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Brief Report

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The Need for Patient-centered Education Among Patients Newly Diagnosed With a Pituitary Tumor

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Abstract

Objectives: Brain tumors, including pituitary adenomas (PA), cause anxiety and distress, with a high unmet need for information correlating with increased anxiety. Condition-specific education may alleviate anxiety. We explored patients' experience around the diagnosis of a PA and piloted a patient education intervention to address peridiagnostic anxiety in adults diagnosed with PA.

Methods: Anxiety, patient satisfaction, patient knowledge, and need for information were measured prior to, immediately after, and 1 month following the appointment in this multimethods study. A phone interview to explore patient diagnostic and intervention experiences was analyzed using qualitative methods.

Results: A total of 17 patients participated in the study; 15 completed the interview. The baseline need for information was high. Disease-specific anxiety decreased, and patient knowledge and satisfaction increased significantly after the initial visit. Interview analysis identified 3 main themes: (1) the importance of communication; (2) the need for information; and (3) the impact of the diagnosis on patient experience.

Conclusions: For patients with newly diagnosed PA, the diagnostic experience was associated with high levels of anxiety. Patients expressed a need for information. Information delivery reduced anxiety and had a positive impact on patient satisfaction.

Practice Implications: The study findings suggest a need for a streamlined diagnostic process with readily accessible information.

Key Words: anxiety, patient satisfaction, pituitary tumors, diagnosis, patient education

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Patients with intracranial tumors, including pituitary adenomas (PA), experience high levels of psychological distress and emotional burden during the diagnosis and course of illness regardless of tumor type [1–3]. Multiple factors influence anxiety and distress, but patient education regarding underlying disease, treatment options, and outcome has also been shown to improve patient anxiety or distress [4].

Previous studies have found correlations between the level of patient anxiety and the need for information [5]. Among those with brain tumors, including pituitary tumors, patients (43%) and caregivers (46%) frequently report the need for disease-related information [6]. It is estimated that 80% of internet users search online for health-related information [7]; however, more than 80% of available online patient education material regarding pituitary tumors is considered "difficult" or "very difficult" to read and comprehend [8]. Patients therefore rely on healthcare providers to meet the majority of their health information needs, but providers do not always accomplish this task with success.

To date, assessment of patient-centered factors among those with pituitary tumors has focused primarily on the long-term impact of pituitary disease or treatment thereof [9, 10]. There is little information on the psychological aspects associated with disease diagnosis, disease-related education, and effective methods of patient education delivery. This prospective proof-of-concept study sought to address these key gaps and enhance understanding of the experiences of diagnosis and education for patients with newly diagnosed PA, and to explore patient preferences regarding educational methods.

Methods

Following approval from the Institutional Review Board, adults referred were considered eligible for study inclusion if they had a pituitary lesion seen on magnetic resonance imaging (MRI) consistent with a PA and hormonal evaluation suggested the lesion was a nonfunctioning PA or prolactinoma. Patients were excluded if they could not speak English (questionnaires and telephone interviews were conducted in English), had severe major depression, cognitive impairment, or significant visual impairment affecting the ability to read questionnaires. Severe major depression was defined as a Patient Health Questionnaire (PHQ)-8 score >20 [11], whereas cognitive impairment was defined as a score of 3 or less on the 6-item cognitive screen [12].

The study was a pilot, prospective multimethods design. Eligible patients completed the following questionnaires: Generalized Anxiety Questionnaire (GAD)-7 [13, 14], Visual Analogue Scale of Anxiety (VAS-A) [15], and a Patient Knowledge Questionnaire (PKQ), [13, 16]. Patient satisfaction regarding information provided, the need for information, and anxiety specifically regarding the pituitary tumor (determined using the following questions modified from the Amsterdam Pre-operative Anxiety and Information Scale [5]: "I am worried about my pituitary disease" and "My pituitary disease is always on my mind") was assessed using a Likert-type scale (1–5). Interpretation of the questionnaires was as follows: GAD scores of >5, >10, and >15 were consistent with mild, moderate, and severe anxiety, respectively [13]. A VAS-A score of >50 mm was suggestive of anxiety, while a reduction of 10 to 15 mm is reported to be clinically significant [15].

For this study, a PKQ was developed. All questionnaires were administered immediately before and following the endocrinology visit and repeated 1 month later either in person or at home. A semistructured phone interview, which was audiorecorded and later transcribed, was conducted 3 to 14 days following the endocrinology visit. Participants were compensated $20 on completion of the study.

