

Special Article – Family Caregivers

Routinely Engaging Caregivers to Understand their Experience and Outcome with the PATH Program

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Incorporating the caregiver experience is vital for improving care delivery within the patient-provider dyad. The Palliative and Therapeutic Harmonization (PATH) model is a clinical approach that prioritizes the consideration of frailty when making treatment decisions. Using comprehensive assessment tools to appreciate the full scope of frailty, the program provides guidance to frail older adults and their families as they navigate complex medical decisions and consider the appropriateness of proposed interventions. As caregiver involvement is an instrumental component of the program, we set out to understand the caregiver experience of the program using six-month follow-up phone calls that were implemented as a revised standard of care and quality assurance to expand program evaluation efforts. Feedback from 32 randomized caregivers offered insight into their personal experience of the PATH process and reinforced the importance of ongoing dialogue following difficult decision-making and times of transition. Despite varying degrees of satisfaction with PATH program services, all 32 caregivers confirmed that they would recommend PATH to any individual in the position of caring for a frail, elderly family member. Important themes emerged from the survey that will be integrated into future PATH program standards of care and aid in the development of materials and guidelines that can support caregivers as they take on the role of substitute decision-maker.

Keywords: Caregiver; Evaluation; Satisfaction; Decision-making; Communication; Care planning**Introduction**

The concept of “patient-centered care” has effectively restructured the care dynamic in which medical treatment and decision-making is facilitated. Paternalistic medical systems have been criticized for using outdated approaches that lack bidirectional dialogue and underemphasize evidence-informed guidelines [1-3]. While modern approaches to bioethics [4-6] focus on patient autonomy, caregivers may also play an active role in directing care decisions [7,8]. Inviting caregivers to join the conversation can be mutually beneficial for providers in terms of obtaining collateral histories, appointing substitute decision-makers, carrying out medical directives, and evaluating services from an additional perspective. This collaborative relationship between caregivers and providers could we provide a citation to the other article we have published in this issue (the editorial Moorhouse P et al.) may be especially valuable in situations where the patient lacks capacity or to the medical scenario involves complex, interacting health conditions (also known as frailty).

The Palliative and Therapeutic Harmonization (PATH) model was designed to support frail older adults and their caregivers facing complex medical decisions. Focused on aligning care with prognosis [9,10], the program proceeds in 4 ordered tasks: (1) assemble pertinent health information to refine an individualized understanding of the patient's frailty; (2) ensure shared understanding of the prognostic significance of frailty between clinician and decision maker(s); (3) foster decision making skills within patients, and families/caregivers; and (4) respond to patient health crises as they arise using navigated

decision making. Previous studies have shown that the PATH process leads to more appropriate care, with one study demonstrating a 75% reduction in patient/family-led demand for medical in surgical procedures in those who are significantly frail [11]. Based on program referral criteria, the PATH patient population consists primarily of moderately frail individuals who are dealing with complex medical decisions (such as whether to pursue a surgical intervention) or severely frail older adults entering their final stages of life. Within the PATH patient population, there are high rates of previously diagnosed (25%) and newly diagnosed (32%) dementia. These characteristics necessitate a triadic model of communication between the patient, caregiver, and PATH physician across each clinical task: frailty assessment, communication, decisional skill building, and crisis management.

Quality assessment involves an evaluation framework that focuses on the effectiveness, efficiency, and optimality of a given service, which can be used to inform best practice in health care. In this study, we set out to understand the patient/caregiver experience of the PATH model [12,13]. However, due to the complex nature of health, social factors, and prevalent cognitive impairment in the PATH patient population, evaluation and quality assurance measures would be difficult to administer directly to patients and are often inappropriate. In such circumstances, caregivers can be targeted for evaluative activities as sources of health information and can act as proxy respondents for older patients with limited capacity [14,15]. Moreover, studies have shown that the experience and needs of those

who care for the frail elderly are frequently overlooked [16,17].

In the context of refining and expanding patient-centered care models, it is crucial that the caregiver experience – and the unique dynamics associated with adding a third participant to the traditional patient-participant dyad – be understood and evaluated. As part of an overall evaluation strategy for the PATH model, we therefore set out to understand the caregiver experience using an open-ended discussion format. Given its design, PATH represents an excellent opportunity by which to evaluate this essential, though often overlooked, component of patient-centered care delivery.

Methods

As a quality assurance initiative, PATH implemented a revised standard of care that includes a 6-month follow-up phone call with assenting caregivers. An outline of 18 semi-structured interview questions (related to patient care, caregiver experience, and overall satisfaction) was used as a conversation guide. Following a typical semi-structured format, the interview allowed for open-ended responses and the evaluator had freedom to vary the wording or question order to maintain conversational flow [18,19,20]. The tone and approach were kept informal, as the primary objective was to hear the participant story, rather than satisfy pre-specified data points. Call lists were generated for patients that were seen 6 to 18 months prior to the date of the phone call; this range was chosen to avoid incorrect recall and to allow time for emotional processing. Based on these criteria, 48 PATH caregivers were identified. Over a period of three months, 32 caregiver phone interviews were completed (16 were unreachable), each ranging between 45 minutes to 1 hour. Calls were not recorded, but responses to the structured questions and statements made during open-ended discussion were entered into a de-identified secure database. Thematic analysis and coding were completed using Atlas.ti 6.2 software.

Results

Sample population

The PATH patients associated with the caregiver participants were 59% male, with an average of 9 comorbidities. Caregiver respondents included spouses (19%), adult children (60%), and siblings (21%). Fifty-percent of caregivers cared for the PATH patient in the patient's home (50%), often with the support of homecare programs. Most caregivers (68%) also acted as the substitute decision-maker.

