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"My life is about to take care of myself": therapeutic itineraries of care for frail older adults

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Abstract *The present study sought to understand how frail older adults perceive their therapeutic care itineraries. This qualitative research was based on Critical Medical Anthropology. Data were collected through interviews in the homes of 22 older adults, whose average age was 79. The emic analysis was guided by the model of Signs, Meanings, and Actions. All interviewees expressed access to professional care in their trajectories, which are understood as insufficient, unprepared, prejudiced, uncomfortable, contradictory, (un) accessible, realization, respectful, and excessive. Therapeutic itineraries were also revealed in the psychosocial and cultural spheres. Several day-to-day actions were evaluated and interpreted in the record of self-care and justified by this end: the time they wake up, sleep, what they eat, and how they behave. They face the lack of care policies in their trajectories, labeling their bodies as undesirable due to physical, symbolic, communicational, attitudinal, systematic, cultural, and political barriers. Thus, they bring to light therapeutic pluralism, challenges, confrontations, insistence, and resistance in maintaining care when experiencing old age with frailties.*

Key words *Older adult health, Anthropology, Culturally competent care*

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Introduction

Aging of Brazil's population has been an accelerated and intense phenomenon and has seen an increase in the number of people aged 80 and above. At the individual level, this phenomenon can be marked by relationships of frailty, dependence, and autonomy, which are reflected in the demand for care[1] and require more effective involvement by the individual[2]. This situation continues to be overlooked in Brazilian society[1,3]. Thus, understanding care needs and strategies from the perspective of frail older adults and developing care models based on their perspective and the context in which they live are priorities[2,3].

The care experience is an individual and collective construction, the product of political processes that can prevent or accelerate suffering[4]. In this regard, self-care reveals the possibility of resistance as an ethical and liberating process directed towards making their own lives, intertwined with the interpersonal, community, social and political dimensions[5]. Therefore, it is essential to know the experiences and, especially in the context of care with frailty in old age[1], consider the power of speech and subjects' ability to act [4].

The socio-anthropological perspective considers the plurality of knowledge and practices in managing daily care[6] and the explanatory models useful for analyzing how individuals find meaning, interpret and guide their actions[7]. Therapeutic itineraries reveal health needs, focusing on the experience of users[3,6]. Particularly for older adults, there are few studies on the practical ways they understand the healthcare process and how it works[7]. This knowledge can contribute to evaluating care, understanding the meanings of care relationships, and articulating more effective actions[3,6].

In addition, frailty has been recognized in multiple interrelated domains[8] and occurs dynamically and malleably[8-11]. In old age, this frailty process takes the form of an experience of vulnerability with clinical and social consequences[8]. This multidimensional process is correlated to the physical, psychological, social, environmental, and life course domains, as well as to social and economic determinants[9,12,13]. However, the literature lacks studies on the care network accessed by frail older adults[13]. In this sense, the present study aims to understand how frail older adults perceive their therapeutic itineraries of care.

Method

This qualitative research is based on the theoretical-methodological framework of Critical Medical Anthropology[7,14-16]. In this approach, health impairment is understood as an experience in which cultural factors are central since they shape behavior, care, diagnosis, and treatment[7,14]. This orientation focuses on health, disease, and the body and on people's life experiences and subjectivity[14]. Thus, it historicizes and decentralizes biomedical knowledge by overcoming the dichotomy and capturing the co-production between biology, culture, and technologies manipulating life[15]. In this perspective, the *disease* is the pathology in the medical, biological view; *illness* is the human, psychosocial experience of the disease, while *sickness* considers the position in society and other macrosocial forces: economic, political, cultural, and institutional. These are inseparable aspects, not isolated, but in constant interaction in the health-disease phenomenon[3,7,14].

Data were collected through comprehensive interviews, using a semi-structured script on the following issues: perceptions about health, aging, frailty, care, and the strategies used to address these issues – community and personal resources. The selection of participants was intentional, conducted using the baseline database from the multicenter study Frailty in Older Brazilians (*Fragilidade em Idosos Brasileiros* – FIBRA) from the Center of Belo Horizonte, Minas Gerais (MG)[17]. The inclusion criteria aimed at a greater heterogeneity of participants regarding age, gender, functional condition, and region. People who were physically and cognitively unable to respond to the interview were excluded. Interviews were scheduled at home by telephone. The challenges in locating the participants were due to changes in telephone numbers and death. None of the older adults refused to participate. Averaging one hour in length, the interviews were conducted by three psychologists and a physiotherapist, professionals who were experienced and specialized in the area of human aging. The conclusion of the interviews was based on the quality, quantity, and intensity of the data collected that would allow the approximation of the phenomenon's complexity[18].

The interviews were recorded and transcribed. In the field diary, the perception of the researchers was recorded. The data analysis was based on the model of "*Signs, Meanings, and Actions*," in which the usual logic is reversed: it starts from the subjects' actions to access the se-

mantic level as a privileged access route to cultural systems[19]. The *emic perspective was used*[14]. The analysis began with an in-depth reading of the material collected to approximate the context and emerging issues of interest. Subsequently, successive readings were carried out to identify levels of signs, meanings, and actions. We used an Excel spreadsheet to record our data, where each horizontal row corresponded to a participant, and columns were arranged from the manifested themes to examine the relationships between the levels. In this process, the content of each interview was sectioned and organized, and categories emerged. Each category was refined to deepen the analyses.

This research is part of the project "Frailty in Older Adults: perceptions, cultural mediation, coping and care (*Fragilidade em idosos: percepções, mediação cultural, enfrentamento e cuidado*)," approved by the Ethics Committee of the René Rachou Institute – Fiocruz, under opinion No. 2141038/15. The participants signed or registered their fingerprints on the Informed Consent Form (ICF). To ensure confidentiality, respondents were identified according to gender (H for men or W for women).

Results and discussion

The study participants were residing in Belo Horizonte, the capital of Minas Gerais, Southeastern Brazil, with a population of 2,523,794 inhabitants, in 2017. In 2010, the municipality achieved a result of 0.810 on the Municipal Human Development Index, but with great social inequality (0.60 Gini index). The aging rate in the municipality was 8.67%, and life expectancy at birth was 76.7 years[20].

