

Development of an Ehealth and GP Assisted Programme for Persistent Physical Symptoms: Qualitative Exploration of Users' Needs

Pernille Ravn Jakobsen (✉ prja@ucsyd.dk)

UC SYD <https://orcid.org/0000-0002-0199-1972>

Mette Trøllund Rask

Aarhus Universitetshospital

Jane Clemensen

Odense Universitetshospital

Marianne Rosendal

Aarhus Universitetshospital

Lisbeth Frostholt

Aarhus Universitetshospital

Research article

Keywords: eHealth, General Practice, Persistent Physical Symptoms (PPS), Self-care, Self-help, COM-B model

Posted Date: September 21st, 2020

DOI: <https://doi.org/10.21203/rs.3.rs-61755/v1>

License:   This work is licensed under a Creative Commons Attribution 4.0 International License.

[Read Full License](#)

Version of Record: A version of this preprint was published on February 7th, 2021. See the published version at <https://doi.org/10.1186/s12875-021-01380-5>.

Abstract

Background

The prevalence of patients with persistent physical symptoms (PPS) in general practice is estimated to be 17%. Hence, general practitioners (GPs) play a central role in both diagnostic assessment and management of PPS. However, a large body of literature indicates a need to improve GP strategies and ways to support patient self-help. Additionally, the use of eHealth in the field of general practice is growing. Therefore, this study aims to explore users' needs in order to understand their requirements to an eHealth and GP assisted self-help programme for PPS in general practice.

Methods

Seven days of field studies in general practice and twenty semi-structured interviews (6 GPs and 14 patients with PPS) were conducted in the Region of Southern Denmark. Interviews were audiotaped, transcribed verbatim and analysed using a five-step thematic analysis. Analysis was done inductively and separately for patients and GPs. The identified themes were mapped to the COM-B behaviour change model to allow translation from GPs' and patients' needs to the development of an eHealth intervention.

Results

The analysis identified 11 subthemes in the patient interviews and 7 subthemes in the GP interviews. They were mapped into the three COM-B components: capability, opportunity and motivation. The main themes from patients and GPs corresponded and focused on understanding and explanation of symptoms, timing of this, uncertainty and consultation premises. Furthermore, important motivational elements for an eHealth programme were identified – especially the need for hope was emphasised.

Conclusions

The identified themes provide insight into potential behavioural interventions to facilitate self-care among patients with PPS in primary care settings through eHealth. Key learnings include: 1) a need to bring PPS into play early on in the consultation and take a more bio-psycho-social approach in the management of PPS. 2) Patients and GPs need better skills to manage uncertainty. 3) Patients need guidance from their GP in how to self-manage their PPS. Our design of a new eHealth and GP assisted self-help program for patients with PPS will target these identified key factors.

Background

Patients with persistent physical symptoms (PPS) such as pain, dizziness and fatigue visit their general practitioner (GP), medical specialists and emergency departments twice as often as other patients. The frequent attendance ranks their medical costs among the highest of all patient groups (1, 2). The prevalence of PPS in adults is estimated to be 10% in the general population according to standardised interviews (3) and 17% in general practice according to questionnaire screening (4). In general, PPS are

associated with high morbidity, distress to patients and their families, high healthcare costs (5) and high risk of work capacity loss (6).

PPS refers to the experience of bodily sensations perceived as possible signs of disease and consequently lead the patient to contact the healthcare system. PPS represent a spectrum of severity ranging from mild symptoms over moderate conditions to severe and chronic disorders (7).

Often the term medically unexplained symptoms (MUS) is used, because the majority of PPS are based solely on subjective complaints and not on verifiable clinical or para-clinical findings (8). However, this term is arguably misleading according to newer research, and it is unhelpful to patients with PPS (9, 10). Instead, a recent survey among the general population argues that the term *persistent physical symptoms* may be the most appropriate and acceptable term (11). Consequently, we have chosen to use the term PPS as an umbrella term *including* MUS and similar terms and *excluding* recent-onset symptoms.

General practice is the first point of entry to healthcare, and hence GPs act as frontline in the healthcare system and play a central role in both diagnostic assessment and management of PPS (12). A qualitative study of GP consultations on PPS showed that patients reported a mismatch between their GP's and their own agenda. Patients indicated that the GP evoked an uncomfortable feeling in them during the consultation and did not provide a specific management plan for their symptoms. In general, patients found the GP inadequately prepared for the consultation, and they perceived prejudices in the GP during the consultation (13). In line with this, GPs often experience this type of patients as difficult to treat (14), and negative attitudes towards patients with PPS are prevalent among GPs. (15). A meta-synthesis describing challenges faced by GPs when managing patients with PPS found that GPs struggle with the incongruence between patients' symptom presentations and the explanatory models for biomedical disease (16). Likewise, Rasmussen and Bø conclude that the bio-psycho-social frame helps GPs understand and handle PPS better than the biomedical frame does (17). The lack of treatment strategies for patients with PPS is a problem as a growing body of literature highlights that improved early management of PPS in general practice could reduce the burden on patients, clinicians and society (18).

eHealth refers to health services or information provided by the internet and related technologies (19). eHealth interventions have shown to be effective in promoting healthy behaviour, and their effectivity may be further improved by integrating self-regulation techniques (e.g. personal goal setting and coping strategies). In doing so, eHealth may assume some of the tasks of GPs prompting them to address self-management in the consultation (20). Online self-help interventions designed to be conducted independently of specialised healthcare might be a new way of overcoming the challenges and form a valuable addition to current treatment options for patients with PPS in general practice (21). However, there is a lack of knowledge about how such eHealth tools should be designed to meet the needs of both GPs and patients. Studies have shown that eHealth programmes, which have not involved GPs in the development process, are not readily accepted and are not properly integrated in routine care. Additionally, one of the major challenges of eHealth is to make it beneficial and easy to use for healthcare providers and patients; otherwise neither professionals nor patients will use it (22).

