

“Never waste a good crisis”: A qualitative study of the impact of COVID-19 on palliative care in seven hospitals using the Dynamic Sustainability Framework

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Abstract

Background: The COVID-19 pandemic led to rapid adaptations among palliative care services, but it is unclear how these adaptations vary in relation to their unique organizational contexts.

Aim: Understand how the pandemic impacted the implementation of new and existing palliative care programs in diverse hospital systems using the Dynamic Sustainability Framework.

Design: Twelve in-depth interviews with 15 key informants representing palliative care programs from seven hospital systems between April and June 2020.

Setting: Public, not-for-profit private, community, and academic teaching hospitals in the San Francisco Bay Area with existing palliative care programs that were expanding services to new clinical areas (e.g. new outpatient clinic or community-based care).

Results: Six themes characterized how palliative care programs were impacted and adapted during the early stages of the COVID-19 pandemic: palliative care involvement in preparing for surge, increased emphasis on advance care planning, advocating for visitors for dying patients, providing emotional support to clinicians, adopting virtual approaches to care, and gaps in chaplaincy support. There was variation in how new and existing programs were able to adapt to early pandemic stresses; systems with new outpatient programs struggled to utilize their programs effectively during the crisis onset.

Conclusions: The fit between palliative care programs and practice setting was critical to program resiliency during the early stages of the pandemic. Reconceptualizing the Dynamic Sustainability Framework to reflect a bidirectional relationship between ecological system, practice setting, and intervention levels might better guide implementers and researchers in understanding how ecological/macro changes can influence interventions on the ground.

Keywords

Implementation science (MeSH), qualitative research (MeSH), palliative care (MeSH), COVID-19 pandemic (MeSH)

What is already known about the topic?

- In the early stages of the COVID-19 pandemic, palliative care programs rapidly adapted to meet the needs of patients and providers.

What this paper adds?

- Well-established palliative care programs played a key role in surge planning and were able to adapt to the organizational demands of the pandemic; new programs were utilized less in pandemic response efforts.

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Implications for practice, theory, or policy

- Implementing palliative care requires outreach and relationship building with providers, which was a challenge during the pandemic, and thus has implications for implementation strategies for palliative care. This study suggests refinements to the Dynamic Sustainability Framework that reflects how ecological system level changes had domino effects on practice settings and palliative care programs.

Introduction

Given the broad impact of COVID-19 on healthcare systems, variations among palliative care programs within regional systems have the potential to shed light on common factors that are critical to understanding how palliative care services adapted to pandemic challenges. High mortality from COVID-19 early in the pandemic initially garnered attention for palliative care as a resource for communication and person-centered care.^{1–5} It was also anticipated that palliative care could play a crucial role in helping resolve ethical dilemmas and supportive needs associated with COVID-19.^{5–7}

However, specialty palliative care is a scarce resource,^{8–10} which was only further exacerbated in the context of COVID-19. A rapid review identified that palliative care services required flexibility to implement wide ranging changes in order to meet patient and provider needs during the pandemic.⁶ Palliative care programs did rapidly adapt in several ways including: streamlining access to palliative care; extending specialist palliative care support; increasing outreach to generalist services; and adoption of technological solutions to provide care.^{11–14} Despite adaptations, integration of palliative care during the pandemic has been variable reflecting challenges at multiple levels—from the patient and family to organizational leadership.¹² Such variability likely reflects a dynamic fit between palliative care services and the hospitals and institutions in which they sit. However, much of this work on understanding adaptations and the relationship to their settings has focused on single health systems and been atheoretical.

The COVID-19 pandemic was incredibly disruptive, influencing infrastructure, policy, and funding—all of which are influential in the implementation and sustainment of innovations.¹⁵ Because the implementation and impact of interventions cannot be divorced from the unique contexts in which they are implemented, it is important to understand the dynamic fit between palliative care programs and how they adapted to the environment created by the pandemic.^{16–19} We therefore set out to use a theoretically informed approach to characterize programmatic experiences and adaptations of diverse palliative care programs during the onset of the pandemic.

