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A comprehensive assessment of family caregivers of stroke survivors during inpatient rehabilitation

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Introduction

Approximately 795,000 persons experience a stroke in the U.S. each year. Of these, nearly 77% are first-time strokes. Stroke is a leading cause of major disability in older Americans [1] with almost 4.8 million stroke survivors living with some level of disability.[2] For those patients who require inpatient rehabilitation, the average length of stay from diagnosis to discharge home is approximately 3 weeks.[3, 4] Some patients are admitted to an inpatient rehabilitation facility (IRF) directly from the intensive care unit. In the extensive research examining the relationship between stroke patient attributes and discharge home after a stay in an IRF, the patient's functional status,[5-7] age,[8] and/or availability of a family member to assume the caregiving role [9] are highlighted as primary determinants of discharge destination. As advances in medical treatment continue to improve survival rates for stroke patients, more family members will be called upon to provide some level of assistance post-discharge.

In recent years, the deleterious effects of caregiving have been identified as a major public health concern.[10] A preponderance of literature has established that caregivers are often adversely affected by the demands of their informal caregiving role. Stroke caregivers have been identified as a group at high risk for poor outcomes as a result of the suddenness of stroke and the potential for the patient to require a high level of care due to significant functional loss following stroke.[10-16] Greenwood and colleagues have systematically

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reviewed quantitative [17] and qualitative studies [18] to determine the factors that influence positive and negative outcomes for stroke caregivers. They concluded that many crucial factors are omitted from studies and that methodological shortcomings are identified across research paradigms. Lutz, Young, and colleagues [19] concluded that stroke survivors and their family caregivers experienced two crisis events as a result of stroke: the first occurred when the person had the stroke followed by a second crisis when the stroke survivor was discharged home from an IRF. Clinical recommendations included improved continuity across the continuum of care and seamless transitions between rehabilitation and home as well as more effective case management and integrated caregiver assessment.[19, 20]

Needs of Stroke Family Caregivers

Patients and informal caregivers rapidly move from intense therapy and access to 24-hour nursing care while in the IRF to little or no formal support or assistance after discharge, feeling “abandoned by services once they have returned home.”[21] (p. 2590) Despite this, few studies have explored the needs of new stroke caregivers as care recipients' transition from hospital to home, [22] and those that have consistently indicate that these caregivers are inadequately assessed and/or trained for their new roles.[23-26] Specifically, studies exploring the needs of caregivers during discharge planning indicated that caregivers 1) were not adequately assessed or prepared for the caregiving role [19, 27, 28]; 2) had many unmet educational needs [26]; 3) had difficulty applying training and information received prior to discharge once they were home [19]; and 4) need to be kept informed about the patient's progress and involved in the discharge planning throughout the hospital stay [19, 29] even though this may be problematic due to confidentiality issues.[30]

Studies identifying the educational and information needs of stroke caregivers suggested patients and caregivers want training in the following areas: 1) clinical information on causes, effects, and prevention of stroke; stroke recovery and prognosis; and treatment decisions; 2) practical information related to daily care of the patient, e.g., bathing, toileting, nutrition; and 3) information on follow-up care and community resources.[21, 26] Bakas et al. found that in the first 6 months post-discharge, stroke caregivers had needs and concerns related to information, emotions and behaviors, physical care, instrumental care, and personal responses to caregiving [31] and that their information needs change during the course of patients' recovery from stroke.[32] This trajectory of needs indicates the importance of assessing the match between caregiver capacity and patient need, and coordinating and tailoring caregiver educational programs as patients transition through the continuum of care from acute care to inpatient rehabilitation to home.[26] Without this assistance, caregivers develop their own solutions and strategies to meet the needs of the care recipient after discharge.[31, 33] Unfortunately, these strategies are often ineffective and may result in safety issues for patients (e.g., falls, skin breakdown, choking) and care-related injuries and poorer health for caregivers (e.g., back injuries, increased stress and anxiety).[31, 34]

Assessment of Caregivers

A standard part of stroke patient rehabilitation is the ongoing evaluation of functional abilities to help determine what level of care will be needed after discharge. In many cases, a

successful discharge to the community hinges on the expectation that family members or close friends will provide this care. However, systematic assessment of the commitment, capacity, concerns, and preparedness of those most likely to take on the primary caregiving role is generally overlooked,[35] and several studies indicated that the assessment of family caregivers prior to patient discharge from rehabilitation is a neglected area.[12, 19, 36-38] Many tools have been developed to assess the effects of caregiving after the caregiver has been providing care for some period of time.[13, 24, 26, 28, 34, 39]. For example, the Caregiver Strain Index was designed to assess strain in caregivers of post-discharge heart failure and hip surgery patients.[40] The Mutuality and Preparedness Scales of the Family Care Inventory were developed with caregivers 6 months post-discharge to evaluate the quality of the caregiver/care recipient relationship, to screen for the level of caregiver preparedness, and to recommend further assessment (respectively).[41, 42] However, *there are no instruments to assess the capacity of family members to assume the caregiving role prior to patient discharge from rehabilitation.*

