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Developing e-health applications to promote a patient-centered approach to medically unexplained symptoms

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SUMMARY

Medically unexplained symptoms (MUS) are physical symptoms that cannot be (fully) explained by organic pathology despite adequate diagnostic testing. MUS are highly prevalent in all areas of medicine and range from single, self-limiting complaints to constellations of chronic and disabling symptoms. Apart from the suffering and impairments MUS impose on patients, they are also very costly for society due to the associated productivity losses and burden on health care. Current etiological models assume that MUS are the result of an interaction between predisposing, precipitating, and perpetuating factors. Predisposing factors make a person vulnerable for developing MUS, precipitating factors trigger the onset of symptoms, and perpetuating factors hinder recovery. Since the pathophysiology of MUS remains unclear, most treatments are aimed at creating the optimal conditions for recovery by targeting perpetuating factors. However, evidence-based treatment options for MUS are limited. The overall aim of this thesis was to develop e-health applications, offering solutions to three major obstacles in the treatment of MUS (see table 1).

Table 1. Obstacles in the treatment of MUS with potential solutions, provided by e-health applications.

	I	II	III
Obstacles	Inadequate communication between patients and healthcare providers	Limited use of effective psychological treatments	Heterogeneity; inadequate match between problem and intervention
Solutions	Education & training for healthcare providers	Increasing reach and acceptability of psychological interventions	Personalizing explanation and treatment
E-health applications	Online course ('e-learning') for healthcare providers	Online self-help: 1) Self-help website 2) Guided self-help intervention	Online assessment: Reports and treatment algorithms, based on results of online questionnaires & diaries

Part I: Development of an Online Course for Healthcare Providers

Communication problems between patients and healthcare providers are an important, but often overlooked, perpetuating factor for MUS. In general, there seems to be a discrepancy

between patients' needs and healthcare providers' responses to patients with MUS. Since many healthcare providers feel insufficiently able to manage patients with MUS, a first step in improving patient-doctor communication is educating and training healthcare providers. An innovative form of education that could be used to improve healthcare providers' knowledge, skills, and attitude, is online learning ('e-learning'). Online learning is at least as effective as traditional teaching methods, such as lectures or workshops. In addition, online learning is attractive for healthcare providers, because of its flexibility, convenience, and self-controlled learning pace.

The first part of this thesis comprised a pilot study, describing user experiences of an online, interprofessional course we developed to promote a patient-centered approach to managing MUS (*Chapter 2*). A survey before the start of the course confirmed earlier findings that healthcare providers experience patients with MUS as difficult and that many of them do not feel well equipped to manage these patients. A survey at the end of the course revealed that pilot study participants – a convenience sample of healthcare providers from various professions, with varying levels of experience – were extremely satisfied with the course. In addition, self-reported learning gains regarding knowledge and skills were generally rated very positive by the participants. Thus, from the perspective of these healthcare providers, our online course is an effective and satisfying way to learn about MUS.

Part II: Development and Effectiveness of Self-help Interventions

Even though psychotherapy is one of few evidence-based treatments for MUS, only a small proportion of patients benefits from this type of treatment. Many patients with MUS are not willing to visit a mental healthcare facility for treatment, because it makes them feel stigmatized. Furthermore, because psychotherapy is relatively time-consuming, costly, and requires highly trained professionals, it is scarce and usually offered exclusively to patients with multiple, severe and chronic symptoms. Self-help interventions have the potential to overcome some of these barriers, because they do not have to be offered in the mental healthcare setting and do not require guidance of trained professionals. Consequently, self-help, especially when offered online, can provide a widely available and acceptable treatment option for patients with MUS.

