

The son with pervasive developmental disorder: the mothers' perception of daily care**O filho com transtorno global do desenvolvimento: percepções de mães acerca de cuidados cotidianos****El hijo con trastorno generalizado del desarrollo: percepción de las madres a cerca de cuidados diários****Received: 19/12/2015****Approved: 03/04/2016****Published: 01/05/2016****Chalimar da Cunha¹**
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The objective of this study was to understand and analyze the mother's perception on the care and care demands by the sons with Pervasive Developmental Disorder (PDD). Qualitative research, with data collection conducted through semi-structured interviews with seven mothers and analysis through content analysis method, thematic modality. Two core themes emerged, and they were entitled Difference; and Care and Overload *versus* Protection. It showed that mothers perceive the changes by their children from the comparison with other children, especially in the context of social interaction. The overload for children's intensive care is emphasized, and they perceived them as extremely fragile, reinforcing the need for protection. Actions are required with mothers of children and adolescents with PDD, especially in the organization of the evaluation process of mental disorders and the process of personal and social adjustment in the face of changes experienced.

Descriptors: Mothers; Mental health; Child; Adolescent; Nursing.

O objetivo deste estudo foi conhecer e analisar a percepção de mães sobre o cuidado e as demandas de cuidado do filho com Transtorno Global do Desenvolvimento (TGD). Pesquisa qualitativa, sendo a coleta de dados realizada através de entrevistas semiestruturadas com sete mães, e a análise através do método de análise de conteúdo, modalidade temática. Emergiram dois núcleos temáticos intitulados Diferença; e Cuidado e Sobrecarga *versus* Proteção. Evidenciou-se que as mães percebem as alterações apresentadas por seus filhos a partir da comparação com outras crianças, e principalmente no âmbito da interação social. A sobrecarga pelos cuidados intensivos com os filhos é ressaltada, e os percebem como extremamente frágeis, reforçando a necessidade de proteção sobre eles. São necessárias ações dirigidas a mães de crianças e adolescentes com TGD, principalmente na organização do processo de avaliação dos transtornos mentais e no processo de adaptação pessoal e social frente às alterações vivenciadas.

Descritores: Mães; Saúde mental; Criança; Adolescente; Enfermagem.

El objetivo de este estudio fue conocer y analizar la percepción de las madres sobre las demandas de atención y cuidado de niños con Trastorno Global del Desarrollo (TGD). Investigación cualitativa, con la recogida de datos realizada a través de entrevistas semiestructuradas con siete madres, y el análisis a través del método de análisis de contenido, modalidad temática. Surgieron dos temas centrales Diferencia; y Cuidado y Sobrecarga *versus* Protección. Se demostró que las madres perciben los cambios de sus hijos por la comparación con otros niños, especialmente en el contexto de la interacción social. La sobrecarga de cuidados intensivos de los niños fue apuntada, y estos son percibidos como extremadamente frágiles, lo que refuerza la necesidad de protección en ellos. Si requieren acciones dirigidas a las madres de niños y adolescentes con TGD, especialmente en la organización del proceso de evaluación de los trastornos mentales y el proceso de ajuste personal y social en la función de los cambios experimentados.

Descriptorios: Madres; Salud mental; Niño; Adolescente; Enfermería.

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INTRODUCTION

In face of the diagnosis of a mental or physical disorder in one of their children, any family begins a difficult process of adaptation, and often needs to rethink its structure and organization as a group, as taking care of a child with this disorder demands the constant presence of a caretaker, which generally ends up being the mother^{1,2}.

As it is widely accepted, as soon as a woman is found to be pregnant, she and the father of the child start making plans about his or her future, and hardly ever consider the possibility that the kid may be born with any "abnormal" characteristic. Pregnancy and birth are generally moments of celebration and expectation, and any unexpected or unplanned eventuality may be difficult to assimilate². We believe that, to a greater or lesser degree, all the expectations of any family will need to be re-evaluated, as the kid with a disorder will certainly frustrate the idealization of its fathers in one or another aspect³.

In this study, a specific mental disorder will be investigated: the pervasive developmental disorder (PDD). In the International Statistical Classification of Diseases and Related Health Problems - 10th revision (ICD - 10), the PDD is characterized as a group of disorders, autism being one of them, which compromise three main developmental fields - social interaction abilities; communication; repetitive and restrict behaviors and interests.