Methods

Design and framework

An exploratory qualitative study using interviews with key stakeholders conducted at the start of a longitudinal evaluation of the implementation and effectiveness of new expansions of existing palliative care programs. We undertook these interviews in the spring of 2020, when the pandemic started, with the specific aim of addressing the following question: how are both the existing palliative care programs and new expansions being impacted by the pandemic? The goal was to understand how the pandemic was impacting both the setting in which these new programs were being implemented and the programs themselves. We selected the Dynamic Sustainability Framework as a sensitizing lens to examine common factors that influence the implementation and sustainment of funded services across all seven hospital systems. The framework draws on ecological theory and posits that the sustained effect of interventions depends on the fit between the *intervention*, the *practice setting* (e.g. hospital), and the *ecological system*, and thus, adaptation over time is not only inevitable, but encouraged.¹⁷

Setting

The Stupski Foundation funded seven hospital systems with existing palliative care programs in the summer of 2019 to expand palliative care services in San Francisco and Alameda counties over a 3-year period. The programs all focused on the following areas of palliative care enhancement: providing care in inpatient, outpatient, and/or community settings; increasing linkages to social services; increasing advance care planning; and supporting caregivers. In early 2020, the programs were primarily in planning stages, such as hiring for new positions and organizing staff trainings.

At the time of data collection, COVID-19 was having the following impacts on the health system within the region which serve as background information for how informants described the responses of palliative care within their organizations: California state-imposed mandates to increase hospital capacity by 40%, regional shelter-in-place orders effected on March 17, 2020, supply shortages of personal protective equipment (PPE), and an

early, though smaller than anticipated surge as compared to other parts of the United States.

Sample

Key informants were selected for interview if they were either: listed in their implementation grant application as having responsibility for implementing the new programs, or leaders of existing palliative care programs within the seven systems funded by the Foundation. The majority of participants fulfilled both criteria. As the external evaluator of these programs, interviewers were known to most of the implementation teams from preparation work for the study and approached each informant via email with an information sheet and invitation to participate.

Data collection

Semi-structured interviews focused on exploring the impact of the emerging COVID-19 pandemic on hospitals and their respective new and existing palliative care programs. Using the DSF, we conceptualized the COVID-19 pandemic as related to the *ecological system*; interviews focused on the subsequent impact that this had on the organizational context (*practice setting*), and how palliative care services (*intervention*) fit within those changing contexts. Interview topics included: impact of the COVID-19 pandemic on the organization, including priorities, challenges, and main concerns; how palliative care provision changed during the pandemic; barriers to and gaps in providing palliative care; ability to identify patients needing palliative care and meet needs; changes to expansion plans; lessons learned; and concerns moving forward (see Supplemental Material). Interviews were conducted by LMH and/or HZM, who are trained qualitative, health services researchers. Interviews were recorded with permission and transcribed for analysis. In addition to interviews, we observed two virtual meetings in which attendees from the same hospital systems discussed their programs and ongoing challenges due to the pandemic; notes were individually taken by LMH and HZM and written up in a narrative form for analysis.

Analysis

Transcripts and observation narratives were uploaded into NVivo (released March 2020) and analyzed thematically. An initial coding framework was developed from the DSF and topic guide, with additional emergent codes added during analysis. LMH and HZM individually coded one interview, then met to discuss the codebook and refine emerging themes; this process was repeated a second time and then all interviews were independently coded with the researchers checking in weekly to discuss emerging themes and refine the codebook. After all

Table 1. Characteristics of interview participants.

Characteristic	<i>n</i> = 15
Female	14
Role ^a	
Operational/administrative	11
Clinical (e.g. physician, nurse practitioner)	5
Project support	2
Consultant	1
Spiritual	1
Hospital system type	
Public/district hospital	7
Not-for-profit integrated system	4
Academic medical center	2
Non-profit, community hospital	2

^aNumbers do not total 15 as five participants had both operational/administrative and clinical/spiritual roles.

interviews and meeting notes were coded, themes were consolidated through discussion and coded data were analyzed using a matrix approach to identify patterns. Data quality checks were conducted using guidance by Miles et al.²⁰

Ethical issues

The study was reviewed and approved by the Stanford Institutional Review Board, #55905. Ethical risks of the study were perceived to be minimal as interview questions did not include personal health data or sensitive subjects. We utilized the Standards for Reporting Qualitative Research.²¹

Results

Twelve in-depth interviews were conducted with 15 key informants (three interviews were joint interviews with two informants each) between April and June 2020. All but one participant was female, most held operational or administrative roles within the hospital/health system; five of them also provided clinical or spiritual care directly to patients (Table 1). Interviews lasted between 29 and 61 min (median 47 min). Observation notes from two virtual meetings (2.5 h total) were also included in analysis.

