



Health care practices among people living with diabetes: an anthropological, ethnographical approach with a gender perspective

Los cuidados de la salud en personas que viven con diabetes: enfoque etnográfico antropológico y perspectiva de género

Ana Domínguez Mon¹

¹Phd in Anthropology. Regular Associate Professor, Universidad de Buenos Aires. Researcher, Instituto Interdisciplinario de Estudios de Género (IIEGE) [Interdisciplinary Institute for Gender Studies], Instituto de Investigaciones Gino Germani (IIGG) [Gino Germani Research Institute], Universidad de Buenos Aires, Argentina. ✉ 

ABSTRACT Diabetes, a disease that constitutes a syndrome, is growing more quickly in societies with precarious living and working conditions. Daily care practices are fundamental in preventing it from progressing. This work shows the heuristic and interpretative value and the explanatory potential of an ethnographic approach and a gender perspective in the analysis of care practices in a group of elder adults living with type 2 diabetes. The research was carried out with diabetes group participants and health professionals in a primary healthcare center in José León Suárez, municipality of San Martín, province of Buenos Aires, during the period 2013-2016. We identified and analyzed care activities (including self-care) that resulted from the authoritative knowledge of the group in connection with the healthcare center professionals. Such individual, group and collective actions generate care logics that promote care of oneself. The methodological proposal of this study is framed within the tradition of collaborative fieldwork.

KEY WORDS Medical Anthropology; Ethnography; Diabetes Mellitus, Type 2; Gender; Argentina.

RESUMEN La diabetes es una enfermedad que constituye un síndrome, cuyo crecimiento se registra con mayor velocidad en sociedades con condiciones de vida y de trabajo precarias y los cuidados cotidianos son fundamentales para controlar su progresión. El presente trabajo muestra el valor heurístico e interpretativo y la potencialidad explicativa del aporte del enfoque etnográfico y de la perspectiva de género para el análisis de las prácticas de cuidado en un grupo de adultos mayores que vive con diabetes tipo 2. El trabajo se llevó a cabo con un grupo de diabéticos y con profesionales de la salud en un centro de atención primaria de salud (CAPS) de José León Suárez, municipio de San Martín, provincia de Buenos Aires, en el período 2013-2016. Identificamos y analizamos acciones de cuidado (incluido el autocuidado) producto del conocimiento autorizado del grupo en articulación con los profesionales de salud del CAPS. Estas acciones individuales, grupales y colectivas conforman lógicas de cuidado que promueven el cuidado de sí. Esta propuesta metodológica se inscribe en la tradición del trabajo de campo colaborativo.

PALABRAS CLAVES Antropología Médica; Etnografía, Diabetes Mellitus Tipo 2; Género; Argentina.

INTRODUCTION

The specificity of anthropological work [...] is not in any way incompatible with the work carried out by colleagues of other social disciplines, particularly when, in exercising their activity, they articulate empirical research with the interpretation of the results. [Translation of the original: *A especificidade do trabalho antropológico [...] em nada é incompatível com o trabalho conduzido por colegas de outras disciplinas sociais, particularmente quando, no exercício de sua atividade, articulam pesquisa empírica com interpretação de resultados.*]⁽¹⁾

Interdisciplinary theorizing on the gender phenomenon needs ethnographic data in order not to lose connection with what is actually going on in the world, and anthropology needs feminist criticism to formulate relevant questions to understand the gender phenomenon.⁽²⁾

Since the end of the 20th century, chronic or long-term diseases have become a major concern for the medical sciences as well as a methodological challenge for the social sciences.^(3,4) Since the second half of the 20th century, numerous research studies have been conducted, leading to great advances in the lives of patients suffering from chronic diseases. These studies include various theoretical and methodological approaches, such as symbolic interactionism, grounded theory and studies inspired by the contributions of Paul Ricoeur's phenomenology. All highlight the need to consider the meaning of chronic disease in the context of patients' lives, understanding the particular situation of living with an incurable disease.

Diabetes also occupies a prominent place among the epidemiological challenges of the 21st century due to the increase in the life expectancy of populations, and because its rapid expansion represents a threat to healthcare systems through a growth in disabilities caused by cardiovascular events and high costs in

diagnoses, treatments and therapeutic innovations. There is evidence that adverse living and working conditions accelerate the onset of diseases such as diabetes and hypertension, which have higher morbidity and mortality in socioeconomically vulnerable populations or in situations of poverty.^(5,6)

Diabetes is characterized by the inability of the body to adequately process glucose due to the deficient secretion of insulin by the pancreas, producing "blood glucose." At present, there are very complex taxonomies for diabetes; however, two types of diabetes are commonly recognized: Type 1 diabetes, which is linked to childhood and adolescence (also considered an autoimmune disease) and Type 2 diabetes, a disease predominant in, though not exclusive to, older adults, which has significantly increased in recent years in those countries with the highest poverty rates⁽⁷⁾ and, in the core countries, in those groups with the highest levels of social, cultural and economic inequality.⁽⁸⁾

In Argentina, almost three million individuals suffer from diabetes.⁽⁹⁾ It is a silent disease because those who contract the illness only become aware that they have it after the results of laboratory tests. The disease is linked to the consumption of foods with high sugar, carbohydrate and fat contents and is associated with sedentary lifestyles. In epidemiological terms, diabetes is a syndrome that includes a set of factors which may themselves also be pathologies, such as obesity.

