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Old age, disability and care in public health

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Abstract *Aging of the population profoundly changes the scope of action of public health, altering the profile of morbidity-mortality and increasing the demand for chronic care. In the aging population, disability serves as an indicator of health and a guideline for actions and policies. This enquiry, with a qualitative approach, based on interpretative anthropology and the emic perspective, aims to understand the way of thinking and acting of old people in the face of 'old age with disability' and their relationships with public health. Individual interviews were held at the subject's homes, using a semi-structured script, with 57 old people living in the city, including participants from the cohort of Bambuí. Collection and analysis of the data was oriented by the methodology of Signs, Meanings and Actions, making possible anthropological investigation of the representations and concrete behaviors associated with disability in old age in the local culture. Two categories relating to the relationships between old age, disability and public healthcare emerged from the analysis: (i) experience of care in old age with disability; and (ii) the fear of lack of care. The results reveal that public health needs to review its concepts about disability in old age and incorporate disability into the agenda of the functional dimension of health and care for old age.*

Key words *Disability, Elderly people, Public health, Qualitative survey, Care*

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Introduction

Memento mori. With this motto, which means "Remember that you will die", each Roman soldier left for war, certain of his finitude. Early, announced death of this type has long become a thing of the past, since the fall in mortality of all ages and the gain in life expectancy has made it possible, for the first time in human history, not only for exceptional individuals, but for entire populations to succeed in growing old[1,2]. This fact has its repercussions on society, on the family and on individuals[1-6], because it radically changes the profile of morbidity-mortality and the demands for the public health system[3,7]. In our milieu, this challenge is further increased by social and gender inequality[2,3] and by the different perceptions of old age[4-6]: Those who are more positive[4] favor autonomy, and reinsertion into society, for elderly individuals. However, others, more negative[5], use to deprive us of any investment in health, while they strengthen the image of old age as a time of exclusion[6], and a culture in which aging can be worse than dying[7].

Aging, disability and public health

Public health tries to foresee, interpret and modify illnesses, disability and death, having as its cardinal functions: vigilance, development of policies, and guaranteeing of care[1]. The aging of the population profoundly modifies the scope of operation of this policy, since the health demands of the aged population reflect the change of the profile in morbidity-mortality, with the increase of situations that require chronic care[1-3,8-10]. For the elderly contingent, the functional dimension of health[10] assumes a primordial function, while disability serves as an indicator and guide for actions and policies of this age group[8].

However, people with disability usually have limited access to the health services and its actions of promotion of health and prevention of illness[1-3,8,9]. And, although the demographic and epidemiological transitions are pressuring public health to include care for such people in its agenda, there is a certain slowness of policy in putting this into effect[1]. This may, perhaps, be because the traditional emphasis of public health on reducing mortality, morbidity and disability could lead to the inference that the occurrence of disability would be equivalent to a failure to prevent the associated conditions in the assisted population[1]. The other explanation would be the traditional model of healthcare, which erroneously reduces disability to a problem of the individual, supposing that each one should adapt his/her activities and expectations to his/her functional limitations[9].

This mismatch, or backwardness, on the part of collective health in care – the concept 'care' being understood here as part of a cultural system, built based on a social context and a context of personal experiences, cut across by political, economic, historic and biological factors[10] – to people with disability[1] threatens the autonomy and independence of the patients, strengthens prejudice, discrimination, lack of accessibility and the absence of government policies, compromising the social participation of the individual[8,9], more than his/her functional limitations[9].

To confront this contradiction, the World Health Organization publishes the International Classification of Functioning, Disability and Health – the ICF[11], seeking to increase the value given to the functionality and social participation of the individual, and recognizes that, even though the experience of becoming ill is essentially individual, it depends on the context[11]. It is important to evaluate the functional decline, and also the way in which such limitations are lived through by the individual, from the basis of the personal and social resources that the individual has available[9-12]. There is a notable lack of preparation on the part of health professionals for care for elderly people with disability[8], which can make them even further vulnerable to deteriorations of health[1], social exclusion and violence[13].

Also, the perception of professionals (which almost always orients public health) tends usually to be associated with biomedical knowledge, whereas the perception of a population (which orients behaviors) would appear to be related to a network of symbols articulating biomedical and cultural concepts[14]. It is crucial to be aware of this phenomenon from different points of view[1]: (i) the epidemiological or quantitative, to speak to the managers, health professionals and taxpayers, which all of us are[1]; (ii) the ethics approach , since, for society, the presence of disability preannounces the death of the subject[7], in both physical and social terms; and (iii) the subjective, which is fundamental for ensuring that the subject who lives through disability in his/her old age has a voice[4,14]. In this present study, the attempt has been made to understand the way of thinking and acting of old people, when faced with the condition 'age with disability' and their relationships with public health.

