

Digital storytelling tool in cancer care: The effects of narrative structures on patient engagement in Shared Decision Making

Master Thesis

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STUDENT REPORT

When cancer patients attend their first consultation at the Department of Oncology, they face one of the most difficult conversations of their lives. For many patients, this is when they will learn more about their diagnosis and discuss treatment options. Cancer treatments can have a big impact on patients' lives, which makes discussing what is important to the patient crucial, so considerations can be made. However, the current decision making process used in most hospitals in Denmark is that of Informed Consent, where the patient's values and preferences are not included [1, 2]. An alternative decision making process is Shared Decision Making (SDM). SDM is a patient-centered decision making process, where the clinician fills the role as the expert of medicine, and the patient has the role as the expert of their life and brings forward their own values and preferences [51, 28, 6, 17]. SDM encourages patients to consider how much they want to be part of the decision making and gives them the opportunity to be an active part of their treatment. Additionally, a longitudinal study showed that patients' preferred decisional role is related to their quality of life after completed treatment [24].

As a part of this study, we set out to understand the clinicians' and patients' perspectives on the decision making as it currently is, and what they think of SDM. Here we learned that both patients and clinicians think positively of SDM. However, the patients were not familiar with SDM before we spoke with them and found it difficult to fully understand the importance of their values and preferences. Therefore, we decided to explore how cancer patients can be prepared for SDM before their first consultation. For the second part of this paper, we sought to answer the research question:

What is the effect of narrative structures on patients' self-efficacy and decisional-role preferences in cancer care?

To answer this research question, we explored storytelling as a communication tool, as storytelling is known as an effective way to explain a concept or to reflect on personal experience [37].

Through Segel and Heer [42] we learned that in information presentation, three different narrative structures exist: Interactive Slideshow, Drill-Down, and Martini Glass. We decided to include two of these structures, as we knew we would not be able to recruit enough patients to have sufficient data on all three narrative structures. We wanted to see if there is a difference in the narrative structures, and as the Martini Glass structure is a midpoint between Interactive Slideshow and Drill-Down, we decided to test the two extremes.

Therefore, we developed a prototype with two different navigational flows, one for each narrative structure. For the prototype, we developed seven short, animated videos, informing the patients about SDM and aspects they should consider to encourage self-reflection.

The two narrative structures were tested at the Department of Oncology by 18 patients using a between-subject study design. In these tests, we measured self-efficacy and the patients' preferred decisional role before and after using the prototype. The tests were concluded by a semi-structured interview, where we explored the patient's opinion on the prototype.

The findings from our statistical analysis showed that there was no statistically significant difference in self-efficacy and decisional role preferences between the Interactive Slideshow and Drill-Down conditions. From the interviews, we found that the patients in general did not have a clear preference between the conditions, but some patients described feeling overwhelmed by the number of choices they have to make. These patients preferred the Interactive Slideshow condition, as it limited how many choices they have to make, meanwhile they described the Drill-Down condition as overwhelming.

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ABSTRACT

Patient-centred care is a key focus in healthcare, aiming to empower patients and promote their active participation in their healthcare decisions. Prior studies have shown beneficial results in using digital storytelling tools in healthcare to empower, educate, and encourage patient engagement in decision making. However, limited research has employed digital storytelling tools in healthcare. This paper explores the role of a digital tool in encouraging patient engagement in shared decision making (SDM) and self-reflection. We examine and compare the effects of two different narrative structures: Interactive Slideshow and Drill-Down. Our prototype was evaluated by 18 patients recruited from the Department of Oncology at Aalborg University Hospital. Our findings highlight the potential benefits of implementing a digital tool to prepare patients for SDM. Our qualitative analysis indicates that the patients value the storytelling format, as it promotes self-reflection and allows them to retain information more easily. Additionally, we found that exposure to information overload can lead patients to feel unnecessarily overwhelmed and stressed. When developing a digital tool within the healthcare context, it is crucial to recognise and consider the mental state of patients to avoid overwhelming them while delivering information for self-reflection.

KEYWORDS

Patient-Centred Care, Cancer care, Shared Decision Making, SDM tool, Storytelling, Narrative Structures, Self-efficacy

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1 INTRODUCTION

The patient's right to self-determination was introduced into the Danish healthcare legislation in the middle of the 20th century [10]. The current state of the Danish healthcare system is mainly based on the principle of informed consent (IC) when making decisions about a patient's medical care [1]. However, in recent times, patient-centred care (PCC) has been the subject of interest, including the practice of shared decision making (SDM) [10, 11]. Furthermore,

the practice of SDM has been a prioritised focus area across the six hospitals in the Capital Region of Denmark, since 2022 [11].

Confusion sometimes arises when SDM is conflated with the concept of IC [10]. The key difference is that IC is often a one-way communication process in which a patient receives complete information about a specific treatment option with associated risks and benefits. The patient must then either accept or decline the treatment offered based on the given information [1, 10, 11]. Conversely, SDM is a two-way communication process in which clinicians and patients jointly participate to make healthcare decisions, while considering the patient's values, preferences, and goals. This approach is particularly appropriate in instances where more than one available treatment option is presented, along with their associated risk and benefits [2, 44, 49]. Although the benefits of SDM are well documented in the healthcare sector of Denmark, the process of implementing the approach on an institutional level remains challenging and is still far from standard practice [10, 11, 44]. In particular, when caring for patients with complex illnesses and care needs such as cancer since treatment can have adverse effects on the patients' lives [44].

Prior work shows that a digital SDM tool can encourage patient engagement in decision making [18]. Additionally, using digital storytelling tools in healthcare has shown beneficial results in educating and empowering patients to understand their health-related needs and concerns [12, 13, 37]. However, we were unable to find studies that have examined the potential of using digital storytelling in serious illnesses such as cancer to promote introspection and self-efficacy. To address these challenges, we designed two variations of a patient-centred digital storytelling tool to explore the potential benefits of these tools in preparing patients for SDM. This paper aims to examine and compare the effects of two different narrative structures, i.e. Interactive Slideshow and Drill-Down, to promote self-efficacy in cancer patients and examine potential changes in their preferred decisional role. Specifically, we aim to examine patients' perspectives on using a tool to prepare them for SDM and gain insights into their preferences regarding an author-driven or reader-driven narrative structure. Therefore, in this paper, we aim to explore the following research question: *What is the effect of narrative structures on patients' self-efficacy and decisional-role preferences in cancer care?* To investigate this, we worked closely with the Department of Oncology at Aalborg University Hospital.

Our main findings include how a digital tool can potentially prepare patients for SDM. During the interviews, the patients explained that the storytelling format is their preferred way of receiving healthcare-related information, as it helps them to understand the information more easily and retain pertinent details. Furthermore, six patients mentioned that empowering patients is important, as it

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allows them to take an active part in the decision making. We also found that our quantitative analyses are inconclusive regarding whether the Interactive Slideshow or Drill-Down is better in terms of improving the patients' self-efficacy and encouraging an active decisional role. However, the qualitative analysis indicates that the Interactive Slideshow could be the favoured condition, as it can mitigate decision fatigue if the patients are easily overwhelmed. Based on the quantitative and qualitative research that we have conducted, our contributions include the following: (1) An understanding of how a digital storytelling tool can encourage patient engagement in decision making; (2) Preliminary research on how narrative structures influence a patient's self-efficacy and decisional role; (3) Findings that can aid designers and researchers implement best practices when designing an interactive digital system in the context of healthcare-related decisions.

2 RELATED WORK

In this section, we examine the literature affecting the research question addressed in this paper. This section is divided into three parts: Firstly, we present the fundamental concepts and knowledge surrounding SDM. Secondly, we explore which Decision-Support Tools already exist and examine the insights they offer. Lastly, we look further into how information can be presented to a user, specifically investigating the use of Chatbots, Data Videos, and Storytelling to convey and present information.

2.1 Shared Decision Making

Shared Decision Making (SDM) is a process used in healthcare, for patients and clinicians to collaboratively make decisions regarding treatment. In this process, the patient and the clinician discuss all potential treatment options along with their advantages and disadvantages. The clinician provides the medical knowledge, while the patient expresses their values and preferences. Collaboratively, the patient and clinician make a decision that aligns with the discussion they have had [6, 17, 28, 51]. An example of SDM within cancer care could be a patient and a clinician discussing the possibility of using either chemotherapy or radiation therapy as a treatment, based on which treatment is most advantageous and aligns with the patient's values.