From the perspective of anthropological tradition, ethnography revolves around three concepts: approach, method and text. The ethnographic *approach* is the cornerstone of anthropological fieldwork that seeks to acknowledge variability in the ways of life of social groups based on their own perspectives. The aim of this knowledge production is the understanding and explanation of phenomena in the terms of the actors and for comparative purposes. A comprehensive interpretation is that which is conducted based on the individuals' values and reasons and not on the researchers' views of those actions. For that reason, fieldwork-based anthropology has developed the *ethnographic method*,

the use of which is not just scientific; its main technique is the observation of the daily life of the individuals under study. In this way, the method presupposes that a phenomenon such as chronic disease not only impacts on the somatic level but also affects the various dimensions of the lives of people who are directly or indirectly connected to diabetes. Observing the daily life of people living with diabetes and understanding in their own terms the value they assign to their disease enables us to interpret and understand the way that this phenomenon is related to other life dimensions that are often undervalued or unaddressed in a medical consultation. Finally, ethnographers often record their works in texts called *ethnographies*, which are accounts that respect the logic based upon which individuals view issues in their lives. We can write about diabetes as a *disease*, but we cannot acknowledge it as an *illness* or *ailment* without understanding how patients with diabetes experience this disease. Hence, in the present work we identify individuals just as they refer to themselves in the interviews: as diabetics.

The objective of this work is to identify bridges between the ethnographic approach and gender studies, as both provide elements with which to understand viewpoints and perspectives that are often denied or unexplored in traditional works, particularly in the field of medical anthropology. This sub-discipline borrowed from anthropology the criticism of universalism that was typical of western medical thinking, without managing to problematize and incorporate it as another sociocultural system. This relationship was problematized in the second postwar period of the 20th century, when Marxist and social conflict theories were incorporated, well into their maturity, during the 1960s. Until then, analyses failed to problematize Western medical knowledge, naturalizing care activities as intrinsically feminine tasks. Thus, since the 1970s, different feminist theorists have critically examined the knowledge produced in anthropology,⁽¹⁰⁾ making visible female voices in the fieldwork as well as their own voices in academia. However, there

has always been a conflictive relationship between anthropology and feminism: the anthropology concerned with difference and variability could not fully account for the articulation between variability and inequality in gendered terms,⁽¹¹⁾ a problem derived from the colonial origin of this discipline. It is not in my interest to include in this introduction the points of convergence and divergence between anthropological ethnographic fieldwork and gender studies, especially given the contributions of feminist theories. We can affirm that at the end of the 1980s, the ethnographic approach was of use to the theoretical contributions of Pierre Bourdieu and Anthony Giddens in the elaboration of theories related to social action as well as to the incorporation of feminist criticism of academic epistemology through the revision of western ethnocentrism and its derivations in epistemocentrism and androcentrism in modern science.^(10,12) Notions such as resistance, subalternity and hegemony were appropriated and reformulated in the anthropologies of the south. The feminisms of equality and difference were discussed in the light of the critical perspectives of Latin American theorists. The gender perspective was incorporated into the agenda of international agencies in the 1990s but reducing gender to women, omitting in the analysis that gender, like class, is a relational category⁽¹³⁾ – not an essence related to the sexes, but rather a historical-political construction.

In this work I intend to articulate the ethnographic approach with a gender perspective, particularly in relation to older adults living with diabetes who formed a peer group in a public primary health care center in a municipality of Greater Buenos Aires.

It is common to hear the affirmation that “it is in women’s nature to care for others.” Even if the number of individuals that perform health care activities, that care of the sick or dependent, were quantified and it was proven that most of them are women, it could not be inferred that they are more skilled than men in performing this activity, but only that they do so in a greater proportion than men. To understand why, we would

need to explore the sexual division of labor in modern societies.

I chose the topic of care as the central category of analysis because it is often considered the cornerstone of discussions related to the control of non-communicable or *long-term* diseases – as chronicity speaks to an irreversible life situation^(14,15) and not as a moment in a larger social and cultural process. Given that the category of care comprises a wide range of activities aimed at well-being, we understand health care to be comprised of concrete practical activities, particularly the care conducted by individuals with the aim of providing protection to those whom they consider to be their dependents (either temporarily or permanently) or who are in a vulnerable situation (also temporarily or permanently) or any other person who may require care in order to maintain and sustain his or her life. In the countries of the northern hemisphere, the anthropological contributions of Kleinman⁽¹⁶⁾ and Mol⁽¹⁷⁾ should be highlighted. In Brazil and Argentina, we should mention María Epele,⁽¹⁸⁾ Augusto Bonet,⁽¹⁹⁾ Soraya Fleischer and Monica Franch⁽¹⁵⁾ as well as María Cristina Chardon in psychology.⁽²⁰⁾

Daily health care involves activities that are often performed in the domestic sphere. We will consider care actions as work, whether or not they are commercialized, and non-professional care as domestic work or non-commercialized private work, according to the specialized bibliography.⁽²¹⁾

Generally speaking, the theoretical discussions regarding care are organized around the idea of alterity and personal status.⁽²⁰⁾ A large part of the theoretical discussions and public policies on care issues^(22,23) contemplate questions such as: Who should be cared for? Who should do it or want to do it? How should it be done? We can affirm that care has been incorporated into the analysis of the health-disease process of long-term conditions, especially since the crisis of the curative model of modern medicine^(15,18,24) whose primary origin is the treatment and cure of acute illnesses during the second half of the 19th century.