Methodological route

This qualitative survey is based on interpretative anthropology, which makes possible a freedom for auto-reflection to investigate aging and disability, based on an emic perspective[14]. In it, the person is invited to talk about life and about him/herself, more specifically about his/her conditions of health and his/her insertion in and interaction with the field of health. Thus, the interpretation is constructed based on the point of view of the interviewees[15].

The collection and analysis of data was guided by the model of Signs, Meanings and Actions[16], in which a new conception of the relationship between individuals and culture emerges[17].

This approach understands culture as a universe of symbols and meanings that enables the subjects of one group to interpret their experiences and guide their actions, based on webs of meaning that the group itself has created[17]. This model[16] is based on the concrete behavior of the individuals to reconstruct the underlying conceptual logics, defined as 'specific ways of thinking and acting'[18].

This survey was conducted in the urban area of the town of Bambuí, Minas Gerais, 270 kilometers from Belo Horizonte, capital of the state of Minas Gerais. The town's principal source of income is productive commercial operation with natural resources, in farming, cattle-raising and mining. The total estimated population in 2010 was 23,000, including the rural and the urban zone[19], of which one-third are in a state of poverty, eligible for registry in the Family-Grant (Bolsa-Família) Program, but not all of them have obtained this benefit[19,20]. As is seen in Brazil since the middle of the 20th century, Bambuí has undergone intense urbanization, and accelerated aging: the percentage of elderly people in the urban population of the municipality increased from 16%, in 1950, to 85% in 2010, while its population of elderly people quadrupled between 1960 and 2010[19].

The public healthcare network[21] has six Basic Healthcare Units (UBSs), which are part of the Family Health Strategy (ESF), a Health Center, a unit of the Family Health Support Center (NASF), a hospital of the Hospital Foundation of Minas Gerais State, a municipal hospital and an Advanced Studies Post of Fiocruz, operating under a working agreement with the prefecture.

Since 1996 the municipality has hosted the Bambuí Project, a prospective study of the population base, which aims to investigate predictors of mortality, hospital admission, and physical and cognitive limitation in elderly people[22]. Data from the baseline of that project indicate that 23% of the elderly people interviewed have some degree of disability for carrying out basic activities of daily life[23], which reveals the significant magnitude of this condition in the elderly population[8].

To reconstruct the universe of representations and behaviors[10,16,18] associated with functional disability, ensuring the multivocality of the participants, the group of interviewees includes people of both sexes, of various ages, with a range of functional levels and resident in different regions of the city. Since when the study was carried out the youngest survivors of the cohort of the Bambuí Project were already 70 years of age or more, it became necessary to select elderly people aged less than 70, resident in the city, provided they were registered in the six UBSs and attended by the ESF.

The identification of operational aspects of redundancy and repetition of data, theoretical factors of consistency and representativeness of elements associated with disability, and the quality of the information obtained on functionality, contributed to the decision of a determined point of saturation in the sample[15].

The investigation technique used in the collection of data was the semi-structured interview, which made it possible to amplify the field of speech of the people participating[15]. After signing the free and informed consent form, all the interviews were carried out in domicile, and recorded. Attempt was made to investigate the evaluation of the interviewee's own health and functionality, based on a description of his/her daily life, using the following as generating questions: a) How do you feel you are in terms of health? b) For you, what is good health? And bad health? c) What is your daily life, your routine, like? What is a day in your life like? Based on the answers obtained, other questions were asked in an open manner, dealing with the bio-psycho-social context, the resources, the impact and the meaning of disability.

Each interview was transcribed, read several times and then fragmented in an attempt to identify signs relating to the themes: health, illness and disability, and their relationship with public health. Based on them, the explanations, actions and reactions caused were identified, and also the specific impact of different elements of the personal, social and cultural context on the construction and evolution of reactions and behaviors[10,14,16,18].

To ensure anonymity of the interviewees, each one was identified by gender M for woman (*mulher*) or H for man (*homem*) and by a sequential number taken from the chronological order of the interviews.

Ethical aspects

This research is part of a larger project entitled "Anthropological Approach to the Dynamics of Functionality in the Elderly", whose objective is to explore functionality as an essential component of health of the elderly as well as its dynamics, in terms of personal factors (attitudes, behaviors, beliefs), contextual factors (environment and resources), factors of participation (social support network), and conditions of health. This project has been approved by the Ethics Committee for research on human beings of the René Rachou Research Center. All the participants signed a term of consent, in accordance with National Health Council Resolution 466 of December 12, 2012.

