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Early communication is key — Designing a new communication tool to immediately empower people with psychogenic nonepileptic seizures

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ABSTRACT

Introduction: Patient empowerment and shared decision-making has been increasingly recognized as key factors for a favorable prognosis. This is particularly true in complex brain disorders such as psychogenic nonepileptic seizures (PNES) which go along with several challenges. People with PNES (PW-PNES) often feel lost in the healthcare system. Early clear communication is one of the few favorable prognostic variables. Our goal was to design a new ultrashort user-friendly communication tool allowing immediate patient empowerment.
Methods: We conceptualized a design thinking process with patient engagement of PW-PNES.
Together with a larger group of PW-PNES, we developed a comprehensive user-friendly 1-page document summarizing the key features of PNES. We applied document engineering (DE) as a cognitive science-based new methodology. Document engineering is well established in the aviation, oil, and mining industries and measurably reduces comprehension and performance errors.
Results: The design thinking process encompassed 5 phases (empathize, ideate, define, prototype, and test). A prototype of a 1-page document, the 1-Pager-PNES, was created which contained the essential 7 domains organized in a simple structure such as a promise-question-answer (PQA) format. Information was kept poignant, complete, easy-to-read integrating cognitive principles to optimize navigation. The prototype "1-Pager-PNES" was subsequently tested in a 7-member focus group. All patients expressed significant improvement in understanding their disease and felt immediately empowered. Implementing their specific feedbacks, reiterative testing, and involving PNES experts resulted in the final version of the "1-Pager-PNES".
Conclusion: A promising new communication tool reduced to 1-page only is introduced which improves patient guidance and enables better coping mechanisms with this complex disease. The patient/user is empowered quickly through finding answers to pressing questions. Our study is unique for three reasons: 1) it engaged patients in the developing process, 2) it produced a tool for immediate communication for PW-PNES, which follows principles of human behavior and cognitive science, and 3) it used cross-industry thinking. Despite all limitations, we consider our small pilot study an inspiration for future studies with focus on patient empowerment through user-friendly documents.

1. Introduction

The prognosis in complex diseases is determined by multiple factors that include disease-inherent components, treatment options, healthcare logistics, and last but not the least, patient compliance. The importance of patient engagement for healthcare outcomes gained increasing attention over the last decades. In 1988, the Picker Institute coined the term "patient-centered care" ("Through the patient's eyes") meaning to stress the importance of better understanding the experience of illness and of addressing patients' needs within an increasingly complex and fragmented healthcare delivery system [1,2]. Shared decision-making and patient empowerment are strong components of this conceptual framework.

Psychogenic nonepileptic seizure (PNES) is a disorder that lends itself to where this approach might be very helpful and essential. The prevalence has been estimated at 50/100,000 [3]. There is still a lot of uncertainty around this complex brain disease in the borderland of

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Neurology and Psychiatry. To make the patient an informed partner, appropriate early communication is essential. The following facts have to be part of this difficult conversation:

- Terminologies have been constantly changing to avoid stigmatization [4], with PNES being the most widely used term. Most experts define PNES as paroxysmal motor events, disturbances of sensation or of responsiveness that do not result from abnormal electrical activity of the brain and lack of characteristic electrographic features [5].
- Interrater agreement for the diagnosis of PNES was only moderate in a video-monitoring study, and distinction from epileptic seizures can be challenging [6].
- The coexistence with epilepsy in 10–20% makes the diagnosis and communication more complicated [7].
- The pathophysiology is not well understood.
- A history of traumatizing events and physical or sexual abuse in keeping with a functional neurological disorder is reported in the wide range of 25% [8] to 100% [9]; however, many patients lack any evidence for a dissociative process at all [10].
- A more integrative model suggests a biopsychosocial disorder with both organic and psychological factors involved [11,12]. Structural and functional Magnetic Resonance Imaging (MRI) data support biological changes in a subset of these patients [13–15].
- Systemic failures of the healthcare system play a critical role in this dilemma. Patients with PNES often encounter difficulties in finding access to the healthcare services or get lost within the referral network. They often bounce back and forth between neurologists diagnosing the disorder and referring them to mental health specialists and psychiatrists who refer them back questioning the diagnosis and misdiagnosing them again as epileptic seizures [16].
- Healthcare systems do not consistently offer the multidisciplinary & integrated care needed and often lack a standardized diagnostic approach [17].
- Physicians often feel overwhelmed and lack the specific training that is needed in this borderland of neurology and psychiatry. This often results in a significant delayed diagnosis, which was reported to be 7.2 years on average in a large cohort [18].
- The prognosis in PNES is still poor with 50%–70% of the patients not becoming free of PNES episodes despite initial improvement [19], and half of them are reported to be disabled [20].
- Favorable prognostic factors include early communication of the diagnosis, learning about the condition, acceptance of the diagnosis, and participation in feedback process [19,21,22].

