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Dignity as Wisdom at the End of Life: Sacrifice as Value Emerging from a Qualitative Analysis of Generativity Documents

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Abstract
End of life and palliative care are viewed in chaplaincy as an important time when spiritual support is considered highly beneficial. Dignity therapy is an important care strategy in this field. This article lends support to the Chochinov protocol using Schwartz's matrix of values. Five dignity therapy "generativity documents" prepared for terminally ill patients using interpretative phenomenological analysis were analyzed using qualitative thematic analysis. The results showed the role of values in the construction of wisdom and confirmed the importance of family relationships. The value of sacrifice, which is supported by various religious traditions, emerged as a perceived factor, indicating personal wisdom. The most significant result is the discovery of sacrifice as a positive value. Since hedonism, another of the values of Schwartz's matrix, is quite common in contemporary culture, it is important that those applying dignity therapy pay sufficient attention to the value of sacrifice, understanding that it could be recognized as a characteristic component of wisdom by those who are terminally ill. The implications, not only for end of life counseling but also for other fields and disciplines focusing on spiritual care, in particular for pastoral psychology, are significant.

Keywords End of life · Dignity therapy · Sacrifice · Wisdom · Generativity

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End of life and palliative care are viewed in chaplaincy as an important time when spiritual support is considered highly beneficial. Indeed, both in Europe and the United States, chaplains from various religious backgrounds are members of multidisciplinary clinical teams that care for end-of-life patients and their relatives because they are able to make an important contribution by addressing suffering and death-related anxieties (Kernohan et al. 2007). Working in this field takes empathy in order to venture gently into the core of the existential privacy of dying patients. However, psychological instruments useful to guide the dialogue toward patients' awareness that they are finally standing on holy ground, which is the beginning of an authentic comforting and, especially, healing existential relationship, are still scarce.

At the present time, the only validated psychotherapy that has been shown to improve the quality of life in terminally ill patients, helping relatives to manage anticipatory mourning and improve relationships, is dignity therapy (DT) developed by Harvey M. Chochinov (2002). The Canadian author focused his research on the idea of 'dignity,' which can be considered the main value, composed of respect and recognition of the constellation of all unalienable personal existential reference points (Chochinov 2012). Tested and evaluated across the world, Chochinov's model is a psychological intervention that has the potential to conserve the essence of this unalienable dimension. Its efficacy has been widely evidenced by both Chochinov (2012) and other researchers who have conducted trials to show the model's greater benefits for DT participants than control groups and describe its cross-cultural congruence with dignity (Hall et al. 2012; Goddard et al. 2012). Considered an elective method of the medical humanities (Ahlzén 2007), through the question protocol DT addresses the key existential and spiritual issues that patients and families have to face, fostering their self-worth and reducing their distress significantly. The most commonly discussed topics that emerge usually are love, lessons learned in life, hopes and dreams, catalysts, overcoming challenges, and guidance for others (Li et al. 2014; Montross et al. 2011). Since DT can be authentically performed by chaplains (Chochinov 2002), it is important to recognize the main pivotal concepts that can both help to manage this kind of relationship to empower patients, thereby reducing their passive resignation and negative stagnation, and are also of interest in the field of pastoral psychology. To pursue this fundamental aim, the present article lends support to Chochinov's perspective (Chochinov 2002) using Schwartz's matrix of values (Schwartz 1992, 1994) and the constructs of wisdom elaborated by Erik Erikson and colleagues 1986. All three of these perspectives share the similar idea that the end of life can be optimized by valuing biography and past experiences.

Schwartz's matrix of values identifies about twelve motivationally distinct values and further describes the dynamic relations among them. Its simplified and best-known schema lists the following nine value areas: benevolence (preservation and enhancement of the people with whom one is in frequent personal contact—friends and relatives); universalism (tolerance and protection for the welfare of all people and for nature); self-direction (independence and self-determination); security (safety, family and national security, reciprocity, sense of belonging); conformity (obedience, politeness, honoring parents and elders); hedonism (pleasure, enjoying life, self-indulgence); achievement (ambition, success); tradition (religion, devotion, acceptance of limitations); stimulation (dealing with challenges in life); and power (authority, social recognition).

