Treating Meningioma: does the patient benefit? A paradigm shift from tumor to patient

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Chapter 5

Unmet needs and recommendations to improve meningioma care through patient, partner, and health care provider input: a mixed-method study

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ABSTRACT

Background

It has been suggested that lack of ongoing registration of patient-centred outcomes resulted in existing care trajectories that have not been optimized for sequelae experienced by meningioma patients. This study aimed to evaluate the structure of current meningioma care and identify issues and potential high impact improvement initiatives.

Methods

Using the grounded theory approach, a thematic framework was constructed based on the Dutch Comprehensive Cancer Organisation survey about issues in meningioma care trajectories. This framework was used during three semi-structured interviews and two focus groups with patient-partner dyads (n=16 participants), and two focus groups with healthcare providers (n=11 participants), to assess issues in current meningioma care trajectories and possible solutions, including barriers and facilitators for implementation.

Results

Identified issues (n=18 issues) were categorized into three themes: availability and provision of information, care and support, and screening for (neurocognitive) rehabilitation. A lack of information about the intervention and possible outcomes/complications, lack of support after treatment focusing on bodily and psychological functions, and reintegration into society were considered most important. Sixteen solutions were suggested, such as appointment of case managers (solution for 11/18 issues, 61%), assessment and treatment by physiatrists (22%), and routine use of patient-reported outcome measures for patient monitoring (17%). Barriers for these solutions were lack of budget, capacity, technology infrastructure, and qualified personnel with knowledge about issues experienced by meningioma patients.

Conclusions

This study identified issues in current multidisciplinary meningioma care, which are considered unmet needs by patients, partners and healthcare providers and could guide innovation of care.

Key words

Case manager, Meningioma, Patient Reported Outcome Measures (PROMs), Value-Based Healthcare

INTRODUCTION

Meningiomas are tumours developing from the leptomeninges, accounting for 36.4% of primary intracranial tumours.[1,2,3] More than 80% of meningiomas are benign (WHO grade I) and patients have a near-normal life expectancy.[2,5] Morbidity is due to compression of the central nervous system and/or cranial nerves and vessels.[5,6] Recent European and Dutch guidelines advise a wait-and-scan policy in patients with asymptomatic meningiomas, and surgery or stereotactic radiotherapy in case of symptoms or established tumour growth.[4] Even though their life expectancy is near-normal, the limited data currently available suggests that patients suffer from long-term neurological sequelae and that their health-related quality of life (HRQoL) is impaired on all domains compared to the general population, both before and after interventions.[7]

Meningioma literature and guidelines traditionally focus on the extent of tumour resection, recurrence and neurological outcomes.[4] While these outcomes are highly relevant, they fail to reflect the continuing impact of the tumour and treatment on a patient's daily life.[8] Due to the lack of HRQoL data and other patient-reported outcomes, the few existing current care trajectories have not been optimized for these long-term sequelae.[4,7] This is supported by recent results from a patient survey in meningioma patients performed by the Dutch Comprehensive Cancer Organisation (DCCO), which showed that patients experience various problems and unmet needs during their care trajectory, such as a lack of information on the treatment and outcomes and lack of meningioma-specific care, e.g. meningioma-specific rehabilitation after intervention.[9] Although the results of the DCCO survey provided insight into the magnitude of the problem on a national level, the survey lacked detailed information on the actual experienced issues and possible solutions needed to improve current care trajectories.

As we are in the process of reorganizing meningioma care, we investigated in detail the current state of meningioma care trajectories, particularly focusing on issues that were perceived as problematic. We also studied possible solutions for the identified issues, as perceived by patient-partner dyads and healthcare providers. In addition, we aimed to assess barriers and facilitators for the implementation of proposed solutions that might have a high impact on the outcomes of meningioma care trajectories, as perceived by healthcare providers.

MATERIALS AND METHODS

Sampling of patients, partners and healthcare providers from meningioma care trajectories

In the Netherlands, meningioma care is primarily organised in academic and a few large teaching hospitals. Asymptomatic patients are followed by a neurologist and in case of symptom development or evident tumour growth, patients are referred through a tumour board to a neurosurgeon or radiation oncologist. After intervention, most patients are again followed by a neurologist or in select cases an endocrinologist. Before and after an intervention some patients are seen by an ophthalmologist, endocrinologist or healthcare providers from another specialty (e.g. physiatrist) depending on tumour localization and symptoms.

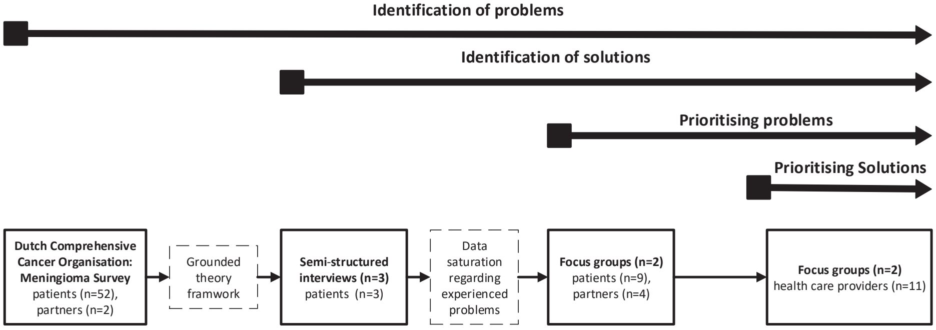
Patients with a clinical suspicion or histopathological confirmation of a WHO grade I or II meningioma, during wait-and-scan follow-up or after surgery or radiotherapy followed at the Leiden University Medical Center (LUMC) or Haaglanden Medical Center (HMC) between November 2017 and April 2018, were invited to participate in this study. Purposive sampling was used to ensure patients were included from all possible care trajectories, i.e. based on intervention (surgery, radiotherapy or wait-and-scan), and follow-up by neurologist or endocrinologist. In addition, they were included based on their sociodemographic and clinical characteristics, i.e. age, gender and tumour location (convexity versus skull base), to ensure generalizability of the study sample towards the general meningioma population.[10] Only patients with at least four months of follow-up after receiving their last treatment (surgery, radiotherapy) or after initiation of a wait-and-scan follow-up were selected to ensure that patients had experienced a large part of a meningioma post-diagnostic care trajectory. Additional inclusion criteria were 18 years of age or higher, and adequate Dutch language skills. Partners were eligible if they had accompanied the patient to their appointments on a regular basis. Informed consent was obtained on paper before study participation.

