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Health Information Needs and Behaviours Before and After Brain Tumour Surgery: A Qualitative Study

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Abstract

Background/Objectives: Patients with brain tumours face informational and emotional challenges across diagnosis, surgery and recovery. This study explored their health information needs and information behaviour across the surgical pathway, focusing on trusted sources, motivations for independent information seeking and modes of engagement before and after surgery. **Methods:** A qualitative descriptive study used semi-structured interviews with 29 adult patients at a university hospital in Croatia. Twelve participants were interviewed before surgery and 17 after surgery; the two groups were independent. Interview transcripts were analysed using qualitative content analysis. **Results:** Participants described diverse information needs concerning their diagnosis, treatment, surgical outcomes and recovery, including retrospective accounts of experiences before surgery provided by postoperative participants. Healthcare professionals, particularly neurosurgeons, were the most trusted sources, whereas participants frequently questioned the reliability of online information. Perceived gaps in the availability, completeness and timing of professional information prompted independent searching. Participants described active seeking, passive or limited engagement and deliberate information avoidance; family members and friends sometimes searched with or for them. Postoperative participants' retrospective accounts suggested that information seeking and avoidance may vary with informational and emotional circumstances rather than reflect fixed individual orientations. **Conclusions:** The findings suggest that information support should be an ongoing, responsive component of clinical care. Assessing patients' information needs, preferences and readiness to engage with information at different stages may help tailor its content, amount, timing and delivery and support access to trustworthy resources. Longitudinal research is needed to examine individual changes in information engagement across the surgical pathway.

Keywords: health information behaviour; health information needs; information seeking; information avoidance; brain tumours; qualitative research

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Academic Editor: Jonas Wolf

Received: 5 October 2026
Revised: 13 November 2026
Accepted: 16 November 2026
Published: 20 November 2026

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1. Introduction

Patients with brain tumours face complex informational challenges across diagnosis, surgery and recovery. The uncertainty associated with diagnosis and treatment, together with the cognitive and emotional effects that may accompany brain tumours, can make access to and engagement with health information particularly important [1,2]. Health information plays a crucial role throughout the diagnostic and treatment trajectory. Providing

timely, accurate and comprehensible information has been associated with reduced anxiety, improved treatment adherence and more active participation in healthcare decisions [1,3,4]. Information needs may change across the disease and treatment trajectory, reflecting the different challenges patients encounter at different stages. Consequently, patients require information that is not only evidence-based but also adapted to their changing informational and emotional needs [5,6]. Recent evidence specific to patients with brain tumours further highlights the need to tailor information to individual preferences regarding its content and amount, as well as how it is provided, particularly as diagnostic shock and cognitive or emotional distress may limit patients' capacity to absorb and retain information [2]. Cancer patients have diverse information needs encompassing not only diagnosis and treatment but also prognosis, psychosocial support and broader aspects of living with and managing their illness [7]. Although digital resources have substantially increased access to health information, healthcare professionals remain highly trusted sources, while patients may experience difficulties in identifying reliable online information [4,8]. Information-seeking behaviour therefore varies considerably according to patients' individual characteristics and circumstances, as well as their coping styles and preferences for information [9,10]. Information behaviour extends beyond active information seeking to encompass a broader range of ways in which individuals encounter, receive, evaluate, share, limit and avoid information. In health contexts, these forms of engagement may range from deliberate avoidance and passive receipt to active seeking and verification [11]. Research with cancer patients has similarly identified heterogeneous patterns of information acquisition, including intensive, complementary, fortuitous, minimal and guarded approaches [12]. These perspectives suggest that health information behaviour is better understood as a repertoire of information practices than as a simple distinction between seekers and non-seekers. Importantly, different modes of information engagement need not be mutually exclusive or stable over time. Information seeking and information avoidance, for example, may coexist as strategies for managing illness-related uncertainty [13–15]. Individuals may seek information in one context while limiting or avoiding it in another, suggesting that information behaviour is contingent on informational, situational and emotional circumstances. Despite growing research on the information and decisional needs of patients with brain tumours, less is known about the information needs and modes of engagement with health information that patients describe in relation to different stages of the care pathway, particularly around surgery. Existing research is also characterised by considerable heterogeneity in brain tumour diagnoses, stages of disease and study populations, with some studies combining the perspectives of patients, family caregivers and healthcare professionals [2]. This heterogeneity limits understanding of how patients themselves experience and manage health information across different stages of the surgical pathway. Examining information behaviour across these stages offers an opportunity to explore not only what information patients need and where they seek it, but also how different modes of engagement with information are manifested under conditions of changing uncertainty and informational priorities. This study therefore approaches the surgical pathway as a temporally structured context in which different forms of information behaviour can be examined through the accounts of patients interviewed before or after surgery, including retrospective descriptions of earlier experiences provided by postoperative participants. These forms of information behaviour include active seeking, passive or limited engagement, seeking with or through others, verification and information avoidance. Understanding these experiences may contribute to more responsive management and communication of patient-centred health information across different stages of care. The aim of this study was to explore the health information needs and information behaviour of patients with brain tumours across the surgical pathway, focusing on trusted information sources, motivations

for information seeking and different modes of engagement with health information as described in relation to the periods before and after surgery.

