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Evaluation of an online tool about the expected course of disease for glioblastoma patients—A qualitative study

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Abstract

Background. Patients with glioblastoma have a short life-expectancy, with median survival rates of 9 to 12 months. Providing information about the expected course of the disease can be complicated. Therefore, an online tool has been developed. The objective of this tool is to better inform patients and proxies, and decrease their uncertainties and improve their quality of life. This study aims to gather experiences of an initial cohort of patient-proxy dyads, to identify if the tool meets the previously mentioned objectives.

Methods. This is a qualitative study based on thematic analysis. Interviews were conducted with 15 patient-proxy dyads. For these interviews, a combined method of think-aloud sessions and semi-structured interviews were used. Audiotapes of these interviews were transcribed verbatim and thematically analyzed.

Results. The analysis revealed four major themes, namely, unmet information needs, improvement possibilities, effects of the tool and clinical implementation. Participants indicated that this tool could decrease uncertainties and increase their perceived quality of life. Also, they often mentioned that it could have a positive effect on the efficiency and quality of consultations.

Conclusion. Participants considered this tool to be useful and effective in decreasing uncertainties for both patients with glioblastoma and their proxies. Moreover, participants brought up that this tool could positively influence the efficiency and quality of consultations. This could lead to more patient participation and empowerment, and could therefore enhance shared decision making and timely advanced care planning.

Keywords

advance care planning | glioblastoma | neuro-oncology | palliative care | qualitative research

Glioblastomas are responsible for the majority of deaths among patients with primary brain tumors. The age-adjusted incidence of glioblastoma multiforme (GBM) in Europe is 4.2/100.000 persons,[1,2] making them the most common type of glioma as well as the most severe.[3] The median survival rates for GBM are 9 to 12 months, with 2-year survival rates of only 8–12%.[4]

The combination of fast progression, intensive treatment and symptoms of glioblastoma complicates adequately informing patients and their proxies about the expected course of the disease. Apart from headaches, seizures and/or focal deficits, patients with GBM may also experience personality and behavioral changes.[5] Progressive cognitive decline can seriously interfere with the ability of patients to make deliberate decisions about further treatment or to express their wishes concerning the end of life (EoL).[6] Therefore, it is important to involve patients and proxies early in the disease trajectory in shared decision-making (SDM) and offer timely counselling about advanced care planning (ACP).

The aim of ACP is to involve patients and their proxies at an early stage in decisions about future best supportive care and EoL care. ACP has many benefits, the most important one is a more frequent match between the patient's preferences for care and the received care.[7,8] Structured ACP could also improve health-related quality of life (HRQoL) as well as symptom control for GBM patients.[9]

The optimal timing for starting a conversation about ACP is a matter of debate;[10,11] however, it has been suggested to encourage ACP early in the course of the disease.[12,13] To have a conversation about ACP, patients and proxies have to be adequately informed. Based on the current evidence, a combination of spoken and written or visual information is remembered best.[14] Research has shown that the majority of online information about GBM is accurate but incomplete. Moreover, the readability of this information was generally inappropriate.[15]

In summary, ideally patients and their proxies should receive a combination of spoken, written and visual information. This information should be accurate, complete and understandable for everyone. To this point, information that meets all these criteria about the expected course of disease for GBM has not been available. Therefore, we developed an online tool (Figure 1A and 1B). The aim of this tool is to decrease uncertainties about the future for GBM patients and their proxies. In this study, we evaluate to what extent the tool meets the needs of patients and their proxies. Therefore, the primary objective of this study is to explore the experiences of a cohort of patient-proxy dyads with the tool. Secondary objectives include exploring possible improvements for the quality and aesthetics of the tool.

Methods

Study Design and Data Collection

Approval for this study was granted by the Ethics Committee of Erasmus University Medical Center Rotterdam (Date 19/11/2021/No. MEC-2021-0461). This study used procedures conform to the Declaration of Helsinki. A qualitative research design was used to explore the perspectives of proxy–patient dyads. Sessions were conducted with patient–proxy dyads to explore and clarify participants' perspectives on the tool. These sessions consisted of a combination of a "think-aloud session", while the participants used the tool for the first time and semi-structured interviews afterwards, following the "Consolidated Criteria for Reporting Qualitative Research" reporting guidelines.[16]

For the think-aloud sessions, patient–proxy dyads were instructed to use the tool and continuously think out loud, meaning they verbalize their thoughts and feelings. They did not receive instructions on how to use the tool. Most of the participants did not access the tool prior to the interview, but as it was already available online, some participants had seen it before.