The Eriksonian contribution identifies generativity as the opposite of stagnation and as one of the most striking peculiarities of adult wisdom (Erikson and Erikson 1978, 1998; Erikson et al. 1986. According to this theory, achieving wisdom in the last phase of life is comprised of revisiting previous critical experiences and renewing psychosocial achievements. During this

period, individuals fear meaninglessness and feel the desire to make contributions to others, transcending personal interests and sharing the values on which their legacy is based. In this way, generativity helps to preserve the identity and dignity of individuals, affirming the values in their culture and continuing them by showing unconditional love and care for people who are part of their significant relational networks (Chochinov et al. 2008, 2011). Since all these dimensions are related to representations of immortality (Facco et al. 2018; McAdams and De St. Aubin 1992; Solomon et al. 2017), it is important to relate any dialogue about such issues to the future and to spiritual/religious dimensions.

Unfortunately, little qualitative research has been done on the DT generativity documents and no study has yet analyzed the wisdom and values emerging from these texts. The present article aims to fill that gap and offer reflections useful in the area of pastoral psychology.

Aims

Assuming the Eriksonian idea of wisdom as a key factor in the construction of meaning of life, the first important step toward the further explication of Chochinov's concept of dignity (Chochinov 2002, 2004, 2007) was the specification of the values falling within the acknowledgment of a meaningful life when it is coming to an end. To this end, we introduced the categories of the fundamental values developed by Schwartz (1992, 1994) in order to recognize the essence of the biographies of terminally ill patients and the ways and means through which they understand the past and "still present life" that could be given as a legacy and testimony to those remaining. Another area we wanted to examine was participants' understanding of finitude, the limits of their knowledge, and the translation of their knowledge into a specific and particular structure of wisdom at the end of life, supporting the religious and/or spiritual dimension.

Methodology

The study adopted a qualitative health research design based on a psychosocial background (Testoni et al. 2018). The assumption of a qualitative theory-driven conceptual framework has already been justified by many authors, especially in the health care fields (Alvesson and Skoldberg 2000; Gibbs 2008; Testoni et al. 2019b, 2017; Thorne 2011; Zamperini et al. 2015).

Data collection

The DT protocol is composed of the following prompts: (1) Tell me a little about your life history; particularly those parts that you either remember most or think are the most important. (2) When did you feel most alive? (3) Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember? (4) What are the most important roles you have played in life (family roles, vocational roles, community service roles, etc.). (5) Why were they so important to you, and what do you think you accomplished in those roles? (6) What are your most important accomplishments, and what do you feel most proud of? (7) Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say once again? (8) What are your hopes and

dreams for your loved ones? (9) What have you learned about life that you would want to pass along to others? (10) What advice or words of guidance would you wish to pass along to your [son, daughter, husband, wife, parents, other(s)]? (11) Are there words or even instructions you would like to offer your family to help prepare them for the future? (12) In creating this permanent record, are there other things that you would like included?

From these prompts, the written and recorded legacy emerges. The experience results in the creation of a 'generativity document,' which has the potential to uplift family and friends in their time of bereavement. The text is edited and supervised by the patient until it is approved. The object of the analysis is the interpretative repertory, a cluster of terms used to characterize narrations showing the relationships between dignity and wisdom.

All interviews were conducted by a counselor trained to use interpretative phenomenological analysis (Gill 2014), which is an approach to qualitative research with an idiographic focus. The research aims were to offer insights into how a given person can make sense of an issue inherent in experiences of some personal significance, such as major life events. It is distinct from other approaches because of its combination of psychological, interpretative, and idiographic components (Larkin and Thompson 2011; Pietkiewicz and Smith 2014; Testoni et al. 2019a). These in-depth interviews were done in the homes of the patients. About six to eight DT sessions were dedicated to each patient, lasting between 60 and 90 min, in order to produce the first draft of the generativity protocol. All interviews were audiotaped and transcribed verbatim. A total number of 33 sessions were realized in about 40 h of dialogue.

The research followed the American Psychological Association's Ethical Principles of Psychologists and Code of Conduct and the principles of the Declaration of Helsinki and met the required regulatory standards for research with human participants. The study was approved by the Ethical Committee of the University of Padova.