The study addressed the following research questions:

RQ1. *What health information needs do patients with brain tumours describe in relation to the periods before and after surgery?*

RQ2. *Which information sources do patients with brain tumours trust across the surgical pathway?*

RQ3. *What motivates patients with brain tumours to seek health information independently?*

RQ4. *What patterns of information behaviour are evident across the surgical pathway, and how do participants' accounts indicate variation in engagement with health information across different stages?*

2. Materials and Methods

2.1. Study Design

This qualitative descriptive study used semi-structured interviews to explore health information needs and information behaviour as described by patients interviewed before or after brain tumour surgery. This approach enabled an in-depth examination of patients' experiences, perceptions and information practices within the context of their care. Two independent participant groups were included to capture preoperative and postoperative perspectives while taking into account the vulnerability of this patient population and the practical and ethical challenges of longitudinal follow-up, including uncertain clinical outcomes, potential deterioration in health and difficulties in maintaining participation over time. Although participants were grouped according to the timing of their interviews, their accounts were not necessarily limited to experiences from that period. In particular, participants interviewed after surgery could retrospectively describe information needs and behaviours experienced before surgery.

Ethical approval was obtained from the Ethics Committee of University Hospital Center Osijek, Croatia (No. R1-11259/2023, 2 October 2023). The study was conducted in accordance with the Declaration of Helsinki. The approved research procedures focused on patients' information experiences through qualitative interviews and did not include the extraction of detailed clinical information from medical records. Accordingly, tumour histology, tumour grade and treatment characteristics were not systematically collected as part of the research dataset.

Potential participants were initially approached by members of the clinical team, and only those who expressed willingness to participate were referred to the first author for an interview. Before each interview, the first author explained the study's purpose, the voluntary nature of participation, confidentiality, the use of anonymised information in scientific publications, and the need for audio-recording for subsequent analysis. Participants were informed that their names and other directly identifying information would not be collected during the interviews or disclosed in research publications. They were given the opportunity to ask questions and confirm their willingness and ability to participate, while the interviewer informally assessed their ability to engage through direct interaction, including for patients interviewed on the day of surgery. Verbal rather than written informed consent was chosen to minimise potential discomfort associated with signing formal documents, particularly among older patients, and to establish trust in a clinically sensitive setting. Audio-recording commenced only after participants had verbally confirmed their willingness to participate and to be recorded, thereby avoiding recording individuals before they had consented. Consequently, verbal consent was not captured in

the interview recordings, and no separate written or audio-recorded record of individual consent was maintained.

2.2. Participants and Recruitment

The study included 29 adult patients diagnosed with a brain tumour who were recruited using purposive sampling at University Hospital Center Osijek, Croatia. Participants were recruited from two patient populations: those scheduled for brain tumour surgery and those who had undergone surgery during the preceding five years. Potential participants were identified through hospital records by members of the clinical team, who established initial contact and invited them to participate. Patients who agreed to participate were subsequently interviewed by the first author. Participants formed two independent groups based on the timing of their interviews in relation to the relevant surgical procedure: 12 were interviewed before surgery and 17 were interviewed after surgery. This classification refers exclusively to participants' surgical status at the time of data collection and does not determine the temporal context of the experiences described in their interviews. Group allocation was based on the timing of the interview in relation to the relevant surgical procedure, irrespective of any previous surgical history. No participant was interviewed at both stages. The exact interval between surgery and interview was not systematically collected and therefore could not be reported for individual participants. The sample comprised 15 women and 14 men, aged 28–79 years (Table 1). The final sample size reflected the number of eligible patients who consented to participate during the recruitment period. Formal data saturation was not systematically assessed and was therefore not used as a criterion for determining sample size. Given the purposive, single-centre sampling approach, the sample was not intended to be statistically representative of the broader population of patients with brain tumours. The findings should therefore be interpreted in terms of their potential transferability to comparable clinical contexts rather than statistical generalisability.

Table 1. Participant characteristics by timing of interview relative to surgery.

Interviewed Before Surgery (n = 12)			Interviewed After Surgery (n = 17)		
Participant	**Sex**	**Age**	**Participant**	**Sex**	**Age**
P2	F	63	P1	F	70
P3	F	57	P5	F	28
P4	M	65	P12	F	42
P6	M	60	P13	M	68
P7	M	79	P15	F	34
P8	M	37	P16	F	46
P9	M	76	P17	F	53
P10	F	43	P19	M	30
P11	M	68	P20	M	37
P14	M	28	P21	F	36
P18	F	63	P22	F	50
P25	M	57	P23	F	53
			P24	F	61
			P26	M	44
			P27	M	50
			P28	F	51
			P29	M	30

Note. Group classification is based on the timing of the interview relative to surgery and does not necessarily indicate the period to which participants' reported experiences refer.

