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Patient experience and expectations with collaborative management between pharmacies and primary care: a qualitative study of a trial (USFarmácia) exit focus group

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Abstract

Background We aimed to explore patient concerns and behaviors about their health condition, experience with current care, and expectations with the new collaborative care model, and elicit concepts of interest to inform a patient preference study.

Methods We conducted a qualitative study using a trial exit face-to-face patient focus group underpinned by thematic analysis using both selective and open coding. Pre-identified codes were used for the concepts identified through preliminary literature review. The sections of text containing these concepts were grouped into pre-defined themes. Sub-themes later emerged from the focus group discussion. The focus group was conducted in Portugal (Figueira da Foz). Patients were recruited from a sample of trial intervention patients who experienced collaborative features. The focus group discussion was audio-recorded, de-identified, transcribed, and thematically analyzed. For this study, we partnered with representatives of a coalition of patient advocacy groups who provided interview guide review, input for the discussion of findings, critical review of the manuscript and publication plans.

Results Eight patients participated in the focus group. Various concepts under the pre-identified themes emerged: awareness prompted by symptoms or medical appointment, level of concern according to health condition; positive experience with pharmacy and some issues in experience with primary care; overall benefits and innovative features most meaningful to patients perceived with the new collaborative care model; and other therapy areas and wider advertising as future improvements.

Conclusions The key concepts that emerged from the trial exit focus group were useful in understanding patients' concerns, behaviors, and attitudes related to their condition, experience with current care, and expectations with the new collaborative care model. The findings also informed the attributes and levels for a patient preference study. The provisions in the legislation for contractual arrangements with Portuguese pharmacies represent an opportunity

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to use the insights from the patient's voice captured in this study to further advance collaborative practice between pharmacies and primary care.

Trial registration Current Controlled Trials (ISRCTN): ISRCTN13410498, retrospectively registered on 12 December 2018: <https://www.isrctn.com/ISRCTN13410498>.

Keywords Pharmacy services, Primary care, Integrated collaborative care, Chronic disease management, Qualitative research, Focus group, Patient experience data

Background

Current evidence supports the use of integrated or collaborative care between community pharmacies and primary care, namely in chronic disease management [1–12]. There is evidence of improvements in health outcomes associated with certain public health services provided by pharmacists within an appropriate collaborative environment with physicians [1–3], including in reducing cardiovascular risk, hypertension, and hyperlipidemia [1, 4–12].

Whilst quantitative data are useful for exploring the effectiveness and cost-effectiveness of collaborative care interventions, qualitative data about patient experience data (PED) may provide insights into subjective preferences regarding such care interventions. PED are data collected through patient engagement in different activities on patients' experience of their health status, symptoms, disease course, preferences, quality of life, and impact of healthcare. PED involves quantitative sources of evidence, such as patient-reported outcome measures (PROMs) or patient-reported experience measures (PREMs), but also qualitative sources (e.g., patient interviews or focus groups) [13]. PROMs and PREMs are standardized, validated questionnaires that are completed by patients and may or may not be scored.

Within Europe, focus groups conducted in eight countries with 58 patients with multimorbidity revealed that patients valued a holistic approach, continuity of care by healthcare providers, and trust as vital to a good care process [14]. Another qualitative study using 233 face-to-face interviews with stakeholders of 17 European integrated care programs for persons with complex needs also highlighted the following crucial elements: mental health and social condition in addition to physical health; continuity of care; relationships between professionals facilitated by continuous communication; and patient involvement in goal setting and decision-making [15]. The Association of Cardiovascular Nursing and Allied Professions of the European Society of Cardiology published a statement which outlines the evidence for integrated cardiovascular care, identifies challenges, and offers advice for practice, education, and research, acknowledging the relevance of strong leadership skills across the care workforce, new technologies, transdisciplinary approaches, and starting

patient narratives with families and clinicians with shared decision-making [16].

More generally, little is known about patient experience and expectations of collaborative care between pharmacies and primary care. Most qualitative research studies seem to explore pharmacists', physicians', and other stakeholders' experiences and expectations of collaborative care between pharmacists and physicians [17, 18]. Very few studies address patients' perspectives.

A search performed in Medline/PubMed on 30 June 2024 found eight research studies published between 2011 and November 2023 focusing on or including patient focus groups or interviews with patients enrolled in collaborative care between community pharmacists and physicians (search terms included: patient, focus group, interviews, qualitative, mixed methods, collaborative care, integrated care, collaborative practice, community pharmacy, primary care, general practice, physician, and alike). These studies were conducted in the UK (3), Australia (3), Switzerland (1), and Canada (1) and addressed the following disease areas: dyslipidemia management [19], medication-assisted treatment for opioid dependence [20], diabetes prevention [21], urinary tract infection management [22], opioid tapering for patients with chronic pain [23], patients with multiple long-term conditions [24], patients with subthreshold depression [25], and oral health services [26].

The study in Canada compared the efficacy of a physician-pharmacist collaborative primary care (PPCC) intervention in dyslipidemia management, where pharmacists requested laboratory tests and adjusted medication dosage, to the usual care (UC) for patients under treatment with lipid-lowering medication [19]. One study in Australia aimed to better understand enablers and barriers to a collaborative model for medication-assisted treatment for opioid dependence [20]. One study in the UK looked at prioritizing factors that could influence delivery of, and people-participation in, community pharmacy-based diabetes prevention services, and identifying strategies to facilitate successful implementation [21]. Another study, also in the UK, aimed to identify opportunities to enhance the role of community pharmacists in the management of service users with suspected or confirmed urinary tract infection [22]. A second study in Australia described the development, implementation,

and acceptability of a primary healthcare opioid tapering intervention involving GP advice; nurse monitoring, and potential engagement with the community pharmacist [23]. The study conducted in Switzerland aimed to characterize conflicting medication information perceived by patients with long-term conditions, understand the related impact on patients' medication self-management and healthcare system navigation, and explore ways in which such events could be prevented [24]. The third study in the UK examined adults with subthreshold depression and a minimum of one long-term health condition recruited from community pharmacies/local general practices and offered a brief psychological support intervention [25]. Finally, the last study conducted in Australia described consumer experiences within primary oral healthcare and views about pharmacy staff roles and boundaries in providing oral health services [26]. In general, patients expressed positive experiences and expectations of collaborative care between pharmacists and other healthcare providers. Only one study addressed dyslipidemia management [19]. However, none reported clinical decision algorithms for pharmacists pre-agreed with general practitioners (GPs) and embedded in the pharmacy software with data exchange between the pharmacy and primary care systems.

