Experiences with counselling to people who wish to be able to self-determine the timing and manner of one’s own end of life: a qualitative in-depth interview study

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ABSTRACT
Background In the Netherlands, Foundation De Einder offers counselling to people who wish to be able to self-determine the timing and manner of their end of life. Aim This study explores the experiences with counselling that counselees receive(d) from counsellors facilitated by Foundation De Einder. Methods Open coding and inductive analysis of in-depth interviews with 17 counselees. Results Counselling ranged from solely receiving information about lethal medication to combining this with psychological counselling about matters of life and death, and the effects for close ones. Counselees appreciated the availability of the counsellor, their careful and open attitude, feeling respected and being reminded about their own responsibility. Most counselees felt dependent on the counsellor, or questioned their competency. Most counselees collected lethal medication. This gave them peace of mind and increased their quality of life, but also led to new concerns. Few were inclined to use their self-collected medication. Counselling contributed to thinking about if, when and how counselees would like to end their life. Conclusion Having obtained means to end their lives can offer people feelings of reassurance, which can increase their quality of life, but can also give rise to new concerns. Next to providing information on (collecting) lethal medication, counsellors can play an important role by having an open non-judgemental attitude, providing trustworthy information and being available. These positively valued aspects of counselling are also relevant for physicians taking care of patients who wish to self-determine the timing and manner of their end of life.

INTRODUCTION
In the Netherlands, people with a wish to end their life have the option to request for physician assistance in dying (PAD) under the Dutch Termination of Life on Request and Assisted Suicide Review Procedures Act.1 Not everyone who requests PAD obtains means to be able to self-determine the timing and manner of their end of life. These organisations provide information from publications about methods to end your life in a non-violent manner, also referred to as self-euthanasia.6–10 In practice, this usually entails ending your own life by self-ingesting self-collected lethal medication, or voluntarily stopping eating and drinking.

Research into Foundation De Einder—see table 1 for a description of history, aim and working procedures of this organisation—has shown that people who seek DAS are not always currently suffering, often have not requested their physician for PAD, nor have an active wish to end their life (yet).11 These findings are explained by distinguishing a group of people who are seeking reassurance to prevent possible future suffering. This is in line with an idea that Huib Drion had already expressed in 1991, ‘without much doubt, I have the feeling that many older people would be greatly relieved by knowing that there is a means to end their life respectably at the moment suitable to them, based on what they can reasonably expect from that point on’.12 By seeking DAS, people (know how to) obtain means to be able to self-determine the timing and manner of their end of life.

The idea of reassurance is supported by research conducted by Chabot.9 However, his study did not explore the experiences with the counselling people received. Our study aims to give insight into the experiences with the counselling provided by counsellors working in cooperation with Foundation De Einder by interviewing counselees about (1) what is discussed in the counselling (2) how they...
experienced the counselling, and (3) what happened afterwards, especially in relation to collecting medication and the manner and timing of their own end of life.

METHODS
Design
A qualitative interview study was chosen because of the explorative nature of the research objectives.

Recruitment
A notice about this study was published in the magazine of Foundation De Einder, stating we were looking for people who were willing to be interviewed about their experiences with this counselling. This magazine was sent to people donating money to the Foundation, including—but not limited to—people seeking counselling. Also, counsellors were asked to notify people seeking their counselling, either in person, through postal letters or email.

Participants
Twenty-four potential participants enrolled themselves—20 through intermediation of the counsellor, and four through the notice in the magazine—by contacting the researcher (MH) by telephone or email. All potential participants were contacted by telephone to ask five screening questions concerning gender, age, motivation to contact the counsellor, former request for PAD and personal contacts with which counsellor. These screening questions, based on a previous quantitative study, were asked to ensure diversity in the participants. Some potential participants had not (yet) had a personal consult with a counsellor. These people were excluded from participation (n=3), because they often were still in an orientating phase where counselling does not entail providing information on ways to end their lives.

Three potential participants were not willing to participate in a personal interview (eg, due to emotional burden). Finally, one potential participant was not selected for participation due to similarity with already selected participants (data saturation). This resulted in 14 interviews with 17 people. Three interviews were conducted with couples who sought counselling together. Counselees from all seven counsellors facilitated by Foundation De Einder at the time of the interviews were included. The selected sample reflected the population of people seeking counselling from a counsellor facilitated by Foundation De Einder.

