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FACT-MNG: tumor site specific web-based outcome instrument for meningioma patients

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Abstract To formulate Functional Assessment of Cancer Therapy-Meningioma (FACT-MNG), a web-based tumor site-specific outcome instrument for assessing intracranial meningioma patients following surgical resection or stereotactic radiosurgery. We surveyed the relevant literature available on intracranial meningioma surgery and subsequent outcomes (38 papers), making note of which, if any, QOL/outcome instruments were utilized. None of the surveyed papers included QOL assessment specific to tumor site. We subsequently developed questions that were relevant to the signs and symptoms that characterize each

of 11 intracranial meningioma sites, and incorporated them into a modified combination of the Functional Assessment of Cancer Therapy-Brain (FACT-BR) and SF36 outcome instruments, thereby creating a new tumor site-specific outcome instrument, FACT-MNG. With outcomes analysis of surgical and radiosurgical treatments becoming more important, measures of the adequacy and success of treatment are needed. FACT-MNG represents a first effort to formalize such an instrument for meningioma patients. Questions specific to tumor site will allow surgeons to better assess specific quality of life issues not addressed in the past by more general questionnaires.

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Introduction

Outcomes and Quality of Life (QOL) assessment instruments are important for assessing the results of surgical and radio-surgical treatment, as well as comparing results across studies [16]. Many of these instruments assess QOL but not in a manner that addresses the CNS symptoms/signs of specific tumor sites. This becomes increasingly relevant when dealing with tumors that tend to arise in specific intracranial locations which can lead to distinct symptom complexes with unique effects on QOL that can be overlooked by less specific QOL instruments. Recognizing these location-specific symptom complexes allow us the opportunity to personalize the QOL assessment towards distinct patient groups.

Meningiomas comprise one such class of location-specific intracranial tumors [31]. Accounting for some 20% of intracranial tumors, they are generally histologically benign and slow growing, but may become locally invasive. Due to the risk of tumor growth and development of focal neurological deficits from mass effect, standard treatment usually consists of surgical resection or stereotactic radiosurgery.

QOL assessment provides information regarding efficacy of surgical/radiosurgical treatment and may serve as an important decision-making tool for patients and physicians who are weighing the risks and benefits of brain surgery, especially if their meningioma is of the benign variety. While there are a variety of outcome assessment tools currently available, they vary widely in terms of scope (post-surgery QOL, post-cancer therapy QOL, post-brain surgery QOL, etc.), and none are currently location-specific. Currently, the instrument most accurately targeted at assessing QOL following brain tumor resection is the validated Functional Assessment of Cancer Therapy-Brain (FACT-BR) [22, 23, 40].

The location-specific nature of clinical symptoms and signs of intracranial meningiomas provides an opportunity for an even more targeted QOL assessment; one that takes into account site-specific symptoms [42]. This would allow for a more detailed examination of an individual patient's QOL based on tumor site and pre/post-surgery signs and symptoms. With these goals in mind, FACT-MNG was created. An important part of developing such an instrument was making it available freely in a web based platform so that patients could access the questionnaire on regular set intervals without the need for direct physician contact or instruction. The VisionTree Optimal Care™ (VTOC) secure web-based portal allows for patients to enter the site through self-registration and complete the FACT-MNG electronically. Upon registration, the patient automatically receives an email with their secure login information providing ongoing access to the survey. VTOC includes full reporting/tracking capabilities to query the data which can be exported to Excel for additional analysis.

Methods

Initial data was gathered by way of reviewing relevant literature (via PubMed) which discussed and examined intracranial meningioma surgical therapy as well as subsequent outcomes. With 38 papers [1–15, 17–22, 24–30, 32–41] in hand meeting our search criteria, we reviewed the assessment instruments utilized in each. While all of the papers included outcomes, when it came to QOL assessment, 2 of the 38 used SF36 [3, 19, 39] others used FACT-BR [5, 22, 40], and 8 used a more basic patient functionality-oriented Karnofsky Performance Status (KPS) comparison [10, 13, 28, 32, 34, 36, 37], and less than half (15 of 38 papers) utilized any QOL instrument at all (FACT-BR, SF36, KPS Scale, or some other instrument). None of the papers utilized site-specific questions.

