

Development of a decision aid for primary treatment of patients with advanced-stage ovarian cancer

Citation for published version (APA):

den Ouden, J. E., The, R., Myren, B. J., Boll, D., van Driel, W. J., Lalisang, R., Kruitwagen, R. F. P. M., & van Altena, A. M. (2020). Development of a decision aid for primary treatment of patients with advancedstage ovarian cancer. International Journal of Gynecological Cancer, 30(6), 837-844. https://doi.org/10.1136/ijgc-2019-001095

Document status and date: Published: 01/06/2020

DOI: 10.1136/ijgc-2019-001095

Document Version: Publisher's PDF, also known as Version of record

Document license: Taverne

Please check the document version of this publication:

• A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.

• The final author version and the galley proof are versions of the publication after peer review.

 The final published version features the final layout of the paper including the volume, issue and page numbers.

Link to publication

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these riahts.

Users may download and print one copy of any publication from the public portal for the purpose of private study or research.

- You may not further distribute the material or use it for any profit-making activity or commercial gain
 You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license above, please follow below link for the End User Agreement:

www.umlib.nl/taverne-license

Take down policy

If you believe that this document breaches copyright please contact us at:

repository@maastrichtuniversity.nl

providing details and we will investigate your claim.

INTERNATIONAL JOURNAL OF

Additional material is

2019-001095).

end of article.

Correspondence to

Judith E den Ouden.

Obstetrics and Gynecology,

denouden@radboudumc.nl

Received 22 November 2019

Revised 3 February 2020

Published Online First

9 April 2020

Accepted 18 February 2020

Nijmegen, Netherlands; judith.e.

Radboudumc, 6525 GA

published online only. To view

please visit the journal online

For numbered affiliations see

(http://dx.doi.org/10.1136/ijgc-

Development of a decision aid for primary treatment of patients with advanced-stage ovarian cancer

Judith E den Ouden ^(b), ¹ Regina The, ² Britt J Myren, ¹ Dorry Boll, ³ Willemien J van Driel, ⁴ Roy I Lalisang, ^{5,6} Roy FPM Kruitwagen, ^{6,7} Anne M van Altena¹

HIGHLIGHTS

- There is need for a tool supporting shared decision-making in patients with advanced-stage epithelial ovarian cancer.
- · Patients lack information on treatment options and prognosis.
- A novel tool supports information sharing and dialogue between patients and clinicians.

ABSTRACT

Introduction Despite renewed treatment options for advanced epithelial ovarian cancer, survival remains poor. The Patient Association and the Gynecological Oncology Working Party in the Netherlands have identified a need for a tool to improve shared decision-making. The aim of this study was to develop an evidence-based online decision aid for patients with advanced epithelial ovarian cancer and their medical team.

Methods First, we identified the patients' and clinicians' needs using surveys and in-depth interviews. Second, we conducted multidisciplinary face-to-face meetings with representatives from all stakeholders (clinicians and patient representatives) to determine the content of the decision aid. Third, we developed the decision aid using standardized criteria and national guidelines. Finally, we tested the usability of the tool with patients and clinicians who participated in the needs assessment.

Results Patients and clinicians indicated the need for more sources of reliable information that include all treatment options available in the Netherlands. Although most interviewees were satisfied with the level of information available at the time of their own treatment. the majority (90%) of the patients stated that no choice of treatment was offered. We developed a consultation sheet and an online decision aid based on patient interviews and team discussions. The sheet contains a summary of all treatment options and login codes for the decision aid; it will be offered to patients at their first consultation. The decision aid can be used at home and includes information about epithelial ovarian cancer and all available treatment options and questions about quality of life and treatment preferences, delivering a personalized summary for discussion during the following consultation about the primary treatment choices.

Discussion In cooperation with patients and clinicians, we developed a decision aid for advanced-stage epithelial ovarian cancer patients and their medical team to support shared decision-making, based on a confirmed need for more extensive information sources. The decision aid is currently under assessment in a multicenter implementation trial.

INTRODUCTION

Emphasis on shared decision-making is growing in contemporary medical practice. Decision aids are part of the decision-making process, whereby they encourage patients and clinicians to jointly decide on interventions, based on clinical evidence and the patients' informed preferences.¹ In the Netherlands, patients with ovarian cancer involved with the patient association 'Stichting Olijf' have indicated a need for information resources containing details of different treatment options available for advanced-stage epithelial ovarian cancer. Additionally, clinicians identified a need for improved shared decision-making during a meeting of the Gynecological Oncology Working Party.

Currently, advanced-stage epithelial ovarian cancer (defined by the International Federation of Gynecology and Obstetrics (FIGO) as stage IIb-IV) is treated with aggressive multimodal treatment; however, the prognosis remains poor.² Standard therapy consists of a combination of surgery and chemotherapy. The order in which the treatment components are delivered is often decided at a multidisciplinary team meeting, as recommended by the European Society for Gynecologic Oncology,³ and determined by the stage, extent, and localization of the disease, physical status of the patient, and relevant logistical aspects.⁴ However, the use of neoadjuvant chemotherapy remains controversial as studies have shown that complete primary debulking surgery is associated with the most favorable prognosis.^{4–6} As a result, there is a considerable variation in clinical practice,⁷ which has not led to differences in overall survival between regions. As such, it has been proposed that the patient's preference should be included in the decision regarding the order of treatment.^{7–9}

Previous studies have shown that patient involvement in decision-making for primary treatment of epithelial ovarian cancer is minimal; the main reasons

BMJ

BM.J.