Interviews
Between September and December 2012, in-depth qualitative interviews were held with people who were receiving or had received counselling from counsellors facilitated by Foundation De Einder. The interviewer (MH) has a background in training for professional and personal communication in psychology and had previously worked as a counsellor in cooperation with Foundation De Einder. This prior experience contributed to a considerable knowledge about DAS and experience with discussing the subject, but could also lead to a potential interviewer bias. The difference in position and the necessary skills as an interviewer compared with a counsellor have been addressed in the research team. All interviews took place at the residence of the respondent except for one, which—at the request of the interviewee—was held at a conference room at the VU University Medical Center. All respondents lived in the Netherlands. All were informed about the purpose of the study, and signed an informed consent form for participation in accordance with the procedure approved by the Ethical Committee of the VU University Medical Center. The interviews lasted between 1 and 2.5 hours.

One of the main aims of the interviews was to learn more about the experiences of the respondents with the counselling. Given the sensitive subject, it was decided to start with a general opening question such as ‘how are you doing now?’ However, it turned out the respondents were very eager to talk about the subject so later interviews were started with the question, ‘What has been the motivation to contact foundation De Einder?’ The consecutive questions were based on what the respondent said. A topic list was used as a reminder of the subjects that should be addressed in the interview. These topics included the content of the counselling, the experiences with the counselling and plans for the timing and manner of their own death. See online supplementary appendix 1 for the complete topic list of the interview.

Analysis
The interviews were recorded and fully transcribed. Field notes were made during and after the interview. For the purpose of this study, all interviews were analysed focusing on the research questions about the experiences with the counselling. Analysis followed the principles of sequential and thematic analysis. First, all interviews were thoroughly read to become familiar with the data, and case reports of every participant were made by the interviewer (MH), and discussed within the research team (BDOP, HRWP, MCS, KE). Consecutively, all interviews were analysed by the interviewer (MH) and one or two other coders.
The start of the current counselling ranged from as long as 10 years ago until as recently as 2 months ago. Counselees received between 1 and 24 personal counselling sessions. Almost half of the interviewed couples and individuals involved other people to their counselling. The majority of the counselees had already obtained lethal medication (see table 3).

### Content of counselling

All counselees received information about ways to end their lives. While some received information about PAD, voluntarily stopping eating and drinking, and/or inhaling helium, all counselees received information about lethal medication (see table 3). For example, which (combination of) lethal medication to use, the availability of this medication, storing and testing medication, careful preparation and performance of a self-euthanasia by self-ingesting lethal medication, and preparations for the situation after death. For some counselees this was the only reason they sought counselling (see box 1, Quote 2).

A ‘screening’ of the counselees’ wish to seek counselling was part of the counselling for most counselees. Some also specifically sought counselling to discuss psychological or mental aspects of the process to be able to self-determine the timing and manner of their end of life. For example, having conversations about the moral aspects of ending your own life and the meaning of life and death (see box 1, Quotes 3 and 4).

Besides having loved ones involved, discussing the subject of loved ones was part of the counselling for about half of the counselees. For example, the effects of ending your life on others, acting responsibly towards others and/or the counselling of loved ones (see box 1, Quotes 5 and 6).
Experiences with the counsellor and counselling

All participants were positive about the counselling and/or counsellor, while some also expressed criticism. Criticism concerned feeling dependent on the counsellor who owned information that a counselee wished to obtain, secrecy around how to obtain medication and a counsellor being regarded as incompetent in psychological guidance due to a background in an unrelated work field (see box 1, Quotes 7 and 8).

The positive remarks focused on the trustful and careful attitude of the counsellor. The matter of preparing for a suicide could be openly discussed as a normal subject and was not treated as a taboo. It resulted in people experiencing being...
listened to, and feeling recognised and respected (see box 1, Quotes 9–11). They regarded the counsellor to be critical in an open respectful manner. The counsellor clearly reminded people about their own responsibility in preparing for self-euthanasia. They experienced not being stimulated, pushed or forced in a certain direction (see box 1, Quotes 11–13). Finally, people expressed being positive about the availability of the counsellor (see box 1, Quotes 14 and 15).