In 2007, Barskova and Wilz described the interdependence of stroke survivor outcomes and caregiver attitudes and health. They concluded that “caregivers merit attention in their own right as part of various rehabilitation interventions designed to reduce the incidence of handicaps after stroke.”[43] p. 1489 Other authors have identified specific assessment domains that must be considered when evaluating caregivers. In 2003, Feinberg identified 12 domains including five important neglected areas of caregiving assessment: “1) actual tasks performed by family caregivers beyond personal care functions; 2) skills necessary to provide the care; 3) quality of care provided; 4) values and preferences of the care recipient and the caregiver; and 5) positive aspects of caregiving.”[35] p. 28 Some of Feinberg's domains are incorporated into the *Nursing Standard of Practice Protocol: Family Caregiving* by the Hartford Institute for Geriatric Nursing in which the following areas of caregiver assessment are recommended: 1) caregiving context—including relationship to patient, roles and responsibilities, physical environment, resources, and cultural background; 2) caregiver's understanding of the patient's health and functional limitations; 3) level of preparation for and knowledge about the caregiving role; 4) quality of family relationships; 5) pre-existing issues, such as marital discord and poor management of finances; and 6) caregiver's physical, mental, and emotional health.[14]

Teel, Duncan, and Lai suggested that a comprehensive assessment of stroke caregivers “should include determination of caregiver perceptions about the caregiving situation.” [29] p. 59 Van Heugten, Visser-Meily, Post and Lindeman assessed the literature to identify evidence of 13 topic areas to be included in identifying caregivers at risk and the assessment of caregiver burden.[44] The 2008 Canadian stroke care clinical practice guidelines indicated that there is “level A” evidence that “stroke survivors and their caregivers should have their individual psychosocial and support needs reviewed on a regular basis.”[45] p. E61 The 2010 Department of Veterans Affairs and Department of Defense (VA/DoD) *Clinical Practice Guideline for the Management of Stroke Rehabilitation* strongly stated that “it is essential that the rehabilitation team view the patient and family/caregiver as the unit of care” and conduct a thorough psychosocial assessment of “all stroke patients and family caregivers.” [46] p. 47 Thus there is strong evidence in the literature suggesting that

assessment of caregivers prior to patient discharge from an IRF is a critical and often neglected area of rehabilitation care. The purpose of this article is to delineate critical assessment domains identified by spousal stroke caregivers during semi-structured interviews that were conducted pre- and post-discharge from rehabilitation as part of a research study to identify caregiver and stroke survivor needs as they transitioned home from inpatient rehabilitation. We provide rich examples of the complexity of the assessment domains and the relevance for their impact on stroke survivor long-term outcomes.

Methods

The aim of this grounded theory study was to understand the needs of spousal caregivers of stroke survivors during the transition from rehabilitation to home. The study specifically focused on those caregivers of first-time stroke survivors who were referred to inpatient rehabilitation with the goal of discharge home.

For this study, we analyzed the data from fourteen spousal caregivers (3 black, 10 white, 1 Native American), who were part of a larger study.[19] We chose to focus this analysis (and this paper) on the needs of spousal caregivers because they were the primary caregivers for all but one of the dyads in the original study sample. Study participants were recruited from two IRFs; one was a free-standing IRF in a large urban area; the other was free-standing, but part of a large academic medical center in a mid-sized urban area. Both treated patients from a wide geographic area, both urban and rural. Table 1 summarizes the sample demographics of the caregivers and care recipients (stroke survivors). [Insert Table 1 about here]. Case managers at each IRF assisted in recruiting stroke patients and their caregivers for the study. The Institutional Review Board of the study facilities and the university approved the study prior to data collection. The research team explained the study to each participant and obtained informed consent before the start of the first interview.

Caregivers participated in one to two interviews depending on their availability. The two interviews were scheduled as follows: 1) a few days prior to discharge to a few weeks post-discharge from the IRF and 2) within 3 to 6 months post-discharge. Eight caregivers participated in both interviews and six participated in one post-discharge interview for a total of 22 interviews. The caregivers and stroke survivors were given the option of being interviewed together or alone. In 17 of the interviews the dyad chose to be interviewed together. In five interviews, the caregiver chose to be interviewed alone or the stroke survivor was not able to participate. The Principal Investigator (PI) (2nd author) or the research assistant (a PhD student, 3rd author) trained in qualitative research methods set up the interview times and locations convenient to each study participant and conducted the interviews. An informal interview guide[47] with open-ended questions was used outlining the key topics to be asked and allowing for maximum input from study participants. The first interview focused on the patients' and family members' stroke rehabilitation experience and plans for post-discharge care. In the second interview, participants were asked to compare their experiences of stroke recovery and caregiving to their initial expectations. A total of 22 interviews are thus included for this analysis.