Check for updates

© IGCS and ESG0 2020. No

commercial re-use. See rights

and permissions. Published by

To cite: den Ouden JE, The R,

Myren BJ. et al. Int J Gynecol

Cancer 2020;30:837-844.

Original research

for this are the complexity of the therapy and the challenges associated with grasping the implications of therapy.^{10 11} Furthermore, treatment complexity increases with the addition of modalities, such as intraperitoneal chemotherapy and hyperthermic intraperitoneal chemotherapy. The complexity of choice of treatment, variation in clinical practice, and considerable vulnerability of the patients at high risk for poor outcomes regardless of treatment modalities indicated an urgent need for a tool to support shared decision-making in epithelial ovarian cancer, specifically.^{7 12 13} The aim of this study was to develop an online decision aid to help patients with advanced-stage epithelial ovarian cancer and their medical team make a well-informed decision for primary treatment through shared decision-making.

METHODS

We followed a four-stage development process under the supervision of a multidisciplinary team as described below.

Stage 1: Patients, Multidisciplinary Team, and Expert Panel

Patients with stage IIB-IV epithelial ovarian cancer treated at four Dutch hospitals (Radboud University Medical Center Nijmegen, Maastricht University Medical Center+, Catharina Hospital Eindhoven, and Netherlands Cancer Institute Amsterdam) were invited by their treating physician to participate in either the interview and/or survey between December 2017 and November 2018. We assembled a nationwide multidisciplinary team of gynecologic oncologists, medical oncologists, specialist nurses, representatives of the patient association ('Stichting Olijf' and Dutch Patient Federation (NPF)), an implementation expert, and an expert in development and implementation of decision aids. In order to gain national support, the multidisciplinary team included members of all Dutch regions and they were mandated to participate by their professional association. Six face-to-face meetings over the course of a year were organized to discuss the scope and content of the decision aid. Additionally, an expert panel involving a comparable group of clinicians was formed to determine their opinion on the decision aid; the aim of this was to prevent bias since they were not involved in the development process.

Stage 2: Needs Assessment Among Patients and Clinicians

The needs assessment consisted of a semi-structured in-depth interview, conducted by two researchers (J0, RT) and a survey shown in Online supplementary tables 1 and 2, respectively. The goal was to obtain information on the patients' need for information to enable them to make a well-informed decision about treatment. The purpose of the survey was to collect more quantitative information in addition to the interviews. Patients were eligible to participate in either the interview and/or survey if they had completed primary treatment (ie, debulking surgery and (neo)adjuvant chemotherapy) and had no signs of disease relapse. All patients provided written informed consent, and the relevant institutional review boards approved the study protocol (No. 2017–3788). Clinical data were extracted from patients' medical records.

The interview guide was based on literature and expert opinion provided by professionals from ZorgKeuzeLab.¹⁴ Follow-up questions were based on the participants' reflections and experiences. The survey was developed using a previously-validated tool used

in another malignancy that was adapted for epithelial ovarian cancer.¹⁵ Surveys were either filled online, using Castor Electronic Data Capture, or on paper. A panel of experts and a multidisciplinary team were asked to complete two surveys. The first survey interrogated their views on current information provisions, barriers, and facilitators of decision aids and treatment options to be included in a decision aid for patients with epithelial ovarian cancer. The second involved a two-round Delphi process to identify the order in which treatment options included in the decision aid should be arranged. Agreement within the expert panel was assessed with answers to seven statements graded on a five-point Likert scale.

Stage 3: Development of the Decision Aid

The decision aid was developed in accordance with the International Patient Decision Aid Standards criteria and the Dutch guidelines for decision aid development.^{16–18} The content was based on current guidelines, needs assessments and usability tests among patients and clinicians, and the discussions in the multidisciplinary team.¹³ The end product consisted of a consultation sheet and an online support tool.

Usability Testing

Patients who participated in the interviews and clinicians from the expert panel were asked to test a draft version of the decision aid. Two researchers (J0, RT) performed the tests on Skype or telephone. Skype enabled observation of the patient going through the decision aid and captured non-verbal reactions. All patients were asked to describe the context in which the decision aid was handed out by their clinician during the consultation. They were asked to tuse the decision aid as if they were preparing for the next consultation. During this usability test, patients were also asked to think aloud so that the researchers were able to follow their thought processes.¹⁹ All clinicians were asked to study the sheet and online tool beforehand. Finally, the interviewers asked both patients and clinicians for their feedback on the aid and how to improve it.

