voor leveren van hoogwaardige zorg. Helaas blijft onderzoek naar, maar ook de toepassing van gezamenlijke besluitvorming binnen in de hoofd-halsoncologie beperkt. Dit proefschrift richt zich daarom op de vraag of, en hoe gezamenlijke besluitvorming in de complexe chirurgische oncologie kan worden verbeterd, met specifieke aandacht voor hoofd-hals oncologie en een focus op mondkankerchirurgie. Het proefschrift is opgebouwd uit twee delen.

In het eerste deel van dit proefschrift onderzochten we 1) waarom patiënten naar ondersteuning zochten en 2) de communicatie van zorgverleners, de betrokkenheid van patiënten bij gezamenlijke besluitvorming beïnvloeden. We wilden hiermee inzicht krijgen in hoe de praktijken van patiënten en zorgverleners bijdragen aan de communicatie over de behandeling en gezamenlijke besluitvorming (Deel I: Het zoeken naar ondersteuning en gezamenlijke besluitvorming toepassen). Hiervoor voerden we twee kwantitatieve studies uit: één gericht op het onlinezoekgedrag van patiënten met kanker (Hoofdstuk 2) en de andere gericht op het onderzoeken van de huidige, zowel de ervaren als geobserveerde, mate van gezamenlijke besluitvorming binnen de hoofd-halsoncologie (Hoofdstuk 3). In het tweede deel richtten we ons op de rol van audiovisueel materiaal als ondersteunende vorm van patiëntenvoorlichting. Daarbij onderzochten we de potentie van audiovisueel materiaal om de voorlichting over, en de gezamenlijke besluitvorming tussen patiënten, zorgverleners en informele zorgverleners in de complexe chirurgische

oncologie te verbeteren (Deel II: Ondersteunend audiovisueel materiaal). Hiervoor voerden we een systematische literatuurstudie uit naar audiovisuele materialen (Hoofdstuk 4) en verkenden we de behoeften, voorkeuren en verwachtingen van patiënten, zorgverleners en informele zorgverleners als potentiële eindgebruikers van audiovisueel materiaal (Hoofdstuk 5).

Deel I: Het zoeken naar ondersteuning en gezamenlijke besluitvorming toepassen

In **Hoofdstuk 2** namen we eerst een bredere kijk op het onlinezoekgedrag van patiënten naar ondersteuning, om inzicht te krijgen waarom patiënten met kanker online op zoek gaan naar informatie en/of emotionele steun. Deze kennis is belangrijk om te begrijpen hoe patiënten zich kunnen voorbereiden op gesprekken met hun zorgverlener en hoe zij deze gesprekken aanvullen met online informatie. Op basis van deze kennis hebben wij patiëntprofielen geïdentificeerd. Elk van deze patiëntprofielen wordt gekenmerkt door een uniek motivatieprofiel met betrekking tot het zoeken naar online informatie en/of emotionele steun. Ook onderzochten we hoe deze profielen verschilden in termen van psychologische kenmerken, achtergrondkenmerken en de ervaring van patiënten met de zorg. (Ex)Patiënten ontvingen via Kanker.nl per e-mail een vragenlijst waarin werd gevraagd naar hun motieven om online informatie en/of emotionele steun te zoeken. Daarnaast waren in de vragenlijst vragen opgenomen gerelateerd aan hun angst, omgaan met kanker, digitale gezondheidsvaardigheden, ervaringen met de zorg, evenals hun demografische en medische kenmerken. In totaal vulden 181 deelnemers de vragenlijst in. Met behulp van een exploratieve hiërarchische clusteranalyse werden verschillende patiëntprofielen geïdentificeerd, waarna aanvullende analyses, zoals een eenzijdige ANOVA en een chi-kwadraattoets, werden uitgevoerd om te onderzoeken hoe deze patiëntprofielen van elkaar verschilden.

Uiteindelijk identificeerden we drie patiëntprofielen, die elk verschilden in hun motieven voor online zoekgedrag naar ondersteuning. Het meest actieve profiel was de “overall seekers“ (algemene zoekers). In vergelijking met de andere twee profielen waren patiënten in dit profiel het meest gemotiveerd om Kanker.nl te gebruiken voor het zoeken naar informatie, het aanvullen van informatie van hun zorgverlener en het omgaan met tegenstrijdige informatie. Daarnaast leken zij het meest gemotiveerd om online emotionele steun te geven en/of te ontvangen. De “occacional seekers” (incidentele zoeker) vormden de op één na grootste groep. Patiënten binnen dit profiel toonden weinig motivatie om Kanker.nl te gebruiken voor het zoeken naar aanvullende informatie en het omgaan met tegenstrijdige informatie, en het minst gemotiveerd om emotionele steun te geven en/of te ontvangen. Het derde profiel, de “contact exchangers” (contact

uitwisselaars), was het minst gemotiveerd om Kanker.nl te gebruiken voor aanvullende informatie en het omgaan met tegenstrijdige informatie, maar gebruikte de website voornamelijk om contact te leggen met lotgenoten. Verder verschilden de profielen niet alleen in hun motieven om online te gaan, maar ook in hun mate van digitale gezondheidsvaardigheden. Interessant genoeg scoorde het derde profiel (de contact exchangers) het hoogst op digitale gezondheidsvaardigheden vergeleken met de andere twee profielen. De bevindingen van deze studie suggereren dat patiënten, naast het vertrouwen op zorgverleners als primaire informatiebron, verschillende motieven hebben om online aanvullende informatie en/of emotionele steun op te zoeken. Deze inzichten kunnen zorgverleners helpen om nauwkeurige, betrouwbare (online) ondersteuning te bieden die is afgestemd op de behoeften, voorkeuren en persoonlijke omstandigheden van patiënten binnen het gezamenlijke besluitvormingsproces.