Data Analysis

Data were coded using dimensional [48-50] and constant comparative analysis.[51, 52] These types of analysis are naturalistic analytic strategies developed for use with text or narrative data in grounded theory studies.[47-50] Dimensional analysis utilizes line-by-line coding to capture the participants' experience of the phenomenon being studied.[47-50] Applying a symbolic interactionism perspective, the researcher identifies how individuals perceive their reality, resulting in a framework that defines this “reality” from the participants' understanding. This framework becomes the basis for an explanatory model grounded in the experience of the participants.[47, 50]

Comparative analyses [51, 52] was conducted within and across the perspectives of spousal caregivers, NVivo 8.0, a qualitative data management software, [53] was used to manage the data, facilitating comparisons within and across texts. As themes were discovered in the data, they were verified with other study participants as a way to substantiate their cogency with the developing conceptual framework. For example, in an early interview, one caregiver identified that her adult step-children aligned themselves with their father (the stroke survivor) and she felt [like] they were second guessing her decisions about his care. Initially, we believed this finding was about the relationship of adult step-children to the biological parent in the dyad. However, when we explored this provisional finding with other caregivers in later interviews, we found that many adult children (biological or step) aligned themselves with one person in the dyad and that these family dynamics had implications for the amount and type of informal support that was provided to the caregivers.

The study research team, led by the study PI, a nurse, and co-investigator, a rehabilitation counselor (2nd and 1st authors, respectively), met biweekly to discuss the ongoing analysis with the other team members which included graduate research assistants / PhD students in nursing (3rd & 4th authors), and undergraduate nursing students. The team kept an ongoing audit trail of field notes and memos [51, 52, 54] to document and track methodological and substantive decisions made during the analysis. The team also met with a larger multi-disciplinary qualitative data analysis group, which included faculty and graduate students from nursing, rehabilitation sciences, occupational therapy, anthropology, and public health, at least quarterly to present preliminary findings and receive constructive feedback and questions on the findings.

In this article we discuss the emerging domains of caregiver assessment identified in our analysis and provide recommendations for caregiver support and follow-up that are often overlooked or minimized during inpatient rehabilitation following stroke. Each domain is described, illustrated with relevant quotes, and interpreted by the authors. Such a presentation of findings is consistent with Sandelowski and Barroso (2002) definition of findings as “the data-based and integrated discoveries, judgments, or pronouncements researchers have offered about the events or experiences under investigation.” [55] p. 214. Reflection on these findings in light of existing literature is included in the discussion section.

Findings

The findings of this study build on the previous work of the authors which documents the discharge home as being a time of crisis for caregivers.[19] This article targets a subset of data from spousal caregivers who seemed particularly vulnerable at the time of transition from rehabilitation to home. Twelve out of 14 of the spousal dyads described the transition from the IRF to home as very difficult, sometimes even traumatic. As one caregiver explained, “The first 3 weeks [post-discharge] were 3 weeks from hell!” [C 9] Caregivers were committed to their spouses but sometimes felt pressured to take the patient home despite feeling unprepared. Some reported that what would be expected of them as caregivers had been poorly communicated. For those who were able to attend training at the IRF, the skills they learned often did not transfer well to the home setting. Even when referrals were made for home health care, caregivers continued to describe feeling totally overwhelmed, isolated, alone, and abandoned. They tried to figure out how to provide safe care to their spouses recovering from stroke while juggling a multitude of additional tasks required for managing the patient's recovery and singly maintaining the household. As one caregiver described, “I felt like I was a little old Eskimo woman that they put on this ice block, chopped it off and sailed it out into the middle of the ocean.” [C11] Another said, “It was horrible. It's a terrible, terrible experience. I had no one to guide me, no one to help me.” [C2]

Sleep disruption and exhaustion, not surprisingly, compounded the problems. Caregivers described how the constant vigilance needed to secure the patients' safety and well-being 24 hours a day/7 days a week had left them completely drained and in despair. They described putting their own needs aside to maintain the high intensity care previously provided by multiple professionally trained caregivers while the patient was in the IRF. Even the spousal caregivers who had help from family members or paid personal care assistants described feeling totally overwhelmed. They also described a heavy sense of loss about future plans now unattainable because of the stroke. They realized their lives had changed forever; their sense of grief and despair was palpable.

Realizing that the data supported the notion of a very difficult transition for caregivers, 12 domains (shown in Table 2) emerged from the spousal data as critically important for the assessment of caregivers prior to discharge from rehabilitation. The 12 domains are grouped into three categories: caregiver commitment, caregiver capacity, and overall impact of stroke. Caregiver commitment focuses on the strength of the caregiver-care recipient relationship and the willingness of the caregiver to provide the necessary care. Caregiver capacity includes assessment of pre-existing caregiver health issues and self-care strategies, home accessibility, availability of resources, and pre-stroke roles, responsibilities, and caregiving experience. Finally, the assessment should include questions that focus on the overall impact of stroke and implications for the future. Examples from the data are included demonstrating a compelling need for each area of assessment. [Insert Table 2 about here]

Caregiver Commitment

1. Strength of caregiver/stroke survivor relationship—The success of the transition home depended on the pre-injury strength of the relationship between the patient

and the caregiver. Some dyads had very strong relationships pre-stroke, “We each had our problems in life, but we had never had one where we separated; we never separated. We never left one another either way. We’ve been married 54 years, and we’ve been together 54 years.” [C13] In other relationships, there were existing conflicts that became exacerbated during the crisis of stroke. Past resentments arose over unresolved issues that were now the caregiver’s responsibility. Some caregivers blamed the stroke survivor due to lack of self-care and preparation prior to the stroke, adding to the crisis.

Husband [Stroke survivor]: Well, I had high blood pressure, but what?

Wife: You weighed 300 pounds.

Husband: Well, that’s not good. [Embarrassed laughter].

