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Cover Page Footnote

We would like to gratefully acknowledge the family caregivers, patients, and providers who participated in this research and on our advisory board. Your dedication makes our work relevant and grounded.

Family-centered caregiving from hospital to home: Coping with trauma and building capacity with the HOPE for Families model

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Abstract

Informal caregivers and families play a significant role in the recovery process of trauma survivors. However, the needs and outcomes of orthopedic caregiving family members in the months following traumatic injury have received almost no attention in the literature. Our study sought to understand the factors impacting orthopedic trauma families' experience and their ability to cope and provide care post-acute hospitalization. Based on these findings, we designed a hospital-based program to enhance family coping and adjustment post-discharge. Caregivers (N=12) of patients with orthopedic trauma injury engaged in three in-depth semi-structured face-to-face interviews to identify their most salient concerns. Once home, subjects described caregiving life at home, their coping strategies for managing the patient's recovery, and help they received from formal and informal sources. Analysis of the qualitative data found that trauma care lacks a unified system of coordination after the patient's return home. Thus, the role of "secondary caregivers" - longtime friends, family members, church groups, neighbors - was significant. Without an organized system of support and information, the caregivers in our study turned to their established communities for comfort and assistance. Conclusions: Based on these findings, we designed a family caregiver program, Holistic Orthopedic Patient-centered Engagement (HOPE for Families), to support families in this early transition, and to enhance collective and continuous caregiving capacity. HOPE for Families uses peer mentors as "central care organizers" to identify and engage the family's secondary caregivers system, using the HOPE Care Planning tool to identify stressor/demands and caregiver resources to meet anticipated needs.

Keywords

Family caregiver, building capacity, caregiver experience, traumatic injury, patient experience

Introduction

With the continued and growing interest in improving population health outcomes¹ and understanding that disease is only one of many determinants of outcomes,² health care delivery systems are searching for interventions that reduce use of unnecessary services through better care delivery. A systematic literature review of people with heart failure and pneumonia identified social determinants as a driver of hospital readmission.³ Health systems are exploring interventions that go beyond disease to address broader causes of bad outcomes.⁴

An individual's capacity to successfully manage their condition(s) is determined in part by the severity of their condition, the number of conditions, and factors in their environment such as the degree to which an overwhelmed individual receives support from an informal caregiver (those providing unpaid assistance to the aged, disabled, and chronically or acutely ill).⁵ These caregivers are most commonly family members⁶ constituting an extension of the patient as "the patient and family system."

The concept of "caregiving" emerged as women moved from roles of full time home making to the paid work force. Women were traditionally entrusted with "family care" which involved caring for children, the elderly, and the ill.⁷ The homemaker managed the instrumental tasks of family care (cooking and cleaning), and the emotional tasks, such as maintaining personal relationships, providing personal attention, and listening; "caregiving" was indistinguishable from "family care" or "homemaking." In 1870, over 70% of women were full time homemakers in the US; women in the work force were more likely to be immigrants, non-white, and the poor. By 1960, just 56% of women were full time homemakers, and by 2000, that number dropped to 29%.⁷

The work of informal caregiving is varied. Caregivers provide physical and emotional support, monitor the patient's treatment, manage symptoms, and assist with personal care.⁸ Caregiving is becoming increasingly complex as the morbidity for chronic illness and disability increases and care formerly provided in the hospital is

being managed by family members at home.⁸ Care at home commonly includes helping with prescription medications by mouth and injection, monitoring wounds and illness profiles, and changing dressings.⁹ In addition to providing direct care to the patient, caregivers assume family responsibilities previously managed by the patient while continuing to manage their own family and professional responsibilities.