Eligible healthcare professionals were neurosurgeons, neurologists, ophthalmologists, radiation oncologists, psychologists, endocrinologists, and physiatrists, who treated a minimum of five new meningioma patients per year and worked at or were affiliated to a Dutch meningioma intervention centre.

Study design and concept

This study consisted of four consecutive steps, including data analysis from the DCCO survey (step 1) and semi-structured interviews and focus groups (step 2-4), and was approved by the medical ethics committees of both LUMC & HMC Institutions. Details on the study concept and design are presented in Figure 1. General procedures for all four steps are described in Supplementary Text 1.

Figure 1 – Study concept and design



Step 1: Dutch Comprehensive Cancer Organisation (DCCO) survey

Two researchers independently identified issues from data of the DCCO survey, which were used to construct a thematic framework of issues for each part of the Dutch meningioma care trajectory as identified by meningioma patients (Supplementary Table 1).[9] The thematic framework was constructed following the principles of the grounded theory approach, which is an inductive method through which theoretical insights are generated from collected data, rather than being restricted by existing theoretical frameworks.[11] Detailed information on the patient population cannot be provided, as the DCCO survey collected data anonymously. During both the semi-structured interviews and focus groups, the whole meningioma care trajectory was discussed and for each part of the care trajectory the relevant themes as described in the thematic framework were discussed (Supplementary Table 1).

Step 2: Semi-structured interviews with patients

Separate semi-structured interviews were conducted with three patients. Using the thematic framework from step 1, participants were asked to identify issues regarding their meningioma care trajectory, as well as possible solutions for these issues. This was done until data saturation was reached, which was defined as the point at which no new issues were brought up.[10,11]

Step 3: Focus groups with patient-partner dyads

Two focus group sessions (n=6 and n=7 participants) were organised with patients and their partners in an effort to generate possible solutions for issues reported during the semi-structured interviews, and to evaluate previously reported solutions. The issues were prioritised based on importance at the end of each session.

Step 4: Focus groups with healthcare providers

Two focus groups sessions (n=5 and n=6 participants) were organised with healthcare providers, aiming at identifying potential solutions for issues reported by patient-partner dyads from a healthcare providers' perspective, as well as more details on the raised issues and possible solutions. Through an elaborate process, solutions were prioritised using an adapted Eisenhower matrix, according to the perceived importance and degree of effort (both: high versus low) at the end of each session. In addition, participants were asked to identify barriers and facilitators for high importance, high effort solutions.

Qualitative analysis of semi-structured interviews and focus groups

Results of the semi-structured interviews and focus group sessions were transcribed verbatim and anonymously analysed by two researchers (AHZN & JPMvdM) independently in a three-step approach, as described in previous studies.[12] In step 1, meaningful units were identified, which were allocated to subconcepts in step 2 and grouped into comprehensive concepts in step 3 (an example is given in Supplementary Figure 1). Discrepancies between the two researchers were discussed after each step and when no consensus was reached, a third researcher (LD) mediated the discussion. Issues reported as important in at least two focus groups or semi-structured interviews are reported.

Barriers and facilitators were categorised into six categories, using the well-established framework of Grol and Wensing, which consists of the following categories: innovation, individual professional, patient, social context, organizational context, and external environment (political and economic factors).[13]

Reporting was done according to the COnsolidated criteria for REporting Qualitative research (COREQ).[14]

Quantitative analysis

Baseline sociodemographic and clinical characteristics are reported for patients, partners and healthcare providers separately. Continuous data are reported as medians with an interquartile range (IQR), due to the small number of participants and the skewed distribution of variables. Nominal data are reported as proportions. All statistics were performed using IBM SPSS Statistics for Windows version 23.0 (Armonk, NY, USA).

RESULTS

In total, 52 patients and 2 partners completed the DCCO survey after a median of 66 months (range: 6-348). In addition, 12 patients, 4 partners and 11 healthcare providers participated in the semi-structured interviews and focus groups. Demographic information on the participants of the semi-structured interviews and focus groups are presented in table 1. Most of these patients were surgically treated (n=11, 92%) and 4 (25%) patients had also received radiotherapy. Median lengths of follow-up after the last intervention was 24 months (range:

4-148). Postoperative complications occurred in 2 patients, namely ischaemic stroke of the temporal lobe with transient aphasia and transient deterioration of visual acuity.

