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## ***Lost in fragmentation:***

### **exploring patients' experiences with coordination of care when somatic symptoms persist, a qualitative study**

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## **Abstract**

**Background:** GPs can play a central role in the care for patients with persistent somatic symptoms (PSS). To date, little is known about patients' experiences with the coordination of care.

**Aim:** Exploring experiences of patients with PSS with the coordination of care -in particular by their GP- during their illness trajectory.

**Design and setting:** Qualitative study, part of a multi-center prospective cohort study on the course of PSS (PROSPECTS).

**Method:** Thematic content analysis of fifteen interviews.

**Results:** We identified three themes: 1) care fragmentation during the diagnostic trajectory; 2) transition from the search for a cure to coping; and 3) reframing to coping: GP's role in facilitating supportive care. Patients experienced misalignment between healthcare providers (HCPs) during the diagnostic trajectory and some ended up in a 'collusion of anonymity' (repeated cross-referrals between specialists). Guidance by their GP in a process of shared decision making was positively valued. Moving focus from searching for a cure to coping with symptoms was described as a personal endeavor, challenged by ongoing uncertainty. When reframing to coping, the extent to which patients were aligned with their GP played a role in whether their supportive care request was met.

**Conclusion:** Patients experienced difficulties navigating the diagnostic trajectory and shifting to coping. Our findings underline the importance of collaboration and alignment between GPs and other HCPs during the diagnostic trajectory. We recommend that GPs provide pro-active guidance and are sensitive to patients who shift to coping by providing supportive care in a process of shared decision making.

**Keywords:** medically unexplained symptoms; persistent somatic symptoms; general practice; primary care; qualitative research; coordination of care.

**How this fits in:** In healthcare systems where the GP acts as a gatekeeper, such as the Dutch healthcare system, GPs can play a central role in providing care for patients with PSS. To optimize the coordination of care and identify best practices it is necessary to understand how patients with PSS currently experience the coordination of care. In this study patients frequently reported that they experienced fragmented care during the diagnostic trajectory and mentioned challenges in finding support to cope with symptoms when they made the transition from the search for a cure to coping. Our findings underline the importance of collaboration and

alignment between GPs and other HCPs when providing care for patients with PSS. We recommend that GPs provide pro-active guidance in the diagnostic trajectory and are sensitive to patients who shift to coping by providing supportive care in a process of shared decision making.

## Introduction

GPs regularly encounter patients who present with somatic symptoms, the origin of which remains unclear after adequate history taking, physical examination and, if warranted, additional investigations (1-3). In primary care, these symptoms are commonly referred to as 'medically unexplained symptoms'. A recently introduced and more appropriate and patient-centered term -that puts less emphasis on the mind-body dualism in the origin of symptoms- is *persistent somatic symptoms* (PSS) (4-6). We decided to use this term throughout this paper. Patients with PSS account for a substantial proportion of the frequent attenders in primary care (7). Having PSS is associated with elevated psychological distress, functional impairment (8, 9) and high medical care utilization (10, 11), putting patients at risk of iatrogenic harm (12-15).

As a diagnosis is an expected outcome of a medical interaction, both doctors and patients can feel frustrated and lost without one. A cultural result of modern medicine is that there is a compelling expected narrative in the management of illness. Arthur Frank outlined this as the 'restitution narrative': most individuals make sense of their illness by approaching it as a narrative. In the 'restitution narrative' every disease has a name- a diagnosis- and is preferably followed by a successful cure resulting in a happy ending (16). Patients need to make sense of their illness stories in a culture that prefers restitution stories. In case of PSS, a diagnosis and cure remain absent. This can cause deep discomfort and may hamper the provision of adequate chronic care for individuals suffering from PSS.

GPs encounter challenges in the management of care for patients with PSS. They tend to find these symptoms difficult to manage (17), experience less satisfaction (18, 19) and a high workload in caring for patients with PSS (20). The biomedical disease model, in which the ultimate aim is to correct disease and restore normal functioning (which is in line with the culturally appropriate 'restitution narrative') still prevails in medical education and practice. Most GPs struggle with the incongruence between the dominant disease model and the reality of patients suffering from PSS (21). Despite GPs' frequent struggle with PSS management, most GPs consider it their task to manage the care for these patients in primary care (17). In current guidelines, GPs play a central role in the guidance and management of patients with PSS in healthcare systems with a gatekeeper system such as the Netherlands (22-25).

