
EXPERIENCE OF WOMEN WITH A SCHOOL-AGE CHILD WITH DOWN SYNDROME¹

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ABSTRACT: The aim of this study was to understand the experience and expectations of women having a school-age child with Down Syndrome. Participants were ten mothers of children with this syndrome who attended a mainstream school and were interviewed in June 2011. The following categories emerged from the testimonies: 'coping with challenges', 'search for balance', 'future projection of the child with Down Syndrome' and 'conciliation among being a woman, worker and mother to a child with Down Syndrome'. The women feel overburdened by the need to conciliate multiple roles. They are concerned with not knowing who will take care of their child in the future, do not have time to take care of themselves and everything related to the personal life is referred to as a postponed desire. Despite nuances of particularities, these women's experiences represent a typical behavior that characterizes the action of women having a child with Down syndrome.

DESCRIPTORS: Woman's health. Mothers. Down Syndrome.

VIVÊNCIA DA MULHER COM UM FILHO COM SÍNDROME DE DOWN EM IDADE ESCOLAR

RESUMO: Objetivou-se compreender a experiência e as expectativas da mulher que convive com um filho com Síndrome de Down em idade escolar. Participaram dez mães de crianças com esta síndrome que frequentavam a escola regular e que foram entrevistadas em junho de 2011. Dos depoimentos emergiram as categorias: 'enfrentamento dos desafios', 'busca de equilíbrio', 'projeção do futuro do filho com Síndrome de Down' e 'conciliação do ser mulher, trabalhadora e mãe do filho com Síndrome de Down'. As mulheres sentem-se sobrecarregadas pela necessidade de conciliar os múltiplos papéis. Preocupam-se por não saber quem cuidará do filho no futuro, não dispõem de tempo para cuidar de si mesmas e tudo que se refere ao plano pessoal é referido como desejo adiado. A experiência desta mulher, embora apresente nuances de singularidades, constitui-se em um comportamento típico que caracteriza a ação das mulheres com um filho com Síndrome de Down.

DESCRIPTORIOS: Saúde da mulher. Mães. Síndrome de Down.

VIVENCIA DE MUJERES CON UN HIJO CON SÍNDROME DE DOWN EN EDAD ESCOLAR

RESUMEN: Se buscó comprender la vivencia y expectativas de mujeres con hijos con Síndrome de Down en edad escolar. Se entrevistaron, en junio del 2011, diez madres de niños con ese síndrome que asistían a escuelas regulares. De los discursos se identificaron las categorías: 'enfrentamiento de los desafíos', 'búsqueda del equilibrio', 'proyección del futuro del hijo con Síndrome de Down' y 'conciliación del ser mujer, ser trabajadora y ser madre de hijo con Síndrome de Down'. Las mujeres se sienten con sobrecarga por la necesidad de conciliar sus múltiples funciones. Se preocupan por no saber quién cuidará de su hijo en el futuro, no disponen de tiempo para cuidar de sí mismas y lo referente al ámbito personal es siempre un deseo postergado. La experiencia de esta mujer, aunque presente matices de singularidades, es un comportamiento típico que caracteriza la acción de mujeres con un hijo con Síndrome de Down.

DESCRIPTORIOS: Salud de la mujer. Madres. Síndrome de Down.

INTRODUCTION

Since the 1970's, the share of women in the workforce has increased significantly, thus contributing to a comprehensive transformation of the role of Brazilian women, especially in middle classes.¹

Although several changes can already be observed in the behavior of society concerning the role of women, there still are strong claims for them to remain accountable for home tasks, children care and family demands, which represent extra burdens for economically active women.²

In addition to the issues related to the multiple activities, in cases when the contemporary woman has a child with Down Syndrome (DS), the burden is even heavier. These mothers experience the impact of the disease as quite a painful process, full of conflicts, as the woman usually feels unprepared to cope with the new caregiving demands toward the child.