We found no such study conducted in Portugal either. However, a cross-sectional survey was performed on a representative sample of the Portuguese population in 2015. Respondents identified collaborative pharmacy services with primary care, such as the support in maintaining chronic disease under control and automatic renewal of prescriptions for chronic disease patients, as very important (92%) or important (89%) pharmacy services, respectively [27].

Collaborative care between pharmacies and primary care is foreseen in Portuguese legislation. The Decree-Law no. 62/2016, enacted in 2016, contains the first reference to the possibility of contractual arrangements with Portuguese pharmacies for collaborative services with primary care and remuneration if effective and cost-effective [28].

In addition to PED, patient engagement in the actual planning, conduct, and dissemination of research, as research partners, offers an opportunity to co-create evidence that is more relevant to patients' needs. In 2018, the European Patients' Academy on Therapeutic Innovation (EUPATI) developed guidance supporting patient engagement. A systematic review covering the period 2011–2021 identified 316 studies reporting patient engagement in research. Of these, only 49% included patient experts as co-authors. The top three stages of research with patient engagement were study design (79%), dissemination of results (50%), and data analysis (43%) [29]. A survey study conducted in Portugal

involved 27 representatives of cancer-related patient organizations and revealed that 26% had participated in clinical trials. Patient engagement involved primarily two stages of research: patient recruitment and informed consent review [30].

While patient engagement in clinical drug trial research is important to define clinical outcome assessment, particularly patient-reported outcomes, it is also relevant to engage patients in real-world evidence (RWE) studies to improve efficiency and outcomes that matter most to patients and advance value-based healthcare.

This work was part of a wider research project on the economic evaluation of a pharmacy-based collaborative public health intervention with primary care [31–35]. We first conducted a pragmatic controlled trial to assess the effectiveness of a collaborative care intervention between pharmacies and a primary care unit in hypertension and hyperlipidemia management in Portugal (USFarmácia) [33]. Next, we used the main trial findings to experiment with a proof-of-concept cost-effectiveness and cost-utility study [34]. Third, we conducted a qualitative study in a sample of trial intervention patients, as presented in this paper. Finally, we conducted a patient preference study using a discrete choice experiment and further incorporated willingness-to-pay into a cost-benefit study [35].

This Patient-Centered qualitative research is the third part of this wider mixed-method research project which used a trial exit focus group with the following aims: (1) to understand patients' concerns, behaviors, and attitudes related to high blood pressure and/or high blood cholesterol; (2) to perceive patient lived experience in pharmacy and primary care; (3) to understand patient expectations with the new collaborative care model; (4) to inform the attributes and levels for the patient preference study.

Methods

Brief description of the trial

A pragmatic controlled trial between pharmacies and primary care took place between 2016 and 2019 in Portugal. The intervention arm involved seven pharmacies and one National Health Service (NHS) primary care unit (PCU) that sought to work as an integrated patient unit by following integrated care pathways (ICPs) using clinical decision algorithms for pharmacists pre-agreed with GPs. These algorithms were embedded in the pharmacy software, and data were exchanged between the pharmacy and primary care systems. A bundled payment to intervention pharmacies was tested for the first time.

We developed ICPs and negotiated them with primary care providers before the trial. The technology team further embedded ICPs in the pharmacy software, assisted by researchers. Intervention pharmacists followed the decision algorithms based on each patient's situation at

each visit. Referral criteria for primary care and timing of referral were explicitly defined in those ICPs. Partial delegation of tasks from primary care GPs to pharmacies was expected in the collaborative model. Since data exchange between settings was planned by design, feedback from GPs to the pharmacist would also feed the ICP to determine further actions at the pharmacy or direct requests sent to the GP for a non-scheduled medical appointment.

The designed collaborative complex and multifaceted health intervention package included 10 components, some of them implemented for the first time in Portugal: (1) point-of-care measurements at the pharmacy/PCU and data exchange; (2) cardiovascular risk assessment at the pharmacy/PCU and data exchange; (3) medication management at the pharmacy/PCU and data exchange; (4) request for a repeat prescription to the PCU; (5) lifestyle counseling; (6) referral and direct request/scheduling for a medical appointment; (7) feedback from the PCU and follow-up at the pharmacy; (8) refill text reminders from the pharmacy to patient's smartphone; (9) regular interprofessional meetings between pharmacists, GPs and nurses (Quality Circles); (10) reporting a potential adverse drug event.

Details of the effectiveness trial are reported elsewhere [33].

Study design

This qualitative research used a trial exit focus group to address the study objectives, as processes and interactions within focus groups facilitate exploring people's insights and can enhance the depth and breadth of the information obtained. This was underpinned by thematic analysis.

The focus group methodology was chosen to overcome the limitation of patient interviews, where participants may feel constrained in discussions on a one-on-one basis, as this involves patients reporting experience with current care in their pharmacy and primary care, and expectations with the new collaborative care model. The group discussion in a friendly environment is useful for exploring people's opinions, experiences, and expectations.

We followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist in the reporting of this qualitative research study [36] (Additional File 1) and the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) checklist for reporting patient and public involvement in research (Additional File 2).

Patient and public involvement

Patient and public involvement in this study used two complementary approaches. We elicited concepts of interest from trial patients through the focus group.

In addition, we partnered with Plataforma Saúde em Diálogo, a leading national coalition of 69 patient and consumer organizations, EUPATI Portugal, and three chronic disease patient associations: Liga Portuguesa Contra as Doenças Reumáticas [Portuguese League Against Rheumatic Diseases], RESPIRA [Portuguese Association of People with Chronic Obstructive Pulmonary Disease and other Chronic Respiratory Diseases], and Associação Portuguesa de Hipercolesterolemia Familiar FH Portugal [Portuguese Association for Family Hypercholesterolemia]. Patient representatives of these patient advocacy groups (EFM, IMG, JV) were engaged in the focus group interview guide review and refinement, discussion of findings, critical review of the manuscript, and publication plans.

Participant selection

We elicited expressions of interest from trial patients to participate in the focus group.

A purposive quota sampling technique using maximum variation sampling was used to recruit participants for the focus group to obtain diverse perspectives and experiences. We recruited a sample from trial intervention adult patients on medication for hypertension and/or hyperlipidemia who had experienced some of the components of the collaborative care model. Trial patients signed an informed consent form at the onset of the trial that included permissions for telephone interviews at baseline and successive follow-up time points.