A PDD can manifest itself through ritualistic behaviors and invariable habits, not to mention frequent tantrums, self-aggressiveness, sleep and eating alterations, lack of awareness of dangerous situations, hypo- or hyper-reaction to sensory stimuli such as light or sound, attachment to schedules. Children with this syndrome generally do not establish physical, visual, auditory, nor affective contact^{4,5}.

The caretaker, usually the mother, and the families, may suffer uncomfortable and frustrating experiences, especially since these individuals find it difficult to feel and demonstrate affection^{2,6}. The impact caused

by the child is clearly noticed by people who are close to the family, and who are involved in their daily affairs, and on the child's daily care^{4,5}.

Some studies have discussed the social support network to families of children and adolescents with chronic health problems, as well as the point of view the families have regarding this type of care^{2,7-9}. However, it's having found some gaps in these networks, and has let the following question guide our research: How are the children and adolescents with PDD being cared for, and what kinds of care are demanded, according to the mothers? This aspect, especially regarding Nursing - a field which is still beginning to discuss this question¹⁰, is paramount to the construction of a type of care which is more coherent to the needs of this families. From this perspective, this study aims at analyzing and getting to know the perception of mothers regarding the care of their children with PDD, and the demands regarding this care.

METHOD

This is a qualitative, descriptive and exploratory research, conducted in a Center of Psychosocial Care for Children and Adolescents - (CAPSi, in the Brazilian-Portuguese acronym) in a country town in São Paulo, center which is responsible for children and teenagers with serious mental health disorders and their families.

Seven mothers of children and adolescents with PDD as a potential diagnosis participated in the study, as registered in the CAPSi medical record. The convenience sample was composed according to the following criteria: (i) only mothers with at least one child or teenager who had a potential diagnosis of PDD; (ii) only mothers which, after receiving this diagnostic hypothesis, had followed-up treatment at the CAPSi for more than 6 months before data collection started; (iii) there must be subjects enough for the study to find redundant information; (iv) more subjects should be considered and included, until a profound discussion about the subject could be achieved.

All mothers who could not fit into these criteria were excluded from the study. The CAPSi coordination provided us with a list of nine mothers which fit into these criteria, being that data saturation was achieved with seven of those mothers - these being selected according to their availability to participate in the interviews.

In order to achieve the aims of this study, data collection was conducted through semi-structured interviews with the mothers. The interviews followed a script which allowed us to explore data regarding the mother's understanding of their children's diagnosis and care, their difficulty to deal with their kids, and the elements that aided them to deal with situations they lived alongside their kids. The script, previously defined by the researchers, had open-ended guiding questions.

Before data collection, the research project was approved by the Ethics Committee of the Medical College of Jundiaí, SP, Brazil (CEP-FMJ), in September 14, 2011, under the protocol nº 228/2011. After approval, the authorization of the coordination of the CAPSi was requested, and according to the demands of Resolution nº 196/96, from the National Health Council, the subjects who agreed to participate signed two copies of an Informed Consent Form, one of which remained with the participant, and the other with the researcher in charge.

Initially, in May 2011, the researchers got familiarized, through visits to the place of the study, with the CAPSi, its professionals, and their proposals for the dynamics of medical care, aiming at establishing a bond in order to help the posterior data collection. Data collection with the mothers started in September, 2011, after the interviews were scheduled through telephonic conversations with the researchers, according to the availability of the subjects. Interviews were conducted at the CAPSi itself, and lasted for an average of 50 minutes; they were recorded in an MP4 device after the research and its objectives were explained to the mothers, and their informed consent obtained. In order to guarantee the anonymity of the participants, fictional names were used to identify them (names of flowers) and the proper names mentioned along the interviews have been identified through their initials.

Data were analyzed through a thematic content analysis¹¹. To carry out this proposal, the following steps have been followed: previous analysis; data prospection; data treatment and analysis.

RESULTS

The Table 1 brings the main characteristics of the participants of the study. Two thematic categories emerged from data analysis: "Difference" and "Caring: overload *versus* protection".

Table 1. Subject characterization according to diagnostic hypothesis, age, gender and number of children, who directed them to the CAPSi, and for how long have they been treated there. São Paulo-Brasil, 2011.

