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### Betwixt and between

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DOI:  
[10.33612/diss.195066742](https://doi.org/10.33612/diss.195066742)

**IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.**

*Document Version*  
Publisher's PDF, also known as Version of record

*Publication date:*  
2021

[Link to publication in University of Groningen/UMCG research database](#)

*Citation for published version (APA):*

Gol, J. (2021). *Betwixt and between: medical care for functional somatic symptoms*. [Thesis fully internal (DIV), University of Groningen]. University of Groningen. <https://doi.org/10.33612/diss.195066742>

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# **Chapter**



*General Introduction*

### ***A Clinical Encounter***

*Psychiatrist: What has brought you here?*

*Patient: I'm suffering from physical complaints not otherwise specified.*

*Psychiatrist: Interesting..... [ ], the addition not otherwise specified.*

*Patient: Two years ago I was diagnosed with an anxiety disorder not otherwise specified.*

*And now I have these physical complaints that don't fit in anywhere. , .....so my internist sends me to you.*

### ***Physical Symptoms that Cannot Be Explained by a Well-Defined Medical Disorder***

How to relate to physical symptoms that cannot be explained by a well-defined medical disorder, do not have a proper name or unequivocal treatment approach, is not only a challenge for patients, but also for health professionals and researchers.

The patient above reacted with a light tone of sarcasm. Other patients are much more pronounced in their frustration asking confronting questions like: “Why can modern medicine transplant a heart, but cannot do anything about my tiredness ?” A lot of these patients primarily express their despair. They feel left out of medical support and are insecure, will they ever be healthy again <sup>1</sup>? Of course, there are patients who are able to cope with their unexplained physical symptoms. They are not the ones who pay repeatedly visits to their general practitioner, are sent to a number of different medical specialists or seen in psychiatrists’ or a psychologists’ offices. This thesis is about the large number of patients who are demoralised by their symptoms and therefore seek help from medical care professionals. The patient above not only gave her own label to her symptoms, but by doing so, made a connection with psychological problems. For some patients this connection is a no-go area, while for other patients it is part of their illness perception.

This thesis is also about doctors, whose training emphasizes the importance of signs (“objective” abnormalities) above symptoms in defining a specific disease <sup>2</sup>. They struggle with feelings of insecurity, frustration and sometimes despair as well as they are trying to find a manner to understand and explain these “medically unexplained” symptoms and offer relief <sup>3-5</sup>. What makes it even harder for them is that the inability to make a diagnosis is not a rare phenomenon. Research shows that 30 to 50 % of the patients visiting an internal medicine outpatient clinic, as the patient above did, do not receive a medical explanation for their distress <sup>6</sup>. This percentage is not unique for internal medicine as it also applies to other medical specialties <sup>6</sup>. With the enormous advancements in modern

medicine in areas such as imaging technologies, the human genome and biotechnology expectations would be that “medically unexplained symptoms” are on their return. However, the reverse seems more likely<sup>7</sup>.

To study a phenomenon defined by what is not, rather than by what is, is a real “headache” for a researcher. It is hardly surprising that a lot of research thinking in this field is dedicated to identifying a positive term, which would be more acceptable for patients and of greater use for doctors and other health professionals. A term that has a clear theoretical concept based on empirical evidence, reduces unhelpful dualistic thinking and can facilitate the adoption of a multi-disciplinary (medical and psychological) treatment<sup>8</sup>. This thesis illustrates that the discussion about the correct term continues unabatedly by using different terms, namely functional somatic symptoms, medically unexplained symptoms and persistent physical symptoms. Although there is now a tendency to use a term which is neutral regarding aetiology and pathology and which can also be used in patients who have a medically recognized disease as well<sup>9,10</sup>. For purposes of clarity, the term functional somatic symptoms (FSS) will be used from now on in the introduction and discussion sections.

Although the central paradigm nowadays holds that FSS is the outcome of complex interactions between physiological, psychological and social factors, researchers in their efforts to unravel the mysteries of these symptoms are particularly drawn to the underlying biological mechanism<sup>11</sup>. Alterations of the autonomic nervous system (ANS), the hypothalamic -pituitary - adrenal (HPA) axis and the immune system are investigated in order to find support for the idea of stress- responsive dysfunction as mediator between psychosocial or physical stress and FSS<sup>12</sup>. Research in this area has generated interesting findings, but until now they have not been conclusive nor have they led to biomarkers for clinical use. The same applies to research in the area of central sensitization, a leading, explanatory theory of chronic pain<sup>13</sup>.

This thesis is not about the aetiology of FSS. It is rooted in clinical practice where patients and doctors meet and try to get a grip on these symptoms and the suffering that accompanies them. It fits therefore into the category of applied research. By examining daily clinical practice more closely, back to basics, the authors wish to discover new insights and solutions to everyday problems in the clinical encounter of the patient with functional somatic symptoms and their doctor.

### *Back to the Basics*

All the empirical studies in this thesis are based on naturalistic research. This examines spontaneous behaviour in a natural setting with the researcher interfering as little as possible with the subjects or phenomena. Observing people as they go about their normal activities instead of observing them in controlled circumstances increases the ecological validity of the research. This is especially the case when it is done with an open mind, also recognizing aspects not thought of before but worthy of attention. In this way - and this is another asset of naturalistic research - new ideas can be generated during data collection. Naturalistic research also has its drawbacks. It is a time-consuming activity when compared to other options such as carrying out a survey or conducting a focus group. For this reason sample sizes are often small which limits the ability to generalize. Replication of natural research is difficult as behaviour in natural setting is characterized by a large number of uncontrolled variables. Naturalistic research can be performed in quantitative as well as qualitative mode by carefully observing among other things written texts, videotapes or audio recording or social media expressions. In this thesis both modes were used depending on the research question. The most basic way of characterizing quantitative studies is to describe their aims as seeking answers to questions on “how many” or “how much” of a well-defined aspect of a phenomenon, while qualitative studies are characterized by questions about the “what, “how” or “why”<sup>14</sup>.