We purposively randomly sampled a list of 40 patients (matching the 10 most representative patient profiles (gender, age group, education, employment status, medication for hypertension and/or hyperlipidemia) who had participated in the baseline and 6-month trial telephone interviews to obtain diverse perspectives and experiences.

Detailed patients' demographics, economic, and clinical profiles, and inclusion criteria are reported in the effectiveness trial study [33].

Patients were sequentially approached by a researcher following the 6-month telephone interview and were invited to participate in the focus group, according to an invitation script explaining the objectives, process, date, and time. We aimed at obtaining 10 to 12 patients. Twenty-two patients were approached. Twelve patients refused to participate, and two did not answer our calls. When a patient refused to participate, the researcher would contact the next patient with a similar profile in the original random sequence pool of 40 patients. Eleven patients agreed to participate. Text reminders were sent and phone calls made prior to the date of the focus group to minimize dropouts. Despite our efforts, three dropped out at the last minute (two patients reported illness, and one could not participate due to unforeseen

circumstances). The final sample size comprised eight patients.

Patients were offered a Pharmacy Customer Loyalty Program Saúda® gift voucher of 10 EUR for their time at the end of the focus group discussion, which they could redeem at their preferred pharmacy.

Setting

The face-to-face focus group was conducted in Figueira da Foz (trial intervention arm site), Portugal, on 28 May 2019 and moderated by one senior female market researcher (MG) with a psychology background, experienced in conducting patient interviews and focus groups; assisted by a junior pharmacist researcher who acted as an observer (MR). The focus group was semi-structured around a script (interview guide) and audio recorded. No one else was present besides the patients and researchers. Patients had no relationship with and knew no personal characteristics about the moderator.

Interview guide

One senior pharmacist researcher (SC) conducted a review of a variety of documents: (1) USFarmácia Collaborative Care Trial Project Description, Patient Leaflets, and Informed Consent; (2) Project Primary Outcomes

(effectiveness, process, economic, quality, and preference outcomes); (3) International Consortium for Health Outcomes Measurement (ICHOM) Hypertension Data Collection Reference Guide [37]; (4) Spanish Hypertension Quality of Life Questionnaire MINICHAL® [38]; (5) Definitions of Collaborative Practice [39, 40]; (6) Results from a population-based survey on a new pharmacy model in Portugal [27]. This review was used to generate a preliminary conceptual framework summarizing the key themes relevant to collaborative care between pharmacies and primary care in hypertension and hyperlipidemia. This informed the design of a draft interview guide (SC) to be used for the focus group.

This draft was further developed by the senior market researcher (MG) and then fine-tuned by pharmacist researchers (SC, MR, SR) for clinical relevance. Patient experts (EFM, IMG, JV) reviewed the focus-group interview guide to assess content validity and adjust to lay language.

The final interview guide comprised a series of open-ended questions addressing the objectives and prompts to help generate discussion by exploring aspects around three key themes (Table 1).

Participants were asked specifically about their thoughts on the key differentiating features of the collaborative care model: 1) point-of-care measurements at the pharmacy/PCU and data exchange; (2) cardiovascular risk assessment at the pharmacy/PCU and data exchange; (3) medication management at the pharmacy/PCU and data exchange; (4) request for a repeat prescription to the PCU; (5) lifestyle counseling; (6) referral and direct request/scheduling for a medical appointment; (7) feedback from the PCU and follow-up at the pharmacy; and (8) refill text reminders from the pharmacy to the patient's smartphone.

The final version of the interview guide in Portuguese is available (Additional File 3).

Data collection

On the day of the face-to-face focus group and before commencing, the moderator (MG) introduced herself and the junior pharmacist researcher, recalled the scope, objectives, process, anonymity, confidentiality, and expected benefits to patients, and reconfirmed the requested consent that included permission to use audio recording.

Field notes were taken by one researcher (MR) during the focus group. All questions in the interview guide were first explored in spontaneous mode and probed in a second round. The focus group continued until saturation of themes was reached, for approximately 2 ½ hours. We included a coffee set in the room, allowing participants to get up from time to time and grab a cup of coffee and a snack to keep people engaged. The moderator ensured

Table 1 Key themes and questions in the interview discussion guide

1. Patient concerns, behaviors, and attitudes related to high blood pressure and hyperlipidemia
• Signs or symptoms that led to the diagnosis, and immediate reactions after the diagnosis.
• Level of importance perceived/patient involvement in high blood pressure and hyperlipidemia.
• The extent to which this is a condition that affects their daily life.
Reasons.
• Main concerns/fears. Reasons.
• What do they do to control/manage their condition.
• The extent to which they feel they have support regarding their condition. Reasons.
• The types of support they still feel are lacking. Reasons.
2. Patient experience with pharmacy and primary care
• Level of impact and interest.
• Main likes and dislikes.
• The extent to which it met the needs they may feel. Reasons.
• Advantages and disadvantages versus the previous care.
• Any difficulties/ limitations felt. Reasons.
• Potential behavior changes regarding the control of their condition.
• Value attributed to different pharmacy interventions/ initiatives.
Reasons.
3. Patient experience and expectations with the new collaborative care model
• Awareness/ Lack of awareness of the new collaborative care model.
• Likes and dislikes.
• Unmet needs required. Reasons.
• Main benefits preferred.
• Advantages and disadvantages. Reasons.
• Aspects that could be improved.

each participant contributed to the focus group session. She then summed up and asked about the participants' preferences and recommendations, and closed the focus group, thanking participants for their time and effort. No repeat focus groups were performed.

Data analysis

The moderator (MG) transcribed the audio-recorded interview verbatim, ensuring the removal of all patient identification. Each patient was given an anonymous and unique identification (ID) number that was used to identify their data transcription and analysis, preserving patient anonymity. The audio recording was deleted after transcription and review.

Transcripts were reviewed and analyzed using Braun and Clarke's Thematic Analysis [41–43] and coded by one coder (MG) using both open and selective coding. Pre-defined codes were used for the concepts identified in the preliminary conceptual framework. The sections of text containing these concepts were grouped into pre-defined themes, then subthemes emerging from the focus group.

