**Supplemental Table 1: Physician-reported negative experiences**

**In our REDCap survey, physicians were asked to share any negative experiences that resulted from making an FND diagnosis, and to relate how this altered their practice. All responses are included below. One response was edited to preserve anonymity, but otherwise responses were not altered. Each entry below is an independent response by a single physician.**

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| **Negative experiences during FND-related care** |  |
| |  | | --- | | - incorrect diagnosis, later changed to narcolepsy and cataplexy - care givers, school find it very difficult to understand when there is coexisting neurologic disorder and functional disorder - stigma and inferior care for any other condition when this diagnosis is listed in the problem list | | 1. A child whose father was sexually molesting her-Paternal rage-report to mother and psychologist 2. Fcnal gain from increased attention from the boyfriend\_Counseling and referral to Psychologist 3. Report to parent with initial denials and anger from them-referral to child psychologist and counselling | | 1. Must be accompanied by a billable neurological diagnosis (R56.9, R25.8, G25.9) or payment may be denied. 2. Not well accepted by parents who often seek a second opinion which often may find a minor abnormality on repeat EEG yielding an epilepsy diagnosis. | | 1) when I have made the diagnosis in the absence of objective evidence I have been wrong. It is difficult to recover a therapeutic relationship in that situation, especially with this diagnosis. 2) it is easier for patients to accept the diagnosis in the face of objective evidence from EEG. When patients accept the diagnosis, treatment is much more effective. | | A family did not like this diagnosis and pursued further extensive evaluation through other routes (not neurology office) and I was supposed to comment on the results of these studies even though I found them unwarranted to pursue. I still give people this diagnosis but know that it comes with a significant time burden in discussing the diagnosis with families, seeing the patient frequently, reassurance, getting family to invest in CBT, etc. | | A patient was given diagnosis (by others) of NES without psychiatric support and the patient suicided | | Although I answered No, we do not label FND and forget about the patient: there are still many ways to assess for biological causes, and many medical treatments. FND is a symptom diagnosis, but like other F codes often has identifiable biological causes. | | Anger from family members who disagreed with diagnosis | | Angry families. Complaints to patient affairs at my institution. I spend a lot of time trying to gently communicate about FNDs now. But some families do not want an "emotional" diagnosis. They simply feel we are missing something. And, we all have seen a few cases of frontal lobe seizures originally diagnosed as non-epileptic w/o capturing an episode as they can be so unusual. | | angry family complained that I missed the diagnosis. It did not escalate beyond the division, but it was upsetting. | | As a resident, I had one patient that had a very functional appearing exam (ie said she felt like she couldn't walk or was weak, but when helped her stand up had gait that appeared like Astasia abasia and although she would not initiate movements if I placed her arm above her head she could then hold it in place and seemed to just have breakaway on confrontation). Did not LP or image initially because exam appeared functional. Others also felt exam functional initially. 4 weeks later patient showed up to Er, profoundly weak. They had not come in earlier because thought it was functional. Since then, if suspect functional weakness early on in a presentation, I set up close neuro follow up to track exam in case it evolves to be more consistent with true weakness. | | At times have not had patient or family acceptance of diagnosis. Has not significantly changed my diagnosis practices. | | At times patients and families are not accepting of diagnosis, and may be come angry or defensive. This is uncommon in the epilepsy unit, but more common in the general neurology service. | | Complaints to patient relations. Patients being lost to follow up, never returning to the clinic. In my practice I am now more likely to ease into explaining the diagnosis slowly so that I may gauge the family's reaction. I also encourage families to seek second opinions particularly when they do not agree with the diagnosis. | | Complaints to the hospital Friends and Family | | contact patient liaison that escalated to pediatric administration. Threatened with legal action for not appropriately taking care of patient. Refusal to continue to follow with me and want to get a second opinion elsewhere | | denial | | Denial and criticism by the family. | | Denial by parents or patient, sometimes angry. I did not truly alter my practice (truth is truth), but rather altered my presentation over time, such that I feel I have maximized patient retention and families agreeing with the diagnosis. | | Depending on how it is diagnosed and delivered, some patients are often felt unheard or reluctant to accept the diagnosis and will no longer follow-up as they seek care elsewhere. | | Diagnostic testing was not yet completed, and spine MRI identified a small lesion | | Didn't alter practice. Parents unhappy with diagnosis despite much discussion of the role of stress in generating symptoms, and wanted another opinion | | Difficulty managing patient's reaction | | Do more testing to keep family happy | | doing more tests | | drove me out of a job that I was happy with due to bad patient reviews. it did not matter that my diagnosis was accurate, it did not matter that I spent a ton of time with the families, it did not matter that I did testing that was not even technically indicated and was negative. Just remember, patient satisfaction surveys assume (since everyone's input is weighted the same) that the percentage of unreasonable people (to euphemistically state it) is 0%. Why KNOW that's not true, cause people are voting for Trump. | | Families can be angry or not understand. However, they usually do accept the diagnosis and gain understanding over time. It does require long conversations. | | Families may be unwilling to accept FND diagnosis, and may transfer or discontinue care. I typically do not make the diagnosis until I am certain, so my practice of completing an extensive evaluation prior to discussing my suspicion has not changed. I also continue to maintain the suspicion of a functional disorder superimposed on a medical condition, ideally to prevent missing an evolving condition. | | families sometimes have a very hard time accepting that as the diagnosis. They mistrust us and feel we are likely missing something because they feel it's "real" to them despite extensive explanation that it IS real, but not purely neurological... | | family and/or pt in denial | | Family angry for entering that diagnosis in chart | | Family became very upset and actually wound up trying to sue. I try to make sure all other possibilites are ruled out before diagnosing as functional | | Family becomes upset and goes to seek a second opinion. It has changed the way I counsel. I also try to set up the diagnosis, finish the tests, and then come back to it as confirmation, and this helps a lot. | | Family called patient relations to complain. This did not change my practice. | | Family complained to patient relations and I had to go for a talk | | Family disagreed with diagnosis and indicated they were going to seek additional opinions. | | Family felt upset and did not return | | family got upset. wrote me a bad review. went doctor shopping | | family not agreeing with diagnosis. Has made me more careful in framing the conversation. | | family upset, sought 2nd opinion | | Family yelling at me in clinic--now use term "physical manifestations of anxiety" | | family/ patient is angry, or in denial, insistent that patient must have something serious or "real". I have greatly altered my discussion and explanations with family, emphasizing that stress and anxiety can result in a variety of symptoms. I try to destigmatize and avoid blaming the patient | | Grievance, lawsuit, pt complaint, poor patient review, hauled to chief and chairman's office, poor in hospital reviews, poor online reviews, additional work, demands to change medical record | | Have had negative feedback in social media forums related to giving the disorder. I do not think this substantively changed my practice. I have found if approached right, MOST of the time, families can take the diagnosis pretty well. They do poorly if not enough time is spent with them, however. I have had many second opinions that went quite well and probably should have gone well the first time but weren't handled ideally. | | Hospital complaint. No impact. | | I have not but do fear them | | I had one patient who left my practice and was referred to my partner after he presented with a functional disorder. For her, he then developed non-epileptic seizures. However, his mother doesn't accept the diagnosis and continues seeking other opinions. | | I have been fired by several patients/families. I have also incorrectly diagnosed functional movement disorder and the patient was later found to have a progressive neurologic condition. | | I have encountered stubborn resistance to diagnosis (mostly psychogenic seizure disorder) from multiple families in the course of training and practice, mostly in training. Each encounter did have difficult interactions, though beyond these I have not had specific negative consequence. My subspecialty (epilepsy) training, wherein I had most of these experiences, taught me to both remain compassionate/understanding but also recuse myself from responsibility in the treatment course. | | I have had