After counselling: self-collected lethal medication
Most counselees had already obtained lethal medication (see table 3). This lethal medication was ordered via internet from countries abroad or via the black market in the Netherlands. Some had not (yet) obtained medication because the idea that they could was satisfying enough for now, or felt they ‘did not yet reach that stage’. (Knowing how) to obtain medication brought reassurance, which was expressed by giving peace of mind, a safe feeling, reassurance to be able to decide for yourself and take your own responsibility (self-determination), and to be independent of healthcare professionals (see box 2, Quotes 16–18). This reassurance added to their quality of life because they experienced less uncertainty about the possibility of having to continue in a state of unwanted suffering, memory problems felt less threatening, a depression became easier to deal with and it offered energy to continue with life (see box 2, Quotes 16, 17, 19–21).

Table 3 Setting and content of counselling and collection of lethal medication

<table>
<thead>
<tr>
<th>Counselee</th>
<th>Start of counselling (time ago)</th>
<th>Personal contacts, n</th>
<th>Involved others</th>
<th>Information about manners to end own life*</th>
<th>Collected lethal medication</th>
<th>Counselling about mental aspects</th>
<th>Counselling about/of others</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2 months</td>
<td>2</td>
<td>No</td>
<td>MED (which medication, obtaining, careful performance, consequences of law, after death)</td>
<td>No</td>
<td>Meaning and expectations life and death, hope, passion, ambivalence, responsibility</td>
<td>Current relationships, effect of self-euthanasia on others, saying goodbye, consequences of law on others</td>
</tr>
<tr>
<td>2†</td>
<td>3 years</td>
<td>6</td>
<td>Yes</td>
<td>VSED, MED (which medication, obtaining, careful preparation, performance)</td>
<td>No</td>
<td>Death wish, meaning life and death, preparing for suicide, emotions</td>
<td>Effect of self-euthanasia on others, preparing others for goodbye, consequences of law on others</td>
</tr>
<tr>
<td>3</td>
<td>3 months</td>
<td>6</td>
<td>Yes</td>
<td>PAD, Helium, MED (which medication, obtaining, after death)</td>
<td>Yes</td>
<td>Meaning completed life, death wish, fear of dying alone, emotions</td>
<td>Preparing others for goodbye</td>
</tr>
<tr>
<td>4</td>
<td>1 year‡</td>
<td>1</td>
<td>No</td>
<td>MED (which medication, obtaining, careful preparation (withdrawal), performance)</td>
<td>Yes</td>
<td>Not mentioned</td>
<td>Not mentioned</td>
</tr>
<tr>
<td>5</td>
<td>8 years§</td>
<td>24</td>
<td>Yes</td>
<td>MED (which medication, obtaining, storing, performance)</td>
<td>Yes</td>
<td>Meaning life and death</td>
<td>Current relationships, saying goodbye, presence of others</td>
</tr>
<tr>
<td>6/7¶</td>
<td>5 years</td>
<td>1</td>
<td>No</td>
<td>MED (which medication, obtaining)</td>
<td>Yes</td>
<td>Intake, screening death wish</td>
<td>Not mentioned</td>
</tr>
<tr>
<td>8</td>
<td>3–4 years</td>
<td>1</td>
<td>No</td>
<td>MED (which medication, obtaining, delivery)</td>
<td>Ordered</td>
<td>Not mentioned</td>
<td>Not mentioned</td>
</tr>
<tr>
<td>9/10¶</td>
<td>2 years</td>
<td>1</td>
<td>No</td>
<td>MED (which medication, obtaining, testing)</td>
<td>No</td>
<td>Intake, screening death wish</td>
<td>Meaning relationship</td>
</tr>
<tr>
<td>11</td>
<td>1 year</td>
<td>3</td>
<td>Yes</td>
<td>MED (obtaining)</td>
<td>No</td>
<td>Righteousness to end own life</td>
<td>Counselling of others (system)</td>
</tr>
<tr>
<td>12/13¶</td>
<td>3 years</td>
<td>3</td>
<td>Yes</td>
<td>PAD, MED (which medication, obtaining, storing)</td>
<td>Yes</td>
<td>Not mentioned</td>
<td>Counselling of others (system)</td>
</tr>
<tr>
<td>14</td>
<td>10 years</td>
<td>3</td>
<td>No</td>
<td>PAD, VSED, Helium, MED (which medication, consequences of law, obtaining, careful performance, after death)</td>
<td>Yes</td>
<td>Meaning life (events), timing</td>
<td>Effect of self-euthanasia on others, consequences of law on others</td>
</tr>
<tr>
<td>15</td>
<td>1 year</td>
<td>1</td>
<td>No</td>
<td>VSED, Helium, MED (which medication, careful performance, consequences of law, after death)</td>
<td>Yes</td>
<td>Current life situation (grief)</td>
<td>Preventing harm to others, consequences of law for others</td>
</tr>
<tr>
<td>16</td>
<td>8–9 years</td>
<td>3–4</td>
<td>No</td>
<td>MED (which medication, obtaining)</td>
<td>Yes</td>
<td>Not mentioned</td>
<td>Not mentioned</td>
</tr>
<tr>
<td>17</td>
<td>1 year</td>
<td>1</td>
<td>Yes</td>
<td>MED (which medication, obtaining)</td>
<td>Yes</td>
<td>Not mentioned</td>
<td>Not mentioned</td>
</tr>
</tbody>
</table>

