# **ORIGINAL PAPER**

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Funding source: Fondo Nacional de Investigación y Desarrollo en Salud, (FONIS) SA14iD0027. FONIS did not influence the design of the study, the collection, analysis or interpretation of the data, or the preparation, review, or approval of the manuscript

**Declaration of conflict of interest:** The authors declare that they have no conflict of interest

Received: 6 June 2022

Accepted: 12 August 2022

Online publication: 12 September 2022

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Cite as: Dois A, Bravo P, Uribe C, Martínez A. Women's involvement in medical decisionmaking during pregnancy and childbirth. Rev peru ginecol obstet. 2022;68(3). DOI: https://doi. org/10.31403/rpgo.v68i2430

## Women's involvement in medical decision-making during pregnancy and childbirth

## Participación en el proceso reproductivo: toma de decisiones durante el embarazo y parto

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#### DOI: https://doi.org/10.31403/rpgo.v68i2430

#### ABSTRACT

Introduction: Enhancing women's participation during pregnancy and childbirth is in line with the call of the World Health Organization and is linked to effects on user satisfaction, clinical health outcomes and better management of health care providers. Objective: To discover women's needs for participation in decision making during pregnancy and childbirth. Methods: Secondary analysis of a descriptive qualitative study with hospitalized women from the puerperium service of two hospitals in Santiago, Chile. The data analysis was carried out using the method proposed by Grounded Theory. Results: Twelve women participated in two focus groups. The relational analysis showed that participation in the reproductive process is interfered by two groups of factors linked to cultural meanings and to the violation of women's rights. Conclusions: Women's participation in clinical decisions during pregnancy and childbirth is still scarce and power is still held by health professionals, perpetuating practices of institutional violence. To advance in obstetric practice centered on women, it is important to recognize the active role that women want and can play in order to have a positive and satisfactory experience.

Key words: Patient participation, Joint decision making, Pregnancy, Obstetric delivery

#### RESUMEN

Introducción. Potenciar la participación de las mujeres durante el embarazo y el parto se alinea con el llamado de la Organización Mundial de la Salud y se vincula con efectos en la satisfacción usuaria, resultados clínicos de salud y una mejor gestión de los prestadores de salud. Objetivo. Descubrir las necesidades de participación en la toma de decisiones de las mujeres durante el proceso del embarazo y parto. Método. Análisis secundario de un estudio cualitativo descriptivo con mujeres hospitalizadas del servicio de puerperio de dos hospitales en Santiago de Chile. El análisis de los datos se realizó utilizando el método propuesto por la Grounded Theory. Resultados. Participaron doce mujeres en dos grupos focales. Del análisis relacional se desprende que la participación en el proceso reproductivo es interferida por dos grupos de factores vinculados a significados culturales y a la vulneración de los derechos de las mujeres. Conclusiones. La participación de las mujeres en las decisiones clínicas durante el proceso de embarazo y parto es aún escasa y el poder sigue manteniéndose en los profesionales de la salud, perpetuándose prácticas de violencia institucional. Para avanzar en una práctica obstétrica centrada en las mujeres, es importante reconocer el papel activo que ellas guieren y pueden cumplir para vivir una experiencia positiva y satisfactoria.

Palabras clave. Participación del paciente, Toma de decisiones conjunta, Embarazo, Parto obstétrico

### INTRODUCTION

Pregnancy, childbirth and puerperium are periods of great significance in the lives of women and constitute an opportunity for them to assume an active role in the care of their health and that of their children<sup>(1,2)</sup>. Public policies<sup>(3)</sup> in force in Chile promote the involvement of people in health care by strengthening the accompaniment of women during pregnancy and up to early childhood, as an element associated with the satisfaction and quality of care<sup>(4)</sup>. Although promoting women's participation in medical decisions related to pregnancy and childbirth, through shared decision making, has been recognized as a standard of quality in obstetric care, its implementation requires the preparation of the health team



and women<sup>(5)</sup>. Studies have shown that pregnant women are relegated to a passive position, with few possibilities of participation<sup>(6-8)</sup> while a high prevalence of hierarchical and medicalized care and the overuse of unnecessary procedures and cesarean sections, mostly chosen by health professionals without the participation of women, are observed worldwide<sup>(9,10)</sup>, which has a negative impact on user satisfaction with the care received. In this scenario, it is necessary to know what would be women's expectations of participation in decision making, something that has not been published in the Chilean context. This study seeks to discover women's needs for participation in decision-making during pregnancy and childbirth.

### **METHODS**

A secondary analysis of data from a descriptive qualitative study was carried out on two focus groups, using recorded audios of women hospitalized during the puerperium period who were attended in the Santiago Public Health System and who participated in the National Health Research Fund (FONIS) Project SA14iD0027 directed by the same research team.

Secondary analysis is a strategy to investigate the reality in a different way than the one initially used by the researchers, in order to improve its understanding<sup>(11)</sup>.

The inclusion criteria were to be a woman over 18 years of age and to be hospitalized in postpartum services. Women who had decided to give their child up for adoption or who had had a stillbirth or stillbirth were excluded.

