

Original Article

Exploring the Human Emotion of Feeling Cared for During Hospitalization

Judy E. Davidson, DNP, RN, FCCM, EBP

Research Nurse Liaison UC San Diego Health, San Diego, USA

Margarita Baggett, MSN, RN

Chief Clinical Officer, UC San Diego Health, San Diego, USA

Maria Magdalena Zamora-Flyr, DrPH, CNM, CNS, MN, MPH

Neighborhood Healthcare, San Diego, USA

Laura Giambattista, BSN, RN

Nurse Educator, UC San Diego Health, San Diego, USA

Linda Lobbestael, MSN, RN-BC

Nurse Educator, UC San Diego Health, San Diego, USA

Judith Pfeiffer, PhD, RN

Director, Nursing Education, Development and Research, UC San Diego Health, San Diego, USA

Catherina Madani, PhD, RN

UC San Diego Health, San Diego, USA

Correspondence: Judy E. Davidson, 200 W. Arbor Dr. mail code 8929 San Diego CA USA 92103.

E-mail: jdavidson@ucsd.edu

Abstract

Background: Previously we reported study results exploring the emotion of feeling cared for in workplace employees. This project extends that work exploring feeling cared for from the perspective of stroke patients and families. Joanne Duffy's Quality Caring Model focuses on building caring relationships and fostering the emotion of feeling cared for. When people feel cared for they are more likely to engage in health-promoting activities.

Objective: The objective of this study was to explore behaviors that stimulate feeling cared for during hospitalization.

Methodology: An open-ended question survey was designed, validated, and administered electronically or telephonically (per subject preference) within 3 months of discharge from the hospital. Data was analyzed using thematic content analysis.

Conclusion: Telephonic contact was attempted in 74 patient/families; 13 could not be reached, 61 were offered the survey, 22 (36%), (17 patients, 5 family) completed the survey (7 English, 15 Spanish speaking). Two investigators analyzed the data; themes were derived inductively achieving 100% consensus for: Care with competence (knowledge and skills), care with information/involvement, and care for personhood. No difference was found between patients and families. Spanish responses uniquely conveyed the importance of affection within a caring manner: "Me hablaban y me consentian" [they talked to me and pampered me]. "Me tocaban Los hombros y me daban palmadas" [they touched my shoulder and patted me]. "Me trataban con cariño" [they treated me with love].

Significance: These preliminary findings provide insight into behaviors which elicit the human emotion of feeling cared for stroke patients and their families. Promoting these caring behaviors amongst those who provide care for stroke patients has the potential to facilitate timely discharge, improve the healing environment, optimize the patient experience and facilitate healing.

Keywords: Empathy, compassion, caring, patient satisfaction, research, theory, stroke

Introduction

Joanne Duffy's Quality Caring Model served as the theoretical framework for this study. The model advises that people will heal faster in an environment where they feel cared for. Further, it is proposed that people who feel cared for are more likely to engage in health-promoting activities such as following the treatment plan and maintaining healthy life choices (Duffy, 2013). Although the Quality Caring Model and Caring Assessment Tool have been validated (Duffy, 2013; Duffy et al, 2007; Duffy et al, 2012), the specific concept of feeling cared for during hospitalization has not been directly explored. The purpose of this research project was to explore factors driving the emotion of feeling cared for in the hospital setting from the perspective of stroke patients and their families.

Research Question

What behaviors stimulate the human emotion of feeling cared for during hospitalization in stroke patients and their families?

Methodology

This pilot study was conducted with open-ended question survey design and is the sequel to a study previously reported on exploring the human emotion of feeling care for in the workplace (Baggett et al, 2016).

Sample

Patients and family members who were admitted within the last three months for either embolic or hemorrhagic stroke were eligible for inclusion into the study.

Institutional Review Board (IRB)/Ethics

This project was approved by the Investigational Review Board (project 141756). Documented consent was waived. Return of the survey or participation in the phone interview constituted consent to participate in research. Translators were authorized by the IRB to perform translation of documents, conduct interviews and translate transcripts.

Survey development

The questions used for this survey were first validated by a panel of experts (nurses with experience in survey design). Three validation points were assessed:

- 1) Appropriate to aims/goals yes: keep/no: delete
- 2) Appropriate to methodology yes: keep/no: delete/ no: revise with these suggestions
- 3) Clearly stated: Yes: keep as is/ No: Revise with these suggestions:

Face validity was then provided by patients and families approached in the outpatient stroke clinic who validated clarity of the questions. It was established a priori that 80% consensus was needed with each group to accept the wording of the survey question. Validation required two rounds. The final questions are reported in table 1. The survey was then translated into Spanish by one authorized investigator and back-translated for quality control by a second authorized Spanish speaking investigator.