Om te bepalen of gezamenlijke besluitvorming verbeterd moet worden binnen de complexe besluitvorming in de chirurgische oncologie, zoals bij mondkanker, was het belangrijk inzicht te krijgen in de huidige communicatie en informatievoorziening in deze context. In **Hoofdstuk 3** hebben we daarom onderzocht in hoeverre gezamenlijke besluitvorming wordt toegepast in de dagelijkse praktijk van de hoofd-halsoncologie. In totaal werden 42 consulten waarin beslissingen over behandelingen werden genomen opgenomen bij vijf hoofd-hals chirurgen (variërend van 5 tot 7 consulten per chirurg) op de polikliniek. Van deze opnames werden 36 consulten geïncludeerd en geanalyseerd door twee onafhankelijke beoordelaars. Zij beoordelen de mate van gezamenlijke besluitvorming op alle zeven items van het OPTION^{MCC+} instrument, om zo de objectieve mate van gezamenlijke besluitvorming te kunnen vaststellen. Daarnaast werden de ervaren mate van gezamenlijke besluitvorming en de voorkeuren voor patiëntbetrokkenheid in kaart gebracht met behulp van vragenlijsten. Deze vragenlijsten bestonden uit de SDM-Q-Doc/SDM-Q-9-vragenlijsten en de Control Preference Scale, die zowel door chirurgen als patiënten na afloop van het consult werden ingevuld.

De resultaten laten zien dat gezamenlijke besluitvorming bij behandelkeuzes binnen de hoofd-halsoncologie slechts in beperkte mate wordt toegepast. Ook blijken chirurgen zich in beperkte mate in te zetten op de onderdelen die essentieel zijn voor gezamenlijke besluitvorming. De hogere OPTION $^{MCC+}$-scores van chirurgen weerspiegelden vooral de bespreking van behandelopties, terwijl het expliciet achterhalen en integreren van de waarden, doelen en voorkeuren van de patiënt minder de aandacht kregen. Tegelijkertijd ervoeren zowel chirurgen als patiënten de mate van gezamenlijke besluitvorming relatief hoog. Hoewel zowel patiënten als chirurgen doorgaans een voorkeur hadden voor gezamenlijke besluitvorming, waren de aannames van chirurgen over de gewenste mate van patiëntbetrokkenheid slechts in twee derde van de gevallen juist. In dertien consulten kwamen deze aannames van de chirurg niet overeen met de daadwerkelijke

voorkeur van de patiënt. Verder bleken alleen de duur van het consult en de OPTION $^{MCC+}$-score van de patiënt samen te hangen met de mate van geobserveerde gezamenlijke besluitvorming van chirurgen. De resultaten van deze studie wijzen er dus op dat zowel de communicatie rondom, als de gezamenlijke besluitvorming zelf binnen chirurgische mondkankerzorg verbetering behoeven, aangezien de waarden, doelen en voorkeuren van patiënten nog onvoldoende worden achterhaald en geïntegreerd in de overweging van behandelingsopties.

Deel II: Ondersteunend audiovisueel materiaal

Om beter te begrijpen hoe gezamenlijke besluitvorming binnen de complexe chirurgische oncologie verbeterd kan worden, onderzochten we het potentieel van audiovisuele materialen ter ondersteuning van de informatievoorziening in het gezamenlijke besluitvormingsproces. In **Hoofdstuk 4** voerden we daarom een systematische literatuurstudie uit om de effectiviteit van audiovisuele materialen die informatie voorafgaand aan de behandeling in de oncologie bieden, te beoordelen op verschillende patiëntuitkomsten. Na het doorzoeken van vijf verschillende elektronische databases werden in totaal 15.138 artikelen geïdentificeerd, waarna op basis van de inclusiecriteria 37 artikelen werden geïncludeerd voor verdere analyse. Hierbij haalden we uit elke studie zowel de resultaten als de relevante studie- en interventiekenmerken. De studieresultaten werden gecategoriseerd in directe, middellange- en langetermijneffecten van het audiovisuele materiaal, op basis van het Six Function Model of Medical Communication.

De resultaten laten zien dat audiovisuele materialen als ondersteuning in de voorlichting aan patiënten met kanker vooral direct een positief effect kunnen hebben, op uitkomsten als kennis. Dit effect was met name zichtbaar wanneer de standaard zorg wordt vergeleken met de standaardzorg aangevuld met een opgenomen video of animatie video. Verder werden op langere termijn ook positieve effecten gevonden op kennis, begrip, angst en de fysiologische reacties van patiënten, zoals hartslag, bloeddruk en ademhalingsfrequentie. Tegelijkertijd bleek dat audiovisuele materialen geen duidelijke meerwaarde hadden, bijvoorbeeld in situaties waarin zowel de interventie- als de controlegroep aanvullende materialen ontvingen. Ten slotte werden geen langetermijneffecten aangetoond ten gunste van de interventiegroep die het audiovisuele materiaal ontving. Al met al suggereert deze review daarom dat audiovisuele materialen, zoals (geanimeerde) video's, het gezamenlijke besluitvormingsproces tussen patiënten en zorgverleners binnen de chirurgische oncologie kan ondersteunen door de kennis en het begrip van de patiënt te verbeteren, zij het voornamelijk op de korte termijn en als aanvulling op de standaard zorg.

In **Hoofdstuk 5** werd, als eerste stap in de ontwikkeling van audiovisuele materialen voor gezamenlijke besluitvorming, onderzocht welke strategieën het meest effectief zijn voor het ontwerpen en implementeren van animatievideo's bij complexe behandelkeuzes binnen de chirurgische mondkankerzorg. Hiervoor brachten we de behoeften en voorkeuren van patiënten, hun informele zorgverleners en zorgprofessionals in kaart ten aanzien van de inhoud, vormgeving en gebruikersacceptatie van (2D/3D)-animatievideo's voor communicatie bij complexe chirurgische behandelkeuzes in de mondkankerzorg. Zes focusgroepssessies en twee individuele interviews met patiënten (n = 17), informele zorgverleners (n = 2) en zorgverleners (n = 13) werden geanalyseerd met behulp van een reflexieve thematische benadering. Uit deze analyse kwamen elf thema's naar voren met betrekking tot de huidige communicatiepraktijken en de inhoud, de vormgeving en de vereisten voor implementatie van animatievideo's. Hoewel er enige overlap bestond tussen de verschillende eindgebruikersgroepen, kwamen er ook duidelijke groep specifieke verschillen en zorgen naar voren, met name met betrekking tot de inhoud, de vormgeving en de inbedding in de werkprocessen van zorgverleners en het zorgtraject van de patiënt.

