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ARTICLE

Understanding the role of parents' information sharing and withholding on emerging and young adults' caregiving and coping during their parents' advanced cancer

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ABSTRACT
Emerging and young adult caregivers (EYACs) who provide care to their parents are a hidden, unsupported population of caregivers. Research identifies information sharing or withholding as a key aspect of caregivers' ability to cope and adjust, which may be especially critical when a parent is diagnosed with advanced cancer. The goal of this study was to examine the impact of parent information sharing/withholding on EYACs' caregiving and coping experiences. We conducted in-depth, semi-structured interviews with 33 EYACs between the ages of 18–35 who cared for a parent that died of advanced cancer. Interview transcripts were thematically analyzed. Three factors played a role in how parents' information sharing/withholding affected EYACs' caregiving/coping: 1) *topic,* 2) *timing,* and 3) *who is included.* Findings highlight the adaptive functioning of parents' information sharing and negative outcomes associated with information withholding, illustrating how parents' disclosure decisions function to promote or inhibit EYACs' care involvement and coping.

KEYWORDS
caregiving; communication

Introduction

When families face an advanced cancer diagnosis, how they communicate impacts their ability to cope and psychologically adjust.[1] Although openness is linked with better coping and health outcomes, deciding what to share (or not to share) with family members is difficult dilemma, particularly for parents who are diagnosed (heretofore referred to as diagnosed parents).[2–4] Their information-sharing decisions with their children are motivated both by a need for support and a desire to buffer their children's

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distress,[5–8] including their emerging and young adult children (aged 18–35) who are involved their care.[9] Yet, diagnosed parents' decisions to withhold information may result in unintended effects that negatively impact emerging and young adult cancer caregivers' (EYACs) involvement in caregiving tasks and their coping ability.[8,10,11]

Caregivers in early adulthood account for 43% of all adult caregivers in the United States, and nearly half of these provide care to their parent or parent-in-law.[12] Labeled the "hidden" generation of caregivers, EYACs are largely absent from cancer caregiving literature even though they are not uncommon.[13,14] Given their age and intergenerational dynamics, EYACs face unique challenges when providing care to a parent with advanced cancer. They experience higher rates of emotional and psychiatric distress than both older adult caregivers and their similarly aged non-caregiver peers.[15–17] A recent systematic review examined the impact of parental cancer on adolescents and young adults' psychological functioning and identified links to increased depression, anxiety, stress, worry, and post-traumatic distress.[18] Understanding how diagnosed parents' information sharing and withholding can impact EYACs' coping and caregiving experiences is important to generating supportive resources for this underrepresented and psychologically vulnerable caregiving population.

Research on parental disclosure in illness typically focuses on parents' initial decision to reveal their diagnosis; however, disease progression requires patients to make ongoing decisions about what cancer information they are willing to share with family members and what information they prefer to withhold, or keep to themselves.[8,19,20] They may change the frequency and type of information they want to discuss at different stages of the disease trajectory (e.g. preferring to discuss facts and medical information at diagnosis rather than feelings).[21,22] They can be especially complicated in the context of aggressive or advanced cancer diagnoses, where the accelerated timeline both makes parents more reluctant to share distressing news and increases the risk for EYACs' mental distress.[15,23,24]

Currently, there are no known communication- or coping-focused resources targeting EYACs of parents diagnosed with advanced cancer, but previous studies have indicated that both diagnosed parents and EYACs support navigating distressing conversations.[25] To better understand the impact of diagnosed parents' ongoing disclosure decisions and inform the development of tailored support interventions, the purpose of this study was to identify factors that play a role in how parents' information sharing and withholding affects EYACs' caregiving and coping experiences across the disease trajectory, including during bereavement.

