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



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| ARTICLE INFO   | A B S T R A C T   |
|--|---|
| <i>Keywords</i> :<br>Bladder cancer<br>Patients' experiences<br>Audiovisual intervention<br>Interviews<br>Qualitative research | Objective:       This qualitative study explored the experiences of patients with bladder cancer with a tailored 'explanimation' 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

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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 'explanimation' 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 'explanimation' 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  $\geq 18$  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 "explanimation" video?' The mean duration of the interviews was 39 minutes (range: 28-60 minutes). Due to restrictions concerning the COVID-19 outbreak, faceto-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 'explanimation' 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<br>transcribed the interviews. Immersion of the data started while<br>transcribing the interviews. All transcripts were read<br>thoroughly MJ and MWZ to become familiar with the data and<br>gain an overall impression.  |
| 2. Generating initial codes  | MJ and MWZ conducted initial coding, keeping the<br>importance of giving each data item equal attention in mind.<br>After initial coding by both researchers, codes were compared<br>and discussed in joint (digital) meetings after each two to<br>three interviews until consensus was reached to avoid shifting<br>definitions. Observational, theoretical and methodological<br>memos were systematically processed. SV (an experienced<br>postdoctoral researcher, specifically in qualitative research)<br>guided the coding process and partly participated in coding<br>processes. Results of the codes were discussed in (digital)<br>meetings with two or all three researchers (MJ, MWZ and SV),<br>working towards consensus about the coding and<br>interpretation of the data. |
| 3. Searching for themes  | Codes were collated in potential themes. The relevance of the<br>themes emerged throughout the interview process.<br>A description of potential themes and subthemes was made<br>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).   |
| <ol> <li>Defining and<br/>naming themes</li> <li>Producing the<br/>report</li> </ol> | Using the transcripts, the specific content of each theme was<br>finished, and themes were named and defined (MWZ and SV).<br>MWZ wrote a concept of the scientific report and selected<br>quotes supporting the (sub)themes. The report was reviewed<br>by the two postdoctoral researchers (SV and SW). All feedback<br>was processed and discussed, and the final scientific report<br>was finished (MWZ).<br>Finally, MZW wrote the article, which was reviewed by the<br>entire research team: fellow researcher (MJ), postdoctoral<br>researcher (SV), urologist (RM) and clinical nurse specialist<br>(MvE), who contributed to the study preparations (enrolment<br>strategies, patient information letter, topic list) and study<br>design.   |

MJ: Marielle 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<br>(in years) | Disease        | Treatment             | Time since receiving the EV <sup>a</sup> (in months) | Educational level <sup>b</sup> | Digital experience <sup>c</sup> |
|------------------|--------|-------------------|----------------|-----------------------|--|--------------------------------|---------------------------------|
| 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                        |

<sup>a</sup> EV = 'explanimation' video on bladder cancer

<sup>b</sup> International Standard Classification of Education Sept 2011 re-edition I© UNECO-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

<sup>c</sup> 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 decisionmaking. 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. |  |
|-------------|--|
| Topic List  |  |

| TOPIC                                      | Elaboration on topic                         |
|--|--|
| First question: 'What did you like about t | he 'explanimation' 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                | Experience with orally given information     |
| information tool                           | Experience with leaflets                     |
|  | Value compared to orally given               |
|  | information/leaflets                         |
|  | EV: feelings of reassurance                  |
|  | Recommendation for others                    |
| Perceived disadvantages EV as an           | Complexity EV as information tool            |
| information tool                           | Value compared to orally given               |
|  | information/leaflets                         |
|  | EV: feelings of commotion                    |
| Perceived effect on patients' behaviour    | Provision of information                     |
| towards HCP                                | F.e. during consultation, outpatient clinic, |
|  | communication with HCP                       |
| Perceived role of EV in preparation of     | Preparation for consultation                 |
| consultation with HCP                      | Efficiency en effectiveness of consultation  |
|  | Role EV in Shared Decision Making            |
|  | Consistent with information given during     |
|  | consultation                                 |
| Suggestions for improvement EV             | Lack of certain topics, usage, lay-out       |
| Additional questions regarding previous    |  |
| or not discussed topics                    |  |