Given the challenges within PPS and the potential of empowering patients with self-help approaches, we wish to develop an eHealth and GP assisted self-help programme for these patients in general practice. The overall aim with the research programme is to improve health and quality of life for adult patients with PPS. The present study is the first phase of a larger four-phased mixed method study. Our specific aim with this first study was to identify the GPs' and patients' needs related to self-management of PPS. Identified key factors will subsequently be included in the development of an eHealth treatment programme.

Methods

Design

We conducted a qualitative study by performing field studies in general practice and semi-structured individual interviews with GPs and patients with PPS. The COM-B model, a framework that enables a systematic evaluation of behavioural aspects, guided our interviews and analyses. The COM-B model proposes three interacting conditions for behaviour change to occur: *Capability*, *Opportunity* and *Motivation* (23). *Capability* is defined as the individuals' psychological and physical capacity to engage in the activity concerned. It includes having the necessary knowledge and skills. *Opportunity* is defined as all factors outside the individual that enable the behaviour or prompt it. *Motivation* is defined as all those brain processes that direct behaviour, e.g. goals, conscious and analytical decision-making, habitual processes and emotional responding. A given intervention might change one or more of these components.

Recruitment

To include GPs who varied in age, gender and level of interest in PPS and eHealth, we adopted a purposeful sampling strategy (24) including GPs with high/low interest in PPS, high/low interest in eHealth, GPs of different sex and age and GPs with different practice types. Firstly, GPs were recruited and informed about the study. Secondly, the patients were recruited by the GPs if they fulfilled the inclusion criteria listed in table 1. The patients could be undergoing diagnostic workup concurrently.

Table 1: Inclusion criteria for participants

GPs	Patients
· General practice in the Region of Southern Denmark	· PPS not explained by co-existing physical disease or mental disorder
· Varying age and sex	· Age: 18-65 years
· Urban/rural practice	· Any sex
· +/- Special interest in PPS	· Be able to understand and read Danish
· +/- Special interest in eHealth	· Not on long-term sick leave

If the patients fulfilled the inclusion criteria, they were given an information letter about the study and what participation entailed. Furthermore, all patients were asked to complete a validated symptom checklist: the 25-item Bodily Distress Symptoms (BDS) checklist to identify relevant cases and to obtain further information on the patients' symptoms (25). The 25-item BDS checklist is developed and validated as a self-report instrument that can be used for case finding in both clinical practice and in research. It was previously developed on the basis of large sample of patients from primary and from neurological and internal medicine departments. It contains questions within three symptom groups; a cardiopulmonary group, a gastrointestinal group, a musculoskeletal group and a general symptom group. The checklist opens with the question: 'Have you in the last four weeks been bothered by' followed by a list of symptoms. The BDS checklist has a five-point response scale for each listed symptom ranging from 0 ('not at all') to 4 ('a lot') (25). A patient was included in the study if 4 or more symptoms were scored at or above 2.

The patients were contacted by phone by the first author and were informed verbally about the study prior to accepting participation. If they agreed to participate, a time for interview was scheduled.

Data collection procedure

Field studies

Prior to the individual semi-structured interviews, a total of 7 days of field studies were conducted in the four included general practices. The aim was to make the GPs familiar with the study and to inform them about the patients we wished to include in the study and the recruitment process. Furthermore, the field studies were conducted to achieve a clear understanding of the field to be able to develop an interview guide. Field notes were made during the fieldstudies.

Interview guides

The interview guides were developed in an iterative process by the research team and tested by performing pilot interviews with one GP and one patient who were not enrolled in the study. The interview guides included general questions related to aspects of capability, opportunity and motivation among both GPs and patients as well as the participants' general experiences of persistent physical symptoms and their attitude towards using an eHealth programme for this purpose.

Semi-structured interviews

The first author (PRJA), a female researcher with a PhD in health science, conducted the field studies and semi-structured interviews. All interviews were initiated with a presentation of the study and the researcher's background and interest in the research topic. The GPs were interviewed in their practice, and the patients were interviewed in their homes (n=13) or at their workplace (n=1). In all interview situations, only the participant and the interviewer were present in a quiet and uninterrupted environment. No repeated interviews were carried out. In the GP interviews, the focus was on how they experienced and managed patients with PPS based on capability, opportunity and motivation to identify barriers and

enablers in providing self-help through an eHealth intervention. In the patient interviews, the focus was on describing their symptoms and their experiences of having PPS, again based on capability, opportunity and motivation to identify barriers and enablers in promoting self-management of PPS. The interviews lasted 37-87 minutes with an average length of 54 min.

Analytical procedure

All interviews were recorded and transcribed verbatim and additional field notes were written down immediately after each interview. Data were subject to a thematic analysis by the research team, guided by Braun and Clarke’s five step framework (26) (table 2). Analysis was done inductively and separately for patients and GPs in an iterative process. Finally, the identified themes were mapped to the COM-B framework to allow translation from GPs and patients needs to development of the eHealth intervention (23). Saturation was reached since no new themes and codes were found during the last coding process.

Table 2: Thematic analysis

Step	Description
I	Familiarisation with data (PRJA, MTR, LF)
II	Inductive coding of data (PRJA, MTR and LF coded data independently and generated an initial list of ideas about what is in the data)
III	Discussion of codes and consensus reached of emerging themes (PRJA, MTR, LF)
IV	Review of the themes whereby a set of subthemes were explored and refined, including similarities and differences between interviews (PRJA, MTR, LF, JC and MR)
V	Themes and subthemes reviewed, revised and agreed upon and mapped into the COM-B model by all members of the research team and results summarised.