Informed Consent (IC) is currently the most common decision making process in Danish hospitals, although it does not consider the patient's values as much as SDM [1]. IC only requires the clinician to present the one treatment option they find the most appropriate, which the patient can then accept or decline [2]. IC could therefore be considered to be a one-way communication, whereas SDM is a two-way communication. SDM grants patients the autonomy to decide their desired level of involvement in the decision making process [6]. Furthermore, research indicates that SDM often increases the patient's active participation [6, 26, 28, 51]. Since discussing different treatment options and what they entail are integral parts of SDM, the patient's knowledge of treatments, side effects, advantages, and disadvantages are enhanced [6]. This effect is demonstrated in a longitudinal study conducted by Hack et al. [24]. They examined the relationship between patients' preferred role in decision making and their quality of life after completing treatment for breast cancer. Hack et al. found that patients who

reported having experienced active involvement in the decision making of their treatment had a higher quality of life than patients who were more passive during the decision making. Of the patients who had been passive in the decision making, 9% reported regret towards not being more actively engaged. In an effort to explain and comprehensively implement SDM, Elwyn et al. [17] proposed the Choice, Option and Decision talk model. Choice talk refers to making the patient aware that they have a choice and that nothing is forced upon them. Option talk refers to informing the patient about treatment options, what they entail, the advantages and disadvantages, and potential side effects. In Decision talk, the focus is to understand what matters most to the patient and start progressing towards a decision. Within the context of this model of SDM, we focus on the Choice talk phase. We seek to encourage the patients to actively engage in decision making and aid them to understand why their values and preferences are important.

2.2 Decision-Support Tools

Multiple tools have emerged in the HCI literature to assist clinicians in their decision making process, commonly referred to as Clinical Decision Support Tools (CDST). These tools provide healthcare professionals with computer-generated clinical knowledge, as explored by studies conducted in clinical settings [33, 34, 43, 48, 50, 52]. However, it should be noted that while CDSTs aid in clinical decision making, they are not classified as SDM tools since the patient does not play an active role in the decision making process, which is a key component of SDM.

The current body of literature on SDM explores how to utilise text-heavy interfaces [45], graphs [21], and virtual agents [8, 9, 22, 38, 51]. Zhang and Bickmore's virtual decision coach [51] is an SDM tool specifically designed for patients. The tool is aimed at assisting pregnant individuals in deciding if and what type of prenatal testing they want to use when screening for Down syndrome. In an evaluation of the system with 12 participants, the results showed a significant increase in participants' knowledge of prenatal testing, and the participants reported high satisfaction with their decision. In another study, Constantin et al. [9] developed a virtual training doctor called PrepDoc that allows users to practice SDM before visiting their general practitioner. The system was evaluated by 19 participants aged 65 and older, and the results showed that the system had good usability in general. However, some participants described that the system was condescending towards them, while 17 out of 19 participants reported that the system did not provide them with all the available choices or opportunities to direct the conversation. Although digital tools hold promise for improving SDM in clinical settings [51], research on this topic remains limited. However, we found no studies on the effect of SDM on self-efficacy in patients, which could improve their active participation in decision making. Therefore, we want to explore how a digital tool can prepare patients for SDM and improve their self-efficacy.

2.3 Information Presentation

Prior research has empirically proven that technologies such as Chatbots, Data Videos, and Storytelling are capable of cultivating behaviour change. In this section, we will present related work and their findings in the area of information presentation.

2.3.1 Chatbot. Chatbots, also referred to as conversational agent or intelligent assistant, is a tool that uses machine learning and artificial intelligence to mimic human conversation either through text or voice interactions [31, 35, 46]. To produce responses, chatbots operate using natural language [31, 35, 46]. In the 1960's ELIZA was developed, one of the earliest conversational agents that could convincingly simulate human conversation [35, 46]. ELIZA was developed to mimic the responses of a Rogerian psychotherapist during a therapy session [35, 46]. The core technology behind ELIZA is pattern matching and pronoun substitution, giving the illusion of empathy even though it has no built-in knowledge [35, 46]. However, in recent years voice-based chatbots are often deployed through mobile devices such as Siri [35], computers, and smart speakers such as Amazon's Alexa [35, 46], and Google Home [46]. Text-based chatbots can be accessed through applications such as Messenger [31], Kik, Slack, Telegram [46], websites [31, 46], or mobile applications [31, 46].

Chatbots are widely deployed in various areas [31, 46]. For example, there are chatbots for education [46], customer service innovations [46], research [47] and healthcare [31, 46]. Within the area of healthcare and education, Hefny et al. [16] developed two character-based chatbots for different domains: an academic chatbot that supports students during their education and a COVID-19 chatbot designed to provide users with information regarding the pandemic. Both chatbots were designed with three characteristics which are "empathic", "formal", and "tough". Both chatbots were evaluated by 40 students from the German University in Cairo between the ages of 20 and 29 years. The results showed that the System Usability Scale for both chatbots were positive. The assessment of the likeability and trustworthiness of the characters indicated that the participants preferred the empathic characteristic, followed by the tough characteristic and the formal characteristic. Furthermore, the findings from this study indicated that the participants perceived the characteristics as intended by the researchers. However, the chatbots developed by Hefny et al. [16] do not consider the users' needs and preferences, which can cause biases to arise in certain user groups.

2.3.2 Data videos. In 2010, Segel and Heer [42] presented seven genres of narrative visualisation, where data videos are recognised as one of the seven forms [4, 41, 42]. Data videos combine motion graphics with audio, visuals, or interactions to tell data-driven stories [4, 32, 41]. These types of videos have gained prominence among content producers, disseminators [32], leading media outlets [4], journalism, education, political messages and campaigns [41], often aimed at promoting behavioural changes [32, 41]. Data video provides a compelling and engaging way to convey information in a way that is more natural, seamless, and effective than text or pictures [41]. Furthermore, their ability to appeal to an audience and communicate a large amount of data in a short period of time [4, 41], has made them an increasingly popular communication medium [4, 32, 41]. The growing interest in data videos aligns with the pace of life in today's society as obtaining information quickly is much more critical than in the past [41].

Data videos have attracted the attention of researchers within HCI. To better understand the viewers' emotional response to health-related data videos and how those responses are related

to viewers' behavioural health change intentions Sallam et al. [41] conducted two empirical online studies. The initial study focused on examining the experienced effects, personalities, and potential attitude changes of Amazon Mechanical Turk workers in relation to health-related data videos. In total, 102 participants were recruited with ages ranging between 21 and 70. For the second study, they recruited 119 Amazon Mechanical Turk workers to explore the effect of including two types of solution in data videos: "a broad/generalisable solution", and "a concrete/actionable solution" [41]. The baseline for this study was compared to a data video that had no solution at all.

Their results showed that data videos have the potential to improve the viewers' intention to adopt behavioural changes if they are carefully designed. If the viewer perceived the data video as useful, it was easier to influence their attitude. By including health-related solutions to data videos it was proven that the viewer's anxiety levels were lowered, and they perceived the videos as more actionable and useful.

2.3.3 Storytelling. Storytelling is a powerful learning tool and is known to be the oldest form of teaching [12, 25]. The power of stories has been recognised as an ideal way of presenting information in a meaningful way [25]. It has often been used to deliver educational, social, or cultural messages and to explain or illustrate abstract and complex concepts in a way that makes them more accessible [25, 40]. Storytelling is a way for people to reflect on the story told and relate it to one's personal experiences [12, 25]. In healthcare, storytelling can be used as a tool to educate and empower patients to understand their health-related needs and concerns [12, 13, 37].

The use of digital storytelling to translate knowledge in healthcare is an effective method as it can be used to explain a concept or to reflect on personal experiences [37]. Additionally, it serves as a means to encourage patients to move beyond passive recipients and become active participants by enabling them to determine which stories are shared and when they are shared. [25, 37].

Studies within HCI have looked at how digital tools can support the communication of stories among children and their families [40]. This includes tools that support collaborative storytelling [5, 29] and enhances the storytelling experience using technologies such as robots, social agents, and video feeds [15, 19, 39]. For instance, a system using FlashCam technology was created to support children and their long-distance family members to combine live-action characters portrayed by the family members while reading a story together [19]. Another area of work in HCI has looked into how storytelling can support depression and anxiety among college students [25]. The mHealth is a self-guided application that uses cognitive behavioural therapy, interactive storytelling, and gamification to support and help college students with depression and anxiety [25].