The qualitative analysis

Following the checklist of the consolidated criteria for reporting qualitative research (COREQ; Tong et al. 2007), our analysis was theory-driven, framing interpretations within Schwartz's intercultural theory of universal human values (Schwartz 1992, 1994), which tries to measure basic values throughout all major cultures.

Data were analyzed using the framework method for thematic qualitative analysis, which allows sources to be examined in terms of their principal concepts or themes (Cassell and Symon 2004; Marshall and Rossman 1999). Two researchers used this approach, which is particularly appropriate in ethnographic health care research (Pope 2000). The textual analysis of the final generativity documents, that is, the texts developed and edited by the counselor with each patient, was structured following six main phases: (1) preparatory organization, (2) generation of categories or themes, (3) coding data (4) testing emerging understanding, (5) searching for alternative explanations, and 6) writing the report (Marshall and Rossman 1999). The process was substantially realized by respecting both prior categories consisting of the nine fundamental values ('top-down') and categories that only became clear as analysis proceeded, exploring connections between explicit statements and implicit meanings of discourses ('bottom-up'). Finally, the corpus of the texts processed for the qualitative analysis was composed of 6622 words (Mara: 1854; Ilaria: 1700; Anna: 1632; Luca: 841; Marco: 595). Thematic analysis was performed with ATLAS.ti, a computer program that allowed us to identify thematic networks. The analysis resulted in network graphs describing logical relationships between words, concepts, and categories.

Participants

The participants were five patients followed by a home palliative care team, and the interviews were done at the patients' homes in the northern region of Italy. Family members, when it was possible, participated only in the last meeting.

Anna at 89 years old was suffering from a carcinoma of the esophagus. She lived with her daughter, her son-in-law, and her grandson who was about eight years old. She could not eat orally but was fed by parenteral nutrition administered by her daughter. She did not show signs of fear of death but did express sorrow for the pain her death would cause to her mother. She did not believe in an afterlife or in God. A total of seven meetings were organized. She became emotional when talking about her son, Antonio, who had passed away prematurely at the age of two in France. She was glad she participated in the study and was able to leave behind a documented story of her mother. Her daughter, reading the generativity document, was surprised to see several details she had not been unaware of.

Ilaria had a carcinoma of the colon at 88 years of age. She had a large family, eight children and several grandchildren, and one of her daughters was her caregiver. A total of six meetings were held with her because she passed away before the scheduled seventh meeting. She was a very religious woman and showed no anxiety about her death. She wanted to preserve her autonomy, so she was unwilling to accept analgesic therapy. She gladly talked about her life, focusing on work and sacrifice for her family. She was also happy to talk about a friend whom Ilaria considered as pious because she sacrificed herself to help others despite having a serious illness. Her children claimed they wanted to hand down the generativity document to their children as an example of significant values.

Luca, suffering from a metastasized carcinoma of the colon, was 76 years old. He was married and had two daughters and four grandchildren. He had already seen his brother, his sister, and his father die of a different type of cancer. He should have been checked regularly, but he did not do it on time, in order to prevent the cancer. His wife and daughters took care of him in his illness. He was not religious and faced death with anxiety for he was very worried about the future of his wife, sad about the lack of a cure for his cancer, and concerned about his unfinished affairs.

Mara was 66 years old and had a breast carcinoma that had metastasized to the bones. She was a calm, quiet, and positive woman, and her daughter and her grandchildren, together with her husband, were taking care of her. She did not seem to be afraid of death, and she accepted her fate and trusted her doctors. Eight meetings were held, the last one in her husband's presence. He became truly emotional while reading the generativity document. She was very glad for this experience and the opportunity it afforded her to contribute to the research.

Marco was 78 years old and was suffering from pulmonary carcinoma with metastases to the bones. He had a wife, two daughters, and two grandchildren, and was being taken care of by his wife and daughters. Seven meetings were held with him, but the last one was held without him because he had recently died. The generativity document was handed over to his wife, who did not open it immediately. After some months, during an appointment for permission to use the text in the research, she revealed an omission in the generativity document. Marco had been a champion in cycling, very well known in his town, but during the meetings he had never mentioned this, perhaps because he had prioritized sports over his family, who then took care of him during his illness with love. In the interviews, he claimed not to have made sacrifices for the family and said he was surprised to see all of them so close to him. He knew he was going to die and was worried about the 'pranks' he had done as a child.

