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Living through the end: The phenomenon of dying at home

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ABSTRACT

Objectives: To explore the unique lived experiences of one patient who died at home and her family members, and to interpret how dying at home influenced patterns of bereavement for this patient's family.

Methods: Benner's (1985) interpretive phenomenological approach was employed to get at the embedded nature of the social phenomenon of dying at home, uncovering what may be taken for granted by participants — in this case, during and after the patient's home hospice course. The participants were a 78-year-old female diagnosed with amyotrophic lateral sclerosis six months prior to death, her husband, and three of her four children. In line with the patient's wish to die at home, she voluntarily forewent food and drink when she no longer wished to watch her body deteriorate and felt that her life had run its course. She informed her family of this plan, and all were supportive. For data collection, separate single in-depth interviews were conducted with the deceased three months prior to death, and after death with three of her four children and her spouse of 60 years. For data analysis, the interview transcripts were coded for paradigm cases, exemplars, and themes.

Results: The paradigm case, "The Meaning of Being at Home," revealed that for study participants, remaining home with hospice provided a richly familiar, quiet, and safe environment for being together over time and focusing on relationships. Exemplars included "Driving Her Own Course" and "Not Being a Burden." Salient themes encompassed patient and family characteristics, support, emotions, the value of time, and aspects of the healthcare team.

Significance of results: End-of-life care providers need to hold a patient-centered, family-focused view to facilitate patient and family wishes to remain home to die. Investigation into family relationships, from the perspectives of both patient and family members, longitudinally, may enrich understanding and ability and help patients to die at home.

KEYWORDS: Family relationships, Home death, Hospice, Phenomenology

INTRODUCTION

By 2030, those over 65 years of age in the United States are expected to expand from 12.5 to 20% of the total population (Christ & Sadhna, 2009). Meanwhile, international studies overwhelmingly reveal that roughly 50 to 95% of patients prefer to die at home (Beccaro et al., 2006; Holdsworth & Fisher, 2010; Tang et al., 2010; Neergaard et al., 2011). In the United States, 82 to 87% of patients consistently name home as their preferred place of death (Pritchard et al., 1998; Tang, 2003). And yet, while roughly half or more of patients die at home across the globe (Eoin et al., 2002; Beccaro et al., 2006; Neergaard et al., 2011), the ability to actualize U.S. patients' choice for home death is at the lower end of the international list, ranging from less than 25 to 31% (Teno et al., 2004; Muramatsu et al., 2008). This speaks

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poignantly to an inability to help patients remain at home, enjoying family relationships at the end of life, in line with their final wishes.

As compared to hospital death, home death with hospice care has been shown to offer significantly improved mental health outcomes for both patients and family. While roughly half or more of terminal patients are affected by depression and/or anxiety (Higginson & Costantini, 2008; Irwin & Ferris, 2008), end-of-life patients at home experience significantly less anxiety and depression than those who die in acute care (Grande et al., 2000; Gomes & Higginson, 2004; Temel et al., 2010; Shepperd et al., 2012). Family caregivers of patients who die at home have better outcomes in bereavement and suffer less complicated bereavement, posttraumatic stress (Wright et al., 2010), and depression (Bradley et al., 2004) than caregivers of those dying in hospitals. Caregivers whose relatives died at home also reported better physical health than caregivers of those who die in acute settings (Grande et al., 2004; Wright et al., 2008). This further decreases stress on healthcare resources while improving mental and physical health, and bereavement, both for the dying and their relatives.

Quantitative researchers point to caregiver burden (Jordhøy et al., 2000; Choi et al., 2005; Funk et al., 2010a; Neergaard et al., 2011) and poor communication — among families, and between families and the healthcare team — as barriers to home death (Salmon et al., 2005; Ray et al., 2006; Taylor et al., 2007; Higginson & Costantini, 2008). Interventions increasing communication between patient, family, and the healthcare staff, and providing a multidisciplinary palliative care team, are effective in both decreasing caregiver burden (Jordhøy et al., 2000; Shepperd et al., 2012) and increasing rates of death at home (Jordhøy et al., 2000; Enguidanos et al., 2005; Brumley et al., 2007). Authors of a recent comprehensive review underscored the gap in the literature in the areas of caregiver bereavement outcomes, contextual factors for death at home, and the need for an individualized, family-based approach to care (Funk et al., 2010a).

