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Measuring symptoms and functioning in glioma patients

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CHAPTER 5

Measuring patient-reported outcomes in glioma patients in clinical practice: the perspective of patients and clinicians

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Abstract

Introduction

Routine assessment of patient-reported outcomes (PROs) in oncology has shown to improve the quality of the delivered care and to prolong survival. However, for successful implementation of routine assessment of PROs, more knowledge on their usability in clinical practice is needed.

Objective

This study aimed to cross sectionally assess the perspective of patients and clinicians on the practicality of routinely measuring PROs in clinical practice for glioma patients.

Methods

Semi-structured interviews were conducted evaluating the role of health care professionals (HCP) in discussing results of PRO measures (PROMs), and the preferred topics, methods and frequency of PRO assessment. Glioma patients, their proxies and HCPs involved in the treatment of glioma patients from 8 centers in the Netherlands were included.

Results

Twenty-four patients, 16 proxies and 35 HCPs were interviewed. The majority of patients, proxies and HCPs (92%, 81% and 80%) were willing to discuss PRO results during consultations. Although HCPs prefer that results are discussed with the nurse specialist, only one third of patients/proxies agreed. Functioning of daily life was considered important in all three groups. Most participants indicated that discussion of PROM results should take place during standard follow-up visits, and completed at home about one week in advance. On group level, there was no preference for administration of questionnaires on paper or digitally. Lastly, all centers had staff available to send questionnaires on paper.

Conclusion

This study shows that routine assessment of PROs is desired by patients, proxies and HCP's in neuro-oncological care in Dutch hospitals.

Introduction

Gliomas are the most common malignant primary brain tumors in adults, with an incidence of six cases per 100.000 persons per year^{1,2}. The prognosis of glioma patients depends on the histological type, grade and molecular markers of the tumor, with median survival rates ranging from 15 months in high-grade gliomas up to 16 years in low-grade gliomas³⁻⁵. Due to the incurable nature of gliomas, treatment is not only directed at prolonging survival, but also at maintaining or improving the patients' functioning and well-being. Patient-reported outcome measures (PROMs) are increasingly being used to monitor these outcomes. A patient-reported outcome (PRO) is directly reported by patients and based on the patient's perception of the impact of a disease and its treatment on their health⁶.

In clinical trials, PROMs can be used in conjunction with information on survival to determine the net clinical benefit of a new treatment strategy. In clinical practice, PROMs can be used to monitor patients' functioning during the disease trajectory⁷. Routine use of PROMs in clinical practice in oncology has shown to result in better communication between the patients and their physicians⁸⁻¹⁰, and an increased frequency of discussions of health-related quality-of-life (HRQoL) issues⁹ and other topics that are important to patients¹¹. Furthermore, the incorporation of PROMs in routine clinical care in patients with a metastatic malignancy resulted in improved HRQoL and also led to significantly prolonged survival^{12, 13}. An explanation was that routine PRO assessment might help in early detection of adverse treatment effects or tumor progression¹², and that treatment or referral to another health care professional (HCP) could be initiated if necessary.

Although implementation of routine assessment of PROs can possibly improve the quality of patient care and outcomes⁸⁻¹³, it is not yet widely used in healthcare in glioma patients. Several challenges have been described, including the choice of PROM, the method of data collection (e.g. paper or electronic), and the frequency and timing of assessments¹⁴. Other possible barriers are the need to train physicians to interpret the results of PROMs and the need for human resources to administer the questionnaires¹⁵ or discuss the results.

Routine assessment of PROMs in standard neuro-oncological care in Dutch hospitals, with the goal to improve psychosocial care, is one of the quality aspects of glioma care deemed important by the Dutch Neuro-Oncology Society (Landelijke Werkgroep Neuro-Oncologie, LWNO). Currently, this quality aspect is not yet met in most hospitals and the LWNO has initiated a study to assess how this can be achieved. A first step was to gain more insight in the preferred type of PRO(M)s, frequency and method of assessments, and the willingness to discuss the results of PROMs. In addition, practical barriers for implementation needed to be identified. Here we present

the perspectives of patients, their proxies and HCPs on the practicality of measuring PROs in clinical practice of glioma patients in Dutch hospitals.

