



Patients' experiences with an audio-visual intervention, the use of a tailored explanation video in patients with bladder cancer

Marjon Wolters-Zwolle^a, Marielle M.E. de Jongh^a, Maarten W. van Elst^b,
Richard P. Meijer^b, Sigrid C.J.M. Vervoort^{c,*}

^a University Medical Centre Utrecht, Clinical Health Sciences, Nursing Science, Utrecht University, Utrecht, the Netherlands

^b Department of Urological Oncology, Division of Imaging & Oncology, University Medical Centre Utrecht, The Netherlands

^c Division of Imaging & Oncology, University Medical Centre Utrecht, The Netherlands

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ABSTRACT

Objective: This qualitative study explored the experiences of patients with bladder cancer with a tailored 'explanation' video (EV) as a supportive information tool used before and during treatment.

Methods: Using a qualitative approach, data were collected through semi-structured interviews with 12 patients with bladder cancer and thematically analysed.

Results: Participants advised future use of the EV, noting it is user friendly and has a fitting difficulty level and clarifying animations. However, some mentioned practical information on 'life after treatment' was lacking, and some emphasized the importance of choosing the right moment of delivery. Patients' experiences were described in four major themes: taking own responsibility, providing opportunity for postponed information supply, easing decision-making processes and gaining a sense of calm.

Conclusion: Findings indicate the EV supported patients with bladder cancer in the process of being informed and in decision-making. Future use of the EV in the treatment of patients with bladder cancer is recommended.

Innovation: The use of audiovisual information in patient education is innovative. Tailored audiovisual information in shape of the EV is a step forward in streamlining information processes, meeting individual preferences and highlighting the most important general information for patients with bladder cancer.

1. Introduction

Cancer is the second leading cause of death globally, resulting in an estimated 10 million deaths in 2020 [1]. The incidence of urogenital cancer in the Netherlands was over 10,000 in 2020 [2]. A total of 12,940 people were treated for a diagnosis of bladder cancer in Dutch hospitals in 2019 [3]. During treatment, patients with bladder cancer need information to cope with the disease and participate in decision-making processes [4].

Shared decision-making (SDM) is currently acknowledged (inter)nationally as best practice in healthcare, whereas traditionally, the physician decided on the course of treatment [5-12]. SDM is defined as a process whereby healthcare providers (HCPs) and patients cooperate in making healthcare choices and it is fundamental for informed consent and patient-centred care [9,10]. Patients being well-informed is of utmost importance for SDM to be successful. Patients need tailored information about diagnosis, treatment and prognosis [13,14]. Such personalised information equips patients better for a dialogue with HCPs regarding treatment options [8,11].

Studies on SDM in urogenital cancer care have demonstrated the importance of SDM in decision-making processes [15-20]. Being informed enables patients with cancer and their relatives to understand and process the diagnosis, consequences and treatment of cancer [4,21,22]. Information is mostly provided verbally by physicians and nurses during consultations. However, consultation time is often limited, leaving less time for considering patients' emotions. Emotions have a negative influence on how patients receive information [13]. Furthermore, patients' retention of medical information is limited; 40 to 80 percent of the provided information is not remembered, and recalled information is often incorrect [23]. Age and stress are detrimental to retaining information, especially when a cancer diagnosis has just been announced [13,24].

Due to patients' need for information and the available online sources, an increasing number of patients are using the internet to obtain information on disease and treatment. However, distinguishing between correct and incorrect data in the information overload is challenging [25,26,27]. Information gathered on the internet, including online videos, can lead to misconceptions based on outdated information [25-27]. Offline

* Corresponding author.

E-mail address: svervoor@umcutrecht.nl (S.C.J.M. Vervoort).

¹ Postal address: Universitair Medisch Centrum Utrecht Postbus 85500 3508 GA Utrecht The Netherlands

audiovisual information (AVI) tools have been developed to prepare patients for a physician consultation and prevent them from being misinformed [26,28]. Video images that explain treatment and its consequences and display physical examinations promote a better understanding of spoken or written texts and help patients know what to expect [28-31]. Furthermore, AVI can provide direct access to reliable and quality information while condensing voluminous information into smaller chunks for easier assimilation [28]. Evidence of AVI improving patient care is inconclusive; however, studies have indicated improvements in patient knowledge and in satisfaction with information processes [28-31]. In the Netherlands, AVI is increasingly being used in breast and cervical cancer patient care [32-36]. In 2018, an AVI tool was developed for patients with bladder cancer – the so-called ‘explanation’ video (EV), coined from the words ‘explanation’ and ‘animation’. The EV was developed to improve and streamline medical and practical information concerning treating and living with bladder cancer. Moreover, the EV is helpful for recapping information to gain a better understanding and comprehension (see the [textbox](#) Intervention and [Fig. 1](#)).

In the evaluation of an intervention, it is important to explore its usefulness and effects as experienced by the users. The evaluation contributes to understanding the intervention, provides knowledge on both its content and use and enables adaptations of the intervention in healthcare [37-39].

Our evaluation study focusses on the experiences of patients with bladder cancer regarding receiving and using the EV. The aim was to determine whether and how the tool contributes to patients being well-informed and benefits SDM from the patients’ point of view. The study outcomes provide information about the value and acceptability of the EV and highlight possible adjustments to the EV in order to tailor it to the process of bladder cancer care.

2. Methods

2.1. Design

An explorative descriptive qualitative study was conducted to enable an in-depth exploration and description of patients’ experiences with the EV [37,40].

