

Shared decision making in high-grade glioma patients—a systematic review

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Abstract

Background. Shared decision making (SDM) has proven to be a valuable approach in different patient populations when treatment decisions are called for. Along the disease trajectory of high-grade glioma (HGG), patients are presented with a series of treatment decisions. At the same time, HGG patients often experience cognitive deterioration and reduced decision-making capacity. This study aimed to review the current knowledge about shared decision making from the perspective of the HGG patient.

Methods. Systematic searches were performed in MEDLINE, CINAHL, PsycINFO, and EMBASE. Studies were reviewed against the inclusion criteria and assessed for methodological quality. Descriptive data from the included studies were extracted and a narrative synthesis of the findings was performed.

Results. The searches resulted in 5051 original records. Four studies involving 178 HGG patients fulfilled the inclusion criteria. The narrative synthesis revealed that most HGG patients in the included studies appreciated an SDM approach and that sufficient information and involvement increased patients' emotional well-being. The use of a patient decision aid showed the potential to increase knowledge, decrease uncertainty, and affect the treatment decision making of HGG patients.

Conclusion. The results indicate that many HGG patients prefer an SDM approach and that SDM can lead patients toward improved emotional well-being. The evidence is weak, however, and firm conclusions and practice guidelines concerning SDM in HGG patients cannot be made. Future research is warranted to improve decision support for HGG patients.

Keywords

brain cancer | high-grade glioma | patient involvement | shared decision making

Shared Decision Making

Shared decision making (SDM) is a decision-making process in which a shared decision is reached based on the clinician's professional expertise and the patient's knowledge of his or her own health, values, and preferences.^{1,2} One aspect of SDM is the use of patient decision aids, which have been found to increase the patient's awareness of specific treatment options and help patients clarify and express their needs, values, and preferences. Patient decision aids are often online or paper-based tools that describe the decision at stake, provide evidence-based, balanced information about the different options and their tradeoffs, and encourage patients to reflect on their own values in relation to the decision.^{3,4} Patient decision aids have been developed and evaluated for a variety of health care decisions such as surgery, screening, genetic testing, and medication choices.⁴ In cancer populations, particularly within the area of prostate, colon, and breast cancer, SDM has been explored and found to increase patient awareness of specific treatment options and to help patients clarify and express their needs, values, and preferences.^{1,4,5} A patient decision aid can be used as a supplement to the clinician's standard information and help the clinician explain options in cases where one treatment is not definitively better than another.⁴ The use of SDM and decision aids has been shown to enhance the patients' knowledge and their experience of being sufficiently informed.⁴ Furthermore, it supports patient-clinician communication, increases patient involvement, and results in lower decisional conflict. SDM enhances the probability that all possible treatment options are discussed with the clinician responsible for treatment.⁴

Decision Making and High-Grade Glioma

High-grade glioma (HGG) is classified as gliomas grade III and IV according to the World Health Organization (WHO) and is a life-threatening type of brain cancer characterized by aggressive tumor growth.⁶ Both the disease and its treatment can result in substantial physical and cognitive impairments.⁷⁻⁹ Patients often feel a lack of control both over their future and daily life as well as an increasing dependency on relatives and health care professionals.^{7,8}

During the disease and treatment trajectory, HGG patients are required to engage in a variety of decision-making situations about treatment and care, keeping in mind that no curative treatment exists. At the same time, many patients experience that their reasoning, understanding, and decision-making capacity decreases.¹⁰⁻¹²

Though SDM has previously been studied in a range of cancer populations,⁵ for example, breast cancer,¹³⁻¹⁷ prostate cancer,¹⁸⁻²¹ and others,⁴ little is known about how HGG patients experience being involved in decision making about treatment and care. It can be speculated whether HGG patients' cognitive deficits and the life-threatening nature of the disease could impair active involvement in SDM and thus the effectiveness of SDM interventions for this patient population.

The objective of this study was to systematically review current knowledge about treatment decision making from the perspective of the HGG patient, with an emphasis on involvement preferences and how patient involvement in decision

making affects the decision made and the patients' emotional well-being related to feelings of anxiety, depression, uncertainty, satisfaction, and ability to cope with their disease.