2.3. Data Collection

Data were collected through semi-structured interviews conducted during the last quarter of 2023 primarily at the Departments of Neurosurgery and Neurology of University Hospital Center Osijek. Patients awaiting surgery were interviewed before the procedure, whereas postoperative participants were contacted by telephone and invited to participate. Four interviews were conducted via Zoom because participants were unable to attend in person, and two took place at the Faculty of Humanities and Social Sciences in Osijek at the participants' request. The interview guide (Supplementary Material S1) was developed by the first author based on the study objectives and informed by theoretical and empirical literature on health information needs and information behaviour, including previous qualitative research with cancer patients [4]. The questions were designed to address key dimensions identified in the literature while remaining sufficiently open-ended to capture participants' individual experiences. The interviews explored patients' information needs, trusted information sources, motivations for seeking information and patterns of information behaviour in relation to different stages of the surgical care pathway. All interviews were conducted by the first author, who has experience in qualitative research and health information behaviour research and was not involved in the participants' clinical care. The first author had no prior relationship with any of the participants. The clinical co-authors (N.K. and A.S.K.) were involved in participant recruitment, and some participants were patients under their care or received care at their respective departments. The use of a common semi-structured interview guide supported consistency across interviews while allowing participants to describe their experiences in their own terms.

2.4. Interview Procedure

The interviews were conducted in Croatian, audio-recorded with participants' consent and transcribed verbatim. Consistent with the semi-structured design, interview questions were adapted to participants' surgical status and individual experiences. Participants interviewed after surgery were asked about their information experiences before and after surgery, whereas participants awaiting surgery were asked about their experiences up to the time of the interview. Questions concerning postoperative experiences were not applicable to participants awaiting surgery, while follow-up questions about independent information seeking were omitted when participants reported that they had not engaged in such activities.

Interview duration varied depending on participants' experiences and the extent of their information-seeking behaviour, with some interviews lasting less than 20 min and the longest approximately 60 min. The interviews were transcribed and analysed in Croatian. Participant quotations selected for inclusion in the manuscript were subsequently translated into English by a professional English-language editor.

2.5. Data Analysis

The interview transcripts were analysed by the first author using qualitative content analysis informed by the methodological principles described by Elo and Kyngäs [16], with MAXQDA used to support coding and data organisation. The transcripts were read repeatedly to achieve familiarisation with the data. Initial codes were developed inductively during close reading of the transcripts, reflecting participants' descriptions of their experiences. Related codes were subsequently compared, refined and grouped into broader categories based on similarities in meaning and their relevance to the study aims. To illustrate the analytical process, P12 described encountering distressing content on an online forum and subsequently deciding to stop searching for information: "I decided not to look at anything anymore. And I really did not look at anything until the surgery" (translated from

Croatian). This account was interpreted as deliberate restriction of information seeking in response to distressing content, an analytical meaning represented within the broader category of information avoidance. The resulting categories were then considered in relation to the research questions and existing literature on health information needs and information behaviour during the interpretation of the findings. The analysis considered accounts from participants interviewed before and after surgery within a common set of categories, focusing on the identification and interpretation of information needs and behaviours across the dataset rather than on systematic comparisons between the two independent groups. Retrospective accounts provided by participants interviewed after surgery were also considered when interpreting how they described their information needs and behaviours in relation to different periods of the surgical pathway. These accounts were treated as participants' recollections rather than longitudinal evidence of changes over time. The trustworthiness of the analysis was supported by sustained engagement with the interview data, iterative refinement of codes and categories, and their grounding in participants' accounts. The first author's expertise in information science, information behaviour and qualitative research informed the analytical approach and interpretation of the findings. Interpretations were also discussed with the clinical co-authors (N.K. and A.S.K.), providing complementary clinical perspectives on the findings. Participants were assigned anonymous identification codes (P1–P29). The final themes, categories and subcategories were organised into a summary table using Microsoft Word, together with participant frequencies and illustrative quotations to provide a structured overview of the findings. The reporting of this study was assessed against the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist [17] (Supplementary Material S2).

2.6. Use of Generative AI

OpenAI ChatGPT (**GPT-6**) was used during manuscript preparation for language editing and refinement of the authors' original text. The tool was not used for data collection, coding or analysis.

3. Results

3.1. Health Information Needs

Four main categories of health information needs were identified: understanding the disease, surgical concerns, post-surgical recovery, and doctors' competence (Table 2). Information needs related to understanding the disease encompassed questions about tumour types (n = 9), treatment options and processes (n = 5), and causes of the tumour (n = 1). One participant expressed a broader need for comprehensive information about the disease (n = 1).

Surgical concerns centred on survival and prognosis (n = 7), anticipated changes in physical appearance, awareness and functional abilities (n = 7), and treatment success (n = 7). These concerns reflected participants' interest in the potential consequences and outcomes of surgery.

Post-surgical recovery was another area of information need, with participants expressing concerns about postoperative limitations (n = 7). Information needs relating to doctors' competence were less frequently identified, with one participant explicitly questioning the surgical expertise of the treating physicians (n = 1).

These categories were not mutually exclusive, as individual participants could express multiple information needs. The reported frequencies therefore indicate the number of participants whose accounts reflected each subcategory rather than distinct groups of participants. Illustrative quotations for each subcategory are provided in Table 2.