Method

Sampling and recruitment

Eligible participants were: (1) aged 18–35; (2) ≤5 years bereaved after caring for a parent with cancer whose disease trajectory (i.e. diagnosis to death) was less than 12 months. From November 2020 to January 2021, we used purposive sampling to recruit EYACs using two online recruitment strategies: (1) posted study advertisements in cancer, caregiving, and grief forums on the social media site Reddit; and (2) disseminated emails to potential participants *via* Research Match, a U.S. national health registry that has a large population of volunteers who agreed to be contacted by researchers about health studies. The study advertisement included a link to a screening survey hosted by REDcap with the option to submit contact information for an interview. Participants who met inclusion criteria were contacted to schedule a Zoom or phone interview. These procedures were approved by the Institutional Review Board at a large Southeastern university. This data were collected as part of a larger, convergent parallel mixed-method study examining EYACs' experiences.[26]

Procedures

We conducted in-depth, semi-structured interviews with EYACs using the Retrospective Interviewing Technique (RIT),[27,28] a widely used lifespan interview technique that capture changes in one's experiences across time. Participants are asked to complete a graph detailing every significant experience (or turning point)[29] in their communication with their diagnosed parent across their disease trajectory. During the interview, the graph is used as a guide to elicit rich detail from participants regarding their communication with their parents, individual and family coping, and their caregiving experiences over the course of their parents' cancer.[28] In addition, we asked questions also examining their adjustment and family dynamics during bereavement (e.g. "How did your parent's death affect your family as a whole? What has helped you cope after your parent's death?"). Participants received $35 for participation in the interview. Interviews ranged from 40 to 113 min ($M = 81$ min).

Analysis

The interviews were audio recorded and transcribed using a professional transcription service, totaling 817 single-spaced pages of interview data, which were managed using ATLAS.ti software. Two authors conducted a thematic analysis of the interview transcripts using a constant comparative method approach[30] and the following analytical steps:[31] 1) identify concepts in text and assign them codes; 2) use thematic saturation criteria (repetition, reoccurrence, and forcefulness)[32] to collapse these codes and group them into emergent categories (i.e. themes); 3) axial code data within each theme to identify their thematic properties. Meetings were held throughout the analyses to discuss and refine themes and develop the codebook, which a third author used to analyze a subset of the transcripts to verify the analysis and ensure rigor.[33]

Results

The sample consisted of 33 EYACs, whose age at their parents' diagnosis ranged from 19 to 34 (*M [SD]* = 26.39 *[4.18]*). The sample was predominately White (72.72%), female (57.58%), and included caregivers of patients with a variety of cancer sites, with the highest frequencies being pancreatic cancer (21.21%), lung cancer (18.18%), and brain cancer (15.15%) (Table 1).

In general, EYACs described their parents' information sharing more positively, while information withholding was described more negatively. The following three factors "mattered" or played a role in how parents' information sharing and withholding affected EYACs' caregiving and coping

Table 1. Participant demographics.

Demographics	
Caregiver gender	
Man	13 (39.39%)
Woman	19 (57.58%)
Nonbinary	1 (3.03%)
Caregiver age at diagnosis, M *(SD)*	26.39 (*4.18)*
Patient gender	
Man	21 (63.63%)
Woman	12 (36.36%)
Time since diagnosis	
1 year or less	15 (45.45%)
2–3 years	6 (18.18%)
4–5 years	12 (36.36%)
Race and ethnicity	
Asian	1 (3.03%)
Black/African American	1 (3.03%)
Hispanic/Latino	4 (12.12%)
Multiracial	3 (9.09%)
White	24 (72.72%)
Patient disease type	
Adenocarcinoma	1 (3.03%)
Bile duct cancer	1 (3.03%)
Brain cancer	5 (15.15%)
Breast cancer	2 (6.06%)
Esophageal cancer	2 (6.06%)
Gastric cancer	3 (9.09%)
Kidney cancer	1 (3.03%)
Lung cancer	6 (18.18%)
Lymphoma	2 (6.06%)
Neuroendocrine cancer	1 (3.03%)
Pancreatic cancer	7 (21.21%)
Rectal cancer	1 (3.03%)
Skin cancer	1 (3.03%)

experiences: 1) *the topic matters,* 2) *the timing matters,* and 3) *who is included matters.* Each factor (i.e. theme) is further characterized with thematic properties (in italics below) using EYACs' narratives to illustrate the influential role of each factor on EYACs' coping and caregiving experiences (Table 2). Participants' age at their parent's diagnosis and relationship to the parent are included with each quote for contextual richness.

