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Living with stable angina: patients' pathway and needs in angina

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Aims **There is evidence that stable angina patients may suffer from emotional disorders that further impair their quality of life. However, the emotional experience of living with stable angina from the patient's perspective still has to be explored. Thus, the main aim of this study was to explore patients' emotional experience of having stable angina and their reported needs during the pathway from the first symptoms, through the process of diagnosis, to management and related lifestyle changes.**

Methods **A survey was conducted in 75 chronic ischemic heart disease patients with angina (Brazil, China, Romania, Russia, and Turkey) using a 75-min, face-to-face in-depth interview.**

Results and Conclusion **Patients' responses highlighted the need to increase individuals' awareness on the first signs and symptoms of the disease. The survey also showed that chronic stable angina patients need constant emotional support to overcome stress, anxiety, and depression. Finally, this study suggests the need to offer greater space for dialogue with healthcare professionals to get more comprehensive and 'patient-friendly' information.**

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Introduction

Angina and ischemic heart disease (IHD) are the leading causes for death and disability in both sexes.[1] The most frequent, and often the first, manifestation of IHD is chronic stable angina.[2] Angina because of IHD affects approximately 112 million people in the world.[3,4] Notably, up to 30% of IHD patients with stable angina continue experiencing symptoms despite treatment.[5]

Of note, recurrence of angina, impaired exercise capacity, and quality of life (QoL) remain an issue even after optimal revascularization. There is evidence that between 20 and 40% of relapses occur after revascularization and lead to higher healthcare costs.[6,7]

Persistent angina symptoms are associated with chronic anxiety, depression, impaired physical functioning, and poor QoL, all leading to a striking increase of indirect costs.[8,9] There is evidence that impaired QoL in angina patients is associated with worse prognosis.[10,11]

However, little is known about patients' subjective needs and emotional experiences during the clinical course of the disease.

Taking into account these issues, a survey study was administered to explore the patients' reported experience of living with stable angina.

First, the patient's pathway (from physical and psychological points of view) from initial symptoms through diagnosis to management and related lifestyle changes was explored.

Second, the study aimed to collect patients' reported information about their relationship with the healthcare professionals (HCPs) involved in management, key milestones, and day-to-day challenges.

Third, the survey aimed to explore patients' awareness on their disease, the process of seeking help, the degree of satisfaction with the information sources and possible gaps in the communication process.

Methods

A sample of 75 patients were enrolled from Brazil, China, Romania, Russia, and Turkey according to the following inclusion criteria: both sexes; 50% of sample to be aged 65 years or less; being managed by a HCP for their angina; both private and public settings; any educational levels; being not affiliated to a pharma company.

A 75-min, face-to-face in-depth interview was carried out between April and May 2018. Interviews were conducted by a research partnership company and their local partners in the relevant countries: Brazil (Exafield), China (Plamed), Russia (O+K Research), Turkey (Eksen), Romania (SODA).

nterviews were conducted and audio recorded in the local language and analyzed in English by native speakers.

The interviews were carried in an anonymous way.

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Table 1 Demographic and clinical characteristics of participants $n = 75$

Sex	38 females/37 males
Age	Total = 60.3 years old 59.6 Brazil 62.7 China 62.3 Romania 65.9 Russia 51.2 Turkey
Disease duration	$n = 19$ less than 1 year $n = 22$ between 1 and 5 years $n = 34$ with more than 5 years
Data on patient history and co-morbidities[a]	$n = 42$ MI $n = 11$ patients 1 month-post PCI $n = 13$ post-PCI symptomatic $n = 33$ diabetes $n = 17$ LVD or HF

HF, heart failure; LVD, left-ventricular dysfunction; MI, myocardial infarction; PCI, percutaneous coronary intervention. [a] Patients could belong to more than one group.

Interviews consisted of the following sections: introduction and overall journey with stable angina; personal information (e.g. age, marital status, etc.); detailed patient journey; prediagnosis; first time encountering the symptoms; behavior when symptoms occurred; type of medical professional contacted for the first time; triggers to look for medical help; emotions during the period; diagnosis-time of establishing; specialist, healthcare institution, type of tests, and emotions at knowing the diagnosis; information and advice from the healthcare professionals on the disease; lifestyle; treatment initiation, treatment changes and compliance; percutaneous coronary intervention (PCI); symptoms, consultation frequency, treatment after the PCI; sources of information.