A semi-structured interview guide, as seen in Supplementary Information 1, was developed to ensure standardization of interviews. We pilot tested this interview guide on an independent former proxy before starting the interviews. The vast majority of the interviews took place in the hospital. Three sessions were conducted online, and one at the workplace of a patient, due to logistic reasons.

All sessions were audio-recorded and transcribed verbatim for analysis. Patient details were removed.

After interview nine (phase 1) data saturation had been reached because participants repeated the same feedback during almost every session. Based on the feedback, several modifications to the tool were made. Afterwards, the tool was evaluated again and data saturation was reached after interview thirteen, leaving two interviews to confirm this finding (phase 2).

Participants

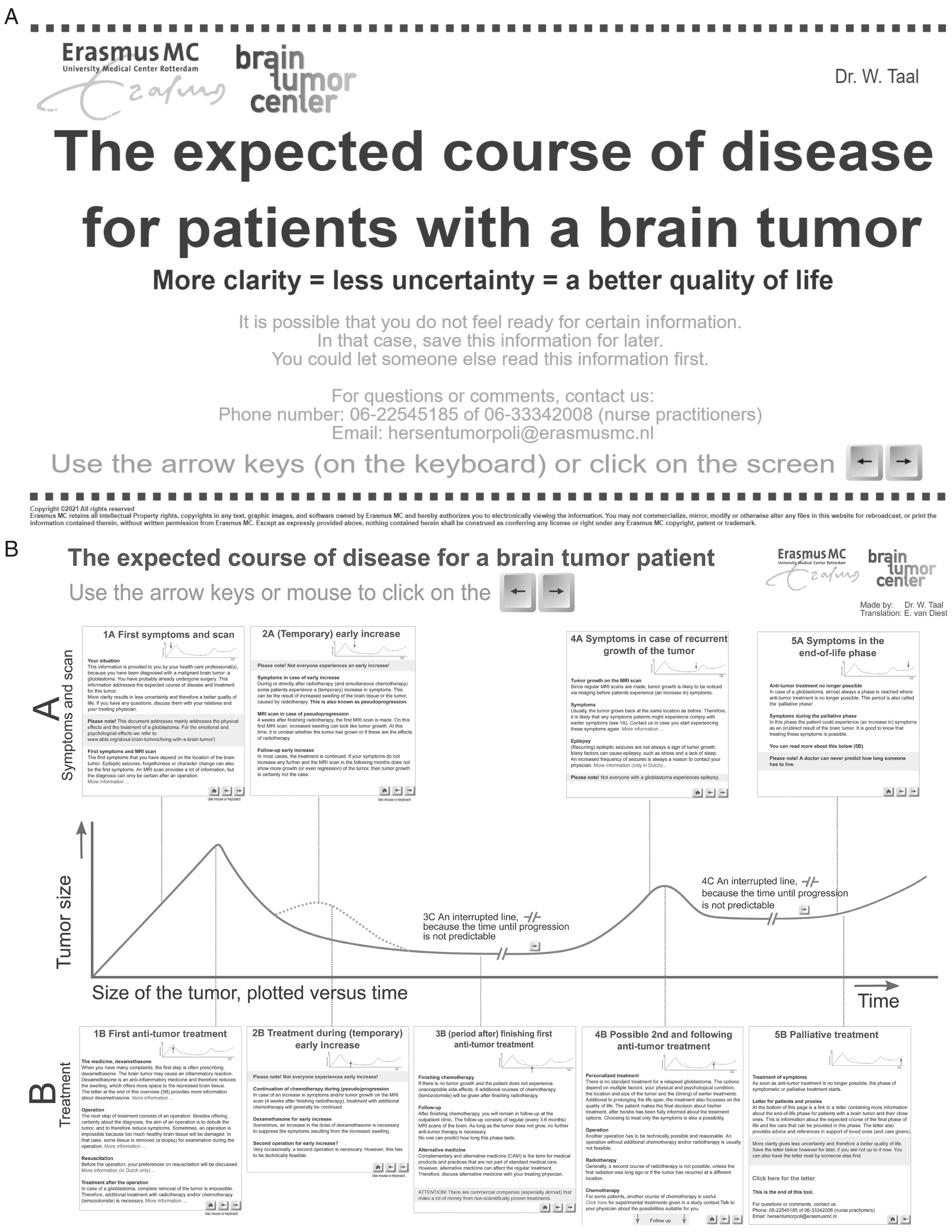
Patients older than 18 years with a histologically confirmed glioblastoma and their proxies were considered eligible, visiting the outpatient clinic of the Erasmus MC between July 12th and August 20th, 2021. Isocitrate dehydrogenase mutational analysis was done with immunohistochemistry or DNA sequencing. They had to either be undergoing primary treatment or be in the follow-up phase after primary treatment. Furthermore, they had to be Dutch-speaking because the tool language was Dutch and their cognition and speech had to be suitable for usage and evaluation of the tool. Patients were excluded if they had a relapsed glioblastoma or had seen the tool before.

