# VIDEVAL: A QUALITATIVE EVALUATION OF AN 'EXPLANIMATION' VIDEO IN PATIENTS WITH BLADDER CANCER

# Masterthesis

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## Abstract

*Title* A qualitative evaluation of an 'explanimation' video in patients with bladder cancer. *Background* In order to improve information provision and benefit shared decision making processes a tailored 'explanimation' video for patients with bladder cancer was developed. It consisted of short animation films concerning bladder cancer and treatment. After piloting this audio-visual intervention an evaluation in product and process was needed to gain insight in user experiences and in 'mechanisms of impact'.

*Objective* To explore the experiences of bladder cancer patients with this tailored 'explanimation' video as supportive information tool used before and during treatment and strengthen possible adjustments in both process and product.

*Methods* A generic qualitative descriptive study was conducted. Using a purposive sampling strategy, data were collected through semi-structured interviews with twelve bladder cancer patients and thematically analysed. NVivo 11.0 software supported analysis.

*Results* Most participants considered the 'explanimation' video user-friendly, with fitting difficulty and clarifying animations. All participants advised future use of the 'explanimation' video, although some mentioned practical information on life after treatment was lacking. Others indicated the time of delivery; for them the 'explanimation' video provided too much information too soon. Process based four major themes were derived from the data: 'taking own responsibility', 'opportunity for postponed information supply', 'easing decision-making processes', and 'gaining a sense of calm'.

*Conclusion and recommendations* Findings reflected most participants appreciated the 'explanimation' video; it supported them in the process of being informed and decision-making. Future use of the 'explanimation video' in the treatment of bladder cancer patients is recommended. However, focussing on tailored content is important to meet individual preferences. Developing a similar audio-visual intervention with adjusted content in different patient categories can be of value; piloting and evaluating in product and process are recommended to consider.

*Keywords* Bladder cancer, Patients' experiences, Audio-visual intervention, Interviews, Qualitative research.

## Samenvatting

*Titel* Een kwalitatieve evaluatie van een videofolder voor patiënten met blaaskanker. *Achtergrond* Ter verbetering van de informatievoorziening en bevordering van gedeelde besluitvormingsprocessen werd een videofolder voor patiënten met blaaskanker ontwikkeld. Deze bevatte korte animatiefilmpjes betreffende blaaskanker en behandeling. Na de pilotfase van deze audiovisuele interventie was een product – en proces evaluatie nodig om inzicht te verkrijgen in gebruikerservaringen en in wat gebruik van de videofolder heeft opgeleverd voor patiënten.

*Doel* Inzicht verkrijgen in de ervaringen van blaaskankerpatiënten met deze op maat gemaakte videofolder als ondersteunende informatie tool voor en tijdens de behandeling en mogelijke aanpassingen in zowel proces als product te ondersteunen.

*Methode* Het onderzoek is generiek kwalitatief beschrijvend van aard. Participanten werden geworven middels doelgerichte sampling. Data werden verzameld door semigestructureerde interviews met twaalf blaaskankerpatiënten en vervolgens thematisch geanalyseerd. Dataanalyse werd ondersteund door NVivo 11.0 software.

*Resultaten* De meeste participanten beschouwden de videofolder als gebruiksvriendelijk, met passende moeilijkheidsgraad en verhelderende animaties. Alle participanten bevolen toekomstig gebruik van de videofolder aan, alhoewel sommigen aangaven dat praktische informatie over het leven na de behandeling miste. Anderen onderstreepten het tijdstip van ontvangst: de videofolder gaf hen te vroeg teveel informatie. De procesevaluatie leverde vier thema's op: 'je verantwoordelijkheid nemen', 'mogelijkheid tot uitgestelde informatie voorziening', 'vergemakkelijken van het besluitvormingsproces', en 'een gevoel van rust krijgen'.

*Conclusie en aanbevelingen* Studieresultaten geven weer dat de meeste participanten de videofolder waardeerden; deze was bevorderend in het proces van informatievoorziening en beslissingen maken. Toekomstig gebruik van deze videofolder werd aanbevolen. Het is van belang te focussen op informatie op maat, teneinde tegemoet te komen aan individuele voorkeuren. Het ontwikkelen van dergelijke audiovisuele hulpmiddelen voor andere patiëntencategorieën kan waardevol zijn; na de pilotfase is het belangrijk een evaluatie uit te voeren zowel qua proces als product.