Alle groepen gaven de voorkeur aan animatievideo's die informatie bieden over de medische en technische aspecten van de behandeling en postoperatieve zorg, evenals de impact hiervan op het dagelijks leven. Patiënten blijken daarbij sterk de voorkeur te geven aan uitgebreide informatie over alle aspecten van het zorgtraject, terwijl zorgverleners en informele zorgverleners hun bezorgdheid uitten dat te veel (gedetailleerde) informatie kan leiden tot onrealistische verwachtingen. Zij benadrukten dat animatievideo's de zelfredzaamheid van patiënten moeten versterken, concrete strategieën moeten bieden voor het omgaan met de aandoening en oog moeten hebben voor de emotionele impact van de behandeling. Verder gaven de meeste patiënten en zorgverleners de voorkeur aan geanimeerde video's, omdat deze als minder confronterend werden ervaren dan realistische videobeelden. Tegelijkertijd werden met name 3D-geanimeerde video's als belastend en angstopwekkend ervaren vanwege de mate van detail en realisme. Wat betreft de vormgeving bestond er brede consensus. Een video moet eenvoudig en goed te volgen zijn en zich richten op het helder en nauwkeurig overbrengen van één onderwerp. Ten slotte constateerden we aanzienlijke verschillen tussen patiënten, informele zorgverleners en zorgverleners wat betreft de bruikbaarheid en het gebruiksgemak, evenals het beste moment om een video in het zorgtraject van de patiënt in te zetten. Hoewel de meeste deelnemers in deze studie (3D-geanimeerde) video's als waardevol beschouwen, uitten informele zorgverleners en sommige zorgprofessionals twijfels over hun geschiktheid als aanvullende informatiebron. Chirurgen hadden met name zorgen over mogelijke verstoring van hun werkprocessen en de consulttijd, terwijl verschillende paramedici juist voordelen zagen in termen van efficiëntie en tijdswinst wanneer patiënten de video's samen met een zorgverlener voorafgaand of tijdens consulten bekijken.

Zij stellen daarom voor om zorgdiscipline video's te ontwikkelen, zodat patiënten de informatie stapsgewijs kunnen verwerken tijdens hun zorgtraject. Kortom deze studie suggereert dat het ontwikkelen en implementeren van animatievideo's in complexe chirurgische oncologie, zoals voor operaties van mondkanker, moeilijk is. Verschillen in de behoeften, voorkeuren en zorgen van eindgebruikers maken het een uitdaging om video's te ontwikkelen die patiënten goed informeren en ondersteunen, terwijl angst wordt beperkt en verwachtingen realistisch blijven.

Dit proefschrift levert op verschillende manieren een bijdrage aan het gezondheidszorg communicatie vakgebied. Ten eerste dragen de resultaten bij aan de nog beperkte literatuur over gezamenlijke besluitvorming bij complexe behandelkeuzes binnen de chirurgische oncologie, in het bijzonder bij mondkanker. Ten tweede biedt de mixed-methodsbenadering een uitgebreid inzicht in de communicatieprocessen en het zoeken naar ondersteuning die de betrokkenheid van patiënten bij het besluitvormingsproces beïnvloeden. Daarnaast geven de resultaten concrete aanknopingspunten voor het verbeteren van gezamenlijke besluitvorming in complexe chirurgische oncologie. Ten derde laat dit proefschrift zien dat informatiebronnen, zoals audiovisuele materialen, een veelbelovende aanvulling vormen op de standaardzorg binnen de chirurgische mondkankerzorg. Dit is met name relevant in het licht van de verwachte toename van de incidentie van mondkanker en de daarmee gepaarde behoefte aan verdere digitalisering in de gezondheidszorg. Ten vierde wijzen de bevindingen erop dat effectieve besluitvorming over behandelingen niet noodzakelijk steunt op geavanceerde visuele technologieën, zoals de in de inleiding besproken virtuele biomedische tweelingmodellen, om patiënten met mondkanker effectief te informeren. Mogelijk kunnen relatief "eenvoudige" visuele hulpmiddelen, zoals animaties met gezondheidsinformatie, al bijdragen aan het verbeteren van patiëntuitkomsten. In lijn hiermee benadrukt dit proefschrift hoe uitdagend gezamenlijke besluitvorming bij de behandeling van mondkanker en de ontwikkeling van audiovisuele materialen al zijn. Ten slotte onderstreept het ook het belang van interdisciplinaire samenwerking bij het uitvoeren van communicatieonderzoek in een complexe medische omgeving.

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Chapter 1: General introduction and dissertation outline

Manuscript preparation:	SD
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Chapter 2: Profiling cancer patients based on their motives for seeking informational and emotional support online

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Manuscript – editing and review:	AL, EMS, ES, JvW

Chapter 3: Exploring the state of shared decision-making in head and neck oncology: Assessment of treatment communication

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Data collection:	SD, AH
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Manuscript – editing and review:	AB, AL, GH, JvW, LvdM, MvdB, RD, RvS, RT,

Chapter 4: The immediate, intermediate, and long-term effectiveness of audiovisuals for providing pre-treatment information to patients with cancer: A systematic review

Study conceptualization:	SD, AB, AL, MvdB, JvW, RvS
Methodology:	SD, JvW, RvS, SG, SvM
Data collection:	SD, RvS, SG, SvM
Data analysis and interpretation:	SD, AB, AL, MvdB, JvW, RvS
Manuscript – writing original draft:	SD
Manuscript – editing and review:	SD, AB, AL, MvdB, JvW, RvS, SG, SvM

Chapter 5: Exploring the needs and preferences for animated videos in complex surgical oncology communication: A focus group study with patients, informal caregivers, and healthcare providers

Study conceptualization:	SD
Methodology:	SD, AL, JvW, SÖ
Data collection:	SD, AL, SÖ
Data analysis and interpretation:	SD, AB, AL, JvW, MvdB, RvS, SÖ
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Chapter 6: Summary of the results

Manuscript preparation:	SD
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Chapter 7: General Discussion

Manuscript preparation:	SD
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PhD training

