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Strategies for managing the costs of chronic illness in the context of limited financial resources: a qualitative study in Dominican persons with arthritis

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Abstract

Objective: Persons in low- and middle-income countries often have insufficient resources to pay for treatments prescribed for their medical conditions. We aimed to determine, using qualitative methods, how people with arthritis in the Dominican Republic manage the costs of chronic illnesses.

Methods: We conducted individual interviews with 17 Dominican adults with advanced arthritis undergoing total knee replacement (TKR) or total hip replacement (THR) at a hospital in Santo Domingo, Dominican Republic. Interviewers followed a moderator's guide with questions pertaining to the financial demands of arthritis and strategies participants used to pay for treatments. Interviews were audio-recorded, transcribed verbatim, and translated into English. We used thematic analysis to identify salient themes.

Results: The thematic analysis suggested that health system factors, such as the extent of reimbursement for medications available in the public healthcare system, along with personal factors, such as disposable income, shaped the individual's experience of managing chronic illness. These systemic and personal factors contributed to a sizeable gap between the cost of care and the amount most participants were able to pay. Participants managed this resource gap using a spectrum of strategies ranging from acceptance or "making do with less," to resourcefulness or "finding more." Participants were aided by strong community bonds and religiously-oriented resilience.

Conclusion: This qualitative study illuminates the range of strategies Dominicans with limited resources use to obtain healthcare and manage chronic illness. The findings raise hypotheses that warrant further study and could help guide provider-patient conversations regarding treatment adherence.

Chronic medical conditions, such as arthritis, are the leading cause of illness, disability-associated life years, and mortality in both high- and low-income countries¹⁻⁴. It is estimated that osteoarthritis (OA), the most prevalent form of arthritis, affects 10% to 15% of adults over age 60 worldwide⁵⁻⁸. Patients in resource-limited countries typically manage

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arthritis with a combination of analgesics, anti-inflammatory medications, home remedies⁹, and behavioral coping mechanisms¹⁰. In the latter category, religion often plays an important role in coping with illness^{10–11}. Purchasing treatments places a sizeable financial burden on individuals in low- and middle-income countries^{12–14}, leaving them to forego part of the treatment or identify additional resources^{15–19}. Higher out-of-pocket costs contribute to lower adherence^{16, 20–22}, and individuals with lower socioeconomic status are less likely to adhere to treatment regimens^{23–26}.

There exists limited research on the ways in which individuals in resource-limited settings manage the costs of chronic illness given scant personal resources^{27–28}. In particular, few qualitative studies have addressed this topic^{16, 29–30}. These studies suggest that individuals with limited financial resources may delay care, substitute alternative medicine, and/or draw on social resources for transportation or financial support^{16, 29–30}. There remains a need to understand how these individuals make decisions whether to utilize care and, when deciding to seek care, how they bridge any gaps in available resources. Further qualitative research can help provide nuanced insights into the coping and payment strategies utilized by patients with chronic illness in a resource-limited setting, identify obstacles to care, and generate hypotheses for future studies. The objective of this study is to use qualitative methods to examine how people with arthritis living in the Dominican Republic, a middle-income country with stark income inequality³¹, make decisions about utilizing healthcare given the scant resources available to them. The study's guiding questions were, "How do Dominican individuals living with arthritis and other chronic conditions manage the costs of chronic illness? How do they make healthcare utilization decisions?"

Participants and Methods

Setting

The Dominican Republic occupies the eastern portion of the Caribbean island of Hispaniola. Approximately 30.5% of the population lives below the international poverty line³². The government spends roughly 4.4% of the per capita gross domestic product (GDP) of \$6,722 on healthcare^{33–34}. The government-subsidized health insurance plan (the 'subsidized regime'), Seguro Nacional de Salud (SENASA), is the most widely used among impoverished, unemployed, or disabled Dominicans³¹. SENASA covers much less expenditure than the plans covering salaried workers ('contributive regime') and the quality and reliability of services is known to be lower³¹. SENASA benefits typically cover the costs of catastrophic care, some medications, and ambulatory care, but provide limited coverage for specialty care, including joint replacement, and multiple medications.

