Journal of the Neurological Sciences 437 (2022) 120251

Contents lists available at ScienceDirect

Journal of the Neurological Sciences

journal homepage: www.elsevier.com/locate/jns

To the emergency room and back again: Circular healthcare pathways for acute functional neurological disorders

Stefan Williams [a,d,*], Clea Southall [a], Samantha Haley [a], Thamer Ba Dhafari [b], Steven Kemp [a], Samuel D. Relton [a], Jane E. Alty [c,d], Owen Johnson [e], Christopher D. Graham [f], Melissa Maguire [a,d]

[a] Leeds Institute of Health Science, University of Leeds, UK
[b] Division of Informatics, Imaging and Data Sciences, University of Manchester, UK
[c] Wicking Dementia Centre, University of Tasmania, Australia
[d] Department of Neurology, Leeds Teaching Hospitals NHS Trust, UK
[e] School of Computing, University of Leeds, UK
[f] School of Psychology, Queen's University Belfast, Ireland

ARTICLE INFO

Keywords:
Functional neurological disorders
Emergency medicine
Process mining
Healthcare pathways
Acute neurology

ABSTRACT

Background and objectives: Studies of Functional Neurological Disorders (FND) are usually outpatient-based. To inform service development, we aimed to describe patient pathways through healthcare events, and factors affecting risk of emergency department (ED) reattendance, for people presenting acutely with FND.
Methods: Acute neurology/stroke teams at a UK city hospital were contacted regularly over 8 months to log FND referrals. Electronic documentation was then reviewed for hospital healthcare events over the preceding 8 years. Patient pathways through healthcare events over time were mapped, and mixed effects logistic regression was performed for risk of ED reattendance within 1 year.
Results: In 8 months, 212 patients presented acutely with an initial referral suggesting FND. 20% had subsequent alternative diagnoses, but 162 patients were classified from documentation review as possible (17%), probable (28%) or definite (55%) FND. In the preceding 8 years, these 162 patients had 563 ED attendances and 1693 inpatient nights with functional symptoms, but only 26% were referred for psychological therapy, only 66% had a documented diagnosis, and care pathways looped around ED. Three better practice pathway steps were each associated with lower risk of subsequent ED reattendance: documented FND diagnosis (OR = 0.32, $p = 0.004$), referral to clinical psychology (OR = 0.35, $p = 0.04$) and outpatient neurology follow-up (OR = 0.25, $p < 0.001$).
Conclusion: People that present acutely to a UK city hospital with FND tend to follow looping pathways through hospital healthcare events, centred around ED, with low rates of documented diagnosis and referral for psychological therapy. When better practice occurs, it is associated with lower risk of ED reattendance.

1. Introduction

Functional neurological disorder (FND) can be defined as a disorder of the voluntary motor or sensory system, with symptoms that can be positively identified as internally inconsistent or incongruent with recognised pathophysiological disease [1]. FND is common, accounting for 15–20% of new neurology clinic patients [2]. There is growing understanding of the factors that might contribute to development and maintenance of FND [3] but outcomes are often unfavourable [4], and no treatments yet have a substantive evidence-base. It is thus, perhaps, unsurprising that the quality of care for FND patients has often been variable or poor [5]. There is emerging clinical appreciation that interventions such as clear communication of the diagnosis, management with physiotherapy, and psychological therapies, can improve prognosis. Indeed, in 2012, National Health Service (NHS) Scotland proposed a stepped care approach for FND [6], in 2017 the Joint Commissioning Panel for Mental Health produced guidelines for Medical Unexplained Symptoms (MUS) services in England in 2017 [7], and the UK Improving Access to Psychological Treatment (IAPT) service has begun implementing MUS treatment [8]. There is then, increasing

* Corresponding author at: Leeds Institute of Health Science, University of Leeds, UK.
E-mail address: stefanwilliams@doctors.org.uk (S. Williams).

https://doi.org/10.1016/j.jns.2022.120251
Received 24 September 2021; Received in revised form 29 March 2022; Accepted 2 April 2022
Available online 6 April 2022

momentum to provide better and joined up care for FND, but to do this, we need to understand the current healthcare pathways of people with FND.