Table 2 Description of focus group participants

Participant	Sex	Age (years)	Educa- tion (years)	Employment status	On medi- cation ^a for:
#1	Male	81	4	Retired/pensioner	Hypertension and hyperlipidemia
#2	Male	67	9	Retired/pensioner	Hypertension
#3	Male	64	12	Employed	Hypertension and hyperlipidemia
#4	Fe- male	68	4	Employed	Hypertension and hyperlipidemia
#5	Fe- male	71	15–17	Retired/pensioner	Hypertension and hyperlipidemia
#6	Fe- male	60	9	Retired/pensioner	Hypertension
#7	Fe- male	60	12	Employed	Hyperlipidemia
#8	Fe- male	46	12	Employed	Hyperlipidemia

^a Patients could be on medication for hypertension and/or hyperlipidemia as per the trial

No data saturation analysis was performed. No second coder was employed, but data were reviewed to assess the coding framework and confirm the interpretation of themes and subthemes for all transcripts (MR). Researchers (MG, MR) also analyzed handwritten field notes.

Subsequently, a careful review by a senior researcher (SC) was performed. Any discrepancies or disagreements were settled through discussion and consensus among the core research team (MG, MR, SC).

No software was used to manage the data. Participants were not requested to provide feedback on the findings.

Patients' quotes were translated from Portuguese into English and are presented along with participants' ID numbers to highlight the findings in this article, summarized in the conceptual framework.

Results

Demographics

We conducted the focus group with a total of eight participants, including five women and three men. Our sampling strategy achieved a broad representation of the age groups, education level, employment status, and medication for hypertension and/or hyperlipidemia, most represented in our trial intervention population (Table 2).

Theme 1: Patient concerns, behaviors, and attitudes related to high blood pressure and hyperlipidemia

Awareness prompted by symptoms or medical appointment

Regardless of their health condition (hypertension and/or hyperlipidemia), participants became aware of their condition basically when they visited a doctor with the results of blood pressure and risk assessment measurements and/or blood tests. These visits were prompted by some complaints/ symptoms they had felt (e.g., frequent headaches, balance problems):

"I have always suffered from migraine... one day I was driving and saw the road sideways, which I thought was very strange. I went to the healthcare unit, and my (systolic) blood pressure was 220. They prescribed my medication. This happened 7–8 years ago, and since then I have been on medication." [#5, female, age 71, hypertension and hyperlipidemia].

Other visits were prompted by a routine medical appointment, a check-up, an emergency room visit at the hospital, and/or a family history of high blood cholesterol or hypertension.

Level of concern according to health condition

Although all the respondents showed some level of concern with their condition, it depends on the condition they have. Two profiles stood out with different attitudes

and behaviors on how they face and deal with their condition:

- Group 1 (“Concerned with high blood pressure”): Patients with high blood pressure displayed a more concerned profile and a “more proactive” attitude in terms of the care/ control of their condition.
- Group 2 (“Little Concerned with hyperlipidemia”): Patients with hyperlipidemia displayed a less concerned profile or even a certain ‘carelessness’ regarding the care/ control of their condition.

Group 1 (“Concerned with high blood pressure”) Group 1 (“Concerned with high blood pressure”) was more aware of the risks associated with high blood pressure, which was perceived as a very severe problem that may even be life-threatening. These patients mentioned their strong fears of having a stroke or a heart attack:

“I fear having a stroke and becoming an invalid!”
[#3, male, age 64, hypertension and hyperlipidemia].

These fears increased in patients with relatives with the same condition / clinical history who suffered a stroke or a heart attack:

“When I became aware of it, I was worried because my father-in-law had a stroke due to high blood pressure, and he never left his bed again; it was a challenging time...” [#5, female, age 71, hypertension and hyperlipidemia].

These patients also felt that high blood pressure is a condition in which symptoms are more easily perceived and affect their daily life (e.g., mood swings/irritability, severe headache...):

“I may be feeling good, but if I suddenly remember that I did not take my blood pressure pill, I become nervous, fearing that something could happen. Fearing that my blood pressure starts to rise, and those unbearable headaches appear!” [#6, female, age 60, hypertension].

Therefore, they seemed to be more attentive and stricter in controlling their condition and attempted to take some precautions. We can identify two types of behaviors: (1) respect for the diagnosis and not questioning the GP; (2) search for alternative solutions to manage the problem (in patients with hyperlipidemia and hypertension). Patients who respect the diagnosis and do not question the GP were more disciplined/stricter with controlling their condition by often monitoring their blood pressure

and/or lipid profile, mainly at the pharmacy (because it is more practical/ convenient than the health care unit) or at home with a blood pressure/cholesterol measurement device.

These patients also ensure they always have a spare medication package at home:

“It may happen that I do not take the pill one day because it ran out and the pharmacy was closed. But I go there the next day for sure...” [#3, male, age 64, hypertension and hyperlipidemia].

They also seemed to strictly comply with the prescribed medication regimen following the recommended dose, time, and time intervals between doses:

“I suffer from high blood pressure. I started taking medication, and now it is controlled. I take one pill every day in the morning, and it lasts the whole day. I have to take my medication; otherwise, my blood pressure rises!” [#2, male, age 67, hypertension].

“If, for instance, I do not take the pill at night, which I feel is the most important one, two days in a row, one thing is for sure: the blood pressure rises, and I start feeling those headaches here in the back of my neck...” [#6, female, age 60, hypertension].

“I have to take it exactly as it was prescribed; I cannot forget...” [#3, male, age 64, hypertension and hyperlipidemia].

Some patients even stated they try to put the medication in “strategic” places, so they do not forget to take them (e.g., in the bathroom next to the toothbrush, in the kitchen next to the coffeemaker, or in the bedroom next to the glass of water they drink every day...):

“My pills are always close to the washbasin because if they are not, I forget to take them...In the morning when I brush my teeth, I have to see my pills there...” [#4, female, age 68, hypertension and hyperlipidemia].

Other patients reported they changed some habits/life-styles by avoiding the consumption of certain foods/typical snacks (e.g., cheese, sausage, and similar products, bean stew, sweets/ sugars), or avoiding eating fats (fried food, meat high in fat) and trying to reduce the amount of salt, or by drinking a glass of red wine during meals, or by considering other healthier alternatives such as vegetables, soup, and fruit, or by exercising regularly (e.g., they try to walk every day and/or in the weekend at least for one hour or in some cases 10 km, cycling, dancing) because they were told that it was beneficial to their health:

"I used to eat too many sausages. Not anymore!" [#2, male, age 67, hypertension].

A second subgroup of patients with hyperlipidemia and hypertension showed a greater propensity to adhere to alternative solutions to control their condition due to their belief that it is an easily manageable problem, and can be controlled using some strategies such as a balanced diet and regular physical activity, or natural food supplements (e.g., based on red rice) perceived as healthier, non-addictive and without the negative effects of the medication for hyperlipidemia.