Qualitative research on death at home focuses primarily on family caregivers and/or the healthcare team (Goldsteen et al., 2006; Stajduhar et al., 2008; Hirano et al., 2011; Slort & Blankenstein, 2011). There is a dearth of qualitative research on contextual factors for death at home (Funk et al., 2010*b*; Forbat et al., 2012; Retrum et al., 2013) and about the exploration of family relational factors — including how family members negotiate dual and sometimes conflicting roles as both caregiver and family member (McGraw & Walker, 2004; Badr & Acitelli, 2005; Forbat et al., 2012). The quality of family relationships, including having more than one family member involved, is important for dying at home (Higginson & Sen-Gupta, 2000; Steinhauser et al., 2001; Gomes & Higginson, 2006). How these relationships may be helpful is largely unstudied (Ratner et al., 2001; Higginson & Costantini, 2008; Weibull et al., 2008). There is a call for qualitative research into family members who are not caregivers — arguably the vast majority of those affected by death at home (McNamara, 2004; Higginson & Costantini, 2008), and a need for deeper, interpretive views into family relationships (Funk et al., 2010b). A qualitative approach is uniquely positioned to explore these family relationships at home in the context of dying.

Researchers have also discovered what is commonly called “caregiver gain.” Salmon et al. (2005) noted that caregivers report burden, but also speak of personal meaning, relationship closure, and comfort in caregiving. Home caregivers in other studies (Weibull et al., 2008) insisted they would “do it all again,” noting a positive impact on bereavement, gratitude for being able to help, and pride in accomplishing more than they thought possible. In one work (Singer et al., 2005), even as caregivers acknowledged challenges, over 90% reported death at home as positive, versus 61% of those whose relative died in hospital. In another study (Thomas et al., 2004), a majority of caregivers insisted they wanted to offer care, reaffirming a preference for death at home both before death and after.

Yet, several lacunae in knowledge vis-à-vis family relationships must be addressed before interventions to increase rates of home death can prove consistently effective. Studies have shown that spending time with family was perceived as critical to positive outcomes at end of life (Patrick et al., 2001), but also that family relationships were affected during home hospice care (Forbat et al., 2012). These relationships can become strained as death approaches, with problems in communication among family members and a need for assisting families with rapidly changing relational needs (Ward-Griffin et al., 2007; Forbat et al., 2012; Retrum et al., 2013). Studies focusing on family relationships at the end of life at home are sparse (Patrick et al., 2001; Forbat et al., 2012) and rarely include the essential voice of the patient (Shepperd et al., 2012). While it is beginning to be understood that family and caregiver gain may be a component of death at home, with family members reporting better outcomes when relationships were positive (Stajduhar et al., 2008), this research is not only scant, but the patient’s voice is silenced.

Finally, much of the knowledge on death at home calls for a need to support human development through end of life (Steinhauser et al., 2000; Salmon et al., 2005), and to empower patients and families to live well and die well, in the way they choose (McCall & Rice, 2005; Gomes & Higginson, 2006; Grande et al., 2009; Walker et al., 2011). Theoretically, these precepts underpin the patient-centered, family-focused approach championed within the philosophy of hospice and palliative care (Teno et al., 2001; Strohbuecker et al., 2011; Lokker et al., 2012).

A phenomenological lens is ideal for addressing contextual factors in rich, nuanced detail, with a particular focus on embedded family relationships, taken-for-granted practices of healthy grieving, and meaning-making surrounding death at home. A hermeneutic/phenomenological view, with emphasis on meaning, practice, and rich, emic experience, is well suited to address these gaps. The goal of this study was to conduct a retrospective, interpretive phenomenological study exploring lived experiences of one terminal patient dying at home and her family members. The specific aims were to

1. explore the unique, lived experiences of one patient who died at home and her family;

and

2. interpret how dying at home influenced patterns of bereavement for this patient's family