DATA ANALYSIS

The results of the surveys were summarized using descriptive statistics. The patient interviews were audio-taped and transcribed verbatim. After reading the transcripts, preliminary themes were defined by two researchers (JO, RT). In addition, thematic content analyses were performed by open coding and constant comparison within- and between-interview transcripts by two researchers (J0, BM). Consensus regarding the main themes was reached through an iterative process, and unresolved issues were discussed and agreed on jointly with a third researcher (RT). ATLAS.ti version 8 for Windows (ATLAS.ti Scientific Software Development GmbH, Germany) was used. In the Delphi process we calculated median scores, summarized comments, and discussed the outcome in the multidisciplinary meeting. Remaining points of discussion were presented again to the expert panel, and were discussed in the next meeting of the multidisciplinary team where consensus was reached. Usability tests were analyzed point-per-point, the feedback was summarized, the researchers proposed changes based on the patients' feedback, and critical issues were discussed in the multidisciplinary meeting. The Consolidated Criteria for Reporting

Original research

Qualitative Research were used; these criteria provide guidelines for best practices in the reporting of qualitative research.²⁰

RESULTS

Needs Assessment Among Patients

Twelve patients participated in the interviews, and an additional 43 patients provided answers to the surveys (Table 1). The main outcomes of the interviews were consistent with those of the surveys. When asked if they were offered different treatment options, the majority of the patients did not feel that actual treatment choices were presented to them. Furthermore, they expressed a need for additional information about the risk of disease recurrence, recovery after treatment, and workforce reintegration. The identified needs are summarized in Table 2.

In the survey, 60% (n=43) of patients indicated being informed by their doctor regarding different treatment options, while only 10% (n=4) stated that they were given options to choose and decide. Three of these last four patients chose intraperitoneal chemotherapy as treatment. The majority (90%) of patients stated that according to their doctor, there was only one viable treatment option available at the time treatment was required. Moreover, 41.9% of patients indicated they had not been informed of the advantages and disadvantages of the options presented to them. The vast majority (87.5%) of the surveyed patients indicated the importance of receiving information about their likely prognosis. Moreover, in the ranking exercise on the importance of the topics discussed, the topic 'life expectancy' was ranked first by the patients, emphasizing the importance of providing prognosis-related information (Table 2); 'no anti-cancer treatment' was ranked last by the patients.

Needs Assessment Among Clinicians

The survey response rate among the participating clinicians in the multidisciplinary and expert teams was 95% (Table 1). The majority (85%) of experts wanted to provide information about all treatment options available in the Netherlands, including the best supportive care (95%), (Table 3) In the two-round Delphi-consensus process, additional statements were tested on the level of agreement: 19/22 experts responded. The majority (60%) agreed to provide information on treatment options before a multidisciplinary meeting. However, they emphasized the importance of patient awareness that restrictions may apply, and that not all patients are eligible for all treatments. In addition, 84% of expert respondents agreed with the statement: "When there is not a preference from the multidisciplinary tumor board on starting with surgery or chemotherapy, the patient can choose the order of treatment". Moreover, 63% agreed with the statement: "When the multidisciplinary team prefers primary debulking surgery, the patient can choose whether to start with surgery or chemotherapy".

Multidisciplinary Steering Team

In the clinicians' opinion, the starting point to shared decisionmaking was to present all treatment options available in the Netherlands. An additional meeting was organized to reach consensus on the order in which treatment options should be presented. The most recent literature on primary debulking surgery versus neoadjuvant chemotherapy was reviewed to ensure that the information given to patients was clear, balanced, and up-to-date. As a result, the

| Table 1 Characteristics of the patients and clinicians | | | | |
|---|------------------------|----------------------------|--------------|---------------------------|
| Patients' characteris | stics | Intervie (%)) (n=12) | (| Survey (n %)) n=43) |
| Age (years) (median (| range)) | 67 (41– | 84) 6 | 68 (41–84) |
| Time between end of and interview/survey (median (range)) | | 12 (0–4 | 8) 1 | 4 (0–75) |
| Hospital where patier treated: | nts were | | | |
| Antoni van Leeuwe Hospital | nhoek | 2 (16.7 | 7) 3 | 8 (7.0) |
| Catharina Hospital | | 2 (16.7 | 7) | 12 (27.9) |
| Maastricht UMC+ | | 3 (25.0 |)) 1 | 0 (23.2) |
| Radboudumc | | 5 (41.7 | 7%) 1 | 8 (41.9) |
| Level of education | | | | |
| Low | | 4 (33.3 | 3) 2 | 28 (65.1) |
| Medium | | 4 (33.3) | | 2 (27.9) |
| High | | 4 (33.3 | 3) | 2 (4.7) |
| Unknown | | - | | 1 (2.3) |
| FIGO stage of diseas | e | | | |
| Stage II | | 1 (8.3) | | 1 (2.3) |
| Stage III | | 10 (83.4 | 4) 2 | 28 (65.2) |
| Stage IV | | 1 (8.3) | 1 | 4 (32.5) |
| Type of treatment | | | | |
| PDS + adjuvant chemotherapy | | 4 (33.3 | 3) 1 | 7 (39.5) |
| NACT + IDS | | 8 (66.7 | 7) 2 | 26 (60.5) |
| Received IP chemoth | erapy | 3 (25.0 |)) | 7 (16.3) |
| Received HIPEC | | 1 (8.3) | | 0 (0.0) |
| | | | Expert | |
| Clinicians' | Multidisci team (n) | plinary | panel (n) | Usability tests (n) |
| characteristics | (n=11) | | (n=11) | (n=10) |
| Clinician type | | | | |
| Nurse specialized in oncology | 3 | | 4 | 3 |
| Medical oncologist | 2 | | 4 | 4 |
| Gynecologic | 6 | | 3 | 3 |