2.2. Population and domain

Participants were purposively selected from patients with bladder cancer who received and used the EV after diagnosis and were still receiving or recently finished treatment. Participants were eligible when they used

Intervention

The ‘explanation’ video (EV) is a supportive information tool consisting of six compartments which all deal with a topic related to bladder cancer. The structure of the tool follows the care and treatment process. The compartments comprise animation videos in which information is given in the form of moving animation images supported with spoken text. The EV is a stand-alone device with its own charger and is designed with a display and buttons integrated in a sturdy cardboard cover. The EV starts with an introduction film when opening the cover. All compartments have a start button and options for play, pause and skip forward and backwards. On the inside of the cover, short instructions are presented. Patients receive the EV after the bladder cancer diagnosis has been communicated at their first consultation at the hospital, when treatment options are also discussed. During the process following, decisions concerning treatment are made and executed.

the EV in 2019 to prevent recall bias, as the study was conducted in March 2020 [39]. In total 59 patients received the EV in 2019. Seven of them were deceased, leaving a research population of 52 for our purposive selection. The inclusion criteria were patients aged ≥ 18 years and physically and mentally able to participate in a qualitative interview. Patients unable to speak and understand Dutch were excluded. Maximum variation within the sample was strived for to increase diversity of perspectives [41,42]. Heterogeneity was sought in differences in age, gender, educational level, digital experience and elapsed time since receiving the EV. The sample size was determined by data saturation. Recruitment was executed until saturation was reached, and no new insights were derived from the data [43].

2.3. Data collection

Semi-structured interviews, using a topic list, were conducted between February and April 2020 by MZW, a novice female researcher and experienced oncology nurse. Prior to the study, no relationship existed between the researcher and participants. The topic list ([Appendix A.1](#)) was based on recent qualitative studies on (digital) interventions in healthcare and expert opinions of a urologist, a clinical nurse specialist and the secretary of the Dutch Bladder and Renal Cell Carcinoma Society [44-48]. The graphic designer of the EV gave input about usability topics, and an experienced postdoctoral researcher reviewed the topic list. The topic list was adjusted throughout data collection.

A patient information folder, an informed consent form and a letter signed by the urologist were sent by post. The letter stated the researcher would contact patients within two weeks. The researcher contacted patients by telephone and asked them to participate. Additional information on research purposes was given, and questions could be asked. After obtaining consent, an interview appointment was made, considering the participants’ preferred location. Nine face-to-face interviews were conducted: four at the hospital and five at participants’ homes. Only the participant and interviewer were present, except once when a spouse was attending. Prior to the interview, demographic data were collected. During the interview ‘probes’ and ‘prompts’ were used to connect with the participants and obtain ‘deeper’ data on their experiences. All interviews started with the opening question: ‘What did you like about the “explanation” video?’ The mean duration of the interviews was 39 minutes (range: 28-60 minutes). Due to restrictions concerning the COVID-19 outbreak, face-to-face interviews were substituted by telephonic interviews, with an average duration of 26 minutes (range: 21-32 minutes). All interviews were audio-recorded, transcribed verbatim and anonymised. During the interviews, observational memos were made. After 10 interviews an interim analysis was conducted and the topic list was adjusted.

Sampling and data collection continued until data saturation was reached after 12 interviews; no new information was obtained concerning patients’ experiences with the EV [43,49].

2.4. Data analysis

Data analysis was guided by thematic analysis – the inductive approach by Braun and Clark ([Appendix B.1](#)) [50]. Researcher MWZ familiarised herself with the data by transcribing, reading and rereading the interviews. Coding was performed by two researchers (MJ and MWZ) and discussed until consensus was reached. An experienced postdoctoral researcher (SV) provided guidance; coding processes were discussed in three meetings involving MJ, MWZ and SV. After 10 interviews an interim analysis was performed, and codes were discussed, revised and grouped into categories (MWZ and SV). The categories were discussed and collected into potential themes and subthemes with accompanying quotes. In two additional meetings, elaboration of the themes and the discussion continued until definitive (sub)themes were agreed upon (MWZ and SV). See [Table 1](#) for details. During analysis, methodological and theoretical memos were written and processed. Data analysis was supported by NVivo 11.0 software (QSR International Pty Ltd., Version 11.0, 2014) [51].



Fig. 1. Content and picture of the ‘explanation’ video

Table 1
Thematic analysis phases (Braun and Clarke)

Phase	Description of the process and role of authors
1. Familiarizing with the data	The researcher MWZ interviewed the participants and transcribed the interviews. Immersion of the data started while transcribing the interviews. All transcripts were read thoroughly MJ and MWZ to become familiar with the data and gain an overall impression.
2. Generating initial codes	MJ and MWZ conducted initial coding, keeping the importance of giving each data item equal attention in mind. After initial coding by both researchers, codes were compared and discussed in joint (digital) meetings after each two to three interviews until consensus was reached to avoid shifting definitions. Observational, theoretical and methodological memos were systematically processed. SV (an experienced postdoctoral researcher, specifically in qualitative research) guided the coding process and partly participated in coding processes. Results of the codes were discussed in (digital) meetings with two or all three researchers (MJ, MWZ and SV), working towards consensus about the coding and interpretation of the data.
3. Searching for themes	Codes were collated in potential themes. The relevance of the themes emerged throughout the interview process. A description of potential themes and subthemes was made and discussed in joint meetings (MWZ and SV).
4. Reviewing themes	To ascertain the consistency of the potential themes with the interview data and the codes, inconsistencies were discussed, and potential themes further refined (MWZ and SV).
5. Defining and naming themes	Using the transcripts, the specific content of each theme was finished, and themes were named and defined (MWZ and SV).
6. Producing the report	MWZ wrote a concept of the scientific report and selected quotes supporting the (sub)themes. The report was reviewed by the two postdoctoral researchers (SV and SW). All feedback was processed and discussed, and the final scientific report was finished (MWZ). Finally, MWZ wrote the article, which was reviewed by the entire research team: fellow researcher (MJ), postdoctoral researcher (SV), urologist (RM) and clinical nurse specialist (MvE), who contributed to the study preparations (enrolment strategies, patient information letter, topic list) and study design.