The topic matters

Parents' sharing or withholding of information regarding two topics impacted EYACs' coping and caregiving experiences. First, EYACs reported that when parents initiated or engaged in conversations about their *death and end-of-life (EOL) care*, it allowed EYACs to prepare emotionally for their upcoming loss. This daughter explained: "We never wanted to sugarcoat. … We had to talk about what the future was going to be like without Mom. We had to talk about it and move on and be honest with each other" (Daughter, 28). When parents acknowledged the severity of their cancer, it opened the door for honest conversations about death that ultimately enabled EYACs to be more involved in their parents' EOL care and provide more support to other family members: "A lot of my mom and I's conversation were, 'What are we going to do after [Dad] passes?'- the stuff we have to sell, logistics like how to take care of him" (Daughter, 22).

When parents were unwilling to address EOL information, EYACs reported this negatively affected their ability to cope in the moment and adjust during bereavement. This EYAC described this further in his care experience with his diagnosed mother:

> She never wanted to discuss it with me or acknowledge that [her cancer] was terminal. … I came home on leave really ready to have serious discussions, and I kind of confronted my mother. … [I said] "I'd really like us to talk about what you want to do with this time, and how I can support you and making the most of this and finding your peace." And she was still kind of in denial. She didn't really want to talk about it, and I think that was very painful. (Son, 22)

If parents did not initiate these conversations, EYACs were reluctant to bring up the possibility of death or EOL care plans for fear of upsetting their parent, as this daughter shared:

> If I asked her all these things about her life, she's going to think that I know that she's going to die, and I didn't want her to think that. … That's one of the regrets that I have now, that I should have asked more questions about everything that was going on when I had a chance because she deteriorated so fast. (Daughter, 26)

At times, EYACs who were not able to have open or honest conversations about death with their parent reported struggling with regrets and

Table 2. Themes, thematic properties, and exemplar quotes.

Thematic property	Parents' sharing or withholding information	Exemplar quotes
Theme: The topic matters		
Death and end-of-life care	Information sharing example	We had to be very pragmatic about it. [Mother's death] was going to happen whether we were going to talk about it and admitted or not. So, we had to decide, prioritize things, and try and figure out the next 12–18 months. *(Son, 33)*
	Information withholding example	We spent a lot of time after [Dad] passed away, especially trying to figure out what he would have wanted, and it frustrated me sometimes. He had an opportunity to help with that and to figure out what he even – like beyond his assets – what he wanted in terms of a memorial, how he wanted to be remembered, and how he wanted us to do things. And he just did not. It was frustrating to me, and it still is kind of frustrating to me. And it's a weird emotion and one I struggle with, because you do not really want to be mad at your dad that died of brain cancer. *(Daughter, 34)*
Illness and treatment information	Information sharing example	[My parents] also would both let me, particularly me, in on conversations with his doctors. So, I talked to [father's] oncologist. I talked to the surgeon who is performing his brain surgery. I really appreciated that. … [My mom] wanted to make sure if we had any questions for the doctor, we were able to address them just as though we were there, which [was] very appreciated. *(Daughter, 34)*
	Information withholding example	My dad did not really want any of us involved in that. … I had made myself available so that I would be happy to go [to medical appointments] if he seemed interested in that. … I told him, "I can take off work." "No, no, you're a [occupation]. You got to go help all these people. You got to go to your work." … I was willing to make the time, and he just seemed like he did not really want us going with him. *(Daughter, 33)*
The timing matters		
Knowing their parents' current condition	Information sharing example	After [Mom] was diagnosed, all of her kids got on board together. My older sister was taking her to all of her appointments, monitoring her medications, picking her up. I was calling my mom on a daily basis to check in with her, see how she was doing, ask her if she had eaten that day, and my younger sister did the same thing for her as well. *(Daughter, 27)*
	Information withholding example	In the beginning, [my parents] were very transparent. They were very, "Hey, here's my last labs. Take a look at them." … Then the closer we got to the end, I think for them it was just exhausting, and they didn't want to worry me. Because everything that happened, it was like, "Oh God, another thing." … When you just continuously have things pop up [like] you do with cancer and chemo, you do not want to update people on everything because it's something new every day. *(Daughter, 25)*

(*Continued*)

Table 2. Continued.