Many studies on the experiences of patients with PSS focus on interpersonal communication between the GP and the patient and what patients expect from their GPs. These studies highlight that patients regularly feel dissatisfied with the care they receive, frequently experiencing prejudices (8, 26) or being told by their doctor that ‘there is nothing wrong’- which does not match their experience of severe symptoms that affect their daily lives (27). They long for an explanation for their symptoms (28), would like to be more involved in agenda setting and treatment decisions - focus on what matters to *them* (8, 26, 29).

Ensuring optimal care coordination in case of PSS may be challenging for both patients and GPs, especially when many care providers are involved. With care coordination, we mean “the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services” (30). When referred to specialist care for further examination, patients with PSS may for example end up in a ‘collusion of anonymity’. This phenomenon, first described by Michael Balint in the 1950s, refers to a situation in which “the patient is passed from one specialist to another with nobody taking responsibility for the whole person” (31). In interviews we conducted with patients with PSS, they reflected on their illness trajectories. Fragmented care during these trajectories and the search for supportive care played an important role in their illness narratives. Though the initial aim and purpose of these interviews was to explore patients’ experiences with fluctuations in their PSS over the course of their illness trajectories (32, 33), we decided to explore patients’ experiences with care coordination in more detail as a secondary aim. To the best of our knowledge, no prior study focused primarily on how patients with PSS experience the coordination of care –in particular by their GPs- during their illness trajectory.

## Method

This qualitative study is part of a larger prospective cohort study that monitors the course of symptoms and functional health in patients with PSS (see Box 1) (34, 35). We conducted semi-structured (in-depth) interviews to obtain information about the experiences of patients with PSS over the course of their illness trajectory.

**Box 1. The PROSPECTS study**

The PROSPECTS study is a Dutch longitudinal cohort study following patients (N=325) with persistent somatic symptoms (PSS). PSS patients aged between 18-70 years were recruited in general practices (N=218) and in specialized PSS programs of secondary and tertiary care organizations (N=107) across the Netherlands in 2013-2015. Initially patients were followed over a period of three years with five measurements in time (baseline, 6, 12, 24, 36 months of follow-up). In 2017, the follow-up period was extended and the study is still ongoing. Baseline characteristics and information on the recruitment process and first two years of follow-up have been published elsewhere (34, 35).

Definition of PSS: PSS was defined as the presence of physical symptoms that had lasted at least several weeks and for which no sufficient explanation was found after proper medical examination by a physician. This is in line with the current Dutch multidisciplinary and general practice guidelines for Medically Unexplained Physical Symptoms (23, 25).

## **Sample**

For the interviews we invited patients from the PROSPECTS study who completed the three- year follow-up and gave informed consent to be contacted for future research. We used purposive sampling to ensure a diversity of participants in terms of nature of symptoms, age, gender, social characteristics (educational level, living area) and recruitment setting (general practice, specialized PSS program). Because of the main aim of the interviews (33), patients with either clinically relevant fluctuations or clinical stability (based on minimal clinically important differences) in symptom severity (PHQ-15) (36) and physical functioning (RAND-36 PCS) (37) were approached. In total, 21 patients were approached by phone by HB or EW. Two patients were not willing to participate because of personal reasons; three patients declined participation because of time constraints. One patient cancelled the interview appointment for work-related reasons. Fifteen patients agreed to participate and were interviewed. All selected patients provided written informed consent. All recruited patients experienced (episodes of) severe PSS, and most experienced symptoms for an extensive period of time (>5 years). The nature of symptoms varied. Almost all (N=14) had symptoms in at least two symptom clusters, and a substantial number (N=10) in at least three symptom clusters. Details on experienced symptoms and other characteristics of the patients are shown in table 1.

## **Data collection**

The original interviews took place between January and April 2019. Based on the preference of the patient, eleven interviews were conducted at the patient's home and four at the research department of the university in a private meeting room. All interviews were digitally recorded. Interviews lasted 60 minutes on average (range: 33-93 minutes). Patients received a €15 gift voucher. Participants were informed that the main interviewer (HB) is a GP registrar and researcher, and the second interviewer (EW) a medical intern involved in a research project on PSS. Both interviewers are female. HB received training in qualitative research and was supervised by an experienced qualitative researcher. Interviews were loosely structured using a topic guide with relevant areas that were explored in depth. We asked open ended questions and encouraged patients to talk freely about their experiences and expand on any aspects they felt were relevant. The initial topic guide consisted of five main topics: (1) the experienced course of symptoms and how symptoms interfered with their daily activities, with a special focus on stability and fluctuations over time (day, week, month, year(s)); (2) factors contributing to fluctuations in symptoms; (3) management of symptoms and fluctuations; (4) the role of their social and work environment; and (5) the role of the healthcare system and care providers. After analyzing the first two interviews, the (lack of) coordination of care was an important topic in patients' narratives, we therefore added the following topics: need for/experienced coordination

of care by health care professionals (HCPs), and experienced and preferred role of the GP in the organization and delivery of care.

