

Expanding the Palliative Care Domains to Meet the Needs of a Community-Based Supportive Care Model

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Abstract

Background: Whole person care is appropriate for seriously ill persons. The current framework of palliative care domains in the National Consensus Project (NCP) Guidelines for Quality Palliative Care offers an opportunity to reassess the domains of care delivered at home, earlier in the course of illness. **Objective:** This qualitative study was used to test the applicability of a proposed, expanded set of domains. The results were used to inform a home-based, upstream model of supportive care for serious illness. **Methods:** Quotes relating to the experience of late-life serious illness were derived from transcripts of 12 semi-structured group interviews conducted with patients, family, and professionals. Quotes originally coded to the NCP domains of palliative care were then coded to the proposed domain set, which included new categories of family/caregiver, legal/financial, and legacy/bereavement domains. **Results:** A total of 489 quotes were assigned to the proposed expanded set of domains. One hundred one (19%) coded to the family/caregiver domain, 28 (5%) to the legacy/bereavement domain, and 27 (5%) to the legal/financial domain. Ninety-seven (87%) of the 111 quotes coded to family/caregiver had been initially coded to the NCP social aspects of care. Family/caregiver themes included challenges, rewards, insights, and family growth. **Conclusion:** The preponderance of family-related issues suggests that including the family domain may promote recognition and support of family caregivers and the services they provide. Although this study provides some support for including the legacy/bereavement and legal/financial domains, additional research is needed to determine whether there is a basis for including them in the domain structure.

Keywords

domains, palliative, guidelines, whole person, lay health-care worker, National Consensus Project

Introduction

Whole person care has been proposed as a new paradigm for the care of serious illness.¹⁻³ The discipline of palliative care extends holistic features of primary care⁴ and geriatrics⁵ into a coherent practice that acknowledges the nonmedical facets of suffering.⁶ Beginning in 2006, the National Consensus Project (NCP) for Quality Palliative Care developed guidelines defining deliverables of palliative care and providing benchmarks for quality improvement.⁷⁻⁹ These guidelines were arrayed within a framework of domains such as social, spiritual, or physical aspects of care. The domain structure was developed using patient/family surveys, existing recommendations, and statements of principle.¹⁰⁻¹⁴

This domain construct supports performance metrics intended to reflect the interdisciplinary nature of palliative care programs. Although obvious in one sense, this orientation to measurement draws us away from the source of holism—the person herself or himself. As palliative care enters earlier in disease, are there opportunities to enhance the person-centered aspects of the NCP domain framework?

Four aspects of the framework deserve mention. The social aspects of care domain is broad, encompassing interpersonal relationships, finances, work, sexual intimacy, caregiver stress, and social networks.⁹ Understanding the depth of the social aspects of care domain could guide training and practical implementation for workers in the field.

A second reality of the current domain framework is its orientation to the activities of professional disciplines. In the example of social aspects of care, implementation has been described in the context of social workers operating in health-care settings.¹⁵ Revisiting the domains provides an opportunity to position their implementation upstream in the course illness and across disciplines.

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Table 1. Interview Participants.

Group Type/Location	Patients	Family	MD or NP ^a	RN ^a	Psychosocial-Spiritual ^b	Other ^c	Total	%
Residential hospice and nursing home	3	6		1	1	1	12	16
Senior living continuum	5	8	4	1	4		22	30
Grief group		8					8	11
Patients and Providers	2	2	3		3		10	10
Disease advocacy organizations ^d	7	4			1	1	13	18
Church	6	1			1		8	11
Total	23	29	7	2	10	2	73	100
%	32	40	10	3	14	3	100	

^aPhysician (MD); advanced practice nurse (NP); registered nurse (RN); 3 participating also as caregivers.

^bSeven spiritual care and 3 social work; 4 participating also as caregivers.

^cOne occupational therapy also participating as caregiver and 1 administrator.