Table 2 describes characteristics of the seven hospital systems, their existing palliative care programs, and planned expansions that began toward the end of 2019. The hospitals represent a mix of non- and not-for-profit, academic, community, and public health systems of various sizes and lengths of palliative care service. The hospitals predominantly serve non-white populations with a mix of socioeconomic status, reflective of San Francisco and Alameda counties.

Using the DSF as an organizing framework for our findings, we first briefly describe how participants perceived

Table 2. Characteristics of hospitals and palliative care programs.

Organization	A	B	C	D	E	F	G
Hospital system description	Non-profit, community hospital part of small integrated system	District hospital	Public hospital system	Public hospital	Academic medical center	Not-for-profit, large integrated health system	Not-for-profit, large integrated health system
Inception of existing palliative care services ^a	Inpatient 2014	Inpatient 2016	Inpatient 2008; Outpatient 2016	In- and outpatient 2009	Inpatient 1999; Outpatient 2015	Inpatient 2005; Outpatient 2008	Inpatient 1999; Outpatient 2011
Planned palliative care expansion	Outpatient	Outpatient	Expand inpatient to new hospitals in the system	Expand outpatient	Expand outpatient	Community-based ^c	Community-based
Patient characteristics served by palliative care							
% Non-White	99%	69%	65%	70%	62%	59%	58%
% Medicaid ^b	43%	20%	45%	56%	3%	4%	49%
Mean age	71.5	77.1	71	63	73.6	80.8	73.5

^aYears indicate when patients were first seen in those settings; most services began in cancer settings and expanded to other disease groups.

^bIncludes Medicaid only and Medicaid/Medicare.

^cCommunity-based includes programs delivered in patients' homes and skilled nursing facilities.

that the pandemic led to changes at the organizational level which then had a downstream effect on individual services and programs. We then describe the six thematic groups of adaptations to palliative care which reflect the nested relationship of the *intervention* (i.e. palliative care) within the *practice setting* (i.e. hospital systems), and draw out differences in adaptations between the diverse practice settings where relevant.

High level changes to the practice setting brought about by the pandemic (ecological)

Informants in all hospitals described the COVID-19 pandemic as a catalyst for immediate operational changes that brought a variety of stakeholders together to effect needed changes:

There's a phrase that I like, which is never waste a good crisis. [. . .] When your back is against the wall, you can make things happen. I think that that is something we all need to recognize and understand that we can probably do more of that in a non-crisis situation. (Interview 10)

The changes that participants noted at the organizational level (*practice setting*) that were perceived to have a downstream effect on palliative care programs included: a shift in organizational priorities toward preparing for a surge in COVID-19 patients; financial stress due to a reduction in revenue from elective procedures that were cancelled as part of surge preparations; and organizational efforts to support the workforce emotionally and financially. These changes provide contextual information about the *practice setting* in which the below changes to palliative care programs were made.

Adapting palliative care services to a pandemic-impacted practice setting

Palliative care involvement in surge preparations. All informants described preparing for a surge in COVID-19 cases as the priority for their hospital. In some organizations, palliative care providers were involved in creating policies for rationing care during resource scarcity (e.g. ventilator allocation) and being called upon to have difficult discussions with patients and families. In the larger organizations (hospitals E, F, G), these efforts were typically proactive and intentional, with palliative care viewed as an integral part of surge planning to prepare for an anticipated increase in demand for palliative care support:

[Palliative care] have had a surge planning team that has essentially tried to organize materials, and content, and tools, and training [. . .] to increase the capacity for access to palliative care consultation and/or just tools, so to do it for oneself. Because the reality is a lot of physicians were facing the reality that they might have to be doing care that they're not traditionally doing, and palliative care is one of them. (Interview 3)