We identified the issue of early sensitive communication as our priority for the presented pilot project. Several papers emphasize the importance of early communication, which is effective and acceptable for the patient [20,23]. They address particularly the challenge to deliver the idea to the patient that psychologic causes may be involved. Outcome has been found to be better with clear early communication and acceptance of the diagnosis [24]. One in six patients became free of PNES in a short term following an organized early communication protocol [25]. Effective communication significantly reduced healthcare utilization and healthcare costs [26,27].

Most of the widely published information leaflets on PNES are well written for readers. Complete and detailed comprehensive information can be as long as 27 pages [28]. We believe we can learn from users in other environments such as technical industry. They often express their frustration with lengthy procedure documents as follows “can't find things”, “overwhelming”, “too wordy”, “keep getting lost”, “too long”, “confusing”, “not telling me what I need”, and many more [29]. Can we take this lesson to healthcare? Our goal was to empathize with people with PNES (PW-PNES) and design an early communication tool to put them into a user perspective. Users act differently than readers. They want immediate clear, concise, and helpful answers to their most burning questions in the shortest way possible. We postulate improved immediate patient empowerment with this user perspective approach. In order to arrive at our ambitious goal to develop content for a comprehensive 1-pager communication tool, we had to consider principles of the science of cognition and human behavior. Our pilot study is an example of innovative cross-industry thinking originating from lessons learned in the aviation industry [30].

2. Methods

The starting point of this research project was a PNES workshop held at the community agency Epilepsy Toronto on March 13, 2018. One of the authors (BP) provided an updated state-of-the-art review of all scientific knowledge of various aspects of the diagnosis, treatment, and prognosis of PNES. The subsequent discussion (moderated by SE and RS) revealed as highest priority for PW-PNES early patient engagement, patient empowerment, and ultimately shared decision-making.

Our primary goal was to develop together with the PNES community a 1-page document for PW-PNES named “1-Pager-PNES” that encompasses all critical information with regard to definition, causes, diagnosis, treatment, favorable factors for outcome, prognosis, and challenges. This highly informative document aimed to provide the most honest, poignant, and easy-to-understand state-of-the-art knowledge of PNES. We controlled for easy comprehension by using a low Flesch–Kincaid reading index of 7 [31]. The 1-Pager-PNES included on purpose all the uncertainty and complexity of the medical condition to avoid frustration and make the patient right from the start an informed partner in the dialog with the healthcare professional (HCP). It creates patient empowerment.

We followed an innovative approach and used the principles & methodology of document engineering (DE) developed by CAT-i in the field of the safety of science (Communication and Training International, Calgary, Alberta, www.usabilitymapping.com). One of the authors (BP) is a certified auditor and controller of usability mapping and DE. The biggest learning regarding DE comes from the aviation industry where difficult-to-read user-unfriendly documentation repeatedly caused misunderstandings and subsequently fatal and avoidable incidents [30].

