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DEVELOPING PATIENT-CENTERED CARE EVALUATION IN A LONG-TERM GERIATRIC CARE SETTING

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ABSTRACT

This paper proposes an evaluation model that assesses quality of care from a patient-centered care (PCC) perspective by incorporating the PCC concepts of empowerment, dignity, and respect, to determine whether the standard of care meets patient expectations and to gain a sense of quality of life measures from the perspective of the patient. It begins with a review of the core concepts of PCC and develops a general model of patient-centered care evaluation. A case study of a long-term care geriatric PACE organization is utilized as a means to illustrate an assessment of an organization's PCC evaluability and evaluation efforts. This assessment is followed by the construction of a PCC evaluation framework that includes an example logic model, a set of indicators, and data collection methods and procedures that are based on PCC principles. The paper concludes with recommendations that are made to improve the organization's capacity to conduct PCC evaluations.

Keywords: evaluation, geriatric care, patient-centered, patient satisfaction

INTRODUCTION

Healthcare providers are increasingly concerned with not just improving physical and mental health, but providing interventions that lead to outcomes in which the patient perceives an improvement in overall quality of life. This comes from the position that, if after an intervention has been implemented a patient does not see an overall improvement in his or her quality of life, one might question whether the intervention was worthwhile. This is due to the fact that patients might have different priorities as they weigh the costs and benefits of participating in certain treatment regimens.

This paper proposes an evaluation model that assesses quality of care from a patient-centered care (PCC) perspective by incorporating the PCC concepts of empowerment, dignity, and respect, to determine whether the standard of care meets patient expectations and to gain a sense of quality of life measures from the perspective of the patient. It begins with a review of the core concepts of PCC and develops a general model of patient-centered care evaluation. A case study of LifeCircles, a long-term care geriatric PACE organization is utilized as a means to illustrate an assessment of an organization's PCC evaluability and evaluation efforts. This assessment is followed by the construction of a PCC evaluation framework that includes an example logic model, a set of indicators, and data collection methods and procedures that are based on PCC principles. The paper concludes with recommendations that are made to improve LifeCircles' capacity to conduct PCC evaluations.

Patient-centered Care: Theory, Concepts, and Benefits

Patient-centered care (PCC) has emerged as a conceptual model of health care delivery that is distinguished from traditional disease-oriented health care models in its emphasis on holistic practice and its focus on insuring that healthcare decisions respect the perspectives, needs, values, and priorities of the patient (Robinson, Callister, Berry, & Dearing, 2008). PCC attempts to treat the person as a whole, placing importance on understanding the physical, psychological, emotional, and social status of the patient and incorporating this understanding into health intervention planning. A higher priority is placed

on the provider-patient relationship over the tasks of a clinical agenda, and the goal of PCC is to enable the healthcare provider to develop individualized treatment plans based on the contexts within which each person's ailments or dysfunctions occur (Edvardsson, Winbland & Sandman, 2008; Galland, 2006).

A core element of PCC is the concept of shared decision making, in which patients are given the information and education such that they are empowered to make informed decisions about their healthcare in collaboration with trained medical professionals (Irwin & Richardson, 2006). This requires that the healthcare organization develop partnerships between patients, their families, and medical practitioners such that all relevant information is shared, and the patient has an opportunity to participate actively in negotiating treatment goals and interventions. These goals are given priority and are at the center of assessment, intervention, and evaluation, as the provider listens to and respects patient's values while adapting interventions to meet patient's needs, as distinct from merely providing diagnostic services (Robinson et al, 2008).

Implicit in the PCC model is the requirement that patient care be culturally sensitive, accepts a patient's perspectives and way of being, makes the client feel valued and content, and preserves his or her sense of dignity (Tucker, Herman, Ferdinand, Bailey, Lopez, Beato, Adams, & Cooper, 2011). This comes from the recognition that patients may differ in the priorities they assign to particular health conditions, which is largely dependent on cultural and social factors (Berry, et al, 2008; Davidson, Cockburn, Daly & Fisher, 2004). Respecting these priorities and allowing the patient to take part in the healthcare planning process results in better adherence to medical regimens and improved self-care (Galland, 2006; Tucker, et al, 2007; Irwin & Richardson, 2004). PCC takes a distinct role in long-term geriatric care, where family members or caregivers often play a larger role in the care of the patient and there is a risk of losing a sense of the personhood of a client in cases of degenerative cognitive diseases, such as Alzheimer's Disease and dementia, and thus their perspectives should also be taken into account during healthcare planning (Miller, 1997).

Patient-centered care has many associated benefits, and has been shown to improve health communication, increase patient self-care and adherence to treatment regimens, improve continuity of care, and increase patient satisfaction (Irwin & Richardson, 2006, Tucker et al, 2007; Myers, 1998, Robinson et al, 2008). In some cases, increased adherence can lead to improved clinical outcomes and functional statuses (Galland, 2006; Tucker et al, 2007; Sidani, 2008). PCC also has organizational benefits, as it can empower staff members improve physician performance, and increase patient retention (Myers, 1998; Irwin & Richardson, 2006).