Participants

Seventeen participants were selected from the 42 patients chosen for Operation Walk Boston (OpWalk Boston) 2017. As there were no exclusions for this study, a random assortment of OpWalk participants was approached either before surgery (at least 2 hours) or postoperatively (not on the same day as surgery). OpWalk Boston is a nonprofit, volunteer organization that has conducted annual trips since 2008 to provide total hip and knee

replacement (THR and TKR, respectively) surgeries to financially limited individuals in the Dominican Republic.

Patients learn about OpWalk through advertisement, word of mouth, or physician referral, and are selected based on financial and medical criteria. Patients are considered financially eligible if they do not have sufficient health insurance or personal funds to cover the costs of surgery. Medical eligibility criteria include symptomatic, radiographically advanced hip and/or knee arthritis, and otherwise stable health status. All participants were assured that their participation was voluntary, anonymous, and would not affect the care administered to them by OpWalk. All participants provided verbal consent. The study was approved by the Partners Healthcare IRB (protocol number 2010P_000082).

Procedures

Two interview teams, each including at least one native Spanish speaker, performed 17 interviews over 3 days during OpWalk Boston 2017. Interviews were conducted in Spanish and audio-recorded. Interviewers followed a moderator's guide (Table 1), developed and reviewed by Boston and Dominican members of the research team to ensure that all questions were comprehensible and appropriate. Interviews were organized to flow as a conversation might, beginning with general questions about experiences with arthritis and progressing to more specific probes about coping with the financial demands of healthcare. Recordings were transcribed and translated into English by one of the authors, who is bilingual (CC), and verified by a second bilingual colleague. Participant identifiers were removed from the transcripts, and speakers are identified by study ID number alone.

Thematic Analysis

With data from all transcripts, we conducted thematic analysis, a commonly used inductive method of qualitative analysis³⁵. First, investigators coded a portion of the transcript text, using words or phrases to identify the most basic segments of data deemed meaningful in relation to the guiding questions of the study: *How do Dominican individuals living with arthritis and other chronic conditions manage the costs of chronic illness? How do they make healthcare utilization decisions?* Comparing the transcripts coded by each investigator, a single coding scheme was developed. Two co-authors (JN, CC) then coded the remaining data according to this scheme, adding codes when necessary to reflect relevant ideas that we had not identified in the first portion of data coded.

Next, themes were generated. Themes express patterns in the data in relation to the guiding questions of the study, often by grouping codes or otherwise expressing relationships among them. The investigators met to develop an initial thematic scheme comprising themes, subthemes, and ideas about the relationships among them. Two investigators (JN, CC) linked all transcript excerpts with the appropriate themes using qualitative data analysis software (Dedoose). Themes and their interrelationships were portrayed visually in a thematic map (Figure 1). All investigators met to refine the thematic scheme and thematic map, and all approved the final versions.

Results

Participants

Of the 42 individuals participating in OpWalk 2017, 17 were approached for interviews and all consented. Two were male and 15 were female, all between the ages of 32 and 86. Nine had suffered from joint pain for 5–15 years, and 8 for over 15 years. One participant had rheumatoid arthritis (RA), while the rest had OA (risk factors among the participants with OA included prior injury, obesity, and older age). Nine of the participants lived in Santo Domingo (where the hospital is located) and 8 were from outside the capital city.

Results of Thematic Analysis

Themes were identified and grouped into two broad categories: factors contributing to an imbalance between participants' resources and their healthcare needs (Figure 1, top half), and the spectrum of coping mechanisms addressing this imbalance (Figure 1, bottom half). The following section describes each theme or subtheme and presents supporting interview data. A comprehensive list of supporting quotations is provided in the online appendix.