The impact of caregiving on caregiver quality of life and well-being has been studied in detail for a variety of patient populations. Symptoms of psychological distress for those caring for both the chronically ill and the traumatically injured include depression, anxiety, poor social adjustment, and post-traumatic stress disorder; this distress has been noted to negatively impact the ability to provide quality care.¹⁰⁻¹³ According to The National Alliance for Caregiving, over half of all caregivers indicate that their caregiving-associated decline in physical and emotional health impacts their ability to provide care.¹⁴ As such, researchers note a particular need for interventions that encourage the family to participate in care,^{12,15-19} prepare families for the transition from hospital to home,^{11,12} foster self-management,^{15,17} and teach the skills needed to care for the patient.²⁰⁻²²

Innovations are underway in the field of chronic care management that enhance organizational coordination and delivery of evidence-based community programs for patient care post-hospitalization. For example, Haynes et al²³ developed an evidence-based leadership council (EBLC) to provide coordinated communication, training, and service delivery between healthcare institutions and community-based organizations. Based on The Chronic Care Model,²³ the EBLC connects health systems and community-based organizations that provide patient-centered evidence-based services, which is theorized to lead to improved patient self-empowerment and improved health outcomes. The focus of the council is to bring these entities together, enhance coordination efforts, and coordinate data collection and evaluation. The American Trauma Society's Trauma Survivors Network (TSN), available in trauma centers nationally, provides a patient-focused and patient-staffed volunteer program designed to support trauma survivors during their hospitalization and recovery. The focus of the TSN is to ease caregiver and patient stress through peer connections and practical information.^{24,25}

Our caregiver study illustrates these findings in the orthopedic trauma population. Orthopedic trauma is the leading cause of trauma hospital admissions for adults under the age of 65.²⁶ These traumatic injuries can lead to an abrupt change in physical and psychological functioning; mobility is impaired and psychological disturbances can occur in response to the traumatic event and subsequent losses incurred from the new disability.²⁷⁻²⁹

Informal caregivers and families play a significant role in the recovery process of trauma survivor; however, the needs and outcomes of orthopedic caregiving family members in the months following traumatic injury have received almost no attention in the literature.³⁰ The impact of caregiving is moderated by levels of caregiver support: evidence points to the association of caregiver well-being and use of external resources during hospitalization^{11,21,22,31-34} and home rehabilitation^{31,33,35-37} for those caring for patients recovering from traumatic brain injury (TBI). We offer an innovative strategy to engage, prepare, and facilitate self-management among family members overseeing the recovery process of their loved ones.

Our study sought to understand the factors impacting orthopedic trauma families' experience: their ability to cope, actively engage in the caregiving role, and attain higher levels of self-efficacy. This paper reports on some of the resources families have relied upon to cope with their orthopedic trauma experience and manage the tasks of caregiving once home; a previous publication provides insight into these caregivers' experiences in the hospital setting.³⁸ Based on these findings, we then propose a hospital-based program, HOPE for Families, designed to enhance family coping and adjustment and expand the family's capacity to manage patient care and a return to pre-trauma functioning in the community.

Methods

We focused on understanding the caregiver experience and meaning of the caregiver role using a blend of the case study and ethnographic approaches to qualitative research design. A case study is useful for exploring an issue using individual "cases" within their context; each case – a family system, for instance – can be studied over time, and can provide data about the phenomenon of interest.³⁹ Investigating the experiences of multiple cases reassures the researcher that the events and conditions in one case are not "wholly idiosyncratic";⁴⁰ this allows the researcher to observe processes and outcomes across several cases and develop a better comprehension and stronger theories. An ethnographic approach involves the close exploration of several sources of data, including participant observation, interviews, and other collaborative information that inform the researcher regarding the culture, environment, conditions and norms of the community.⁴¹ The intent of an ethnographic study is to create a detailed, in-depth description of everyday life, going beyond reporting events and details of the experience to providing a rich description with a cultural interpretation. While trauma caregivers do not necessarily share a unique culture, with shared patterns of behavior, language, and beliefs, they do share a common experience and interact with a culture-sharing medical system. Family caregivers of trauma patients share a routine of caregiving,

strive to overcome similar challenges, and interact with common support structures during the patient's recovery. An ethnographic approach allows for the exploration of these common experiences, challenges, and communities.