The researcher identified every possibly eligible patient prior to their appointment. During the consultation, they were asked for participation by their treating physician. The researcher obtained verbal informed consent from all participants by telephone or during a consultation prior to scheduling the interview.

Sample sizes for in-depth interviews commonly vary between 12 and 20 participants with the aim of maximum variation sampling in qualitative studies.[17] Therefore, we aimed to include 15 patients and 15 proxies.

Data analysis

The sessions were transcribed verbatim using NVivo 12. The data were thematically analyzed by using an inductive approach.[18] First, one researcher read through all the transcripts to become more familiar with the data. Two researchers independently coded the first six transcripts. Afterwards, codes were compared and adapted, differences in coding between the two researchers were resolved in consensus. This resulted in a modified coding tree (Supplementary Information 2). Subsequently, the remaining transcripts were coded independently and discussed with the research team to come to a final consensus. During these consensus meetings, potential bias was continuously discussed.



Erasmus MC
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brain tumor center

Dr. W. Taal

The expected course of disease for patients with a brain tumor

More clarity = less uncertainty = a better quality of life

It is possible that you do not feel ready for certain information.
In that case, save this information for later.
You could let someone else read this information first.

For questions or comments, contact us:
Phone number: 06-22545185 of 06-33342008 (nurse practitioners)
Email: hersentumorpoli@erasmusmc.nl

Use the arrow keys (on the keyboard) or click on the screen ← →

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The expected course of disease for a brain tumor patient

Use the arrow keys or mouse to click on the ← →

Made by: Dr. W. Taal
Translation: E. van Diest

1A First symptoms and scan

Your situation
This information is provided to you by your health care professional(s), because you have been diagnosed with a malignant brain tumor: a glioblastoma. You have probably already undergone surgery. This information addresses the expected course of disease and treatment for this tumor.
More clarity results in less uncertainty and therefore a better quality of life. If you have any questions, discuss them with your relatives and your treating physician.

Please note! This document addresses mainly addresses the physical effects and the treatment of a glioblastoma. For the emotional and psychological effects we refer to: www.abta.org/about-brain-tumors/living-with-a-brain-tumor/)

First symptoms and MRI scan
The first symptoms that you have depend on the location of the brain tumor. Epileptic seizures, forgetfulness or character change can also be the first symptoms. An MRI scan provides a lot of information, but the diagnosis can only be certain after an operation.
More information ...

2A (Temporary) early increase

Please note! Not everyone experiences an early increase!

Symptoms in case of early increase
During or directly after radiotherapy (and simultaneous chemotherapy) some patients experience a (temporary) increase in symptoms. This can be the result of increased swelling of the brain tissue or the tumor, caused by radiotherapy. **This is also known as pseudoprogression.**

MRI scan in case of pseudoprogression
4 weeks after finishing radiotherapy, the first MRI scan is made. On this first MRI scan, increased swelling can look like tumor growth. At this time, it is unclear whether the tumor has grown or if these are the effects of radiotherapy.

Follow-up early increase
In most cases, the treatment is continued. If your symptoms do not increase any further and the MRI scan in the following months does not show more growth (or even regression) of the tumor, then tumor growth is certainly not the case.

4A Symptoms in case of recurrent growth of the tumor

Tumor growth on the MRI scan
Since regular MRI scans are made, tumor growth is likely to be noticed via imaging before patients experience (an increase in) symptoms.