Data were collected between June 2015 and January 2016. Two focus groups were developed based on a thematic script validated by experts. The criterion for completion was theoretical saturation. Each focus group was transcribed verbatim. Each focus group had a single session, the group of participants was different in each of them and their duration was 59 and 56 minutes, respectively. Each focus group was led by the principal investigator with the participation of two co-researchers. The women attended with their newborns.

The data were analyzed from a descriptive point of view according to Grounded Theory proce-

dures<sup>(12)</sup>, using open coding to identify emerging concepts, their properties and dimensions. The computer software ATLAS.ti version 6 was used. The steps of the analysis process were: a) broad and exhaustive reading of the transcribed narratives of each focus group, to obtain a sense of the whole; b) second reading to identify the themes or categories related to the phenomenon, based on textual phrases; and, c) organization of the categories around broader units of meaning, which account for the essence of the phenomenon under study.

The study and the informed consent process were approved by the Scientific Ethics Committee of the Faculty of Medicine of the Pontificia Universidad Católica [approval number: 14-212] and the Scientific Ethics Committee of the South East Metropolitan Health Service. All participants signed the informed consent form.

## RESULTS

Twelve women participated in two focus groups held in two public hospitals in Santiago, Chile. The average age was 28 years. All the women had planned their pregnancy and were in a couple relationship at the time of participating in the study. Seventy percent had given birth vaginally and 50% were primiparous.

### DESIRE TO PARTICIPATE AFFECTED BY CULTURE AND RESPECT FOR THEIR RIGHTS

Open coding shows that women expect to participate during pregnancy and childbirth. From the descriptive analysis, it can be deduced that during pregnancy, the topics that arouse the greatest interest in participation in decision making are related to ultrasounds, vaccinations and prenatal classes. During childbirth, the most significant issues that emerge are pain management, participation of the father/family, type of delivery and some obstetric procedures.

From the relational analysis, two major categories emerge that would directly influence women's participation in their pregnancy and childbirth process: cultural meanings and the violation of women's rights; both categories would influence each other and would also have a direct effect on user participation in both pregnancy and childbirth (Figure 1).

#### CULTURAL MEANINGS FOR WOMEN'S PARTICIPA-TION IN MEDICAL DECISIONS

The category related to cultural meanings related to the reproductive process shows how vertical and hierarchical styles that maintain a relational logic based on the power of 'the one who knows' (physician) and the passivity of the one who 'does not know' (client) are still reproduced.

*Woman 3 "Nobody reports anything here, they just make the decision. I feel that we are a laboratory" (FG2).* 

Woman 3 "How can I decide if it is not good for me and my child when the system does not allow me to participate? Instead, they force and impose what the doctors say" (FG1).

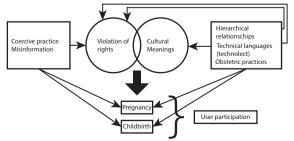
This imbalance of power is deepened by the use of technical language typical of the medical profession, which creates a linguistic barrier between women, their partners and professionals and increases women's self-perception of vulnerability, limiting the exercise of autonomy in decision making and distancing them from the possibility of real participation.

Woman 6 "I had some complications and the problem was that they used technical language, and I did not understand what they were saying and nobody cared" (FG1).

This category also includes obstetric practices and procedures loaded with cultural meanings that are accepted despite the fact that they often go against their wishes and beliefs and have been validated in the collective imagination.

Woman 4 "Since we are part of the public health system, we have to accept that Pedro, Juan and Diego put their hands on us" (FG2).

FIGURE 1. ELEMENTS LIMITING WOMEN'S PARTICIPATION IN THEIR PREGNANCY AND CHILDBIRTH PROCESS.



\*The figure was created by the authors based on the analysis of the focus groups.

Woman 2 "The midwife told me 'when the anesthesiologist comes, you have to say that your pain is immeasurable, otherwise it is a waste of time for him'" (FG1).

Woman 5: And besides, I don't know if you have heard here, but most of them tell us "No, you don't have to complain because if you complain it will be worse" and sometimes you are, like, wallowing (FG2).

## VIOLATION OF RIGHTS THAT LIMIT WOMEN'S PARTICIPATION IN MEDICAL DECISIONS

The second category is related to the violation of women's rights, which according to the participants is materialized in judgments towards them, coercive practices and misinformation that prevent them from exercising their freedom in decision making.

Woman 2 "You mommies were responsible because here the hospital did not get you pregnant" Those were their tones and their phrases, so I find that I... why would you want to have a child if a midwife is telling you that" (FG2).

Among the coercive practices are professional behaviors that force women to proceed in a certain way, for example, by attending prenatal workshops, and whose main interest is in the fulfillment of health goals rather than in the specific benefit for the woman or in the true interest for people and respect for their beliefs, preferences and values.

Woman 1 "But if I did not attend [the prenatal workshop] they would take away my milk or not give me the midwife's check-up. So how can I, as a patient, decide what is good for me and for my child and as a mother-to-be if the system does not allow me to do so, imposes it on me and also pressures me (FG2).