General skill courses	Organizer	Year	ECTS*
Introduction to PhD in Communication science	ASCoR	2021	2
Ethics and Integrity in Science	OOA	2021	2
Academic Writing	ASCoR	2021	2
BROK AvL specific meeting	OOA	2023	0.5
Good Clinical Practice	OOA	2023	1
Dentists for non-dentists	ACTA	2024	1
Statistics and Methodology	ACTA	An exemption was given for this course	
Specific courses			
Basic Oncology course	OOA	2022	2
Entrepreneurship in Health and Society	Amsterdam UMC	2022	1
Indesign	OOA	2024	0.2
Grant Writing	ACTA	2024	1

Scientific activities

Event	Organizer	Year	ECTS*
Annual supervisory OOA committee meetings (incl. writing annual reports, discussions, midterm presentation)	OOA	Sept, 2021 Apr, 2022 Oct, 2022 Nov, 2023	2
PhD Communication Research Club	ASCoR	Bimonthly, Feb 2021-Jan 2025	2
OOA retreat	Amstelveen Cobra Museum, OOA	2022	0.5
OOA retreat	Renesse, OOA	2024	2
Insights into clinical practice			
Attending multidisciplinary team meetings (MDO)	Department of Head and Neck Oncology and Surgery, NKI-AvL	Every Monday afternoon, 2023	2
Attending surgery in operating room	Department of Head and Neck Oncology and Surgery, NKI-AvL	2021-2025	1.5
Attending new patient consultations	Outpatient clinic, Department of Head and Neck Oncology and Surgery, NKI-AvL	2023	0.5

Attending speech therapist consultations	Outpatient clinic, Department of Head and Neck Oncology and Surgery, NKI-AvL	2022-2023	0.5
Supervising			
Supervision 6-month internship Simona Barboiu	NKI-AvL	2022	2
Supervision 7-month internship Serife Öcal	NKI-AvL	2022-2023	2
Organizing			
Organisatiecommissie 12e Jonge Onderzoekersdag KNO congress	NKI-AVL	2023	1.5
"*Bridging the divide: A symposium on the symbiosis of theory and practice in healthcare*" (ICCH 2024 conference workshop)	EACH[4]/ICA[5] Partnership group	2024	0.3
"Tech tools unleashed – Elevating your science and teaching productivity with AI and other software" (ICCH 2024 conference workshop)	Early Career Committee of EACH	2024	0.3
"Should I stay or should I go?"(Webinar)	Early Career Committee of EACH	2023	0.1
"Diversity in healthcare communication" (Webinar)	Early Career Committee of EACH	2024	0.1
"Deep work – Strategies for productive scientific work and writing" (Webinar)	Early Career Committee of EACH	2024	0.1
"Biographical approach: A shift in how we approach doctor-patient relationship and care" (Webinar)	Early Career Committee of EACH	2025	0.1
"A patient's voice on healthcare communication" (Webinar)	Early Career Committee of EACH	2025	0.2
"Technology acceptance in health(care) communication" (Webinar)	EACH/ICA Partnership group	2025	0.1
"The 1-on-1 mentorship opportunity" (Webinar)	EACH/ICA Partnership group	2025	0.1
"Q&A Grant writing" (Webinar)	EACH/ICA Partnership group	2025	0.2
"When AI enters the conversation: Rethinking clinical communication" (Webinar)	EACH/ICA Partnership group	2026	0.1

4 International Association of Communication in Healthcare
5 International Communication Association

Attendance (Inter)national conferences, symposia, theme days

Event	Location / Organizer	Year	ECTS
D.C. Health Communication (DCHC) Conference	Online, Virginia, USA / George Mason University	2021	0.5
NWHHT Jonge Onderzoekersdag (JOD)	Het Groninger Forum, Groningen, the Netherlands / Hoofdhals oncologie werkgroep Groningen UMC-MCL	2021	0.5
International Communication Association Conference	Online / International Communication Association (ICA)	2021	2
Symposium “Hoe mensen met kanker het internet gebruiken”	Online, Tilburg University, the Netherlands / Integraal Kankercentrum Nederland (IKNL)	2021	0.1
Nederlandse Werkgroep Hoofd-Hals Tumoren (NWHHT) Congress	De Vereeniging, Nijmegen, the Netherlands / NWHHT	2021	0.5
Symposium “Health literacy and misinformation”	Online / De Alliantie Gezondheidsvaardigheden, Amsterdam Center for Health Communication	2021	0.3
International Conference on Communication in Healthcare (ICCH)	Caledonian University Glasgow / International Association for Communication in Healthcare (EACH)	2022	2
Symposium “Nieuwe ontwikkelingen bij hoofd-hals kanker	Online, Utrecht UMC, Utrecht, the Netherlands / Department Head-Neck Surgical Oncology, Utrecht UMC	2022	0.1
NWHHT Jonge Onderzoekersdag (JOD)	De Balie, Amsterdam, the Netherlands / Department of head and neck oncology and surgery NKI-AvL	2023	0.5
Symposium “Wearable Tech for Health”	University of Amsterdam, Amsterdam, the Netherlands / Amsterdam Center for Health Communication (ACHC)	2023	0.5
ETMAAL Communication conference	University of Twente, Enschede, The Netherlands	2023	1

Symposium “Decision aids and vulnerable groups”	University of Amsterdam, Amsterdam, the Netherlands / Amsterdam Center for Health Communication (ACHC)	2023	0.5
Symposium “How to use PROMs for Shared Decision Making: Potential opportunities for clinical care”	Amsterdam UMC, Amsterdam, the Netherlands / Amsterdam UMC in collaboration with APH Personalized Medicine, APH Quality of Care, ZonMw & the PROM Expertisepunt	2023	0.2
International Conference on Communication in Healthcare (ICCH)	Wyndham Grand Gold & Beach Resort, Rio Mar, Puerto Rico / Academy of Communication in Healthcare (ACH)	2023	2
15th International Netherlands Cancer Institute Head and Neck Symposium: Diagnosis and Treatment of Head and Neck Cancer – The Pivotal Role of Imaging and Image Guidance	Department of head and neck oncology and surgery NKI-AvL, Amsterdam, the Netherlands	2023	0.5
ETMAAL Communication conference	De Doelen, Rotterdam, the Netherlands / Erasmus School of History, Culture and Communication	2024	1
NWHHT Jonge Onderzoekersdag (JOD)	Huize Heyendael, Nijmegen, the Netherlands / Hoofdhals werkgroep Radboud UMC-Rijnstate Arnhem	2024	0.5
International Conference on Communication in Healthcare (ICCH)	Residencia de Estudiantes Ramón Pignatelli, Zaragoza Spain / International Association for Communication in Healthcare (EACH)	2024	2
Symposium “Socialeconomische status en kanker: Hoe dichten we de kloof?”	TivoliVredenburg, Utrecht, the Netherlands / Integraal Kankercentrum Nederland (IKNL)	2024	0.4
Themamiddag “Communicatie met kwetsbare patiënten”	Nivel, Utrecht, the Netherlands / Patient-Provider Interaction (PPI) group, NVMO-workgroup Communication, EACH Netherlands	2024	0.2

