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"It's Put a Lot of Responsibility on Me to Make Sure That She's Being Taken Care of": Latino and African American Young Carers of Family with Dementia during the COVID-19 Pandemic

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Abstract: Intersectionality of identities—minority, youth, and caregiver—situated within the current health crisis of the COVID-19 pandemic may combine to impact vulnerable young African and Latino caregivers, "young carers," helping in the care of older adults with Alzheimer's and related dementias (ADRD). This qualitative study aimed to describe these vulnerable, minority young caregivers' experiences and changes due to the pandemic. As part of a larger study on caregiver identification of crises and early warning signs of ADRD in the Latino and African American community, Latino or African American youth (N = 20) were interviewed to assess how the COVID-19 pandemic was affecting/had affected their care experiences. Qualitative interviews with youth lasted between 20 and 40 minutes and were transcribed for clarity and analyzed using conventional content analysis. Several themes emerged from the interviews, including lack of respite care, increased or decreased caregiving, changes in care recipient mood, changes in the caregiver's schooling, and increased young carer worry. Participants described a complex identity—that of caregivers, youth, and students. Youth report similar care task stressors as adult caregivers, but the latter's stressors may be amplified via intersectionality with other at-risk group memberships, especially during pandemic-induced social isolation, and limited care supports, which have disproportionately affected minority communities of color. Thus, minority youth providing care during a global health crisis may experience uniquely powerful stressors that require additional support as the health crisis continues, despite aspects of normal daily life resuming.

Keywords: *Young Carers, Latino Caregivers, African American Caregivers, COVID-19, Dementia Caregiving, Health Communication*

Background

With lockdowns and lack of access to health care and social supports, the abrupt onset and extended timeline of the COVID-19 pandemic presented unique challenges for informal caregivers. Social isolation and lack of access to services were exacerbated in communities of color, who prior to the pandemic faced many barriers in accessing adequate care (Oh et al. 2020; Williams and Wyatt 2015). Moreover, given the culturally strong focus on family, care is largely provided by family members, often with little outside support (Mukadm et al. 2015). While family caregivers are primarily adults (AARP and National Alliance for Caregiving 2020), a large and growing number of family caregivers are children and youth, under the

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age of 18 years, known as "young carers" (Joseph et al. 2020; AARP and National Alliance for Caregiving 2020).

Young Carers

Tasked with many of the same care responsibilities as adults (National Alliance for Caregiving 2017; Kavanaugh et al. 2015) children and youth are an integral part of the family care unit, yet are largely left out of state and national programs, services, and research (Armstrong-Carter et al. 2021), including young Black and Brown caregivers (Lewis 2020). Well before the pandemic, young carers across groups experienced social isolation and poor school attendance and performance (Siskowski 2006; Cohen et al. 2012; Kavanaugh, Noh, and Studer 2015), leading to the potential for negative mental health and well-being of young carers (Nakanishi et al. 2022). Despite potential for negative outcomes, young carers remain deeply engaged in care, including for Alzheimer's disease and related dementias (AD/ADRD) (National Alliance for Caregiving 2017).

Alzheimer's Disease and Related Dementia

Affecting nearly 6.5 million people across the US (Alzheimer's Association 2022), African Americans and Latinos are at a higher risk of having ADRD (Vega et al. 2017). Approximately 18.5 percent of African Americans and 14 percent of Latinos have ADRD, while 10 percent of non-Latino White adults have ADRD (Rajan et al. 2019). Similar findings detail a doubled prevalence of ADRD in the African American community and 1.5 times the risk in the Latino community (Gurland et al. 1999; Haan et al. 2003; Potter et al. 2009; Rajan et al. 2019; Samper-Ternet et al. 2012). While some genetic factors do increase risk among non-White racial groups, these factors do not fully account for the significant increase in risk found in African American and Latino communities (Chin, Negash, and Hamilton 2011; Yaffe et al. 2013).