Mothers	Diagnostic Hypothesis	Age/Gender of the Children	Referral Origin	Length of Treatment at CAPSi
(11) Azalea	Asperger Syndrome	14 yo/M	Rehabilitation Center at Jundiaí-CRJ	4 years
(12) Hydrangea	Asperger Syndrome	10 yo/M	Integrated Health Center - NIS	2 years
(13) Camellia	Behavior alterations compatible with PDD	10 yo/F	Therapeutic Association for the Stimulus of Hearing and Language -	8 months
(14) Daisy	Autism	8 yo M	Association of Parents and Friends of the Disabled - APAE	5 years
(15) Violet	Autism	5 yo M	Therapeutic Association for the Stimulus of Hearing and Language ATEAL	2 years
(16) Rose	Asperger Syndrome	10 yo/M	Private Psychiatry	2 years
(17) Fleur-de-lis	Asperger Syndrome	8 yo M	Private psychiatry	1 years

- Difference

In this part of our work we bring the view of the mothers regarding the beginning of the alterations in their children's behavior, and also the route covered by them since the evaluation of their kids until the establishment of a treatment targeted at those alterations. The differences between their children's behavior and interpersonal relationships, and those of other children, were noticed by the mothers, and recurred in their reports:

... I found her behavior different from those of other children (...) for instance, the way she walks... she walked, but it was different from other kids when she got up a stair, right, that called my attention. Camellia
... the only thing I noticed is that he didn't speak, he muttered a lot (...) the pediatrician said it was normal, but that was bugging me (...) the year after that, P. started school, and then I could see the huge difference between his behavior and that of kids his age. Daisy

After noticing these changes, the mothers started a long, slow and painful route through the evaluation of the kids and the posterior establishing of a specific treatment to their kids; they point out that this route traverses several places, exams, professional offices, that do not converse or organize as a network:

... then he was referred to the Rehabilitation Center at Jundiá (...) then he had an evaluation at APAE... then he was 5 years old, because these things take time right, these things, it isn't as fast as we want... Then we went to APAE, evaluated, then, it took a long time for the result to come out, he didn't make it easy, he couldn't stay in the room... then the Rehabilitation Center referred him here (CAPSi), then here too they made lots of evaluations, to see if it was really this... Azallea

.. because it isn't right if he goes to regular school or APAE (...) they're all very messy, they call you, schedule appointments, they doesn't say if you take the kid, you get there and doesn't have to take the kid, you need to be always asking (...) and they doesn't have communication among them, even being in the same building, what I said to the neuro, I said to the psychologist twice, the same story... Violet

... you don't understand, don't know what's happening with your kid, there was a point... it didn't seem he was born from me... "No, not my son, that's not possible, I think he was exchanged in maternity", you know, like that... Azallea

(...) the first appointment, at the office, she (psychiatrist) got to me and said "Mom, we should already think of autism as a diagnosis", my world collapsed, I got home a wreck, cried myself to sleep, on the other day I couldn't

work because you think "Oh, why would this happen to me?" Daisy

Something else the mothers noticed as a "Difficulty" was the insertion of their kids in school, which is seen as a consequence of behavior alterations. They reported, as factors which made this insertion difficult, problems regarding the inability of the school and lack of knowledge of teachers to receive these kids; questions regarding specific pedagogical approaches; and, especially, the difficulty their children had to interact socially:

... he couldn't stay in class, they put him in the principal's office to carry paper, and then they started working with him, what could they do, because no one knows what to do, nobody knows how to deal, right! It looks like it's laziness, lack of shame, does not say it has a problem! Azallea

... the worst moment was P. in the actual school, the regular one, I say that as a mother, the regular school isn't ready to what they call social inclusion (...) sometimes I got there and P was like, in a corner, like a cornered little animal and everyone around looking like this, they didn't know what to do, the teacher was crying because she didn't know how to deal with P. Daisy

- Caring: overload versus protection

Mothers report that the care of their children revolves around them, generating an overload of several sources - the intense day-to-day treatment schedule for their children with PDD; the caring for the other children and the house; the absence of help from their partners or other family members.

