

# A Race to the End: Family Caregivers' Experience of Medical Assistance in Dying (MAiD)—a Qualitative Study



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**BACKGROUND:** The June 2016 legalization of medical assistance in dying (MAiD) provided an added layer of choice to end-of-life care in Canada. Family caregivers play an important role in patient end-of-life decision-making. They may experience unique psychological burden or distress associated with their role. However, we know little about the caregiver experience associated with patient MAiD requests and the nature of psychosocial supports caregivers require before, during, and following MAiD intervention.

**OBJECTIVE:** The objective of this study is to better understand the caregiver experience of MAiD within the Canadian legal landscape following Bill C-14.

**DESIGN:** Caregiver experience was examined based on qualitative, semi-structured interviews.

**PARTICIPANTS:** A total of 22 caregivers of patients who had requested MAiD were interviewed.

**APPROACH:** Transcripts were recorded, transcribed, and analyzed based on grounded theory methodology.

**KEY RESULTS:** The caregiver experience of MAiD within the legal framework was found to be understood as a “race to the end,” with the ultimate goal of creating an ideal dying experience for the patient while balancing a threat to capacity that would undermine their access to MAiD. Caregivers can be described within the overarching framework as either co-runners or onlookers. Sources of caregiver distress were linked to these roles.

**CONCLUSIONS:** The “race to the end” theoretical model contributes new knowledge and understanding that can inform the development of tailored support services for caregivers, the impact of legislative changes on this population, and future research examining decision-making near end of life and the caregiver experience.

**KEY WORDS:** quality of care; assisted dying; caregiver distress.

J Gen Intern Med 37(4):809–15  
DOI: 10.1007/s11606-021-07012-z  
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## INTRODUCTION

On June 17, 2016, medical assistance in dying (MAiD) was legalized in Canada through Bill C-14. Under this legislation, patients must be at least 18 years of age, have a reasonably foreseeable natural death, intolerable physical or psychological suffering, and be able to provide consent, both at the time of initial request and at the time of the intervention itself. One key procedural safeguard is a mandatory 10-day reflection period between the date of the MAiD request and the date of the intervention. This delay is intended to provide patients an opportunity to carefully consider their decision. Under certain circumstances, such as a fast-approaching natural death or an impending threat to capacity, this waiting period may be shortened.<sup>[1]</sup>

In Canada, healthcare legislation and practice are patient-centred, informed by the valuing of individual autonomy and privacy. This approach extends to end-of-life care where, from a legal perspective, family caregivers have no mandated role in the MAiD decision-making process and patients have the right to decide how much information to share with their families about their MAiD decision. However, even if families are not involved in MAiD decision-making, they are often significantly involved in the end-of-life experience.<sup>[2]</sup> In fact, family caregivers of patients with advanced disease report levels of distress that are equal to or even greater than what is reported by patients.<sup>[3, 4]</sup> It is estimated that approximately 20% of caregivers experience high levels of distress or depression.<sup>[5–7]</sup> Despite this, they face more barriers accessing psychosocial support.<sup>[8]</sup> A patient's decision to pursue MAiD may negatively impact caregivers by causing relational strain<sup>[9]</sup>, moral distress, feelings of isolation and secrecy<sup>[19]</sup>, and influencing their perception of quality of death.<sup>[10, 11]</sup>

Family caregivers of those at the end of life are an understudied and underserved population, particularly in the context of MAiD in Canada, despite being one of the groups most affected by these circumstances.<sup>[12]</sup> The present study

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*The results have been presented at the Canadian Association of Psycho-social Oncology (CAPO) 35th Annual Conference July 2020, the Canadian Association of MAiD Assessors and Providers (CAMAP) Fall 2020 Symposium on MAiD October 14, 2020, and the University Health Network (UHN) Palliative Care, Culture and the Clinic Symposium January 2021.*

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Received February 23, 2021

Accepted June 25, 2021

Published online July 21, 2021

aims to bridge this gap by employing qualitative methodology to better understand the experience of assisted dying through the lens of caregivers in Canada.

## METHODS

### Participants and Procedure

Caregivers of patients requesting MAiD were recruited as part of a larger ongoing mixed-methods study at two academic health centres and through community-based MAiD providers in Toronto, Ontario. Inclusion criteria were family caregivers who were over 18 years of age and able to complete an interview in English.