Symptoms
Usually, the tumor grows back at the same location as before. Therefore, it is likely that any symptoms patients might experience comply with earlier symptoms (see 1A). Contact us in case you start experiencing these symptoms again. More information ...

Epilepsy
(Recurring) epileptic seizures are not always a sign of tumor growth. Many factors can cause epilepsy, such as stress and a lack of sleep. An increased frequency of seizures is always a reason to contact your physician. More information (only in Dutch)...

Please note! Not everyone with a glioblastoma experiences epilepsy.

5A Symptoms in the end-of-life phase

Anti-tumor treatment no longer possible
In case of a glioblastoma, almost always a phase is reached where anti-tumor treatment is no longer possible. This period is also called the 'palliative phase'.

Symptoms during the palliative phase
In this phase the patient could experience (an increase in) symptoms as an (in)direct result of the brain tumor. It is good to know that treating these symptoms is possible.

You can read more about this below (5B).

Please note! A doctor can never predict how long someone has to live.

1B First anti-tumor treatment

The medicine, dexamethasone
When you have many complaints, the first step is often prescribing dexamethasone. The brain tumor may cause an inflammatory reaction. Dexamethasone is an anti-inflammatory medicine and therefore reduces the swelling, which offers more space to the repressed brain tissue. The letter at the end of this overview (5B) provides more information about dexamethasone. More information ...

Operation
The next step of treatment consists of an operation. Besides offering certainty about the diagnosis, the aim of an operation is to debulk the tumor, and to therefore reduce symptoms. Sometimes, an operation is impossible because too much healthy brain tissue will be damaged. In that case, some tissue is removed (a biopsy) for examination during the operation. More information ...

Resuscitation
Before the operation, your preferences on resuscitation will be discussed.
More information (in Dutch only) ...

Treatment after the operation
In case of a glioblastoma, complete removal of the tumor is impossible. Therefore, additional treatment with radiotherapy and/or chemotherapy (temozolomide) is necessary. More information ...

2B Treatment during (temporary) early increase

Please note! Not everyone experiences early increase!

Continuation of chemotherapy during (pseudo)progression
In case of an increase in symptoms and/or tumor growth on the MRI scan (4 weeks after finishing radiotherapy), treatment with additional chemotherapy will generally be continued.

Dexamethasone for early increase
Sometimes, an increase in the dose of dexamethasone is necessary to suppress the symptoms resulting from the increased swelling.

Second operation for early increase?
Very occasionally, a second operation is necessary. However, this has to be technically feasible.

3B (period after) finishing first anti-tumor treatment

Finishing chemotherapy
If there is no tumor growth and the patient does not experience unacceptable side effects, 6 additional courses of chemotherapy (temozolomide) will be given after finishing radiotherapy.

Follow-up
After finishing chemotherapy, you will remain in follow-up at the outpatient clinic. The follow-up consists of regular (every 3-6 months) MRI scans of the brain. As long as the tumor does not grow, no further anti-tumor therapy is necessary.
No one can predict how long this phase lasts.

Alternative medicine
Complementary and alternative medicine (CAM) is the term for medical products and practices that are not part of standard medical care. However, alternative medicine can affect the regular treatment. Therefore, discuss alternative medicine with your treating physician.

ATTENTION! There are commercial companies (especially abroad) that make a lot of money from non-scientifically proven treatments.

4B Possible 2nd and following anti-tumor treatment

Personalized treatment
There is no standard treatment for a relapsed glioblastoma. The options depend on multiple factors: your physical and psychological condition, the location and size of the tumor and the (timing) of earlier treatments. Additional to prolonging the life span, the treatment also focusses on the quality of life. The patient makes the final decision about his/her treatment, after he/she has been fully informed about the treatment options. Choosing to treat only the symptoms is also a possibility.

Operation
Another operation has to be technically possible and reasonable. An operation without additional chemotherapy and/or radiotherapy is usually not feasible.

Radiotherapy
Generally, a second course of radiotherapy is not possible, unless the first radiation was long ago or if the tumor has recurred at a different location.

Chemotherapy
For some patients, another course of chemotherapy is useful.
Click here for experimental treatments given in a study context.Talk to your physician about the possibilities suitable for you.

↓ Follow up ↓

5B Palliative treatment

Treatment of symptoms
As soon as anti-tumor treatment is no longer possible, the phase of symptomatic or palliative treatment starts.