Table 2. Overview of themes, categories, subcategories and illustrative quotations from participant interviews.

Theme (Section)	Category	Subcategory/Code	n (of 29)	Illustrative Quotation (Participant ID; Interview Stage)
Health information needs (Section 3.1)	Understanding the disease	Types of tumour	9	*I wanted to know something about the types of tumours. (P15; Post-S)*
		Treatment options/process	5	*What postoperative consequences I might have… and later, treatment and therapy options. (P15; Post-S)*
		Causes of tumour	1	*What I was most interested in was the cause of the tumour. (P26; Post-S)*
		Comprehensive information	1	*I wanted to know everything relating to my disease, the thing that can kill me in a couple of months. (P29; Post-S)*
	Surgical concerns	Survival and prognosis	7	*Whether I will be able to leave this hospital alive or not, whether everything will be all right or not. (P7; Pre-S)*
		Physical appearance, awareness and functional abilities	7	*How will I look; will my appearance be normal? How much will I be aware of the world around me? (P2; Pre-S)*
		Treatment success	7	*I wanted to ask about the outcome of tumour treatment. (P25; Pre-S)*
	Post-surgical recovery	Postoperative limitations	7	*What worried me was the recovery… the recovery mattered a lot. (P12; Post-S)*
	Doctor's competence	Surgical expertise	1	*Whether the doctors in Osijek are competent enough to perform the surgery or not. (P26; Post-S)*
Trust in information sources (Section 3.2)	High trust	Doctors	18	*I have 100% trust in doctors. They are gods. There are no other gods but them. (P4; Pre-S)*
	Moderate trust	Other personal sources	6	*I obtained the first piece of information from my doctor and then, when I came home, I asked a work colleague… the nurse… (P17; Post-S)*
	Low trust	Internet	10	*I heard that there are plenty of information and disinformation on the net, so you should not rely on such. (P7; Pre-S)*
Motivators for information seeking (Section 3.3)	Lack of information from the doctor	Information not provided	3	*I had got almost nothing before I came to the hospital for radiotherapy. (P5; Post-S)*
	Insufficient information from the doctor	Incomplete information	2	*Nobody told me not to drink lemonade, orange juice, to reduce intake of citrus fruits. I had to find out all by myself. (P15; Post-S)*
	Untimely information from the doctor	Information provided too late	1	*Look I am not very happy about not getting any radiotherapy-related information from the oncologist, for instance, what the procedure looks like, how long it lasts* etc. *I should have found out about that earlier. (P5; Post-S)*

Table 2. *Cont.*

Theme (Section)	Category	Subcategory/Code		n (of 29)	Illustrative Quotation (Participant ID; Interview Stage)
	Concern and desire for better understanding of the disease	Symptoms/medication effects		5	*The new symptoms, those relating to the drugs against epilepsy which I have as a result of the head opening surgery. I would like to know which pills have effect on what, how to take them, how to reduce some side effects*, etc. *(P15; Post-S)*
Information behaviour (Section 3.4)	Active information seeking	Intermediary and social seeking	Proxy information seeking	4	*No, I didn't search for anything. My wife and younger son did that for me. (P27; Post-S)*
			Collaborative information seeking	4	*My son performed a search in English and I did in Croatian. (P17; Post-S)*
					I wrote a post on Facebook […] Any information, anything at all related to brain tumours […] any treatment options […] just send it to me. […] I received over 1000 different comments, pieces of advice, messages, and recommendations for supplements, clinics, microbiologists, and all sorts of other things. (P29; Post-S)
		Fortuitous information seeking		1	*I just typed in the name of the operation, and [the name of a person who had undergone a similar procedure] came up. (P12; Post-S)*
		Intense information seeking		4	*During that month and a half, I shut myself in my room and read from morning till night. Everything. From forums, Reddit and similar sites to medical encyclopaedias, medical articles and research. (P15; Post-S)*
		Complementary information seeking (Verifying)		4	*I also had an opinion from another private institution in Croatia, and those two opinions were more or less consistent. (P19; Post-S)*
		Asking questions		14	*I didn't ask that many questions about the disease, but I asked quite a lot about the surgery. (P5; Post-S)*
	Passive engagement with information	Minimal information seeking		2	*I just typed in 'meningioma' and found that it was the most common type of benign tumour. […] Once I saw that, I felt somewhat reassured, so I didn't search any further. (P28; Post-S)*
		Receiving information		5	*They told me everything themselves. (P9; Pre-S)*
	Information avoidance	Deliberate information avoidance		10	*I deliberately chose not to seek that information because I knew it would upset me. (P23; Post-S)*

Note. Pre-S = pre-surgery interview; Post-S = post-surgery interview. These labels indicate participants' surgical status at the time of the interview, not necessarily the period to which their statements refer. Participants interviewed after surgery could also retrospectively describe information needs and experiences from the preoperative period. Categories are not mutually exclusive, and *n* indicates the number of participants whose accounts reflected each subcategory. The quotations illustrate the identified subcategories and should not be interpreted as representing their distribution between the two groups.