Caregivers were interviewed by phone or in-person shortly after the initial MAiD request at the participants' discretion. This multi-site study received Research Ethics Board approval at the relevant institutions, and all provided written, informed consent prior to participation.

### Interviews

Qualitative semi-structured interviews were conducted by trained interviewers (ET and EA). Caregivers were asked about their views regarding the patient's MAiD request, their own experience of the process of obtaining MAiD for the patient, and their support needs. All interviews were audio-recorded, transcribed verbatim, and de-identified prior to analysis. Given the nature of the topic, psychosocial safety measures in place included assuring participants they were free to skip any question or stop the interview completely. They were also provided with contact information for the research team if they had any further questions following the interview. For participants expressing significant emotional distress, the study investigators were notified and psychosocial resources were recommended if needed.

### Data Analysis

Grounded theory methodology was used to develop the qualitative model.[13] General themes and patterns relating to the caregiver experience leading up to the MAiD intervention were identified in an initial read of the transcripts. Following this, a dynamic model of caregiver experience was created based on additional emergent themes and patterns. The transcripts were iteratively coded based on this model. Changes to the model were subsequently made to better reflect the data and researcher understandings of the relationships between and among themes until sampling saturation was reached.[14] The process was documented using study memos and discussed at weekly meetings with senior research team members. Regular feedback helped to mitigate biases and generate alternative interpretations of the data.

## RESULTS

### Sample

Interviews were conducted with 22 caregivers of patients who requested MAiD between May 2018 and October 2020. Demographic data are outlined in Table 1. All patients were approved for MAiD and had a primary cancer diagnosis. Twelve interviews were conducted shortly after the patient's death while the remaining ten were completed prior to the

Table 1 Characteristics of Study Participants (N=22)

Variable	N (%)
Gender (female)	19/22 (86%)
Age (years) (M [SD]; range)	63 (11); 36–83
Marital status	
Married/common law	16/21 (76%)
Separated/divorced	3/21 (14%)
Single	1/21 (5%)
Widowed	1/21 (5%)
Ethnicity	
White	19/22 (86%)
South Asian	1/22 (5%)
Other: mixed	1/22 (5%)
Other: Ashkenazi Jewish	1/22 (5%)
Religion	
None	6/21 (28%)
Did not wish to respond	5/21 (24%)
Non-specified Christian	2/21 (9%)
Jewish	2/21 (9%)
Agnostic	1/21 (5%)
United Church	1/21 (5%)
Anglican	1/21 (5%)
Catholic	1/21 (5%)
Ecumenical	1/21 (5%)
Protestant	1/21 (5%)
Highest level of education completed	
High school	2/21 (10%)
College/Trade	4/21 (19%)
Undergraduate	8/21 (38%)
Post-graduate	7/21 (33%)
Combined family household income	
\$30,000 to \$59,999	4/22 (20%)
\$60,000 to \$99,999	3/22 (10%)
\$100,000 to \$199,999	7/22 (35%)
\$200,000+	6/22 (25%)
Did not wish to respond	2/22 (10%)
Relationship with patient	
Child	10/22 (45%)
Spouse/common-law partner	4/22 (18%)
Parent	4/22 (18%)
Sibling	2/22 (9%)
Nephew	1/22 (5%)
Parent-in-law	1/22 (5%)
Living arrangement	
Living with spouse/partner	9/22 (41%)
Living with spouse/partner and children	8/22 (36%)
Living alone	5/22 (23%)
Moral opposition to MAiD	
Yes	1/22 (4%)
No	21/22 (96%)
Time of interview	
Pre-death	10/22 (45%)
MAiD date set	5/10 (50%)
MAiD date not set	5/10 (50%)
Post-death	12/22 (55%)
Natural	1/12 (8%)
MAiD (expedited*)	8/12 (62%)
MAiD (not expedited*)	5/12 (38%)

Notes. \*Expedited MAiD refers to instances where, as a result of rapid deterioration or concerns about waning capacity, the date of MAiD is moved up and the need for the 10-day reflection period is waived. Demographic data from one participant is missing for marital status, religion and education

patient's death. Only one patient died prior to receiving MAiD; all other caregivers experienced the loss of a patient due to MAiD intervention (Table 1).

