

Original Article

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Heterogeneity in hospital service for children and adolescents with functional somatic symptoms

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ABSTRACT

INTRODUCTION. Functional somatic symptoms are commonly encountered among paediatric patients. Even so, little is known about the current treatment practice. We aimed to explore the current organisation of clinical care for children and adolescents with functional somatic symptoms in a hospital setting.

METHODS. A de novo questionnaire with 60 items about practice patterns for children and adolescents with functional somatic symptoms was developed, tested and distributed to all Danish paediatric departments.

RESULTS. All 19 paediatric departments in Denmark participated. Two departments had no available treatment programme, whereas the remaining 17 departments offered a treatment programme. Overall, substantial variation was reported in the number of patients in treatment, the composition of multidisciplinary teams and in the tasks and training of these teams. A future increase in paediatric patients with functional somatic symptoms was expected by 95% of the departments. Still, 59% reported a reduction in resources allocated to this group over the past five years. Two thirds of the departments expressed a need for clinical guidelines.

CONCLUSIONS. Substantial variation was observed in the healthcare services offered to paediatric patients with functional somatic symptoms referred to the Danish hospital setting. Clinicians called for guidelines, which, in the light of the decreasing resources allocated and the increasing patient numbers, may help ensure a systematic approach and better quality of care for this patient group.

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Functional somatic symptoms (FSS) refer to somatic symptoms that cannot be adequately explained by organic pathology [1]. FSS are common in children and adolescents with prevalence rates of 25-35% [2, 3]. They range from transient, non-impairing symptoms to chronic, debilitating and treatment-demanding symptoms [1, 4]. In line with this, a “stepped care approach” is recommended where the level of intervention is determined by symptom severity [5]. FSS account for approximately 1-12% of admissions to paediatric departments [5, 6], but the prevalence of clinically significant FSS is not easily determined as various terminologies and diagnostic classifications pervade the field. In the somatic setting, diagnoses for functional somatic syndromes like juvenile fibromyalgia, functional gastrointestinal disorders and chronic fatigue syndrome typically prevail, whereas in

the psychiatric setting, somatoform disorders are diagnosed according to the International Classification of Diseases, tenth version (ICD-10) and somatic symptom disorders are diagnosed according to the Diagnostic and Statistical Manual of Mental Disorders, fifth version (DSM-5) [4].

The disease burden in adults is associated with high healthcare costs, work disability and a lower self-rated health [7, 8], underlining the need for timely recognition of FSS. Accordingly, clinical guidelines have been published in the UK [9], Denmark [1] and the Netherlands [10]. These guidelines, however, do not cover children and adolescents. Even so, in the US, the lack of standardised care has recently triggered the development of a clinical pathway for paediatric patients with somatic symptom disorders [11]. Inspired by this work, we aimed to investigate: 1) the treatment services for children and adolescents with FSS in Danish paediatric hospital settings, including the collaboration between paediatric departments and child and adolescent mental health services (CAMHS), and 2) potential differences in the composition of treatment programmes across paediatric departments.

METHODS

Study design

This study was a nationwide questionnaire-based survey distributed to all paediatric departments in Denmark. The study was conducted from February to July 2019.

Questionnaire

We developed a de novo questionnaire inspired by former recommendations [12] and other surveys exploring clinical practice patterns [13, 14]. Two of the authors (CUR and KK) conducted a focus group interview with a multidisciplinary team (MDT) (including a paediatrician, paediatric nurses, physiotherapists, a social worker and a special educator) working with children and adolescents with FSS in a paediatric hospital setting to obtain information about the organisation of care, clinical pathways, staff competencies and collaboration. The first version of the questionnaire was based on this information and additional literature [11]. Face validity was tested by a paediatrician and a paediatric nurse who were both part of a MDT responsible for young patients with FSS within a tertiary hospital. Subsequently, the questionnaire was adjusted by optimising the wording of questions and including a few additions to the response categories. The final questionnaire consisted of 60 questions within six themes ([Appendix A https://ugeskriftet.dk/files/a02210119_-_supplementary.pdf](https://ugeskriftet.dk/files/a02210119_-_supplementary.pdf)). The questionnaire was set-up in the Research Electronic Data Capture (REDCap) to allow electronic distribution.

Respondents and data collection

The head of each of the 19 Danish paediatric departments was informed of the project by email and asked to identify a single respondent; the person holding the main responsibility for patients with FSS at the department. Next, the respondent was given a link to access the electronic questionnaire. The first author (KK) was available to answer clarifying questions by telephone. A maximum of two reminder emails were sent to non-responders, which was followed by contact via telephone.