Before the interviews, patients had to fill-in a 30 min preinterview task-based diary translated into their local language. The Research Partnership‘s local fieldwork partners were responsible for translating the answers into English.

This study follows the methodology of the survey, and is therefore descriptive. Data are expressed as frequencies and percentages.

Compliance with ethics guidelines

The interviews were conducted according to the ethical standards of BHBIA and EphMRA.

Results

Demographic and baseline characteristics

All patients enrolled ($n = 75$) completed the survey. Demographic and clinical characteristics are shown in Table 1.

Patients were also stratified according to duration of stable angina since diagnosis (Table 2). Descriptive data on patients' disease history and comorbidities are available upon request.

Awareness of symptoms

Whenever initial symptoms occurred, 19 of the 75 patients reported to have been scared as they did not understand what was happening; many patients also felt frustrated about the impact on their lives.

The most frequently reported symptoms were: chest pain, shortness of breath, sweating, tiredness. About 56 patients (75%) reported having experienced typical chest pain-angina, and respectively 19 patients (25%) reported atypical symptoms. Twenty-six (47%) of the typical angina patients and 12 (63%) of the patients with atypical symptoms ignored the symptoms initially, some of them for months, and were unaware of angina manifestations before they received the diagnosis, or had limited knowledge about it (SDC Figs. 2-10, http://links.lww.com/JCM/A241).

If symptoms were more discreet and indistinct, often patients did not consider them as serious enough to need medical attention immediately.

For those who did not seek immediate help, it took between 1 month and years after initial symptoms before the patients asked for medical help.

Before seeking medical help, the interviewed patients (who provided an answer) reported having used the following coping strategies: self-medication (e.g. pain killers/sedatives) (15 patients); stopping activities/deep-breathing and waiting for symptoms to pass (18 patients); avoiding stressful situations/getting upset (3 patients).

The degree of awareness increased if patients had a family member who was engaged with them.

Initial symptoms started most commonly after an emotional stress (e.g. argument with family member, stuck in traffic, etc.) or during physical exercise.

Forty-three patients (57%) were diagnosed at the emergency room/hospital and 32 (43%) at the outpatient setting with the general practitioner playing an important role in half of the cases.

The diagnosis was perceived by patients as a time of worry, especially because of its long-term impact, and patients reported the need to be reassured.

Table 2 Patients' stratification according to duration of stable angina

Sample	Brazil	China	Romania	Russia	Turkey	Total
Patients diagnosed less than 1 year ago	5	4	1	2	7	19
Patients who first suffered symptoms between 1 and 5 years ago but who were not diagnosed in the last year	5	5	5	5	2	22
Patients who first suffered symptoms over 5 years ago but who were not diagnosed in the last year	5	6	9	8	6	34
Final sample	15	15	15	15	15	75

Among the interviewed patients who gave an answer, 18 reported having had anxiety, 15 having felt scared and helpless, 12 having been fearful about the future, whereas only 6 reported avoidance, and only 4 having felt relief at the moment of diagnosis.

At diagnosis, patients were overall satisfied [$n = 37$ (86%) out of the 43 patients who provided an answer] with information provided by the HCPs. The main advice they got related to lifestyle, diet, treatment but some wished they had more time to discuss their condition more deeply especially regarding how to apply these lifestyle changes.

Consultations with cardiologists occur every 3–6 months, with an average length of 30 min. Although the majority of patients reported satisfaction with the relationship with their physicians, 44% expressed the need for longer discussions with them.

As for unmet needs related to the consultations, four patients reported the need for more regular appointments (mainly in Brazil) and the difficulty in scheduling appointments. Second,10 patients reported the need to get more time with physicians/more constructive conversations – to discuss conditions more and in greater detail, including the impact on their lives. Third, four patients reported the need for physicians to consider more often their emotions (BR, TK min) and spent more time to listening. Fourth, three patients reported the need for HCPs to provide more explanations on stable angina (min esp. CN) – what caused it, how to manage it. Finally, two patients reported needing multiple sources of information, for example, leaflets provided by HCPs.

The most common reported sources of information were: family and friends (38 patients); Internet (31 patients); TV (24 patients); social media (14 patients).

