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The Impact of Interactions with Providers on Stroke Caregivers' Needs

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Abstract

Purpose—Preparation for caregiving is improved through engaged interactions between stroke family caregivers and healthcare providers throughout the care trajectory. We explored caregivers' perceptions about interactions with providers in rehabilitation, and how these experiences affected caregiver preparation.

Design—Seventeen caregivers, included in this grounded theory study, were interviewed during a rehabilitation stay and post-discharge. Data were analyzed using dimensional and comparative analysis.

Findings—Caregivers described interactions with providers on a continuum from collaborative to disconnected, and a range of strategies to enhance interactions.

Conclusions—Caregivers want to be actively engaged with providers during inpatient rehabilitation and collaborative interactions enhance preparedness and care satisfaction.

Relevance—Family members should be assessed for caregiving capacity and interactions between providers and caregivers should be individualized to specific needs. Providers must also be aware that many caregivers are not active information seekers. They must engage caregivers who may not even know what questions to ask.

Keywords

stroke; caregiving; family-centered care; interaction; qualitative research

“Every 40 seconds, someone in the United States has a stroke” (Roger et al., 2012, p. e100). Of the nearly 800,000 strokes that occur each year, approximately 75% are first-ever attacks. Although stroke is still one of the top causes of death, mortality rates have been declining, resulting in greater survivorship. Many survivors have long-term disabilities requiring varying levels of ongoing assistance (Kelly-Hayes, Beiser, Kase, Scaramucci, D’Agostino, & Wolf, 2003), most of which is provided by family members following discharge home (Sumathipala, Radcliffe, Sadler, Wolfe, & McKevitt, 2012; Dewey et al., 2002). These families often have little time to prepare themselves and their homes for this new caregiving role, owing both to the abrupt nature of the stroke and short lengths of stay in the acute and rehabilitation settings. Considering less than a third of survivors will receive further

outpatient rehabilitation (Centers for Disease Control and Prevention, 2010), it is imperative that families be included in all aspects of care as early as possible.

Only 4–20% of caregivers are currently involved in family members' therapy in rehabilitation (Monaghan, Channell, McDowell, & Sharma, 2005), despite literature showing its positive impact on survivors' functional and psychosocial recovery (Harris, Eng, Miller, & Dawson, 2010; Maeshima et al., 2003; King, Shade-Zeldow, Carlson, Feldman, & Philip, 2002). Further, stroke survivors and their family caregivers note educational needs important to the provision of care that continue to be unmet by healthcare providers (Hafsteinsdóttir, Vergunst, Lindeman, & Schuurmans, 2011), despite their reliance on providers as the primary source of this information (Cameron, Naglie, Silver, & Gignac, 2012). These include a desire for more information regarding diagnosis and prognosis (Garrett & Cowdell, 2005), education on fall prevention and proper nutrition (MacKenzie et al., 2007), and training to manage survivors' behavioral changes and physical care needs (Hinojosa & Rittman, 2007; Bakas, Austin, Okonkwo, Lewis, & Chadwick, 2002). Some caregivers are able to obtain this needed information and training by taking the initiative and seeking it out (Brereton & Nolan, 2002). Others either do not seek out information on their own or they experience significant barriers to acquiring it, such as limited availability of information and limited time with healthcare providers (Eames, Hoffmann, Worrall, & Read, 2010).

In addition to identifying and meeting family members' needs as they relate to providing care to patients post-discharge, caregivers must be assessed for their commitment and capacity to provide this care. While caregiver assessments have been proposed, these are generally based upon caregivers' self-care needs and levels of burden after the initiation of the caregiving role (Guberman, 2006; Family Caregiver Alliance, 2006). Family caregiver assessment must occur early and throughout the trajectory of care in order to provide healthcare teams with the opportunity to identify family strengths and problems in coping and illuminate possible barriers to successful caregiving. "Family well-being is jeopardized if caregiving demands exceed a threshold unique to that family system, and the collapse of the family system will in turn harm the patient who has sustained the stroke" (Brashler, 2006, p. 14).

Adopting a family-centered care model is one way for providers to increase caregiver involvement, assess families' ability to handle these new roles, and facilitate caregivers' access to needed information, education, and support (Visser-Meily et al., 2006). Such a model of care encourages collaboration among patients, families, and providers with respect to the planning, delivery, and evaluation of health care in order to individualize care for patients and families (Institute for Patient- and Family-Centered Care, 2010). Family members are constant supports in patients' lives who will be with them long after discharge and yet they are often relegated to passive roles in healthcare. By actively involving family caregivers throughout the trajectory of care, providers have the opportunity to ensure individualized patient care and provide ongoing family education and training. Involvement in care planning has also been shown to improve caregiver satisfaction with and ability to care (Shyu, Chen, Chen, Wang, & Shao, 2008; Bull, Hansen, & Gross, 2000). Additionally, current stroke clinical practice guidelines have identified the need for caregiver education and involvement on multidisciplinary teams (Management of Stroke Rehabilitation Working Group, 2010; Duncan et al., 2005; van Heugten, Visser-Meily, Post, & Lindeman, 2006) as well as caregiver mental and physical assessment, information provision, and counseling (Miller et al., 2010).