MJ: Mariëtte de Jongh; MWZ: Marjon Wolters-Zwolle; SV: Dr SCJM Vervoort; SW: Dr SWM Weldam; RM: RP Meijer, MD PhD FEBU; MvE: MW van Elst MSc RN

2.5. Trustworthiness

The credibility of the data collection and analysis was strengthened by researcher triangulation, which improved the accuracy of coding processes and reduced the risk of potential bias [43,52,53]. Observational, theoretical and methodological memos were processed and used for monitoring the development of the study, ensuring quality, discussing progress and writing the report [43]. Dependability was warranted in a clear description of inclusion procedures, design, data collection and analysis. Reporting was in accordance with the consolidated criteria for reporting qualitative research, enhancing trustworthiness (Appendix C.1) [54].

2.6. Ethical issues

This study was conducted according to the Declaration of Helsinki (Version 2013) and the Medical Research Involving Human Subjects Act (WMO) [55,56]. An earlier request made to the hospitals’ ethical committee (research protocol 17/769) was approved as nonliable to WMO criteria in 2017. Another amendment was filed for ethical approval. Confirmation of nonliability to WMO criteria was granted. In all cases, participants gave informed consent.

3. Results

Purposive selection amongst the 52 eligible participants was executed until data saturation was reached. Twenty-six patients were approached to participate. Thirteen of them refused participation for reasons such as ‘too confronting’ (two), being occupied with treatment (four), experiencing complications (two), not using the EV due to technical errors (three), being unable to speak Dutch (one) and being uninterested in participating (one). Three patients could not be reached despite several attempts, leaving 10 participants. After the interim analysis, two more patients who received the EV in 2020 were recruited. Of the 12 participants, eight were male. The mean age was 70 years (range: 57-78 years). Mean elapsed time since receiving the EV was nine months (range: 1-15 months). Additional data are presented in Table 2.

All participants had access to different sources of information during treatment: HCPs, brochures, the internet and the EV. The participants expressed the wish of being equipped for treatment decisions and for living

Table 2
Participants' demographics

Participant code	Gender	Age (in years)	Disease	Treatment	Time since receiving the EV ^a (in months)	Educational level ^b	Digital experience ^c
P1	Male	78	Bladder cancer	Cystectomy	15	High	Basic
P2	Male	72	Bladder cancer	Cystectomy	12	Medium	Basic
P3	Female	69	Bladder cancer	Cystectomy	9	High	Advanced
P4	Male	72	Bladder cancer	Cystectomy	11	High	Advanced
P5	Female	57	Bladder cancer	Cystectomy	10	Low	Advanced
P6	Male	57	Bladder cancer	Alternative treatment	14	Low	Advanced
P7	Male	69	Bladder cancer	Bladder lavages (BCG)	13	High	Advanced
P8	Male	75	Bladder cancer	Cystectomy	8	High	Advanced
P9	Male	74	Bladder cancer	Cystectomy	6	High	Moderate
P10	Male	71	Bladder cancer	Cystectomy	13	Medium	Advanced
P11	Female	78	Bladder cancer	Cystectomy	2	Medium	Basic
P12	Female	68	Bladder cancer	Cystectomy	1	Medium	Moderate

^a EV = 'explanation' video on bladder cancer

^b International Standard Classification of Education Sept 2011 re-edition I© UNESCO-UIS www.uis.unesco.org 2011. Low: junior general secondary education for adults. Medium: vocational education, professional training diploma, senior general secondary education for adults, vocational education or middle management training diploma. High: bachelor's degree

^c Grant DM, Malloy AD, Murphy MC. A Comparison of Student Perceptions of Their Computer Skills to Their Actual Abilities. Journal of Information Technology Education: Research 2009 January;8(1):141-160. Basic: able to use a smartphone/computer and send an email. Moderate: additional basic knowledge of programmes such as Word, PowerPoint and Excel. Advanced: additional specific knowledge of programmes such as Word, PowerPoint and Excel.

with the consequences of bladder cancer. Participants underlined the importance of consultations with HCPs for being informed through 'a trustworthy and warm relationship'. Depending on their personal needs, participants valued the other sources of information. Brochures were read, but the information was not always memorised. For some participants the internet was an easily accessible source, especially for 'hearing peer experiences'; others, however, 'felt overwhelmed by the abundant information' or 'experienced feelings of fear'. Overall, participants' stories revealed that for most, the EV was complementary to the information provided by HCPs during the treatment process. All participants affirmed others could benefit from the EV and that it should be given to future patients with bladder cancer.

Based on participants' experiences with the EV, the results are described in two sections: EV user experiences and the EV and its role in becoming informed. Throughout the process of diagnosis, discussion of the treatment options and the decision-making processes, being informed is important for patients. Information clarifies the health problems patients are facing and supports the decision-making processes concerning treatment. The needs, the level and details of being informed differed between participants.

3.1. User experiences

Most participants stated that the EV was easy to use. Only less digitally skilled participants experienced problems and preferred more detailed instructions. Some participants encountered technical problems, which they described as 'frustrating', 'a pity' or 'a reason for not using the EV'.