During the endocrinology visit, which was conducted by a single physician (D.D.) for each patient, patients received education (conveyed information determined a priori) regarding the pituitary gland, pituitary tumors, testing, and possible treatment. Information conveyed as part of the "education" was determined prior to the start of the study; however, the ultimate plan discussed was unique to each patient's needs. Education was provided using an illustrative method (pamphlets and real-time drawing) delivered by the physician, lasting approximately 10 to 15 minutes and supported by an adjunctive patient information leaflet designed to be at 6th to 8th grade reading level. The complete visit lasted approximately 45 to 55 minutes.

Data analysis

To assess the effect of the educational intervention on anxiety measures, and patient knowledge and satisfaction over time, a mixed-effects linear model was tested separately for each of the 5 outcomes (GAD-7, APAIS, VAS-A, patient knowledge, satisfaction). A mixed-effects model was appropriate, as observations were repeated for participants [17]. These models account for interdependencies within participants. A 3-level time variable (corresponding to 3 data collection time points) was entered as the predictor in each model. Satisfaction was an ordinal variable; hence a mixed-effects generalized linear model using a cumulative logit function was tested. Post hoc pairwise comparisons of marginal means were conducted for fixed effects. Analyses were conducted using SAS software version 9.4 (Cary, NC, USA).

Qualitative analysis

In this study, we used a grounded theory approach to perform our qualitative analysis. We conducted a series of immersion (in-depth data analysis) or crystallization (theme identification through reflection) cycles to analyze the content of the de-identified transcripts. This was performed by 3 members of the research team, (D.D., T.G., and A.C.). Each read all the transcripts individually and met to discuss observations deemed important. A provisional coding scheme was developed, applied to the transcripts, and refined until agreement was reached in the coding process. When new data did not result in the identification of new codes, theoretical saturation was reached [18]. All transcripts were coded, and team members reviewed all coded transcripts and met to identify broader themes. QDA Miner Lite (Provalis Research, Montreal, Canada) was used to facilitate data analysis.

Results

Seventeen patients (mean ± standard deviation [SD] age 46 ± 19 years; 10 women) agreed to participate in the study, of whom 15 completed the phone interview (See Table 1 for patient demogrpahics). Anxiety, measured by the GAD-7 and VAS-A, was high prior to the endocrinology visit (51.1 ± 26.9 and 9 ± 6, respectively), as was the need for information (4.64 ± 0.6) despite high baseline patient knowledge about pituitary tumors (15/18 on initial PKQ). Patient satisfaction was low at baseline (2.8 ± 1) (Table 2). Following the visit, general anxiety (GAD-7 and VAS-A) decreased significantly at 1 month compared with the baseline ($P = 0.009$), while anxiety specifically related to the pituitary tumor improved immediately after following the endocrinology visit and was sustained on follow-up at 1 month, ($P < 0.01$ and $P = 0.008$). Patient knowledge regarding pituitary tumors ($P = 0.045$) increased even further and patient satisfaction increased significantly ($P = 0.002$) immediately after the visit. VAS-A, GAD-7, or satisfaction did not differ by underlying pathology prior to, immediately after, or 1 month after the visit.

Review of the transcripts revealed that the diagnostic process for a patient with a possible pituitary tumor is complex. Patients saw an average of 2.6 ± 1.3 providers prior to the endocrinologist and had numerous tests performed. In the majority of cases, the pituitary tumor was an incidental finding and was not the cause of the presenting symptom. The average time from MRI to endocrine appointment was a median of 2 months (interquartile range [IQR] 1–3.4). From the endocrine visit to the phone interview, no patient had surgery; however, those with a prolactinoma were initiated on cabergoline during this time. Table 3 lists themes and associated subthemes with descriptive quotes from the qualitative interviews.

Table 1. Sample characteristics

Measure	Frequency (%), n = 17
Age, years (mean, standard deviation)	45.8 ± 19
Female	10 (59)
Clinic attendance	
Alone	6 (35)
Spouse/partner	7 (41)
Friend	1 (6)
Children	1 (6)
Other	1 (1)
Race	
White	14 (82)
Black or African American	3 (18)
Marital Status	
Married	10 (59)
Single	6 (5)
Widowed	1 (6)
Highest school grade completed	
High school	4 (24)
Some college	5 (29)
Bachelor's degree	5 (29)
Master's degree	3 (18)
Employment status	
Full-time	10 (59)
Part-time	1 (6)
Retired	3 (18)
Unemployed	3 (18)
Tumor type	
Nonfunctioning	13 (76)
Prolactinoma	4 (23)
Median tumor size (mm, IQR)	5 (2–23.4)

Theme 1: communication

Patients described the diagnostic process as protracted and cumbersome. *"And it was just test after test after test. Everything was extremely overwhelming, and it took my brain into overload" T7*. Many experienced a delay in receiving test results from providers and/or obtaining appointments. As a result, patients voiced frustration and a sense of being overwhelmed by the diagnostic process. *"If this is serious—and I don't know if it is or not—then that's that much longer I have to wait" T15*.