In the public hospital settings, where palliative care programs tended to be smaller, involvement of palliative care was less strategic and palliative care became the default referral service for all difficult cases, such as communicating triage decisions for ventilator rationing:

What we noticed [in creating hospital surge plans], whenever there was an area that was going to involve patients, communication that might take a little time, [then] it was designated to palliative care. (Interview 11)

Size of the palliative care program was also linked to strategies to disseminate palliative care and communication skills widely which were expected to be in high demand during surges. Larger health systems were proactive in their educational efforts, such as forging connections with intensive care unit teams to ensure timely consult requests or identifying providers with advanced communication skills to increase access to that skillset. In contrast, hospitals with smaller programs were wary of being inundated with requests for consults that could not be fulfilled given their smaller staffing numbers. However, for new programs, they recognized that this was an opportunity to gain traction and showcase the value of palliative care.

A common strategy, regardless of palliative care program size or maturity, was to improve the communication skills of the primary attending physician by distributing pocket cards with communication tips or holding educational sessions virtually.

Increased emphasis on advance care planning. Palliative care programs commonly described a focus on completing Physician Orders of Life Sustaining Treatment forms (i.e. resuscitation orders). While this was perceived to be a common part of palliative care work, the emphasis on documentation was perceived to increase substantially reflecting concerns over what might happen to seriously ill patients in the setting of COVID-19. Providers at outpatient programs, in particular, worked to have wishes documented for patients most at risk should they need hospital care. However, the lack of in-person contacts due to social distancing needs meant that many providers had to develop creative workarounds to get forms signed, such as creating a “drive-by signing” in the parking garage or using apps to capture electronic signatures.

We presented an advance care planning webinar directed at primary care physicians so they could learn how to fill out the (electronic) [physicians orders of life sustaining treatment form] during their virtual visits. (Interview 1)

Advocating for visitors for dying patients. Palliative care providers played a role at the organizational level in advocating for exceptions to the restrictive visitor policies implemented to reduce the risk of spreading COVID-19 to allow for one or two visitors for a dying patient. Having even one visitor for a dying patient was perceived to be a “win” for palliative care given the restrictions in place.

I think the visitation issue came up very early on. That was just sort of listening to the [Department of Public Health] rules around visitation in the hospitals and needing to come up with a rule. But there was immediately a huge need for, okay, so how do you make exceptions to this rule? How can we still have someone there or multiple people there or whatever is possible for patients who are dying? (Interview 6)

Providing emotional support to clinicians. Informants noted that physicians and nurses experienced high levels of stress due to safety concerns and caring for patients under extreme circumstances. In response, informants described a variety of resources provided by their organizations to support staff well-being: creating meditation spaces, mental health hotlines, support groups, financial assistance programs, and utilizing chaplains for employee emotional support. Palliative care providers, particularly chaplains who were paid staff, took on a unique role in providing emotional support to hospital providers and staff to aid in their coping.

Staff could call or email the chaplain for one-on-one check-in or progress, chaplains could be invited to staff meetings, or when they were rounding to give inspirational messages (Interview 10)

Adoption of virtual approaches to care. Palliative care, like most areas of health care, shifted much care to virtual or telephonic formats, with outpatient visits moving exclusively to virtual formats. For inpatient services, palliative care providers described the challenges of having goals of care discussions virtually, specifically because it was hard for families to understand the patient’s condition without seeing them in person. In hospital C where inpatient palliative care was new, iPads procured by the palliative care team to connect patients with families when visitors were not allowed became a valuable way to demonstrate the new palliative care service to other providers:

The telecare work has actually been a Trojan horse for us in terms of just getting in the room and also demonstrating immediate utility. [. . .] I’m here offering a solution right away, which has led to a substantial amount of political capital in terms of what palliative care can do because that’s really what palliative care does. Like, it’s a very cold view of a very warm thing, but the reality is, palliative care comes in and solves hard problems. (Interview 11)

Hospitals with new outpatient programs (hospitals A, B) experienced challenges in establishing new patients via virtual care, and eventually paused enrollment for their new programs. One program described how they had not developed the trust of patients to successfully make the transition to a virtual format.