Letter for patients and proxies
At the bottom of this page is a link to a letter containing more information about the end-of-life phase for patients with a brain tumor and their close ones. This is information about the expected course of the final phase of life and the care that can be provided in this phase. The letter also provides advice and references in support of loved ones (and care givers).

More clarity gives less uncertainty and therefore a better quality of life. Save the letter below however for later, if you are not up to it now. You can also have the letter read by someone else first.

Click here for the letter

This is the end of this tool.

For questions or comments, contact us:
Phone: 06-22545185 of 06-33342008 (nurse practioners)
Email: hersentumorpoli@erasmusmc.nl

Figure 1. A: Print screen of home page. B: Print screen of the overview page. When using the arrow buttons, users zoom in on the text boxes in chronological order. Afterwards it is also possible to click on the text boxes to zoom in on the textbox. Home buttons in the text boxes zoom out to the overview page. The end of the tool contains a link to the EoL letter (added as Supplementary Information 3).

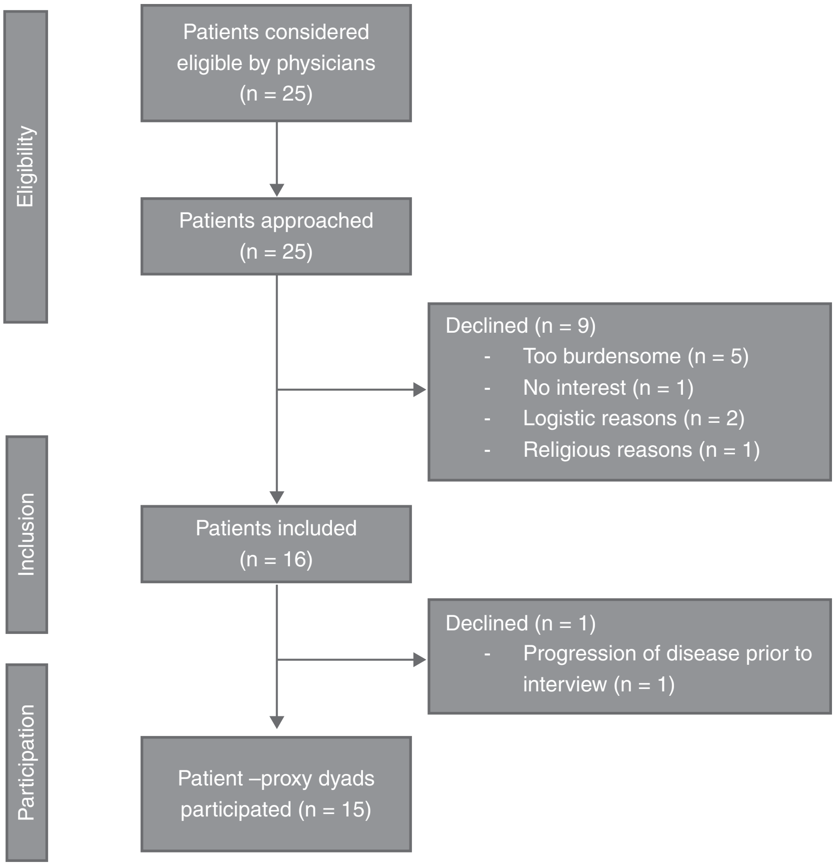

Figure 2. Flowchart Inclusion.

Results

Participants

Twenty-five patients were invited to participate in the study, of whom 9 patients declined participation (Figure 2). The most frequent reason to decline was that it was too burdensome to participate or for logistical reasons. The final sample consisted of 15 patients and their proxies. The patient's median age was 61 years (range 28–83) and the proxy's median age was 56 years (range 26–74). The sample of proxies consisted of mostly spouses (*n* = 12) and most respondents received higher education (17 respondents [56.7%], Table 1).

Qualitative Themes

The analysis revealed 4 major themes, namely, unmet information needs, improvement possibilities tool, effects tool and clinical implementation.

Unmet information needs.— Participants felt inadequately informed about the expected course of the disease, although all participants were satisfied with information provision about daily practices, such as the logistics of treatment. When reflecting on the first period after diagnosis, participants often described their journey as a "roller coaster," due to the fast succession of appointments and scans. This leaves little space to ask questions about more long-term expectations and treatment possibilities in case of tumor progression.

