

# Evaluation of An Online Tool About the Expected Course of Disease for Glioblastoma Patients – A Qualitative Study

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## Research Article

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# Abstract

## Background

Patients with glioblastoma have a short life-expectancy, with median survival rates of nine to twelve months. Providing information about the expected course of 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 future end-users, to identify if the tool meets the previously mentioned objectives.

## Methods

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

## Results

The analysis revealed four major themes: 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 and improving the quality of life 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.

## Introduction

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 nine to twelve months, with two-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 patients 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]

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 disease.[12, 13] In order 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 experiences of future end-users with the tool. Secondary objectives include exploring possible improvements for the quality and aesthetics of the tool.

## **Methods**

### **Study design**

A qualitative research design was used to explore future end-users' perspectives. 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 sessions' and semi-structured interviews, following the 'Consolidated Criteria for Reporting Qualitative Research' reporting guidelines.[16]

### **Participants**

Patients older than eighteen years with a histologically confirmed glioblastoma and their proxies were considered eligible, visiting the outpatient clinic of the Erasmus MC between July 12<sup>th</sup> and August 20<sup>th</sup>

2021. 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 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.

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 12-20 participants with the aim of maximum variation sampling in qualitative studies.[17] Therefore, we aimed to include 15 patients and 15 proxies.

## **Data collection**

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.

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. Patients 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).

## **Data analysis**

The sessions were transcribed verbatim using NVivo 12. The data was 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 by 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.

# **Results**

## **Participants**

Twenty-five patients were invited to participate in the study, of whom nine patients declined participation (Figure 2). The most frequent reason to decline was that it was too burdensome to participate or logistical reasons. The final sample consisted of fifteen patients and their proxies. Patient's median age was 61 years (range 28-83) and 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 four major themes: unmet information needs, improvement possibilities tool, effects tool and clinical implementation.

### Unmet information needs

Participants felt inadequately informed about the expected course of 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 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 nine (phase 1) were 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 (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 use 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 to 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 in 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**

Participants found the tool easy and straight-forward to use. Participants generally went through it in chronologic 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 clear picture about what awaits you. (...) For us, it has clarified a lot.”(Patient 8)

## **On quality of life**

The vast majority 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 to 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 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 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 favors 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 future end-users indicate that this tool about the expected course of disease for glioblastoma patients effective in decreasing uncertainties and could improve their QoL. 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 for shared decision making (SDM).[24] The results of this study show that our tool provides insight into valuable information about the expected course of disease and therefore decreases uncertainties for patients and proxies. Future end-users can access the tool whenever they feel emotionally ready and in their own surroundings, improving the chances 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 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.

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 is advised.

The concept of an online tool about the expected course of 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.

## **Conclusion**

In 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.

# Declarations

## Author contributions

All authors contributed to the study 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](https://hersentumorcentrum.nl/wp-content/uploads/2021/11/ACPv7P_En.sozi_.html)

**Conflict of interest:** The authors have no conflict of interests to disclose.

**Data availability:** The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

**Ethical approval:** Approval 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 the Declaration of Helsinki.

**Consent to participate:** Informed verbal consent was obtained from all individual participants included in the study.

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# References

1. Houben MP, Aben KK, Teepen JL, Schouten-Van Meeteren AY, Tijssen CC, Van Duijn CM, Coebergh JW (2006) Stable incidence of childhood and adult glioma in The Netherlands, 1989-2003. *Acta oncologica (Stockholm, Sweden)* 45:272–279. doi:10.1080/02841860500543190
2. van der Sanden GA, Schouten LJ, van Dijck JA, van Andel JP, Coebergh J (1998) Incidence of primary central nervous system cancers in South and East Netherlands in 1989-1994. *Neuroepidemiology* 17:247–257. doi:10.1159/000026177
3. Ostrom QT, Cioffi G, Gittleman H, Patil N, Waite K, Kruchko C, Barnholtz-Sloan JS (2019) CBTRUS Statistical Report: Primary Brain and Other Central Nervous System Tumors Diagnosed in the United States in 2012-2016. *Neurooncology* 21:v1–v100. doi:10.1093/neuonc/noz150
4. Levin VLS, Gutin P (2001) Neoplasms of the Central Nervous System. In: Devita V.T HS, Rosenberg S.A. (ed) *Cancer: Principles and Practice of Oncology* 6th edition Lippincott Williams & Wilkins Publishers, Philadelphia, PA, Lippincott-Raven, pp 2022, 1997, -2082
5. Catt S, Chalmers A, Fallowfield L (2008) Psychosocial and supportive-care needs in high-grade glioma. *Lancet Oncol* 9:884–891. doi:10.1016/s1470-2045(08)70230-4