Sampling method

With IRB approval the discharge follow up phone list was used to identify potential subjects who had been discharged following any stroke within the last 3 months. The nurse who normally conducts the phone calls screened patients for interest in involvement in the study. A Spanish speaking nurse translated for Spanish speaking patients. Once interest in involvement was secured, a bilingual nurse from the research team contacted the potential subject over the phone and asked whether they would like to do the survey over email or on the phone. The questions were administered according to their preference. The phone interviews were conducted in Spanish when indicated or subjects were sent the Spanish version of the survey. The Spanish phone interviews were typed verbatim in Spanish and then translated. Both the phone and electronic survey responses in Spanish were translated by one investigator and then back-translated for quality control by a second Spanish speaking investigator.

Table 1: Questions

Patient and Family Questions
Please tell us about a time when you felt cared for during your hospitalization or during the hospitalization of a family member at UCSD
What did people in the hospital do to make you feel cared for?
Tell us what was most important about this event?
Is there anything else we should know about your experience of feeling cared for?

Table 2: Themes and subcategories

Care with Competence	Care with information/involvement	Care of Personhood
<ul style="list-style-type: none"> • Professional Compartment • Timeliness/promptness of service • Confidence in medical/nursing knowledge and skill 	<ul style="list-style-type: none"> • Kept me informed/involved in plan of care • Listened to me 	<ul style="list-style-type: none"> • Customer service; details; the little things • Concern • Going above and beyond • Attentiveness/ Authentic Presence • Attention to Privacy and comfort • Maintenance of autonomy • Responsiveness to requests • Kindness

Figure 1: A Visual Model of Caring

An anatomical model of the heart and mannequin hands were used for this mixed-media art piece. The heart “held” by the hands represents a visual model of caring. The concept explores the nature of the patient experience and the feeling of being “held” and “cared for” by the nursing staff. The anatomical heart with words expressed by patients are directly related to survey data obtained from research participants aiming to understand the feeling of being cared for. The idea is that feeling heard, allows people to express their feelings is a powerful way of caring. This piece also explores the concept that as nurses we are responsible for our patients’ anatomical safety as well as their emotional needs. – Artist Laurel Prince RN



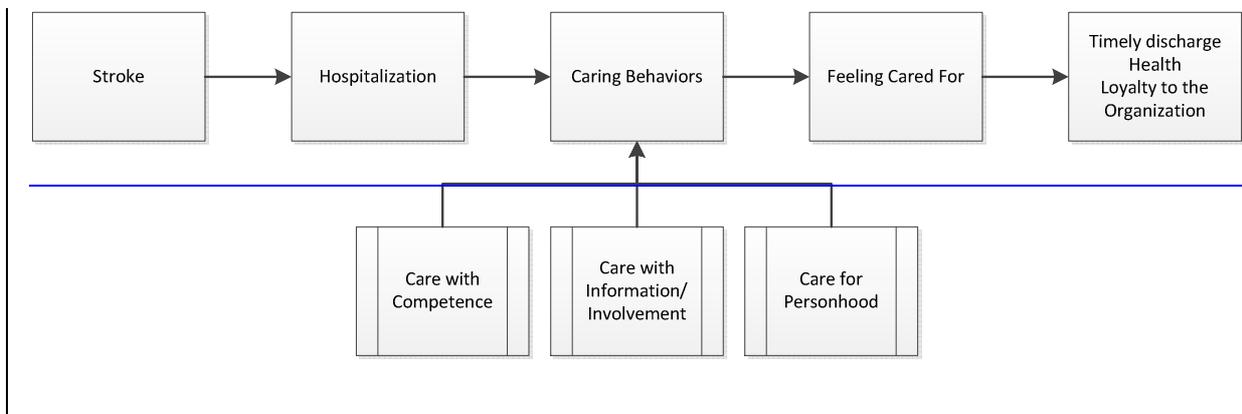


Figure 2: Feeling Cared for During Stroke Hospitalization. Art by Laurel Prince RN