Statistics

Data were analysed using descriptive statistics. We categorised departments based on their estimated annual numbers of patients with FSS (≤ 30 and > 30 patients/year) to explore possible associations between patient intake and the extent of their programme. This was based on the pragmatic assumption that assessing > 30 patients annually would correspond to a relatively large clinical FFS function. A χ^2 test was conducted to evaluate any differences between the departments. Due to the exploratory nature of this study, no adjustment

was made for multiple testing. Probability values were two-tailed, $p < 0.05$. All analyses were performed using IBM SPSS software.

Ethics

Data were collected without including any personal items of information. Under Danish law, the study did not need approval from the Central Denmark Region Committees on Health Research Ethics.

Trial registration: not relevant.

RESULTS

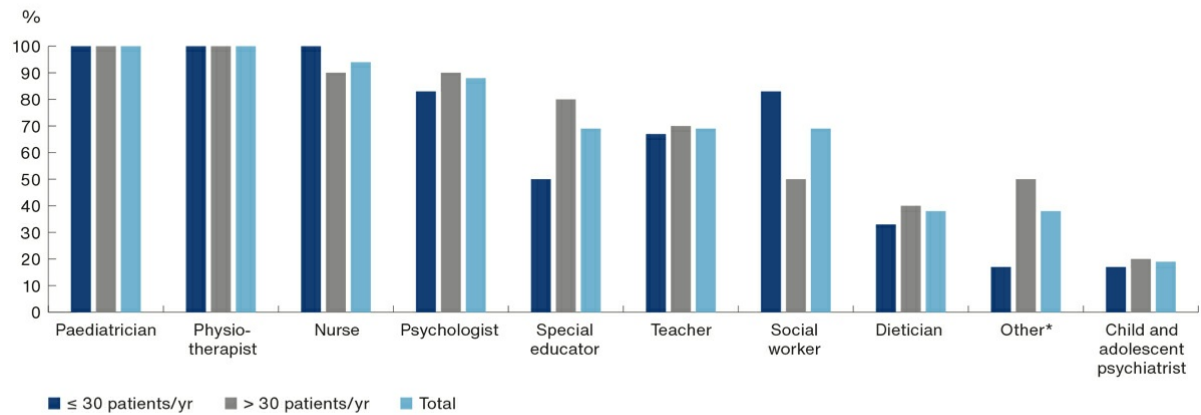
All 19 paediatric departments participated in the survey. Respondents were paediatricians ($n = 16$), child and adolescent psychiatrists ($n = 1$), psychologists ($n = 1$) and special educators ($n = 1$). Two departments had no programme for patients with FSS, leaving 17 departments to be included for further analyses. These departments managed a varying number of patients annually (≤ 30 patients/year: 6/17 (35%); > 30 patients/year: 6/17 (35%) and > 100 patients/year: 4/17 (24%); unknown number: 1/17 (6%)). Most patients were enrolled in the programme through internal referrals (16/17 (94%)), but half of the departments also accepted external referrals (9/17 (53%)) from different health sectors (other paediatric department: 9/9 (100%); general practitioner: 6/9 (67%); CAMHS: 6/9 (67%); other hospital department: 4/9 (44%); other specialist: 4/9 (44%) or other health sector: 1/9 (11%)).

All departments had the option of admitting patients and (with one exception) offered outpatient consultations. Among admitted patients, the typical duration of hospitalisation was less than five days (7/17 (41%)) or six to ten days (7/17 (41%)), and few departments had a longer hospitalisation time (> 11 days (3/17 (18%))). Overall, patients were typically affiliated with the department for more than three months (3-6 months (7/17 (41%)), 6-12 months (1/17 (6%)) or > 12 months (2/17 (12%))). Only two departments had a programme with an average duration of less than three months (2/17 (12%)), whereas the rest were *uncertain about the average treatment duration in their programme* (5/17, 29%).

Multidisciplinary team constitution and tasks

The 17 departments had a MDT to care for patients with FSS. The team involved four to ten different healthcare professionals (HCPs): a paediatrician (17/17, (100%)), a physiotherapist (17/17, (100%)), a nurse (16/17 (94%)), a psychologist (15/17 (88%)), a special educator (11/17 (65%)), a teacher (11/17 (65%)), a social worker (11/17 (65%)), a dietician (7/17 (41%)), another HCP (6/17 (35%)) and a child and adolescence psychiatrist (3/17 (18%)). **Figure 1** shows the constitution of the MTDs categorised by patient intake. No significant difference was observed between number of HCPs or the composition of the MDT and departments with a low or high patient intake. In most departments (12/17 (70.5%)), MDT conferences were held weekly or else every other week (3/17 (17.5%)), once a month (1/17 (6%)) or ad hoc (1/17 (6%)). Most HCPs were responsible for several different tasks (**Table 1**). Five departments collaborated with a specific consultant from the CAMHS (5/17 (29%)); and in three of these departments, this child and adolescent psychiatrist formed part of the MDT.