In general, as main caretakers, the mothers end up living the life of their children, nullifying themselves when faced with the demands a child with PDD needs addressed:

Well, for me, there's no me, there's us, if you're single, there's just you, when you become a mother, everything is ours, our paycheck, our walk, our pizza... it stops being the pizza you like to become the pizza everyone likes... Violet

...I know I left my two kids to the side, and my husband, and the house, to take care of G. Fleur-de-lis

It's also interesting to remark how these mothers worry and dedicate themselves to offer a greater autonomy to their children, to prepare them to deal with the necessities of life in a society in an independent way. They understand that the greater advantage of CAPSi is that it

promotes such independence through its actions, allowing the mothers to be less affected by the daily practices and activities. Simultaneously, however, another reason for worrying emerges: the fear of death. Considering how hard it would be for their children to lead a normal life without the presence of their mothers to protect them from problems:

... I worry, too, about dying today! Then I say "My Lord, wait at least until V. is ready" (...) so it's a worry, that I die and leave him, because he's like this, can't think of any evil or malice, he's pure (...) I don't know if he would survive alone. I know we're all going to die, right, but I ask God not to take for now, "Oh Lord, do not take me yet, let me take care of him!" Azallea

... it's because I know I won't last forever, me and my husband, so I need to prepare P. so he can manage in the future (...) so I want P. to have a good life, regardless of having or not a family, but to not need a mother or father forever because he won't have (...) he doesn't need to go to the best college, just to have a good life. Daisy

I bought a horse for him to do EAT (Equine-Assisted Therapy) (...) went after his Welfare, because since I can't work I need to prepare for him to have everything he needs... regarding his health insurance (...) it's like moving, I'm moving to another house, so I'm taking the mobiles one by one, because he knows the house he lives in as a house, so it has to be done slowly (...) because if we move suddenly, at three a.m., he's going to wake up wanting to leave, so it has to be done slowly... Violet

I'm already taking measures, we lived in an apartment at the Alpha condo which is bigger, has parks, places to bicycle (...) so I'm already getting ready to move back there in December, during the kids' vacation. Fleur-de-lis

Mothers have reported that there is a strong tendency to stigmatize their children at school, from school workers, students, and students' families. The prejudice against PDD is felt by the mothers especially when they look for a school for their kids and are subjected to exclusion:

Now this year the teacher said "This one and that one are good, but he sometimes is difficult...", I don't know, because no one wants a kid here right (...) and so I said it's a little bit him, but a little bit what he has, the condition he has... Hydrangea

It's something that hurts any mother, when you see that the other kids, the other people, are going to be very hard with your son, I even heard other mothers saying as I got my son at school "Are you sure this is the best place to your kid?" (...) not to mention the other kids were mean to him, fought with him and he couldn't defend himself... Daisy

By noticing the frailty of their child beyond society, mothers also feel frail, which

leads them to protect the child even more, and to see the kid as helpless; they take care of the kid almost completely by themselves, and have a hard time delegating to others this responsibility, which increases the overload of problems and situations they have to deal with:

... everywhere people said "Oh, what a rude boy", so today they don't, we learned, and started saying to people "Look, he has a condition, that's way he's like this", no, we were embarrassed because he isn't normal, but after the treatment you talk to people, saying the truth is much better than hiding it. No, I didn't hide, I protected, yes... Azallea

... and suddenly someone looks at your kid and says he's different, and you suddenly see he is actually different, you don't think about anything else, just about the prejudice, nothing else. Violet

The mothers' intense connection with their kids, given the nature of their relationship, occasionally makes them feel depersonalized, as if they and their children were only one person; the mothers, then, try to find ways to cope with this situation⁶. The mothers in this study, in an attempt to cope with the loss of the ideal son, seem to favor a speech full of unconditional love and compensating thoughts, such as the idea of a mission being accomplished:

... we were chosen, right, to have V., so, I always think, in a million, I... in every million, one kid is autistic, so I am one in a million... Violet

Last week I read at Amarati a little paper, one of the girls who are cared for over there wrote about what it is to be exceptional, "It is a light and strong wind" (...) but I think there is a reason, and we find it as time goes by... G. is teaching me a lot, the patience I didn't have, the faith that before this happened I also thought I didn't have, the joy he brings to our lives (...) Fleur-de-lis

DISCUSSION

Based on what the subjects have said and on the literature about the subject, we noticed that, generally, the alterations on the children's behavior, which are typical symptoms of the Pervasive Developmental Disorders - such as lack of speech, social isolation and pervasive retardation of development - start being noticed when the child is two years old (30 months) and after they start preschool¹².