*Key woorden* Blaaskanker, Patiënt ervaringen, Audiovisuele interventie, Interviews, Kwalitatief onderzoek.

#### Introduction

Cancer is the second leading cause of death globally, resulting in an estimated 9.6 million deaths in 2018<sup>1</sup>. The incidence of urogenital cancer in the Netherlands amounted 22,000 in 2017<sup>2</sup>. Altogether 13,965 people diagnosed with bladder cancer were treated in Dutch hospitals in 2017<sup>3</sup>. During their entire treatment patients with bladder cancer need information in order to cope with their disease and to participate in decision-making processes<sup>4</sup>.

Research on oncology patients' needs stresses the importance of tailored information during the diagnostic phase, treatment and recovery<sup>4-6</sup>. 'Being informed' enables patients and relatives to understand and process both diagnosis and consequences of disease and treatment<sup>4,5 6</sup>. Information is mostly provided by physicians, who have extended knowledge on disease and treatment. However, consultation time is often limited and leaves less time for acknowledging patients' emotions, which negatively influences information recognition by patients<sup>7</sup>. Simultaneously, patients' memory for medical information is reduced; 40 up till 80 percent is not remembered and recalled information is often incorrect<sup>8</sup>. Age and stress contribute negatively to remembering information; especially when the diagnosis cancer has just been communicated<sup>7,9</sup>. Therefore, the exchange of information between health care professionals (HCPs) and patients is considered essential and regulated in law, like the European Patient Guideline and Dutch Medical Treatment Agreement Act<sup>10,11</sup>. Previously, the physician decided which treatment was suited. Nowadays shared decision making (SDM) is embraced (inter)nationally as best practice in decision making in healthcare<sup>12-19</sup>. SDM is defined as a process whereby HCPs and patients cooperate to make healthcare choices. It is fundamental to informed consent and patient-centred care<sup>16,17</sup>. Internationally, research on SDM processes in urogenital cancer care has been executed. The results show the importance of SDM in decision making processes<sup>20-25</sup>. An important part of SDM is providing patients with tailored information on diagnosis, treatment and prognosis<sup>7,26</sup>. Provided with tailored information patients are better equipped to enter a dialogue with HCPs on choices concerning disease and treatment options<sup>15,18</sup>.

Currently, an increasing number of patients uses Internet to obtain information on disease and treatment. Although Internet is an accessible source of information; distinguishing between correct and incorrect data in the overload of information is challenging<sup>27,28,29</sup>. Tailored audio-visual information (AVI) supports in providing information to patients. AVI is used in patient care and though evidence is not conclusive, results show improvements in patient knowledge and – satisfaction<sup>30-33</sup>. In the Netherlands, AVI is increasingly used in oncology patient care for breast- and cervical cancer patients<sup>34-38</sup>. No recent Dutch studies on AVI in urogenital care were found.

In 2018, a Dutch university hospital investigated the information flow towards patients with bladder cancer and their needs, using the EORTC QLQ-INFO 25 questionnaire<sup>39,40</sup>. The information flow was abundant and fragmented. Information was mainly given orally by HCPs during outpatient consultations and in written form, like leaflets and brochures<sup>39</sup>. These results underlined the need to change information flows towards patients in order to benefit SDM processes. Considering the limited recall of medical information patients experience, a tailored 'explanimation' video (EV), a joined term of explanation and animation, was developed. Consisting of an integrated display in book form with a clear overview of short animation films concerning diagnosis and treatment, a digital device or Internet connection was unnecessary for use<sup>39</sup>. The EV was given to patients after the diagnosis and treatment plan were communicated.

After piloting this intervention, an evaluation in both process and product is important to yield information on what patients gained from using the EV and user experiences<sup>41-43</sup>. The outcomes of this qualitative study provide deeper insight into patients' experiences with the EV and strengthen possible adjustments in process and product which can improve patientcare. Furthermore, if study results reflect a positive response concerning information provision, tailored use of an EV in other patient categories can be considered.

#### Aim

The aim was to gain insight in the experiences of bladder cancer patients with a tailored 'explanimation' video as supportive information tool used before and during treatment in a hospital setting.

#### Method

#### Design

Since patients' experiences with the EV were explored and a qualitative evaluation in both process and product was conducted, the study had a generic qualitative descriptive design<sup>41,44</sup>.