The purpose of this study was to explore the experiences of family caregivers of stroke patients as they interacted with healthcare providers in the rehabilitation setting. Within the

context of these interactions, we also sought to identify how caregivers discussed their needs and how prepared they felt to take on the caregiving role. We were interested in exploring how caregivers were involved in the rehabilitation setting and whether or not these were consistent with the practice of family-centered care and current clinical practice guidelines.

Methods

The data set for this study consisted of interviews with 17 stroke family caregivers. These interviews were part of a larger, on-going grounded theory study exploring stroke caregivers' experiences and needs as they transitioned from inpatient rehabilitation to home. The goal of the parent study is to understand caregivers' expectations for caregiving and to develop a risk profile of the stroke patient/caregiver dyad. During analysis of the interviews with patients and caregivers in the parent study, it became apparent that the caregiver/provider interaction was an important part of the caregivers' experiences and needed further exploration and analysis.

Data Collection

After receiving institutional review board approval from the university and inpatient rehabilitation facilities (IRF), English-speaking patients - experiencing their first stroke and who planned on being discharged home - and their family caregivers were informed about the study by members of the IRF stroke team. Patients and their primary family caregivers who were interested in participating were then contacted and consented by a member of the research team prior to the first interview. Interview times were set up with interested patients and family members while the patient was still in rehabilitation or as close to discharge as was convenient for the caregiver. The second interview was conducted within four months of discharge in a location convenient for caregivers and survivors. All interviews were conducted by the principal investigator (PI) (second author) or one of the study research assistants (RA). The RAs were trained by the PI in qualitative interviewing techniques and all hold a master's degree in nursing science. Interview questions for the study were loosely structured, focusing on pre-discharge expectations and post-discharge experiences. Interviews began with open-ended questions such as, "What skills and information do you think you will need to care for [patient's name] at home?" and "How could the staff at the rehab hospital have helped you prepare for being at home?" As participants discussed their interactions with providers, we asked follow-up questions to further explore their experiences. All interviews were audio-recorded, transcribed verbatim by a professional transcriptionist, and verified for accuracy by the interviewer. This study includes interview data from 17 stroke family caregivers from two IRFs, 6 from Site 1, and 11 from Site 2.

Data Analysis

We specifically explored the data for descriptions of experiences of stroke family caregivers as they interacted with healthcare providers in the rehabilitation setting. We sought to examine how these caregivers identified and discussed their needs within the context of these interactions and how this impacted their preparedness for the caregiving role. Specifically, the following questions informed our data analysis: What are caregivers' self-defined needs during their stay at the IRF, as they prepare for discharge, and upon discharge home? How do caregivers describe the interactions they had with healthcare providers while the patient was in the IRF? How are these interactions described in the context of identifying and meeting their self-defined needs? What are the experiences of caregivers who directly approach healthcare providers with specific needs versus those that do not?

Data were analyzed using dimensional analysis (Bowers & Schatzman, 2009; Schatzman, 1991) and comparative analytic strategies (Charmaz 2006; Strauss, 1987) within a symbolic

interactionist perspective. Symbolic interactionism is a sociological perspective that relies heavily on language and communication, enabling researchers to understand social interactions (Charon, 2010); dimensional analysis is an analytic method by which grounded theory of a phenomenon can be generated (Bowers & Schatzman; Kools, McCarthy, Durham, & Robrecht, 1996; Schatzman). Analysis based upon this framework begins within the data and is built up through induction, such that the resulting explanatory model is grounded in data (Bowers & Schatzman; Schatzman).

Data were analyzed in progressive states, initially hand-coding paper copies of the transcripts line-by-line, focusing on the emerging categories and themes pertinent to the research questions. The research questions relating to caregiver/provider interactions were identified from early analysis within the parent study; we began to code specifically around the construct of interaction after its identification. This axial coding allowed us to dig deeper in the data in a more focused and theoretical manner (Corbin & Strauss, 2008), identifying over 100 related codes. These codes were transferred onto index cards and several card sorts were conducted among research team members and within a qualitative data analysis group at the university. The themes and categories identified were organized into an explanatory matrix, which helped us further identify and explicate the context, conditions, processes, and consequences of the central perspective of interaction (Kools, McCarthy, Durham, & Robrecht, 1996; Santos, 2006; Schatzman, 1991). Such a method was helpful in illustrating the connection between groupings of data and to assist the researchers in reaching consensus about the developing model. Throughout the analytic process, we continued to compare and contrast developing ideas, themes, and categories within and across interviews in keeping with the constant comparative technique central to grounded theory methodology (Corbin & Strauss, 2008; Strauss, 1987).

The analysis was led by the primary author in close collaboration with the PI and Co-investigator (Co-I); both the PI and Co-I are experienced qualitative researchers. A multidisciplinary research team and a qualitative data analysis group consisting of faculty and both graduate and undergraduate honors students helped with the card sort and to revise the developing model. The primary author met weekly with the research team as part of the main study and to discuss ongoing analysis. Memos and modified coding records were also kept as part of an ongoing audit trail.