Methods

Search Methods

Because of the scarcity of known studies exploring SDM from HGG patients' point of view, we decided to perform a full systematic review employing a very broad search strategy to uncover the existing evidence in the field.

Systematic searches were performed in MEDLINE, CINAHL, PsycINFO, and EMBASE databases on September 2, 2019. Additionally, reference and citation searches based on the included articles were performed using the Web of Science database. The review protocol was submitted to PROSPERO (ID137988) before the search was initiated. The search strategy was structured around the population (patients with HGG) and intervention (patient involvement in decision making) of interest and was developed in collaboration with a research information specialist. Searches included both free text and subject headings related to the overall search terms: "high-grade glioma" and "decision making." The searches were unlimited concerning language, publication date, and study design. (See [Supplementary material](#) for the complete search strategy.) Retrieved records were processed in the software programs Endnote (Endnote X9, Clarivate Analytics) and Covidence (Covidence systematic review software, Veritas Health Innovation), where duplicates were removed.

Eligibility Criteria

All study designs were eligible for inclusion if they were compatible with the review objective and met the inclusion criteria outlined as follows: Full-text, published, and peer-reviewed empirical studies with a patient population of adult (age ≥ 18 years) study participants diagnosed with HGG WHO grade III or IV were included if they explored the treatment decision-making process from the patient's point of view with an emphasis on patient involvement and SDM. Studies performed on a mixed cohort of HGG patients and other patient populations were eligible, but only if the results directly relating to the HGG patients could be extracted and included in the synthesis. Studies on patients with other types of brain tumors or brain tumors without WHO classification were excluded. Likewise, studies exploring SDM from perspectives other than that of the patients were excluded.

Study Selection and Data Extraction

Titles and abstracts were reviewed in the software program Covidence by 2 authors (H.S.E., K.P.) independently. Potentially eligible studies and studies whose title and abstract carried insufficient information to make a decision were read as full-text articles by H.S.E. and K.P. and

assessed against the inclusion criteria. Disagreements were solved through discussion. Data relevant to the review objective were extracted from the selected studies, using a predefined template, including study design, participants, the decision in focus, intervention, and patient-reported outcomes. HSE and KP discussed the data to ensure that all relevant data were extracted. A third author (F.P.) assessed the extracted data sheets, and potential disagreements on the relevance of the extracted data were discussed and solved.

Quality Assessment

Validity and methodological quality of the included studies were assessed by using the mixed methods appraisal tool (MMAT).^{22–24} The MMAT is based on 2 general screening questions and 5 specific questions for each study design for concomitantly appraising qualitative, quantitative, and mixed-methods studies.²³ The questions were answered by “yes,” “no,” or “can’t tell,” and questions not applicable for the specific study design were marked NA. H.S.E. and K.P. carried out the quality assessment individually, and potential disagreements were discussed and a consensus obtained with a third author (F.R.P.). The assessments were performed to gain insight into the methodological quality of the eligible articles and resulted in no further exclusions.

Narrative Synthesis

Because of the potential diversity between the eligible study designs, we decided to perform a narrative synthesis guided by the review objective. Inspired by Popay et al,²⁵ we divided the synthesis into 3 steps: (i) developing a preliminary synthesis, which is presented in the narrative synthesis section; (ii) exploring the relationships and differences within and between the studies; and (iii) assessing the robustness of the synthesis in the discussion and limitations. A minimum of 2 included studies was required for the synthesis. For studies performed in mixed patient cohorts, only data regarding participants with HGG were included in the synthesis.

