A Nurse's Responses to Stroke Family Caregivers using a Web-based Intervention

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Caring Web

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ABSTRACT

Background. Approximately 795,000 people experience a first time or recurrent stroke every year and most are cared for by family caregivers in home settings. Web-based interventions provide 24/7 access to support services and have been explored in the literature with caregivers of persons with chronic conditions, such as cancer, dementia, and stroke. Current research into nurses' interactions with family caregivers in these web-based interventions is lacking.
Purpose. Guided by Friedemann's Framework of Systemic Organization, the aim of this descriptive study was to examine a nurse specialist's e-mail comments to stroke family caregivers participating in a web-based supportive intervention used in a one-year randomized controlled trial (RCT).
Methods. With institutional review board approval, caregivers in Ohio and Michigan (n=36) accessed the intervention support group and communicated by email with this nurse. These caregivers were primarily white women caring for a spouse, with an average age of 54 years (SD=12.2). The nurse moderated the group, answered caregivers' questions, and offered support. Data were collected over a period of four years and the nurse's responses were examined using rigorous content analysis.
Results. From the nurse specialist's narrative responses and questions/answers posted to the support group, five themes emerged and were drawn to Friedemann's Framework. These themes included: socializing (coherence in Friedemann's terms), dealing with emotions of the caregiver (individuation), taking care of the caregiver (individuation), accepting the caregiver role (individuation/system maintenance), and providing medical advice or referral related to the care recipient (system maintenance).
Conclusions. Healthcare providers can use this information to provide better, more informed care, and directed interventions for caregivers in dealing with stroke and its outcomes.

BACKGROUND

- Approximately 795,000 people experience a stroke every year, making it one of the leading causes of disability in the United States.
- Family members experience life altering changes after stroke, as many must learn how to manage caregiving at home.
- Since many family caregivers receive no formal instruction on how to perform tasks, they often feel unprepared and overburdened and have questions and need information regarding care for the survivor.
- The Internet is a relatively quick and inexpensive way to connect nurses and other healthcare professionals with caregivers and direct them to information to assist them in caring.

PURPOSE

The aim of this study was to examine a nurse specialist's e-mail comments to stroke family caregivers participating in a web-based supportive intervention used in a one-year randomized controlled trial (RCT).

METHODS

Design and Setting:

- A qualitative, descriptive study with a secondary analysis of email data.
- The nurse specialist was a board certified psychiatric nurse with years of experience working with family caregivers:
  - Moderated web-based groups, answered caregivers' questions, and offered support through email messages.
- Caregivers resided in northern Ohio or southern Michigan:
  - Enrolled from rehabilitation centers following the stroke survivor's return to the home setting.

Data Collection:

- All email messages were collected during the first year of being a caregiver of a stroke survivor enrolled in the RCT.
- These email data were extracted from two support group components of the intervention from May 2002 through December 2005:
  - Caretalk is a non-structured email discussion group between all the caregivers and a nurse specialist.
 - Ask the Nurse is an email group where questions may be asked confidentially of the nurse specialist.

Subjects:

- 36 family caregivers completed one-year of the web-based intervention and were included in this secondary data analysis.

METHODS (continued)

Data Analysis:

- Norwood's (2000) 3-phase, eclectic approach for content analysis was used to examine the **2,148 email messages**:
  - Deductive phase
  - Inductive phase
  - Integrative phase.

- The themes that emerged were then drawn to the process dimensions of Friedemann's (1995, 2013) framework of systemic organization.

- This framework suggests that a nurse may recommend multiple strategies to help caregivers reach the four process dimensions (listed below) that enable caregivers to deal with stroke:
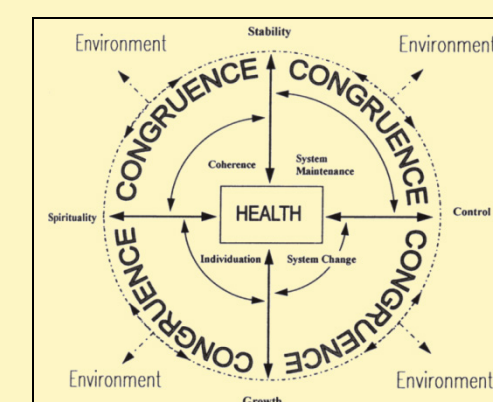
Coherence: A variety of actions leading to renewed energy and a positive attitude.

System Maintenance: Actions undertaken to maintain well being, e.g. rest & sleep, good nutrition.

Individuation: A process of self-development through learning, experiencing, and finding a purpose in life.

System Change: Changes made in priorities, attitudes, & values, and as a result, new behavior patterns are assumed.