3.2. Trust in Information Sources

Three levels of trust in health information sources were identified: high, moderate, and low. Trust in physicians, particularly neurosurgeons, was identified in 18 of the 29 participants' accounts, reflecting their perceptions of physicians as knowledgeable and reliable sources of information. This trust was expressed through explicit statements of confidence, a preference for physicians over other information sources, or reliance on professional advice when considered sufficient and reliable.

Trust in other personal sources was identified in six participants' accounts, including nurses and individuals within participants' social networks who had medical knowledge or relevant experience. These sources were associated with moderate trust.

Concerns about the reliability of online information were identified in ten participants' accounts, particularly regarding unverified or potentially misleading content and the difficulty of distinguishing trustworthy information from conflicting or inaccurate claims. Such concerns reflected lower levels of trust in certain online sources rather than a general rejection of Internet-based information.

These levels describe participants' evaluations of different information sources rather than mutually exclusive groups of participants. Representative participant quotations illustrating these levels of trust are presented in Table 2.

3.3. Motivators for Information Seeking

Four main motivators for information seeking were identified: lack of information from physicians, insufficient information from physicians, untimely provision of information, and concern and desire for better understanding of the disease. Lack of information refers to information that was not provided on a particular issue, whereas insufficient information refers to information that was provided but perceived as incomplete or inadequate.

Lack of information from physicians was identified in three participants' accounts, insufficient information in two, and untimely provision of information in one. Participants described seeking information independently when information from physicians was unavailable, incomplete, or provided later than they felt it was needed. Concern and a desire for better understanding of the disease were identified in five participants' accounts, particularly in relation to symptoms and medication effects.

These motivations were not necessarily mutually exclusive, as concerns about the disease could coexist with perceived gaps in the availability, completeness, or timing of information. The categories describe factors that motivated participants to seek information rather than the forms of information behaviour they subsequently adopted. Although emotional responses such as concern and uncertainty could motivate information seeking, they could also contribute to information avoidance, as discussed in Section 3.4. Representative participant quotations illustrating these motivators are presented in Table 2.

3.4. Information Behaviour

Three overarching patterns of information behaviour were identified: active information seeking, passive engagement with information, and information avoidance. These patterns describe information-related practices identified in participants' accounts rather than mutually exclusive types of participants. Active information seeking refers to intentional efforts to obtain information, including independent searching, consulting other people, and asking healthcare professionals specific questions. Passive engagement with information refers to predominantly receptive or limited engagement with health information, including information received during healthcare encounters and brief, minimal information-seeking activities. Information avoidance refers to deliberately limiting, postponing, or discontinuing engagement with particular information because it is perceived

as distressing or otherwise undesirable. Not undertaking independent searches was not, in itself, interpreted as information avoidance. Individual accounts could reflect more than one pattern, either simultaneously or at different points in participants' experiences. Accordingly, the frequencies reported for individual subcategories indicate the number of participants whose accounts reflected each specific information-related practice rather than mutually exclusive groups of participants. Within these overarching patterns, participants described different modes of engagement with information, varying in the intensity of seeking, the role of other people in the information process, and the extent to which information was actively pursued, received, limited, or avoided. Active information seeking varied in intensity and form. Some participants engaged in intense information seeking (n = 4), attempting to obtain extensive information from multiple sources, including the Internet, written materials, and healthcare professionals. Others engaged in complementary information seeking and verification (n = 4), supplementing or comparing information obtained from different sources. Fortuitous information seeking (n = 1) was also identified when potentially useful information emerged unexpectedly during an intentional search. Information seeking sometimes involved family members or friends, either through proxy information seeking (n = 4), when others searched on participants' behalf, or collaborative information seeking (n = 4), when participants searched together with others. Active information seeking also included asking questions (n = 14), particularly questions directed at healthcare professionals, even when participants did not undertake additional independent searches. Passive engagement with information refers to receiving or encountering information without extensive independent information seeking, including instances of minimal, short-lived information seeking. Some participants described minimal information seeking (n = 2), undertaking only limited searches and discontinuing them once they had obtained information they considered sufficient. Others described receiving information (n = 5), relying primarily on information provided by healthcare professionals without initiating additional information-seeking activities. Reliance on professional information did not necessarily exclude participants from asking questions during healthcare encounters; however, such purposeful questioning was considered a form of active information seeking rather than passive information acquisition.

Information avoidance involved deliberate disengagement from health-related information. Deliberate information avoidance was identified in ten participants' accounts, involving the restriction or avoidance of information perceived as distressing or anxiety-provoking, often as a way of managing emotional responses. In some accounts, information avoidance followed earlier information-seeking experiences, illustrating how different patterns of information behaviour could coexist within individual experiences.

Retrospective accounts from postoperative participants also illustrated how information engagement was described as varying across different stages of the surgical pathway. P12 recalled seeking information after diagnosis, temporarily discontinuing her search after encountering distressing online content, and resuming information seeking during recovery from an earlier operation. At the time of the interview, she was also preparing for a further surgical procedure. P19 described more extensive information seeking after surgery, when histopathological findings enabled a more focused search for information about the tumour. These accounts reflect participants' recollections of their experiences rather than longitudinally observed changes in information behaviour. Representative participant quotations illustrating the identified forms of information behaviour are presented in Table 2.