Results

A total of 27 men and 30 women were interviewed, aged between 62 and 96: 25 widowed; 24 married; 1 in a stable union, and seven single. Most of them had children and lived with family members. The universe surveyed was predominantly of the Catholic religion, with low level of schooling and of rural origin.

All the interviewed ones had answered the referring questions to its perceptions of health, having been possible to notice that the very aged people had lived deeply more losses and situations of deaths throughout the life and that women who had worked outside of house presented different perceptions of that they had not made it, as for the care in health, as for example in the story of one lady who worked outside:: "*One needs to take care of one's health all one's life – starting in youth*" (M17, aged 61, married) – and a housewife on what to do to age well: "*Only with the help of God*" (M4, aged 81, widow). Two categories that summed up the relationships between old age, disability and public healthcare emerged from the analysis: Experiences on healthcare in old age with disability; and Fear of lack of care.

Experiences of healthcare in old age with disability

In this analytical category, difficult experiences over the course of a life assume great importance, as this lady commented:

I was still young and my [female domestic employer] *used to say: 'Give this away, give that away, because it's no longer any good to eat'. Sometimes it was rice full of stones, broken up, sometimes it was fat that had already fried a lot of things, it was even black* [...], *or corn flour that was old, full of lumps. This was a sin, because poor people also have a taste in the mouth* [...]. *We would be walking close to the butcher's shop, we would see those more beautiful meats, we could not buy them. We bought pig heads. We even bought innards. Now, thank God, we buy whatever meat we want to,* [...] *we can buy as much milk as we want. It's got so much better, but it's not only here in Bambuí, it's everywhere. Life has improved a lot, and will improve more because now the younger children will see what things are like. There will be equality.* (M24, aged 86, widow)

If, on the individual plane, aging reflects a process that implies multiple life paths, on the collective plane it is built on different influences of a social-cultural nature, such as: access to educational opportunities, adoption of care in health, and accomplishment of actions that follow the course of life and extend to the later phases of life, such as old age[24]. In spite of the progressive gain in life expectancy, people do not age according to their age, but according to their social origin and the type of activity they have carried out over the whole of their life: The relationship with aging brings with it its experience of social inequality[25]. Certainly, the only solution to the problem of old age with disability and dependency would be, over time, education of all – a utopia which would not resolve all the accidents of life, but would give people an effective chance to exercise their free will[25] and age with dignity.

Many of the interviewees had migrated from the countryside to the city seeking access to education for their children; others to have access to health services, as in this report: *The problem is the advanced age* [...]. *We were going to stay here doing what? God forbid! Ill, without resources and without conditions?* (H36, aged 84, married).

Anchored on the certainty that old age is the destiny of all people, one of the participants made a point of warning younger people: *There are young people who think they won't go down this road… when you're young, you don't think, but you too are going there. You can be certain, that you're going – going. Go!* (Laughs) *Whether he wants to or not he'll go! Old age arrives!* [...] *sometimes when you are a kid you want to go on being a young man for a long time.* [...] *Even so, with every year that you age, more of your life flows away.* (H25, aged 74, married)

According to Canguilhem[26]: "Health is a state of unconsciousness where the individual is the subject of his body". When he becomes ill, this subjectivity is seen to be threatened and, when asked, the ill person provides a particular reading of his problems and evokes what in his eyes is determinant in his state[26]. In the universe researched, since '*the problem is age*', what leads to conditions of life and health that are so unequal is not questioned. Therefore, even though our democratic societies place equality of conditions in the vanguard of their needs, western culture assumes consumerist and individualist values[27], based on youth[5] and on the self-sufficiency of the individual[13,28]. Thus, the pretended equality always comes back in the eye of the Other[29], revealing the reluctance of the youth to recognize himself in the old person who is in front of him; and a healthier person hesitates even further when encountering the person who is lacking a physical ability, because both reflect the image of weakness and of an infirmity that interferes with the self-image and the self-esteem of those involved[29]. The younger generations especially have been saved the sufferings and obligations, such as going to funerals, visiting the ill, participating in old age, in disability and in the death of people who are close to them. On the level of meanings, this lack of socialization of the process of death and of dying threatens the elaboration of social relationships in old age[7], since, while the imagination takes refuge in the super-potent narcissistic scenario, the symbolic construction seems to be rooted in the disjunction between life and death[27], as if death was not the final destination of man[28].