A disabled child represents an abrupt interruption in the expectations toward the idealized child. The woman undergoes difficult times of anguish and fear, as she feels threatened by the limitations of the child.³

As a result of their own life experiences, parents accumulate beliefs and values, mostly negative, regarding the intellectual disability. In order to cope with the child's disability, parents will have to elaborate the feeling of oddness caused by the newborn and rebuild all their expectations and projects for the conceived child.⁴

Having overcome the initial stage, the mother will cross over the first obstacles regarding the disability and seek to restore her emotional balance, in order to allow her to raise the child based on the real situation. She will realize her need to review her role as a mother and transform her perspective of the world, so that she may be capable of establishing an affectionate relationship with her child in which the disability is not the core value.⁵

Mothers of children with DS comprise a social group with specific projects and needs that must be addressed. Few studies address the experience of women having children with DS in school age and their multiple roles: woman, worker, possibly a mother to other children, as well as their expectations toward the future based on her intellectually disabled child.

There is a significant absence of research focusing on the context of women having children

with DS in higher age groups, who have already acquired life experiences and are more adapted to the healthcare and education demands of these children.

The following concerns have guided the present study: how do these women feel about having a child with DS? How do they play their roles of being a woman, mother, mother of other children, and worker? How do they conciliate personal and professional lives with maternity and all other daily activities? What are their expectations toward the future, taking into account the fact of being mothers of children with DS?

In light of such issues, the aim of this study was to understand the experience and expectations of women having children with DS in school age. The comprehension of these mothers' meaning contexts can produce relevant knowledge toward helping them to deal with the disabled child, thus contributing to their quality of life and the establishment of healthier family relationships.

METHODOLOGY

The present study employed the qualitative methodology, based on the Social Phenomenology approach. The choice of this reference point resulted from the fact that the life experience of this woman is not restricted to individual intentionality. Her socially built experiences, therefore, constitute an intentionality that translates such experiences within the context of social relationships pervaded with intersubjectivity.

According to this phenomenological approach, social action is grounded on projects set forth by men, and motivated both by existential objectives pointing to the future - "reasons for" - and by reasons guided by lived experiences - "reasons why".⁶

The research was carried out with ten mothers of children with DS in school age (6-10 years old) in the city of São Paulo in June of 2011. Besides taking care of their children, these women had formal jobs out of their homes and lived with a mate.

The school age was defined by taking into account the admission of the child in the educational system (6 years old), as intellectual requirements enhance significantly at this age. The 10-year-old limit resulted from the fact that, from this point on, adolescence is initiated, a phase with increasingly specific conflicts and crises that generate strong impacts even in the relationship between mother and child.⁷⁻⁸

The interviewed women were approached applying the Snowball Sampling, in which the first interviewees are required to indicate other participants to the study.⁹

The testimonies were obtained by means of open interviews, beginning with the following guiding questions: tell me how is it to be a mother of a child with DS? How is it for you to conciliate being a mother of a child with DS and your roles of being a woman, a mother to other children and a worker? Being a mother of a child with DS, what do you expect for the future?

The amount of participants in the research was not previously set. The interviewing process was interrupted as soon as the testimonies started being repetitive and the content of the speeches responded to the questions and the objective of the study.

The interviews were carried out on a date and place chosen by the women, and lasted one hour and thirty minutes in average. The women were asked whether or not the interviews could be recorded.

Following the oral interviews, the conversations were transcribed by the researcher, aiming to preserve both the language and the details of the interviewees' speeches. In order to safeguard the women's anonymity, the interviewees were identified as M1, M2, M3...M10.

The analysis of the testimonies of the interviewed women was performed in accordance with the steps adopted by researchers in the social phenomenology field:¹⁰⁻¹¹ meticulous reading of each testimony, seeking to apprehend the global sense of the lived experience; identification and grouping of the significant aspects in the speeches aiming to compose concrete categories emerging from the lived experiences; analysis of these categories and discussion of results in the light of the Alfred Schütz reference point and other studies related to this issue.

The research project was approved by the Research Ethics Committee of the University of São Paulo, School of Nursing, under protocol number 1047/2011, and complied with the resolutions of the Health National Council for research involving human beings. All participating women were advised on the objective of the study and the preservation of anonymity, and signed the Free and Informed Consent Form.

RESULTS

Eleven (11) women were interviewed. One report was discharged following the disclosed information that the woman did not live with her mate anymore.

