Cross-cultural adaptation of the *Zero Mothers Die* (ZMD-App) in Brazil: contributing to digital health with the approach on care centred for *e-pregnant* woman

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Abstract

Objectives: to describe the adaptation process of the Zero Mothers Die app, developed in Europe, is to combat maternal mortality, was brought into the Brazilian context with an individualized auscultation methodology for pregnant women and mothers who attended a high complexity referred teaching hospital.

Methods: the research consisted of two parts: the participant observation technique was used by health professionals to translate the platform; with an approach in the service with online forms for pregnant women, and the content analysis was performed by grounded theory of the data. During five months, 109 pregnant women and mothers installed the app, but only 17 completed the questionnaire.

Results: the women and health professionals pointed out questions such as interactivity, application interface, content, pregnancy and childcare clinical management, which contributed for the Brazilian version.

Conclusions: the participatory medicine and e-pregnant woman are new premises of a humanization policy for women and childcare. The insertion of an app with information based on the best evidence in the prenatal routine in the health establishments with teaching activities that can provide new dialogue connections with the pregnant women and chances to update the professional in training.

Key words *Woman's health, Child health, Maternal mortality, Telemedicine*

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Introduction

Maternal mortality is a worldwide public health problem. According to the World Health Organization (WHO) in 2010 there were approximately 287 thousand deaths, the majority were avoidable and in developing countries. This problem has so many causal factors that the United Nations (UN) Millennium Development Goals concluded in 2015 did not succeed in reducing this rate by 75% in the world, including Brazil.[1]

The differences between impoverished and wealthy regions are abyssal. Whereas in developing countries in 100 thousand live births 239 women die, in developed countries this number reduced to 12 women. Therefore, one of the goals of the Third Sustainable Development Goals called "Health with quality" (from 2016 to 2030), is to reduce the maternal mortality rate to less than 70 per 100 thousand births worldwide and no other country should have a maternal mortality rate more than the double of the global average.[2]

In Brazil, there are many underreporting problems that hinder consensus on an exact number. In a 2002 survey, the maternal mortality rate was estimated at 54.[3] on a set of Brazilian State Capitals. After adjustment and refining, the maternal mortality in the country in 2011 was 64.8 and was still above 64 in 2017.[3]

Women who survive severe complications of pregnancy, childbirth and postpartum have much in common with those who have died of these same complications.[4] This similarity led to the development of the concept of maternal near miss, defined by WHO as "a woman who nearly died but survived a complication that occurred during pregnancy, childbirth or within 42 days of pregnancy termination" that became a way to verify the quality of prenatal care.[5]

Although we are living in an information society, connected by networks, the lack of information to prevent pregnancy complications contributes to deaths resulting from childbirth, postpartum and abortions.[6] The excess of information with no quality verification, which has multiplied since the emergence of the internet, also aggravates the situation.[7]

Interventions on digital health[8] have been arising throughout the world to address the widespread misinformation related to reproductive health. Quality certified entities on health information from websites, international guidelines in how to design and evaluate cell phone apps are available for managers, the academic community and the population.[9]

The *Zero Mothers Die* (ZMD)[10] project consists of a global collaboration to save pregnant women and their babies' lives by spreading technologies to improve its access to healthy pregnancy and first aid information. It is a multilateral public-private partnership with adherence in African countries, with UNAIDS, telecommunication companies and others key actors.

Among these partnership products there is the ZMD app for smartphones, available for free in English and French for Android platforms. It is a digital health initiative on the m-health modality aimed for pregnant women, mothers with zero to one year old children and health professionals, in which the main goal is to reduce maternal mortality throughout the world, providing key-information to these interlocutors about health care. The app consists of a section divided into weeks to accompany the pregnancy and another part divided into months to monitor child development in the first year of life. There is also a section aimed for primary care health professionals with audiovisual resources for continuing education.

The care centered for patient , a practice adopted in various health systems, assumes its discourse will also reach caregivers and family members,[11] which requires participative methodology to qualify the care. On the other hand, the connected patient reacts in a different way, interacting with the digital ecosystem, as what has been termed the *e-patient*.[12] In Brazil, this care centered practice related to pregnant woman and child in the early years of life has achieved in many policies and strategies, in particular, humanization and integral care on prevalent childhood diseases.

