

# Processes and Meanings of the Patient-Family Caregiver Dyad in Palliative Care During the Hospital-Home Transition

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# Background



According to the WHO, 29 million people required palliative care in 2011.

The low capacity of health care systems added to the high demands of palliative care, result in short hospital stays focused on the control of symptoms and not in an integral attention.

# Background

The hospital discharge is the moment in which the patient leaves the hospital and returns home or is moved to another institution in the community.



Adequate hospital discharge is related with a better quality of life for both patients and caregivers.

# Background

To recognize the experiences of patients with cancer in palliative care and family caregivers will help to improve the care strategies during the hospital discharge in palliative care.

AIM

To explore the meaning of the cancer patient in palliative care-family caregiver dyad during the transition process between the hospital and the home in a health care institution in Bogota-Colombia.

# Design

Qualitative study conducted with the method of the grounded constructivist theory of Charmaz.

Participants:

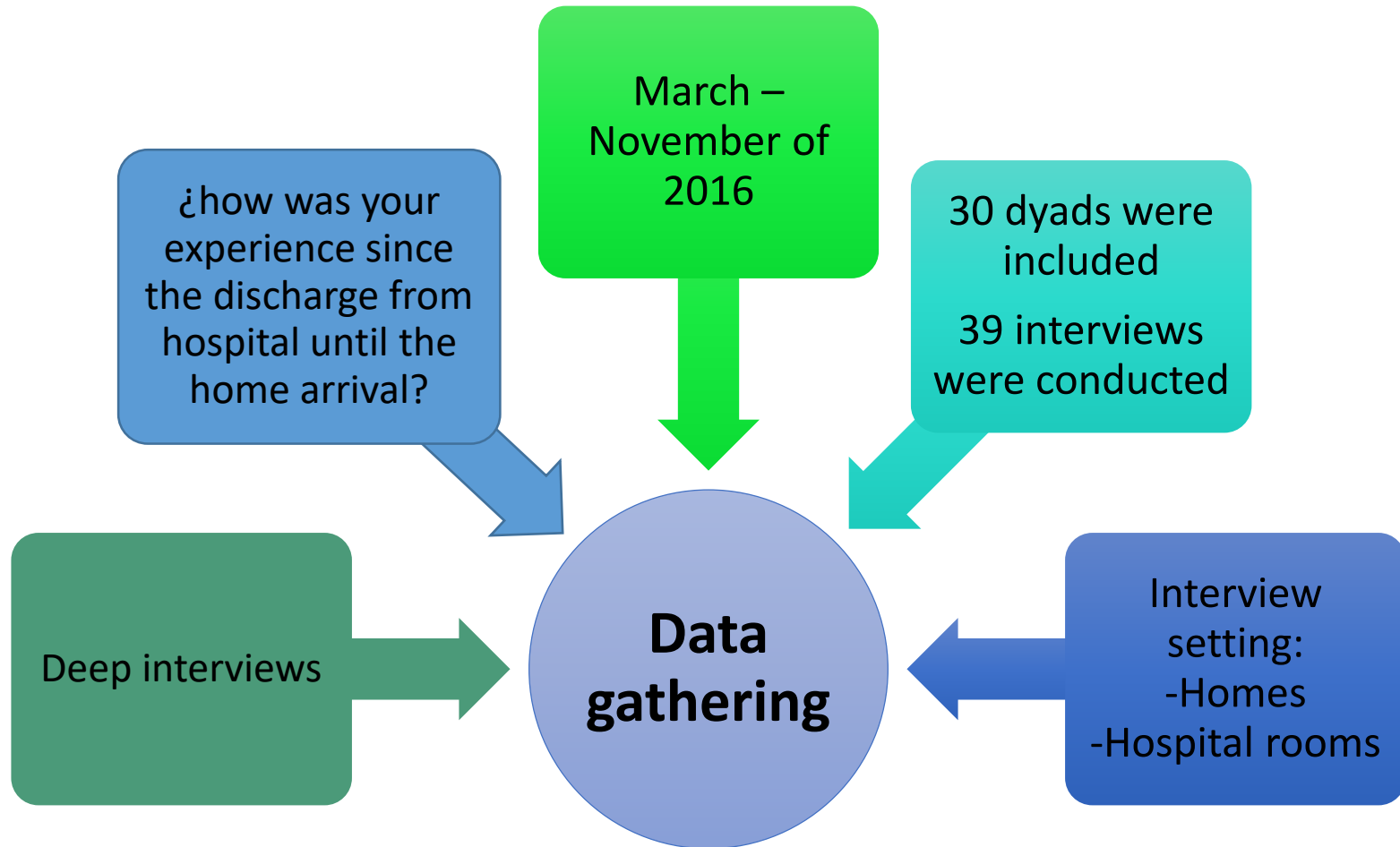
Patients with cancer in PC and Family caregivers, admitted in an inpatient PC unit, that had a hospital discharge order, were over 18y/o.

