

Building New Teams for Late Life Care: Lessons From LifeCourse

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Abstract

This article details team development within a longitudinal cohort study designed to bring team-based, whole person care early in the course of serious illness. The primary innovation of this approach is the use of nonclinically trained care guides who support patients and family members by focusing care around what matters most to patients, linking to resources, collaborating with other providers, and offering continuity through care transitions. By describing the development of this team, we document the kinds of questions others may ask during the process of team creation.

Keywords

teams, interdisciplinary, hiring, training, innovation, support

Introduction

Hospice is frequently thought to be the “gold standard” in team-based end-of-life care. It is the most comprehensive, high touch model in the last weeks to months of life, improving the experiences of patients and their family members.¹ One of the central tenets of hospice care is an interdisciplinary team approach that includes physicians, nurses, chaplains, social workers, home health aides, and other staff, who work with patients’ caregivers and existing providers to develop a holistic care plan.² Interdisciplinary teams are able to provide comprehensive care when they integrate diverse expertise, share responsibility for care that includes medical and nonmedical needs, create a productive team culture, and are able to sustain a commitment to care through their working relationships with one another.³⁻⁵ Patients and their family members benefit from the use of team-based holistic care focused on understanding individuals’ own values, goals, and preferences as medical and nonmedical needs arise.⁶

A limitation of hospice team-based care, however, is that through Medicare reimbursement, it is restricted to persons expected to live 6 or fewer months. Given the benefits of hospice and demographic changes to the United States that will sharply increase the proportion of Americans living with serious illness, some have argued for moving hospice and palliative services earlier in the course of illness.⁷ These attempts have primarily focused on separating palliative care from end-of-life and integrating the palliative approach across the life course.^{8,9} Earlier implementation is often hindered by the cost of team-based care and limitations on reimbursement for individuals who are still seeking curative therapies along with palliation.¹⁰⁻¹³

Is it possible to design a team-based approach that closes the gap between when one might benefit from a hospice-like approach and when they are eligible? Might this team use the tenets of hospice and palliative care, but avoid feasibility issues? This article documents one such attempt, called LifeCourse, highlighting challenges and opportunities in the process of forming, hiring, training, and working with this team, as well as reaffirming why creative thinking is necessary given current health care challenges.

Team-Based Care

In considering how to implement teams earlier in the lives of patients, several unanswered questions become apparent. Definitions of teams vary widely across settings and studies, as does the terminology used to describe them.^{14,15} Although hospice and palliative teams are typically called interdisciplinary, other health care teams have adopted terms like transdisciplinary, multidisciplinary, or collaborative instead. Subtle distinctions exist between these terms; however, most studies of teams do not provide enough detail about the structure of the team or the context under which the team works to fully understand what makes some team approaches work better than others.^{16,17} Furthermore,

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discussions of team-based care tend to be more conceptual than empirical, making it difficult to accumulate knowledge about how to develop and work with teams.^{18,19}

Despite issues in defining teams, the future of medicine will likely include team-based care. Recent suggestions for improving primary care have centered on using teams to provide comprehensive, long-term care.²⁰ Teams are especially effective for meeting the complex needs of aging and fragile patients.¹⁷ Successful interdisciplinary models of comprehensive care for older adults can be built into existing care structures (primary care, home-based care, nursing homes, etc) and are effective for improving quality and outcomes of care, as well as lowering health care expenditures or use of high-cost services.²¹ However, these supplements to care as usual are limited in their ability to support across the care continuum and move beyond episodic interventions. A team-based approach that builds on the successes of hospice and palliative care teams but innovates to provide long-term, consistent, and coordinated care across various providers is needed to continue to improve late life care.

How should a team like this be structured? Who should be on the team? How should the team be managed? What kinds of processes are required to build an effective team? Given the lack of terminological clarity and empirical evidence, we do not currently know enough about the process of conceptualizing, forming, hiring, training, revising, and duplicating teams, especially for complex patient issues that arise in late and end-of-life care. This article does not provide definitive answers to these questions. Instead, it describes the process by which one team-based project, called LifeCourse, developed their team approach. By documenting this process, this article provides essential information about the complexity of decisions that must be made when forming and using health care teams.