A. Factors Contributing to Imbalance Between Available and Needed Resources

1) Healthcare Systems: Participants noted that private healthcare has a variety of advantages over public healthcare but is not affordable for the majority of Dominican citizens. The individuals selected for OpWalk were all insured by government-subsidized SENASA, which does not cover costly elective procedures such as THR and TKR. Many participants talked about the barriers arising from lack of adequate insurance or personal resources:

“With the insurance I had he charged me 500 pesos...† But...they took my insurance away, and when I returned to him I had to pay 1,500. I no longer have that so I go home.” (1021)*

Others mentioned quality issues, including specialist scarcity, in the public hospitals that they used when private clinics were not accessible:

“I don't worry about going to doctors that are good. Because if I don't have money I go to the Goico [a public hospital], I go to the medical dispensaries that are in the poor neighborhoods, you see?” (1021)

2) Cost: A major contributor to limited access was the cost of healthcare, which inhibited both care and treatment:

“Moderator: Ok. If you can't pay for a medical appointment, generally do you lose the appointment, or try to find the money somehow?”

1073: No—well sometimes I lose it ...

* At the time of the interview 500 Dominican pesos was worth approximately 12 U.S. dollars at an exchange rate of 40 pesos per dollar.

† Ellipses indicate nonverbal utterances and redundant phrases that the authors removed for the sake of presenting quotations succinctly.

Moderator: Have you ever had problems to—to buy those medications?

1073: Of course! Of course.”

Often, the inability to afford medicine offered at an ordinary pharmacy drove participants to seek cheaper options at economy pharmacies. These *boticas* offer a variety of alternative treatments (e.g. menthol) as well as reduced doses of standard over-the-counter painkillers. However, some of the participants expressed distrust in these economy pharmacies because the medicine purchased there may be less effective.

“I don’t like medications from the economy pharmacy because...[they] don’t have many ...components.” (1063)

To manage financial limitations, some participants received discounts from social services:

“There, you go and after they give you the little paper you go to a department that they send you to, Social [services], and...if you can prove with your information that you don’t have the capacity to pay what is needed to pay, they reduce the price.” (1031)

3) Transportation: Lack of transportation also emerged as an important barrier. Sometimes the burden of finding a ride to the hospital proved immense. Furthermore, not all participants lived within the vicinity of the hospital.

“Sometimes I was late, because from here in the city to where I live takes about two hours.” (1076)

Some sought rides with family members or friends, but others were restricted to public transportation, which in some cases became another financial burden:

“1015: I have to get around in a taxi.

Moderator: Ok and if you don’t have enough for the fare... Do you lose the appointment?

1015: I lose the appointment.”

Some participants mentioned being unable to make the trip to the pharmacy due to limited physical function. Participants called on family members to make these trips or utilized pharmaceutical delivery services.

4) Disease Experience: Most participants had been suffering from joint pain for several years. Many also reported having comorbidities that required medical attention, hypertension being especially common. Some used wheelchairs to move around. Many reported severe limitations in daily routine.

“It has affected my life...immeasurably. Because... it has deteriorated my knees, everything, and I can’t walk.” (1054)

While some participants were able to obtain analgesics for their joint pain, others lacked the necessary resources:

“If you get sick, and you don’t have medications, what are you going to do, tell me? You have to stay that way because you don’t have medications.” (1021)

Ultimately, many were dissatisfied with their situations. Some expressed frustration with the system or felt ignored due to lack of coverage:

“1029: The Hippocratic oath does not exist anymore.

Moderator: You think [doctors] are insensitive?

1029: Totally”

Together, these first four themes portray an imbalance between participants’ healthcare needs and the resources required for accessing healthcare. Due to this imbalance, participants faced difficult decisions: how to expend resources, prioritize treatments, and manage their illnesses without added costs.

B. Strategies to Cope with an Imbalance Between Available and Needed Resources—Participants adopted coping strategies in response to lacking the resources needed to acquire healthcare. We identified eight themes, which encompass six additional sub-themes, regarding these strategies. We plotted these on a spectrum, in which the left end represents strategies employed to “make do with less” and the right end represents acquiring additional resources (Figure 1). We note that some of these strategies represent deliberate choices by participants (e.g. decisions to miss doses of medications to make a fixed supply last longer), while in other circumstances the strategies seemed less deliberate but ultimately served the same purpose of stretching resources (e.g. genuine fear of medications).