Methods

Study design

In this cross-sectional study, we evaluated the view of patients, proxies and HCPs (including both physicians and nurses) using semi-structured interviews on the practicability of measuring PROs in clinical practice of glioma patients in four academic and four non-academic (teaching) hospitals in the Netherlands. Written consent was obtained from patients and proxies.

In addition, an inventory was sent to the local principal investigator (PI) of each hospital to assess aspects of their infrastructure which were deemed important to measure PROs in a clinical practice setting.

Study population and sample size

Per center, three adult patients with a histologically confirmed glioma visiting the neuro-oncology outpatient clinic, their proxies (if available and willing to participate), and HCPs on a regular basis involved in the treatment of glioma patients were recruited. Patients were selected by their treating physician based on purposive sampling (i.e. heterogeneous sample with respect to tumor type). Patients had to have sufficient understanding of the Dutch language to undergo the interview, as determined by the treating physician. Proxies were eligible if they were a spouse, family member or close friend of the patient, providing emotional and physical support. Lastly, we aimed to include a neuro-oncologist, neurosurgeon, radiation oncologist, medical oncologist, nurse specialist per center.

Data collection

Sociodemographic and disease-related characteristics of patients were obtained from the medical records or via the study-specific questionnaire. In addition, information about the HCPs and proxies was retrieved by means of an interview.

The interviews, based on directed content analysis, were pilot tested and conducted by two trained researchers without any relationship to the patient (GSGJO, medicine student and MCMP, PhD student). Interviews took place by means of a telephone call or at the patients' home, depending on their preference, and were digitally audio recorded with permission of the participant.

The following topics were discussed with patients and proxies (open questions): (1) willingness to discuss PROM results and reasons for not wanting to complete

PROMs; (2) preference for a specific HCP (physician/nurse) to discuss PROM results with and reasons for this specific choice; (3) preference for prespecified topics (that could be measured with PROMs) and the three most important topics; (4) preferred frequency of completion of PROMs; and (5) preference to complete PROMs on paper or digitally with reason. HCPs also had to answer questions 1-4, but in addition answered a question (6) on their ability to interpret PROM results and on the necessity to train HCPs to interpret the results obtained with different PROMs. Furthermore, data on the infrastructure (e.g. human resources, available systems, etc.) in each participating center was assessed by means of a questionnaire sent to the local PI.

Analysis

This study was designed to combine both qualitative and quantitative analysis. The interviews were independently and thematically analyzed per topic by two researchers (GSGJO and LD), according to the framework approach¹⁶. This approach consists of seven stages; (1) transcription of the data, (2) familiarization with the interview, (3) coding of the data, (4) development of a working analytical framework, (5) application of the analytical framework, (6) charting data into the framework matrix, and (7) interpretation of the data. Disagreements were resolved in consensus. If data saturation was not achieved after the intended number of patients, more patients would be approached. Due to the limited sample size and the qualitative nature of the data resulting from the interviews, findings were not reported as numbers or percentages, but merely as general descriptions.

Descriptive statistics have been used to report patient- and tumor-related characteristics, characteristics of proxies and HCPs and to quantify data, only where relevant, from the interviews. All quantitative analyses were performed with SPSS 23.0 for Windows.

Results

Participant and interview characteristics

Table 1 shows the characteristics of the participants; 24 patients, 16 partners and 35 HCPs. Interviews lasted a median of 12 minutes (range 4-323). One patient interview was not considered, as the recorder stopped recording after 35 seconds.

Question 1. Willingness to discuss PRO results

Overall, most participants were willing to discuss the results of PROMs during a consultation (Supplementary figure 1). The reason patients/proxies, and a minority of HCPs, did not want to discuss results was that they felt it had no added value. Some

HCPs, mostly physicians, indicated that they had insufficient time or considered this a task for the nurse specialist.