Thematic property	Parents' sharing or withholding information	Exemplar quotes
	Who is included matters	
Controlling family involvement	Information sharing example	My sister was calling me and giving me updates, and then I was talking to my mom. … It was definitely more communication with my mom, but some communication with my sister as well, which really kind of helped us to work out work on our relationship and in our communication. *(Daughter, 28)*
	Information withholding example	I told [Dad], "If you don't tell me what to do or anything, I cannot help." And he was like, "Yeah, you don't have to do anything. That's fine." So it was very frustrating. *(Daughter, 30)*

unresolved feelings during bereavement. Some wished they had help navigating these conversations before it was too late: "I think had [hospice care] offered someone to come to us, … we could have had conversations to help us process what was happening. I wish [Dad] could have been part of that conversation" (Daughter, 28).

Still, some EYACs described their parents' decision to withhold information about their prognosis positively, noting that it helped them cope both during and after the illness: "I was already struggling a lot, and I still kind of am. But I think I would have been in a way worse state if it had started off with the thought of [Mom] dying" (Son, 19). Similarly, this EYAC shared: "I am glad we didn't talk about it. I think that would have put a lot of more negative feelings and a lot more sadness to the situation. … It would have been a lot harder to handle" (Daughter, 19).

In addition to EOL information, EYACs reported that parents' sharing the details of their *illness and treatment information* mattered. Such disclosures allowed them to take on more caregiving responsibilities, which then helped them cope. For example, an EYAC shared how her parents gave her the task of researching specialists and treatment options for her diagnosed father. She perceived that contributing in this way helped her and her father cope: "[Mom] was like, 'That brought him so much hope throughout all of this.' So, I am thankful for that still. … I felt like it was kind of my job" (Daughter, 23). Parents' disclosure of illness information also enabled EYACs to provide emotional support to their parents, which facilitated family coping: "We fully processed what we were dealing with. We were able to communicate the initial treatment plan, which was chemo, and we were just ready to be there, and be supportive, and just ready to support him through this" (Son, 27).

However, EYACs reported that when parents withheld illness-related information (e.g. treatment plans, test results, appointments) or details of disease severity (e.g. stage, cancer type), they were not able to be as active in their parents' care. EYACs felt their parents withheld these details to protect them, as this EYAC whose father would not disclose his cancer stage explained: "He said he didn't ask, which I thought that was kind of weird. But I learned later … he did ask. It was a Stage IV. He didn't want me to look it up or anything" (Son, 27). Although EYACs recognized their parents were being protective, they also described how their parents' withholding created stress, frustration, and other complex emotions: "It's awful because then you're like, 'Really, just freaking tell me!' … I definitely had a tiny bit of resentment, … which sounds awful because these are sick people who are freaking dying, and you're getting mad" (Daughter, 25). Similar to the previous theme, there were EYACs who described how their parents' withholding of illness-related information actually helped them cope by protecting them from cancer-related details that may be distressing:

> I didn't really want to know like, "This is her blood count," or "This was what the surgeon said." … I didn't really want to know the gritty details. I wanted to kind of preserve my relationship with her and learn that she would be okay. (Daughter, 28)

The timing matters

While parents varied in when or how often they shared updates with their EYACs (which also fluctuated across the cancer continuum), the timing of parents' disclosures or lack thereof mattered for one primary reason. EYACs felt it was important *knowing their parents' current condition* (i.e. how they were doing both on a daily basis, as well as when their condition deteriorated). Frequent information sharing influenced EYACs' coping and caregiving experiences because it helped them cope day to day. Notably, EYACs who received frequent condition updates did not report experiencing the stress and anxiety described by others, and it was often described in tandem with increased family communication: "My family just kept each other in the loop a lot. … We were talking in our group text and checking in with everybody pretty much every day" (Daughter, 30).

