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Betwixt and between

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Chapter

9

Summary and General Discussion

This thesis started with a clinical encounter. The patient concerned was a young woman who had experienced both physical and psychological symptoms for over two years. She had repeatedly visited health care professionals during this period. Initially she paid several visits to her general practitioner (GP), then was referred to an internal outpatient clinic of a general hospital in her home town and subsequently to a mental health care service. Finally, she was referred for a second opinion to our university hospital where her internist advised her to see a psychiatrist specialized in functional somatic symptoms (FSS). Her tour through healthcare, consisting of repeated visits to healthcare professionals, is not unique, but shared by many patients with FSS. This thesis originates from clinical practice; it studies several of the large number of steps taken in these healthcare routes. By examining spontaneous behaviour in natural settings, it provides a look behind the scenes about what happens in daily clinical practice for patients with FSS.

The objectives addressed in this thesis are largely derived from social anthropological ideas. They arose out of a desire to alleviate the suffering of a group of patients betwixt and between diagnostic categories and forms of medical care. At the internal medical outpatient clinic of the University Medical Center Groningen, more than half the patients presented physical symptoms that could not be explained by a well-defined medical disorder. The idea was to offer to these patients right from the start a specific diagnostic and treatment facility not based on a purely biomedical or a purely psychological approach, but on a balanced integrated. At that moment in time, the GPs approached thought that their patients did not want to be referred to this type of interdisciplinary integrated outpatient clinic. The research in this thesis started with a practical problem to be solved: how to identify patients with FSS so that they could be approached.

Findings in Perspective

Going into the field of internal medicine as a psychiatrist and interacting on an almost daily basis with a group of internists yielded the following observation: internists claimed that by reading the GP's referral letter they were able to predict whether or not a patient had FSS. If this claim was valid, these patient could offered combined care involving an internist and a psychiatrist from the first consultation onwards. Chapter 2 of this thesis shows that it is indeed possible to predict the risk of FSS on the basis of information from the GP's referral letter. By analyzing 451 referral letters, a selection tool (PROFSS) was developed based on candidate predictors for the main outcome measure, which was a final diagnosis of FSS made by the internist. The tool consisted of the following independent predictors: female gender, type of symptoms, somatic and psychiatric comorbidity, absent-

ce of abnormal physical findings, and the use of illness terminology. This study resulted in two remarkable findings. First: the “unknown” GP characteristic, the terminology in which the letter is written, is a strong predictor of a final diagnosis of FSS. Second: absence of previous and co-existing somatic symptoms in the referral letter was also linked to an increased likelihood of a final diagnosis of FSS. Apparently, GPs have a clear grasp of whether a complaint is functional or not, and by consciously or subconsciously hinting at this they are not embarrassed about an incorrect referral. These findings are a plea for the GPs’ freedom to make their own selection and presentation of the information in the referral letter. Valuable contextual information will be lost if GPs’ referral letters are standardized.

Psychiatric problems are thought to be more strongly associated with FSS than with well defined medical diseases. This idea is in line with our finding that psychiatric comorbidity in the GP’s referral letter increases the likelihood of a final diagnosis of FSS. As is shown in chapter 3 of this thesis, this supposition turned out to be less straightforward. Among 325 patients of the internal medicine outpatient clinic, the proposed management strategies from the return letter of the medical specialist were explored, including referral to mental healthcare. Differences in the proposed management strategies were found for patients with FSS compared to patients with ESS. Negative strategies such as non-referral and no treatment prevailed for patients with FSS. Positive strategies, on the other hand, such as medication, follow-up by the internist, and referral to another somatic specialist, were the main strategies for patients with ESS. A remarkable finding was the equal percentages of patients with FSS and patients with ESS treated in specialized mental healthcare before and three years after consultation of the internist. In other words, consultation of an internist did not contribute to mental healthcare treatment of patients with FSS. However, it led to a temporary decline in the numbers of patients with ESS in mental healthcare. Psychiatric problems of patients with ESS were underreported in the referral letters of the GPs. This might be a deliberate choice as was argued in chapter 2, but it also might be the outcome of confirmation bias, i.e. the tendency to interpret information in a way that confirms or supports prior beliefs or values. After all, previous studies have shown that a majority of GPs felt that patients with FSS suffer from personality problems, psychiatric illness or distress resulting from earlier experiences or current life circumstances^{1,2}. Another cognitive bias, the bandwagon effect, is the tendency for people to mention the things they know that are emphasized or done by others. Internists mention providing explanations more often in their return letters as a management strategy for patients with FSS compared to patients with ESS. This is not surprising, since, the scientific literature and the medical

training emphasize providing (plausible) explanations as an important management strategy for FSS³⁻⁶.