According to the mothers, the health professionals have not considered the look in the infants eyes as a worthy subject of evaluation, although they did that themselves

- that is, the mothers found the look in the children's eyes "weird". Even considering the complexity of a PDD diagnosis, partly caused by the limits of child psychiatry evaluations², we also noticed, in the reports, that some of the responsible professionals, although they are in a privileged position to do so, did not conduct a good anamnesis, which could be done by taking steps as simple as listening and welcoming the mothers. That, of course, could have facilitated a lot the observation of possible behavior alterations. Considering not only the special necessities of the children, but also the needs and perceptions of their caretakers, we believe that such actions could provide subsidies for an integral and satisfactory care, aimed at the needs of this population¹³.

Studies show that the moment of the diagnosis, or the search for one, is crucial for the mothers, as it generates a number of feelings – anguish, doubts, anxiety, sadness, guilt¹⁴. The lack of organization and communication among the specialized sectors responsible to care for these children ends up retarding the beginning of the adequate treatment, causing more anxiety still to the mothers regarding their children's situation. We corroborate the studies and authors who say that health care can only be integral as a result of an intersectoral work and as it allows equal access to care; according to this perspective, the access is related to the "diagnostic ability" to organize the adequate referrals for each situation. According to the literature, the limitations and deficits present at primary health care and the "lack of fluidity" in the health system are the main points where an intervention would be necessary to make this process less convoluted^{13,15}.

It is agree with the literature as it says that, as soon as the mothers notice their kid's alterations and are told PDD is a potential diagnosis, they *spontaneously* start a process of research aiming at finding the name of the strange alterations their children presents, demanding evaluations, diagnosis and treatments, because they expect that their children will be cured¹⁶; this, added to the questions mentioned above, regarding the

articulation of the services which are charged with this demand, makes the process even harder and more painful; a study showed that some parents, since the health services lack information, turn to the Internet in order to search for some knowledge about their kids' pathology¹⁷. At this point, an idealized kid becomes a kid with PDD, and all the expectations the parents had built around he or she become frail; they start noticing there is not going to be a cure for the problem their child presents, and that the real kid will not reach their ideals. The mother, as she generally participates more thoroughly of the child's care, feels that the kid is a stranger, and questions on how to raise him or her rise¹⁸:

After first faced with a potential PDD diagnosis, the mothers start a process of elaboration and adaptation to face this new situation. At this point, it is paramount to look to these mothers with attention, through actions to help them with their suffering; however, literature shows that the health services cannot organize themselves to do such; a study also indicated that the parents and kids with mental disorders present a greater risk of having neglected caring needs, and difficulties to access health services¹⁹.

Social interaction, according to the literature, is one of the three main functions that are disturbed by the PDD, being that these kids find it difficult to respond to the emotions of others; that indicates a failure in their ability to interpret and respond to emotion signals, which brings difficulties to their relationships¹⁹. As such, the school is another important reference to the parents of children and adolescents with PDD; after searching tirelessly for treatments to their kid, they need and have the right to integrate the child into our society, and putting the kid in a school can help that cause. However, this moment ends up generating a crisis, as it materializes "the question of the difference and the limits regarding learning"¹⁶.

Still according to the mothers, the school has not been effective in answering to all the special educational needs of kids with PDD. This, according to the literature, impairs not only the cognitive development of the

kid, but also his or her social development²⁰. Studies show that intersectoral actions involving particularly the schools as partners in the identification and prevention against damages to the health of children and adolescents, help to improve the well-being of kids with PDD and their families, since family and school are inarguably the most relevant subsystems in these individuals' lives²¹.

Caretakers have complaint about the fatigue caused by the day-to-day life with the person with a mental disorder, which entails physical and emotional overloads to their lives, lives they choose to deprive themselves from in order to provide adequate care²².