Considering the present scenario, this study describes the adaptation process of the ZMD app into the Brazilian context, with the methodology of individualized auscultation for pregnant women users at a high complexity referred teaching hospital

Methods

This is a descriptive study of an exploratory nature that has adapted a digital intervention for a public health problem for the Brazilian interlocutor. Since ethnographic research has been used to observe a specific social scenario and processes that are composed of multiple and changing elements,[13] the current investigation was made on a qualitative nature using an ethnographic research technique called the participatory observation to translate the platform by health professionals.

The research scenario was at the *Instituto Nacional de Saúde da Mulher, da Criança e do Adolescente Fernandes Figueira* (Fernandes Figueira National Institute of Woman, Child and Adolescent Health), a public reference hospital of medium and high complexity for high fetal risk pregnancies and for children with chronic complex conditions. It is a technical scientific unit of the *Fundação Oswaldo Cruz* (Oswaldo Cruz Foundation) teaching hospital located in Rio de Janeiro, Brazil, whose 2018 structure comprised 12 beds for pregnant women, 14 beds for accommodation and three rooms of pre-childbirth, childbirth and immediate postpartum .

At the first stage of the research, a bibliographic review was made, combined with live and virtual meetings with a specialist multitask group. Students of the medical residency programs, nursing and multidisciplinary as well as other areas involved in the programs were sensitized and recruited at the same hospital. They composed an on demand multidisciplinary group for translation and technical revision monitored by the research team and their preceptors.

The research group was composed of thirteen researchers, namely: a pharmacist, a food engineer, a physiotherapist, a pediatrician, an obstetrician, a pediatric surgeon, a psychologist, a journalist, and nursing and health worker residents. Among them there were five PhD professionals, one doctoral candidate, and six were acting as preceptors in the residency courses at the hospital. There was a French native speaker which allowed the group to compare the English and French app versions.

The translation was done based on consensus assessment methodology among the specialists and concluded with a re-translation activity,[14] registered in field diaries. Throughout the cross-cultural adaptation alterations were made with multiple tools in the healthcare field,[15] involving translation, re-translation, technical revision and semantic evaluation, content validation by professionals in the area, tool assessment by a sample of the target population, by means of evaluating comprehension levels.

In the second part of the research, we intend to present the initial profile of this e-pregnant woman, the informational needs for the quality of life for the woman and her baby. Pregnant women, usersof the prenatal services and of the human milk bank were approached by professionals at these services to volunteer to install the app on the pregnant women's smartphones and later contacted them to fill out the online evaluation form. As exclusion criteria, the option was not to approach women with severe fetal malformation, whose outpatient service is done in a different way and on specific days.

The investigation was performed between November 2017 and December 2018 and had seven stages as demonstrated below:

1. Translation of the material performed by a professional.
2. Revision and adaptation performed by a multidisciplinary team.
3. Submission of the originals to the ZMD team in Europe to review and to integrate the content with the app.
4. Publication and release of the Brazilian Portuguese version at the Google store.
5. Recruitment of pregnant women at prenatal and pediatric clinics and the human milk bank.
6. WhatsApp contact and individual fill out survey.
7. Analysis of the responses of the survey

The approach with the pregnant women had a theoretical reference based on the Grounded Theory Data (GTD). According to GTD, the data were collected and analyzed concomitantly in a circular movement, aimed at theoretical saturation and verifying the investigated hypothesis.[16] The sample of prenatal service volunteers was non-probabilistic, which reinforces this reference, that works with the concept of theoretical sampling,[17] and refers to the possibility of the researcher to seek their data in the testimony of people who were indicated of having the knowledge about the reality to be investigated.

Data collection took five months and was led by a data capturing team. In terms of the approach, the team started with a simple explanation of the ZMD app. The team explained how to download the app on the Android smartphones. Afterwards, they invited the pregnant women and mothers' group during the lecture activities on prenatal care, postpartum or feeding at the human milk bank by participating in the assessment research.