Methods

This article documents the team efforts of an intervention designed to serve patients earlier in the course of serious illness. LifeCourse is a multiyear study of how to innovate a care model for people with serious illness, funded by the Robina Foundation. LifeCourse aims to supplement hospice and palliative care initiatives through providing holistic care during the last several years of life and remaining constant between acute inpatient episodes. LifeCourse is able to do this by revising the interdisciplinary team to include a non-clinically trained professional, called a care guide. In collaboration with the interdisciplinary team, the care guide helps to coordinate care across the team and patients' existing providers. LifeCourse strives to employ holistic, person-centered care before an individual's needs increase, allowing patients to live well with serious illness. As models, LifeCourse draws from the National Consensus Guidelines for Hospice and Palliative Care, The National Framework and Preferred Practices for Hospice and Palliative Care Quality, and the Hospice and Palliative Nurses Association competencies for interdisciplinary team members.²²⁻²⁴

We document the process of conceptualizing and developing this team using several forms of exploratory data. First, the majority of the authors (4 of 5) have been leaders in the LifeCourse team development, so their experiences within this process serve as primary data from which we draw these conclusions. Serving as key informants, these 4 authors have reflected on their experiences as they drafted the article, discussed revisions, and received feedback from others. Second, official reports, work plans, job descriptions, and other documents were used to build out information about the team development process. Each of the authors gathered documents that recorded decisions made, changes in approach, and key moments for the team. The second author collected these documents and used them to construct the descriptions of team process. Finally, all authors came together with their documents and reflections to hold a group data collection session. The collected documents allowed participants to construct a timeline for the team, fill in details for each time point, and discuss key challenges, successes, and milestones. This session was recorded and transcribed and then coded and analyzed by the second author.

From these forms of exploratory data, we construct the following results, broken down into chronological stages: conceptualizing, hiring, training, and working together. Each section details the decisions made in this project but also illustrates questions essential for others seeking to develop an innovative care team.

Results

Conceptualizing

The first step in the development of the LifeCourse team was to conceptualize the team, required work, and necessary roles. LifeCourse began by engaging other team models, including hospice and palliative care. Leaders met to describe the current state of late life care and how the ideal state differed from current state. One insight from early meetings was that even for hospice and palliative care practitioners, doing the right things for patients sometimes involved working around organizational constraints. LifeCourse sought to create a model that began with patients' and caregivers' preferences and built in their experiences throughout the development of the team. Additionally, because leaders wanted to create a model sustainable several years before death, they also considered other innovative models, especially those that included a care coordination role, like companions, care guides, and community health care workers.^{21,25-29} The assumption was that long-term affordability of the model would require thinking creatively about staffing. Through these models, LifeCourse leaders decided to add additional professional roles to the team and integrate a non-clinically trained care guide as the primary patient contact. Following initial studies of the use of care guides in primary care clinics, LifeCourse sought to use the care guide to form long-term relationships between patients and the care team.^{26,29} The LifeCourse care guide role also focused on

Table 1. Team Members' Ownership of the Work.

Care Guides DO NOT:		Total Tasks (N = 43)	Percentage of Tasks
• do physical examinations	Care guide	24 Examples: validation of patient story, recognize cues that signify change, anticipate future needs, facilitate discussion with patient and family, use shared decision making, support family, and coordinate care	56
• create plan of care			
• perform discipline specific	Chaplain	4 Examples: counseling on relationships, counseling on grief and loss, spiritual intervention, and bereavement care	9
• administer medication	RN	9 Examples: physical examination, anticipate future needs, advance care planning, medication reconciliation, manage symptoms, assess for dying phase, and educate patient and family	21
• provide hands on care	MFT	6 Examples: facilitate family conference, conflict management, advocate for patients, counseling on relationships, family therapy, counsel on loss, and bereavement care	14
	MSW	8 Examples: advance care planning, refer to community resources, facilitate care conference, conflict management, coordinate plans for dying, advocate for patients, and coordinate legal support	19
	Pharm	2 Examples: medication reconciliation, manage symptoms, and side effects	5

Abbreviations: MFT, marriage and family therapist; MSW, Master of Social Work; RN, registered nurse.

building long-term professional relationships with other providers, partnering with patients and families, and sharing decision making, thus integrating relationship-centered care into this model.³⁰