The research team consisted of five females employed as researchers at either a Danish University Hospital or a Danish research institution. They all hold a PhD in health science and one is professor. They have a common interest and +10 years of experience in PPS, general practice, qualitative research and involvement of patients and healthcare professionals in the design and development of new digital healthcare solutions.

Results

Participant characteristics

During January and February 2019, a total of six GPs from four general practices were recruited. They all agreed to participate. Four GPs were female and two were male. The age of the GPs ranged from 46 to 62 years (mean 52.8). All participating general practices were either partnership or group of solo practices. One practice was rural and three were in urban areas.

From January to March 2019 16 patients were asked to participate in the study. Two patients were excluded due to severe mental disorders. In total 14 patients were recruited (table 3). Ten patients were female and four were male. The age ranged from 20 to 58 years (mean 35). The BDS score ranged from 5 to 25 (mean 13.4) and the duration of symptoms from 2.5 to 108 months (9 years) (mean 29 months). Ten patients were employed, one was unemployed and three were on sick leave.

Table 3: Characteristics of participating patients in individual interviews (n=14)

Participant	Sex	Age	BDS score (Max. 25)
P1	F	56	6
P2	F	42	15
P3	F	23	20
P4	M	27	8
P5	M	39	10
P6	F	37	7
P7	F	30	18
P8	F	58	11
P9	F	32	25
P10	F	20	19
P11	F	38	19
P12	F	37	16
P13	M	22	9
P14	M	33	5

The analysis identified 11 associated subthemes in the patient interviews and 7 subthemes in the GP interviews that were mapped into the three different COM-B components (table 4). In the following, we will describe the identified themes firstly in the patient interviews and secondly in the GP interviews.

Table 4: Themes from the patient and GP interviews mapped to capability, opportunity and motivation (COM-B model). Italics indicate the identified subthemes.

COM-B Component	Theme (patients)	Theme (GPs)
Capability	Physical <i>A jungle of management strategies</i>	Physical <i>Missing biomedical reassurance</i>
	Psychological <i>Understanding causes of PPS</i>	Psychological <i>Dealing with uncertainty</i>
	<i>Dealing with uncertainty</i>	<i>Timing in bringing PPS into play</i>
	<i>Timing in bringing PPS into play</i>	
Opportunity	Physical <i>One consultation – one symptom</i>	Physical <i>Lack of resources</i>
	Social <i>Shift in social roles due to PPS</i>	Social <i>Cultural norms in the healthcare system</i>
	<i>The GP as a partner of discussion</i>	
Motivation	<i>Guidance from the GP</i>	<i>Fewer and beneficial consultations</i>
	<i>Need for hope</i>	<i>Better prepared for consultations</i>
	<i>Tracking of symptoms</i>	
	<i>Easy access to self-help strategies</i>	

Identified themes in the patient interviews

The patient interviews provided information about how the patients experienced PPS. The three domains in the COM-B model were used to identify patients' needs in relation to self-management of their symptoms.

Theme 1: Capability

Capability was explored with patients to establish whether they felt they were physically and psychologically capable in self-management of their PPS.

Physical capability

A jungle of management strategies

The patients in general described a lack of skills and knowledge about how to manage their symptoms. They managed their symptoms in many different ways by making use of various offers in the community. Ten of the patients were seeing a psychologist due to psychological problems. One had tried

metacognitive therapy. Some used a physiotherapist, a masseur, an osteopath, an acupuncturist or a chiropractor when they experienced muscular skeletal pain or symptoms. Others participated in mindfulness or yoga sessions or exercised in hot water.

They all described a jungle of information and asked for specific recommendations in relation to their own symptoms. They experienced that the guidance from GP wasn't sufficient and did not meet their needs.

Psychological capability

Understanding causes of PPS

Psychological stress was often presented as a starting point for the symptoms. Stress could be caused by different circumstances in the participants' life and be present for a long period of time with subsiding and recurring symptoms before PPS occurred, e.g. triggered by stress at work. However, when the symptoms occurred, the patients were unsure whether they were caused by stress or by physical factors. This was not further elaborated on in the consultation, and the patients were often referred to physical investigations at the hospital as described by this participant:

"It was a tough period for me. Small kids and busy at work. Suddenly, I felt like my legs could not carry me anymore. My GP referred me to the hospital, but the neurologist could not find any explanation. Later I realised myself the causality between stress and physical symptoms" (P6, female, aged 37)

Other patients described that their present symptoms might be a result of severe life events such as divorce (P5), childbirth (P12), car accident (P9), mid-life crisis (P8), establishing a family (P10, P14), unbalanced body (P2), concerns about the future (P4, P13) or stress in general (P6, P7). However, this was not broached during the consultation since the focus was on the physical aspect of the symptoms, which is described as an admission ticket to visit the GP. Participant 14 suggested that if the GP had been more focused on how he was doing in general instead of only on the stomach symptoms, it would have been more helpful in identifying the root cause of the symptoms:

"I was worried; a new-born baby, a new house, the symptoms from my stomach and being unsure whether I would be able to keep my work, you know, a jumble of thoughts. And then I think that my GP could have helped me if she had asked how I was actually doing instead of only focusing on the symptoms from my stomach" (P14, male, aged 33)

Dealing with uncertainty

Nine of the participants described uncertainty about whether a serious health condition might explain the symptoms and had thoughts about not being examined sufficiently. As this participant, a woman aged 32 with persistent low back pain, described:

"I really need some more physical investigations to be sure that nothing severe is wrong with me, and if they show that everything is fine, we can take it from there" (P9, female, aged 32)

If the patients were referred to specialists, the uncertainty was more about whether the doctor was thorough enough as described by this participant, a woman who was referred to a gynaecologist because of persistent symptoms from her stomach:

"I keep on thinking about whether the gynaecologist was thorough enough. He was very busy that day, and there were a lot of patients in the waiting room" (P11, female, aged 38).