Explaining the unexplainable would seem a paradox. Chapter 4 explores how GPs explain FSS in daily practice, 39 video-recorded consultations of 18 GPs and 39 unique patients were presented. GPs provided explanations in nearly all consultations with patients with FSS. They did this by making use of seven building blocks, namely: defining symptoms, stating causality, mentioning contributing factors, describing mechanisms, excluding explanations, discussing severity of symptoms, and normalization. No pattern was discovered in the many different ways these building blocks were used separately or as a group. GPs usually provided short, not very detailed explanations that were often communicated in a tentative manner. Using the metaphor of a building, it can be said that the constructions were not very solid. They were also quite different from what GPs in a focus group study reported about their explanation practices⁷. GPs for instance reported the use of metaphors to give patients some insight in the hypothesized interactions between physical symptoms and psychosocial factors. However, in our study, GPs were rarely observed doing this.

Patients also elucidate their hypothesized interactions between physical symptoms and their psychosocial life during consultations. Unfortunately, literature suggests that most of the time these insights are disregarded by their GP⁸.

Chapter 5 examines the ways patients talked about their physical symptoms in relation to negative emotions. To this end 47 primary care consultations with 15 patients with FSS were analyzed. The patients in this study presented, often spontaneously, a wide range of emotions related to their physical symptoms. Quantitative researchers in this field have focused on measuring symptoms of depression and anxiety experienced by patients with FSS⁹. Given the fact that these researchers had to restrict themselves to a limited number of questionnaires, it is hardly surprising that they chose brief self-report questionnaires focusing on those aspects considered important in the prevailing disease models. This blind spot concerning emotions such as anger, irritability, frustration and shame is not found in the work of qualitative researchers. They showed that these feelings are an inherent part of FSS. However, studies on emotions associated with FSS typically focus on the frustrations of doctors who feel ill-equipped to provide high-quality care, rather than on the frustrations of patients who suffer from these symptoms¹⁰⁻¹². We discovered three ways by in which patients linked their physical symptoms to their emotions: separated, i.e. patients deny any link between the two; connected, i.e. they perceive the symptoms and emotions as distinct, connected entities; and inseparable, i.e. symptoms and emotions are

combined in a single entity. An interesting finding was that patients themselves suggested all kinds of connections; some even openly exploring the possibility of their symptoms being part of some affective disorder. However, when their symptoms were attributed to depression or anxiety by medical specialists among which their own GPs, this was often not appreciated and patients tended to deny such a link. Apparently, patients want a say in the matter when the customary conversation and attempts to find a cause and cure for physical symptoms in medical settings, i.e. the symptomatic idiom fall short ¹⁰.

In research and education, substantial efforts are put in to the development and training of explanatory models, as if making sense is enough to cope with the symptoms. Provided that making sense would mean normalization of the symptoms, the conclusion might indeed be drawn that nothing else is needed ¹³. However, patients with FSS do not endorse this: they want their GP to be clear about what they should do after leaving the consultation room. Many patients have pointed out that they lack a specific management plan ¹⁴. GPs have several management strategies at their disposal, for instance wait and see, medication and referral to physiotherapists or psychologist or some other professional. They might also provide advice about what patients can do themselves to reduce their symptoms.

Chapter 6 is dedicated to a hitherto neglected area of research, namely the actions outside the medical realm undertaken by patients to limit the intensity or impact of their symptoms. The term symptom management is used here for these self-help actions. Despite the fact that symptom management was not mentioned by the GPs in the focus group studies discussing how to deal with patients with FSS, it became clear by analyzing the video-recorded consultations of 39 consultations with 18 GPs and 39 unique patients that symptom management was a considerable part of the care of FSS in general practice ^{7,15}. GPs advised different types of symptom management strategies related to cognitions and emotions, interaction with healthcare professionals, body focus, symptom knowledge, activity level, and external conditions. However, advice on symptom management often was non-specific and was communicated in an ambiguous manner. A logical follow-up question is: What makes a symptom management strategy acceptable to a patient so that it is tried out?

In chapter 7, an analysis is presented of 12 series of primary care consultations specifically for patients with FSS. This analysis shows that it is not the type of symptom management strategy, but the degree to which patients were involved in its creation that made them embrace a strategy. Four themes related to the adoption of these strategies were identified: proposal of the strategy by the patient, proposal driven by the narrative of the patient, cocreation of the strategy, and higher complexity of creation by adding diverse motivatio-

nal or practical elements to the strategy. Apparently, patient with FSS not only want a say in the matter, but also want to be empowered to take charge of their own health, which is in line with the ideals of person-centered care ¹⁶.