negative feedback from a few familes who would not accept diagnosis. One litigation - has made me more cautious about how to approach these families with this diagnosis. Some hesitacy to see patients with known dx of functional disorder. | | I have had patient family complain to patient relations for giving a diagnosis of PNES. At the last institution I worked at this required a written response from myself and from the division chief. The chief agreed with my diagnosis and responded to the patient advocate that some families can become frustrated with the diagnosis but they had received appropriate care. So no long term ill consequences, but I don't like upsetting families. | | I have had patients give a negative assessment of me to Other providers and the referring provider. I have had patients request second opinions (which isn't really a negative experience exactly as I encourage them to get another opinion if they are unsatisfied with mine). I believe I have become more upfront about a diagnosis of functional neurological disorders ONCE MY EVALUATION IS COMPLETE. I will tell you parents/patient what I suspect whenever I do suspect functional disorder, but I encourage the family to pursue the testing to investigate biological disease before formalizing the diagnosis. | | I have had patients refuse the diagnosis and leave hospital against medical advice to seek second opinion, they would not return for follow up and counseling. | | I have had patients that are upset with the diagnosis and a few that have sought other opinions/left the practice. I try to ensure that the patients/families understand the diagnosis as best I can to prevent repeated testing for this diagnosis. | | I have had to justify FMLA to insurance and employers for patients with disabling FNSD. This has cost a lot of time. The main negative impact is the time it takes to care for these patients when I am not qualified to treat their FNSD. | | I have not faced any negative consequences as of yet. But this possibility can't be denied. Some patients have chosen to to switch the physician (me) to alternate options. Not sure if this counts as negative consequence. | | I replied no. There were no long-term consequences per se, but certainly more difficult relationships with some families. May be more distrust if they do not agree. | | I usually try to anticipate the problems, and spend a lot of time with the family/patient, and refer for 2nd opinion to an independent provider. | | I was informed by the billing department that psychological/psychiatric codes are not paid. | | I was wrong once. Missed a temporal lobe tumor. | | I was wrong; the child really did have seizures and presented in status epilepticus | | I work hard with families to explain this diagnosis, and make sure they fully understand how valuable it is to recognize, and manage functional disorders | | I've been upfront about a dx of NES for 40 yrs. I have had patients rarely leave me for another doc but they do not seem to change the dx and they often come back., I hate it that icd10 often does not have words we use like nonepileptic seizure-it lists them as conversion disorder f44.5 but not all are conversion disorder | | I've had a few pts who were angry, but for the most part, they come around. | | if parents are not accepting they often do not return or transfer care to another provider | | if parents do not understand they seek care elsewhere with repeated tests and lengthy extension of the child's illness. | | If the patient is unwilling to accept the diagnosis, they will go elsewhere and start over. I have had patients send me scathing emails when other providers have diagnosed seizures, autonomic dysfunction, whatever, subsequently to my diagnosis of FND. | | In training I saw a child who presented with leg pain and refusal to ambulate. He was called conversion by other because good strength and intact reflexes who came back 2 weeks later with obvious GBS. Since then, I am more hesitant to label as functional before testing is done. | | Infrequently I have received a bad patient review but this has not altered my practice. | | It always takes longer to share this diagnosis but it is essential for success. Few patients look for another opinion which is always endorsed | | It did not alter my practice, but a family became quite upset inpatient. | | It didn't alter my practice with respect to patient care however it did alter my relationship with other pediatric colleagues and that we were not able to agree (they wanted more work up despite my saying this wasn't needed) caused a schism in our working relationship | | It hasn't altered my practice much. The negative experience was the family being angry and not wanting to follow-up with me or requesting to not be followed by me if on service. | | It's a challenging diagnosis to get the parents to understand, so it takes a long time and requires many conversations. I wouldn't characterize this as a negative consequence, though. | | Lack