A community advisory board (CAB) consisting of caregivers, patients and providers, was involved throughout the project to offer guidance and feedback and increase the validity, relevance, and credibility of the research. The study was designed and implemented as a dissertation project under the guidance of qualitative research advisors and health policy experts; the student researcher had previously worked at the research-site hospital as a trauma social worker prior to her public health doctoral studies. The student researcher relied upon open feedback from the CAB and advisors when making the shift from the social work to research perspective during individual interviews. Approval for the study was obtained from the hospital's Institutional Review Board. All recruitment, enrollment, and data collection were conducted by AN; analysis was conducted jointly by the AN and the CAB; writing was conducted by AN, GM, and HM.

A convenience sample of study participants was recruited one day each week for three months upon their admission to the Level 1 trauma center located in a well-resourced suburban county near Washington DC. Eligible participants were identified by the nursing staff then approached by AN for enrollment. Inclusion criteria included caregivers of patients aged 20-60 years sustaining serious orthopedic injuries and hospitalized at least five days. Caregivers of patients with a diagnosis of a TBI or spinal cord injury (SCI) were excluded from the study.

In the first five months post-injury, participants engaged in three in-depth semi-structured face-to-face interviews designed to identify their most salient concerns at the time of the interview. In the hospital, participants described what had occurred since they first learned of the trauma, their internal and external resources, and factors most impactful on their wellbeing and ability to cope. These findings are reported in a previous publication.³⁸ Once home, participants described caregiving life, their coping, their strategies for managing the patient's recovery, and help they received from formal and informal sources. All interviews were recorded and de-identified by AN and transcribed by a professional medical transcription service.

Data analysis began with the development of a set of themes derived from the first several transcripts. Themes were refined iteratively and collectively, with coding disagreements evaluated and reconciled by the research team. Coding fragments relevant to each theme were extracted from individual transcripts and compiled into separate datasets. Further analysis of themes and patterns across and between cases allowed us to identify the range

of experiences and common themes regarding burdens, stressors, facilitators, barriers, coping, and impact.

Results

Participants

Twelve caregivers enrolled in the study and completed an initial interview in the hospital; eleven completed a second interview during the first month home; and 10 completed a third interview 4-5 months post-injury (Figure 1). Characteristics of study participants can be found in Table 1, including relationship to patients, patient injuries and discharge dispositions; caregiver participants' unique barriers and facilitators to adjustment are reported in Table 2. Despite each patient having a steady income and healthcare insurance at the time of their injury, each of the 12 participant caregivers experienced complications unrelated to the injury during the recovery process. These included family members' military deployments, multiple family members injured, deaths associated with the trauma, absence of local extended family, job and insurance loss, pending divorce, high care needs of other family members, and inaccessibility of the home. As such, each family tapped into resources unique to their situation to facilitate adjustment to the challenge. These facilitators included extended family members relocating during the recovery, employers providing flexibility, supportive church groups and strong faith, strong organizational skills, and personal optimism (Table 2).

The trauma patient was typically at a very vulnerable state upon return to home, requiring considerable care at the outset. This transition marked the beginning of the most extensive phase of the patient's recovery in which the family assumed primary responsibility for the work of caregiving and health care management. Even after the primary caregiver returned to work, the patient often continued to require care and assistance – in eight of the twelve cases their needs dominated the caregiver's life for several months.

Burdens and Stressors: Care Management Challenges

Study patients and family discovered that trauma care lacks a unified system of coordination after the patient's return to home^{42,43} so the caregiver assumes the role of care coordinator. This new role can be both terrifying and confusing. One mother stated, "I didn't have anyone to tell me how to do it, I had to try and figure out-- that's what terrified me... It was as scary as when I brought her home when she was first born and I had no experience with little kids. Suddenly she's depending on me, and I don't know if I can do it."