However, limited research has explored the use of patient-centred digital storytelling in healthcare [37]. We would therefore like to explore how digital storytelling can encourage and prepare cancer care patients to engage in decision making. In particular, how a digital storytelling tool can empower and educate patients to understand their health-related needs, preferences, and values.

Specialisation within oncology		Experience (year)
C1	Breast cancer	16
C2	Gastrointestinal cancer	13
C3	Cancer of the upper part of the gastrointestinal area	9
C4	Breast cancer	9
C5	Prostate and bladder cancer	22
C6	Melanoma, head and thyroid gland cancer	13
C7	Cancer in prostate, bladder, testicle and radiotherapy	19
C8*	Lung cancer and cancer of the pleura	12
C9*	Lung cancer and cancer of the pleura	20
C10	Breast cancer and prostate cancer	1
C11	Brain tumour, melanoma skin cancer and cancer of the uterus	19
C12	Gastrointestinal cancer, lung cancer and radiotherapy	>1

*Group interview

Table 1: Details of the participating oncologists.

3 CONTEXTUALISATION

In this section, we present the context and the collaborative efforts with the Department of Oncology in our research study. The Department of Oncology furnished us with participants for interviews, observations, and user evaluation so forth that we signed patient confidentiality agreements.

3.1 The Department of Oncology

Our data-gathering process for the study was conducted at the Department of Oncology at Aalborg University Hospital. More than 3000 patients with cancer receive treatment at the department every month. The Department of Oncology takes care of patients with multiple different types of cancer in various parts of the body such as prostate cancer, gastric cancer, lung cancer and many more [30]. The current list of registered health professionals at the Department of Oncology consists of 54 clinicians and 143 nurses. The department has earned the award of The Patients' Award, as a result of its ongoing commitment to providing patient care that is respectful of, and responsive to, individual patients' preferences, goals, and needs [3].

As previously established, the Danish healthcare system mainly uses the practice of IC, currently. However, the Department of Oncology has increased its focus on implementing SDM into its practice - and is used as a method to increase the level of patient engagement in the decision making process [30]. Furthermore, by implementing SDM systematically, the patients are more likely to make decisions consistent with both the clinical evidence and the patient's personal preferences, goals, and values [6]. Even though the Department of Oncology has increased its focus on SDM, it has yet to be systematically implemented and its use is mainly dependent on the individual clinician.

When a patient comes in for their first consultation at the department, the clinician would ask questions concerning the patient's health, mental state, daily life, and review their health history. In addition, the clinicians use the consultation to understand and learn about the patient's general health, concerns, and personal life. Clinicians are responsible for presenting the treatment options they deem most suitable for the patient, considering their diagnosis and

individual needs. When the clinician has gathered all the information necessary, they will then present the possible treatments along with the associated advantages and disadvantages. The patient and clinician will in most cases agree on a treatment during the first consultation followed by the clinician recommending a course of action, and talking about when the treatment should take place.

4 STUDY 1: INTERVIEWS AND OBSERVATIONS WITH PATIENTS AND CLINICIANS

In this study, we conducted a series of qualitative research to improve our understanding of the complex context we work within [30]. In the following two sections, we describe the method and the findings from the study.

4.1 Method

During this study, we conducted a qualitative study in the form of observations and semi-structured interviews at the Department of Oncology, see Appendix A, B, and C for the interview guides. First, 12 clinicians (3 men and 9 women) were interviewed to understand their perspective of SDM and how they might implement it in their current practice, see Table 1 for further information on the clinicians [30]. Additionally, this understanding was used as a basis for informing our questions in the patient interviews and allowed us to better understand the situation the patients experience, before interacting with them, see Appendix B and C. The interviews varied in length, ranging from 20-42 minutes (mean duration = 29.14) [30]. Two of the clinicians asked to be interviewed together to efficiently manage their office time. The two clinicians are marked in Table 1. Some of the interviews were conducted at the clinician's office at the hospital, while others were conducted online using Microsoft Teams. All interviews were audio recorded and later transcribed. The clinicians interviewed will be referred to as C1-C12 for the remainder of this paper.

Second, 16 patients (11 men and 5 women) within the age range of 56 to 80 (mean age = 65.3) were interviewed, see Table 2 for further information on the patients [30]. Among the 16 patients, five were

	Age	Gender	IT expertise	Cancer diagnosis	Duration of treatment	Other people present
P1*	57	Man	Daily	Malignant Melanoma	1 week	Nurse, other patient
P2	77	Woman	Daily	Endometrial	1 week	Nurse, relatives
P3	68	Man	Daily	Prostate	1 week	
P4	61	Man	Daily	Gastric, Esophageal	1 week	Nurse, relatives
P5	78	Man	Daily	Prostate	1 week	Nurse, relatives, other patient
P6	56	Man	Daily	Prostate	6 years	
P7	76	Man	Daily	Lung	3 years	Nurse, other patient
P8	57	Man	Daily	Lung	2 months	Relatives
P9	71	Man	Daily	Colon /Rectal	5 years	Nurse, other patient
P10	74	Man	Daily	Prostate	1 month	Relatives
P11	77	Woman	Daily	Colon	3 weeks	Nurse, relatives, other patient
P12*	57	Man	Daily	Malignant Melanoma	1 month	
P13	72	Woman	Daily/weekly	Pancreatic	5 months	
P14	76	Man	Daily	Lung	2 months	Relatives
P15	80	Woman	Daily	Lung	2 months	
P16	65	Woman	Daily	Urethral	2 months	

*Patient who was interviewed twice

Table 2: Details of the patients interviewed.

interviewed on the day of their first treatment, one week after their initial consultation, while the remaining 11 had undergone multiple treatments. This approach allowed us to gather insights from both relatively new patients and patients who were further along in their treatment, enabling a comprehensive understanding of their perspectives. During these interviews, we asked questions regarding how active the patients had been in the decision making during their consultation, what their opinions were on SDM and their preferences regarding the presentation of information. The interviews varied in length from 5 to 27 minutes (mean duration = 12) [30]. These interviews were conducted at the hospital, either while the patients were receiving treatment and laying in a hospital bed, or after the treatment in a meeting room, see Figure 1. 11 of the patient interviews were audio recorded, and later transcribed, whereas for five interviews we had to take notes, as we were not allowed to make audio recordings while another patient was present in the room, or if a patient did not want to be audio recorded. Table 2 specifies the interviews where relatives, another patient, or a nurse were present in the room. The patients interviewed will be referred to as P1-P16 for the remainder of this paper.

Furthermore, we conducted five observations during patients' initial consultations at the department. Recognising the sensitivity and emotional nature of these situations for the patients, we aimed to avoid any disruptions during the consultation. To achieve this, the observer took on the role of an observer participant. After being introduced by the clinician to the patient, the observer quietly occupied a corner and recorded notes in a notebook.

The notes and transcriptions were analysed using Reflexive Thematic Analysis [7]. This method of analysis was chosen as it enables us to acknowledge the bias each group member inevitably brings and reflect on how our values and experience might influence the analysis. Due to the sensitive nature of cancer care, it is difficult to not be influenced by own experiences, and perhaps it would be apathetic not to. One group member has experienced the passing



Figure 1: Nine of the interviews in Study 1 took place in a room such as this, with the participant placed across from the interviewer

of family members due to cancer, while a second group member lives with chronic diseases [30].

The analysis was initiated by selecting two transcriptions from the interviews with clinicians which were coded individually by each group member. Following, the group members reconvened to produce a shared codebook, see Figure 2 and Appendix D, E and F. The remaining interviews were distributed between the group members and were coded using the shared codebook. This procedure was repeated for the patient interviews and notes from the observations.

The analysis resulted in several notable themes. The five most prevalent themes will be described in the following section, as they cover the major findings from the interviews.

4.2 Findings

The findings from this study consisted of five major themes based on the aforementioned qualitative data gathering and analysis. The first theme **SDM(non-)use** covered the clinicians' current use or non-use of SDM in their daily work. All the clinicians who were interviewed were familiar with the term SDM and a majority stated that they actively incorporate it during their interaction with the patients. However, the clinicians vary in their approach to doing so. This is partially caused by personal variables in the patients' preferences, such as their authoritarian beliefs and the process the patient has undergone before arriving at the Department of Oncology. Multiple clinicians mentioned that patients who have not been involved in or introduced to SDM by their general practitioner are less inclined to be an active part of the decision making later on in the process.

