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Care Act

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Abstract

Background and Objectives: As our population continues to age and experience chronic conditions, family caregivers become increasingly critical to our long-term care system. The Caregiver Advise, Record, and Enable (CARE) Act was designed to support caregivers and care recipients. To date, no direct guidance has been provided to healthcare systems on how to best implement the law. The objective of this study was to describe how a large healthcare system is acting on what was learned from the CARE Act implementation study.

Research Design and Methods: We conducted a follow-up cross-sectional questionnaire that expands on a larger mixed methods CARE Act implementation study (Blinded for Review). The questionnaire was developed based on the Plan-Do-Study-Act (PDSA) Cycle. Responses were analyzed using a directed content approach.

Results: Responses indicate the need to restart the PDSA Cycle. Plans for improving implementation were informed by three key lessons

a. collaboration can have unexpected benefits

b. broaden communication and instruction methods

c. adapt coordination processes

Discussion and Implications: Healthcare systems that plan to or are in the process of implementing the CARE Act would benefit from partnerships, multiple communication channels, and standardizing workflow and documentation. These findings can help other healthcare systems shape models of care that aspire to include family caregivers in hospital care.

Translational Significance: Lessons learned from a large academic medical center on systematic collaboration, communication, and coordination are shared to help health systems and providers improve their systematic inclusion of family caregivers in routine care.

Keywords: Quality improvement; Healthcare policy; Hospitals; Caregiving

Introduction

As our population continues to age and experience more chronic conditions, family caregivers become increasingly critical to our long-term care system and achievement of the Triple Aim [1]. The AARP recognized the need to improve caregiver support and has championed passage of the Caregiver Advise, Record, and Enable (CARE) Act. These state laws require hospitals to

a. provide patients the opportunity to identify and record the name of a caregiver

b. inform the caregiver when discharge is to occur

c. provide the caregiver with instruction of medical tasks to be performed in the home [2].

Only five years after this healthcare policy was introduced, nearly 40 states have enacted the CARE Act. This shift towards family-centered care signifies not only the important role caregivers play in the daily lives of their loved ones, but also in helping health systems achieve the Triple Aim. Despite the enactment of the CARE Act across the United States, no guidance has been provided to hospital systems on how to best implement the law's primary components.

Implementation and translational science have encouraged partnership models to overcome policy constraints [3]. Evidence suggests that healthcare improvements can occur more rapidly within a supportive, collaborative context designed to share information [4]. In addition to enhancing communication efforts, collaborative partnerships excel when they encompass diverse members with complementary skills [3]. Likewise, the success of the implemented innovation depends on the quality of the health system's leadership. Visible administrative and clinical leadership helps to reinforce essential support of the policy [5]. Based on this information, several factors may contribute to improvement in implementation; however, little is known about the strategies that hospital systems are using to encourage use of the CARE Act tenets.

Best practices in implementation science and the Plan-Do-Study-Act (PDSA) Cycle [6] give us the structure to examine uptake of the CARE Act following its 2016 passing in the Commonwealth of Pennsylvania. For the present study, we referred to the final step of the Plan-PDSA Cycle. We chose to focus on this quality improvement model step to help advance knowledge and improve application of the CARE Act. Accordingly, the following research question was asked:

What modifications were identified as needing attention to improve CARE Act implementation?

Methods

We conducted a follow-up cross-sectional questionnaire to expand on the larger mixed methods CARE Act implementation study that had been previously reported (Blinded for Review). Approval from the academic medical center's Quality Improvement Review Board was obtained prior to collecting and analyzing data.

Data Collection

Prior to developing a questionnaire, the first two authors met and reviewed step four of the PDSA Cycle to guide item construction (see Appendix for questionnaire). Open-ended items concentrated on exploring what lessons were learned from the CARE Act implementation study and strategies for making improvements. Once these items were finalized, the first author invited a member of the implementation study team, the Director of Patient Education and Shared Decision Making, via email to complete the questionnaire within the month.

Appendix

Name	
Title	
Date	
Purpose of Project	To describe how a large healthcare system is acting on what was learned from the CARE Act implementation study.

Questions:

1) What do you consider your largest lessons learned or the most important findings from the CARE Act implementation study?
    a. What results are you encouraged by?
    b. What results did you identify as potential opportunities for improvement?
2) Can you tell us about modifications that are being discussed (or are being planned for discussion) within 'Blinded for Review' due to the CARE Act Implementation study? \
    a. How are you prioritizing next steps?
    b. Will you use a process improvement method (e.g. PDSA, Lean, Six Sigma)? If so, which one and why?
    c. Who are the key stakeholders? Are there new individuals from the initial CARE Act implementation team? If so, who joined the team and why?
3) From a system perspective, what factors may influence (positive or negative) any modifications to improve implementation of the CARE Act components?

4) From a clinical perspective, what factors may influence (positive or negative) any modifications to improve implementation of the CARE Act components?

5) Using the table below, in which of the recommendation areas do you think you will be able to make the greatest improvements?
    a. Which will have the largest impact on changes in clinical practice?
        i. Why do you believe this?
    b. Which will have the largest impact on caregiver and patient outcomes?
        i. Why do you believe this?