FIGURE 1 The percentage of departments with healthcare professionals included in the multidisciplinary team caring for patients with functional somatic symptoms, subdivided into departments with a low number of patients (≤ 30 patients/yr) and departments with a higher number of patients (> 30 patients/yr). Total number of departments = 16. Three missing departments include two departments without a treatment programme and one department that was uncertain about the number of patients.



*) Occupational therapist, anaesthesiologist or nurse anaesthetist.

TABLE 1 Areas of responsibility for healthcare professionals.

HCPs (departments with HCP in MDT, N)	Task	Responsible for task, %, (n/N)
Paediatricians (17)	Initial assessment of somatic complaint	94 (16/17)
	Scheduled conversations with patient and/or family	47 (8/17)
	Ad hoc conversations with patient and/or family	88 (15/17)
	Medical treatment of somatic illness	88 (15/17)
	Prepare notification to municipal/social authorities	88 (15/17)
	Participation in MDT meeting incl. municipal staff	94 (16/17)
Physiotherapists (17)	Other area of responsibility	35 (6/17)
	Scheduled training with patient	53 (9/17)
	Ad hoc training with patient	65 (11/17)
	Physiotherapeutic testing	88 (15/17)
	Participation in MDT meeting incl. municipal staff	47 (8/17)
Nurses (16)	Other area of responsibility	35 (6/17)
	Initial patient assessment	44 (7/16)
	Scheduled conversations with patient and/or family	31 (5/16)
	Ad hoc conversations with patient and/or family	94 (15/16)
	Observation of patient and family during hospitalisation	100 (16/16)
	Sleep registration	63 (10/16)
Psychologists (15)	Participation in MDT meeting incl. municipal staff	56 (9/16)
	Other area of responsibility	25 (4/16)
	Initial patient assessment	60 (9/15)
	Scheduled conversations with patient and/or family	53 (8/15)
	Ad hoc conversations with patient and/or family	73 (11/15)
	Psychological testing	53 (8/15)
Special educators (11)	Participation in MDT meeting incl. municipal staff	67 (10/15)
	Other area of responsibility	47 (7/15)
	Initial patient assessment	36 (4/11)
	Scheduled conversations with patient and/or family	73 (8/11)
	Ad hoc conversations with patient and/or family	82 (9/11)
Teachers (11)	Participation in MDT meeting incl. municipal staff	91 (10/11)
	Other area of responsibility	73 (8/11)
	Scheduled teaching	82 (9/11)
	Ad hoc teaching	27 (3/11)
	Assessment of academic skills	91 (10/11)
Social workers (11)	Participation in MDT meeting incl. municipal staff	55 (6/11)
	Other area of responsibility	36 (4/11)
	Prepare notification to municipality/social authorities	55 (6/11)
	Organizing MDT meeting incl. municipal staff	82 (9/11)
	Participation in MDT meeting incl. municipal staff	91 (10/11)
Dieticians (7)	Ad hoc contact with patient and/or family	82 (9/11)
	Other area of responsibility	27 (3/11)
	Diet registration	43 (3/7)
	Scheduled nutritional guidance	0
	AD hoc nutritional guidance	100 (7/7)
Child and adolescent psychiatrists (3)	Participation in MDT meeting incl. municipal staff	0
	Other area of responsibility	14 (1/7)
	Initial patient assessment	33 (1/3)
	Scheduled conversations with patient and/or family	33 (1/3)
	Ad hoc conversations with patient and/or family	33 (1/3)
	Psychiatric assessment	33 (1/3)
	Medical treatment of psychiatric illness	0
Participation in MDT meeting incl. municipal staff	33 (1/3)	
	Other area of responsibility	67 (2/3)

HCPs = healthcare professionals; MDT = multidisciplinary team.

Training of staff

Formalised staff training was offered to new MDT members in 11 departments (11/17 (65%)), primarily by other team members (11/11 (100%)). In a few departments, formalised staff training was sought externally (from other paediatric departments (4/11 (36%)), CAMHS (1/11 (9%)) or other departments (1/11 (9%)). Furthermore, six departments (6/17 (35%)) had no formalised staff training.

