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Caring for Family Caregivers: Perceptions of CARE Act Compliance and Implementation

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Abstract

Background: The Caregiver Advise, Record, Enable (CARE) Act encourages inclusion of family caregivers in the hospitalization process for patients. Translating the state laws into meaningful changes within the health care delivery system can be challenging and requires time. This study sought to examine early compliance with and implementation of the CARE Act reported by hospitals in the Commonwealth of Pennsylvania.

Methods: We sent an online survey to hospital executives in Pennsylvania in 2017. Descriptive statistics were computed to examine hospital characteristics and used to assess compliance and implementation of the CARE Act tenets.

Results: Most hospitals reported that changes have been and are being made to comply with the CARE Act (90.9%). Hospital executives reported that the family caregiver designation is available in 63.6% of the hospitals and notification of patient discharge is available in 45.5%. Hospital executives reported that family caregiver education and instruction is occurring in 31.8% of all inpatient stays. Hospital executives indicated that they are still developing processes to comply with the legislation and to integrate family caregivers into hospital systems and processes.

Conclusions: Our findings suggest that hospitals are complying with the legislation, while fully operationalizing the components of the CARE Act is a work in progress.

Keywords

family caregiver; health policy; hospital processes

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Nearly 18 million Americans are family caregivers of someone aged 65 years or older.[1] Family caregivers support their care recipients in self-care activities and caregiving tasks. These activities and tasks include personal care and hygiene, help with mobility, medication management, and medical advocacy. Family caregivers serve a critical role after hospitalization by helping their care recipients live at home and minimizing the need for costly long-term services and supports.[2,3] Many family caregivers are unpaid and engage in this role with limited or no health care training. Unfortunately, family caregivers have reported dissatisfaction with their involvement in hospital processes, and 93% reported a lack of training for their caregiving role.[4] Consequently, family caregivers have felt inadequate in their ability to assist their care recipients in the home.[5] Lack of family caregiver preparation is problematic, as it can contribute to caregiver burden. An extensive literature base indicates that burdened family caregivers have higher rates of morbidity, mortality, and increased resource use.[6] Conversely, the inclusion of family caregivers in hospital processes is beneficial for clinical staff because family caregivers can support the patients emotionally and with daily activities. Furthermore, family caregivers are considered beneficial for clinical staff when the family caregivers consult during decision-making processes.[7,8] Research further demonstrates this value by showing that the systematic inclusion of caregivers in hospital processes is associated with lower rates of patient rehospitalization.[9] In sum, research suggests that enhancing family caregiver integration in hospital processes may improve patient and family caregivers' outcomes, as well as curb health care expenditure.

A national movement aimed at passing legislation that catalyzes family caregiver involvement in hospitals and other health care facilities is occurring. To date, 40 states have passed a Caregiver Advise, Record, Enable (CARE) Act. Across the states, the CARE Act laws are similar and require identification of family caregivers and provision of instructions to the family caregivers about assisting their care recipients with self-care activities and complex caregiving tasks in the home.[10] The tenets of the legislation include (1) providing patients an opportunity to designate a family caregiver, (2) notifying family caregivers when the patients are being discharged from health care facilities, and (3) educating and instructing family caregivers on the patients' needs, including self-care activities and caregiving tasks that will be required of them when they return home.[10]

However, translating state laws or best evidence into meaningful changes within the health care delivery system can be challenging and requires time, especially as identifying and engaging family caregivers can be an issue.[9,11] The CARE Act is not tied to reimbursement. The incentives are regulatory compliance and improving patient outcomes. Health care facilities are asked to provide education and instruction to family caregivers, ensuring that family caregivers are equipped to provide care in the home. Adequately prepared family caregivers can benefit the hospital, however, through a reduction in readmission rates.[9] As with any new legislation, it is critical to understand compliance and implementation of these laws within hospitals to determine how the laws might need to be altered to ensure optimal patient and hospital outcomes. This may include testing methods of compliance. Ultimately, an enhanced understanding of the law may inform the types of tools that hospitals use to effectively implement the laws for best outcomes.

To this end, we surveyed executives at hospitals within the Commonwealth of Pennsylvania, which enacted the CARE Act in 2017.[12] We surveyed the executives to describe the (1) hospitals' perceptions of the CARE Act benefits, (2) compliance with the CARE Act, and (3) implementation of the CARE Act. To understand the perceived benefits, we examined which persons or entities hospital executives thought would benefit from the CARE Act. For compliance, we assessed changes undertaken by the hospitals to meet the legislation's requirements. Finally, we evaluated implementation by examining the perception that the changes being made are always followed.