6. Sizoo EM, Pasman HR, Buttolo J, Heimans JJ, Klein M, Deliëns L, Reijneveld JC, Taphoorn MJ (2012) Decision-making in the end-of-life phase of high-grade glioma patients. *European journal of cancer* (Oxford, England: 1990) 48: 226-232 doi:10.1016/j.ejca.2011.11.010
7. Kirchoff KT, Hammes BJ, Kehl KA, Briggs LA, Brown RL (2012) Effect of a disease-specific advance care planning intervention on end-of-life care. *J Am Geriatr Soc* 60:946–950. doi:10.1111/j.1532-5415.2012.03917.x
8. Flechl B, Ackerl M, Sax C, Oberndorfer S, Calabek B, Sizoo E, Reijneveld J, Crevenna R, Keilani M, Gaiger A, Dieckmann K, Preusser M, Taphoorn MJ, Marosi C (2013) The caregivers' perspective on the end-of-life phase of glioblastoma patients. *J Neurooncol* 112:403–411. doi:10.1007/s11060-013-1069-7
9. Walbert T (2014) Integration of palliative care into the neuro-oncology practice: patterns in the United States. *Neuro-oncology practice* 1:3–7. doi:10.1093/nop/npt004
10. Wen PY, Weller M, Lee EQ, Alexander BM, Barnholtz-Sloan JS, Barthel FP, Batchelor TT, Bindra RS, Chang SM, Chiocca EA, Cloughesy TF, DeGroot JF, Galanis E, Gilbert MR, Hegi ME, Horbinski C, Huang RY, Lassman AB, Le Rhun E, Lim M, Mehta MP, Mellinghoff IK, Minniti G, Nathanson D, Platten M, Preusser M, Roth P, Sanson M, Schiff D, Short SC, Taphoorn MJB, Tonn JC, Tsang J, Verhaak RGW, von Deimling A, Wick W, Zadeh G, Reardon DA, Aldape KD, van den Bent MJ (2020) Glioblastoma in adults: a Society for Neuro-Oncology (SNO) and European Society of Neuro-Oncology (EANO) consensus review on current management and future directions. *Neurooncology* 22:1073–1113. doi:10.1093/neuonc/noaa106
11. Fritz L, Zwinkels H, Koekkoek JAF, Reijneveld JC, Vos MJ, Dirven L, Pasman HRW, Taphoorn MJB (2020) Advance care planning in glioblastoma patients: development of a disease-specific ACP program. *Supportive care in cancer: official journal of the Multinational Association of Supportive Care in Cancer* 28:1315–1324. doi:10.1007/s00520-019-04916-9
12. Bausewein C, Hau P, Borasio GD, Voltz R (2003) How do patients with primary brain tumours die? *Palliat Med* 17:558–559. doi:10.1177/026921630301700615
13. Kerrigan S, Ormerod I (2010) Advance planning in end-of-life care: legal and ethical considerations for neurologists. *Pract Neurol* 10:140–144. doi:10.1136/jnnp.2009.200113
14. Thomson AM, Cunningham SJ, Hunt NP (2001) A comparison of information retention at an initial orthodontic consultation. *Eur J Orthod* 23:169–178. doi:10.1093/ejo/23.2.169
15. Yang F, Ingledew PA (2021) Quality of Glioblastoma Multiforme (GBM) Resources Available on the Internet. *Journal of cancer education: the official journal of the American Association for Cancer Education*. Mar26edn
16. Tong A, Sainsbury P, Craig J (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care: journal of the International Society for Quality in Health Care* 19:349–357. doi:10.1093/intqhc/mzm042