Standard treatment programme

A written description of a standard treatment programme was available in less than half of departments (7/17

(41%). Most of the departments were either satisfied (11/19 (58%)) or very satisfied (3/19 (16%)) with their current treatment programme. A significant association was observed between departments having a written description and being satisfied (satisfied/very satisfied) with their current programme ($p = 0.038$).

Needs for future guidelines

A need for clinical guidelines was expressed by most departments (13/19 (68%)), whereas the rest were in doubt about such a need (*maybe/uncertain* (6/19 (32%))). Most departments with a programme had experienced a decrease in resources (10/17 (59%)) allocated to FSS patients over the past five years, whereas others had experienced either stable (4/17 (23.5%)) or increasing resources (3/17 (17.5%)). Departments experiencing a decrease in resources were less likely to have a named consultant from the CAMHS ($p = 0.045$). Beyond this, no significant association was seen between the development in resources and the number of HCPs in the MDT or the level of satisfaction. All departments except one expected the number of paediatric patients with FSS to increase in the future.

DISCUSSION

In this national Danish survey, we found that all but two paediatric departments have a MDT dedicated to providing care for children and adolescents with FSS. In most locations, the patients were affiliated with the departments for long periods (more than three months), indicating that FSS is prevalent and resource consuming [8]. Clinicians expect an increasing number of patients with FSS, which is in line with a recent Danish study showing a steady increase in girls and boys with hospital records related to unspecific physical symptoms [15]. Still, a reduction in resources allocated to this patient group in the past few years was reported by 59% of departments. Further research is warranted to explore the type of reduction and determine which resources were affected. The literature is sparse, but a study on hospital service for young patients with FSS in America also reported a decrease in funding [14].

Evidence-based treatment

This survey showed substantial variation in several aspects of the current paediatric practice for young patients with FSS. There is best evidence for psychological interventions provided as specialised treatments for youth with moderate to severe FSS [16]. Though psychologists were well represented, namely in 88% of MDTs, they only had scheduled conversations with patients in 53% of departments. We did not explore in detail how much of the psychologist's time was allocated to direct work with the patients and/or family, and additional studies are needed to determine how psychologist resources are best utilised to promote an evidence-based practice for patients with FSS in paediatric departments.

Collaboration with child and adolescent mental health services

The clinical pathway suggested by Ibeziako and colleagues recommend that a "request for psychiatry consultation should occur as soon as FSS is suspected" [11] due to the high prevalence of concurrent psychiatric diagnoses in patients with FSS [5, 17]. We found that only 18% of departments engaged a child and adolescent psychiatrist as part of the MDT, and 29% had a named contact person from the CAMHS. The lack of paediatric mental health provision in paediatric settings has been documented to stem from limited resources as well as a cultural gap in terms of communication and patient approach [18]. A recent Danish study has shown that referral letters concerning young patients with FSS prepared by paediatric departments for the CAMHS were generally vague and imprecise [5], supporting the need for a more systematic approach.

Need for clinical guidelines

The paediatric staff demonstrated a clear desire for clinical guidelines in this area. This has previously been recognised by HCPs working with FSS patients [19]. Furthermore, we found that many of the HCPs working with paediatric patients with FSS handle several tasks and schedule patient conversations on an ad hoc basis. This may potentially cause discontinuity of care, which has been reported by young patients with FSS and their families as a cause for dissatisfaction and poor treatment outcome [19]. Evidence suggests that the implementation of a clinical guideline may increase efficiency in clinical practice and decrease hospitalisation time while reducing hospital costs [20]. Moreover, guidelines may serve to standardise the visitation process of paediatric patients with FSS, thereby promoting the recommended “stepped care approach” [5] on a national level. Important considerations in the development of official guidelines include the diversity of this patient group and the limited clinical evidence on this topic, which may result in a guideline mainly derived from consensus based on adult patients.

Strengths and limitations

The most notable strength of this study is the participation of all paediatric departments in Denmark, which allows for a nationwide evaluation of clinical practice in the field. However, the limited number of eligible departments and corresponding respondents resulted in a small dataset with limited power to perform more sophisticated analyses to explore these differences further. Moreover, the discrepancy in both the terminology and practice in this field complicates the use of statistical analysis. Another limitation is the lack of a more wide-ranging field testing of our de novo questionnaire, which was due mainly to the desire to include all departments in the subsequent survey. Finally, though our questionnaire covered various aspects of this topic, during our analysis and interpretation of data, we identified areas where more in depth knowledge is needed to better understand the strategy behind current practice: differences between admitted patients and patients seen in outpatient clinics, development in resources and the different roles of HCPs in the MDT.

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