

Glimpsing the raging seas that stop swans: A qualitative look at living with multimorbidity and pain in patients from a tertiary care service

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Abstract

Multimorbidity requires complex and ongoing care. Understanding the subjective illness experience is critical to effective care. Literature isn't clear about illness perception in patients with multimorbidity followed in services of high complexity. This study aims to investigate the illness experience based on narratives about daily living and symptoms of patients with multimorbidity and pain in a tertiary health care service.

Methods: Qualitative narrative inquiry design with framework analysis from semi-structured interviews at a tertiary internal medicine outpatient clinic. Patients with Elixhauser comorbidity index ≥ 3 or and pain during the last week were included. Framework analysis was performed using 3 main patterns of illness experience from a previous study: “Gliding swan” (Resilience); “Stormy Seas” (Vulnerability); and “Stuck adrift” (Disruption); and identifying subthemes. One case study was selected from each main category. 43 patients, 14 classified as “gliding swan,” 12 as “stormy seas” and 17 as “stuck adrift.” Within the “gliding swan” group, positive examples of how to navigate through physical and emotional factors to sustain their wellbeing based on comprehension; In the “stormy seas” group, themes revolved around vulnerability, burden and ambiguity in relation to the health team. In the “stuck adrift” group the main content was about overwhelmed feelings and limitations.

Conclusion(s): Narratives brought the content about lacking personalized understanding of diseases, with great emotional repercussion. Some meaningful anchors were highlighted. This study reinforces multimorbidity and pain interact and that healthcare professional should be aware of the turbulences that can disturb navigation in the raging seas of long-term multimorbid conditions.

Keywords

Multimorbidity, chronic disease, multiple chronic condition, illness perceptions, internal medicine

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Introduction

Multimorbidity is defined as living with two or more diseases.¹ These are often long-term health conditions which require complex and ongoing care.¹ Chronic diseases and their effects could be understood as a symbolic bridge that connects the body, the subjective “self” and the society, in a network that involves biological processes, meanings and relationships, resulting in a unique internal experience.² Health professionals have a privileged role of being able to alleviate symptoms and suffering, contributing to care.

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This kind of care should be ideally multidisciplinary and patient-centered, relying on patient education and shared decisions, weighting disease and treatment burdens as well as the psychosocial context.³ Although the knowledge and proposals for the care of patients with multimorbidity in primary care have been developing in recent years, the care of such patients in tertiary attention has not been discussed with the same frequency.

Multimorbidity is measured with different instruments in particular scenarios,⁴ such as Elixhauser comorbidity index,⁵ which is composed of a list of selected diseases whose simple sum of those present in the individual is its result and correlates with health outcomes and mortality. Besides the metrics, there's relevance in understanding the personal health experience. Every person under the care of the health team has beliefs and adaptive reactions to their condition, which are influenced by their health status, nature of the disease, personal and family experiences, personality characteristics, environmental factors, gender issues and health information.^{6,7} Perceptions of diseases are decisive in the assessment of symptoms, in the interpretation of their causes and evolution, as well as in the decisions to adhere to medical recommendations or health advice.⁸⁻¹¹ Perception of diseases is the structure or model that people build to make sense of their symptoms and medical conditions.⁷ Individuals with the same disease may have different perceptions and have different emotional reactions to it.^{6,12} There is a correlation between perception and favorable and unfavorable outcomes, as well as quality of life during treatment, behavior, adherence to treatments and tests and functionality, regardless of the severity of the medical condition.^{6,7,12-14} There are different models and theories that come from behavioral and social sciences that identify relevant concepts for understanding how individuals evaluate, perceive and respond to their health conditions, relating to stress, adaptability and resilience, generating behaviors and aspects that can be observable or not (cognitive and affective).¹⁵ In this article, we adopt the lived experience of symptoms as a concept that results from the perception and the daily living of people with multimorbidity, embracing aspects related to treatment, lifestyle changes and cultural and social environments in which those people live.

