Patient and Caregiver Quality of Life:
Early Results from the LifeCourse Intervention

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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

Quality of life (QOL) refers to an individual's self-reported physical, psychological, and social well-being.

QOL for patients with multiple chronic conditions at the end of life is a serious concern among policymakers, consumers, and family members due to this population's:

- deteriorated health, changes in role expectations, and problems with care coordination
- poorer clinical outcomes and higher use of services and medications
- implications of QOL for payment and policy initiatives

RESEARCH OBJECTIVE

This study investigates whether participation in LifeCourse provides better QOL for late life patients with chronic conditions and their caregivers compared to usual care controls.

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.

Measures

QOL is measured quarterly, using standardized, validated instruments.
- Patient QOL: FACIT-PAL to assess physical, social/family, emotional, and functional wellbeing, and palliative care.
- Caregiver QOL: PROMIS-29 to address physical function, anxiety, depression, fatigue, sleep disturbance, satisfaction with social role, and pain interference.
- Patient and caregiver qualitative interviews about their QOL

ANALYSIS

Mixed methods approach, consisting of adjusted change score models for QOL, supplemented by qualitative data analysis. Change in QOL indicators was modeled between baseline and 6 months among LifeCourse enrollees and usual care patients.

FINDINGS

- Stability in QOL for LifeCourse patients versus negative change for usual care
- Improvements for LifeCourse patients in emotional and palliative care subscales (Table 1)
- Interviews provide examples of how LifeCourse participants experience a positive impact across all subscales (Table 2)
- Marginal positive scores for caregivers enrolled in the LifeCourse intervention compared to usual care controls, including improved scores for anxiety and physical function subscales, and the global health item (Table 3)

Table 1. Patient quality of life baseline to 6 month change score models

Domain	No. Intv.	No. Usual Care	Beta	95% CI	P-Value	Adj. R² (%)
Physical Wellbeing	166	97	-0.17	-1.35, 1.01	0.779	41.7
Social Wellbeing	153	92	-0.92	-1.99, 0.14	0.089	48.0
Emotional Wellbeing	158	92	-0.99	-1.95, -0.03	0.044	40.8
Functional Wellbeing	158	92	-0.86	-2.11, 0.39	0.177	48.6
Palliative Care	166	99	-2.19	-4.33, -0.05	0.045	54.5
FACIT-PAL Total	139	85	-4.62	-9.20, -0.03	0.048	62.5

Crude models adjusted for baseline domain scores. Treatment group was coded dichotomously with the intervention group in the reference category. Confounders were variables that changed the crude beta for treatment by more than 10%. Confounding was controlled for through adjustment in regression models as appropriate. Variables considered as confounders were age, gender, diagnosis, comorbidity score, marital status, level of education, race, location, death after enrollment, proxy consent, and an indicator for Pioneer/ACO assignment.

Table 2. Patient quality of life qualitative findings

Domain	Quote
Physical	"I have the congestive heart failure which slowed me down because of the shortness of breath. [My care guide] just gave me encouragement because I...made up my mind I'm going to do what I want...the doctor told me to lose weight and I had gained weight. But I started to lose, and she just kept giving me encouragement that way." – NN, heart failure, age 77, with LC 16 months
Social	"Talking about end of life issues? You don't talk about it, husband and wife. It's like, if I would ever say anything about senior living, [my husband] would change the subject... [our care guide] has brought us into facing the reality of the possibilities and has helped [our family] realize more that we do have to deal with these issues." – AD, husband diagnosed with heart failure, age 85, with LC for 9 ½ months
Emotional	"It is an important part of healthcare, because the person who is sad or anxious or worried or hurt is not very healthy. Those emotional aspects intertwine with the other things that are the facts. I think you guys are doing a great job, and I think this study is going to be very valuable. People think they know what old people like, and sometimes they don't." – JS, dementia and cancer, age 90, with LC for 9 ½ months
Functional	"I think it's made me a lot more alert to not only my situation, but also [my wife's]. She's also 85, so we both know that we have limitations." – JD, heart failure, age 85, with LC for 9 ½ months
Palliative	"I would have been afraid to question my cardiologist about it, because if they say you should do it, you do it. Because of [my care guide], I am able to say 'why do I need to do it?' and actually feel like I had some control over my treatment." – JB, heart failure, age 58, with LC 17 months
Overall	"I love you all to pieces...I found that somebody cared about how I was doing each day. It has incredibly changed everything. It has changed, as I said before, the way the doctors treat me. It has changed so many pieces of the puzzle. It has changed the fact that I was alone here, and everybody was so busy." – BK, heart failure, age 76, with LC 10½ months

Table 3. Caregiver quality of life baseline to 6 month change score models

Domain	No. Intv.	No. Usual Care	Beta	95% CI	P-Value	Adj. R² (%)
Lower scores better						
Anxiety	170	82	1.63	-0.44, 3.70	0.122	38.9
Depression	174	81	0.22	-1.57, 2.01	0.808	38.6
Fatigue	171	78	0.28	-1.88, 2.44	0.797	38.8
Sleep Disturbance	169	79	0.33	-1.36, 2.02	0.703	41.7
Pain Interference	170	79	-0.31	-2.23, 1.61	0.754	44.6
Global – Pain	161	72	0.18	-0.34, 0.69	0.499	42.3
Higher scores better						
Physical	174	82	-0.91	-2.29, 0.47	0.197	67.7
Social	168	79	-0.23	-2.55, 2.09	0.846	26.5
Global – Health	167	79	-0.21	-0.39, -0.03	0.024	50.4
Global – QOL	167	78	-0.06	-0.26, 0.14	0.564	47.9

Crude models adjusted for baseline domain scores. Treatment group was coded dichotomously with the intervention group in the reference category. Confounders were variables that changed the crude beta for treatment by more than 10%. Confounding was controlled for through adjustment in regression models as appropriate. Variables considered as confounders were age, gender, marital status, race, level of education, relationship type, cohabitation with patient, and frequency of contact with patient.

CONCLUSIONS

- LifeCourse helped maintain stability or even improve some QOL domains. This is notable because late life patients face declining health and their caregivers often have high caregiving burden.
- LifeCourse assessments of patient and caregiver QOL meet a need for vital information about patient and family functioning and the role of health care delivery for whole-person care.
- Whole-person supportive care interventions like LifeCourse are a promising approach for patients and caregivers affected by complex chronic illness at the end of life.