Patient-centered Care Evaluation: Measurement Concepts

In long-term care, measurement of patient quality of life is an important indicator of the performance of the healthcare provider. However, "quality of life" is by nature subjectively defined, and it can be difficult to capture. Traditional methods of assessing quality of life are typically a measurement of physical and mental health outcomes combined with psychosocial indicators (Tucker et al, 2007). Some sense of the healthcare provider's performance can be captured through quality of life measures of health status and outcomes, but in cases of long-term care when patients face degenerative conditions and diseases, this may not be an appropriate measure as health conditions will not see improvement. For this reason, the expectations, satisfaction, and adherence to mutually agreed-upon medical regimens are better measures of program performance than health outcomes. Ultimately, patient perception is the most reliable measure of patient-centeredness (Robinson et al, 2008).

The key to assessing an organization's performance in a long-term care setting is to measure how well the organization adapts programs to meet individual needs and styles, and the degree to which it is successful in empowering patients to increase their self-care. Patient-defined needs and expectations are central to the assessment of quality of care (Redman & Lynn, 2005), and patient satisfaction is an important indicator (Hush, Cameron, & Mackey, 2011). The process of healthcare service delivery and the interaction with staff are correlative with satisfaction measures (Hush, Cameron, & Mackey, 2011), and satisfaction is theorized to directly relate to adherence (Tucker et al, 2007; Sofaer & Firminger,

2005). However, relying on global satisfaction surveys alone is problematic for several reasons. First, satisfaction is a relative concept and thus satisfaction measures are unreliable, as reported levels of satisfaction may vary from person to person, may be dependent on the individual's health conditions, and may vary depending on the method of measurement (Redman & Lynn, 2005; Hush, Cameron, & Mackey, 2011).

Second, global satisfaction surveys provide limited information, as they require patients to think back about several different care experiences and generalize a rating for all of them, when in fact there may have been great variation in satisfaction among particular care experiences (Redman & Lynn, 2005; Sofaer & Firminger, 2005). At best, global satisfaction surveys should be combined with other methods of measurement, such as event-specific surveys, interviews, or focus groups to provide a deeper understanding of patient satisfaction levels. Research emphasizes that measurements of patient-centeredness must reflect a patient's effort to adhere to treatment plans and his or her desire to participate in decision-making (Robinson et al, 2008). Therefore, utilizing expectation theories to highlight the difference between what is expected on the part of the patient, and what occurs as a part of treatment and service delivery, is a better practice (Sofaer & Firminger, 2005).

Case Analysis: LifeCircles of Muskegon, Michigan

LifeCircles of Muskegon, Michigan was selected as a case study for an analysis of patient-centered care in a geriatric setting. Personal interviews with program staff and management were conducted in conjunction with a review of the organization's financial statements, quality improvement plans, data collection instruments, and internal documents related to quality assessment and improvement in an effort to assess organizational readiness and evaluability of the Program for All-inclusive Care for the Elderly at LifeCircles of Muskegon, Michigan. A review of the literature on patient-centered philosophy, evaluation models, and methodology informed the construction of an evaluation model centered on the psychosocial aspects of patient perceptions and quality of life.

History, Mission and Values

The Program for All-inclusive Care for the Elderly (PACE) was designed with the purpose of providing family, caregivers, and professional health care providers the flexibility to meet the health care needs of the elderly while helping them to continue living in the community instead of meeting their needs through institutional care (National PACE Association [PACE], 2010). As such, PACE embodies PCC principles and is designed to be a one-stop shop for all health care services, offering a comprehensive service package emphasizing preventative care, and any services not offered by the PACE provider are coordinated through care plan management with contracted providers. PACE coordinates care across disciplines through individualized care plans, with a holistic model that attempts to address the physical, mental, and psychosocial needs of its participants with the intention of improving quality of care and reducing costs.

LifeCircles is a PACE provider, and was given operational status in February 2009 to serve Muskegon and Ottawa counties in Michigan. The founding board members of LifeCircles identified a particular need for comprehensive services for the elderly in the Muskegon-Ottawa county area, since a disproportionate number of residents in this area are below the Federal poverty line (PACE, 2010), and the aging population was in need of coordinated medical care. To address these needs, LifeCircles was founded with a mission "to provide comprehensive, compassionate, and team-based care to the frail elderly in partnership with their families and caregivers in order to maximize independence and their quality of life", with the vision "to be recognized community-wide for consistently exceeding customer expectations through a smooth and effortless mode of service delivery". In part due to the particular socioeconomic characteristics and needs of residents in the Muskegon area, LifeCircles is currently one of the fastest growing PACE providers in the nation (LifeCircles, 2010).

Service Delivery Model

PACE organizations provide all the services of Medicare and Medicaid as well as additional medically necessary care and services not covered under these programs. These services include, but are not limited to the following:

- Prescription Drugs .
- Occupational therapy
- Home care
- Dental & eye care
- Nursing home care
- Adult day care
- Transportation
- Meals
- Daytime activities
- Nutrition counseling
- Physical therapy
- Social services
- Medical clinic
- Counseling
- Classes
- Caregiver & family support

PACE programs operate on integrated Medicare-Medicaid financing, and all Medicare-covered services are offered by the PACE provider and are paid for by Medicare. Participants who are eligible for Medicaid are not liable for any additional costs, while those who are not eligible for Medicaid pay monthly premiums equal to the Medicaid capitation rate. There are no types of deductibles, coinsurance, or other types of cost-sharing for any portion of the PACE program (LifeCircles, 2010). This payment structure is designed to provide participants with consistent, predictable expenditures, and also intends to provide quality care to those with limited incomes and savings. The global payment model that funds PACE providers is based on Medicare risk adjustment and capitation rates and is designed to encourage flexibility and creativity in service and health care delivery.

