



Published in final edited form as:

Soc Work Public Health. 2015 ; 30(6): 486–495. doi:10.1080/19371918.2015.1058730.

From Discharge Planner to “Concierge”: Recommendations for Hospital Social Work by Clients with Intracerebral Hemorrhage

Kristen F. Linton, MSW, Ph.D¹, Marissa M. Ing, MSW², Megan A. Vento, BS², and Kazuma Nakagawa, MD^{2,3}

¹Assistant Professor, Health Sciences Program, California State University, Channel Islands, One University Drive, Camarillo, CA, 93012

²Neuroscience Institute, The Queen’s Medical Center, Honolulu, HI

³Department of Medicine, John A. Burns School of Medicine, University of Hawaii, Honolulu, HI

Abstract

Purpose—The Affordable Care Act and budget cuts have changed the role of hospital social workers by placing pressure on them to conduct speedy discharges and decrease readmission rates. This qualitative study aimed to assess if hospital social work is meeting the needs of clients in the hospital and post-discharge.

Methods—Semi-structured interviews with 10 clients with intracerebral hemorrhage (ICH) and 11 caregivers were conducted.

Results—Participants reported that social work services were not meeting their needs. Clients with ICH and their caregivers expressed needs from social workers that surpassed their roles as discharge planners, including counseling, help with finances and insurance, and advocacy. Participants wanted social work services to begin early in acute treatment with continuity post-discharge.

Conclusion—Social workers should conduct ethical social work by meeting clients where they are, addressing needs as prioritized by the client, and advocating individually and organizationally for clients.

Keywords

discharge planning; hospital social work; stroke; Patient Protection and Affordable Care Act; case management

The Patient Protection and Affordable Care Act (ACA; 2010) and budget cuts have changed the role of hospital social workers (Spitzer, Davidson, & Allen, 2013). Budget cuts are forcing hospitals to prioritize speedy discharges of clients (Levack et al., 2011). Simultaneously, the ACA has also implemented reductions in Medicare reimbursements for

Corresponding Author, Kristen F. Linton, Assistant Professor, Health Sciences Program, California State University, Channel Islands, One University Drive, Camarillo, CA, 93012, socialworker2you@yahoo.com, phone 213-700-3541, fax 702-895-4079.

Declaration of Conflicting Interests

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of the article.

hospitals with “excess readmissions.” A readmission is defined as an admission to a hospital that occurs within 30 days of a discharge from the same or another hospital by clients with vascular conditions, which will include Intracerebral Hemorrhage (ICH) in 2015. Excess readmissions are measured using a ratio of a hospital’s readmission performance (ACA, 2010; Fontanarosa & McNutt, 2013). Clients with ICH have had readmission rates ranging from 11–17% (Liotta et al., 2013; Morgerstern, et al., 2010). Acceptable readmission rates for clients with other vascular conditions range from 4 – 12% (Centers for Medicaid and Medicare Services, 2014).

The complexity of ICH not only requires medical interventions, but chronic disease management and a system of coordinated care to decrease readmission rates (Rehman & Siddiqui, 2013). To improve readmission rates, hospitals have placed pressure on social workers to conduct quick assessments, collaborate with community providers, and expedite the discharge process (Reisch, 2012). Since the enactment of ACA, hospital social workers are primarily responsible to conduct discharge planning or planning for the many needs of clients to prepare them for hospital discharge (Peterson, 2012). Hospital social workers are capable to and have held many roles historically including addressing crises, connecting clients with community resources, and addressing psychological distress (Craig & Musket, 2013; Reckrey et al., 2014). The purpose of this qualitative study of an ethnically diverse group of clients with ICH and their caregivers was to assess if hospital social work is meeting their overall needs while inpatient and after discharge.