| Clinicians' characteristics | team (n) (n=11) | (n) (n=11) | tests (n) (n=10) |
|----------------------------------|--------------------|---------------|---------------------|
| Clinician type | | | |
| Nurse specialized in oncology | 3 | 4 | 3 |
| Medical oncologist | 2 | 4 | 4 |
| Gynecologic oncologist | 6 | 3 | 3 |
| Hospitals | | | |
| Specialized | 9 | 10 | 9 |
| Semi-specialized | 2 | 1 | 1 |

The values are numbers (n) and percentages (%) unless otherwise specified.

FIGO, International Federation of Gynecology and Obstetrics; HIPEC, hyperthermic intraperitoneal chemotherapy; IDS, interval debulking surgery; IP chemotherapy, intraperitoneal chemotherapy; Maastricht UMC+, Maastricht University Medical Center+; NACT, neoadjuvant chemotherapy; PDS, primary debulking surgery; Radboudumc, Radboud university medical center.

Table 2 Needs assessment among patients. The results of the (A) interviews (n=12), (B) surveys (n=43), and (C) ranking exercise (n=43)

| () | |
|---|---|
| Opinion on current information provision | Processing of the results in the DA |
| Experienced doctor's delay from symptoms to diagnosis | Explanation of reasons of delay in diagnosis including patient examples added in the DA |
| Experience of not having a choice for treatment | Addition of all available treatment options in the Netherlands together with eligibility criteria |
| Feeling insecure about own treatment after hearing about other options afterwards | The possibility to tick the box on the option grid of the treatment options the patient is eligible for |
| Not aware of the severity and prognosis of the disease at time of diagnosis | Addition of general information on prognosis in the DA |
| Missing information on the aftercare process | Recommendation for future research |
| Facilitators and preference | |
| Trust in treating physician | The DA will not replace the doctor, but it is set up as an addition in providing information |
| Receiving information on all available treatment options in the | The DA contains all options offered in the Netherlands |

Netherlands

| (B) Surveys | | | |
|---|--------------|------------|-------------|
| Questions (translated from Dutch) | Yes (n (%)) | No (n (%)) | N/A (n (%)) |
| Are you aware of the different treatment options? | 32 (74.4) | 11 (25.6) | - |
| Are you aware that some patients start with chemotherapy while others start with surgery? | 39 (90.7) | 4 (9.3) | - |
| Were you informed about different treatment options by your treating physician? | 26 (60.5) | 17 (39.5) | - |
| Were you informed about the (dis)advantages associated with the treatment by your treating physician? | 24 (55.8) | 18 (41.9) | 1 (2.3) |
| At the time, was there a choice in treatment options according to your doctor? | 4 (9.3) | 38 (88.4) | 1 (2.3) |
| At the time, did you feel prepared to make a well-considered decision? | 32 (74.4) | 4 (9.3) | 7 (16.3) |
| Were you informed that your opinion was of influence in the decision-making by your treating physician? | 24 (55.8) | 9 (20.9) | 10 (23.3) |
| Did your doctor ask you what is important for you in daily life? | 17 (39.5) | 17 (39.5) | 9 (21.0) |
| Was your opinion on what is important in life taken into consideration when the decision was made? | 16 (37.2) | 16 (37.2) | 11 (25.6) |
| Did you feel you had a choice of treatment? | 21 (48.8) | 12 (27.9) | 10 (23.3) |
| (C) Ranking exercise (top five) among patients for the ques | stion: "What | | |

| knowledge do you think is most important in making a decision for | $\mathbf{Detiente} \left(\mathbf{r} \left(0 \right) \right)$ | Mean score |
|---|--|-----------------|
| treatment?" | Patients (n (%)) | (5-point scale) |
| 1 Life expectancy | 10 (23.3) | 4.58 |
| 2 Likelihood of successful surgery | 9 (20.9) | 4.74 |
| 3 All available treatment options | 6 (14.0) | 4.16 |
| 4 Recurrence of disease | 6 (14.0) | 4.58 |
| 5 Long-term effects of treatment | 6 (14.0) | 4.33 |

DA, decision aid; N/A, not applicable.