Wife: There were a lot of things that weren’t good. You need to have your house in order, which he didn’t have—documents. You know. I’ve got my documents. He had no records. I had to run all over the county to get his documents.

Husband: What documents?

Wife: Everything. You need a birth certificate, marriage certificate, and you need your taxes. You need; you know he had rental properties. He didn’t have any files on rental properties. You know. The car was a big mess. I had to get rid of the car. I had to do all this. Nobody did this for me.” [C2]

Another caregiver who was actually separated from her spouse before an amputation and subsequent stroke, described her husband this way: “Sometime he get right bossy, but I go on and don’t pay no attention. But I’ll tell him right quick, “You ain’t got nowhere else to go to, so you might as well stay here and take that medicine and do the things[(sic)] I ask you to do.”; He’d look at me. You know when you been by yourself so long, you can’t get adjusted to no- to nobody else.” [C3]

It is important to identify and understand existing and potential conflicts that occur as a result of the stroke. A caregiver assessment should probe for the nature of the pre-stroke relationship, potential sources of conflict, and the level of commitment to continuation of the relationship in the role of caregiver. When high levels of conflict or low levels of commitment are identified, family counseling should be considered.

2. Caregiver’s understanding of and willingness to perform care—Because the stroke event was a sudden, unexpected life crisis for which few caregivers were prepared or trained, they had little understanding of the functional limitations and care needs of the patient upon discharge. The circumstances were especially difficult when patients were discharged with a catheter, needed insulin or anticlotting injections, had complicated medication regimens, or required other skilled care. One caregiver commented on being concerned about giving her husband insulin injections post-discharge. “He has to take insulin because he is a diabetic, and I’m not so good at that.” [C1] Several months after discharge, she still was uncomfortable with the medication regimen. “The medicine to me has been the hardest thing I’ve had to deal with, being sure the medicine is right. You have to make sure you’re doing it just right, and you’re not a nurse.” [C1]

Assessing the caregivers' understanding of caregiving tasks, such as assistance with toileting and medication management is critical to a smooth transition home. While clinicians are skilled at providing this type of information to caregivers, the caregiver's comprehension and understanding of the stroke survivor's post-discharge level of need for assistance is often not systematically assessed. In rehabilitation, the caregiver will often perform a demonstration of a medical task under the watchful eye of the nurse or therapist, but may lose his or her confidence and become stressed when attempting the same task at home when professional supervision is unavailable.

Willingness to provide care is another area that is critical to successful caregiving. One spouse stated: "I know I couldn't handle him home 100 percent relying on me that every time he wanted a glass of water, he was saying ___ I need a glass of water. I need somebody to help me go to the bath room. I need for you to help me get dressed. That's too much for any one person. I have found out why the caregivers wind up dying first. Because once everything get on you. It was just such an awful load to have to bear. And people hardly, you know I love him, it has nothing to do with love. It has to do with reality." [C11] In this situation, the caregiver realized that she was not willing to assume the full burden of 24/7 caregiving because of the impact it might have on her own health.

Caregiver Capacity

3. Pre-existing health issues—Several caregivers had physical, mental, or emotional problems that made caregiving more challenging. For example, one caregiver's preexisting back problem was exacerbated by repeated transferring of the patient, creating a scenario where further injury to the caregiver or injury to the patient as a result of a fall or being dropped could have occurred. One caregiver stated bluntly, "I've gotten hurt. I've hurt my knee...I've hurt my back. I've had a cortisone shot in my back." She also stated, "I will do this until the day that we finally both crash to the floor or I break a hip or he breaks a rib. Then we will both end up in a nursing home together." [C14] The same spouse described a preexisting depression that was exacerbated by her circumstances of caregiving. "I said there are things worse than death, and this is it. This is the living dead. You're looking at us right here, he and I." [C14]

Thus, a caregiver assessment should assess the health care needs and preexisting conditions of the caregivers in addition to the functional capacity of the stroke survivor to determine when caregiving may increase risk of injury to both members of the dyad, or when placing the stroke survivor in a nursing home or another living situations may be a necessary alternative.

4. Pre-stroke roles and responsibilities—Because of the suddenness of stroke, families do not have time to anticipate and prepare for its long-term consequences. Life will never be the same for many stroke survivors and their spousal caregivers. In our sample, nine stroke survivors and six caregivers were working prior to the stroke. Of these, at the time of our second interview, none of the stroke survivors had returned to work and all of the caregivers either had to quit working or had reduced their work effort to provide care for the stroke survivor.

One caregiver talked about the importance of flexibility on the part of his employer: “I’m very fortunate that my employer has let me, I’m an account manager and I have 5 sites that I check...and they will let me work at night and I wasn’t going in the daytime so I’ll take care of her in the daytime and then I’d do some of my work from the house in the daytime, and I’d go out at night and do some of my work, but they’ve been very good about letting me change my schedule to accommodate her since we didn’t have anybody to take care of her. [C4]

Understanding pre-stroke roles and responsibilities for both the patient and the caregiver, and helping the caregiver anticipate and plan for role changes and new responsibilities post-stroke is an important part of a comprehensive assessment. The assessment should include questions about pre-stroke work efforts, child care or other dependent care responsibilities, work load division within the dyad, whether the caregiver believes she/he can manage existing responsibilities while assuming the new caregiving tasks, and who else may be able to help provide assume some of the additional duties.