Results

Prevalent themes

All participants typically began the dialogue with the counselor by sharing general autobiographical information they perceived as significant, such as their personal development based on their family context. Most importantly were times of passage, often marked by rituals such as marriage, celebrations, and mourning. Family life was the prevalent theme in all the texts, and it appeared as a cross-dimensional component in which various values were expressed. The main value found in the narrations concerned 'benevolence.' In fact, the descriptions of marriage and intimate relationships were dotted with expressions of love, pride, and satisfaction: "Important! My marriage was the most significant moment of my life because my family is what I hold dearest. We have two daughters. My wife and I managed to get them to study and now both of them are accountants. Now both of them work as employees. We are really proud of this" (Luca). In their families, patients learned and manifested pro-sociality, respect, equity, and commitment to others: "My marriage was very important. I would still remarry my husband. After marriage, I lived together with my husband and his family. We were ten, and we were able to be good to each other. Otherwise, bad things would have happened, but we were able to face everything with love and dedication, sacrificing ourselves for each other, without living this as suffering." (Ilaria). The second value within which this theme develops was that of 'security,' where there was also a dimension of mutuality and reciprocity: "I've learned in my life to value family. I understand that family relationships are the most important treasure because when you need something there is always someone who sacrifices himself to help you. In my life, I discovered the love of my family and the sacrifices they made. Their devotion and generosity were absolutely intense and precious because I feel I'm not abandoned!" (Marco).

The second major area of thematic prevalence was that of work and the role of work, which assumed 'self-direction' and 'achievement' as pivots. "The family was also important in my work. I worked for my brother. I was able to promote a production that he didn't believe would be successful. Working for my brother, I made him produce chargers that he did not want to make, and now he makes thousands of them, hundreds of thousands. Then he acknowledged me for this success. I was incredibly happy when my brother recognized me for this important success. I was very excited" (Luca). "I've worked hard for the family and the house. I also worked a lot for the breeding of cows for milk, and with the production of cheese we could gradually build our house. We got this house here, it was an old house, with the tiles all broken. We refurbished this house for ourselves and then slowly, with the money from the milk and cheese, we also did the stalls and other things" (Ilaria). Work was the essential element in achieving personal recognition: "Unfortunately, no importance is attached to women's work. Work was very important. Work is also important for women because it allows them to decide for themselves what they think is right for them. Before working, I was a nullity. I was happy when I went to work. I worked every day, even when I was sick. I once went to work with a fever of 40 degrees [Celsius; 104 degrees Fahrenheit]." (Anna).

Death related to spirituality and wisdom

The theme of spirituality remained nuanced because the protocol does not provide explicit questions about it. However, when evoked, the participants' responses were related to values and to 'tradition' in particular. Such a connection is particularly evident in Ilaria's report: "I have always acted thinking that God was present. I always thank God for everything He gave

me. I pray and thank Him for what he has done for our family, for keeping it together. Thank you, Lord, that you have always kept us together, you have always helped us, and we have always been good." Specifically, she emphasized the importance of marriage in the church: Marriage is a sacred thing and is long-lasting in church. If marriage not done in church, where there is no prayer, it is not lasting." Ilaria gave great importance both to prayer and to work: "I worked hard and I prayed. Prayer was important to me. I liked to pray while working because it gave meaning to my actions. I worked hard and I prayed a little." Furthermore, despite its not being a central them, the theme of one's own death was significant. Indeed, all participants were aware that they were soon going to die, so their death was a more or less implicit presence, or, better, an impending but invisible presence, as Mara described: "Recently, I met my former colleague at the oncology day-care center. I perceived in her eyes that she was one of those people who believed they have overcome the disease. Unfortunately, she died barely four months after. It was on that occasion that I began to reflect. Her face was beautiful and was not as dreary as mine. I began to wonder where she was, what it means to die, and all this makes me think a lot about the meaning of spirituality."