METHODS

Participants

This single case study followed a 78-year-old, otherwise healthy, white Jewish female who had been diagnosed with amyotrophic lateral sclerosis (ALS) six months prior to death. The family was known to the principal investigator, a psychiatric mental health nurse practitioner, and was chosen through convenience sampling. In line with the patient's wishes to die at home, she chose to exercise self-determination in the manner of death, voluntarily foregoing food and drink when she felt ready for death and no longer wished to watch her body deteriorate with ALS. She had informed her (79-year-old) husband of 60 years and 4 middle-aged (52 to 58 years) children of this plan, and all were supportive. She had no underlying mental health issues complicating her decision to die, including no history of depression. She was admitted to home hospice approximately 2.5 weeks before death, and stayed in her home of 28 years, surrounded by family. Soon after hospice admission she ceased eating and drinking. She was kept comfortable with a thirst prevention protocol and, as death approached, lorazepam and a fentanyl patch. Besides simple nursing care, her condition did not require further measures until she died 15 days later.

Data Collection

Interviews were conducted via telephone, as participants lived in several different states. An interview approximately three months before the patient's death was conducted with the patient, inquiring as to the meaning of living with ALS and how she viewed the end of her life and her legacy. Interviews with family members occurred approximately 8–9.5 months following the patient's death. Interviews lasted from under 20 minutes (with the patient herself) to an hour. Only one family member, a son of the patient, politely declined to be interviewed, indicating he felt the dying trajectory had lasted too long (15 days), and he wished it could have ended earlier, in line with his mother's wishes to die as soon as she was ready.

Ethical Issues

The study was approved by the institutional review board of Oregon Health and Science University. All five participants voluntarily gave informed consent after an iterative process of having the study described to them verbally, and through in-depth printed information. Each semistructured interview began by reminding participants they could stop the interview at any time, decline to answer questions, and/or request the audio recording be discontinued. No participant subsequently requested any of these accommodations, and several mentioned they felt the interview had been therapeutic. Interviews were transcribed and stored in doubly password-protected computer files. During the initial verification reading, names in transcripts were deidentified.

Data Analysis

Data were analyzed in accord with Benner's (1985) phenomenological approach. This approach "seeks to study the person in the situation" (p. 1) by pulling paradigm cases, exemplars, and themes from the text. Paradigm cases denote a particularly strong pattern, relationship, or meaning that stands out in narrative texts — in this case, interview transcripts of the terminally ill patient at the end of life and her family members after death. Exemplars signify smaller vignettes that capture meaning or relationships, and thematic analysis is a common qualitative technique. In this work, thematic analysis underscored themes representing the embedded meaning of the phenomenon of dying at home. Transcripts were coded by both investigators, one an expert in qualitative research and palliative care. Transcripts were read and reread recursively. Initially, codes were collapsed into themes. A paradigm case then stood out from each transcript, which was mined for quotations that revealed rich meaning for all participants. Finally, smaller exemplars arose that further uncovered patterns of relationship and meaning in the family. To ensure trustworthiness, two additional research experts reviewed findings until consensual agreement was reached.

FINDINGS

Paradigm Case: The Meaning of Being at Home

The patient wished to stay home through the end of life, her long-time home where she and her family members felt most comfortable. The embedded meaning of what "home" connoted was found in every narrative. Family members spoke of what dying at home meant to the patient and also what it meant to them, both during her dying trajectory and in their bereavement. Several excerpts illuminate the deep meaning of home for the patient:

> [Second son:] Her home. Her place where she felt most comfortable in the world. (. . .) Being home made her feel safe in familiar surroundings and enhanced the quality of her experience. It was her space that she loved. She was in her sanctuary. Her home. Home is our special place. It is our safe place. It is our known place. She was able to go through this extremely stressful and difficult disease and deterioration ending in death at home, and not have the added stress of being in an unfamiliar place like a hospital or some other place. That was a blessing.
>
> [Daughter:] Doing it her way, in a dignified manner, in a gentle, peaceful manner, in her home, her place of refuge, surrounded by all of us. (. . .) That's what home meant to her. It meant she could die with dignity and no one could take that away.
>
> [First son:] In her own house, in her own bed with her family around her. (. . .) Home is where we are comfortable. Nobody wants to be in the hospital. If we have a nice home that we love, and she did love her home. (. . .) It was a great environment for the whole process, not just for Mom. It was much nicer for all of us being at her house.