of acceptance by parents and patient. | | Lack of reimbursement Did not affect my coding | | Lack of understanding by primary physician and nursing staff; lack of understanding by patient and family, need for extensive discussion, lack of competent psychological consultation, demands for further extensive testing of no value, none of which has changed my extablished mode of practice. | | loss of patients or patient switching providers. | | lower patient satisfaction | | Mad family | | Made diagnosis of PNES prior to capturing episode on EEG and family became very angry. When EEG was performed itconfirmed PNES, but by then family was already angry and re4fused psychiatric care. This happened several times and I now do not make functional diagnoses without good supportive evidence (exam, labs, imaging, etc) | | Mainly families being unhappy - not institutional problems. Last bad experience was many years ago. I often use neuro symptoms.org now to help families | | Making an FND diagnosis has lead to highly contentious conversations with families that lead to distrust of the medical system by the patient. I have also been involved in a case that was litigated in a Munchausen case, which is somewhat related. | | Multiple patent complaints due to disagreeing with the diagnosis, though with the acknowledgement that it was handled well. Participation in one lawsuit (I was not attending, but resident, but called as witness). | | needed to have an extra visit and discuss with both parents in attendance, or with one on the phone, along with the patient - to present the dx as a good result of the presenting sx. | | Negative feedback from patient and family that diagnosis is incorrect and something pathological is causing symptoms | | negative feedback from patients, from other providers | | Negative feedback from the patient and lack of mental health resources to deal with the diagnosis. | | Negative in terms of lack of patient trust/ discussion not going as well as hoped, or other providers (from other subspecialties or with incomplete information) questioning the diagnosis, and thus family continues to pursue/switch providers etc., negatively affecting pt's ultimate care. | | Negative patient feedback. Complaints to patient relations. | | negative patient reviews, reviews were considered and when appropriate internalized | | Negative physician review left on 3rd party doctor rating website. I did not alter my practice. | | Never faced negative consequences. There is an expected reaction that sometimes includes anger, frustration and mistrust, but this can be overcome with repeat visits and acceptance. | | Occasionally, parental and patient resistance to the diagnosis (on rare occasions resulting in patient advocate complaint). The vast majorities of families are receptive after an open discussion. | | Often from parents and sometimes colleagues | | Ombudsman complaint; phone call from parent requesting to change diagnosis. I have not altered my practice, except to explain my rationale more fully | | One of the families asked me to take away the diagnosis and did not agree which was cut ally given my previous provider | | one patient had atypical autoimmune encephalitis, presented as FND, evolved several months later. Now I try to follow FND better/longer to prevent that | | Parent anger Patient anger | | Parent got very upset and opened a complaint with hospital patient's advocate and we had to file a formal report. | | Parent was upset, didn't agree, thought we were dismissive and/or not listening and/or not testing enough; some sought 2nd, 3rd, 4th opinions, fortunately they also agreed. | | parental disagreement and frustration | | Parental dissatisfaction, but not frequently | | Parents angry | | Parents can get upset. I spend an extensive period of time teaching and educating patient and family. | | parents complained, expressed dissatisfaction, sometimes become hostile | | Parents disagreed. Financial gain involved. | | Parents felt it was offensive diagnosis | | parents insulted, angry i was wrong | | parents irate, wanted another opinion | | Parents mad and complaining publishing bad reviews online. Didn't alter my practice | | Parents may not agree with diagnosis. It didn't alter my practice but they may have sought out a different provider. | | Parents were upset and left the practice and went to a reputed teaching institution In NYC who diagnosed the child with "complicated migraine " initially and then later came to terms with the diagnosis of functional disorder | | Patient advocate calls, bad review given on patient comment card. Now I make sure I have buy in from family and approach the topic a lot more delicately than before. | | Patient and family dissatisfaction | | Patient and family not accepting diagnosis, leaving practice, seeking second opinion. This hasn't really altered my practice | | Patient and family resistant to diagnosis and insisting on further testing | | Patient and parental