Hospital Social Work Roles

Historically, hospital social workers were asked to wear many hats. Self-proclaimed as bouncers, janitors, glue, firefighters, jugglers, and challengers in focus groups of 65 urban hospital social workers, they reported that they are asked to deal with behavioral problems, clean up messes, organize family meetings, link clients and families with resources, deal with crises, and advocate for clients (Craig & Muskat, 2013). Reviews of medical charts also found that 10% of social work referrals were for caregiving coping issues and 14% of referrals were for other issues, which included, but was not limited to: arranging cleaning of cluttered apartments, coordinating home-based recreational services, assisting moving apartments, and caregiving for pets (Reckrey, et al., 2014). Therefore, about one-fourth of social work referrals were for responsibilities that are not typical to discharge planning, but reflect duties that social workers described as janitorial, glue, and firefighting (Craig & Muskat). Social workers typically receive training in counseling and crisis management, which prepares them for these roles (Gibbons & Plath, 2006).

While social workers may voluntarily take on many roles, recent research shows that social workers are mostly wearing the discharge planner hat. A review of medical charts in a hospital found that 69% of referrals to social work were for clients’ benefits, home care, and community resources, which are typical discharge planning responsibilities (Reckrey, et al., 2014). Another study found that almost half of 377 hospital social workers spent the majority of their time doing discharge planning (Judd & Sheffield, 2010). This reflects that, while social workers have expertise beyond discharge planning, they may have succumbed to the pressure to solely plan for clients’ discharge due to ACA. Research has also found that

social workers are effective in their role as discharge planners. Galati, Wong, and Wu (2011) found that discharge rates at one hospital were statistically significantly lower by 48.9% on days when social workers were on vacation versus regular days. No studies were found that demonstrate hospital social workers' impact on readmission.

Hospital Social Work Challenges

Many challenges face hospital social workers to be successful in meeting the demands of the ACA and the unique needs of diverse clients. One challenge is time. A study found that almost half of hospital social workers had caseloads larger than 60 per month (Judd & Sheffield, 2010). Because of pressure to conduct speedy discharges, social workers often felt as though they did not have enough time to conduct adequate assessments (Chapin et al., 2014). Focus groups with 25 hospital social workers found that it was a "common and appropriate form of practice" to only have a single session with a client prior to their discharge. The single sessions were demanding and intense, since the process of engaging clients, building rapport, assessing, providing information, validating, challenging beliefs and behaviors, and counseling happened in a short period of time (Gibbons & Plath, 2006). To address the time issue, social workers were honest, respectful, honored self-determination, attempted to set up assistive technology for clients, and gave them their cards for future contact (Chapin et al.; Gibbons & Plath). However, most social workers reported that they never heard from clients after discharge (Gibbons & Plath). This could be a positive sign that the clients received adequate services, and did not need to follow up; however, health disparities indicate that clients from racial or ethnic minorities may need additional support post-discharge (Tsivgoulis et al., 2014). A second challenge was a lack of communication between physicians and social workers. Social workers reported attempting to improve this by taking rounds with physicians and using multiple modes of communication, such as medical charts and email (Chapin et al.).

Lastly, social workers complained that hospitals' use of assessments based on the medical model was limited. Person-centered assessments were recommended by social workers to improve holistic knowledge about clients' goals (Chapin et al.). While person and family-centered approaches to discharge planning have improved satisfaction of clients and caregivers, research has found that goals prioritized by health professionals were often those related to physical functioning, had short achievement timeframes, and conservative estimates of progress (Levack et al., 2011; Shyu et al., 2008). Levack and colleagues suggested that person-centered goals often were consistent with professional and ethical obligations to adequately prepare clients for discharge, yet conflicted with the hospitals' financial obligations to discharge clients as soon as possible. Person-centered assessments may also be consistent with Rehman and Siddiqui's (2013) recommendations to not only provide medical care, but a system of coordinated care and for chronic diseases, including ICH (Rehman & Siddiqui, 2013).

Although hospital social workers have proven to be effective at speedy discharge planning, research shows that they also receive referrals for many other tasks that could ultimately benefit client and caregivers' outcomes, such as counseling (Craig & Muskat, 2013; Galati et al., 2011). Furthermore, cultural aspects of interventions may also improve health disparities

(Bean, Davis, & Valdez, 2013). Given the challenges facing hospital social work in the current medical climate, this study assessed whether social workers are meeting the needs of ethnically diverse clients with ICH. To address these concerns, semi-structured interviews with 10 clients who have experienced intracerebral hemorrhage (ICH) and 11 of their caregivers were conducted to assess their inpatient and post-discharge needs pertaining to hospital social work. The interviews also aimed to receive recommendations for improvements to hospital social work.