I think the biggest difference is it’s a really, really new program. We literally started in February (2020) and we got patients enrolled and then the pandemic hit. We don’t have a well-established program and also the trust between patients and our care team hadn’t been really established when the pandemic hits. The patients are more reluctant to continue their service with us during the pandemic because I think some other big hospitals, they have a really well established,

a well-run program already and so the patient visits with the providers is on ongoing basis. (Interview 4)

Public hospitals, particularly, described challenges getting patients to use video visits, with most preferring telephone visits. This challenged providers who felt telephone visits were suboptimal because they could not see the patient. The public hospitals described this more commonly as a key problem than the larger, private health systems, which informants attributed to serving lower income populations with limited access to technology.

When things shifted in March (2020) and all of our visits went remote, we have reached out to as many of our patients as we can contact to ask them about their access to technology and their willingness to try. And our experience has been that the majority of people either do not have the technology or are not willing to try. (Interview 2)

Gaps in chaplaincy support. One of the challenges for inpatient programs was that the visitor restrictions applied to volunteers. Chaplaincy services were particularly affected by these restrictions with reduced capacity for support:

The majority of our spiritual care in the hospital overall is delivered by volunteers. But during shelter-in-place, volunteers are not allowed to be in the hospital seeing patients, so that's meant that our hired spiritual care staff are spread very thin because they're trying to meet all of the needs across the hospital. (Interview 2)

Discussion

Main findings

The COVID-19 pandemic impacted existing palliative care programs and fledgling expansions in both positive and negative ways. Hospital wide concerns over resource scarcity and the uncertainty around disease progression spotlighted the specialized communication skillsets of palliative care providers fostering demand for inpatient support. Demand in turn prompted innovation and rapid scaling up of services.^{6,22} The challenges and adaptations to existing services that we identified in our study mirror findings reported elsewhere.^{11,23} However, the impact on new programs is not well understood. We found that new outpatient services had difficulty maintaining a minimum patient panel using telehealth and were underutilized and deprioritized as organizational focus shifted to the inpatient setting. Our study identified that stresses caused by the COVID-19 pandemic did not impact palliative care programs equally; inpatient programs, whether new or existing, had greater success in adapting to the pandemic environment than new outpatient services and community-based services which were hampered by lack of in-person contact necessary for building relationships to establish a new service.

While no programs entirely abandoned their expansion goals in the COVID-19 tumult, unsurprisingly, no programs maintained their milestones in the early pandemic as organizations prepared for surge, indicating a clear nested relationship between interventions and practice settings, as suggested by the Dynamic Sustainability Framework.¹⁷ Surge planning efforts narrowed the focus of stakeholders including other providers who otherwise would have engaged with these developing programs. Good palliative care is delivered by an interdisciplinary team, including primary providers.²⁴ However, provider lack of education and understanding of palliative care is a commonly identified barrier to specialty palliative care access.^{8,25,26} All the programs relied to some degree on building relationships and educating referring providers on the role of palliative care; competition for provider attention due to surge preparations became a barrier for new programs. This relational nature of palliative care in creating connections with providers and establishing trust with patients and providers became a vulnerability in program implementation, particularly for the outpatient programs. Recognizing this dependence on relationship building and outreach as an associated activity to education is a key implementation lesson for palliative care programs.

These findings demonstrate a multi-level effect that the pandemic at the *ecological system* level had at the *practice setting* and palliative care *intervention* levels. While there were commonalities related to organizational responses, there were differing impacts on programs which primarily related to the delivery setting (i.e. inpatient, outpatient, community) and maturity (i.e. existing vs new) of palliative care within the hospital system, with new outpatient and community-based services experiencing more disruption (e.g. pausing outpatient enrollment at hospitals A and B). The implication for palliative care services being that as they become more established in their setting, the way in which they are impacted or utilized in their organizations in future waves of the pandemic or other crises will likely differ.