However, the older we are, the more we need care, the '*more of your life flows away*', the more death approaches and today's man finds himself alone, faced with his death or with the death of those close to him[13,27,28].

Note that the term 'disability', as described by biomedical knowledge[30], did not appear spontaneously in the subjects' speech, nor was it recognized when presented to the participants. It was translated in the sign '*not to manage*'[30], as this interviewee explains: *Now, heavy work, I can't manage that. To walk a long distance, I can't manage… and we just run down… little by little* (H49, aged 77, single).

'*Not to manage*' modifies the relationship with the world and with work and reveals their consciousness of their own finitude[7]. This lady explains why she would prefer not to grow old: *God wanted it that way… I even said that I would not like to get old, but I'm getting, really, too old.* [...] *When I was younger, I used to say: I don't want to die old!* [...] [Why would you not want to die old?] *Oh it causes people a lot of trouble! People don't think that, but I do.* (M4, aged 81, widow). The sign identified for the need for care by third parties was *to cause a lot of trouble*[30], and we see the fear of otherness[29] emerging in this speech, and the consciousness of the speaker's own finitude[7].

Old age with disability is understood as an illness arising from the conditions of life, of work, of lack of care of health and of repetition of errors, as these reports illustrate:

I've done lots of exams, I've already done three x-rays, they don't show anything and they won't show anything – because this is just old age. It's old age! And it is, really one puts things together when one is young and one does a lot of exciting things. A lot of extravagances. Picks up a lot of weight, gets wet when one shouldn't, roasts coffee and goes out in the rain, doesn't take care [...] *And I'm feeling it now.* (M19, aged 83, widow)

The times that I went to see a doctor in Belo Horizonte, the doctor said: "Things like this – it's that when you were young, you were obliged to work a lot". (H20, aged 69, single)

I got ill [...], *a very serious problem in the heart, I even did the tests, I did the electro test, then they said that the muscle of my heart had grown. When we are very young we make a lot of effort, so it grows. And I didn't treat it. I didn't feel anything, how was I meant to treat it?* (H25, aged 74, married)

In the past there was one time when I was in bed for 10 days without managing to turn over in bed. Then it gets better, we forget it and we go and do something wrong, again. (M10, aged 72, married).

Or, to pay 'debts' of the past, as this woman explains:

I believe that we won't (cause a lot of trouble), *I don't have the sort of illness for lying in bed, only for paying something.* (M44, aged 69, separated)

A man talks about how he evaluates his health: *Well, more or less good, because, thanks be to God, I'm still walking, I can still take a bath,* *make my food. I'm not yet falling apart* (laughs) [...] *Thanks be to God* (H49, aged 77, single).

If health is a grace of God, disability in old age is a question of time. In the local culture, strongly influenced by the Catholic Church, faith in God appears as a refuge, support and comfort for elderly people who deal with illnesses and disabilities[31]. Another consolation is to know that there is someone in a worse situation[32], as this gentleman explains: *I just have to keep still and not try to move anything.* [...] *but there's always someone more falling apart than me.* (H23, aged 82, married)

The social pressure exercised by the existence of old people with disability calls for reflections from the public health about its ethical responsibility toward them. If, in their old age, healthcare means dealing with illnesses, carrying out tests and periodic accompaniment with doctors, when they seek such care, one interviewee complained of the little availability of the professional to hear her: [...] *we don't need to say much – and they are already giving the prescription* [...] (M55, aged 86, married). Another man receives, as orientation, an invitation to resignation:

I consulted the doctors here, they asked for a test, I did the test, I took it there and there was nothing. [...] *I said: 'I'd like you, doctor, to explain to me what you think is wrong with me, you please tell me and I'll be very satisfied to know what this problem is'. He is systematic. He lowered his head like this, and didn't say anything. He just said to me: 'You don't need to worry much sir, just look for a way of being less worried, of relaxing. What you are mainly feeling now is just age. At this age, one thing appears here, another appears there, you shouldn't be worrying, no'.* [...] *Now it's just a question of convincing oneself how it is, relaxation, don't do too much, and use the medication. That's it.* (H36, aged 84, married).