Results

Search Results

The systematic search in the databases resulted in 6266 records. No eligible records were found in additional reference and citation searches. After the removal of duplicates in Endnote, 5302 records were imported into Covidence. Further duplicates were identified and removed, resulting in 5051 original records. When screening titles and abstracts, we allocated all studies regarding even elusive aspects of SDM in an HGG or brain tumor context to full-text screening. H.S.E. and K.P. assessed independently in full text the resulting 24 records. The vast majority of the excluded 5047 records were based on studies regarding

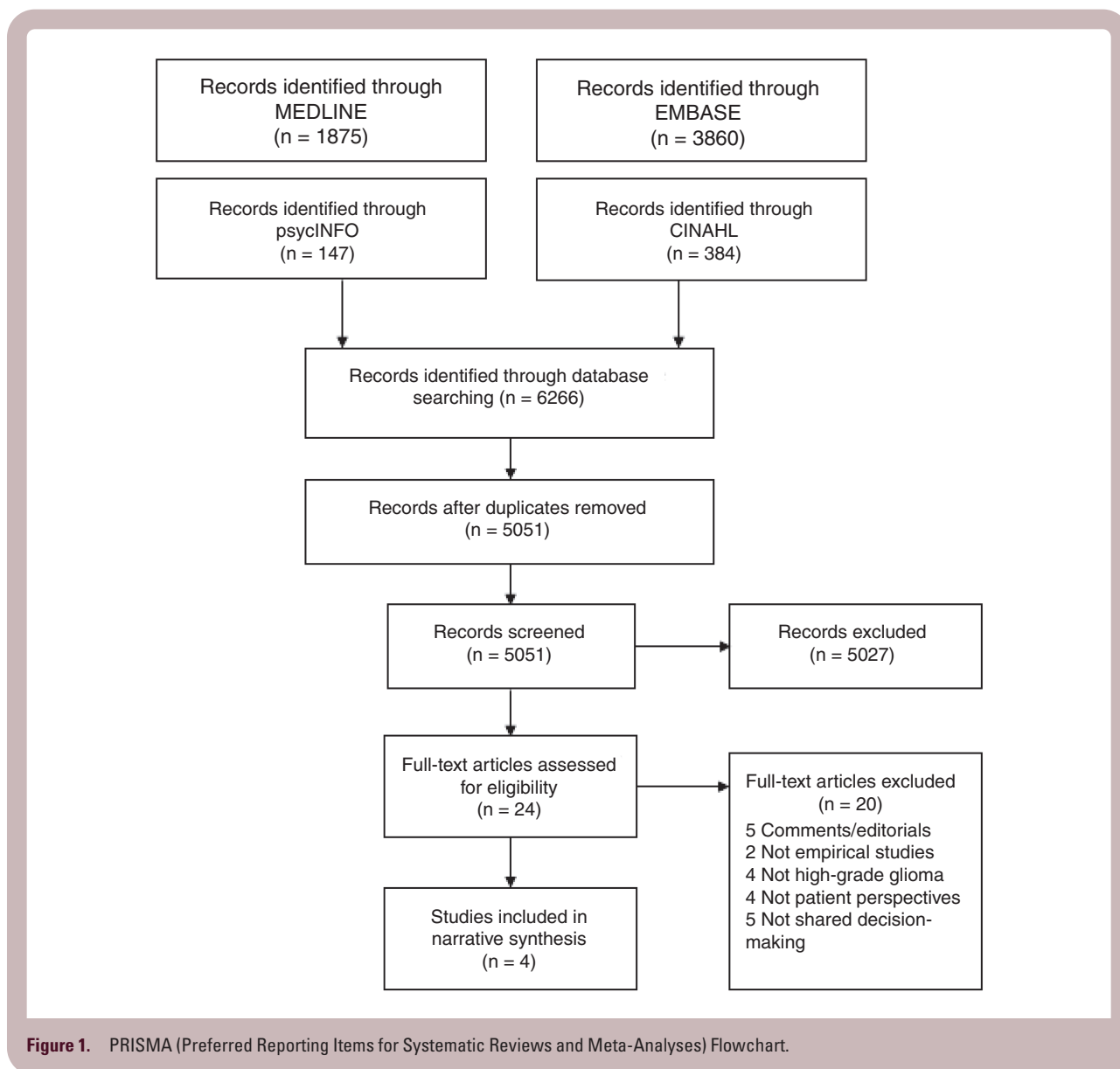
diagnostics, prognostics, or treatments related to HGG patients or other patient populations without any information on SDM. No SDM-related studies were excluded based on the inclusion criteria for mixed patient cohorts or the perspective of family caregivers. The screening and selection processes are outlined in the PRISMA (Preferred Reporting Items for Systematic reviews and Meta-Analyses) flowchart²⁶ (Figure 1).