Table 2 provides an integrated overview of the themes, categories, subcategories, participant frequencies, and illustrative quotations across the four dimensions of health information needs and behaviours examined in this study.

4. Discussion

4.1. Health Information Needs

Patients with a brain tumour expressed diverse information needs related to understanding their diagnosis, the surgical procedure, postoperative recovery and the competence of their physicians. Consistent with previous studies, clear, comprehensible and reliable information appeared important for helping patients understand their condition and treatment and navigate the uncertainty surrounding surgery [1,3]. The importance of clear explanations in the context of surgical preparation is consistent with Gautschi et al.'s [18] observation that the amount of information provided within a short period may overwhelm patients who are unfamiliar with medical terminology, particularly when they are frightened or distressed. More recent qualitative evidence from patients with glioblastoma and their caregivers similarly highlights discrepancies between information provided about treatment-related side effects and patients' actual experiences, underscoring the need for information tailored to individual circumstances and different stages of care [19]. Beyond its practical value, health information appeared to help patients manage uncertainty and prepare for treatment and recovery, consistent with the broader role of information in responding to uncertainty described by Case [20].

The findings also draw attention to the temporal context of patients' information needs across the surgical pathway. Participants described information needs concerning tumour characteristics, treatment options, surgical risks, possible outcomes, and postoperative recovery. The analysis included accounts from patients interviewed before surgery and retrospective descriptions of preoperative and postoperative experiences provided by patients interviewed after surgery. Importantly, the timing of the interview did not necessarily correspond to the period to which the reported information needs referred. These accounts provide insight into informational concerns associated with different stages of the surgical pathway without establishing systematic differences between the two independently recruited groups. This interpretation is consistent with previous research suggesting that information needs are context-dependent and may vary across the course of illness and treatment [5,6].

Retrospective accounts from participants interviewed after surgery also illustrated how information engagement could vary across different stages of the surgical pathway. P12 described seeking information before surgery, temporarily discontinuing her search after encountering distressing online content, and resuming information seeking during recovery. P19 reported more extensive information seeking after surgery, when histopathological findings enabled a more focused search for information about the tumour. Although the study was not longitudinal, these retrospective accounts illustrate how participants recalled engaging with information at different points in their surgical experiences, without establishing directly observed within-person changes over time.

These accounts also complicate interpretations of information seeking and avoidance as relatively stable individual orientations. Although monitoring and blunting have been conceptualised as dispositional tendencies in responses to threatening information [21], retrospective accounts from postoperative participants suggest that engagement with information may also be situational and responsive to changing informational and emotional circumstances. These findings are consistent with a more dynamic understanding of health information behaviour, in which informational priorities and modes of engagement may vary across the surgical pathway.

4.2. Trust in Information Sources

Physicians, particularly neurosurgeons, emerged as the most trusted sources of health information. Participants associated this trust primarily with physicians' expertise, clinical

experience and responsibility for treatment outcomes. This finding is consistent with previous research highlighting the central role of healthcare professionals as information sources for patients undergoing cancer treatment [4]. The contrast between high trust in healthcare professionals and low trust in online information is particularly relevant in an information environment characterised by abundant but unevenly trusted health information. Participants' accounts suggest that access to information was not in itself sufficient; the perceived authority, credibility and interpretability of information sources shaped whether and how information was used.

In contrast, although participants recognised the abundance of health information available online, some participants questioned its reliability and described difficulties distinguishing trustworthy information from inaccurate or conflicting content. Similar concerns have been reported in previous research, which has highlighted the difficulty patients may experience in identifying credible and accurate health information online [8]. These findings highlight an important distinction between access to health information and the ability to evaluate its reliability, suggesting that the availability of health information does not necessarily translate into confidence in its credibility or usefulness.

4.3. Motivators for Information Seeking

The findings suggest that uncertainty played an important role in motivating patients to seek health information. Participants' accounts reflected concerns about their condition, treatment and prognosis, alongside efforts to obtain information that could help them better understand these issues. These findings can be considered in relation to established information behaviour research on the recognition and formulation of information needs [22,23] and the role of uncertainty in information seeking [24]. Rather than demonstrating a uniform progression from uncertainty to information seeking, the findings suggest that patients' responses to uncertainty depended on their particular informational concerns and circumstances.

Independent information seeking was also prompted by perceived gaps in the information provided by physicians, including its absence, incompleteness or untimely delivery. In some accounts, participants sought additional information to supplement professional advice and improve their understanding of the disease and treatment process. These findings are consistent with previous research emphasising the importance of timely and individualised information provision for patients undergoing cancer treatment [4].

Taken together, these findings suggest that information-seeking behaviour was shaped not only by uncertainty but also by the perceived adequacy and timing of information provided to patients. More broadly, access to health information alone did not necessarily ensure that patients' information needs were met. Information was more useful when it was not only available but also timely, comprehensible and perceived as trustworthy. Unmet information needs may therefore arise not only from insufficient information but also from a mismatch between the information available and what patients need, trust and are willing to engage with at a particular point in the care pathway.