Clients with ICH were chosen as participants, because they have a vascular condition which may be impacted by the ACA's readmission policy and increases their potential need of supportive services due to a high likelihood that they experience substantial disability upon hospital discharge. For example, one study found that clients with ICH were dependent on another person's support to complete almost half of daily motor and cognitive tasks prior to receiving rehabilitation (Katrak, Black, & Peeva, 2009). In addition, ethnic disparities exist among people who experience strokes (Horner et al., 2009; Perrin, Heesacker, Uthe, & Rittman, 2010; Tsvigoulis et al., 2014). Native Hawaiians and Pacific Islanders (NHPI) that experienced strokes were statistically significantly younger and had more risk factors than white clients (Nakagawa et al., 2012).

Methods

Participants ($N=21$) were recruited from an ongoing cohort study of ICH clients at The Queen's Medical Center (QMC) in Honolulu, HI. University of Hawaii at Manoa and QMC institutional review boards provided approval for this study. For the longitudinal ICH cohort study, participants must have been hospitalized for ICH, discharged for at least three months, over 18 years old, a resident in Hawaii for more than three months, with a telephone, and available for an in-person interview. Clients could not participate in the cohort study if their ICH was directly related to trauma or subarachnoid hemorrhage from ruptured cerebral aneurysm due to the original purpose of the cohort study. Since eight to twelve interviews are recommended for phenomenological research to meet saturation, 30 potential participants were approached by telephone to participate in the study, and 21 agreed to participate (Padgett, 2008). Purposive sampling was used to obtain a sample that was representative of the Hawaii population, which primarily includes NHPI, Asians from various ethnicities, and whites (Table 1). Both clients and caregivers were recruited to participate in the study, because clients were sometimes unable to remember their inpatient experience due to their recovery and caregivers were able to provide their perspective of social work services while the client was in the hospital. In addition, caregivers were primarily responsible for coordinating the client's services.

Interviews were conducted by the second and third authors utilizing an interview script and probes to gain more information about the participants' responses. The first author was also involved in two interviews for training purposes. The interview script covered topics related to ICH, such as overall experiences, emotions, and, receipt of information in the hospital and post discharge. The needs described by participants were directly related to hospital social work. Participants either described hospital social work roles or specifically referred to "social work" or "social workers". The interviews were audio-recorded. Twelve interviews

were conducted with all interviews including one client and one caregiver with the exception of one with two caregivers and another with one client. Interviews ranged from 36 to 86 minutes.

Interviews were transcribed and pseudonyms were provided to participants for confidentiality. Inductive content analysis was used. All data were read by the first three authors to identify initial codes. The authors met several times to discuss their agreement of the codes and develop prominent themes. Subsequently, a codebook was developed by the authors. Triangulation was used to prevent bias in the identification of themes since the authors have both neurological, medical, and social work backgrounds. The first two authors coded each transcription with the final codebook. Every segment of text could be double-coded. Adequate interrater reliability ($k = .72$) was reached on a total of 154 codes (Orwin, 1994).

Results

Participants primarily expressed the need of information about community resources and eligibility of those resources. They were also seeking emotional support from social workers. Clients and caregivers recommended more than discharge planning support from hospital social workers. In addition, they wanted services to start early in the hospitalization and include follow-ups post-discharge. Though not all clients spoke of self-advocacy, some reported advocating for themselves or had professional experience with healthcare, thus they did not need as much support.