#### **Population and domain**

The study population consisted of patients with bladder cancer. Participants were purposively selected from bladder cancer patients who received the EV after diagnosis and had meanwhile finished or were still receiving treatment. Use of the EV was preferably in 2019; recall bias could influence findings<sup>45</sup>. 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 in order to increase diversity in participants, allowing more perspectives to take into account<sup>46,47</sup>. Heterogeneity was sought in differences in age, gender, educational level, digital experience and elapsed time since receiving the EV.

Altogether, 59 patients received the EV in 2019; seven patients were deceased, leaving 52 eligible participants. Twenty-six patients were approached to participate. Thirteen patients refused for reasons as 'too confronting' (two), occupied with treatment (four), complications (two), EV not used due to technical error (three), inability to speak Dutch (one), not interested (one). Three patients were not reached despite several attempts. Ten patients participated. After interim-analysis, two more patients were recruited who received the EV in 2020.

#### Figure 1 'Explanimation' video

#### **Data collection**

Semi-structured interviews, using a topic list, were conducted between February and April 2020 by a female researcher, finishing a Master in Nursing Science and oncology nurse for over twenty years. Prior to the study, no relationship existed between researcher and participants.

The topic list (Appendix 1 and 2) was edited using various sources. Recent qualitative literature on (digital) interventions in healthcare was searched<sup>48-52</sup>. Furthermore, an urologist and a nurse practitioner were approached for input as well as the Dutch Bladder- and Renal Cell Carcinoma Society. A graphic designer of the Oncology Imaging Department was asked about usability topics and an experienced post-doctoral researcher reviewed the topic list. The topic list was adjusted throughout data collection and with findings from the interim analysis.

Nine face-to-face interviews were conducted; four in-hospital and five at participants' homes. Only participant and interviewer were present, except once when a spouse was attending. Prior to the interview demographic data were collected. The topic list contained an opening question and 'probes' and 'prompts' were used during interviewing. 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. Average duration of three telephonic interviews was 26 minutes (range: 21-32 minutes).

All interviews were audio recorded, transcribed verbatim and anonymized. During the interviews observational memos were made. Sampling and data collection continued until data saturation was reached after twelve interviews; no new information was obtained concerning patients' experiences with the EV<sup>53,54</sup>. A member check was not performed.

#### Procedures

A patient information folder, informed consent form and a letter signed by the urologist were sent by post. Within two weeks, the researcher contacted the patients by telephone and asked them for participation. Additional information on research purposes was given and questions could be asked. In case of consent an interview appointment was made at a location of participants' preference.

The researcher attended a qualitative interview workshop and examined literature on qualitative interview techniques prior to data collection<sup>55,56</sup>. The first interview was discussed with an experienced post-doctoral researcher on both interviews skills as well as attitudes.

#### Data analysis

Analysis was guided by the six phases of thematic analysis, inductive approach, by Braun and Clark (Appendix 3)<sup>57</sup>.

The researcher (MWZ) familiarized with the data by transcribing and rereading the interviews. Coding was performed by two researchers (MJ,MWZ) and discussed until consensus was reached. An experienced post-doctoral researcher (SV) provided guidance and coding processes were discussed in three meetings (MJ,MWZ,SV). After ten interviews an interim analysis was performed, codes were discusses, revised and grouped into categories (MWZ,SV). The categories were discussed and collected in potential themes and subthemes with quotes. In two additional meetings elaboration and discussion continued until definitive (sub)themes were agreed upon (MWZ,SV). During analysis methodological and theoretical memos were written and processed. In Table 1 a description of process and role of researchers per phase is given.

#### Table 1 Phases of Thematic analysis by Braun and Clarke

Data-analysis was supported by NVivo 11.0 software (QSR International Pty Ltd., Version 11.0, 2014)<sup>58</sup>.

#### **Trustworthiness**

Credibility of data collection and analysis was enlarged by researcher triangulation, which improved accuracy of coding processes and reduced the risk of potential bias in analysis<sup>54,59,60</sup>. The guidance of an expert in qualitative research enlarged study and data dependability. Observational, theoretical and methodological memos were processed and used for monitoring the development of the study, asserting quality, discussing progress and writing the report<sup>54</sup>. Dependability was also warranted in 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 4)<sup>61</sup>.