5. Accessibility of the home environment—Prior to the stroke patients’ discharge from rehabilitation, caregivers were faced with the details of preparing the home environment. For example, this included modifications in the bedroom, such as moving in a hospital bed or rearranging furniture, and in the bathroom, such as installing handrails or raised toilets. In many instances, caregivers required skilled workers and financial resources to install handrails or a ramp for home accessibility. “We didn’t have any handrails for the front steps to start with, and we had to put up a set of handrails to make it easier to get in and out of the house. Also, we installed some handrails to get in and out of the tub.”[C6] For some families, the only way they could manage the demands of caring for their loved ones at home was by moving to a different location. This also required financial and logistical resources. For instance, one dyad had to move in with their daughter and grandson upon discharge from the IRF because they had been living in a recreational vehicle (motor home) that was no longer accessible. Because the daughter did not have enough room in her apartment, the family had to rent a new apartment and move—all in a matter of a few weeks while the stroke survivor was in rehabilitation.

There is strong evidence for conducting a pre-discharge home visit to evaluate the home environment, yet in the U.S., this is not routinely done. Therefore, rehabilitation professionals need to think of other ways to access this information. The caregiver who lives in the home is the best informant for assessing the barriers to care in the home. Accessibility of entrances, doorways, surfaces, bathrooms, and bedrooms should be evaluated. A description of the home environment where the patient will be living is usually included in the patient assessment process. However, obtaining the perspective of the caregiver regarding potential issues or asking specific questions about carpeting, placement of furniture, and layout of bathrooms and bedrooms may be overlooked. Asking the caregiver to provide a video or photographs of the home environment would provide additional assessment information helpful in discharge planning.

6. Availability of informal support resources—The support of other family members, friends, or people in the community was considered critical to a successful return

home according to the participants. The experiences ranged from positive and supportive—“we have friends who bring food, and we've done a little cooking but not much” [C13]—to significant lack of expected support. In addition, adult children were sometimes a source of conflict. Whether biological or step-children, they sided with one parent or the other—the caregiver or the stroke survivor—creating increased tension and frustration in the relationship. In one case, an adult daughter blamed her mother, the caregiver, for not immediately recognizing her dad's stroke symptoms, even though they were not classic symptoms. In another case, the adult daughter blamed her father, the stroke survivor, for not trying hard enough to improve and help her mother, the primary caregiver, with his care. In the cases of step-children, one spouse often blamed the other spouse's children if they did not help out, as this dialogue between one couple suggested:

Wife: “His son is traveling.”

Husband [Stroke survivor]: “My son travels all over the world.”

Wife: “He didn't have time [to come visit his dad].”

Husband: “He's in Hong Kong and Asia and London, and all.”

Wife: “It's just excuses... I'm sorry. I just don't buy it. It's his father for God's sake.” [C2]

Often, expected and promised help from adult children and friends did not materialize as described by another caregiver.

When he came home [from rehab] two of them [adult children] were here, and they stayed. I've heard over and over about how much money they lost ...Everybody makes you feel guilty for being needy. And I'm not normally a needy person and neither is he.... Where is the support system? Where is everybody? Where are all the friends? There was a stack of cards this high that were sent to him. There's a stack of people this big that came to see him for more than 2 minutes. And we lost everything, and it's such a feeling of overwhelming hopelessness. [C14]

A systematic caregiver assessment should include creating an accurate and realistic list of people who can be called upon to help in the transition. Identification of specific needs and who in the informal support system is willing and able to help is an important part of the assessment. Looking at this information from a family systems perspective may be helpful, especially if there is evidence of dysfunctional relationships at the family level.

7. Financial resources—“The suddenness of increased [medical] expenses and decreased income” as described by one caregiver [C10] was difficult for many dyads to manage post-stroke. A clear understanding of the financial situation of the family is critical to planning follow-up services and support. For example, a couple with resources may be able to hire outside help when needed, while a couple with limited resources may not have that option even for respite care. Furthermore, navigating the U.S. social support systems designed to provide financial assistance in times of medical crisis proved to be quite challenging for many caregivers, as described here:

We applied [for Social Security benefits] in July, but we have to wait until January to find out if we're going to be approved. So we have no income coming in. And we have been told, or warned, that we may not get it. They have no compassion whatsoever. We waited in line for food stamps, and we had applied for everything else we could think of. I took him [stroke survivor] over to the food stamps office. We were waiting for 2 hours. Finally, one woman came out who seemed knowledgeable. I said something like, "Well, you know, it is noon, and I have to take him home to get something to eat [because of his diabetes]." I said, "How much longer? And she said, "Well, there are six people ahead of you, and you'll just have to wait." So I said, "I'm sorry." Then they called the next day and said, "You didn't make your appointment." I said, "Yes I did. You just didn't take us. [C8]

Because the formal social safety net in the U.S. is fragmented and each system has its own eligibility criteria and application procedures, an individual with a stroke or a caregiver may need a sensitive assessment and timely assistance to make sure that needs are met prior to discharge. Caregivers also need to be assessed on their understanding of the complex issues of insurance, wills, power of attorney, health care surrogacy, long-term care costs, and information or interventions provided when needed.