Resources. *“We don’t know what to ask for”*

A theme emerged from the interviews demonstrating a gap of knowledge in practical areas of stroke care. Interviews revealed that clients attended numerous outpatient appointments and post-stroke surgery long after discharge from the initial hospitalization, and that frequently it was the caregiver who assumed responsibility of coordinating care. Comments from the interviews indicated that caregivers sought practical information on where to receive quality post-stroke care, social services, and financial supportive services. They also wanted to know about eligibility for existing services. Abian, a 51-year old Filipino, male caregiver demonstrated this need, “They can refer us to any place that we need to go to and stuff like that – but to be suggestive of what we need. Well we don’t know what to ask for.” The caregiver’s comment reflects a frustration commonly expressed by participants whom desired more guidance and information on the overall pathway and stages of stroke recovery. Jing, a 68-year old Chinese, female caregiver reflected on the uncertainties and hardships she encountered while caring for her grandmother:

I think it would have helped if someone told me what to expect...I don’t know if everyone has to live and learn from experience—probably but it’s just even the doctor—they don’t really tell you what to expect, and you’re wondering, ‘Ok is this the result of—is she acting like this as a result of the stroke or is it because of dementia? Or is it because it’s just her?’

Abian illustrates the complexity of post stroke care and the effortlessness by which many become confused by the system:

... We didn't readjust her plans to outpatient until I went back to see [Doctor #4] because I didn't even know who my physiatrist was until I went back to see him, and he said, "I'm your physiatrist." Because—I mean, what is that? The insurance guys asked, "Who's your physiatrist? Because they're the ones who got to make the plan." I asked my PCP provider and she goes, "I don't know—I'm not your physiatrist." And when I finally went back to [Doctor #3]. Then, because I didn't know what a physiatrist was. Come to find out that's the Physical Therapy Doctor."

Emotions. "Full of emotion and tied up"

When reflecting on past hardships, caregivers such as Jing mentioned, "wish someone would have told me," the possible difficulties to look out for throughout recovery. This statement demonstrates one of many frustrations that participants mentioned throughout the interviews. Client and caregivers wanted more wisdom and emotional support during times of heightened emotion when they found it most challenging to make life-changing decisions. According to Brian, a 64-year old white, male caregiver:

...There was no convincing argument to me to say, "You really need to do this and stuff," when you're left with a choice, because you're full of emotion and tied up with so much other stuff that what might be considered to be an important and necessary decision, gets pushed off if no one seems to impress that on you.

When Leilani, a 55-year old Native Hawaiian, female client was asked about support systems, she responded:

...Maybe more of the emotional. To have had maybe I guess a follow-up on that. Because I didn't know why I had the stroke, because I was not that demographic. There were so many different doctors we had to see. And for me—it was the ups and downs of "Well you could possibly have this, so you need to see this doctor. And could possibly have this, but you're going to have to see this doctor. You're going have to wait 3 weeks for the information to come back after taking the test or whatever.

As Leilani demonstrates, clients desired more than information on where to obtain services, but also psychological counseling during recovery.

Recommendations. "Maybe concierge...because I still see that lacking out there"

Narratives from interviews conveyed the belief that having access to a resource that could encompass or consolidate their needs and answer any questions during the continuum of their stroke care would be valuable. While the hospital social worker was mentioned as a resource, the participants expressed that hospital social workers did not meet all their needs. Comments included the description of a person or service that could help support them through unexpected systemic challenges. Adrian, a 54-year old Asian Indian, female caregiver wanted help with things such as paper work: "It would be helpful to have just one person I could go to for things like 'I need help with these insurance things, I need help to get signed for my employer.'" Seung, a 58-year old Chinese, female client said:

Maybe concierge isn't the right word, but some kind of service—because I still see that lacking out there. Of all the help I got...whether it was social workers, or if it

was through friends, you know through different things, none of it seemed to consolidate it.

Abian corroborated:

...if you had the social worker, maybe from an outside source – one that would force the contact rather than be the one waiting to be contacted...come about every 2 months to make sure we're using all the available resources we have access to... granted I don't have the best medical insurance but at least the last social worker we had...she pointed us to a point where we could at least get professional home-care provided for us. Of course my insurance didn't like it, so it was an avenue that my PCP provider and the [hospital], [doctor], they had to write like an outpatient plan for her—total plan before they would approve paying for the caregiver.