Treatment

Twenty patients (27%) were taking statins, 50 (67%) had antiplatelet therapy and only 42 (56%) were taking antianginal drugs at the time of the interview. Of the 61 patients who provided an answer, 45 declared being highly engaged with their treatments and to believe they would be helpful in improving their conditions. However, 16 patients reported no engagement with their treatments.

Patients reported that information on treatments mainly came from physicians. Although the majority of patients seemed to be content, some wished they had been provided with more information. For example, 33 (44%) patients pointed out that they needed longer discussions with the HCPs on the general management.

In general, reported patient knowledge of treatments is minimal. Very few patients recall being told about the mode of action or efficacy of their treatments. A minority would have liked more information on medications, for example, on how they work, different options, side effects (CN, TK) and/or felt they did not get the opportunity to discuss treatment with physician/get replies to their questions.

Regarding interventional procedures as a treatment approach, patients who underwent a planned PCI ($n = 25$) usually had it within 2 weeks after diagnosis except for patients in Romania, where it took between 4 and 8 months.

Patients reported having little input in taking the decision, but because of the explanations received from the HCP, they are usually optimistic about the impact of the procedure on their condition.

Among the 11 patients who had undergone PCI less than 1 mol/l before the interview, 6 reported encountering symptoms after the procedure. The same patients did not seem to be bothered and did not appear, therefore, to be aware that it might be a problem.

In general, out of the 75 patients, 70 did not monitor angina symptoms on a regular basis.

Lifestyle changes

Patients' answers indicate that lifestyle adjustments had the following meanings/implications: not being able to live their lives fully; restricting themselves to less strenuous physical activity; avoiding strong efforts and stressful situations; reducing/stopping smoking (felt to be most difficult change: 45% of the patients pointed to finding it difficult to stop smoking and, for those who stopped, the main driver was fear of the consequences on their health condition); less socializing/going out; giving-up/reducing work; struggling to stick to dietary changes; feeling it to be a challenge in social situations; other family not accepting dietary changes.

The majority of patients reported following HCPs' advice; however, many stated that they struggled with lifestyle changes. Overall, lifestyle changes were pointed out to have brought a negative emotional impact in their life by the majority of patients.

Living with stable angina

Patients' reported main challenges are 'disease emotional impact' and 'dealing with a restricted lifestyle'.

As for emotional impact, only seven patients claimed to be content with their lives/not frustrated with the disease. Thirty-seven patients reported anxiety and fear; uncertainty (i.e. never knowing when an attack may happen); living in fear; worried about dying [more than myocardial infarction (MI)]. Of note, anxiety is not only related to the moments of occurrence of symptoms (only 16 patients pointed out being worried only when symptoms occur) but it is constant within the course of the disease. The severity of symptoms appears to have a larger influence on the disease perception rather than its duration.

The majority of the patients reported trying to stick to their 'previous'/'normal' lifestyle and to limit the impact of the condition.

Yet although patients try to live an 'unrestricted'/'normal' life, they report frustration; increased boredom and loneliness; reduced activity/restricted lifestyle; they are unable to go out and socialize as much as would like to; unable to exercise regularly or strenuously; unable to work. These implications get more tangible with time, being more prevalent in older patients with a longer time since diagnosis.

Financial problems are reported by the majority of the participants. Cost of treatment is reported as a problem and is exacerbated by the inability to work. Some patients stated that social services provide little support.

Also, the overall emotional burden of the disease does not seem to alleviate over time.

Family and friends are reported as the main source of support for the majority of patients. A minority of patients stated they use sources of information other than their HCPs.

Discussion

The main result of the survey indicates the need to increase patients' awareness of the signs and symptoms of stable angina. The need to increase the common awareness about the disease and first symptoms is suggested by the high percentage (more than half) of patients stating they were completely unaware of what stable angina was before diagnosis, and this might have delayed a timely diagnosis and earlier beginning of treatment. This result is in line with existing data demonstrating that low disease awareness is associated with higher rates of undiagnosed angina.[12,13]

A better awareness of the triggers for angina (behavioral factors, stressors, etc.) may be, therefore, helpful. Common misconceptions may cause patients to avoid these triggers, which could lead to de-conditioning, worsening angina and low mood.[14] HCPs should be more aware of the factors that could hinder or stimulate healthy lifestyle changes as well.