Even though some of the patients believed that an underlying disease was not the cause of their symptoms, they required the physical investigations to be on the safe side prior to bringing other explanations such as stress into the consultations. To some patients, the more physical investigations, the better. Some of the patients described the ambivalence between being on the safe side and being worried when they were referred to physical investigations.

Timing in bringing PPS into play

When the patients were asked if they would like to participate in the study, the GP had explained about PPS, and for some patients it was the first time that they were introduced to this focus. This was an eye-opener for some of the patients, and they argued that it would have been helpful if PPS had been provided as an alternative explanation during concurrent physical investigations as suggested by this participant:

"My GP could have told me that of course we have to investigate whether it is a critical condition but maybe you should just learn to manage your symptoms and understand what might cause them" (P8, female, 58 years).

By bringing PPS into play earlier, the patients thought that they would be more willing to accept it as a reasonable explanation if physical investigations showed no findings and explanations. However, the timing was important since some of the patients argued that if the GP had introduced PPS as a possible cause the first time they showed up in the consultation and prior to physical investigations, they would not have accepted it, the reason being that the patients need to be sure that nothing serious is wrong with their body. As the same participant explained:

"If it had been introduced to me the first time I had symptoms from my heart in connection with my father's death of a heart attack, I do not think that I would have been prepared to accept it. At that time, I really needed to be sure that there was nothing wrong with my heart" (P8, female, aged 58)

Theme 2: Opportunity

Physical opportunity was explored with PPS patients to understand how the environment, resources and the locations in general practice affected their self-management of PPS. Social opportunity was explored

to better understand how the cultural norms and the interpersonal relations affected the experience and self-management of PPS.

Physical opportunity

One consultation – one symptom

Visiting the GP with diffuse persistent symptoms was a challenge because of the time available in the consultation. A GP has in average 10 minutes for each patient, and the consultation is structured in a way so that the patient is supposed to address only one symptom per consultation. This was a challenge to patients with PPS since most of the patients explored diffuse, multiple and vague symptoms, which they found time-demanding to explain to their GP.

Social opportunity

Shift in social roles due to PPS

Patients described how their role in relation to their social network and families had changed after the symptoms started and described a feeling of guilt since they were not able to be the friend, mother/father or wife/husband they used to be.

“And I have to be there for my little son, but when I get dizzy, I have to go into the bedroom and relax, and I really think that it is hard to accept” (P14, male aged 33)

Some experienced social isolation since they only to a limited extent were able to participate in normal activities with their friends and families due to their symptoms.

Patients described how they had delegated different daily activities to other family members. As an example: P1 had asked her husband to prepare the meal when they invited guests, P2 asked her son to do the laundry, and P3 asked her boyfriend to do the cleaning.

The GP as a discussion partner

Overall, the patients voiced a good relationship with their GP, and five patients described that they used their GP as a discussion partner, like P2:

“It helps to visit my GP even though we only talk together” (P2, female, aged 42)

Some of the patients had a high degree of trust in their GP and trusted their ability to deal with a possible serious disease.

Theme 3: Motivation

Various factors were explored in relation to motivation for self-management among patients with PPS through an eHealth intervention. Central subthemes were as follows: (1) Guidance from the GP, (2) need

for hope, (3) tracking of symptoms and (4) easy access to self-help strategies.

Guidance from the GP

Guidance in how to manage the symptoms, especially by the GP, was a key motivator for most of the patients. Patients felt that being offered an eHealth programme by their GP would increase their motivation for using it, but even though it was meant to be a self-help programme, patients wished the GP to guide their activity in the programme and follow up on their activity. Some patients found the follow-up important (P5, P8 and P10).

"I think it could be nice if you could get a sort of homework in an online programme and then your GP would follow up on whether you have done it or not" (P10, female, aged 20)

Overall, the patients underlined the importance of the self-help programme being a part of a continuity of care in collaboration with their GP rather than an alternative to GP visits.

Need for hope

Some patients described a feeling of hopelessness concerning PPS. They worried about their future and whether they would be able to work, take care of their family and whether the symptoms would persist for their entire life. They felt that the GP and other healthcare professionals focused overly on acceptance and learning to live with symptoms. P2 and P9 were directly told by their GP that the symptoms would be chronic. They described a need for seeing other patients with PPS and how they successfully managed their daily life as described by participant 3:

"It could be really helpful if you could get a feeling of not being alone by talking to or seeing others in the same situation and see how they manage their symptoms" (P3, female, aged 23)

Six patients suggested a forum where they could meet peers or some videos or case stories where the patients could see how people like themselves have managed PPS. It was important to the patients that the focus was on hope and positive experiences and strategies.

Tracking of symptoms

The patients found it very helpful to fill in the BDS checklist prior to the interviews, since it gave them a visible and precise overview of their symptoms. They suggested that the BDS checklist could be used to track their symptoms and provide them with a continuous status of their symptoms as described by P9:

"It is really difficult to tell how you are doing from day to day. Therefore, it is really helpful to have this checklist to monitor if you are going in the right direction" (P9, woman aged 32)

One patient (P6) suggested that the BDS checklist could be filled in prior to seeing their GP. This would help patients to better prepare for the consultation and participate in treatment decision-making. P5 stated that having the opportunity to fill in the BDS checklist at home could be a way of 'parking the

symptoms in storage' and then take them out when visiting the GP. According to P5, this might help to not 'having to' sense the symptoms all the time out of fear of not being able to remember all the symptoms when presenting them to the GP.

Easy access to self-help strategies

Generally, the patients seemed motivated to self-manage their symptoms, but since PPS were not discussed as a reasonable explanation for the symptoms in the consultation, it was not easy to talk about self-management strategies with their GP. They proclaimed that being prescribed a self-help programme by their GP would be a safe and easy way to increase their self-management of PPS since they had a high degree of trust in their GP and thereby trust in the content in the program.