Major Sources of Support

Funding structures

LifeCircles was founded with the financial support and investment from three major equity partners who serve on its board of trustees: Porter Hills Retirement Communities and Services (PHRCS), Senior Resources of West Michigan (SRWM), and Mercy General Health Partners (MGHP). The primary funding stream for LifeCircles activities comes from capitated Medicare-Medicaid rates. Congress sets the capitated payment rates that are administered through the Centers for Medicaid and Medicare (CMS), and these rates are based on individual risk adjustment scores and reassessments. While it is a small portion of LifeCircles budget, small endowments are also given by past participants and are testimony to the impact that the program has had on some of its members.

Technical support and program resources

In addition to providing funding through capitated rates, CMS is also a major source for technical support. Evaluation team members found CMS staff to be very helpful and willing to answer questions and to give advice on programmatic and regulatory matters. The National PACE Association is also a major source of technical support, as it aggregates data from all PACE providers, provides information and support online, and holds conferences that disseminate information on benchmarks and best practices.

LifeCircles is housed within Tanglewood Park, a day center facility that houses three other organizations that serve the elderly population through coordinated programs: (1) Senior Resources, which identifies and harnesses community resources for the elderly in the community; (2) Agewell, which provides onsite classes, dietician services, day center meal, and meals on wheels services; and (3) 2-11, a resource hotline service. In addition to these organizations, there is an in-house Michigan Department of Human Services (DHS) worker whose duties are to streamline the intake approval process and renew

Medicaid benefits. All of the aforementioned organizations are independently funded and staffed, but have mutually beneficial relationships as they work together to serve the same population. Finally, LifeCircles also benefits from a healthy bank of volunteers who give their time to socialize with and facilitate conversations between participants to foster a sense of community, as well as assist in various functions related to activities in the day center.

Organizational Evaluability Assessment

An evaluability assessment is a method of assessing an organization's ability to conduct program evaluation. This assessment was conducted at the organizational level at LifeCircles and is based on data collected through personal interviews with members of senior management, evaluation and quality team staff and program staff, as well as an internal review of the organization's financial statements, quality improvement plans, data collection instruments, and internal documents related to quality assessment and improvement. The assessment was highly influenced by the Evaluation Capacity Building (ECB) framework provided by Boyle and Preskill (2008) and is based on factors of leadership, organizational culture and learning, the political environment, resources, structures, and current work on evaluation.

Leadership. Leadership is a critical aspect to evaluation implementation, as an effective leader manages the political environment, influences members to achieve common goals, and promotes a culture of learning. As defined by Alaimo (2008), a leader takes eight major action steps:

- (1) linking goals to the mission
- (2) prioritizing
- (3) planning
- (4) budgeting
- (5) driving
- (6) using results
- (7) realizing benefit
- (8) understanding.

On these fronts, the leadership (board and senior management) at LifeCircles is effective and is very supportive of evaluation efforts. The board is hands-on and is actively involved in decision-making, and quality management staff members have found board member's recommendations to be extremely useful. Quality assurance is a high priority, and time and space are provided for quality improvement planning in accordance with the organizational mission. The executive director (ED) has used community connections to hire talented staff members, and leverage resources. He has encouraged evaluation champions, places a high value on selecting the right staff and putting them in the right place, and sees himself as a facilitator and coach in helping staff make good team decisions. The ED maintains an open door policy to extend this coaching to all staff members.

Organizational Culture and Learning

Organizational culture is important to evaluation because it establishes congruence between values and operating norms (Alaimo, 2008). The culture at LifeCircles is very conducive to effective evaluation, as it emphasizes a team model in which staff members from all levels within the organization are encouraged to give input on quality improvement. Quality is stressed from a staff member's first day, as it is a component of every employee's basic training regimen. Regular morning meetings and posters throughout the center diffuse a culture of quality, and there are signs and posters in prominent locations that describe the importance of quality, value, and mission, and encourage staff participation and open dialogue. In interviews, it was found that staff members generally understand the importance of quality and evaluation measures. The organization holds a weekly staff meeting with a quality assurance and improvement educational piece included in each meeting, and there is one training each month that is open to all staff. Senior management emphasizes that mistakes and failures are opportunities for learning, not opportunities

to place blame. All of these factors create a culture of quality, promote continuous learning, and encourage all staff to vocalize their opinions.

The culture of LifeCircles is highly conducive to an effective evaluation and communication on quality issues. However, although quality is included in every employee's orientation, LifeCircles lacks a formalized training program that transfers knowledge of quality evaluation activities to a broader group of staff members. Currently, only the quality manager has in-depth knowledge and understanding of the regulations, requirements, and methods of data aggregation, and she bears nearly all of the responsibility for quality care plan development, implementation, and reporting. Second, there is a deficiency in training on existing data collection instruments, as some staff members report being unfamiliar with the protocol for specific quality instruments. There is also some lack of consistency in how grievances and satisfaction measures are implemented, analyzed and reported, which can have a significant impact on their validity and reliability. Third, there is a lack of a succession plan for key staff members, and at the time of this assessment, there was no long-term strategic plan outside of a pro forma that covers only financial goals. Finally, the formalized evaluation plan does not articulate long-term goals and outcome measures at the organizational level, and it does not match program activities to the organizational mission and vision in a formal logic model.