One lady, referring to her health problems, explains: *I don't like to talk about this, no. Because I find myself being watched* (M5, aged 77, widow). This gentleman who is battling various chronic illnesses since his infancy until today, dealing with an insidious, intermittent process of disability, but one that is progressive and without any prospect of improvement, recognizes:

I don't keep quiet, no. If you don't keep active the tendency is to get worse. With these illnesses, if I had not been accompanied by medicine my whole life, I would have already died, I would have died in bed. [...] *Hope of improvement in the future, I have none.* [...] *I've been taking anti inflammatories for more or less 50 years, and it has started to affect my kidneys* [...] *from then on it just gets worse. Just gets worse. Then this diabetes comes, then this problem that I had of a heart attack* [...] *as time goes on, I think it's very unlikely that there is any way of my changing. Have to just go on, go on in this rhythm of life that I have followed for years, that I can't do anything.* (H43, aged 62, in stable union)

This man judges himself to be *somebody different* because:

I don't go looking for things. It's like if you get a car, an old car. If you take it to the mechanic every day, you'll find something wrong with it every day. So you just live with a little noise here, a little noise there… Because if you start taking it to the mechanic at every first noise, sometimes that's okay, you think: There's a little noise there. But you take out that little noise and another little noise appears. (H18, aged 65, married)

Even so, this interviewee exempts the medical professional from any responsibility: *The doctors are good, that's okay, because it's the illness itself that won't go away.* (M24, aged 86, widow).

The results of this survey confirm the impression of Uchôa et al.[4] according to which the experience of the illness cannot be considered to be a simple reflection of the pathological process in the biomedical sense of the term; but should be conceived as a cultural construct expressed in 'specific ways of thinking and acting'. These are subjective interpretations, the popular explanatory models for infirmity (illness) – *not managing to be able* – which differ from the professional explanatory models of the disease (disability)[10,18]. These differing interpretations between patients and doctors represent a significant hiatus for comprehension of the process of health-illness and for integrating the person being cared for[33]. Lay people construct their own conceptions and rationalities about illnesses, based on the experiences that they have lived and on the cultural context[33] – social class, cultural beliefs, education, occupation, religious affiliation and prior experience with the illness and with healthcare[10].

In the universe researched, disability, translated in the expression *I can't manage to*, is understood as natural (*it's the age*), irreversible *(there's no way)* and painful *(everything hurts)*[30,31], but the biomedical knowledge disseminated in the local culture[34] perceives the process of age-illness-disability as an individual burden[9], naturalizes the illnesses of old age[9,10] and still blames the elderly people for their present condition[34]. In the speeches, the interviewees repeat the same mechanistic logic of the biomedical knowledge which sees the human body as a machine made up of separate parts and illness as the expression of bad functioning of its elements[10]; admitting the presence of illnesses and the limitations of advanced age as natural[1,9,34]. Thus, the ethno-etiology[10,33] of *I can't manage…* to do activities is attributed to old age itself; to moral debts relating to extravagance in youth; to non-compliance with medical recommendations; to excessive work; to situations whose results, with the advance of age, limit the subject from working and doing what he likes.

When the unproductive confrontation occurs between the popular explanatory models and those of the professionals, during individual or collective care[10], medicine "does not hear with this ear, it participates in a knowing culture, restricted to a restricted group"[12], the language of the doctor is not the language of the bodily experience of the ill person immersed in the attitudes and values of his own cultural adhesions, which the medical culture is unaware of, because he participates in the other world of values and of knowledges[13,28,34]. In old age, this difference is even greater, because it reveals the profound relationship between the knowledge of the certainly of one's one fragility and finitude that the elderly person feels when he/she lives with old age and disability in his/her own body[7], and on the other hand, what Gadamer[28] called "the impetus and urgent not-wanting-to-know of this type of consciousness".

Thus, the encounter of old age with disability shows itself to be doubly incapacitating: the person who experiences it lives, painfully, the inequality of his social condition compared with those who are neither old nor dependent[29]. This suffering is less due to the reality of disability seen in the individuals in question, than to the stigma projected upon them, because in the face of words like "old", "dependent", and "disabled", the person experiences an unconscious rejection, arising from a strong semantic charge and inscribed in a temporal representation woven into ancestral memories and fears[29]. The vision of a person incapacitated by a deep disablement or of an old person walking or talking unsteadily is unbearable to us because it activates in us the hidden fears of physical decadence and death[29]. In public health, the image of dependent old people may be difficult to bear, less because of the social and financial costs that they impose[1], than because of the mental representations that they provoke in those who care for them – health professionals who are younger and functionally independent.