Among the participants, the macro-social aspects serve as the backdrop against which care processes occur:

I always go to the doctor. We have P.'s Health Center nearby; the Health Center has a very good service. They are well-organized, so everything we need, we have there [...]. We try to do check-ups whenever the doctor, who is always there, asks [...] I had cataract surgery last year [...]; the doctor said I had to have varicose vein surgery, although I had asked for cataract surgery before. Then she sent me to the Specialty Center to do the exam, and from there, he sent me to São Geraldo (ophthalmological hospital), which is nearby [...] So, we've been preventing this for a long time. I walk and try to attend the doctor's appointment. Anything I feel, it's easy, I seek... it's... take advantage of the facilities we have, right? (W4)

I started to understand older adults when I started going to doctor's appointments; due to the spine, those aging problems began, and every doctor says something, "Oh, there is no way," "This can't be solved because of your age" [...] Except I didn't go for them. I went to find someone who could talk to me better. [...] (Dr. C and Dr. J.) had that healthy conversation that did not put anyone down [...] The laboratory [staff] comes here; I avoid leaving often because it's like they say, right, I'm old, I'm not 20, 30 years old anymore (W5).

This doctor, who I spent [money] on that I was not able to pay this doctor, because of this leg [...] they referred me to a doctor up the street, then I went by bus, being careful about others not bumping against my leg, as the downtown buses are very crowded. Still, I went there to the doctor [...] Then I took to go there, plus [spend] 250 (reais) for each appointment. I didn't have that money, but I got it [...]. it's like this with an older adult who depends a lot on others, depends a lot on people when they can afford it, a person to walk with us [...] I can walk by myself, but I am afraid [...] if I need to go to the Health Center, I go alone, but the girls [daughters] don't let me (W13).

And it's not possible for me to leave here today and go there, help my mother—because I can't take a bus, because the bus, the passengers won't let me get out [...] They don't give their seat to me, as they think I'm healthy. Then I get tired, exhausted. [...] Mom was here [...] She is 96, healthy, but stopped taking walks, and everything, not because of her age, but because of the events of her life [...] For example, people do not respect older adults on the bus. No way! They mistreat us … In hospitals, the same thing [happens] (W20).

Participants report going to Health Centers (HC), Emergency Care Units (ECU), and private appointments with specialists when possible. They also said they obtain help from others to maintain their care in a timely, transient, or lasting way (partial or full) and seek a variety of resources to take care of themselves.

Speakers repeatedly stated that the location of services, financial resources, social stigmas, and cultural appreciation can impact the care process. For older adults in frailty processes, the need for care is complex and changeable, and the adequate provision of health services must be carried out without social, financial, organizational, and cultural barriers[10].

The municipality of Belo Horizonte has a Health Vulnerability Index (HVI) for its mi-

cro-regions that considers the conditions of sanitation, housing, education, income, health conditions, and age of the head of household.[21] This indicator identifies inequities in census tracts and points out priority areas for intervention of social and health services, including for the older population. Areas with higher HVI have worse health conditions, and the probability of having exclusive users of the Brazilian Unified Health System (*Sistema Único de Saúde* – SUS) was five times higher than those at lower risk.[21] Medium and high complexity services are mainly found in public and private networks in the Central-Southern region where the hospital is located, creating inequality in terms of space and in the provision of services[22].

Figure 1 depicts a map of the HVI of the neighborhoods of Belo Horizonte, MG, where the lighter tones represent the lowest indexes and the darker tones the highest, in which points represent the geographical distribution of the 22 participants. The literature recognizes that health equity considering social determinants is an ethical imperative for enhancing the population's health[10]. To broaden the understanding of the scenario, the characterization of the participants in Chart 1 follows.

Regarding the care itineraries, one interviewee explains:

(I) have already had 11 surgeries, apart from the small ones I don't count [...] My daily life is going to doctor's appointments and hemodialysis (laughs). [...] I spend a third of the day lying down because it's good to recover too. The rest [of the day], I sit in the living room, watching TV. If I have to go to the bank, I will. [...] My life is about taking care of myself […] I have the power to feed correctly every day, go to the doctor [...]. Many young people do not care for themselves as I do for myself. [...] If I have to drive today, I don't drive anymore, right!? I can't! My family won't let me either. Do you think that we, that I don't want to? I have said I would like to drive, but I think I'm a lot different from 10 years ago (M12).

The perception of therapeutic itineraries was organized into two categories: "There is no good medicine for healing" addresses the perception of the care trajectory, and "Vicissitudes of the care process" refers to multiple actions in the search for care.

"There is no good medicine for healing"

All interviewees stated that they frequently use health services and medicines for treatment, diagnosis, and prevention, as elucidated in this narrative fragment:

Because I had, first, hepatitis, and then cancer, GD [swearing]..., hepatitis B, so these hypotheses [...] so anything she [the daughter] wants to know, she sends me to the hospital to get tested, I have a lot of tests (M7).

The trajectories in health services receive different interpretations, according to Chart 2.

The interpretations by the interviewees mostly reveal experiences of uneven therapeutic itineraries, with comings and goings throughout the care network, on long and complex paths with a lack of humanization and delays in meeting demands. But some older adults are able to access it and feel welcomed. Some who seek better care experience resource limitations and seek additional help from the family, whereas some determine they are being subjected to excessive treatment.

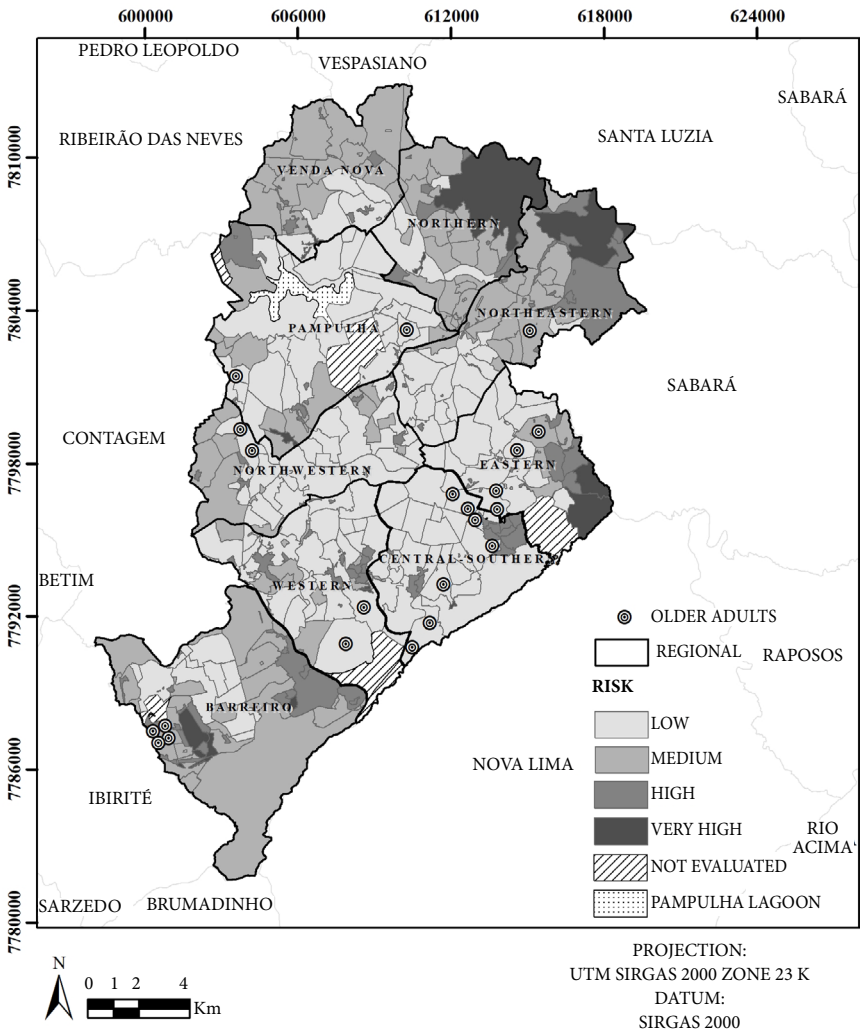
The explanatory models indicate the need for greater investment in quality of care and interpersonal communication. Similar to the data in this research, fragmented health systems respond poorly to the growing frail older population[8,10]. Although comprehensive and integrated care could increase the quality-of-life satisfaction, improve the care experience and reduce costs[10], there is disrespect for what older adults say and their exclusion from conversations about decisions about their health[22].