The sexual division of labor is a criterion

that organizes and controls productive activities as well as those who carry them out, especially in the modern industrial-capitalist order. It has reinforced, both socially and morally, the subaltern female position in tasks that demand “vocation” and “abnegation,”⁽²⁵⁾ particularly in health and education.

My interest lies in showing the heuristic, interpretative and explanatory value of the contributions of ethnography and the gender perspective to the analysis of care practices particularly linked to diabetes in older adults. I believe that both approaches recognize a point of convergence: that the meanings of phenomena are diverse and variable and that individuals dispute such meanings depending on the capitals or resources that they have in a specific field (remembering both Bourdieu and Giddens) at a given historical time. The results that I obtained are relative to this group in the particular moment when I gathered and analyzed them. I will contrast perspectives on diabetes that make reference to two conflicting interpretative frameworks: that of diabetological biomedicine and that of the practical logic of care of patients living with diabetes. From a methodological perspective, contrasting both perspectives allowed me to recognize possible bridges for establishing a dialogue between them. To this end, I will analyze the relationships of care implied in diabetes, based on the model of diabetes *self-care*, grounded in a *logic of conscious choice* of actions to achieve the control of the disease.⁽¹⁷⁾ This perspective is expressed in the four traditional pillars of present diabetology: *education, diet, physical activity and self-monitoring*.

The self-monitoring of a person with diabetes requires that the patient perform a series of simple tests and readings. The aim of self-monitoring of diabetes is to achieve blood sugar levels as close as possible to normal standards and to keep them there as often as possible.⁽²⁶⁾

From this interpretative framework, these four pillars provide guidance and enable, through medical control, the treatment to be

maintained or modified depending on the medications available.

Moreover, the *practical logics* of care are the actions that individuals deploy not always consciously. Identifying and analyzing them enable us to identify life dimensions that go beyond or are not recognized as part of *self-care*, or what Annmarie Mol calls “the logic of choice,”⁽¹⁷⁾ considered a conscious and individual practice. We will use the concept of *care of the self*, proposed by Michel Foucault⁽²⁷⁾ and reelaborated by Nora Muñoz Franco in the case of health care “as a historical concept that involves the conception and the reference that one has of oneself, and to that extent, of others.”⁽²⁸⁾ We will address *care of the self* in the relationship of individuals with their own body, with others and with the environment (understanding “we” as the proximate context). These notions enable us to identify logics of interpretation about what it is like to live with diabetes, as in the case of the group surveyed. I intend to demonstrate how this group has promoted the reelaboration and resignification of individual and group experiences related to diabetes, which has enabled the emergence of logics of care that are de-gendered, that is, not exclusively produced by women.^(24,29)

FIELDWORK METHODOLOGY

Our team is made up of female researchers in the field of social sciences, mostly trained in gender studies and feminism – anthropologists, sociologists, social communicators, philosophers, general medical practitioners, undergraduate and graduate students, lawyers and psychologists – as well as people living with diabetes who are part of the peer group *Los Dulces de la Esperanza*, who joined the team in 2014 and will be mentioned in this work as *Los Dulces*. The interdisciplinary conformation of this group enabled the combination of academic work and territorial experience, fostering horizontality in the intellectual work and in the discussion of our results.

Every activity conducted underwent a process of explanation, discussion and consent with the *Los Dulces* group; these included group meetings, accompaniment of activities inside and outside the primary health care center (CAPS) [*centro de atención primaria de salud*], as well as the production of two videos featuring their experience in relation to the daily care of their health as part of a peer group. All this material was reflected in the documentary video *Aprendiendo a cuidar(se)*⁽³⁰⁾ [Learning how to take care (of oneself)] made in the year 2014, in which three active members of the group, with the consent of their peers, shared significant aspects of what it is like for them to live with diabetes,

The data presented below have been recorded in a video that is available for public consultation, and all those participating in the video gave their consent for its making. We received the collaboration of a group of documentary filmmakers from the Faculty of Social Sciences of the Universidad de Buenos Aires (Fabián Fattore, Marcelo Burd and Martín Aratta), who joined the fieldwork in dialogue with *Los Dulces* during their group meetings. In the Spanish version of this work, we decided to use the letter “x” to establish non-sexist language (given that in the Spanish language the plural forms are always masculine) when including the masculine minorities, and only used the feminine form when the plural clearly so required; such efforts are not necessary in the English language as adjectives and nouns, both singular and plural, are not inherently gendered. In the field of health, and particularly in the first level of care, the majority of users and professionals are women. We inscribe our work within the methodology of collaborative ethnography, a dialogical and interlocutory proposal that emerged in Latin America, particularly in intercultural projects, through co-authorship, in permanent and consensual dialogue with our interlocutors in the production and the generation of knowledge.⁽³¹⁾ This methodology emerges in response to criticism of ethnographic authority by academic researchers as well as a result of activist debates in

indigenous social movements, especially by Latin American feminists starting at the end of the 20th century and increasingly over the last decades.⁽³²⁾

Los Dulces...