## Findings

The caregiver experience of MAiD in the context of the Canadian legislation following Bill C-14 can be understood through a race analogy (Table 2). Caregivers waited for the mandated 10-day reflection period to pass and monitored for decline in patient capacity that would undermine their access to MAiD. Even in the absence of a perceived threat to patient capacity, caregivers still experienced a sense of haste once the process was initiated and the need to set a date was introduced. As one caregiver stated: "Even though you think you have everything put in place, no matter what, death or about to die hits you really fast and you still feel like you're scrambling."

Within the race analogy, the caregivers' experiences can be described as those of *co-runners* or *onlookers*. As a *co-runner*, they felt responsible for advocating and supporting the patient's decision, with some *running at the same pace* as the patient, and others *running off-pace*. As an *onlooker*, they more passively watched as the patient navigated the decision-making terrain themselves. Regardless, all caregivers were involved in *setting up the finish line*, including planning and preparing for the MAiD intervention. Caregiver experiences of MAiD and the roles they held were informed by their own personal attitudes towards MAiD, level of acceptance of MAiD, and relationship with the patient. Sources of caregiver distress were linked to their different roles.

### Co-runner

Most caregivers in our sample held the role of a co-runner. These caregivers were very involved throughout the MAiD process, advocating on the patient's behalf, supporting their decision, and experiencing pressure to ensure the patient's ability to access MAiD was maintained.

We have been an advocate for [Patient] from day one and we participated in every aspect of his [MAiD] decisions and interviews with the doctors etcetera. So, if he didn't think to ask a question, we had no difficulty in putting our oar in and finding out. (CG573-1)

Participants who were highly involved did not describe any moral opposition to MAiD and often had a close relationship with the patient. They also perceived the patients' decision to pursue MAiD to be consistent with their personality and value system, such as being a long-time supporter of assisted dying or someone who preferred to be in control or highly independent.

I think that for my mother it was the best outcome in very difficult circumstances because she lost a lot of agency in her last three, four months. She's always

been in charge of her own things and she's very proud of that. And then with the illness, I felt like she lost a lot of control of her life, but this was something that she decided and requested ... it gave her some agency and so I think that it was really the best outcome for her. (CG573-1)

The experience of caregivers who had the same level of acceptance of the MAiD decision as the patient could be understood as *running alongside and at the same pace* as the patient in the race. These caregivers felt "honored," but also "extremely responsible to carry out [the patient's] wishes as [they] wanted." The metaphor of co-running also captured the "fear," "anxiety," and "concern" felt by the caregiver on behalf of the patient, to maintain cognitive capacity and ultimately access MAiD. As one caregiver expressed: "My biggest fear is if [the patient] is not cognitive on the very last day to say [that they] still want MAiD [they are] still going to suffer." Another participant noted:

The anxiety in our family is, every time he forgets somebody's name, it's like (mock gasp). My dad always forgets people's names (laughs) but every time he does it, it's like 'is it now, did we miss it?' (CG534-1)

In some circumstances, caregivers were *running with patients in the race but at a different pace*. This occurred when there was hesitancy or "some degree of denial" in accepting the timing of MAiD:

Control is very important to him. So, I think he had kind of processed it, and said he wanted to go ahead with it, and he wanted me to support it. And I had a hard time supporting it because I still said, 'maybe it's too early, maybe there's hope because you responded to the radiation well, and this radiation sickness could pass.' (CG571-1)

In maintaining their role as co-runners, these caregivers remained closely involved despite questioning the patient's choice of timing and feeling "shutdown" and "alone." This also led to feelings of guilt if the patient's goal was not met, and the race ended in a non-ideal way.