^dDementia and chronic lung disease

Third, the inherent limitations of biopsychosocial assessment tools argue for robust representation of whole person within the domain structure. The NCP guidelines reference the Edmonton Symptom Assessment System (ESAS), commonly used in palliative research and practice for assessing medical and emotional symptoms.¹⁶ When applied to patients with severe heart failure, ESAS symptom scores exhibit poor correlation with validated measures of social functioning and self-efficacy, attributes that independently mediate drivers of effective self-care.^{17,18} Studies of persons with advanced lung cancer or heart failure reveal they suffer distress from impending mortality, functional loss, and social isolation.¹⁹ Even when emotional distress is identified, it may be a marker for suffering in other, unarticulated domains.²⁰ As Cassel points out, we are known and suffer as unitary beings, not as the sum of whole person components.²¹ Without balanced exploration of the broader psychosocial and spiritual experience of illness, even multidimensional assessment tools could result in a reductive and inadvertently medicalized approach to the complexity of individuals.

Finally, delivering palliative care earlier in the course of illness may raise previously unidentified issues in distinct aspects of personhood. Key issues in nonmedical domains may be better appreciated if the work is approached from an intentionally holistic perspective.

Owing to the breadth of the NCP social domain, the professional orientation of guidelines, and the limitations of clinical assessments, the framework of domains offers opportunity for refinement.

The current study explores the applicability of an expanded palliative care domain set to patient and family experiences of serious illness. This analysis will explore evidence for expanding the current NCP domains to include the additional domains of family/caregiver, financial/legal, and legacy/bereavement.

Methods

This analysis is part of a late-life supportive care research study begun in 2012 for patients with serious illness potentially in their last 3 years of life. The intervention is designed to

systematically support whole person care. The clinical intervention uses trained lay health-care workers to meet with patients and families in their homes. These workers, called care guides, provide whole person support and linkage to medical and nonmedical resources.²² Successful implementation of care guides for managing chronic conditions in the clinic led the researchers to propose a trained lay person working in the community as part of the health-care team.²³

The supportive care approach used in this research was developed with inputs from caregivers, patients, and providers. The clinical team also provided insights in the pilot phase. Based on these inputs, the NCP domain framework was expanded early in the approach. Three expanded domains were proposed: family/caregiver, financial/legal, and legacy/bereavement.

Participants and Procedures

Twelve semi-structured focus interviews were conducted with groups of 2 to 8 participants between March 3, 2012, and June 30, 2012. Participants who had experience with a variety of chronic medical conditions were recruited from senior living communities, faith communities, provider organizations, and disease advocacy associations (see Table 1). Of 73 individuals, 23 were patients, 29 were family, and 19 were professionals. Of the professionals interviewed, 4 were palliative-trained clinicians: 2 physicians, 1 social worker, and 1 chaplain. The remainder included physician/advance practice nurse providers (5), nurses (2), chaplains (6), social workers (2), occupational therapist (1), and administrator (1). Eight of the professionals related personal experiences caring for loved ones, and it was these quotes that were included in the data set; professionals' comments on patients or on care they provided were not included. Diagnoses relevant to the patients and caregivers were dementia (28), cancer (16), chronic respiratory disease (11), heart failure (5), and other (3). Participants received no compensation. Interviews were facilitated by a family physician and lasted 90 to 120 minutes. Questions were selected by the facilitator from a question set to stimulate discussion within the group. Not all questions were asked of each group (Appendix A).

Table 2. Definitions of Domains.

National Consensus Project Domains		Expanded Domains	
Spiritual, religious, and existential aspects of care	Practices are known, distress identified, rituals are honored	Spiritual/religious/existential	Varying levels of spiritual resilience and coping, suffering identified, inclusion of traditions and rituals
Social aspects of care	Strengths, needs, and goals, family context, community resources, financial need	Social Family Financial and legal	Social network, early conversation with family and social supports, identify gaps and needs Family and person are the unit of care, identify planning, and support needs Common legal issues in supportive care and the relationship of ownership to legacy
Psychological and psychiatric aspects	Recognizing and addressing psychological distress, delirium, grief, and bereavement	Psychological Legacy and bereavement	Mental well-being, coping, and support. Anticipatory grief. Recognize anxiety, depression, demoralization, and delirium Legacy is both what we leave and how we live. Grief is recognized and bereavement support is offered
Physical aspects of care	Managing physical symptoms. Care fits disease status. Family are educated to engage in care	Physical	Assessment of symptoms and comfort, functional status and safety, understanding of one's illness
Ethical/legal aspects of care	Respecting choices. Identify complex ethical issues. Advance directives	Ethical Financial and legal	Advance directives. Recognition of impaired decision-making capacity, recognition of internal moral distress, and use of an ethics committee Common legal issues in supportive care and the relationship of ownership to legacy
Cultural aspects of care	Care is linguistically and culturally sensitive	Cultural	The culture domain includes who you are, what's important to you, and how you interact with others. Sensitivity to decision-making, advance care planning, and information sharing wishes
Aspects of care at the end of life	Honoring wishes and rituals of dying. Managing symptoms. Activating a bereavement plan	Care at the end of life	Preparation, recognition, and engagement in the final stage of life. Anticipating symptoms, fears, and care needs. Individualizing preferences for care and closure