In an innovative and creative way, Reeve and Cooper¹⁶ proposed a categorization based on the narratives of primary care users to understand how they face health needs despite disease status. The authors emphasize the impact of long-term conditions on daily living and consider the biographical flow with or without health-related disruption, the continuity of daily life and the preponderant themes in the narrative as decisive for the health needs and experience of the disease. The three categories identified were: (1) The "Gliding swan" group, with Resilience as keyword: where there was continuity of the person's biography, absence of significant health-related disruption and daily life was the dominant narrative theme. (2) The "Stormy

seas" group, with Vulnerability as keyword: the narrative of daily life was continued but there was significant health-related disruption, characterizing the speech by managing disease and treatment in the context of daily life, with health care as the dominant narrative theme. (3) The "Stuck adrift" group, where the keyword is Disruption and daily life narrative was completely interrupted by illness or treatment burden, being these themes the preponderant ones in the narrative.¹⁶ The emotional repercussions and burden caused by diseases are products of a complex interaction between functional capacity, social and clinical aspects.^{17,18} The possibility of listening to patients' self-reports allows assessment of truly psychosocial constructs that reflect suffering.

Pain is in general an experience that comes through the body with little or no control over its course, giving this condition a threatening autonomy, requiring the person who suffers from pain to undertake the most everyday activities.¹⁹ The study of pain and its impact on disease representations is not so commonly discussed in the literature and when it is, it is specifically related to specific diseases; this particular issue has not been evaluated in the presence of multimorbidity.

Thinking about the systems approach recommended by WHO¹ and to the best of our knowledge, there are no previous studies about the lived experience of symptoms in patients with multimorbidity in tertiary care. Selecting patients with different diseases but with multimorbidity and the presence of pain as the connecting thread that unites them, this study aims to address patients' life experience of multimorbid long-term diseases including pain, from the description of their narratives in the context of their daily life. In other words, our questions are: "How do people experience long-term conditions? What are the components of the life experience when chronic diseases and pain are present?"

Methods

This study was part of a broader protocol exploring the determinants of disease perception at the internal medicine outpatient clinic of a highly complex university hospital. The protocol was initiated after approval of the local ethics in the research committee (CAAE 66093217.2.0000.0068-CAPPesq/HC-FMUSP). Patients followed at a tertiary care internal Medicine service were invited to participate before their scheduled medical appointment, after explanation and application of the informed consent form. Patients were individually approached in the waiting room and then taken to one of our outpatient offices for the interview. The sampling was done by convenience. After the interview, a review of medical records was carried out. All interviews were conducted by the main author, as well as all data tabulation and narrative transcription. The average duration of interview, including other structured

questionnaires that were not included in the present analysis was 1 hour.

Participants characteristics

The inclusion criteria were: (1) people with follow-up at the internal medicine outpatient clinic at our tertiary care hospital with a scheduled appointment to the days of study; (2) age between 18 and 80 years; (3) understanding and acceptance of the informed consent term; (4) Elixhauser Index greater than or equal to 3 AND presence of pain defined by an affirmative answer to the question “Throughout life, most of us have experienced pain from time to time (such as minor headaches, sprains and toothaches). During the last week did you have any pain other than these common pains?” The rationale for defining these inclusion criteria was to include for qualitative analysis patients with greater multimorbidity and with the presence of pain. Of 100 patients who participated in the interviews, 65 had pain. After medical records review, patients with Elixhauser Index greater than or equal to 3 were selected for this analysis. Thus, we had 43 patients included for the present study.

The included population was composed of 20 men and 23 women, mean age of 57.5 ± 12.1 years; Working status: 10 people were working; 5, unemployed; 28 were retired or on leave due to illness. Marital state: 3 patients were single; 27 were married; 8 separated or divorced; 5 widowers. Regarding schooling: 30 patients had 8 years of schooling or less; 10 had up to 11 years of schooling; and 3 patients concluded college.