Symptom validation during their diagnostic process even if those symptoms were unrelated to the pituitary tumor was important. When a patient felt unheard, the healthcare provider (HCP)–patient relationship was weakened, and on occasion, terminated. *"It's just sort of a blasé reaction of like, 'yeah you and a hundred other people have the same symptoms. Deal with it.' And that's not acceptable" T8*. The sense of dismissal regarding the patients' health concerns. *"He was very personable, but he didn't really listen to what I had to say, I would say mainly"T4*. Questions extended to accompanying family members. "*My husband asked him a question that he just kind*

Table 2. Anxiety and patient knowledge scales: means (standard deviations) by time (n = 17)

Measure	Previsit Mean ± SD	Postvisit Mean ± SD	1-month Follow-up Mean ± SD	F-value	*P*-value
VAS-A	51.1 ± 27.0[a]	46.1 ± 28.4[a]	30.8 ± 20.1[b]	5.54	0.009
GAD-7	9.1 ± 6.0[a]	7.9 ± 5.7[a,b]	6.2 ± 5.1[b]	5.56	0.009
Need For information*	4.6 ± 0.6[a]	4.6 ± 0.7[a]	3.9 ± 1.1[b]	6.80	0.004
Worried about pituitary disease*	3.5 ± 1.2[a]	2.2 ± 0.9[b]	2.5 ± 0.9[b]	12.32	<0.001
Pituitary disease always on mind*	3.2 ± 1.3[a]	2.5 ± 1.4[b]	2.2 ± 0.9[b]	5.63	0.008
Patient knowledge	15.0 ± 2.2[a]	15.9 ± 1.8[b]	15.8 ± 1.3[b]	3.43	0.045
Patient satisfaction*	2.8 ± 1.0[a]	4.2 ± 1.3[b]	4.5 ± 0.6[b]	7.97	0.002

Post hoc comparison results indicated with superscripts; different superscripts represent a significant ($P < 0.05$) difference between time points. GAD Scores of >5, >10, and >15 were consistent with mild, moderate, and severe anxiety, respectively. A VAS-A score of >50 mm was suggestive of anxiety, while a reduction of 10–15 mm is reported to be clinically significant. Patient knowledge is scored out of a total of 18

Abbreviations: VAS-A, Visual Analogue Scale for Anxiety; GAD, Generalized Anxiety Disorder; SD, standard deviation.

*Assessed using a Likert-type scale (1–5).

of brushed off as . . . as a silly question"T9. Patients preferred care that was personalized or tailored to their needs.

Following the visit, patients voiced that (1) patient-centered, (2) face-to-face approach, and (3) understandable communication, with the ability to ask questions, as key skills they valued during an appointment. Specifically, patients wanted to know how their tumors may or may not relate to their presenting symptoms. Most patients favored face-to-face discussions. A minority liked the idea of digital methods. The use of drawings, radiological images, or written instructions were helpful and were used by patients to then educate friends and family.

Theme 2: information

Given the challenge in accessing specialist appointments, patients found it difficult to obtain pituitary-specific information, as the referring healthcare providers deferred further information to the specialists consulted. As a means of obtaining further disease-specific information, several patients sought information online. Some found the online information relatable and reassuring. Many patients reported deliberately avoiding the internet for additional information on their condition because they questioned the reliability of the internet as an accurate source of information. *"I went on the computer, but then you get told you know, you can't believe everything that's on the computer" T12*.

Interviewees expressed having a need for information about their condition. Most indicated that the more information they had, the better they felt. They described being more knowledgeable following the education received. A patient also reported that it was important to hear from their healthcare provider that their pituitary tumors were benign. While some noted that the information provided by their HCP was repetitive, this was not considered redundant, yet was perceived as reassurance that the information provided was accurate. "*Was . . . it was reassuring to hear all of this information being told to me by—again, you can't really trust the internet, so. To have your doctor confirm all this stuff is reassuring" T17*.