Some participants brought up not feeling adequately informed about the benefits and burdens of treatment. They emphasized the importance of overseeing possible outcomes with and without treatment, and make up the balance for themselves.

> I just want to know, what will this all bring me? Will this prolong my life with 5 years? What quality of life will I have? (Patient 1)

Improvement possibilities of the tool.— Three categories of modifiable usability issues were identified (Table 2). The main adjustment made after session 9 (phase 1) was simplifying the overview page, linguistic alterations and clarifying the end of the tool.

Content All participants perceived the information provided in the tool and the EoL letter at the end

Table 1. Patient characteristics

	Patients	Proxies
Total *n*	15	15
Sex (*n*)		
Male	6	9
Female	9	6
Age category (years):		
≤29	2	1
30–39	2	3
40–49	2	1
50–59	1	3
60–69	5	4
70–79	2	3
≥80	1	0
Educational level (*n*)		
Elementary education	0	2
Secondary education	2	0
Further education	3	6
Higher education	10	7
Stage of treatment (*n*)		
RT[a] and concomitant TMZ[b]	5	-
Adjuvant TMZ[b]	6	-
Follow-up phase	4	-
Religious (*n*)		
No	10	11
Yes, not very important	3	3
Yes, important	2	1
Proxy's relationship to patient (*n*):		
Spouse	-	12
Parent	-	1
Child	-	1
Daughter in law	-	1

[a]RT = radiotherapy.
[b]TMZ = temozolomide.

(Supplementary Information 3) as clear and of added value. Most participants missed more in-depth information on topics such as experimental treatments and psychological support. Also, adding practical advises about the driving ban and paperwork was proposed by some participants.

The language used in the tool was appropriate for the majority of participants. However, some thought of it as "too formal" or "too complicated" due to the incidental choice of words and length of some sentences.

Participants commented that the tool was a great summary and a pleasant overview. All relevant information is summarized in one place. Also, due to the emotional burden of the consultations, many participants mentioned that they often forget information given during these appointments. It is pleasant to have the possibility of going over that again on a reliable website.

> I was a little afraid that I would read things, that I thought, well, I really don't want to hear this, but it's all right. It is simply useful information, neutral information. (…) It is clear, that is what's important, that it's clear for people. (Patient 4)

Aesthetics Before alterations, all participants were dissatisfied with the overview page. The major criticism was the readability, as it showed an overview of all the information in the tool. Some letters were too small, which was confusing and overwhelming. Based on this feedback, we decided to only show the headings in the boxes. Afterwards, the overall aesthetic of the tool was considered appropriate.

Opinions on adding images varied. Some participants were in favor, they thought it could make the tool look more friendly and inviting, increasing its readability. Those against it thought it would distract from the content and that it was unnecessary. Also, these participants mentioned that suitable images of such an emotionally charged subject could be hard to find. Many participants brought up the added value of an "overview picture" in every text box, showing what phase on the graph you are reading about. This could increase the clarity of the tool, as some lost track of where in the graph they were while reading the text boxes.

> For me, it's perfect like this, but I'm a well-educated Dutch lady. I can imagine that a couple of images should be added for the readability. (Patient 9)

Navigation The participants found the tool easy and straight-forward to use. Participants generally went through it in chronological order. In the original version, most participants commented that it was unclear when they reached the end of the tool. After alterations, this was evident.

An important finding was that patients with a high dose of dexamethasone might have problems using the tool, due to restlessness. This was observed in a patient who was unable to navigate through the tool and had to be instructed by the researcher and her partner because she was unfocused and hyperactive due to a recent increase in her dose of dexamethasone.

Effects of the tool

On uncertainties Participants expected that using this tool would decrease uncertainties. Some participants felt more confident after using the tool, as they recognized that they were already well-informed. Most patients did not feel knowledgeable about the expected course of disease when being asked prior to using the tool. However, afterwards some recognized that they did not acquire much new information. Participants experienced this as a pleasant conformation. Also, some participants found it reassuring to have confirmed that they understood the information correctly because they were insecure about this.