1) Religiosity and acceptance: On the far left of the spectrum are the strategies derived from acceptance of one’s condition (as opposed to actively trying to change it). Religiosity was a means of support:

“One prays, ‘God help me take away this pain’, because, He is the one who can do everything.” (1008)

Others ascribed to their deity the power to improve their condition:

“Well, that’s how I held on until God wanted ...waiting to find something someday.” (1063)

Acceptance allowed participants to feel as if they had adapted to the circumstances of their illness:

“I adapt to my--my circle of poverty...that exists.” (1076)

2) Non-adherence: Moving to the right on the spectrum, some participants were deliberately non-adherent to their treatment regimens²². This non-adherence had the result of reducing the gap between needed and available resources. As noted earlier, some participants described being non-adherent for reasons other than conserving resources. Some felt that treatment was either unnecessary because their condition was not debilitating enough, or useless due to the advanced degree of their disease:

“I no longer use anything because it hurts all over.” (1011)

Others were non-adherent less purposefully, due to forgetfulness:

“Sometimes I don’t take it because I forget to.” (1073)

3) Fear of medications: Several participants expressed fears that commonly prescribed arthritis medications would impact their health negatively if taken too frequently. Such fears provided another, distinct motivation (in addition to lack of resources) for using less medication. Some described a fear of addiction that motivated deliberate under-dosing:

“I take [medication] when it hurts, when I feel too much pain. I don’t like to get myself addicted.” (1015)

Others discontinued use of arthritis medications because they feared side effects:

“I don’t want to saturate my liver and my kidneys.” (1029)

Having comorbidities, such as gastritis, diabetes, and/or hypertension made some participants more wary of medication side effects.

“I go to the doctor for rheumatism, the muscle pains. I go for my stomach...eh...I go...you know that, the stomach is something that is harmed by those medications you take.” (1031)

4) Internal resources (resilience, endurance, pride): Many participants used internal resilience, endurance, and other emotional resources to cope with advanced disease:

“Moderator: Last year you didn’t see any doctors for your legs?

1063: Mmm no. I put up with it.

Moderator: And why...do you prefer to not go to the doctor?

1063: Well, because the solution was an implant and I couldn’t get it.”

Some emotional resources, such as pride, discouraged participants from searching for additional material resources:

“Because if a poor person doesn’t have [money] they’re not going to do what they can’t afford because then they lose their merit and dignity.” (1021)

5) Prioritization: Participants commented on the challenge of balancing different financial responsibilities. The low socioeconomic status of many participants placed them in the position of choosing among basic needs.

5a. *Prioritize basic needs:* Some participants chose to use their scant economic resources to cover basic needs, such as food and housing, with the awareness that it would impact their treatment regimen:

“I have had times where I have enough to buy the medication but not to eat the food I need on a daily basis. So I have to take out from what I saved for my medication in order to buy the week’s food.” (1031)

5b. Stretch the prescription: Unwilling to forego treatment entirely, some participants employed strategies to make their medications last longer, either skipping doses, using an incomplete course of treatment, or using lower doses of their prescribed medications:

“Moderator: Have you ever omitted doses or stopped taking the medication, or used a lower dose because you couldn’t pay for the prescribed amount?”

1049: Well, sometimes, because sometimes you have limitations and I’ve had to lower [the dose]. I’ve put up with this pain, due to not having [medication] in those moments”

5c. Prioritize medications: Some participants were steadfast in prioritizing their medications above other necessities:

“Moderator: Would you stop buying other things, like clothes?”

1029: Of course yes. I even stopped buying quality food.”

6) Save money: Another strategy toward the right of the spectrum was saving money for medications. Some participants did so by allocating resources for medications immediately after receiving their monthly income:

“At least I almost never miss [my medication], because every month I take money to buy it...I set that money [aside]. I take it out first.” (1054)

Others sought less costly treatments, even if they were less effective:

“Sometimes I take more acetaminophen, which is another thing for the pains. Because it is less expensive, you see? If I don’t have money then I have to buy what’s least expensive to always maintain myself.” (1021)

7) External sources of money: On the far right of the spectrum we placed strategies focused on finding additional resources. External sources of money, those which would not be within the participant’s immediate reach under other circumstances, were a significant help for many in accessing health care.