In contrast, EYACs whose parents withheld day-to-day condition changes reported struggling with uncertainty and frustration, which impacted their ability to cope. This EYAC explained:

> It made me way more anxious about it because I couldn't really see what's going on. … It's like when you leave a child at home by themselves, [and] you don't know what they're going to do to the house. It was like that feeling because I wasn't constantly updated. I can't tell what was progressing and what was stable or not stable, and for a while at school, it was really hard for me to focus. And in general, I think I just started getting a bit depressed. (Son, 19)

EYACs reported that the frequency of information sharing varied across the disease trajectory, receiving fewer and fewer updates as their parents' condition worsened and there was less good news to share. This led to an overall decrease in communication with their diagnosed parent:

> The first thing I would do in the morning was text my family and be like, "How's Dad doing?" I wouldn't text him directly. … It kind of limited our communication because I didn't want to call him. I waited for him to call me, which is way less frequent than me calling him. (Daughter, 23)

Infrequent condition updates were especially detrimental to EYACs who were geographically distant from their parents, as they were unaware of the speed of their parents' disease progression. They described their shock and frustration upon learning that the severity of their parents' deterioration was withheld: "I realized, 'Oh, my God, like he's actually wasting away.' He was tiny compared to the last time I saw him, and I was like, 'Why did nobody tell me that?'" (Daughter, 25). EYACs reported that this negatively affected their coping for the rest of the illness trajectory as well as during bereavement. An EYAC explained this further, noting that although her parents' infrequent updates were intended to help her focus on work and school, she still struggled to cope day-to-day and later endured feelings of regret when she learned how advanced her father's cancer was: "I wish I had known the truth because at the end of the day, I [still] dropped my school. I left my job. … And I would have been spending more time with my dad" (Daughter, 30).

Who is included matters

Parents' decisions to share or withhold information were interrelated with decisions about who was included (i.e. given information) or excluded (i.e. information was withheld from). Who was included/excluded mattered and affected EYACs' experiences for one primary reason: it functioned as a means of *controlling family involvement,* in both caregiving tasks and family coping. Information sharing promoted EYACs' opportunities to be part of their parents' illness experience (e.g. providing support or taking on more responsibilities in their parents' care), which also helped them cope better individually and communally as a family. For example, this EYAC, who was geographically distant, recalled sending her mother food deliveries whenever she shared that she was too sick to cook, which ameliorated this EYAC's feelings of helplessness: "It gave me some kind of control over the situation. It gave me control over my feelings as to what was happening with her" (Daughter, 27). When illness information was shared freely not just with EYACs but throughout their family, EYACs reported being able to collectively process information with other family members (i.e. communally cope), share caregiving burdens, and exchange emotional support with each other. An EYAC recalled how sharing information with multiple family members was important: "If somebody in the family found out more information, I think they would readily tell the rest of us. Family didn't want to keep each other in the dark" (Daughter, 24).

Conversely, parents' information withholding restricted EYACs' involvement in their parents' care, and decision-making, as well as limiting the support they were able to provide to their diagnosed parent and other family members and leaving them feeling helpless:

> I also knew that the caregiving that my mom was having to do [for diagnosed father] was getting more and more overburdening. … And it sucked. … There was only so much I could do from where I was. Even though I wanted to be there, I knew he didn't want me to be there. So, it definitely sucked. (Daughter, 27)

In these instances, EYACs reported feeling like they failed to support their parents in their time of need, which led to frustration and regret that affected their coping both during their parents' illness and in bereavement:

> I wasn't a support system for [diagnosed mom], and that's what I felt the worst stuff about—that I couldn't be there for her when she's always been there for me when I've been in trouble or anything or sick. And I just felt really bad. (Daughter, 26)

Even when parents shared information freely, they still controlled family involvement by asking EYACs to withhold details about their cancer from other family members, particularly younger siblings. This limited EYACs' emotional support system and left them unable to share the mental and physical burdens of coping and caregiving. This EYAC described the complicated feelings she had after being asked to withhold information from her brother and take on the caregiving role along:

> On one side, you have that like, "Well, Mommy trusts me" -kind of attitude, and "I'm a big girl, and I'm going to take care of the family." And on the other side, I didn't know what the hell I was doing. (Daughter, 23)

Discussion

Diagnosed parents and their spouses typically control the flow of cancer information throughout their family system, often withholding information from both school-age and adult as a means to protect them.[9,34] Our findings indicate their withholding may not always be helpful to EYACs' coping or involvement in caregiving, highlighting the largely adaptive functioning of parents' information sharing during their advanced cancer and the negative outcomes associated with their information withholding. This study enhances our understanding of the potential adaptive or maladaptive functioning of diagnosed parents' information sharing *versus* withholding by isolating key decision-related factors (e.g. the topic, the timing, who is included) that can play a role in EYACs' coping and care experiences.