The meanings of the duties of mothers of children with Down Syndrome in school age within the context of their experiences was organized and categorized as follows: 'coping with challenges', 'search for balance', 'future projection of the child with Down Syndrome' and 'conciliation among being a woman, worker and mother to a child with Down Syndrome'.

Coping with challenges

The initial periods of time following the birth of a child with DS bring about a series of demands and challenges to the mothers, who need to rethink their world views in order to adapt to the new conditions: [...] *and as we have zero experience, the situation looks like a nightmare, I mean, the difficulties! It seems that all we will have are difficulties [...]* (M10); [...] *well, it is very complicated in the beginning. We dream about that child in a certain way, and then he comes out in another way [...]. The issue with the DS is the fear of the unknown* (M5).

The major concern of the mothers regarding their children with DS was the health aspect. *She was born and headed straight to the ICU [...]. Then, I began to deal with everything... The syndrome was relegated to a second plan. So, up to the fifth month I took care of her heart. After the surgery [...]. I said: now it's time for the DS!* (M1).

The mothers express their concerns about the literacy process of their children: [...] *we keep thinking, will he be capable of learning how to read? Will he be capable of learning how to write more easily or will he find difficulties to learn?* [...] (M8); [...] *her classmates speak much better than her, so sometimes she is not able to make herself properly understood [...]. Now that her literacy process started everything has been very difficult for her and I keep trying to help her [...]* (M10).

The mothers also reveal a sense of guilt for not being able to dedicate more time to their children. *This is something I overpunish myself for. I never feel like I'm doing enough, because of my job. I often sense that there are things I'm not doing for the kids. So, I always think that I could do more for her [...]* (M2).

Mothers place themselves in the position of being responsible for seeking and finding means of favoring the development of the child with DS as a whole being. Therefore, they live the lives of their children and commit themselves to ensure the children have every possible opportunity. [...] *we always have to be careful with all the issues, so it's hard to relax. I think that every mother has that sense of pressure regarding the development of the kids, and being a mother of a child with DS, I feel that I charge myself even more than if my older daughter did not have this disability [...]* (M9).

Search for balance

In accordance with the experience of each mother, distinct ways of accepting the situation were observed in this research. *It is not the worst thing of all! I know that there are much worse things out there! Is he my child? As my husband says, 'if one of your kids is born with ten legs and twenty arms, he is going to be your kid!' And this is exactly what we had in mind. He was our kid!* (M1). Other mothers need more time to cure the pain: [...] *with my second experience as a mother I grew up very much, I needed to go after many things for my other child also* (M2).

Other mothers reported on the need of having a job in order to increase the family income and balance the home budget. Additionally, the work offers the possibility of personal satisfaction. But, on the other hand, these mothers feel quite burdened. *You just can't do everything perfect at the same time. Then, you have to have a routine. One inch out of the routine and I'm lost. I have two jobs, I have a house and no maid [...]* (M1); [...] *I have to work. But, as a mother, it hurts me deeply* (M2).

Some mothers prioritize the family and leave work on a second plan. [...] *I just got stuck professionally speaking, at least in this period. On a second thought, I actually went backwards. It's tough [...]* but then I think to myself, *my daughters are fine, and that's what matters to me* (M9).

The mothers recognize themselves as primarily responsible for the caregiving and treatment of their children with DS, but they also count on a support network. *When they are not in school, they stay with my mother [...]* (M3); [...] *I'm lucky to always have someone, either my mother-in-law, or my mother, or my sister, someone is always there to help me out* (M8).

The testimonies showed that the women who were able to face the initial challenges and strived to accept their disabled children were able to experience the pleasure of being mothers of children with DS. *Will it be difficult? Of course it*

will! Sure! You are not happy all the time. You have ups and downs [...] I do not generate expectations about that. Each conquest is a victory for me. Then, from this point on, I'm more relaxed (M1); *I learned how to be happier, I learned to value the small things* (M2).