8. Pre-stroke caregiver experiences—Having educational, work, or life experiences gave some spouses the skills they needed to assume the caregiving role. One caregiver said, "I didn't have to figure out anything because we had taken care of her mother for 17 years with a stroke. And so, I more or less knew what we had to do." [C13] Other caregivers had previous experience as nurses or in other health care professions. However, this sometimes created unrealistic expectations about what they could do post-discharge. One caregiver who had been a nurse for several decades and did not expect to have any problems caring for her husband post-discharge described how it had been a "challenge" and that assuming the care 24 hours/7 days a week gave her a "whole different perspective" about how difficult caregiving was. She described how she was exhausted from regular interruptions from her husband for assistance throughout the night. This made them become "irritable with each other." [C9] In other instances, caregivers found that they had to give up or reduce their external workload. For those who enjoyed being employed or needed the income, cutting back or quitting a job caused added stress.

It certainly has been an adjustment. Being torn between needing to go back to work and trying to balance everything so that everything flows smoothly and all things are attended to, so you don't take away from his [stroke survivor's] care. [C10]

Without an adequate understanding of the pre-stroke life experiences of the patient/caregiver dyad, it is impossible to develop a discharge plan that will meet their needs as they transition home

9. Sustained capacity to provide care—An assessment should include a discussion about whether the caregiver has thought about how he/she will sustain the long-term caregiving responsibilities. During inpatient rehabilitation, caregivers focused on the present and had not thought about the long-term implications of stroke to themselves, the stroke

survivor, and the extended family. However, once they were home and had been providing care for some period of time, they began to realize the enormity of the role:

It's just, this is never going to end. It's never going to end. He's the same today as he was yesterday and the same tomorrow and the same next week. He just had his 69th birthday, this could be forever. [C12]

Discussing the long-term implications and assisting caregivers develop a plan to sustain the caregiving role long-term while finding time to care for self should be a priority of a comprehensive rehabilitation plan.

10. Strategies for self-care—Family members described coping strategies of exercising, reading, or even working for stress relief. “The trick is to keep a balance. I don't need to work full-time, but I need something. Work is my therapy. My husband [the stroke survivor] likes me better when I go to work, too.”[C9] However, many caregivers indicated they were unable to care for themselves because their focus was on the stroke survivor. They missed their own medical appointments, forgot to take their medications, and gave up exercise regimens and social contact with friends. In one particularly distressing interview, the caregiver described a crisis she was experiencing before the interview. The home health therapist was so concerned about the mental health of the caregiver that he insisted that the caregiver go to her doctor right away. As the caregiver explained: “I knew he went over and talked to someone over there because they called me and said, you have an appointment at 1 o'clock, 1:30 come in, and I said, I can't come in at 1:30. I said I have no way to get there. They said you can't find someone to watch your husband for an hour. I said believe it or not that's absolutely true.” [C14] Finding coverage for an emergency, much less a regular appointment, seemed to be a huge obstacle to her self-care.

Caregivers need to be asked about their coping styles and existing strategies for self-care. They should be encouraged to continue to engage in healthy coping and self-care activities, such as taking time for hobbies, socializing with friends, and maintaining their own health so that they may continue to be effective caregivers for the long term. A systematic assessment can help to better understand how they care for themselves and identify post-discharge strategies to help them continue with activities to promote their own health and address issues of ineffective stress management.

Overall Concerns

11. Stroke as a crisis—The stroke event represented a sudden, unexpected life crisis for all of the caregivers.[19] By the time the stroke patient was admitted to rehabilitation, the caregiver's apprehension of the potential imminent death of the loved one had passed, but the outcome and long-term prognosis were still uncertain. Stroke patient caregivers found themselves in unfamiliar territory and often had no previous experience on which to base their current situation. One spouse indicated her anxiety about the experience, “I didn't know what to expect because it was all new to me, including stroke and heart attack.” [C8]

Furthermore, caregivers used the patient's pre-stroke function as a basis for future expectations, while therapists focused on improving function from the patient's baseline

upon entering rehabilitation. This created a disconnect for many caregivers and increased their uncertainty of what the future would bring.

It took me a long time to buy into the rehab therapists ... being pleased with small little gains and I tried to look at it from their point [of view]. They know nothing about him. They do not see him until the first day he is here. So that is the history they have of him, so every little thing that he does that gets better they see as great progress. It's very difficult [when they didn't] know the way he was before the stroke. [C12]

A comprehensive caregiver assessment should begin by using a crisis intervention approach [55, 56] to discover the nature of the event and its meaning to the caregiver, as well as the adjustment phase of the caregiver. The grief response can be very strong as indicated by this spouse approximately 3 weeks after discharge.

Maybe mine was an overreaction to be sitting huddled on the floor with the blanket wrapped around me, but you know people have moments of grief.... Life has been ripped out from under him. All of it, other than the fact that he's still alive and living and breathing...I really haven't had any time to grieve; it's been nonstop. [C14]

The consequences of unacknowledged grief, anxiety, and fears of the caregiver may have long lasting repercussions.