1. Family: Perhaps the most important external source of money was the participant’s own family, whether small or large, nuclear or extended, near or far. Larger families provided more security in this regard. Asked what they would do if they needed more money, one participant answered:

“I ask for it. That’s what I have four boys for. Four daughters and four boys, I have eight.” (1063)

2. Other social networks: Participants described calling on additional social networks, such as employers or religious communities.

“I belong to the church of the Adventists, and they have helped me with a prescription.” (1011)

One woman who worked as a domestic employee recalls:

“I have worked in a house. They helped me a lot... I am alive today because of them. However many times I got sick, they would lay me down, call their doctor, and they would take care of me.” (1051)

Some even utilized their social connections to obtain medications on credit:

“The people at the pharmacy are very good friends of mine. I never have to worry about the payment. I pay my last bill and I take a medication.” (1029)

3. **Loans:** Others deferred to more formal mechanisms and applied for loans:

“Well I took loans. Since we teachers have a cooperative bank that we save up in, so I had to take a loan... Later they discount it from my own salary.” (1049)

8) **Home remedies:** One strategy that was employed throughout the entire spectrum was the use of home remedies as adjunctive, lower-cost therapies⁹. Thirteen of the participants described some type of home remedy in their treatment repertoire. Home remedies varied in their composition and use, from soursop leaf teas to sesame seed mixtures with honey.

“I wash the sesame seeds, leave them to dry, and then I heat them in a pot and I pour in the honey to eat it. It works for your bones.” (1053)

C. Thematic map—The thematic map (Figure 1) depicts relationships among the themes and subthemes described above. Themes in the top half represent contributors to an imbalance between participants’ healthcare needs and the resources available. The remaining themes represent the strategies that participants report using in response to this imbalance. These range from strategies that decrease utilization of healthcare (whether intentionally or coincidentally) at the left, to strategies that involve actively seeking additional resources at the right (summarized by the principles “make do with less” and “find more,” respectively).

Discussion

We conducted 17 interviews to understand how individuals in resource-limited settings cope with chronic arthritis and other comorbid illnesses and seek resources to obtain care. We found that systemic factors related to the public healthcare system, insurance access, and transportation contributed to an imbalance between the healthcare participants could afford and their perceived needs. In response, participants developed diverse coping mechanisms and resource acquisition strategies.

Our qualitative approach allowed us to identify a range of strategies that underinsured Dominicans may use to manage chronic illness in the context of low resource availability. Two previous qualitative studies in the same setting (Hospital General de la Plaza de la Salud, Santo Domingo) have investigated modes of coping with arthritis. Yu and colleagues found that participants coped with pain while utilizing relatively little pain medication, in part by using non-pharmacologic therapies and social support networks¹². Niu et al. similarly identified strategies that patients used to manage pain without medication (e.g., prayer) and to obtain medication (e.g., family financial support)¹¹. Recognizing that comorbid conditions present competing demands for a patient’s resources, we elicited a

more complete picture of factors that influence participants' utilization decisions by asking participants about how they obtain medication and other healthcare in general, not exclusively for arthritis. We note, for example, that hypertension and diabetes are common among Dominicans with osteoarthritis; thus patients' needs often include treatments (e.g. medications) for these comorbid illnesses.

A similar suite of strategies emerged in a qualitative study of individuals in a medically underserved area of the United States. Participants described prioritizing their basic living expenses, drawing on social networks for financial and transportation help, and delaying care or managing conditions independently as long as possible³⁰. Previous studies also suggest that individuals with limited financial resources compensate with social resources to access healthcare²⁷, and that alternative medicine plays an important role²⁹.

Elaborating on prior findings, we found that individuals' coping strategies could be viewed along a spectrum (Figure 1) from accepting limited resources to seeking additional resources. The strategies toward the left of this spectrum are generally more passive. Religious beliefs, for example, were often cited as helping participants accept their illnesses, reflecting the well-documented importance of religion in Dominican culture¹¹. Moving further to the right on the spectrum, participants harnessed their resilience, creativity, and entrepreneurialism to find additional resources for healthcare.