The most frequently mentioned reasons to discuss PROM results by all participants were to generate new or other information, focus on topics that are important for patients, and monitoring and solving problems (Supplementary Table 1 for all reasons). A minority of patients wanted to compare their level of performance with other brain tumor patients. About a quarter of HCPs also mentioned that PROMs are a tool to better structure the consultation.

Table 1. Sociodemographic and clinical characteristics of patients, proxies and health care professionals participating in a study on the practicality of routinely measuring patient-reported outcomes in clinical practice for glioma patients

	Patients n=24	Proxies n=16	Health care professionals n=35
Sex, n (%)			
Women	13 (54%)	7 (44%)	15 (43%)
Men	11 (46%)	9 (56%)	20 (75%)
Age (years), median (range)	53 (37-71)	50 (37-66)	47 (36-65)
Level of education, n (%)			
Low	10 (42%)	9 (56%)	
High	14 (58%)	7 (44%)	
Marital status, n (%)			
Single	1 (4%)	-	-
With partner	23 (96%)		
Time since diagnosis (months) median (range)	29 (1-227)	-	-
WHO ¹ 2016 grade			
Diffuse astrocytoma, IDH ⁺ mutant	3 (13%)		
Diffuse astrocytoma, NOS	1 (4%)		
Anaplastic astrocytoma, IDH mutant	2 (8%)		
Glioblastoma, IDH wildtype	8 (33%)		
Glioblastoma, IDH mutant	1 (4%)		
Glioblastoma, NOS	2 (8%)		
Oligodendroglioma, IDH mutant and 1p19q codeleted	3 (13%)		
Oligodendroglioma, NOS			
Missing	2 (8%)		
Tumor location, n (%)			
Left hemisphere	12 (50%)	-	-
Right hemisphere	12 (50%)		
Tumor position, multiple options possible n (%) ^a			
Frontal	11 (46%)	-	-
Occipital	4 (17%)		
Temporal	10 (42%)		
Parietal	8 (33%)		

Table 1. Continued

	Patients n=24	Proxies n=16	Health care professionals n=35
Previous anti-tumor treatment, n (%) ^a			
Resection	19 (79%)	-	-
Re-resection	3 (13%)		
Chemotherapy	15 (63%)		
Radiotherapy	20 (83%)		
Current anti-tumor treatment, n (%) ^a			
Chemotherapy	10 (42%)	-	-
Radiotherapy	4 (17%)		
Karnofsky performance Status (KPS) score median (range)	80 (70-100)	-	-
Specialism, n (%)			
Neuro-oncologist	-	-	10 (29%)
Neurosurgeon			4 (11%)
Radiation oncologist			8 (23%)
Medical oncologist			4 (11%)
Nurse specialist			9 (26%)
Experience with care of gliomas (years), median (interquartile range)	-	-	10 (6-18)
Number of gliomas treated on an annual basis, median (interquartile range)	-	-	50 (35-100)
Duration interview in minutes (median (range))	14 (6-32)	9 (4-19)	12 (7-20)

[†]WHO: World Health Organization. [‡]IDH: isocitrate dehydrogenase. ^aMultiple options possible.

Question 2. Preference for HCPs to discuss results of PROMs with patients

Half of patients and one third of proxies indicated that they preferred to discuss the results with the physician, the main reason being that the physician has more medical knowledge. Others preferred discussion of the results with the nurse specialist, mainly because they are more accessible and more frequently in contact with patients. The remaining patients and proxies indicated that both the nurse specialist and physician should discuss the results, or had no preference (Figure 1).

All HCPs indicated that a nurse specialist should be involved in the discussion of the results. More specifically, half of the HCPs reported that the results should be discussed by the nurse specialist only (8/9 nurse specialist preferred this versus 10/26 physicians), while almost half of the HCPs indicated that the nurse specialist should discuss these results extensively, and subsequently inform the physician. The preference for the nurse specialist was substantiated by the consideration that the nurse specialist has more time and tranquility, is more approachable and has more experience with psychosocial topics (Supplementary Table 2 for all reasons).