Procedures

The interview was initiated by questions about socio demographic issues (birth date, marital state, working status, family income, schooling, and religion). Then, the participant was asked which disease(s) he/she accompanied in the service and then the question that triggered the narrative interview was posed: “What is it like to live with [the diseases that the participant mentioned]?” The method of obtaining data was that of the narrative interview, whose main characteristic is the non-interference of the researcher in the interviewee’s report, encouraging spontaneous and undirected narration. If the narrative was interrupted, the patient could be asked “Do you want to say anything else?” The narrative interview was considered finished when the participant declared its end or the silence was continuous, without any time limitations. The narrative had the audio digitally recorded—a voice recording feature of a personal cell phone was used. Only the voice was recorded on the device, and later on the digital cloud storage, without any patient identification.

Two of the authors (MHF and ACCGG) participated in the qualitative analysis of the transcripts. They read and re-read the transcriptions independently and meet regularly to

discuss the identity and group meaning unit until no new information appeared. After that, the framework analysis^{20,21} was carried out, considering both authors are novice qualitative researchers. The protocol proposed by Reeve and Cooper¹⁶ was adapted, first identifying examples of an almost normal daily life in the course of chronic illness, following a search for evidence of disruption of the biographical flow related to health problems and which narrative thread (daily life, illness or healthcare) was dominant in their narrative, trying to categorize each patient in one of the three patterns of illness experience previously proposed in the following way: The “Gliding swan” with continuity of the person’s biography, absence of significant health-related disruption and daily life as the dominant narrative theme; The “Stormy seas” group, with continuity of daily life but with significant health-related disruption, with health care as the dominant narrative theme; The “Stuck adrift” group, in which daily life narrative was completely interrupted by illness or treatment burden, being these themes the preponderant ones in the narrative.¹⁶ After this first division in the three categories, content analysis was performed in order to identify specific characteristics within each group. After clarifying the characteristics that united the groups, verifying the homogeneity within each group and identifying the differences between them, a case study that represented each main category was chosen. Despite using the model proposed by Reeves as a determinant for the analysis; after categorizing the narratives in the three main groups, we found particularities of our population, which brought the need to rename and reframe some aspects within the groups. Thus, the terminology that we will present in the results and discussion may differ in part from the original study, but it was thus chosen to represent the ideas brought by the participants in greater depth. Bringing case studies to better illustrate each category was a strategy to provide a holistic and integral view of the participating subjects. Besides case studies, we added some quotes highlighting treatments aspects, also related with the context involving the life experience of symptoms. Some quotes are also presented in Table 1 and in Boxes 1–3 to exemplify and clarify the characteristics of the three groups.

Participant validation of the transcripts and findings was not undertaken. For the writing of this text, the quotes from the interviews were translated from Portuguese to English, trying to maintain the original meaning of colloquial expressions and transcribed syntactic constructions in the quotes that appear in this paper.

Results

Forty-three patients who had an Elixhauser score equal or greater than 3 and presence of pain were included in the qualitative analysis. Mean Elixhauser comorbidity score of 4.6 ± 1.5 . Of the 43 patients, 14 were classified as “gliding swan,” 12 as “stormy seas” and 17 as “stuck adrift.”

Table 1. Summary of narratives' categories and case studies.