> The thing is that on the one hand, it can clarify important issues and on the other hand, it provides a

Table 2: Feedback on the tool during interviews

(Sub)themes	Phase 1 (session 1–9)	Phase 2 (session 10–15)
Content	+ Information in tool was useful + Provided a clear overview + Information was generally understandable - Inconsistency in headings - Some unclear terms (such as "too long") - Use of jargon (such as "biopsy") - Incidental use of difficult words or long sentences - Missing information about multidisciplinary team meetings - Missing contact information in case of (urgent) questions - First mention of resuscitation in inappropriate place in tool - Psychological aspects of this diagnosis were not mentioned - Some passages were very long, and therefore overwhelming and not very inviting to read	+ Information in tool was useful + Provided a clear overview + Information in tool was generally understandable + Clear headings + Link to information on psychological aspects in first text box very important + Information on treatment options for tumor relapse gave hope - The need for more emphasis on psychological aspect - The need for a possibility of accessing more in-depth information about topics such as experimental treatments, psychological support, resuscitation, commercial enterprises, euthanasia, types of operations, epilepsy and alternative medicine - The need for a short clarification on the overview page about the graph
Aesthetics	+ Looked very decent and clear + House style of hospital was recognizable in the colors used in the tool - The overview page was overwhelming - The text on the overview page was unreadable - Headings should be in bold and bigger - Different opinions on the need for images in the tool	+ Looked very decent and clear + Could use some professionalization of the design + Blue boxes with important messages and information were considered very pleasant and useful - The need for a picture of the graph in every text box, with an indication (arrow or colored box) of what phase you are reading about - Different opinions on the need for images in the tool
Navigation	+ Simple navigation, easy to use + Useful to have the option of choosing what you want to read first or going through tool in chronological order - Avoid unnecessary zooming to prevent confusion - End of the tool was very unclear	+ Simple navigation, easy to use - Option of a more personalized approach, where users answer questions to beget more suitable information (for example, "are you a patient or a proxy?") - A more clear warning needed, a pop-up, with only heading of a text box and question "do you want to read this? Yes/No", gives you time to think about it

+ = positive aspects.
– = improvement possibilities.

> clear picture about what awaits you. (…) For us, it has clarified a lot. (Patient 8)

On quality of life Although no formal quality of life survey was done, the vast majority of both patients and proxies thought the tool could have a positive influence on the quality of life (QoL). Most participants directly linked less uncertainties to a better QoL, because this resulted in less unnecessary worrying and anxiety.

> I mean, if you feel confident about your life, you have a more pleasant and good life. And the same goes for an illness like this. When you have less insecurities and you just feel better because of that, then your quality of life is better. (Patient 13)

On consultations Participants thought that the efficiency and quality of consultations will be improved after using the tool because they could ask more specific questions. The doctor could go more in-depth about the treatment options and decisions, instead of losing time on basic information. Participants would also feel more confident and empowered when discussing their concerns with health care professionals.

Some participants pointed out that they preferred to receive information about the course of the disease from a health care professional first. They emphasized the importance of the traditional doctor–patient relation and mentioned the fear that human contact would be replaced by electronic contact.

> I prefer to speak to someone face to face, instead of reading the whole story on the computer. To me, it is just more confrontational, but well, if someone says

> it straight to your face, that's also quite confrontational (*laughs*). But that's fine. (Patient 4)

Clinical implementation

Method of introduction to the tool Participants preferred to be introduced to this tool during a consultation at the hospital, in combination with a written reference in a letter to take home. This "dual" method is necessary, because of the amount of information participants receive during the start of treatment in combination with the emotional load.

> When it's about myself it becomes more complicated, because there are lots of emotions involved. (…) I think that this tool should be referred to during a consultation, and that afterwards there should be a letter saying 'this is what we have discussed'.(Patient 8)

Timing of introduction to tool The vast majority of patients and proxies wanted to be introduced to this tool as early as possible after diagnosis because they wanted to be well-informed before starting treatment.

> If you're only looking ahead on the short term, then every time you'll be shocked by what comes next. (…) If you keep hiding for the fact that someday, it'll come back (*meaning the glioblastoma*). Well, then that news will only hit you harder. (Patient 12)

Location of using the tool The vast majority of participants favor the usage of the tool at home. Participants brought up the importance of emphasizing who to contact in case of urgent questions when offering to use the tool at home.

> I'd rather use it at home, but that is very personal. I'd rather look at it when I feel ready. (…) It's good that you can take a break if you want to, that you give some autonomy back to the patient instead of dumping a whole load of information on them, when you don't feel prepared for it. (Patient 14)

Some participants might not be capable to use the tool without supervision, due to limited IT-skills or impaired cognition. For this reason, health care providers should assess if individual future users of this tool might need assistance while using the tool and a printable version should be available.

