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Caring for children with Congenital Zika Syndrome: the unmet needs of mothers in Southern Colombia

Abstract

In Latin America, the Zika virus (ZIKV) epidemic of 2015-2016 resulted in children being born with a spectrum of neurological disorders called Congenital Zika Syndrome (CZS). This resulting in mothers being the primary caregivers of those children. The objective of the study was to identify the perceived needs of women to care for their children with CZS in Southern Colombia. In 2019, a qualitative ethnographic study was conducted in southern Colombia including 21 women belonging to a self-managed support group and who had prenatal ZIKV between 2015 and 2016 and, as a consequence, their children were born with CZS. Three discussion groups and six semi-structured interviews were conducted and analyzed through a qualitative content analysis. Three main perceived needs to care for their children were identified: knowledge and skills to provide the complex care their children require and for which they did not feel prepared, economic and social support. This study showed that women face unmet needs when caring for their children with CZS, especially regarding social support. Therefore, it is urgent to generate public policies and intervention strategies for professionals to support these women in order to meet not only the needs of their children, but also their own.

Keywords: Women, caregivers, needs assessment, Zika virus, qualitative research, Colombia.

Introduction

The Zika virus (ZIKV) epidemic of 2015 and 2016 in Colombia resulted in a social emergency due to 696 children being born with a spectrum of unexpected neurological complications called Congenital Zika Syndrome (CZS) (Cuevas et al., 2016).

CZS is characterized by neurological alterations, especially severe microcephaly, convulsive syndrome, alteration of cognitive development, auditory and visual alterations, dysphagia, reflux and musculoskeletal problems and as a result, children have intellectual disabilities, alterations in motor development, recurrent complications, such as pneumonia, and other respiratory problems, feeding difficulties, abnormal sleeping patterns, self-injurious behaviours, hyperactivity and irritability that includes almost constant crying and difficulty in calming them down (Satterfield-Nash et al., 2017; Wheeler, 2018). This condition involving multiple and chronic disability results in complete dependence and complex care for their whole lives. This responsibility mainly falls on the mothers of children with CZS (Bailey & Ventura, 2018), yet they have received little attention in research (Kuper et al., 2019).

Research on the ZIKV epidemic in Latin America has mainly focused on clinical and epidemiological aspects (Nithiyanantham & Badawi, 2019), while few studies have addressed the impact and consequences on women's lives (Gray & Mishtal, 2019). In Brazil, which was the epicentre of the epidemic, studies have discussed the problems surrounding caring for children with CZS (Elpidio de Sá et al., 2017), mainly focusing on the social and economic repercussions on the mothers' lives (Barbeito-Andrés et al., 2018; Freitas et al.,

2020; Souza et al., 2018), as well as the implications on women's mental health (Carla da Silva Reis et al., 2020; Dos Santos Oliveira et al., 2017; Freire et al., 2018; H. Kuper et al., 2019). This has made women's needs more visible in terms of more attention, understanding and psychosocial support by institutions and professionals involved in the process, alongside a broader understanding on the children's conditions (MacDonald & Holden, 2018).

In Colombia, the second Latin American country after Brazil most affected by the epidemic (Rate 48.650 per 1000 population) (Pan American Health Organization, 2018), studies have focused on the experiences of women affected by ZIKV during pregnancy. Alterations in women's mental health when faced with prenatal diagnosis (Romero-Acosta et al.), women's lack of knowledge about the infection, the need for support from partners, families, and health professionals after receiving the diagnosis, as well as concerns and fears about the consequences of the infection on their unborn children (Tirado et al., 2020), difficulties and delays in accessing health services and limited guidance from health professionals (Gomez et al., 2020) have been documented. However, caregivers' specific experiences when caring for the children have not been explored in Colombia.

Although Colombia declared the end of the ZIKV epidemic in mid-2016 (Ospina et al., 2020; Pan American Health Organization, 2018), it continues to pose a relevant public health problem due to the need to understand and respond to the consequences of the epidemic on children and their families (MacDonald & Holden, 2018). Therefore, the objective of this study was to identify mothers' perceived needs to care for their children with CZS in Southern Colombia.