Document engineering tries to integrate concepts of language localization theory, modern linguistics, Gestalt psychology, motivation & learning theory, neurobehavioral psychology, and multiple other aspects of neuroscience (Fig. 1). It measurably reduces comprehension and performance errors in users particularly when working under pressure with strong features such as cognitive linking and navigation (www.usabilitymapping.com). Document engineering is well established in the oil and heavy tool industry, but not in healthcare. Fig. 2 illustrates the critical components of successful DE as a result of behavioral and cognitive science.

The process of developing the 1-Pager-PNES happened in close collaboration with Epilepsy Toronto, a community epilepsy agency for both people with epilepsy and PNES in the city of Toronto. We decided to follow a design thinking process with 5 phases engaging patients with PNES in all subsequent steps as outlined in Fig. 3.

The prototype of the 1-Pager-PNES documented was tested in a 7-member focus group of Epilepsy Toronto.

All participants provided consent. Five participants were patients with PNES, 1 was a caregiver, and 1 was a long-term partner of a patient with PNES. After integrating the feedback of the focus group, the updated version of the 1-Pager-PNES was presented at the American Epilepsy Society Meeting in New Orleans 2018 [32] inviting further feedback by PNES experts. We presented the final version of the 1-Pager-PNES after integrating all valuable comments and specific input by experts.

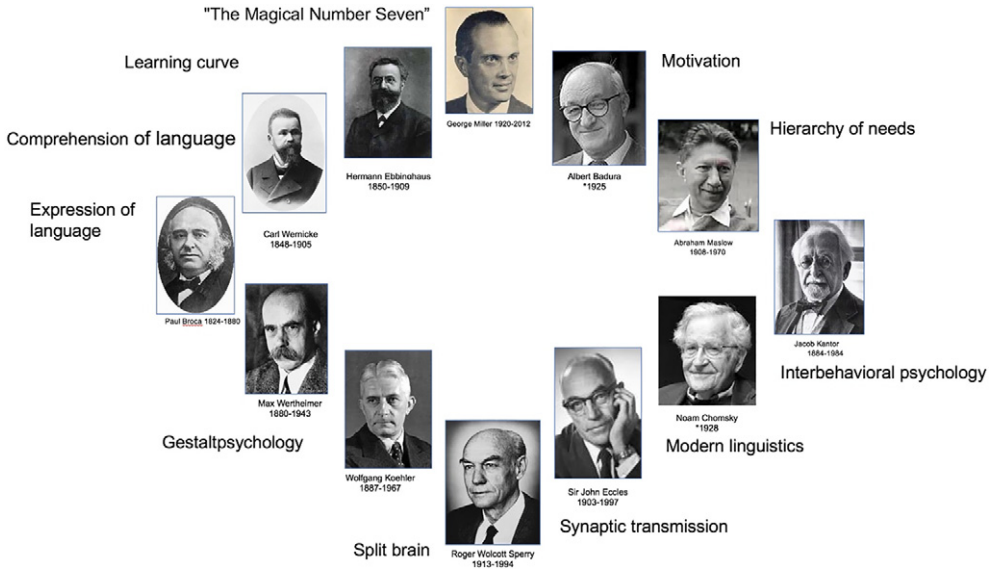


Fig. 1. Influential thinkers with impact on methodology of usability mapping.
(Modified from Hofer K. www.usabilitymapping.com)

3. Results

Fig. 3 details the 5 phases of the design process of the 1-Pager-PNES (emphasize, define, ideate, prototype, test):

Phase 1 (empathize): After a public presentation of the PNES topic at the Community Epilepsy Agency (CEA) Epilepsy Toronto (authors BP and SE) in front of a large audience of people with PNES, we listened with respect and compassion to all the individual stories and concerns.

Phase 2 (define): As part of a needs assessment, we analyzed common themes and patterns, identified specific obstacles in the healthcare system, and recognized the most urgent needs.

Phase 3 (ideate): Brainstorming together with patients revealed that being lost in the healthcare system and lack of appropriate early communication had the highest priority.