Most participants considered the moment of receiving the EV as suitable. However, some said it was too early and that the EV provided them with information they did not want to know yet, as one participant said, 'It overwhelmed me'. Participants appreciated the distribution of the information in different chapters; they expressed that they could choose which topic(s) they wanted to rewatch. The difficulty level of the spoken text was found fitting, and the animations understandable; some participants added that real urostomy pictures or a short surgery video would have been supportive. One participant stated, 'It would have given me a better understanding of what really happened in my body'. Participants stated the EV mainly provided information on diagnosis and treatment; they said practical information 'on life after treatment', concerning daily activities, sexuality and sports, was missing. They suggested adding information or links to reliable websites to the EV.

3.2. The EV and becoming informed

Participants' experiences with the EV are described in four themes and one subtheme (in italics): (1) taking responsibility, (2) providing opportunity for postponed information supply, (3) easing decision-making processes (*better understanding of physical implications of cancer*) and (4) gaining a sense of calm.

3.2.1. Taking responsibility

The use and potential importance of the EV for participants is based on whether participants took responsibility to make their own decisions. Participants said they had to decide and no one else could decide for them. Decision-making was facilitated when they were properly informed (the extent differed among the participants). Different sources of information, including the EV, were available to the participants. Whether and how extensive the EV was used differed between participants. This concept of taking responsibility can be described as a basic underlying value for the participants. This value emerged during the process of becoming informed. Participants explained that at a certain point, a decision 'just had to be made' and obtaining more information was unnecessary.

For me the EV was too simplistic. And [...] the decision is up to yourself. [...] You have to take your own responsibility. [...] I wanted to know my options, you really need to know your options before you can make a decision. (P6)

Like other things in life, you have to handle when problems arise. You need to look for answers yourself and weigh what really matters [...] and you decide in favour or against it. (P9)

3.2.2. Providing opportunity for postponed information supply

Some participants refused to obtain more information at first and said they were in some sort of denial of the cancer diagnosis. They were hesitant to watch the EV since the information confronted them with the 'bad news' they had received. Participants struggled with the diagnosis and needed time. One participant noted that after a while, when he had to decide between a urostomy or neobladder, the need for knowing what happened was growing, so he used the EV. Participants who decided to finally watch the EV experienced it as informative and helpful in the process of becoming informed and felt equipped for decision-making.

But once home, I did not have the courage to watch. The surgery was already scheduled; I just wanted it to be over. I thought when I use the EV I might get scared, I don't know, but I don't want to take the risk. [...] After surgery I wanted to know what happened to my body. So I watched the EV, and it

was very clear and not distressing at all. (P3)

The EV ... I was quite resistant in the beginning due to everything that happened. I guess I was in some sort of denial. And I did not want to know or hear anything about stages ... concerning cancer [...] So actually, I started looking at the EV when I had to make a choice. OK, my bladder has to be removed [...] Will I opt for a neobladder, an urostomy ... so I started looking [for] what these options meant. (P8)

3.2.3. Easing decision-making processes

Decision-making processes were eased through receiving customised information. Being well-informed supported participants in their decision-making. Some participants said the EV was supplementary in the process of information provision and enabled them to choose between bladder deviations and other treatment options (such as bladder lavages). The EV also gave them insight into the different bladder cancer stages and matching treatment options.

The urologist made a new appointment, and then I had to make the choice. So I watched the EV again, read some brochures, and I decided eventually [...] to opt for the BCG bladder lavages. (P7)

If being properly informed helped in making choices? Yes, naturally. Everything helped, the EV as well. But I simply detest using Google [...] all the inconsistent information, vague information ... it didn't help at all.

[(P10)]

3.2.4. Better understanding of physical implications of cancer

The EV contributed to a better understanding of the physical consequences of having cancer, which helped participants to better understand the symptoms they were experiencing. Several participants noted that the medical vocabulary used in consultations with HCPs ('tumour growth through the bladder wall', 'TNM classification' etc.) was difficult to understand. Participants expressed it was often hard to reproduce this information once home. Participants described that the combination of animations and spoken text in the EV was helpful to comprehend the medical context and supported them in understanding 'what was going on in their bodies', which was supportive in decision-making processes.

And then I got EV, and I found information on ... what would happen later on and also on the urostomy. [...] And I liked watching it, to hear it, to see it, because of the animations. It gave me a better impression. (P2) The urologist told about the bladder wall and if the tumour had grown through the wall, and I heard what he said. [...] At home I used the EV and watched some topics two, three times. Whenever I thought what was this or that, or there was a word I didn't understand, I looked it up again [...] and sometimes I made some notes.

[(P11)]

3.2.5. Gaining a sense of calm

During a consultation, HCPs provide much information. The EV gave participants a sense of calm during consultations; not everything had to be remembered straightaway. The EV contained the given information and could be watched at home. Participants mentioned they gained a sense of calm, as they could repeatedly go through the information on the EV afterwards, at home, at their own pace and time.

When you have received the EV, you can take your time at home and look it up once more. [This is helpful] for patients who don't have accompanying loved ones or cannot remember what has been said due to nervousness. It enabled me to go through all the information again at home. To me the voiceover was quite soothing, and it was easy to understand. (P2)

Participants expressed that receiving information during consultations, directly after the cancer diagnosis, was difficult to process due to their emotional state. The participants acknowledged a great deal of uncertainty throughout the consultations in the diagnostic phase while receiving information from HCPs. This hampered information processing. Participants stated the information given during the consult was only partly remembered. Participants mentioned the EV enabled them to watch the animations and listen to the spoken information at their own time and pace at home, when their emotions were somewhat reduced.

I was quite restless and emotional during consultations. [...] A lot is going on, and I am less attentive to what is said; it goes in one ear and out the other. (P7) Once home, my head was spinning. The EV enabled me to take my time and look it all up once again; what was said, what are my treatment options. [...] It provides rest during consultation. Sort of, I don't have to remember everything. (P7)

Some participants described they experienced substantial pain or other physical discomfort during consultations with HCPs, resulting in a decreased ability to process the given information. As described with emotions hampering information processing, the EV provided the means to repeatedly go through the given information at home. P12 stated, 'I must admit I heard some new things on the EV because at some point I was in so much pain during consultation. Not all the information came across'.