Table 1: Baseline sociodemographic and clinical characteristics of patients, partners and healthcare providers included in the focus groups and semi-structured interviews

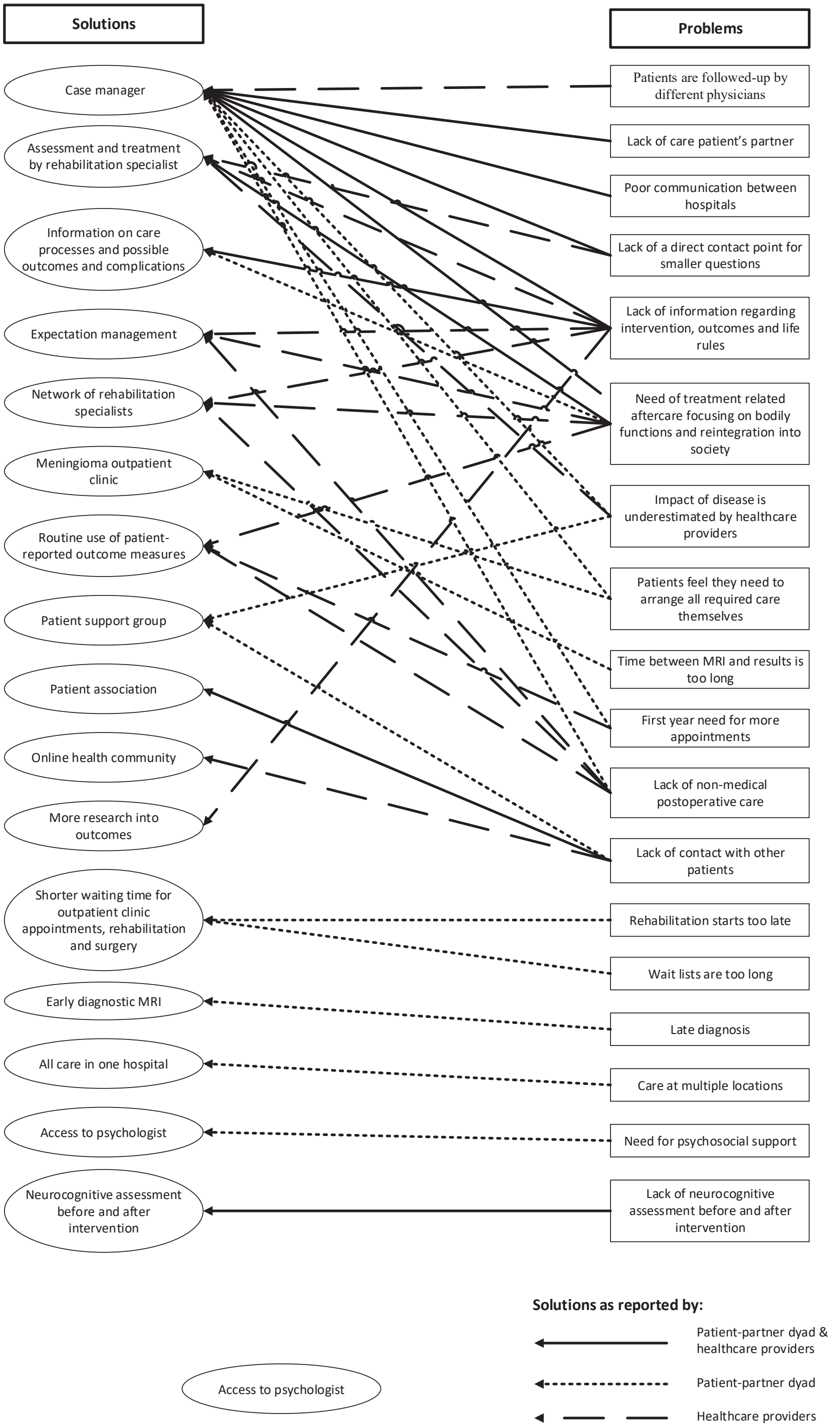
	Patients (n=12)	Partners (n=4)	Healthcare providers (n=11)
Age in years at interview, median (range)	52 (39-70)	56 (47-65)	42 (39-53)
Sex, n (%) female	10 (83%)	0 (0%)	6 (55%)
Highest obtained educational degree, n (%)			
Primary/Secondary	0 (0%)	0 (0%)	-
Vocational/technical	5 (42%)	1 (25%)	-
Academic/University	7 (58%)	3 (75%)	-
Paid job, n (%)	9 (75%)	3 (75%)	-
Tumour location, n (%)			
Convexity	4 (25%)	-	-
Skull base	8 (75%)	-	-
Karnofsky Performance Status, median (range)	100 (50-100)	100 (100-100)	-
Charlson Comorbidity Index, median (range)	1 (0-7)	1 (0-1)	-
Surgery, n (%)	11 (92%)	-	-
Radiotherapy, n (%)	4 (25%)	-	-
Months since last intervention, median (range)	24 (4-148)		
Neurological deficits, n (%)	1 (8%)	-	-
Visual deficits, n (%)	1 (8%)	-	-
Academic hospital, n (%)	8 (68%)	2 (50%)	9 (82%)
Years' experience, median (range)	-	-	9 (8-20)
Average number of new meningioma patients seen each year, median (range)	-	-	20 (10-25)

n=number

Issues and solutions

Following the principles of the grounded theory approach, issues were eventually categorized into a thematic framework consisting of the following three themes: (1) availability and provision of information, (2) care and support, and (3) screening for (neurocognitive) rehabilitation. A complete overview of all issues and possible solutions is presented in figure 2 and supplementary Table 2. Data saturation on the identified issues was reached after the semi-structured interviews, so the focus groups primarily focused on evaluating these issues into more detail and on identifying possible solutions for these problems (Figure 1). Examples of quotes from participants in the semi-structured interviews and focus groups are presented in Supplementary Text 2.