The same procedure was used by the data capture team in approaching individuals in outpatient care. The women who were willing to join signed a consent form, received a leaflet with additional explanations in how to fill out the online form (see Appendix I), gave their personal email and WhatsApp contact.

After a week, the research team sent the form link again by WhatsApp. The content of the questionnaire was based on the e-health literacy scale (eHEALS)[18] and its configuration was done in online research software where the attendees recorded their app experience (See Appendix II). eHEALS is designed to assess users' perceived

competencies in the use of health information technology and to help determine the suitability of applications for public health programs. Afterwards, a content analysis was made from the WhatsApp chats and filled out forms and grouping codes. The online contacts and forms registered impressions, opinions and reports on pregnant women and mothers about the usage of the app.

This research was submitted to Plataforma Brasil under CAAE number 85439418.8.8.0000.5269 and approved by the Ethics Committee number 3.005.922.

Results

The health professionals held fifteen face-to-face meetings and facilitated a virtual discussion group between October 2017 and November 2018. Activities and observations were registered in meeting minutes and online chats were filed in the app.

Alterations recommended by health professionals

A first finding was that the app when simulating a conversation with a pregnant woman and in early maternity, had addressed the same content, but with different narratives, in both languages. In this sense, the research group made four changes that were highlighted as the guidelines in care in the country were compared to the international recommendations.

1. Procedure of umbilical cord clamping in emergency childbirth and prematurity

In the text related to the seventh month of pregnancy, the app raises the subject of early emergency childbirth. Besides modifying the cold, direct and synthetic language so as not to alarm the pregnant woman for no reason, we added in the app that if it occurred the baby would be considered premature and would need special care. Giving clear instructions about umbilical cord clamping for the woman, a midwife or a layperson was an overall group concern.

In Aristotle[19] studies had already pointed out that waiting for a few minutes until the cessation of the umbilical cord pulse, before clamping it, it would improve the future health of the baby. The reason is that the additional blood volume gained by this practice may benefit the development of the newborn, especially among premature babies born before the 37th week of pregnancy.

Considering the benefits of most newborns, the American College of Obstetricians and Gynecologists[20] now recommend the delay of umbilical cord clamping on full-term and premature babies, for at least 30-60 seconds after birth, except if there is any contraindication related to the umbilical cord or the need for neonatal resuscitation.

After many discussions, the final text was written as below:

> "Put the baby stomach up between the mother's legs. Wait until the cord pulse ceases. Afterwards, tie two clean strings or laces around the cord. The first knot should be made a thumb-length from the baby's belly. The second knot should be three finger widths distant from the first. Tighten the knots. Cut the cord between the two knots."

2. HIV positive breastfeeding

The WHO and United Nations Children's Fund (UNICEF), recommend that in poor countries the benefits of exclusive breastfeeding must be considered in regard to virus transmission risk,[21] taking into account that breastfeeding considerably contributes to reduce child morbimortality rates from diseases like diarrhea, respiratory diseases and malnutrition. Included in this context, breastfeeding is exclusive until six months old and supplemented until two years of age or more to babies of HIV positive mothers, as long as the mother has been under antiretroviral therapy (ART).

The viral load on the mother's milk is one of the major causes of vertical transmission of HIV, because the viral particles are freely excreted by the milk monocytes of the infected woman, regardless of whether or not she presents with symptoms, and are transmitted to the baby by the nasopharyngeal mucosa and gastrointestinal tract, which as it is still maturing, is a virus entry point.[22]

Antiretroviral treatment (ART) during pregnancy and postpartum by HIV positive women reduce vertical virus transmission. However, it is important to highlight that this therapy does not control the elimination of HIV-1 in mother's milk. Therefore, there is a consensus in Brazil – Ministry of Health[23] – that breastfeeding should be contraindicated.[24] Other reasons associated with this consensus are related to late diagnosis and insufficient adherence to treatment.[25]

For this reason, the team chose to write in the app a translated text about breastfeeding planning referring to the second semester, its contraindication for HIV positive pregnant women:

"If you are HIV positive, you may talk to your physician about how to breastfeed your baby without transmitting the virus. He/she will guide you."