To avoid slipping into the already known and comfortable hospice and palliative care model, leaders gathered a diverse group of individuals (primary care physicians, social workers, nurses, care managers, chaplains, family caregivers, lay people, and long-term care partners) together to explore the work involved in caring for people near the end-of-life. They used the National Quality Forum consensus report on preferred practices for quality hospice and palliative care to guide a group conversation about the work of caring for someone with serious illness.²³ Based upon these preferred practices, the group compiled a list of expected interventions and activities that would serve individuals and their families in the last several years of their life. They then delineated which tasks could be completed by a nonclinically trained care guide. They pushed to expand existing perspectives: Which parts of the work currently done by clinicians are universal or could be shared by all without requiring a professional license? This exercise allowed leaders to think beyond the existing models, concluding that over half (56%) of the activities related to late life care for the whole person could be completed without a clinical license. This was evidence enough that the LifeCourse model could be built around the use of a lay care guide.

Table 1 shows the results of the work task exercise. Note that the group first clearly defined what lay care guides were not permitted to do because of licensure restrictions (upper left of Table 1). Turning to the main table, see that from the total list of tasks, care guides were determined to be able to complete

56% of care tasks. They were then assigned primary ownership of 24 tasks and examples are given. The remaining 44% of the care tasks were divided among the clinician team members, though some tasks could be completed by multiple clinicians, so the percentage equals greater than 100.

Aside from the care guide role, many of the LifeCourse team members overlapped with hospice and palliative care teams. The team will be described in more detail subsequently. The primary innovation above and beyond hospice and palliative care teams was that by adding the care guide, LifeCourse permitted higher caseloads for the clinically trained team members, allowing them to work at the top of their licenses.³¹ Care guides provide primary services within their scope, using clinicians as consultants and directly involving them in patient care when discipline specific triggers are identified. Additionally, because care guides have lower case loads, they are able to spend more time with patients, establishing relationships and gathering knowledge about what is important to patients and their family members. This relational knowledge is then useful for care guides as they coordinate care within their team and with existing providers.

Hiring

The previous section described the conceptual background of the LifeCourse team, but translating that ideal into action was a complex process. When attempting to innovate on existing care models, a decision about how to select team members must be made. This section will describe how LifeCourse selected and hired high-quality team members who performed their roles while also helping to continually evolve the

conceptual model. This required selecting team members and managers who were open to work that was not yet well defined, interested in the challenge of creating a new vision, and committed to using their skills in new ways.

Although project investigators were present throughout the conceptualization stage, team managers were recruited as LifeCourse transitioned into the implementation stage. A project manager who had worked on Allina's previous care guide project was selected because of her extensive clinical knowledge, previous experience with research, and demonstrated ability to guide others through operationalizing new ways of working. Two clinical managers were then selected to oversee the team. One manager was a trained nurse, with many years of dedication to hospice nursing, and a curiosity about new ways to bring these principles earlier in the life course. The other manager was a social worker who had worked on similar projects that sought to rethink care delivery. Leaders in LifeCourse stated that all 3 managers stood out because of their skills as care providers, their exceptional operational experience, their commitment to innovation, and their willingness to help build the intervention.

Of the 3 managers, 2 had worked in the health system before coming to the LifeCourse project, so their knowledge of internal resources and potential team members to recruit was essential for building and training the team. Because the model was created alongside the team, LifeCourse did not begin with concrete sets of trainings, tasks lists, or knowledge of potential issues moving forward. Leaders had a conceptual vision and ideas about core competencies, desired characteristics of staff, and required positions, but the operationalization of each of these was a process, from which managers learned a great deal and relied on feedback from the team to refine over time.

Using existing guidelines for core competencies within hospice and palliative care, LifeCourse generalized a set of core competencies and experiences that were interchangeable across members of the team, so that everyone who approached patients and families had the same set of skills. Skills and criteria for initial hire and ongoing competency included experience working or living with serious illness, empathic presence, compassion, ability to collaborate with others, individual self-awareness, motivation to do the work, and computer proficiency. Most of these competencies were based upon general principles of supporting patient-centered care, communication, coordination, collaboration, and team work.^{32,33}

Although licensed professionals were expected to come to the team with a set of discipline-specific skills, care guides were expected to come with a variety of professional experiences that would be conducive to building relationships with patients and their family members. Care guides were then trained in the particular skills of LifeCourse work through collaborative work with managers and mentorship from licensed professional team members. Additionally, because leaders designed this model as part of a test of innovative practice, managers selected persons with a desire to help change the health care system and tolerance for ambiguity. Although this approach guaranteed that LifeCourse hired individuals who could provide excellent care

for those in late life, it also required that team members be able to adapt to change and have a passion for creating a new approach.