4.4. Information Behaviour

Patients described diverse and often overlapping patterns of engagement with health information, including active information seeking, passive or limited engagement and deliberate information avoidance. These findings are consistent with conceptualisations of health information behaviour as encompassing multiple forms of engagement with information rather than a single pattern of information seeking [10], and with research describing a spectrum of health information interaction ranging from avoidance and passive receipt of information to active seeking and verification [11]. The findings therefore support a

broad understanding of information behaviour that encompasses not only whether individuals seek information, but also how intensively they seek it, whether they receive or limit information, and whether they verify or deliberately avoid it.

Importantly, information seeking and information avoidance were not necessarily mutually exclusive or fixed orientations. Retrospective accounts from participants interviewed after surgery illustrated how the intensity and extent of independent information seeking could vary at different points in their experiences.

Although these accounts do not provide longitudinal evidence of individual change, they suggest that different modes of information engagement may become more or less prominent in participants' retrospective descriptions of their informational and emotional circumstances. This interpretation is consistent with Brashers et al. [13], who conceptualised seeking and avoiding as related responses to health-related uncertainty.

Information avoidance should therefore not necessarily be interpreted as a lack of interest in one's health or as the simple absence of information seeking. Participants described deliberately limiting exposure to information they perceived as emotionally overwhelming. Similar observations have been reported by Barbour et al. [25], while Hicks et al. [15] conceptualise information avoidance as a meaningful information practice through which individuals moderate their interaction with information rather than simply disengage from it. Bronstein et al. [26] similarly position avoidance within a broader set of practices through which individuals regulate information flow and access, including the amount, intensity and timing of engagement with information. Viewed from this perspective, seeking, limiting and avoiding information can represent different ways of managing engagement with information under conditions of uncertainty.

Information seeking was also not exclusively an individual activity. Family members and close friends sometimes searched for information on participants' behalf or sought information together with them. These findings highlight the socially situated nature of health information behaviour and indicate that access to and engagement with health information may be facilitated through interpersonal networks as well as through individuals' own searching. Together, the findings suggest that health information behaviour across the surgical pathway is better understood as a repertoire of different modes of engagement with information than as a distinction between stable categories of information seekers and avoiders.

4.5. Implications for Health Information Management Practice

The findings have several implications for health information management practice. First, health information provision should be viewed as an ongoing and responsive process rather than a one-time intervention. Across the sample, participants described diverse information needs and modes of engagement with health information, suggesting that information support should address not only the accuracy and comprehensibility of information but also its amount, timing and mode of delivery.

Information support should therefore be sufficiently flexible to accommodate differences in how much information patients wish to receive, when they wish to receive it and how actively they wish to engage with it. The need for responsive information provision is also reflected in international patient advocacy perspectives, which identify persistent gaps in access to high-quality information about treatment options, challenges related to health literacy and inconsistencies in information provision and communication across brain tumour care [27]. In practice, clinical teams could incorporate brief assessments of patients' information needs and preferences into preoperative consultations, discharge planning and postoperative follow-up. These assessments could address patients' immedi-

ate questions, preferred level of detail and willingness to receive additional information, allowing information provision to be adjusted as their circumstances evolve.

Second, the findings highlight the importance of supporting patients in navigating health information from multiple sources. Although physicians, particularly neurosurgeons, were the most trusted information source, participants also sought information independently and reported difficulties evaluating the reliability of online information. This suggests a need not only to provide trustworthy information but also to support patients in identifying and evaluating reliable sources. Health information specialists may have a potential role in this process. Medical librarians and other health information specialists were not mentioned in participants' accounts, although the interviews did not specifically examine their involvement in patients' information pathways. Previous research has identified opportunities for collaboration between libraries and health services in supporting health information seeking and health literacy, particularly through signposting to reliable information and targeted education [28]. Closer collaboration between clinical teams and health information specialists could therefore provide an additional avenue for directing patients towards trustworthy resources and supporting the navigation and evaluation of digital health information. Such collaboration could include developing and maintaining a curated list of reliable, accessible information resources on brain tumours, surgical procedures and recovery, which clinicians could share with patients during consultations or at discharge. Health information specialists could also support the development of brief guidance to help patients assess the credibility of online health information and recognise potentially misleading or unverified claims.

Finally, information support should recognise that active seeking, limited or passive engagement and information avoidance may all form part of patients' information behaviour. The findings suggest that the relevance of these different modes of engagement may vary according to patients' informational and emotional circumstances and their readiness to engage with information. Standardised information provision may therefore be insufficient to accommodate the diversity of patients' information needs and preferences across the surgical pathway. Incorporating ongoing assessment of information needs and preferences into information provision could help align support more closely with individual patients while preserving healthcare professionals' central role as trusted sources of health information. For patients who find extensive information distressing, clinicians could provide essential information in manageable stages, while offering opportunities to revisit particular topics and ask additional questions later. This approach would accommodate patients' emotional readiness without withholding information necessary for informed decision-making.