Figure 1. Recruitment and data collection summary

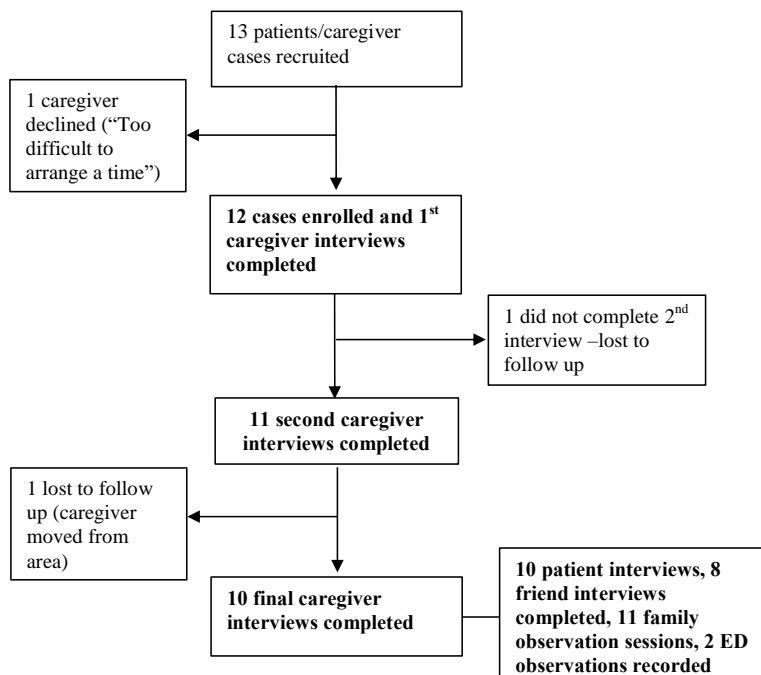


Table 1. Characteristics of Participants; n=12

<i>Relationship to Patient</i>		<i>Patient Injuries</i>	
Wife	6	Single leg fracture	3
Husband	2	2 extremity fractures	4
Mother	2	3+ extremity fractures	4
Daughter	1	Leg amputation	1
Girlfriend	1		
<i>Age of Patient</i>		<i>Length of Initial Acute + Rehab Stay</i>	
20-29	2	3-6 days	3
30-39	3	1-3 weeks	7
40-49	1	4-6 weeks	2
50-59	6		
<i>Gender of Patient</i>		<i>Disposition</i>	
Male	8	Home	5
Female	4	Rehabilitation	7
<i>Mechanism of Injury</i>		<i>Extended Family Support</i>	
Motorcycle crash	3	Local adult children	5
Motor vehicle crash	5	No local extended family	12
Fall: ladder/horse/wall	2		
Bike/pedestrian struck	2	<i>Health Insurance Status</i>	
		All patients insured	

Table 2. Case Summaries of Participants

MVC: Motor vehicle crash; **MCC:** Motor cycle crash; **BKA:** Below the knee amputation; **AH:** Acute Hospital; **AR:** Acute Rehab; **SNF:** skilled nursing facility; **fx:** fracture; **h:** hour; **d:** day; **wk:** week; **y:** year; **C:** caregiver; **pt:** patient