Theme 3: impact-patient worry

The disruptive effect and impact on life that this diagnosis would have on day-to-day life was a concern, as was the potential need to take time off from work for extensive investigations, surgeries, and follow-up appointments or ability to fulfill daily responsibilities.

Patients were anxious due to uncertainty about the condition and often catastrophized and were fatalistic. "*Well you hear brain tumor, you die" T7*. They also expressed concerns about the uncertainty of whether surgery was part of their treatment plan.

Information about their condition resulted in (1) an understanding, and (2) reassurance. After the 1st endocrine clinic visit, patients described a better understanding of their condition. Some admitted to not remembering all the information provided during the visit but were able to refer to the written information provided as a resource. The delivery of information provided a deeper understanding about their condition, which in turn relieved some of their anxiety and provided reassurance. Although increased knowledge improved patient anxiety, it did not completely eliminate it. "*So I did feel better about that, but of course I still worry a little" T2*.

Discussion

This pilot study demonstrates that patients with newly diagnosed pituitary tumors experience significant anxiety, as demonstrated by elevated VAS-A and GAD-7 scores, and supported by low patient satisfaction scores and themes highlighted in the interviews. In-depth interviews revealed that difficulties interacting with healthcare systems, limited communication of information, and anxiety surrounding their diagnosis contributed significantly to this experience. Although patients possessed knowledge about pituitary tumors, participants

Table 3. Themes identified during phone interview regarding patient perceptions before and after endocrine visit

Theme 1: *COMMUNICATION*			
Before		**After**	
Delay	"The only problem I have with the whole process, is it just kept on becoming a month out, a month out, a month out, and living with that kind of information." T8	**Patient-centered**	"It was the fact that [the doctor] talked to us like a human being (laughing). If we asked a question, [the doctor] didn't make us feel like we were dumb." T9
Dismissal	"I just felt very brushed off. .. He just said, 'nah, you're alright.' . . . He just brushed me off." T2	**Face-to-face**	"[The doctor] took the stool and sat down right in front of me and then drew out everything so that you know, she wasn't standing up . . . I mean, [the doctor] just looked me right in the eyes." T12
Depersonalization	"I didn't like the fact that when I went in, he didn't even know how old I was. I felt like he hadn't familiarized himself with my chart, and I'd seen him a few times."T4	**Understandable**	"If I didn't understand it, I asked her right there and she said it in a different way for us to understand." T9 "[The Doctor] explained everything very simply for the common man. Made it very plain". T15
Theme 2: INFORMATION			
Before		**After**	
Lack of knowledge about tumor	"Not knowing what it is and something's growing in my brain. And we have no education, no knowledge of anything." T7	**Need**	"I'm a detail-oriented individual, and the more information I have on anything, the happier I am. I want more than just the basics." T15
	"She told me I had a tumor in my brain. She didn't give me any more information than that . . . That's why I wanted more answers." T9		"I tend to kind of be a sponge when it comes to that though, like I like to learn things . . ... I'd rather have too much than too little." T3
On-line content	"sometimes to me it can be more confusing . . ...I would read something and then if I went to another article about the same thing, it might say something completely different." T12	**Most important**	"I'm not going to die. So that was a good thing" T4 "I worried most about it being benign or cancerous" T1
	"The information was helpful . . .. I learned a lot. And it kind of helped me when I went into the doctor's appointment because I understand more of what [the doctor] was talking about." T9		
Theme 3: IMPACT: Patient Worry			
Before		**After**	
Impact on life	"I take care of my husband's mother . . . I do everything for her . . . I just pray I can keep my driving abilities." T12	**Understanding**	"I think clarity and what it was that we're dealing with or that I'm dealing with, I had a lot of things that I learned that made sense for me in in that meeting with [the doctor]." T3
Uncertainty	"It was just something you know like- my god what is it? Is it something that could erupt and, and kill me. Is it like an aneurysm?" T5	**Reassured**	"She went over everything, all the what-ifs it could be, and just not to worry. And I felt very reassured because she was very thorough." T2
	"I would say I worried most about it being benign or cancerous." T1		

reported a high need for disease-specific information. The delivery of information was associated with a reduction in both measured (surveys) and communicated (interviews) anxiety and led to an increase in patient satisfaction.