Several previous studies of people with FND evaluated cohorts from neurology outpatient clinics [2,9]. However, such patients regularly present to acute hospital services, including the Emergency Department (ED) [10–12]. These settings may be less equipped to assess and treat FND, risking ineffective care and iatrogenic harm [12–15]. In order to inform future service improvement for FND, we prospectively identified a cohort of people who presented with symptoms of FND to acute neurology and stroke services at a United Kingdom city hospital over a period of 8 months. We then retrospectively reviewed their hospital electronic records over the previous 8 years to describe the pathways taken by these people through healthcare events and also identify factors associated with risk of ED reattendance.

2. Methods

2.1. Ethical statement

This work was part of a local service development project, approved by the information governance and audit team at Leeds Teaching Hospitals NHS Trust, UK. All event logs were anonymised.

2.2. Data collection

We conducted the project at the Leeds Teaching Hospitals National Health Service Trust. This is the hospital service for the city of Leeds in the United Kingdom, part of the National Health Service (NHS). The city of Leeds has a population of around 800,000 [16]. All acute hospital care in the United Kingdom is provided by the NHS. Within this system, patients can directly seek acute medical assessment from either a community family physician ('general practitioner') or a hospital emergency department (ED). The hospital neurology and stroke clinicians working 'on-call' will then take referrals for admission, review or advice from either of these sources (or more rarely from another hospital specialty service).

Every 48 h for an 8-month period (April to December 2017), SW telephoned neurology and stroke teams at Leeds Teaching Hospitals NHS Trust (UK) to collect the details of all patients referred acutely with a possible FND diagnosis, including referrals from ED clinicians, general practitioners, and other hospital specialties. The hospital electronic clinical documents (e.g. clinic letters, discharge letters) for each patient were reviewed for the preceding 8-years and we (CS, SH) manually logged the date of each healthcare event including: documented diagnosis, ED attendance with functional symptoms, outpatient clinic attendance, inpatient admission, investigations, and referral to clinical psychology or liaison psychiatry.

The diagnosis of FND was categorised as 'possible', 'probable' or 'definite', based on combined review of electronic documentation by a neurology specialist doctor, with four years' experience of practising neurology (SW) and two medical students (CS, SH). The following categories were used. 'Possible FND': clinical records documented FND as a possible or differential diagnosis, but further investigations were outstanding. 'Probable FND': documentation implied FND as defined by DSM-V, i.e. symptoms incompatible with recognised neurological or medical conditions, not better explained by an alternative diagnosis, and causing distress or impairment [17]. All such 'probable' FND documentation: (1) described neurological symptoms, (2) did not name any diagnosis, (3) described normal investigations without further investigations planned. 'Definite FND': FND or a related term was documented by the neurology clinician, with a documented clinical assessment in accordance with DSM-V diagnostic criteria [17].

An ED attendance was classified as related to functional symptoms (including ED attendance with non-neurological symptoms) if clinical documentation described incompatibility between the symptom and recognised medical conditions and the documentation suggested that the symptom or deficit was not better explained by another medical disorder. For example, this might be the case in the documentation of an attendance with 'atypical chest pain'.

Prior to statistical analysis, the data was pseudonymised, with all personally identifiable information removed.

2.3. Pathway mapping

To explore patient care journeys through hospital services, patient pathways through healthcare events over time were plotted as dynamic maps using a modified 'Clearpath' process mining method [18], and Fluxicon Disco software [19].