One clinician stated: *"We have the problem that we now have a lot of focus on shared decision making, but as we talked about, the patients have gone through 100 steps before they come to us, where perhaps there is not a lot of shared decision making"* - C2

To mitigate this issue, there is a need for SDM to be implemented throughout the health sector, starting with the patients' general practitioners and departments that the patients may be referred to before they arrive at the Department of Oncology.

The second theme **Understanding the patient** was a central topic throughout all the interviews and the observations. Clinicians attempt to gain a holistic understanding of each patient to identify the appropriate treatment for their individual needs. This entails understanding the patient's health history and hereditary diseases but also their personal values and preferences. For example, if the patient is well educated and has experience within the field of medicine, they may prefer statistical information and medical terms to be used during their consultation. If the patient is of old age and values spending time with their family, they may prefer not receiving treatment to live their remaining life without side effects from the treatment and hospital visits. Some patients do not feel qualified to actively engage in the decision regarding the choice of treatment as they do not possess the same medical expertise as the clinician. This issue was mentioned by one of the clinicians:

"Although I think I make an effort, sometimes I also think that we almost end up leaving some patients to do something they simply don't think they have the prerequisites for, even if we try to give them the prerequisites to be able to do it." - C5

It is a challenging task for clinicians to gain a comprehensive understanding of their patients in the limited time they have available and it is, therefore, important for the patient to be aware and vocal about their preferences.

Information overload covers findings about the information the patients receive during their first visits to the Department of Oncology. Both clinicians and patients mentioned the difficulties in retaining the large amounts of information the patients receive in a short time. This is often caused by the clinicians wanting to make sure that the patients are well informed of their diagnosis and the treatment including potential side effects before making a decision. The issue of information overload was mentioned by multiple patients during the interviews.

"I would say that in some cases it can also be too much information for you to be able to comprehend it at all [...] I then got a 10-minute introduction to two different products, that is concluded by asking, which one do you want?" - P8

Some patients may simply not have the desire to actively engage in the decision making and rely on the clinician to make the decision for them, which should also be respected.

Another relevant theme was **Decision ownership** which covers the duality of patients wanting autonomy over their decision while basing their decision on the medical expertise of the clinicians. Most patients do not have a medical background and therefore little knowledge of their diagnosis and the potential treatment being offered. Therefore, the patients rely on the clinician to inform them of the facts and their options. Based on this information, the patient then decides whether or not they will accept the treatment being offered. A majority of the patients interviewed expressed a wish to make their own decision but also stated a high belief in the authority of the clinicians and some patients expressed an inability to disagree with the clinician's advice, as they do not think they can engage in the decision making on equal terms with the clinician.

The last theme **Role of the relatives** was a topic of great importance throughout the interviews and observations. During the interviews, the clinicians mentioned how the relatives of the patient have an overall positive effect on the process as they provide emotional support and aid in remembering the large amounts of information being provided. However, it can be a challenge if the relatives have opposing preferences to those of the clinician or patient as it may cause the patient to change their decision in order to accommodate the wishes of their relatives. This is often the case if the patient does not want to receive treatment while the relatives are having difficulties accepting losing a family member.

"It often also makes the patient feel some kind of guilty conscience if they don't do everything they can to fight [...]" - C3

During the observations, a majority of the relatives actively engaged and mediated the conversation in cases of miscommunication between the clinician and the patient. Both the positive impact and the challenges brought on by the relatives were experienced during the interviews with the patients. The relatives were actively engaging in the interviews to varying degrees and in some cases answered the majority of the questions on the patient's behalf without discussing it with them first. In these cases, it is difficult to determine whether or not the patient was of the same opinion or if the relatives stated their own beliefs.

4.3 Discussion

During the interviews, a majority of the patients stated that they do not wish to be presented with information exclusively by graphs or text-based interfaces. They found graphs and statistics challenging to interpret, as they often lack clarity regarding the potential positive or negative response to a treatment. According to the clinicians, if a patient preferred graphs and statistics they may have a background in mathematics or other means which enables their understanding of statistics. Furthermore, text-heavy interfaces which use a lot of medical terms can be detrimental for patients without sufficient medical knowledge, as they do not understand it and therefore will not retain the information. Some patients mentioned



Figure 2: In the process of producing the codebook

that they prefer other types of visual presentation, such as explanatory videos or medical imaging. The latter was true for P2 who was presented with the X-ray images which helped her understand her diagnosis.

These findings led to the design guideline: **The SDM tool should not exclusively use text- or graph-based interfaces**

We found that patients valued the face-to-face interaction they have with the clinicians during the consultations. It is during these interactions that patients are informed of their diagnosis, and potential treatments while allowing them to voice their own opinion. This was mentioned as one of the main contributors to the patients being able to make the decision. The patients had high praise for the clinicians as they felt they received the necessary information in a sympathetic manner, despite often feeling overwhelmed by the amount of information. The overwhelming amount of information is often caused by the limited time available for each consultation which is usually one hour. During this time, the clinicians have to present all the relevant information to the patient while getting to know each patient on a personal level in order to consider their lifestyle and preferences when suggesting them a treatment. If an SDM tool were to be used during these consultations it has to be effective, reliable, and cause little to no distraction. Since the time for each consultation is limited to one hour, we do not wish to implement a tool that could reduce the time spent between clinician and patient. Furthermore, we found that an SDM tool would have a greater potential for a positive effect as a preparation tool before the consultation, which would still allow for the expertise of the clinicians to be fully utilised.

This resulted in the second guideline: **An SDM tool should not be implemented during the consultation, as it would take time away from the patient-clinician interaction**

Related to this guideline is the topic of informing the patient of their diagnosis and treatment. As previously mentioned, the clinicians are very skilled at presenting relevant information to the patients during the consultations, as stated by the patients during the interviews. Some patients expressed hesitation towards

seeking information online as it might lead them down the “rabbit hole” of incorrect information. Patients further mentioned that when seeking information online, they have a tendency to focus on the negative, resulting in them having a pessimistic disposition toward their diagnosis. Similarly, if a tool were to inform the patient of their diagnosis before the consultation, they will not have a medical professional to discuss their situation with. This could result in the patients seeking information online entailing the risks of misinformation or anxious thoughts. During the face-to-face consultations, the patient can ask the clinician questions which can aid in mitigating the anxious thoughts. The third guideline seeks to avoid inducing anxious thoughts in the patients by not providing medical information on their diagnosis and potential treatment in the tool.

The SDM tool should not inform the patient of their diagnosis and treatment

It is important for patients to be aware of the beneficial impact that SDM can have on their experience and their overall satisfaction with the treatment. However, most patients are not familiar with SDM before their first consultation and have therefore not had time to reflect upon their own thoughts and values beforehand, in the context of SDM. The patients may therefore have difficulties in expressing their preferences while processing all the information they receive during the consultation. We, therefore, suggest developing a tool that informs the patients of SDM and encourages them to reflect on their own values and preferences. This might improve the patient’s ability to verbalise their thoughts and thereby promoting patient engagement in SDM. The final design guidelines thus reads:

The SDM tools should prepare the patient to participate in SDM

5 PRESENTATION OF THE PROTOTYPES

We developed two prototypes, as we want to test which narrative structure, Interactive Slideshow or Drill-Down, is best for preparing cancer patients for SDM. In this section, we present the context, development, and limitations of the prototypes.

5.1 Context

As described in Section 4.3, the tool should be used by the patient before their first consultation at the Department of Oncology. If the digital tool were to be implemented, they would be granted access to the system through the digital invite they already receive on Digital Post, e-Boks, or similar services where citizens, companies and public authorities can send and receive safe digital mail. As such, the patients have the opportunity to use the tool while at home where they can go through the content at their own pace.

5.2 Narrative structures

For Study 2, we created two different navigational flows, as we want to explore how different narrative structures can influence the patient’s self-efficacy and decisional role, as illustrated in Figure 3. Segel and Heer [42] describe three narrative structures: author-driven, reader-driven, and a hybrid that combines elements of both.