Phase 4 (prototype): Together with the patients, we defined the key areas for the prototype of the 1-Pager-PNES: definition, causes, diagnosis, treatment, criteria for success, prognosis, and challenges. The authors organized the content of the 1-Pager-PNES according to this 7-item list, implementing the methodology of DE. Document engineering is aiming to provide an easy-to-read and easy-to-comprehend document to improve communication between the patient and the HCP such as the neurologist. Key features to support this process include embedding navigation, controlling

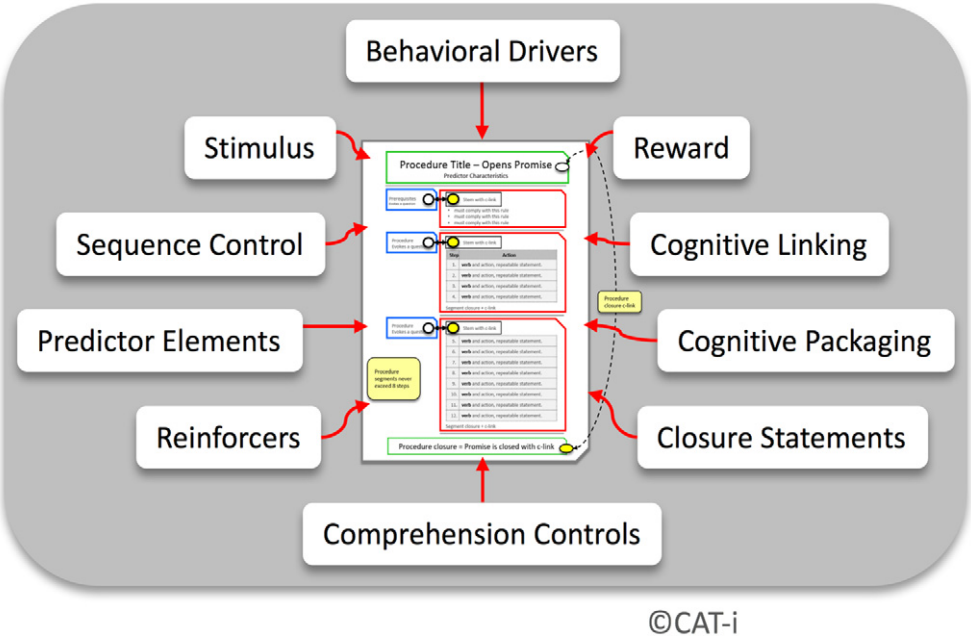


Fig. 2. Critical components of behavioral science driving document engineering.
(With permission by K.Hofer, www.usabilitymapping.com)

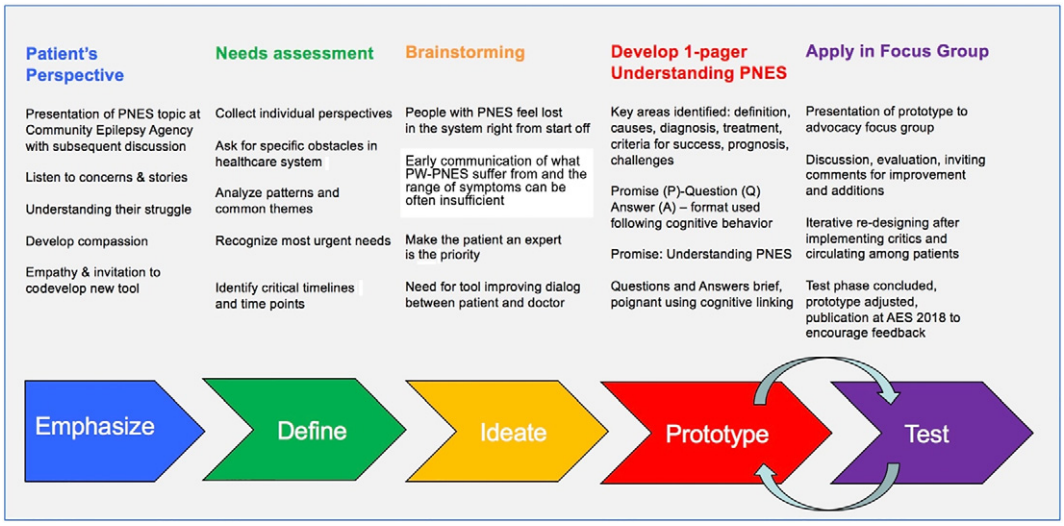


Fig. 3. Design thinking process in the development of the early communication tool 1-pager PNES engaging patients with PNES throughout this process.

comprehension and reading grade, reinforcing behavior, and following a simple structure such as a promise-question-answer (PQA) format [29].