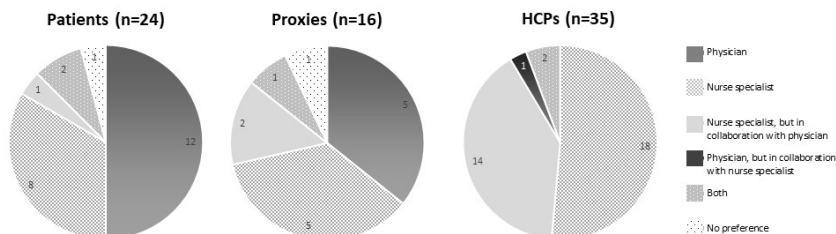


Figure 1. Preference of patients and proxies for a specific healthcare professional (HCP) to discuss the patient-reported outcome results with, as well as the preference of HCPs.

Question 3. Preference for topics of PROMs

Participants were presented a list of possible topics to be measured. In patients, cognitive complaints (75%), followed by functioning of daily life (67%) and HRQoL (50%) were most frequently reported as being important. Proxies reported HRQoL most frequently (63%), followed by cognitive complaints (56%) and functioning in daily life (50%). Both patients and proxies mentioned the topic mood less often (17% and 19%, respectively).

In contrast, HCPs reported functioning of daily life (77%) most frequently, followed by mood (including anxiety and depression; 60%) and symptoms and signs (57%). Furthermore, about a quarter of HCPs indicated that it would also be important to include questionnaires to evaluate the patients' experiences with care. Table 2 presents an overview of all preferences.

Question 4. Preferred frequency of completing PROMs

In line with the frequency of standard follow-up visits, the majority of low-grade glioma patients and HCPs indicated that a PROM should be completed twice a year (71% and 51%, respectively) and four times a year for high-grade glioma patients (35% in patients versus 43% in HCPs). Other preferences are displayed in Supplementary Figure 2.

Question 5. Preferences to complete PROMs

Overall, patients and proxies had a similar preference for the completion of PROMs on paper or digitally (Supplementary Figure 3). Reasons to prefer one mode over the other was that participants found that specific mode of administration more pleasant or convenient.

Moreover, all patients and proxies preferred to complete questionnaires at home, and liked to receive the questionnaires one week, or a few days, in advance.

Table 2. Preference for topics of patient-reported outcome measures

Topics	Glioma patients			Proxies (n=16)	Health care professionals (n=35)
	Total (n=24)	Low-grade glioma (n=7)	High-grade glioma (n=17)		
Health-related quality of Life (n)	12	4	8	10	19
Symptoms and signs (n)	10	2	8	7	20
Mood (n)	4	1	3	3	21
Cognitive complaints (n)	18	7	11	9	17
Functioning in daily life (n)	16	6	10	8	27

n = number

Question 6. Ability to interpret PRO results

Slightly more than half of HCPs had previously worked with PROMs, mostly in clinical practice or in the context of a clinical trial. About half of HCPs answered that they were able to interpret the results of PROMs, the main reason being that the results speak for itself, while about one third indicated that they need some explanation. Only 20% of HCPs (all physicians) said they could not interpret the results because of a lack of knowledge. Notably, only about half of HCPs who had ever worked with PROMs in clinical trials or even practice indicated they were able to interpret the results. The majority of HCPs indicated that training would be necessary to interpret the results uniformly.

Infrastructure

All eight participating centers indicated that it is possible to send questionnaires to patients on paper, for which staff is available, i.e. the nurse specialist (63%) or the secretary (38%). In almost all centers (88%) this person could also monitor when a completed questionnaire is returned and when a new questionnaire should be sent. In 75% of hospitals the completed questionnaires could be loaded into the hospital system as a document only.