The peer group was created on August 20, 2001 at a particular historical moment in Argentina, in the context of an institutional and banking crisis which led to the blocking of bank accounts and high levels of unemployment. The group initially started with 14 participants, and now includes more than 30 people, 22 women and approximately 10 men. Most of them live in central neighborhoods of different localities of the San Martín area of the province of Buenos Aires: José León Suárez, Villa Ballester, Necochea, Caren, Hidalgo, Chilavert and Carcova. San Martín is historically an industrial district and, since the late 1990s it has suffered a significant loss of jobs: factories were closed and many people became unemployed. In 2016, this situation has reemerged. *Los Dulces* members are adults over 50, most of them retired. Except for those with access to social security, health coverage comes from the *Programa de Atención Médica Integral* (PAMI) [Comprehensive Medical Attention Program] for retirees and pensioners. The men in the group have worked as public employees, blue-collar workers or were self-employed; there is also a professional and a student (a 23 year-old man). The women identify as housewives, public administrative employees, nurses, factory seamstresses, some are self-employed or informally sell manufactured products (food, handicrafts) or household items. Two of them are health care promoters who receive municipal remuneration for their promotion activities. The men living in poverty receive State subsidies because of a specific disability (diabetes-related blindness) or due to socioeconomic or family situations. The participation of the women in community activities or in the CAPS is noteworthy. Few members remain from the original group for

different reasons: deaths, having moved, or inability to get to the group on their own. Nevertheless, the group has grown steadily over the years.

LIVING WITH DIABETES IN A NEIGHBORHOOD OF SAN MARTÍN, GREATER BUENOS AIRES

The municipality of San Martín is one of the districts with the largest population in the province of Buenos Aires. According to the 2010 Census it has a population of 414,196 people, 198,094 men and 216,102 women, with a male to female ratio of 91.7; 9.1% (37,850 people) were born abroad, 44% of which are from Paraguay (16,717 people).⁽⁷⁾ This municipality is made up of twenty-seven localities that are crossed from the southeast to the northwest by the Mitre Railway Line. The distribution of the population follows this same direction according to unfavorable geographic conditions. José León Suárez is located at the edge of the Reconquista river, the second most contaminated river basin in the country. The neighborhood known as *Barrio Esperanza* or *Villa Corea* is characterized by its single-story houses and the frequent violent episodes that take place there. Among the users of the CAPS 10 are the first residents of the neighborhood, who recall having built their houses in the middle of the 20th century, with no sewer system, gas connection or tap water.

The health care center was established at its current site at the beginning of the 1980s. It is an institution with social visibility, in a municipality that implemented the Diabetes Program of the Province of Buenos Aires (PRODIABA) in 1995, before the province itself did in 1996, which shows the proactivity of this institution at the time. The group *Los Dulces* was created with educational purposes linked to diabetes.^(24,29,33)

Over the years, these activities led to other types of initiatives that were more related to promotion and prevention. Since 2005, *Los Dulces* members have been invited

to attend general medicine conferences, PRO-DIABA institutional meetings, and gatherings of general medicine residents. The CAPS has offered psychological support as well as secondary prevention activities for its members, such as the following: physical activity workshops, coordinated by a physical education teacher and a gym instructor; a body posture and movement workshop, coordinated by a kinesiologist; a cooking workshop, coordinated by a nutritionist; as well as the actions promoted by the group in articulation with the professionals of the institution. The creation and group dynamics were defined by the particular organization that was generated in the CAPS during the 1990s. At the time of the fieldwork, they met in assembly and had weekly meetings (Thursdays from 9:30 to 11:30 AM), where different topics were discussed. All members could participate in the discussions and ask to speak. In all the observations and interviews conducted, all members expressed that they had produced important changes in themselves and in the institution, for example they had participated in the election of the CAPS director and had requested and obtained approval for hiring a podiatrist for the institution. In 2009, they wrote a letter to the Ministry of Health of the Province of Buenos Aires complaining of the Ministry's failure to deliver diabetes test strips; the letter was also signed by other groups in Greater Buenos Aires, in the areas of José León Suárez, Hurlingham, Esteban Echeverría, Malvinas Argentinas, Moreno, Lomas de Zamora and Tres de Febrero. They then had to take legal action, filing a lawsuit and a writ of protection to have the test strips delivered as required. They consider that the achievements involving their claims to the State were the result of their collective group participation in conjunction with professionals and neighbors, which led to the social recognition of *Los Dulces* within the institution and as interlocutors in other spaces outside the CAPS. From being called "Alcatraz," after the American prison, the CAPS 10 is today a flagship institution for those wishing to train in general medicine, social work and psychology at the primary care level. Although the

professional staff has not varied significantly in number (twelve in 2001 and eleven today), job stability for them has changed: there are currently only six in-house professionals.