The findings of our qualitative analysis should be viewed as hypothesis-generating. These qualitative data suggest a set of themes related to managing chronic illness with scant resources, but further detailed, quantitative studies are needed to confirm these observations. Additionally, participant characteristics limit the extent to which we may generalize findings. Our participants were all Dominicans with advanced arthritis who were scheduled to undergo joint replacement. The majority were female. Coping strategies might differ in individuals with less severe arthritis, males, and people living in countries with different cultural practices and policy contexts.

These findings suggest avenues for further research and also have implications for clinical practice and policy. For clinicians working in low-income settings, it would be valuable to understand the strategies a patient may use when managing chronic illness, such as skipping doses or eliminating certain medications entirely, and why they may employ these strategies. Participants reported that coverage under SENASA was often insufficient even for basic medications and office visits. In addition, transportation was a significant barrier for many participants. The findings highlight the need for policies addressing underinsurance and transportation-related barriers to care. Without changes in the cost of services or the level of support provided to patients, the trends noted in our work will likely persist.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Significance and Innovations

- Provided insights into decision-making within a societal context that perpetuates a lack of access to healthcare, in a middle-income country with stark income inequality (Dominican Republic)
- Illuminated a range of strategies used by Dominicans to manage chronic illness when available resources are insufficient for accessing healthcare
- For clinicians working in resource-limited settings, provided insights into strategies that patients may use to manage chronic illness when lacking resources for medications
- Highlighted the need for policies addressing underinsurance and transportation-related barriers to care