Future projection of the child with Down Syndrome

The performance of the child in adulthood is a reason for great concern to mothers who wish their children to have an independent and autonomous life. A sort of contradiction can be observed in their wish, though. On the one hand, they work toward sustaining an intense agenda aiming at the development of their children's potentials; on the other hand, they embody quite an overprotective posture. [...] *I'm raising him to be independent. When they are born we think that it will be much easier. I saw from the beginning that it would be very difficult. But now I see that it is not impossible. I want to follow him up, I want him to live on his own when I go away* (M4).

The mothers also make their best so that their children with intellectual disability develop their potentials. Nevertheless, when the mothers report on their expectations toward an independent life to their children, they set the parameters for that to occur. *I do not expect much from my disabled child. The only thing I desire is that he can be an independent person, someone who is capable of doing things all by himself. Going to work, to school, taking a bus, the subway, cooking basic food, using a mobile phone, communicating [...]* (M8).

Although it is expected that parents die before their children, the presence of a disabled child generates great concern. The perception of the mothers is that no one will be up to the task of replacing them in taking care of their children. *Someday, I'm not going to be here anymore, the father is not going to be here either, so the brothers will have to get along. But, I do hope they get along in a friendly environment, not based on obligations. It's a concern that I have, I live this everyday [...]* (M3); *When I start thinking about the future, about what will become of [son with DS], what I will do with him, with my life, I sort of flip out. I think, 'oh my goodness, what will I do? Then, I try not to think about it* (M6).

Conciliation among being a woman, worker and mother to a child with Down Syndrome

The women pointed out the performance of multiple activities in their daily lives. Speaking of their assignments as mothers, workers and the

ones in charge of taking care of the whole family they affirmed not to have much time left to dedicate to their personal care. All mentions regarding setting apart time for self-care are expressed as a postponed desire, something that may occur in the future. [...] *the role of woman, spouse, the part of taking care of myself, this is all left aside, it's all kept in a box. Whenever there is time left, I take care of myself. But, it is very tough, it stands in a third plan [...] and even when I try to settle a schedule, I prefer not to follow it [...] (M2); Next year I intend to, I don't know, try to have time and resources to work out [...] to do something that can give me some self satisfaction [...] (M5).*

Being a mother is ranked number one in the list of priorities for these women. Nevertheless, the research did not identify any level of dissatisfaction resulting from the wide array of tasks these women had to perform. They hope such conflicts to be temporary, focusing their present experience and hoping that in the future they can have more time for themselves.

The analysis of the results allowed us to see the mother of a child with DS in school age as one who faces challenges related to the health and the education of her child, and someone that walks several extra miles for the children's development. Little by little, she accepts the disabled child and reorganizes her daily life, working to enhance the family income and improve her personal satisfaction, playing the role of caregiver and, hence, feeling overloaded with the need of harmonizing maternity, professional life and all other day-to-day activities. She seeks to be balanced, experiences the pleasure of being a mother and values the conquests of her child. She expects her child to reach autonomy and independence, but at the same time is overprotective of him. She is concerned about who will her child's caregivers be in the future, does not have available time to take care of herself and all her personal needs are referred to as postponed desires.

DISCUSSION

Women in this study experience the challenges brought about by being mothers of children with DS. The way these mothers deal with their child, reorganize their daily schedule and seek balance is a reflection of their biographical situation and body of knowledge acquired throughout their lifetime.

Biographical situation allows each one of us to interpret the world based on the stock of

previous experiences and expertise transmitted by others like us – the body of knowledge. That stock serves as a reference point for people to comprehend the world and is built throughout a lifetime.⁶

Having a child with DS causes mothers to build relationships with other women with similar experiences. This intersubjective relationship presupposes the bonding of people into distinct social relations, in which they both comprehend and are comprehended.⁶⁻¹² Man acts in the world based on existential motives. The motives grounded on past experiences are called “reasons why” and are made accessible to the researcher by means of the subject's testimonies.⁶

Their biographical situation and body of knowledge also bring about the motives that lead them to act in the world and to be in a given way – the “reasons for”.⁶ In this study, these motives are represented by the following categories: ‘coping with challenges’, ‘search for balance’, ‘future projection of the child with Down Syndrome’ and ‘conciliation among being a woman, worker and mother to a child with Down Syndrome’.