Only 3/8 (38%) of the centers, one academic and two non-academic, had the possibility to send questionnaires digitally and 2/3 centers had an online system available to send the questionnaires by the nurse specialist, although it was not possible to calculate scores automatically or present results graphically.

Discussion

This study on the practicality of routinely measuring PROs in the care of glioma patients in Dutch hospitals focused on the perspective of patients, their proxies and clinicians. We found that patients and their proxies, as well as HCPs are positive regarding the discussion of PROM results during a consultation. Potential advantages were the generation of new or other information that is potentially useful in treatment decision-making, better focus on issues that are important to the patient, and better ability to monitor and solve patient-perceived problems. Possible barriers included the interpretation of the results, lack of suitable online tools, lack of time and the preference of patients and their proxies to discuss PROM results with their treating physician, whereas HCPs indicated that the results should preferably be addressed during consultations with nurses.

In other diseases, similar results with respect to implementation of PROMs in clinical practice have been found. Indeed, barriers for HCPs were lack of training and practice on the interpretation of PROM results, and lack of time¹⁷. Furthermore, patients' compliance with the completion of PROMs is an important barrier. For example, in a study on the administration of the Short Form Health Survey 36 (SF-36) questionnaire in the general population, patients with a lower educational status and those over 75 years old had more missing data and were inconsistent in their answers¹⁸, limiting the value of routine PROM assessment. In glioma patients, the median age at diagnosis ranges from 43-63 years¹⁹, with more than half of them being highly educated, so their ability to complete PROMs is likely to be relatively favorable. Nevertheless, in daily clinical care impaired health literacy and neurocognitive problems could possibly play a role in non-completion of PROMs. In those cases, proxies may be considered the source of information on the patients' functioning and well-being.

An important issue with the implementation of PROMs in routine care is not only to administer them, but also to act according to the obtained results and taking the necessary follow-up steps, e.g. an intervention or referral^{17,20}. A review on screening for cancer-related distress showed that psychosocial care was received in only 20-30% of patients that indicated problems, and that patients were most likely to receive psychosocial care if screening was directly linked with an intervention or referral¹⁷. The Dutch study on the organization of glioma care, initiated by the LWNO and which led to the initiation of the current study, found that more than half of the neurologists in the Netherlands do not screen for physical and neurocognitive impairments, HRQoL and/or psychosocial care²¹. Importantly, they found that psychosocial care in neuro-oncological hospitals is still is not widely available.

Regarding the topics that were considered most important to measure with PROMs, we found that functioning of daily life was considered important by all participants. Particularly instrumental activities of daily living (IADL) (e.g. activities such as

housekeeping or working) may be important for glioma patients, as these activities are sensitive to changes in neurocognitive functioning, which is characteristic of brain tumor patients²². An instrument to measure IADL in brain tumor patients is currently under development²³. Moreover, neurocognitive complaints, symptoms and signs, and mood were also considered important. A multidimensional questionnaire addressing all relevant aspects seems preferable. Implementation of selected PROMs in glioma routine care would be the next step. We found that most patients and a third of proxies preferred to discuss PROM results with the physician, the main reason being that the physician has more medical knowledge. However, most HCPs found the nurse specialist more suitable, since they often have the role of case manager, more time for their consultation, and more experience with psychosocial topics. Therefore, we recommend that the nurse specialist discusses the results with the patients, and then provides the treating physician with a short summary of this discussion, focusing on issues that require action from the physician. Regarding the timing of PROMs, patients and proxies in our study indicated that they were willing to complete PROMs at standard follow-up (MRI) visits, two times a year for low-grade and four times for high-grade gliomas. This is both practical and valuable, as possible changes in functioning and well-being can be detected within this time period, which can also be linked to radiological and neurological outcomes.