#### **Ethical issues**

This study was conducted according to the Declaration of Helsinki (Version 2013) and the Medical Research Involving Human Subjects Act<sup>62,63</sup>. An earlier request at METC UMCU (research protocol 17/769) was approved as not liable to WMO criteria in 2017. Concerning this study, another amendment was filed for ethical approval. Confirmation of non-liability to WMO criteria was granted. In all cases informed consent was given by participants.

#### Results

Of the twelve 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 month(s)). Additional data are presented in Table 2.

#### Table 2 Participants' demographics

All participants had access to different sources of information during treatment: HCPs, brochures, Internet and the EV. They expressed the wish of being equipped for treatment decisions and living with the consequences of bladder cancer. Participants underlined the importance of consultations with HCPs for being informed within 'a trustworthy and warm relationship'. Depending on their personal needs participants valued the other sources of information. Brochures were read, but information was not always memorised. For some participants Internet was an easy accessible source, especially for 'hearing peer experiences'; others 'felt overwhelmed by the abundant information' or 'experienced feelings of fear'. Overall, participants' stories revealed that for the majority the EV was complementary in information provision during their treatment process. All participants could imagine other patients would benefit from the EV and confirmed it should be given to future patients with bladder cancer.

Based on participants' experiences with the EV, results are described in two sections: a product evaluation; user experiences with the EV and a process evaluation; themes and subthemes reflect what participants gained from using the EV.

#### **User experiences**

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

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

#### Themes

Participants' experiences with the EV are described in four themes and three subthemes (in italics): (1) Taking own responsibility, (2) Opportunity for postponed information supply, (3) Easing decision-making processes (*Better understanding of physical implications of cancer*) and (4) Gaining a sense of calm (*Emotions or Physical discomfort hampering information processing*).

Table 3 Main themes and subthemes

#### Taking own responsibility

Participants said they had to decide, no one else could decide for them: it's your own responsibility. Different sources of information were available for participants, one of them the EV. But ultimately, when participants felt properly informed- to which extend differed between individual participants- 'the decision was only mine to make' phrased a participant. This 'concept' of taking one's own responsibility can be described as a basic underlying value for participants. It sort of emerged to the surface during the process of becoming informed. Participants explained at a certain point decisions 'just had to be made'; obtaining more information was unnecessary, it was time they decided.

'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 others 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)

#### **Opportunity for postponed information supply**

Some participants refused to obtain more information at first and said they were in denial of the diagnosis cancer. They were hesitant to watch the EV since the information confronted them with the 'bad news' they had received. After a while- one participant said when he had to decide between a urostomy or neo bladder, another after surgery when the need for knowing what exactly happened was growing- participants decided to watch the EV after all and they experienced it to be helpful and informative.

'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 neo bladder, an urostomy...so I started looking what these options meant..' (P8)

#### Easing decision-making processes

Being well-informed supported participants in 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 (like bladder lavages). The EV also gave them insight in the different bladder cancer stages, matching treatment and eased participants' decision-making processes.

'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)

#### Better understanding of physical implications of cancer

Several participants said the medical vocabulary in consultations with HCPs ('tumour growth through the bladder wall', 'TNM classification') was difficult to understand. Participants expressed it was often hard to reproduce this information once home. Participants described the combination of animations and spoken text on the EV were helpful to comprehend the

medical context and supported them in understanding 'what was going on in their bodies'. Furthermore, this was supportive in the 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 for 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)

#### Gaining a sense of calm

Some participants said knowing they had the EV gave them a sense of calm during consultations; not everything had to be remembered straightaway; the EV contained the given information as well and could be watched at home. Others mentioned they gained a sense of calm simply by the fact 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. 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)

'So I came home and 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)

#### Emotions hampering information processing

Participants expressed receiving information during consultations, directly after the cancer diagnosis, was difficult to listen to due to the emotional flow they were in. Throughout the consultations in the diagnostic phase, while receiving information from HCPs, a lot of uncertainties were acknowledged by participants, which hampered information processing: information was only partly remembered by them. 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. Others said it was helpful loved ones were present during consultations or they recorded the consultations.

'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)

#### Physical discomfort hampering information processing

Some participants described they experienced substantial pain or other physical discomfort during consultations with the HCP, resulting in a decreased ability to process the given information. In the same manner as described with emotions hampering information processing, the EV provided means to repeatedly go through the given information at home.