Methods

Design

The study is part of a larger study aimed at understanding the experiences of women who experienced prenatal ZIKV infection during pregnancy and after the birth of their children with CZS in the Department of Huila, Colombia (South Colombian University, project code 2706/2019) (Laza et al., 2020; Laza et al. in press; Laza et., al 2021). A focused ethnography was carried out focusing on studying small social groups' shared experiences of limited phenomena (Rashid et al., 2015). This design allowed women to share their perspectives regarding their problems by interacting with others in the social context in which they live, with the aim of understanding their primary care needs for caring for children with CZS better.

Context and participants

The fieldwork took place between August and November in 2019 in the city of Neiva, the capital of the Huila Department (Southern Colombia). Participants were twenty-one women residing in the Huila Department who suffered a prenatal infection by ZIKV between 2015 and 2016 and their children were consequently born with CZS. Since 2018, twenty-four women took part in a support group (SG) after they were identified in a medical assessment consultancy for their children (by doctors belonging to a research group of Surcolombiana University) and were personally invited to participate in the SG. The participants of the SG showed symptoms of ZIKV infection during the first trimester of pregnancy and the diagnosis was confirmed contrasting the symptoms with the microcephaly of the fetus. These women

underwent gestational follow-up and during the third trimester, a fetal diagnosis of microcephaly was made by pelvic ultrasound. At the University Hospital of the Department of Huila where they were treated, upon confirmation of the ZIKV infection diagnosis, they were advised to terminate the pregnancy, which the participants did not accept. After birth, all children were monitored by pediatric neurology specialists for microcephaly and other central nervous system defects. Twenty-one agreed to participate in the study and three of them refused because they did not want to talk with people outside the SG. The age range of the group was between 18 and 37 years (average age is 25 years). Seventeen women belonged to a low socioeconomic level, meaning that their family income was below the minimum monthly wage, and 18 were unemployed. Seven were single when they got pregnant, four got divorced after their children were born, and the rest had stable relationships (Table 1).

Data collection

Three successive focus group discussions (FGD) were held with all 21 participants, lasting between 60 and 90 minutes. FGDs facilitated the exploration of in-depth information on perceptions and attitudes of participants who share similar experiences through a conversation and dynamic interaction, creating a synergy among participants (Krueger et al., 2015).

Subsequently, six of them were interviewed individually, lasting between 90 and 129 minutes each, with the aim of broadening, delving into and clarifying any issues that emerged in the FGD. A question guide was prepared to register the women's biographical information, childcare experiences and needs. Both the FGDs and the interviews were conducted by the

first author, and two research assistants conducted non-participating observations and took notes. Both were carried out until reaching data saturation. Both the interviews and the FGDs were recorded and transcribed verbatim.

Data analysis

Two researchers, CLV and EBV, conducted a qualitative content analysis (Graneheim & Lundman, 2004) in three steps supported by the software ATLAS.ti-8: reading the transcripts, identifying sentences or paragraphs referring to perceived needs, assigning open codes to them and, finally, grouping the codes according to their similarity to create categories and subcategories.

Following an emerging design, the collection and analysis of the information was carried out at the same time. All the authors participated in the discussion and reflection of the categories identified in the results. The preliminary analysis was presented to the participants in a meeting with them and they were approved without any necessary modifications.

Ethical considerations

The approval of the Research Ethics' Committee of the Faculty of Health of the Universidad Surcolombiana was obtained (Act 005 of 13th August 2019). Data confidentiality was guaranteed by anonymizing the transcripts and assigning a number to identify the participants. All participants voluntarily participated in the study and signed the corresponding informed consent.

Results

Results are structured into three main categories corresponding to women's needs: 1. Women's needs to obtain specific skills and knowledge to care for their children; 2. Women's needs for financial support and 3. Need for social support (Figure 1).

1. Women's needs to obtain specific skills and knowledge to care for their children

The women expressed that their lives radically changed from the moment their children with CZS were born. From that moment on, these women had to dedicate their whole lives to exclusively caring for their children, as they are completely dependent for all daily activities due to the multiple disabilities by which they are affected.

"[...] and also, as many say, life since she was born [my daughter], my life has taken a 360° turn [180]". (FGD 1, participant 13)

"[...] I need to be aware almost 24 hours a day, I'm the one who understands him and I know what's hurting him and I know what to do [...]" (FGD 1, participant 4)

Caring for children with CZS requires specific skills and knowledge due to episodes that children regularly have, such as convulsions, attempted self-injury, swallowing disorders, food inhalation, insomnia, irritability and continuous crying for no reason. Thus, very soon they realized that they did not have the knowledge and skills to take care of a child with special needs and to adequately face all the problems that the CZS entailed. In addition, women were young and inexperienced, as for many of them it was their first child.