Discussion

The results of our study show that patient–proxy dyads indicate that this tool about the expected course of disease for glioblastoma patients is effective in decreasing uncertainties and could improve their QoL, although no formal QoL survey was done. Participants reported that this tool could improve the efficiency and quality of their medical consultations. Patients and proxies preferred introducing this tool as soon as possible after diagnosis during a consultation. To introduce the tool, they advised completing the verbal introduction with a leaflet or letter summarizing the information. Most participants favored using the tool at home.

Adequate information provision is important for various reasons. Wakefield et al. concluded that personalized information provision about the global symptom trajectory and "what to expect" empowered patients.[19] Having knowledge enhanced self-management, increased confidence and helped patients to regain a sense of motivation and self-responsibility.[20–23] Also, Bélanger et al. showed that unmet information needs are known to be one of the biggest barriers to shared decision making (SDM).[24] The results of this study show that our tool provides insight into valuable information about the expected course of the disease and therefore decreases uncertainties for patients and proxies. Patients and/or proxies can access the tool whenever they feel emotionally ready and in their own surroundings, improving the chances of processing the information better.[25,26]

When patients and proxies are well-informed, consultations can be more efficient and this could enhance SDM. Participants of this study indicated that this tool would make them attend a consultation more knowledgeable and confident. This could make patients better SDM-partners and improve patient participation. The efficiency of consultations is expected to increase because the physician needs to provide less basic information and has more time to answer well-thought-of questions. This could create more time for in-depth conversations about patients' personal preferences.

The lack of time during consultations is known to be an impairing factor for discussing advanced care planning (ACP).[11] Timely ACP significantly decreases the risk of potentially inappropriate EoL-care.[27] For GBM patients specifically, Koekkoek et al. showed that if patients expressed their EoL preferences, these were met in 90% of cases.[28] It has been suggested that early palliative care planning through structured ACP improves symptom control and QoL for GBM patients.[9] Our tool could be helpful for patients to start these discussions.

Strengths and limitations

Strengths of this study include that the views of both patients and proxies were researched, as these are both targeted end-users. A recent study emphasized the importance of empowering patients to include their social networks in future care planning.[29] In the EoL phase, approximately 50% of caregivers for primary brain tumor patients have reported a high burden and feelings of stress.[30] Providing accurate and easily accessible information on the expected course of the disease can be helpful for proxies to prepare for the future.

A limitation of this study might be that the included participants may have had more proactive attitudes towards ACP than average patients and proxies. This may have led to more positive perceptions about the tool and different barriers than within the general population of glioblastoma patients and proxies. Furthermore, participants overwhelmingly had received higher education, which is not an ideal representation of society.

This tool should be introduced to patients as soon as possible after diagnosing a glioblastoma. To obtain more knowledge about the effects of this tool and to ensure further uptake, ongoing evaluation and monitoring are advised.

The concept of an online tool about the expected course of the disease could also be applied to different diseases. Not only for other tumors but also for diseases such as cardiac insufficiency and multiple sclerosis. This could enhance patient empowerment and participation, as discussed earlier. Therefore we hope that this tool will be used by glioblastoma patients and proxies worldwide. Furthermore, we are planning to do research with QoL measurements using the tool.

Conclusion

GBM patients and proxies indicated that this tool gives them a clear overview of their future trajectory, which decreases their uncertainties. Moreover, participants brought up that this tool could positively influence the efficiency and quality of consultations. This could lead to more patient participation and empowerment, and could therefore enhance SDM and ACP.

Supplementary Material

Supplementary material is available at *Neuro-Oncology Practice* online.

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Conflict of interest statement. None declared.

Author Contributions

All authors contributed to the study's conception and design. Material preparation, data collection and analysis were performed by Eva van Diest, Marit Eland and Wendy H Oldenmenger. The first draft of the manuscript was written by Eva van Diest and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.
Link to tool: https://hersentumorcentrum.nl/wp-content/uploads/2021/11/ACPv7P_En.sozi_.html (Translated by Eva van Diest for publication purposes, reviewed by Walter Taal)
Consent to participate: Informed verbal consent was obtained from all individual participants included in the study.

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