'I must admit I heard some new things, because at some point I was in so much pain during consultation, not all the information came across..' (P12)

#### Discussion

This qualitative study provides insight in the experiences of bladder cancer patients with a tailored 'explanimation' video as supportive information tool used before and during treatment. Product evaluation reflected the EV was mostly appreciated as user-friendly, the difficulty of the text was fitting and the animations clarifying. Nevertheless, results showed practical information on life after treatment was lacking and the time of delivery was sometimes unfitting; the EV provided too much information too soon. Considering the process evaluation participants' experiences can be described in four themes: 'Taking own responsibility', 'Opportunity for postponed information supply' 'Easing decision-making processes', and 'Gaining a sense of calm'.

The study results showed participants considered it their own responsibility to make decisions and found the EV supportive in easing decision making processes. This partly contradicts findings of an RCT on AVI and decisional support. Patients in the 'AVI group' evaluated a higher level of decisional support, but patients had varying levels of preferred involvement in treatment decision-making<sup>32</sup>. Older age, being male, lower educational attainment, and poorer socioeconomic status correlated with a preference for less active roles in the decision-making process<sup>32</sup>. Our study described the EV helped participants understand how bladder cancer and treatment affected their body. This matches results of a RCT, which showed that using AVI improved patients' knowledge of illness and illnessrelated treatment compared to verbal communication<sup>25</sup>. Our results showed emotions and physical discomfort hampered information processing, having the EV gained participants a sense of calm; the EV could be repeatedly watched once home. This corresponds with results of previous studies displaying a positive effect of AVI on knowledge and information recall<sup>30,64-66</sup>. Nonetheless, no previous studies showed significant differences in anxiety reduction or satisfaction and preference when using AVI in addition to conservative information methods<sup>30, 7,64-66</sup>. Our results reflected the importance of consultations with HCPs and participants considered the EV as an addition to consultations, but not necessarily increasing the quality. Unlike the results of an RCT, which concluded the quality of consultations by health care professionals increased compared to not using AVI<sup>67</sup>.

This qualitative study has several strengths. Exploring participants' experiences through semi-structured interviews provided detailed an 'rich' data on the use of the EV. Maximum variation in different factors was obtained and gained diversity in participants' perspectives. Data saturation was reached, increasing transferability. The researcher was unknown to participants prior to the interview, which might have increased the representativeness of the findings. Trustworthiness was strengthened by researcher triangulation and the support of an experienced postdoctoral researcher in analysis processes. Nevertheless, some limitations need to be considered. Due to the covid-19 outbreak face-to-face interviews were no longer allowed after March 17<sup>th</sup>, three telephonic interviews were conducted. Telephonic interviews are reported to be shorter and could entail less detailed data compared to face-to-face interviews, but can be used productively in qualitative research<sup>68,69</sup>. Elapsed time since receiving the EV was on average nine months. Although individual differences in elapsed time enlarged variation, recall bias could have influenced the results. Memberchecks were not performed, although an interim-analysis was conducted after ten interviews and findings were used to edit the topic list for two additional participants.

Future use of the EV in clinical practice is advocated. However, HCPs should be aware of the timing and accompany the transfer of the EV with clear instructions. Adjustments to content, concerning practical information, are recommended as well as links to trustworthy websites, pictures or videos. Awareness of personal preferences of patients is important. Use in different patient categories can be considered, but a thorough evaluation after piloting is necessary.

The study results gained deeper insight in patients' experiences with the EV bladder cancer. For most participants the EV was a supportive information tool and supported them in the process of being informed and decision-making. However, focussing on tailored content is important in order to meet individual preferences. Simultaneously, more robust qualitative research on patients' experiences with AVI is needed in order to better address patients' needs.

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# **Tables and figures**



#### Figure 1 Content of the 'explanimation' video

Phase	Description of the process and role of authors
1. Familiarizing with the data:	The researcher interviewed the participants and transcribed
	the interviews; by doing so immersion of the data immediately
	started while transcribing the interviews. All transcripts were
	read thoroughly by two researchers (MJ and MWZ) to become
	familiar with the data and gain an overall impression.
2. Generating initial codes:	Both researchers (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
	in order to avoid shifting definitions. Observational, theoretical
	and methodological memos were systematically processed. A
	third researcher (SV), an experienced post-doctoral
	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 joined meetings (MWZ and SV).
4. Reviewing themes:	In order 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
	further finished and themes were named and defined (MWZ
	and SV).
6. Producing the report:	One researcher (MWZ) wrote a concept of the scientific report
	and selected quotes supporting the (sub)themes. The report
	was reviewed by the two researchers (SV and SW). All
	feedback was processed and discussed and the final scientific
	report was finished (MWZ).