Woman 2 "They wanted to force me to get the influenza vaccine and I made the decision a long time ago that I was not going to get that vaccine anymore, because in the end it ended up worse... I don't get colds in common and they were forcing me, so I found that it was against my rights to practically force me" (FG1).

Added to these practices is the lack of information necessary for them to make decisions during pregnancy and childbirth.



Woman 3 "They called my partner and said 'we have to do a cesarean section, so go and get ready'. And my partner said 'why do we have to do this? I need you to explain to me'" (FG2).

Woman 2 "I know they will do what's best for my baby, but I need to know what they are planning to do!" (FG2)

### DISCUSSION

This study describes women's needs for participation in decision-making during pregnancy and childbirth for a group of Chilean women and shows that women expect to play an active role. However, health practices and the style of relationship between professionals and clients make it very difficult for them to exercise their right to make decisions regarding their health.

Shared decision making in reproductive care begins in pregnancy, with the accompaniment of health professionals to deal with the normal evolution of the process, as well as with unexpected situations and complex decisions in childbirth and postpartum<sup>(13)</sup>. The participants describe that, during pregnancy and childbirth, they presented low possibilities of participation or even decisions that were not respected. These results are in agreement with those of previous studies<sup>(5,14,15)</sup> which show that, on occasions, there is mistrust on the part of the women regarding clinical procedures, which is deepened by insufficient communication and unilateral decisions by the health professionals.

This situation could be explained in part by the separation of the institutional process from the biological process of birth. In this sense, the institutional process has placed its central objective on the fetus and the newborn, relegating the mother to a second plane where intervention and control over women's bodies is a necessary requirement to achieve the objective<sup>(16)</sup>. In addition, it is linked to a lack of preparation of health teams and women to identify the need to share decisions in this health context, which limits the exercise of an active role of the users<sup>(5)</sup>.

The violation of rights in this context would be due to a model structured on hierarchical relationships that subordinates women to the needs of medical personnel and to the standardization of the pregnancy and childbirth process<sup>(14)</sup>, shifting the focus of health care from a model centered on the person to a model centered on the system that ignores the participation of women in their reproductive process as an inalienable right linked to the right to health<sup>(17)</sup> and that ignores the guarantees established in public policies and current legislation<sup>(15,18)</sup>, which is consistent with the findings of other authors<sup>(18,19)</sup>.

Likewise, it perpetuates obstetric practices that are experienced by women in a violent manner, as a consequence of social learning related to the birth process linked to childbirth care in the public health system and that systematically fail to respect women as active subjects in decisions related to their health, subordinating their autonomy to the decisions imposed by the institutions<sup>(20)</sup>.

On the other hand, a vicious circle is produced that legitimizes a form of violence based on hierarchical relationship patterns between professionals and users that deepens the gaps in health care<sup>(17)</sup> and transgresses the right to good treatment in health care. Good treatment is a particular form of relationship, characterized by the use of empathy to understand and give meaning to the needs of women, respect their priorities and highlight their knowledge and expertise in relation to their own situation, making an appropriate exercise of authority and power in relationships, since to the extent that women feel welcomed and perceive an empathetic and individualized treatment, a therapeutic alliance can be established with the professionals who care for them<sup>(21,22)</sup>. The Alma-Ata Declaration recognizes the importance of empowering people to take responsibility for their own health care. Therefore, promoting the involvement of women during pregnancy and childbirth would seem to be an essential part of the management of health professionals and institutions, in line with the call of the World Health Organization for care to be focused on the person and her needs, and therefore to be respectful, empathetic, competent, efficient and sensitive to her needs, values and preferences, providing her with the required information so that she can participate in decisions related to her care<sup>(23)</sup>. These characteristics have been linked to significant effects on user satisfaction, medium and long-term clinical health outcomes and better organization and coordination of the services provided by health care providers<sup>(24)</sup>.

Since the legislative changes in Chile, which recognize the right to a respected gestation period and childbirth and sanction obstetric violence<sup>(25)</sup>, it is necessary to advance in practical and training elements that allow the exercise of obstetric care centered on women and that strengthen their capacities and autonomy. Future research is needed to quantify the level of women's participation in these decisions, as well as the evaluation of needs from the perspective of the health professionals involved in this process.

### CONCLUSIONS

The birth of a child is an important milestone in the biography of women. However, according to the experience of the women in this study, participation in clinical decisions during the pregnancy and childbirth process is still scarce and power is still held by health professionals, perpetuating practices of institutional violence that promote clinical practices far removed from respectful childbirth, limit the exercise of autonomy in decision-making by users and prevent the possibility of real participation. In this scenario, it is necessary to advance towards a change of paradigm that recognizes women's rights in this health context, for which the training of professionals and the preparation of health system users should be promoted, in order to enable them for a respectful and participatory clinical encounter.

### LIMITATIONS

This research represents an advance in the state of the art of women's participation in decision-making in the reproductive process. However, given that the participants were users of maternity wards of the public health system of two hospitals in Santiago, the results may not be generalizable and therefore are not necessarily transferable to other realities.

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