Group	Gliding Swan/ Resilient	Stormy seas/ Vulnerable	Stuck adrift/ overwhelmed
Defining characteristics ¹⁶	Biographical continuity, disease don't disturb everyday life	Biographical continuity but with significant health-related disturbance; health care as the dominant narrative theme	Narrative of everyday life completely interrupted by the disease or the burden of treatment, these being the preponderant themes of the narrative
Main themes and quotes from different participants	<p>1. Understanding of the disease and its course "When I started to get a sense of going after some treatment (...) That's why I came to get treatment again (...) These are new symptoms that are coming before my migraine" (Patient 6)</p> <p>2. Positive way to navigate, through adaption "Then I recognized that there are times when we have to stop, breathe and throw a ball in a different way" (Patient 35)</p> <p>3. Positive view of healthcare "I have followed all the instructions that the doctors give me. I never stopped coming for appointments and exams. And taking my pills too" (Patient 34) "So I go to the doctors. You help me" (Patient 12) "When I got here I found these angels, who look at us, who ask for exams and examine and discover what we have" (Patient 10)</p>	<p>1. Difficult and incomplete adaptation to disease and treatment "I've done everything you can imagine: panoramic, x-ray, filming, tomography" (Patient 17) "I'm getting used to it, in quotes, you have to try to live with it, asking God for strength. I'm trying to live, it's hard" (Patient 14) "If I walk too much i get tired. To take a shower, and a shower is nothing, I get tired. I clean my house . . . I sweep once and sit 10 times" (Patient 38)</p> <p>2. Ambiguity in the description of the healthcare "I treat thrombosis, but in reality my problem is lupus, right? It's the lupus that should be treated." (Patient 3)</p> <p>3. Individual vulnerability "I have a pain in my body that is increasing every year (.) When the pain appears, where am I going to run to?" (Patient 17) "When crisis come" (Patient 2) "I lay well and woke up with an incurable disease in the body" (Patient 14)</p>	<p>1. Limitations due to illness and treatment "I am no longer able to work. Even at home things are difficult" (Patient 26) "I am very weak . . . depending on others . . . it is very bad to depend on people to do everything" (Patient 16) "My marriage is over. Because not everyone can live with a person with deformities or pain all the time" (Patient 40) "I feel pain in my whole body, everything, from head to toe" (Patient 43)</p> <p>2. Not understanding; Perplexity "I'm not sure if it is the cyst that causes the pain. When we know the cause of the pain, we get even better . . . but when we don't, one has the pain and one doesn't know where it comes from" (Patient 13) "I've never smoked, I've never drank, I've never had an addiction to anything and then it came this disease. It is cruel" (Patient 22)</p> <p>3. Aspirations and values not related to the disease are lost "My life changed a lot after this disease. I was the happiest, most joyful person, it affected my emotional part a lot" (Patient 11) "I was a very healthy person, very strong, I didn't feel anything. He worked night and day. And suddenly, I find myself in the state I'm in." (Patient 42)</p> <p>4. Insufficient, unsatisfactory or overwhelming health care network "But we are following it closely to see if it improves. Because one does the treatment, it seems that the same thing continues. And in the end it got worse and I had to do it all again" (Patient 20) "I do treatment for one thing harming another" (Patient 15)</p> <p>5. Fear "Danger, right, danger" (Patient 23)</p>

Demographic data and summary of diagnoses in medical records and charts as well individual classification into groups are available in Online Appendix 1.

Within the "gliding swan"—more resilient—group, themes commonly identified were (Table 1): understanding disease and its course; positive examples of how to navigate the physical and emotional resources to sustain their wellbeing;²² being in charge of one's own situation. They feel adapted to their conditions. Almost all the narratives included in this group had

quotes about a positive view on health care, either with hope, either with adaptation to measures, or with description of support by the health team, mainly doctors. As an illustration, we present some quotes and we discuss Case study number 1 (Box 1).

Taking into account the "stormy seas"—vulnerable—group, the thematic tree that opens up is broader (Table 1) and includes with equal frequency quotes about sources of information about the disease (medical staff, religious community and others) and understanding processes

Box 1. #1—GSC (Patient 35).