Data analysis

Several methods of thematic analysis were conducted before achieving consensus on the results. At first, we attempted to match the themes found in our previous study on feeling appreciated in the workplace (Baggett et al, 2016). In that workplace study the data matched themes derived from Chapman and White's languages of workplace appreciation (Baggett et al, 2016; Chapman & White, 2011). The languages of workplace appreciation were derived from Chapman's previous work on languages of love (Chapman, 1995). Coded concepts stimulating the emotion of feeling cared for either did not match to a theme, or matched to multiple themes, or the coders could not agree on themes (poor inter-rater reliability). Next, because the theoretical framework for the study was the Quality Caring Model which includes 8 essential caring factors that had previously been validated as caring behaviors, we attempted to code according to those caring factors (Duffy, 2013). The same problems persisted with reliably assigning data to the caring factors. Many data points did not align to a caring factor, and others were assigned to more than one caring factor. This led us to believe that for these participants the caring factors and their definitions were not discrete enough to serve as themes tied to the specific human emotion of feeling cared for. A third round of coding was then done inductively, allowing the themes to emerge from the data organically. Two investigators coded for themes

independently and then collaboratively. Another round of coding was performed with two additional investigators independently and then collaboratively until consensus was achieved. The entire research team (all authors) reviewed the final coded data set of 13 subcategories which were then reduced to 3 major themes.

Results

Telephonic contact was attempted in 74 patient/families; 13 could not be contacted, 61 were sent survey links, 22 (36%), (17 patients, 5 family) completed the survey (7 English, 15 Spanish). The number of responses for each theme and subcategory are reported below in parentheses. There were 139 coded comments, 27 of which were negative (constructive). Subcategories containing the most negative comments were customer service/the little things (7) and timeliness (5). The negative comments all matched to general themes and subcategories further validating that the absence of a behavior could prevent feeling cared for during a hospitalization. Examples are provided below. There were 5 pieces of data that coded to 2 subcategories. After review, the overlap appeared appropriate to the situation. For instance, a comment about being informed by being given access to the physician's cell phone was seen as both *being informed* and *going above and beyond*. However, not all data in the being informed group represented going above and beyond, and similarly not all data in the going above and beyond subcategory were associated with being informed.

Lastly, no data were left un-coded after sorted into subcategories and themes.

The three major themes were: Care with Competence: Knowledge and Skill, Care with Information/Involvement, and Care for Personhood (Table 2). Quotes from the themes and their subcategories are presented below. The number next to the subtitle infers the quantity of comments associated with that particular theme.

Care with Competence: Knowledge and Skill (37)

Comportment refers to professional image; the way we present ourselves as professionals (Roach, 2007). A positive comportment generated the feeling of being cared for, while a negative comportment eroded it. The speed with which the stroke team provided care came up repeatedly. The stroke code response cultivated an impression of caring. Perceived competence drives the feeling of being cared for. The following are direct quotes from these subcategories of Care with Competence. Words in brackets replace actual names to de-identify the data set.

Professional comportment (7)

“Most important of all, the ER medical professionals (physicians and nurses) who came to see me had world-class bedside manner”

“Dr [name of doctor’s] team was bad, they were loud and came to the unit laughing most of the time. I don’t think they were showing respect to all the sick people in the unit and the family members.”

Timeliness/promptness of service (19)

“I arrived on Sunday and they took care of me right away, everything excellent, they showed interest in taking care of me. They put an IV and gave me fluids and did studies fast.”

““They promptly took care of me and that made me feel better every day. They also took care of my needs fast. excellent medical attention all the test were done fast and were timely”

“My husband and I were headed to the emergency, however, I encouraged my spouse to head to Dr. [name of doctor] clinic instead. Dr. [name of doctor], my primary physician squeezed me in her full schedule. After giving me some neurological tests, she determined that I could be experiencing a stroke. She orders that we proceed to the ER and upon arrival at the ER, there were neurological team...waiting for me. That to me was a testament of care, attention, and concern by my primary physician and the ER team at [name of medical center]

“There was a time when my husband was wet and it took hours for them to come and clean him. I had to complain...”

Confidence in medical/nursing knowledge and skill (11)

“When my father was in the hospital, I felt he was in good hands”

Care with Information/Involvement (23)

A large number of responses surrounded the concept of being kept informed and involved with the plan of care. Simple acts like introducing yourself by name made patients feel as if they were cared for. Being listened-to was important, and when the patient felt not listened-to they did not feel cared for. The following direct quotes reflect the responses within Care with Information/Involvement:

Kept me informed/involved in plan of care (20)

“At shift change they made sure I knew who they were, charge nurse and everybody. That is why I only go to [name of medical center] and no other hospital”

“I noticed that they explained everything they did. My children asked questions and they explained what was going on”

Listened to me (3)

“They had patience to hear me talk”

“It was as if they did not care what I said”

Care for Personhood (79)

The Care for Personhood category carried the most responses overall. There were many subcategories within this theme: customer service, doing the little things, concern, going above and beyond, attentiveness and authentic presence, attention to privacy and comfort, maintenance of autonomy and responsiveness to requests. The following quotes reflect this theme:

Customer service, detail, the little things (15)