A public television crew filmed the sessions. Unrelated content was edited out, and dialogue was transcribed by a researcher. These transcripts provided the data for analysis. Quorum Review Institutional Review Board (IRB) granted approval for use of the transcripts.

Analysis

Qualitative method. A 3-step approach was used to assign quotes to domains. Two researchers (E.W.A., M.S.F.) deductively double coded 25% of transcripts to assign quotes to the 8 existing NCP domains.⁹ Coding rules for the NCP guideline domains were established using an iterative process (see Table 2).^{9,24} Coding agreement was 95.0%. This set of quotes was then coded to the proposed expanded domain set. Twenty-five percent of interviews were coded by both researchers, with 99.0% agreement. The remaining transcripts were coded by 1 researcher (E.W.A.). Thematic analysis was conducted as a third step within the second cycle. NVivo 10.0 software was used for data management.²⁵ Simultaneous coding was used, applying quotes to more than 1 domain.²⁴ The data were numerically represented by enumerating the one-to-many relationships between quotes and domains.²⁶ Deidentified transcripts and coding assignments are available from the authors.

Results

Four hundred eighty-nine quotes were coded a total of 591 times to the NCP domains (see Table 3). The left side of Table 3 shows results of first cycle coding to the NCP domains, and the right side shows results of second cycle coding to the expanded domains. The proposed domains of family/caregiver, legacy/bereavement, and financial/legal accounted for 168 (29%) of all quotes. Of the 111 items coded to the family/caregiver domain, 97 had been coded originally to the NCP social aspects of care domain. The remaining 13 were split between ethical–legal, psychological, and spiritual, with a single quote from the physical domain. The main sources of quotes for the financial legal domain were originally coded to NCP ethical (13) and social (11) aspects of care. The proposed legacy/bereavement domain was composed largely of quotes from the NCP psychological (15), social (5), and spiritual (4) aspects of care.

Thematic Analysis of the Proposed Domains

Family/caregiver domain. Six broad subthemes emerged, describing challenges, collective family actions, rewards, family growth, insights from experience, and honoring wishes of the person in care (Table 4). Participants voiced many challenges

Table 3. Distribution of Serious Illness Interview Content to Domains.

National Consensus Project Domains			Proposed Domains		
Domain	n ^a	% of Quotes	Domain, n	n	% of Quotes
Social	218	37	Social	61	10
			Family/caregiver ^b	111	19
Physical	101	17	Physical	117	19
Psychological and psychiatric	88	15	Psychological	76	12
Spiritual, religious, and existential	85	14	Spiritual	83	14
			Legacy/bereavement ^b	28	5
Ethical and legal aspects	55	9	Ethical	42	7
			Financial/legal ^b	27	5
Care of the patient at end of life	26	4	Care at end of life	29	5
Cultural	18	3	Cultural	17	3
Total	591	100		591	100

^an = number of quotes.

^bProposed expanded domain.

Table 4. Thematic Analysis of Family/Caregiver Quotes.

Themes	n	%
Challenges of caregiving	43	39
Families acting together to address needs and find resources	40	37
Rewards of caregiving	22	20
Growth or change as a family	22	20
Insights from caregiving	9	8
Being true to the loved one's wishes	6	6
Total ^a	109	100

^aSome items coded to more than 1 theme and the total shown is the number of unique items.

of caregiving. Family members struggled with obligations to parents, spouses, and children, while needing more than their families could sometimes provide.

My siblings have been good with support. I don't think they all get it. . . . But my circle of friends—people who have been through it—have just been an incredible source of information and support.