All three of the patient's adult children, and the patient's spouse, spoke eloquently about how being situated at home, supporting the patient in her wish to die there, allowed a safe and relaxed context to focus on relationships. They suggested this not only helped the patient feel her life was fulfilled, but also offered an ideal environment for their own anticipatory loss and bereavement:

> [Daughter:] Because she was comfortable and because we were doing everything she wanted, it made it so much easier for us. I don't think we have regrets. I don't think we feel guilty about needless procedures that traumatized her or us. I was with her all day long, every day, as long as I could be there: in the bed, on the bed, taking a nap with her, holding her, touching her, making her comfortable when she would grimace or groan, caressing her until she would fall back to sleep. It was a really beautiful death [because] she was able to stay home. It created a better death for her and a better grieving for us, who know she died the way she wanted to. And that's what Mom's death made me realize. Everyone should have the good fortune to leave life in the way they want and to live life the way they want until the moment of death.
>
> [First son:] [There was] plenty of opportunity to interact with her and have meaningful conversations with her and finish unfinished business. So that was huge. She was very wonderfully open with me about what she was going through, and we were able to talk openly about what was happening. Just that feeling of not being pressured and having plenty of time to let whatever arises arise. I feel incredibly lucky and blessed that it's eight months later and I have had no feelings that I wish anything had really been any different. (. . .) It seems to me every other relationship in the family, between siblings and between Dad and his children; they've all been transformed in some way. Totally for the better.
>
> [Husband:] She was ready to die, because she had made peace to the extent she was able to with her family; all of her family and with each person individually. The love that she expressed from everybody, that she received from everybody. She felt fully fulfilled in her life and didn't appear to have any regrets, or unfulfilled desires or expectations. She wasn't afraid. She didn't express any fear of dying. She gave me plenty of time to be prepared mentally and emotionally. And she and I were able to talk, to experience each other. And I was able to experience my love for her. So I didn't have any unfulfilled desires that interfered with or contaminated my bereavement. There was complete closure. I was ready when she was ready.

Thus, the intimacy and peacefulness of the home environment afforded each participating family member, and the patient, an ideal and safe time to be present with each other and process the inevitable end of their relationships. Shorter exemplars also focus on other salient features of this case that contributed to positive outcomes for participants.

Exemplar: Driving Her Own Course

The patient was strong, self-determined, and courageous. All family members spoke to these qualities, and to the sense of control she had about the end of her life, epitomized by choreographing a death at home in line with her wishes:

> [Second son:] She felt in control, so I think that helped her a lot, and certainly made me feel better because she was able to make the decisions. I would have been much more in distress if I felt she didn't like what choices were being made, or wasn't able to make the choice of how and where she was going to die. Having that power was incredibly comforting to her. It would be tough to overstate the importance of that for the quality of the experience that she went though. The power to decide, and then do, and then make it happen.
>
> [Daughter:] What was amazing was how she was able to drive her own course. She had control. She felt like she could do whatever she wanted to do. And what was important to her was being at home, driving her course, having us around her.
>
> [First son:] It gave her a lot of comfort in the end to know that she was going out on her terms. Maybe she couldn't beat this thing, but at least she could decide how she was going to go down. And that would be a source of comfort to me, and I am sure it was a source of great comfort to Mom.
>
> [Husband:] The fact that she could take control and avoid the lingering discomfort and indignity of her illness was a plus. That was a plus. That made her death a better death.

Exemplar: Not Being a Burden

Like most terminal patients (Gott et al., 2004; Thomas et al., 2004; von Gunten, 2012), one of the patient's main concerns was to not be a burden to her family. She stated, "I hate having my family watch me in physical distress, and it's hard to ask my husband to do all these things. I feel badly for him." However, her family did not feel she was a burden and, on the contrary, expressed that the manner in which she chose to die at home alleviated burden:

> [First son:] [It was a] gift that she gave us. (. . .) It relieves an enormous amount of burden from the family.
>
> [Husband:] I didn't feel it was a burden. I didn't resent it. I didn't think, "Oh, this is difficult," although it obviously was. I didn't have any of those negative thoughts. I felt love for her. She accepted [ALS] without complaint or grimace or comments — just accepted it. She kept her spirits up, and I think she did that in substantial part for the benefit of me and her family and her friends. She accepted her situation and was living with it the best she could.