The birth of a baby with Down Syndrome stirs a series of new demands and challenges in the woman. The special child brings plenty of conflicts not only to her, but to the whole family, who has to adapt to the new reality and reorganize entirely in order to cope with the challenges of the experience of living with a disabled child. This new situation involves feelings of vulnerability and demands steps toward emotional readjustments, a process that takes time.¹³

The child with DS represents the mother's interruption of expectations toward an idealized baby. After the initial shock, this mother will need to review her concepts of the world and seek to establish a satisfactorily affective relationship with this child in the real world.⁴

The health issue was addressed by the mothers as the major cause of concern regarding their children. A study carried out in a genetics outpatient clinic located in the Southeastern region of Brazil showed that the congenital cardiac disease was recorded in 56.5% of assessed children with DS.¹⁴ The study observed that whenever a child with DS is born with a serious health problem, the problem ends up becoming the primary focus of attention of the parents, who tend to leave the issues regarding the disability aside in order to seek treatment alternatives.

The intellectual damage occupies a central place in the DS; as the child grows up, new issues

appear. In the final stage of the elementary education, mothers get really upset at realizing that their children are not capable of catching up with their peers. Most of the times, such difficulty does not stand out as an impediment for the disabled children to learn.¹⁵

It is worth highlighting that the regular education structure is not yet ready to undergo structural changes in order to receive children with DS and to take care of their specific needs. They are tested in the sense of verifying whether they can adapt to the curriculum proposal of the regular educational system, without a guarantee of adequate resources for the promotion of learning and appreciation of differences.¹⁶

Mothers express feelings of guilt for not having more time to take care of their children and for not being able to closely follow up their growth process. Nevertheless, it is clear that aspects other than external factors, such as lack of time or work overload, also account for these feelings. It is likely that the guilt feeling, which can be observed in various stages of the mother-disabled child relationship, be intrinsically correlated with the guilt of having given birth to an imperfect child.^{3,17-18}

These mothers feel responsible for ensuring that the child with DS can be granted all the necessary conditions toward developing their potentials. Aiming to guarantee the best opportunities, the mothers nearly stand in their child's place and do whatever they can for them, and such action hinders the child's acquisition of certain individualities and abilities that could be experienced despite their disability.⁵

The Granato and Aiello-Vaisberg framework is applied in order to assess the devotion relationship between the mother and the child with DS. The framework is based on the Primary Maternal Preoccupation concept, developed by psychoanalyst Winnicott. The present study proposes the Special Primary Maternal Preoccupation concept directed toward the mother of a child with disability.

In the Primary Maternal Preoccupation concept, the energy of the mother is utterly directed toward her baby, from the end of the pregnancy up until the first weeks or months following delivery. As time passes and as the baby grows up, the mother resumes her life.¹⁹⁻²⁰ In case of a baby with disability, the Primary Maternal Preoccupation will be a special one, less focused on the intensity and more focused on the length of the event. The absolute dedication of the mother to the baby

may be a long-standing process. Moreover, such behavior may either come back in critical times or even last for a lifetime.¹⁹

It was possible to identify several ways of accepting the disability. For some mothers, the acceptance is easier; for others, they need more time to elaborate the new reality. It was also observed that when their children reached the school age, most of the mothers more naturally accepted the disability.

The interviewed women reinforced their need for having a job, either to contribute to the family income or for their personal fulfillment. Nonetheless, they maintain their status of being responsible for the home, children and family affairs, which generate an overload of tasks, especially for those who work outside the home.²

The majority of them feel physically and mentally overwhelmed as a result of their multiple family tasks. Family and work are deemed to be priorities to these women and, as such, the harmony between career and maternity is a desirable plan.²¹

In this survey, mothers revealed that the independence and autonomy of their children in the adult life constitute one of their major concerns regarding their children with DS. They hope that their children can study and get a job. They also express the desire that the children can date and even get married. Nevertheless, the adoption of quite a protective posture does not facilitate the children's path toward this autonomy, creating obstacles on their way to self-identity.