Struggles with gender roles are reflected in a man's discomfort at buying incontinence diapers (Table 5) and on comments by female caregivers about their role carrying the emotional burden, ("I think women kind of take on the emotional piece"). Finally, participants described the irremediable weight of caregiving, the "plodding, endless trek."

Amidst these challenges, families acted together to address needs and find resources. Families organized and managed complex care, often with little outside direction. Although

participants commented on temperamental differences in the family, most expressed gratitude for teamwork.

Participants also described rewards of caregiving, such as having time with their loved one, feeling changed for the better by the experience, entering new communities and relationships, and receiving gifts of grace from their loved one. ("I was only able to do [his caregiving] because . . . of the type of person he was. He was just a wonderful, wonderful, wonderful man.")

According to participants, families experienced growth and change. Adult children accepted the challenge of role reversal, while trying to support their parents' autonomy. Several participants spoke of modeling caregiving for future generations. ("This is how we take care of people . . . This is what family does.")

Participants also shared personal insights gained from caregiving. Quotes revealed learnings about setting limits, finding balance in life, and accepting spirituality.

Finally, the theme of honoring the loved one's wishes was expressed in 2 ways. When the ill person articulated his or her wishes, it relieved family of the potential for conflict. When wishes were unclear, families routinely spoke of the struggle to make decisions. ("She had Parkinson's, and by the time it progressed she couldn't tell us [what she wanted] . . . So that was very difficult.")

Financial/legal domain. Quotes shown in Table 6 demonstrate a range of issues in this domain. Paperwork, lawyers, wills, and insurance were topics of concern in the interviews. Families feared losing assets to pay for care, and they found legal and financial paperwork daunting. Other quotes dealt with the cost of care for a protracted illness, overshadowed by the threat of impoverishment. Legal and financial decisions often were the substrate from which intense interpersonal experiences emerged, exemplified by the final quote in the legal/financial section of Table 6.

Legacy/bereavement domain. In this proposed domain, patients spoke of the continued search for meaning, despite their impending mortality. ("We are in a position where people are helping us now. It is nice not to always be helped. It is nice to be helping.") Both patients and family spoke of actions taken before death that would affect how they would remember or be remembered (Table 6). Patients and families commented on each other's reactions to discussions of legacy. For some family members, it was an uncomfortable reminder of their loved one's mortality. ("My son said to me, he don't want to talk about it.") For others, it was affirmation of the qualities they admired in their seriously ill family member. ("My mother wrote her own obit, she planned her funeral. She took care of everything.") Family caregivers acknowledged the accumulating burden of losses that precede death, and they shared the grief of multiple losses. ("I've lost 2 people—my wife and my son, in less than a year.") Survivors reflected on how their loved one constructed their legacy and continued to value it as a connection to the deceased.

Table 5. Exemplars of Themes in the Family/Caregiver Domain.