decision aid included information on the non-inferiority of interval to primary debulking surgery in terms of overall survival and on the lower morbidity associated with interval debulking. Additional information regarding primary debulking surgery is provided, stating that, among eligible patients, primary debulking surgery resulting

in complete cytoreduction is associated with the longest overall survival.21-25

Furthermore, ways of involving the patient in the treatment decision and improving shared decision-making were discussed. Initially, although not every professional involved in the steering

| Table 3 Needs assessment | among clinicians (n=21) |
|--|---|
| Expected advantages of a DA | Expected disadvantages of a DA |
| Better informed patients | Time consuming during implementation |
| More prepared patients during consultation; more structured consult, may save time | Less confidence in treatment |
| Well-informed decision of patients, leading to more satisfied patients | Unrealistic expectations; because the patient is not eligible for a treatment |
| Objective information about treatment options and consequences | Temporary decrease in QoL because they receive 'fair' information and awareness occurs |
| Visual support during the consultation | Practice medicine according to a fixed protocol |
| More insight into wishes of the patient | |
| Opinion on current information | provision |
| Sufficient (70%) | |
| Satisfied with reliability of information | ation (68.4%) |
| Opinion on information needed | l in DA |
| All available treatment options fo Netherlands (80%) | r which a patient is eligible in the |
| Best supportive care (95%) | |
| IP chemotherapy (85%) | |
| HIPEC (70%) | |
| Chemotherapy alone (61.1%) | |

DA, decision aid; HIPEC, hyperthermic intraperitoneal chemotherapy; IP chemotherapy, intraperitoneal chemotherapy; QoL, quality of life.

team declared their recognition of the importance of shared decision-making, over the course of the discussion a consensus was reached in which all participating clinicians acknowledged the role of shared decision-making in patient care.

The Decision Aid

The final content included in the decision aid was presented as a consultation sheet/option grid and combined with an online tool. The text was edited by a text writer at language level B1 (common Dutch). The option grid was developed to include an overview of available treatment options and a login code to access the online tool, which can be handed out when the (suspected) diagnoses are discussed during consultation (Online supplementary figure 1). Patients can log in from home and read about advanced epithelial ovarian cancer (step 1) and the available treatment options (step 3). In addition, the patient is asked to answer questions regarding personal values and answer statements on quality of life versus life expectancy (step 2 and 4). (Box 1) The results are provided as a printable personalized summary with an overview of the answers given in steps 2 and 4, which can serve as a springboard for discussions with the treating physician during subsequent appointments (Online supplementary figure 2).

Usability Testing

Online supplementary table 3 shows the changes made to the decision aid after usability testing, involving seven patients and

| Box 1 | Content of the decision aid DA (translated from |
|-------|---|
| Dutch | i into English) |

Step 1: About ovarian cancer

General information What is ovarian cancer? What are the symptoms? Which clinicians are involved in your medical team? What are the diagnostic tests usually performed? What are the different stages of disease and where can metastasis be found? Is ovarian cancer hereditary? What is your life expectancy?

Step 2: About you

Which activities in daily life do you enjoy? How is your physical status?

Can you walk for more than 30 min?

Can you get dressed without help? Can you do your own grocery shopping?

What do you notice about the disease? Possibly you have complaints, you lost weight, your diet changed, or your physical status declined?

What do you hope to achieve with the treatment? What do you want to continue doing after treatment?

Step 3: Treatments

| What are the treatment options in the Netherlands? |
|--|
| Which option(s) are you eligible for? |
| What is anti-cancer treatment? |
| What does the surgical procedure involve? |
| Which complications can occur during surgery? |
| How does chemotherapy work? |
| What is intraperitoneal (IP) chemotherapy or hyperthermic intra- |
| peritoneal chemotherapy (HIPEC)? |
| What does the symptomatic treatment involve? |
| Where can you find more support? |
| |

Step 4: Your considerations (contains statements, which patients can answer by moving a slider)

"I want to live as comfortable as possible even though it may be shorter" vs "I want to live as long as possible even though it can be less comfortable"

"I think it is acceptable if nothing is done against cancer growth" vs "I want something to be done against the cancer growth, even though I experience side effects"

"I do not want to visit the hospital a few times a month" vs "I do not mind visiting the hospital a few times a month"

"I do not want a stoma, even though this negatively affect my prognosis" vs "I can live with a stoma if this gives me a better chance of survival"

Do you have any additional information about your considerations, or do you have any further questions?

Step 5: Summary

A summary of the answers given in steps 2 and 4 is provided, which the patient can print out

10 experts, including changes to the text, illustrations, and visibility of textual changes and supportive care options. An example of the decision aid interface is shown in Figure 1.

Original research

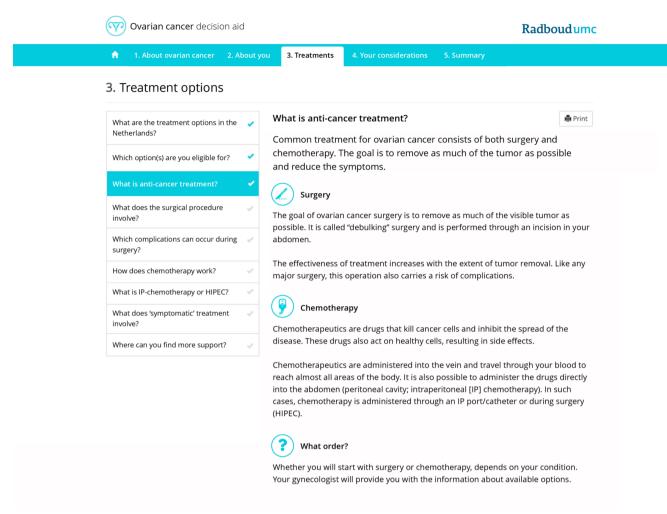


Figure 1 An example of the decision aid interface.