The overload of tasks and special demands with which the mothers are faced can provoke potentially stressful and emotionally tense situations^{15,19}. Parental tasks are not equally shared by the couple; that is not a result of intentional actions by one of them, but of the particular demands of the PDD victim, and of the organization the family takes in order to deal with them²³. Regarding the father's tasks, the literature indicated a tendency for them to offer occasional help in quotidian situations, not taking on any regular tasks, and making it clear that the mothers are mainly responsible for the day-to-day activities of the kid with PDD. They are charged with tasks such as helping their child to feed, bathe, brush his or her teeth, get dressed and take care of their personal hygiene, not to mention accompanying the kid to health services and treatments²³.

The changes to the familiar dynamic and routine due to the characteristics of these kids and adolescents also need to be discussed. It is important to understand that the PDD brings about familiar changes; adapting to these changes and continuing to grow while searching for alternatives for them is a process which requires a slowly built experience, it is not something one learns suddenly; that, possibly, allows for mothers to organize themselves in order to face these new situations²⁴.

These changes and adaptations in the familiar dynamic worry these mothers,

especially regarding the establishment of a financial structure which can promote a guarantee to their children. They also worry about the choice of day-to-day practices as, for instance, the disposition of furniture in the house, the purchase of items to boost learning or the simple avoidance of the exaggerated reactions that come with the condition of the child or adolescent and tire the mothers a great deal. Also, the literature has shown some concern to the siblings of these individuals, who live through complex and intense fraternal relationships, and have their individual and familiar routines altered, generally because of the brother with a PDD²⁵. The literature corroborate the importance of using strategies to plan future care, like, for instance, preparing a future tutelage, savings, health insurances, learning about the rights of people with PDD and searching for resources in the community²⁶:

The preoccupation about what third parties say in places the kids frequently visit shows that the mothers worry too much about the opinion of *other people*. They understand the prejudice and stigmatization as if it was directed toward them. The perspective of other people is something else that influences these mothers. They feel the discomfort other people show in the presence of their kids as prejudice against themselves¹⁶.

This study has corroborated these findings. When mothers worry too much about protecting their kids, with unnecessary interventions or frequent repressions, they reduced the number of opportunities the kid has to explore and experiment the external world though his or her behavior²⁷.

A recent study which investigated the link between quality of life and depressive symptoms in mothers of individuals with PDD has indicated these mothers have more depressive symptoms and a lower quality of life. Also, they were shown to be less satisfied with the place they live in, regarding characteristics such as health care and information access, housing, leisure opportunities, recreation, social interaction, and transportation²⁸. Literature reinforces the demand for preventive and therapeutic

inventions, since interaction and maternal stimuli are extremely important for the healthy development of children, as well as for the well being of kids and adolescents who suffer from mental disabilities^{27,29}.

CONCLUSION

Our main goal in this study was to understand and analyze the perception of mothers, regarding the care they give and are demanded to give to their children with PDD. We have noticed that mothers see clearly the abnormality in their children's behavior when they compare him or her to other kids, especially in social interactions and after they start preschool.

Regarding the care they are demanded to provide, they mention an overload of demands, added to their other functions as mothers and women. They feel their kids are stigmatized, especially in school, and feel as if this prejudice was reflected toward themselves. They also understand these kids as extremely frail and increase even more the protection given to them. Idealistic and compensating thoughts, such as the idea of the accomplishment of a mission, are used as coping mechanisms.

If conclude, therefore, that actions directed toward the mothers of children and adolescents with PDD are an extreme necessity, as they would help these mothers to deal effectively with day-to-day situations. This applies, specially, in the organization of the process of evaluation of mental disorders, the moment of diagnostic elucidation, and the processes of personal and social adaptation to the specific changes presented by the child. Apart from this, we have shown the necessity of an intersectoral work with these families, which is still a challenge to our health system.

The nurses, who have an important social role in this context, need to be actively present in discussions regarding prejudice and the physical and emotional overload to which the mothers of kids with PDD are subject, acquiring knowledge and abilities which subside and improve their practice. Nonetheless, other studies that aim at clarifying aspects of the mental health of

children and adolescents from the perspective of other actors in other services and sectors dedicated to their care, are necessary to complement the findings of this study.

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CONTRIBUTIONS

Chalimar da Cunha conceived the study and was responsible for outlining its methodology, data collection, and data analysis. **Raquel Godinho Hokama Santos** took part in the data analysis for the article, and conducted a critical review of its contents. **Diene Monique Carlos** guided the conception and outlining of the study, its data discussion and analysis, and its critical revision.

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