2.4. Statistical modelling

To understand the factors influencing ED reattendance within 12-months, a descriptive model was fit using mixed effects logistic regression. Variables known at the time of the initial ED visit were as follows: gender, mental health comorbidity (documentation of mental health diagnosis at any point in time), social stress (clinical documentation specifically described social difficulties or stresses, such as housing difficulties, relationship breakdown etc); referral to outpatient neurology in the previous 12-months; neuroimaging; other investigations. We also included the following variables occurring after initial ED attendance, but before reattendance (or 12-months elapsed, whichever occurred first): documented diagnosis of FND; referral to clinical psychology; referral to liaison psychiatry, referral to outpatient neurology. On the basis that social stress and mental health can vary with gender, we initially fit a mixed effects LASSO model [20] as a variable selection tool. At this stage, the mental health gender interaction was dropped as a weak predictor of ED reattendance. We then refit the model without LASSO, keeping the theoretically-based predictors and the social stress gender interaction term.

The variables were selected to ensure that the sample was large enough for robust estimates, respecting the common rule-of-thumb that 15 events per variable are required at a minimum. They were chosen using clinical knowledge of FND patient pathways, rather than statistical techniques that may introduce overfitting. A random effect was used to capture individual patient variance and ensure that very frequent attenders did not bias the group results. The model was fit using the glmer function in the lme4 package, within R. The standard deviation of our random effect is also given. The model fit was checked by plotting Q-Q plots of the residuals and random effects, and a calibration curve to assess model accuracy.

3. Results

212 patients were referred to acute neurology and stroke services with a potential diagnosis of FND over the 8 month period. 7 patients had no records available (incorrect ID number) and 43 patients subsequently received a non-FND diagnosis, most commonly stroke or migraine.

The remaining 77.8% of patients (162 out of 205) had documentation of 'possible' ($n = 28$), 'probable' ($n = 45$) or 'definite' FND ($n = 89$). The mean age was 42 years (range 17–83) and 73% were female. The proportions of broad symptom categories were sensorimotor (44.5%), movement disorder (21%), functional seizures (15.5%), and other (e.g. speech, vision) 19%. Over the preceding 8 years, the 162 patients had 563 ED attendances (mean 3.5, median 2, range 0–58) and 1693 hospital inpatient nights (mean 10.5, median 2.5, range 0–206) related to functional symptoms.

134 patients (83%) were classified as 'probable' or 'definite' FND, but of these only 89 (66%) were 'definite', i.e. had a documented diagnosis. This suggests that communication of the diagnosis had not occurred in one third of the FND patients (assuming that documentation

of diagnosis is a surrogate for communication of diagnosis). Median time from the first presentation with neurological symptoms to a documented diagnosis was 65 days (mean 19.2 months, range 0 days to 11 years). For those patients with 'definite' FND, only 40% were referred for psychological therapy (clinical psychology or liaison psychiatry): 26% of the 'probable' and 'definite' FND total. Median time from diagnosis to referral for psychological therapy was 17 days (mean 28 weeks, range 0 days to 4.8 years).

Process maps of healthcare events over time demonstrated looped patient pathways centred around the ED, showing frequent reattendances. The next event after ED attendance was four times more likely to be ED reattendance than referral to psychology, Supplementary Video S1 (and an illustrative still from the video is shown in Fig. 1).

Table 1 shows the risk of ED reattendance within one year among patients with 'probable' or 'definite' FND. Factors associated with reduced risk of ED reattendance were a documented diagnosis (OR = 0.32), referral to clinical psychology (OR = 0.35), and attendance at outpatient neurology appointment (OR = 0.25). Liaison psychiatry referral was associated with increased risk of ED reattendance (OR = 3.4). The overall accuracy of the model was 88.4%, indicating a good explanation of factors underlying reattendance within 12 months. The marginal R2 value was 0.36 and the conditional R2 value was 0.57. The analysis of variance table is provided in Supplementary Material.