All participants received a summary of the interview afterwards for a member check; no major changes in content were made.

### **Data analysis**

All interviews were transcribed verbatim and coded using Atlas.ti version 7. As indicated before, this study is a secondary analysis of the interviews collected in 2019: the first aim was to explore patients' experiences with fluctuations in their PSS over time (33). For this analysis we focused on the parts of the interviews in which patients spoke about their experiences with the healthcare system and care providers, and more specifically the need for/experienced coordination of care by HCPs, and the preferred role of the GP in the coordination of care. We did not aim for data saturation on this matter, but to identify important key themes. Our analysis was based on thematic analysis as described by Braun and Clarke (38). As fragmented care played an important role in the illness narratives of the first two participants, this may have fueled a preconception on the part of the researchers. To limit the impact of this preconception, open ended questions were asked and the researchers stayed critical on this preconception when analyzing the data. At least two authors (HB, EW, FB) were involved in all phases to enrich the analysis. All results were discussed in the research team. Finally, the report was produced, and quotes related to the themes were extracted.

### **Results**

We identified three overarching themes in the illness trajectories important in the organization and delivery of care: 1) care fragmentation during the diagnostic trajectory; 2) transition from the search for a cure to coping; and 3) reframing to coping; GPs role in facilitating supportive care. Subthemes related to these overarching themes are discussed below.

#### **1. Care fragmentation during the diagnostic trajectory**

In line with the restitution narrative, the search for a diagnosis or explanation and cure for the symptoms was a starting point in all illness trajectories. Although it varied, most experienced a rather extensive and lengthy diagnostic trajectory for their PSS, resulting in a series of aborted trajectories. Within this search, patients in this study faced challenges concerning organizational factors, guidance and communication between HCPs.

### ***Ending up in a 'collusion of anonymity'***

Some patients in this study felt that no one took the lead during the diagnostic trajectory and ended up in a 'collusion of anonymity', being stuck in this cycle of cross-referrals from one specialist to another.

*"Nobody knows. And they refer you to the next one. And that went on for such a long time. [...] I really thought 'just talk to each other', you know. Explain 'this is a patient, I've ruled out this and this'. Because you'd be referred to the next one and he'd have the nerve to start talking about what the other one just ruled out. (P3, F)*

Participants assumed that the GP would receive information from the medical specialists and be updated on the diagnostic developments - although some experienced this was in fact not the case.

*"You don't even think of going back to that GP, because you have now started the trajectory he (GP) put you on. [...] They'll say 'we will send a letter to your GP'. As a patient you think, at least I did, 'well, that's good, then he is informed'. [...] But then when I went there (to the GP) the next time, for something completely different, he said 'Oh, you've seen a lot of specialists lately'. 'Yes, that's right, you referred me'. 'Oh yes, now that you mention it'. [...] I really think the GP should play an active role here." (P3, F)*

### ***Risk of misalignment when seeing several GPs***

Participants who were confronted with several GPs during the diagnostic trajectory experienced this as hindering, because they felt nobody had a clear overview and misalignment could arise in those situations.

*"I am in this duo practice, with two GPs who run the practice. What happens is that you go back and forth between them. (...) Of course they keep their notes in the computer, but they read a different story in these notes. And this can result in...how would you call that...differences." (P8, M)*

### ***Contradictory information***

In their search for a diagnosis, patients in this study regularly had to deal with contradictory information from the HCPs they encountered. In these situations, physicians and other HCPs disagreed on the diagnosis for their PSS, leaving some patients puzzled.

*"So, I don't have arthrosis at all. [...] 'No', he said, 'it's fibromyalgia'. [...] So, then you don't have what you thought you had, but I had to process that, the fact that 'I don't have arthrosis'." (P12, F)*

### ***Guidance in the diagnostic trajectory: role of the GP***

Patients in this study appreciated it when the GP took or would have taken an active role during the diagnostic trajectory. They indicated that the GP was the preferred person to take the lead in coordinating the diagnostic trajectory, as all information eventually ends up at the GP. Some patients had a GP who actively asked the patient to come back after the consultation with the medical specialist. For some patients, this was guided by a clear plan drawn up together with the GP prior to the referral. This active role of the GP and the shared decision making were experienced as positive, making the patient feel they are being taken seriously, while also maintaining a certain degree of control.