Study Participants

For this study, we included interviews from 17 family caregivers (13 spouses, 2 adult children and their spouses; 7 males, 10 females) from two IRFs; 2 caregivers were Black and 15 were White. Because two caregivers were not available at the time of the first interview during inpatient rehabilitation, only 15 caregivers completed the first interview; all caregivers completed the second interview within four months post-discharge for a total of 28 interviews. Many families wanted to discuss their experiences together, therefore twelve stroke survivors (7 males, 5 females) and three other family members (all male, who were not primary caregivers) also participated in at least one interview. At the time of the second interview, one of the stroke survivors had been readmitted to the hospital and one was living in a subacute facility. The average age of the stroke survivors was 69 years (range 51–84), and the family caregivers' average age was 65 years (range 43–83). The average discharge FIM™ score of stroke survivors was 82, with a range of 57–105. The FIM™ is an 18 item functional status measure used in inpatient rehabilitation. It has six domains related to cognitive and motor function and has been validated with inpatient rehabilitation populations; total scores range from 18 (totally dependent) to 126 (totally independent) (Keith, Granger, Hamilton, & Sherwin, 1983).

Findings

As families anticipated eventual discharge home, they expressed concerns over their preparation for the new caregiving role. This preparation included the need for information, which caregivers and stroke survivors expected to be obtained through their interactions with rehabilitative healthcare providers. As they attempted to navigate through the rehabilitative process and prepare for discharge home, family caregivers experienced a wide range of interactions and attempted to manage these through various strategies of their own. Participant quotes are included from both pre- and post-discharge interviews, as their perceptions of their interactions with providers did not appear to shift between these two times.

Caregivers' Information Needs and Concerns

The caregivers in this study identified several types of information and educational needs as they prepared for the stroke survivors' eventual discharge home. They also discussed numerous concerns they had about the care the stroke survivor received during rehabilitation as well as concerns regarding their own preparation for assuming a full-time caregiving role. "Well one of the things that's uncertain is not knowing when she's coming home and also not knowing what level of care she'll need" [C15].

Information needs focused on prognosis for recovery, how to provide care for the stroke survivor post-discharge, and resources that might be available to assist them with post-discharge caregiving. Topics included physical care, medication administration, diet, home accessibility, insurance issues, and post-discharge therapy. "I'm afraid I'm going to help him too much and he won't get better, so I don't know [about the need for preparation and assistance]" [C9]. Unfortunately, this information could change day-by-day depending on the stroke survivors' recovery. "Well, I've been thinking about it all along but probably another week when we know, have a better idea of where we are..." [C1] Regardless, caregivers generally wanted this information early on in order to prepare themselves. "It'd be nice when a patient is in the hospital and has had her stroke, or his stroke, if there was some information on, okay, these are some of the issues you're going to be facing. Like where should she go from the hospital, or what could happen, how much more extensive care they may need, you know, just to kind of give us more of an idea what we're headed for" [C12]. They were also concerned about their own emotional support needs and providing emotional support for the stroke survivor, concerns they felt were often not adequately addressed. One caregiver suggested that "the biggest thing is how to handle things mentally," while another mentioned that "it would be nice to have something like a family therapist" to help them address these needs. While discussing the management of her husband's altered mental state, this caregiver noted, "If they did [discuss it with me], I don't remember it either." [C1].

Caregivers were also concerned that providers knew about patients' pre-stroke life; these family members wanted to be involved in decisions about patients' preferences for care. They believed that their knowledge of their family members' pasts would be helpful to providers in developing treatment plans. "I think I could provide a little bit of input...a voice for my mother...I could probably also provide a little bit of history" [C12]. They were also very concerned about the long-term implications for stroke and every family discussed uncertain expectations for what life after discharge might bring. These ranged from a return to pre-stroke life to one of adaptation and adjustment – "Nobody said you couldn't work. Maybe you can't do the same job you were doing before...We've all changed jobs" [C4].

Caregivers looked to the rehabilitation physicians, therapists, nurses, and other staff to address their concerns and meet their needs for a successful transition back home.

Caregivers and patients depended on this information from providers in order to make plans for discharge. “The case manager told me she would give me a list of the things that we would be needing...I don’t know [what I’ll need] until the case manager maybe tells me today” [C13]. Necessary information regarding patient safety at home, continued therapy needs, and the proper administration of medication was not always provided in a way that was understandable for the family caregivers – “They say [the insulin is] on a sliding scale here, which to me I don’t think is working as well as the one before each meal, but I don’t know, it’s just me I guess saying that” [C13]. Some caregivers sought out this information via alternate means – “They don’t have any information...I even went online” [C10]. Most caregivers, however, relied on their healthcare providers and were left without necessary assistance if providers did not give them this information. “I don’t really know what to expect” [C9].