4. Discussion

To inform service development, we prospectively identified a cohort of FND patients that presented to acute neurology or stroke services over 8 months in a UK city hospital. Review of documentation for the preceding 8 years demonstrated that these patients tended to follow pathways through hospital healthcare events that looped around recurrent ED attendance. There were low rates of 'better practice' pathway steps. For probable or definite FND, diagnosis was documented in only 66% and psychology referral was made in only 26%. However, when these interventions did occur, they were associated with significantly reduced

Table 1
Variables associated with risk of Emergency Department (ED) reattendance within one year for patients with 'probable' or 'definite' Functional Neurological Disorders (FND). MUS: Medical Unexplained Symptoms.

Variable	Odds ratio (95% CI)	*p*-value
Intercept	N/A	0.04
Variables known at ED attendance		
Symptom type: non-epileptic attacks	3.71 (0.77, 17.9)	0.10
Symptom type: non-neurological (MUS)	0.77 (0.03, 21.2)	0.88
Symptom type: 'other' FND	0.08 (0.01, 0.82)	0.03
Symptom type: sensorimotor	0.8 (0.21, 3.08)	0.74
Mental health comorbidity	1.61 (0.64, 4.04)	0.31
Social stress comorbidity	1.5 (0.59, 3.8)	0.4
Male gender	0.13 (0.03, 0.54)	0.005
Social stress, male gender Interaction	19.1 (2.78, 130.8)	0.003
Attendance at neurology clinic (before ED attendance)	1.13 (0.52, 2.44)	0.75
Variables occurring between ED attendance and ED reattendance or 1 year		
Documented diagnosis of FND	0.32 (0.15, 0.69)	0.004
Referral to Clinical Psychology	0.35 (0.13, 0.97)	0.04
Referral to Liaison Psychiatry	3.4 (1.15, 10.1)	0.03
Attendance at outpatient neurology clinic (after ED attendance, but before reattendance or 1 year)	0.25 (0.13, 0.48)	< 0.0001