Data show disparities disappear when we account for health and socioeconomic factors (Kukull et al. 2002; Plassman et al. 2007; Yaffe et al. 2013), a point underscored by the structural racism that produces social and environmental disparities such as poorer quality education, increased poverty, and discrimination (Bailey et al. 2017; Bailey, Feldman, and Bassett 2020; Glymour and Manly 2008; Weuve et al. 2018; Zhang, Hayward, and Yu 2016).

Given the focus on family caregiving and lack of consistent and accessible supports, understanding the care experience of young carers in ADRD is critical. Indeed, the majority of young carers in the US provide care for people with Alzheimer's disease or related dementias (AARP and National Alliance for Caregiving 2020). With lockdowns and social isolation, how care, and the intensity of care, changed during the COVID-19 pandemic may have direct implications for the development of targeted programs for caregivers in communities of color, who often experience higher social isolation with, or without, a pandemic.

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Care during the Pandemic

Kent, Ornstein, and Dionne-Odom (2020) suggested three major stressors for adult caregivers during the pandemic, namely psychological, social, and economic. First, caregivers are already experiencing isolation, loneliness, and adverse health effects, exacerbated by the pandemic. Caregivers struggle to ask for help, and this may be compounded by fear during the pandemic of exposing their loved ones to illness. Social isolation may also be exacerbated among caregivers of at-risk populations such as a family with ADRD in underserved communities of color.

Second, caregivers may experience greater economic stressors, lack of access to stable living-wage jobs, or the requirement to stay at home to provide care instead of engaging in the workforce. In addition, during the height of the COVID-19 pandemic, many lower-wage adult workers and primary income earners were considered "essential workers" and found themselves in the dilemma of either being required or pressured to go to work and yet facing high risks of infection and spread of the virus in their family network.

Finally, caregivers may have new healthcare decisions that are more difficult; struggling to weigh healthcare needs with reducing risk of exposure may increase mental health struggles for caregivers. While the above points have implications for all caregivers during the pandemic, the impact of social isolation combined with increased care responsibilities is potentially pointed for young carers. Indeed, in the UK, Nakanishi et al. (2022) found that young carers showed significantly poorer mental health one year into COVID-19 lockdown procedures compared to adolescent non-carers.

Intersectionality of the Young Carer Experience during COVID-19

Exploring the potential impact of COVID-19 on young caregivers, this article is guided by the acute-on-chronic framework of stress theory (Gabrielli and Lund 2020), developed to address children living in poverty, children with disabilities, and children with families experiencing high levels of conflict.

Embedded in the theory is the concept of intersectionality (see Figure 1), or the overlap of multiple identities, which may intensify potential risks, including psychological and social, for vulnerable youth, such as young carers. Moreover, the theory considers vulnerable youth who have marginalized racial/ethnic identities. This inclusion is useful in understanding the complex experience of young carers during the pandemic, given disproportionally higher cases of COVID-19 in marginalized racial and ethnic groups, who also experienced pandemic-related racial prejudice, including conspiracy theories espousing cause based in these populations (Lund 2020). It may be that these issues were also experienced by young carers caring for underserved older adults with dementia.

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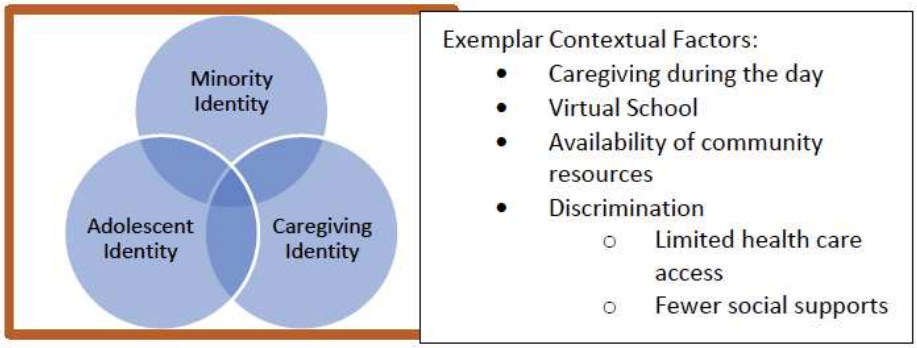

Figure 1: Intersectionality

The current study aimed to describe a sample of minority young carers who had or were experiencing changes within their care experience due to the COVID-19 pandemic and to describe those changes. With little data in this area, we sought to qualitatively explore these experiences, to guide the potential development of a future model of intersectionality with young carers, marginalized communities, and caregiving, situated within the context of the COVID-19 pandemic. This purpose of this article could have important implications for developing targeted stress reduction and support creation models with young carers, regardless of being in a pandemic.