Thematic Analysis

Multiple themes came through in the narratives (see Table 1). Perhaps most importantly, Patient Characteristics —her personality — informed events that led to her death at home. Family members spoke of her innately open communication style, grace, dignity, gratitude, positive attitude, and sense of humor

Table 1. *Themes contributing to successful home death*

- **Patient characteristics**
  - Personality: direct communication, grace, dignity, courage, determination, gratitude, positive attitude, sense of humor
  - Acceptance of illness and death
  - Life completion
  - Giving gifts
    - Material gifts
    - Memories
    - Wisdom for living
- **Family characteristics**
  - Positive family relationships
  - Open communication
  - Material resources
- **Support**
  - Honoring patient's wants and needs
  - Supporting patient decision making
  - Supporting each other
- **Emotions**
  - Love
  - Gratitude
  - Sensitivity to each other's emotions
- **Time**
  - Being with/spending time
  - Illness time
  - Sacred time
  - Time to say goodbye
  - Dying time
- **Aspects of the healthcare team**
  - Access to information
  - Respect for patient and family autonomy
  - Accessibility
  - Family member as healthcare professional

throughout. Her acceptance of illness, sense of life completion, and ability to give gifts to those she would leave behind — material gifts, special shared memories, and wisdom for living — helped create a dying trajectory that was ideal for her and her family:

> Grace was one of her ideals and strengths in certain ways, and it was a very graceful way to go.
>
> She really had a great attitude. She just said, "I've lived a great life, I've been blessed, I've done everything I want to do, there is nothing on my bucket list."

Not surprisingly, Family Characteristics dovetailed well with Patient Characteristics, as positive family relationships were a value the patient seemed to have instilled in family members for decades. Like her, they felt comfortable with open communication. This particular family also enjoyed material resources, affording the patient formal caregivers, further relieving burden on the family. All this created a rich environment for life completion and emphasis on family relationships:

> I attempted to communicate with her on a deep level.
>
> There are endless stories of families bickering. (. . .) But everybody was very large spirited. We handled it better than a lot of families seem to.
>
> I really appreciate my caregivers, how kind and helpful they are. It has meant a lot to me and I feel sorry for people that can't afford to have such wonderful help and assistance.

Several forms of Support were a pervasive theme throughout narratives. Family members honored the patient's choices, supporting her decision making, regardless of what she chose. They also spoke of supporting each other throughout the dying process and beyond:

> We all gave Mom permission to live the end of her life however she wanted.
>
> She felt she was in control and she had family support, no matter what she was going to do.
>
> We all came with very different life experiences, and we had never been through this. We've had to cooperate in ways we didn't have to before. I've been surprised how well we've done.

Emotions were a critical aspect of this support. It was evident that family members loved the patient and felt loved by her. Participants spoke openly about sharing love through words and actions and feeling that love in return. Gratitude was often expressed on the part of both family and patient for each other as well. And an almost taken-for-granted sensitivity to and respect for each others' emotions pervaded this family's story:

> (. . .) Expressing to her that I loved her. And she telling me she loved me.
>
> She received wonderful expressions of love and admiration and respect.
>
> It was very precious. An experience, and memory, and connection with her.

The value of Time, a critical construct in any phenomenological study, was expressed throughout. Spending time together when little time was left, having the duration of illness to concentrate on relationships, and the sacred time of sharing last days were underscored as themes. Time to say goodbye and time spent together during the active dying phase were also noted by participants:

> If you want to let Mom know she means something to you, now is the time. That was very gratifying to her and very comforting.
>
> It was about spending time with Mom and trying to be there for her.
>
> Those last couple weeks (. . .) to be there every day and to have a fairly leisurely goodbye, and for her to know I was there, and that I cared.

Aspects of the Healthcare Team provided a vital link that created a successful trajectory for this family. The patient and family expressed that they had access to information when needed, and the hospice team, as well as the patient's clinicians, supported the patient's autonomy in decision making. The team was responsive and accessible to patient and family concerns. One of the patient's children worked as a healthcare professional, and this family member's ability to navigate the healthcare team, in balance with the patient's needs, was perhaps an unusual feature of this case that furthered success:

> (. . .) Having good doctors that she had confidence in to help her and answer her questions (. . .)
>
> It was nice to have hospice there for everyone to rely on.
>
> She was so comfortable with [family member] caring for her. It really helped her feel comfortable and loved and safe.