His death was exactly the opposite of what he wished. He could have had more control, more peaceful way of dying, and that's what he wanted. And I really feel guilty because I did not advocate for that strongly enough. (CG571-1)

### Onlooker

Some caregivers were more emotionally removed from the MAiD process for several reasons. Their passive experience can be captured as onlookers of the race; they watched the

Table 2 Caregiver Roles Within the Race Analogy

Role	Description	Illustrative quotes
Co-runner (n=18)	<p>These caregivers were very actively involved in patient care. Once they accepted the patient's decision to follow through with MAiD, they were strong advocates for the patient's ability to access MAiD. Stress around preserving capacity was a common occurrence.</p> <p>If the caregiver had not accepted the patient's decision, their experience could be understood as running at a different pace in the race. There was often some resistance and the potential for guilt if the patient's goal was not met.</p>	<p>"I was very concerned before our appointment with [MAiD Provider] that, because of the holidays there could be a problem and I was a bit anxious about that because I didn't want to be in a situation where she was stuck for a couple weeks, maybe not being able to have it." (CG576-1)</p> <p>"For right now, the anxiety in our family is every time he forgets somebody's name... it's like (mock gasp)... but my dad always forgets people's names (laughs) but every time he does it, it's like "is it now, did we miss it?" (CG534-1)</p> <p>"The one concern I have is that you have to give permission and final consent right before the procedure. My dad's been a little confused off and on so we're kind of- we're like closely monitoring him, yes. So that part's a little scary, and I've been reading online of different cases where patients have moved up their date because they're worried that they're going to have a stroke or something and not be able to give their permission." (CG566-1)</p> <p>"My biggest concern was that he would miss the opportunity knowing that he wanted it. So, my focus was on getting it done... So, it then became how do we make this happen? And he was declining very quickly, so that was a priority. It was never a question for me, should we quit- it was always, that's what he articulated he wanted, we're going to do everything to make that happen. And so, from that perspective it was focused on getting it done." (CG 588-1)</p> <p>"I would say that he's a person who- control is very important to him. So, I think he had kind of processed it, and said he wanted to go ahead with it, and he wanted me to support it. And I had a hard time supporting it because I still said, "maybe it's too early, maybe there's hope because you responded to the radiation well, and this radiation sickness could pass, you can take the medication..." (CG571-1)</p> <p>"His death was exactly the opposite of what he wished... He could have had more control, more peaceful way of dying, and that's what he wanted. And I really feel guilty because I did not advocate for that strongly enough." (CG571-1)</p>
Onlooker (n=4)	The caregiver observes the patient go through the process of MAiD from a respectful distance, watching to see how everything will ultimately fall into place. There was often a sense of resignation.	<p>"The giggling at the back of me is she may not go through with it. And the only reason that is, is that I have seen her time and time and time again, enthusiastic about something, throwing herself into it, and you know, one month, one year, three years later, it's hell. I'm just praying that that doesn't happen here." (CG509-1)</p> <p>"I knew she was in good hands so I wasn't worried and there's nothing I can do." (CG597-1)</p> <p>"Well, like I say, I wasn't told very much about it, I read a lot online, (Patient) told me that's what he was doing. And that's the extent of it. So, I don't feel I really need to know more about MAiD, because if he's got his mind set in a certain direction, it doesn't really matter what I think of MAiD." (CG572-1)</p> <p>"Well I said, "explain it to me! Oh, for God's sakes..." So, he explained it to me. So, then I said "(Patient), I always told you, whatever you want to do, and decide, it's your body, and do what you want to do. I don't have to agree with it, but if that's what you want, then do it." (CG572-1)</p>
Tending to the finish line (n=22)	All caregivers held some role in managing the logistics of patient care, end of life and/or MAiD day itself. Given the demands of this role, caregivers' personal needs tended to take a backseat.	<p>"I just can't seem to get away from it. Every time I think I am, something else comes up that I have to do. So, to me, two weeks between approval of the procedure and the carrying out of the procedure is an eternity." (CG509-1)</p> <p>"I probably won't be the one holding her hand. I think my sister might. Because of their nature, the nature of their relationship. That would be a step too far for me. I'll be in the room, I'll be visible to her, until she goes out at least. I'll step out of the room as the process is completed, as I can't contribute anything anyway." (CG509-1)</p> <p>"I had to organize the funeral and you know, and then Judaism you've got 48 hours and you've got to figure out who's going to speaking and giving tributes and you give them a heads up... it's a process, right? It doesn't just end with death, there's the after-death stuff." (CG548-2)</p> <p>"I think I'm more worried about all the things that have to- like there's supposed to be a package of [MAiD] supplies being delivered Wednesday night, and I'm thinking, when are they going to come. And at the front desk [of the nursing home] will</p>