Identified themes in the GP interviews:

GP interviews provided information of PPS from the healthcare professionals' perspective in general practice. The three domains in the COM-B model were used to identify GP needs in relation to support patients with PPS to self-manage their symptoms.

Theme 1: Capability

Capability was explored with GPs to establish whether they felt they were physically and psychologically capable to support patients with PPS in self-management of their symptoms.

Physical capability

Missing biomedical reassurance

The six GPs participating in the study agreed that their roles as a GP are to diagnose, treat and reassure the patients in the consultation. During field studies, we observed that the GPs often conducted a simple screening of their patients in the consultation by listening to the heart and lungs with the stethoscope and making referrals to blood tests. However, when it came to patients with PPS, simple screening with the traditional biomedical methods did not reveal anything, and therefore the GPs were challenged when applying solely a biomedical approach to the patients. Hence, the patients were often referred to further tests at the hospital, even though the GP was quite sure that everything was normal:

"And I have to admit that sometimes you refer the patient to further tests at the hospital even though you have a clear expectation that everything is normal. But when blood test and scanning confirm this, the patient is reassured to a higher extent" (GP 2).

However, when symptoms persist, negative test results may prompt further healthcare seeking and an Odyssey of referrals and investigations. Most of the GPs were aware of this dilemma and reflected on the challenges of the missing biomedical reassurance to patients with PPS and claimed that they really needed a valid investigation and diagnostic tool to help the patients understand and accept the presence of PPS.

Psychological capability

Dealing with uncertainty

Diagnostic uncertainty is well known in general practice, and all the GPs described this problem. As an example, GP1 described that she always conducted some biomedical tests to be sure that the symptoms were not explained by any physical condition prior to introducing PPS as a possible diagnosis:

“I do not feel a huge degree of uncertainty when it comes to patients with PPS. However, we have to hedge our bets, because we are so afraid of missing severe illness in the patients. Therefore I always start with biomedical investigations” (GP1)

The GPs described different opinions about expressing the uncertainty to the patients. GP2 argued that she sometimes expressed her thoughts to the patients when she referred the patient to physical investigations at the hospital. She could sometimes tell the patient that she did not expect any critical findings and that the investigations were just conducted to be sure that no underlying disease was causing the symptoms. GP5 argued that he was dealing with the diagnostic uncertainty by sometimes expressing his uncertainty this way:

“When you have been a GP for almost 20 years, you have a certain experience and then you are coping with diagnostic uncertainty and you are also able to express your uncertainty to the patient. I often say to these patients that I am not sure what is causing your symptoms, but I am sure based on the findings that it is nothing severe” (GP5)

Timing in bringing PPS into play

All GPs agreed upon the importance of bringing PPS into play in the consultation as early as possible to avoid unnecessary investigations, and they described that they often considered alternative diagnoses early in the consultation when the patients presented symptoms which were not easily diagnosed. However, the GPs in general experienced difficulties in early introduction of their considerations and the concepts of PPS. Some described a barrier related to worries about how the patient would receive the message and whether the patient would accept the term PPS (GP1).

Theme 2: Opportunity

Physical opportunity was explored with the GPs to better understand how the environment, resources and the locations in general practice affected their support of patients with PPS in self-management of their symptoms. Social opportunity was explored to better understand how the cultural norms and the social cues affected the way GPs think about and manage patients with PPS.

Physical opportunity

Lack of resources

The GPs described that consultations with patients with PPS in general are time-consuming, and often patients present a variety of multiple, vague and diffuse symptoms not fitting into the construction of a consultation concentrating on one or few symptoms. Hence, the GPs described that they need more time and more concrete and easy accessible tools in the management of patients with PPS.

"I think that I omit patients with PPS because we have only few options to help these patients. And because of that I feel much more hesitant" (GP6)

Being a GP without effective tools to diagnose, treat and reassure patients with PPS was described as frustrating and time-consuming, since it often leads to less effective consultations as described by GP2:

"As a GP you really want to diagnose and reassure the patient satisfactorily, since they come in my practice with the expectation that I can tell them what is the matter with them and give them the needed treatment. However, when it comes to patients with PPS, I neither have the time nor the tools to help them sufficiently" (GP2)

GP6 described that he often manages patients with PPS by talking to them regularly and offers them continuous follow-up appointments in the absence of better treatment strategies:

"I think that the only way to manage those patients is to offer them some follow-up appointments and just talk with them" GP6

Social opportunity

Cultural norms in the healthcare system

GPs described a general negative attitude and feeling of fatigue towards patients with PPS in their colleagues. GP 4 described an attitude in the specialised healthcare system that patients with PPS are not their business and that the responsibility lies with the GPs. However, they do not collaborate with the GPs but start an Odyssey of biomedical investigations and treatments rather than bringing PPS into play. Furthermore, GP4 requested a better collaboration with the specialised departments at the hospitals and expressed a strong wish that the departments would bring PPS into play rather than keeping referring the patients to more examinations:

"I think it is a huge problem that we keep examining the patients just because none of us are able to say that there might not be a physical explanation of their symptoms. And instead the patients become more and more nervous because we all keep searching for an answer that is not there" (GP4)

Theme 3: Motivation

Various factors were explored in relation to motivation for supporting patients with PPS to self-manage their symptoms through eHealth. Central subthemes were as follows: (1) Fewer and more beneficial consultations and (2) better prepared consultations.

Fewer and more beneficial consultations

Combined with the frustration about the lack of time and missing diagnostic and management tools, the GPs wished that the patients would show up less frequently in the practice. The frequent consultations with no strategy generated a feeling of insufficiency in the GPs. Therefore, the GPs were highly motivated by the thought of having easy access to self-management tools for the patients, potentially resulting in fewer consultations.

The GPs agreed that an online self-help programme could be a great supplement to the face-to-face encounter with the patient.