17. Braun V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3:77–101
18. Lorelli S, Nowell JMN, Deborah E, White, Nancy J, Moules (2017) Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of Qualitative Methods* 16. doi:10.1177/1609406917733847
19. Wakefield D, Bayly J, Selman LE, Firth AM, Higginson IJ, Murtagh FE (2018) Patient empowerment, what does it mean for adults in the advanced stages of a life-limiting illness: A systematic review using critical interpretive synthesis. *Palliat Med* 32:1288–1304. doi:10.1177/0269216318783919
20. Harley C, Pini S, Bartlett YK, Velikova G (2015) Defining chronic cancer: patient experiences and self-management needs. *BMJ supportive & palliative care* 5:343–350. doi:10.1136/bmjspcare-2012-000200rep
21. Henriksen KM, Heller N, Finucane AM, Oxenham D (2014) Is the patient satisfaction questionnaire an acceptable tool for use in a hospice inpatient setting? A pilot study. *BMC palliative care* 13:27. doi:10.1186/1472-684x-13-27
22. Kane PM, Ellis-Smith CI, Daveson BA, Ryan K, Mahon NG, McAdam B, McQuillan R, Tracey C, Howley C, O'Gara G, Raleigh C, Higginson IJ, Murtagh FE, Koffman J (2018) Understanding how a palliative-specific patient-reported outcome intervention works to facilitate patient-centred care in advanced heart failure: A qualitative study. *Palliat Med* 32:143–155. doi:10.1177/0269216317738161
23. Mikkelsen HE, Brovold KV, Berntsen S, Kersten C, Fegran L (2015) Palliative Cancer Patients' Experiences of Participating in a Lifestyle Intervention Study While Receiving Chemotherapy. *Cancer Nurs* 38:E52–58. doi:10.1097/ncc.0000000000000235
24. Bélanger E, Rodríguez C, Groleau D (2011) Shared decision-making in palliative care: a systematic mixed studies review using narrative synthesis. *Palliat Med* 25:242–261. doi:10.1177/0269216310389348
25. Blinder D, Rotenberg L, Peleg M, Taicher S (2001) Patient compliance to instructions after oral surgical procedures. *Int J Oral Maxillofac Surg* 30:216–219. doi:10.1054/ijom.2000.0045
26. Ley P (1979) Memory for medical information. *Br J Soc Clin Psychol* 18:245–255. doi:10.1111/j.2044-8260.1979.tb00333.x
27. Boddaert MS, Pereira C, Adema J, Vissers KCP, van der Linden YM, Raijmakers NJH, Fransen HP (2020) Inappropriate end-of-life cancer care in a generalist and specialist palliative care model: a nationwide retrospective population-based observational study. *BMJ supportive & palliative care*. doi:10.1136/bmjspcare-2020-002302
28. Koekkoek JA, Dirven L, Reijneveld JC, Sizoo EM, Pasman HR, Postma TJ, Deliëns L, Grant R, McNamara S, Grisold W, Medicus E, Stockhammer G, Oberndorfer S, Flechl B, Marosi C, Taphoorn MJ, Heimans JJ (2014) End of life care in high-grade glioma patients in three European countries: a comparative study. *J Neurooncol* 120:303–310. doi:10.1007/s11060-014-1548-5
29. Fliedner M, Zambrano S, Schols JM, Bakitas M, Lohrmann C, Halfens RJ, Eychmüller S (2019) An early palliative care intervention can be confronting but reassuring: A qualitative study on the

experiences of patients with advanced cancer. *Palliat Med* 33:783–792.

doi:10.1177/0269216319847884

30. Faithfull S, Cook K, Lucas C (2005) Palliative care of patients with a primary malignant brain tumour: case review of service use and support provided. *Palliat Med* 19:545–550.

doi:10.1191/0269216305pm1068oa

## Tables

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	4	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 <sup>a</sup> and concomitant TMZ <sup>b</sup>	5	-
Adjuvant TMZ <sup>b</sup>	6	-
Follow-up phase	4	-
Religious (n):		
No	10	11
Yes, not very important	3	3
<i><sup>a</sup>RT = radiotherapy</i>		
<i><sup>b</sup>TMZ = temozolomide</i>		

	Patients	Proxies
Yes, important	2	1
Proxy's relationship to patient (n):		
Spouse	-	12
Parent	-	1
Child	-	1
Daughter in law	-	1
<i><sup>a</sup>RT = radiotherapy</i>		
<i><sup>b</sup>TMZ = temozolomide</i>		