3. Tuberculosis transmission by mother, family members and lactating women

In the twelfth week of pregnancy, the team added besides caring for a pregnant woman with tuberculosis, it is also important to observe respiratory symptoms in the family members and seek tuberculosis testing at a health unit as well as mentioning that this treatment is available for free in the *Sistema Único de Saúde* (SUS). (Public Health) units in Brazil.

We corrected the withdrawal time for tuberculosis transmission prevention measures from two to 15 days, according to the recommendations of the Ministry of Health in Brazil. It was observed in the literature[26] that a patient is considered non-infectious if they have no previous tuberculosis treatment history, nor another known risk of drug resistance, in which after 15 days of treatment it will present a clinical improvement. However, based on the evidences of drug resistant tuberculosis transmission, the Brazilian Ministry of Health recommends that consideration should be given to obtain a negative bacilloscopy so that precautions with contagion should be suspended.

4. Mother and baby always included in the discourse

At the first meetings with the multidisciplinary team of professionals involved in the research, the fact that the app focused on the health of the pregnant woman, mother and baby was highlighted, and despite have included in the content very important aspects about the health of the pregnant woman, mother and baby, it did not include a slightly more 'inclusive' welcome on healthcare for the main interlocutor and user of the app, which is, the mother.

Although the original texts in the app bring aspects related to the mother's healthcare, they always had a final appeal, albeit with an "implicit" intention to be addressed to the mother, the main emphasis was on the concern the mother should have about her baby's health, when at the end of each pregnancy week the text emphasized:

"If this week you want to do something good for your baby…".

Although *a priori* this detail sound trivial, considering the psychic and emotional aspects of a pregnant woman, it is important to stress throughout the texts that the concern is mainly about her health, calling on her for co-participation and responsibility for her self-care, as a form of early intervention not only on her physical but also her mental health.

Therefore, as the mother is mentioned in the speech that is directed to her, and at all times 'perceives' and sees herself as truly important and essential at that moment, she will feel welcomed as a participant in the pregnancy, realizing how important it is that not only the baby is well, but especially that she is well, thus gradually urging her to approach and concern herself with her wellbeing and that of the other who lives in her, and thus enabling, through reading the dialogues and instructions given by the app, which although 'implicitly' and minimally, will generate the first bonds between her and her baby.

Thus, after reflections about this aspect's importance, this is how the final text was constructed:

"If this week you want to do something good for you and your baby…""

Pregnant woman and mother's profile

At the hospital 109 pregnant women were approached between September and November 2018. All of them received the information leaflet with the form link as well as the instructions about the app, which was downloaded and installed on their smartphones with the assistance from the data gathering team. After seven days they were contacted by WhatsApp in order to respond the online form about their app usage.

The list of questions was filled out by 17 users, 14 pregnant women and three new mothers. Three women decided not to identify themselves.

The pregnant women answered seven closed and one open question. They also provided age and schooling information. The woman's mean age was 34 years old, varying between 21 and 44 years old. All the twelve women who informed their schooling had nine years of basic schooling and nine of them declared being undergraduates.

In terms of the relationship between the pregnant woman and the app interface while searching for her health information, the electronic literacy results for pregnant women and mothers were overall and above average satisfactory according to six questions presented on the electronic form (Table 1).

The seventh question was presented in a free and open format, gathering a range of observations and suggestions for ZMD improvement, whose circular content analysis was planned by using GTD[27] combined with the registered WhatsApp chats of the pregnant women that participated. After re-reading and combining, supported by *Atlas.ti* software, three categories emerged from open, axial and selective codification:

• Questions and opinions about the use of the app;

• Interactions among women, services and app;

• Organic modifications and pregnancy complications.

The synthesis-images demonstrate the code clusters that were laid out on a tree with their respective citations and co-occurring codes from bottom to top.

The pregnant women who browsed the app on their smartphones pointed out programming errors and the absence of some tools that other apps offered (Figure 1). One noteworthy question was put by a pregnant woman who made a content observation related to the Brazilian cesarean epidemic.[28]

> "Some information that I found on the app […] does not properly encourage normal childbirth and its demystification." (M1:3)

The code clusters addressing among services, women and app interaction covered topics on services for pregnant women about prenatal consultation, suggestions for sharing information about ZMD and activities inside the app for the pregnant woman, as well as encouraging meetings among the pregnant women (Figure 2).