***Aprendiendo a cuidar(se)* [Learning how to take care of (oneself)]**

So is the title that we gave to one of the films that we made with *Los Dulces* and the participation of CAPS professionals, who in 2015 became the protagonists of the second documentary called *El cuidado de los cuidadores* [Caring for caregivers].⁽³⁴⁾

In the first film, all film participants were selected in the assembly meeting. We agreed on the central moments of their lives that we wanted to record and decided to shoot scenes of practices related to four key areas in diabetology: *the monitoring of blood sugar levels; medication intake; diet and physical activity; and medical consultation and group meetings*. The description and analysis of these actions are part of the works that were discussed during scientific meetings and published by the team.^(24,29) We sought to show the daily actions of self-care proposed by diabetological knowledge, the fulfillment of which is based on *free and autonomous* decisions. The *daily measurement of blood glucose levels* is conducted as many times a day as is required by the medicine and/or insulin being administered. Although this procedure is performed in privacy, it is part of the group activities at the beginning of the Thursday meetings.

Blood glucose measurement

As soon as all the participants arrive, a member of the group takes a blood sample and measures the morning blood glucose levels. At the beginning of the activity (August 2001) and due to the lack of resources, the measurement was done by subdividing the reagent strips that were obtained from laboratory donations or from PRODIABA. These strips are essential supplies for the measurement of

blood glucose levels and should be available to all patients as provided by Law 23753 on Problem and Prevention of Diabetes, which was sanctioned and enacted in 1989.

At the time of the fieldwork, the great majority of *Los Dulces* members had glucometers and arrived at the meeting with the information of the measured values that they had obtained in their homes. It is an instance of control but also of emotional support: "My blood glucose level was 140 but I had a bad week". There are no value judgements, the results are reported and recorded in a spreadsheet. It is emphasized that bad glucose scores should not alter one's well-being. High blood glucose levels are often related to economic problems or family conflicts. The women state that "emotions" and "distress" are the main reasons for this rise in blood glucose levels. These facts were also recorded by Liliana Saslavski⁽³⁵⁾ in her book, in which she includes an investigation conducted in the 1990s.

The medication

In the case of diabetes, just like in any long-term illness, the availability of resources expresses differential qualities concerning the daily care of health. According to Law 26914,⁽³⁶⁾ which modifies Law 23753 enacted in 1989, all individuals with diabetes must receive compulsory medication within the subsystem of employment-based health insurance [*obras sociales*] and prepaid medical plans if they are salaried employees, as well as in the public subsystem or in the PAMI. Since 2014, with the regulation of the law through Resolution No. 1156/2014, the spectrum of medicines to be provided at no charge to diabetic patients has been extended. In the municipality of San Martín, at the time of the fieldwork, all 20 CAPS provided 100% coverage of rapid blood glucose measuring devices, and the test strips were regularly delivered. PRODIABA supplied free of charge NPH (Neutral Protamine Hagedorn) insulin and standard insulin, as well as some ultra-slow acting analogs, metformin,

glibenclamide and reagent strips. At the time of the fieldwork, metformin, glibenclamide, antihypertensive drugs and diuretics were delivered through the *Remediar* program of the Argentine Ministry of Health. The municipality also received medicine donations from laboratories, as reported by a personal communication with the coordinator of Chronic Diseases of San Martín in August 2016. However, this did not always occur in the case of special requirements, such as insulin pumps or the increased consumption of reagent strips. In these situations, doctor's appointments and physician indications were essential to obtain free access. If these supplies are denied, it is important for patients to know how and to whom to complain.

Annemarie Mol⁽¹⁷⁾ considers that "care" in diabetes sometimes has the same effect as "cure." Having a pen or a continuous insulin infusion pump or rapid-acting insulin not only stimulates a quick response from the body, but produces, in symbolic terms, something similar to a "cure." This symbolic efficacy is not only the result of the rapid effect of the dose, or of the absence of pain following the needle prick. I am referring to recognizing oneself as part of a fairer system that redresses and reduces the inequalities of those who could not have access to these drugs and devices through the market. These resources are part of the right they have by law and their availabilities should not be subject to laboratory donations. A donated good is considered a gift but not a right. Having these technologies implies less invasive, more efficient and dignified and, therefore, less stigmatizing practices. In a part of the film *Aprendiendo a cuidar(se)*,⁽³⁰⁾ due to his blindness, Teo uses an audible pen to give himself an insulin shot. He has participated as a communicator with authorized knowledge of his illness as he is in his fourth year of a health sciences program at Universidad Nacional de La Matanza. He has explained to the students how blind people can effectively inject themselves using this mini injection in pen format.