He divides his life into before and after dermatomyositis and he shows empowering since the first symptoms: “at 47 years old, there was a little pain in my knee. This little pain in my knee I found . . . ah . . . I haven’t been exercising for a while, it must be lack of exercise. The first thing I did was look for a gym, but instead of getting better, it got worse. It got worse and, since then, my knee, my waist have hurt, I started to lose my balance. And a lot of tingling in my hands. I started to worry, I said something was wrong. And I started looking for doctors. I went to the general practitioner, orthopedist, everything that is a doctor, except a healer. When I got here, I didn’t even walk anymore.” He describes a lot of confidence in the treatment and in the health team and a great capacity for adaptation and understanding of the disease: “I see the disease as a normal process in my life. I live with it, I adapt myself. Do I have to take medication? Good, I do. Even things I found a little difficult, like taking insulin, now are normal.” His narrative brings various aspects of his life, with criticism and realism about his life before his illness: “I recognize that I had a lot of energy. I worked 12 hours a day. I studied. It was good if I slept 4 or 5 hours. When I realized, my son was almost my size. I worked so much and used to do so many things, because sometimes things go and do not happen the way we want.” The social and family context is clearly displayed, as he talks about his wife, ex-wife and children: “One person helped me a lot in order to be here today, as well as I am now. It was my wife. She had a fundamental role in this whole process of recovering my health.” Financial difficulties were also mentioned, since the stop of formal work, the non-acceptance of social security benefits, until the beginning of carrying out voluntary work. The main characteristic identified in this narrative was the ability to adapt, which even before the onset of the disease was already exemplified: “in the company I worked for, over time, they implemented some qualification rules. And if one did not follow up, he would no longer serve. I, instead of leaving, decided to follow.” Adaptation to treatment has already been described above, but he brings elements of adaptation and reframing of his life after the disease. “At first I believed I was not sick. But, where did my strength go? Where did it end up? It couldn’t be. Then I recognized that there are times when we have to stop, breathe and throw the ball in another way, because it wasn’t working. So I did.”

related to their health, including the proposed therapeutic planning. Some of the participants talked about the impression of knowing that she/ he is doing his part. Adaptation to

multimorbidity is described, but it is sometimes costly, difficult and incomplete. Health care is ambiguously described, with patients with a positive and engaged view, considering it as support or foundation, sometimes laborious but positive, but it also appears as unsatisfactory and as an overload with which the person has to deal. The vulnerability is made explicit; the lack of definition of diagnosis and the need to undergo exams is described as paralyzing and both concern and hope or belief in overcoming appear. Health-related limitations are reported. As a sample of this group, case study number 2 was selected along with some quotes from participants (Box 2).

In the “stuck adrift”—disrupted—group the unanimous content is about limitations. These limitations are described as caused by both symptoms and treatment (Table 1). Regarding comprehension, the most common contents were of not understanding, perplexity and bewilderment. Difficulties and negative aspects are described in statements that provide little information about who that individual is: their aspirations and values unrelated to the disease are left behind. Health support is brought mainly in terms of being insufficient, unsatisfactory and also above what would be tolerable, that is, overwhelming. Fear and vulnerability also appear. Case study number 3 exemplifies this group (Box 3).

Beyond the burden of illness—symptoms and disability caused by illness—we must consider the burden of treatment,²³ mainly regarding that patients are from a tertiary health care service. Our patients brought in their narratives argumentation confluent to previously identified burden of treatment, such as²³:

(1) different burdens in the interaction of the health system:

They [doctors] have already told me that they do not operate it here. And you have to wait for the appeal by the Ministry of Health, I can’t either do it in my city (. . .) When the crisis hits, where shall I run to? Patient 17—Stormy Seas, vulnerability

(2) Medication burden:

I had the desire for a big tattoo, but because of the anticoagulant, I can’t. Patient 25—Stormy Seas, Vulnerability

They [the doctors] suspended the insulin. I think I was not able to see the right amount, they do not want it because I was having hypoglycemia. Patient 32—Stuck adrift, Disruption

It is medicine over medicine, there is no one who can stand it. When I finish the last pill, the first one wants to come back. My stomach has no more place. Patient 38—Stormy Seas, Vulnerability

(3) Lifestyle changes:

[One has] to make dietary restrictions, to take medications correctly, to have some limitations. But several times we don’t get it. I don’t think anyone can make it right all the time. Patient 18 Gliding swan, Resilience

Box 2.. # 2—AAL (Patient 14).