Theoretical sampling was used:

To choose participants

To expand categories after

# Design



# Design

**Data analysis:** we used the constructivist analytical method, two of the researchers analyzed the data in Atlas-ti program.

1. Line-by-line codification 350 initial codes

2. Initial codes with similar characteristics were grouped 112 topics

3. A focused coding was used to group the topics in 14 multiple characteristics.

4. Based on conceptual meaning of these characteristics 4 categories emerged.

# Results

Table. Socio-demographic characteristics of the dyads.

	Age	Sex	Karnofsky index	Relationship / occupation
<b>Patient with cancer</b>	60.4 yo average / min 28 – max 81	Male: 13 Female: 17	30 average /min 10 – max 50	-
<b>Caregiver</b>	45.7 yo average / min 18 – max 70	Male: 5 Female: 25	-	Daughter – wife Home, self-employed





# Results

Looking for control at the end of life through the bond

**Yearning for home**

Yearning the discharge

Learning from the health team

Mobilizing the social support

**Recognizing the burden**

Economic burden

Living with the symptoms

Overwhelming administrative procedures

Changing the daily routines

**Ambiguity and lack of control**

Communication with the health team

Care preparation

Departure and farewell

**Achieving control**

Strengthening bonds

Learning to cope

Restructuring the home

Facing reality together



# *Yearning for home*

During the hospitalization the symptoms are controlled; but they want to be at home, miss their daily habits, yearn for independence, intimacy and the perception of stability.

They point out that when they come back home is it possible to count with the support of the family.

During the transition they recognize the importance of learning to deal with the care condition at home.



# ***Recognizing the burden***

One of the main aspects that increases the burden is the restricted access to opioids due to the overabundance of administrative procedures required to obtain them

Once the dyads return home, things quickly become overwhelming due to changes in daily routines.

There is an increase in economic burden from the cost of home supplies.



# *Experiencing uncertainty and lack of control*

The dyads experience uncertainty, a lack of preparation of home handling (transport, mobilization).

During the first days at home the presence of exacerbating symptoms, generate a feeling of lack of control.

The proximity of death perception is one of the aspects that also generates uncertainty in the situation.

The lack of communication with the health team is another variable that exacerbates the lack of control perception.



# ***Achieving control***

They face the reality in a joint manner, the physical contact, the company, interaction, the affection and the gratitude consolidate themselves as factors that favor the coping process.

The restructuring of the home is centered on preventing accidents, anticipating, organizing and planning visits.

Control was increased when relationships were deepened with other family members.



# ***Looking for control at the end of life through the bond***

- The P/FC relationship is strengthened through the care experience, even more so during transitions such as the discharge from hospital to home.
- The diad moves in a search pattern in which the control of the symptoms, the available support and, in general, the handling of any disease related events are a desirable goal.
- The bond becomes an efficient mediator and an optimal agent in the search of control.



# Conclusion

We identified that the hospital-home transition is a complex process, characterized by a high physical, emotional and economic burden for the dyad in palliative care.

The bond that is generated between them is a vital element that help to cope with the transition from the hospital to home.



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