Political Environment

Although the senior management has indicated that there are some difficulties in communications with state-level administrators, it has found CMS staff to be extremely helpful and has been successful in managing the expectations and reporting requirements of external regulators. The senior management and board has also been very effective in harnessing community resources, evidence that the community is highly supportive of the PACE model and its program activities. LifeCircles also benefits from strong, positive relationships with its internal partners in Tanglewood Park and nurtures these relationships through regular communication, shared training, and facility-wide parties. The board does not interfere with day-to-day activities, but has a hands-on role in strategic development and planning and it regularly meets to assess the financial condition and program issues of LifeCircles. The executive director presents the Quality Assurance and Performance Improvement (QAPI) plan to the board annually for approval, and the board assumes final authority and responsibility for ensuring that adequate resources are committed to quality improvement efforts and that a culture that supports continuous improvements is instilled in the organization.

Resources

LifeCircles has a stable and relatively consistent funding stream through Medicare and Medicaid capitation rates, and there are adequate financial resources for evaluation practices. However, evaluation funding is spread throughout administration costs in the budget, and there are no funding sources specifically dedicated to evaluation. LifeCircles enjoys the support from the National PACE Association, its Region V PACE affiliates, and CMS, which constitute communities of practice and share best practices. There is also a healthy connection between LifeCircles and a local community college's medical records management program, as the quality manager at LifeCircles is an instructor in that program. The quality manager has been able to select students from among her classes to create a successful joint internship program.

LifeCircles has limited staff who are trained in evaluation methods, however. The quality manager is the only staff member with an understanding of the regulations, reporting requirements, and methods of evaluation, and her duties are broad. At present, personnel resources for records management, data collection, analysis, and reporting are limited. The organization also lacks a comprehensive information management system that limits the organization's ability to aggregate and analyze evaluation indicators and outcomes measures.

Structures

LifeCircles has an organizational structure that is conducive to conducting effective evaluations. Its board provides oversight over the senior management team and finance committee, which provide leadership for major organizational initiatives. There are also committees that are unique to the PACE model that aid communication, quality assessment, and evaluation sustainability:

- *Senior Management Team* – composed of the executive director, medical director, center manager, quality assurance manager, and other representatives as necessary to review QAPI program initiatives and reports and provide oversight for implementation of changes in quality improvement measures.
- *Interdisciplinary Team (IDT)* – composed of medical and clinical staff, social workers, recreational therapists, home care coordinators, and other program staff to design, implement, and assess an individualized care plan for each participant.
- *Quality Assurance (QA) Committee* – is composed of a mix of medical and clinical staff, social workers, program staff, and the quality manager to meet monthly to discuss quality issues and to design an annual Quality Assessment and Performance Improvement (QAPI) plan.
- *Participant Advisory Committee (PAC)* – a rotating panel of participants that is facilitated as a focus group to elicit concerns, comments, and feedback from participants in the program.
- *Ad Hoc Committees* – organized to address particular issues and quality concerns and are composed of members relevant to the defined issue, including safety, pharmacy quality, and immunizations.

The various committees provide adequate space and opportunity for communication and serve as feedback mechanisms. They frequently utilize root cause analysis, flow-charting, fishbone diagrams, and other analytical tools to define issues. The minutes of all committees are recorded and are shared with the board on a regular basis and are used to inform decision-making at all levels of the organization.

Current Evaluation Work

LifeCircles is required to collect and report data on a wide range of measures to its regulators on the state and federal level. Senior management members and quality assurance members, however, find the data collected for reporting to be a resource drain and a small fraction of the measures are deemed useful for decision-making purposes. Current data collection includes a number of measures on: demographics, in-home service statistics, hospital and medical care utilization statistics, preventive medical services, pharmacy activity, immunizations, enrollments, incidents, deaths, participant satisfaction, participant grievances, and other specific medical conditions.

Most of the data is reported for compliance and financial purposes, while little is used to address whether the program has an impact on the quality of life of LifeCircles participants. This is driven by the state and federal regulatory bodies under a Pay for Performance plan (P4P), which provides capitated payments linked to efficiency measures and risk adjustment. This global capitation-based payment system encourages LifeCircles to maintain accurate records and to issue standardized reports, but it does not require additional quality outcome measures or evaluation work.

Each year the quality assurance committee develops a Quality Assessment and Performance Improvement Plan (QAPI). The 2011 plan identifies the quality evaluation benchmark indicators and data collection measures divided into functional categories, as seen in Table 1. The QAPI plan also identifies clinical outcome measures of importance, including: (1) physiological and clinical well-being; (2) functional status data; (3) cognitive functioning data; (4) emotional/mental health; (5) participant welfare and safety; and (6) medical adherence.

In addition to the evaluation framework outlined in the QAPI plan, an IDT composed of staff members appropriate to the needs assigned to a participant completes individual care plans at intake. These care plans identify and set goals in communication with the participants and are designed to be a holistic and

comprehensive health care plan that covers the physical, mental, and psychosocial needs of the participant. Each member of the IDT identifies specific objectives within his or her area of discipline for each goal and plans of measurement for each functional category. Care plans are reassessed at regular intervals to determine the level of progress made toward the identified goals, which is communicated to the participant and his or her caregiver, and their feedback is incorporated into the set of goals identified for the updated care plan.