To deal with the fact of *not managing*, one notes different behaviors: That of the person who *refuses to stay inactive* because he believes that medicine can help and seeks resources; that of the person who thinks that these are just *things of old age* so that there is nothing to be done, except *wait for God*; that of the person who prefers not to talk so as *not to be watched* and that of the person who *just doesn't want to know*. The most resigned are also those who profess religious belief[31], strongly disseminated in the universe researched, which consoles the individual suffering in the hope of a future compensation of salvation of the soul and of the body[31]. However, the same belief strengthens guilt, and the elderly people's disbelief in the existing public apparatus, as well as helping to minimize the social responsibility for the person being cared for[35]. Meanwhile those who seek more in terms of resources are in the group that is more aware and has access to private health services, including rehabilitation, preferring to pay because he/she assesses the public healthcare as *less specialized*[34]. In any event, on the local public health agenda, few interviewees had access to rehabilitation, there were no records of formal support from the health service for in-home care, and the traditional model of healthcare that recommends that people must adapt to disability prevails[9]. These results point to the need to invest in pre-, during-, and post-, disability, in interventions in the social sphere[1,8-11] and inter-generational sphere, and in increase in the capacity of the public health network for care of elderly people[8].

The fear of lack of care

Asked about the outlook for the future, the interviewees reported various fears: the fear of losing the remaining abilities, of loneliness, of dying alone and without being found *after three days*, of the violence that has happened in the lives of people they know, which keeps them imprisoned at home, of the lack of patience of people who care for them, and/or of the support of the family. However, the fear that by far is most powerful and which is even greater than that of dying is related to *causing trouble*[30], that is to say, depending on the care of others. A study made on the same population recognizes a culture according to which caring for an elderly person in the family who is dependent is a "natural" obligation of the woman[35]. However, according to the interviewees, the guarantee of being well cared for in the family does not exist, as can be seen in these speeches:

[...] *a comparison: In a family there are people of many types. One of them will do something with affection, with love, another will do the same thing unwilling, and is sometimes ashamed to see others do something and he doing nothing. That's where I ask God, for God to take me away suddenly – from one moment to the next, without needing to be in bed, to cause trouble to others, I would be very thankful for that.* (H36, aged 84, married)

When one has a stroke and doesn't die, one loses a part of the body, and thus can't manage to walk anymore, goes into a wheelchair, find one's self depending on others. [...] *It's very sad! I feel so sorry for the person who's there… Sometimes they lose the ability to speak, they can't even speak anymore with that person who's taking care of them.* [...] *So many people lose patience!* (M4, aged 81, widow)

He (the son) said: "Mother, will you scream tonight?" – making fun of me. I said: "Look here, you son of a b…., when I brought you up, I didn't ask whether you were going to keep quiet or not, I kept my eye on you all night". Ah, but when the pain is strong, the neighbors don't sleep, sometimes they come and take me to the clinic themselves. (M2, aged 69, married)

This study reveals that, in the absence of formal resources, the elderly person appeals to the community, which also supports people who have families but cannot count on them. Possibly this reflects the changes in the way that families organize themselves[2], with families becoming more nuclear and more women working outside the home. However, as according to Hareven[6], the transformation itself and the redefinition of the functions and values of the modern family have led to the establishment of stricter frontiers between family and community and the transfer of the functions of wellbeing, formerly concentrated in the family, to institutions. In the industrialized societies, the care that was considered as a part of the obligation of families was gradually transferred to specialized institutions. Thus, the family ceased to be the only source available of support for its dependent members, and the community ceased to be supported on the family as the principal agency of wellbeing and social control[6].

However, in this study, the woman who takes care of the children, of the husband, of parents, has no guarantee of being taken care of by her family: it is the neighbors who come to help her, who warn of the 'risk of extinction' of the traditional figure of the caregiver (wife responsible for the domestic tasks and for taking care of the children, aged and ill, or single unmarried daughter who did not have a previous occupation), and this also takes place in a country town of Brazil's hinterland.

All this underlines the importance of putting in place policies for long-term care in Brazil[2], since, in spite of a vast legal framework that ensures support for the caregiver and for the elderly person who needs care[8,36], the need and the responsibility for systematization of domiciliary care remain largely insufficiently met[35]. Perhaps because we live in an era of anonymous responsibility, as Gadamer[28], affirms, in which one cannot name who is responsible, or is responsible to whom – because none of us is responsible[28].

Conclusion

Paraphrasing Simone de Beauvoir[37], the results of this study show that we are not mortal when we are born, we learn to be so as life goes on, in different experiences of life, of losses, of deaths. The image of pseudo-self-sufficiency of a person who can do anything conflicts with the point of view of coming to need care in daily activities. If health is value, illness is blame. If youth is value, old age is lack of value, and aging with disability, like the image of proximity of the inexorable finitude, becomes undesirable, ugly, tacky, unbearable, ignorable.