Timing. “Even in the ambulance”

Clients were specific regarding their recommendations for times in which they needed the most help. The majority of participants reported that a hospital social worker should introduce themselves as early as possible even when in the “ICU” or “even in the ambulance”, because some clients arrived at the hospital alone. Even if the hospital social worker introduces themselves to the clients early, participants hoped for a continuation of services post-discharge. Maile, a 62-year old female, Native Hawaiian caregiver explained, “You’ve got to implant it early to say, ‘we’re here’, and then later on you bring it on again, ‘We’re still here’ because if not, they’re going to totally forget it. Check up on them later...a couple of weeks later.” However, other clients expressed that they “pretty much just slept” in the hospital, and would appreciate a social work intervention that would include connections to resources, psychological support, and advocacy to begin after discharge from the hospital or, if they were to go to inpatient rehabilitation, then post discharge from rehabilitation. Seung expressed “because after that it’s like, ‘OK, we’re going to go home, what’s the next step?’”

Advocacy. “You really need to be on top all of this.”

Participants who did not have as many requests for improved social work services were good self-advocates or had caregivers who advocated for them. Upon being overcharged for hospital services, Leilani’s caregiver took the steps to collect a reimbursement from their insurance company. Leilani said,

...had he not been as diligent in going through it—and I’m sure some people just give up and pay for it if they have the finances. But because he went in, he knew no it was supposed to be this way and that way, and he called them and dealt with them, that we didn’t have to pay as much...

In addition, the fundamental knowledge of the value of advocating and being present in the client’s healthcare plan was advantageous. According to Brian:

You really need to be on top all of this. Watch, and ask a lot of questions and things like that.” So that’s why I kept a journal of everything. I was in the room a lot and asking lots of questions. If [the client’s doctor] could remember, I was probably the

number one pest around him and every time they entered the room I was just a sponge for information.

Professional Training. “I’m a trainer”

Caregivers who did not mention difficulties held a profession in healthcare or social services, and/or maintained a close relationship with a person who had professional experience with stroke and/or disability. Adrian, whom held a career in social services explained, “I’m really fortunate, because I’m actually a trainer for people with disabilities, or else I wouldn’t even know like how to integrate some of these things...I’ll push as much as he’ll [the client] do and he just needs to do it.” Chen, a 71-year old Taiwanese, female caregiver of a Psychiatrist and mother of two physicians admitted, “We are kind of lucky. This field, lots of people—my son, my daughter, him [the client], and a good friend, a family friend, all are close friends”.

Discussion and Applications to Social Work

The results of the study have implications for the ACA’s readmission rate reimbursement policy. Clients with ICH and their caregivers expressed needs from hospital social workers that surpassed their roles as discharge planners, including counseling, help with finances and insurance, and advocacy. Participants wanted these interventions to begin early in acute medical treatment with continuity of services post-discharge suggesting that additional post-discharge support may be needed to prevent readmission. Participants reported that the current social work services are not meeting their needs. One client named a desired intervention as a “concierge” service, which reflects a need for hospital social workers to encompass their many potential roles as bouncers, janitors, glue, firefighters, jugglers, and challengers (Craig & Muskat, 2013).

Even though it was not the only aspect of hospital social work needed, this study demonstrated that discharge planning is a vital service for clients and their caregivers, which supports the ACA’s efforts to prioritize this aspect of care (2010). Participants wanted information about resources and eligibility for those resources, responsibilities of medical professionals, and ICH symptoms. Discharge planning services were not solely meeting the needs of most clients and caregivers in this study (Judd & Sheffield, 2010; Reckrey et al., 2014). Therefore, in order to decrease readmissions among clients with ICH, social workers may need time to provide additional support outside of discharge planning, especially related to clients’ emotions and advocacy. Challenges facing hospital social workers may contribute to the lack of satisfaction of their services. For example, high caseloads, pressure for speedy discharges, and the use of medical model assessments may limit the ability for hospital social workers to provide adequate referrals and the detailed information desired by clients and caregivers (Chapin et al., 2014; Judd & Sheffield). While hospital social workers may not be able to control high caseloads, demand for speedy discharge, or prioritization of other medical professionals, they may be able to implement person and family-centered assessments in social work (Levack et al., 2011; Shyu et al., 2008). In addition, since participants who possessed self-advocacy skills were more likely to independently have their

needs met in this study, social workers may focus on teaching clients and caregivers self-advocacy skills to increase their independence.