Patients reported that barriers of healthy behaviors include lack of time (because of family, household and occupational responsibilities), access issues (to transport, facilities and resources), financial costs, entrenched attitudes and behaviors, restrictions in the physical environment.

Reported facilitators include a focus on enjoyment, health benefits including healthy aging, social support, clear messages, and integration of behaviors into lifestyle. These data are consistent with existing literature.[15]

The recognition of these barriers can help HCPs to tailor intervention and treatment around each individual patient. This is an issue related to the type and organization of healthcare services provided around different healthcare systems. In spite of the differences, there is one common pattern: patients get more information from family, friends, social networks and mass-media, rather than from their treating doctor or another HCP. They seem not to be aware of the mode of action and potential side effects of the treatment they get. Among those who underwent an interventional procedure, very few patients mentioned being informed about potential implications of the procedure before or after.

Another main result of the survey is that out of the 75 patients, 70 did not monitor angina symptoms on a regular basis. The need for constant monitoring of the symptoms may be life-saving and is strongly related to the patient's disease awareness.[16] Patients' answers suggest that HCPs should offer greater dialogue, providing more comprehensive and 'patient-friendly' information. This may allow patients to better understand their condition both from physical and emotional points of view and to follow symptoms over time.

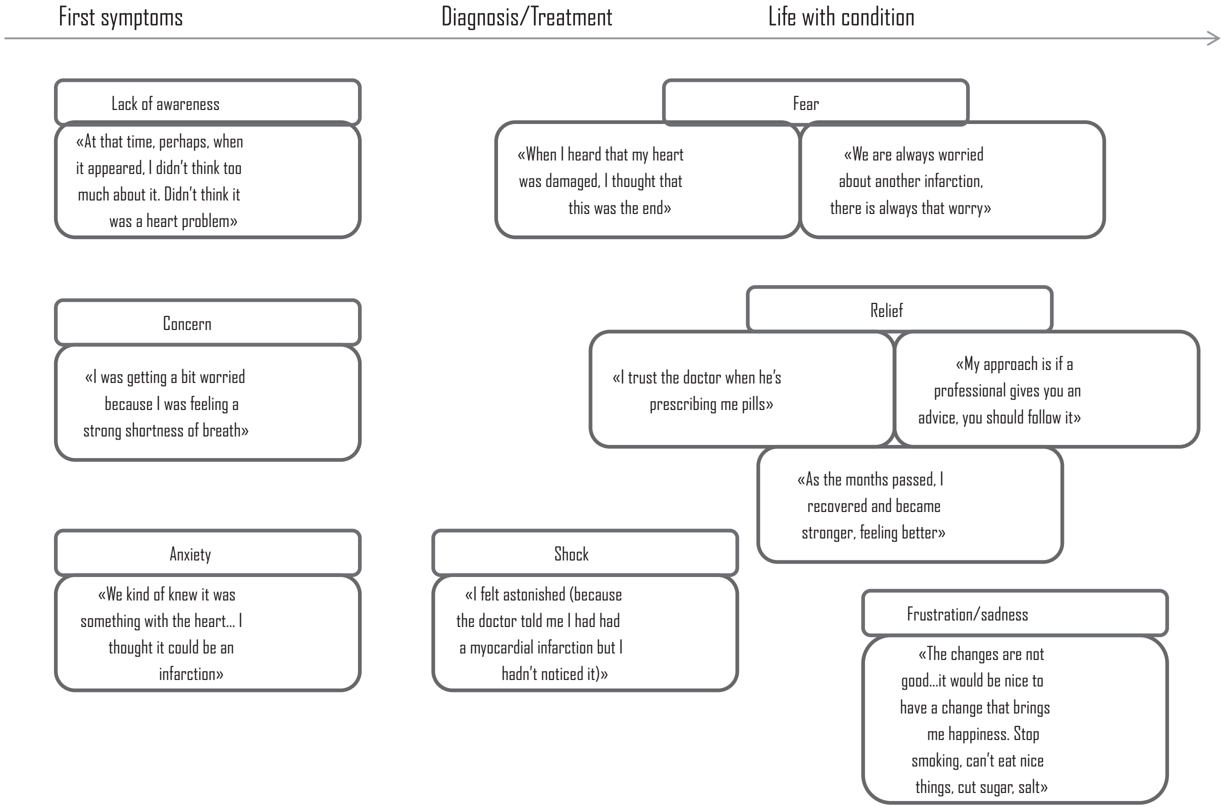
In particular, the results show that stable angina patients in our sample need more psychological support to overcome stress, anxiety, and depression. Such emotional support may help patients to change lifestyles, monitor conditions, and to be compliant with treatments and check-ups over time. These results are in line with studies in patients with IHD, showing that depressive symptoms are strongly associated with poor patient-reported health status, including symptom burden, physical limitation, poor QoL and worse prognosis.[17,18] Depression is related to behavioral risk factors, such as poor adherence to medication, diet, exercise and smoking cessation.[19] Similarly, anxiety is a risk factor for worse prognosis, MI or death among patients with IHD.[20]