Aging, whether *managing* or *not managing,* is a proof of having survived in spite of the unhealthy conditions of life and of work, the lack of preventive care over the course of life, chronic illnesses that limit, healthcare actions that help and actions that hinder, and of the fear of a future that is even more difficult due to lack of care. However, nobody questions what determines this condition of health in old age. In their ways of dealing with disability, to relieve the double suffering – of being made culpable and of the lack of resources – what remains to them is to *not want to know, not to think, not to talk about this*, to resist the gentile care that strengthens present and future dependence or, if convinced of it, to *just keep quiet and inactive and use the medications*, and *wait for God*.

However, not everything *is just because of age*: if the elderly person becomes unable to *manage* routine activities, effective access to rehabilitation can prevent that person from *giving trouble,* or delay it. Thus, recognizing the importance of the functional dimension of health in old age, the public health system, at all the management levels (municipalities, states and the federal government), should review its concepts on the interaction between health, aging and disability. The comprehension of disability in old age as something natural and irreversible, and the lack of public policies of care by the Brazilian State contribute to the idea that nothing can be done, and prevents maximum use being made of resources such as the NASF – which was created with the purpose of ensuring the integral nature of care and rehabilitation of conditions of health, in an interdisciplinary manner, more capable of providing solutions and integrated to primary healthcare. For this, health professionals need to be enabled in skills that give value to the person over the whole of the course of their life, including when they are old, or have some disability, and are, inexorably, increasingly close to the end of life.

Collaborators

KC Giacomin and JOA Firmo participated in all stages of the research.

References

1. Lollar DJ, Crews JE. Redefining the Role of Public Health in Disability. *Annu. Rev. Public Health* 2003; 24:195-208.
2. Camarano À, Mello JL. Introdução. In: Camarano AA, organizador. *Cuidados de longa duração para a população idosa: um novo risco social a ser assumido?* Rio de Janeiro: Ipea; 2010. p. 13-37.
3. Lima-Costa MF, Facchini LA, Matos DL, Macinko J. Mudanças em dez anos das desigualdades sociais em saúde dos idosos brasileiros (1998-2008). *Rev Saude Publica* 2012; 46(Supl. 1):100-107.
4. Uchôa E, Firmo JOA, Lima-Costa MFF. Envelhecimento e saúde: experiência e construção cultural. In: Minayo MCS, Coimbra Júnior. CEA, organizadores. *Antropologia, saúde e envelhecimento*. Rio de Janeiro: Editora Fiocruz; 2002. p. 25-35.
5. Debert GG. A dissolução da vida adulta e a juventude como valor. *Horiz. antropol*. 2010; 16(34):49-70.
6. Hareven TK. Novas imagens do envelhecimento e a construção social do curso da vida. *Cadernos Pagu* 1999; (13):11-35.
7. Giacomin KC, Santos WJ, Firmo JOA. O luto antecipado diante da consciência da finitude: a vida entre os medos de não dar conta, de dar trabalho e de morrer. *Cien Saude Colet* 2013; 18(9):2487-2496.
8. Brasil. Portaria nº 2.528, de 19 de outubro de 2006. Aprova a Política Nacional de Saúde da Pessoa Idosa e determina outras providências. *Diário Oficial da União* 2006; 20 out.
9. Dubuc N, Hébert R, Desrosiers J, Buteau M, Trottier L. Disability-based classification system for older people in integrated long-term care services: The Iso-SMAF profiles. *Arch Gerontol Geriatrics* 2006; 42(2):191-206.