### *Aims and Outline of this Thesis*

This thesis follows the journey of a patient seeking help for physical symptoms that cannot be explained by a well-defined medical disorder in the light of current medical knowledge. Before becoming a patient with severe unexplained physical symptoms, a routine clinical practice is the consultation of a medical specialist to confirm or rule out a well-defined medical disorder. In the Netherlands, consultation of a medical specialist requires a general practitioner's (GP) referral letter.

Chapter 2 examines data from GPs' referral letters of consecutive patients referred to an internal outpatient clinic in two time periods. The aim was to develop and validate a brief screening tool for predicting functional somatic symptoms. In 2006 an integrated internal medicine and psychiatric outpatient clinic for patients with FSS was started. The question was if it was possible to predict the presence of functional somatic symptoms by specific

items present in the referral letter. If so, this knowledge may enable efficient allocation of patients to an integrated treatment facility from the first patient contact onwards.

After being examined and diagnosed, no matter what the outcome is, the question for the patient always is: What next?

In chapter 3 this question is explored by extracting the proposed management strategies from the return letter of the medical specialist. This was not only done for the patients with FSS but also for those with medically explained symptoms (ESS).

Then the thesis moves from the outpatient clinic to primary care practice. Most patients with FSS will be looked after by their general practitioner after the consultation in the outpatient clinic of a medical specialty has ended. After all, the central coordination of care for patients with FSS is done by the GP<sup>15</sup>. The GP's task then is to make sense of the patient's symptoms. In the scientific literature the importance of valid and convincing explanations of the physical symptoms is stressed; not only for reassurance and the maintenance of a good doctor-patient communication and relationship, but also for a possible therapeutic effect<sup>16</sup>. For a long time, in primary care, the reattribution consultation model was advocated in teaching and research. This model in which the physical symptoms are attributed to a psychological cause, is now considered too simple<sup>17</sup> and a great deal of effort has been put into the development of new explanatory models for functional somatic symptoms<sup>18,19</sup>. However, little is known about how GPs explain FSS in daily practice. Chapter 4 explores how GPs explain functional somatic symptoms to their patients in daily general practice consultations.

Although the current explanatory models are more sophisticated than the reattribution model, many patients with FSS still express their fear that doctors and others presume their symptoms are "all in the mind", that they might be seen as weak or "faking" their symptoms or as having a psychiatric disorder. This does not mean that these patients do not talk about their feelings or provide psychosocial cues<sup>1,20</sup>.

Chapter 5 examines how patients with FSS describe their negative emotions in order to help GPs recognize the patient's starting point in such discussions.

These discussions are important as emotions and related thoughts have the potential to play a part in worsening or maintaining physical symptoms, in addition to being a response to the symptoms. Addressing these emotions and thoughts in connection with the physical symptoms can be an important element in the management of functional

somatic symptoms for certain patients. This brings us to the following topic of this thesis: symptom management.

For most patients, an explanation for their symptoms is not enough. They want to know what can be done in order to improve or relieve their physical symptoms. A recent meta-analysis showed that self-help for functional somatic symptoms was associated with a significant reduction in symptom severity and improvement of quality of life <sup>21</sup>. Current primary care guidelines for FSS underlines the potential of symptom management, in which patients themselves have to act on their symptoms. These guidelines recommend to GPs to encourage activating behavior and give practical advice that patients can apply straight away <sup>22,23</sup>.

Chapter 6 describes the different types of symptom management strategies proposed by GPs when confronted with patients with FSS.

Before going to their GP, it is likely that patients with FSS have thought about some kind of home remedy and perhaps have even tried it. They also expect practical advice from their GP <sup>24,25</sup>. We also know they want to be taken seriously and be treated as an equal partner in the consultation <sup>25</sup>. We do not know how symptom management strategies emerge during consultation and what contributes to their adoption.

Chapter 7 explores the proposal, negotiation and adoption of symptom management strategies through a series of primary care consultations specifically for patients with FSS.

Chapter 8 contains a quite different study. Patients and doctors do not meet each other in a vacuum. It is not merely a matter of diagnosis and treatment, especially in the case of patients with FSS who, more than any other patient group need a tailored treatment. In order to improve clinical care, and reduce the suffering and / or, increase the feeling of being understood it was hypothesized that contextual aspects of this patient-doctor encounter should be optimized. Although this chapter presents empirical data its aim is primarily conceptual; it integrates the findings of empirical analyses and clinical experiences with the theoretical framework developed by Duranti and Goodwin for analyzing the relationship between a focal event, in our case the doctor patient encounter, and its context <sup>26</sup>.

## ***Betwixt and Between***

The term “betwixt and between” is derived from the work of Victor Turner, a British cultural anthropologist<sup>27</sup>. He was interested in rites of passage and elaborated upon the work of Van Gennip who showed that all rites of passage are marked by three phases: separation, liminality and assimilation. According to Turner, liminal individuals or entities are “neither here nor there”. They are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremony. In other words, they fail to fall into socially constructed categories. This liminal state often lead to feelings of alienation or confusion, but it also offers an opportunity for a transformative process where new patterns are established. The patient portrayed in the clinical encounter sensed very well that she was “betwixt and between” diagnostic categories and what this meant for her emotional well-being and for her search for help and support.