#### Table 1 Phases of Thematic Analysis by Braun and Clarke

*MJ:* Marielle de Jongh, MWZ: Marjon Wolters-Zwolle (students Nursing Science) SV: Dr. SCJM Vervoort, SW: Dr. SWM Weldam

		Participant n or mean (range)
		n = 12
Age (in years)		70 (57-78)
	50 - 60	2
	60 – 70	4
	70 – 80	6
Gender	Male	8
	Female	4
Disease	Muscle invasive bladder cancer	11
	Non-muscle invasive bladder cancer	1
Treatment	Cystectomy	10
	Alternative treatment	1
	Bladder lavages (BCG)	1
Time since receiving EV <sup>a</sup> (in months)		9 (1-15)
· · · ·	0 - 6	3
	6 -12	6
	12 -18	3
Educational level <sup>b</sup>	Low	2
	Medium	4
	High	6
Digital experience <sup>c</sup>	Basic	3
	Moderate	2
	Advanced	7

#### Table 2 Participants' demographics

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

<sup>b</sup> International standard classification of education (ISED) sept 2011 re-edition I© UNECO-UIS <u>www.uis.unesco.org</u> 2011

Low: junior general secondary education for adults

Medium: vocational education, professional training diploma, senior general secondary education for adults, vocational education, middle management training diploma High: Bachelor

<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, send an email.

Moderate: additional basic knowledge in use programmes as Word, PowerPoint, Excel.

Advanced: additional specific knowledge in use programmes as Word, PowerPoint, Excel.

#### Table 3 Themes and subthemes

Themes	Subthemes
Taking own responsibility	-
Opportunity for postponed information supply	-
Easing decision-making processes	Better understanding of physical implications of cancer
Gaining a sense of calm	Emotions hampering information processing Physical discomfort hampering information processing

# Appendix 1: Topic List

TOPIC	Elaboration on topic	
First question: 'What did you like about the '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 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	Lack of certain topics, usage, lay-out	
Additional questions regarding previous or not discussed topics		

EV = 'explanimation' video, HCP = Health Care Professional

# **Appendix 2: Topic List in Dutch**

ONDERWERP	Uitweiding qua onderwerp	
Vraag: 'Wat vond u prettig aan het gebruik van de video-folder 'Blaaskanker' ?"		
Algemene ervaringen VF	Tijdstip van uitreiken VF aan patiënt Uitleg over VF door professional VF: lenen of gift	
Gebruik VF	Volledig benutten VF Frequentie in gebruik VF Herhaaldelijk gebruik Headset Bekijken via website of portal Gebruik met naasten	
Functionaliteit VF	Bruikbaarheid/gebruiksvriendelijkheid Lay-out: keuzetoetsen, animaties Taal: moeilijkheidsgraad, begrijpelijkheid	
Bemerkte voordelen van VF als informatiebron	Ervaring met mondeling gegeven informatie Ervaring met folders Waarde i.v.m. mondelinge informatie/folders VF: geruststelling Aanbeveling voor anderen	
Bemerkte nadelen van VF als informatiebron	Complexiteit VF als informatie bron Waarde i.v.m mondelinge informatie/folders VF: geeft onrust	
Bemerkt effect gedrag patiënt t.o.v. professional	Verstrekken van informatie Bijvoorbeeld gedurende consulten, op de polikliniek, communicatie met professional	
Bemerkte rol van VF in voorbereiding op consultative met professional	Voorbereiding voor consult Efficiëntie en effectiviteit van consult Rol VF in Shared Decision Making Consistent met gegeven informatie tijdens consult	
Suggesties voor verbetering VF	Ontbrekende onderwerpen, gebruik, lay-out	
Aanvullende vragen betreffende eerdere of niet besproken onderwerpen		

VF = video-folder 'Blaaskanker'

Professional verwijst naar arts, verpleegkundig specialist of verpleegkundige

# Appendix 3: 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 4: Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist

No. Item	Guide questions/description	Reported
Domain 1: Research team and reflexivity		
Personal Characteristics		
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
Relationship with participants		
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 inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Yes
Domain 2: study design		
Theoretical framework		
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
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive,	Yes

	snowball	
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
Setting		
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
Data collection		
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		
Data analysis		
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
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes
30. Data and findings consistent	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

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.