4.6. Limitations

This study has several limitations. First, it was conducted at a single healthcare institution in Croatia, which may limit the transferability of the findings to other healthcare settings and patient populations. Second, the preoperative and postoperative participants constituted two independent groups, and no participant was interviewed at both stages. Differences between the two groups therefore cannot be interpreted as directly observed within-person changes over time. Although retrospective accounts from postoperative participants provided some insight into how information needs and modes of engagement were recalled as differing across stages of the surgical pathway, these accounts may have been influenced by recall bias. Third, several participants were interviewed on the day of surgery, when heightened anxiety may have influenced the depth and complexity of their responses. Fourth, the clinical and temporal heterogeneity of the sample, particularly the postoperative group, should be considered. Differences in tumour type, disease severity, treatment history and time elapsed since surgery may have influenced participants' infor-

mation needs and behaviours. As detailed clinical characteristics and the exact interval between surgery and interview were not systematically documented in the research dataset, their potential influence on the findings could not be examined.

Fifth, the qualitative analysis was conducted by a single researcher without independent coding or member checking, and formal data saturation was not systematically assessed. Repeated engagement with the interview data, iterative refinement of codes and categories, and interdisciplinary discussions were used to support the trustworthiness of the analysis. Although the first author had no prior relationship with the participants and was not involved in their clinical care, the involvement of clinical co-authors in recruitment and their existing clinical relationships with some participants should be considered when interpreting accounts of patient–physician communication. Despite these limitations, the qualitative design provided detailed insights into patients' health information needs and information behaviour at different stages of the surgical pathway. Future research should adopt longitudinal designs that follow the same patients from diagnosis through treatment and recovery to examine how information needs and modes of engagement with health information change over time. Further research should also evaluate different models of information support, including the potential contribution of health information professionals to helping patients access, understand and evaluate health information and participate in informed healthcare decision-making.

5. Conclusions

This study provides insight into the health information needs and modes of engagement with health information reported by patients before and after brain tumour surgery. By examining information needs, trust, motivations and modes of engagement together, the study highlights the value of considering these dimensions as interconnected aspects of patients' information experiences. Importantly, the findings suggest that the absence of independent information searching should not be equated with a lack of engagement with health information, as patients may actively ask questions, rely on information provided by healthcare professionals or deliberately limit exposure to particular content. They also highlight a potential distinction between patients' information needs and their readiness to engage with information, particularly when certain content is perceived as emotionally distressing.

Participants described diverse informational priorities associated with diagnosis, treatment and recovery, while retrospective accounts from postoperative participants suggested that the intensity and extent of information seeking could vary across the surgical pathway. These accounts illustrated how information seeking could be restricted in response to distressing content or become more focused as additional clinical information became available. Although these accounts do not establish longitudinal changes, they suggest that both what patients need to know and how they engage with health information may be shaped by their informational, emotional and situational circumstances.

Healthcare professionals, particularly physicians, remained the most trusted sources of health information, yet perceived gaps in the timing, clarity and completeness of information sometimes prompted independent information seeking. At the same time, access to abundant online information did not necessarily translate into confidence in its reliability. These findings underscore the importance of distinguishing information availability, perceived credibility and willingness to engage when examining patients' information behaviour. Meeting patients' information needs therefore involves more than providing access to information; it also requires attention to its timing, comprehensibility and trustworthiness.

From an information behaviour perspective, the findings support an understanding of patients' engagement with health information as a repertoire of different, potentially overlapping modes rather than fixed orientations towards seeking or avoiding information.

From a health information management perspective, information provision should therefore be conceived as an ongoing and responsive process that accommodates differences in what information patients need, when they need it, how much they wish to receive and how actively they wish to engage with it. Such an approach may help align information support more closely with individual needs, assist patients in navigating complex health information environments and support informed participation in care. Longitudinal research is needed to establish whether and how modes of information engagement change within individuals over time.

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/healthcare14224000/s1, S1: Semi-structured interview guide; S2: COREQ checklist.

Author Contributions: Conceptualization, I.M. and N.K.; methodology, I.M.; investigation, I.M., N.K. and A.S.K.; formal analysis, I.M.; writing—original draft preparation, I.M.; writing—review and editing, I.M., N.K. and A.S.K. All authors have read and agreed to the published version of the manuscript.

Funding: This research received no external funding.

Institutional Review Board Statement: The study was conducted in accordance with the Declaration of Helsinki and approved by the Ethics Committee of University Hospital Center Osijek, Croatia (No. R1-11259/2023, 2 October 2023).

Informed Consent Statement: Verbal informed consent was obtained from all participants prior to the interviews. Participants were informed about the purpose of the study, the voluntary nature of participation, confidentiality, and the use of anonymised information in scientific publications. Audio-recording commenced only after participants had verbally agreed to participate and to be recorded.

Data Availability Statement: The interview data generated and analysed during the current study are not publicly available due to the sensitive nature of the data and to protect participant confidentiality.

Acknowledgments: The authors would like to thank all patients who participated in this study and generously shared their experiences. OpenAI ChatGPT was used to assist with language editing, textual refinement, and formatting during manuscript preparation. All AI-assisted revisions were reviewed and approved by the authors. The authors take full responsibility for the content of this publication.

Conflicts of Interest: The authors declare no conflicts of interest.

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