Table 1 SF-36 Questions incorporated into FACT-MNG

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I am limited in performing vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	0	1	2	3	4
I am limited in performing moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	0	1	2	3	4
I have difficulty climbing several flights of stairs	0	1	2	3	4
I have difficulty walking several blocks	0	1	2	3	4
I have difficulty bathing or dressing myself	0	1	2	3	4

Table 2 Site-specific questions incorporated into FACT-MNG

	Not at all	A little bit	Somewhat	Quite a bit	Very much
<i>Olfactory Groove Meningioma</i>					
My sense of smell is altered	0	1	2	3	4
My sense of taste is altered	0	1	2	3	4
My vision is altered	0	1	2	3	4
My short term memory is worse	0	1	2	3	4
<i>Tuberculum sellae meningioma</i>					
My vision is altered	0	1	2	3	4
Compared to before my surgery, my vision is improved	0	1	2	3	4
My short term memory is worse	0	1	2	3	4
<i>Optic nerve sheath meningioma</i>					
My vision is altered	0	1	2	3	4
Compared with prior to treatment, my vision is improved	0	1	2	3	4
<i>Sphenoid wing meningioma</i>					
My vision is altered	0	1	2	3	4
Compared with prior to treatment, my vision is improved	0	1	2	3	4
I have numbness on my forehead	0	1	2	3	4
I have numbness on my cheek	0	1	2	3	4
I have double vision	0	1	2	3	4
My short term memory is worse	0	1	2	3	4
<i>Cavernous sinus meningioma</i>					
My vision is altered	0	1	2	3	4
I have double vision	0	1	2	3	4
I have numbness on my forehead	0	1	2	3	4
I have numbness on my cheek	0	1	2	3	4
I have numbness on my chin	0	1	2	3	4
<i>Parasagittal/falx meningioma</i>					
My short term memory is worse	0	1	2	3	4
My leg is weak	0	1	2	3	4
My leg is numb	0	1	2	3	4
My arm is weak	0	1	2	3	4
My arm is numb	0	1	2	3	4
I have a blind spot in my vision	0	1	2	3	4
<i>Tentorial meningioma</i>					
My vision is altered	0	1	2	3	4
I have double vision	0	1	2	3	4
I have numbness on my face	0	1	2	3	4
My short term memory is worse	0	1	2	3	4
I have a blind spot in my vision	0	1	2	3	4
<i>Petroclival meningioma</i>					
My vision is altered	0	1	2	3	4
I have double vision	0	1	2	3	4
I have numbness on my face	0	1	2	3	4
My short term memory is worse	0	1	2	3	4
My coordination is affected	0	1	2	3	4
My arm is uncoordinated	0	1	2	3	4
My leg is uncoordinated	0	1	2	3	4

Table 2 continued

	Not at all	A little bit	Somewhat	Quite a bit	Very much
My hearing is worse than prior to treatment	0	1	2	3	4
My balance is worse than prior to treatment	0	1	2	3	4
<i>Cerebellopontine angle (CPA) meningioma</i>					
I have numbness on my face	0	1	2	3	4
I have pain in my face	0	1	2	3	4
My hearing is worse than prior to treatment	0	1	2	3	4
I have ringing in my ear on the side of surgery	0	1	2	3	4
I have weakness of my face	0	1	2	3	4
I have problems with dizziness	0	1	2	3	4
My balance is worse than prior to treatment	0	1	2	3	4
My coordination is affected	0	1	2	3	4
My arm is uncoordinated	0	1	2	3	4
My leg is uncoordinated	0	1	2	3	4
<i>Cerebellar convexity meningioma</i>					
My coordination is affected	0	1	2	3	4
My arm is uncoordinated	0	1	2	3	4
My leg is uncoordinated	0	1	2	3	4
My balance is worse than prior to treatment	0	1	2	3	4
My arm is weak	0	1	2	3	4
My leg is weak	0	1	2	3	4
My arm is numb	0	1	2	3	4
My leg is numb	0	1	2	3	4
<i>Foramen magnum meningioma</i>					
I have neck pain	0	1	2	3	4
My speech is slurred	0	1	2	3	4
I have trouble swallowing	0	1	2	3	4
My voice is hoarse	0	1	2	3	4
My balance is worse than prior to treatment	0	1	2	3	4
My walking is worse than prior to treatment	0	1	2	3	4
I have shoulder pain	0	1	2	3	4

Results and discussion

To address the issue of site specificity, we created FACT-MNG (Functional Assessment of Cancer Therapy-Meningioma), an amalgamation of FACT-BR, SF36, and newly formulated questions addressing tumor site-specific signs and symptoms. Specifically, we started with FACT-BR as our base and added questions from SF36 that were more detailed in ascertaining the patient's physical capabilities (e.g., ability to perform light, mild, or strenuous activity without difficulty) (Table 1). Our most significant modification was the creation and inclusion of questions that were relevant to the signs and symptoms that characterize one of 11 tumor sites: olfactory groove, tuberculum sella, optic nerve sheath, sphenoid wing, cavernous sinus, parasagittal, tentorium cerebelli, petroclival region, cerebellopontine angle, cerebellar convexity, and foramen magnum (Table 2, 3).