12. Long-term meaning of stroke—Several months post-discharge, many caregivers were just beginning to recognize the long-term impact of stroke on their lives. They began to realize that the plans they had made for retirement were no longer realistic and what may have seemed like a bright future was now forever changed by the stroke. For example, one wife described how she and her husband had plans to travel extensively in retirement, but a severe stroke left her husband with significant functional limitations requiring around-the-clock care. Another caregiver shared similar feelings, stating, “You have to redesign your entire life. I mean, literally, life will never be the same.” [C10]

The loss and grief that accompany the functional limitations of stroke are profound and chronic. Caregivers and patients need ongoing support and advocacy to assist them as they try to reconcile and integrate the devastating loss related to stroke. A caregiver assessment should also include a holistic assessment of the meaning of the stroke event on the caregiver's life story and the implications of the positive and negative aspects of caregiving on the overall well-being of the caregiver. Acknowledging the rewards and challenges of the caregiving experience early in the rehabilitation process may give the prospective caregiver the personal strength to commit to the future of caregiving.

Discussion

In the interviews from this study we identified multiple unmet needs of caregivers that should be addressed both at the IRF and after discharge home. We have developed recommendations in the following areas: the need for 1) conducting a comprehensive, systematic caregiver assessment when the patient is admitted to the IRF to identify potential

post-discharge risks; 2) addressing unmet needs through caregiver support, advocacy, and transitional care interventions; and 3) recognizing stroke as a family crisis and implementing crisis intervention and family counseling strategies for family's identified as most risk for poor post-discharge outcomes.

First, a comprehensive, systematic caregiver assessment to understand the caregiver's commitment, capacity, and overall concerns about stroke will help the rehabilitation team to develop a plan to address unmet needs and better prepare family caregivers to take on the caregiving role. The typical IRF admission assessment tool includes only a few lines for family and psychosocial history. Caregiver needs are overlooked because the caregiver is typically viewed as a resource for the patient, rather than someone who needs support and assistance. Findings from this study and other research, [15, 19, 20] strongly confirm the need for an in-depth caregiver assessment interview. The twelve domains described here are to be assessed soon after the stroke patient is admitted to the IRF (see Table 2). They overlap with some of the domains identified by Feinberg [35] including caregiving context, knowledge, physical and mental health, social support, financial, legal and employment information, and coping strategies. Prior to discharge, data from this interview should be combined with data about the care recipient's functional level and the specific tasks that the caregiver needs to do to develop a post-discharge risk profile. On-going, post-discharge caregiver assessment should include Feinberg's [35] domains of competence and confidence in the caregiving role, and the positive aspects of caregiving.

Existing caregiver assessment tools are designed to evaluate caregivers after they have been providing care for some period of time, when they already have a good understanding of the demands of caregiving. Findings from this study suggest that a primary prevention approach to caregiving is needed, where the potential risk factors for poor outcomes for caregivers and stroke survivors can be identified during inpatient rehabilitation. Based on the 12 domains identified in the study reported here, we have developed and are currently piloting a focused caregiver assessment interview to be conducted early in the rehabilitation process. The interview is conducted with stroke caregivers while their family members with stroke are receiving inpatient rehabilitation and includes questions focusing on the 12 domains identified in this study.

Second, in addition to conducting a caregiver assessment, caregivers also need someone who understands their particular situations and can provide them with support tailored to their needs and advocate for them with formal support services such as Social Security, food stamps, transportation services, and home health care. Simply providing caregivers with a list of agencies and phone numbers, expecting them to make initial contacts and applications, often increases their burden, especially if they are not familiar with the specific services of each agency and the types of questions to ask.

For those issues that cannot be addressed sufficiently during inpatient rehabilitation (e.g., when patient's needs surpass caregiver's capacity), a transitional plan of care should be developed that addresses the post-discharge care and support needs for the patient *and* caregiver. More comprehensive than the standard discharge plan that patients currently receive, the transitional plan should include services traditionally covered in the current

discharge plan (e.g., home health care, appointments with the primary care provider, and prescriptions) and additional services, such as referrals for counseling, social services, case management, transportation, management of activities of daily living and respite care. Respite services, such as adult day care services, in-home respite, or institutional respite, are particularly important to provide caregivers with needed time for themselves to engage in self-care activities, including social activities, recreation, running errands, or getting needed rest.

Many facilities provide support groups for caregivers. For the caregivers in this study, support groups were not usually a reasonable option because the caregivers could not leave the stroke survivor at home alone to attend a support group. Furthermore, during the transition home and in the first few months following discharge, the time when caregivers needed the most assistance, support groups were viewed as one more obligation that they did not have time or energy to attend. Instead, in this critical time, they needed assistance with the day-to-day management of the multiple responsibilities they were shouldering. As one caregiver explained, "I didn't need support; I needed help."

Third, stroke is a crisis event that leaves patients and families traumatized.[19, 56] They find they are dealing with issues of loss and grief that are not addressed. Furthermore, family relationship issues that were invisible or not discussed prior to the stroke may become visible and disruptive, making the stroke recovery period more difficult for both patients and family caregivers. Rolland [57] provides a framework for addressing the needs of families in crisis, including tasks such as understanding the family system, understanding the illness in psychosocial terms, grieving loss and accepting the permanence of the condition, sustaining hope, finding meaning in the experience, and establishing a functional collaborative relationship with health care providers. Referral to a qualified family counselor with experience in assisting families through the transitions of life-changing conditions, such as stroke, should be considered. This type of counseling would help those families who are willing to address these issues and resolve or minimize conflict. Home-based counseling services may be an even better option, as adding one more appointment to the already packed schedules of caregivers may not be feasible.