Research Design and Methods

Data from this article were collected as an administrative supplement to a National Institutes of Health study [1R21AG061307-01] to identify ways in which the Latino and African American caregivers can identify early warning signs of ADRD and crisis points leading to accessing formal dementia care services. The project was halfway through data collection when the pandemic started, thus the administrative supplement was an excellent opportunity to return to the respondent families and conduct additional interviews about their COVID-19 care experience.

Participants were recruited through the local Alzheimer's Association and a large social service organization serving the Latino community. Additionally, African American participants were recruited through a local network of predominately Black churches. These organizations were chosen specifically due to the high trust associated with them in both the Latino and African American communities and their long-standing relationships with the study Principal Investigator (PI). Recruitment used flyers, and in-person sessions and meetings with the above organizations in both communities, by study staff who identify with these communities. Latino recruitment was conducted in both Spanish and English. Adult caregivers of a person with ADRD were identified and asked whether there was a child/youth under the age of 18 in the family who was also engaged in care for the person with ADRD. While we collected data on the adult caregivers as well, this article focuses on the experiences of young carers in these families.

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Young carers participated in individual interviews lasting 25–40 minutes, focusing on their care experiences during the pandemic. Youth were asked the following questions: (1) How has the COVID-19 pandemic affected the care that you provide to your family member? (2) In what ways does social distancing impact the care that you provide? (3) How does social distancing affect the well-being of your family member with Alzheimer's or related dementia? All interviews were audio-taped for accuracy in analysis. All participants signed consent (over 18 years) and assent (under 18 years). Parents signed consent for minor/youth participants, and the study was approved and governed by the study PI's University (Institutional Review Board.

Table 1: Care Recipient by Gender and Ethnicity

Care Recipient	*African American*		*Latino*		*Mixed Ethnicity*	
	Female	*Male*	*Female*	*Male*	*Female*	*Male*
Grandparent	2	3	5	1	1	0
Great Grandparent	1		1			
Great Aunt			2			
Parent	1					
Step Grandparent	1	1				
Uncle/Aunt	1					
Total	6	4	8	1	1	0

Participant Data

As shown in Table 1, youth study participants (n = 20) ranged in age from 13 to 19 years and included 15 females (75%) and 5 males (25%). Race/ethnicity breakdown: n = 10 African Americans (50%) and n = 9 Latinos (45%), 1 mixed ethnicity (5%). The majority provided care for a grandparent (n = 12) (60%), n = 2 great-grandparents (10%), n = 2 step-grandparents (10%), n = 3 great-aunt/uncle (15%), while 1 cared for a parent (5%).

Data Analysis

Data analysis was conducted using conventional content analysis (Hsieh and Shannon 2005) to identify categories and themes, arising from multiple readings of the transcripts. No predetermined coding scheme was used. The coding process involved several steps including independently reading the transcripts multiple times, which generated codes based on recurrent patterns and ideas. The authors came together to discuss the defining characteristics of each and reached agreement about the final categories. Some of the reported categories were based on responses from as few as four or five participants. These were kept and considered critical, given the limited information in this area. Indeed, Ryan and Bernard

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(2003, 87) describe categories as "abstract constructs that link expressions," arguing that the number of repetitions included to constitute an important category is open to discretion.

Results

Qualitative analysis revealed several main themes exploring how COVID-19 and social distancing affected the care experience of young carers: (1) change in care overall; (2) lack of respite care; (3) school and caregiving; (4) general sense of worry; and (5) loss of care role.