She was diagnosed with lupus 9 months before the interview. Fear and vulnerability are described in different ways and in different situations. The onset of the disease is described as quite frightening, both for having previously known two people who died of the disease and for the fact that its onset was very rapid. *“I’ve met two people who died of lupus, so it was very scary, because if that person died, of course it would happen to me too.”* Her perception of the onset of the disease is that it was abrupt and definitely a watershed towards the unknown. *“It is difficult because, at the age of 40, I did not take any medicine even for a headache, I’ve never had any health problems. Then I lay down well and woke up with an incurable disease in my body.”* This fear of the course of the disease gives rise to a religious belief in healing and throws her in an expectation that doctors will solve her problems, with powers that they may not have. *“I ask God, if it is something serious, that will affect other organs, for God to guide me to come to the doctor soon. (. . .) The hand of God and the doctors here have helped a lot. What I would like would be to see the doctors more often. But the doctors know what we do. If they see the exam and think that within 3 months I can keep it up, they know. I would come every month for myself. Because I do have that concern- Am I okay? Am I okay? (. . .) For me, the happiest day is the day to go to the doctor, because they will see my exams, and if there’s anything wrong, they will cut it already.”* There is another dimension of fear that is the feeling of taking risks or that something bad can happen at any time. *“I was afraid of everything, of eating, of having bacteria, because everything results in the disease. My house is always clean, but everything is scary . . . if I’m doing all the right things, the clothes, everything, I end up sanitizing it right, going to the right bathroom. Because you hear other people say that lupus is like that, but each organism in a different way. And then you hear a person say that they had to bathe with filtered water., it really isn’t mine. I was wondering, I’m not filtering my water, will it hurt me?”* In this sense, the medical team’s information is viewed with great confidence and with an important authority weight. *“The 19th of January, I was discharged. Then the doctors said that I was very well, that I would hardly be admitted again.”* The treatment and support of the health system has been important since the beginning of the disease and the trajectory along the different levels of health care is described. *“I found out fast, within 3 months of the disease in my body. Then they sent me here [the university hospital]. And here I think the treatment was, thanks to God, but it was fast. I’m fine but I’m getting used to it.”* How quickly the treatment was initiated is seen as positive. *“Even though I didn’t have a disease and I wasn’t used to go to the doctor, I decided to go. I had an insight. I saw that it wasn’t normal. Then I looked for a basic health unit, I was trying to take care of myself. And they were agile, although there is bureaucracy in health, within their limits, that I live in a small neighborhood, within their limits, they were quick. Then they rapidly indicated me for nephrology. And I had to pay because I couldn’t run to the public service, because otherwise I think that I would be waiting until today. That was when the nephrologist discovered that I had lupus. (. . .) Then, thank God, the first time I came, I already got an appointment and from there I would stay hospitalized.”* Another excerpt that demonstrates the great religiosity, as well as the trust in the health team is *“I believe that doctors are angels left by God. They study for it but their intelligence, everything, I believe it was God who gave it, and they are here to take care of us. I believe in them too. Under God, I believe in them [in doctors]. And I’m trying to live, it’s difficult. My hair is falling out. They say lupus can make it fall, but I’ve been for 9 months with lupus and it’s not all gone yet. The doctor says that I’m probably going to stay with a little bit of hair. Then there’s some hair growing, I’m getting hopeful. But everything is about adapting myself. I’d rather go bald and not feel pain. The important thing is that I am not in pain and thank God the pains I feel are weak, nothing about rolling around in bed. (. . .) God holds hands and we go, I take it. If it was our chance or the doctors’ chance to cure me, I believe I would do it, they would do it for me. But I don’t think it’s in their hands. What is in their hands they are doing. They are taking care of the medication, each one doing their part.”* Elements that bring the panorama of her life come as concerns: *“I was hospitalized for 3 months. Because the disease hit my kidney, then it gave me other things. It gave me other viruses in the blood, so I was hospitalized. I even spent the New Year hospitalized, all of which touches your emotional, because I have a son, husband, family.”* Other support networks in the illness process appear: *“I ended up meeting people who have lupus, I’ve met sisters in the church who have lived for 35 with lupus and today they don’t take any medicine.”*