Better prepared consultations

Some GPs mentioned that an online self-help programme with a symptom screening could result in the patient being better prepared for the consultation as the GPs could use the data provided by the programme as a starting point for the dialogue with the patient. In contrast, the GPs explained how they often use half of the consultation to create an overview of the patients' symptoms. The GPs were generally worried about the increasing work load in general practice. Thus, they saw great potential in online symptom screening prior to the consultation allowing for more time for dialogue in the consultation, which was a high priority for the GPs. This was seen as improved quality of the consultation and thereby improved patient treatment.

Discussion

This study addresses both patient and GP needs when it comes to improved self-management of PPS. The findings highlight the need for certain aspects of capability, opportunity and motivation to be addressed in the design and development of an eHealth self-help programme for patients with PPS prior to the implementation in general practice. The main themes from patients and GPs corresponded and focused on understanding and explanation of symptoms, timing of this, uncertainty and consultation premises. Furthermore, important motivational elements for an eHealth programme were identified – especially the need for hope was emphasised.

Regarding capability, it was apparent that there was a gap between patients' and GPs' explanatory models in the consultation. Even though the patients clearly had concerns regarding severe diseases, most of them were aware that other factors could explain their symptoms as documented in an earlier study (27). However, they presented physical symptoms as the starting point in the consultation, since this was considered an admission ticket to the GP. The GPs then tended to use a biomedical approach to rule out serious disease and sometimes referred patients to physical investigations in secondary care using a defensive biomedical approach. A consequence of this dynamic seemed to be that psychological and social factors were rarely discussed in the initial consultations.

Studies have shown that patients need support and compassion, but GPs provide somatic screening and interventions (28, 29). Salmon et al concluded that patients with somatoform disorders feel satisfied and empowered by medical explanations that are tangible and involving. Empowering explanations has the potential to improve these patients' well-being and help reduce the high demands they make on health services (30). For the GPs, participation in this study meant that they employed the term PPS to include patients. The patient inclusion therefore became a tool for the GP to initiate a conversation about PPS using a biopsychosocial frame, which several of the included patients found helpful.

This highlights the potential of bringing PPS into play earlier in the consultation process in an easy and understandable manner. Such an approach might empower the patients to engage in self-management of their symptoms using a future eHealth programme.

The main reason for not bringing PPS into play earlier in the consultation is uncertainty in both patients and GPs. *"Dealing with uncertainty"* and *"timing in bringing PPS into play"* are central subthemes in both patients and GPs interviews. The patients described worry and expressed that they wanted to be sure that their symptoms were not caused by severe disease. Likewise, the GPs were afraid of overlooking severe disease and agreed upon the importance of conducting biomedical investigations first and foremost prior to talking about differential diagnoses such as PPS. In addition, a study has showed that GPs face difficulties recognising and labelling PPS. Even when there is no indication of a somatic problem, GPs still experience uncertainty and fear of overlooking a serious disease (31). Alam et al claim in a systematic critical review that diagnostic uncertainty is greatest in general practice due to the undifferentiated symptoms GPs are often presented with and is a routine inevitability (32).

Our findings on capability show a need among both patients and GPs to acquire improved knowledge and skills with regard to their understanding of PPS, communicating about PPS and dealing with uncertainty. The GPs in our study argued that they did not communicate about PPS as they did not have any valid treatment if PPS was the diagnosis. This was a main barrier among the GPs as they perceive that their role as a GP is to diagnose, treat and reassure the patients. Henningsen states that good communication with the patients is essential at all stages of PPS and levels of care, including reassurance, anticipation of likely outcomes of diagnostic tests, positive explanations of the functional character of the disorder and motivation of the patient to actively engage in the coping with bodily distress (14). Since PPS is not communicated sufficiently in the consultation, the patients in our study sought alternative management strategies than those provided by their GP. Therefore, many patients felt lost in *a jungle of management strategies* and various investigations when they really are in need of GP assisted self-help strategies.

Under the theme *"Opportunity"*, *"Lack of resources"* was an issue for GPs and especially when it came to patients with PPS as these consultations were found to be time-consuming. Furthermore, the GPs described *cultural norms in the healthcare system* causing a general feeling of frustration towards patients with PPS. This results in patients with PPS being referred to examinations continuously in search of the missing biomedical explanation leaving the patients in 'no mans land'. The patients

described that they often used their *GP as a partner of discussion*. However, they were also aware of, and to some degree restrained by, the finite resources in general practice and requested more time to just talk to the GP to be able to discuss the symptoms more broadly. The limitations of practice consultations in Denmark are per se a barrier to patients with multiple and unspecific symptoms such as PPS. Likewise, Houwen et al concluded in their study that communication in consultations on MUS could be improved if the GPs pay more attention to the patients' agenda and if the GPs prepare their consultations and focus on the issues that matters to the patients. Furthermore, they suggest that GPs should be honest with patients when they do not understand the origin of symptoms (13). However, our study pointed out that GPs are reluctant to share their diagnostic uncertainty with the patient.

When exploring opportunity issues with the patients, it became clear that the patients needed support as to how to involve their social network in the management of PPS since they experienced a *shift in social roles due to PPS*. They described that they missed seeing peers and other patients to get motivated on how to manage PPS in their daily life. The importance of social network for good health is also described by Holt-Lunstad, Smith and Layton (33). The patients also expressed a great *need for hope*. By having the opportunity to follow other patients' good examples, the patients thought that they could gain more hope for the future and become more motivated for self-management of their persistent symptoms.