Figure 2 – Issues and solutions in meningioma care trajectories



Availability and provision of information

Both patient-partner dyads and healthcare providers reported the following issues as important: 1) not receiving sufficient information about the logistics of care during the period prior to the intervention (surgery or radiotherapy), 2) a lack of information about the intervention itself and what to expect afterwards, including information on complications and symptoms, and 3) what they are allowed to do after the intervention (Patient quote: "How will I feel after the surgery? And how long will it take to have a somewhat normal life again?").

A potential solution for these unmet needs was the availability and provision of information (e.g., flyer/website) on the care trajectories, treatment options, short- and long-term outcomes and potential complications, as suggested by both patient-partner dyads and healthcare providers. Patient-partner dyads who had positive experiences with guidance from case managers for their comorbidities, suggested that a specialized nurse / case manager could potentially provide this information. Healthcare providers confirmed the necessity, however, also indicated that more outcome research is necessary to provide evidence-based information on outcomes.

Care and support

Both patient-partner dyads and healthcare providers reported that patients experience a lack of support, especially on the long-term, by healthcare providers after being diagnosed and treated for a meningioma. Specifically, information was lacking information on 1) bodily functions, 2) reintegration into society, 3) psychosocial aftercare, and 4) care for the partner of the patient (Patient quote: "If I only had someone during the process whom to call to ask questions, such as whether it's normal to be so tired the entire day, [...] or whether I was allowed to cycle [...] I had no idea of what I was capable of doing."). Patient-partner dyads reported the need for a contact person to ensure continuity of care and for minor everyday questions. They furthermore reported they missed a patient support group and believed that the overall impact of the disease is often underestimated by healthcare providers. Both patient-partner dyads and healthcare providers reported that a specialized nurse or case manager could be of assistance to inform and guide patients and their partners after an intervention. Psychological aftercare provided by a specialised healthcare provider focusing on cognitive revalidation, self-management strategies, and mood disorders such as anxiety and depression is also currently missing according to patient-partner dyads. In addition, patient-partner dyads expressed the wish for shorter waiting lists for scans, outpatient clinic appointments and intervention.

Screening for (neurocognitive) rehabilitation

Patient-partner dyads reported the need for a neurocognitive assessment and health-care providers the use of PRO measures (PROMs) both before and after the treatment to provide patients with information about the impact of treatment and the possible need for (neuro-cognitive) rehabilitation. Healthcare providers and patient-partner dyads reported the need to have the possibility to refer more patients to a physiatrist to determine whether rehabilitative treatment should be initiated focusing on neurological, and physical functions (Patient quote: “Fair enough, I received some exercises in the hospital the first two weeks, but after that, there was nothing. I did not know what I had to do at all.”).

Prioritisation and implementation of solutions

A total of 16 solutions were identified during all the focus groups. Potential solutions for most of the problems could be the appointment of a case manager in current care trajectories (solution for 11/18 problems, 61%), assessment and treatment by a physiatrist (22%), routine use of PROMs (17%) and providing expectation management (17%). Most solutions (56%) were categorised by at least one participant as highly important, low effort solutions, which should readily be implemented, e.g. access to a (neuro)psychologist and the availability and provision of information on interventions and outcomes of treatments (Figure 3).

Figure 3 – Eisenhower matrix categorising solutions based on their importance/effort ratio.