Another barrier in the implementation of PROMs in routine practice are the anticipated difficulties interpreting PROM results. Indeed, the scoring systems of PROMs that are regularly used in glioma care may be perceived as complicated. Scores of scales/domains can in most cases not be directly interpreted from completed questionnaires, but need to be calculated first. Furthermore, in the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (QLQ)-C30 for example, a higher score may reflect better functioning but also more symptomatology, complicating interpretation²⁴⁻²⁷. To facilitate the knowledge of HCPs on assessment, interpretation and discussion of PROM results, we would recommend a repeated training by the (inter)national organizations (in person or via an e-learning, which is currently developed at the EORTC) for HCPs. Moreover, the introduction of an electronic data capture system would be very useful to facilitate PRO assessment in clinical practice, as such a system can calculate scale/domain scores and also visually display the results over time^{28, 29}. To standardize psychosocial care, it would be desirable if one electronic system with graphic or calculating functions could be introduced in as much hospitals as possible. See also Table 3 for an overview of all recommendations.

As this study had a qualitative design, reported frequencies must be interpreted with caution. Given the relatively small number of patients included in the study, it was not possible to draw conclusions on possible differences in preferences of low- and high grade glioma patients. Patients and proxies were purposefully selected in order

Table 3. Recommendations assessment of patient-reported outcomes in Dutch neuro-oncological care

Question	Topic	Recommendations
1-2	Discussion of PRO results	We recommend that the nurse specialist discusses the results of the PROMs with the patients and the physician receives a short summary of this discussion, which can subsequently be used during their consultation.
3	Preference for topics	We recommend questionnaires about functioning in daily life and HRQoL.
4	Frequency of completing PROMs	We recommend to link PRO assessment to standard follow-up (MRI) visits of patients.
5	Preference to complete PROMs on paper or digitally	We recommend implementing an electronic data capture system in all hospitals to facilitate PRO assessment and interpretation. However, for those patients that are not willing to complete the questionnaires online, assessment on paper should be offered.
6	Ability to interpret PRO results	We recommend organizing a training (whether organized in person by the (inter)national working groups or via an e-learning) for HCPs in the interpretation and discussion of PROM results to standardize the neuro-oncological care.

to represent heterogeneity within this population, however the proportion of patient with different characteristics may be significantly different from the average glioma population. Another limitation is that selection bias may have occurred through the purposeful sampling and small sample size. Nevertheless, data saturation was reached with this population and conclusions would probably not have changed if we had recruited more participants. Patients who agreed to participate might be more interested in the completion of PROMs. Also, the number of patients and their reasons for non-participation were not systematically recorded, and not all specialist were willing to participate, resulting in the finding that not all hospitals represented all professionals backgrounds. However, we interviewed a heterogenous population including patients, proxies and HCPs, recruited from both general and academic hospitals throughout the Netherlands. Although the situation in the Netherlands may differ from other countries, for example with respect to the availability of a nurse specialist, the results highlight solutions that could possibly be considered to improve the care.

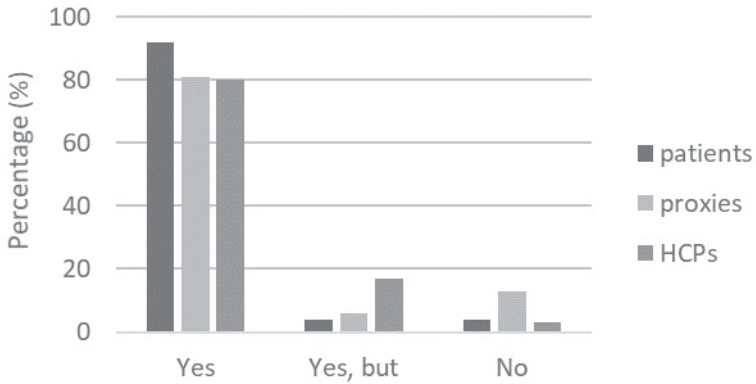
In conclusion, this study shows that routine assessment of PROMs is desirable by patients, proxies and HCP's in neuro-oncological care in Dutch hospitals. Overall, we recommend to routinely measure PROs in glioma patients using an electronic data capture system with a focus on functioning in daily life and symptoms, preferably assessed during standard follow-up moments and first discussed with the nurse specialist. A next step would be to implement routine monitoring of PROMs in glioma care and to evaluate its impact on the outcomes of patients as well as the perceived quality of care.