Previous research has examined that self-help is associated with a reduction in symptom severity and improvement of quality of life among patients with MUS (21). Therefore, we discussed motivational factors relevant to an eHealth and GP assisted self-help program for persistent symptoms with both the patients and the GPs. In addition to *need for hope, guidance from the GP, tracking of symptoms* and *easy access to self-help strategies* were integral elements of the patient theme motivation. It became clear that the patients in general were motivated to self-manage their symptoms, but the GP would still have an important role in guiding the patients in the right direction. Despite face-to-face contact is essential to both patients and GPs, the GPs were motivated to have an eHealth program that could result in *fewer and beneficial consultations* and *better prepared consultations*. All motivational factors related to support the patients in self-management in their own environment to avoid the patients' dependence of continuous contact to the GP. This motivation is partly due to the well-known negative attitude of many GPs towards patients with PPS and the lack of effective management strategies in general practice (15). Both patients and GPs think that if the patients could be better prepared for the consultations it would help creating a better starting point for a better communication about PPS.

Strengths and weaknesses

To the best of our knowledge, this is the first study to address patients' and GPs' needs prior to the development of an eHealth and GP assisted self-help program for PPS. The use of qualitative interviews in this study allowed in-depth understandings of patients' and GPs experiences and opinions on dealing with PPS to better understand their needs.

The use of the COM-B inspired interview guides and the COM-B as framework for the analysis facilitated the identification of themes that are to be addressed in future eHealth intervention for PPS and

furthermore highlighted areas that need to be taken into consideration when eHealth programs are to be implemented in general practice. However, the majority of interventions guided by the COM-B model have been targeted at lifestyle including diet and exercise behaviours and there are only few examples of using the COM-B model within the bio-psycho-social area (34). Despite this, we found the use of the COM-B model helpful to guide the inductive research process, which is necessary especially in the field of PPS where a lot of different perceptions and experiences are explicated.

The study was conducted by a multidisciplinary research group (general practitioner, psychologist, public health researcher and health service researcher). Multidisciplinary and continuous discussions throughout the whole research process, from development of the interview guide to analysis and preparation of the paper helped to minimise the risk of our findings being dominated by preconceptions.

In general, we think that the above-mentioned factors strengthened the study. There are however some weaknesses that need to be considered. The transferability of the study results may be hampered. GPs in the study were recruited by purposeful sampling based on one of the author's personal knowledge of the participating GPs. This relationship may have caused the participating GPs to express a more positive attitude to patients with PPS than they would have otherwise. Another limitation of the study was that many of the included patients had suffered from PPS for longer than the intended target group. Thus, their attitudes and experiences may differ from that of patients with more recent symptom onset. We wished to have more newly diagnosed patients in the study. However, we think that the patients in our study share the same experiences and needs as more newly diagnosed PPS patients, and hence we still think our findings give a valid and an in-depth understanding of both GPs' and PPS patients' needs.

Future research

This is the first phase of development and test of the eHealth intervention eASY. The next phase will aim at designing and developing an eHealth intervention in an iterative process. Further extensive testing of the feasibility, acceptability, satisfaction and usability of the eASY program from the patients' and GPs' perspective will be assessed prior to quantitative evaluation of the programme.

Conclusion

In conclusion, several identified needs emerged from the in-depth qualitative work with PPS patients and GPs. It is clear that an eHealth and GP assisted self-help program for patients with PPS is desirable if it meets the users' needs. Key learnings include 1) a need to bring PPS into play early on in the consultation in order to take a more bio-psycho-social approach in the management of PPS, 2) patients and GPs need better skills to communicate about PPS and manage uncertainty and 3) patients need guidance from their GP in how to self-manage their PPS. Our design of a new eHealth and GP assisted self-help program for patients with PPS will target these identified key factors. We will use these findings to design an eHealth and GP assisted self-help program for patients with PPS that targets the identified key factors.

Abbreviations

BDS: Bodily Distress Symptoms, COM-B: Capability, Opportunity, Motivation – Behaviour, eHealth: Electronic Health, GP: General Practitioner, MUS: Medically Unexplained Symptoms, PPS: Persistent Physical Symptoms

Declarations

Ethics approval and Consent to Participate

All participants were informed about the study and provided written consent prior to being enrolled in the study. According to Danish law, it is not necessary to apply for scientific permission to conduct qualitative studies, as they are of a non-bio- medical character. The study was approved by the Danish Data Protection Agency.

Consent for publication

Not applicable

Availability of data and materials

The datasets generated during and/or analysed during the current study are not publicly available due to transcripts in Danish but are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding

Innovation Fund Denmark and Trygfonden fund the study. The funders are funding research projects that aim to design, develop and test new digital health solutions. They were not actively involved in the study.

Authors' contributions

PRJA designed the study, collected the data, participated in the analysis and wrote the first and subsequent drafts of the manuscript. MTR, LF, MR and JC participated in the design and data analysis, and commented on all drafts, including reading and approving the final manuscript. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted. PRJA is the guarantor.

Acknowledgements

Thanks to the participating patients and GPs for their contributions.