“[...] the first time my child had a convulsion I almost died. Or better still, I didn’t know what to do, I didn’t know [...] it was all new”. (Interview, participant 6)

Women did not receive much information from the health professionals who attended them.

“[...] it was when he was born when they explained everything to me about the disease and the consequences, and what microcephaly was and what my child would be like”. (Interview, participant 4)

In view of this, they tried to acquire specific knowledge by searching on the Internet and by asking the other women in the SG.

“I remember that anything I saw I looked it up on the Internet, if I saw she did a strange movement, I looked it up. Because I didn’t know a lot, when she was ill, or couldn’t do something, I looked it up [...]”. (Interview, participant 2)

“It’s been an unconditional support [support group]. Furthermore, it’s great because for some mums, sometimes their kids have a convulsion, so they ask, someone tells them what to do or how to react”. (FGD 2, participant 5)

2. Women’s need for financial support

The birth of a child with CZS generated greater expenses to meet the demands to care for them: paying for medical consultations, medication, therapies and diagnostic tests that health

insurances delayed or denied authorization, other alternative treatments not covered by health insurance, and the cost of multiple trips in and out of town to receive medical treatment.

“[...] there are many expenses involved with them. Normal children come with expenses, imagine when your child has a special condition. There are many things”.

(Interview, participant 2)

Most of the participants already had scarce economic resources. In addition, in order to care for their children, all but three of the participants had to quit their jobs.

“Well I’ve almost always worked, fixing apartments, when I haven’t worked it’s because of my [daughter], because I’ve always worked”. (FGD 2, participant 13)

Some of their partners had to leave the city and their home to get a better job and they felt forced to enter the informal labour market to contribute to the family income.

“Since she [daughter] was born, I haven’t gone back to work, although I sell hamburgers, tamales or anything on the weekend”. (FGD 2, participant 13)

To meet the financial needs that looking after children with CZS requires, in addition to the regular personal, family and household ones, women had to rely on financial support from other family members, such as parents or uncles/aunts, as well as from government institutions and non-profit entities, such as charities.

“[...] it’s a great support because he [father of the participant] adores him [son], so he says to me ‘What does he need?’ ‘Let’s go and buy him it’. It’s a great help, because our salary isn’t enough for everything”. (FGD 2, participant 1)

“Sometimes people buy him things [...] a woman called me the other day to ask if she could give him [son] some things. She asked, ‘What does he need?’ So I said whatever she wanted to give me, so the woman started to give me nappies and milk for him [son]”. (FGD 2, participant 1)

3. Need for social support

3.1 The need to delegate care vs. the difficulty of doing it

Women described the need to have support from other caregivers to delegate the responsibility of care regularly. They considered this as essential in order to be able to rest, study or work, as well as to recover the social life they had before their children were born, such as meeting with friends and leisure activities.

“[...] I need to be aware 24 hours, so I can’t study, and I can’t work, and I’m fighting for that because I’m young and I honestly need some help in that sense, because I feel exhausted and sometimes I feel that I can’t do anymore”. (FGD 1, participant 4)

Nonetheless, it was not easy for women to leave their children with other caregivers. Mothers feared that others were not going to be able to communicate effectively with their children,

to understand their needs and desires, nor to know how to act in an emergency, such as a convulsion, bronchospasm or when they fall.

“It’s difficult for me to leave her in the hands of another person who isn’t able to understand the situation one goes through every day with them. To say, careful, make sure they don’t fall, don’t let them hit their head [...] So that’s an incredible difficulty for me that I need help from someone, but that’s my biggest fear”. (FGD 2, participant 14)

Only three of them decided to partially delegate care to other non-family caregivers and despite their experience, women had to “train” them. At first they did not trust that they would care for their children with the same care and dedication as mothers would do.