One's death is also seen as anticipating the end of life of the body, as in Ilaria's case, who spoke about losing her husband and of how his death meant the end to her: "Poor boy, he is dead, and I'm left alone. I've suffered so much from his death. I realized that he was my whole world and now I am alone. This was all my life. It's impossible to get back all the life that was lost with his death." Emotional relationships thus have a primary value as opposed to biological life, as in Anna's case, who described the death of her first child when he was still a baby as a grief that has never passed, despite the two daughters she had afterwards. Her sense of guilt for having entrusted him to hospital doctors never left her: "At the funeral, when he was buried, I would have loved to throw myself into the coffin, to bury myself with him because I died with him. I'm dead inside, I still cannot resign myself to it. It's as if this son has never abandoned me and has always lived with me my whole life. But now that it's my turn, what will happen? Maybe we'll meet again? I believe that there is something that will allow us to understand."

The clearest expression of wisdom before death was shown by Luca, who, when interpreting his own life, talked about his cancer and his regret over not having followed a proper preventive strategy: "Unfortunately, I underestimated the value of prevention. It should be made known to all that it is important to have preventive checks in order to catch the disease in time. After the first symptoms, I should have immediately had a colonoscopy. If I had done that, they could have diagnosed it one or two years earlier. Instead, I did a gastroscopy because my father died of a tumor in the stomach. It is important to let it be known that genetic aspects of cancer diseases." Luca spent his remaining weeks trying to transmit serenity to others. "As long as I'm fine, you don't need to be anxious. When I feel ill, we'll go to the hospital and do what is needed. Don't worry, we all know that sooner or later, we all must die. We won't be left behind. When it comes, we'll go away." The characteristics of the wisdom originating from his capacity to accept the elusiveness and unpredictability of death gave Luca the ability to live in the 'here and now' while also being able to offer the others the serenity to live the last period of his life well.

Sacrifice as wisdom

In the grounded ('bottom-up') part of our analysis, at a certain point we realized that sacrifice was being connoted as a positive value, capable of creating continuity between one's past life and one's present suffering. The tendency to sacrifice and to accept loss became a means of resilience for facing the present, as Luca put it when he referred to his ability to save money:

"If I took ten, I could spend maybe up to eight to save two. Saving money made me feel good. Today everyone prefers to spend everything, even more than they might have. But instead of giving value to what you buy and to money, it takes value away, because it does not make you understand that there is a limit. Renouncing something is certainly a sacrifice, but it gives value to what you already have" (Luca). Being able to save rather than spend with no limits gave Luca pride instead of regret. Nobody seemed to be sorry for not having enjoyed the money not spent or for not having not taken opportunities for pleasure. Quite the contrary, hedonism gathered a negative tonality, similar to how Luca put it: "There are people who spend everything they earn and even more. If you do that, then in your life you miss everything. It is important to work to earn, but when you die you know that it is not good to work to earn more and more and to spend more and more. You waste your time doing things you don't mean. It is better to make a sacrifice for a renunciation that allows you to live rather than sacrifice your life to buy more things" (Luca).

Other elements that included renouncing and sacrifice concerned work and the struggle to leave a legacy for one's children. Luca expressed this in the following way: "In fact, work is sacrifice because you have to work hard and it takes you a lot of time. You have to know that work is sacrifice, and that is why I always remind my family how much effort we have made to live together, to build the house and not to lack the essentials. I want them to remember the sacrifices we made for this piece of land that could give us some money, but not anymore, therefore, we take whatever comes." The same structure is also present in Ilaria's narration: "Work is sacrifice, but it is what allows you to live and grow. We had cows, we couldn't travel or go out while leaving them behind, as we had to feed and milk them. We started with little, and slowly, with a lot of hard work, we built all this, which is ours and will remain for our children and grandchildren who will come. They will be able to make less effort than us, thanks to our sacrifices.. .. Today, we tell our children: we give you everything, we live on our retirement benefits, the money that is coming in from our work now is yours, you can enjoy it, but we will help you as long as we are able to." She added, "I want my children to remember the good I have done for them ever since they were very small and the work I have done to raise them, the struggle and how much I have loved them. Anyway, they'll remember."

Perhaps the most touching testimony is that of Anna, who said, "I was able to endure my grief for the death of my child because I lived next to a woman who was very sick. We all knew about her illness, but she never complained to anyone about the great suffering she had to endure. To avoid disturbing anyone, she silently endured all her suffering, making a great sacrifice. Not only that, she was the first to help anyone in need and she did so with a smile. She sacrificed her free time for sick persons. She worked, suffered, and helped the ill. When my grief was unbearable, I would think of her or look for her and I would have the courage to face my life. She was a saint, and her testimony of the ability to make sacrifices helps me also now."