In the field diary, the therapeutic itinerary that triggers aspects involved in one of the interviewee's perceptions of the care professionals receive was recorded. She complains of "bad surgeries," nerve, shaky leg, and tinnitus: "I feel a buzzing in my head [...], it's like a pressure cooker [...], it never stops (the tinnitus), it never stops, it is all day, all night" (W6), and she adds:

It's only God, only God [...] We do our part, and they [the doctors] studied; they know how to prescribe [medicines]. It is hampering, hampering life, prolonging life more (W6).

The interviewee's son passed by the kitchen where the interview was taking place, interpreted the mother's speech from his perspective, and scolded her. He stated she could not stop medications and medical follow-ups (Field Diary, W6, May/2018).

Thus, the therapeutic itineraries also highlight the relationship and cultural dimension with family members and professionals. In most Western capitalist societies, medicine is a hegemonic knowledge about the body, and its logic reduced only to the biological anatomist scope desacralizes, objective, and fragments the body[23].



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DATA SOURCES: IBGE, 2007, 2010; SMASA, 2010, PRODABEL, 2011; SMAPU, 2014.

Figure 1. HVI by neighborhoods in the municipality of Belo Horizonte, Minas Gerais.

Source: IBGE, 2007, 2010; SMASA, 2010, PRODABEL, 2011; SMAPU, 2014.

For W2, while she experiences arthritis/*disease* and *the* prescription of several surgeries/*disease,* in her body, she feels pain/*illness* and fear of inefficiency/*illness*. She fears the adverse effects of *treatment/illness* and the possibility of being unable to access *the necessary treatment/sickness.* Thus, her experience is reported as an eventuality of old age with frailty she must deal with.

In this study, the interviewees interpret exams and medications ambivalently: sometimes as necessary and essential, sometimes as excessive, insufficient, and contradictory. In this context, the medicalization of life is present as a heterogeneous field of objectives, tactics, and strategies that impose discourses of truth about health and life, maximizing the number of consumers[24]. Moreover, the view of old age as a disease reinforces this practice. In Brazil, medicine plays an important role in everyday care, reconciled with a culture that disseminates the pharmaceutical dialect and naturalizes it as the solution to problems[25]. However, the literature points out that as

Chart 1. Characterization of older adults based on reports obtained in the interviews.

Person's ID/ gender	Age	Family configuration*	Source of income (profession)	Description of health condition (main complaint)
M1	74	She lives with her husband, her son lives upstairs at the same property, and her brother-in-law lives next door	Retired (houseworker)	History of hypertension, suspected minor stroke, recent report of weakness, weight loss, and anemia
M2	72	She lives alone. Widowed and childless. A niece lives nearby, but she complains about being alone	Pensioner and retired (houseworker)	Peripheral neuropathy, depression, use of sleeping medication, history of falls, diabetes, hypertension, arthrosis, vertebral fracture, wear and tear of the spine, knee problems, headache, and reflux
H3	79	He lives with his wife and has two daughters	Retired (engine mechanic)	Trouble moving, burning in the leg, wear and tear of the cervical spine, high cholesterol, pre-diabetes, and history of kidney stones
M4	74	She lives with her husband and has two daughters	Retired (sewage worker, nutrition technician)	History of gallbladder, varicose vein, and cataract surgeries
M5	76	She lives with two grandchildren but has one more daughter who lives on the same land lot (with three grandchildren). Widow, has seven children (three died)	Cleaned houses at 70 years old because she was not retired	History of falls and fractures
M6	89	She lives with her husband. Three children take turns to be present	Retired (houseworker and sewage worker)	History of appendix and gallbladder surgery. Currently, tinnitus in the head, shaky leg, and "nerve" [anxiety]
H7	81	He lives with his wife and has three children	Retired (banking and law graduate)	Hepatitis virus, hernia surgery, pressure change, and ear obstruction
M8	93	She lives with her niece, a professional caregiver. Single, used to lived alone	Retired (teacher)	Three falls [Parkinson's disease]
H9	76	He lives with his wife and a child. He has two children	Retired (automotive mechanical engineer)	Diabetes, neuropathy, cataract surgery, lower back pain, and vitamin B12 replacement
H10	79	He lives with his wife and one daughter but has two more daughters who live on the same land lot. He has eight children	Retired (mailman)	Takes medicine for his thyroid and reports a history of dizziness and nervousness. Has headache and suffers from alcoholism
M11	86	She lives with two daughters; one works, and the other is bedridden. She has a professional caregiver at home. A widow, she has 12 children (two died)	Retired (teacher)	History of arthrosis that limits her movement, recent conjunctivitis, and onset of pneumonia
H12	86	He lives alone and pays two full-time caregivers. He is divorced and has eight children	Retired (road manager)	He's been on dialysis, has a history of 11 surgeries, and has a femur fracture
M13	74	She lives with her husband and daughter and has two other daughters who live on the same land lot. She has eight children	Beneficiary of the Continuing Benefit (day houseworker)	Diabetes with food restriction and difficulty healing - reports wound that took ten years to heal, led to hospitalization and limited functionality

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Chart 1. Characterization of older adults based on reports obtained in the interviews.