The highest number of considerations concerning the app hypermedia was the "conversation" with the user, where they give opinions about possible improvements for the app from the expansion of the operational system up to service aggregation. Many of them felt the absence of audiovisual resources in relation to their doubts about pregnancy and baby care.

It was possible to deduce through a WhatsApp chat one fetal death occurrence (Figure 3) and that an asynchronous chat from a cell phone app can comfort and clarify doubts in some determine situations.

Discussion

Theoretical-conceptual aspects of e-pregnant woman emergencies in health services may be seen in the results. The e-patient, in the words of the precursor of the idea,[29] is much more than someone who researches about her own health on the internet. It is someone who is equipped, able, qualified and engaged with her wellbeing and her care decisions. The question with the major implication on health services has been the third element among this health team and patient relationship – the myriad of information on the digital ecosystem.[30] It is possible to perceive from the form responses that there is a gap in instructive audiovisual information for pregnant women. Another pertinent consideration is that while pregnant women consider finding content in the app easy, in their opinion, it has a complementary character for clarifying doubts about pregnancy.

In this sense, it is necessary to prepare the prenatal team to make qualified information available for pregnant women, whether on their smartphone or another device. The participatory medicine movement foresees a transformation in acquisition of knowledge, clinical team skills and attitudes related to the patient. Debronkart[11] suggest a new participatory medicine model, where these "*e-patients*" change from mere passengers to drivers in charge of their family health, sharing part of the responsibility to maintain their wellbeing and find cures. In the case of maternity, this approach has a double function, the maintenance of the mother's health and of her future baby.

The interdisciplinary team of health professionals involved in prenatal care must develop the skills to build a data bank of pregnancy sites, including discussion groups and patient communities, in order to reduce the dissemination and influence of low quality or commercially motivated sites.

The communication channel between prenatal services and the pregnant woman must be extended to explanations of research method, evidence levels and complex health concepts as well as how to advise patients on searching for information in certified places, translating the clinical jargon to the language of the future mothers and inspire them to get involved in decision taking about their health and their baby's.[31]

Two limitations of this investigation must be pointed out, considering that the ZMD app assumes a normal pregnancy: 1) the fact that the interviewed mothers had been at a high complexity service, specialized in twin childbirth, infecto-contagious diseases, hypertension pregnancies, hemolytic diseases and congenital malformation in general; 2) the service, although a National Institute, is located in an upmarket neighborhood in a State capital , and for this reason has more patients from the host city. This may influence the high schooling level of the