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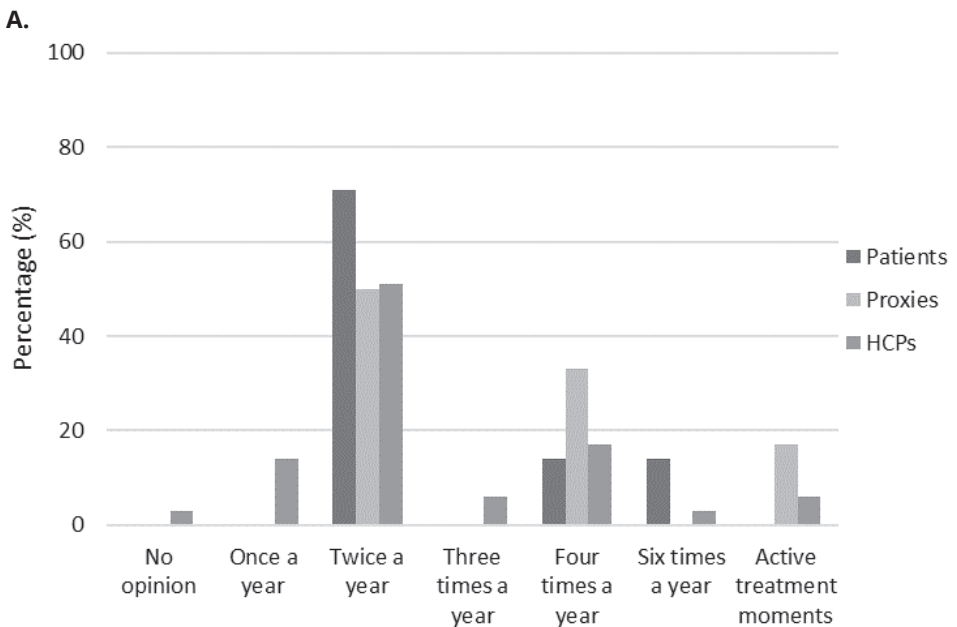
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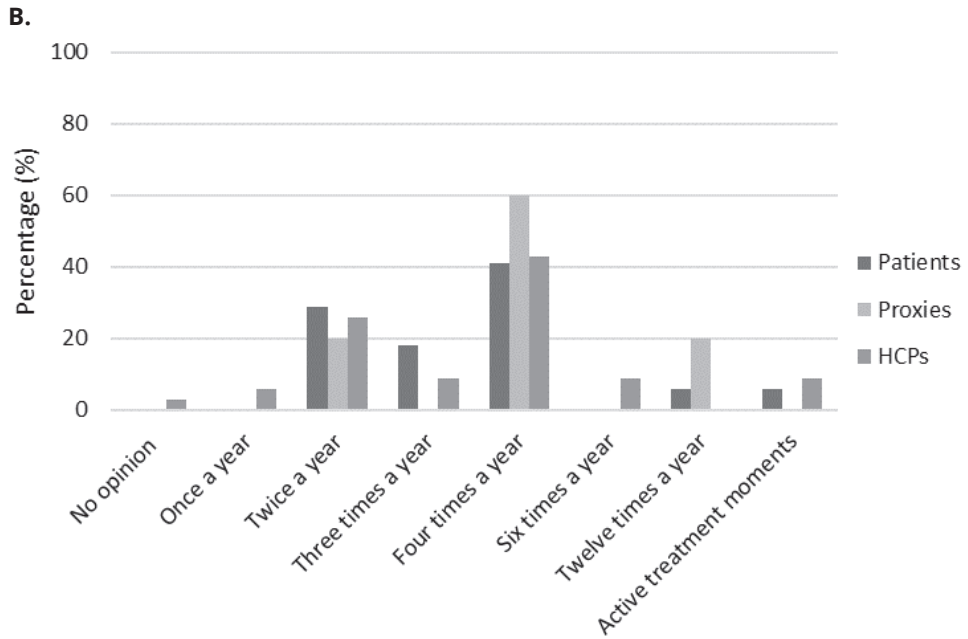
Supplemental material