#### 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<br>the transcripts have been checked against the tapes for 'accuracy'.   |
| Coding            | <ol> <li>2. Each data item has been given equal attention in the coding process.</li> <li>3. Themes have not been generated from a few vivid examples<br/>(an anecdotal approach), but instead the coding process has been<br/>thorough, inclusive and comprehensive.</li> </ol> |
|                   | <ol> <li>All relevant extracts for all each theme have been collated.</li> <li>Themes have been checked against each other and back to the original data set.</li> </ol>   |
|                   | 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<br>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;<br>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

| 131   |   |          |
|---|---|----------|
| No. Item  | Guide questions/description   | Reported |
| Domain 1: Research                              |   |          |
| team and reflexivity                            |   |          |
| Personal Characteristics 1. Interviewer/        | Which author/s conducted the interview or focus                                   | Yes      |
| facilitator                                     | group?  | 165      |
| 2. Credentials                                  | What were the researcher's credentials? E.g.                                      | Yes      |
|   | PhD, MD   |          |
| 3. Occupation                                   | What was their occupation at the time of the                                      | Yes      |
|   | study?  |          |
| 4. Gender                                       | Was the researcher male or female?  | Yes      |
| <ol> <li>Experience and<br/>training</li> </ol> | What experience or training did the researcher have?                              | Yes      |
| Relationship with                               | nave:   |          |
| participants                                    |   |          |
| 6. Relationship                                 | Was a relationship established prior to study                                     | Yes      |
| established                                     | commencement?   |          |
| 7. Participant                                  | What did the participants know about the  | Yes      |
| knowledge of the                                | researcher? e.g. personal goals, reasons for doing                                |          |
| interviewer<br>8. Interviewer                   | the research<br>What characteristics were reported about the                      | Yes      |
| characteristics                                 | inter viewer/facilitator? e.g. Bias, assumptions,                                 | 163      |
| characteristics                                 | reasons and interests in the research topic                                       |          |
| Domain 2: study                                 | ¥ *   |          |
| design  |   |          |
| Theoretical framework                           |   |          |
| 9. Methodological                               | What methodological orientation was stated to                                     | Yes      |
| orientation and                                 | underpin the study? e.g. grounded theory,<br>discourse analysis, ethnography,     |          |
| Theory  | phenomenology, content analysis   |          |
| Participant selection                           | phenomenology, content unarysis   |          |
| 10. Sampling                                    | How were participants selected? e.g. purposive,                                   | Yes      |
|   | convenience, consecutive, snowball  |          |
| 11. Method of                                   | How were participants approached? e.g.  | Yes      |
| approach  | face-to-face, telephone, mail, email  |          |
| 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      |
| Setting   | dropped out. Reasons.   |          |
| 14. Setting of data                             | Where was the data collected? e.g. home, clinic,                                  | Yes      |
| collection                                      | workplace   |          |
| 15. Presence of                                 | Was anyone else present besides the participants                                  | Yes      |
| non-participants                                | and researchers?  | ¥        |
| 16. Description of<br>sample                    | What are the important characteristics of the sample? e.g. demographic data, date | Yes      |
| Data collection                                 | sample: e.g. demographic data, date   |          |
| 17. Interview guide                             | Were questions, prompts, guides provided by the                                   | Yes      |
| -   | authors? Was it pilot tested?   |          |
| 18. Repeat interviews                           | Were repeat interviews carried out? If yes, how                                   | Yes      |
|   | many?   |          |
| 19. Audio/visual                                | Did the research use audio or visual recording to                                 | Yes      |
| recording<br>20. Field notes                    | collect the data?<br>Were field notes made during and/or after the                | Yes      |
| 20. 11010 110103                                | interview or focus group?   | 103      |
| 21. Duration                                    | What was the duration of the interviews or focus                                  | Yes      |
|   | group?  |          |
| 22. Data saturation                             | Was data saturation discussed?  | Yes      |
| 23. Transcripts                                 | Were transcripts returned to participants for                                     | Yes      |
| returned  | comment and/or correction?  |          |
| Domain 3: analysis<br>and findings              |   |          |
| Data analysis                                   |   |          |
| 24. Number of data                              | How many data coders coded the data?  | Yes      |
| coders  |   |          |
| 25. Description of the                          | Did authors provide a description of the coding                                   | No       |
| coding tree                                     | tree?   |          |
| 26. Derivation of                               | Were themes identified in advance or derived                                      | Yes      |
| themes  | from the data?  | Vee      |
| 27. Software                                    | What software, if applicable, was used to manage the data?                        | Yes      |
| 28. Participant                                 | the data?<br>Did participants provide feedback on the                             | Yes      |
| 20. i ai ucipalit                               | findings?   | 100      |
| checking  |   |          |
| checking<br>Reporting                           |   |          |
| -   | Were participant quotations presented to illustrate the themes/findings? Was each | Yes      |

#### Appendix C.1 (continued)

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

From: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care 2007 Dec;19(6):349-357.

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