Change in Care Overall

The majority (n = 17) reported some changes in the overall care experience due to COVID-19, including fear of infection (n = 12), requiring a more "hands-off" yet still engaged care experience, through masks, gloves, and barriers. For many, the care increased (n = 7), specifically due to the lack of outside care, requiring an increase in care routine. One youth detailed how they had to adapt their own routine to provide care alongside other family members.

> I switched to a night job to take care of grandma during the day. I work on days…let's say that if I work tonight…I always do it so that the day that I am here, and it is my turn to sleep my mom is always here so that my grandmother is never alone, and I can rest.

Lack of Respite Care

Several participants (n = 4) described how the closing of the local adult day center was a major (or "huge") disruptor. The adult day center had provided culturally relevant health, social, recreational, and support services to adults with cognitive and/or physical impairments during daytime hours and was a long-standing support for those living with ADRD, thus providing respite for family caregivers. The closure was loss of a major support system for the older adult with ADRD, as stated by this 17-year-old:

> Since he [person with ADRD] can't go to the [center], he really struggles with not being able to talk to his friends, or he always brings up how he wishes he could go and see his friends.

Indeed, the closing of the center specifically increased the level of care provided by the young Latino carers as exemplified in this quote from a 14-year-old:

> It's put a lot of responsibility on me to make sure that she's being taken care of, and also because she can't go, anymore, to [center], so we have to tend to her, like, all day.

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School and Caregiving

The lack of physical access to school magnified the care experience and social isolation for (n = 3) the youth, specifically the Latino youth who had previously relied on the care center, as described by this 17-year-old:

> Since they [the center] closed, I'm taking classes online and since my mom keeps working, I'm the one who now spends the most time taking care of her because now I'm the one who's in the house longer. We have to invest more time taking care of her because we have to give her food during the day, we have to take her to the bathroom.

Critically, some of the youth had understanding teachers, who allowed for the camera to be turned off during the online class, to allow for care, as described by this 17-year-old:

> When I had to be in front of a camera, I would give her breakfast or put her to do something so that while I was in class, she would be busy. Sometimes if she called me because she wanted a glass of water or something, the teachers understood because many had children and they had no problem that I would turn off my camera for a moment, take care of Grandma and come back.

While having an understanding teaching may be a great stress relief in the moment, how these youths were able to focus and learn over the length of the pandemic and online courses is unclear.

General Sense of Worry

An overriding, broad theme that emerged for the majority of participants (n = 14) was a general sense of worry—worry for the well-being of their loved one (n = 8) and/or worry that they would not get the right type or quality of care (n = 6).

Young Carer Worry for Well-Being of a Loved One

In what may be a direct relation to the COVID-19-driven reductions in access to support and therefore, changes to the typical routine critical for persons living with ADRD, many youth participants (n = 11) described a clear change in personality or mood of their family member, which caused them to worry about their well-being. This is described by a 14-year-old, who states: "I feel he's quieter, he doesn't want to talk, he doesn't want to do anything. He doesn't have the will to do anything"; while another youth, aged 14, expressed similar worry, stating:

> He has to deal with this isolation, he can't take a walk to get his—probably get memories back, and, like, he can't go to the park and—he can't do regular stuff. Like, he has to stay in one place and just stay there.

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Responding to this recognition of loneliness, one youth noted how they sought to try and alleviate the isolation, stating:

> Because he does have that depression that comes along with being inside all day, so, he really struggled with that, so I would go up and make sure he was okay, just go and talk to him for a little bit, so he had someone to be there for him, 'cause he couldn't go outside.

These comments underscore how young carers use their concern for family members' well-being to adapt their care roles, as they became keenly aware of how social isolation was affecting their loved ones. In addition to worrying about the well-being of their loved one with ADRD, young carers worried about making sure their family member receives appropriate care outside the home and does not get COVID-19. The following quote from a 15-year-old details this worry, stating:

> Since he doesn't have strength, he falls sometimes, I wonder how he'd be if he had to go to the hospital. Since there are so many people infected, how would they take care of him without infecting him or if something happens to him?