4. Discussion and conclusion

4.1. Discussion

This qualitative study demonstrated that participants experienced the EV as a supportive information tool used when before and during treatment. The EV was most appreciated for being user-friendly. The difficulty level of the text was appropriate and the animations were assessed as clarifying and informative. Nevertheless, the results indicate that practical information on life after treatment was lacking and the EV was sometimes received at an unsuitable time. Participants' experiences with the EV can be described in terms of four themes: 'taking own responsibility', 'providing opportunity for postponed information supply', 'easing decision-making processes' and 'gaining a sense of calm'. The study results indicate that participants considered it their responsibility to make decisions and found the EV supportive in easing decision-making processes. These results partly resemble the findings of a randomised clinical trial on AVI and decisional support where patients in the 'AVI group' indicated a higher level of decisional support, but patients had varying levels of preferred involvement in decision-making on treatment [30]. Our study shows that the EV helped participants to understand how bladder cancer and treatment were affecting their bodies. These findings are in line with the results of a randomised clinical trial which showed that using AVI improved patients' knowledge about illness and illness-related treatment compared to verbal communication [20]. Our results demonstrate that experiencing emotions and physical discomfort hampered information processing, but having the EV put participants at their ease, as the EV could be repeatedly watched at home. This corresponds with the results of previous studies displaying a positive effect of AVI on knowledge and information recall [27,57,58]. Nevertheless, no previous studies have shown significant differences in anxiety reduction or satisfaction and preference when using AVI in addition to conservative information methods [28,35,57,59]. This qualitative study has several strengths. Qualitative studies on patients' experiences with AVI are scarce. The findings of this study contribute to a better knowledge of how AVI is valuable for becoming better informed. Exploring participants' experiences through semi-structured interviews provided detailed and 'rich' data on the EV use. Maximum variation in age, gender, educational level, digital experience and elapsed time since receiving the EV was ensured, resulting in a wide range of participants' perspectives. Data saturation was achieved, increasing the transferability of the findings. The researcher was unknown

to the participants prior to the interview. Trustworthiness was strengthened by researcher triangulation and the support of an experienced postdoctoral researcher in the analytical processes. The topic list was adjusted based on both the interviews and their analysis. An interim analysis was conducted after 10 interviews and findings were used to edit the topic list for two additional participants. Nevertheless, certain limitations need to be considered. Due to the COVID-19 outbreak, face-to-face interviews were no longer allowed after 17 March 2020; the last three interviews were therefore conducted by telephone. Telephone interviews are reported to be shorter and include less detailed data compared to face-to-face interviews but can be used productively in qualitative research [60,61]. Elapsed time since receiving the EV was, on average, nine months. Although individual differences in elapsed time widened variations, recall bias could have influenced the results.

4.2. Innovation

Throughout treatment patients with bladder cancer need information, which supports them in the process of SDM. Open and frank communication and trust in the HCPs form an important basis in the consultations with HCPs; the EV is an innovative tool and of added value in the process of becoming informed. The EV has been a step forward in streamlining information processes and highlighting the most important general information for patients with bladder cancer. Video images that explain treatment and its consequences and display physical examinations facilitate a better understanding of spoken or written texts only and help patients know what to expect [28–31]. Our study results show participants can repeatedly read and watch the provided information which puts them at ease and increases knowledge on illness and treatment. The EV is also helpful in preliminary discussions concerning decisions with important others as it provides everyone with similar information. It is important to focus on the right time to present the EV.

4.3. Conclusion

The study findings demonstrate that the EV is a practical and valuable tool in bladder patient care. Information provision improved, and patients perceived the tool as helpful in decision-making. Therefore, future use of the EV in clinical practice is advocated. However, HCPs should be aware of when to present it and accompany the transfer of the EV with clear instructions. Content adjustments concerning practical information are recommended, as well as pictures or videos. Awareness of the personal preferences of patients is important. Tailored use in different patient categories can be considered, but a thorough evaluation after piloting is necessary. Simultaneously, more robust qualitative research on patients' experiences with AVI is needed to better address patients' needs.

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Informed consent and patient details

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

Declaration of Competing Interest

None.

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Appendix

Appendix A.1

Topic List

TOPIC	Elaboration on topic
First question: 'What did you like about the 'explanation' video?	
Experiences in general EV	Moment of delivery EV/timing Explanation of use EV by HCP EV: borrowed or given
Use EV	Full-scale use EV Frequency of use Repetition in use Headset Portal use or website use Use with significant others
Functionality EV	Usability/user-friendliness Lay-out: buttons, animations Language: difficulty, comprehensibility
Perceived benefits EV as an information tool	Experience with orally given information Experience with leaflets Value compared to orally given information/leaflets EV: feelings of reassurance Recommendation for others
Perceived disadvantages EV as an information tool	Complexity EV as information tool Value compared to orally given information/leaflets EV: feelings of commotion
Perceived effect on patients' behaviour towards HCP	Provision of information F.e. during consultation, outpatient clinic, communication with HCP
Perceived role of EV in preparation of consultation with HCP	Preparation for consultation Efficiency en effectiveness of consultation Role EV in Shared Decision Making Consistent with information given during consultation
Suggestions for improvement EV Additional questions regarding previous or not discussed topics	Lack of certain topics, usage, lay-out