Table 1: LifeCircles QAPI

<p>Service Utilization</p> <ul style="list-style-type: none"> • Indicators: hospitalization admissions and length of stay, emergency room visits, nursing home placements, rehabilitation services, psychiatric services, day center services, outpatient services • Data collection methods: ongoing medical records and utilization of data review <p>Caregiver and Participant Satisfaction</p> <ul style="list-style-type: none"> • Indicators: caregiver and participant self-reported satisfaction • Data collection methods: annual satisfaction survey <p>Nutritional Services</p> <ul style="list-style-type: none"> • Indicators: weight gain/loss, nutritional risk • Data collection methods: medical records review <p>End of Life</p> <ul style="list-style-type: none"> • Indicators: number of participants with signed advanced directives on file • Data collection methods: medical records review <p>Home Environment</p> <ul style="list-style-type: none"> • Indicators: structural barriers that limit mobility, safety hazards, sanitation hazards, telephone access, assistive devices that are present or needed in the home • Data collection methods: initial and semiannual reassessment of structural barriers by home care staff <p>Occupational, Recreational & Physical Therapies</p> <ul style="list-style-type: none"> • Indicators: mobility, functioning, motor skills • Data collection methods: initial and bi-annual reassessment by physical therapy staff <p>Social Work</p> <ul style="list-style-type: none"> • Indicators: participant self-reported satisfaction with interaction and contact, self-rated quality of life, depression, cognitive functioning, frequency of behavior problems • Data collection methods: informal interviews conducted by social work staff, Geriatric Depression Scale, Mini-mental Status Examination (MMSE)
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The care plans are a comprehensive outline of participant goals and incorporate appropriate measures for objectives defined in functional categories by medical discipline. They also adequately capture participant expectations and utilize shared decision-making between program staff, participants, and caregivers in the setting of healthcare goals. However, there is some inconsistency in the language used to identify objectives, and some objectives lack specific, measurable outcomes, which can lead to inconsistencies and make reassessment difficult. The organization also does not aggregate individual goals for analysis at the program level, and it does not use quantitative analysis or summary reporting for global physical, mental, and psychosocial health indicators.

LifeCircles also conducts ongoing grievance reporting, an annual participant satisfaction survey, and regular focus group PAC meetings. The results of each of these measures are aggregated and shared with staff members through prepared reports and staff meetings. However, grievance collection procedures lack consistency, which could result in under-reporting. Satisfaction surveys, as a global data collection

measure, fail to provide concrete measures of satisfaction around particular events, and are limited in their analysis for the reasons cited in the literature above. Finally, the PAC meetings, which are run as a focus group, could be enhanced with structured topics that draw attention to issues that emerge through grievances, complaints, and satisfaction results.

Summary of Evaluability Assessment

LifeCircles has the proper leadership, structures, resources, tools, and learning environment that are conducive to effective program evaluation. It currently uses appropriate data collection methods such as medical records, patient care plans, focus groups, interviews, and other assessment tools and methods as part of an effort to make data-driven decisions. However, as outlined in the preceding sections, there are some areas that could be improved to enhance its data collection, analysis and reporting. A summary table of the findings, in terms of strengths and weaknesses, is included in Table 2.

Table 2: Evaluation Strengths and Weaknesses

<u>Strengths</u>	<u>Areas for Improvement</u>
<ul style="list-style-type: none"> • <i>Solid structures for evaluation and quality improvements</i> • <i>Leadership and culture committed to continuous quality improvement</i> • <i>Involvement in quality improvement at all organizational levels</i> • <i>Use of analytic tools</i> • <i>Good use of local brain trust and knowledge of development through internship programs</i> • <i>Use of benchmark data to guide decisions</i> • <i>Use of patient feedback for quality improvement</i> • <i>Relevant performance data can be obtained at reasonable cost</i> • <i>High staff competency and resources for evaluation plan implementation</i> 	<ul style="list-style-type: none"> • <i>Capturing patient expectations, satisfaction and grievances</i> • <i>Tracking, aggregating & reporting participant goals and outcomes</i> • <i>Lack of standardized care plan language, improve specific and measurable goals, objectives and indicators</i> • <i>Limited quality improvement & evaluation personnel</i> • <i>Consistency in data collection, analysis, reporting, dissemination of program evaluation measures</i> • <i>Standardized training on evaluation and data collection instruments</i> • <i>Information management systems</i> • <i>No financial resources specifically dedicated to quality improvement & evaluation</i> •

Patient-centered Care Evaluation Framework

The State of Michigan, CMS, and PACE regulations include reporting requirements on a host of indicators. Some of these indicators may not be deemed important by staff for the purposes of program evaluation and quality improvement, but there is danger in treating data collection and reporting as a chore—it can often lead to disregarding information that could help inform decision-making. What is important is to identify and focus on indicators and outcome measures that are considered useful by program staff, can serve as measures of program performance, and serve to enhance organizational knowledge. The following section outlines a framework for patient-centered care evaluation that is designed to serve these functions, and includes a program logic model, measurable indicators, and data collection methods.

Logic model

The patient-centered care logic model was designed in collaboration with senior management and various program staff and in reference to the literature on PCC. The model was constructed by first identifying an overarching set of goals and objectives that became the basis for the **impact** section of the logic model. Second, **outcome** measures were defined based on factors that contribute to long-term impact. Third, **activities** provided by LifeCircles that have the potential to contribute to the desired outcomes were identified. Finally, the **resources** available to implement the program activities were defined. Each of these components of the logic model is depicted in Table 3 below.