Dutch SDM symposium	Leiden UMC, Leiden, the Netherlands	2025	0.5
KWF Impact Summit	DeFrabrique, Utrecht, the Netherlands / KWF Kankerbestrijding	2025	0.3

Presentations at (inter)national conferences

Presentation title	Conference	Year	Type of presentation	ECTS
"Profiling Cancer Patients Online: Using Cluster Analysis based on the Motives for Online Health Information-Seeking"	D.C. Health Communication (DCHC) Conference	2021	Oral	1
"Profiling cancer patients based in their motives for seeking informational and emotional support online"	OOA retreat Amstelveen	2022	Poster	0.5
"Profiling cancer patients based in their motives for seeking informational and emotional support online"	International Conference on Communication in Healthcare (ICCH)	2022	Oral	1
"A systematic review of the effect of audiovisuals for information provision to cancer patients on immediate, intermediate, long-term outcomes"	ETMAAL Communication Science	2023	Oral (Work in progress)	1
"The effect of audiovisuals for the provision of information to cancer patients on immediate, intermediate and long-term outcomes: A systematic review"	International Conference on Communication in Healthcare (ICCH)	2023	Oral (Work in progress)	1
"Exploring the State of Shared Decision-Making in Head and Neck Oncology: An Investigative Study"	ETMAAL Communication Science	2024	Oral	1
"Investigating Shared Decision-Making in Head and Neck Oncology: A Comprehensive Exploration"	International Conference on Communication in Healthcare (ICCH)	2024	Oral	1
"Exploring the Perspectives of End-users for Animation Videos in Head and Neck Surgical Oncology"	International Conference on Communication in Healthcare (ICCH)	2024	Oral (Work in progress)	1

"Exploring the State of Shared Decision-Making in Head and Neck Oncology: Assessing treatment communication"	OOA retreat Renesse	2024	Oral	1
"Exploring the Perspectives of End-users for Animation Videos in Head and Neck Surgical Oncology"	NWHHT Jonge Onderzoekersdag (JOD)	2024	Oral	1
"Exploring the state of shared decision-making in head and neck oncology: Assessing treatment communication"	Dutch SDM symposium	2025	Oral	1

Followed webinars[6]

Event	Organizer	Year	ECTS
"Reframing SDM using Implementation Science"	International Shared Decision Making Society (ISDMS)	2024	0.05
"A return on investment: The benefits to doctors for shared decision-making"	International Shared Decision Making Society (ISDMS)	2025	0.05
"Opportunities and challenges in delivering SDM through digital transformation"	International Shared Decision Making Society (ISDMS)	2025	0.05

International committee work

Committee	Role	Experience	ECTS
Early Career Committee of EACH	Co-chair	2023-ongoing	6**
EACH-ICA partnership working group	Co-chair	2023-ongoing	6**
rEACH Summer School organization committee	International Association for Communication in Healthcare (EACH)	2025	0.2
Scientific Review committee	International Association for Communication in Healthcare (EACH)	2026	0.4

6 Additional webinars attended beside those organized as co-chair of the Early Career Committee of EACH or co-chair of EACH/ICA partnership group.

Other

Activity	Organizer	Experience	ECTS
Grant Writing Integraal Zorg Akkoord (IZA) Digital Transformation - Shared Decision-Making (Decision aids theme)	Digital Transformation Grant Writing Committee at the NKI-AvL	September 2024-April 2025	6**

*1 ECT credit is on average equivalent to 28 hours of study load

** Although the maximum number of ECTS credits was awarded for this activity, the actual time invested exceed the formal allocation more time and effort than officially rewarded.

Total ECTS: 76.45

LIST OF PUBLICATIONS

Duimel, S. L. L., Linn, A. J., Smets, E. M. A., Smit, E. S., & van Weert, J. C. M. (2023). Profiling Cancer Patients Based on Their Motives for Seeking Informational and Emotional Support Online. Health communication, 38(14), 3223–3237. https://doi.org/10.1080/10410236.2022.2144287

Heirman, A. N., **Duimel, S. L. L**[7]., Tellman, R. S., Dirven, R., Linn, A. J., Halmos, G. B., van Son, R. J. J. H., van der Molen, L., Balm, A. J. M., van Weert, J. C. M., & van den Brekel, M. W. M. (2025). Exploring the state of shared decision-making in head and neck oncology: Assessing treatment communication. Patient education and counseling, 135, 108733. https://doi.org/10.1016/j.pec.2025.108733

Duimel, S. L. L., van Son, R. J. J. H., Linn, A. J., van den Brekel, M. W. M., Balm, A. J. M., van der Mierden, S., Giani, S., & van Weert, J. C. M. (2025). The immediate, intermediate, and long-term effectiveness of audiovisuals for providing pre-treatment information to patients with cancer: A systematic review. Patient education and counseling, 130, 108399. https://doi.org/10.1016/j.pec.2024.108399

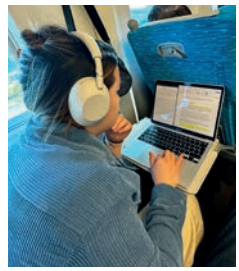
Duimel, S. L. L., van Weert, J. C. M., Öcal, S., Barboiu, S., van den Brekel, M. W. M., van Son, R. J. J. J., Balm, A. J. M., & Linn, A. J. (n.d.). Exploring the needs and preferences for animated videos in complex surgical oncology communication: A focus group study with patients, informal caregivers, and healthcare providers. European Journal of Health Communication. (In revision)