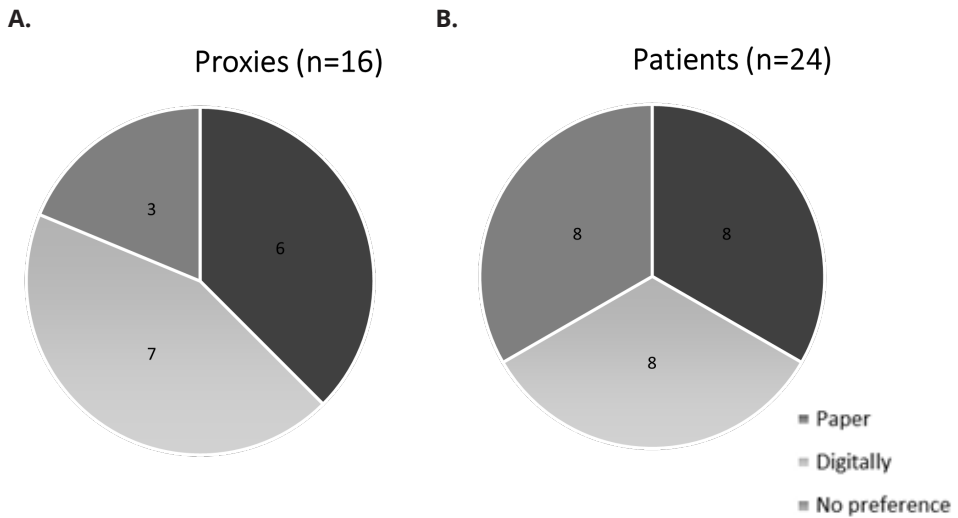
Supplementary Figure 1. Percentage of participants willing to discuss patient-reported outcome (PRO) results



Supplementary Figure 2A. Preferred frequency of completing PROMs, separately for low-grade glioma (A) and high-grade glioma (B) patients (see next page)



Supplementary Figure 2B.



Supplementary Figure 3. Preference to complete patient-reported outcomes (PROs) on paper or digitally, separately for patients (A) and proxies (B)

Supplementary Table 1. Reasons to discuss PRO results, separately for patients, their proxies and health care professionals

	Patients (n=24)	Proxies (n=16)	HCPs (n=35)
Generation of new or other information (n)	11	5	19
Focus on topics that are important for the patient (n)	2	4	17
To monitor and solve problems (n)	4	2	11
To improve the care of glioma patients (n)	2	0	6
Better communication between the patient and HCP (n)	1	1	0
Having someone to listen (n)	0	1	0
To better structure the consultation (n)	0	0	9

n = number

Supplementary Table 2. Reasons to discuss results with physician or nurse specialist, separately for patients, their proxies and health care professionals

	Patients (n=24)	Proxies (n=16)	HCPs (n=35)
Nurse specialist has more time and rest (n)	1	1	25
Nurse specialist is more accessible (n)	4	3	13
Nurse specialist has more experience with psychosocial topics (n)	1	2	12
Discuss results with the nurse specialist to relieve the physician (n)	1	0	5
Patient is the responsibility of the physician (n)	0	0	7
The nurse specialist has the role as case manager (n)	2	2	8
The physician has the role as case manager (n)	2	2	0
Physician has more (medical) knowledge (n)	4	4	0
More confidence in the physician (n)	2	0	0
Most frequent contact with the physician (n)	4	0	0
Most frequent contact with the nurse specialist (n)	4	2	0
More information for the physician (n)	3	0	0
Good contact with all HCPs (n)	1	1	0
Both have enough knowledge (n)	1	0	0

n = number