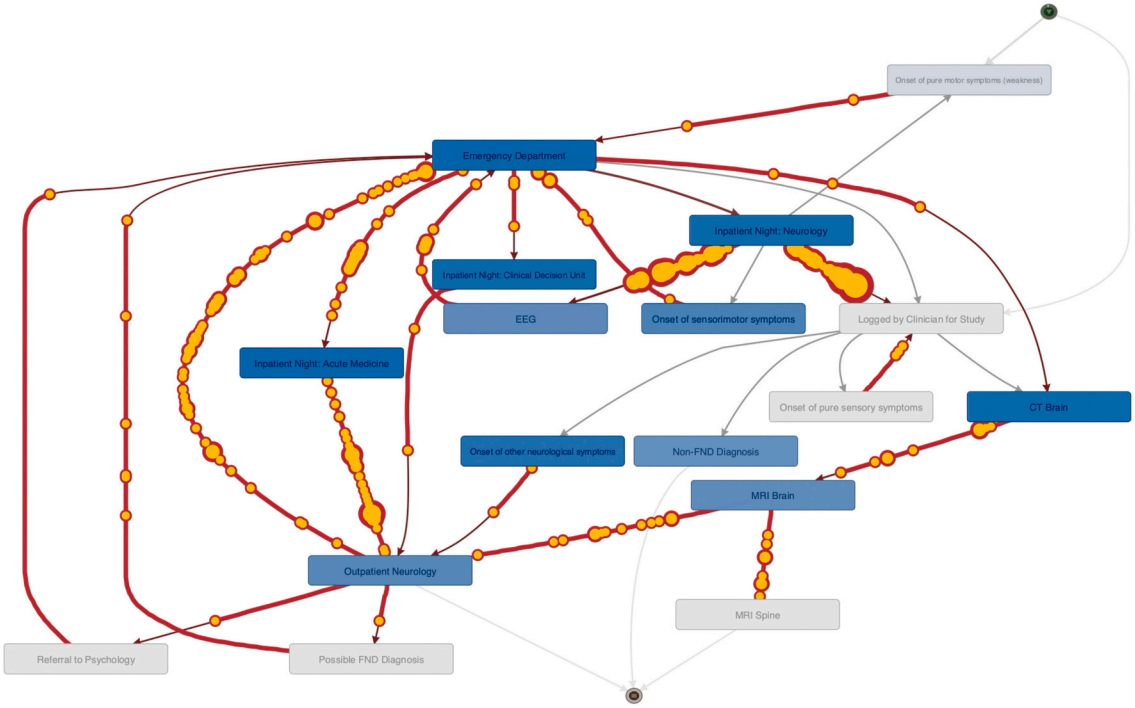

Fig. 1. Illustrative still taken from Supplementary Video S1, which shows moving process maps of healthcare events over time, and demonstrates looped patient pathways centred around the ED, with frequent reattendances. Yellow dots are patients moving between events over time. After outpatient neurology attendance, a much larger stream of patients moves next to ED rather than to referral to psychology.

risk of ED reattendance within one year (OR 0.32 for diagnosis, OR 0.35 for psychology referral), and this was also true for outpatient neurology clinic attendance (OR 0.25).

Our findings show good agreement with existing evidence. We have demonstrated that acute FND is not an uncommon presentation, approaching one referral a day to acute neurology / stroke services. A large economic evaluation in the United States (US) retrospectively identified FND patients presenting to ED and/or admitted to hospital and reported annual costs of $1.2 billion, similar to other common neurological disorders [12]. A New Zealand study identified a cohort of acute FND hospital admissions, and found that they represented 1 in 10 of all acute neurology admissions [21]. In that study and ours, the most common symptom category was sensorimotor (contrasting with outpatient studies in which pure sensory symptoms were most common [2]). The New Zealand rate of acute attendance was lower than ours (0.22 vs 0.77 patients per day), but with a higher number of ED attendances for a cohort that coincidentally also numbered 162 patients (671 ED presentations in 3 years vs 563 in 8 years). The difference is likely related to the fact that our cohort was identified at the point of referral to hospital services and thus not necessarily admitted to hospital. The patient numbers are likely to be an underestimate in both studies. In our study, cases would be missed if FND was not considered at the time of acute presentation. In the New Zealand study, cases would be missed if an acute FND presentation was not admitted to hospital.

Previous work has shown a high hospital revisit rate for people presenting to acute services with FND. In a US study of 7964 patients, FND revisit rates were 18.25 per 100 patients per month, compared with 17.78 for seizures and 3.90 for transient global amnesia [22]. Our work provides a visualisation of this phenomenon by showing patients moving through hospital healthcare events over time in pathways that loop around the ED.

Published evidence is consistent with our finding that rates of better practice care, such as referral for psychological therapy, are low among people that present acutely with FND [12]. Our rate of 26% referred for psychological therapy is very similar to the New Zealand inpatient study in which only 22% were referred [21]. An even more fundamental step in care for FND is communication of the diagnosis [6], an element of care that has not been measured in previous studies of acute FND. Using documentation of diagnosis as a surrogate for communication of diagnosis, we provide new evidence that clear communication of diagnosis is a far from universal (66%) step in FND patient pathways through healthcare.

Our results move beyond existing studies of acute FND because we also tested the association of better practice care with the risk of ED reattendance. We found that communication of diagnosis, referral for psychological therapy and attendance at outpatient neurology clinic were all associated with significantly reduced risk of ED reattendance. Referral to liaison psychiatry was associated with increased risk of reattendance (OR 3.4), which may reflect a tendency to refer more complicated, severe, inpatient FND to that service. The communication of diagnosis is frequently described as beneficial for prognosis in FND [6,11] but the evidence cited to support this is usually a single study in non-epileptic attacks [23]. Ethical considerations preclude an interventional trial. Although association is not causation, our findings provide evidence consistent with the idea that communication of diagnosis helps prognosis, because it was associated with reduced risk of ED reattendance. Contrasting with this to some extent, a previous study of a non-epileptic attack cohort reported that latency to diagnosis was not predictive of attendance with seizures [9].