	Subj. # 1	C: Mother, African American Pt: 22y, African American	Subj. # 2	C: Wife, African American Pt: 47y, African American	Subj. # 3	C: Husband, African American Pt: 38y, Caucasian
Trauma	MVC; femur & ankle fxs; AH 5d		MVC; acetabular fx; AH 7d , AR 7d		MVC; left wrist & right knee fxs; AH 7d, home 2 wks, AH 7d	
Challenges & Barriers	2 teens died. Pt: pain control issues, infection; lost job. No local family/friends. C: work inflexible (no time off). Media attention. Home >1 hour from AH.		2 family members in crash/injured. New to area; no local family or close friends or church community.		Pt 34 wks pregnant. 4 children < 10yrs. No local family. Pt difficult: critical, unhappy with C's care, pain; very high maintenance toddler in the home.	
Facilitators	Affordable Care Act: Pt able to move to C's health insurance.		19y daughter helpful. C: Flexible schedule, very organized, positive. Pt appreciative, positive.		Many supportive community groups. C calm problem solving nature. Military benefits paid during caregiving.	
	Subj. # 4	C: Wife, Caucasian Pt: 45y, Caucasian	Subj. # 5	C: Wife, Caucasian Pt: 45y, Caucasian	Subj. # 6	C: Mother, Caucasian Pt: 20y, Caucasian
Trauma	Fall from tree; back and rib fxs; AH 7d		MCC; 2 hip fxs, liver laceration, BKA, lung injury; AH & AR 6wks, 1 mo @ brother's		MVC; elbow, ankle, clavicle, knee fxs; AH 10d, AR 2 wks .	
Challenges & Barriers	Pt: Multiple Sclerosis. No local family. Teenage daughter w/ significant medical needs 2 mo. after pt's injuries.		Pt: Complications & setbacks. Home > 1 hr from AH. Long time (3mo) away from home. C: no local close friends/family. Pt: depressed, angry, difficult for C.		Pt: Very difficult to care for – resistant, unhappy, unappreciative. Home > 1 hr from AH. 2 other children in home.	
Facilitators	Engaged church community. Adult daughter helpful. C: flexible schedule, strong faith, positive attitude, organized.		C: Organized, determined, strong advocate. Supportive employer		C: Organized. Flexible employer. Excellent support from other children, husband, sister , extended family and local community.	
	Subj. # 7	C: Daughter, African American; Pt: 47y, African American	Subj. # 8	C: Wife & Mother, Caucasian; Pt: 43y, Caucasian	Subj. # 9	C: Wife, Caucasian; Pt: 47y, Caucasian
Trauma	MVC; knee, elbow, shoulder fxs; AH 1 wk		Pedestrian hit by car; tib/fib, collarbone, back fxs; eye injury; AH 7d		Fall from ladder; elbow, hip, ankle, heel fxs (3 extremities); AH & SNF 20d	
Challenges & Barriers	No local family. Pt uncertain re: ability to return to work (dancer). Home >1 hour from AH. C: single mother of 5 year old.		Pt and wife separated. Pt's family not local. 2 dogs in home with significant medical needs; strained relationships		Pt: Setbacks, infections, prolonged recovery. 2 young children at home.	
Facilitators	Strong community of support. C very organized, enjoys problem-solving challenges.		Pt's mother moved into home to care for pt and dogs. Pt recovered quickly.		Excellent community support. C: flexible schedule, excellent self/family care capacity. Pt positive and appreciative. Strong marriage.	
	Subj. # 10	C: Husband, Caucasian; Pt: 49y, Caucasian	Subj. # 11	C: Wife, Caucasian; Pt: 58y, Caucasian	Subj. # 12	C: Girlfriend, Caucasian; Pt: 30y, Hispanic
Trauma	MCC; back, ankle, rib fxs, lung injury; AH 7d		Fall off bike; pelvic & elbow fxs; AH 8d, AR 9d		MCC; right knee, femur fractures; AH & SNF x 4 wks	
Challenges & Barriers	C also in MCC. No local family. Live > 1 hour from AH. C & pt uncomfortable asking for help. C had to return to work upon pt return home.		Pt: Complications & setbacks in recovery. C: Also responsible for daily care of father. Sister with medical challenges and needs.		Home inaccessible; C moved pt into her very small apartment; 1 hr from AH; no time off from work; no local support; pain control issues. Relationship stress.	
Facilitators	Adult son moved in x 1 wk. Pt's parents helped x 3 wks. Very strong marriage. Helpful neighbors. Home with accessible living area.		C: Flexible schedule; optimistic person. Pt: Very positive, appreciative, motivated. Returned from rehab nearly independent; healed quickly. Strong marriage.		C: Organized, natural advocate. Rehab enabled pt. to be safe at home.	

Participant caregivers report receiving conflicting provider advice and information, resulting in unclear direction for the care they provide. A typical example of such an experience is articulated by a caregiving wife: “He's got three or four different people that are managing him, we need to make sure they don't contradict each other... when [bad] things happen most of the time it's not because of incompetency or ill intent, it's because the communication isn't clear and you have several experts and they're all seeing it only from their one little piece and

there needs to be somebody that's able to pull that together.”

Other participants, like this mother, echoed this sentiment once charged with the management of the patient: “We're getting, like, clashing advice. One orthopedic nurse, she said, ‘You know, that seems strange to me. You need to check this out, you know,’ and then I go back to the doctor, and he says, ‘No, it's normal.’ All these questions just make me feel like I'm not being involved

enough in his care or doing what I'm supposed to be doing.”