Appendix B.1

A 15-point Checklist for Good Thematic Analysis

Process	Criteria
Transcription	1. The data have been transcribed to an appropriate level of detail and the transcripts have been checked against the tapes for 'accuracy'.
Coding	2. Each data item has been given equal attention in the coding process. 3. Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive. 4. All relevant extracts for all each theme have been collated. 5. Themes have been checked against each other and back to the original data set. 6. Themes are internally coherent, consistent, and distinctive.
Analysis	7. Data have been analysed – interpreted, made sense of - rather than just paraphrased or described. 8. Analysis and data match each other – the extracts illustrate the analytic claims. 9. Analysis tells a convincing and well-organized story about the data and topic. 10. A good balance between analytic narrative and illustrative extracts is provided.
Overall	11. Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
Written report	12. The assumptions about, and specific approach to, thematic analysis are clearly explicated. 13. There is a good fit between what you claim you do, and what you show you have done – i.e., described method and reported analysis are consistent. 14. The language and concepts used in the report are consistent with the epistemological position of the analysis. 15. The researcher is positioned as active in the research process; themes do not just 'emerge'.

From: Braun, V., & Clarke, V. Using thematic analysis in psychology. *Qualitative research in psychology*. 2006; 3(2), 77-101.

Appendix C.1

Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist

No. Item	Guide questions/description	Reported
Domain 1: Research team and reflexivity		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	Yes
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Yes
3. Occupation	What was their occupation at the time of the study?	Yes
4. Gender	Was the researcher male or female?	Yes
5. Experience and training	What experience or training did the researcher have?	Yes
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	Yes
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Yes
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Yes
Domain 2: study design		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Yes
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Yes
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Yes
12. Sample size	How many participants were in the study?	Yes
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Yes
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Yes
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Yes
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Yes
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Yes
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	Yes
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Yes
20. Field notes	Were field notes made during and/or after the interview or focus group?	Yes
21. Duration	What was the duration of the interviews or focus group?	Yes
22. Data saturation	Was data saturation discussed?	Yes
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Yes
Domain 3: analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	Yes
25. Description of the coding tree	Did authors provide a description of the coding tree?	No
26. Derivation of themes	Were themes identified in advance or derived from the data?	Yes
27. Software	What software, if applicable, was used to manage the data?	Yes
28. Participant checking	Did participants provide feedback on the findings?	Yes
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each	Yes

Appendix C.1 (continued)

No. Item	Guide questions/description	Reported
30. Data and findings consistent	quotation identified? e.g. participant number Was there consistency between the data presented and the findings?	Yes
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes

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References

- [1] WHO World Health Organization. Cancer. [Internet]. Available from: <https://www.who.int/news-room/fact-sheets/detail/cancer>; 2020. [Accessed 26th August, 2021].
- [2] Nederlandse NKR, Kankerregistratie. Cijfers over Kanker. [Internet]. Available from: <https://www.cijfersoverkanker.nl/>; 2020.
- [3] Centraal Bureau voor de Statistiek. StatLine 2021. [Internet]. Available from: <https://statline.cbs.nl>. [Accessed 26th August, 2021].
- [4] Gaston CM, Mitchell G. Information giving and decision-making in patients with advanced cancer: a systematic review. *Soc Sci Med*. 2005;61:2252-2264. <https://doi.org/10.1016/j.socscimed.2005.04.015>.
- [5] Elwyn G, Laitner S, Coulter A, Walker E, Watson P, Thomson R. Implementing shared decision making in the NHS. *BMJ*. 2010;341:971-3. <https://doi.org/10.1136/bmj.c5146>.
- [6] Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med*. 2012;27:1361-1367. <https://doi.org/10.1007/s11606-012-2077-6>.
- [7] Elwyn G, Tilburt J, Montori V. The ethical imperative for shared decision-making. *Eur J Pers Cent Healthc*. 2013;1:129. <https://doi.org/10.5750/ejpc.v1i1.645>.
- [8] Elwyn G, Frosch DL, Kobrin S. Implementing shared decision-making: consider all the consequences. *Implement Sci*. 2016;11:114. <https://doi.org/10.1186/s13012-016-0480-9>.
- [9] Legare F, Thompson-Leduc P. Twelve myths about shared decision making. *Patient Educ Couns*. 2014;3:281-6.
- [10] Towle A, Godolphin W. Framework for teaching and learning informed shared decision making. *BMJ*. 1999;7212:766-71.
- [11] Hoving C, Visser A, Mullen PD, van den Borne B. A history of patient education by health professionals in Europe and North America: From authority to shared decision making education. *Patient Educ Couns*. 2010;78:275-81. <https://doi.org/10.1016/j.pec.2010.01.015>.
- [12] Scholl I, Loon MK, Sepucha K, Elwyn G, Légaré F, Härter M, et al. Measurement of shared decision making – a review of instruments. *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen*. 2011;105:313-324. <https://doi.org/10.1016/j.zefq.2011.04.012>.
- [13] Visser LNC, Tollenaar MS, Van Doornen LJP, De Haes HCJM, Smets EMA. Does silence speak louder than words? The impact of oncologists' emotion-oriented communication on analogue patients' information recall and emotional stress. *Patient Educ Couns*. 2018;43-52.
- [14] Rijksoverheid. Informatievoorziening als ondersteuning voor een passend zorgaanbod 2017. [Internet]. Available from: <https://www.regelhulp.nl/documenten/publicaties/opaz/rapporten/1/rapport-informatievoorziening-als-ondersteuning-voor-een-passend-zorgaanbod>. [Accessed 13th January, 2022].
- [15] Chamie K, Saigal CS, Lai J, Hanley JM, Setodji CM, Konety BR, et al. Quality of care in patients with bladder cancer: a case report? *Cancer*. 2012;118:1412-1421. <https://doi.org/10.1002/cncr.26402>.
- [16] Chawla N, Arora N. Why do some patients prefer to leave decisions up to the doctor: lack of self-efficacy or a matter of trust? *J Cancer Surviv*. 2013;7:592-601. <https://doi.org/10.1007/s11764013-0298-2>.
- [17] Galsky MD, Diefenbach M, Mohamed N, Baker C, Pokhriya S, Rogers J, et al. Web-based tool to facilitate shared decision making with regard to neoadjuvant chemotherapy use in muscle-invasive bladder cancer. *JCO Clin Cancer Informat*. 2017;1:1-12. <https://doi.org/10.1200/CCL17.00116>.
- [18] Leo MC, Gilbert SM, Wendel CS, Krouse RS, Grant M, Danforth KN, et al. Development of a goal elicitation measure to support choice about urinary diversion by patients with bladder cancer. *J Urol*. 2019;202:83-9. <https://doi.org/10.1097/JU.0000000000000203>.
- [19] McAlpine K, Lavallée LT, Stacey D, Moodley P, Cagiannos I, Morash C, et al. Development and acceptability testing of a patient decision aid for urinary diversion with radical cystectomy. *J Urol*. 2019;202:1001-1007. <https://doi.org/10.1097/JU.0000000000000341>.
- [20] Winter M, Kam J, Nalavenkata S, Hardy E, Handmer M, Ainsworth H, et al. The use of portable video media vs standard verbal communication in the urological consent process: a multicentre, randomised controlled, crossover trial. *BJU Int*. 2016;118:823-828. <https://doi.org/10.1111/bju.13595>.
- [21] Rutten LJF, Arora NK, Bakos AD, Aziz N, Rowland J. Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). *Patient Educ Couns*. 2005;57:250-61. <https://doi.org/10.1016/j.pec.2004.06.006>.
- [22] Tariman JD, Doorenbos A, Schepp KG, Singhal S, Berry DL. Information needs priorities in patients diagnosed with cancer: a systematic review. *J Adv Practitioner in Oncology*. 2014;2014:115-22.