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Table 2. (continued)

Role	Description	Illustrative quotes
		<p>they realize what it's for and will that mess everything up, (laughs) so just anxiety around that." (CG566-1)</p> <p>"My life became really unbalanced towards the end. Like I was doing the job of the caregiver, I was coming to the hospital every day, he would phone me and say, "bring me a coffee from Starbucks," and I was- I just wanted to do anything I could to help him feel more comfortable. So, I didn't really even think about "hey, what do I need to do for myself." I just put all that aside during the hospital admission." (CG571-1)</p> <p>"I took a leave from my work, just because I can. I can't do everything, and that's the part I can give up right now. Part of my work wants me to get counselling or something in order to take the leave, well when the hell do you fit that in? So, I'm just trying to figure that out... how do you fit that in? Like I don't have time..." (CG534-1)</p>

patient from the sidelines to see how things would unfold. This sidelining occurred when the patient preferred the caregiver be left out of the MAiD process and was often accompanied by a sense of caregiver resignation. There was often pre-existing interpersonal strain between the patient and caregiver or some uncertainty about whether the patient would ultimately proceed with MAiD:

I don't know whether he uses it a little bit as a crutch, saying 'oh, maybe today would be a good day to do that,' or 'maybe I should do it on my son's birthday' or, he said to his sister, 'I'll do it on your birthday.' ...Like I mean, I don't know why. It's almost like he's holding this carrot in front of our face. Like 'hmm, I guess whenever I feel like I want to do it, I'll do it.' (CG572-1)

The experience of an onlooker was also associated with some moral or religious oppositions towards MAiD:

Part of what underlies my discomfort is that, I think that suicide in any form is a bit of a coward's way out. It solves a lot of problems for the person who is undergoing it. It leaves a whole ton of problems for the people behind...in my mind, it's the ultimate self-ish act. (CG509-1)

For caregivers sidelined due to moral or religious oppositions, this experience brought a sense of distress that could extend beyond MAiD and into the bereavement period:

They were horrified, they don't even want to talk about it. Both my sister-in-law and my brother actually have not told their community that [the patient] chose MAiD because they're so embarrassed by it and upset by it. (CG611-1)

### Tending to the Finish Line

Caregivers assumed much of the logistical burden of patient care and end-of-life planning, regardless of their role as a co-runner or onlooker. Unlike "natural" deaths, MAiD day is often carefully organized to create an optimal death experience. This was a significant caregiver responsibility unique to the context of MAiD, with the added pressure of completion within the 10-day reflection period. As one caregiver described:

I think I'm more worried about all the things that have to- like there's supposed to be a package of [MAiD] supplies being delivered Wednesday night, and I'm thinking, when are they going to come? And at the front desk [of the nursing home], will they realize what it's for and will that mess everything up, (laughs) so just anxiety around that. (CG566-1)

Given the burden and urgency of managerial responsibility, caregivers' own personal needs were often neglected. They acknowledged they "can't do everything" and "don't have time":

My life became really unbalanced towards the end... I was coming to the hospital every day, he would phone me and say, "bring me a coffee from Starbucks," and I just wanted to do anything I could to help him feel more comfortable. So, I didn't really even think about 'hey, what do I need to do for myself?' I just put all that aside during the hospital admission. (CG571-1)

For caregivers who had some opposition to MAiD, their involvement around MAiD day itself was particularly distressing:

When he phoned and said, 'Would you come and be with me?' It was the hardest thing that anybody could

have ever asked of me. But because it was my brother, I was going to do this. (CG611-1)

## DISCUSSION

The caregiver experience in the context of advanced disease has been previously compared to a “marathon,” with a long, gruelling, yet gratifying terrain.[16, 17] Our results capture the final days of this journey in the context of MAiD as a sprint to the end. In our study, the mandated reflection period and capacity requirement in Canada, paired with the capricious nature of disease, created a sense of urgency and set the stage for a race analogy where caregivers acted as co-runners or onlookers. One study in Switzerland suggested that a lack of time for all to agree upon and process the MAiD decision can be a source of relational strain.[18] This suggests that even in jurisdictions without the capacity requirement at the time of the intervention, the medico-legal process, unpredictability of illness trajectory, and specificity of a predetermined date of death can create a sense of haste and pressure on caregivers.