DISCUSSION

In 1997, the Institute of Medicine defined a successful or good death as “free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ and families’ wishes” (Field & Cassel, 1997). Yet the widening gap between patient and family wishes for preferred place of death on one hand, and actual place of death on the other, is of growing clinical and policy concern. This case illustrates what may be construed as an ideal or good death, including a patient who was self-determined, accepting of her illness, and who enjoyed support of her family and healthcare team. This case reinforces the important work of Patrick et al. (2001) toward a model for quality end-of-life care. These authors noted several domains as essential for end-of-life quality, including preparation for death, family involvement, respect for treatment preferences, and whole-person concerns. Teno et al. (2001), in a comprehensive review of expert guidelines on quality end-of-life care, cited 14 domains as critical to success. Arguably, all of these were present in our case, including: physical well-being, psychological well-being, autonomy in decision making, patient-centered care, family-centered care, coordination and continuity of care, spirituality/transcendence, social well-being, autonomy in advanced care planning, attention to grief and bereavement, access to care, dignity, caregiver well-being, and affordable financial impact.

Other features adding to success in this case included a chronic illness that allowed sufficient time to plan and fulfill patient wishes for death at home and hospice care (as opposed to sudden death). An appropriate hospice admission to include adequate planning and palliative care, autonomy, and support for patient and family was also essential. The patient’s physically uncomplicated dying trajectory simplified care so that the focus could remain on evolving family relationships.

Perhaps what patients envision is a scenario much like the ideal scene presented here: a simple, pain-free, peaceful end of life and death, surrounded by those they love, in a safe and familiar environment, with time and space for final goodbyes. Seemingly precious few patients enjoy the autonomy, family and healthcare support, and communication skills to actualize such a meaningful death. Yet this is the model supported throughout the hospice and palliative care literature, and is surely the goal.

LIMITATIONS

This study has several limitations. A single case can add to the extant body of knowledge on death at home, yet it is not particularly transferable to other settings and samples. Findings will need replication before further conclusions can be drawn. The cross-sectional retrospective interviews also excluded change over time, and were undoubtedly limited by recall bias. Finally, one family member declined participation. Although he did this expressing his clear support for the patient’s decision to die at home in the way she wished, his viewpoint is still unheard in this case and detracts from the richness of the findings.

IMPLICATIONS

This work confirms prior findings that patients wish to die at home, and that doing so contributes to life completion for patients and productive bereavement for family members. This case is simply a single step toward exploring deeply embedded family relationships in the dying context at home. Further qualitative research is needed into these relationships, with purposeful sampling to investigate diverse family relationships in the dying context at home, including for those with whom the dying trajectory does not proceed smoothly. Additionally, longitudinal investigation into dyadic views of relationships — from the perspectives of both patient and family members — may do much to enrich our ability to help patients die at home as they desire.

One factor only briefly mentioned heretofore pertains to commonly voiced *perceptions* on the part of family members about what the patient and each other were thinking, feeling, and desiring. Family members in this study gave much consideration to each other in a reflexive, taken-for-granted way. This “we-ness” thinking is a hallmark of positive relationships (Badr & Acitelli, 2005). However, qualitative analysis of family relationships in the dying context at home, viewed through a dyadic lens, does not yet exist in the literature. The home-based end-of-life care literature emphasizes the need for more work into multiple family relationships in the dying context, and family contextual factors that affect patient course and bereavement. Further work analyzing these family relationships and describing how interpersonal relationship factors affect patient end of life and family member bereavement is a rich source for future research.

CONCLUSIONS

For this patient and family, remaining home with hospice provided a richly familiar, quiet, safe, and comfortable environment for being together over time, sharing what needed to be said, exchanging love, and successfully focusing on family relationships. For the family, this time also allowed productive grief before and after death. Almost a year later, each participant spoke of what a positive experience they and the patient had had, in line with her wishes.

Death at home with hospice honors patients' and families' vital last wishes, providing them with the death they choose. Dying at home has also been shown to extend lives through hospice and palliative care, ease the financial burden on patients and families, and offer a sustainable solution to a financially overextended healthcare system.

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