Timmer, A., Heirman, A. N., **Duimel, S. L. L**., de Visscher, S. A. J., van den Brekel, M. W. M., Halmos, G. B., & Festen, S. (n.d.). Identification and discussion of patient goals, values, and preferences during treatment decision-making in patients with head and neck cancer: An examination of physicians' communication. Patient Counseling and Education. (Under review)

Pinker, I., Bras, I. J. M., Etenaille, M., Frerichs, F., Hoffman, B. L., Spencer, N. E., & **Duimel, S. L. L.** (2026). Growing stronger together: Developments and future directions of Early Career EACH (EC-EACH). *Patient education and counseling, 146, 109554.* https://doi.org/10.1016/j.pec.2026.109554

7 Shared first authorship

ACKNOWLEDGEMENTS



Thinking back to the little girl in the white coat in the prologue of this dissertation, would she have foreseen her older self sitting here[8] carefully writing this final chapter and very likely the most read one of her dissertation? Maybe, who knows. These last five years (?!?) have been incredibly special, beautiful, rewarding, insightful, and comforting in unexplainable ways, but also pushing, stressful, challenging, and eye-opening. Nevertheless, in the end, I would not have wanted it any other way! I got to experience the clinical and academic fields up close, work with highly intelligent, interesting, and inspiring people, travel to conferences, and meet the most amazing, supportive, and incredible people I now get to call friends or even family (Ohana ☺). Most importantly, I look back with a sense of professional and personal growth, and I feel I have gotten to know myself better. Still, I could not have succeeded (nor survived) this pleasurable yet tumultuous journey without the encouragement, guidance, and (indirectly or directly) support of many. Without some of you, this journey would not have been the same or even achievable. Therefore, with this final "chapter", I would like to extend my heartfelt gratitude and place some of you in the spotlight you so deserve!!!

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8 In the plane to Tokyo, a bit later in the Shinkansen high-speed train to Kyoto, and two weeks later at the airport of Taiwan during a layover and in Melbourne.

things you do, and it continues to amaze me. If I had to define your style of supervision, I would say that you are a true matriarch. I really appreciate(d) your heartfelt words of support and our WhatsApp conversations, whether on holiday, during the weekend, or late in the evening. How special it is/was to be able to do this so comfortably with your supervisors. I really hope our collaboration does not end here!

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Dear **Fons** (Prof. Dr. Balm, MD), I will never forget that random Monday 3 PM meeting in front of Julia's office, when I was totally unaware of what was about to happen. Little did I know about the extensive work and research project you set up. I feel lucky to have received your trust and belief in me to continue the project. Much did I like our one-on-one online meeting during the OIO-writing retreat. You interestingly listened to my visions, ideas, and ambitions for the future. Thank you for your warmth, your help in making sense of all the medical knowledge, support, praise, and the time you dedicated to my dissertation. Even when you were "officially" not part of my promotion team, you clearly were one of the backbones!

My defense opponents

Dear **Arwen** (Dr. Pieterse), I believe we could get along immediately during our junior-senior pairing meeting at ICCH 2022 in Glasgow. From then on, our paths kept crossing, including the KWF summit 2025 and the Dutch SDM gathering. Oh, how I appreciated our long talk at the Dutch SDM, even though we both missed the last session, oops. Thank you for showing interest in my career, ambitions, and ideas, and for your assessment of my dissertation and, of course, your critical question(s) during my defense. May our paths keep crossing.

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Participants in my research

During my research, I received a lot of help from many individuals. Without you, my dissertation would not have been possible nor of value to those who deserve all the support and best care: current and future patients with head and neck cancer, including oral cancer. I would like to express my heartfelt appreciation and gratefulness to **all participants** for their trust in me and for their contributions to my studies. Your insights, ideas, and openness have been of great value, not only to my research but also to me as a researcher and person.

I also want to specially thank **Kanker.nl**, the **Dutch Head and Neck Patient Association** (PVHH), and **PanelCom** for their help in recruiting participants. Thank you for the collaboration and your confidence in my research.

My colleagues at the Netherlands Cancer Institute-Antoni van Leeuwenhoek

Coming into the world of medicine, and specifically oncology, as a health(care) communication scientist with a theoretical background has not always been easy. Clinical practice differs greatly from academia, and making sense of the culture, procedures, and (medical) jargon was occasionally challenging. Luckily, I was fortunate to receive help from many colleagues in the Head and Neck Surgery and Oncology department at the Netherlands Cancer Institute-Antoni van Leeuwenhoek. Thank you to all of you who made this process easier.

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See and Schladming to the trip on Dominique's and Bernd's boat, the falafel/humus and bowling night, the game café dinners, the Jonge Onderzoekersdag (JOD), the OOA retreat, the OIO-meetings and drinks, the writing retreat in Zeewolde, and the weekend away in the VT-Wonen Villa at the island Vlieland, they all contributed to the wonderful group we created. And a special thanks to you, **Marise**, for being so warm, joyful, and always interested. I really appreciated and had fun during our Groningen night (looking at a wall from the hotel room, haha. I even had two hotels in Japan from where I had a view onto a wall again, and it made me immediately think of our wonderful view back then), our ski lessons in Austria, and a little hunt for a goat during our search for the sauna.

My colleagues at the University of Amsterdam

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The best of friends

I feel greatly fortunate to call myself rich in friendship. I have met many friends from all walks of life, and each one adds a flavor to the taste of life. To all of you, thank you for providing me with the companionship, community, and love that were so crucial for my well-being, self-growth, and the person I have become.

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If there has been one decision in my academic career so far, it would have to be that of joining the Early Career Committee of EACH. I am profoundly thankful for my fellow

committee members; I now get to call my friends. **India**, **Max**, **Noelle**, **Beth**, **Emmanuel**, **Iris**, **Tamara**, **Wiebke**, **Sara**, and **Wei Wei**, thank you for your unwavering and heartfelt support, your advice and tips, and the warmth and humanity in all of our interactions. I hope you know how much of a safe haven you have been through the sometimes intense and emotional times during my PhD rollercoaster.