I don’t know where to go to get occupational or speech therapy on my own...They never gave any suggestions as to what were my other options...or if there was an agency or...a health care that I could have gotten. [C1]

Caregiver-Provider Interactions

Caregivers’ identification of their educational, information, and post-discharge preparation needs was an ongoing process throughout patients’ stay at IRF. Because providers base care plans and discharge dates on patient progress, caregivers’ needs could change from one day to the next. How providers interacted with caregivers in turn influenced how families identified and managed these changing needs. The caregivers we spoke to described their interactions as ranging from disconnections to collaborations, as illustrated in Figure 1.

Toward disconnection—Some caregivers’ interactions with providers were seen as disconnected and uninvolved. Caregivers who wanted more dialogue with providers or felt that their attempts at interaction were unsuccessful often felt that they were perceived as bothersome or that their providers were “too busy” or just in it “for the job” – “The technical side works...The personal side does not work” [C12]. Although not experienced by most caregivers, some discussed instances where they were outright degraded – one involved spouse recounted his being called “the hemorrhoid” – or otherwise ignored by their providers.

I asked [one health care provider]...and he looked directly at me and then looked over to the [other health care provider] and just started talking and completely ignored me. So I brought it up again, and he ignored me again. He ignored me several times. [C10]

Because families and patients often arrived at the IRF with specific goals and timelines for recovery that did not always coincide with that of the healthcare team it was important for providers to explain the rationale for treatment and discharge criteria as early as possible. When this information was not provided or understood, both patients and families became frustrated, confused, or even hesitant to continue with treatment.

[We were] led to believe that my mom would be here for potentially up to three months, as long as it was still evident that she had the ability to continue to progress. And then...only about less than two weeks ago [we were told the discharge date] and we thought, “Well, how could you ever come to that conclusion?” That was a little bit disappointing. [C12]

The first day he was here he called me wanting to get out of here...That may be one thing they could have explained to him a little better, that the first couple days you’re going to get frustrated because we’re going to have to figure out where you

are, and maybe they didn't explain... There was nobody that really took us through that and explained that. [C1]

Family members had a desire to engage providers in an effort to resolve these issues and believed that their input would lead to better quality, individualized care. Some felt dismissed, and this lack of being listened to led to increased caregiver frustration and dissatisfaction with care. "It gets frustrating as a caregiver to be his daughter and say, 'Hey, you know, this is probably the reason why he's doing this,' and to not be listened to" [C10].

Caregivers also wanted to know what to expect, in general, on the day of and those days following discharge home. Although they usually found it helpful to ask their providers questions concerning post-discharge needs and expectations, difficulty arose when caregivers were not prepared proactively.

No one's talked to us...I'm personally disgusted with it. [C4]

I was given some prescriptions the day of discharge and I wish I'd known maybe a day or two ahead what they were prescribing because I went and filled them all and I had some medications already on hand she'd previously taken I could've used. [C15]

While caregivers acknowledged part of their responsibility was to inquire about some of their needs, many did not even know where to begin. "It's hard to ask questions about things when you don't know [what to ask]" [C2].

Toward collaboration—Other caregivers painted a very different picture of their interactions with rehabilitation staff, discussing their interactions with providers as more collaborative and engaging. While not all of these family members felt that they were 'part of the team,' many described being kept up to date and informed by providers or having some level of involvement in patient care and decision-making. It was important to these caregivers that necessary information was provided in a timely manner, that this information was pertinent to the care of their loved ones, and that providers ensured they understood the importance of this information. "They were always so wonderful about telling me what they were doing and why they were doing it" [C11].

When caregivers were invited to ask questions and felt that providers were attentive in their responses, they felt more prepared in their abilities to take on their new caregiving role. Caregivers also discussed the positive experiences of being involved in patients' therapies, and how this added to their sense of preparation and confidence.

We had a discharge meeting, and they went over everything that was going to happen at discharge, and we had a question and answer period so we could have asked any questions, and we did ask a few questions. [C7]

So it was a very good learning experience... The thing I like about the [IRF] is making you a part of it... you feel like you have achieved something... So then the nursing staff doesn't worry... It's a great feeling. [C11]

Caregiver involvement included not only asking questions and training, but also being listened to by providers regarding concerns they had for their family members' care or suggestions they had for healthcare providers in tailoring care and education to their specific needs. A few caregivers discussed how providers engaged them as 'experts' in patients' normal/baseline status, and how the information they provided served to assist providers in care. "I get a call from the hospital... 'Your wife seems confused. Does she behave like this?'" [C8]. While not all caregivers were explicitly asked for information, it was important to them that their input not be discounted when given. "They didn't ask me for input, but

they accepted my input” [C7]. These caregivers generally considered their interactions with providers to be collaborative and felt more satisfied with the patients’ care at IRF. They were also confident in their preparation for discharge due to both their involvement and the individualized nature of the care provided.

Caregiver Interactive Strategies

In response to their interactions with providers, caregivers employed a range of strategies (shown in Figure 2), from passive to active, in an effort to manage their diverse needs and experiences.