Table 3: Program Logic Model

Resources	Activities	Outcomes	Impact
<ul style="list-style-type: none"> • Funding (Medicaid, Medicare, donations, equity partners) • 2 partner organizations <ul style="list-style-type: none"> • Pioneer resources (transportation) • AgeWell (food, classes) • Staff (bus drivers, CNAs, RNs, doctors, PT, OT, MSWs, rec therapists) • Day center facility • Volunteers (help in day center) • Committed family members & caretakers • Other positive & motivated participants 	<ul style="list-style-type: none"> • Provide transportation • Provide a day center for gathering, eating, socializing and reducing responsibility for caregiver • Provide group activities (arts & crafts, outings, puzzles & games, music, physical exercises, group meals) • Mediate and facilitate social interaction (introducing new participants, pair participants with similar interest, encourage buddy system) • Encourage participants to take responsibilities at the day center (buddy system, small tasks, leading singing groups & activities) • Actively engage family and participants, help facilitate dialogue with doctors & medical staff • Create collaborative health goals with medical staff, patients, and caregivers • Provide support for caregivers (validate concerns, timely answers to questions, provide social support) • Provide literature and classes on medical & personal health topics • Hold independent & group classes (internet, arts classes, etc.) (Teach new skills) 	<ul style="list-style-type: none"> • Participant Outcomes <ul style="list-style-type: none"> • Decreased loneliness • Feel more appreciated and respected • Improved communication between participant, staff, providers caregiver, others • More informed about healthcare and personal health condition • Improved understanding of patient rights • Improved mood • Improved cognition • Reduced stress • Become more active and engage in more group activities • Make more friends/develop more relationships • Caregiver/Family Outcomes <ul style="list-style-type: none"> • Reduced stress – relief of caregiving responsibility 	<ul style="list-style-type: none"> • Participant Impact <ul style="list-style-type: none"> • Better social network for addressing issues • Less behavioral and emotional problems • Improved capacity to make life decisions • Feel empowered to make independent decisions, become more vocal about personal needs, desires, and interests • Quality of care better meets participant needs • Gain a sense of purpose • Improved relationship with caregiver/family • Greater adherence to care plan • Caregiver/Family Impact <ul style="list-style-type: none"> • Feels empowered • Improved relationship with participant • Greater knowledge of participant health issues • Improved mood • Organizational Impact <ul style="list-style-type: none"> • Improved community image • Decreased disenrollment

Indicators

A set of indicators was identified from outcomes identified in the program logic model. These indicators, seen in Table 4, serve the basis of the program outcome measures and were defined at three points of data collection and measurement: (1) participant level; (2) caregiver/family level; and (3) staff level. Data on these indicators can be collected through a mixture of quantitative and qualitative methods.

Table 4: Selected Patient-Centered Care Indicators

Participant Level	Caregiver Level	Staff Level
<ul style="list-style-type: none"> ✓ Attendance at day center on scheduled days ✓ Number of activities participants engaged in per scheduled day <p>Participant reported:</p> <ul style="list-style-type: none"> ✓ Depression scale score ✓ Grievances ✓ Loneliness ✓ Level of feeling appreciated and respected ✓ Level of effective communication – with staff, providers, caregiver, others ✓ Level informed about healthcare and personal health condition ✓ Level of understanding of patient rights ✓ Quality of friendships and relationships ✓ Level of social network for addressing issues ✓ Capacity and level of feeling empowered to make independent life decisions ✓ Perception of quality of care meeting needs ✓ Level of having a role in developing care plan ✓ Sense of purpose ✓ Relationship status with caregiver 	<p>Caregiver reported:</p> <ul style="list-style-type: none"> ✓ Caregiver stress scale ✓ Observed participant’s capacity to make life decisions ✓ Participant level of vocalizing personal needs, desires, and interests ✓ Supportive network for addressing issues ✓ Participant behavioral and emotional problems (depression, etc.) ✓ Relationship status with caregiver ✓ Level of communication – with participant, staff, providers, caregiver, others 	<p>Staff observed:</p> <ul style="list-style-type: none"> ✓ Participant’s capacity to make life decisions and level of independence ✓ Participant acclimation to social setting ✓ Participant level of vocalizing personal needs, desires, and interests ✓ Participants adherence to healthcare regimen

Data Collection Tools, Methods, and Analysis

Quantitative survey instruments can be used to gather data on participant perceptions, satisfaction, cognitive and emotional status, and grievances, and can also gather data on caregiver/family perceptions and stress levels. However, Quantitative data only tells half of the story. In order to interpret the numbers form quantitative data sets, more information about the population is required. Qualitative methods complement quantitative methods by gathering additional data on participant and caregiver defined issues, perceptions, and communications, as well as to identify staff perceptions as they relate to individual participants. These methods, used in conjunction with quantitative measures are an integral part of a dynamic evaluation system that can be adapted to emergent issues. The specific methods and instruments used to collect this data with suggested data collection procedures are listed below.