From an analysis of other teams, the conceptual model of care, and feedback from expert care providers, LifeCourse determined that the clinical roles on the team would include a chaplain, registered nurse, social worker (licensed clinical social worker [LCSW] or Master of Social Work), pharmacist, and a marriage and family therapist. Although most hospice and palliative care teams include chaplains, nurses, social workers, and pharmacists, the LifeCourse approach added the marriage and family therapist in response to comments from expert groups, input from family care givers, and reading of literature related to family systems.³⁴ As illness progresses, there is a shift in roles and responsibilities from the norm in each family system. These additional stressors of role reversal caused by illness change the "ecosystem" of the family unit.³⁵ From expert feedback, we determined that a clinically trained marriage and family therapist would have the skills necessary to help reorient care to the family unit—and not just individual patients. Although this set of skills (individual, couples, and family therapy) may have some overlap with the skills of LCSWs, we determined that a family-based approach was important enough to include both a social worker and a marriage and family therapist. All of the clinically trained professionals served as consultants to care guides and gap fillers for patients. Revised roles for clinicians posed some challenges, discussed in a later section.

Training the LifeCourse Team

Training LifeCourse team members required altering typical training for health care professionals. All team members came in with a skill base: for professionally trained team members, this included educational training and domain-specific knowledge and experience, while for care guides, this included interpersonal skills and experience with care giving. Training for LifeCourse built on these existing skills to define and develop core competencies in the work. Training focused on grounding team members with a broad understanding of heart failure, late stage cancer, and dementia; bringing in experts from outside to speak about advance planning and shared decision making; integrating trainings on adaptive leadership, team dynamics, and personal boundaries; and encouraging self-care exercises. Existing resources were leveraged to complete these forms of training. One challenge to using existing resources was that most resources were built around single professional groups (or silos) and had to be revised to fit the LifeCourse team as it attempted to redefine the work through a care guide perspective in ways that challenged professional divisions. Leaders learned that providing more information to internal resources before the training sessions was helpful to tailoring the message for the LifeCourse team.

To supplement traditional training, LifeCourse also integrated stories of patients' experiences to keep their perspectives centered within the LifeCourse approach. Managers

showed videos of patients' struggles during the last years of life and organized observations of patients within inpatient palliative care, outpatient palliative care, and home health teams. Each day of training started out with a review from the previous training day, then a story was told to ground the learners to the new topic. Once topics were grounded in patients' experiences, managers integrated expert content. Each day ended with a review of lessons learned and feedback on the training. Team members were also encouraged to explore team and individual self-care activities, including relaxation, guided imagery, meditation, journaling, yoga, acupressure, washing of hands, and the use of ritual.

During the initial phase of LifeCourse, all team members trained together. Care guides spent additional time with one another to develop their new roles within the team. Through this process, managers learned several things that have informed subsequent trainings. For instance, while care guides likely needed time with one another to develop their role, clinician team members may also have benefitted from more time with one another. Because LifeCourse pushed clinicians to practice differently than they would in most other settings, they also had to develop new ways to think about their work. Second, the model of LifeCourse emphasizes relationships with patients and their family members, but through this experience, managers learned that a balance must be struck between emphasizing relationships and providing focus to visits with care team members.

Listening to Team Members and Working Together

Team collaboration within the LifeCourse project has included several things: involving team members in decisions about the model, allowing the team to self-manage their own development and process improvement, integrating time for team members to care for themselves, and acknowledging the unique position of team members within a research project. Each of these involves listening to team members and examining the kinds of expertise they bring. Throughout this process of team development, LifeCourse leaders have remained committed to understanding how best to recognize and use the various forms of expertise team members bring to the project.

Since the onset of LifeCourse, team members have been invited to be members of work groups for model development. The initial approach brought them into a typical health care project model, which was sometimes intimidating and overwhelming to care team members. Through extensive time commitments and structured team exercises, LifeCourse has since moved to an appreciative inquiry model by asking team members to inform the project through their expertise and experience with patients, their family members, and other providers. Managers learned how modes of communicating with team members shaped their participation. When tensions surfaced, managers found that structured exercises were often not as effective as opening up conversation and actively listening. In a project like this, where the goal is to innovate on existing models of care, it is possible to go too far in a single

direction and need to correct the course of the project. LifeCourse found that involving the team from the ground up was more successful than imposing changes from management without input.

