

# How to take care of mothers of children with autism spectrum disorder and/or disability? The CACTO program as a possibility

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Maternity, in its essence, represents agape, unconditional love, engaging and continuous care, but how to take care of the mother? How to care for the mother of a child with Autistic Spectrum Disorder (TEA), Congenital Zika Virus Syndrome (SCZ) and other deficiencies? Motivated by such questions, this editorial aims to present to society the CACTO: unit care program for mothers of children with TEA and/or disability.

In the light of Jean Watson's Science of Unitary Care<sup>(1-2)</sup>, mother can be understood as a concrete expression of human care in its purest and most sacred form. Watson argues that care is a deeply human and spiritual act that transcends the physical and reaches the soul of the other person<sup>(2)</sup>. In this sense, being a mother is experiencing, in its fullness, the art of ca-

ring with compassion, presence and dedication.

Jean Watson proposes that care is at the heart of nursing and human life<sup>(1)</sup>. Under this perspective, the mother becomes a living and immortal symbol of transpersonal care. She cultivates a connection with her child that transcends the biological, and both engage in an affective, spiritual and emotional bond aligned with the "caritas care moments," fundamental principles of her theory. These moments are based on attitudes of love, respect and authentic presence, elements that reveal themselves with intensity in the everyday maternal life.

The sacrality of the mother is manifested in the ability to offer an environment of healing (restauration), comfort and security, similar to the therapeutic

space Watson proposes as essential for transpersonal care<sup>(1)</sup>. The touch, the look, the word and the listening of the mother are actions that generate bonds and promote the integral development of the being, respecting its individuality and its time.

To consider Mother Being as sacred is to recognize that her role goes beyond physical care: Mother nourishes the soul, strengthens hope and serves as a source of emotional balance. By welcoming and caring with love, the mother becomes a true field of positive and healing energy. Therefore, motherhood is, in its essence, one of the most authentic and profound manifestations of human care, worthy of reverence and recognition as sacred.

The Mother Being has its concept modified according to the beliefs and customs of each civilization, the cultural atmosphere that surrounds it and its experiences. For some women, it can be a dangerous, painful experience, while for others, interesting, satisfying and/or indescribable. However, the idealization of a perfect child in its dimensions of aesthetics (appearance), competence (quality and lifestyle) and future (capacity for study and professional competence) is a common feeling for every woman before the decision to conceive a child<sup>(3)</sup>.

However, the diagnosis of TEA, SCZ and other deficiencies breaks the dreamed expectation and makes emerging the socially excluded maternity school, which lives with negative emotions in the face of the grief of the ideal child and drives the construction of complex and exhausting therapeutic itineraries in search of the best development of the child<sup>(4)</sup>. In this itinerary, numerous and varied are the challenges experienced by these mothers,

such as lack of welcoming, prejudice to the indiscrete gaze of repulsion to difference, discrimination, social exclusion and, at times, a violent daily life, which reveals an environment not prepared for the ways their child is in life<sup>(5)</sup>.

In addition, while being a caregiver, the mother of a child with ASD, schizophrenia, and other impairments puts herself second in order to provide opportunities for the child to develop their potential despite neurodevelopmental limitations. This generates accumulation of maternal tasks and roles, with impairments in occupational performance and professional performance, as well as physical, psycho-emotional and socio-economic overload, resulting in repercussions on self-perception, self-care, self-image, quality of life and uncertainties about your life project<sup>(4)</sup>.

Therefore, reflecting on how society relates to each mother and her children is a sine qua non condition for building inclusive public policies that can lay the foundation for mother care in the Health Care Network (RAS). Faced with the few specific care initiatives for mothers that are known, CACTO<sup>(6)</sup> is developed. The objective of CACTO is to restore (healing) the balance between body-mind-soul of mothers and to foster the exercise of the autonomy of professional caregiver – worker regularly enrolled in class council and who exercises unit care with quality and efficiency<sup>(7)</sup>.

CACTO is a social technology that offers a spotlight to the mother herself so that she can illuminate her life project, take on the protagonism of her existence by facing prejudice, discrimination and resigning her action in the world<sup>(6)</sup>. Guided by the health needs of the body, mind and soul dimensions, which are expressed by mothers, the care encounters in CACTO

seek transcendence, the connection between professional caregiver and mother, the creation of a unitary energy field that transcends physical space, consciousness and the notion of time. It is less concerned with the number of consultations performed, bodily signs of illness, fragmentation and intervention of the body, medicalization and excessive request for examinations, therefore, it constitutes as a contra-hegemonic care program<sup>(7)</sup>.

The CACTO care meeting, which occurs between mother and professional caregiver, is the sovereign space for mothers to rebirth the silenced Being Woman, a moment to put their worries, sorrows, fears, sadnesses, inconveniences, organize thoughts, define paths to follow, in addition to enjoying the benefits of traditional care and integrative and complementary practices.

In CACTO, the professional caregiver abandons his ego, the overlap of scientific power and immerses himself in the mother's cultural field. He is willing to offer relational, intersubjective, and proximal care that embodies humanitarian values—care that listens attentively, maintains eye contact, remains silent when needed, contemplates, welcomes, understands, refrains from judgment, and values and motivates mothers to build new life possibilities, even when this requires confronting a capacitivist and patriarchal society<sup>(7)</sup>.

The implementation of CACTO progresses throughout the national territory, provoking reflections on the romanticization of maternity, free and autonomous choice of pregnancy/maternity, impacts and repercussions in the life of the woman, irresponsibility of the parent and the unidealized child, themes that should be addressed in primary health care. At

the same time, we urge healthcare professionals to understand the mother as a Woman in her sacrality and integrity, and not just as therapeutic support for the development of rehabilitating actions in the domestic environment.

Conscious of the health needs that make the mother being vulnerable to illness, the CACTO program has woven unique and emancipatory care that conforms the answer to the questions that started this editorial. Therefore, CACTO is a program, scientifically based on care theory, methodologically robust, in the test phase of effectiveness, which seeks qualification of professionals and offers care modalities to be applied by professional careers and mothers.

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