Group 2 ("Little Concerned with hyperlipidemia") Group 2 ("Little Concerned with hyperlipidemia") seemed not to be very much aware of the consequences of hyperlipidemia and some did not even know the risks they could run or they did not feel particular fear or concern, either because they did not feel ill / they do not feel the symptoms and therefore the condition does not affect their daily life, or because they show some disbelief in the maximum values that are currently perceived as safe (when compared to the past):

"The old medical books said that 220 was the maximum (reference) level, and my cholesterol level is always 220. But now they have lowered these numbers a lot. I had tests done, and the doctor wanted me to take a pill to lower my cholesterol levels. But I said no because I did not want to become a slave to a pill for the rest of my life! And so, I started taking (DRUG BRAND NAME) and in fact, my cholesterol levels lowered... But I take that for a month, then I stop for another month. I prefer this because I know I can stop with no harm done." [#5, female, age 71, hypertension and hyperlipidemia].

"If in the past the cholesterol level of 220 was considered good, why is it no longer that?" [#5, female, age 71, hypertension and hyperlipidemia].

These patients paid less attention to the relevance of controlling their condition. Some were more reluctant to take medication for high blood cholesterol because they perceive statins are often associated with side effects (muscle pain), or they state this medication can cause dependency, and concluded that it is not worth taking it, as it makes them very apprehensive.

"Once my doctor prescribed me pills that would lower my cholesterol levels. I bought them, but the result was not good...I started having muscle pains. I read that statins have this effect. I stopped taking them on my initiative..." [#5, female, age 71, hypertension and hyperlipidemia].

Others said they take only the medications they consider more urgent or essential to their condition (e.g., for high blood pressure and/or depression and/or thyroid problems) vs. hyperlipidemia:

"I may not take all the other medications, but I never forget the two I take for my depression!" [#4, female, age 68, hypertension and hyperlipidemia].

These patients expressed less concern about taking the prescribed medication because they either forget or do not like to take medicines:

"Sometimes I do not take the medication for weeks because I forget, and I hate taking medicines!" [#8, female, age 46, hyperlipidemia].

Some patients reported they stopped taking the medication when their lipid levels became lower. They do not consider it relevant to comply with the prescribed medication regimen long term and prefer to postpone or avoid filling in the prescription as they perceive it is a superfluous type of medication that is not associated with very imperative or immediate needs:

"If my cholesterol levels are low, there is no need to take a pill every day... I do not take a pill a day..." [#4, female, age 68, hypertension and hyperlipidemia].

In short, these findings highlight a subtle apparent difference between high blood pressure and high blood cholesterol in terms of patient concerns, behaviors, and attitudes, with the former being perceived as more severe.

Theme 2: Patient experience with pharmacy and primary care

Positive patient experience with the pharmacy

Patients valued proximity, availability, support, and the variety of services provided in pharmacies:

"We are already friends, they make our life easier, they clarify our doubts, and they know their customers. I have been going to the same pharmacy for 20 years." [#1, male, age 81, hypertension and hyperlipidemia].

Pharmacies appear as a personalized and friendly health-care environment with flexibility for dispensing prescriptions and payment, advice, clarification of issues, and a relationship based on trust and friendship. Patients also perceived a growing availability of services with the possibility of performing a more comprehensive set of rapid

diagnostic tests (e.g., blood sugar, blood pressure, triglycerides) and benefits such as the Pharmacy Customer Loyalty Program.

Some issues in patient experience with primary care

Patients expressed some concern with distance, staff shortage, and lack of time in the primary care unit:

"The support has dwindled, there is a staff shortage, they are always in a hurry; there is no humanity." [#3, male, age 64, hypertension and hyperlipidemia].

Patients felt staff cuts affected the service they received in primary care, such as scheduling tests and appointments. They reported that the relationship with patients seemed less attentive, and it was more difficult to access simple services, such as blood pressure measurement:

"I went there to have my blood pressure measured. She noticed I had been there two weeks before, and she scolded me, saying there was no need to go there so often, it was a waste of time." [#2, male, age 67, hypertension].

Patients also perceived there is a lack of communication with patients, and there ought to be more advertising of health initiatives:

"For instance, some time ago, there was a 'Walking for the Heart' initiative. Many people would have liked to have joined, but they could not because it was not advertised as it should have been. Sometimes, there are even blood sugar testing initiatives at the Jumbo supermarket, and there is no information whatsoever from the healthcare unit. They could send us a text about it!" [#7, female, age 60, hyperlipidemia].

Theme 3: Patient experience and expectations with the new collaborative care model

Overall patient experience with the new care model

The pharmacist's influence was the motivating factor for patients to participate in the USFarmácia Collaborative Care Trial, mainly due to the proximity and relationship they already had with the pharmacist, his/her ability to engage with them, and his/her credibility:

"It was the way Dr. P... from the pharmacy explained it to me... it was great, she explained everything!" [#3, male, age 64, hypertension and hyperlipidemia]
"I remember going to the pharmacy, and when Dr. A... looked at my clinical file, she showed me the leaflet and asked if I was interested in joining. Then

she explained everything to me..." [#7, female, age 60, hyperlipidemia].

The project leaflets patients received at the pharmacy worked as an important complement to the previous explanation from the pharmacist. These leaflets were viewed as very useful tools.

Patients seemed a bit confused concerning the exact innovative features of the USFarmácia Collaborative Care project. One patient seemed not to be aware of the collaboration with the primary healthcare unit, or had low awareness:

"I think there was some mistake because the pharmacist approached me, but did not explain that it had to do with the healthcare unit. She measured my blood pressure, and nobody told me anything about it since then..." [#5, female, age 71, hypertension and hyperlipidemia].

"They told me that there was this pilot project, that it was unique and had begun here in Figueira da Foz with the healthcare unit, and that not every pharmacy was involved... They wanted to know about the pharmacies' customer service..." [#2, male, age 67, hypertension].

Another patient associated it with the telephone interviews (for the effectiveness study):

"I was contacted several times over this last year, and I was interviewed for ten minutes at least three times. They wanted to know what I had done to get better..." [#7, female, age 60, hyperlipidemia].

However, there was no clear perception of major changes in the support experienced in the new collaborative care intervention in hypertension and hyperlipidemia management when compared to the previous usual care in patients' pharmacies and PCU.

When the collaborative care project between pharmacies and primary care was further explained to patients in the focus group, it generated enthusiasm due to the perceived potential: (1) to facilitate changes in patients' behaviors and attitudes to become more aware of the relevance of controlling blood pressure and hyperlipidemia, such as checking lipid (and blood pressure) values on a more regular basis and taking the medication as prescribed (mainly for hyperlipidemia); (2) to enhance the communication between pharmacies and the healthcare unit and overcome some of the shortcomings previously identified at the PCU.