Design and Characteristics of the Included Studies

Four studies including 178 HGG patients met the inclusion criteria. Owing to the diversity of the included studies, they will be described individually. Study characteristics are also presented in Table 1. Each study is presented chronologically based on year of publication.

The study by Díaz et al²⁷ is a quantitative descriptive study with the purpose of analyzing the relationship between information and anxiety in patients with HGG during the surgical decision-making process. The participants were all inpatients with a suspected diagnosis of HGG, and the decision at stake was whether to undergo primary surgical treatment. The suspected diagnosis was later confirmed in all included participants. Patients who were unable to comprehend information or make decisions and patients who did not want any information about their disease were excluded from the study.²⁷ At time of discharge, the participants answered a paper-based, 5-item questionnaire developed by the study authors about their information preferences, comprehension of information, experiences of sharing worries and asking questions to health professionals, the health professionals’ attentiveness and listening, and satisfaction with the information received.²⁷ Anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS), and data were collected from interviews performed by a psychologist.²⁷

The randomized controlled trial (RCT) by El-Jawahri and colleagues²⁸ aimed to explore how adding a video decision aid to basic verbal information affected HGG patients’ treatment preferences at the end of life.²⁸ The verbal information and the video both presented 3 levels of care: life-prolonging care, basic medical care, and comfort care. All included participants had a verified diagnosis of HGG and were randomly allocated by a computer randomization scheme to either the intervention (verbal information + video) or the control group (verbal information alone). Patients with a Mini-Mental Status Examination (MMSE) score below 24 were excluded from the study.²⁸ After the participants had listened to the verbal information (control group) or listened to the verbal information and watched the video (intervention group), they were asked about their preferences for level of care at the end of life and their preferences toward cardiopulmonary resuscitation (CPR). Knowledge was assessed using 6 questions about CPR in hospitals, and decisional conflict was measured using the Decisional Conflict Scale. Participants in the intervention group were also asked about how comfortable they were watching the video and how helpful they found it. All outcome data were collected through



a structured interview by a nonblinded research team member.²⁸

The quantitative descriptive study by Lucchiari et al²⁹ focused on the relationship between participants' information and involvement needs and their health-related quality of life. The included participants were inpatients diagnosed with HGG within 3 months prior to participating and undergoing oncological treatment. Eligible participants were assessed for cognitive status and excluded if they presented with any serious clinical condition.²⁹ The decisional needs of the participants were assessed using 8 information and involvement questions selected from a validated Needs Evaluation Questionnaire (NEQ). Based on the results of the NEQ, the participants were divided into 3 clusters: 1) complete satisfaction and no unmet needs, 2) a need to be more involved in decision making, and 3) at least 3 instances of unspecified unmet information and/or involvement needs. Performance status and cognitive ability were assessed using the KPS and MMSE, respectively. There was a sex imbalance between the clusters, with significantly

more men in cluster 3. Otherwise, the clusters were homogeneous with regard to age, education, MMSE, and KPS. Health-related quality of life and the participants' level of anxiety and depression were measured both at baseline and after 3 months. The assessments were based on the Functional Assessment of Cancer Therapy–Brain (FACT-Br) scale and HADS. The article did not describe how assessments were performed or how data were collected.²⁹

The study by Brom and colleagues³⁰ is a qualitative interview-based study with the objective of obtaining insight into cancer patients' preferences for involvement in treatment decision making at the end of life. The study had a mixed participant cohort consisting of 64.3% HGG patients and 35.7% metastatic colon cancer patients. Participants with HGG were included at the beginning of their adjuvant temozolomide treatment. HGG patients with disease progression and cases where the clinician thought participation would be too burdensome for the patient were excluded. Inclusion was ended when theoretical data saturation was reached.³⁰ Data were collected

Table 1. Characteristics of Included Studies.