Challenges of caregiving	<p>I get frustrated because I want to be there for him, and yet I have a daughter at home, who is only 11. So, I'm torn between needing to be there for her, needing to be there for my husband, needing to be here for my dad, needing to help my sister, and my other siblings.</p> <p>I'm not sexist at all, but God I wished for a sister when I was doing this. This is a much better job for a female. I don't want to be sexist, but, oh my God, buying her diapers, it was so difficult for me. In Walgreens, I'm sneaking around with a pile of diapers, and oh my God, it was painful!</p> <p>I feel powerless. I can't change this, I can't fix this, and that's where I get all the frustration. It seemed to be a managed crisis for a long time. Now, it has just become an ordeal. It's just become a trek. And you just keep plodding day after day after day. And it just seems like you are always on the tundra, never at the peak. Just always climbing.</p>
Families acting together to address needs and find resources	<p>So we would clean the bandages, take care of her, dump the drainage tubes. That was just our normal process. We had a normal system. My dad had piles and lists of what medications to give her, super organized, but the whole time it was just surreal.</p> <p>One thing that has really helped is just plain email. We are able to send an email out and say, "Here's what's going on, here's what's happening with dad," so I don't have to pick up the phone five times and call everybody.</p> <p>I have a brother who was equally as involved, but emotionally, he didn't take it . . . it's just different. There's six of us that all live and can help with my mom, did help with my mom and are presently helping with my dad . . . They all have different strengths, different time constraints, but they're all united to do the best for our dad presently.</p>
Rewards of caregiving	<p>Those are some of the blessing. Grace comes to mind, in terms of watching someone, and being with them and walking with them on the journey. This is where we are going. That's a wonderful opportunity for families.</p> <p>And for my mom with Alzheimer's, she was very resistant and hard to deal with, with her disease. She kind of fought it and was confused, kind of angry, but at the end when she accepted caregiving, oh it was such a sweet thing.</p> <p>But, as I've worked through it with my wife, I've come to change my mind a little bit. It's like we've both become different people through the experience. And I've met so many people I would not have met otherwise, who are all great people. I've gotten involved with organizations that do wonderful work and I've learned how to become part of a community that I never would have done before.</p>
Growth or change as a family	<p>As I take care of my mother, my kids are watching this. This is what you do. I hope that is what they are picking up. That is really important too, that they will pick that up. This is how we take care of people when they are ill or when they get old. This is what family does.</p> <p>My example was, my grandmother was here, she died at a 105 ½ and she was here for quite a while and I watched my mom and dad, same age as I am now, take care of my grandmother. They were an excellent example to us.</p> <p>It's important to not just accept at face. Be prepared to dig and research and do some, for you to do that. For the individual, the child to do that. It's incumbent on us, just as our parents would have done that for us when we were younger and couldn't do it. So the role has completely switched around.</p>
Insights from caregiving	<p>For me, caregiving, it's the giving. It's the giving out, giving out, giving out. So sometimes you have to be in that receiving mode whether it's the quiet or the creativity or the walks with friends. Or you really get out of balance.</p> <p>I know for me personally, I know I could not do this without God's help. I could not do this unless, I believed in Jesus Christ, who can give me the power and strength, patience, the whatever it is that I need at this moment, that I can ask for.</p> <p>Given this goal of keeping Linda as happy as we can all the time gives you something to live for and think about outside of yourself. And to expand to all the other people who are suffering. Turning outward has really been the thing that I see as the positive aspect of this disease.</p>
Being true to the loved one's wishes	<p>Especially in larger families, it's 5 of us, 6 of you, that fact that my mother said Margie, you can be my health surrogate, bill you're gonna be in charge of the finances, it eliminated that kind of discussion, or what could arise problems with the siblings. Why not me, I'm the oldest boy, or whatever. So that is a nonissue. It was her choice.</p> <p>Whatever you have to say, so in some cases, it bites you in the back side. It is hard to turn that off. I had to really think about that and at times say "Ok, I'm done. I'm just your daughter, I won't butt in, I won't give you any advice, I won't make those suggestions.</p> <p>She just so wanted everybody to know how she wanted things to be. That she still had that power at the end, whether she was able to say or not. That it was in place, she had done it, she had organized it. She was always a very organized woman anyways. So, that was a great gift that she gave us kids.</p>

Table 6. Examples of Content in the Financial/Legal and Legacy/Bereavement Domains.

Financial/legal	<p>I thank heaven that my sister is willing to do all of that. I'm like "paperwork?" Here you go. I'll clean his apartment. I'll drive. I'll play cards with him. Here . . . here's the bank statements.</p> <p>This is a disease that's always takes a long, long time and is generally not covered by anyone's insurance policy and the expenses involved with it are just devastating . . . The policy is society says, here's the system. You pay for it until you are broke and then we will take over.</p> <p>[She said to her husband], "How can you say you want to go there [the VA nursing home], you've never been there?" He said, "I won't even know the difference." He cried, the lawyer cried, and I cried. He just wanted to make it easy for me, as easy as he could.</p>
Legacy/bereavement	<p>I've made plans for cremation. Yes, I did. My son said to me, he don't want to talk about it. Fine, don't talk about it. So, I got, I have stuff in the apartment . . . I made a book about, who am I going to give it to? My grandchildren, stuff like that. So that's it. Almost like a will. That's about it.</p> <p>Some of them [the losses] are huge and really in your face, but some are very small. But they are there, and they are cumulative.</p> <p>And now he's been dead a year and four months, and I think I am beginning to know what he is trying to tell me in this poem that he had copied from somewhere.</p>

Discussion

The intervention informed by these focus groups was intended to address the needs of patients and their families during the last 2 to 3 years of life with serious illness. During this time, when patients continue to receive aggressive medical support from their regular care teams and hospice is a future consideration, the interviews provided an opportunity to explore palliative needs long before end of life. These needs were most clearly identified in the proposed family/caregiver domain.