Conclusions

The aim of this study was to qualitatively examine the contents of the DT generativity documents produced by a counselor who had an authentic, positive relationship with her terminally ill patients. All participants had reached a sense of acceptance with respect to most of their previous life difficulties and negative experiences. Particular attention was paid to the themes inherent in values and wisdom that involved hopefulness, overcoming adversity, resilience, love, and spirituality.

If we consider wisdom as an overarching perspective, then the time close to death can be an opportunity to gain such insight into one's own life and that of others. If wisdom results in expertise in dealing with the meaning and conduct of life (Sternberg 1998), it is possible to confirm that Chochinov's protocol, aimed at maintaining the dignity of dying persons, explores the fundamental values that persist as generators at the end of life as well. Consistent with prior studies (Hack et al. 2010), our results confirmed that people approaching the end of life are willing to talk about a wide set of life experiences, beliefs, and relationships when given such an opportunity. Despite their personal anticipatory mourning, they were able to collaborate with the counselor for the good or well-being of their own selves and that of others through the production and editing of the generative document. The legacy creation component of DT was particularly beneficial in the exploration of their values. DT provided a significant opportunity for our participants to reflect on and affirm certain aspects of their lives that were most important to them. In all the interviews with participants, both empathy with and significant suggestions for future generations were expressed.

Furthermore, despite the fact that DT is a relatively brief and targeted intervention, a more comprehensive characterization of wisdom can be deduced from our analysis. From the results of the thematic analysis of these texts, some significant properties of wisdom emerged: the ability of these patients to cope with their difficult condition and, much more, to appreciate their life, knowing their personal limits and the uncertainties of their situation. Thus, we can say that wisdom is metaheuristic, that is, a heuristic that organizes the sense of all the narrations. At a high level of aggregation of the values that organize the virtues surrounding the fundamental pragmatics of life, it is possible to consider that the empowerment granted by Chochinov's protocol may help terminally ill persons to elaborate on a specific form of wisdom, one in which the sense of sacrifice can be particularly significant. In fact, our most significant discovery was that 'sacrifice' was an important value at the end of life of these participants. Indeed, each story was supported by core values that appeared to facilitate their search for meaning, particularly when faced with adversity or stressors. The participants' own mortality was seemingly accepted from this perspective as well, being enlightened by an anti-hedonic viewpoint that was developed through a practice of renunciation throughout their lives and in their present suffering. Therefore, carefully tailoring the DT to the needs, wishes, and abilities of dying patients requires the reconsideration of this anti-hedonic value in order to optimize the intervention in this phase of life.

The study has important implications for pastoral and spiritual care in general and, more specifically, for hospital chaplains focused on end-of-life issues with dying patients and their families. Indeed, pastoral and spiritual care practitioners are in many cases already conversant with the theological discourse linking sacrifice and wisdom, depending on their particular faith tradition. For example, the Christian faith tradition fully supports being "people for others," if we put it in the language of Ignatian spirituality, in which this is fundamental to living a life of meaning. Additionally, in the Book of Common Prayer, the words of a prayer at mealtime ask God to make us mindful of the needs of others (The Episcopal Church 1979), in keeping with the words of St. Paul: "Let each of you look not only to your own interests, but also to the interests of others" (Phil. 2:4). It is important to give further reflection to the theological language of sacrifice and wisdom and to the extent to which it lends support for the application of DT to the practice of pastoral and spiritual care and to hospital chaplaincy.

Limitations and future directions

One limitation of this study is that the analysis was limited by the relatively low number of participants. Also, the intervention emphasized the integration of important life stories, memories, values, and other related themes regarding family and work as opposed to active resolution of past conflicts or unfinished affairs. Future studies may consider extending their focus to the latter and include participants with more difficulties and present needs. It is important to underline that there were a few instances when participants decided to remove portions of text because they thought that they were unsuitable for their families to read, and only after that editing were the generativity documents analyzed. In the future, we hope to explore the unedited interview transcripts.

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