In our study, all caregivers outwardly supported the patient decision for MAiD despite any personal qualms they may have had, consistent with previous research.[15] Active and passive caregiver involvement during the “decision-making phase” of MAiD have been previously described.[19] In our study, actively involved caregivers, or *co-runners*, shared common values with the patient and were more involved in the MAiD process. Caregivers who were passively involved, or *onlookers*, carried a higher burden of moral distress.

Understanding a caregiver’s role within our race analogy can help predict sources of distress and inform possible clinical interventions. Co-runners at the same pace as the patient often felt honoured to be closely involved in this meaningful process. However, this was accompanied with the burden of responsibility to ensure the patient’s wishes were honoured. Although MAiD does afford some control over the circumstances of death, many factors remain beyond control and support aimed at lessening this perceived responsibility may be beneficial. Co-runners not at the same pace as the patient were distressed and felt shut down and isolated. Support aimed at exploring opposing views and facilitating communication within families regarding MAiD may be helpful. Interventions targeting onlookers may explore their various sources of distress: complex relational dynamics, uncertainty of intent behind a MAiD request, or sense of conflict from being involved in a process to which one may have moral opposition.

Although caregivers have generally described stress related to managerial duties at the end of life,[8] stress related to tending to the finish line and organizing a single event that holds such finality is unique to the MAiD experience. Support aimed at guiding caregivers on how to organize and approach the day of MAiD intervention may be beneficial. Despite these challenges, the expectation of impending death and shortened duration of caregiving in the context of hastened death may

result in less caregiver burden.[20] One study found no significant difference in depression, grief, or mental health service use between caregivers whose loved ones requested assisted dying and those whose loved ones did not. However, those whose loved ones received a lethal prescription were more likely to believe that their loved one’s choices were honored and less likely to have regrets about how their loved one died.[21] Further research is needed to better understand the impact of assisted death on the bereavement period.

Our study has several noteworthy limitations. Our results are subjected to selection bias whereby we may not be capturing the experiences of those fundamentally opposed to MAiD or more private in their views. Secondly, our sample consists of predominantly White individuals of higher socioeconomic status. Though it has been shown that MAiD recipients in Ontario do tend to be from higher income brackets,[22] our results may not be applicable to caregivers from minority or marginalized groups who may experience MAiD through a different cultural or socioeconomic lens, or collectivist worldview. Furthermore, our sample only included caregivers of cancer patients. Although cancer is the most common medical condition of those requesting MAiD,[22] MAiD may be experienced differently in other disease contexts with varying disease trajectories.[23] Lastly, our sample included only caregivers of patients who had been approved for MAiD, and all caregivers except one eventually experienced the loss of a patient due to MAiD. Caregivers of patients with more questionable eligibility or who have been approved but did not end up receiving MAiD may have a different experience. Future studies should include these caregivers and explore the role of palliative or hospice care throughout the MAiD process.

In March 2021, Bill C-7 received Royal Assent.[24] The new MAiD law includes removal of the 10-day reflection period, possible waiver of final consent where death is reasonably foreseeable, and a two-track approach to procedural safeguards for persons whose natural death is and is not reasonably foreseeable. These changes may relieve the sense of haste arising from the unpredictability of the illness trajectory observed in this study conducted prior to the MAiD law changes. However, the ability for those not at the end of life to access MAiD may create a different set of caregiver concerns and needs. As the MAiD legislation in Canada continues to evolve, it will be necessary to consult caregivers as essential stakeholders in the MAiD process to inform approaches to their care.

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**Acknowledgements:** We would like to acknowledge and sincerely thank each participant for their time and vulnerability and for trusting us with their stories.

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**Funding:** We would also like to thank the Canadian Cancer Society for funding this study (grant #705663).  
**Conflict of Interest**

The authors have no conflicts of interest other than their roles within the MAiD programs at University Health Network (ML) and Sunnybrook Health Sciences Centre (DS, SB, EJ).

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