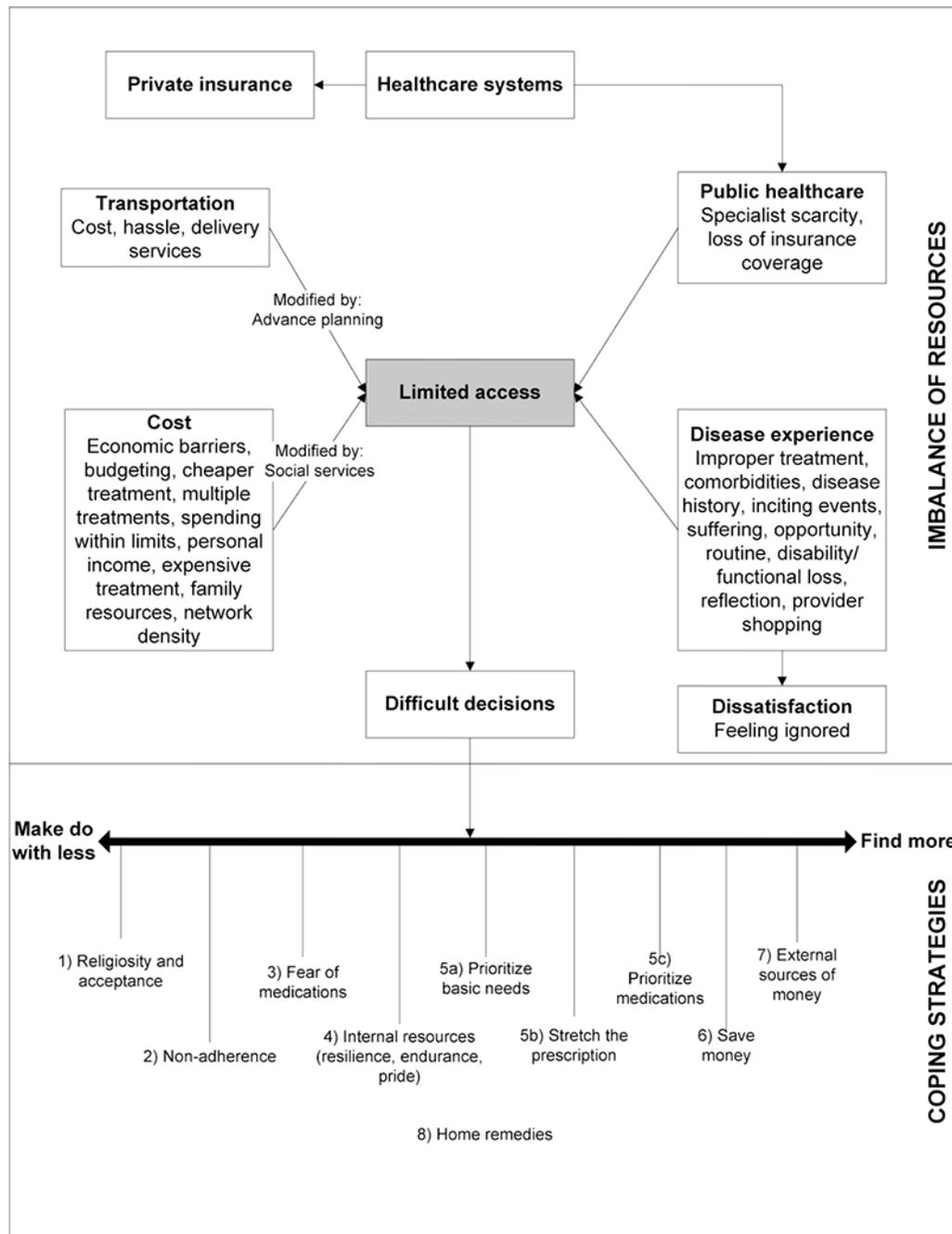


Figure 1.
Thematic map

Table 1:

Moderator's guide

Topics	Questions
Demographics	<ol style="list-style-type: none"> 1 Level of education? (None, elementary complete/incomplete, high school complete/incomplete, university complete/incomplete) 2 What kind of setting do you live in? (City, town, or small village)
Arthritis experiences	<ol style="list-style-type: none"> 1 For how many years have you experienced pain or problems related to arthritis? 2 How many years ago was your arthritis <i>diagnosed</i>? 3 Tell me about your arthritis. How has it affected your life? 4 Do you take daily medication for your arthritis?
Affording arthritis medication	<ol style="list-style-type: none"> 1 Where do you get your medicine from? Have you ever had limited access to medications due to transportation issues? 2 Do you know the cost of your medication? Do you have insurance that covers it? <ol style="list-style-type: none"> a. If you are short of money for medications, do you find other ways of getting the money or do you have to miss doses? How can you ask for money if you need more than you have? 3 Do you ever have to make choices between paying for medication and something else (food, school, clothes, housing, etc.)? 4 Have you ever skipped doses, stopped taking your medication, or switched to a lower dose because you were unable to pay for the prescribed amount?
Affording medication in general	<ol style="list-style-type: none"> 1 Are you on any other medications? <ol style="list-style-type: none"> a. If so, have you had problems paying for these medications? b. If you have had problems paying, what do you do? Find the money somehow? Miss doses? Get medications donated from community members? 2 If you have difficulty paying for medications, do you try other treatments that are less expensive? <ol style="list-style-type: none"> a. Probe: for example, switching to a different medication for the same disease without consulting your doctor, herbal remedies, teas, prayer, song, spiritual healing?
Visiting a doctor	<ol style="list-style-type: none"> 1 What do you see a doctor for? In the last year, how many times did you see a doctor for arthritis pain? 2 Is there any reason why you would not see the doctor more often (payment, travel distance, work requirements, etc.)? 3 Can you think of times when you had to miss a visit because you could not afford to pay for it, or when you could not find transportation? 4 If you cannot pay for a visit, do you usually miss it or do you find the money somehow? How?
Insurance	<ol style="list-style-type: none"> 1 Do you have insurance that covers your doctors' visits? 2 If yes: <ol style="list-style-type: none"> a. What type of insurance do you have (National/Private)? b. Does the insurance cover the whole visit, or do you have to pay for part? How much do you pay for? Does anyone help you pay for these visits? c. How do your friends and family pay for medications and doctors' visits? 3 If no: <ol style="list-style-type: none"> a. How do you pay for these visits? b. Does the doctor ever charge less for people who can't pay as much? 4 Do you think that difficulty with paying for medications and doctors' visits has worsened your health?