Some families tried to rationalize when information was not provided to them, noting that staff was too busy, it was the insurance company’s fault, “it was the system,” or providers were not aware that some information was not universally known.

I think maybe, because they do it every day, they probably assume that everybody knows what’s going on. [C1]

I think there are a lot of assumptions in there...Maybe that might have been mentioned had I not been a person of, that knew, that had vast knowledge. Maybe that would have been an issue that was mentioned. [C11]

Despite what caregivers believed to be true about why information was not being provided, they nevertheless attempted to manage their situations through a variety of means.

Some of the caregivers we spoke with were more passive recipients of information, those who took no action. These caregivers tended to wait for providers to initiate interactions – when asked about discharge needs, one noted that the family would just wait “for the [discharge] meeting” - and rarely asked for elaboration when information was provided. “I don’t know what the purpose is yet. I didn’t ask...I’m just too laid back to worry about things” [C8]. These caregivers were usually confident that the healthcare team would provide them with any necessary information. If nothing was provided, they indicated that they assumed there was no cause for worry or concern. “And it was nothing earth=shattering, so that was okay, and the next day was gonna be discharge day, so I just figured he’d be ready to come home and we would just continue living” [C2].

Other caregivers moved beyond waiting toward more questioning and watchful diligence, making plans to seek out information without always following through. These caregivers were generally observant and opportunistic. They watched providers with patients and sometimes felt as if they did not need explanations for certain tasks of care. “They didn’t have to show me how to turn the bed alarm off. I saw them do it once, I know exactly how to do it” [C7].

As caregivers became more actively involved, they began to engage with providers by providing explanations and proactively assisting with certain care tasks. They expected that the explanations they provided to the healthcare team would help with individualizing patient care. Family members believed that their knowledge of patients’ pasts and preferences was important for providers to understand in order to tailor treatments to specific patient needs – “The [health care provider] acted like he was a beast because he was poking her...and I told him ‘She’s got a bad shoulder, she’s got bad feet, she’s got a bad hip’” [C8]. These caregivers were also proactive in assisting both patients and providers with daily care tasks without necessarily being asked. “The weekend before [discharge], I came home and I measured [the bed], and then when we went up [to rehab], I raised the bed so it was the same height [as the hospital bed] and I said, “Okay, let’s see how well you can get in and out”” [C7]. By ensuring individualized and tailored care in addition to assisting in

care tasks, these caregivers felt more satisfied with their family members' care and were generally confident in their ability to provide care post-discharge.

Active caregivers were also more direct in their interactions with providers and their pursuit of information. Instead of waiting for providers to initiate conversations, these caregivers approached providers directly with their needs. "I've even asked. I've said, 'Tell me who I need to call, what I need to look for, and I'll do it'" [C10]. These caregivers knew that they would be providing total care after discharge and proactively sought out information and training in order to become proficient in this role. "I take all the menus for comparison here...this is very important. If I maintain [her blood sugar], then I can fix her a proper diet without any overexertion on her" [C5]. Some caregivers spoke of the need to be assertive, even to the point of aggression, in order to get what they needed from providers. These caregivers noted how they sometimes felt like they had to be a "squeaky wheel" or use "as loud a voice" as they attempted to direct providers toward more individualized care for their loved ones. "And after a lot of complaining, then they did start doing it" [C11].

Discussion

Most stroke survivors are discharged home to the care of family members who are themselves thrust abruptly into this new and unforeseen role. Our findings underscore the crucial responsibility of inpatient rehabilitation healthcare providers in engaging caregivers through interactions that enhance their knowledge and preparation for this life changing experience. It is through their interactions with providers that the caregivers interviewed as part of our study came to identify and attempt to meet their various information and educational needs; caregivers' needs identified in this study are consistent with previous research studies (Bakas, Austin, Okonkwo, Lewis, & Chadwick, 2002; King & Semik, 2006), as well as that family caregiver rely on healthcare providers as the primary source of information (Cameron, Naglie, Silver, & Gignac, 2012). Unfortunately, the types of exchanges that were most salient to the family caregivers in acquiring their information and educational needs often did not occur unless initiated by the caregivers themselves. Thus, those who were prone to waiting and doing nothing were left feeling frustrated and dissatisfied with care or unaware of the realities they faced upon discharge. Further, those caregivers who were proactive in seeking information or assistance were not always successful.

Other studies have shown that the level and nature of caregiver involvement depends not only on the assertiveness of the caregiver but also on the practice of individual healthcare providers (Walker & Dewar, 2001) and that providers may actually filter the information provided to family caregivers based upon discipline, training, or personal assumptions (Stirling et al., 2012). Our findings are consistent with those of Nolan & Brereton (2002) who identified ways in which caregivers sought out information and attempted to be more involved in patients' care. Interestingly, our findings also mirror those of Nelms & Eggenberger (2010), whose exploration of families' experiences with critical illness involved a similar range of family-nurse interactions; while some families described their connections as positive and supportive, others revealed negative interactions that increased families' distress during an already stressful time.