Participants' request for emotional support was coupled with discharge planning. While addressing depression was discussed as a challenge for clients and caregivers, there were also descriptions of a juxtaposition of emotional distress and making decisions related to treatment and discharge planning. Depression has been reported as a common psychological challenge among people who experienced strokes and their caregivers (McCarthy et al., 2011). However, little attention is paid to psychological distress experienced by clients and caregivers specific to discharge planning and making medical decisions. Reckrey and colleagues (2014) found that hospital social workers spent about one-fourth of their time on caregiver coping and other issues that seemed related to easing anxiety during discharge planning, such as assistance in moving. However, other research also found that it is typical for social workers to only have a single session with a client (Gibbons & Plath, 2006). This study demonstrates a need to maintain time for counseling during discharge planning interventions to address psychological distress or obtain resources to minimize distress. In addition, participants requested a continuity of services including follow-ups post-discharge. While social workers in a previous study explained that they never heard from clients after discharge, clients and caregivers in this study asked that social workers initiate the conversation and not wait to be contacted by clients (Gibbons & Plath). Participants used examples of receiving a follow-up phone call from the social worker, thus a hospital social worker could conduct this type of follow-up even while remaining in the hospital. This may be needed to improve readmission rates. Social workers may not currently be meeting this need among clients by initiating contact with their clients post-discharge due to the many challenges they face, such as large caseloads, yet they need to advocate for their clients by explaining their needs to hospital administration.

While the roles of hospital social workers may be shifting towards solely discharge planning, clients with ICH and caregivers may still be in need of counseling, advocacy, and other support according to this study. Social workers have demonstrated that they increase the rate at which clients are discharged, thus their role is essential to the ACA, in addition to holding many other roles (Galati et al., 2011). Hospital social workers should conduct ethical social work by meeting clients where they are and addressing needs as prioritized by the client, which may require that they redefine their roles to reflect a broader definition of hospital social work similar to a "conciierge" (Chapin et al., 2014; Gibbons & Plath, 2006). In addition, social workers should advocate not only for their individual clients, but in their organizations to ensure that systems as meeting the needs of clients (Levack et al., 2011; Shyu et al., 2008).

The limitations for this study include limited generalizability. The sample size used was small; qualitative inquiry often sacrifices breadth or depth. Future research should aim to generalize these findings using larger sample sizes. In addition, this study only used one location with a population that is ethnically diverse, yet not generalizable to the U.S. population as a whole. Purposive sampling was utilized to gain a sample representative of the ethnic diversity of the Hawaii population, yet the sample may not be generalizable to the State of Hawaii, since participants volunteered and were conveniently chosen. In addition,

rural disparities exist in access to care. This study only included participants from an urban location in Hawaii since interviews were conducted in person.

Acknowledgments

Funding

We gratefully acknowledge The Queen's Medical Center's Native Hawaiian Health Program for supporting this study and the National Institute on Minority Health and Health Disparities of the National Institutes of Health under Award Number P20MD000173 for supporting this study. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute of Health.

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Table 1

Participant Characteristics

	Caregiver (n = 11)	Client (n = 10)	Combined (n = 21)
Male	6	3	9
Female	5	7	12
Age, mean (s.d., range)	60.8 (9.1, 49–76)	61.1 (13.2, 42–82)	60.9 (11.0, 42–82)
Education			
<Highschool	1	2	3
Highschool	2	1	3
Some college	1	2	3
College	7	4	12
Unknown			
Race/Ethnicity			
White	2	2	4
Taiwanese	1	1	2
Asian Indian	1	1	2
Filipino	1	2	3
Japanese	1	1	2
Chinese	2	1	2
Native Hawaiian	2	3	5
Other Pacific			
Islander	1	0	1
Relationship to Client			
Parent	1	N/A	1
Spouse	6	N/A	6
Son/Daughter	1	N/A	2
Friend	1	N/A	1
Niece/Nephew	1	N/A	1