The primary reason for referral to the PATH program included: the need for a decision about whether to proceed with cardiac surgery (23%) and other medical/surgical procedures (32%); and general care planning unrelated to a pending procedure (45%). Seventy-eight percent of patients lacked capacity and 32% were newly diagnosed with dementia during their initial PATH assessment.

Patient outcomes

At completion of PATH, 66% of participants decided to forgo the proposed procedure or intervention. Thirty-eight percent of patients, who by standard criteria would be seen in the emergency department or admitted to hospital, avoided hospital admission through PATH follow-up care planning and crisis support. Respondents provided straightforward reports on the patient's functional ability, cognitive

status, symptom burden and health trajectory. Of the 32 patients, 14 had died in the follow-up period: 12 of whom had specified a preference with respect to location of death, four of these 12 died in their preferred location (which in every instance was at home). As expected, in severe frailty, respondents reported that PATH patients had suffered decline in functional status (63%) and cognition (69%) and that overall health had worsened (72%) since their last PATH appointment. Twenty-two percent of caregivers contacted PATH during a health crisis.

Caregiver experience

For the majority of the respondents, a sharp contrast was observed between the first and second half of the phone call; though some maintained a neutral attitude throughout. Generally, as the conversation turned toward the caregiver experience in the second half of the conversation, the stiffness of the question-response portion of the call diffused, and the caregivers relayed their own narrative with marked openness. Interestingly, caregiver accounts of specific episodes differed depending on whether they were reporting from the patient's point of view or their own; this reinforces the notion that the caregiver experience is unique from and cannot be reduced to the patient experience. Open-ended question probes found that 88% of respondents were satisfied with PATH services. Eighty percent felt positively about the PATH experience, 11% had negative associations with the PATH process and 9% were neutral. Caregiver respondents indicated that engaging a routine follow-up process designed specifically for caregivers was an opportunity for program improvement (50%). Other comments encouraged more support for family members taking on the responsibility of directing care as a proxy (23%). When asked if they would recommend the PATH program to other patients and caregivers in similar situations, 100% of respondents indicated that they would. Most respondents expressed gratitude for the opportunity to express their feelings about the PATH program, reporting that they had been eager, prior to the call, for a follow-up measure or platform in which to discuss their experiences. They spoke candidly about how PATH had affected them, and its influence on their patient family member, their decisions.

Three main themes emerged during data analysis: empowerment, information, and choice. Caregivers felt a strong sense of empowerment after being given the tools and skill set to direct the care of the patient. By building a trusting relationship with the PATH physician, caregivers gained confidence in their own ability to make decisions. The second broad theme was the enhanced ability for caregivers to make decisions, which was related to PATH's communication strategy. Caregivers acknowledged the importance of receiving information in a clear and frank manner. PATH communication gave caregivers the ability to weigh their options based on information about the status of their family member's health and what to expect in the future. Finally, the theme of choice seemed to resonate with respondents. Before the PATH interaction, nine families felt pressured to follow the advice of the attending specialist and were unaware that they had options to choose from.

An obligatory aspect of caregiving is the immense selflessness required for the prolonged, emotionally draining, and physically demanding work of caring for a frail family member. Accordingly, many caregivers described that they appreciated the opportunity to

discuss their experience (as opposed to only patient's), relieving them of the duty of acting as the proxy voice of the patient for the duration of the call. When caregivers discussed their own experience, common themes emerged:

- Caregiver support during times of decision-making can influence the caregiver experience and empowers them to take pride in their ability to choose the best options for their family member.
- Clearly identifying the title, purpose and plan behind any referral based health care service like PATH can help caregivers better understand why they were referred and could avoid confusion during future health system encounters.
- Despite varying individual experiences, each caregiver respondent said that they would recommend the PATH program to someone else in their position (caring for a frail, elderly patient).
- The caregiver voice should be an integral and ongoing part of any health care service that strives to deliver patient and family-centered care. Follow-up contact demonstrates a commitment to the family of the patient in question and allows the caregiver to vocalize their feedback and discuss important questions that have arisen since program completion.

Valuable suggestions were put forth that caregivers needed more assistance in coordinating care between groups such as home nursing vs home care services wanted more follow-up and home visits, and earlier referrals to PATH so families could make decisions in advance, when possible. Several respondents wanted specialists to continue to follow the patient, despite their choice to forgo active treatment. Families indicated that feeling supported in their decisions was of central importance, and wanted assurance that PATH would be there throughout the health trajectory to assist with navigating services in the future.

Conclusion

The model described here offered important insights into the 'third-leg' of the patient-provider dyad. Following intense emotional experiences, caregivers deserve the opportunity to express their personal experience and process of decision-making. In these situations, the personal narrative can help define the impact of a dedicated health care service, like PATH. Moving forward, the PATH program will continue to implement the practice of issuing follow-up phone calls to consenting caregivers at 6-month intervals and will strive to integrate their constructive feedback into overall program improvement and quality assurance.

Several learning opportunities presented themselves over the course of the follow-up call period. Though specific in some ways to the PATH program, these observations nonetheless offer some generalizable lessons for incorporating the caregiver experience in care delivery. As it was sometimes difficult to contact caregivers, collecting updated caregiver contact information should be part of standard consent form processes. Families should be reminded that the PATH program needs updated information when the address or phone number changes following PATH completion. More focus on promotion of the PATH program, as well as explanation regarding the referral process would be helpful for potential patients and their families. A surprising finding was that caregivers wanted to

be contacted and respondents were pleased to receive the follow-up phone call. Ultimately, the caregiver voice, whether relaying positive or negative experiences (or some combination of the two) were grateful to be heard; listening to it, additionally, will be important for improving care delivery in the future.

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