My heartfelt appreciation also extends to my dearest friends. Thank you, **Peter**, for being the awesome friend and DJ you know you are. **Iris**, we immediately clicked at the ICCH2022 Glasgow conference dinner and since then have been each other's rock and lighthouse in the world of SDM research. Thank you for your insights and feedback, our discussions, your friendship, and support. **Shelina**, I really appreciate our long friendship, from being little girls dancing to Last Christmas from Wham at primary school, to where we are now. Thank you for your interest in my research, your support and camaraderie, our delightful girl dinners and trips, and our future adventures. **Linde**, how much I love that we went from roomies to great friends. Thank you for your friendship and support, our discussions and deep talks, and the love we both share for top restaurants as vegetarian foodies. **India**, I deeply appreciate your support and friendship. Thank you for all the advice, input, feedback, and admirable kind words of encouragement you have provided me over the years; we really do "finish each other's sandwiches". **Goswin**, it is a good thing that our time spent together and the deep talks we have are more talented than we are in tennis. Thank you for being my cocktail, wine, and tennis buddy; you really know how to de-stress me. **Anosh**, I truly believe that our connection shows that friendship knows no boundaries. Thank you for your support and camaraderie, but most of all for your encouragement and for setting the example of staying young, light-hearted, and enjoying life to its fullest. **Jonathan**, how lucky was I when you became my neighbor and friend. I think we instantly connected and knew we would become friends. Thank you for your uplifting energy, the spontaneous "cry" tea, dinners, and tennis viewings. Know how much I appreciate your unwavering support, friendship, and the always openness (haha yes, including BSO plant school and chair rent). And most of all, a special word of thanks to you, **Sofie**, my fellow "can't read a word in Chinese partner in crime". To me, you really are one of the kindest, genuine, most supportive, and sweetest people in the world. Thank you for your unwavering friendship and all the laughter that we share; I hold you dear to my heart.

To my cherished group of plants, the Vaste Plantjes, know how dear to my heart you are. **Renske**, **Fleur**, **Lianne**, **Simone**, **Lisanne**, and **Yentl.** I feel humbled to be surrounded by such powerhouses and ambitious women. We have so many great memories, and I hope we continue to create beautiful moments. Looking back, I feel honored to have been one of the plantjes for so long and to be able to compile such a long, great list of activities we

have done. Thank you for your support, love, joy, and kind-heartedness. A special thanks to **Yentl**, you are really one of the strongest and most resilient humans I know.

I would also like to express my appreciation for my Party Every Day friends: **Felipe**, **Loes**, **Kristell**, **João**, **Linde**, **Devanshi**, **Milia**, **Merle**, **Adrian**, **Manuel**, **Anna**, and **Eva**. Everyone talks about romantic loves and high school friends, but one should never underestimate the friendships you develop at a "later" age. Sharing my late twenties and now early thirties with you has been so joyful and filled with warmth. Thank you for the friendship, the interesting and philosophical talks, the blissful brunches, dinners, and game nights. I really hope we get to go on many more adventures!

Lieve **Marianne**, hoe fijn is het toch elke keer om je samen met Lizzie te zien wanneer ik thuis ben. Over de jaren heen heb je mij zien opgroeien. Altijd gezellig samen met oma Gerda op de donderdagen, jullie verwelkomden mij altijd zo lief en warm thuis. Bedankt voor al je liefde, steun en warmte en voor het zijn van mijn "derde oma".

Dearest **Joëlle**, we cannot often enough tell the story of how we met across the globe in Australia, and I am still amazed. Becoming friends with you was one of the best decisions I have ever made. How special and honorable it is to have you as a friend for life, who has been there through thick and thin, and to continue to walk the path of life with you. To think of how far we have come, from just little guppies that moved to Amsterdam and Haarlem, to where we are now. I have seen you grow and come into your true self over the years, and I hope you know how grateful I am for the unwavering friendship you provide. And yes, I promise to never again stay at a hostel with you, to do my ninja karate kicks when snorkeling, or to have you hold the gas stove buttons!

My wonderful paranymph elves

As William Shakespeare once wrote: "Words are easy, like the wind, but faithful friends are hard to find." I really could not have done this without you, and I hope you know how much of a pillar and beacon of support and comfort you have been throughout this journey. You really stood by me, and your unwavering friendship and love really have given me the strength and confidence I needed to head the challenges I faced. I am grateful to each of you and hope to continue walking this strange but wonderful path we call life together!

Dearest **Kristell**, ma cher ami et mon compagnon dans le monde sauvage, never could I have imagined that a side job at the HEMA takeaway, with our "doctorate" first in swirling ice creams and in preparing hot dogs and sausages, would lead to such a deep emotional and spiritual connection. Perhaps the universe just knew I needed someone like you to

make life feel brighter and better. Thank you for your constant encouragement and belief in me, for being my fellow academic traveler, and specifically for inspiring me to reach new heights both professionally and personally. I feel honored to call you mon trésor préféré and to be Elodie's godmother, knowing we will make many more lasting memories together. Merci d'être toi!

Dearest **Loes**, my ray of sunshine and the author of my happiest chapters, how grateful I am to find our way back to each other. To me, you embody the joy that enriches my life, and in every moment we meet, I look forward to it, especially when it is combined with a warm, homemade dinner. You have the rare ability to light up every room you enter, and you consistently amaze me in all your endeavors. As I reflect on our friendship, I feel wholesome and deeply the effortless bond we have. Thank you for taking me along in life, for uplifting me when I needed, and for being your spontaneous and loyal self! I am immensely grateful for your gift of designing my dissertation cover, but even more for your presence in my life.

Dearest **Felipe**, mi familia elegida y mi refugio en un mundo caótico, they sometimes say that some things in life happen for a reason. Some souls just do not meet by accident. I truly believe we were meant to meet that day you came to sit next to me during our OOA painting workshop. Your empathy, openness, integrity, warmth, and unique perspective on life really are inspirational. Thank you for allowing me to be my unapologetic self, for willingly listening to all of my crap (even when I am roasting you), for being there during critical moments, and for helping me see my own worth when needed. You truly make my life better by just being in it!