Study	Study design	Objective	Participants (N total/high-grade glioma patients), age range, y	Decision(s)	Intervention	Patient-reported outcomes
Díaz et al, Spain, 2009 ²⁷	Quantitative descriptive	To analyze relationship between anxiety and information during surgical decision-making process	Inpatients in diagnostic phase (26/26), 45-81	Primary surgery or not	None	Experience of communication and information; anxiety and depression
El-Jawahri et al, USA, 2010 ²⁸	Quantitative randomized controlled trial	To determine whether use of a goals-of-care video can improve end-of-life decision making for patients with cancer	Outpatients in unspecified disease and treatment phases (50/50), 32-77	Preferred level of care at end of life	Video-based decision support tool	Preferences for level of care; decisional conflict; perceived value of intervention
Lucchiari et al, Italy, 2010 ²⁹	Quantitative descriptive	To evaluate health-related quality of life in patients grouped according to different decisional needs	Inpatients diagnosed within 3 mo prior to participating (84/84), 26-65	Nonspecified future treatment decisions	None	Information and involvement needs; anxiety and depression; health-related quality of life
Brom et al, Netherlands, 2014 ³⁰	Qualitative individual interviews	To obtain insight into cancer patients' preferences for involvement in treatment decision making at end of life	Outpatients about to begin adjuvant chemotherapy (28/18), 27-82	Nonspecified end-of-life treatment decisions	None	Preferences for involvement in decision making

through semistructured interviews guided by questions about the participants' preferences for involvement in decision making and their communication with physicians. The Control for Preference Scale was used to initialize the preference discussions. All interviews were performed by the first author. Interviews were recorded and transcribed verbatim and the data were coded through a constant comparative method. Two authors independently developed a list of codes, and key themes were identified through discussion in the research group.³⁰

Methodological Quality Assessment

All 4 studies had a clear research question, and the collected data in each study were appropriate to answer the respective research question.^{23,24} The methodological quality assessment is presented in [Table 2](#).

The study by Díaz et al²⁷ used a consecutive sampling strategy among inpatients with HGG. Among the eligible patients, 21.1% were excluded because either the patient or the patient's family did not want the patient to be informed. Because the variable of interest in the study was the patients' experience of information during the surgical decision-making process, the exclusion of patients because of information preferences represents a high risk of nonresponse bias. This is also acknowledged by the study authors. The study applied a study-specific questionnaire that had not been evaluated for its psychometric properties. The descriptive and differential statistical analysis seemed appropriate to answer the research question.

In the RCT study by El-Jawahri et al,²⁸ the random assignment was appropriately performed by using a

computer randomization scheme. Baseline characteristics of the 2 groups showed that despite random assignment, the participants in the intervention group had a higher mean age, a higher percentage of male patients, and a lower percentage of married people compared to controls, suggesting that the study was underpowered. There was no significant difference in baseline knowledge or preferences toward CPR between the groups. All participants completed the study and adhered to the assigned intervention. The outcome assessments were performed by a nonblinded research team member, which imposes a high risk of bias.²⁸

The study by Lucchiari and colleagues²⁹ applied a consecutive sampling strategy among inpatients with HGG undergoing oncological treatment. Among the eligible 109 patients, 15 patients (13.76%) declined to participate for unknown reasons. We, therefore, assess the risk of nonresponse bias to be low to moderate. The study used 8 selected items from the NEQ to divide the participants into 3 decisional needs clusters. The questionnaire had been tested and evaluated for its psychometric properties in its full length as an instrument to evaluate the general needs of hospitalized patients,³¹ but the appropriateness of how it was used in this study had not been validated. The initial statistical analysis did not reveal any significant differences between the 3 clusters, but the applied post hoc analysis seemed appropriate for answering the research question.

We assessed the study by Brom et al³⁰ against the methodological quality criteria for qualitative studies because it was defined by the authors as a qualitative descriptive study. However, it applied a quantitative measurement in the form of a Control Preference Scale to support the

Table 2. Methodological Quality Assessment of Included Studies.