Overall, the collaborative care model was perceived as bringing more benefits to improve hypertension and hyperlipidemia control than the previous usual care.

Patients also acknowledged they viewed the pharmacy as an easier, quicker, and more convenient alternative to the PCU for some services.

Innovative features of the new care model most meaningful

Patients valued the following new (intended) features of the collaborative care model as highly relevant (+++), relevant (++), somewhat relevant (+) and not relevant (-): request for a medical appointment from the pharmacy to the PCU using digital communication (+++); request for a repeat prescription from the pharmacy to the PCU using digital communication (++); point-of-care measurements and cardiovascular risk assessments (+); medication management (+); refill text reminder sent before the end of medication from the pharmacy to the patient's smartphone (-).

Request for medical appointment from the pharmacy to the primary care unit

This feature went unnoticed by most patients, except one. However, this was the most valuable feature perceived by patients for a collaborative care model between pharmacies and primary care. In addition, patients reported it would save them time on the phone or from going to the PCU to schedule an appointment, something they perceive as very difficult:

"How many times have I spent hours going to the healthcare center to schedule an appointment? It is time I am away from my work, and I have to explain. I call the healthcare unit time and time again, and they do not answer the phone. Instead, I hear music and that for a long time...and then I end up going there to schedule an appointment!" [#7, female, age 60, hyperlipidemia].

For some patients, this feature seemed to calm or comfort them (a more emotional benefit) regarding their blood pressure and/or high blood cholesterol control:

"This way, the doctor becomes immediately aware of the situation!" [#1, male, age 81, hypertension and hyperlipidemia].

One patient experienced this innovative feature and expressed a high level of satisfaction with the immediate action taken at the pharmacy and the response of the PCU to the request for scheduling a medical appointment when the blood pressure and cholesterol levels went high:

"I went to the pharmacy to check my blood pressure and cholesterol levels, and they (the results) were not good at all! They contacted the healthcare unit, and the healthcare unit contacted me to schedule an

appointment... I have already been to the doctor, he ordered blood tests, and now I am going to a lab..." [#7, female, age 60, hyperlipidemia].

Request for repeat prescription from the pharmacy to the primary care unit

This innovative feature went unnoticed by most patients in the focus group, but was highly valued to overcome hurdles in accessing repeat prescriptions at the PCU and avoiding wasting the time of employed patients:

"I have to wait 3 or 4 days at the healthcare unit to get the prescription, and I do not take the medication for these 3 or 4 days!" [#5, female, age 71, hypertension and hyperlipidemia].

"It is annoying to have to go to the healthcare unit just to get another prescription!" [#7, female, age 60, hyperlipidemia].

They expressed, however, doubts about how they would pay for the primary care user charge fee:

"It is very nice, but how do we pay the user fee? Is that when we go back to the healthcare unit?" [#3, male, age 64, hypertension and hyperlipidemia].

Their consent for the pharmacist to request a repeat prescription on their behalf from the pharmacy requires two conditions be met: 1) the user fee can be paid at the pharmacy when they purchase the medication as they do not like the idea of having to go to the PCU just to settle that payment; 2) the amount of the user fee remains the same they already pay at the PCU (3.50 euro):

"But someone will have to pay the user fee regarding this..." [#4, female, age 68, hypertension and hyperlipidemia].

"Ideally, we would pay it right then and there. We pay 7 euros for the medication and the 3.50 euros of the user fee..." [#2, male, age 67, hypertension].

Point-of-care measurements and cardiovascular risk assessment

Almost all patients noticed this feature, although the data exchange between the pharmacy and the PCU was not fully achieved due to interoperability issues reported elsewhere [33].

Although this is something they are already very familiar with, the frequency of measurements and tests was determined per ICP. Those patients who received a warning note from their pharmacy (via text message or at the pharmacy) reported a higher frequency of point-of-care measurements and tests than those who received an occasional warning note:

"I received an alert on my cell phone for the second time from the pharmacy telling me to go there to check my blood pressure levels but I deleted it ...and two weeks later when I went there, Dr. M. told me immediately that I should have checked my blood pressure before..." [#3, male, age 64, hypertension and hyperlipidemia].

For some patients, mainly from the "Concerned" profile, performing regular point-of-care measurements has become a habit. They tend to have this type of monitoring done regularly at the pharmacy because it is an easier and quicker alternative to the PCU (nevertheless, some of them view the pharmacy cholesterol tests as less reliable vs. lab exams) and meets their desired need of having their levels controlled, or because the pharmacy sends them alerts to do this monitoring or prompts them to do this, as per ICP.

Other patients, mainly those from the "Little concerned" profile, performed these tests only once, right at the start of the project (more than 6 months before the focus group), and did not receive further alerts:

"The pharmacy never said anything about it again to me!" [#4, female, age 68, hypertension and hyperlipidemia].

Some patients would prefer to have these tests done more often:

"If the time intervals were shorter, we would get better control!" [#3, male, age 64, hypertension and hyperlipidemia].

"I work in Coimbra but live in Figueira da Foz, and I do not like to waste my time. When I joined the project, I started to have blood tests at the pharmacy, and they told me I could go there any time I wanted, even on Saturdays! I think this is great because I only did it when I went to the doctor. I could even have high blood pressure and cholesterol and not know it...and this was a way for me to keep it under control..." [#7, female, age 60, hyperlipidemia].

"I would prefer the lab exam... There was a problem with the machine, and after that, I became a bit suspicious of the results of the test..." [#2, male, age 67, hypertension].

Last, the fact that tests and measurements were free of charge for patients (reimbursed by a third-party payer) was viewed as a highly valued benefit.

Patients did not realize the pharmacy did not prompt them to perform point-of-care measurements as often as desired by patients, but rather according to the ICP pre-agreed with GPs.

Medication management Almost all patients noticed this feature, although the data exchange between the pharmacy and the PCU was not fully achieved.

It was felt very useful/important that pharmacists ensure patients understood what the doctor prescribed. Some patients said pharmacists even write the treatment scheme on packages (regardless of the condition) so that patients know/do not forget how to take the medication. Pharmacists also check if patients take the medication as prescribed and how they are feeling in terms of their high blood pressure and/or hyperlipidemia.

"This is what pharmacists say to me whenever I go there. Sometimes we throw away the prescription, but they write everything on the packages..." [#7, female, age 60, hyperlipidemia].