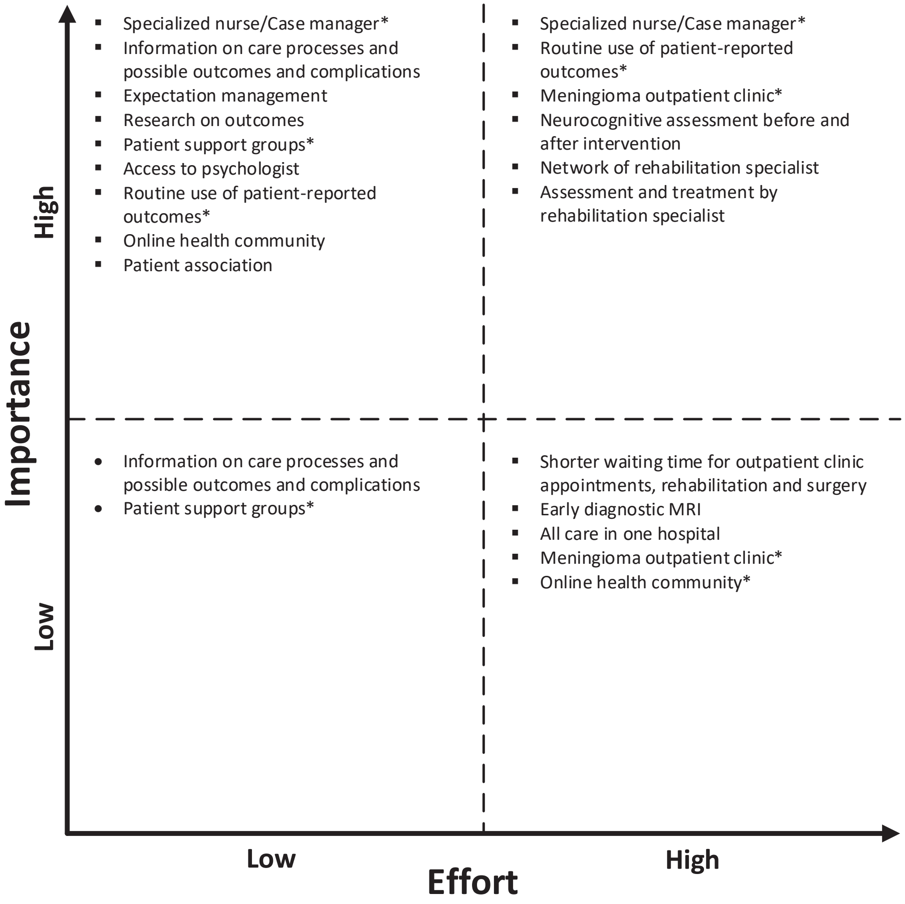


Table 2: Barriers and facilitators for high effort high importance solutions

Solution	Barrier (category)	Facilitator (category)
Case manager	• Lack of qualified personnel (Organisation context) • Multidisciplinary meningioma care (Organisation context) • Lack of capacity (Organisation context) • Lack of budget (Economic and political context) • Training of nurses (Individual professional)	• Qualified personnel (Organisation context) • Interdisciplinary consultation by case manager (Organisation context) • Budget (Economic and political context) • Use examples from other diseases (Innovation) • Saves time of doctors (Innovation) • Results in improvement quality of care (Innovation) • Priority hospital / board of directors (Social context)
Routine use of patient-reported outcomes	• Lack of time (Organisation context) • Lack of link with electronic patient record (Organisation context) • Lack of ICT infrastructure (Organisation context) • Implementation problems (Organisation context) • Lack of budget (Economic and political context) • Non-validated PROMs (Innovation) • Unmotivated patients to complete PROMs (Patient)	• Qualified ICT team (Organisation context) • Link with electronic patient record (Organisation context) • Use examples from other diseases (Innovation) • Use of tablets (Innovation) • Well-developed and validated PROMs (Innovation) • Motivated patients to complete PROMs (Patient)
Meningioma outpatient clinic	• Lack of capacity (Organisation context) • Lack of space and equipment (Organisation context) • Lack of budget (Economic and political context) • Heterogeneity disease (Patient)	• Budget (Economic and political context) • Results in publicity for hospital (Innovation) • Results in higher patient numbers (Innovation) • Results in improvement quality of care (Innovation) • Patient association voicing the need (Patient) • Priority hospital / board of directors (Social context)
Neurocognitive assessment	• Lack of qualified personnel (Organisation context) • Lack of capacity neuropsychologist (Organisation context) • Lack of budget (Economic and political context)	• Incorporation reimbursement system (Organisation context) • Link with electronic patient record (Organisation context) • Budget (from board of directors) (Economic and political context) • Simultaneous use of data for research (Innovation) • Inform patients on usability neurocognitive assessment (Patient)
Physiatrist network	• Lack of budget (Economic and political context) • Unfamiliarity other disciplines with rehabilitation possibilities (Individual professional) • Lack of know-how (Individual professional) • Lack of interest by other disciplines (Individual professional)	• Physiatrist part of multidisciplinary team (Organisation context) • Budget (Economic and political context) • Results in improvement quality of care (Innovation) • Priority hospital / board of directors (Social context)
Physiatrist screening	• Lack of capacity (Organisation context) • Lack of budget (Economic and political context) • Choice of screening instrument (Innovation)	• Budget (Economic and political context) • Results in improvement quality of care (Innovation) • Patient self-screening (Patient) • Priority hospital / board of directors (Social context)

Barriers and facilitators are categorised following the framework of Grol and Wensing into six categories: (1) innovation, (2) individual professional, (3) patient, (4) social context, (5) organizational context, and (6) external environment (political and economic factors).[14]

High importance/high effort solutions (38%) were: incorporation of a case manager in current care trajectories, creating a meningioma-specific outpatient clinic, performing neurocognitive assessments before and after an intervention, routine use of PROMs, and routine assessment of the need for rehabilitative therapy by a physiatrist, preferably in a network of physiatrists. The most important barriers for implementing these solutions were a lack of budget, capacity, ICT infrastructure, qualified personnel with knowledge about the management of meningioma patients and treatment issues focusing on HRQoL (Table 2). The most important identified facilitators were: using examples from other diseases and hospitals, and prioritisation by the hospital board. Most barriers and facilitators could be classified according to the Grol and Wensing criteria as factors associated with organizational aspects or the innovation (solution) itself.

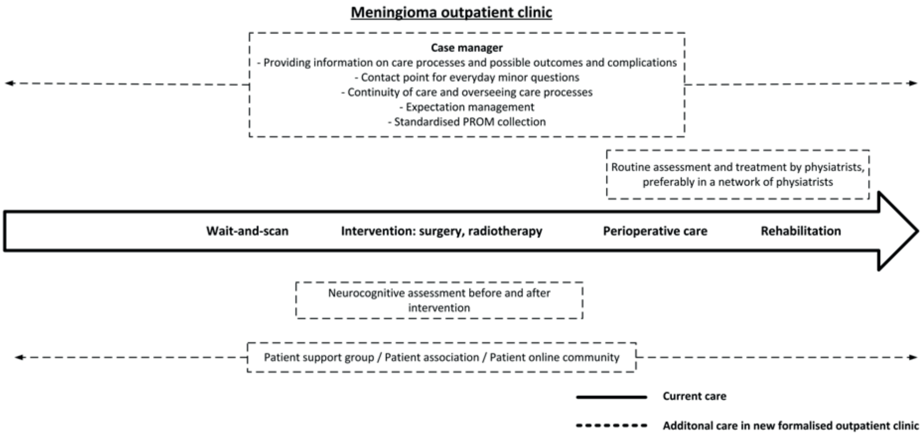
DISCUSSION

This study identified issues in current multidisciplinary meningioma care, which are considered unmet needs by patients, partners and healthcare providers that potentially contribute to delivering suboptimal care. This is the first study systemically evaluating these needs, including the identification of potential high impact solutions to improve care.