Revisiting the Dynamic Sustainability Framework

The Dynamic Sustainability Framework provided a useful lens for exploring the fit between interventions, practice settings and the wider environment. While the model is “dynamic,” the visualization and description of the framework implies that the change that “ripples across multiple levels” moves from the intervention to the outer, ecological system.¹⁷ Our findings show that the model might also be visualized in reverse: events in the wider environment (i.e. pandemic) influenced organizational responses (i.e. preparation for surge), and had a domino effect at the program level (e.g. providing virtual care) (Figure 1). While

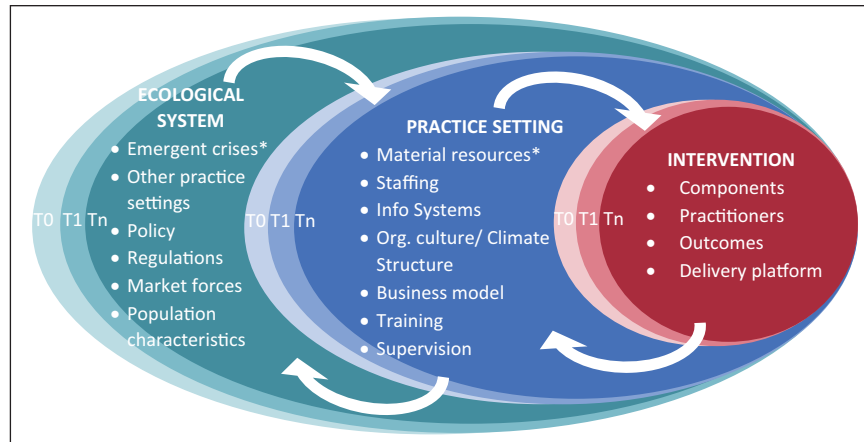


Figure 1. Revised visualization of Dynamic Sustainability Framework¹⁷ representing domino effect of ecological system on practice setting and intervention, and feedback to ecological system.

this might be expected as we aimed to explore the impact of the pandemic on the organization and palliative care programs, at the early stage of the pandemic, we did not identify evidence of intervention or practice setting features influencing the ecological system. Additionally, our findings suggest the appropriateness of adding two features to the model: at the ecological level, the addition of “emergent crises,” encompassing events such as pandemics, epidemics, or other disasters; and at the practice setting, “material resources,” reflecting items such as ventilators, masks, or iPads (equipment/ supplies).

A reverse ordering of the model and bidirectional arrows may be an important addition to the conceptualization of monitoring the fit between interventions and setting; that is, key changes in the ecological or practice setting level may warrant an assessment to check for intervention effectiveness to guard against “voltage drop.”¹⁷ The suggested alternative order may also more clearly reflect the outer implementation setting as dynamic with many features that can impact the organization, but are out of organizational control, such as policy, funding, and third party organizations.¹⁶

Limitations

The Bay Area counties entered lockdown in March 2020; we were not able to get access to key informants for interviews until the imminent threat of the surge had subsided. As much of the world experienced, we had to develop remote strategies for collecting data, which meant conducting interviews via Zoom and observing virtual meetings. While we as researchers were able to passively observe virtual meetings by switching off our camera and microphones, at times some participants also had cameras off or had technological issues which may make observational data less reliable. We therefore relied primarily on what was said during meetings rather than non-verbal cues.

Conclusions

This study enhances understanding of how palliative care programs are influenced by their contexts by examining how seven existing and expanding palliative care programs adapted to the early stages of the COVID-19 pandemic. The fit between programs and the practice setting was critical to resiliency during the early stages of the pandemic; those with strong pull from the hospital, rather than relying on push from palliative care, had greater success. Results suggest that the Dynamic Sustainability Framework is conceptually informative for palliative care implementation, but that it also can be conceptualized in reverse, with the ecological system level creating a cascade influencing the dynamic fit between the palliative care programs and the hospital systems in which they exist. Such a change might better guide implementers and researchers to attend to how sweeping contextual changes like COVID-19 influence interventions on the ground.

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Authors' contributions

LMH, KAL, and MW conceived and designed the study. LMH and HZM collected and analyzed the data. LMH drafted the manuscript. All authors edited, read and approved the final manuscript.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Ethics approval and consent to participate

The study was reviewed and approved by the Stanford Institutional Review Board, #55905. All participants consented to participate.

Consent for publication

Not applicable.

Availability of data and materials

The datasets generated and analyzed during the current study are not publicly available to maintain confidentiality for participating organizations, but are available from the corresponding author on reasonable request.

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Supplemental material

Supplemental material for this article is available online.

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