Limitations

There is not agreement on the influence of interviewing members of a couple together in a research study.[58-60] We evaluated the advantages and disadvantages to both approaches and chose to have the spousal dyads decide whether to be interviewed together or separately. This strategy allowed them to participate in the study in the way that was most natural for them. When asked their preferences, our dyads who chose to be interviewed together indicated that they were a couple and that they were comfortable being interviewed together. For those who were interviewed alone, it was because the stroke survivor was not able or available to participate in the interview. When we analyzed the transcripts, we did not identify any differences in the needs of caregivers who were interviewed alone versus those who were interviewed together. Furthermore, this gave us the opportunity to observe the interactions between the dyad which provided additional data about the dyad's relationship that was important to our development of the assessment domains.

The sample size and inclusion of participants from two IRFs may also be considered limitations. However, in this study we analyzed over 1000 pages of transcript data plus field notes which was sufficient to reach saturation on the caregiver assessment domains that we identified during the data analysis. Furthermore, we presented the findings from this study to two caregiver support groups, staff at three rehabilitation facilities, and at several national professional meetings. The feedback from these different venues confirmed our findings and supported the need to disseminate these findings to a broader audience.

Summary

The literature review and findings from this study demonstrate important gaps in research and practice related to improving post-rehabilitation outcomes for stroke patients and their spousal caregivers. Two decades of research have been unsuccessful in addressing the crisis-driven approach to decision-making about resource use and discharge placement for stroke patients, culminating in serious mismatches between the care patients actually need and the capacity of spousal caregivers to realistically provide it. A focused, in-depth caregiver assessment and a discharge plan that reflects the findings of the assessment should go a long way toward addressing the needs of stroke survivors and the people who care for them. A next step identified from this research is to create a comprehensive caregiver assessment protocol to help identify areas of concern as a first step to better prepare family members to assume the caregiving role.

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Table 1**Participant Demographics**

	Mean	Range
Caregivers (N=14)		
Age	63	49-82
Stroke Survivors (N=14)		
Age	66	51-84
Admission FIM™		
Total	50	28-73
Motor	27	12-47
Cognitive	23	13-32
Discharge FIM™		
Total	80	56-105
Motor	54	32-73
Cognitive	26	16-32

Table 2**Caregiver Assessment Domains and Recommendations**

Caregiver Assessment Domains	Caregiver Assessment Recommendations
Strength of dyad relationship	<ul style="list-style-type: none"> • Nature of the pre-stroke relationship • Potential sources of conflict • Level of commitment to continuation of the relationship
Understanding of and willingness to perform care	<ul style="list-style-type: none"> • Understanding of the amount and types of care needed • Willingness to do some tasks but not others
Existing physical and mental health issues	<ul style="list-style-type: none"> • Health care needs and preexisting conditions of the caregiver in light of the functional capacity of the stroke survivor • Determine when caregiving may increase risk of injury to either
Pre-stroke roles and responsibilities	<ul style="list-style-type: none"> • Pre-stroke employment of caregiver • Child care or other dependent care responsibilities • Work load division within the dyad • Addition of new caregiving tasks
Accessibility of the home environment	<ul style="list-style-type: none"> • Accessibility of entrances, doorways, surfaces, bathrooms, and bedrooms • Caregiver should be consulted on potential changes needed
Availability of informal support	<ul style="list-style-type: none"> • Accurate and realistic list of people who can be called upon to help in the transition • Identification of specific needs and who in the informal support system is willing and able to help • Assess for evidence of dysfunctional relationships at the family level
Financial resources	<ul style="list-style-type: none"> • A sensitive assessment and timely assistance to make sure that needs are met prior to discharge. • Assess understanding of the complex issues of insurance, wills, power of attorney, health care surrogacy, long-term care costs
Pre-stroke caregiver experiences	<ul style="list-style-type: none"> • Educational, work, or life experiences gave some spouses the skills they needed to assume the caregiving role
Sustained capacity to provide care	<ul style="list-style-type: none"> • Long-term implications and plan to sustain the caregiving role while finding time to care for self
Strategies for self-care	<ul style="list-style-type: none"> • Coping styles and existing strategies for self-care. • Continue to engage in healthy coping and self-care activities, such as taking time for hobbies, socializing with friends, and maintaining their own health so that they may continue to be effective caregivers for the long term.

Caregiver Assessment Domains	Caregiver Assessment Recommendations
Stroke as a crisis	<ul style="list-style-type: none">• The stroke event represented a sudden, unexpected life crisis• Outcome and long-term prognosis still uncertain
Long-term meaning of stroke	<ul style="list-style-type: none">• The loss and grief that accompany the functional limitations of stroke are profound and chronic• Caregivers and patients need ongoing support and advocacy to assist them as they try to reconcile and integrate the devastating loss related to stroke• A holistic assessment of the meaning of the stroke event on the caregiver's life story• Implications of the positive and negative aspects of caregiving on the overall well-being of the caregiver.