Methodological quality criteria		Díaz et al, 2009 ²⁷	El-Jawahri et al, 2010 ²⁸	Lucchiarri et al, 2010 ²⁹	Brom et al, 2014 ³⁰
Screening questions (for all types)	S1. Are there clear research questions?	+	+	+	+
	S2. Do the collected data allow the addressing of the research questions?	+	+	+	+
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?	NA	NA	NA	+
	1.2. Are the qualitative data collection methods adequate to address the research question?	NA	NA	NA	-
	1.3. Are the findings adequately derived from the data?	NA	NA	NA	+
	1.4. Is the interpretation of results sufficiently substantiated by data?	NA	NA	NA	+
	1.5. Is there coherence between qualitative data sources, collection, analysis, and interpretation?	NA	NA	NA	+
2. Quantitative randomized controlled trials	2.1. Is random assignment appropriately performed?	NA	+	NA	NA
	2.2. Are the groups comparable at baseline?	NA	-	NA	NA
	2.3. Are there complete outcome data?	NA	+	NA	NA
	2.4. Are outcome assessors blinded to the intervention provided?	NA	-	NA	NA
	2.5. Did the participants adhere to the assigned intervention?	NA	+	NA	NA
3. Quantitative nonrandomized	3.1. Are the participants representative of the target population?	NA	NA	NA	NA
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?	NA	NA	NA	NA
	3.3. Are there complete outcome data?	NA	NA	NA	NA
	3.4. Are the confounders accounted for in the design and analysis?	NA	NA	NA	NA
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?	NA	NA	NA	NA
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?	+	NA	+	NA
	4.2. Is the sample representative of the target population?	+	NA	+	NA
	4.3. Are the measurements appropriate?	?	NA	?	NA
	4.4. Is the risk of nonresponse bias low?	-	NA	+	NA
	4.5. Is the statistical analysis appropriate to answer the research question?	+	NA	+	NA
Score		5/7	5/7	6/7	6/7

Questions not applicable for the specific study design are marked NA; -, no; +, yes; ?, can't tell.

qualitative data. This could indicate that qualitative data collection methods alone were inadequate to answer the research question. The process of analysis and interpretation was clearly reported in the article, and there was coherence between the qualitative data sources, collection, analysis, and interpretation. We assessed the findings to be adequately derived from the data.

Narrative Synthesis

The focus of 2 of the included studies was on the participants' preferences for information and involvement in decision making. Díaz et al²⁷ found that 50% of the participants wanted to know everything about their illness, 23.1% wanted the most important information, and 26.9% wanted only the most critical information.²⁷ They also found a statistically significant difference between the participants younger than and older than age 65 wherein the younger participants preferred to have more information and also had a better understanding of the information received.²⁷ The main outcomes in the study by Brom and colleagues³⁰ revealed that most patients preferred an SDM approach and that no patients wanted to make the decision alone without considering the physician's expertise. If life prolongation was no longer an option, the participants anticipated that they themselves would want to be more involved in the decision making. Almost all participants found it difficult to define how much they wished to be involved in the decision making overall because they imagined that it would depend on the specific situation and decision at stake.³⁰

An RCT study by El-Jawahri et al²⁸ explored how the use of a patient decision aid affects the treatment preferences of HGG patients and found that the participants in the intervention group preferred a lower level of care compared to the control group. Specifically, 91.3% of the participants in the intervention group preferred comfort care over more invasive care levels and only 8.7% reported a preference for CPR.²⁸ In contrast to this, only 22.2% of participants in the control group preferred comfort care and 29.6% anticipated that they would want CPR.²⁸