Loss of Care Role

While many young carers reported a clear change or even increase in caregiving, several participants reported a sharp decrease in care or a total stoppage of all care tasks and engagement ($n = 6$). Two youth reported this decrease in a matter-of-fact way, stating, "They don't need my help no more" or "I can't visit my aunt as much anymore." However, the majority discussed the loss of care as an emotional loss, addressing the loss of specific things they no longer did, and how this affected them, as described by this 15-year-old, "I haven't been able to do anything, and I feel bad about it."

The emotional loss is reflected by 14-year-old youth caregiver who reported how not being able to touch lessened his care interactions:

> We can't touch him; we just gotta talk. And it's, like, I can't help him, I can't ask him do he want a cup of water, do he want a blanket, is he cold, is he hot.

These data further underscored the toll of worry that lack of physical contact was taking on youth caregivers whose care had decreased.

Discussion

Regardless of the existence of a pandemic, youth—especially in African and Latino families often embedded in cultural expectations—are deeply involved in care for family members. Data from this project affirm youth involvement in care and show that the COVID-19 pandemic affected the care experience. While much data have been published on the overall impact of COVID-19 on adult caregivers, very little is known about the vulnerable and underacknowledged young carers, specifically those in underserved and diverse

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communities—Latino and African American. This is of particular concern, given the intersectionality of being a young carer, student, and minority youth, the stressors from which potentially magnified during the pandemic. These data provide clear evidence that these youth are not only involved in care but experience the same types of isolation, worry, and concern for their loved ones as their adult counterparts, underscoring the need for increased support and resources for all family caregivers, including youth.

The change in care was not simply about the care but included changes to the well-being of the young carer and the care recipient. Given what we know about COVID-19 in communities of color (Lund 2020) both African American and Latino young carers and care recipients were at greater risk of contracting COVID-19, which may require outside health care, further increasing risk and stress for the caregiver. Indeed, young carers in this study showed concern about persons with ADRD getting COVID-19 if they ever required care from a hospital or clinic. In addition to the worry about getting COVID-19, the worry extended to general well-being of their loved one. Highlighting the real and often all-consuming concern for the well-being of their loved one, specifically for those who were not there to help provide care and watch over them at the same pre-pandemic levels.

The care experience was clearly affected by the lack of external social care supports, specifically by the closure of a well-used community center for Latino older adults with memory care needs. Maintaining routine for persons with ADRD is critical and when removed, as by the closure of the Latino care center, can have negative impacts on mood (Jones and Parks 2021). These impacts were identified by young carers in both groups, who realized the need to try to not only provide care themselves but also do something to reinstate routine and provide support to their loved ones, specific to their cultural needs. Indeed, the loss of social support is a key factor in the mental and emotional well-being of caregivers (Hanna et al. 2021) and those living with dementia (Giebel et al. 2021). The COVID-19 lockdown policies not only closed adult day care centers, but they also reduced or eliminated home nursing services, many 24-hour nurses left their jobs and/or no longer made home visits, and occupational therapy and physical therapy services were canceled (Geschke et al. 2022). Youth in the present study took note of these losses during the interviews, exemplifying the loss of important support networks that would normally provide relief for not only adult caregivers (Kent et al. 2020) but also youth providing care in the home.

Even as the day centers, churches and health facilities started phased reopening, health officials urged people to weigh the risks and benefits, given the substantially higher risk to people with ADRD contracting COVID-19 (Alzheimer's Association 2022). Despite the positivity of reengaging with care supports, families did not lose their worry about their loved one's health, putting yet another burden on the adult caregivers to make major health decisions for their loved ones, including these young carers who continued balancing virtual school and care during the day.

Young carers in this study displayed a "care persona," identified in previous research on young carers (Kavanaugh, Noh, and Zhang 2016), describing ways in which caregivers place