“As she [daughter] has swallowing difficulties, I was always scared about the teachers giving her food. Until 3 months ago that I let go and the 3 teachers feed her, they were less scared because I was teaching them bit by bit [...]”. (FGD 2, participant 2)

3.2 Women’s need for time for selfcare

Women were focused on meeting their children’s needs before their own as, for example, not having time to rest properly and caring for themselves, which leads to physical exhaustion.

“[...] Our day-to-day is chaos, because there’s specialists, paediatricians, therapies, endless things, night comes and you’re exhausted and you keep going and going”.

(FGD 1, participant 2)

Paradoxically, women felt that they have to maintain an adequate physical and mental state to efficiently respond to caring for their children, because if they are not well, no one will replace them. The demand to always “be well” for their children implies forgetting about themselves, their needs, their social life and even their physical and emotional health problems.

“[...] now since I’ve had my [daughter] I don’t get ill. I say, I can’t get ill! Nothing can hurt me!”. (FGD 3, participant 2)

As a result, when women experienced health problems, they opted for alternatives, such as self-medication or home remedies instead of attending health services.

“My sister always says, ‘you need to go to the doctor’ [...]. She says, ‘your heel hurts from walking back and forth holding your [daughter], your head hurts [...], I just take Advil forte [painkiller], my health is secondary [...]. I haven’t had a breast exam, a smear test, necessary things for a woman that become secondary because I have a baby [...]”. (FGD 2, participant 17)

3.3 Women's need to have support from their partners

The birth of their children generated drastic changes in family life, leading to difficulties and conflicts with their partners. Women stated that their husbands did not commit to caring for their child and, additionally, six of the couples separated.

“[...] as a couple we had a crisis because I started to hate my husband, I shouted at him that he didn't want to have the child. Because that's the way he is, I'd say, we have a doctor's appointment. He responds 'ah, ok' [husband]. And that's it. He loves him, he hugs him, but I still haven't seen the dedication and commitment that I have with him”. (Interview, participant 4)

Participants would need to delegate tasks to their partners in terms of looking after children in order to unload for a while. Nevertheless, they felt that their partners were not prepared to care for their children, due to their lack of ability to do so and to respond appropriately to the complications children may present. For example, women described fathers as being impatient, afraid of holding them and experiencing difficulties in feeding them.

“Because no, my husband, he holds him, he holds him for a while, but he's impatient because he [son] becomes difficult. So he says, 'Sit down!' 'Why is he doing that?' 'Help me'! [...]. If I leave him with him to make dinner, 'hold him while I go and make dinner', so he starts, 'I'm tired, my arms hurt'. And I say, 'I do it all day and even at night'. So he starts and argues”. (Interview, participant 1)

Women justified the lack of support from their partners due to gender differences. On the one hand, they understood men's lack of interest, patience, dedication and confidence in caregiving, especially when children demand more complex and lifelong care, because they do not have a "maternal instinct" or an "innate feminine ability".

On the other hand, women considered that the main role of their partners is to support the household financially and, therefore, they should rest at home instead of caring for their children or doing housework despite some of the women also having a job.

“I can’t see my husband looking after him all day and especially because he works, and I don’t think he’d be up all night with him. Yes, I also work, but not, I feel more confident that my son is with the night carer than with my husband”. (Interview, participant 1)

3.4 Need for future replacement

Due to the lifelong disability condition of their children and the complex care they require, and being women the main person responsible of looking after them, they expressed concern about the future of their children when mothers would not be able to care for them anymore

“[...] I’m really scared about when I’m not around, because he’s everything to me. No one gives him medicine in the house because I do it, I give him full pasta, because I know he eats it well. My mum doesn’t dare give him medicine, once she went to give

him some and he nearly choked and she was crying [...] So the day I'm not around, what will happen to him? (FGD 3, participant 3)

To ensure someone will take care of their children with a disability, they imagined the possibility of having the support of other women in the family, or having another child, in the cases when the child with CZS does not have any brothers or sisters.

“I also think a lot about that possibility [...] of having another child further on to help me support her or be with her [daughter] [...] they'd then have that responsibility [...]”. (FGD 2, participant 3)

Discussion

This study shows that mothers of children with CZS need specific knowledge and skills to provide complex care, for which they do not feel prepared, as well as economic support to meet the family and medical needs of their children, and social support of other caregivers so the mothers can rest or work. Results suggest that these deficiencies experienced by women could deteriorate both their mental and physical health, so they would require psychosocial support from their social networks and health professionals.