Chapter 8 provides a synthesis of the knowledge from previous studies and presents this in a theoretical framework in order to broaden the scope of our current thinking. It is hypothesized that contextual aspects of the doctor patient encounter influence treatment outcomes substantially. Patients and doctors do not meet in a vacuum. It is not merely a matter of diagnosis and treatment, especially in the case of patients with FSS, who need, more than any other patient group, a tailored treatment. Patients also take into account setting, non-verbal communication and the way things are formulated to assess a doctor's competence to help. Support was found for the idea that early identification of patients with FSS, early treatment, a neat appearance and an organized office interior, a warm and friendly nonverbal approach and a non-defensive language use are contextual parameters which could contribute to the improvement of the care of functional somatic symptoms.

Methodological considerations

As outlined in the introduction, all empirical studies in this thesis are based on observations of spontaneous behaviour of patients and doctors in daily clinical practice. Naturalistic observation traces its roots back to anthropology. It attempts to observe with an open mind, and not to intervene. Observing objectively and without any impact on the field studied, no matter how invisible the researcher becomes, is of course an illusion. However, this does not imply that useful accounts beyond reproducing subjective experiences are impossible. For naturalistic observation to be a valid and reliable method, critical reflexivity is needed ¹⁷. Transparency about the interrelationship of the researchers and the field studied is needed. In our research, we did not interact with the participants in any way. This made us complete or external observers instead of participant observers, who join in and become a part of the group they are studying. Complete observers compared to participant observers have more difficulty in recognizing significant and worthwhile aspects of behaviour because they lack the insider's perspective. They are, however, are less prone to over-involvement and the associated biases ¹⁸. Some of the authors of this study have hands-on experience and therefore inside knowledge regarding the treatment of patients with FSS. This clinical expertise was an advantage in addressing real clinical issues in the field of FSS and probably also in the ordering the data. For instance, clinical work has taught the author that patients with FSS want an explanation, but above all a solution to their physical symptoms, although many patients cannot believe that a solution is possible

without a known cause. This inside knowledge made the authors focus on symptom management strategies, a neglected topic until now. Naturalistic research is a time consuming activity as data collection methods are designed to minimize data reduction and data tend to be voluminous and hard to manage. Fortunately, data collections made by others were available; by using these the problem of over-involvement was avoided. It, however, had the disadvantage that there was no going “back to the field” to make additional observations or to allow participants to challenge assumptions about the meaning and relevance of concepts and categories.

Future Directions for Research

The starting point of this thesis was “back to the basics”, to the daily clinical practice of the doctor- patient encounter, in the awareness that not all the healthcare problems of patients with FSS could be resolved with the “biology first approach”. No questionnaires were used to answer the research questions. This was a deliberate choice, not to mention the fact that an anthropological approach and questionnaires are not an obvious match. The author was intrigued by the search for markers and wondered whether it would be possible, in analogy to biomarkers, to identify social or linguistic markers from readily available sources to allow early detection of patients with FSS. In medicine, and especially in psychiatry, self-report questionnaires are used in the diagnostic process. Questionnaires, however, have disadvantages. There is always the problem of validity: to what extent do they measure what they were designed for? In addition, people nowadays are flooded with questionnaires and might develop an aversion to them¹⁹. We proved that it was possible to develop a simple prediction tool for FSS without collecting new data from questionnaires or interviews. Instead, social markers were extracted from available sources, namely the GPs referral letters. Similar work was done on linguistic markers, by a research group who found that linguistic features, such as the moment at which patients share information with the doctor, can help to discriminate between epilepsy and non-epileptic disorders²⁰. To overcome the current liminal state of being betwixt and between diagnostic categories, more naturalistic observational research is needed to define FSS by different types of “positive” clinical markers. However, this is not sufficient for patients and doctors to be on firm ground again.

Listening very carefully to the audio and videotapes of the doctor-patient encounters, the author became convinced that patients with FSS may require different explanations than doctors are taught to provide in their medical training²¹. Are patients in need of a targeted, tangible and preferably biological explanation in their own language of the causes of their symptoms? Certainly, but the problem is that explanations of causes still have a hypothe-

tical character and are therefore open to discussion, while a well-founded rationale for a symptom management strategy under the motto “what works is true” can be tested by patients in their daily lives. Studies focusing on the implementation and effectiveness of symptom management strategies can help broaden our understanding of how to encourage patients to develop confidence in using their own skills and knowledge to manage their own symptoms.

Final Remarks

The female patient who labeled her physical symptoms as “not otherwise specified” was willing to put her skeptical attitude aside for a while. She was intrigued by the question what made her investment in coming to the hospital worthwhile. She formulated her own outcomes. After five sessions she said goodbye. She left the room with the remark that her psychiatrist was very kind, and added proudly that she had done it all by herself.