(4) Financial burden

And it gets complicated. To come here now I need to spend a ticket. It is good that I am looking for my health, but it costs a little money. Money that I don’t have. Patient 26—Stuck adrift, Disruption

The medication restricts mobility. Sometimes I’m in my small business, sitting. And I sleep. And someone appears at the counter and keeps calling me. This has happened several

times, there is even my wife’s concern, when she leaves, to leave me there. Patient 37 Stormy Seas, Vulnerability

(5) Learning about condition and treatment or about transitioning in the healthcare system.

There are things that I can’t understand, no matter how much the doctors explain. Doctors explain, explain but I can’t understand what it really is. Patient 16 Stuck adrift, Disruption

Box 3. #3—CVS (Patient 11).

In this narrative, the participant makes it clear that the disease was a moment of rupture in her life. She speaks clearly about her desires and plans frustrated by the existence of the disease. She talks about “living” and not just “surviving.” *“My life changed a lot after this disease. I was the happiest, the happiest person. With it came . . . It affected my emotions a lot because I can’t do the things I did before. For example, I can’t take a long time in the park with my son, because I feel pain and I can’t do it. (. . .) [I am] Very restricted. I’m not that one anymore. One ends up losing heart. Sometimes people say ‘let’s go for a walk?’, Then I remember the pain. Ah . . . I will go and then it will hurt. Mentally, I’m already with, that . . . I end up . . . staying. So you end up, in a way, ceasing to live a little, living with pain.”*

It is precisely the exam I have here that was not done. And until today nobody told me why it wasn’t done and why I didn’t do anything else. Patient 36 Stormy Seas, Vulnerability

Together, our results suggest that the predominant view of the disease from the analyzed narratives is of fear, threat, feeling of vulnerability. The presence of pain and other somatic symptoms and limitations to daily life are remarkable and dominate the understanding of what it is like to live with these diseases. Treatment-related aspects also often carry a negative charge, configuring burden and overwhelming aspects related to both diseases and their treatments.

Discussion

Two antagonistic poles in the narratives, which help to characterize the different groups of patients’ life experience, were the ability to integrate or not health issues into everyday life through being able to personalize their problems mainly through understanding.¹⁶ The differences in comparison to Reeve’s results,¹⁶ mainly related to the themes and similarities within each main group, may be related to our scenario, specialized tertiary care, with multimorbidity and the presence of pain in all patients, in addition to likely educational and cultural differences. Applying the inclusion criteria of our study, none of the patients included in Reeve’s study would be included in ours, as only two patients from that sample had an Elixhauser index equal or bigger than 3 but none of them had pain. Ploeg et al.²⁴ qualitatively explored the experience of patients with multiple chronic diseases, caregivers, and healthcare providers, demonstrating that living with and managing multiple chronic conditions could be defined as “overwhelming, draining and frustrating.” Our results come in the same way and they show that most patients feel overwhelmed and

frustrated, with disease experiences described as difficult, lousy and harsh. Physical limitations have also been prominently named and the feeling of vulnerability, of being at the mercy of the course of disease, is also latent. Patient complexity is defined in addition to the state of multimorbidity and medications, and must assess socioeconomic, cultural, biological, genetic, environmental, and behavioral factors.^{24–26}

The care of a patient with multiple diseases is challenging for different reasons,^{18,27} such as conflicts in therapeutic decisions due to indications and contraindications to the same treatment in the same individual; and inconclusive evidence for the treatment and follow-up of those individuals.²⁸ People with multimorbidity who need care in a tertiary service have probably experienced treatment failures in primary care or have rare diseases or are people whose care requires more complex measures, sometimes with worse therapeutic results. Patients with multiple diagnoses may have a worse perception of the health care received²⁹ and poorer treatment adherence.²⁸ If pain is present, complexity intensifies,¹⁸ conceptualizing complexity as the gap between the person’s needs and the capacity of healthcare services to meet those needs.^{24,28,30,31} Physical limitations, loss of social interactions and psychological distress are related to the experience of pain in specific conditions¹⁹ as well as in our patients with multimorbidity and diverse pathologies.