METHODS

We conducted our analysis with data collected from the Discharge Planning: Involvement of Caregivers survey distributed from August to October 2017, shortly after the CARE Act took effect in the Commonwealth of Pennsylvania. It consisted of 66 questions developed by an interprofessional clinical and health services research team. The survey took approximately 20 minutes to complete. Informed consent was confirmed electronically through a description of the research and survey, and data were secured through Qualtrics. Only qualified members of the research team had access to the data. All procedures were approved by the University of Pittsburgh Institutional Review Board.

Our team collaborated with The Hospital and Healthsystem Association of Pennsylvania (HAP) to generate a statewide sample and distribute the survey to hospital executives responsible for quality and compliance. Our sample included 117 executives, each from unique facilities, who were designated as being responsible for quality and compliance. Our convenience sample was selected to provide perspective on the structures and processes generated for compliance and implementation for the CARE Act. The executives represent hospitals participating in HAP's Hospital Improvement Innovation Network. The HAP included the open, online Qualtrics survey link in its August 2017 HIINformation Exchange newsletter and followed up with 2 e-mail reminders for voluntary survey completion by the hospital executives. We used 2 methods to ensure unique responses from a health care facility. We checked IP addresses to ensure only 1 response per location, and we looked for duplication in hospital bed size and type.

Measures

Researchers created question sets that measured discharge planning practices, patient and family caregiver engagement, and hospital characteristics. To measure discharge planning practices, we used the valid and reliable Discharge Planning of Ward Nurses instrument and a survey designed for critical care nurses.[13,14] We supplemented these items with patient and family caregiver engagement survey questions informed by evidence-based and best practice transitions of care models.[15–18] Hospital characteristics questions were structured to match the categories used by the American Hospital Association.[19] Refinement of the survey was completed with input by stakeholders, including hospital executives, health care policy experts, and family caregiving experts. Refinement was completed prior to dissemination of the survey through HAP.

Specific to the CARE Act, hospital executives were asked about the benefits of the legislation, the actions being undertaken by the hospital to engage family caregivers, and barriers experienced with the ongoing implementation. To understand the perceived benefits of the CARE Act, we examined who hospital executives thought would benefit from the CARE Act, including patients, family caregivers, clinical staff, hospitals, or the community. Compliance was defined as whether required changes had been undertaken by the hospitals to meet the legislation's requirements. Implementation was defined as the perception that the changes made were being followed. Compliance and implementation for the CARE Act included the following 3 components: (1) the patient can identify a family caregiver, (2) family caregivers are notified of discharge, and (3) family caregivers receive education and instruction on the patient's needs, including self-care activities and caregiving tasks that will be required of them when they return home. The interprofessional research team developed the final question set around these 3 components. Free text was an option throughout the survey for respondents to indicate their specific actions or plans. Respondents were able to review and change their answers by use of a back button.

Statistical analysis

No statistical corrections were used to weight items or responses. We analyzed surveys with complete data to answer the research questions related to who will benefit, compliance, and implementation. Researchers summarized results using Stata 15.0 (Version 15.0, StataCorp, College Station, Texas). We computed descriptive statistics to examine characteristics of hospitals that initiated and completed the survey. We summarized the variation of compliance and implementation based on free-text responses. No formal qualitative methods were employed because of the limited number of free text responses, preventing qualitative data saturation.

RESULTS

Forty-nine hospital executives began the survey (41.9%). Twenty-two (19%) executives completed the survey. Those who completed the survey primarily represented not-for-profit, community-based, non-teaching hospitals that were affiliated with a larger system of health care facilities (Table 1). All participants reported knowing about Pennsylvania's CARE Act (N = 22).

Respondents reported that patients (n = 13) and family caregivers (n = 12) will benefit from the CARE Act a great deal. Fewer reported that clinical staff (n = 4), hospitals (n = 5), or the community (n = 5) would benefit to that extent (Table 1).

Approximately two-thirds suggested that they created a field in the patient admission report where the patient can identify his or her family caregiver in the patient's medical record. Less than half of respondents indicated that their hospitals had made alterations for the other 2 CARE Act components. Respondents provided free text descriptions that demonstrated compliance with the CARE Act requirements. One respondent stated that they, "added a field in our electronic record to capture the family caregiver information and added a section to the education field to document discharge education provided."