Person's ID/ gender	Age	Family configuration*	Source of income (profession)	Description of health condition (main complaint)
M14	78	She lives with her husband and has three children	Retired (higher education teacher, psychology graduate)	She has a stent in her heart
M15	83	She lives with her husband (dependent person); a son lives on the same land lot	She works in a fair, selling snacks. (She provided no information about social security)	She is under oncology treatment and requires hernia surgery
M16	83	She has lived with her daughter's family for 10 years. Widowed, she has three children. She lived in the countryside until her husband's death	She provided no information	Shoulder fracture, body pain, cervical spine problem – lordosis; blood pressure and cholesterol treatment
H17	86	He lives with his wife and special needs daughter. He has three children. Another daughter lives nearby	Retired (architect and engineer)	Early-stage Alzheimer's dementia
H18	69	He lives with his wife. He has four children and six grandchildren	He provided no information	He treats chronic myeloid leukemia and had prostate surgery
M19	74	She lives with her husband. He has three married children	Retired (nursing technician in hospital)	She reports some insomnia
M20	72	She lives with her husband (frail). At the time of the interview, there were two sons, a daughter-in-law, grandchildren, and grandchildren's friends	She provided no information. She takes care of her husband and domestic activities	Complains about her balance
M21	74	She lives with a mentally ill brother	Retired (does not detail professional activity)	Heart problem.
H22	74	He lives with his wife and three daughters. The daughters help with the bills, in paying for health insurance	Retired (theologian)	He lost 50% of the vision in one eye and 90% in the other due to maternal toxoplasmosis. Hypertension

Elements of family configuration. Complementary aspects: three couples were interviewed: M3 and W4, M10 and W13, W14 and M7. Among the 22 participants, 16 specified how they access health services: nine were exclusive users of the SUS; among these, four reported paying privately for some procedures or appointments with specialists; and seven claim to have medical insurance and participate in cooperatives or health service cooperatives.

Source: Authors

a consequence of medicalization, there is a tendency for people to move away from taking responsibility for their own health[15], an impossible distance in the interpretation of the interviewees who continue to build alternatives for their self-care. Several day-to-day actions are evaluated and interpreted in the record of self-care and justified by this end: the time they wake up, sleep, what they eat, and how they behave. A repeated search for a technical solution that, in some situations, is presented as excess medication[15] and exams is also observed in the interviewees with socioeconomic resources, immersed in the logic of the market and the private health system. Marked social inequality, limited investment in public health, high consumption of pharmaceuticals, and majority access to a vast number of over-the-counter medicines are still practices in the country[16].

Criticism is observed on the part of the interviewees to the treatment made available and to which they resort: *Although there is no good*

Chart 2. Interpretations of care trajectories by frail older adults in Belo Horizonte, Minas Gerais.

Sections	Meaning
He [the doctor] said I would have to get it. I already had surgery on both shoulders, but it didn't help because I have arthrosis. [...] I have my knee here; Doctor C2 sees this as more swollen than that. There are days when it is really [swollen]. [Due to] attrition, he ordered me to have a shoulder replacement. I don't feel like it at all. Maybe it will get worse later; I've seen two people who got worse and can't stand walking. (W2)	Insufficient
God takes care of the older adults because waiting for medicine is a failure for them unless they have a lot of money, which I don't. I trust God, and I'm standing; if I weren't, I'd be in a wheelchair. I went to get an X-ray. I couldn't stand to stay there to do it. I was forced to do that in terrible pain. It looks like the fracture is even worse. They are professionals [...] who are not prepared to mess with injured older adults. [...] I have a cardiologist. He's old; he knows my frailty. I get there; he doesn't treat me like an equal; he feels young, but I think he's older than me. (W5)	Unprepared
If we go to the doctor, he doesn't ask me how I'm feeling; he asks the girls [daughters]. If I go alone, they don't even consult me. 'Do you know you have to have someone [with you], a companion?' I know what I'm feeling. Do I need a companion to tell me!? But it's their way, right!? They think we don't know or making up that we're feeling something, anything, '—Oh, but we need to have a companion'... —as if we were a child; I don't like to be treated like this because we are just lowering more and more, we see that we're not worth anything, that we don't know anything, I don't know, that we're not telling the truth, I don't know, being an old person is not good! It's not good! Like if I were maybe an old person who attended a club, who was like that, who went out, who was in a park, something like that, perhaps it would be better, but I'm not going anywhere [...] then I talked to the doctor [at the Health Center], I asked the doctor: "I need a geriatrician." He said—But what? Ma'am, are you tearing up money? I said, no.—Are you getting lost on your way home? I said no, like that.—So you don't need one, you don't need a geriatrician." (W13)	Prejudiced
[...] the street passes, on the top side is a vacant land plot with a bit of bush, and on the bottom side is the asylum, and she was sitting there; I said, oh, what will it be, that she had already passed in life? It's there like that, didn't the family want her? Is she so bad that her family doesn't want her? Being at home, they put her there because she's not that old, she's not that old, and she's a corpulent older woman; what is she doing there? And I got this in my head, thinking, how life is ungrateful, how we don't know how it's going to be, the end of life. [...] [if someone] says they want to get old and go to the asylum, I will say, don't go, don't go! There it's like every person for themselves, every person for themselves. (W13)	Discomfort
[...] this medicine is ruining another one, you know? So I stopped [taking it] by myself. I said I'm not going to take this, and I'm going to do what's best for me, so I'm going to reduce excess work, medication, and I'm going to police myself more. [...] I have to know if I'm benefiting from that medication and if it is doing me good or hurting me. (W5)	Contradictory

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medicine for healing, we live our lives! (M10). They understand there is no treatment to resolve their situation despite the recurrent access and the range of resources prescribed. Despite this, they continue to live, reveal the uniqueness and potential iatrogenic effects of professional intervention and the use of medications resulting from their comorbidities, change prescriptions, and invest in building alternative therapeutic itineraries. In another survey of older adults with chronic diseases, 9.2% reported a desire to make fewer medical appointments; 23.3% considered the procedures useful, and 14.7% undesirable[26].

In general, the interviewees expressed their desire to choose among the treatment options, weighing their interests, despite the medical indications. Similar to what was presented by the protagonists of the present study, other studies show the unpreparedness of health services for the care of older adults[8,10], the lack of motivation of professionals for this care,[9] and the scarcity of geriatric and gerontological care[8,10].

Chart 2. Interpretations of care trajectories by frail older adults in Belo Horizonte, Minas Gerais.