Table 2  
Feedback on the tool during interviews

(Sub)themes	Phase 1 (Session 1-9)	Phase 2 (Session 10-15)
Content	<ul style="list-style-type: none"> <li>+ Information in tool was useful</li> <li>+ Provided a clear overview</li> <li>+ Information was generally understandable</li> <li>- Inconsistency in headings</li> <li>- Some unclear terms (such as 'too long')</li> <li>- Use of jargon (such as 'biopsy')</li> <li>- Incidental use of difficult words or long sentences</li> <li>- Missing information about multidisciplinary team meetings</li> <li>- Missing contact information in case of (urgent) questions</li> <li>- First mention of resuscitation in inappropriate place in tool</li> <li>- Psychological aspects of this diagnosis were not mentioned</li> <li>- Some passages were very long, and therefore overwhelming and not very inviting to read</li> </ul>	<ul style="list-style-type: none"> <li>+ Information in tool was useful</li> <li>+ Provided a clear overview</li> <li>+ Information in tool was generally understandable</li> <li>+ Clear headings</li> <li>+ Link to information on psychological aspects in first text box very important</li> <li>+ Information on treatment options for tumor relapse gave hope</li> <li>- The need for more emphasis on psychological aspect</li> <li>- 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</li> <li>- The need for a short clarification on the overview page about the graph</li> </ul>

+ = positive aspects

(Sub)themes	Phase 1 (Session 1-9)	Phase 2 (Session 10-15)
Aesthetics	<ul style="list-style-type: none"> <li>+ Looked very decent and clear</li> <li>+ House style of hospital was recognizable in the colors used in the tool</li> <li>- The overview page was overwhelming</li> <li>- The text on the overview page was unreadable</li> <li>- Headings should be in bold and bigger</li> <li>- Different opinions on the need for images in the tool</li> </ul>	<ul style="list-style-type: none"> <li>+ Looked very decent and clear</li> <li>+ Could use some professionalization of the design</li> <li>+ Blue boxes with important messages and information were considered very pleasant and useful</li> <li>- 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</li> <li>- Different opinions on the need for images in the tool</li> </ul>
Navigation	<ul style="list-style-type: none"> <li>+ Simple navigation, easy to use</li> <li>+ Useful to have the option of choosing what you want to read first or going through tool in chronological order</li> <li>- Avoid unnecessary zooming to prevent confusion</li> <li>- End of the tool was very unclear</li> </ul>	<ul style="list-style-type: none"> <li>+ Simple navigation, easy to use</li> <li>- Option of a more personalized approach, where users answer questions to beget more suitable information (for example, 'are you a patient or a proxy?')</li> <li>- 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</li> </ul>
<p><i>+ = positive aspects</i></p>		

*- = improvement possibilities*

## Figures

Erasmus MC University Medical Center Rotterdam **Erasmus** 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 and email address

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

Erasmus MC University Medical Center Rotterdam **Erasmus** brain tumor center

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

**A Symptoms and scan**

**1A First symptoms and scan**  
Your situation: You experience a problem to you for your health and you experience symptoms you have been diagnosed with a diagnosed brain tumor. This information addresses the expected course of disease and treatment options. You have probably already undergone surgery. This information addresses the expected course of disease and treatment options. You have probably already undergone surgery. This information addresses the expected course of disease and treatment options. You have probably already undergone surgery.

**2A (Temporary) early increase**  
Please note: For extensive experience an early increase  
Symptoms in case of early increase  
MRI scan in case of progression  
Please note: For extensive experience an early increase

**4A Symptoms in case of recurrent growth of the tumor**  
Tumor growth on the MRI scan  
Symptoms  
Please note: For extensive experience an early increase

**5A Symptoms in the end-of-life phase**  
Antitumor treatment no longer possible  
Symptoms during the palliative phase  
Please note: For extensive experience an early increase

**B Treatment**

**1B First anti-tumor treatment**  
The expected course of disease  
Operation  
Please note: For extensive experience an early increase

**2B Treatment during (temporary) early increase**  
Symptoms of chemotherapy during progression  
Please note: For extensive experience an early increase

**3B (period after) finishing first anti-tumor treatment**  
Please note: For extensive experience an early increase

**4B Possible 2nd and following anti-tumor treatment**  
Personalized treatment  
Please note: For extensive experience an early increase