Transition of care

In our tertiary referral centre, multiple initiatives have been introduced in the last years to improve the care for patients with skull base and intracranial lesions. For those developing endocrine dysfunction or ophthalmological deficits, a formalised care trajectory was developed, including appointment of dedicated nurse case managers, standardised outcome measurements with PROMs, and implementation of self-management interventions, which all generally showed improvement of care outcomes.[15–18] Results of our study strongly support the need of a similar transformation of care and support system for meningioma patients, as depicted in Figure 4. Particularly, patients and healthcare providers reported the need for availability and provision of information about the intervention and its possible outcomes and complications, (continuity) of aftercare for patients and their partners including PROM use, focusing on bodily and psychological functions and reintegration into society, a point of contact for smaller (non-) medical questions, and patient support groups. Addressing these issues may possibly contribute to increased quality of care, as well as clinical outcomes. While physicians may be able to provide this needed extra guidance and aftercare, a nurse case manager seems more time- and cost-effective, thereby facilitating value based meningioma healthcare.[19] Furthermore, to ensure high quality care on a national level, quality criteria for meningioma centres should be defined regarding the structure of care, minimum number of operations and routine collection of outcomes. These criteria already exist for other intracranial pathology such as glioma and pituitary tumours, and has even resulted in the appointment of centres of excellence.[20,21]

Figure 4 – Transformation of meningioma care



Evidence for suggested solutions

Multiple studies in meningioma and other patient groups have found that the use of nurse case managers, (cognitive) rehabilitation programmes and routine assessment with PROMS in care trajectories led to better outcomes,[22–28] and that patients and physicians reported high satisfaction with provided care and perceived improvement in quality of care after appointment of a case manager.[30] While in general the effects were perceived as beneficial, large efforts needed to be made in the beginning to ensure proper implementation of these initiatives. Multiple effective meningioma or intracranial tumour rehabilitation programs exist focusing on bodily functions, cognitive rehabilitation and self-management.[15,25,27] Additionally, there are currently ongoing efforts to develop meningioma-specific PROMS and outcome sets.[7,8,30] While routine assessment with PROMs might be perceived as a burden in effort and time, it is beneficial for patient-doctor communication, adequate monitoring of treatment response (e.g. from a patient's home), reduction of the number of outpatient visits, detection of unrecognised symptoms by physicians, and consequently changes in the treatment and care of patients.[31] In general, future studies are needed to assess the actual effect of the suggested solutions on patient's HRQoL and the additional costs for the care trajectories.

Strengths and limitations of this study

A strength of this study is the combination of quantitative and qualitative data, as new issues were identified during the semi-structured interviews and focus groups, which were not mentioned in the DCCO survey data. Another strength is the inclusion of not only patients, but also partners and healthcare providers to cover all relevant themes in current meningioma care trajectories. The absence of nurses during the semi-structured interviews and focus-groups is a limitation, as they could have identified different issues and solutions. Through purposive sampling, an adequate representation of meningioma patients was ensured, and healthcare providers represented almost all specialties involved in meningioma care trajectories. Obviously, like in comparable studies, we could not completely exclude some selection bias, since it is likely that only patients, and possibly also healthcare providers with an interest in this disease and topic, were more likely to participate. Data saturation was reached early in the study process, likely due to the availability of the quantitative results of the DCCO survey. Furthermore, even though we included patients from both an academic and a non-academic hospital, we were only able to include patients from a specific region in The Netherlands for the semi-structured interviews and focus groups, potentially limiting generalisability. However, we were able to include healthcare providers working in different regions of The Netherlands, which is a strength of the study. Although not all results may be generalised to countries other than The Netherlands, evidence for many of the reported issues and solutions are supported by international literature.[22–24,27,28,32–36] A difficulty with qualitative studies is that commonly only issues are identified, and not possible solutions, hampering actual change of care. Therefore, we asked healthcare providers to prioritise the identified solutions based on their perceived importance/effort ratio and to identify barriers and facilitators for implementation of these solutions, which is another strength of this study. Patients were not asked to identify barriers and facilitators for the identified solutions, as we felt that thorough understanding of Dutch hospitals and the Dutch healthcare system was needed for this purpose. Finally, as the median follow-up of patients was 5.5 years for the DCCO survey and 2 years for the semi-structured interviews and focus-groups, our results cover both the period around diagnosis and intervention as well as the longer-term sequelae.

Recommendations and future directions

In conclusion, the most important issues, as identified through patient-partner dyads, were a lack of information about the intervention and its possible outcomes and complications, and a lack of support after treatment focusing on bodily and psychological functions, and reintegration into society. To improve most of these unmet needs of patients, partners and healthcare providers, it is advisable to appoint a case manager, routinely use PROMs, and to incorporate a (neurocognitive) rehabilitation screening programme into current meningioma care trajectories. These solutions might subsequently result in lower costs and better outcomes, which is in line with the principles of value-based healthcare. Information on the identified barriers and facilitators should be used to successfully implement these initiatives. Ideally, these initiatives should be evaluated within integrated practice units (i.e. IPU), which involve the entire multidisciplinary team around the patient group of interest, to ensure broad support.[37] As it is difficult to reach sustainable change in existing care trajectories, iterative evaluation of implemented initiatives is required. For instance, the PDSA-cycle could be used, which requires initiatives to be redirected based on evaluated outcomes.[38,39] Within our IPU, we are currently training case managers and developing a core outcome set together with and for meningioma patients as a first step to reorganise our care following the VBHC principles.