Table 1

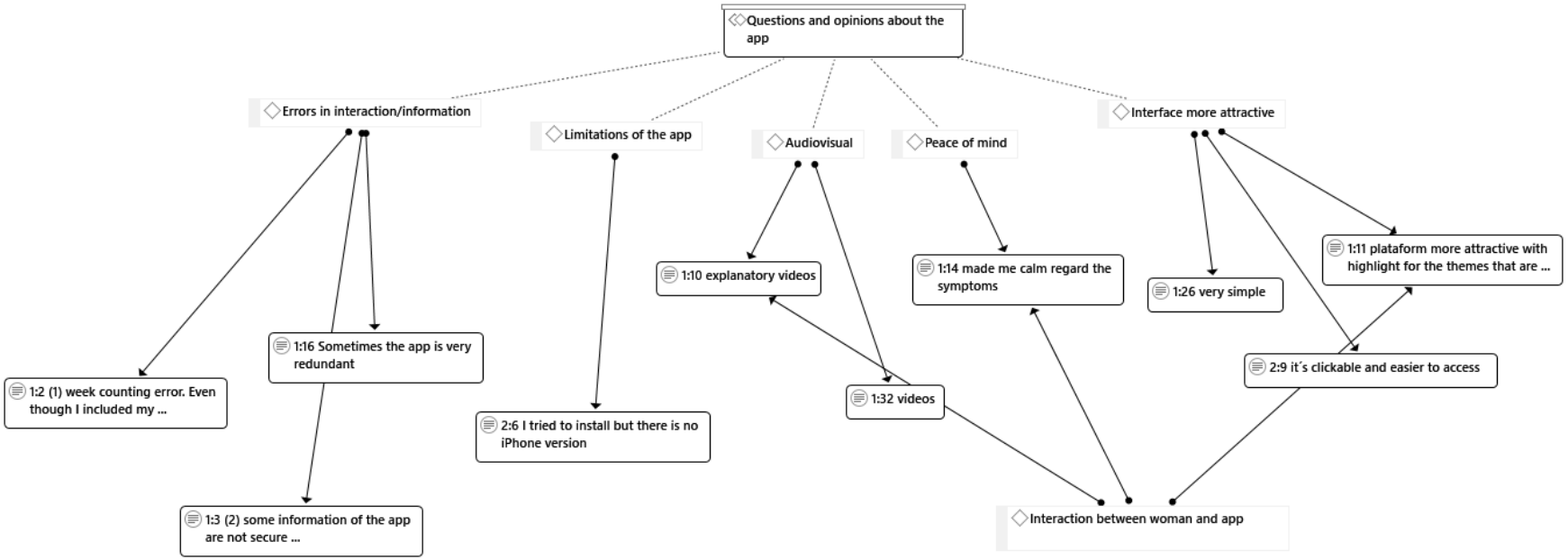
Summary of responses completed on the internet by pregnant women and mothers.

Theme	Questions and questionnaire scale					RM*
Q1	**Efficiency on the assistance for decision making**					
	Not at all effective	Not very effective	Uncertain	Effective	Very effective	
(%)	0	0	24	47	29	
fi	0	0	4	8	5	4.06
Q2	**Importance to assist in clarifying doubts**					
	Not at all important	Not very mportant	Uncertain	Important	Very important	
(%)	12	18	6	47	18	
fi	2	3	1	8	3	3.41
Q3	**Easy to understand hypermedia presentation, interface and navigation**					
	Disagree completely	Disagree	Do not know	Agree	Agree completely	
(%)	0	0	6	88	6	
fi	0	0	1	15	1	4.00
Q4	**Easy to find the desired content in app**					
	Disagree completely	Disagree	Do not know	Agree	Agree completely	
(%)	0	0	12	41	47	
fi	0	0	2	7	8	4.35
Q5	**Easy to use**					
	Disagree completely	Disagree	Do not know	Agree	Agree completely	
(%)	0	12	24	53	12	
fi	0	2	4	9	2	3.65
Q6	**Application of information in the user's daily life**					
	Disagree completely	Disagree	Do not know	Agree	Agree completely	
(%)	0	0	6	76	18	
fi	0	0	1	13	3	4.12

* N = 17 with average ranking applied to the Likert scale. Weighted Average (MP) = $\sum$ (fi.Vi), where fi = observed frequency of each response for each item, Vi = value of each response, which is 1,2,3,4 and 5 respectively. Average Ranking (RM) = MP / (N). The closer to value 5 the MR is, the greater the respondents' agreement level and the closer to 1, the lower the agreement.