The best for last

Dear **Mum**, **Doortje**, **oma Gerda**, how much I wish I could have celebrated this milestone with you. I really hope you still get to party "up there". Mum, thank you for being such an inspiration, for your love, and for just being you, a powerhouse of a woman!! I really do think I get my quirkiness from you, haha. Your journey and strength have inspired me in multiple ways and continue to impact the path I walk in life. I miss you <3

Saving the best for last – to the person that deserves the most credit, my lighthouse in the storm, dearest of them all, **Daddy Cool**, **Pep**. Words cannot fully express, nor do justice to, how much you mean to me or the depth of love I feel for you!!! How do you thank someone who gives you the air you need to breathe, who is the wind beneath your wings, and the sanctuary you call home? My love, appreciation, and gratitude know no bounds. You raised me and shaped me into the person I am today, and it is no secret that we share something

rare, special, and extraordinary. We have faced the hardest times together, survived them, and never lost sight of what truly matters in life. You really are more than my dad – you are the other half of the one soul we share! Thank you for your eternal and unconditional love, for your unwavering support and encouragement, for your strength and resilience, for believing in me and being proud of me, for inspiring me, and for showing me the world in more ways than one! You have always been my anchor in turbulent times, my home away from home, my warmth in the cold, and my sheltering tree against the elements of life. I am, and will always remain, deeply grateful for all that you have done for me, and I really am greatly indebted to you. Makke mai voffel, I love you <3



ABOUT THE AUTHOR



Song L. L. Duimel was born in Zhongshan, China, on January 5th, 1995. From a very young age, she was raised by her parents, Dick Duimel and Dorine Duimel-van Dulmen, in a large blue house by the water. She grew up near the German border in Duiven (Pigeon town), surrounded by her pet guinea pigs, Witje and Bruintje, and her dog, Doortje, as an only child.

Education

In Duiven, Song first attended primary school at the BSO de Kameleon, which she completed in 2007. Rather than continuing her secondary education in her hometown, she enrolled at a high school in Arnhem, a nearby city. In 2014, she graduated from this secondary school, the Stedelijk Gymnasium Arnhem. Over the last two years at this school, her initial ambition to pursue a career in medicine, specifically oncology, had changed. This led her to move to Wageningen University and Research to pursue a bachelor's degree in Health and Society (Gezondheid en Maatschappij), as her interest in health and healthcare was still strong. Rather than approaching health from a medical curative perspective, she believed that care could also be provided in different ways.

After the completion of her bachelor's degree in early 2018, she quickly hopped on the airplane to discover life on the other side of the globe. After a taste of life in the (bigger) cities, such as Melbourne and Sydney, during her solo travel through Australia and Singapore, she moved to Amsterdam's city center for an internship to broaden her perspective on the future and gain industry experience. She interned at Caresharing B.V., which was located near the Dam Square. It was during her time at this ICT company, which delivered healthcare software to first-line healthcare professionals, that Song realized she preferred to pursue a career focused on improving patients' quality of life rather than on delivering software for healthcare professionals. Following her internship, she enrolled in the master's program in Persuasive Communication at the University of Amsterdam in February 2019, from which she graduated in early 2020.

Professional experience

Near the end of her studies, Song became involved in an academic "research project" as part of her master's thesis. Possibly, it was this unique early experience that led her to develop a strong motivation and interest in academic scientific research. Alongside this thesis research project, she also worked as a student assistant at the Department of Persuasive Communication, providing workgroup tutorials for bachelor's students taking the Persuasive Communication course. This was where she discovered her interest in education, which led her to become a part-time junior lecturer in the same department after graduation, from February 2020 onward.

Besides becoming a junior lecturer, Song was also involved in two research projects: a fall prevention project among the elderly at the Amsterdam University Medical Center and a Head and Neck Surgery and Oncology research "internship", that eventually became her PhD project. In February 2021, she officially began her PhD studies in the Department of Head and Neck Surgery and Oncology at the Netherlands Cancer Institute-Antoni van Leeuwenhoek in close collaboration with the Amsterdam School of Communication Research (ASCoR). During her doctoral program, she has published three scientific articles in respective academic journals, with a fourth under revision. Additionally, she presented her research and organized workshops, symposia, and networking panels at both international and national conferences, organized a national symposium, supervised BSc students, and participated in numerous courses and workshops as part of and outside her PhD training program, focusing on transferable and academic skills, as well as on following her personal interests. Moreover, beyond her PhD trajectory, she was also involved in a grant-writing project related to the digital transformation within the Netherlands Cancer Institute-Antoni van Leeuwenhoek, which has been part of the Integral Care Agreement (IZA) in the Netherlands and was recently honored. Song has maintained her junior lecturer position, and today she continues to enjoy teaching and supervising her students, seeing them grow, and guiding them professionally.

Furthermore, as a member of the International Association for Communication in Healthcare (EACH), Song has served as a co-chair of both the Early Career Committee (since June 2023) and the EACH/ICA partnership group (International Communication Association, since November 2023). As part of this role, she actively organizes committee meetings, webinars, online Q&A panels, and more. By the end of fall 2026, Song will take over the chair role from Dr. India Pinker of the Early Career Committee, aiming to lead the committee in a new direction as part of the executive team. Lastly, Song also organized the rEACH (research EACH) Summer School of 2025 as a committee member of the rEACH Summer School Committee and is part of the Scientific Committee for the upcoming

International Conferences for Communication in Healthcare (ICCH) 2026 conference in Belfast.

Personal interests

Personally, outside of her professional life, Song loves spending quality time with family and friends and doing things spontaneously whenever possible. She finds joy in organizing a variety of social gatherings, such as themed dinners and brunch parties, and trying new social activities. Additionally, she likes cooking and trying new recipes from time to time, and fancies a good cup of tea, a nice glass of wine, or a fancy cocktail over a good meal. Moreover, in her free time, she appreciates playing tennis, going to CrossFit, trying new sports classes, and visiting sporting events, as well as visiting museums and (classical) concerts. Lastly, Song adores traveling and discovering new places and has visited over 25 countries throughout her life, including Australia, Singapore, Japan, Colombia, Iceland, the USA, India, Puerto Rico, Canada, and many European countries.

Finally, Song wishes to pursue a career that combines her interests in healthcare, oncology, and healthcare communication, and hopes to find a role wherein she can utilize her skills in networking, educating, and organizing. She still lives in Amsterdam and is optimistic about finding her own place to call home in the near future.

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