Food and physical activities

Generally speaking, type 2 diabetics are overweight due to low energy expenditure. For this reason they should significantly modify their daily life habits: they should give up the consumption of sugar, carbohydrates and fats. They feel obliged to change their “tastes”⁽³⁵⁾ for foods that they dislike or consider “flavorless.” They often reminisce about the things that they can no longer do, sometimes nostalgically and sometimes reproachfully:

I don't think about what I'm going to eat during the day. I see what I have in my fridge and eat that. I don't like meat very much, I hardly ever eat it ... I get up and take a bath and I prick my finger to check "my sugar level on an empty stomach" [measures her blood glucose level] ... 126. [...] I have breakfast, then have a snack or a fruit before lunch. [My lunches] are always very fast, I boil vegetables or cook spaghetti. When my children come to see me it's different, I prepare what they like to eat. I don't eat food that diabetics cannot eat. We can eat whatever we want, but in small quantities. I don't like to do gym but I enjoy walking. That I do like...
[Mari, *Aprendiendo a cuidar(se)*]⁽³⁰⁾

The cooking workshops coordinated by the nutritionist are very popular. Attendees like to incorporate new recipes and to think about how to replace ingredients. These are moments of group celebration. *Los Dulces* members have learned how to cook “healthily,” although they do not always strictly follow instructions. They tend to relativize restrictions: “We can eat whatever we want, but in small quantities,” says Mari in the film. The cooking workshops and the walks in an area close to the CAPS are activities sustained over time; however, they do not elicit significant changes in eating habits, nor can we affirm that they have effectively stirred the men and women’s interest in doing physical exercises. However, participants manage to establish rituals of gathering, exchange and well-being that are closely linked to what we

recognize as *logics of care*, in a process that is marked by ups and downs⁽¹⁷⁾ and various moments, intertwining medical recommendations, personal tastes in which choice plays a role, but above all the possibilities and circumstances of people’s lives.

*On Mondays I attend the cooking classes [at the institute for the visually impaired]. I prepare something to eat, pre-cooked pizzas or savory pies, then we have a group lunch. On Thursdays at 9.30 we have the meeting with the diabetics group. At 8:30 is the group walk. [Teo, *Aprendiendo a cuidar(se)*]⁽³⁰⁾*

Activities within the group: logics of care

The men who live alone do the household chores, although they receive assistance from their daughters, sisters and/or female neighbors. In the group, the women are responsible for many of the inherent responsibilities of domesticity: they are available for consultations, they call or visit their peers in the group, they collect or demand supplies from the state authorities. In the shared activities, male participation is observed in the emotional support of personal problems, with men actively participating and expressing their feelings. Men cook meals in the cooking workshops, coordinating them on several occasions; they also take the initiative in proposing games and recreational activities and participate in neighborhood and community meetings. Although traditional forms of organization of activities based on the sexual division of domestic work prevail, in personal and individual *self-care*, the value of peer networking, as the support for each member’s daily life, can begin to be perceived.

If we think of a larger network, health care institutions are the obligatory reference for the members of *Los Dulces*:

The relationship between the professional and a person living with diabetes is indeed an art. A doctor who explains

what you have to do and why is not the same as a doctor who patronizes.
[Sebastián, *Aprendiendo a cuidar(se)*]⁽³⁰⁾

All members remember situations of abuse in their institutional trajectories, and also perceive fundamental changes in the care processes since attending the CAPS 10, where the professionals are “friends” whom they feel close to because they do not harass them morally. Group activities integrate a larger set of actions, which we consider as part of *care of oneself*.⁽³⁷⁾ They are the result of an institutional process, in which actions are recognized in and by the practices of solidarity that members carry out and not as an individual process or as a result of personal *autonomy*.⁽²⁹⁾ Such actions are expressed in the ability to listen and accompany that members themselves provide to one other through a process of group work in relationship with the professionals, who do not judge or censor but simply support. In the film *Aprendiendo a cuidar(se)*, the coordinator of *Los Dulces* stresses the fact that “*the professional who does not judge, accompanies*.”⁽³⁰⁾ According to our observations, this accompaniment also requires institutional support. *Los Dulces* members and professionals at the CAPS maintain that this support is the fundamental principle for the treatment of a long-term illness: respect of the other (person, patient, professional). By recognizing the other as a peer, members and professionals recognize in themselves the capacity to generate protection and so they revalue this activity^(16,38): “*Respectful accompaniment is a way of caring*” [Sebastián, *Aprendiendo a cuidar(se)*].⁽³⁰⁾

DISCUSSION

The incorporation of a peer group in the case of diabetes is a process by which each member learns from their peers and is recognized as an authorized agent.⁽³⁹⁾ They know about the disease from their own experiences and those of their peers, they transfer that knowledge to the public sphere, to other

peer groups, to professionals and to the municipality. This movement is not carried out without conflicts, when for example group members defend their rights. This *authorized knowledge* has a historicity and enables them to speak about an “us”, even when they are telling their own personal story:

The constitution of authoritative knowledge is an ongoing social process that both builds and reflects power relationships within a community of practice [...]. It does this in such a way that all participants come to see the current social order as a natural order; that is the way things (obviously) are.⁽³⁹⁾

Something similar happens when they remember the moment of the diagnosis, already distant in time, and they reconstruct it based on how they currently perceive their treatment, not as a biographical rupture, but rather resignified through their current experience:

When you receive the diagnosis of the disease ... the authoritative biomedical model imposes limits on you ... [but] in reality it restricts your freedom. Information is very useful but by itself is not enough [...] It is difficult because with all the complications of daily life, your health fades into the background. When you are in a group, the illness is on your agenda. [Sebastián, *Aprendiendo a cuidar(se)*]⁽³⁰⁾

Group members emotionally evoke some conflictive situation that they have experienced. The outcome of the disease is reinterpreted in terms of the context in which they received the diagnosis or as a trigger for the onset of the disease; these contexts include family, work, or personal crises, among others.