*"In the last six months I feel I am being taken very seriously. [...] Now we have agreed to wait and see for a while, in particular regarding the pain in my chest; so, when I do come in with symptoms now, no nonsense, straight to the cardiologist. [...] Well, she agreed with that, so that's what we do now."* (P8, M)

One patient indicated she would have appreciated a 'closing conversation' at the end of the diagnostic trajectory with her GP, to reflect on her search for a diagnosis and cure and help her find closure with the fact that there was no readily available cure for her illness.

*"I had expected that she (GP) would be the linking pin and all information would come back to her. [...] At some point I decided to go back to her to tell her 'well, the conclusion was that there's nothing they can do'. And I sort of expected that she would take the initiative for a kind of final, concluding conversation. But that doesn't happen either. [...] Nobody really takes the lead."* (P4, F)

### ***Communication and alignment between HCPs: preventing a 'collusion of anonymity'***

Some mentioned that communication and alignment between HCPs may be crucial role in breaking the cycle of aborted diagnostic trajectories and shifting towards a more holistic approach to their PSS.

*"They all just look at their own thing. But I actually don't fit into anyone's thing. [...] And if they had just discussed that beforehand or at some point along the way. I think the circle would have been closed sooner".* (P3, F)

## **2. Transition from the search for a cure to coping**

Though some of the patients we interviewed continued their search and remained dedicated to finding a diagnosis and cure, others acknowledged the unexplained nature, quitted their search and shifted their focus towards coping with their PSS the best they could. Moving away from the restitution narrative towards focusing on symptom management in itself was described as challenging.

### ***Transition to coping ('flipping the switch'): a personal endeavor***

Several patients literally described the transition from searching for a diagnosis or explanation and cure for their symptoms towards coping the best they could as 'flipping the switch' and underlined that this was a personal endeavor.

*"So, it's just a switch you have to flip. And if you don't, you'll never ever find a way out. Because you have to do it yourself." (P1, F)*

### ***Transition to coping: the challenge of ongoing uncertainty***

Patients spoke about ambivalent feelings regarding the uncertainty they had to deal with when making the transition: the little chance that a rare diagnosis was missed or that new findings and scientific developments eventually would result in a diagnosis stayed in the back of their head.

*"Yes, they said 'we cannot find anything'. Then you have to believe that. You have to believe just that. They say that I am physically healthy. I take that for 90%. And for 10% it remains open... and...well... no one can take that away from me. So... I leave it there. Within healthcare there may be a part that we just haven't figured out. The knowledge is just not there yet." (P1, F)*

## **3. Reframing to coping: GPs role in facilitating supportive care**

When patients visited their GP for coping strategies and supportive care, the extent to which they were aligned with their GP seemed to play a role in whether patients' request for supportive care was met.

### ***Misalignment when reframing to coping: hindering supportive care***

Some patients in this study experienced that their GP downplayed their symptoms when there was no diagnosis, obstructing further supportive care and symptoms management plans.

*"I have had a GP and other people saying 'but then there's nothing wrong with you'. But you walk in my shoes for a day, it's not nothing. [...] I have also heard things like 'just keep going' or put your back into it and you will be better in six months'. And that made me think 'well, that's what I've been trying*

*for a couple of years now’.” (P3, F)*

### ***Alignment when reframing to coping: ‘working it out together’***

When the patient and GP seemed to be aligned in their focus on coping, patients reported positive experiences of searching for possible solutions and ways to cope with their symptoms together with their GP.

*“It’s searching for things that may or may not help, together with my GP. It feels good that we decide together. That’s really important. At least you’re being heard.” (P11, F)*

These patients underlined the importance of having a good relationship with their GP, in which they feel understood and supported, in order to turn to them for help and advice regarding symptom management. One patient described the experience with her old GP as opposed to her new GP. Her old GP did not understand why she consulted him for her PSS. With her new GP, to the contrary, she seemed aligned and able to engage in supportive care she appreciated.

*“With my old GP I felt like he was thinking ‘I don’t know what to make of it, so what are you doing here?’. And she (new GP) is someone who listens and helps to think along with me.” (P4, F)*

### ***Reframing the request for help: from curing to coping***

Reframing the request for help was mentioned as a strategy to reach alignment with their GP. A patient described how he rephrased the request for help as he moved away from the restitution narrative and was searching for strategies to cope with his PSS.