References

1. Barsky AJ, Orav EJ, Bates DW. Somatization increases medical utilization and costs independent of psychiatric and medical comorbidity. *Arch Gen Psychiatry*. 2005;62(8):903-10.
2. Zonneveld LN, Sprangers MA, Kooiman CG, van 't Spijker A, Busschbach JJ. Patients with unexplained physical symptoms have poorer quality of life and higher costs than other patient groups: a cross-sectional study on burden. *BMC Health Serv Res*. 2013;13:520.
3. Petersen MW, Schroder A, Jorgensen T, Ornbol E, Dantoft TM, Eliassen M, et al. Prevalence of functional somatic syndromes and bodily distress syndrome in the Danish population: the DanFunD study. *Scand J Public Health*. 2019:1403494819868592.
4. Budtz-Lilly A, Vestergaard M, Fink P, Carlsen AH, Rosendal M. Patient characteristics and frequency of bodily distress syndrome in primary care: a cross-sectional study. *Br J Gen Pract*. 2015;65(638):e617-23.
5. Budtz-Lilly A, Vestergaard M, Fink P, Carlsen AH, Rosendal M. Patient characteristics and frequency of bodily distress syndrome in primary care: a cross-sectional study. *Br J Gen Pract*. 2015;65(638):e617-e23.
6. Rask MT, Oernboel E, Rosendal M, Fink P. Long-term outcome of bodily distress syndrome in primary care: a follow-up study on healthcare costs, work disability, and self-rated health. *Psychosomatic Medicine*. 2016;(accepted).
7. Fink P, Rosendal M, Olesen F. Classification of somatization and functional somatic symptoms in primary care. *Aust N Z J Psychiatry*. 2005;39(9):772-81.
8. Fink PaR, M. *Functional Disorders and Medically Unexplained Symptoms. Assessment and Treatment*. Fink PaR, M., editor. Denmark: Aarhus University Press; 2015.
9. Tracey I, Bushnell MC. How neuroimaging studies have challenged us to rethink: is chronic pain a disease? *J Pain*. 2009;10(11):1113-20.
10. Woolf CJ. Central sensitization: implications for the diagnosis and treatment of pain. *Pain*. 2011;152(3 Suppl):S2-15.
11. Marks EM, Hunter MS. Medically Unexplained Symptoms: an acceptable term? *Br J Pain*. 2015;9(2):109-14.
12. Howman M, Walters K, Rosenthal J, Ajjawi R, Buszewicz M. "You kind of want to fix it don't you?" Exploring general practice trainees' experiences of managing patients with medically unexplained symptoms. *BMC Med Educ*. 2016;16:27.
13. Houwen J, Lucassen PL, Stappers HW, Assendelft WJ, van Dulmen S, Olde Hartman TC. Improving GP communication in consultations on medically unexplained symptoms: a qualitative interview study with patients in primary care. *Br J Gen Pract*. 2017;67(663):e716-e23.
14. Henningsen P. Management of somatic symptom disorder. *Dialogues Clin Neurosci*. 2018;20(1):23-31.

15. Rosendal M, Olde Hartman TC, Aamland A, van der Horst H, Lucassen P, Budtz-Lilly A, et al. "Medically unexplained" symptoms and symptom disorders in primary care: prognosis-based recognition and classification. *BMC Fam Pract*. 2017;18(1):18.
16. Johansen ML, Risor MB. What is the problem with medically unexplained symptoms for GPs? A meta-synthesis of qualitative studies. *Patient Educ Couns*. 2017;100(4):647-54.
17. Rasmussen EB, Ro KI. How general practitioners understand and handle medically unexplained symptoms: a focus group study. *BMC Fam Pract*. 2018;19(1):50.
18. Lamahewa K, Buszewicz M, Walters K, Marston L, Nazareth I. Persistent unexplained physical symptoms: a prospective longitudinal cohort study in UK primary care. *Br J Gen Pract*. 2019;69(681):e246-e53.
19. Eysenbach G. What is e-health? *Journal of medical Internet research*. 2001;3(2):E20.
20. Poppe L, Plaete J, Huys N, Verloigne M, Deveugele M, De Bourdeaudhuij I, et al. Process Evaluation of an eHealth Intervention Implemented into General Practice: General Practitioners' and Patients' Views. *International journal of environmental research and public health*. 2018;15(7).
21. van Gils A, Schoevers RA, Bonvanie IJ, Gelauff JM, Roest AM, Rosmalen JG. Self-Help for Medically Unexplained Symptoms: A Systematic Review and Meta-Analysis. *Psychosom Med*. 2016;78(6):728-39.
22. Eysenbach G. The law of attrition. *Journal of medical Internet research*. 2005;7(1):e11.
23. Michie S, Atkins L, West R. *The Behaviour Change Wheel. A Guide to Designing Interventions Great Britain: Silverback Publishing; 2014.*
24. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Adm Policy Ment Health*. 2015;42(5):533-44.
25. Budtz-Lilly A, Fink P, Ornbol E, Vestergaard M, Moth G, Christensen KS, et al. A new questionnaire to identify bodily distress in primary care: The 'BDS checklist'. *J Psychosom Res*. 2015;78(6):536-45.
26. Braun VC, V. Using thematic analysis in psychology. *Qual res psychol*. 2006;3(2):77-101.
27. Risor MB. Illness explanations among patients with medically unexplained symptoms: different idioms for different contexts. *Health (London)*. 2009;13(5):505-21.
28. Salmon P, Dowrick CF, Ring A, Humphris GM. Voiced but unheard agendas: qualitative analysis of the psychosocial cues that patients with unexplained symptoms present to general practitioners. *Br J Gen Pract*. 2004;54(500):171-6.
29. Salmon P, Ring A, Dowrick CF, Humphris GM. What do general practice patients want when they present medically unexplained symptoms, and why do their doctors feel pressurized? *J Psychosom Res*. 2005;59(4):255-60; discussion 61-2.
30. Salmon P, Peters S, Stanley I. Patients' perceptions of medical explanations for somatisation disorders: qualitative analysis. *BMJ*. 1999;318(7180):372-6.

31. Ringsberg KC, Krantz G. Coping with patients with medically unexplained symptoms: work-related strategies of physicians in primary health care. *J Health Psychol.* 2006;11(1):107-16.
32. Alam R, Cheraghi-Sohi S, Panagioti M, Esmail A, Campbell S, Panagopoulou E. Managing diagnostic uncertainty in primary care: a systematic critical review. *BMC Fam Pract.* 2017;18(1):79.
33. Holt-Lunstad J, Smith TB, Layton JB. Social relationships and mortality risk: a meta-analytic review. *PLoS medicine.* 2010;7(7):e1000316.
34. Cowdell F, Dyson J. How is the theoretical domains framework applied to developing health behaviour interventions? A systematic search and narrative synthesis. *BMC Public Health.* 2019;19(1):1180.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [COREQchecklist.pdf](#)