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the needs of the care recipient above their own needs, seeing themselves as a caregiver before any other identity. Not at all to be seen in the negative, these youth displayed a strong family connection and relationship. Specifically, concern for the care recipient's mood, when it was changed, was not described as an irritation, rather a clear concern for their well-being and a recognition of the impact of social isolation. Moreover, it showed a positive regard for not only the person with ADRD but for the care recipient's experience in general. Despite prior research that describes a rapid increase in behavioral disorders in people with dementia (Boutoleau-Bretonniere et al. 2020; Lara et al. 2020), associated with higher rates of caregiver depression (Kales, Gitlin, and Lyketsos 2015) and caregiver burden (Baschi et al. 2020; Borelli et al. 2021; Cagnin et al. 2020; Pongan et al. 2021), these youth described more concern and worry than burden, highlighting the dynamic relationship between people with dementia and their caregivers. The care persona is often described in the Latino community as *familismo*, which places high value on dedication, commitment, and loyalty to the family, with an emphasis on prioritizing the needs of the family as a whole, over one's own individual needs (Toro-Morn 2012). Recognizing this value, which is also seen in the African American community, support programs for minority young carers should include this concept and integrate familial and cultural expectations in any programming.

Young carers in this study were not only expected to continue with care or even increase care in many cases, but they were also expected to do so while maintaining their schoolwork during the switch to virtual school. While allowing for learning during lockdown, the virtual world also created a stressful balance for the young carer whose loved one lived with them, distracting from classes, requesting time away from the camera, and adjusting their schedule to ensure their loved one had care. Yet the impact on school due to care responsibilities is not new, rather a continuing of the known experience of young carers who often fall asleep in class after being up all-night caregiving, or who are left out of school activities due to needs at home (Hamilton and Redmond 2020). The current data show that, regardless of pandemic, care impacts young caregivers' school performance and attendance, and further underscores the adoption of a care persona and recognition that the routine and care for the older adult was a balanced priority for the youth as carer and student.

While it was anticipated that the care needs and experience would increase, it was not expected to see a decrease, or even stoppage, in care responsibilities. Yet, given the social restrictions and concerns for the health of the fragile older adults putting them at greater risk, reduction in social interactions was clear and cautions were integrated into the care experience. This lack of engagement in care, limited "hands on" for many, and overall isolation experienced by their loved ones contributed to the increase in worry in these young carers. Indeed, the way in which the youth described the decreased engagement in care was striking, not in terms of relief or respite, but of concern for the well-being of the loved one, worry about their family members' isolation, and lack of quality family time. Importantly, the actual care needs did not reduce during this time, leaving concerns about the care recipient receiving adequate care. This concern, outwardly for the care recipient, while

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dealing with school changes, personal social isolation within communities experiencing extremely high levels of COVID-19, and limited access to health care and social supports, exemplified the complex care experience of these young carers who managed multiple identities during a highly stressful period.

Conclusion and Implications

The present study supports many of the known dyadic interplays previously reported between adult caregivers and persons living with ADRD. Young carers report many of the same stressors, which may be amplified via intersectionality with other at-risk group memberships (underserved minority, student). Not only does their caregiver identity put them at risk for physical and mental health issues as seen in adult caregivers, but the intersection of identities, having to attend virtual school, and minority identity in underserved communities has created a unique experience for minority young carers during the pandemic. The stressors associated with the care experience require additional support even as the health crisis continues and potentially others arise. Above all, the results of this study provide data to help guide the development of programs for young non-White carers, outside of a pandemic.

Targeted supports can be developed within these communities, recognizing the focus on family care and cultural expectations within the African American and Latino communities. Of particular importance is to engage with community schools, creating support programs for young carers, staffed by adults who identify as African American and/or Latino, providing a culturally supportive environment for young carers. Additionally, whether online or in-person, peer-engaged support groups for these youth are needed, in schools or community centers, allowing for an exchange of experiences within similar peers who understand the family and cultural dynamic. Finally, social supports for older adults must also include the continuum of caregivers, including youth, and recognize the important role these young carers play in providing care. Programs within organizations serving older adults with ADRD can be adapted to integrate the young carer, engaging them in care sessions, supports, or social gatherings, bringing together the entire family around the care needs of their older adult with ADRD. Whether in a school setting or through a community organization, acknowledging and providing support for young carers may serve to lessen worry and alleviate their concerns for their care recipients, whether before, during, or after a pandemic.

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Informed Consent

The authors have obtained informed consent from all participants.

Conflict of Interest

The authors declare that there is no conflict of interest.

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