Studies have shown that patients experience significant psychological distress during the diagnostic period, yet literature on patients with PAs assessing patient-reported outcomes have focused on the postdiagnostic period [9, 10, 19–21]. Anxiety is noted to be a specific manifestation of this distress, in studies assessing patients for symptoms suggestive of cancer [22]. Our results support the existing findings that patients experience peridiagnostic anxiety and illuminates an important phase of diagnosis that has not been discussed among patients with PA previously. While some patients expressed concerns about cancer, they recalled being informed that pituitary tumors are typically benign but remained uncertain about their condition and future expectations. Moreover, in the patient knowledge questionnaire, all patients answered "true" to the statement "True or False: Most pituitary tumors are benign (not cancerous)," suggesting that simply stating a tumor is benign is not sufficient when this declaration is not supported by additional information.

Anxiety may be related to the tumor itself or to biochemical or anatomical consequences. Compared with controls, patients with PA—especially, those with Cushing's disease and acromegaly—exhibit fewer coping strategies and higher levels of anxiety, which persists at lower levels following treatment [19, 23, 24]. However, patients with Cushing's disease or acromegaly were excluded in this study. Despite these exclusions, our cohort had documented anxiety prior to the study clinic appointment, and anxiety specifically about the tumor improved following the endocrinology visit, suggesting an additional contributor to anxiety beyond the tumor effect itself. The improvement in general anxiety (as measured by GAD-7 and VAS-A), however, was not statistically significant until the 1-month follow-up. Continued general anxiety as opposed to anxiety about the tumor itself may be expected, as many patients required additional testing following the initial endocrine visit, the process of which may have caused anxiety.

Aside from the tumor itself, several additional factors, such as patient- and environment-related factors, contribute to anxiety. In the interviews conducted, patients indicated that delays in the diagnostic process and the complexity of care contributed to anxiety. To avoid diagnostic delays, rapid diagnostic programs have been proposed. Brocken et al systematically reviewed studies assessing such programs, which suggested a positive effect with rapid diagnosis and a reduction in anxiety for those who received a benign diagnosis [2]. Interviewed patients verbalized a need for information, which was confirmed by a high need for information, which was an average score on the Likert scale. It is worth noting that many preferred the delivery of health-related information through face-to-face interaction as opposed to the internet despite available technology.

Patient education has been proposed as a means of providing desired information to reduce anxiety and increase self-management in a variety of clinical conditions or situations with mixed results [25, 26]. A multicenter randomized controlled trial evaluated a patient education program designed to enhance self-management of patients with pituitary disease. Patient education led to improvements in mood, self-efficacy, and vitality [27]. Administration of such a program early in the diagnosis could be beneficial. In our pilot study, patients' knowledge of PA was high prior to receiving education, yet they still reported a need for more information. It is possible that the PKQ was not sensitive enough to identify a gap in knowledge. In addition, although the PKQ score increased significantly (from 15 to 15.8), it is not clear if this increase is clinically important. The clinical visit and education, however, were associated with a substantial improvement in patient satisfaction (2.8 vs 4.6, $P = 0.002$). Perhaps the ability to ask questions and the reaffirmation of knowledge by a physician is important.

There are several limitations to this study that require comment. This was a small study; however, theme saturation was reached during the interview assessment. Additionally, results of the quantitative analysis are congruent with statements expressed during the interviews. Nevertheless, it is possible that differing diagnostic pathways or subgroups (eg, symptomatic vs incidentally discovered) could have an effect on outcome. This possibility could not be adequately assessed given the small sample size of the study. Lastly, this was not a controlled study and education was provided by only 1 physician; therefore, the differences observed here may be unrelated to the intervention, and instead reflect clinic attendance (although patients had seen nonendocrinology providers prior to the initial endocrine appointment) or provider skill.

Among patients with newly diagnosed PA, the diagnostic experience is associated with high levels of anxiety. Patients desired more information, and the delivery of information had a significantly positive effect on patient satisfaction and led to a reduction in anxiety, highlighting the importance of adequate communication and education. While these observations are not controlled, the themes identified have important clinical implications, as they suggest that a timely, streamlined diagnostic process with readily accessible information can improve the patient experience.

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Ethics Approval: The study was conducted in accordance with the principles set out in the Declaration of Helsinki. Institutional review board approval was obtained prior to the study.

Consent to Participate: All participants provided signed informed consent.

Additional Information

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Data Availability: Restrictions apply to the availability of some or all data generated or analyzed during this study to preserve patient confidentiality or because they were used under license. The corresponding author will on request detail the restrictions and any conditions under which access to some data may be provided.

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