Following its creation, FACT-MNG was converted into a web-based format (currently available for patients/physicians to download for free at <https://www.optimalcare.com>). In addition to the benefits of offering FACT-MNG digitally (streamlined data collection, storage, and analysis), the dynamic delivery offered by a web-based application allows patients to only answer questions pertinent to their tumor's site. At UCSF we plan to introduce patients to the web site and questionnaire with a small business card containing the web site URL and suggested time interval for assessment post-operatively at 3, 6, 12, 18, 24, 36, 48, 60, and 72 months. Any additional intervention will re-start the assessment clock for the initial intervention and begin a new follow-up session. The VTOC system can be configured to release the FACT-MNG into the patient's portal at the specific time points noted above. An email alert is automatically sent to remind the patient to login and complete the survey at each time interval. The process is

Table 3 FACT-MNG

	Not at all	A little bit	Somewhat	Quite a bit	Very much
Physical well-being					
I have a lack of energy	0	1	2	3	4
I have nausea	0	1	2	3	4
Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
I have pain	0	1	2	3	4
I am bothered by side effects of treatment	0	1	2	3	4
I feel ill	0	1	2	3	4
I am forced to spend time in bed	0	1	2	3	4
I am limited in performing vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	0	1	2	3	4
I am limited in performing moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	0	1	2	3	4
I have difficulty climbing several flights of stairs	0	1	2	3	4
I have difficulty walking several blocks	0	1	2	3	4
I have difficulty bathing or dressing myself	0	1	2	3	4
Social/family well-being					
I feel close to my friends	0	1	2	3	4
I get emotional support from my family	0	1	2	3	4
I get support from my friends	0	1	2	3	4
My family has accepted my illness	0	1	2	3	4
I am satisfied with family communication about my illness	0	1	2	3	4
I feel close to my partner (or the person who is my main support)	0	1	2	3	4
<i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box <input type="checkbox"/> and go to the next section</i>					
I am satisfied with my sex life	0	1	2	3	4
Emotional well-being					
I feel sad	0	1	2	3	4
I am satisfied with how I am coping with my illness	0	1	2	3	4
I am losing hope in the fight against my illness	0	1	2	3	4
I feel nervous	0	1	2	3	4
I worry about dying	0	1	2	3	4
I worry that my condition will get worse	0	1	2	3	4
Functional well-being					
I am able to work (include work at home)	0	1	2	3	4
My work (include work at home) is fulfilling	0	1	2	3	4
I am able to enjoy life	0	1	2	3	4
I have accepted my illness	0	1	2	3	4
I am sleeping well	0	1	2	3	4
I am enjoying things I usually do for fun	0	1	2	3	4
I am content with the quality of my life right now	0	1	2	3	4
Additional concerns					
I am able to concentrate	0	1	2	3	4
I have had headaches	0	1	2	3	4
I have had seizure convulsions	0	1	2	3	4
I can remember new things	0	1	2	3	4
I get frustrated that I cannot do the things I used to	0	1	2	3	4
I am afraid of having a seizure (convulsion)	0	1	2	3	4
I have trouble with my eyesight	0	1	2	3	4