The lack of a unified system also meant a lack of a central source of information for trauma survivors regarding resources such as information about the caregiving role, the progression of orthopedic recovery and systems of care, local providers, support groups or advocacy groups. This level of support is available to other patient and caregiver populations through such organizations as the American Cancer Society,⁴⁴ the Alzheimer's Association,⁴⁵ the American Heart Association,⁴⁶ the MS Foundation,⁴⁷ and the Brain Injury Association of America.⁴⁸ The Family Caregiver Alliance⁴⁹ provides caregiver information for numerous conditions, but does not include information on orthopedic trauma.

Facilitators: Case Management Enablers

An important finding of our study was the role of “secondary caregivers”: longtime friends, family members, church groups, or neighbors who are able to take care of specific tasks or assume important roles. Without an organized system of support and information, participants in our study turned to their established communities for comfort and assistance, specifically identifying their secondary caregivers as critical to their coping and well-being. These secondary caregivers were typically identified during the trauma patient's in-hospital phase as they assumed responsibility for details that would otherwise distract the caregiver from their primary need to be with the patient. This role developed over time to include making arrangements for children, providing a buffer between the caregiver and other visitors, providing transportation and, importantly, emotional support. Study participants cite the importance of this “inner circle” support as instrumental in enabling them to attend to their loved one and to receive organized help from the community, often cited as this caregiver does here: “My eldest daughter is making sure they're [other children] getting where they need to go and they're taken care of and fed. I couldn't be devoting the time I do to my husband right now, which is where I feel I need to be, if I didn't have that in place with them.”

Upon the patient's return home, this concrete help provided important support for the caregiver who had assumed all family responsibilities of the patient while maintaining his/her own work and caregiving roles. Furthermore, caregivers were strengthened by the care offered by the community, as this wife describes: “I can picture people from my church coming in my door with armloads of food... Like I said, I just felt like we were wrapped in the arms of people who loved us, and lifted us up through that, so I could go and do what I needed to do.”

The presence of a central organizer relieves the caregiver of significant overwhelm associated with the management of great numbers of well wishers. “Mark's best friend was here immediately so I gave him the job to be the message giver. I'd give him the message, if somebody sends me an email, I said, “Talk to Shawn, talk to Shawn.”

When these secondary caregivers were supportive and actively involved in the caregiving role, caregivers experienced enhanced self-efficacy and an appreciation of community relationships. Crisis management was a shared effort rather than an isolating experience. Families experiencing the greatest stress were those reporting no local family, close friends, or religious community, or having other family members experiencing simultaneous challenges and/or concurrent health or mental health needs, strained relationships, and financial or work-related stressors.

Discussion

The study findings are consistent with the considerable evidence pointing to the association of caregiver well being and social support for those caring for patients recovering from TBI.^{11,21,22,31-34} Social support has consistently been found related to caregiver quality of life in the majority of chronic caregiver studies reviewed by Lim and Zebrack.⁵⁰ In their review of caregiver literature, those reporting greater levels of family and community support were found to be less depressed, healthier, and more satisfied with their lives. Furthermore, several studies found that caregivers benefited from emotional support from friends and family as much as they did from concrete assistance with everyday needs.⁵¹⁻⁵⁴ This study of a new population of caregivers provides evidence for these same needs among those providing care for traumatically injured patients who are expected to recover more quickly than those with chronic illness.

HOPE for Families

Our findings lead us to propose a family caregiver program, Holistic Orthopedic Patient-centered Engagement (HOPE) for Families, for facilitating this early post-hospital transition. A central challenge in health care overall is a lack of professional help with coordination of care in community post-discharge.⁵⁵ At the study hospital, no formal post-discharge program exists that is designed to engage secondary caregivers, and aside from the TSN, no trauma caregiver support program can be found described in the literature. HOPE responds to the need for a family-centered coordinated system of care aimed at enhancing collective and continuous caregiving capacity, offering the opportunity to become aware of family challenges as they may arise and before they develop into significant adversities to recovery.