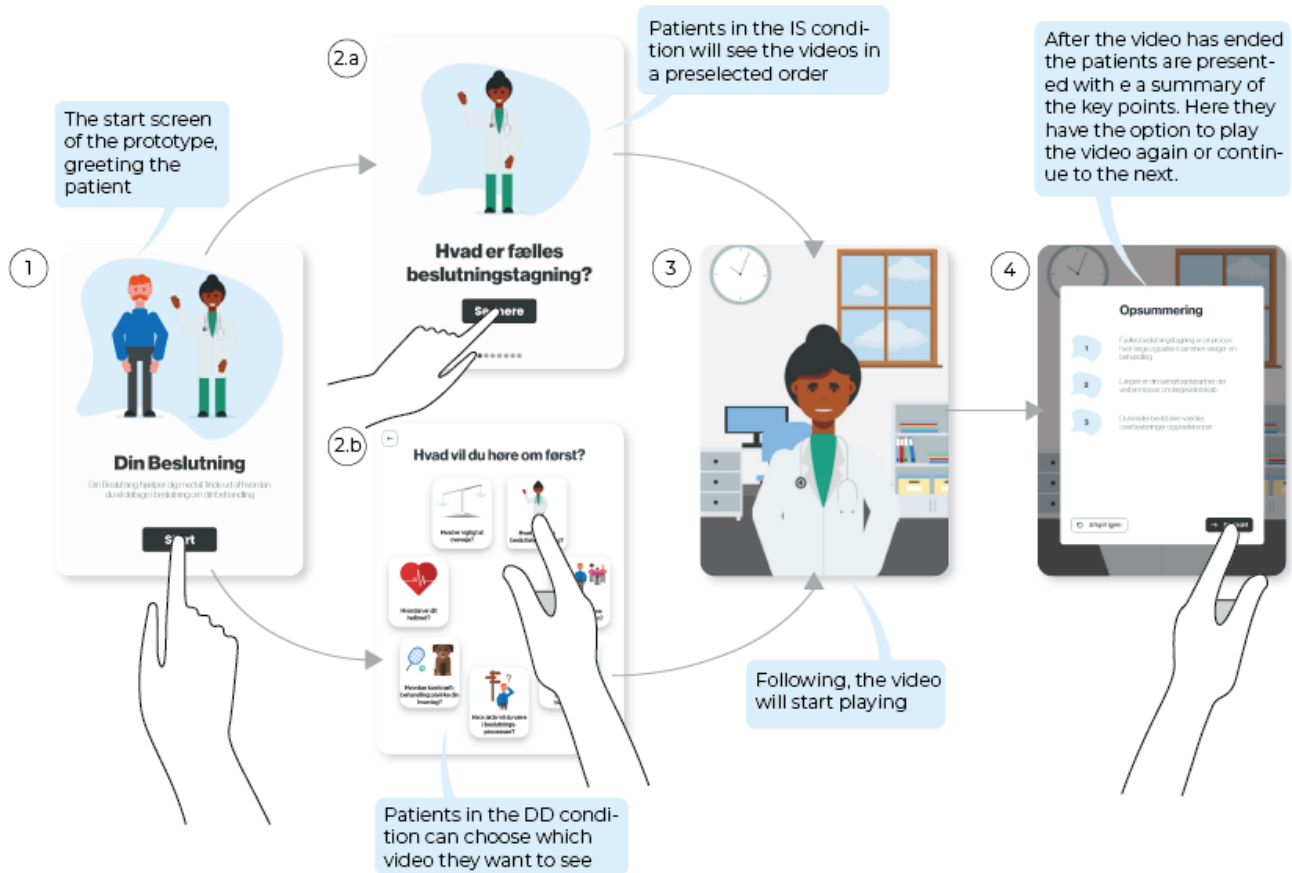


Figure 3: Illustrates the process of the two prototypes: (Top Flow) The Interactive Slideshow narrative structure and, (Bottom Flow) the Drill-Down narrative structure.

In this paper, we will examine how well two of the narrative structures can prepare cancer patients for SDM. The first narrative structure, Interactive Slideshow, has a set order in which the videos will be displayed and can be described as an author-driven approach [42]. The second narrative structure, Drill-Down, is different as the user can choose the order of what video they want to see and is, therefore, a more reader-driven approach [42]. We selected these two narrative structures for testing due to practical limitations, as we could only accommodate two conditions, as explained in Section 6. The Interactive Slideshow and Drill-Down structures were chosen as they represent opposing approaches, which we anticipated would yield the most noticeable differences in the data. Furthermore, it would be interesting to test whether Drill-Down has a bigger effect on the patient's self-efficacy since it allows the user to choose the order of videos, which aligns with the principles of SDM. In contrast, Interactive Slideshow may have less of an impact on the user's cognitive load as they do not have to choose the videos for themselves.

5.3 Development of the prototypes

We wanted the prototype to be accessible to as many people as possible, therefore, we developed seven short animated videos with audio and subtitles. To ensure consistency, we sought to align the visual language of the animated videos to informational animated videos that already exist in Danish healthcare, such as [20, 27]. Therefore, we decided to animate flat design illustrations and use voice-over. When introducing first-time users to the application, they will be presented with a starting screen, and depending on whether they are viewing the Interactive Slideshow or Drill-Down prototype, they will see an introduction screen to the first video, or a menu where they can choose what video they want to see first. The menu screen was implemented for the Drill-Down prototype to allow the user to navigate the topics and thereby create a reader-driven structure. We implemented the introduction screen for the Interactive Slideshow prototype to inform the users of the content they are about to see. Once they have watched a video, they will see a screen with a summary of the main points of the video where they also have the option to rewatch the video or proceed to the next

topic. This screen allows the user to reflect on the information they have just received. The option of rewatching a video was included in case a user wants to go back if anything was unclear to them.

The topics included in the prototypes were chosen based on the knowledge we had acquired in Section 4, where both the clinicians and patients spoke of different aspects that were important to them. For example, the theme **Role of the relatives** was translated into the topic "Who do you want to accompany you at the consultation", and the theme **Decision ownership** was transformed into the topic "How much do you want to participate in the decision making process?". That process resulted in the seven topics: "What is shared decision making?", "Who do you want to accompany you at the consultation?", "Questions about sickness and treatment", "How much do you want to participate in the decision making process?", "How can cancer treatment affect your everyday life?", "How is your health?"; and "What is important to consider?".

Finally, after the prototypes were developed, both the manuscript and videos were mailed to our contact person at the Department of Oncology for medical fact-checking.

5.4 Limitations of the prototypes

The prototypes have a few limitations. For one, the animations were made by the three members of the research team who had limited experience with creating animations beforehand. The quality and refinement of the animations could be enhanced significantly with the involvement of a team of professional animators and voice actors. Their expertise would greatly contribute to improving the overall quality and consistency of the prototypes.

Furthermore, there is potential to improve the usability of the prototypes by incorporating a few additional features. The first feature would be enabling the user to view the summary at a later time, eliminating the need to watch the videos again. This would allow the user to review the important points for further reflection and consideration. This feature has not been included in the prototype, as they are not necessary for the Interactive Slideshow and Drill-Down narrative structures. Another feature would be a check mark, or a similar visual indicator, to appear when the user had watched a video. Without such an indicator, it can be difficult for the user to remember which videos they already have watched. This feature has not been included as it would have required substantial amounts of work to implement in Adobe XD. It could have been easily implemented in Figma. However, a free subscription to Figma does not allow the usage of MP4 files. Since our prototypes heavily rely on MP4 files, we decided to make the prototypes in Adobe XD with the trade-off of not having a visual indicator for each completed video.

6 STUDY 2: EVALUATING NARRATIVE STRUCTURES IN AN SDM TOOL

In this section, we present the study design, the measures collected, interventions employed, participants recruited, procedures undertaken and analysis methods. Our study aimed to investigate how the narrative structure in storytelling can impact patients' self-efficacy and decisional role. By examining two narrative structures in an SDM tool we sought to gain a deeper understanding of patients' information processing and needs in the context of cancer care.

6.1 Study Design

A between-subjects design was employed for this study and participants were randomly assigned to one of two conditions, namely the Drill-Down or Interactive Slideshow. The participants of this study are patients in cancer care who may have limited energy levels due to illness or may not be mentally prepared for prolonged concentration. A between-subjects design was deemed appropriate to minimise the time commitment and potential burden on the participants.

Furthermore, a between-subjects design eliminated the risk of carry-over effects, which could have occurred in a within-subjects design where participants experience both narrative structures. By randomly assigning participants to one of the two conditions, any potential effects of order or sequence were minimised. Random assignment further distributed any potential biases or individual preferences between the two conditions.

6.2 Measures

For this study, several measures were utilised to assess the effects of the digital tool. The independent variables were the two conditions of narrative structures: Drill-Down and Interactive Slideshow. The dependent variables were self-efficacy and the participants' decisional role.