A child with neurological disorders and multiple disabilities demands complex care and implies almost exclusive care for life, which has a negative impact on the lives of mothers (Aplin et al., 2018; DiGiacomo et al., 2017).

For the participants in this study, care implied a greater effort because they were not prepared due to being young and inexperienced, but also because of the low education and socioeconomic level of most of them (14 of them), which is consistent with the characteristics of women with children with CZS in Brazil (Barbeito-Andrés et al., 2018; Freitas et al., 2019). For example, it has been evidenced that primary caregivers with less than 12 years of education are likely to develop symptoms of depression (Kotzky et al., 2019). Furthermore, the novelty of the disease and the syndrome (Bailey & Ventura, 2018), the lack of preparation of health teams, the absence of protocols for early diagnosis and adequate treatment of children with CZS (Freitas et al., 2020) were not a source of support for women during the emergency caused by this epidemic.

In addition, in Colombia, as in all of Latin America, the orientation provided by health professionals was not adequate when children were born with CZS, because they did not have previous experience with CZS cases (Laza et al., in press). Results showed how, due to this lack of preparation, women had to get information from the Internet or the SG in which they participated.

Unfavourable socioeconomic conditions make it more complicated to care for children, which can compromise their well-being because they do not have the necessary resources (Barbeito-Andrés et al., 2018; Souza et al., 2018). Results built upon previous studies in Brazil highlighted how the economic situation and the dependence of women, who were already facing socioeconomic difficulties, were further aggravated by the epidemic due to the strong association of CZS prevalence with the low socioeconomic level in the poorest and most vulnerable areas of the country (Freitas et al., 2020; Souza et al., 2018). It was

impossible for these women to combine full-time care of their children with the jobs they carried out before, which is in line with previous studies in Brazil that also indicated that more than 70% of the participants reported losing their paid jobs (Carla da Silva Reis et al., 2020; Freitas et al., 2019). This, together with increased expenses due to the medical treatment required not covered by health insurance, implies the detriment of the family income and the economic dependence of women on their partners and families (Laza et al., 2021; Tirado et al., 2020), or even charity, as this study shows.

The fact that the participants of the study do not have the support of their partners to care for their children is explained because, in patriarchal societies, such as those of Latin America, women are traditionally constructed as primary caregivers, while the role of fathers in care is minimized and they are recognized instead as providers of financial support (Amato, 2018; Smythe et al., 2019). Thus, as in Brazil, our results show that the ZIKV epidemic reinforced the historical gender inequality, since women are the main caregivers who spend time and energy in directly looking after their children, even quitting their jobs to be able to care for them full time. This fact reinforced the feminization of care, the impoverishment of women and the consequent inequality of power between men and women (Albuquerque et al., 2019; Allen, 2016; Kiernan et al., 2017).

The almost exclusive dedication to looking after their children with CZS resulted in significant social isolation of the participants. Brazilian women also reported profound changes in their daily lives after their children were born, marked by lonely and exhausting routines and feelings of invisibility and isolation (Dos Santos Oliveira et al., 2017). Demands for care limit opportunities for “normal” social experiences, especially when family or other

support systems are not present (Bailey & Ventura, 2018). In this sense, for the participants, participating in the SG contributed to filling this gap.

Childcare support is a protective factor for the well-being of the primary caregiver (Kotzky et al., 2019). Women caregivers of children with chronic cognitive impairments tend to experience a lack of social support and difficulty in finding a replacement to be able to delegate care and, thus, reduce the burden, burnout and isolation (Aplin et al., 2018; DiGiacomo et al., 2017; Gilligan, 1982). Our results add that paradoxically, participants found it difficult to delegate the care of their children with CZS because they feared others are not as dedicated as they are. This is explained by the traditional idealization of motherhood and the sacrifices mothers should make for their children (Knight, 2013), based on the dominant idea of a “good mother” as a woman who is always there for others: a selfless, sacrificing and resilient woman (Kruks, 1992). Applying that to CZS, women direct their efforts to solving the problems and difficult situations their children have (such as convulsions or shallowing problems), forgetting their own health needs, such as attending health services. For instance, women experienced symptoms of depression and anxiety, as is the case of mothers of children with CZS in Brazil (Carla da Silva Reis et al., 2020; Freitas et al., 2020; Kuper et al., 2019) and other regions of Colombia (Romero et al., 2020). This study adds to previous literature that the full-time CZS care requirements also implies women to forget about themselves and feel the pressure of not being able to even get sick themselves. As Bahr and Bahr (Bahr & Bahr, 2001) (35) explained, traditional female behaviours, such as self-sacrifice, can become a “pathology” in which women can even lose themselves for the sake of their children and looking after them.

