

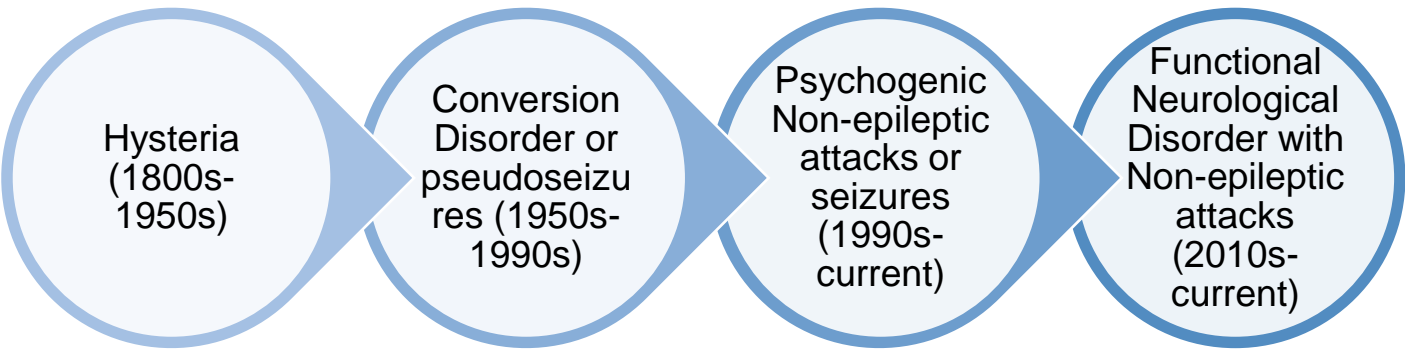
FND Awareness: Bridging the gap in FND Understanding through a psychoeducational brochure in Neurology Settings

Introduction

- Functional Neurological Disorder (FND) is a condition where the brain has difficulty sending or receiving messages to and from the body
- Non-Epileptic Attacks are the most common symptom characterized by seizure-like events that are not accompanied by epileptic discharges

Purpose

- To create an updated psychoeducational pamphlet for patients diagnosed with FND within the URMC system to improve understanding of diagnosis and treatment



Literature Review

- Communicating the Diagnosis:*
 - Focus on bridging connection between neurological & psychiatric symptoms
 - Conceptualize the diagnosis based on inclusion rather than exclusion
 - Stigma associated with historic terms, leads to worse prognosis
 - Iatrogenic harm is associated with poor delivery/delay of diagnosis
 - DSM-5-TR criteria no longer requires presence of psychological stressor, and shouldn't be included in communicating diagnosis
 - Consider Cultural Factors when communicating the diagnosis, such as:*
 - Symptom presentations are consistent across cultures
 - Meaning associated with symptoms depend on the context (i.e. moral judgements, interoceptive affordances)
 - Cultural models view FND as complex form of communication of experiences
- Preferred Terminology by Patients and Families:*
 - Most preferred:* FND with nonepileptic attacks, Functional seizures, FNES
 - Least preferred:* conversion disorder, pseudoseizures, hysteria
- Impact on Patients and Families:*
 - Patients report often feeling dismissed by medical system
 - Significant caregiver burden
 - Lack of patient and family psychoeducation can contribute to worsening symptoms
 - Families of those with FND have greater challenges in problem solving, emotional responses/blending, hygienic problems, & criticism

Methods

- Literature Review:*
 - Searched for articles pertaining to:
 - Functional Neurological Disorder, PNEA, PNES, Functional Seizures, Conversion disorder, Non-epileptic attacks
 - Ways to best communicate the diagnosis
 - Guidelines for treatment of FND
 - Patient experiences with diagnosis and treatment of FND
- Review of informational pamphlets about FND (n=15):*
 - Inclusion criteria for informational pamphlets
 - Top US hospitals with level 4 epilepsy centers and information about FND
 - Top US and UK nonprofit organizations that communicate FND
 - 12 printable patient pamphlets
 - 12 resource pamphlets/websites from hospitals, 3 from Nonprofit organizations
 - 3 directed towards children & families
- Interprofessional Focus Group:*
 - Met with interdisciplinary focus group for feedback on updates to patient pamphlet

Results of Patient Resource Review

Terms	Functional Seizures	FND	Non-Epileptic Attacks	PNEA	PNES	Conversion Disorder
National Library of Medicine		x				
Stanford Medicine		x			x	
Massachusetts General Hospital		x				
NYU Langone Health				x		
University of South Florida					x	
Mayo Clinic		x				x
Cleveland Clinic			x		x	
University of Virginia Medical Center					x	
Harvard Medical School		x				
George Washington University Hospital					x	
Oregon Health & Science University			x			
American Epilepsy Society					x	
FND Hope		x	x			
Emory University					x	
Nationwide Children's Hospital	x				x	
Kennedy Krieger Institute		x			x	
DSM-5		x				x
Total:	1	8	3	1	9	9



Discussion

- Communicating a patient-centered diagnosis*
 - Need to relate diagnosis to patient context
 - Traditional ways of communicating the diagnosis, such as telling patients to feel hope, that symptoms are related to stress, and that their brain is “normal”, can invalidate their experiences
- Bridging the link between Neurological and Psychiatric functioning*
 - Discuss stress within biopsychosocial model
 - Importance of provider education and collaboration to support patients with FND
- FND vs. PNES: Decisions for using FND language for our brochure*
 - FND better encapsulates family systems perspectives of symptoms
 - FND is consistent with DSM-V terminology
 - FND helps explain development of related symptoms (e.g. tremors, weakness, paralysis, sensory issues, etc.)
- Future Directions:*
 - Consultation with Department of Psychiatry Advisory Council of Consumers (DPACC)
 - Consultation with marketing department to assist with design
 - Disseminate brochure to providers and staff in Neurology
 - Discuss new communication recommendations
 - Follow-up data on patient receptiveness to new brochure
 - Patients newly diagnosed vs engaged in treatment