In addition, 36.4% of respondents are still developing processes to comply with the legislation. This percentage includes hospitals that already had made some changes. Two respondents indicated intentions for continued development and quality improvement initiatives, despite already making modifications to comply with the 3 CARE Act requirements. Another 2 respondents were not anticipating that they would make any changes due to the CARE Act. Of the respondents who had made changes, 92.9% reported that the changes were done specifically to comply with the new legislation and otherwise would not have occurred. Nearly all of respondents (92.9%) specified that the changes made by their hospital were not drastic and did not require large overhauls to current processes.

The respondents indicated that implementation of the CARE Act is “a process.” They were asked about the current frequency at which the activities of the CARE Act are occurring across all their patients. The results in Table 2 show that many respondents indicated that family caregivers are always identified upon admission and are notified of the discharge plans, whereas fewer reported that family caregiver education and instruction for caregiving tasks always occurs. Family caregiver education and instruction most often occurs in the form of in-person discussion (n = 14, 63.6%) or written materials (n = 8, 36.4%).

Half believe that there have been positive changes in family caregiver engagement at their hospital as a direct result of the CARE Act or feel that the CARE Act formalized the role of the family caregiver during the discharge planning process. Respondents reported that implementation will require flexibility and changes over time. One respondent noted,

> Caregivers change throughout the hospital stay. The person identified at the time of admission may not be the person who will provide care at the time of discharge. All of this is often dependent on the care needs of the patients and how extensive those needs become during hospitalization. This is a fluid process.

More than 80% of respondents indicated that future quality improvement initiatives to better include family caregivers in the discharge process were likely to occur.

DISCUSSION

The components of the CARE Act are meant to ensure that family caregivers are instructed on their care recipients’ needs before transitioning from the hospital to home. Our findings suggest that in the Commonwealth of Pennsylvania, hospital executives reported that (1) patients and family caregivers will benefit more than clinical staff, hospitals, or the community from the CARE Act, (2) changes have or are being made to comply with CARE Act requirements, and (3) implementation of the law is and will continue be a work in progress. These findings show that processes and structures have begun to be altered to address the gap between the care recipient’s needs after hospitalization and family caregivers’ preparation to assist their care recipient. The value in shrinking the gap aligns with research that demonstrates that few family caregivers report being trained in hospitals, but trained family caregivers may improve outcomes.[4,9] Several important insights warrant further discussion to inform policies and processes that hospitals across the nation can use to implement the CARE Act.

First, hospital executives reported thinking that patients and family caregivers will benefit from the CARE Act legislation, but few reported thinking that the clinical staff, hospital, or community will benefit. The acknowledgment that patients and family caregivers will benefit from the CARE Act suggests that the value of the CARE Act to family caregivers is recognized. This finding corroborates previous study findings that show that family caregivers are critical to patient outcomes and need to be well trained prior to discharge from the health care system.[2,3,5,6] On the other hand, fewer respondents felt that clinical staff, hospitals, or communities will benefit from the CARE Act. Appropriate structures and processes will be important to ensure that the CARE Act benefits clinical staff, hospitals, or communities. The clinical staff has limited time to perform myriad tasks. The requirement of including family caregivers in education and instruction may require a paradigm shift. Hospital executives can work with clinical staff to create structures and alter processes to ensure that family caregivers are woven into care while not overburdening clinical staff.[7,8,20] Furthermore, the CARE Act itself does not change reimbursement for the activities performed in compliance with the law, so assessing compliance with the law in relation to patient outcomes is a key measure. Recent research suggests that systematically integrating family caregivers in hospital processes as being an effective method for reducing resource use.[9] If research identifies a positive association between CARE Act compliance and patient outcomes or resource use, potential exists for that to inspire modifications of inpatient structures and processes to encourage greater caregiver involvement and education.

Second, most of the hospitals have made at least one change to comply with the CARE Act. This finding demonstrates that hospitals are working to change processes to align with the legislation. One year after the effective date for the CARE Act, hospital executives reported that they are still developing processes to comply with the legislation. Given the variation and complexity of patient conditions and hospital discharge processes, the CARE Act does not prescribe specific compliance methods. Despite these variations, family caregivers have consistently reported a gap between their knowledge and the complexity of the tasks that they are required to perform.[4,5] These continued efforts toward implementation are valuable. Implementation of new laws and regulations without clear, prescriptive compliance guidelines involves testing methods of compliance and takes time. The development of hospitals' best practices and outcomes research will assist in the implementation of the legislation.