Management of psychosocial risk factors and implementation of educational interventions are therefore pivotal in angina patients, as recommended by current guidelines.[21] Consistently, cognitive behavioral programs and dedicated angina plan management programs have been shown to improve patients' awareness, motivation, adherence to lifestyle changes and treatment and to improve patients' satisfaction and quality of life.[22–24] Of note, these programs should contain psychotherapy, as it has demonstrated short-term and long-term benefits in improving symptoms, QoL and well being, and is related to better outcomes.[25–27]

Along with lifestyle changes, patients' involvement in the disease management and follow-up is an important part of the treatment in order to motivate them to be more adherent to the treatment.

Our survey suggests very low engagement of patients regarding the monitoring of their angina symptoms. This might be associated with low adherence to therapy along with inadequate evaluation of the current state of the

Fig. 1



«At that time, perhaps, when it appeared, I didn't think too much about it. Didn't think it was a heart problem»

«I was getting a bit worried because I was feeling a strong shortness of breath»

«We kind of knew it was something with the heart… I thought it could be an infarction»

«I felt astonished (because the doctor told me I had had a myocardial infarction but I hadn't noticed it)»

«When I heard that my heart was damaged, I thought that this was the end»

«We are always worried about another infarction, there is always that worry»

«I trust the doctor when he's prescribing me pills»

«My approach is if a professional gives you an advice, you should follow it»

«As the months passed, I recovered and became stronger, feeling better»

«The changes are not good…it would be nice to have a change that brings me happiness. Stop smoking, can't eat nice things, cut sugar, salt»

Emotional states and needs during patient's pathway.

patients during the routine check-up visits, and respectively, not adequate treatment and symptom control.

Of note, half of the patients who had undergone PCI but encountered symptoms did not report being worried, and neither had they shared with their treating doctor. Current data demonstrate that adherence to treatment in IHD is poor (about 40–75%) and is related to worse prognosis.[28–30] Also, low recognition of symptoms by physicians is related to less aggressive treatment escalation and consequent poorer angina control.[31–33]

Our survey suggests that the most suitable and crucial time for treatment adjustment is the period immediately after the diagnosis, when the patient feels more vulnerable and trusts the physician the most. Emotional states and needs during a patient's pathway are shown in Fig. 1.

Monitoring tools like diaries or electronic applications/programs might help patients to follow the symptoms and proactively contact physicians in order to request timely treatment adjustment.[34,35]

In conclusion, this survey highlights the need to educate patients to recognize and understand their disease in order to be involved in the management and collaborate with the HCPs, who – in turn – are asked to provide listening, in-depth information and emotional support. As aforementioned, increasing awareness may be beneficial in terms of seeking help sooner, and therefore to get an early diagnosis.

Study limitations must be taken into account.

First, sample size is small and cannot be representative of the population. As such, results cannot be generalized. Second, because of the methodology of the survey, confounding factors and interview related-biases may lead to overestimating or underestimating the results.

Third, different healthcare systems and cultures because of territorial differences and cultural backgrounds may further confound the results.

Finally, not all patients were asked all the questions of the survey, which additionally makes drawing quantitative conclusions difficult.

Thus, our findings should be considered as purely descriptive and preliminary.

However, these results may be suggestive of relevant management implications regarding angina patients' needs before and after the diagnosis, highlighting the importance of performing further studies on this topic.

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Conflicts of interest

There are no conflicts of interest.

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