DISCUSSION

In this study, we described the systematic development process of a novel decision aid for the primary treatment of advancedstage epithelial ovarian cancer. The patients, as well as their clinicians, expressed the need for additional information about ovarian cancer treatment, including information about prognosis, and no anti-cancer treatment. The majority of the patients did not feel that actual treatment choices were presented to them. A Dutch patient association and gynecologic oncology society acknowledged the importance of a tool to help patients and clinicians with shared decision-making. The importance of shared decision-making is increasingly recognized, given the vulnerability of epithelial ovarian cancer patients who face intensive therapies and poor prognoses. The decision aid was developed using a four-stage rigorous method.

It is noteworthy that the majority of patients indicated that they did not have a choice in their primary treatment, suggesting that patients consent to treatment without being involved in decisionmaking. While patients choose to start treatment, the choice between surgery, chemotherapy, and no treatment appeared to be made by the supervising physician, which highlights the importance of the development of a suitable decision aid. In contrast to the 90% of patients having only one treatment option according to their doctor, 48.8% still answered that they felt they had a choice at the end of the survey. The most obvious explanation for this is that the first question is primarily aimed at different treatment options given by their physician, while at the end patients realized that they had the choice whether or not to start treatment.

The main strength of this study was the collaboration of all parties involved in patient care. This reduced variation due to differences in care paths associated with different hospitals and provided a more objective overview of patients' needs. In general, patients' involvement in clinical research has led to more relevant results, ensured that patients' perspectives and preferences were considered, and improved patients' recruitment and retention in research.²⁶ However, future research should include a palliative care specialist and a general practitioner to ensure all areas of the entire care path are involved. Another strength of this study is that we followed the international criteria combined with the Dutch guidelines on decision aid development. In contrast, detailed information about the development process of decision aids is generally lacking in other studies.¹⁷

Two main obstacles were identified while writing the decision aid content. The first problem was the global discussion about the evidence regarding the order of treatment (starting with surgery versus chemotherapy). Therefore, the steering team discussed the current evidence and reached the consensus that primary debulking surgery results in best survival when reaching complete surgery compared with starting with chemotherapy. Also, they consented to the non-inferiority of interval debulking surgery and its lower morbidity.⁷ Second, there is an ongoing worldwide discussion on the addition of intraperitoneal chemotherapy and hyperthermic intraperitoneal chemotherapy to primary treatment.^{27–30} Standard adjuvant intraperitoneal chemotherapy is not available across all Dutch hospitals or regions; therefore, deciding whether to include it was a point of contention. Following a discussion, the steering team decided to add both options to the decision aid, so that patient information was transparent and uniform. This was further justified given that intraperitoneal chemotherapy combined with primary debulking surgery and hyperthermic intraperitoneal chemotherapy combined in the current national treatment guidelines.³⁰

During the development process, several barriers to adoption were mentioned. Clinicians expected it to be time consuming. However, Stacev et al reported no difference in the duration of consultation when the decision aid was used versus when it was not.³¹ Another barrier for clinicians was the concern of creating unrealistic expectations by presenting all treatment options to the patient. However, the patient representatives involved in the process stressed the need for knowledge about all treatment options, and thus a comprehensive list was included. Nevertheless, to manage patients' expectations, treatment eligibility criteria were included. Clinicians also hesitated about whether to present treatmentassociated life expectancy data in the decision aid, which differ between patients and are difficult to predict. In this case, too, the participating patients indicated the importance of information on life expectancy, stating that patients who do not wish to have this information can move on to another item. As a result, general life expectancy information was included in the decision aid.

Another noteworthy finding from our study is the relatively low ranking by patients of 'no anti-cancer treatment' (mean score 3.56, on a five-point scale); however, in the opinion of the working party, this option should be included in the decision aid. The low ranking of this option may be explained by the fact that all participating patients received anti-cancer treatment and were in a stable phase of their disease, as required by the medical ethics committee. This could have resulted in biased views, since refusing treatment might have not been an option for them, and they might be more positive about the care path. Moreover, a substantial number of patients with epithelial ovarian cancer in the Netherlands never receive any treatment (12%) or receive single therapy only (19%).³²

Although the online component of the decision aid requires internet access, its advantages include the ability to rapidly update medical information, easily disseminate the tool, and track compliance and usage patterns.³³ In addition, internet coverage in the Netherlands is estimated at 96.5%, which suggests that access to the internet should not hamper the use of the decision aid.³⁴ Syrowatka et al have reported that computer-based decision aids are associated with significant improvements in knowledge and decisional conflict compared with usual care or alternative aids.³⁵ Previous analytical data on other decision aids developed by ZorgKeuzeLab professionals showed that most patients ask their relatives to help them use the online tool, which also helps them to discuss the information provided by their doctors. Another noteworthy result was the need for more information about the aftercare process. However, the focus of our decision aid was primary treatment; therefore, this topic was not included. Improved source

information regarding this stage in the care process might be a welcome addition.