Phase 5 (test): The prototype was presented to the focus group, inviting further feedback and comments. This was followed by iterative redesigning of the 1-Pager-PNES until we arrived at a version, which we agreed to publish and present to a large scientific community and caregiver audience at the next Annual Epilepsy Society Meeting. As part of phase 5, all 7 participants of the focus group received an evaluation form with the following five questions/items:

1. My first spontaneous impression,
2. Which topic within the presented 7 items was of most value to you and why?,
3. Please share your spontaneous feelings while reading this tool,
4. What would you like to see done differently in this tool?, and
5. Please provide any additional comments or suggestions.

Item 1 had 5 specific subquestions asking if the 1-Pager-PNES would have provided support, covered the main content, was easy to understand, enabled better communication of the disease and helped to better understand the obstacles. To measure attitudes or opinions, we used a standard 5-point Likert scale ranging from strongly disagree (1 point, minimum) to strongly agree (5 points, maximum), for more details see Table 1.

The evaluation of item 1 showed that all participants expressed high satisfaction with the presented version of the 1-Pager-PNES scoring at average in the range of (4) agree to (5). There was a nonsignificant difference between the score of patients (n = 5) and caregivers (n = 2).

The three best-rated sections covering the topic well (item 2) were causes, diagnosis, and treatment.

Illustrative free comments as reported under items & questions 3 to 5 were as follows: "Cause section vague", "Tool does not say, that epilepsy & PNES coexist", "PNES are not faking seizures", "Reflects well the frustration in the system", "Doctors need urgent training", "Makes me feel, I am not alone with this", and "Add helpful resource link" (not comprehensive list).

In line with the principles of a design process and the need for reiteration and readjustment in the prototype-test phase, we integrated all received input and further adjusted the 1-Pager-PNES. This prefinal version was presented to the scientific community at the Annual American Epilepsy Society Meeting December 4, 2018 in New Orleans, US. This version was further discussed with multiple attendants of the AES, and particularly in detail during a subsequent telephone conference and presentation (BP) with a PNES expert group. All received input resulted in the final version of the 1-Pager-PNES as presented in Fig. 4.