Sections	Meaning
I went to do some tests. I went to ECU there to do a blood test, and it resulted in anemia. Then the SUS doctor took the tests, but a SUS doctor, you know... It's a very time-consuming thing. Then the ECU doctor said, 'It is good for you to talk to your family, and each one helps and will pay for the blood test.' Then my sisters raised all [the money], each one gave a little, and I did the blood tests. All tests resulted in low [indices], all low. Then I said, 'Oh my God!' I went to the cardiologist, and they paid the cardiologist for me [...]; then he asked me to take medicine, I took medicine, and he said I should look for a SUS hospital to do the follow-up. I went to do the follow-up [...], measuring my blood pressure every day. (W1)	(Un)accessible
Every doctor says something, "There is no way," "This can't be fixed because of your age," then I met a physiatrist who said: No! You need to be treated so you can reach a healthy old age. Then I rejoiced, right, because I was 62. [...] so then I started to be treated, seek various treatments, with several professionals, and they, you know, cared little because the older adult is very like that, despised within the framework [...]. At that point, one thinks about oneself, that one is old, that the doctor said this, the doctor said that [...] And doctors always say that to the patient. And the patient believes it. Except I didn't go for him. I went to find someone who could talk to me better. (W5)	Realization
I would like to add that I don't have health insurance, and our health post, in the P. post, I'm very well received. I have been very successful with all the problems I have had, with them, regarding care; I think I'm very well respected. (M3)	Respectful
So you know, she has been my doctor for many years; I'm just [being seen] by her. I've been getting along very well, controlled health, I've done 52 tests, at her request [...] so you see I take care of my health, that way, every six months I go to the doctor, everything I have, everything I feel I report she refers me to other professionals if that's the case. [...] You will take this medicine here for cholesterol. But, doctor, cholesterol is a boy's. [issue] — It is not to avoid; it is to protect your heart because of your age (laughs). We see things happening. Every time I go there, she gives me another pill. There are times when I take it; there are times when I don't. It's not medicine to cure the disease, and it's medicine to protect [health]. Because of our age, we realize that. So that's it, we're living. (M9)	Excessive

Note: our emphasis.

Source: Authors.

The interviewees recognize the ECU as a gateway to access consultations and exams while they carry out longitudinal monitoring and chronic diseases in the HC. Faced with the (im)possibilities of access, many interviewees invest in building a trajectory but depend on financial resources when they need to pay to obtain access to specialists, multidisciplinary teams, exams, and medicines. Similar to our findings, this progressive demand for care is often postponed because they support their families[9], compromising their financial resources and use of their own time.

The interviewees express experiencing prejudice because they are older. This is ageism, a form of discrimination against older adults, which causes a worsening in the quality of life of the population[27]. Difficulty in accessing social and health services appears in qualitative research at the international level among frail older Polish[10], Belgian[9], and Canadian[8] people.

Similar to the interviewees' narratives in this study, frail older adults perceive the insufficiency of the services offered and are frustrated with the long wait for care and lack of formal support[8-10]. This indicates a system unsuited to their needs, compromising their quality of life[8,10]. Other articles have also observed The allusion to the need for access to geriatric evaluation (W5) and the improvement of care provided in the HC[8,10]. Experience of age prejudice, a feeling of being abandoned by the health system and professionals, the inadequacy of staff to meet demand, and the lack of confidence in care have been indicated in the literature[8,9].

The challenges experienced in the care paths of these people in the frailty process are presented in the following category.

Vicissitudes of the care process

There are multiple actions perceived as care itineraries by the interviewees, according to Chart 3.

At the beginning of the interviews, the therapeutic itineraries are named in a manner adapted to that defined by biomedical knowledge. This hegemonic discourse is appropriated and reinterpreted by the interviewees in a translation about diseases and their understanding of health. Throughout the interview, care actions are comprehensive, fluid, intertwined, and diverse, with psychosocial and cultural aspects. There are frequent interpretations as actions in the therapeutic itineraries: interacting well with others, not abusing health and feeling useful, being religious; having companions; being calm and honest; avoiding sadness, resentment, anger, and worry. There are also concerns about the society they are a part of related to precautions on the street, on the bus, to be socially active, and to mentalization, as elucidated by the narratives:

But I'm taking it like this... it hurts, I take medicine that he prescribes, or if not, I stop moving around a little, there's a hot water bag, another time ... it passes, and I'm taking it... I don't take it too seriously, no, they know... yeah, it's tough (W16).

I think that we, to reach this age, well, I think we have to have patience, to get along with people, to try to avoid anything that can annoy us, not to suffer from anxiety [...]. So that's what we always try to do: live a quiet life within our reality. Good nutrition is also very important. Don't have vices like drinking or smoking. Not having addictions like this, of food too, we eat lighter food, more suitable for our body. And, if possible, exercise, go for a walk, do Pilates to strengthen the muscles, this is

Chart 3. Healthcare actions for frail older adults, Belo Horizonte, Minas Gerais.

Narratives
What do I do? Oh, I take some pain medication, do some exercise, and put some hot water bags [...] I take care of myself as I told you, staying home, I go to the doctor, I take my medications [...] and my food; I don't think it's bad, it's good, you know? that thank God I can buy dairy products [...] I like to stay up late watching television. After all, I can get up later, because I'm not sleepy early, you know? And then I'm living my little life here, quiet [...] water aerobics; you have to pay for that, right? It's better to wait until you have the money [...] I'll take care of myself. [...] doing the things I like [...] Sometimes someone is upset; sometimes, if it's talk, you end up mistreating that person; I'd like to stay on my own. It's good to stay away from those things that upset you; I'm not going to take this out of my life; you say this, stay quiet, and oh, you think that, oh, it's when you have something, you do it, to see the consequences. [Q: But does it protect us?] A: Protect, and you get better. It depends on your faith, doesn't it? On your courage, you talk to yourself, to God, and ask for protection because we have to have one protection, and God is one, and He doesn't forsake His children! (W2)
I walk, I climb stairs, I just don't run because age doesn't allow it [...] I try to eat well, follow medical recommendations, go for walks, and do some leisure activities, and I go for a walk. When I can, I go to the theater [to see] a comedy, a movie, little things, and I like soccer on television. [...] So I don't smoke. I try to get along with everyone, especially in the building. I live well with everyone; everyone respects me. [...] I used to go to the farm to travel there at night without a problem; I used to get there, play cards, drink liquor, and smoke a straw cigarette. Barbecue, let's say, with no limits. But all of this, from about 15 years ago, I practically isolated myself from everything, and every man who values his health has to do it because this only creates problems for the person. (M3)
Nothing better than spiritual health [...] for the older adult, excellent medicine is to have friends, talk, speak [...] when I can, and go to church [...] if you know that your age does not allow you to take this medicine or do what you do, don't do it! Older adults have to police themselves [...] It is not that you are old, but it is that the time of limitations has come, whether you want it or not [...] There is that medication that if I don't take it, I will harm others and myself, so I have to take it [...] I always try to have my water bottle by my side, have a television for me to watch [...] avoid smoking, alcohol [...] look for healthy food [...] always try to sleep well [...] obey the rules of the body [...] do mental hygiene [...] physical activity is great, it is very good to walk [...] I come back immediately, and in addition, here in the neighborhood, I do not walk because life has also changed a lot; people don't care much about others, and it doesn't take much for them to throw you on the floor. (W5)

it continues

very important. And it... Be careful when walking to avoid falling - this is very dangerous at our age (W19).