This is an important and distinctive feature for patients towards their preferred pharmacy:

"This is so important that I went one day to a different pharmacy, and they did nothing like this...and I thought 'Where is my pharmacy?'" [#7, female, age 60, hyperlipidemia].

Refill text reminder sent from the pharmacy to the patient's smartphone Patients acknowledged that this feature was somewhat relevant to prevent missing doses. However, they did not seem to quite understand its value.

For the "*Little concerned with hyperlipidemia*": These patients did not feel the need for specific alerts when the medication was running low because they did not view medication adherence as something important.

For the "*Concerned with high blood pressure*": These patients did not feel the need for specific alerts when the medication was running low because they already complied with the prescribed medication, although they acknowledged that it is a benefit that could help them in case they forget and miss doses. It seemed, however, more attractive to busy patients who may forget to take the medication and/or to carers who take care of elderly people at home.

"I always ask them if the prescription is still valid, and they go and check the prescription they have on file..." [#4, female, age 68, hypertension and hyperlipidemia].

"So that we do not forget to buy it! We lead such a busy life...I think this is good..." [#7, female, age 60, hyperlipidemia].

"I have my prescriptions on me all the time, and I control this... I never run out of my medication..." [#2, male, age 67, hypertension].

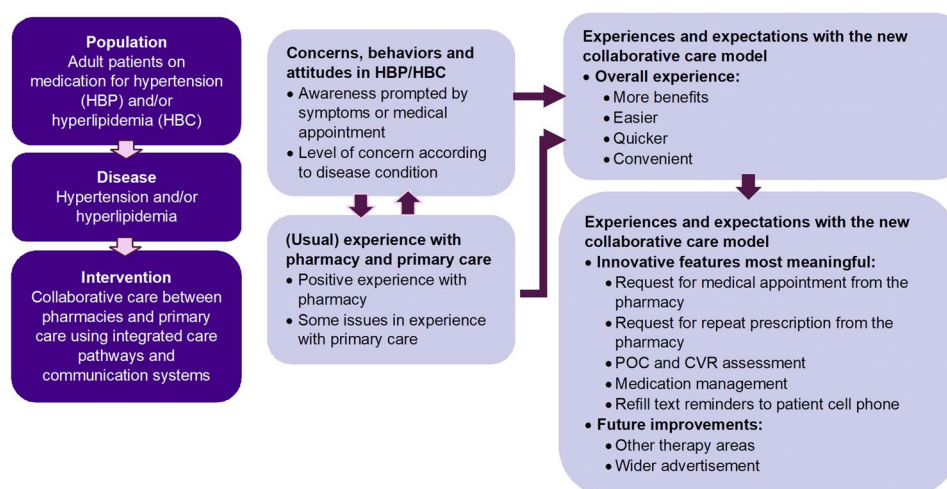


Fig. 1 Conceptual framework that emerged from the focus group. HBP: High Blood Pressure; HBC: High Blood Cholesterol; POC: Point-Of-Care; CVR: Cardiovascular Risk

"This is of no use to me at all because I will go on forgetting it!" [#8, female, age 46, hyperlipidemia].

Future improvements in the collaborative care model

Patients suggested expanding this collaborative care model to other therapeutic areas that are perceived as hard to control, such as diabetes, thyroid disorders, and liver-related conditions.

They also consider that there ought to be wider advertising efforts on the innovative features of this new collaborative care model to increase patient awareness.

Key learnings

Key learnings from this focus group include the following:

- Patient concerns, behaviors, and attitudes regarding their high blood pressure and hyperlipidemia, namely awareness and level of concern, as well as their current experience with pharmacy and primary care, influence their experience and expectations with the new collaborative care model.
- The overall experience with the collaborative care model is positive, with some features perceived as most relevant, with a few suggestions for future improvements.
- Some interviewed participants were not able to fully experience the collaborative care model and were not clear on what the care model was trying to achieve.

Conceptual framework of patient experience

The findings of the focus group were used to develop a conceptual framework summarizing patient experience and expectations with hypertension and hyperlipidemia,

pharmacy and primary care, and the new collaborative care model experienced in the trial (Fig. 1).

Discussion

Summary of key findings

This study identified various concepts: awareness prompted by symptoms or medical appointment, level of concern according to health condition; positive experience with pharmacy and some issues in experience with primary care; overall benefits and innovative features most meaningful to patients perceived with the new collaborative care model; and other therapy areas and wider advertisement as future improvements. These concepts were useful in understanding patients' concerns, behaviors, and attitudes related to their condition, experience with current care, and expectations with the new collaborative care model. This focus group also provided insights to inform attributes and levels for a patient preference study.

Comparison with existing literature

Our findings are in accordance with the qualitative research studies using patient focus groups or patient interviews about PED on collaborative care between community pharmacists and physicians, where patients appreciate and value collaborative care between these providers [19–26].

In the Canadian qualitative study nested within a collaborative care trial, patients on lipid-lowering medication also acknowledged that the intervention was more structured and systematic than previous usual care [19]. Our study also confirms the results of other studies that show a high level of patient satisfaction and positive experience with their preferred pharmacy [27] and some

issues in patient experience with primary care in Portugal [44].

The findings of this study also highlighted a significant unmet need for truly integrated care pathways between pharmacies and primary care capable of improving the waiting time and patient experience for medical appointments, prescription renewal through the pharmacy, data exchange of point-of-care measurements, and medication management.

These findings were further used to inform the attributes and levels for a patient preference study on a larger trial patient sample size using a discrete choice experiment. This preference study was conducted at the end of the trial and detailed the PED previously unveiled in this focus group [35].

Strengths and weaknesses

The collaborative experiment between trial intervention pharmacies and the primary care unit was not fully perceived by the sample patients of this focus group. Researchers encountered some challenges and hurdles in the real-world host trial, mainly due to interoperability issues in the primary care software, which have negatively affected data exchange and collaborative care features, causing the uptake of the model to be lower than expected. Thus, intervention patients were unable to experience the full dimension of the planned collaborative care package. This is reported elsewhere [33].

The concepts were derived from a small number of participants, and we acknowledge that sample selection bias may have occurred, as intervention trial patients in this focus group may have been those with strong views and expectations regarding a collaborative model between providers. However, the quota sampling methods ensured that participants represented the various patient demographics and clinical types of the larger trial intervention patient group.