Self-efficacy was measured using the Decision Self-Efficacy Scale (DSES), as developed by O'Connor et al. [36]. The DSES is a widely used scale that measures an individual's perceived self-efficacy in making health-related decisions. The scale consists of 11 items, rated on a five-point Likert scale ranging from 0 (not at all confident) to 4 (very confident). Higher scores indicate higher levels of self-efficacy in decision making. The scale is divided into three constructs:

- Questions 1-4: Ability to obtain information
- Questions 5-7: Ability to ask questions
- Questions 8-11: Ability to make an informed choice in relation to medical decisions.

For this study, we modified the DSES to exclude the first four questions, as these relate to the ability to obtain medical information such as the risks and benefits of specific treatments. Our design does not seek to inform the patient of their treatment options or their diagnosis, consequently making these questions irrelevant to this study.

The decisional role of participants was assessed using the control preferences scale, a card sorting method developed by Degner et al. [14]. This scale is used to measure how active or passive an individual wants to be during the decision making regarding their health. The card sorting method involves presenting participants with a set of cards in a predetermined order that each displays a different decisional role in the context of making health-related decisions. The cards contain the following description of the decisional roles:

- A: "I prefer to make the decision about which treatment I will receive" [23]
- B: "I prefer to make the final decision about my treatment after seriously considering my doctor's opinion" [23]
- C: "I prefer that my doctor and I share responsibility for deciding which treatment is best for me" [23]

- D: *"I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion"* [23]
- E: *"I prefer to leave all decisions regarding treatment to my doctor"* [23]

Participants were presented with two cards at a time and were instructed to choose and keep the card that they believed best represented their decisional role preference while returning the other card to the facilitator. They were then presented with another card and asked to choose between the new card and the one they kept from the previous round. This procedure continued until all the cards had been sorted, and the participant was left with a single card that represented their decisional role. The order in which the participants received the card was fixed as per protocol: B, D, C, A, E.

The use of the DSES and the card sorting method allowed for the assessment of self-efficacy and decisional role in the context of the two narrative structures Drill-Down and Interactive Slideshow. These measures were chosen based on their established validity and reliability in previous research and their relevance to this study.

Demographic data such as age and gender were collected on all participants as well as their cancer diagnosis, frequency of smartphone, tablet, and computer use, and duration of treatment, see Table 3.

A brief semi-structured interview comprising eight questions was administered at the end of the evaluation. The questions were designed to gather the participants' perceptions and views regarding the concept of utilising a digital tool to prepare patients for SDM, see Appendix G. Additionally, the questions aimed to determine whether the participants preferred a reader-driven or author-driven structure.

6.3 Interventions

Our study compared two different narrative structures, namely Drill-Down and Interactive Slideshow, as interventions in digital storytelling for patients with cancer. These two conditions were chosen as they represent two opposite ends of the spectrum in terms of reader-driven vs. author-driven narrative structures. Examining the effects of these extremes on decisional role and self-efficacy could provide insights into the impact of narrative structure on health decision making.

Drill-Down condition: In this condition, participants were presented with a navigation flow that allowed them to choose the order in which they viewed the topics related to values, preferences, hobbies, and family involvement before their first consultation. The Drill-Down structure enabled participants to have control over the sequencing of the topics while allowing for the topics to be replayed [42].

Interactive Slideshow condition: In this condition, participants were presented with a navigation flow that followed a linear and predetermined sequence of topics. The Interactive Slideshow structure guided participants through the topics in a predetermined order, without the option to choose the sequence. This condition also included the option of replaying the video upon completion [42].

The Martini Glass structure, which combines elements of both Drill-Down and Interactive Slideshow, was not included in this study as we believe exploring the extremes of different presentation structures allows for a more comprehensive understanding of their strengths, weaknesses, and unique features. [42].

The rationale behind selecting these two conditions was to investigate the potential influence of narrative structure on decision making processes in patients with cancer. By comparing the effects of these two narrative structures, the study aimed to contribute to the understanding of how the presentation of information through different narrative structures may impact the decisional role and self-efficacy in the context of health decision making for patients with cancer.

6.4 Participants and procedure

In our study, we conducted interviews with 18 patients, consisting of 13 men and 5 women. For the remainder of this paper, we will refer to the participants as PP1-PP18. The participants were recruited from the Department of Oncology at Aalborg University Hospital. Our objective was to gather information from a diverse range of patients in terms of demographics, in order to obtain a representative understanding of the target population. The majority of the participants fell within the 55-78 age range, with only one patient being 40 years old (mean age = 64.8). See Table 3 for more details on the participant sample. Nearly all of the participants (16 out of 18) reported daily usage of smartphones, tablets, or computers. One patient reported using these devices on a weekly basis, while another patient stated rare usage. The participants had varying diagnoses, including prostate, ovarian, and lung cancer, with the latter being the most common diagnosis among the sample, occurring in five individuals. The duration of which the patients had been in treatment varied, ranging from 1 day to 6 years. This wide range is due to some patients having received previous treatments for cancer, which were included in the total treatment duration.

We aimed to recruit participants who had been to their first consultation and had been in treatment for a maximum of 3 months at the Department of Oncology. These requirements were put in place to ensure that participants would be able to recall their first consultation and to avoid overwhelming new patients who may yet feel comfortable with their situation. Contacting and scheduling tests with patients who have not had their initial consultation may have posed a challenge as the hospital would have to contact potential participants and ask for their consent to pass on their contact information to us. By adhering to these guidelines, we aimed to strike a balance between capturing accurate information and respecting the emotional well-being of individuals navigating a potentially distressing situation. The confidentiality of participants was ensured by using anonymous identifiers (e.g., PP1, PP2) instead of their names in all data collection and analysis.

6.5 Procedure

Prior to initiating the tests at the hospital, we conducted four pilot tests; one with our supervisor, one with our contact person at the Department of Oncology, and two with potential users. The objective of these pilot tests was to obtain initial feedback on the design and usability of the prototypes, while also ensuring that the

	Age	Gender	IT expertise	Cancer diagnosis	Duration of treatment	Test condition
PP1	70	Woman	Daily	Lung	1 week	Interactive slideshow
PP2	55	Woman	Daily	Lung	2 week	Drill-down
PP3	58	Man	Daily	Prostate	6 years	Interactive slideshow
PP4	71	Man	Daily	Esophageal	4 weeks	Drill-down
PP5	74	Woman	Weekly	Ovarian	3 months	Interactive slideshow
PP6	62	Man	Daily	Esophageal	4 weeks	Drill-down
PP7	78	Man	Daily	Colon	4 years	Interactive slideshow
PP8	74	Man	Daily	Esophageal	1 month	Drill-down
PP9	74	Man	Daily	Bladder	1 week	Interactive slideshow
PP10	69	Man	Daily	Lung	1 week	Drill-down
PP11	58	Woman	Daily	Lung	1 day	Interactive slideshow
PP12	62	Man	Daily	Esophageal	4 weeks	Drill-down
PP13	61	Man	Daily/weekly	Head	2 years	Interactive slideshow
PP14	58	Man	Daily	Pancreas/Liver	1 year and 4 months	Drill-down
PP15	61	Man	Daily	Colon	4 months	Interactive slideshow
PP16	68	Woman	Daily	Ovarian	1,5 years	Drill-down
PP17	40	Man	Daily	Brain	5 weeks	Interactive slideshow
PP18	74	Man	Rarely	Lung	10 weeks	Drill-down

Table 3: Details of the patients who participated in the study.

information provided was consistent with the medical practices of the department. The prototypes were refined according to the feedback.

The recruitment process involved obtaining a list of potential participants from our contact person at the hospital. Patients who were potential participants were approached in their hospital rooms and provided with an introduction to the study. If a patient agreed to participate, further details about the study and contact information on the researchers were provided to the participants in case they had any further questions or if they at a later time wants to have their data removed from the study. After the introduction, the participant signed a declaration of consent, and the demographic of the participants was collected, such as their age, gender, and diagnosis.

The participants were introduced to the self-efficacy scale, which they were instructed to fill out to establish their self-efficacy in regard to making decisions about their health before interacting with either of the two conditions. Following the self-efficacy scale, the card sorting technique was used to establish the participants' initial decisional role. This involved providing the participants with a set of decisional role cards, and the last card they held at the end of the sorting process represented their decisional role.

Following the card sorting, participants were presented with either the Drill-Down or Interactive Slideshow condition. After the testing session, the card sorting technique, and the self-efficacy scale were used again after the testing session to assess any changes in their self-efficacy. Lastly, a semi-structured interview was conducted, consisting of eight questions related to the participant's experience with the system, see Appendix G.