*PAD: Physician assistance in dying (as under Termination of Life on Request and Assisted Suicide Review Procedures Act); VSED: Self-euthanasia by voluntary stopping of eating and drinking; Helium: Self-euthanasia by helium method; MED: Self-euthanasia by self-ingesting self-collected lethal medication.
†Partner present at interview to support with gaps in memory.
‡10 years ago present at counselling as partner.
§Received counselling 12 years ago from counsellor not active at time of interviews.
¶Couple together.
Original research

Box 2 Quotes about what happens after counselling

Quotes about self-collected lethal medication

Quote 16 ‘So, it’s peace of mind that I have. I have received the information from someone I trust. I have the means of which the counsellor has sworn they are adequate. So, that’s all stored in a very good, airtight environment. Ready! […] Now I can continue with daily living.’ (Counselee 14)

Quote 17 ‘It gives a very relieved feeling. Now, I have the feeling that I have something as insurance. And every time I panic, because I think I’m starting to have dementia, then at least I have a means as insurance. So it doesn’t have to get that bad. And that gives me peace of mind […] That I don’t panic when I forget something.’ (Counselee 15)

Quote 18 ‘The feeling that you have the medication in your own house and that you can decide for yourself. Maybe you will never use it. But just the feeling that when it is necessary, then I can use it: that is pleasant when you are older.’ (Counselee 07)

Quote 19 ‘MH: Because you already have the medication at home for seven years, the possibility to end your life for seven years. R: Yes, it gives a safe feeling.

MH: Can you tell me more about that safe feeling?

R: The feeling that you just—when you’ve reached your limits, when you really can’t continue any longer—that there’s a door you can enter and that will release you from life […] that gives a good feeling. That gives a safe feeling […] I also think only the fact you would have a legal possibility to end life in a humane way. If you know that, that knowledge is reason enough for people to live longer. That also counts for this medication. I have that medication at home. And it gives me peace. It sounds crazy, but that’s how it works.’ (Counselee 05)

Quote 20 ‘To get the maximum out of life. Yes, I’m not depressed. So I do all these things that I think are important at such a last moment. Yes, many paradoxes […] I will probably leave at the peak of the party. Yes, that’s what it is. I grant myself to leave the party at its peak.’ (Counselee 03)

Quote 21 ‘And I sometimes have the urge to check if the medication is still there. Because if you take that away, then you take a piece of security away from me. And at the same time, the crazy thing, the ambivalence of that medication is that they maybe keep me living longer than when I would not have them. It also has…the whole procedure with taking anti-emetics beforehand, 24 hours before, there’s a certain time frame. That also gives an inhibition. There are moments that I think that when the 24 hours would not be there, I would take them right away …’ (Counselee 05)

Quote 22 ‘But then, we do face a dilemma. Concerning our daughter. She also wants to end life by herself, but that will happen through the medical circuit […] See, the dilemma is: we have the medication in the house for ourselves. But you can’t give that to her, if she would want to.’ (Counselee 07)

Quotes 23 ‘To be able to make an end to my own life in a humane way. And I won’t do that before I have had another conversation with the counsellor, also with the children present […] That I will only do it if there really are no other possibilities to continue life in a dignified way anymore […] That could be a topic to discuss. Yes, imagine I would be in so much pain, and after a conversation with the counsellor, who would say ‘well you could try this, think about it’ I’m just saying as an example—then I could reconsider my choice.’ (Counselee 15)

Box 2 Continued

Quotes about the timing and manner of their end of life

Quote 24 ‘MH: If you have the medication in the house, do you have an image of when you would like to use it?