denial Seek care elsewhere No change in practice | | Patient and their family not happy with diagnosis, expressed dissatisfaction with provider. However it did not change my practice | | patient complains, is angry | | Patient complaint | | Patient complaint / disagreement among practitioners. | | Patient complaints | | patient complaints to patient advocate, department & division heads; exacerbates burnout; increasing likelihood I will not keep practicing | | Patient did not accept the diagnosis and damaged relationship | | Patient dissatisfaction, family expressing unwillingness to accept diagnosis, seeking opinions from less traditional sources | | Patient felt stigmatized and not properly diagnosed | | Patient filed a complaint to the clinic. It did not change my practice. | | Patient got a second opinion and received a diagnosis of epilepsy by that provider. | | Patient had "seizure-like" episodes with no epileptiform correlate on EEG, significant stressors in family, normal exam and MRI. Family did not accept the diagnosis, fired me, and complained to Risk Management. | | Patient had mixed disorder (or embellishment), imaging initially not suggestive, later (weeks) changed but still not consistent with degree of deficits. Patient retaliated with notion that FND is a dx of exclusion (which I disagree). | | patient left my practice to continue their diagnostic journey; in another instance, patient's symptoms exacerbated, family was very upset and continued to take her to the ER for seizures - this altered my practice in that is sensitized me on the effect of this diagnosis on patients and families and prompted me to change my way of conveying the diagnosis and coming up with a therapeutic plan | | patient lost to follow up | | Patient never came back, went to another provider and had inappropriate meds prescribed. Didn't alter my practice much. | | Patient or patient retaliation, insurance lack of coverage and true diagnosis of seizures in pt. | | Patient satisfaction scores went down. | | Patient sometimes seek a second opinion. Has not altered my practice really, I just try to build rapport with them. | | patient sought care elsewhere practice not significantly altered | | Patient stopped following up with me | | patient unhappiness-obtained second opinion, no alteration | | Patient wanted me to change diagnosis backward. I did not change my clinical practice. | | Patient's family becomes upset | | patient's mother unable to accept diagnosis. | | Patient's parents become upset and have left my care for further opinions. This hasn't changed my practice much other than fine tune my counseling to include more examples of physiologic manifestations of stress, as well as introduce the diagnosis early on in the workup as part of the differential. For the most part, families accept the diagnosis but some just need more testing and time. | | patient/ parent disatisfaction | | Patient/family being angry, saying negative things about me, demanding more testing and/ or another opinion. I would not say it altered my practice, apart from learning how I might better present such diagnoses. | | Patient/family dismissive/rejecting of diagnosis, left my practice and went to another local neurology group | | patient/family hostility as they are convinced symptoms are real. But can usually get past this so can provide appropriate referrals | | Patient/family refusal to accept diagnosis. This is expected in some instances and does not alter my practice. | | patient/family went to patient relations when they did not agree with the diagnosis, complained and requested that my note be changed | | Patients / families do not accept the diagnosis and continue to seek medical opinions. One patient ended up in the ER under a care of a new provider but the new provider was reluctant to provide advice to ER. Totally annoying. These cases in general are a reason we need more mental health support in the community and within our clinic operations. | | Patients and families were upset. Did not change my practice | | Patients and families who have been non accepting have filed a formal grievance. | | Patients and parents being defensive, upset, leaving practice. Hasn't changed my practice. | | Patients complain or go elsewhere. Didn't alter my practice | | Patients get upset and seek a second option | | Patients have filed complaints about me with our Patient Relations group. I have also incorrectly diagnosed a patient with FND who turned out to have organic pathology. So I try not to make an FND diagnosis until all of the diagnostic workup is complete. | | Patients leave practice for doctor shopping | | Patients/families can become angry, don't believe diagnosis, and often patient worsens with diagnosis. I bring up possibility before doing testing to set the stage and tend to keep patients in hospital for another day after making this diagnosis to enable additional conversation and examination | | Perhaps some uncomfortable conversations, but