Figure 1

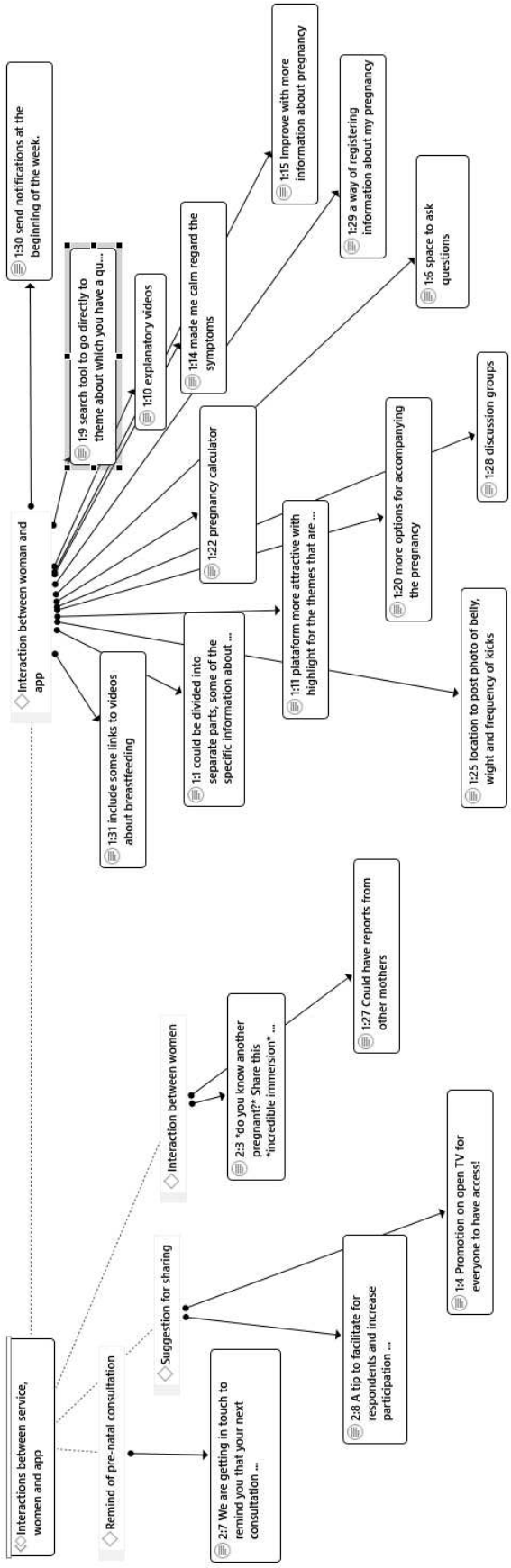
Code group and citations about using *Zero Mothers Die*.



Source: Author elaboration with the assistance of *Atlas.ti software*.

Figure 2

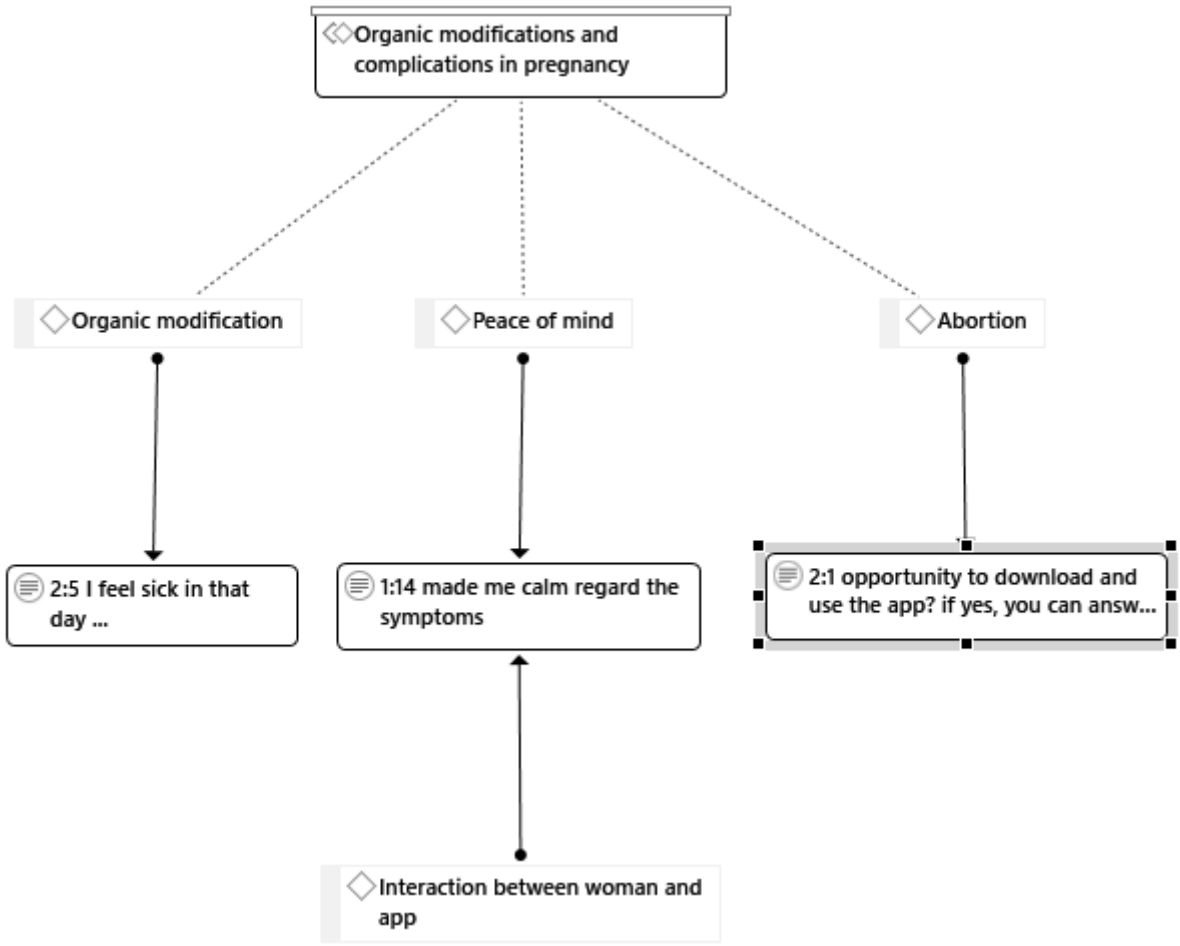
Group of codes and citations about interactions.