*“If nobody brings up a solution, you continue your search. Then you will end up with a different story at the doctor. Not like ‘So I have a back pain, please do a check-up’. But you come to the doctor with the story ‘I have a back pain again, this didn’t help, I tried this, so what do we try next? You tell me. Rephrasing those requests for help. Making your question clearer.” (P13, M)*

## **Discussion**

### **Summary**

This qualitative study aimed to explore experiences of patients with PSS with coordination of care over the course of their illness trajectory. We identified three overarching theme: 1) care fragmentation during the diagnostic trajectory; 2) transition from the search for a cure to coping; and 3) reframing to coping: GPs role in facilitating supportive care. Patients with PSS in this study described fragmentation in care, received contradictory information during the diagnostic

trajectory and underlined the importance of communication and alignment among HCPs. Pro-active guidance by their GP and shared decision making were positively valued. Switching focus from finding a diagnosis and cure towards coping with symptoms was described as a personal endeavor and challenged by ongoing uncertainty. When patients made the transition, the extent to which they were aligned with their GP in their focus on coping seemed to play a role in whether their request for supportive care was met.

### **Strengths and limitations**

To the authors' knowledge, this is the first qualitative study focusing on experiences of patients with PSS with the coordination of care and the role of the GP in this coordination. A strength of this study is the fact that patients were recruited throughout the Netherlands and varied with regard to demographic and social characteristics, and the course and diversity of their symptoms. An important limitation is the fact that this was a secondary analysis of qualitative interviews. The interviews were not primarily focused on the topic coordination of care. We therefore did not aim for data saturation on this matter, but we aimed to identify important key themes. Another limitation is the possible selection bias in the patients that agreed to take part in this study: most already had PSS for many years.

### **Comparison with existing literature**

Kornelsen et al. previously described how many patients with PSS got lost in the medical system and experienced miscommunication between HCPs as "referrals got lost, consultation reports never returned to the initiating physician, and test results remained uncommunicated." (39) Patients with PSS nowadays remain at risk of ending up in a cycle of specialized referrals described by Balint as a 'collusion of anonymity' (31). Though aborted diagnostic trajectories are to some extent inherent to the illness trajectories in case of PSS, the need for guidance, alignment and communication between HCP described in our study, is in line with these prior findings. Though participants in our study indicated that the GP was the preferred person to take the lead, the problem with the 'collusion of anonymity' is that the GP is often side lined. Nevertheless, GPs and other HCPs alike should be aware of these issues and the importance of collaboration and alignment when referring these patients to other HCPs.

The patients with PSS in the study by Kornelsen et al. -like the patients in this study- started with an active search for a diagnosis and gradually moved towards acceptance of uncertainty. The therapeutic relationship seemed important when dealing with this uncertainty (39). Nettleton et al. showed that the narratives of patients with PSS were 'chaotic' and characterized by confusion and uncertainty, as there was no proper restitution narrative available. Patients in their study acknowledged that diagnosis is difficult and an explanation not

always possible, but they were more concerned to secure some form of ongoing medical and social support (27). The patients with PSS in our study faced challenges in gaining access to supportive care. Not only the patient themselves needed to make the transition to coping, but their GP also had to be sensitive to pick up their request for help and able and willing to offer coping strategies and supportive care. Stone described that GPs –like patients- face difficulties reframing the chaos and facilitating the transition to coping with a poorly defined illness. GPs needed to tolerate uncertainty and faced challenges in ‘shifting gear’ from curing disease to coping with illness. Accepting responsibility for care and unconditional positive regard were among the strategies GPs used to manage the care for patients with PSS. Some GPs in this study described a deliberate shift in focus to care coordination, as they gave up their role of technical expert (40). Our findings underline the need for a deliberate shift to supportive care by patients in alliance with their GPs to facilitate the change in focus and meet the supportive care needs of patients severely affected by their PSS.

### **Implications for research and practice**

For future research, it could be useful to study care usage of patients with PSS more extensively (both within and outside of the medical system) and how collaboration between different involved HCPs takes place. In addition, it would be interesting to examine strategies of how patients and GPs can ‘reframe to coping’ together and on how GPs (or other central HCPs) can support patients with PSS to make the transition from the search for a cure to coping. Future studies could also address obstacles and barriers in care coordination and collaboration regarding patients with PSS, both from HCPs and patients viewpoints (including e.g. funding and organizational aspects of care).