R: Not! We do not want to use it at all. We just want to keep on living.’ (Counselee 07)

Quote 25 ‘I can describe it as when I’m totally dependent. Totally dependent on another. And that things happen I don’t want to happen, and especially if—I—that would be really important to me—if I foresee a moment in which I can’t decide for myself. Then I would do it.’ (Counselee 17)

Quote 26 ‘R: Then you think—yes, thank God we are not that far—but if at a certain moment you will say “I don’t want anymore and now I will stop.” […] (Counselee 10)

R2: We don’t know that. (Counselee 09)

R: Of course we don’t… (Counselee 10)

R2: That’s the dilemma that you can’t get away from, certainly not as an outsider. You can’t foresee the experience of the moment. That is a well known fact…that people postpone.’ (Counselee 09)

However, possessing lethal medication also offered new concerns and dilemmas to some counselees who had obtained them. For example, concerns about preserving medication and medication being taken away by the police or loved ones, and a moral dilemma when a loved one wanted to self-determine their own end of life while the counselee owned the means to do so (see box 2, Quotes 21 and 22). Counselees did not worry about impulsivity. They possessed the medication for a long time already, and regarded the necessary 24 hours’ period for taking antiemetics and the wish to have more counselling before acting on a wish to end their life as safeguards against impulsivity (see box 2, Quotes 19, 21, 23).

After counselling: the timing of their own end of life

The counselling and/or collecting the lethal medication contributed to a process in which counselees thought about if, when and how they would like to end their own life (see box 2, Quote 24). While one participant had an appointed date for PAD, and two persons mentioned a time frame (‘the end of the year’, ‘within five years’), most counselees described future situations in which the option to end their lives would become more likely. These situations were overtreatment, memory problems, when life was not dignified anymore or would become unbearable or hopeless, when no other alternatives than a hospital or nursing home would be available, dependency of others and when the burden was greater than the capacity to carry it (see box 2, Quote 25). Often counselees made the side note that one cannot foresee the experience of a future situation, and the likelihood of postponing one’s death due to a gradual acceptance of declining health conditions (see box 2, Quote 26).

DISCUSSION

Summary

People seeking counselling to be able to self-determine the timing and manner of their end of life have all received information about self-euthanasia through self-ingesting self-collected lethal medication. For half of the counselees, this has been accompanied by counselling about psychological aspects and/or the effect of self-determining your end of life on loved ones. All

Continued
counselees are positive about the availability of the counsellor, the trustful, careful and critical attitude of the counsellor, being able to openly discuss the subject, the feeling of being respected, and being reminded about their own responsibility without being pushed or forced in a certain direction. Some counselees are critical about feeling dependent on the counsellor and mentioned incompetency of the counsellor. The majority have obtained lethal medication, which can give rise to new concerns, but also gives counselees peace of mind and reassurance. It adds to their quality of life because of less uncertainty about having to continue in a state of unwanted suffering. Collecting lethal medication does not imply people want to end their lives themselves, nor that they want to end their life soon.

Limitations
A limitation of this study is that only people receiving DAS from counsellors facilitated by Foundation De Einder have been selected. Conclusions therefore cannot be generalised to the whole population of people receiving DAS. Also, counselees have enrolled themselves in this study and most counselees were recruited through a counsellor, which can lead to a possible self-selection bias. This might result in the expression of mainly positive experiences. Furthermore, the subset of people who died shortly after receiving counselling is missing. Therefore, the data may be biased in reflecting that many counselees have no intention to use their collected lethal medication and regard it as a safeguard to prevent situations of future suffering. However, a previous study shows that the group who seeks counselling to prevent possible future suffering forms at least one-third of people receiving counselling.