6.6 Reflexive Thematic Analysis

We chose to use a Reflexive Thematic Analysis approach to analyse our semi-structured interview results as it allowed us to be

more introspective about our own feelings and experiences related to the subject matter of cancer. The sensitive nature of the topic made it important to consider how our own opinions and emotional responses might affect our communication with patients and clinicians, and how we interpret their statements. This approach allowed us to be more reflective and reflexive in our analysis, and to take into account our own subjective perspectives and biases.

We conducted a Reflexive Thematic Analysis to identify and analyse patterns of meaning within the data from the user evaluation of the prototypes at the hospital. The Reflexive Thematic Analysis was guided by the instructions of Braun and Clarke [7], which involves a six-stage process of coding and theme development.

First, we familiarised ourselves with the data by thoroughly reading the notes and statements of the user evaluations. Next, we generated initial codes, by individually coding the results of the same three user evaluation after which we reconvened to agree on a shared codebook, see Appendix H. The remainder of the notes from the user evaluation was distributed among the members of the research team and analysed using the initial codebook. Finally, all codes were collectively reviewed by all group members. The codes of all the user evaluations were then grouped into potential themes, which were reviewed and refined through an iterative process of searching for and reviewing patterns of meaning within the data.

During the theme development stage, we critically examined the potential themes to ensure that they accurately reflected the patterns of meaning within the data, while also being coherent and distinct from one another. We then defined and named the themes that describe the codes covered by the individual themes.

The thematic analysis was finalised by selecting representative codes, effectively capturing the essence of each theme. This process provided an overview and allowed us to understand the types of data encapsulated within them.

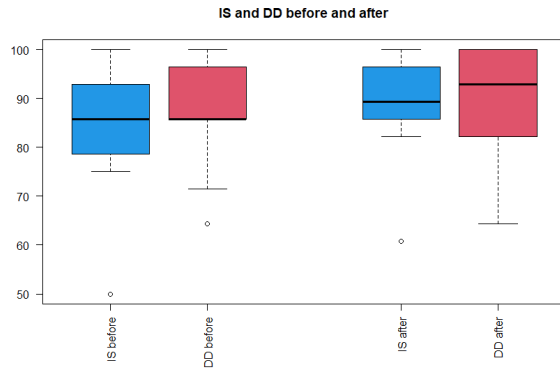


Figure 4: This boxplot visualises the overall difference between the self-efficacy of the Interactive Slideshow and the Drill-Down conditions.

7 RESULTS

In this section, we provide an overview of the findings from Study 2, encompassing statistical analysis of self-efficacy and decisional role changes before and after using the prototypes. Additionally, we present the results of the Reflexive Thematic Analysis performed on the interview data.

7.1 Statistical analysis

The data collection resulted in 18 complete data sets. In order to account for the lack of normality in the data sets, non-parametric tests were employed for the statistical analyses. Prior to conducting these tests, all assumptions associated with the specific analyses were carefully examined, and no violations of these assumptions were found.

7.1.1 Self-efficacy. To analyse the change in self-efficacy between the two conditions, Interactive Slideshow and Drill-Down, a Mann-Whitney U test was employed. The results indicated that there was no significant difference between the delta of self-efficacy of the Interactive Slideshow ($M = 10.72$) and the Drill-Down ($M = 8.28$) conditions ($U = 29.50$, $z = -1.00$, $p = .340$). In Figure 4 we provide a boxplot of both conditions to visualise the distribution. The difference in self-efficacy before and after was analysed to investigate if the videos had an effect on the participants. The results of a Wilcoxon Signed-Rank Test indicate that there was no significant difference between self-efficacy before the patients used the prototypes (median = 85.32) and self-efficacy afterwards (median = 88.30), ($Z = -1.611$, $p = 0.107$).

7.1.2 Decisional role cards. As described in Section 6.2, the cards were assigned a letter from A-E as identifiers. Cards A and B indicate an active decisional role, card C indicates a collaborative decisional role, and cards D and E indicate a passive decisional role, see Table 4. The changes in the patients' preferred decisional role were analysed using Fisher's exact test, due to a low number of participants for Chi Square test. The results of the Fisher's exact test ($p = .083$) do not indicate a significant association between before and after interacting with the Interactive Slideshow prototype. Similar results

	Passive	Collaborative	Active
IS before	2	6	1
IS after	1	7	1
DD before	3	5	1
DD after	1	5	3

Table 4: The decisional role of the participating patients before and after interacting with either the Interactive Slideshow or Drill-Down prototype.

are found for Drill-Down, as the results of the Fisher's exact test ($p = .464$) do not indicate a significant association between before and after interacting with the Drill-Down prototype.

7.2 Thematic Analysis

In this section, we present four themes based on the interviews we conducted after the patients interacted with one of the two prototypes. The four themes are as follows: (1) Reader-driven vs. author-driven preferences; (2) Preferences in receiving information; (3) Content relevance; and (4) Preparing for the consultation.

7.2.1 Reader-driven vs. author-driven preferences. Preference for the Interactive Slideshow condition or Drill-Down condition was split among the patients. The patients often preferred the condition they were exposed to, while others did not have any preferences towards choosing the order themselves or watching the videos in a predetermined order.

A patient who used the Drill-Down prototype specifically said he would not use the tool if he could not choose the order of videos himself. In contrast, another patient who used the Drill-Down prototype disliked choosing the videos and as a result, he only watched one video. The patient then further explained how he would have liked it if the order of videos had been predetermined for him.

"I am not sure if I wanted to use the system, if I cannot choose myself" - PP2

"I would prefer if the order of the videos were predetermined for me" - PP8

Additionally, a small group of patients described how choosing videos is overwhelming and that a predetermined order of videos can mitigate decision fatigue. PP5 described how being sick can cause decision making to be difficult:

"[If the videos are predetermined], then I would not have to think about what videos to play first. Since I got sick, I can feel it has become overwhelming to make another decision." - PP5

7.2.2 Presenting information insightfully. The theme of "Preferences in receiving information" covers how the patients would prefer to obtain health information. The patients' preferred way of receiving information was somewhat divided amongst patients, however, some preferences reoccurred. Two patients specified that they like to receive information verbally, while others dislike it, as it is more difficult to remember:

"I forget what was discussed if I only receive the information verbally" - PP5

Several patients described how the summaries at the end of the videos were helpful in remembering the key points of the videos. Additionally, a patient explained how she really liked the multiple modalities of the prototype:

"No, I think it is fine with both the audio, text and visuals. You can target a wide target group, as people are different. Some would like the visual elements, while others are helped by the text they can read." – PP16

This finding is consistent with the results of Study 1, where we found that the tool should not exclusively use text- or graph-based interfaces. Another consistency between the two studies shows the theme of "Content relevance". In Study 1, we discovered that the patients do not want to receive information that is not relevant or specific to them. Only three patients in Study 2 found one or two of the videos to be irrelevant. The videos mentioned as irrelevant were: "Questions about illness and treatment", "What is SDM?", and "How active do you want to be". However, 15 out of 18 patients found all videos in the prototypes to be relevant to them, as exemplified by PP2:

"All of the information in the videos are relevant to me in one way or another" - PP2

7.2.3 Preparing for the consultation. Another significant finding regards the benefits of preparing for the consultation. During Study 2, we found that patients struggle with receiving too much information in a short amount of time, leading to them feeling overwhelmed. This finding is strongly connected to the theme explored in Study 1, which focused on the issue of "information overload." This shows that patients in both studies face the challenge of receiving an overwhelming amount of information during consultations, underscoring the continued relevance of this issue and the potential benefits of implementing an SDM tool

"I think it is excellent. A lot of people can't handle it all if they are not prepared when they are sitting at the consultation." - PP5

This statement highlights the significance of adequately preparing patients beforehand, as it can help them effectively manage the information provided during consultations and prevent becoming overwhelmed. Additionally, 17 out of 18 patients found that the prototype was relevant and useful for new patients, as described by PP3:

"It is good that they will receive this information before the consultation with the clinician" – PP3

8 DISCUSSION

In this section, we delve into a comprehensive discussion of our study's findings, their alignment with the existing body of literature, the implications of our results, and potential avenues for future research. By examining these aspects, we aim to provide a deeper understanding of the impact of narrative structures, specifically Drill-Down and Interactive Slideshow, on the participants' self-efficacy and decisional role. This discussion will not only shed light on our study's contributions but also highlight the broader significance of storytelling in healthcare.