Finally, displaying various symptoms related to the impact of the mental health of the participants calls for the need for the psychosocial care of women by professionals and the Colombian health system. Literature explains that women with children with CZS suffer from anxiety, depression, distress, stress, among others, due to the unequal burden of care falling upon women (Freitas et al., 2019)). Literature also expresses the change from being paid workers to becoming exclusive caregivers at home, as well as the loss of income (Carla da Silva Reis et al., 2020), feeling blame (Laza et al., in press) and stigma for having a child with CZS (Dos Santos Oliveira et al., 2017), changes in relationships, and even abandonment of partners (Freire et al., 2018), and exhausting therapeutic itineraries in search of care for their children (Freitas et al., 2020).

Limitations

Since data was collected through the FGDs, one limitation could be social desirability in women's discourses. Nevertheless, the trust generated between women in the SG group throughout the 16 months, and the triangulation of information with individual interviews, observation and field notes, helped us to relativize this possible bias. The results are limited to Southern Colombia, and future studies in other regions of the country where children with CZS were born will help to increase knowledge about the conditions in which their care is provided. Interviewing fathers of children, other family relatives and health professionals could also help to complement these views.

Conclusions

This study showed that women with children suffering from CZS face unmet needs in their daily lives to effectively care for their children. The knowledge provided could be useful to generate effective nursing strategies for women with children with CZS, where families and partners are involved. It is also urgent for the Colombian state to develop public policies to support women and prevent further impoverishment and deterioration of their physical and mental health, such as including medical treatment of children with CZS within the health system's free provisions, training the family so they can provide the specialized care these children require and supporting families economically with specialized caregivers with assistance at their homes.

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Figure 1. Categories and subcategories identified during the analysis

Table 1. Sociodemographic characteristics of the women participating in the study

P	Age	Socioeconomic level (Stratum)*	Education level	Occupation	Marital status	N. of children
1	29	Medium (S1-2)	Technician	Teacher	Living with a partner	2
2	30	Medium (S1-2)	University	Teacher	Married	1
3	18	Low (S1)	Primary School	Unemployed	Single	1
4	24	Low (S1)	High School	Unemployed	Married	1
5	20	Low (S1)	Primary School	Unemployed	Living with a partner	1
6	36	Low (S1)	High School	Unemployed	Married	4
7	21	Low (S1)	High School	Unemployed	Single	1
8	19	Low (S1)	High School	Unemployed	Living with a partner	1
9	19	Low (S1)	High School	Unemployed	Living with a partner	1
10	20	Low (S1)	High School	Unemployed	Single	1
11	37	Medium (S1-2)	University	Unemployed	Married	3
12	31	Low (S1)	High School	Unemployed	Living with a partner	1
13	23	Low (S1)	Technician	Unemployed	Single	1
14	25	Low (S1)	High School	Stylist	Single	2

15	25	Low (S1)	High School	Unemployed	Married	2
16	30	Low (S1)	High School	Unemployed	Single	3
17	19	Low (S1)	Primary School	Unemployed	Living with a partner	1
18	24	Medium (S1-2)	Technician	Unemployed	Living with a partner	2
19	24	Low (S1)	Technician	Unemployed	Living with a partner	1
20	23	Low (S1)	High School	Unemployed	Living with a partner	1
21	30	Low (S1)	Primary School	Unemployed	Single	4

*Socioeconomic level is defined in Colombia as socioeconomic stratum, and the number of the stratum is designated to an individual according to the household income and the zone of residence. People living in stratum 1 are considered to be from the lowest class; stratum 2: lower middle class; stratum 3: middle class; stratum 4: upper middle class; stratum 5: upper class; and stratum 6: rich. Source: National System of Statistics (DANE). <http://www.dane.gov.co/index.php/69-espanol/geoestadistica/estratificacion/468-estratificacion-socioeconomica>. Accessed May 6, 2020.