“I have a chewing problem, they brought food for me. Something I could eat”

“The only thing was the food. I am vegan, they kept sending me meat and cheese. I am not the only person who is vegan, we need vegan meals. ”

Concern (12)

“They were concern about my pain and careful because they said I was high risk. They were concern if I would walk. They were also careful to get me out of bed”

Going above and beyond (5)

“My nurse [name of nurse], after I left his unit he came down to check on me in my regular room”

Attentiveness/Authentic Presence (15)

“He actually sat down on the gurney (which was in the hallway) while listening to my symptoms”

Attention to privacy and comfort (8)

“He also put a note on my door and enabled me to sleep the whole day”

Maintenance of autonomy (5)

“The only thing I complain were all the tubes I had attached to me because they made me dependent on them even to get out of bed”

Responsiveness to requests (7)

“The doctors and nurses kept checking on me until my blood pressure became stable. They came to me every time I called for help”

Kindness (12)

“Aside from knowing I would be seen by competent medical professionals, the friendly, caring sensitive attitude towards a patient like me was paramount”

Unique Spanish Speaking Context

We also evaluated whether there were any differences between English and Spanish speaking participants. There were several types of expressions not found in the English speaking participant transcripts that described caring in intimate terms.

"Me hablaban y me consentian " - They talked to me and pampered me

"Me tocaban Los hombros y me daban palmadas" - They touched my shoulder and patted me

"Me trataban con cariño" -They treated me with love

Provided in English from a Hispanic patient: "I had a dream about a nurse and me and in the dream she was taking care of me as a friend, somebody who cared for me. I felt this was true with some of the nurses. "

Outcomes

Participants reported outcomes associated with feeling cared for during stroke hospitalization. These included a safe transfer home, optimal recovery from stroke, speedy discharge and loyalty to the healthcare institution. Conversely, delay to discharge was reported as a negative outcome when caring behaviors were not directed towards attending to the details needed to discharge in a timely manner.

Limitations

This project was limited to a small number of stroke patients and families in Southern California and would need replication to generalize outside of this context. Both methods of interview, phone and electronic survey, were used to collect data because of subject request, whereas one method is generally preferred. In the future, if this study were to be replicated, we would advise in-person semi-structured interviews instead of an electronic

survey design. Even though Spanish translated surveys were available, all Spanish speaking participants requested to do the survey over the phone instead of electronically.

Discussion

Hispanic patients want us to talk in a friendly way, to smile, to ask questions other than those related to their symptoms. Caring touch and warm, friendly actions are important to help to generate the emotion of feeling cared for. Deploying care in this way helps to gain trust, and reassurance. The results emphasize the importance of connecting to our patients as if they were family in a loving manner.

The inability to easily match the coded constructs to the Quality Caring Model 8 caring factors (Duffy, 2013) warrants further analysis. Given our participant responses it is possible that the operational definitions for the caring factors need to be refined. Further, because some of the caring behaviors did not match to the 8 caring factors, there may be additional caring factors other than the ones reported in the Quality Caring Model.

The results inform us of many caring behaviors that generate the human emotion of feeling cared for during hospitalization. The fact that patients and families interpret timely response to needs was an unanticipated act of caring. Although the stroke code response system was developed for the purpose of meeting time standards for best practice treatment of stroke, the code response with a team present on arrival is translated by the recipient of care as competence and an act of caring.

Results were disseminated at a regional research conference in two manners. First, a traditional research report was delivered. Secondly, a group of volunteer artists who were healthcare workers that create art as a hobby were provided the transcripts and asked to create a visual representation of the results.

Five projects were produced using visual, textile, kinetic, and poetic art forms. An example is shown in Figure 1. When asked whether art was a useful medium for translating research findings into knowledge 109:114 (96%) conference attendees agreed with use of art for this purpose.

Conclusion

In conclusion, competence, knowledge, skills, information, involvement in the plan of care, and regard for personhood all generate the human emotion of feeling cared for during hospitalization for a stroke. Absence of these decrease the likelihood that patients and their families will feel cared for during hospitalization. Because feeling cared for is known to stimulate health oriented activities and self-care through illness (Duffy, 2013), the behaviors described by our patients to provide competent, service-oriented, respectful care with a professional and kindly compartment are indicated.

Further, timeliness is perceived as an act of caring. Maintaining competence and providing patient education are forms of caring. Most importantly, the 'little things' are really the big things; small acts of kindness produce lasting memories. Going above and beyond is often perceived because you did something personal to make them feel special. Promoting these caring behaviors amongst those who provide care for stroke patients has the potential to improve the healing environment, improve the patient experience and optimize the healing process. (Figure 2)

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