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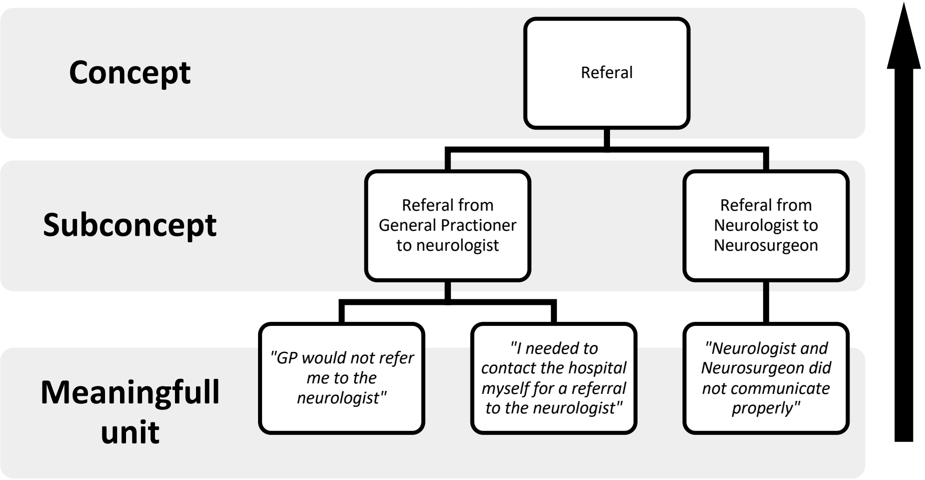
SUPPLEMENTS

Supplementary Table 1: Thematic framework used for the focus group sessions, based on the results of the DCCO survey.

Parts of meningioma care trajectory	Signs and symptoms	Referral	Diagnostics	Support and guidance	Efficiency	Empathy physician	Accessibility care	Quality of care	Information
Before appointment general practitioner							x	x	
Appointment general practitioner	x	x	x		x	x	x	x	x
Before appointment neurologist	x	x	x	x	x		x	x	x
Appointment neurologist	x	x	x		x	x	x	x	x
Before MRI	x		x	x	x		x		x
Before appointment neurosurgeon	x			x			x	x	x
Appointment neurosurgeon	x				x	x	x	x	x
Wait-and-scan	x		x	x	x		x	x	x
Operation	x							x	
Hospitalisation	x			x		x		x	
Postoperative care	x			x	x	x	x	x	x
Before radiation	x			x			x	x	x
Radiation	x				x	x		x	
After radiation	x			x			x	x	
Rehabilitation period	x			x		x	x	x	

Supplementary figure 1: Example of Qualitative analysis trough meaningful units, subconcepts and concepts.



Supplementary text 1: General procedures of semi-structured interviews and focus groups

All semi-structured interviews and focus groups were conducted by AHZN, who moderated the focus group, and JPMvdM, who took notes and managed time. Both researchers had prior experience with, and were trained for, conducting semi-structured interviews and focus groups. No relationship was established between the researchers and patients before this study. The grounded thematic framework based on data of the DCCO survey was used during all sessions (see Supplementary Table 1 for an overview of the aspects in this framework). Non-suggestive open-ended probing questions were initially asked, but when participants were not able to answer the questions, additional examples as identified in the DCCO survey results were provided. Interviews and focus groups were scheduled for 90 to 120 minutes. Interviews were organised in a quiet and comfortable room in the hospital or patient's home, as preferred by the patient and partner. Focus groups were organised in the Leiden University Medical Center. All sessions were audiotaped and transcribed verbatim.

Supplementary Table 2 – Identified issues during focus groups with patient-partner dyads and healthcare providers

Issues	**Patient-partner dyads**	**Healthcare providers**	**DCCO survey**
Lack of information regarding (the period before) surgery or radiotherapy	x	x	11
Lack of information on outcomes, complications, and life rules after intervention	x	x	4
Lack of support after intervention focusing on neurological and physical functions	x	x	4
Lack of support after intervention focusing on reintegration	x	x	2
Lack of support after intervention focusing on psychosocial aftercare (e.g. mood disorders such as anxiety and depression)	x	x	5
Lack of support after intervention focusing on the patient's partner	x	x	
Lack of a direct contact person for smaller questions	x	x	
Lack of a person with a 'helicopter-view' responsible for the care process	x	x	
Patients are not referred to rehabilitation specialist	x	x	
Rehabilitation is initiated too late	x		
Diagnostic MRI should be made earlier in the care trajectory	x		1
Time between MRI and (outpatient appointment) communication of the results is too long	x		1
Long waiting time between the first outpatient clinic visit and intervention	x		
Lack of a patient support group	x		15
Impact of disease is underestimated by healthcare providers	x		9
Patient's symptoms are not always taken seriously by physicians	x		
Need for higher amount of follow-up appointments during the first year after the intervention	x		
Patients feel that they need to arrange all required care themselves	x		
Patients have questions that remain unanswered after visiting specialists	x		6
Patients are followed-up by different physicians	x		6
Care takes place at different hospitals	x		
Poor communication between physicians in different hospitals	x		
Lack of information on the implications of an incidentally found meningioma		x	
Lack of clarity on who is responsible for the patient in the hospital		x	

Supplementary text 2: Examples of quotes from semi-structured interview and focus groups

Availability and provision of information

Quote 1

"I did not know whether they would cut the mastication muscles, but I would have liked to know that beforehand."