A few of the mothers' expectations regarding the future possibilities of their children are exaggerated; on the other hand, we live in an environment that promotes and stimulates the development of people with DS. In the past, these children were stigmatized and relegated to the fringes of society. Now, it is not at all possible to accurately assess their potentials. It is not only a matter of developing abilities, but a matter of developing a person who is capable of properly dealing with personal characteristics and limitations, as well as making personal choices.²²

Still in the field of expectations, the mothers referred to anxiety and preoccupation about who would take care of their children after their death. Parents usually have the feeling that there will not be anyone that could properly substitute them in taking care of their children after they die.

The anxiety of mothers concerning the caregivers of their children with DS after their death

was addressed by a study carried out in Turkey. Women pointed out the lack of family-based programs and organizations aimed to support disabled children in that nation.²³

The discussion on the support alternatives toward people with DS is similarly relevant in Brazil, taking into account the country's social inequalities and the insufficiency of the services directed toward people with disabilities. Investments should be made not only in the survival of people with DS as they grow old, as they also need to have their quality of life ensured.²⁰

The present study highlighted the hardships women have to face to conciliate personal lives and professional careers with the attention to the children and all other daily activities. All of them deemed their professional careers to be extremely relevant and generated plenty of personal fulfillment. They are overloaded by the performance of multiple activities added to their work assignments and perceive a tough limitation toward expanding their careers.

The child with DS, the family and the work take much of their time and it is hard to open any gap that could prompt them to think about personal projects. The expectations of these women toward the future are most often tied up to their family decisions. Self-care plans are always postponed desires.

The testimonies of the mothers interviewed in this study showed the challenges and inherent conflicts of contemporary women who play multiple roles, especially those mothers who take care and worry about the future of children with DS.

The limitation of this study lies in the fact that every interviewed woman belonged to the same socioeconomic context and displayed quite a satisfactory level of information on DS, an aspect that hinders the generalization of results. Nonetheless, the achieved results offer significant elements for action plans aimed at assisting specific needs these women may have.

CONCLUSION

The findings of the current study allow for understanding the experiences undergone by mothers of children with Down Syndrome in school age, as well as their expectations concerning the future. It was possible to apprehend the way these mothers deal with these children, how they reorganize their daily lives, and search for a level of emotional balance that allows for a suitable life.

At the same time, it was possible to identify typical attitudes and behaviors of these women. Their experiences portray a social meaning, as they belong to a specific social group endowed with typical characteristics.

One of the highlights of this study was the focus on working mothers of children with DS in school age, which differs from the vast majority of other published studies focused on demonstrating the birth difficulties and the limitation of children with disability.

Moreover, the study addressed the emotions experienced by the mothers concerning their children with DS, such as guilt, acceptance and anxiety regarding the future; additionally, the research addressed the concept of the Special Primary Maternal Preoccupation, which enables the reflection on the specificity of the mother-disabled child relationship. Such focus broadens the discussion proposed by the majority of current publications, which tend to prioritize the lack of information and knowledge on the disability as one of the major hindrances to the acceptance of the child.

It was clearly shown that not only the woman, but her whole family must be assisted, not only in the initial moments after the birth of the child with DS, but throughout the whole vital cycle. It is up to the health professionals to support these mothers in stressing situations that might take place in the various stages of their children's development.

Another significant aspect of the study resides in the identification of the mother as the one on whose shoulders lay the heaviest burden of finding the solution to the problems of her child with DS. The mother is the recipient of all the responsibility that should actually be shared with the whole family and even with the society.

It is critical for these women to count on a social environment that acts like a safe harbor, as they are generally overwhelmed by the necessary care needed by their children with DS. The reflections on these mothers' real necessities and on alternatives to support them toward the search for favorable conditions must be broadened, so that they can proceed to the fulfillment of their personal and professional projects.

The relevance of this study is supported by the fact that it enables the comprehension of the experiences undergone by women having children with DS, based on their actions in the world and their possibilities of overthrowing their challenges and fulfilling their life projects.

These results may contribute to understand these women's caregiving needs, as well as subsidize new care-based strategies that include not only the woman, but her whole family. The results are also able to encourage further scientific investigative perspectives in this field.

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