In conclusion, we designed a decision aid to help patients with advanced-stage epithelial ovarian cancer and their medical team to improve shared decision-making regarding primary treatment. The presented decision aid is currently under assessment in a multicenter trial, ahead of its implementation into the care path across Dutch hospitals that treat patients with epithelial ovarian cancer.

Author affiliations

¹Obstetrics and Gynecology, Radboud Institute for Health Sciences, Radboud university medical center, Nijmegen, Netherlands

²Development and Implementation of Decision Aids, ZorgKeuzeLab, Delft, Netherlands

³Obstetrics and Gynecology, Catharina Hospital, Eindhoven, Netherlands

⁴Center for Gynecological Oncology, Netherlands Cancer Institute, Antoni van Leeuwenhoek, Amsterdam, Netherlands

⁵Internal Medicine, Division Medical Oncology, Maastricht University Medical Center, Maastricht, Netherlands

⁶GROW, School for Oncology and Developmental Biology, Maastricht, Netherlands ⁷Obstetrics and Gynecology, Maastricht University Medical Center, Maastricht, Netherlands

Acknowledgements The authors thank the volunteers from patient association 'Stichting Olijf' who contributed to the development of the decision aid. They also want to extend a special thank you to Janna Roozendaal and Arlette van der Kolk who participated during the meetings.

Contributors JO, RT, RK, and AA made substantial contributions to the study conceptualization. JO and RT contributed to data acquisition, with help from DB, WD, RL, RK, and AA. JO, RT, and BM performed the data analysis, and all the other authors contributed to data interpretation. RT, RK, and AA contributed to funding acquisition. JO prepared the manuscript, and all the authors reviewed and edited the manuscript.

Funding This research received a grant from Stichting Kwaliteitsgelden Medisch Specialisten (SKMS) (Quality Foundation of the Dutch Federation of Medical Specialists).

Competing interests Regina The reports grants from Stichting Kwaliteitsgelden Medisch Specialisten (SKMS) (Quality Foundation of the Dutch Federation of Medical Specialists) during the conduct of the study; other salary from ZorgKeuzeLab as CEO, outside the submitted work; and a shared copyright of the Decision Aid (DA) together with the Dutch Association for Obstetrics and Gynecology. No licenses have been issued yet.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Data are available upon reasonable request to the corresponding author.

ORCID iD

Judith E den Ouden http://orcid.org/0000-0003-3725-5253

REFERENCES

- Coulter A, Collins A. Making shared decision-making reality; No decision about me, without me. The King's Fund [Report], 2011. Available: https://www.kingsfund.org.uk/publications/makingshared-decision-making-reality [Accessed 12 Jul 2019].
- 2 Timmermans M, Sonke GS, Van de Vijver KK, et al. No improvement in long-term survival for epithelial ovarian cancer patients: a population-based study between 1989 and 2014 in the Netherlands. *Eur J Cancer* 2018;88:31–7.
- 3 Querleu D, Planchamp F, Chiva L, *et al*. European Society of Gynaecologic Oncology quality indicators for advanced ovarian cancer surgery. *Int J Gynecol Cancer* 2016;26:1354–63.
- 4 Wright AA, Bohlke K, Armstrong DK, et al. Neoadjuvant chemotherapy for newly diagnosed, advanced ovarian cancer: Society of Gynecologic Oncology and American Society of Clinical Oncology clinical practice guideline. J Clin Oncol 2016;34:3460–73.

Int J Gynecol Cancer: first published as 10.1136/ijgc-2019-001095 on 9 April 2020. Downloaded from http://ijgc.bmj.com/ on November 18, 2022 at University of Maastricht Consortia Protected by copyright.