Our results also suggested that the extent of hospital service use by people with acute FND does not follow a normal distribution for the number of events and the time to better practice care. Instead, we found positively skewed distributions, so that a minority of patients have much higher counts of service use, or much longer delays to better practice care. For example, the median number of hospital inpatient nights was 2.5 but the mean was 10.5, while the median time to documented diagnosis was 65 days, but the mean 19.2 months. This suggests that it might be possible to group acute FND patients into two different patterns of service use: a majority for whom hospital contact is relatively limited and straightforward, versus a minority for whom care involves high or inefficient service use (a right-skewed distribution). To the best of our knowledge, this heterogeneity of service use in FND has not been previously described. Future characterisation of these groups might aid development of more individually tailored care pathways for acute FND.

Limitations of the work are acknowledged. Retrospective data from documentation cannot establish causation, and electronic documentation does not encompass all possible variables. Recorded diagnosis and ED reattendance may both be related to an unmeasured factor such as the severity or complexity of symptoms. In addition, it is unlikely that our method identified all patients presenting acutely with FND. The diagnosis may be missed at acute presentation, when our cohort was identified, with some people instead diagnosed at a later stage, during hospital admission or at outpatient clinic. For example, other studies have shown that functional seizures are commonly misdiagnosed as epilepsy in acute settings [24,25]. This is a major limitation, as our approach to recording functional presentations relied on information provided by non-specialist clinicians, so it is likely than many patients presenting acutely with functional symptoms were not included in our cohort. Our method also relied on busy acute teams remembering to note and pass on referral details, which may not have always happened. Presentations with motor symptoms were likely better recorded than those with functional seizures, because the stroke team is continually based on-site within the hospital and keeps detailed routine records. Furthermore, the rates of ED attendance are likely an underestimate, as we did not use a prospective method to count future attendances. In general, prospective data collection would have been a more thorough method to capture events. Recording the presence of 'social stress' relied on the interpretation of free text documentation. We have not assessed inter-rater reliability for this qualitative variable, and so the possibility of observer bias places limits on conclusions regarding social stress.

Our rate of subsequent non-FND diagnosis is higher than rates quoted for diagnostic revision in secondary care [26,27]. However, this is because we initially identified patients from acute *referral information* with a *possible* FND diagnosis, rather than initial identification of patients with a diagnosis made by a specialist clinical assessment (such as in a neurology clinic or hospital admission).

We have described rates of referral for psychological therapy as 'low'. However, current recommendations of 'stepped care' for FND suggest that psychological therapy may not be required for 100% of people with FND. In some cases, communication of diagnosis alone may be sufficient as the only care step required [6]. Thus, it is unclear quite how low is too low, for rates of referral for psychological therapy. 26% seems intuitively inadequate, but there is no known benchmark proportion. In addition, while diagnosis and referral for psychological therapy are two steps in FND therapy, we did not record rates of referral to further multidisciplinary therapy, such as physiotherapy (an important part of therapy for many patients with FND). Finally, an 84% accuracy from our descriptive model is high, and although this partly reflects a high number of variables used, it also likely represents a degree of overfitting to the specific data.

We present this data collected and analysed to inform service improvement, as indicative of healthcare use among in acute FND. It suggests patient pathways looping around ED with frequent presentation to acute teams, incomplete good practice care, and better outcomes where better practice occurs. Our conjecture is that in the absence of a specifically designed FND service, such faulty care pathways are probably not uncommon [12], and such data inform the design and implementation of appropriate services to improve patient outcomes.

Data sharing statement

The data that support the findings of this healthcare service project

are not shared, for ethical and data protection reasons.

Funding and competing interests statement

The authors declare that no funding was received for this project, and they have no conflict of interest.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.jns.2022.120251.

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