The second part of this thesis started with a systematic review and meta-analysis, studying the effectiveness of self-help interventions for MUS (*Chapter 3*). This study showed that self-help significantly reduces symptom severity and improves quality of life compared to usual care or a waiting list. Overall effect sizes were not inferior to those of conventional psychological treatments for MUS. Subsequently, the development and content of two online self-help interventions were described. The first intervention was a self-help website for patients with minor head injuries, the occurrence of which is a known precipitating factor for MUS (*Chapter 4*). The second intervention was 'Grip self-help': a web-based, personalized, guided self-help intervention for mild to moderate MUS in primary care (*Chapter 5*). Both of these interventions include a combination of education and practical exercises to reduce the impact of unhelpful cognitions, emotions, behaviors, and social

factors associated with physical symptoms. The effectiveness and successful implementation of these interventions will have to be demonstrated by future studies. This part ended with the protocol of such a study: a pragmatic randomized controlled trial (RCT), studying the effectiveness of 'Grip self-help' compared to care as usual (*Chapter 6*). The primary outcome is physical health-related quality of life at 16 weeks follow-up. Secondary outcomes include severity of physical and psychological symptoms, mental health-related quality of life, cost-effectiveness, and acceptability at 16, 26, and 52 weeks follow-up.

Part III: From Psychosocial Risk Factors to Potential Targets for Personalized Treatment

Symptom characteristics (type, number, duration, and severity of symptoms) and etiological factors vary widely between patients with MUS. An inadequate match between patients' problems and interventions offered might limit the effect of psychological treatments. Personalizing the contents of psychological treatments may thus improve their effectiveness. A first step in personalizing treatment for patients with MUS is properly assessing symptom characteristics and etiological factors. Online self-report questionnaires are a thorough and efficient way to gather information on symptoms and known risk factors for MUS.

In the third part of this thesis, we explored the effects of psychosocial factors on the development and maintenance of MUS. Two large prospective general population cohort studies from this thesis show that childhood parental divorce, parental death (*Chapter 7*), and sexual abuse (*Chapter 8*) are risk factors for developing MUS in Dutch adolescents. Gathering information on such predisposing factors can form a valuable contribution to a personalized explanatory model. Yet, prior life events are impossible to influence with treatment (apart from adapting the perception and meaning of the events). In addition, establishing the presence of risk factors does not necessarily prove a causal link between the risk factor and the symptoms that have developed in a specific individual. Time-series analysis using diary data of individual patients can establish the nature of the relationships between symptoms and perpetuating factors at the level of the individual. We have performed two diary studies that illustrate large inter-individual differences with regard to the influences of daily stress (*Chapter 9*), worry, and anxiety (*Chapter 10*) on MUS. In some individuals, increases in stress, worrying, and/or anxiety preceded an increase in MUS. In others, we found a reversed association: an increase in MUS preceded increases in stress, worrying, and/or anxiety. In addition, some individuals did not show any association between MUS and stress, worrying, or anxiety. Time series analyses can thus contribute to personalization of psychological interventions for MUS, by suggesting relevant treatment targets for specific individuals.

After assessment of symptom characteristics and etiological factors, the results of online questionnaires and diaries can be used to provide patients with insights into the nature, origin, and course of their symptoms. In the Grip self-help intervention, an automatically generated report graphically displays which perpetuating factors (i.e. unhelpful cognitions,

emotions, behaviors, and social factors) are relevant to the individual, based on the results of online questionnaires and diary measures (*Chapter 5*).

Finally, the information collected on symptom characteristics and etiological factors using online questionnaires and diaries can be used to personalize the intervention. In Grip self-help, patient-tailored selection of self-help exercises was enabled by algorithms, matching exercises to specific perpetuating factors (*Chapter 5*).

Concluding Remarks

Most patients with physical symptoms seek help from doctors. Most doctors consider diagnosing and treating *disease* as their fundamental tasks. A problem arises when diagnostic testing does not reveal a biomedical cause for the symptoms. Doctors find it hard to explain MUS, leaving patients with many unanswered questions. In contrast to the field of medicine, thoroughly exploring the patient's experience, perspective, and life story, and analyzing the interaction between the patient and healthcare provider are key areas of concern in the field of psychotherapy. Given the fact that such psychosocial factors can play an important role in the perpetuation of physical symptoms, this approach is of major value in the context of MUS. Integrating knowledge from the field of psychotherapy into the field of medicine can thus advance care for patients with MUS. This thesis shows that e-health applications have the potential to promote a patient-centered approach by facilitating this integration.