4. Discussion

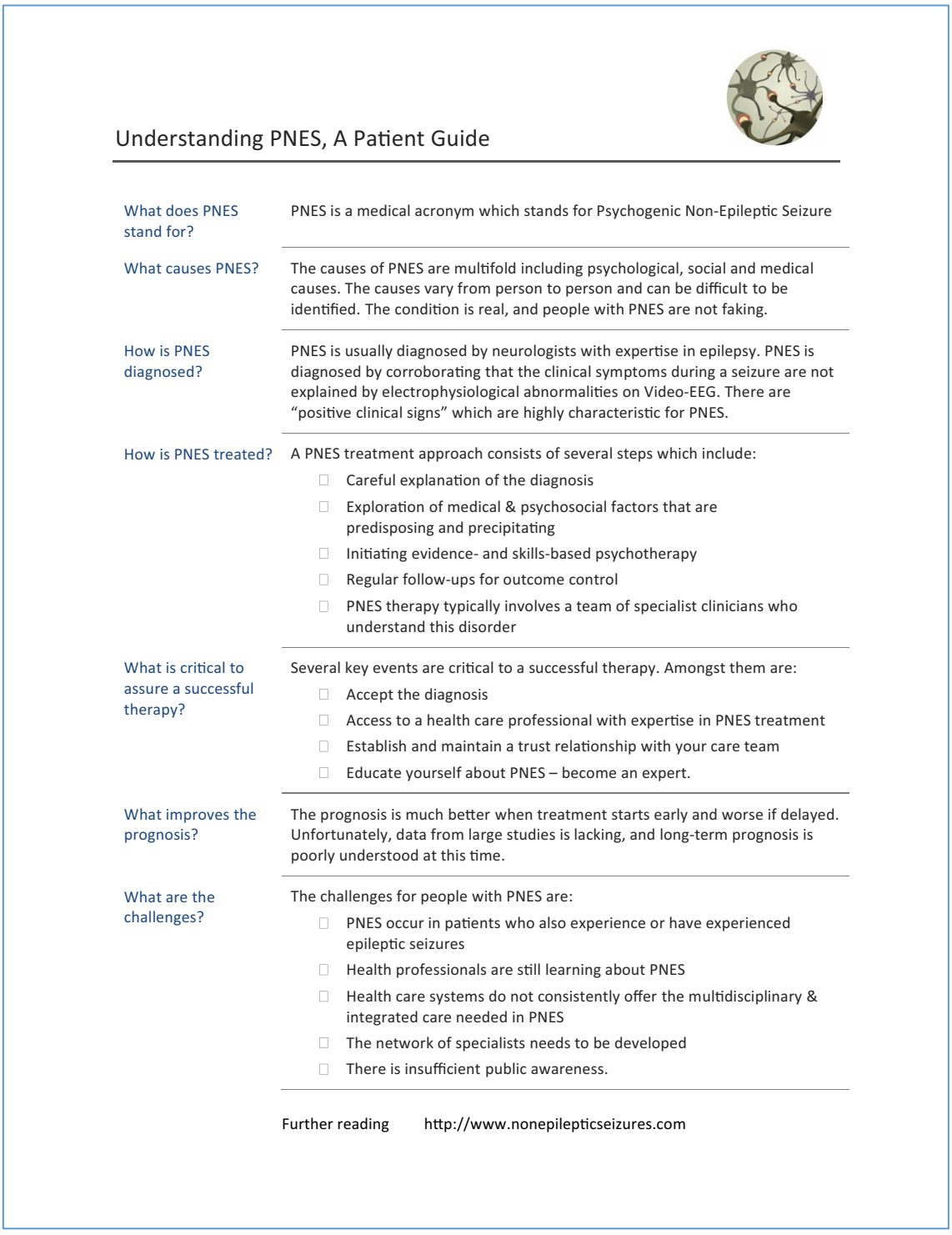
We designed for the first time a 1-Pager-PNES for early sensitive communication with PW-PNES using patient and expert input and DE. We consider our pilot study an inspiration for future research studies with focus on patient empowerment. We are fully aware of the many limitations of our pilot study that include small group size, the semi-quantitative methodology, the lack of a control group, and no long-term follow-up data.

Our presented pilot study is unique and innovative for three reasons: 1) It engaged and empowered patients in the developing process right from the start, 2) it produced a tool that follows principles of human behavior and cognitive science, and 3) it used cross-industry thinking leaving traditional silos [29,30,33].

Table 1
Item 1 of evaluation form after presenting the prefinal version of 1-pager PNES to a focus group of 7 participants.

	Patients only N = 5 Sum score	Patients only N = 5 Average	All participants N = 7 Sum score	All participants N = 7 Sum score
a. This tool would have helped me a lot when I was diagnosed with PNES	21	4.2	31	4.4
b. The topics cover the most relevant information about PNES	22	4.4	32	4.6
c. The content is easy to read	21	4.2	30	4.3
d. The tool enables me to better communicate my disease to others	23	4.6	32	4.6
e. I better understand now some of my obstacles I encountered	23	4.6	33	4.7

Measurement of opinion: Strongly disagree = 1, disagree = 2, don't know = 3, agree = 4, and strongly agree = 5.