Reassurance and quality of life
Drion published the idea that older people would find reassurance in knowing they would have means available to end their own life at a moment suitable to them. This idea clearly resonates in the stories of the counselees, and forms a replication of other interview studies. Having obtained the means to be able to end their lives in a respectable manner (and for some just the knowledge how to obtain these means) does indeed give people reassurance to be able to self-determine the timing and manner of their end of life.

In addition to providing reassurance, it can have other positive effects like worrying less about current problems or about having to continue life in a state of unwanted (prospective) suffering. Some even experience a renewed energy to "get the most out of the time left". To have a wish (to be able) to end your life does not imply giving up on the life you are still living. Rurup et al described this by the existence of simultaneously having a wish to die and a wish to live. This latter might also be an explanation for findings by Van Wijngaarden where people who have a wish to die still "exercise to keep fit and vital" or "consider hip replacement to increase mobility and independence" while planning their death as well.

Owning lethal medication can lead to risks of impulsivity and misuse. Counselees do not share these concerns. However, a new finding is that owning lethal medication does give rise to other new concerns. For example, concerns about the due date of the collected medication, fear that people want to take that medication (and their peace of mind) away and a dilemma what to do with your lethal medication if loved ones seek a peaceful way to end their own life. This raises the question whether the obtained peace of mind outweighs the possible rise of new concerns, and whether the need for reassurance will ever be fully satisfied.

Counselling is more than just giving information about medication
While information about (obtaining) medication forms an important part of the counselling, it is not the only thing that is important. Also, the attitude of the counsellor which allows for an open conversation in which the wish to (be able to) end your life is not regarded as a taboo, is a positively valued aspect of the counselling as well. The importance of this openness in talking about and a non-judgemental attitude towards a wish to die is regarded as an essential aspect in providing care, and is also endorsed by a Dutch suicide prevention organisation, and the multidisciplinary guideline for the diagnostics and treatment of suicidal behaviour. Also the guideline of the Royal Dutch Medical Association on the position of the physician in a self-chosen death by the patient extends on the possibility of the physician to offer DAS, and focuses on having conversations with the patient about the wish to end their own life. If patients feel unable to talk about these wishes, their quality of life may be diminished.

Concerns for counselling
Some negative experiences with the counselling or counsellor offer points of attention for the counselling itself. Counsellors should be aware that possible feelings of dependency might cause counselees to act in a socially desirable way to obtain information from the counsellor. Furthermore, the competence of the counsellor being questioned raises the discussion about when a person is regarded to be qualified and competent to counsel people in this delicate matter. Finally, concerns after having collected lethal medication may ask for specific care or counselling after having collected lethal medication.

Implications
As counselling can have positive effects for the counselee, one recommendation could be that a physician should have a more open attitude towards the role and importance of counsellors. Also, aspects of the counsellor and counselling valued by counselees can offer recommendations for physicians who want to offer DAS themselves to patients who wish to self-determine the timing and manner of their end of life. Although the counsellor might hold a different position than the physician, for example, because a patient might perceive the physician as a person more focused on treating (a wish to be able to end your own life) instead of understanding the patient. The guideline of the Royal Dutch Medical Association on the position of the physician in a self-chosen death by the patient explicates the judicial possibilities for the physician when it comes to providing DAS. Our study can provide physicians with valuable recommendations in providing DAS, for example, the importance of an open non-judgemental attitude, experience with and knowledge about a self-chosen death, providing trustworthy information and being available.

CONCLUSION
This study confirms the idea that having the means available to be able to end your own life in a respectable manner can provide people with reassurance and can increase their quality of life. It can, however, also give rise to new concerns like worrying about the shelf-life of medication or not losing the medication. This study also makes clear that counselling entails more than just providing information on (collecting) medication. Counsellors can play an important role for people who wish to self-determine the timing and manner of their end of life, by having
an open non-judgemental attitude, providing trustworthy information and being available. These positively valued aspects of DAS can provide recommendations for physicians taking care of patients who wish to self-determine the timing and manner of their end of life.

Contributors MH had the initial idea for this study, wrote the research protocol, performed the interviews and the analysis, and drafted the manuscript. MCS and KE performed the analysis, and contributed to the drafts of the manuscript. HRWP and BDOP commented on and contributed to the design, the analysis of the data and the final draft of the manuscript. All authors had access to all the data, can take responsibility for the integrity of the data and the accuracy of the data analysis and approved the final manuscript.

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