Third, implementation of the legislation is being undertaken by hospitals. They reported making changes to comply with the legislation, but early implementation is a work in progress. Implementation of the CARE Act was strongest for creating a family caregiver designation in the medical record system. By requiring designation of the family caregiver upon admission, the clinical staff could know the identified family caregiver from the outset. Then, clinical staff can instruct the appropriate family caregiver on tasks and notify the designated family caregiver about discharge. These findings suggest that efforts are being made to comply with the legislation.

Some executives reported that they were still developing processes for their hospital to comply with the CARE Act, and several indicated plans to conduct quality improvement initiatives that explore the inclusion of family caregivers in their hospitals. The desire to

conduct quality improvement initiatives on this topic suggests that hospitals are committed to implementing the law. Evidence-based tools or processes may facilitate systematic inclusion of family caregivers in health care activities. For example, a family caregiver needs assessment should be developed to aid clinical staff in making decisions about what education and instruction family caregivers require.[21,22] Furthermore, training modules should be refined to provide more options for clinical staff to efficiently educate and instruct family caregivers on various self-care and caregiving tasks.[20]

This study demonstrates that the CARE Act is taking root in health care facilities, and future implementation studies are needed to understand the impacts of the legislation. As such, future studies should examine whether and how the CARE Act requirements influence health and resource use outcomes. A few study limitations warrant specification. Our descriptive, cross-sectional study investigates early implementation of the CARE Act. Causation between the CARE Act and the patient or resource use outcomes may not be inferred. This study examined the self-reporting of compliance and implementation from a small sample (N = 22) of hospital executives in one state. It is possible that responses may be biased toward socially desirable answers. The CARE Act questions were based on the components of the law, not on a validated question set. The hospital executives primarily came from not-for-profit, community-based, system- or network-affiliated hospitals. These characteristics limit the ability to infer generalizability from the study findings. No formal qualitative methods were employed because of the small sample. We asked about the frequency of CARE Act activities across all patient stays, as opposed to those who have specified a designated caregiver. This limits our ability to understand the true occurrence of caregiver notification and instruction and overall compliance with the law. Compliance and implementation may be defined in different ways, and we were limited to understanding compliance and implementation through the narrow lens of information gleaned from an executive survey.

CONCLUSION

Implementation of the CARE Act has the potential to improve family caregiver skills and reduce resource use.[9] This study reports that hospital executives perceive that patients and family caregivers will benefit more than clinical staff, hospitals, or the community from the CARE Act. The hospital executives acknowledged that compliance and implementation are ongoing through the development of procedures in hospitals. This progress is critical to support the millions of family caregivers who are asked to care for individuals after hospitalizations.

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IMPLICATIONS

Systematically integrating family caregivers will require further development of best practices. Specific processes and tools for clinical staff to use in hospitals will be needed. Future research aimed at shaping family caregiver policy should consider compliance with the tenets of a law, as well as the actual implementation processes that include family caregivers in the hospital.

Table 1.

Hospital Characteristics

	N=22	%
Hospital tax classification status		
Not-for-Profit	19	86.4
For-Profit	1	4.5
Missing	2	9.1
Community-based		
Community	20	90.9
Other	1	4.5
Missing	1	4.5
Teaching		
Teaching	8	36.4
Not-teaching	11	50.0
Missing	3	13.6
System affiliation		
Independent	9	40.9
System- or network-affiliated	11	50.0
Missing	2	9.1
Perceptions of who will benefit “a great deal”		
Patients	13	59.1
Family Caregivers	12	54.5
Clinical staff	4	18.2
Hospitals	5	22.7
Community	5	22.7

Table 2.

Number and Proportion of Hospitals Indicating That Compliance and Implementation Always Occur for All Patients With CARE Act Requirements (N = 22)

	Compliance		Implementation	
Change	**N**	**%**	**N**	**%**
Family Caregiver Designation	14	63.6	15	68.2
Family Caregiver Notification of Discharge	10	45.5	14	63.6
Family Caregiver Education and Instruction	9	40.9	7	31.8
Currently Developing New Processes	8	36.4		
No Changes Being Made at This Time	2	9.1		