Díaz and colleagues²⁷ studied how decision making and patient involvement in decision making affects the emotional well-being of HGG patients with regard to satisfaction, anxiety, and depression. They found that anxiety scores were lower for the participants satisfied with the given information during the decision-making process compared to those who were dissatisfied ($P < .001$). No differences in relation to depression were reported. The participants who had a good comprehension of the information ($P < .001$) and those who wanted to know everything about their illness ($P = .005$) also reported lower anxiety scores.²⁷ Lucchiari et al²⁹ also looked at anxiety and depression in relation to the participants' information and involvement needs but found no significant differences in relation to either anxiety or depression. Instead, they found that the participants in cluster 1, who reported complete satisfaction and no unmet decisional needs, had significantly better scores on the FACT emotional (mean values cluster 1: 20.62, SD 0.78; cluster 2: 17.69, SD 0.80; cluster 3: 17.27, SD 0.80) and socio/familial well-being scale (mean values

cluster 1: 21.69, SD 0.90; cluster 2: 17.69, SD 0.88; cluster 3: 16.77, SD 0.87) compared to participants in clusters 2 and 3, who had one or more unmet decisional needs.²⁹ The study by El-Jawahri et al²⁸ showed that the use of a video decision aid had a positive effect on the participants' emotional well-being in the form of less uncertainty regarding the decision making (intervention group: 13.7 [95% CI, 12.8-14.6] vs controls: 11.5 [95% CI, 10.5-12.6]; $P = .002$). The intervention group also gained more knowledge about the options (intervention group: 5.3 [95% CI, 4.7-5.8] vs controls: 4.6 [95% CI, 4.1-5.1]; $P = .08$). All participants in the intervention arm were very comfortable or somewhat comfortable watching the video, and 78.3% found it very helpful.²⁸

Relationships and Differences Between the Studies

Although all 4 studies investigated aspects of SDM from the patient perspective, they showed wide diversity in relation to design, scope, methods, and outcome measures. Additionally, none of the 4 studies focused on the same decisional situation.

Díaz et al²⁷ focused on a specific decision regarding whether to have primary surgery, whereas the studies by Brom and colleagues³⁰ and El-Jawahri et al²⁸ looked at the participants' anticipated decision-making preferences related to future treatment decision making at the end of life.^{28,30} The study by Lucchiari et al²⁹ specified neither the decision at stake nor the time of the decision in relation to the disease and treatment trajectory.

Moreover, the studies included participants who were in different phases of the disease. The studies by Díaz and colleagues²⁷ and Lucchiari et al²⁹ included participants early in the disease trajectory before²⁷ and during²⁹ primary treatment, whereas the study by Brom et al³⁰ included participants who had already ended their primary oncological treatment and were about to start adjuvant chemotherapy. In the RCT study, the inclusion criteria were not specified in relation to the participants' disease and treatment phase.²⁸

All studies excluded eligible participants with different degrees of cognitive impairment, but only the study by El-Jawahri and colleagues²⁸ used a validated tool to assess this. The 3 other studies excluded participants who were unable to make decisions or understand information,²⁷ participants who had a nonspecified serious clinical condition,²⁹ and participants for whom the physician thought participation would be too burdensome.³⁰ Patients who did not want to be informed about their disease²⁷ or who had disease progression at the time of inclusion³⁰ were also excluded.

Validated instruments were used in all of the included studies in combination with either newly developed study-specific instruments,^{27,28} instruments adjusted²⁹ specifically for the particular study, or supplemented by qualitative interviews.³⁰ The validated instruments used were HADS,^{27,29} the Decisional Conflict Scale,²⁸ FACT-Br,²⁹ the Control Preference Scale,³⁰ and a modified version of the NEQ.²⁹ Outcome assessments in 3 studies were partly or totally performed by interviews carried out by either a psychologist,²⁷ a member of the research team,²⁸ or the first author.³⁰ The study by Díaz et al²⁷ also included a paper

questionnaire. Lucchiari and colleagues²⁹ did not report how or by whom the outcome assessment was performed.

Discussion

Existing evidence about SDM from different patient populations shows that most patients wish to be involved in decision making about their own treatment and care and that sufficient involvement and information decreases uncertainty and increases the patients' knowledge and satisfaction.^{4,17,18,21,32,33} These trends are all reflected in the results from this review, indicating that despite the weakness of evidence and the fact that HGG patients differ from other patient populations in certain aspects, it is still relevant to consider SDM for this patient group.