Decreased quality of life, higher mortality rate and increased healthcare utilization and costs result from multimorbidity.^{30,31} It’s not clearly defined how people adapt to living with multimorbidity and associated limitations, but there’s an overall agreement that it reflects beliefs, attitudes and ideologies and that some features such as returning to usual performance despite the disease, increasing adaptability and adequate mental health are its results.³² Whether due to issues inherent to the clinical conditions presented and their treatments, issues of social and family support, culture or religion, non-adaptation and disruptive perception about health-related issues lead to disruption and disconnection of the subjective self from its own life history, remaining paralyzed in matters related to his illness.

The term “world” can be understood as the set of common, immediate and lived experiences and their interpretations.³³ This subjective world often contrasts with the objective world of science, guidelines and mass health policies. The body is a means of experience and a channel for understanding and manifesting both worlds. Therefore, to understand socially and culturally pain and chronic illness is to explore sensations and experiences, both cognitively and bodily.^{33,34} In the reports of patients in this study, corporeality appears very prominently, with a rich characterization of its symptoms, with the description of functional limitations. Such symptoms and limitations contaminate affective relationships, work relationships, desires and plans. Disability and loss of function due to chronic disease and its fluctuating symptoms and uncertain

outcomes lead to disruption in the biographical flow, resulting in behaviors and feelings that are changeable over time.³⁵

The great impact of pain and limitations to daily life has been previously described in multimorbid patients in whom the lived experience was linked to losses in physical, laboral and social spheres in comparison with the previous functioning.¹⁸ Perplexity by what happens with and the feeling that one's body has been divided relates with previous observations.^{18,24} In the same way, treatment burden and the negative impact of treatment have been a matter of discussion in multimorbidity.^{18,24}

When looking at the positive examples from the narratives, the way they face the potentially adverse situation of their health problems and overcome this sea of difficulties until sailing smoothly gives us the idea of a dynamic adaptation, which can be facilitated by the health care team, through information and good relationship, since this process relies on the interaction between internal and environmental aspects all through their lifecourses.²² Navigating through their psychological, social, cultural and physical resources, people can build different relationships to their illnesses, resulting in different experiences related to them.²²

If the health team does not pay attention to the particularities about how each individual adapts to their diseases, health needs, treatments and limitations, the care offered will always be disconnected from the patient's experience and will not be complete.^{24,26,36} Our study has limitations, as it was cross-sectional, but it is the first time, as far as we know, that this type of evaluation is done in a specialized outpatient clinic of high complexity. As we are inserted into a university service, this kind of discussion and observation to how people adapt to pain and multimorbidity can lead to better care structures. We do not believe that the fact that patients had different diagnoses has had an impact on the results, since the adaptive response is influenced by several factors other than the characteristics or severity of each disease itself,^{18,22} in addition to the presence of pain being the guiding thread present in all patients in this studied population.

Conclusion

Narratives were predominantly about the lacking personalized understanding of diseases, with great emotional repercussion described. The presence of many somatic symptoms, including pain, interferes with daily life. People who better float in the watercourse of chronic disease and pain highlighted their meaningful anchors, mainly involving doctors' support. Understanding the components of the life experience when chronic diseases and pain are present and potential ways in which people adapt to multimorbidity may provide a useful model for training professionals in how to better support people with multimorbidity. The present study reinforces that multimorbidity and pain

interact and the importance to be aware of the individual and contextual aspects that interfere on navigation in raging seas of long-term multimorbid conditions.


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Supplemental material

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