- [23] Kessels RP. Patients' memory for medical information. *JRSocMed*. 2003;96:219222. <https://doi.org/10.1258/jrsm.96.5.219>.
- [24] Bol N, Smets EMA, Burgers JA, Samii SM, De Haes HCJM, Van Weert JCM. Older patients' recall of online cancer information: do ability and motivation matter more than chronological age? *JHealth Commun*. 2018;23:919. <https://doi.org/10.1080/10810730.2017.1394400>.
- [25] Boot C, Meijman FJ. The public and the Internet: multifaceted drives for seeking health information. *Health Informat J*. 2010;16:145–56. <https://doi.org/10.1177/1460458210364786>.
- [26] Brabers A, Rooijen M, Reitsma-Van, De Jong J. Gebruik van internet voor gezondheidsinformatie, Huisarts en wetenschap, 55; 2012; 359. <https://doi.org/10.1007/s12445-012-0172-x>.
- [27] Klerings I, Weinhandl AS, Thaler KJ. Information overload in healthcare: too much of a good thing? *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen*. 2015;109:285–90. <https://doi.org/10.1016/j.zefq.2015.06.005>.
- [28] Farrell EH, Whistance RN, Phillips K, Morgan B, Savage K, Lewis V, et al. Systematic review and meta-analysis of audio-visual information aids for informed consent for invasive healthcare procedures in clinical practice. *Patient Educ Couns*. 2014;94:2032. <https://doi.org/10.1016/j.pec.2013.08.019>.
- [29] Meppelink CS, Van Weert CM, Haven CJ, Smit EG. The effectiveness of health animations in audiences with different health literacy levels: an experimental study. *J Med Internet Res*. 2015;17:e11. <https://doi.org/10.2196/jmir.3979>.
- [30] Diefenbach MA, Benedict C, Miller SM, Stanton AL, Ropka ME, Wen K, et al. Examining the impact of a multimedia intervention on treatment decision-making among newly diagnosed prostate cancer patients: results from a nationwide RCT. *Transl Behav Med*. 2018;8:876–86. <https://doi.org/10.1093/tbm/iby066>.
- [31] Synnot A, Ryan R, Pricot M, Fetherstonhaugh D, Parker B. Audio-visual presentation of information for informed consent for participation in clinical trials. *The Cochrane Database Systemat Rev*. 2014;CD003717. <https://doi.org/10.1002/14651858.CD003717.pub3>.
- [32] Lehmann V, Labrie NHM, van Weert JCM, van Dulmen S, De Haes HCJM, Kersten MJ, et al. Tailoring the amount of treatment information to cancer patients' and survivors' preferences: Effects on patient-reported outcomes. *Patient Educ Couns*. 2019;103(3): 514–20. <https://doi.org/10.1016/j.pec.2019.09.024>. S0738-3991(19)30432-X [pii].
- [33] van Vliet LM, van der Wall E, Plum NM, Bensing JM. Explicit prognostic information and reassurance about nonabandonment when entering palliative breast cancer care: findings from a scripted video-vignette study. *JClinOncol*. 2013;31:32423249. <https://doi.org/10.1200/JCO.2012.45.5865> [doi].
- [34] Wouters T, Soomers J, Smink M, Smit RA, Plaisier M, Houterman S, et al. The effect of an animation video on consultation time, anxiety and satisfaction in women with abnormal cervical cytology: Animation video reduces colposcopy time. *PrevMedRep*. 2019; 13:238243. <https://doi.org/10.1016/j.pmedr.2019.01.005>.
- [35] Ketelaars PJW, Buskes MHM, Bosgraaf RP, van Hamont D, Prins JB, Massuger LFAG, et al. The effect of video information on anxiety levels in women attending colposcopy: a randomized controlled trial. *Acta Oncol*. 2017;56:17281733. <https://doi.org/10.1080/0284186X.2017.1355108>.
- [36] Visser A, Prins JB, Jansen L, Radema SA, Schlooz MS, van Dalen T, et al. Group medical consultations (GMCs) and tablet-based online support group sessions in the followup of breast cancer: A multicenter randomized controlled trial. *Breast*. 2018;40 181188. S0960-9776(18)30104-8 [pii].
- [37] Saldaña J. *Fundamentals of Qualitative Research. Understanding qualitative research*. New York: Oxford University Press Inc.; 2011.
- [38] Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ*. 2008; 337:979–83. <https://doi.org/10.1136/bmj.a1655>.
- [39] Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: The new Medical Research Council guidance. *Int J Nurs Stud*. 2013;50:587–92. <https://doi.org/10.1016/j.ijnurstu.2012.09.010>.