We have not performed a formal data saturation analysis where transcripts are usually organized chronologically in waves of interviews, and concepts mentioned in each wave are compared to those mentioned in previous waves to ensure no new concepts appear at some point with the current sample size. However, the moderator sought to explore all questions in the interview guide in spontaneous and probed modes in a very thorough approach until saturation of themes was considered achieved after a single 2 ½ hours interview despite this not replacing data saturation analysis.

Other limitations of the focus group methodology may include potential dominant participants who may influence the nature of a group discussion. In this study, the moderator sought to encourage contributions from all participants by specifically directing questions and eliciting their opinions on the issues discussed, but despite

efforts, we cannot rule out the possibility of this type of bias in a low sample size and using one session only.

We did not have a second coder. However, the other field researcher (MR), acting as observer during the focus group, reviewed all transcripts and field notes to assess the coding framework and emerging subthemes, and discussed outstanding issues with the senior researcher (SC).

The focus group was continued until theme saturation was achieved to ensure that it covered a wide range of opinions from the potential target population.

To our knowledge, this was the first trial exit patient focus group study conducted in Portugal to explore PED on collaborative care features between pharmacies and primary care.

Finally, we partnered with patient experts from the national patient coalition, the national branch of the European Patient Group, EUPATI Portugal, and the three chronic disease patient associations to ensure patients' views and suggestions on the final interview guide, as well as their contribution to the discussion of findings, and critical review of the manuscript. We hope this study will contribute to enhancing future patient expert engagement in real-world studies to improve efficiency and outcomes that matter most to patients and advance value-based health care.

Implications for practice and policy

The findings of this study highlight the importance of integrated Patient-Centered healthcare solutions between pharmacies and primary care involving multidisciplinary teams, across various levels of care. These integrated solutions should follow citizens/patients throughout their journey in the healthcare system, focus on individual needs and preferences, and enable empowerment and autonomy in self-managing health. This may also contribute to improving citizens' navigational health literacy, and therefore, health outcomes, shortening the patient journey across fragmented healthcare services and settings [45, 46].

The network of community pharmacies ensures more ready access to medication and patient care services when coordinated with other healthcare levels.

Chronic disease management and early identification of at-risk patients may include point-of-care measurement, medication review, management and optimization of chronic therapy, and reinforcement of health literacy.

This model should be based on a bidirectional communication system between pharmacies and PCUs grounded on patient electronic health records.

Despite legislation to improve timely and effective patient access to chronic medication, such as provisions on contractual arrangements with pharmacies for

collaborative care and on automatic medication renewal for chronic diseases, there is still a long way to go.

Implications for research

Community pharmacies generate and collect a large volume of citizen/patient-level data daily, including demographics, dispensed medication, behaviors, and health outcomes, representing an important source for generating real-world data. These data combined with PED, such as the case of patient experience shared through this focus group, can assist the economic evaluation of health technologies, such as healthcare interventions depicted in this study, but also innovative medicines.

The strength of the focus group qualitative approach used in this study allowed for an in-depth exploration of an under-researched area to inform future clinical trials, observational real-world studies on the use of new medicines, and health services research making use of information technology-assisted collaborative care between pharmacies and NHS providers.

Conclusion

The key concepts that emerged from the first trial exit patient focus group conducted in Portugal were useful to understand patients' concerns, behaviors, and attitudes related to their condition, experience with current pharmacy and primary care, and expectations with the new collaborative care model. This Patient-Centered qualitative research study has also informed the development of attributes and levels for a patient preference study of a pragmatic controlled trial to assess the cost-benefit of a collaborative care intervention between pharmacies and a primary care unit in hypertension and hyperlipidemia management in Portugal (USFarmácia).

The provisions in the legislation for contractual arrangements with Portuguese pharmacies represent an opportunity to use the insights from patients' voices captured in this study to improve interoperability issues and further advance collaborative practice between pharmacies and primary care. This requires engagement from policymakers, community pharmacy owners, pharmacists, and primary care providers.

Abbreviations

COREQ	Consolidated Criteria for Reporting Qualitative Research
CVR	Cardiovascular Risk
EUPATI	European Patients' Academy on Therapeutic Innovation
GP	General Practitioner
HBC	High Blood Cholesterol
HBP	High Blood Pressure
ICHOM	International Consortium for Health Outcomes Measurement
ICP	Integrated Care Pathway
NHS	National Health Service
PCORI	Patient-Centered Outcomes Research Institute
PCU	Primary Care Unit
PED	Patient Experience Data
POC	Point-of-Care
PREM	Patient-Reported Experience Measure

PROM	Patient-Reported Outcome Measure
RWE	Real-World Evidence

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12875-026-03382-7>.

Additional file 1.

Additional file 2.

Additional file 3.

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Authors' contributions

SC conceptualized and designed the study, defined patients' sample profiles, drafted the interview guide, approached patient experts, interpreted the data, drafted the manuscript, obtained funding, and provided project administration. MG further developed the interview guide, conducted the focus group, collected, analyzed, processed the data, and drafted the results. MR recruited patients, reviewed the interview discussion guide, assisted in the focus group, prepared patient incentives, and reviewed and interpreted the data. SR reviewed the interview discussion guide, supervised the patient approach, and interpreted the data. JV, IMG, and EFM reviewed the interview discussion guide. All authors revised and edited the manuscript for important intellectual content. All authors read and approved the final version of the manuscript to be published. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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Data availability

The de-identified datasets analyzed during the current study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

This study was conducted in accordance with the Declaration of Helsinki and the European General Data Protection Regulation and its transposition into national legislation. The Regional Health Administration ('Administração Regional de Saúde', or ARS Centro) approved the trial (which included provisions for qualitative research) on 09-02-2017, following the opinion of its Ethics Committee ('Comissão de Ética para a Saúde' of ARS Centro) on 01-02-2017 for studies involving humans. The Ethics Committee 'Instituto de Bioética' of Universidade Católica Portuguesa also approved the study (Ethical Screening Report 02/2018) on 20-03-2018. Written informed consent was obtained from trial participants prior to the onset of the trial and reconfirmed for focus group patients prior to the focus group.

Consent for publication

Not applicable.

Competing interests

The authors report the following conflicts of interest: SC and MR were employed by the Associação Nacional das Farmácias (ANF) at the time of the focus group until December 2019 and August 2024, respectively. SR is employed by the ANF. MG reports consulting fees from ANF for conducting the focus group. JV, IMG, and EFM declare they have no known conflicts of interest. The funder had no role in the design of the study; in the collection, analysis, or interpretation of data; in the writing of the manuscript; or in the decision to publish the results.

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