Quote 2

"Actually, I also want the neurosurgeon to explain exactly what is going to happen. About the period before the operation, about the stickers on the head, that the skull is being lifted, what the risks are […]"

Quote 3

"They told me about a patient who started working again after six weeks. I thought that is way too soon, […] Indeed, during those six weeks I was wheelchair bound and I was unable to do anything, I was so tired and I did not have any endurance, I couldn't do a thing."

Quote 4

"What can you expect during the period before surgery?... I would have liked to receive flyers with information about how the day of the surgery will look like."

Quote 6

"*So somebody should have accompanied me to the appointment, because of the MRI results and all the fuss around it…. You are not allowed to drive, nobody ever told me that. I had to find out about those things myself."*

Quote 7

"[…] what really struck us was that you do not receive any life rules, for instance when you can start exercising. When are you able to take a walk again?"

Quote 9

"*A lot of simple questions, such as 'how will they perform the surgery', 'how do they close the skull afterwards'? Those are very simple questions, but we had to ask for them ourselves."*

Quote 10

"*The information provision after discharge should focus on two things; follow-up at the outpatient clinic, and what you can expect afterwards. … I have three solutions; an approachable specialised nurse, an information leaflet about the treatment and care after surgery, and, if it was up to me, an earlier start of a rehabilitation trajectory, which can help to get insight in your current problems."*

Care and support

Quote 1

"These things [the symptoms and impact on daily life] are also the case, I think, with patients suffering from other brain tumours, they do not necessarily have to do with meningiomas. … there is more attention for somebody with a malignant tumour, while everyone thinks: 'right, but it is only a meningioma, you can become old with a meningioma'."

Quote 2

"… my husband suffered from a weak heart and I experienced that entire clinical pathway, and the aftercare is absolutely amazing. Both the patient and the partner can attend information evenings, receive help with their diet and other things, that is absolutely amazing. I therefore said to my husband: 'they should do something like that also for people with a brain tumour."

Quote 3

"Well, my mother had a nurse practitioner, I believe, who she could always call. … That is something I wish I had too."

Quote 4

"Actually, what is lacking in the whole care pathway is a medical doctor who is in charge of the whole care process."

Quote 5

"Someone you can talk to and who listens to you"…someone that speaks out of experience" "Just someone you can go to with questions, somebody who listens to you."

Quote 6

"Yes, I have been three times to the national brain tumour association meeting. That helped me quite a lot". "How did it help you?". "Speaking to people who also suffered from brain tumours" … recognition, that you are not alone."

Quote 7

"Actually it is about the aftercare, and the aftercare is not only medical. It is very much focused, at least in this hospital, on medical care, but everything that has been discussed in this focus group has nothing to do with the medical care."

Quote 8

"The symptoms are vague, such as headaches or concentration problems. These symptoms can also be interpreted as purely psychological, but, in fact, are a result physical problems. You don't get any support for these symptoms."

Quote 9

"There should be recognition for the fact that it is not just tumour surgery, but that you will suffer from many problems in daily life. So there should also be better support, for instance in the form of a case-manager. And indeed, we should also create patient support groups."

Quote 10

"Just somebody you can call who has some knowledge about meningiomas and can advise me about what I should do, who can comfort me with all those weird symptoms I still have."

Quote 11

"Also support and comfort after the surgery. I missed that a lot. There should be a case manager, a nurse practitioner, a specialised nurse, who you can call, who fills the existing gap."

Quote 12

"Why don't they make an MRI earlier in the care trajectory?" "If they would make it earlier, they would not need all those extra steps in the meantime that cost money" "All these steps may actually be more expensive than the MRI."

Quote 13

"And the neurologist did not even know that an MRI was performed. … Afterwards, it turned out that the ophthalmologist sent me to the neurologist for the neurological tests, and that the ophthalmologist had ordered the MRI, so he would receive the MRI results. I understand that the one who orders the scan, will receive the results of that test."

Quote 14

"The first year after surgery I would get an MRI-scan, well, that was hard to get actually, because I had to call them and arrange everything myself."

Quote 15

"There has only been one appointment before surgery. You hear your diagnosis and you receive very limited information. There should be at least another appointment with the surgeon before the surgery is performed. You only see him the day before surgery, and that's it."

Quote 16

"Actually, I think, the first year after surgery you should have more regular appointments."

Quote 17

"They plan the surgeries one week ahead. … In the end, it took eight weeks until it was my turn."

Screening for (neurocognitive) rehabilitation

Quote 1

"I applied for rehabilitation in the rehabilitation clinic. Well, everybody thought that was a smart idea. … A week after the surgery I still had not heard from them, so I called them and they said: "oh, but that is only after two months after surgery", and I thought 'two months? I will surely not lie in bed for two months, right? I just want some guidance, what is allowed and what is not?' It would have been very helpful for me if I could have attended the rehabilitation clinic earlier."

Quote 2

"I will undergo a neuropsychological test in a week and I would have liked to have a baseline measurement of such a test, because I honestly do not know how to interpret the results if I do not know how I scored before surgery."