Here in the building, I get along with everyone. Everyone respects me. [...] So they have to have love, they have to have affection, they have to have a means of locomotion [...] a healthy diet [...] has to give hope to life [...] Dress the way older adults like to dress. [Listening to] music the way older men like it. So, coexistence in everything. And no disrespect (W20).

I got sick in 2007. I had a serious heart problem, and I was hospitalized; I was disillusioned. [...] I was well-medicated, and great doctors took good care of me. And also, with me, there is something that I value immensely, which is the spiritual side: I do spiritual treatment and spiritual surgery. And it gave [me] excellent results. [...] it helps doctors (W21).

Along with biomedical and allopathic professional knowledge, the interviewees resort to informal treatments, following advice, self-treatment, seeking homeopathy and spiritual surgery. Alternative therapies or practices are generally used to complement traditional medicine, whether for relaxation, improved mobility, to provide pain relief, or promote health or general well-being. The cultural circularity of the discourse is observed in a complex tie between recommendations until the final decision that makes sense or not for the person. This connection encompassing the use of natural products, homeopathy, the search for healers, mental and body practices, music, exercises, home remedies, and prayers is presented in another study[28].

In beliefs about care, older adults seek to sustain themselves, invested in their ability to perform everyday activities (shopping, driving, tak-

Chart 3. Healthcare actions for frail older adults, Belo Horizonte, Minas Gerais.

Narratives
I went to the pharmacy, looked for homeopathic medicine, and bought the medicine because when allopathy offers no recourses, we should look at homeopathic medicine. Because I understand a little, I have already used homeopathic medicine, not exclusively; I also take the necessary allopathic medicine. Still, when there is no resource, we look for homeopathy [...] [I take] care not to climb a ladder that can slip [...] I don't like to be stuck here in the house; I like to go out, talk, meet with friends, chat, and have a beer; it's not because I'm old that I'm going to stop doing this, maybe I'm the oldest of them, but they accept me as young, the chat flows, the jokes, the soccer discussions [...] now when the environment is a healthy environment a good environment where the people you live with also stimulate you!? The physical and intellectual activities, you start to gain strength, of course, here at home, my children help me a lot in this part, you know, — Daddy, [there is a] good book, they launched a very good series on Netflix. [...] the environment you live in leads you to be positive or negative. Besides, the conviviality is also not only familiar, no, but I also have social conviviality [...] you have to go out, take a walk, let's go there, let's do it, help me do it, ok!? (M9)
But I'm taking it like this... it hurts, I take medicine that he prescribes, or if not, I stop moving a little, there's a hot water bag, another time ... it passes, and I'm taking it... I don't take it too seriously, no, you know... yeah, it's too hard. (W16)
To reach this age, well, I think one must have patience, live together, try to avoid anything that can annoy us, and not suffer from anxiety [...] So that's what we always try to do: live a quiet life within our reality. Good nutrition is also very important. Not having addictions like drinking, smoking, not having addictions like that; food as well, we eat lighter food, more suitable for our bodies. And, if possible, exercise, go for a walk, do Pilates to strengthen the muscles, this is very important. And... Be careful when walking to avoid falling—this is very dangerous at our age. (W19)
Here in the building, I get along with everyone. Everyone respects me. [...] So you have to have love, you have to have affection, you have to have a means of getting around [...] a healthy diet [...], you have to give hope in life [...] Dress the way the older adult likes to dress. [Listening to] music the way older adults like it. So, coexistence in everything. And I'm not disrespectful. (W20)
I got sick in 2007. I had a serious heart problem; I was hospitalized and disillusioned. [...] I was well-medicated, and great doctors took care of me and also with me—there is one thing that I value immensely, which is the spiritual side: I do spiritual treatment, spiritual surgery. And it gave me excellent results. [...] it helps doctors. (W21)

Note: our emphasis.

Source: Authors.

ing care of the house, washing clothes) as a care resource to maintain their independence[2,13,26], creating means to circumvent the situation, such as taking breaks to continue to be able to perform an activity even in pain[12].

The interviewees report the importance of obeying the norms and limits of the body, engaging in good hygiene, maintaining good sleep habits, measuring blood pressure daily, using adaptive devices when necessary, being concerned about getting retired, and having a plan for this stage of life. As for physical exercise, respondents from a lower socioeconomic status say it has always been present as a manual or professional daily activity (carrying a backpack full of clothes, cleaning, walking long distances), but now it is called "physical activity," assimilated from the statements of health professionals.

Actions performed in youth are interpreted as causes of poor health in old age: *Don't gain too much weight. It is bad to sleep with a wet head* (W13). Some still include in their explanatory model as impact factors in their current experience in old age, walking in the rain, catching a cold, working too late, and not obeying the norms of the body. In the group studied, several myths are associated with old age, and progressive difficulties are considered due to aging and behaviors in youth. Harmful working conditions also appear as an explanation for a problematic old age but are not questioned.

Thus, the person is responsible for the lack of care, as if it were possible to stop being old if the medical guidelines had been followed[29].

Our research shows the difficulty with stairs and the fear of going out on the street. It is known that social relations are essential to human beings, especially with fragility[12]. There is an urgency to improve support for family caregivers and create friendly environments[8]. as well as offer support for aging at home, paying attention not only to physical but also environmental, psychological, and social issues [29], as many care needs are not being met[2].

The literature recognizes that feelings, confrontations, and experiences *(illness)* are often disregarded despite being more important than the disease *(disease),* especially in frail older adults. They often experience symptoms such as loss of functionality, loneliness, anxiety, fear of falling, poor sleep quality, pain, and the complexity of going through multiple issues[3].