**5B Palliative treatment**  
Treatment of symptoms  
Please note: For extensive experience an early increase

Size of the tumor, plotted versus time

Tumor size

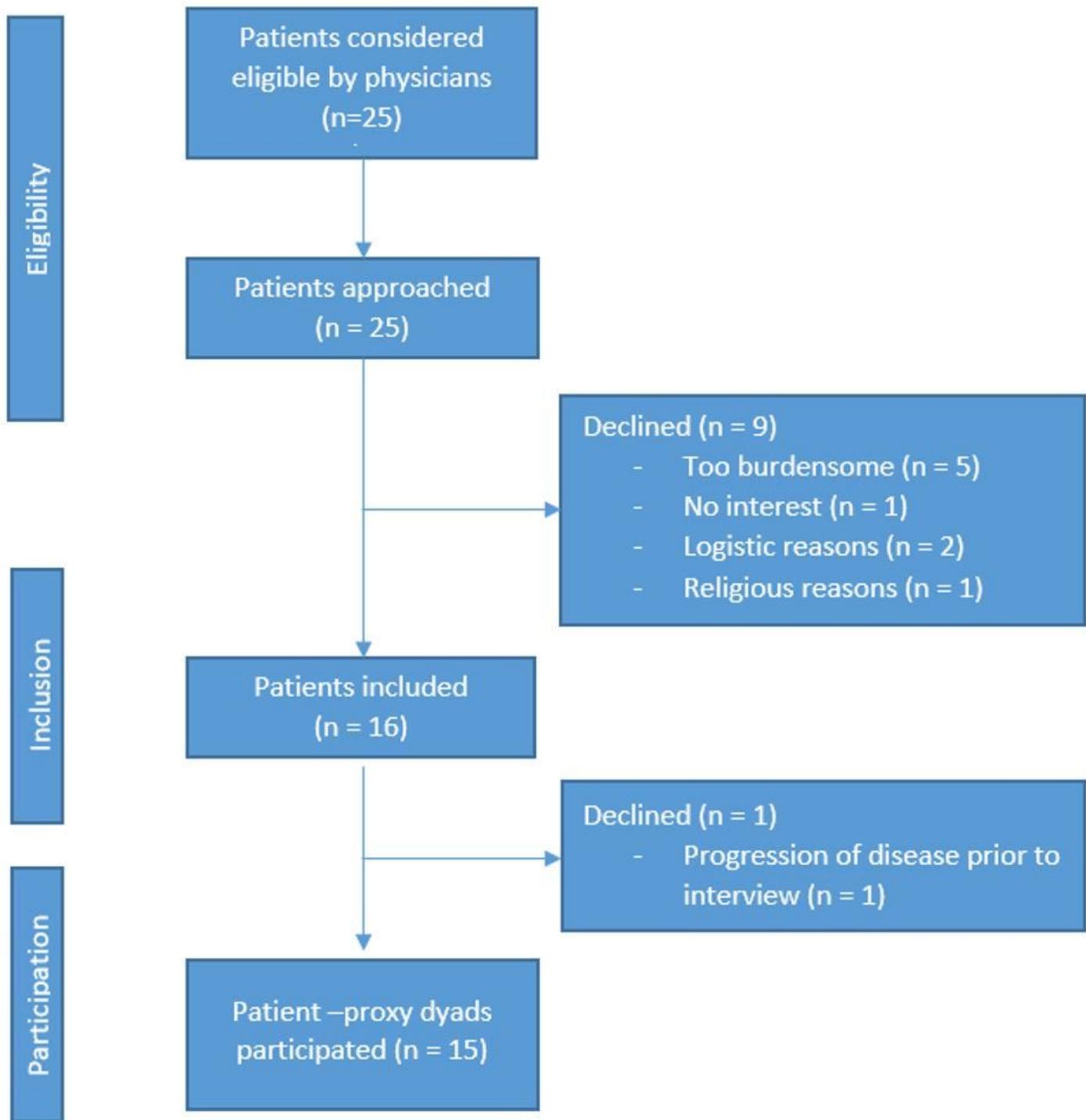
Time

3C An interrupted line. // because the time until progression is not predictable

4C An interrupted line. // because the time until progression is not predictable

Figure 1

1A: Print screen of home page 1B: 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

## Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [Suppl1InterviewGuide.docx](#)
- [Suppl2CodingTree.docx](#)
- [Suppl3EOLletter.docx](#)