The results from previous research regarding SDM are not uniform, however, and demonstrate differences both within and between studies, leading to the conclusion that even though most patients want to be involved, some patients prefer to leave the decision to the clinician or prefer not to have all the available information.^{4,15,18,32-34} These variances were also identified in this review wherein the study by Díaz et al²⁷ showed that half of the included participants wanted to know everything about their illness, whereas 26.9% wanted only the most critical information.²⁷ Likewise, the study by Brom and colleagues³⁰ highlighted that the participants' preferences for involvement varied according to the specific decision at stake.³⁰ This adds to the existing evidence and emphasizes that paying attention to the individual patient's information and involvement preferences is imperative in clinical practice.

The study by El-Jawahri et al²⁸ revealed that HGG patients who were exposed to a video decision aid preferred a less invasive treatment strategy compared to the control group without the video intervention.²⁸ The decision making in the study was based on the patients' anticipated treatment preferences at the end of life.²⁸ Whether these results from hypothetical decision making can reflect real treatment decision making in HGG patients is unknown because of the sparse evidence in the field. Nevertheless, studies of decision aids from other patient populations showed that patients exposed to patient decision aids tended to choose less invasive surgery and more conservative treatments.^{4,5} These results support the findings regarding HGG patients from this review and indicate that patient decision aids can affect the treatment choices of HGG patients.

Most HGG patients experience cognitive impairment in various degrees,¹⁰⁻¹² yet none of the 4 studies included in this review investigated the coupling between mental capacity and decision making. All studies assessed eligible participants for cognitive status and excluded patients who were considered to be too cognitively affected. We know from previous research in HGG patients that cognitive impairment increases through the course of the disease and often affects the patient's decision-making capacity.¹⁰⁻¹² These impairments call for special attention when considering SDM for this patient population. In particular, when informing patients about the different treatment options and the associated risks and benefits, it should be taken into account that HGG can diminish the capacity of patients to understand and

rationally weigh treatment options.^{10,12} In addition, none of the 4 studies included HGG patients with disease progression in their patient population, though evidence shows that all HGG patients will experience progression due to the aggressive and infiltrative nature of the tumor.³⁵ At the time of progression, the HGG patient is forced to engage in a series of challenging decisions regarding treatment and care,^{35,36} and it is of great importance that they receive the right support from the clinicians involved.

Limitations

Several limitations apply to this review. Most prominent are the limited number of studies, the methodological variability between the studies, and the small sample sizes in the eligible studies. Another consideration is whether the statistically significant results from the 3 quantitative studies reflect clinically important differences.

Although the search strings for this review have been developed under the guidance of research librarians and experts in systematic reviews, there may be studies that explore the topic peripherally that we have not found. Additionally, all studies were published between 2009 and 2014,²⁷⁻³⁰ which indicates that the latest developments within SDM research have not included patients with HGG.

Other limitations are i) none of the studies consider the role of relatives in the decision-making process, though previous research outlines the important role of relatives and family caregivers for patients with HGG,^{37,38} ii) patients with disease progression were not included in the study populations, and iii) the relationship between SDM and the patients' mental capacity was not investigated in any of the studies. These important limitations mean that the results found in this review reflect the situation of HGG patients only in good cognitive condition and who are early in the disease trajectory. Because the review results support the previous research in SDM and patient decision aids for other patient populations,^{4,5} we believe that some aspects could also be transferable to patients with low-grade gliomas, but future research is needed to explore this further.

Recommendations

The limitations of this systematic review highlight the need for future research regarding SDM from the perspective of HGG patients. In particular, studies considering the role of relatives in the decision-making process and studies including patients with disease progression and cognitive challenges are warranted to improve decision support for this particularly challenged patient population.

Conclusion

This review indicates that many HGG patients prefer an SDM approach and that sufficient information and involvement can have a positive effect on the emotional well-being

of patients. However, the evidence is lacking and future research is warranted before firm conclusions and practice guidelines concerning SDM in HGG patients can be made.

Supplementary material

Supplementary material is available online at *Neuro-Oncology Practice* (<http://nop.oxfordjournals.org/>).

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