The analysis reveals the biomedical knowledge in the control technologies of the bodies (food, physical activity, change of habit) that operate the subjects' awareness in the name of the quality of life-sustaining the logic of capitalism and liberalism[24]. In turn, the instrumental, standardized form, which dichotomizes body and soul, is also questioned, as well as every form of domination of hegemonic biomedical knowledge, for disregarding the interactions, inventions, and production of life in the relationship with oneself and the other[5]. Disciplining bodies impose conduct, even if the actions are ineffective, and the concrete lives escape the standardization because they invent and resist[4], demonstrating how self-care is a work directed to producing one's life for all life[5].

Research with frail older adults reveals a cultural preference for formal health and social care interventions led by professionals. However, they go beyond those, including among the care actions the involvement in physical, psychological, and social activities in daily life. Having a plan for life, performing household chores, exercising, reading books, using the internet, maintaining professional identity, having friends and pets, engaging in cognitively challenging activities, reviewing medication prescriptions, accessing orthosis and prosthesis when necessary, and participating in groups are intentional for self-care and preventing or reversing frailty[11]. However, the path is not previously designed for everyone.

Figure 2 summarizes the vicissitudes of these therapeutic itineraries.

"My life is about taking care of myself" clarifies that it is no longer possible to have control over the body when aging with frailty, which contravenes modern values of productivity, vitality, youth, seduction, self-control, and individualism. These values tend to progressively and definitively reduce the older adult to the state of their body.[23] Reinforced by the absence of listening and the barriers found in their trajectory for care, individuals in the frailty process understand that *"There is no good medicine for healing"*.

Barriers/*sickness* are not limited to only a system, a political level, or a type of service, but to a broad field that refers to the care of frail older adults[9], to the ageism also present in public services and policies and the absence of long-term care coverage and family support[27]. The care experience in the aging frailty process shows the many ways one can be in and experience the body and the world. One of them is a body with impediments – ignored by the culture of normality that judge this body as undesirable. This issue must not be treated as a problem related to older age; in fact, it must be addressed in terms of morality and bioethics of the society[30].

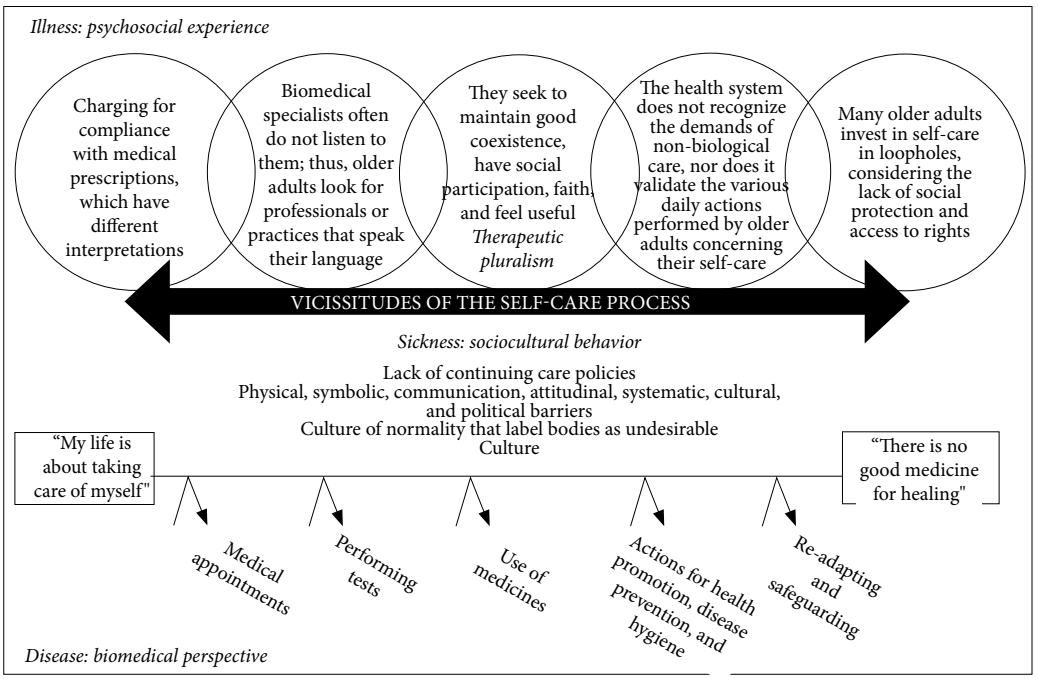

Figure 2. Vicissitudes of therapeutic trajectories carried out by frail older adults. Belo Horizonte/ Minas Gerais.

Source: Prepared from research data.

A limitation of this study is the subjectivity in data collection; the interviewers were identified by the ICF as researchers and health professionals. As a strong point, we observed that the listening space was welcomed by the interviewees and used to share their experiences. This study does not exhaust the possibilities of meanings of the various itineraries that the interviewees follow but aims to shed light on an ignored knowledge "of the imponderables"[15]; indeed, it evidences multiple actions by social actors who take care of themselves, even in a scenario of inequality, discrimination and violation of rights.

Final considerations

Our results revealed invisibility on the part of frail older adults in their care itineraries. Clinical and scientific reasoning must also consider the dimensions of *illness* and *sickness* in understanding care.

"My life is about taking care of myself" is the reflection of the advocacy of older adults in their care process, in weaving their own network, despite almost insurmountable social, cultural, economic, and physical barriers that result in the invisibility of old age as a time for investments and in the lack of policies and continued care for this portion of the population. Despite the processes restricting their autonomy and self-advocacy, frail older adults reflect and act intending to exercise their care. We reaffirm, therefore, the imperative to keep the frail older adult at the Center of their care, discuss possible and accessible trajectories for this public and implement a line of care that allows them to be heard and assisted at all points of the network, considering the variety of experiences and inventive solutions they create in the face of suffering, against subjection and for the right to exist.

Faced with the vicissitudes of care experienced by the interviewees, there is a clear need to respect priority in the formulation of social protection policy as determined in the Statute of the Older Adult, as well as to build community and intersectoral proposals to intervene in social determinants, in the precariousness of life and inequalities, mobilizing joint actions in favor of comprehensive care.

Collaborations

GA Souza worked on the conception and design of the article, the analysis and interpretation of the data, and the writing of the article; KC Giacomin worked on the conception and design of the article, the writing of the article, and the final approval of the version to be published. JOA Firmo worked on the conception and design of the article and the final approval of the version to be published. All authors are responsible for all aspects of the work to ensure its accuracy and completeness of any part.