nothing beyond that. | | poor satisfaction score, risk of reduced compensation | | Pt upset and disbeliving 2 non payment by insurance company who do not understand the complexity all of which puts a great burfen to explaine and stAy with family and nor just refer to behavior hewalth | | pts parents did not beleve me, wanted 2nd opinion, or never returned. | | Rarely Wrong diagnosis ~twice | | Rarely patients are angry with the diagnosis and give negative feedback. Otherwise, no issues with giving FND diagnosis. | | Rejection and anger on the part of the patient in spite of my best effort to explain the neurological validity and functional imaging substrates known.The notion of conversion is a clumsy conversation at best even in light of my background in psychology. Even when clarifying that stressors need not be present and DSM 5 diagnosis present only 50 % of the time, patients seldom satisfied and shop and find a clinician to order more tests. | | Reluctance from the family | | see prior example (not the same as functional movement disorder). I had one child with functional movement disorder who had such persistent symptoms that I ended up having to admit her later to do more work-up but there were no negative consequences. | | Some families do not accept the explanation as the cause, and have became irate. My delivery of these diagnosis has changed over the years, improving acceptance, I believe. Acceptance is still not always, and sometimes with inappropriate behavior by parents. | | Sometimes families are not looking for this type of diagnosis and they are angry, but that is alleviated to a large extent with how you handle the delivery of the information and how well you take care of referring want to do psychiatry services that are needed | | Sometimes families or patients are upset by this diagnosis. This does not typically cause a problem in my practice but does often require a bit more care in my explanation and in my note documentation | | Spending an inordinate amount of time de-escalating a frustrated patient and family member after the diagnosis of functional neurologic illness was documented in a neuropsychology report and read by the patient and family member prior to my neurology visit. | | testing was denied, family was unhappy, payments were reduced because "not complex enough" (!) | | The other Neurologist who had previously diagnosed an "organic movement disorder" disagreed with my new diagnosis of functional movement disorder, and felt insulted when I suggested another opinion from another movement disorder specialist | | The patient and parent often became angry and defensive. Rather than seeking help, they would shop from one physician to another hoping to find whose diagnosis would fit their perception | | the patient sought an opinion elsewhere and were given the same diagnosis | | The patients have gone elsewhere for care.. not necessarily a negative | | The patients posted a bad review and reported I did not do any work up after we had done an EEG, MRI, and lab work all of which had been normal. I had another patient who's parent went to the CEO of the hospital reporting poor care from myself, rheumatology, and pathology when really they just did not like the answer/diagnosis. | | There was at least one time that I was incorrect. The consequence was family anger, and on my part a feeling of guilt. | | Unhappy patients, asked me to change diagnoses. | | Upset families at times, even with a skilled delivery (e.g. symptoms improved, then relapsed and parents were upset about the relapse). | | Upset families. Incorrect diagnosis resulting in less than ideal care. Bias from other providers, caretakers. | | Upset parents; complaining to managers/administrators; patient leaving practice I would not say that it altered my practice | | Upset parents. It did not alter my practice. | | Upset patient. | | Verbal abuse from family, no alterations in practice | | Very difficult and long visits with patients (although parents are often very appreciative once they accept diagnosis) | | While there has not been litigation, it has been threatened. However, there have been clear negative comments made not just in encounter feedback and patient advocate but through social media. | | Yes - a teenage patient from a very conservative family with psychogenic syncope. Dad called our hospital CEO, basically tried to tell the hospital CEO I was unfit to practice medicine. If you need any good examples feel free to look up the google review the patient's sister left (one of our many terrible reviews, of course). {Practice and physician name removed to preserve anonymity} I think it has altered my practice in that I honestly try a little less hard to connect with the PNES patients and help them. I spent hours over several visits with this particular patient trying to help her understand the psychogenic nature of the events. Now I just give them a diagnosis but I am much less involved in follow up. | |  |