Table 3 continued

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel independent	0	1	2	3	4
I have trouble hearing	0	1	2	3	4
I am able to find the right word(s) to say what I mean	0	1	2	3	4
I have difficulty expressing my thoughts	0	1	2	3	4
I am bothered by the change in my personality	0	1	2	3	4
I am able to make decisions and take responsibility	0	1	2	3	4
I am bothered by the drop in my contribution to the family	0	1	2	3	4
I am able to put my hands together	0	1	2	3	4
I need help caring for myself (bathing, dressing, eating, etc.)	0	1	2	3	4
I am able to my thoughts into action	0	1	2	3	4
I am able to read like I'm used to	0	1	2	3	4
I am able to write like I'm used to	0	1	2	3	4
I am able to drive a vehicle (my car, truck, etc.)	0	1	2	3	4
Tumor site-specific questions					
<i>Olfactory Groove Meningioma</i>					
My sense of smell is altered	0	1	2	3	4
My sense of taste is altered	0	1	2	3	4
My vision is altered	0	1	2	3	4
My short term memory is worse	0	1	2	3	4
<i>Tuberculum Sellae Meningioma</i>					
My vision is altered	0	1	2	3	4
Compared to before my surgery, my vision is improved	0	1	2	3	4
My short term memory is worse	0	1	2	3	4
<i>Optic Nerve Sheath Meningioma</i>					
My vision is altered	0	1	2	3	4
Compared with prior to treatment, my vision is improved	0	1	2	3	4
<i>Sphenoid Wing Meningioma</i>					
My vision is altered	0	1	2	3	4
Compared with prior to treatment, my vision is improved	0	1	2	3	4
I have numbness on my forehead	0	1	2	3	4
I have numbness on my cheek					
I have double vision	0	1	2	3	4
My short term memory is worse	0	1	2	3	4
<i>Cavernous Sinus Meningioma</i>					
My vision is altered	0	1	2	3	4
I have double vision	0	1	2	3	4
I have numbness on my forehead	0	1	2	3	4
I have numbness on my cheek	0	1	2	3	4
I have numbness on my chin	0	1	2	3	4
<i>Parasagittal/Falx Meningioma</i>					
My short term memory is worse	0	1	2	3	4
My leg is weak	0	1	2	3	4
My leg is numb	0	1	2	3	4
My arm is weak	0	1	2	3	4
My arm is numb	0	1	2	3	4
I have a blind spot in my vision	0	1	2	3	4
<i>Tentorial Meningioma</i>					
My vision is altered	0	1	2	3	4

Table 3 continued

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have double vision	0	1	2	3	4
I have numbness on my face	0	1	2	3	4
My short term memory is worse	0	1	2	3	4
I have a blind spot in my vision	0	1	2	3	4
<i>Petroclival Meningioma</i>					
My vision is altered	0	1	2	3	4
I have double vision	0	1	2	3	4
I have numbness on my face	0	1	2	3	4
My short term memory is worse	0	1	2	3	4
My coordination is affected	0	1	2	3	4
My arm is uncoordinated	0	1	2	3	4
My leg is uncoordinated	0	1	2	3	4
My hearing is worse than prior to treatment	0	1	2	3	4
My balance is worse than prior to treatment	0	1	2	3	4
<i>Cerebellopontine Angle (CPA) Meningioma</i>					
I have numbness on my face	0	1	2	3	4
I have pain in my face	0	1	2	3	4
My hearing is worse than prior to treatment	0	1	2	3	4
I have ringing in my ear on the side of surgery	0	1	2	3	4
I have weakness of my face	0	1	2	3	4
I have problems with dizziness	0	1	2	3	4
My balance is worse than prior to treatment	0	1	2	3	4
My coordination is affected	0	1	2	3	4
My arm is uncoordinated	0	1	2	3	4
My leg is uncoordinated	0	1	2	3	4
<i>Cerebellar Convexity Meningioma</i>					
My coordination is affected	0	1	2	3	4
My arm is uncoordinated	0	1	2	3	4
My leg is uncoordinated	0	1	2	3	4
My balance is worse than prior to treatment	0	1	2	3	4
My arm is weak	0	1	2	3	4
My leg is weak	0	1	2	3	4
My arm is numb	0	1	2	3	4
My leg is numb	0	1	2	3	4
<i>Foramen Magnum Meningioma</i>					
I have neck pain	0	1	2	3	4
My speech is slurred	0	1	2	3	4
I have trouble swallowing	0	1	2	3	4
My voice is hoarse	0	1	2	3	4
My balance is worse than prior to treatment	0	1	2	3	4
My walking is worse than prior to treatment	0	1	2	3	4
I have shoulder pain	0	1	2	3	4

fully automated within VTOC using templates and calendar reminders to ensure accuracy and compliance. A subset of patients may not be proficient with or have access to computers, either due to educational differences, socioeconomic status, or as a result of their disease process and/or treatment. For these selected patients, notifications by mail can be utilized.

Conclusion

With QOL assessment becoming increasingly important as an information, education and –outcomes assessment tool for both physicians and patients, relying on an outcome instrument too general in scope may leave more detailed, but nonetheless pertinent, issues unexplored and unmeasured. While FACT-BR has been validated as an assessment tool pertaining to brain tumors in general, those tumors which associated with characteristic site-specific signs and symptoms readily lend themselves towards QOL assessment with an even further refined scope. Intracranial meningiomas offer one such opportunity and, on account of their comprising almost one-fifth of all intracranial tumors, warrant the development of an outcome instrument with a narrower scope.

This instrument is not yet clinically validated. Further examination of FACT-MNG should revolve around qualifying its validity as compared to the outcome assessment provided by other QOL instruments (most notably FACT-BR) following meningioma surgical therapy. The authors of this paper plan to investigate the use of this instrument in a prospective fashion on their patient population and report on the results at a future date.

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