Understanding PNES, A Patient Guide

What does PNES stand for?	PNES is a medical acronym which stands for Psychogenic Non-Epileptic Seizure
What causes PNES?	The causes of PNES are multifold including psychological, social and medical causes. The causes vary from person to person and can be difficult to be identified. The condition is real, and people with PNES are not faking.
How is PNES diagnosed?	PNES is usually diagnosed by neurologists with expertise in epilepsy. PNES is diagnosed by corroborating that the clinical symptoms during a seizure are not explained by electrophysiological abnormalities on Video-EEG. There are "positive clinical signs" which are highly characteristic for PNES.
How is PNES treated?	A PNES treatment approach consists of several steps which include: ☐ Careful explanation of the diagnosis ☐ Exploration of medical & psychosocial factors that are predisposing and precipitating ☐ Initiating evidence- and skills-based psychotherapy ☐ Regular follow-ups for outcome control ☐ PNES therapy typically involves a team of specialist clinicians who understand this disorder
What is critical to assure a successful therapy?	Several key events are critical to a successful therapy. Amongst them are: ☐ Accept the diagnosis ☐ Access to a health care professional with expertise in PNES treatment ☐ Establish and maintain a trust relationship with your care team ☐ Educate yourself about PNES – become an expert.
What improves the prognosis?	The prognosis is much better when treatment starts early and worse if delayed. Unfortunately, data from large studies is lacking, and long-term prognosis is poorly understood at this time.
What are the challenges?	The challenges for people with PNES are: ☐ PNES occur in patients who also experience or have experienced epileptic seizures ☐ Health professionals are still learning about PNES ☐ Health care systems do not consistently offer the multidisciplinary & integrated care needed in PNES ☐ The network of specialists needs to be developed ☐ There is insufficient public awareness.

Further reading http://www.nonepilepticseizures.com

Fig. 4. Version 4_1-Pager PNES, a tool for early communication of PNES created in a design thinking process with patient engagement.

4.1. Patient engagement and empowerment

Complex brain diseases need improved communication between patients and HCPs through joint education and interaction. Patient engagement and shared decision-making are vital to optimize outcomes for patients, society, and healthcare systems [34]. While this recommendation comes from the Multiple Sclerosis World, we have, in PNES, a very specific and even more difficult situation. In a recent comment to the International Survey by the International League Against Epilepsy (ILAE) PNES Task Force [35], it was highlighted that there is a lack of comfort that neurologists and psychiatrists have in caring for this group of patients believing that there is no "real" disorder present and that there is a gap in layperson knowledge of this disorder with continued stigma associated with PNES [36]. On top of this, patients with PNES often bounce back and forth in the healthcare system or get entirely lost as there is no organized and integrated approach [16]. Retaining subjects with PNES in mental health treatment and increasing patient adherence is compromised by the lack of multidisciplinary standardized clinical pathways particularly in the initial stage of accessing the healthcare system [17].

As authors, we believe that respectful and compassionate patient engagement and empowerment right from the start with an easy to read 1-pager is very critical to PNES to not lose patients in the further follow-up. The designed document will promote patient activation and self-management by providing high-quality information from credible sources with the most honest overview of the opportunities and challenges of this condition. This will create a trustful stronger relationship between patient and the HCPs in the long term.

There is an important economic aspect to this discussion. One of the major drivers of transformative change in healthcare is the more informed patient. Models of care that encourage patient participation are demonstrating better outcomes and reduced costs to the healthcare system [37].

4.2. Easy to read and digestible for "the brain" — time is prognosis

There are several excellent highly informative PNES leaflets [28] and internet resources with videos focusing on patient/advocate or professional education available (for overview [38]). The scientific community has done marvelous work in conjunction with patient initiatives and advocacy groups.

The presented tool, the 1-Pager-PNES, seems to fill a gap in this scenario as it is ultrashort, complete, easy to read, and immediately improves guidance and "navigating" this complex disease from a patient's & user's perspective.