The doctors told me that diabetes was an incurable but silent disease. I thought it was like cancer [...] Then, I cried and cried all day and night until I said to myself “Mari, come on, pull yourself

together, take care of yourself and move on." And I went to the center because I heard that there was a diabetics group. Now I know that when I'm feeling down or nervous, my sugar levels go up. [Mari, *Aprendiendo a cuidar(se)*]⁽³⁰⁾

For the diabetological medical model, *self-care* is the result of the *free*, individual and conscious *choice* of the patients, as an expression of the autonomy of those who, being aware that they are ill, act to reduce the risk factors. *Los Dulces* members argue practically with this *logic* of conscious and free *choice*. Based on the actions observed and the interviews conducted, they acknowledge their limitations. They know that even if they follow the indications, the disease can progress and that discourages them and at the same time confronts them with the uncertainty of complications, such as retinopathies and neuropathies, among those most feared. They argue and confront moral medical warnings when they are used as threats or "punishment" for failing to duly comply with the treatment. They know that the possibility of choosing to follow instructions is strongly conditioned by the living conditions that each of them have. Thus, insulinization is perceived as the punishment for not duly complying with medical indications ("He told me, if you continue like this, you will end up being insulin-dependent"). This "fear," often mentioned in the meetings, also operates as a disciplinary action, but only momentarily. "You can't live with fear" says Sebastian in the film, in his double role of diabetic and health professional. Fear hinders the search for help; some members, especially men, took a while to start the treatment because of the fear caused by the diagnosis, and as they did not feel any pain, they considered the medical warnings to be unfounded. In other cases, this fear triggered processes that led to complications that manifest themselves more frequently, although not exclusively, in men. From the field of anthropology, we know that consumption and tastes have been culturally and economically constructed in articulation with

class values. The development of capitalism in modern societies has shown that the consumption of sugar, carbohydrates and fast foods rich in saturated fats leads to malnutrition, overweight and morbid obesity,^(39,40) all of them diseases associated with precarious living conditions.

Based in the social sciences and particularly ethnography, we seek to problematize the established common sense: "patients do not take charge of what happens to them," "they lie", "they are transgressors." We do not seek to oppose medical common sense with the agency of people living with diabetes, who often push their physical health to the limit. We are aware that the meanings of care, from the perspective of the protagonists themselves, bring to the fore *agents* that can adhere to or rebel against medical indications, and who do not recognize themselves as *victims*. In the case studied, the *authorized knowledge* in and from group and collective actions takes on a different perspective; they emerge from subaltern class, gender and ethnic situations. The Paraguayans who have resided for more than two decades in the municipality of San Martín, with Argentine children and grandchildren, value the free care, and contrast it with the care their relatives receive in Paraguay. In this group, the women, above all, have lived in situations of great inequality, sexual abuse in the workplace, marital and family abuse and have redefined themselves as older adults.

The literature on care often refers to men's delay in making their first visit to the doctor, and once diagnosed, in starting the treatment. This would reveal the low value that men⁽²⁸⁾ assign to "prevention," supposedly due to the lack of values related to bodily care beyond those necessary to work. On the other hand, women's early consultation is highlighted, as well as their greater adherence to medical indications. In CAPS 10 men who comply with indications usually have care networks articulated by women (health care personnel, relatives and neighbors) that assist them in their daily life; it is no less true for women than for men who are within protective networks that care actions are recognized as effective.⁽⁴²⁾

However, from January 2015 to September 1, 2016, CAPS 10 saw 373 people with diabetes, 186 women and 187 men, with a total of 1835 consultations with different professionals. Could this parity be due to a recognition of the institutional work of the CAPS in the neighborhood?

In the case of this group of older adults, we have identified changes in their life trajectories: what in youth and adulthood was a reason for deferment due to economic deprivation, personal fears or family mandates, becomes a personal achievement, especially in the women at this stage of their lives: “before I didn’t speak my mind”; “I used to accept what the others decided.” Women who in their youth accepted patriarchal orders, such as whom and when to marry, how to take care of the house, how to raise children, produced important life changes after reaching forty. They separated from their partners/husbands, or live in the same house without conjugal cohabitation, work while being retired either for strictly economic reasons or for their own interest; they collaborate in institutions or engage in different forms of community work (most health promoters are women), they enroll in adult secondary schools or join senior citizen groups. They have produced significant changes in their lives. Their illness is one of the reasons for change, but not the only one.⁽⁴³⁾

In this group of older adults, the men learned to cook, not only for themselves, but for the group; they try foods that they rejected when their wives or partners prepared them, express their emotions in the group meetings, prepare dramatizations and recall life experiences with their children and grandchildren. These adults so attached to work, obligations and hierarchies during much of their lives, recognize themselves as part of a collective. They have completed their productive stage, some have lost their life partners, others have decided to separate or divorce. Studies on older adults and diabetes reveal that although diabetes is more prevalent in adult women, diabetic men die earlier than women.⁽⁴⁴⁾ There are works that highlight the role of women in social networks in contrast

to the scant participation of men. Since the beginning of the 21st century, the value of peer groups⁽⁴⁵⁾ has been highlighted as a protective strategy, particularly in long-term illnesses that are currently incurable.