Based upon the concepts described by studies of other teams, LifeCourse allowed space for the team to evolve and test how to provide ongoing feedback to each other, supporting individual growth and team development plans.³⁶⁻³⁸ Improvements in team functioning came as a product of team processes to identify issues and possible solutions. This differs from nonteam-based models, which typically rely on evaluation from a direct supervisor and directives for individuals to seek out external continuing education. Initially, a questionnaire designed to assess the functioning of the team was administered by the managers. Over time, managers realized allowing the team to manage the questionnaire process would be more productive and empowering to the team. The team now takes ownership of the process of evaluating the health and well-being of their own team, using and revising tools that fit their own definition of high functioning teams. The team comes together to review the results and discuss areas that score low to explore opportunities of growth. Additional supports for team development are identified and shared with the clinical manager, who then assists in finding tools and resources.

The LifeCourse model was also designed around improving the well-being of team members. Allowing for team members to develop and maintain self-care activities may support resiliency in team interactions and patient care. Ideally, as self-care activities permit care providers to better understand themselves, they also better prepare themselves for understanding the experiences of their patients. Each member of the team is allowed time each month to support self-care opportunities. Journaling, exercise, and reflection time are all activities that team members report as self-care. Spiritual reflection, led by the chaplain, is spent in reflection on existential suffering, meaning, presence, and healing. The marriage and family therapist leads a meeting every month to explore what it means to be in relationship with fellow team members. Finally, case consultation, drawing on the practice of supervision within counseling and social work, is used to help the team face emotionally challenging work during the course of their work with patients and their loved ones.

Bringing in the voices of the care team has been essential for model development, creating a team culture, directing the division of labor, and creating a feedback process that improves work and respects expertise of team members. Like other research has found, one of the most important things LifeCourse learned was that any high functioning team must include cross-understanding of other team members' roles and responsibilities, respect, and communication.^{17-19,38}

Discussion and Conclusion

Team-based care is becoming more common in health care settings. Although there is great enthusiasm for teams, little

research has explicitly outlined the kinds of questions one should ask as they attempt to develop a team. Effective teams are more than a group of effective individuals and require that organizations provide structures and develop cultures that support the team.³⁹ This article has summarized one attempt to form an innovative health care team, inspired by hospice and palliative care teams, but that moves beyond these to provide comprehensive care earlier in the trajectory of serious illness. By giving examples of the kinds of issues LifeCourse confronted, the decisions made, and lessons learned, we hope the preceding findings will be useful to others.

Moving to this type of care team was not without struggle. In particular, there were many tensions within the development of the care guide role. The most important contribution of the role is supporting an ongoing relational interaction with patients and family members. Many of the clinicians on the team also had a desire to have relationships with patients and families, creating a constant pull between what could/should be provided by a nonclinical lay professional, and what belonged to trained licensed professionals. Team member role redefinition sometimes pushed against conventional professional practices, codes of ethics, and clinical guidelines. When lines between clinical practice and lay practice are relaxed, one must be aware of potential harm that may come to both patients and care providers. Understanding this potential within a team seeking to redefine roles remains a point of tension within LifeCourse. Using a system of team problem solving and drawing on extant resources, managers approached this issue by first setting boundaries of what one could not do. Over time, the team has continued to refine these limits using standard professional boundaries for health care workers as a starting point, but with full knowledge that professional boundary practices in the social and behavioral disciplines will also be used to refine the role.

As the team grows and seeks to serve more patients, the approach must also adjust. This is especially true as LifeCourse experiences tensions between the innovations present in the team and the expectations of the larger health care system. Transitioning from a hierarchical structure to team-based care, using a nonclinical care guide challenges care as usual. Additionally, as the model grows, it is expected that lay care guides may also integrate into existing teams, instead of forming a new team in each setting. Because the current team is part of a grant-funded research project, the future LifeCourse team may also shift as the model adjusts to maximize sustainability. Efforts are currently underway to determine how this approach will be financially supported into the future. This revision of the model will require LifeCourse to revisit some of the questions discussed here. Lessons learned through this intervention highlight issues often left hidden in the process of designing, hiring, training, and working with health care teams. This knowledge is necessary for determining when and how teams may be useful for health care.

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