Information sharing is essential to patients' and caregivers' ability to cope together.[1,11,35,36] Our findings revealed that parents' information sharing and withholding dictates who in the family is allowed to participate in caregiving and family coping. Withholding information from EYACs or other family members robbed them of the opportunity to develop healthy coping skills and to benefit from the support of their family during a traumatic life experience. Being restricted from caregiving left some EYACs feeling helpless during their parents' cancer and struggling with feelings of regret and failure during bereavement. Research shows that EYACs are more prone to maladaptive coping strategies than older caregivers,[15,37] making any barriers to healthy coping even more problematic. Parents who develop a pattern of information withholding to protect their EYAC are likely unaware that their disclosure decisions may not result in their intended impact and, instead, threaten EYACs' well-being as they cope with their parents' illness as well as their loss.

In the Health Disclosure Decision-Making Model, Greene[8] explains that patients undergo a continual disclosure process regarding their treatment options and disease progression. It is important for parents to be made aware of how the topic and frequency of their ongoing disclosure decisions can affect EYACs' coping during both caregiving and bereavement. For example, EYACs with parents who shared their prognosis and engaged in conversations about their emotions and plans related to death were able to prepare emotionally and had better adjustment after their parents' passing. When parents refused to have these conversations, some EYACs struggled significantly both in that moment and up to this day (i.e. while grieving). Others, however, were glad they never discussed their parents' prognosis or possible death. These EYACs were on the younger end of the emerging and young adult spectrum (i.e. 19 years old), which indicates there are likely other variables important to explore. Some EYACs may be more psychologically affected by their parents' cancer, possibly due to their place in the lifespan, and conversations about their death could cause unnecessary harm. Future research should examine this further, as well as how developmental maturity may impact in these information preferences.

Our findings suggest that although information sharing was generally described more positively, there is likely no singular approach to parental disclosure that works best for all EYACs at all points in the cancer trajectory. Similar to older adult caregivers,[5,23] EYACs in this study reported reluctance to initiate conversations with their parents about cancer, meaning the responsibility falls on diagnosed parents to ensure EYACs are having their information and coping needs met. Previous literature demonstrates the many barriers diagnosed parents face when navigating conversations about their prognosis, advanced care planning, and emotions and distress created by cancer,[7,37,38] as well as their desire for communication support.[25] The findings of this study affirm the urgent need for communication skills interventions targeting this specific patient-caregiver dyad and identified opportunities for hospice care teams to help facilitate these conversations at EOL. Clinicians of diagnosed parents can also provide support and assistance in facilitating these critical conversations by emphasizing the importance of healthcare communication within their family early on in the disease journey.

This study was limited in that participants were recruited from cancer and grief support groups. It is possible that there is self-selection bias, as EYACs may be attracted to these groups and to this study because they struggled with coping and need support. This study is also limited by the lack of diversity of its sample, as the participants are primarily White and college-educated, and our findings may not account for important cultural differences that can impact caregivers' experiences and needs.[39] Future studies should explore how EYACs' parent communication preferences may be impacted by culture, as well as other contextual factors like gender, age, and proximity to parents' death.

Conclusions

Parents facing an advanced cancer diagnosis must manage ongoing challenging dilemmas of what to share and not share with their adult children. Still, the consequences of shutting EYACs out of the caregiving process or dictating their involvement may have too great of a negative impact on their coping needs not to engage in them in these conversations. When making disclosure decisions across the disease continuum, parents weighing whether to not to share information can use the following guidelines. First, they should have conversations with their EYACs to identify and meet their information needs, which includes addressing the three factors that matter (topic including level of detail, timing/frequency, and who is included). Second, they should continually check in to determine if EYACs' information needs have changed, as they are likely to evolve as their cancer progresses. Finally, they should seek assistance from their care team or other support resources to facilitate these conversations and promote healthy coping and caregiving involvement from EYACs.

Ethics statement

The study was conducted in accordance with the Declaration of Helsinki, and approved by the Institutional Review Board (or Ethics Committee) of the University of Florida (IRB202001910, date of approval: 7/27/20).

Disclosure statement

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Data availability statement

De-identified data from this study are not available in a public archive but will be made available (as allowable according to institutional IRB standards) by emailing the corresponding author.

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