Overwhelmingly, the family caregivers included in this study noted the importance of being involved in care decisions and treatment planning, and the desire to have information, training, and care individualized to their family members' needs and preferences. This is consistent with findings from other studies where caregivers wanted their input on patients' needs to be considered by the team, citing the need to be "treated as important and not just a visitor" (MacIsaac, Harrison, Buchanan, & Hopman, 2011, pg. 136). In her autoethnography

on caring for a significant other, Williams (2012) also notes the tendency of healthcare providers to not listen to patient and family preferences or to ignore family members' personal knowledge of the patient.

Implications for Practice

Our findings have important implications for healthcare providers working with stroke survivors and their families. Not only does our study contribute to the literature on the identification of caregivers' needs, but it also provides insight into caregivers' perceptions of their interactions with healthcare providers and the impact these interactions have on how they identify and address these needs. Providers must be aware that not all caregivers will be proactive in asking for what they need; in fact, our findings suggest that many caregivers do not even know the questions to ask and rely on providers to initiate these vital conversations. Providers must therefore be vigilant in not assuming that silence indicates understanding. It is also helpful for providers to be aware of the positive impact on caregivers' satisfaction and confidence to provide care when their input is acknowledged and their questions are sufficiently addressed. These implications are consistent with current practice recommendations for rehabilitation nurses (Miller et al., 2010).

Implications for Research

Our findings also have important implications for future research. While this study focused on caregiver perceptions of their interactions with healthcare providers, future studies should incorporate the perceptions of healthcare providers about their interactions with and needs of stroke family caregivers. This has been shown to be neglected in previous research and has great implications for the development of provider-caregiver communication and collaboration (Hall, 2003). Provider research should also incorporate the actual practices of caregiver collaboration and identify potential barriers to the inclusion of family members as partners in care. Further, continued research is needed to fully explore the processes of caregiver needs identification and attainment from both the caregiver and healthcare provider perspectives in order to identify areas of disconnect for possible intervention. While some studies exist that explore the needs of caregivers as identified by various healthcare providers, these have used descriptive survey methods and may not capture the actual beliefs of providers (Cook, Pierce, Hicks, & Steiner, 2006; Åstedt-Kurki, Paavilainen, Tammentie, & Paunonen-Ilmonen, 2001).

Limitations

The findings of this study are limited by several factors. Our participants were primarily White spouses, thus our findings may not be an accurate representation of the experience of all stroke caregivers. Additionally, the analysis was conducted on an existing data set and, therefore, we did not have the opportunity for further prompting of caregiver perceptions of their experiences with healthcare providers. It also does not account for the actual beliefs, intentions, and actions of the healthcare providers. Such issues may limit the transferability of our findings to stroke caregivers in other settings.

Conclusion

Becoming a caregiver for a family member who has survived a stroke is already a time of stress, loss, and biographical disruption (Greenwood & Mackenzie, 2010). Caregivers have continually identified a need for more preparation for this new role (King & Semik, 2006) and Ostwald et al. found that higher levels of preparedness can help reduce caregivers' stress (Ostwald, Bernal, Cron, & Godwin, 2009). Nurses and other members of the healthcare team are oftentimes the only resources available to family caregivers struggling to adjust to

and prepare for the challenges of taking home a loved one who has just survived a stroke. By including caregivers as partners throughout the trajectory of care – already a clinical practice guideline for stroke rehabilitation – we not only benefit from their expertise on the individual patient but we may also increase their confidence and competence to provide the care they are expected to render at home. One way to initiate this process is to proactively engage families at the bedside and begin to see them as the next providers of care along the continuum. Considering reliance on informal family caregivers is only expected to increase dramatically in the upcoming years (Department of Health and Human Services' Office of the Assistant Secretary for Planning and Evaluation, 2003), there is no better time to start incorporating them as partners than the present.