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References

1. Alcantara AO, Camarano AA, Giacomin KC, organizadores. *Política Nacional do Idoso*: *velhas e novas questões*. Rio de Janeiro: Ipea; 2016.
2. Abdi S, Spann A, Borilovic J, Witte L, Hawley M. Understanding the care and support needs of older people: a scoping review and categorisation using the WHO international classification of functioning, disability and health framework (ICF). *BMC Geriatr* 2019; 19(1):195.
3. Rikkert MGM, Melis RJF, Cohen AA, Peeters GMEE. Why illness is more important than disease in old age. *Age and Ageing* 2022; 51(1):1-6.
4. Foucault M. *Ditos e escritos V – ética, sexualidade e política*. Rio de Janeiro: Forense Universitária; 2004.
5. Fassin D. O Sentido da saúde: antropologia das políticas da vida. In: Saillant F, Genest S, organizadores. *Antropologia Médica*: *ancoragens locais, desafios globais*. Rio de Janeiro: Editora Fiocruz; 2012. p. 375-390.
6. Pinheiro R, Gerhardt TE, Ruiz ENF, Junior AGS. O "estado do conhecimento" sobre os itinerários terapêuticos e suas implicações teóricas e metodológicas na Saúde Coletiva e integralidade do cuidado. In: Gerhardt TE, Pinheiro R, Ruiz ENF, Junior AGS, organizadores. *Itinerários terapêuticos: integralidade no cuidado, avaliação e formação em saúde*. Rio de Janeiro: CEPESC/IMS/UERJ-ABRASCO; 2016. p. 13-26.
7. Kleinman A. Concepts and a model for the comparison of medical systems as cultural systems. *Soc Sci Med* 1978; 12(2B):85-93.
8. Giguere AM, Famanova E, Holroyd-Leduc J, Straus SE, Urquhart R, Carnovale V, Breton E, Guo S, Maharaj N, Durand PJ, Légaré F, Turgeon AF, Aubin M. Key stakeholders' views on the quality of care and services available to frail seniors in Canada. *BMC Geriatr* 2018; 18(1):290.
9. Fret B, Donder LD, Lambotte D, Dury S, Van Der Elst M, Witte N, Switsers L, Hoens S, Regenmortel SV, Verté D. Access to care of frail community-dwelling older adults in Belgium: a qualitative study. *Prim Health Care Res Dev* 2019; 20:e43.
10. Kurpas D, Gwyther H, Szwarnel K, Shaw RL, D'Avanzo B, Holland CA, Bujnowska-Fedak MM. Patient-centred access to health care: a framework analysis of the care interface for frail older adults. *BMC Geriatr* 2018; 18:273.
11. Bujnowska-Fedak MM, Gwyther H, Szwamel K, D'Avanzo B, Holland C, Shaw R, Kurpas D. A qualitative study examining everyday frailty management strategies adopted by Polish stakeholders. *Eur J Gen Pract* 2019; 25(4):197-204.
12. Duppen D, Machielse A, Verté D, Dury S, Donder LD, D-Scope Consortium. Meaning in Life for Socially Frail Older Adults. *J Community Health Nurs* 2019; 36(2):65-77.
13. King L, Harrington A, Linedale E, Tanner, E. A mixed method thematic review: health related decision making by the older person. *J Clin Nurs* 2018; 27(7-8):e1327-e1343.
14. Uchôa E, Vidal JM. Antropologia médica: elementos conceituais e metodológicos para uma abordagem da saúde e da doença. *Cad Saude Publica* 1994; 10(4):497-504.

15. Lock M. Antropologia médica: indicações para o futuro. In: Saillant F, Genest S, organizadores. *Antropologia médica: ancoragens locais, desafios globais*. Rio de Janeiro: Editora Fiocruz; 2012. p. 427-453.
16. Leibing A. Sobre a antropologia médica, e muito mais... o corpo saudável e a identidade brasileira. In: Saillant F, Genest S, organizadores. *Antropologia médica: ancoragens locais, desafios globais*. Rio de Janeiro: Editora Fiocruz; 2012. p. 123-138.
17. Vieira RA, Guerra RO, Giacomin KC, Vasconcelos LSS, Andrade ACS, Pereira LSM, Dias JMD, Dias RC. Prevalência de fragilidade e fatores associados em idosos comunitários de Belo Horizonte, Minas Gerais, Brasil: dados do estudo FIBRA. *Cad Saude Publica* 2013; 29(8):1631-1643.
18. Minayo MCS. Amostragem e saturação em pesquisa qualitativa: consensos e controvérsias. *Rev Qualitativa* 2017; 5(7):1-12.
19. Corin E, Uchôa E, Bibeau G. Articulation et variations des systèmes de signes, de sens et d'action. *Psychopathol Afr* 1992; 24(2):183-204.
20. Atlas do Desenvolvimento Humano no Brasil. Belo Horizonte. MG [Internet]. 2021. [acessado 2021 nov 27]. Disponível em http://www.atlasbrasil.org.br/perfil/municipio/310620
21. Braga LS, Macinko J, Proietti FA, César C, Lima-Costa MF. Diferenciais intraurbanos de vulnerabilidade da população idosa. *Cad Saude Publica* 2010; 26(12):2307-2315.
22. Maas LW, Faria EO, Fernandes JLC. Segregação socioespacial e oferta de serviços de saúde na Região Metropolitana de Belo Horizonte em 2010. *Cad Metrop* 2019; 21(45):597-618.
23. Le Breton D. *Antropologia do corpo*. Petrópolis: Vozes; 2016.
24. Rabinow P, Rose N. O conceito de biopoder hoje. *Rev Pol Trab* 2006; 24:27-57
25. Leibing A, Engel C, Carrijo E. Life through medications dementia care in Brazil. *Rev Havard Review Lat Am* 2019; 18(2).
26. Tinetti M, Costello DM, Naik AD, Davenport C, Hernandez-Bigos K, Liew JRV, Esterson J, Kiwak E, Dindo L. Outcome goals and health care preferences of olders adults with multiple chronic conditions. *JAMA Netw Open* 2021; 4(3):e211271.
27. Giacomin KC, Boas PJFV, Domingues MARC, Wachholz PA. Caring throughout life: peculiarities of long-term care for public policies without ageism. *Geriatr Gerontol Aging* 2021; 15:e0210009.
28. Hmwe NTT, Browne GT, Mollart L, Allanson V, Chan SW. Older people's perspectives on use of complementary and alternative medicine and acupressure: a qualitative study. *Complement Ther Clin Pract* 2020; 39:101163.
29. Souza GA, Giacomin KC, Firmo JOA. A necessidade de cuidado na percepção de pessoas idosas em processo de fragilização. *Cad Saude Colet* 2022; 30(4):486-495.
30. Diniz B, Barbosa L, Santos WR. Deficiência, direitos humanos, justiça. *Rev Int Direitos Humanos* 2009; 6(11):65-77.

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