Source: Author elaboration with the assistance of *Atlas.ti software*.

Figure 3

Group of citations about organic changes in pregnancy..



Source: Author elaboration with the assistance of *Atlas.ti software.*

researched women. In this study a question remains if different results would be obtained from women with different schooling levels.

The ZMD app bets on the mother-baby binomial and continues an interaction with the woman through monthly baby follow-up from birth to one year, discussing issues beyond the clinic such as family planning.

In the first year of life, the child must be frequently followed up, totalling seven consultations at this stage. However, from the second month onwards the consultation intervals progressively increases. The official recommendation in Brazil is a consultation in the first fifteen days of life, followed by the first, second, fourth, sixth, ninth and twelfth months of life. The constant evaluations of weight gain or height is vital to a child growth's analysis, and allows early identification of malnutrition risks. Another important monitoring parameter is the cephalic perimeter,[32] but one or another are measured on programmed consultations and registered in the Child's Health Handbook.

The family's participation especially of the mother, on the growth evolution and development of the child is a differential in each stage of the process. In this research data it was observed that 76% of the participants considering that the ZMD app information is effective on decision making about the baby's

health.

As for women's health, it would be interesting to change the format for relating the gestational week on information in the ZMD, because the way it is presented can confuse the layperson. One example is regarding information presented about childbirth in the 36th week. It is a fact that childbirth may happen at any moment after 22 weeks. However, the app format could separate women's organic changes and complaints to the detriment of the childbirth event.

In fact, in the 36th week the belly is heavy and there is vaginal secretion. On the 37th week it is hard to move, on the 38th week it gets hard to breathe. The app demonstrates how to clamp a cord in an emergency childbirth but does not fully explore the daily questions that would relieve some pregnancy doubts.

Thus, the group observation was that two separate modules or even different apps, one for the e-patient and another for the primary care professional should be taken in consideration.

Inserting an app with information based on the best prenatal routine evidence from health units with teaching activities generates two immediate opportunities: 1) the possibility of updating preceptors, residents and researchers; 2) another channel of dialogue with the pregnant woman that can be expanded in the digital health ecosystem. Controlled and longitudinal studies are needed to verify whether the introduction of these apps actually contributes in reducing maternal mortality, including near miss incidence, when applied to the health service.

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Authors' contribution

Silva AB, Assumpção AMB, Regadas CT, Silva CRA, Assumpção MR, Silva DA contributed on the article conception. Filha IGA, Santos RCB, Silvério TO, Pastorelli PPL, Paulino BV, Santos PB conducted the data collection. The content analysis was performed by Silva AB and Filha IGA. The final manuscript version has the approval from all the authors and they publicly acknowledge responsibility for the content of the article.

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