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References

- Åstedt-Kurki P, Paavilainen E, Tammentie T, Paunonen-Ilmonen M. Interaction between family members and health care providers in an acute care setting in Finland. *Journal of Family Nursing*. 2001; 7(4):371–390.
- Bakas T, Austin JK, Okonkwo KF, Lewis R, Chadwick L. Needs, concerns, strategies, and advice of stroke caregivers the first 6 months after discharge. *Journal of Neuroscience Nursing*. 2002; 34(5): 242–251. [PubMed: 12391740]
- Bowers, B.; Schatzman, L. Dimensional analysis. In: Morse, JM.; Stern, PN.; Corbin, J.; Bowers, B.; Charmaz, K.; Clarke, AE., editors. *Developing grounded theory: The second generation*. Walnut Creek, CA: Left Coast Press; 2009. p. 86-126.
- Brashler R. Ethics, family caregivers, and stroke. *Topics in Stroke Rehabilitation*. 2006; 13(4):11–17. [PubMed: 17082164]
- Brereton L, Nolan M. 'Seeking': A key activity for new family carers of stroke survivors. *Journal of Clinical Nursing*. 2002; 11(1):22–31. [PubMed: 11845752]
- Bull MJ, Hansen HE, Gross CR. Differences in family caregiver outcomes by their level of involvement in discharge planning. *Applied Nursing Research*. 2000; 13(2):76–82. [PubMed: 10842903]
- Cameron JI, Naglie G, Silver FL, Gignac MAM. Stroke family caregivers' support needs change across the care continuum: A qualitative study using the timing it right framework. *Disability & Rehabilitation*. Jun.2012 11:1–10. (epub ahead of print).
- Center for Disease Control. Behavioral risk factor surveillance system: Turning information into health data. 2010. Retrieved from: <http://www.cdc.gov/brfss>
- Charon, JM. *Symbolic interactionism: An introduction, an interpretation, an integration*. (10th ed.). Boston, MA: Pearson Education, Inc.; 2010.
- Cook AM, Pierce LL, Hicks B, Steiner V. Self-care needs of caregivers dealing with stroke. *Journal of Neuroscience Nursing*. 2006; 38(1):31–36. [PubMed: 16568811]
- Corbin, J.; Strauss, A. *Basics of qualitative research*. (3rd ed.). Thousand Oaks, CA: SAGE Publications, Inc.; 2008.
- Department of Health and Human Services' Office of the Assistant Secretary for Planning and Evaluation. The future supply of long-term care workers in relation to the aging baby boom generation: Report to congress. 2003. Available online at <http://aspe.hhs.gov/daltcp/reports/ltcwork.pdf>
- Dewey HM, et al. Informal care for stroke survivors: Results from the North East Melbourne Stroke Incidence Study (NEMESIS). *Stroke*. 2002; 33:1028–1033. [PubMed: 11935056]

- Duncan PW, Zorowitz R, Bates B, Choi JY, Glasberg JJ, Graham GD, Reker D. Management of adult stroke rehabilitation care: A clinical practice guideline. *Stroke*. 2005; 36(9):e100–e143. [PubMed: 16120836]
- Eames S, Hoffman T, Worrall L, Read S. Stroke patients' and carers' perception of barriers to accessing stroke information. *Topics in Stroke Rehabilitation*. 2010; 17(2):69–78. [PubMed: 20542850]
- Family Caregiver Alliance. Report from a National Consensus Development Conference. Vol. (Vol. I). San Francisco, CA: Author; 2006. Caregiver assessment: Principles, guidelines, and strategies for change.
- Garrett D, Cowdell F. Information needs of patients and carers following stroke. *Nursing Older People*. 2005; 17(6):14–16. [PubMed: 16161322]
- Greenwood N, Mackenzie A. Informal caring for stroke survivors: Meta ethnographic review of qualitative literature. *Maturitas*. 2010; 66(3):268–276. [PubMed: 20430542]
- Guberman, N. Caregiver Assessment: Voices and Views from the Field. San Francisco, CA: Family Caregiver Alliance; 2006. Assessment of family caregivers: A practice perspective; p. 38-57.
- Hafsteinsdóttir TB, Vergunst M, Lindeman E, Schuurmans M. Educational needs of patients with a stroke and their caregivers: A systematic review of the literature. *Patient Education and Counseling*. 2011; 85:14–25. [PubMed: 20869189]
- Hall JA. Some observations on provider-patient communication research. *Patient Education and Counseling*. 2003; 50(1):9–12. [PubMed: 12767577]
- Harris JE, Eng JJ, Miller WC, Dawson AS. The role of caregiver involvement in upper-limb treatment in individuals with subacute stroke. *Physical Therapy*. 2010; 90(9):1302–1310. [PubMed: 20592268]
- Hinojosa MS, Rittman MR. Stroke caregiver information needs: Comparison of Mainland and Puerto Rican caregivers. *Journal of Rehabilitation Research and Development*. 2007; 44(5):649–658. [PubMed: 17943676]
- Institute for Patient- and Family-Centered Care. What is patient- and family centered care?. 2010. Retrieved January 10, 2012 from <http://ipfcc.org/faq.html>
- Keith, RA.; Granger, CV.; Hamilton, BB.; Sherwin, FS. The functional independence measure: A new tool for rehabilitation. In: Eisenberg, MG.; Grzesiak, RC., editors. *Advances in Clinical Rehabilitation*. Vol. (Vol. 1). New York: Springer-Verlag; 1987. p. 6-18.
- Kelly-Hayes M, Beiser A, Kase CS, Scaramucci A, D'Agostino RB, Wolf PA. The influence of gender and age on disability following ischemic stroke: The Framingham Study. *Journal of Stroke and Cerebrovascular Diseases*. 2003; 12(3):119–126. [PubMed: 17903915]
- King RB, Semik PE. Stroke caregiving: Difficult times, resource use, and needs during the first 2 years. *Journal of Gerontological Nursing*. 2006; 32(4):37–44. [PubMed: 16615711]
- King RB, Shade-Zeldow Y, Carlson CE, Feldman JL, Philip M. Adaptation to stroke: A longitudinal study of depressive symptoms, physical health, and coping process. *Topics in Stroke Rehabilitation*. 2002; 9(1):46–66. [PubMed: 14523722]
- Kools S, McCarthy M, Durham R, Robrecht L. Dimensional analysis: Broadening the conception of grounded theory. *Qualitative Health Research*. 1996; 6:312–330.
- MacIsaac L, Harrison MB, Buchanan D, Hopman WM. Supportive care needs after an acute stroke: A descriptive enquiry of caregivers' perspective. *Journal of Neuroscience Nursing*. 2011; 43(3):132–140. [PubMed: 21796030]
- Mackenzie A, Perry L, Lockhart E, Cottey M, Cloud G, Mann H. Family carers of stroke survivors: Needs, knowledge, satisfaction and competence in caring. *Disability and Rehabilitation*. 2007; 29(2):111–121. [PubMed: 17364762]
- Maeshima S, Ueyoshi A, Osawa A, Ishida K, Kunitomo K, Shimamoto Y, Matsumoto T, Yoshida M. Mobility and muscle strength contralateral to hemiplegia from stroke: Benefit from self-training with family support. *Am J Phys Med Rehabil*. 2003; 82(6):456–462. [PubMed: 12820789]
- Management of Stroke Rehabilitation Working Group. VA/DoD clinical practice guideline for the management of stroke rehabilitation. Washington (DC): Veterans Health Administration, Department of Defense; 2010. Available online at http://www.healthquality.va.gov/stroke/stroke_full_221.pdf