OPENINGS FOR CLOSING

The ethnographic approach and the gender perspective are rich methodological strategies for the understanding of health care in people living with diabetes. Since the last third of the last century the available literature on chronic diseases has shown that there is a very large distance between illness and suffering, and that the latter can affect people by deteriorating their health and causing an early death. We agree with the studies conducted by feminists on daily care⁽³⁸⁾ that inequality in the sexual division of daily care activities elicits discomfort and suffering in the people who care for others, who are predominantly women. The peer groups of older adults living with diabetes, as in the case of *Los Dulces*, show transformations in traditional roles based on the sexual division of labor. We cannot affirm that these transformations are the product of care based on a *logic of free choice*, but rather on a *logic of care* that is product of the group and institutional dynamics and the institutional historical contexts that have accompanied their functioning so far. We affirm that to recognize, conceive of and implement actions, not ascribing them to a specific sex decompresses and empties the places of hierarchical power, at the same time that it grants greater freedom and creativity in their implementation. This is slow work, requiring a predisposition toward the recognition of error and the exercise of acceptance to receive and produce care. *Respectful accompaniment* is care, as well is the attention to and responsibility for the other as a peer. We observed scenes of men accompanying other (male or female) group members although they are very rarely mentioned in the interviews or in the donation of

medicines or unused supplies. This modifies the perception of who the other receiving the action of care is.

In the ethnographic field work, the possibility of identifying points of view and explaining relationships and disputes was not achieved through interviews, but rather through gestures, looks and silences. Below, I quote a field note taken at the CAPS in 2016:

We projected the film "Caring for caregivers" in the last hour of the Los Dulces meeting. Initially we were around fifteen people. I noticed that more people were coming and apparently not for the film. When the video finished, I noticed that the multipurpose room was full: professionals that I have known for three years and neighbors that I didn't know. They had not heard about the video screening, they were coming to an assembly. Although the first exchanges had to do with the video, I realized that they were actually telling their own stories when referring to those of the professionals in the film. There were exchanges about medical responsibilities and the relationship with the patients and health authorities. They sought to conceptualize ideas about care, based on their ways of working: listening, participation and commitment to social suffering. How can care be measured in terms of the number of services offered? How can quality be translated into numbers? In those who spoke, I identified committed professionals, who showed care and respect for people, practicing the logic of care based on the recognition of the situation of social suffering of their patients. Through concrete actions: when they go out to find a patient who has not been to the clinic for month;; when they organize sports or recreational events so that the kids in the neighborhood can feel closer to them and trust them, and mothers can speak about themselves and they can understand and learn about what they are going through... Sitting in a crowded room, wanting to talk and listen, in a

health center located in an area of high social conflict, they were trying to think about their practice, apparently with the excuse of the film. While the different exchanges regarding the value of solidarity with the people (physically present) and of the people with their professionals were taking place, in front of me, a member of Los Dulces approached the coordinator of the group and whispered something that I could not hear well because of the voices of several dozen people filling the room. He handed her two boxes of NPH insulin and a glucometer. The coordinator looks at me and says: "Do you want an example of solidarity? This is already assigned to a 16-year-old kid." (Field note, 2016)

If we think about it in methodological terms, the gender perspective in the observation of daily actions enables us to theoretically direct our gaze to aspects or dimensions that are hidden or imperceptible to the untrained eye. We cannot affirm that gender stereotypes do not prevail in the daily care activities among women and men. However, we have noticed changes that have to do with group dynamics and, we think, with the moment in life that participants they are going through. The ethnographic work and the gender perspective have enabled us to understand, from the logic of care of the interlocutors, the type of authorized knowledge that they have that stems not only from the disease as a limit, but as an expression of agency incorporated into *care of oneself* through group practices of care. The gestures that I learned to recognize are those that the group members allowed me to see in the terms in which they wish to be recognized.

The ethnographic approach, like the gender perspective, embodies gestures, enables us to understand complex relationships based on simple interactions. The de-gendering of practices is a slow and very conflictive task that can be perceived in small actions. Group work among peers to generate *care of oneself* requires, above all,

to relinquish comfortable positions of dominance that often generate suffering: men who cannot face diabetes until they experience the complications or who attend the consultations much more deteriorated than women. Gender mandates in terms of care cannot be easily modified in societies in

which the sexual division of labor persists, or at least, is naturalized. If the tasks of care continue to be considered mainly female and primary care institutions are supported by women in conditions of subalternity, the de-gendering of health care practices will have little visibility.

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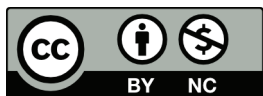
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