Friedemann's Framework

RESULTS

Demographics of the caregivers (n=36):

Characteristics	Sub-Characteristics	n	%
Gender	Male	11	30.6
	Female	25	69.4
Age (in years)	20 – 30	0	0
	31 – 40	6	16.7
	41 – 50	6	16.7
	51 – 60	11	30.6
	61 – 70	8	22.2
	71 – 80	5	13.9
Relationship	Wife	15	41.7
	Husband	9	25.0
	Daughter	6	16.7
	Son	1	2.8
	Other Relatives and Friends	5	13.8
Race/Ethnicity	American Indian or Alaskan Native	0	0
	Asian/Pacific Islander	0	0
	Black not of Hispanic origin	4	11.1
	Hispanic	1	2.8
	White not of Hispanic origin	31	86.1
Education (in years)	None	1	2.8
	Grade School (1 – 8)	4	11.1
	High School (>8 – 12)	10	27.8
	College (>12 – 16)	15	41.7
	Graduate School (>16)	6	16.7

RESULTS (continued)

The following five (5) themes emerged and were drawn to Friedemann's framework:

1: Socializing (*Coherence in Friedemann's terms*)

This dialog accompanied greetings of new members and asked about their caring situation.

An example is: *"Hi, I look forward to having you join our discussion when and if you are ready… . Whom are you caring for? How are you holding up?"*

Other responses acknowledged or thanked caregivers: *"Thanks. …Keep up the great work!"*

2: Dealing with Emotions of the Caregiver (*Individuation*)

Caregivers said they felt anger and frustration with caring and this led to guilt. The nurse offered resources and validation of feelings.

An example is: *"Feeling cheated?…is so normal. Grieving of your old life…you are not being selfish, just real."* The nurse also shared: *"the new journey [in life] can have new rewards."*

3: Taking Care of the Caregiver (*Individuation*)

This discussion centered on taking care of oneself to preserve health and well-being.

The nurse said: *"Glad to hear that you are going to have your 'doctor check-up.' Frequently caregivers put themselves last and never quite get to their own doctor."*

She also offered advice to improve the caregiver's health: *"Reducing stress [through meditation or exercise], eating right, and getting enough rest [sleep] is important."*

4: Accepting the Caregiver Role (*Individuation / System Maintenance*)

After the stroke, the caregivers took on a new role in the stroke survivors' lives.

Many of the nurse's responses addressed their new role: *"Good insight here, indeed, being in the caregiving role places you in a position of the parent; your loved one, the child, at least sometimes…remembering the old role can go a long way towards a healthy relationship."*

She asked: *"What keeps you going?"* But also commented: *"Your life may never be the way it was, as this experience [caring] is now part of your life."*

5: Providing Medical Advice or Referral Related to the Care Recipient (*System Maintenance*)

The nurse frequently interjected advice focused on physical and mental adjustments in the person with stroke.

For instance, in answering a question about inappropriate behavior of the stroke survivor, the nurse commented: *"One thought about the laughing at anything behavior – this is called 'lability' or 'labile emotions' and it is quite common."*

She continued: *"It is unpredictable behavior and can often be interrupted by using distraction or diverting the person's attention to another topic."*

DISCUSSION

Themes and Friedemann's Process Dimensions:

The Nurse's Responses Drawn to Friedemann's Framework of Systemic Organization (1995, 2013)	
Themes	**Process Dimensions**
Socializing	Coherence
Dealing with Emotions of the Caregiver	Individuation
Taking Care of the Caregiver	Individuation
Accepting the Caregiver Role	Individuation / System Maintenance
Providing Medical Advice and Referral R/T the Care Recipient	System Maintenance
None	System Change

Coherence:

- The nurse and caregivers reached out to one another for support as illustrated by the socializing comments.
- They formed bonds with one another indicating togetherness focused on the caring situation.

Individuation:

- The nurse gave the caregivers more information about dealing with their emotions, taking care of themselves, and accepting their new role.

System Maintenance:

- The nurse helped the caregivers do everything in their power to maintain what they and the stroke survivor had.
- The nurse helped caregivers maintain control over their situation by providing medical advice and referral to other resources.

System Change:

- True change takes time and the short period of one-year may not be long enough for true change to emerge.

CONCLUSIONS

Healthcare professionals can:

- Use these themes to intervene with caregivers early in their caring experience as topics for support and education:
  - To encourage caregivers to reach out to others.
  - To gain knowledge about caring processes.
- Consider providing this information in a face-to-face or web-based format.
- Use this information to provide better, more informed care, and directed interventions for caregivers in dealing with stroke and its outcomes.