- Miller EL, Murray L, Richards L, Zorowitz RD, Bakas T, Clark P, Billinger SA. Comprehensive overview of nursing and interdisciplinary rehabilitation care of the stroke patient: A scientific statement from the American Heart Association. *Stroke*. 2010; 41(10):2402–2448. [PubMed: 20813995]
- Monaghan J, Channell K, McDowell D, Sharma AK. Improving patient and carer communication, multidisciplinary team working and goal-setting in stroke rehabilitation. *Clinical Rehabilitation*. 2005; 19(2):194–199. [PubMed: 15759535]
- Nelms TP, Eggenberger SK. The Essence of the family critical illness experience and nurse-family meetings. *Journal of Family Nursing*. 2010; 16(4):462–486. [PubMed: 21051759]
- Ostwald SK, Bernal MP, Cron SG, Godwin KM. Stress experienced by stroke survivors and spousal caregivers during the first year after discharge from inpatient rehabilitation. *Topics in Stroke Rehabilitation*. 2009; 16(2):93–104. [PubMed: 19581196]
- Roger VR, Go AS, Lloyd-Jones DM, Benjamin EJ, Berry JD, Borden WB, Turner MB. Heart disease and stroke statistics – 2012 update: A report from the American Heart Association. *Circulation*. 2012; 125:e2–e220. Available online at <http://circ.ahajournals.org/content/125/1/e2.full.pdf+html>. [PubMed: 22179539]
- Santos GJ. Card sort technique as a qualitative substitute for quantitative exploratory factor analysis. *Corporate Communications: An International Journal*. 2006; 11(3):288–302.
- Schatzman, L. Dimensional analysis: Notes on an alternative approach to the grounding of theory in qualitative research. In: Maines, DR., editor. *Social organization and social process: Essays in honor of Anselm Strauss*. Hawthorne, NY: Aldine de Gruyter; 1991. p. 303–314.
- Shyu YL, Chen M, Chen S, Wang H, Shao J. A family caregiver-oriented discharge planning program for older stroke patients and their family caregivers. *Journal of Clinical Nursing*. 2008; 17(18): 2497–2508. [PubMed: 18705725]
- Stirling C, Leggett S, Lloyd B, Scott J, Blizzard L, Quinn S, Robinson A. Decision aids for respite service choices by carers of people with dementia: Development and pilot RCT. *BMC Medical Informatics and Decision Making*. 2012; 12:21. [PubMed: 22429384]
- Strauss, AL. *Qualitative analysis for social scientists*. New York, NY: Cambridge University Press; 1987.
- Sumathipala K, Radcliffe E, Sadler E, Wolfe CDA, McKeivitt C. Identifying the long-term needs of stroke survivors using the International Classification of Functioning, Disability and Health. *Chronic Illness*. 2012; 8(1):31–44. [PubMed: 22025770]
- Van Heugten C, Visser-Meily A, Post M, Lindeman E. Care for carers of stroke patients: Evidence-based clinical practice guidelines. *J Rehabil Med*. 2006; 38(3):153–158. [PubMed: 16702081]
- Visser-Meily A, Post M, Gorter JW, Berlekom SBV, Van den Bos T, Lindeman E. Rehabilitation of stroke patients needs a family-centered approach. *Disability and Rehabilitation*. 2006; 28(24): 1557–1561. [PubMed: 17178619]
- Walker E, Dewar BJ. How do we facilitate carers' involvement in decision making? *Journal of Advanced Nursing*. 2001; 34(3):329–337. [PubMed: 11328438]

Figure 1.
Range of Caregiver-Provider Interactions

Figure 2.
Caregiver Interactive Strategies