HOPE is comprised of orthopedic trauma survivors, their primary caregivers, and program mentors, who themselves are orthopedic trauma survivors and caregivers, and who become the family's advocate in identifying, engaging and sustaining secondary caregivers (friends, family, neighbors, religious community, employer) in meeting the family's post-discharge care needs. New orthopedic patient and primary caregivers are paired with an existing HOPE mentor. The mentor is the family's liaison during the hospital stay and is the bridging advocate post-discharge. HOPE mentors participate in a hospital training to work with the family pre-discharge to identify and engage critical secondary caregivers in the family's network using the HOPE for Families Care Planning tool (Figure 2), which identifies the stressor/demands, caregiver resources, and plan to meet the anticipated needs.

Patient self-management through technology is becoming increasingly useful for community-based monitoring of health conditions (e.g., see Czaja, 2015), as such information can be directly communicated to family caregivers and the care team to enhance care coordination.

For example, our HOPE for Families Care Planning tool could be developed into an app that can be accessed by the coordinating team and entire support network, allowing the network to stay connected and to update needs, resources and tasks as they change in real-time.⁵⁶

Mentors provide check-ins with the family post-discharge and work with the family to update the resource maps as needed. The signature role for these peer care coordinators is to pull information together and help the family problem-solve care planning in the context of engaging the family's identified community supports. In doing so, mentors provide both instrumental and emotional support to enhance family well-being and prevent problem escalation. In addition, HOPE offers weekly support group meetings at the hospital for patients, caregivers and mentors that focus on adjustment to the caregiver role, information on orthopedic trauma care, pain management, and problem-solving interpersonal concerns.

Program coordinators with a mental health and community outreach background train mentors. Training

Figure 2. HOPE For Families Care Planning Tool

		Date _____	Caregiver _____	Mentor _____			
		Inpatient Hospital Stay	1st Week after discharge	2nd Week	Month 1	Month 2	Months 3-6
Household/patient needs and tasks							
Caregiver needs							
Potential Resources & Support							

covers both the logistical and emotional aspects of mentorship, focusing first on mentors' own experiences as trauma caregivers and next on the step-by-step process of mentoring a new family. New mentors are paired with experienced mentors who provide ongoing training and support during the new mentor's work. Program coordinators connect with mentors through monthly meetings, continuing education, and ongoing review of the caregivers' progress during recovery. This peer mentor model has been successfully used in health and mental health care coordination with other populations. For example, the Veteran Treatment Courts (VTC) use veteran peer mentors to promote "sobriety, recovery, and stability through a coordinated response that involved collaboration" among many community-based resources and organizations⁵⁷ (p. 11). These mentors provide motivation to the veteran and their families and aim to reduce social isolation and facilitate meaningful community connections in helping the veteran receive the services they need. Our HOPE program mentors bring an important understanding of the hospital culture and health care system to the family coordinated care effort, facilitating care decision-making and navigating needed community resources.

Our HOPE program is in line with the EBLC²³ and is aimed at increasing the trauma survivor's family care capacity by using peer mentors as "central care organizers" to identify and engage the family's secondary caregivers system. HOPE recognizes that it isn't enough to simply provide access to services; families need guidance in the early months of navigating the system to understand what services best address their needs. Furthermore, our program builds on the existing TSN program with its volunteer training processes currently in place. TSN volunteers are uniquely positioned to serve as family advocates, and an extra module of training as a HOPE mentor would fit well in their ongoing training regime.

Conclusion

Success in this era of value-based payment is based in large part on the health care delivery system's ability to improve outcomes and thus avoid unnecessary medical resource utilization. Informal caregivers provide important patient care and have an impact on significant outcomes such as hospital readmission. Lack of support for informal caregivers forces them to find it if/when/where they can. A formal system of support is likely to increase the capacity of informal caregivers and have a positive impact on important outcomes. The HOPE program is designed to provide formal support from acute hospitalization to effective self-management at home; evaluation of HOPE or similar programs would be an important step in our efforts to improve systems of caregiver support.

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