- [40] Portney Leslie Gross, Watkins Mary P. *Foundations of Clinical Research. Application to Practice*. 3rd ed. Harlow: Pearson Education Limited; 2014.
- [41] Russell CK, Gregory DM. Evaluation of qualitative research studies. *Evid Based Nurs*. 2003;6:36. <https://doi.org/10.1136/ebn.6.2.36>.
- [42] Smaling A. Generaliseerbaarheid in kwalitatief onderzoek. *Tijdschrift voor kwalitatief onderzoek*. 2009;14:5–12.
- [43] Boeije H. *Analysis in Qualitative Research*. London: SAGE Publications Ltd.; 2010.
- [44] Dunphy EL, Hamilton FL. Acceptability of a Digital Health Intervention Alongside Physiotherapy To Support Patients Following Anterior Cruciate Ligament Reconstruction; 2017.
- [45] Pols AD, Schipper K, Overkamp D, van Dijk SE, Bosmans JE, van Marwijk Harm WJ, et al. Process evaluation of a stepped-care program to prevent depression in primary care: patients' and practice nurses' experiences. *BMC Fam Pract*. 2017;18:26. <https://doi.org/10.1186/s12875-017-0583-7>.
- [46] De Wit J, Vervoort Sigrid CJM, Van Eerden E, Van Den Berg Leonard H, VisserMeily JMA, Beelen A, et al. User perspectives on a psychosocial blended support program for partners of patients with amyotrophic lateral sclerosis and progressive muscular atrophy: a qualitative study. *BMC Psychol*. 2019;7:35. <https://doi.org/10.1186/s40359-019-0308-x>.
- [47] Westland H, Koop Y, Schröder CD, Schuurmans MJ, Slabbers P, Trappenburg JCA, et al. Nurses' perceptions towards the delivery and feasibility of a behaviour change intervention to enhance physical activity in patients at risk for cardiovascular disease in primary care: a qualitative study. *BMC Fam Pract*. 2018;19:194. <https://doi.org/10.1186/s12875-0180888-1>.
- [48] Zwakman M, Weldam SWM, Vervoort Sigrid CJM, Lammers JJ, Schuurmans MJ. Patients' perspectives on the COPD-GRIP intervention, a new nursing care intervention for COPD. *BMC Fam Pract*. 2019;20:78. <https://doi.org/10.1186/s12875-019-0957-0>.
- [49] Creswell JW, Poth CN. *Qualitative Inquiry and Research*. 4th ed. Los Angeles: Sage Publications; 2018.
- [50] Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3: 77–101.
- [51] Richards L. *Handling Qualitative Data: A Practical Guide*. London: Sage Publications; 2005.
- [52] Lincoln YS, Guba EG. But is it rigorous? Trustworthiness and Authenticity in Naturalistic Evaluation, *New Directions for Program Evaluation*, 1986; 73–84.
- [53] Lincoln YS. *Naturalistic Inquiry*, *The Blackwell Encyclopedia of Sociology*; 2007.
- [54] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19:349–57. <https://doi.org/10.1093/intqhc/mzm042>.
- [55] The World Medical Association, (WMA). *Declaration of Helsinki*, 2019; 2008.
- [56] Centrale Commissie Mensgebonden Onderzoek. *Wet Medisch-wetenschappelijk Onderzoek met Mensen (WMO)*, 2018; 2018.
- [57] Huber J, Ihrig A, Yass M, Bruckner T, Peters T, Huber CG, et al. Multimedia support for improving preoperative patient education: a randomized controlled trial using the example of radical prostatectomy. *AnnSurgOncol*. 2013;20:15–23. <https://doi.org/10.1245/s10434-012-2536-7>.
- [58] Kinnersley P, Phillips K, Savage K, Kelly MJ, Farrell E, Morgan B, et al. Interventions to promote informed consent for patients undergoing surgical and other invasive healthcare procedures. *Cochrane Database Syst Rev*. 2013. <https://doi.org/10.1002/14651858.CD009445.pub2>.
- [59] Waller A, Forshaw K, Bryant J, Carey M, Boyes A, Sanson-Fisher R. Preparatory education for cancer patients undergoing surgery: A systematic review of volume and quality of research output over time. *Patient Educ Couns*. 2015;98:15401549. <https://doi.org/10.1016/j.pec.2015.05.008>.
- [60] Irvine A. Duration, dominance and depth in telephone and face-to-face interviews: a comparative exploration. *Int J Qual Methods*. 2011;10:202220. <https://doi.org/10.1177/160940691101000302>.
- [61] Sturges JE, Hanrahan KJ. Comparing telephone and face-to-face qualitative interviewing: a research note. *Qual Res*. 2004;4:107118. <https://doi.org/10.1177/1468794104041110>.