8.1 Storytelling as a communication tool

In this study, we utilised storytelling to explain and illustrate abstract concepts as it allows people to not only retain pertinent

details but also to better understand complex concepts such as SDM [25, 40]. However, we learnt from Study 1 that most healthcare information is either verbal or written. Based on the quantitative analysis, no significant difference was found in the self-efficacy score of patients before the use of the prototype and after. However, 12 out of 18 participants in Study 2 mentioned that the storytelling format was more accessible as it captivated them and helped them to understand the information presented. This indicates that patients are more likely to retain information presented visually than spoken or written words. This aligns with the related work, stating that storytelling is an ideal way of presenting information to patients in healthcare [25, 40].

Our goal was to educate and empower patients in cancer care on the importance of understanding their needs, preferences and values in a healthcare-related context. As one patient mentioned, storytelling can help people to tell about their life and initiate the process of reflection and reflexive learning [37]. Additionally, 6 out of 18 participants mentioned that empowering patients is important as it can help them to take an active role in healthcare-related decision making. This indicates that storytelling enables the patients to reflect on the story told and actively apply it to personal experiences. The use of storytelling in healthcare has the potential as a means of informing clinicians of what matters most in a patient's health and everyday life. This aligns with the related work, as storytelling can be used to educate and empower patients to understand their health-related needs and concerns [12, 13, 37]. Furthermore, it has the potential to empower patients to actively engage in their healthcare decisions by identifying their needs, preference and values [25, 37].

8.2 Promoting self-reflection with digital tools

Our study aimed to investigate the effectiveness of a digital tool in promoting self-reflection before a patient's first consultation with a healthcare professional. Previous research has explored the potential of digital tools as aids for patients in making healthcare decisions. For instance, Zhang and Bickmore [51] developed a virtual decision coach that helped patients make choices regarding prenatal testing for Down syndrome by providing information about medical procedures. In contrast, our prototype focuses on fostering self-reflection while relying on the clinicians' knowledge and expertise to educate patients about the relevant medical evidence.

Among the patients, 12 individuals expressed a preference for receiving information through videos. Additionally, one patient emphasised the potential benefits of using multiple modes of communication to reach a wider range of users. In contrast, Zhang and Bickmore's [51] research demonstrated a significant improvement in participants' understanding of prenatal testing and their high satisfaction with the decisions made.

The qualitative findings suggest that empowering patients through self-reflection has the potential to improve their self-efficacy in making health-related decisions. Patients recognised the importance of being active participants in their healthcare decisions and valued the opportunity to reflect on the stories presented in the prototype. This indicates that interactive digital systems that facilitate self-reflection can enhance patients' understanding of their needs,

preferences, and values, ultimately empowering them to make more informed decisions.

These findings can guide designers and researchers in implementing best practices when developing similar decision support tools in healthcare. By prioritising patient self-reflection and empowerment, designers can create systems that go beyond providing medical evidence and instead foster a deeper understanding of patients' own needs and values. Incorporating storytelling formats that engage patients visually and emotionally can enhance their retention of information and facilitate a more meaningful engagement with the decision making process.

During the development of our prototype, we took into account the concerns raised in a study by Constantin et al. [9] regarding their virtual training doctor called PrepDoc. Some participants expressed concerns about the system's condescending tone and limited provision of choices or opportunities to guide the conversation. To address these concerns, we placed a strong emphasis on creating an inclusive and intuitive system for individuals from diverse backgrounds. Our primary goal was to ensure that the prototype's content was easily understandable and the navigation was intuitive. In contrast to the study by Constantin et al. [9], none of the patients in our study reported similar concerns. This suggests that we successfully achieved a balance in our prototype, delivering information in an understandable manner without being condescending.

The results of our study showed no significant differences in self-efficacy between the two conditions. These results are in line with our qualitative findings that showed patients had varying preferences towards an author-driven or reader-driven structure with a majority preferring the condition they had been exposed to.

Although the results are inconclusive regarding whether the Interactive Slideshow or Drill-Down condition is preferable, the findings highlight the importance of taking into account the mental state of patients who are intended to use the tool. Therefore, we stress the significance of considering the specific context in which the tool will be utilised, particularly in healthcare settings, such as cancer care. If the patients are easily overwhelmed by decisions, or they already have used their cognitive capacity then Interactive Slideshow would be the favourable condition. Conducting similar studies with a larger sample size could provide valuable insights and potentially yield more generalisable results, allowing for more reliable statistical analyses. Furthermore, researchers could investigate whether the utilisation of The Martini Glass narrative structure achieves a favourable balance by avoiding overwhelming patients with excessive options while still providing them with adequate user control.

On a final note, we want to reiterate one of our points from Study 1. We found that the patients cherish the consultation with the clinician and the expertise the clinician possesses. Similar to this finding, in Study 2, patients repeated this point, as some described that they prefer to discuss their diagnosis and treatment with the clinician, as they can provide instant answers to their questions. After Study 2, we still believe that the skills and empathy of the clinicians triumph that of a digital tool, and therefore, we do not recommend designing a tool that informs patients of the state of their diagnosis and potential treatment options. Rather, a digital

tool should encourage and prepare the patients for SDM, so they are aware of their preferences and values.

8.3 Limitations

While this study aims to investigate the potential of a digital tool to prepare cancer patients for SDM, it is important to acknowledge several limitations that may affect the generalisability and applicability of the findings.

The first of these limitations is the challenge of selection bias. The interviews in Study 1, which formed the basis for the information in the prototype, were conducted with patients who had already received information and had been through the initial consultation process. As a result, their statements and perspectives may differ from those of patients who have yet to begin their treatment. Furthermore, the user evaluation of the prototypes in Study 2 was also conducted with patients who had already begun their cancer treatment. Although the participants were informed that the prototype was intended for use before their initial consultation, their prior experience and familiarity with the decision making process may have influenced their perception of the prototype's relevance. This bias may limit the representativeness of the prototype's content and its applicability to patients in the early stages of their cancer treatment. Conversely, patients who have already begun their treatment may offer additional perspectives on the challenges associated with participating in SDM and the needs of the patients. These insights should be taken into account when developing the tool. Another limitation is the limited sample size consisting of 18 patients in the user evaluation of the prototype. This is a relatively small sample size, which may impact the generalisability of the findings. Including a larger and more diverse sample could provide a more comprehensive understanding of the system's effectiveness and applicability across different patient populations. Furthermore, the study was conducted in a single Department of Oncology. The context-specific factors, such as the organisation of the department and the patient population, may influence the findings and acceptance of the system in different settings. On the other hand, if we had conducted user evaluations specifically at the second Oncology Department in Aalborg, which specialises in breast cancer, we could have obtained a more balanced representation of both genders in our study. Lastly, there is the limitation of a short-term evaluation. The user evaluation of the prototype was conducted over a limited duration, focusing on immediate changes in self-efficacy and user feedback. However, the long-term impact of the digital system on patients' decision making processes and outcomes remains unexplored.

9 CONCLUSION

In this paper, we examined and compared two narrative structures i.e. Interactive Slideshow and Drill-down in their ability to promote self-efficacy in cancer patients and their decisional role. By conducting two studies, we advance the body of knowledge on what patients need to engage in SDM and how a digital tool can encourage patients to engage in their healthcare decisions. Patients who interacted with the prototype expressed positive feedback regarding its potential to prepare new patients for SDM. The storytelling format proved to be accessible and relatable, making it easier for

patients to engage in self-reflection. This highlights the promising applicability of such a tool in facilitating SDM in the context of cancer care. We also found significant factors that result in patient burnout such as decision fatigue or high cognitive load. Based on our findings, we recommend that the Interactive Slideshow approach be utilised when designing a tool for cancer patients to use. Our qualitative research contributes empirical evidence for the use of digital storytelling as a tool for encouraging patient engagement in decision making. Specifically, by implementing an interactive digital system in the context of cancer care we found that patients feel empowered, educated, and prepared to partake in healthcare decisions. Furthermore, a digital tool of this nature has the capacity to foster self-reflection among patients, enabling them to explore and articulate their individual needs and preferences. By designing such a tool, we can empower patients to take an active role in their healthcare journeys while still leveraging the expertise of clinicians and supporting the greatly cherished interaction between clinician and patient. In the future, we hope that these findings can aid designers and researchers in implementing tools for patient self-efficacy.

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