Original research

- 5 Meyer LA, Cronin AM, Sun CC, et al. Use and effectiveness of neoadjuvant chemotherapy for treatment of ovarian cancer. J Clin Oncol 2016;34:3854–63.
- 6 Mueller JJ, Zhou QC, Iasonos A, *et al.* Neoadjuvant chemotherapy and primary debulking surgery utilization for advanced-stage ovarian cancer at a comprehensive cancer center. *Gynecol Oncol* 2016;140:436–42.
- 7 Eddes EH, Tollenaar R, Wouters M. *DICA registraties jaarrapportage* 2017. Dutch: D.I.f.C. Auditing, 2017.
- 8 Timmermans M, Sonke GS, van Driel WJ, et al. Neoadjuvant chemotherapy or primary debulking surgery in FIGO IIIC and IV patients; results from a survey study in the Netherlands. *Eur J Obstet Gynecol Reprod Biol* 2018;223:98–102.
- 9 Timmermans M, van der Hel O, Sonke GS, *et al.* The prognostic value of residual disease after neoadjuvant chemotherapy in advanced ovarian cancer; a systematic review. *Gynecol Oncol* 2019;153:445–51.
- 10 Fitch MI, Deane K, Howell D. Living with ovarian cancer: women's perspectives on treatment and treatment decision-making. *Can Oncol Nurs J* 2003;13:8–13.
- 11 Luketina H, Fotopoulou C, Luketina R-R, et al. Treatment decisionmaking processes in the systemic treatment of ovarian cancer: review of the scientific evidence. Anticancer Res 2012;32:4085–90.
- 12 Browall M, Carlsson M, Horvath GG. Information needs of women with recently diagnosed ovarian cancer--a longitudinal study.. *Eur J* Oncol Nurs 2004;8): :200–7.
- 13 Oncoline. WDGiO. Epithelial ovarian cancer, 2012. Available: http:// oncoline.nl/ovariumcarcinoom [Accessed 31 Jul 2017].
- 14 Adams WC. Conducting semi-structured interviews. In: Newcomer KE, Hatry HP, Wholey JS, eds. Handbook of practical program evaluation. Jossey-Bass, 2015.
- 15 Etnel JRG, van Dijk APJ, Kluin J, et al. Development of an online, evidence-based patient information portal for congenital heart disease: a pilot study. Front Cardiovasc Med 2017;4.
- 16 Elwyn G, O'Connor AM, Bennett C, et al. Assessing the quality of decision support technologies using the International Patient Decision Aid Standards instrument (IPDASi). PLoS One 2009;4:e4705.
- 17 Coulter A, Stilwell D, Kryworuchko J, et al. A systematic development process for patient decision aids. BMC Med Inform Decis Mak 2013;13:S2.
- 18 Patiëntenfederatie Nederland hNHG. de Federatie Medisch Specialisten, Verpleegkundigen &Verzorgenden Nederland, Hoe maak ik een keuzehulp bij een richtlijn? Coform: Den Haag. Dutch, 2018.
- 19 Güss CD. What is going through your mind? Thinking aloud as a method in cross-cultural psychology. *Front Psychol* 2018;9:1292.
- 20 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19): :349–57.

- 21 Bristow RE, Chi DS. Platinum-based neoadjuvant chemotherapy and interval surgical cytoreduction for advanced ovarian cancer: a metaanalysis. *Gynecol Oncol* 2006;103:1070–6.
- 22 Kang S, Nam B-H. Does neoadjuvant chemotherapy increase optimal cytoreduction rate in advanced ovarian cancer? Metaanalysis of 21 studies. *Ann Surg Oncol* 2009;16:2315–20.
- 23 Kehoe S, Hook J, Nankivell M, et al. Primary chemotherapy versus primary surgery for newly diagnosed advanced ovarian cancer (CHORUS): an open-label, randomised, controlled, non-inferiority trial. Lancet 2015;386:249–57.
- 24 Vergote I, Tropé CG, Amant F, et al. Neoadjuvant chemotherapy or primary surgery in stage IIIC or IV ovarian cancer. N Engl J Med 2010;363:943–53.
- 25 Onda T, Satoh T, Saito T, et al. Comparison of treatment invasiveness between upfront debulking surgery versus interval debulking surgery following neoadjuvant chemotherapy for stage III/ IV ovarian, tubal, and peritoneal cancers in a phase III randomised trial: Japan Clinical Oncology Group study JCOG0602. *Eur J Cancer* 2016;64:22–31.
- 26 Sacristán JA, Aguarón A, Avendaño-Solá C, et al. Patient involvement in clinical research: why, when, and how. Patient Prefer Adherence 2016;10:631–40.
- 27 Tewari D, Java JJ, Salani R, et al. Long-term survival advantage and prognostic factors associated with intraperitoneal chemotherapy treatment in advanced ovarian cancer: a Gynecologic Oncology Group study. J Clin Oncol 2015;33:1460–6.
- 28 Della Pepa C, Tonini G, Pisano C, et al. Ovarian cancer standard of care: are there real alternatives? *Chin J Cancer* 2015;34:17–27.
- 29 Armstrong DK, Bundy B, Wenzel L, et al. Intraperitoneal cisplatin and paclitaxel in ovarian cancer. N Engl J Med 2006;354:34–43.
- 30 van Driel WJ, Koole SN, Sikorska K, *et al.* Hyperthermic intraperitoneal chemotherapy in ovarian cancer. *N Engl J Med* 2018;378:230–40.
- 31 Stacey D, Légaré F, Lewis K, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev 2017;4.
- 32 Timmermans M, Schuurman MS, Ho VKY, et al. Centralization of ovarian cancer in the Netherlands: hospital of diagnosis no longer determines patients' probability of undergoing surgery. Gynecol Oncol 2018;148:56–61.
- 33 Culver JO, MacDonald DJ, Thornton AA, et al. Development and evaluation of a decision aid for BRCA carriers with breast cancer. J Genet Couns 2011;20:294–307.
- 34 Statistiek CCBvd. Internet; toegang, gebruik en faciliteiten, 2018. Available: https://statline.cbs.nl/Statweb/publication/?DM=SLNL& PA=83429NED&D1=0,2-5&D2=0,3-6&D3=0&D4=a&HDR=T&STB= G1,G2,G3&VW=T [Accessed 6 Jul 2019].
- 35 Syrowatka A, Krömker D, Meguerditchian AN, et al. Features of computer-based decision aids: systematic review, thematic synthesis, and meta-analyses. J Med Internet Res 2016;18:e20.