Quantitative Methods

Individualized Care Plans

The first step in developing an individual care plan is to elicit the concerns, mental and physical statuses, history, and expectations of the participant. Participant expectations, physical, mental, and social outcomes, and staff perceptions can then be monitored through detailed documentation in each participant's care plan, which is documented during intake and reassessment periods and is updated on an ongoing basis. Care plans should incorporate standard language that identifies patient-defined goals and objectives, with indicators that follow SMART guidelines: specific, measurable, achievable, realistic, and time bound. A standardized coding system can be used to track common themes, concerns, and expressed issues for the purpose of identifying trends at the global level, while reassessments are an opportunity to compare patient-defined goals with progress toward outcomes. If goals are not met at the individual level, it is important to note the reason that they were not attained: whether it was due to a worsened health condition that made the goal unattainable; it was not a realistic goal; or whether the participant did not adhere to the medical intervention regimen. This information should be used to guide the design and implementation of the next care planning cycle. Causes for failure to attain goals can also be integrated into a global evaluation as a means of identifying trends and weaknesses in intervention methods.

Psychosocial Instruments

These instruments, which include the Geriatric Depression Scale (GDS), the Mini Mental Score Examination (MMSE), and the Caregiver Stress Index, can be conducted at intake and at regular intervals as deemed appropriate by mental health professionals and ideally can serve as pre-and post-test measures for a participant's cognitive and emotional status. Scores generated from these instruments can be aggregated at the individual level to determine changes in particular participants and caregivers, and can also be aggregated at the global population level for the purpose of conducting trend analysis.

Participant Satisfaction Surveys

This is a measure of global satisfaction levels, and can be an indication of overall program performance. This instrument can be conducted beginning at the end of the first year of enrollment, and can be aggregated at the total population level for the purpose of conducting trend analysis.

Discrete Event Surveys

These brief surveys can be conducted with participants and caregivers shortly after particular services have been delivered. The survey captures the degree to which the service delivery matched patient expectations and respected his or her values, beliefs, and sense of dignity. Data collected from this method can be categorized by type of service and can be aggregated and analyzed at the global level, while also informing the care and service delivery for the particular participant.

Qualitative Methods

Grievance Reporting

Grievance reports are a means for gaining information about specific program weaknesses and are an opportunity for participants to feel that their opinions are valued. They should be collected on an ongoing basis from participants immediately after intake. It is important that participants are educated and aware of the grievance process and that staff members regularly solicit grievance reports as issues arise. Grievance reports can be aggregated and analyzed for common themes and trends and should inform the Continuous Quality Improvement (CQI) process. A grievance committee is recommended to bring multiple perspectives and objectivity to the analysis of particular complaints, grievances, and appeals.

Focus Groups

Focus groups can allow the organization to learn more about participant and caregiver concerns in a comfortable environment that encourages open discussion. LifeCircles can take advantage of the regulatory requirement to facilitate the PAC and by utilizing this mechanism as a focus group, where participants are asked to speak openly about emergent issues and topics of concern. Participants should be actively recruited and there should be a practice of rotating in different participants on an ongoing basis, both to gain insight from multiple perspectives, and to communicate to participants that their opinions are valued. Caregivers could also be recruited to serve on the separate focus group, and incentives can be provided to encourage participation. The PAC and caregiver meetings, while left open-ended in terms of voicing opinions and concerns, should be guided with a structured agenda containing focused questions on particular topics or issues of importance, but space will be provided to discuss any additional items not included in a particular meeting's agenda. Specific focus group topics can be developed from issues identified in interviews, satisfaction surveys, or other sources of data in an effort to explore particular issues in greater detail. A standardized coding system should be used to track common themes, concerns, and expressed issues for the purpose of identifying trends.

Semi-structured Interviews

Interviews can collect highly detailed and specific information centered on particular topics or themes. An interview protocol can be developed to conduct standardized interviews that contain a mixture of closed and open-ended questions and can be updated and adapted to collect information on emergent issues. Specific interview questions can be developed from issues identified in focus groups, satisfaction surveys, or other sources of data in an effort to explore particular issues in greater detail. A standardized coding system should be used to code common themes, concerns, and expressed issues for the purpose of identifying trends around particular issues.

Vignettes

Personal narratives given by participants and caregivers can be recorded through direct interviews by LifeCircles staff. With permission, these stories will be published and distributed to staff, caregivers, and other community members as illustrations of the impact the LifeCircles program has had on individual lives. As personal testimonies, these narratives can bring positive attention to the organization from the community and can aid the development of a culture of care in which staff members take pride in their work and are increasingly motivated upon seeing positive, tangible outcomes of their work.