The way we process written information and "read" content has become an extensive research field with focus on theory [39], role of eye tracking for scanning and skimming information [40], functional and structural imaging findings [41,42], and user perspective specifically [43]. We can learn from other models used successfully in technology that the patient (user) ideally "consults in an interactive way" the document rather than reading it in a linear manner [43]. Fig. 5 illustrates how different the mindset of a "reader" and "user" is. Our product, the 1-pager, is certainly designed to focus on the patient's user perspective. According to cognitive science, readers have a mindset driven by curiosity with a lost sense of time while users want to have answers to their questions NOW with a sense of urgency and stress (the shorter and more poignant, the better for immediate patient empowerment — "Time is prognosis").

Figs. 1 and 2 illustrate in a nutshell the impact of cognitive and neuroscience on DE and its specific elements (limited list of 7 items, cognitive linking, and behavioral enforcers). Patient–HCP interaction will improve as the patient will be enabled to navigate fast and efficiently through this document. He/she will quickly find answers to pressing questions and open up the conversation with the HCP. Our 1-pager differs significantly from all the available lengthy information brochures written in a narrative style addressing the engaged reader. It is intriguing to test our tool in a comparison trial against these brochures with regard to acceptability, effectiveness, and short-term prognosis. We anticipate that this tool will also empower HCPs as he/she hands out this document to patients. It offers the opportunity to start and strengthen the dialog and trust between the HCP and the patient. It can be the basis to explain with more sophistication the various subjects. It will certainly reduce the often experienced "confusion" on both sides. Ideally, this 1-Pager-PNES is not meant to replace other PNES treatment tools, rather, it can be complimentary to the educational material already available.

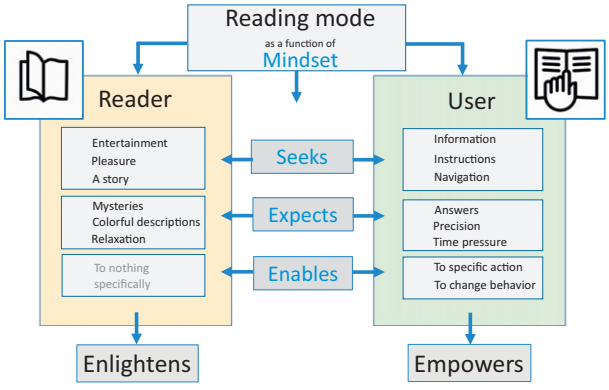


Fig. 5. Reading mode – processing and perceiving written information – as a function of mindset — Reader's "reading" versus User's "reading".

4.3. Cross-industry thinking and leaving traditional silos

Dealing with PNES can be a real challenge for a neurologist and any primarily involved physician as the questions involved often reach beyond their comfort zone and education. There is increasing awareness that complex brain diseases such as PNES do not fit into strict traditional departmental thinking and silos of either neurology or psychiatry. The request for additional training of neurologists in psychiatric expertise is important [44].

With our pilot study, we left usual terrain as we used principles of design thinking as a strong part of our methodology that included planning for need and requirements and culture, content strategy, task flow, prototyping, and testing with users [45].

Fig. 3 illustrates this dynamic process very well. The iterative prototype-retesting scenario was critical to shape the final version of the document.

In this paper, we used lessons from aviation and oil industry to conceptualize a document that fulfills the criteria of readability, clear information, and easy understanding in a short time. It is quite alarming how other industries have already implemented research with regard to eye tracking, human behavior, and navigation to improve communication and comprehension of both written and spatial information [30,46]. With our small project, we hope to inspire stakeholders in healthcare, physicians, HCPs, and scientists to consider research and learning beyond their usual scope.

We are hoping that using this simple but comprehensive instrument for early communication of the diagnosis of PNES will positively impact both short- and long-term outcome of PW-PNES. Larger test studies will be needed to validate this instrument. We encourage our neurology and psychiatry colleagues to start implementing the 1-Pager-PNES document in their daily routine. We anticipate a wide range of applications in the healthcare industry.

Declaration of competing interest

None.

Acknowledgments

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