In healthcare systems where the GP acts as a gatekeeper, we recommend that GPs provide pro-active guidance in the diagnostic process and that medical specialist and other HCPs strive for adequate communication and alignment to prevent a ‘collusion of anonymity’. Moving away from the restitution narrative in a culture that prefers these narratives can be unsettling for patients and GPs alike, especially in the light of ongoing uncertainty. We recommend that GPs are sensitive and supportive to patients who make the transition to coping by providing supportive care in a process of shared decision making. This may eventually improve chronic care for patients with PSS.

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## **Ethical approval**

The institutional review board of the Amsterdam UMC (IRB00002991) approved the research protocol (No. 2018.483).

## **Competing interests**

Apart from the institutional grants mentioned above, there are no other potential competing interests to report.

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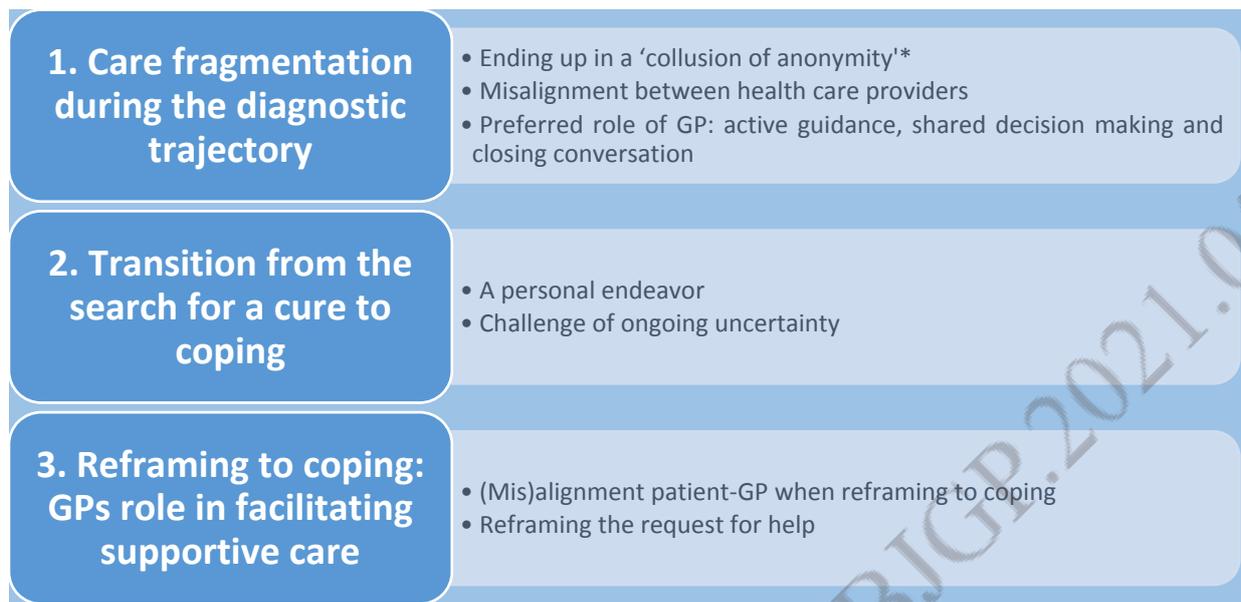
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**Table 1. Patient characteristics**

<b>Mean age (years, range)</b>	55.4 years (range 32-73 years)
<b>Gender</b>	
-male	3/15
-female	12/15
<b>Education</b>	
-higher educational level	4/15
-intermediate educational level	4/15
-lower educational level	7/15
<b>Living area</b>	
-rural area	5/15
-city	10/15
<b>Recruitment setting</b>	
-General Practice	12/15
-specialized PSS program	3/15
<b>Symptoms</b>	
-fatigue	12/15
-musculoskeletal pain	12/15
-headache	6/15
-gastro-intestinal symptoms (e.g. nausea, abdominal discomfort)	5/15
-cardiopulmonary symptoms (e.g. palpitations, atypical chest pain)	3/15
-dizziness	3/15
<b>Fluctuations/ stability</b>	
-fluctuations in symptom severity and physical functioning	9/15
-stable in symptom severity and physical functioning	5/15
-fluctuations in symptom severity, stable in physical functioning	1/15

**Figure 1. Overview of themes**



\* A cycle of cross-referrals between specialists as first described by Michael Balint (in: Balint M, The doctor, his patient and the illness. 2nd ed., rev. & enl., reprinted. ed. London: Pitman Paperbacks; 1968)

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