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Data Analysis and Dependability

Questionnaire responses were saved as a Microsoft Word document for directed content analysis [7]. The first author mapped qualitative data onto the two courses of action proposed in step four of the PDSA Cycle: restart the cycle at the planning phase or discontinue the plan. For this brief report, we used the strategies of peer-debriefing and member-checking. Weekly peer-debriefings [7] were held among the first two authors to reach consensus and ensure consistent interpretation of the data.

Results

Responses reported from the Director indicate plans to restart the PDSA Cycle. Plans for modification to improve the implementation of the CARE Act into the large academic medical center were informed by three

key lessons

Lesson 1: Collaboration can have unexpected benefits.

We [academic medical center] are collecting data now at each hospital (30+) to have more scientific rigor to evaluating caregiver involvement. Working as a collaborative team that includes researchers has taught me personally how important it is to evaluate new processes in a scientific manner. Each hospital is reviewing documentation of 20 patients monthly to identify trends in CARE Act compliance.

We also identified additional stakeholders- local patient education champions. We knew it was important to have executive champions to launch the CARE Act from each impacted area (e.g., nursing, eRecord, admissions, care management) but once implemented, we learned it was more important to have the local patient education champions responsible for spreading the new procedures in their unit.

Lesson 2: Broaden communication and instruction methods.

Communication is challenging in large health systems so many methods must be used. Broad communication such as email/newsletters mixed with local unit-based champions that communicate via staff meetings or unit bulletin boards. It is critical to include “why” the Act is important; Compliance might be higher if staff knew how essential a caregiver present having is to patient outcomes.

We need to find ways to improve the instruction requirement of the CARE Act. We think there is potential to offer patients the opportunity to record the instruction delivery with their smartphone. For instance, sending teaching videos directly to patients and caregivers through email or text may help because many tasks have a visual component. It is better to be able to view tasks/skills again once home, especially prior to having to do them.

Lesson 3: Adapt coordination processes

It is critical to integrate a second person [caregiver] at the patient’s choosing and for that person to be present when the patient receives important self-care information. Operationally, it may be challenging to implement. We learned that staff include family during teaching who happen to be visiting the patient. But this may not be the designated caregiver who will help at home. We have meetings planned to discuss how to modify the documentation platform so that it reinforces the value of educating the person who was identified on admission prior to discharge.

Discussion

Our primary focus was to describe the lessons learned from a large academic medical center and future action to improve the CARE Act implementation. Systematic collaboration, communication, and coordination emerged as essential strategies.

Our study draws attention to the unique contributions of researchers, healthcare practitioners and administrators to positively influence implementation of laws like the CARE Act. Uniting the perspectives of these diverse members with complementary skills evokes “successful implementation and long-term sustainability” [8]. Gainforth, Latimer-Cheung, Athanasopoulos, Moore, and Ginis demonstrate that this type of partnership contributes to knowledge mobilization, or the “act of moving research results into the hands of research users” (p.1). Knowledge mobilization is important because it helps ensure that public policies in healthcare are evidence-based and accessible [9] noted that very few studies have elaborated on the process of building knowledge translation. While completing the PDSA Cycle, our team recognized the value of including local patient education champions to help “circulate information, encourage peers to adopt the innovation, arrange demonstrations, and orient staff to the innovation” [3]. Future research is needed to explore the specific strategies local patient education champions use to facilitate knowledge mobilization in various contexts.

Our findings underscored the use of multiple interpersonal communication channels in influencing the uptake of the CARE Act components. In particular, the Director noted that teaching videos coupled with other communication strategies would improve CARE Act compliance as well as care delivery. This finding is consistent with work by [3] that shared that interactive education and mass media together, promote positive behavior changes, such as practitioners providing instruction to caregivers prior to discharge, and caregivers fulfilling care responsibilities post-discharge. Future research is needed to examine the effect of these distinct communication channels on the Triple Aim components.

No other studies have examined the systematic workflow and documentation challenges associated with the CARE Act, but these challenges have been reported in other healthcare improvement projects [10,11]. Hospitals have historically provided care in a patient-centered manner, which may impede the integration of caregivers into workflow and discharge planning. Many prominent organizations, including the Institute of Medicine and the Institute for Healthcare Improvement, are endorsing a patient and family-centered model of geriatric hospital care [12,13]. Future research can build on our findings by developing and evaluating potential solutions to improve the workflow and documentation challenges that limit caregiver inclusion.

Strengths and Limitations

A strength of this study is the use of professionals with a variety of areas of expertise, as well as iterative planning and management for the successful use of the PDSA Cycle in helping shape the culture of the academic medical center. Despite these strengths, limitations exist. The small sample represents one director from the academic medical center. We did not include other directors primarily because they had a less significant role in the CARE Act implementation process.

Conclusion

This brief report represents actions that an academic medical center is taking in pursuit of more systematic caregiver inclusion in hospital care. Healthcare systems that plan to or are in the process of implementing the CARE Act would benefit from partnerships, multiple communication channels, and standardizing workflow and documentation. Simultaneously pursuing these system components are necessary for fulfillment of the Triple Aim.

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