Analysis and Reporting

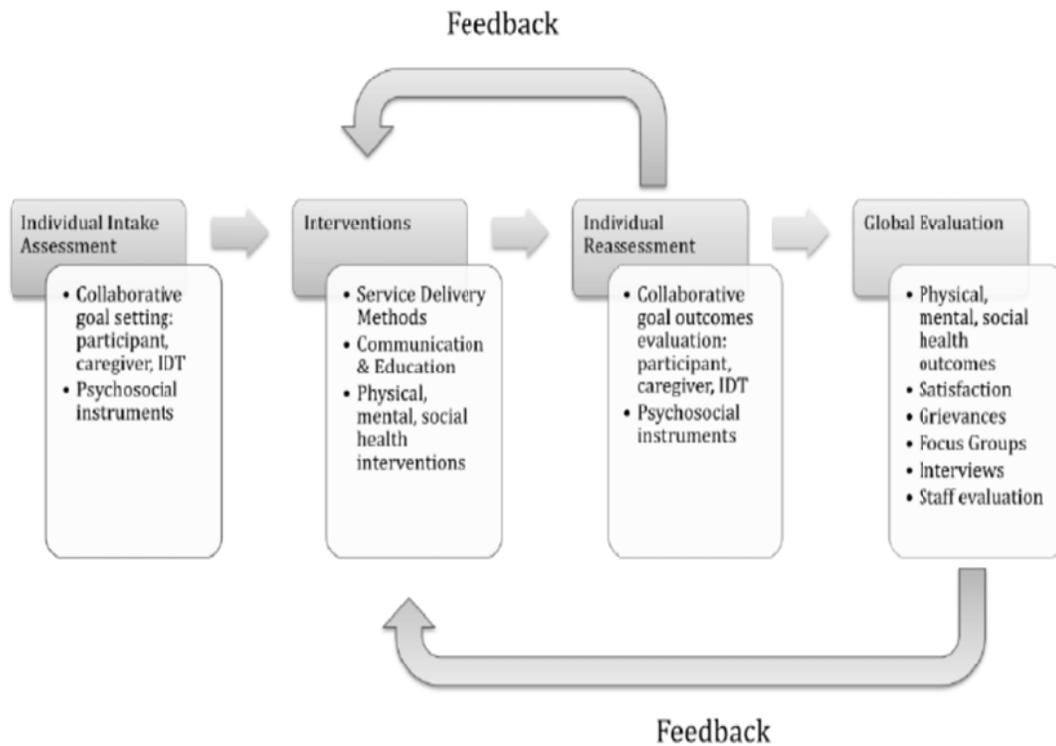
With all data collection methods, it is important that the information obtained is well documented and disseminated to staff members in an effort to stimulate organizational learning. Emergent trends should be identified early and used to inform staff about relevant changes that can be made in communications, documentation or interventions to make program and service delivery improvements. This information should be analyzed both at the individual and the global level in order to distinguish changes that could be made to service delivery for individual participants and changes that could be made in overall program activities. Identified issues can be explored more in-depth through the use of interviews, focus groups, and ad hoc committees. What is most important is that evaluation methods seek to draw data from multiple sources using a variety of quantitative and qualitative methods in an effort to converge information into a meaningful whole by closing feedback loops. The following evaluation framework, seen in Figure 2, is an outline of the evaluation methods and their capacity to inform program improvement.

Action Steps for Moving Forward

The evaluation framework outlined in the previous section can be seen as a set of recommendations in the form of a template that can be modified and adjusted to fit the needs of the organization. However, in

order to maximize the evaluation's effectiveness and impact on quality improvement, staff and management should first come to an agreement on which measures are most relevant, important, and useful for these purposes. Second, organization members must agree on a clear understanding of how evaluation information can be used and how it can inform their specific duties and activities.

Figure 2: Evaluation Framework



These crucial steps of consensus building will improve the likelihood that data is utilized to inform practices. In addition, the following action steps can be incorporated into the evaluation to insure that it remains efficient, informative, and sustainable:

- Link outcome measures to current geriatric health care theory and literature
- Conduct a cross-walk analysis on data collection instruments to insure that all indicators are captured
- Establish clear data collection protocols, standardized data collection instruments, and formalize training for consistent reporting
- Utilize different evaluation methods to triangulate outcome measures.
- Continually revisit and update instruments and outcome measures as needed to reflect the concerns of participants and staff
- Actively recruit caregivers to participate in focus group discussion and provide incentives if needed

Evaluation Capacity Building Recommendations

Evaluation capacity building (ECB) is a means to enhance an organization's ability to conduct effective evaluations through the development of skills, tools, and resources. In order to implement a patient-centered evaluation plan that is informative, effective, and sustainable, LifeCircles could take the following action steps to build evaluation capacity in the organization:

- Develop a clear long-term strategic plan and create logic models for all program areas
- Dedicate financial resources for evaluation and quality improvement
- Expand the evaluation staff, divide responsibilities of the quality manager, and transfer knowledge among a greater number of team members through cross-function training
- Develop clear succession plans for key staff members
- Develop a database and improved technological infrastructure to facilitate better documentation and data aggregation
- Disseminate evaluation results and educate program staff, participants, caregivers, and concerned community members

Implementation of these action steps can insure that the LifeCircles program can meet the core ECB objectives of generating knowledge, developing skills, and making evaluation relevant to the organization (Boyle & Preskill, 2008).

CONCLUSION

This paper used recent research on patient-centered care to inform an evaluation design for a geriatric care setting. LifeCircles serves as an excellent example of a case analysis of an organization that has all of the right resources, tools, and culture to implement quality patient-centered evaluation. The key to any effective evaluation is not to reinvent the wheel, but to utilize the structures and data collection methods that are already in place. With careful thought, planning, staff buy-in, and proper use of resources, patient-centered concepts can be incorporated into an evaluation model in an effort to measure organizational performance in regards to its ability to respect the needs, values, and dignity of a participant while also achieving program objectives of increasing a patient's quality of life. It is important to recognize the uniqueness of each organization, its patient population, and the scope of services provided, which can make comparisons between organizations ineffective (Myers, 1998). However, with the use of a model such as the one proposed in this paper, effective evaluation can be tailored to the organization to help a healthcare organization to harness both the patient and organizational benefits of PCC.

Future research could be conducted on the reliability and validity of specific instruments and evaluation models designed to capture data on patient satisfaction, expectations, and outcome measures within the patient-centered care context. As new research, better instruments, and refined data collection techniques are developed, practitioners of patient-centered care can incorporate the findings of new research to continue to develop the program evaluation model.

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