10. Kleinman A, Eisenberg L, Good B. Culture, Illness, and Care: Clinical Lessons From Anthropologic and Cross-Cultural Research. *Ann Intern Med* 1978; 88(2):251-258.
11. Centro Colaborador da Organização Mundial da Saúde para a família de Classificações Internacionais. *CIF: Classificação Internacional de Funcionalidade, Incapacidade e Saúde*. São Paulo: Edusp; 2003.
12. Sampaio RF, Luz MT. Funcionalidade e incapacidade humana: explorando o escopo da classificação internacional da Organização Mundial da Saúde. *Cad Saude Publica* 2009; 25(3):475-483.
13. Le Breton D. *Antropologia do Corpo e Modernidade*. Petrópolis: Vozes; 2011.
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. Turato ER. Métodos Qualitativos e Quantitativos na Área da Saúde: Definições e seus Objetos de Pesquisa. *Rev Saude Publica* 2005; 39(3):507-514.
16. Corin E, Uchôa E, Bibeau G, Kouma-Re B. Articulation et variations des systèmes de signes, de sens et d'actions. *Psychopathologie Africaine* 1992; 24:183-204.
17. Geertz C. *A Interpretação das Culturas*. Rio de Janeiro: Livro Técnico e Científicos Editora; 1989.
18. Uchôa E, Firmo JOA, Lima-Costa MF, Corin E. An anthropologic study on strategies for addressing health problems among the elderly in Bambuí, Minas Gerais State, Brazil. *Cad Saude Publica* 2011; 27(Supl. 3):S370-S377.
19. Instituto Brasileiro de Geografia e Estatística (IBGE). Dados gerais e informações estatísticas da cidade de Bambuí. [acessado 2013 out 4]. Disponível em: http://www.ibge.gov.br/cidadesat/topwindow.htm?1
20. Rios DFF, Pinto NMA, Loreto MDS, Fiúza ALC. O programa bolsa-família em um contexto de cidades rurais: o caso de Bambuí, MG. *Oikos Viçosa* 2011; 22(2):150-170.
21. Prefeitura Municipal de Bambuí. Dados da História da Cidade. [acessado 2011 out 4]. Disponível em: http://www.bambui.mg.gov.br/
22. Lima-Costa MF, Firmo JOA, Uchoa E. Cohort Profile: The Bambuí (Brazil) Cohort Study of Ageing. *Int. J. Epidemiol* 2011; 40(4):862-867.
23. Giacomin KC, Uchôa E, Firmo JOA, Lima-Costa MFF. Projeto Bambuí: um estudo de base populacional da prevalência e dos fatores associados à necessidade de cuidador entre idosos. *Cad Saude Publica* 2005; 21(1):80-91.
24. Lima AMM, Silva HS, Galhardoni R. Envelhecimento bem-sucedido: trajetórias de um constructo e novas fronteiras. *Interface (Botucatu)* 2008; 12(27):795-807.
25. Augé M. *Une ethnologie de soi: le temps sans âge*. Paris: Seuil; 2014.
26. Canguilhem G. *O normal e o patológico*. 7ª ed. Rio de Janeiro: Forense Universitária; 2011.
27. Le Breton D, Ragi T. Mort et construction identitaire des jeunes. In: Agora - Débats/Jeunesses, 34, 2003. Les jeunes face à la mort. pp. 14-20. [acessado 2013 mar 16]. Disponível em: http://www.persee.fr/web/revues/home/prescript/article/agora_1268-5666_2003_num_34_1_2132
28. Gadamer H-G. *O caráter oculto da saúde*. Petrópolis: Editora Vozes; 2006.
29. Mattéi J-F. La dignité de la vieillesse et du handicap. In: Yves J, editeur. *Vieillir handicapé*. Paris: ERES; 2011. Connaissances de la diversité. p. 169-181.
30. Pereira JK, Giacomin KC, Firmo JOA. Maneiras de pensar e de agir de idosos frente às questões relativas à funcionalidade/incapacidade. *Cien Saude Colet* 2014; 19(8):3375-3384.
31. Santos WJ, Giacomin KC, Pereira JK, Firmo JOA. Enfrentamento da incapacidade funcional por idosos por meio de crenças religiosas. *Cien Saude Colet* 2013; 28(8):2319-2328.
32. Caradec V. Sexagenários e octogenários diante do envelhecimento do corpo. In: Goldenberg M, organizador. *Corpo, envelhecimento e felicidade*. Rio de Janeiro: Civilização Brasileira; 2011. p. 21-44.
33. Calvasina PG, Nations MK, Jorge MSB, Sampaio HSA. "Fraqueza de nascença": sentidos e significados culturais de impressões maternas na saúde infantil no Nordeste brasileiro. *Cad Saude Publica* 2007; 23(2):371-380.
34. Moraes GVO. Influência do Saber Biomédico na Percepção da Relação Saúde/Doença/Incapacidade em Idosos da Comunidade [dissertação]. Belo Horizonte: Centro de Pesquisas René Rachou; 2012.
35. Giacomin KC, Uchôa E, Lima-Costa MFF. Projeto Bambuí: a experiência do cuidado domiciliário por esposas de idosos dependentes. Cad *Saude Publica* 2005; 21(5):1509-1518.
36. Brasil. Constituição da República Federativa do Brasil de 1988. *Diário Oficial da União* 1988; 5 out.
37. Beauvoir S. *O Segundo Sexo*. Rio de Janeiro: Nova Fronteira; 1980.

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