In sheer breadth, the NCP social aspects of care domain is expansive, accounting for 37% of all domain coding in this study. The social domain touches many facets of personhood including caregiving, social networks, family, work life, and financial–legal concerns. Using the proposed domain set, strong empirical support was found for identifying a distinct family/caregiver domain. Caregivers, in this study, described well-documented challenges including gender roles, managing difficult behaviors, caregiving at a distance, the time and physical burdens of caregiving, performing complex medical tasks, helplessness in the face suffering, feelings of depression, and disregard for self-care.²⁷⁻⁴¹ Counterbalancing these, they described rewards of a close relationship, personal growth, a sense of mastery, and self-esteem.^{35,39,42,43}

For most caregivers, these experiences unfolded within a family system. Caregivers described family support,

adaptability, and self-efficacy, all of which improve clinical outcomes or caregiver health in serious illness.⁴⁴⁻⁴⁸ Families transferred values, for example, by engaging in caregiving as a cherished transgenerational activity.^{49,50}

In addition to its substantive presence in serious illness, the family/caregiver domain is important to consider because it highlights tractable barriers to optimal care. Caregivers in this and other studies have described feeling invisible or ignored by the health-care system; this can even arise with home-based services when providers focus on the patient to the perceived exclusion of family.^{51,52} When caregivers feel their needs for practical or emotional support go unmet, they experience distress that is not related to objective measures of caregiver burden.⁵³ It is not surprising therefore that caregivers request practical support, active listening, better 2-way communication, and a more navigable, less complex health system.^{54,55}

Conjoined financial and legal concerns expressed in the interviews led to proposing a financial/legal domain. During the course of serious illness, families provide most of the support to loved ones, while medical costs headline the story of personal bankruptcy.^{56,57} Perceived or real financial constraints can lead to social isolation for caregivers, when they forego needed social services.⁵⁸

The third of the proposed domains, legacy/bereavement, identified issues spanning individual lives and extending across generations. Although legacy is typically seen as work of the patient, and bereavement as work of the survivor, the quotes reveal some interdependence. Patients constructed their legacy as both patient and family began grieving cumulative losses. Caregiving itself was passed down as a legacy of example.⁴⁹

There are limitations to this study. It is a secondary analysis of interviews conducted to gain insights for a new clinical model. General questions related to caregiving were asked, for example, "What are your joys and your challenges in being a caregiver?" but there were no specific questions on legal matters, financial concerns, legacy, or bereavement. Proposals for these smaller domains should be viewed as preliminary until further research can be done. Although the clinical intervention broadly defines family from the patient's perspective, the sample of patients and families interviewed came from traditional family settings.

Conclusions

This study was used to explore the applicability of an expanded domain set to the serious illness experiences of individuals. Results of this study highlight the particular importance of a family/caregiver domain. Families reflected on their roles as care managers and importantly also on their own family and personal transformations. Two additional proposed domains—financial/legal and legacy/bereavement—reflect experiential groupings of concerns around preservation of assets and life transitions, respectively. Both the applicability of these proposed domains and a parallel analysis of the whole person perspective of families' experiences deserve further study.

Expanding the NCP social aspects of care domain by adding the newly described family/caregiver domain more fully describes the day-to-day experiences of patients and families. This understanding supports efforts to deliver whole person care by focusing on key facets of the broad social/family landscape. Honoring the central role of caregivers will set the stage for effective partnerships with patients and families in the consuming work of living with serious illness.

Appendix A

Serious Illness Interview Questions

What conversations have you had with your loved one about the future?

Do you or your loved one have a health-care directive?

What are your joys and your challenges in being a caregiver?

Looking ahead, what is most on your mind?

Who do you go to for help or support when things get difficult?

Did your health-care system fully explain your loved one's diagnosis?

Do you feel supported by your loved one's medical team?

Did your health-care system give you resources for needs or questions?

If you could change one thing about the health-care system, what would it be?

What requests from your loved one are easiest to deliver on?

What requests from your loved one are hardest to deliver on?

What do you find hard to talk about

Do you have enough help in caregiving?

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