Patient and Caregiver Experience with Care: Early Results from the LifeCourse Intervention

Nathan Shippee, MS, PhD[1]; Tetyana Shippee, MS, PhD[1]; Karl Fernstrom, MPH[2]; Cindy Cain, MA, PhD[1,2]; Alissa Jones, MA[2]; Heather Britt, MPH, PhD[2]
[1]Division of Health Policy and Management, University of Minnesota School of Public Health; [2]Division of Applied Research, Allina Health

LIFECOURSE

- Builds upon an expanded set of palliative care domains to promote whole person care
- Uses a family-oriented approach to understand needs, leverage strengths, and empower families to effectively support their loved ones
- Asks patients and caregivers to articulate individualized goals and take part in decision making
- Includes a trained lay healthcare worker as the primary contact across settings and over time

BACKGROUND

Patient experience is a standard health care measure, payment criterion, and pillar in the healthcare Triple Aim. Existing experience measures of chronic care are not particularly useful in understanding or protecting patients and their caregivers in later life.

RESEARCH OBJECTIVE

We assessed experience in LifeCourse, a late-life supportive care intervention, using a new experience tool for patients and caregivers.

DATA

- Intervention sample to date with baseline and six-month data included 373 heart failure, cancer, and dementia patients receiving their healthcare through a large urban health system in the upper Midwest, and 434 caregivers. Usual care included 201 patients and 163 caregivers.
- Experience was assessed quantitatively through quarterly administration of a 30-item tool built to study guiding principles as sub-domains, and overall ratings for care and support. (Table 1)
- Qualitative data come from patient and caregiver interviews.

ANALYSIS

This is a mixed-methods study of initial data from a quasi-experiment assessing LifeCourse versus usual care. We compared change from baseline to six months in the intervention group versus usual care, and used qualitative data to better understand patterns.

FINDINGS

Intervention patients trended toward greater improvements in all subdomains and overall care and support ratings, compared to those in usual care.

- Linear regression results, controlling for baseline levels, trended toward better experience over time for LifeCourse in all but one domain, though only one domain ("unanswered questions") was significant in these initial six-month data. Baseline level was significant in all models (Table 2).
- Qualitative analyses revealed that patients had positive experiences with LifeCourse, and value healthcare providers who solicit and listen to their concerns and provide ongoing support (Table 3).

Findings were more mixed for caregivers.

- Regression results showed caregivers in LifeCourse had better experience than the usual care group in 4 of 6 domains. "Unanswered Questions" and overall support ratings were marginally lower in the usual care group compared to intervention patients after six months (Table 4).

Table 1. LifeCourse patient and caregiver experience domains

Domain	Conceptual Definition
Know Me/Listen to Me	
Repeat Myself	Care team listens and integrates medical and non-medical information
Personal[a]	Care team understands personal circumstances and priorities, helping with those circumstances and priorities in mind
Guide Me	
Goals[a]	Patient defined goals of care are relevant and understood
Unanswered Questions	Questions about health, daily functioning, and how to proceed are answered
Frustration	Frustration from confusion over advice, providers, and care
Choice[a]	Care team supported patient centered choices and helped to make right decision
Respect Me	
Trust[a]	Care team respected patient, centering on individual goals and establishing trust
Support Me	
Time	Care team was available and spent adequate time with patients and caregivers
Care Team[b]	Care team focused expectations, supported, and included the caregiver in the goals of care
Social / Emotional[b]	Caregiver has appropriate social and emotional support

a. Subdomain only assessed among patients; b. Subdomain only assessed among caregivers

Table 2. Patient experience baseline to 6 month change score models

Domain	No. Intv.	No. Usual Care	Beta	95% CI	P-Value	Adj. R² (%)
Repeat Myself	114	85	-0.35	-0.85, 0.15	0.171	10.1
Personal	106	76	-0.31	-0.80, 0.18	0.213	18.7
Goals	105	84	-0.39	-0.86, 0.08	0.100	13.4
Unanswered Questions	109	77	-0.34	-0.62, -0.06	0.018	4.3
Frustration	116	91	0.14	-0.17, 0.45	0.375	4.8
Choice	92	71	-0.26	-0.92, 0.41	0.446	23.1
Trust	114	89	-0.32	-0.66, 0.02	0.067	28.8
Time	115	92	-0.19	-0.57, 0.19	0.327	26.7
Global – Care	123	97	-0.28	-0.67, 0.10	0.151	23.9
Global – Support	122	98	-0.53	-0.92, -0.14	0.008	23.9
Patient Experience Total	80	70	-2.32	-4.55, -0.09	0.041	40.9

Table 3. LifeCourse patient experience domains qualitative findings

Quote
"After they put me on blood thinners and I was trying to cut my toenails, I cut too deep and couldn't stop the bleeding and went to the emergency room, where it took them 2 ½ hours to stop the bleeding, and [my careguide] put me in touch with people who will cut my toenails for me and can see where they're working and have the right tools and won't cut me [laughs], and things like that. And she has made calls and made arrangements for me for various things... I knew that there were some nurses who were kind of moonlighting and coming to people's homes to do that, but she helped me identify who they were."   – DB, cancer and heart failure, age 95, with LC 17 months
"My care guide helped me link things, Uh-huh, things that were disparate now were joined or connected so that I could make a better connection with them. You know, you have loose facts floating around out here, and you don't need them until sometimes, you think, 'What was that?' And so it's good to learn and keep learning and keep learning and keep learning, because there's always something new that comes up."   – JS, dementia, age 90, with LC 14 months
"I think [our Doctor] probably would have mentioned a lot of these things even without the LifeCourse, but it was emphasized again with LifeCourse. It kind of sets your mind at ease, being prepared. Preparation is a good part of it, and knowing what she can and can't do."   – JL, spouse diagnosed with heart failure and cancer, age 73, with LC 12 ½ months

Table 4. Caregiver experience baseline to 6 month change score models

Domain	No. Intv.	No. Usual Care	Beta	95% CI	P-Value	Adj. R² (%)
Repeat Myself	67	33	-0.47	-1.15, 0.22	0.179	27.9
Unanswered Questions	77	37	-0.59	-1.24, 0.07	0.079	36.6
Frustration	78	42	0.58	-0.20, 1.35	0.144	20.9
Time	63	38	-0.32	-1.10, 0.45	0.408	32.1
Care Team Support	76	38	0.06	-0.73, 0.84	0.885	22.4
Social/ Emotional Support	105	61	-0.38	-0.84, 0.08	0.107	48.9
Global – Care	126	65	-0.02	-0.54, 0.50	0.931	19.5
Global – Support	120	63	-0.40	-0.90, 0.09	0.112	13.3
KFF Experience Total	45	27	0.46	-3.01, 3.93	0.791	28.4

CONCLUSIONS

Experience scores trended toward more positive trends for LifeCourse than for comparison patients (though without significance in most domains by six months), though the patterns were slightly more consistent for patients than caregivers, reflecting potential benefits of LifeCourse and challenges to engaging caregivers. We look to longer follow-up and other components of assessment to further test the benefits of LifeCourse. Care delivery and experience tools oriented toward ongoing relationships and later-life care for complex patients may allow for meaningful assessment and better understanding of goals for integrating and streamline care.