

# ANTICIPATORY GRIEF: EXPERIENCE OF THE FAMILY CAREGIVER OF PATIENTS IN PALLIATIVE CARE AT HOME

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anticipatory

grief

**WHAT IS  
THAT?**

# INTRODUCTION

- Anticipatory grief: experienced by patients who are approaching death and their family members and caregivers who care for them before the actual death.
- It involves a complex and sometimes distressing process of adjustment to progressing illness and approaching death (STRADA, 2013).
- It commonly describes the range of grief reactions occurring in family caregivers prior to the actual death of a loved one when the death is expected.

# OBJECTIVE

- To understand how family caregivers undergo anticipatory grief in home-based palliative care



# METHOD

STUDY DESIGN	Descriptive/Qualitative
PARTICIPANTS	15 family caregivers of patients in palliative care
SETTING	Home care sector of a large public hospital in a Brazilian Municipality
DATA COLLECTION	Semi structured interview
DATA ANALYSIS	“Interpretive Description” (Thorne, 2016)

# RESULTS

## ■ PARTICIPANT DEMOGRAPHICS:

Age: 19-61 years (Mean: 43 years);

Patient's age: 15-89 years (Mean: 63 years)

# RESULTS

## Gender:

- Man: n=1
- Woman: n= 14

## Family Income:

- 344 NZD/ month: n=6;
- 688 NZD/ month: n=5;
- 1023 NZD/ month:  
n=3;
- 1376 NZD/ month: n=1

# RESULTS

## Education Level:

- Illiterate: n=1
- Literate: n= 1
- Incomplete high school: n=4
- High school: n=5
- Incomplete college: n=2
- College: n=1

## Degree of Kinship:

- Daughter: n= 9;
- Son: n= 1
- Grand daughter: n=1
- Niece; n=1
- Mother: n=1
- Wife: n=1
- Cousin: n=1



# RESULTS

## 01

Be caregiver in the context of end-of-life care: What does that mean?

## 02

The feelings experienced by the family caregiver in the course of care

## 03

The sources of support to address the situation experienced

# Be caregiver in the context of end-of-life care: What does that mean?

- *“At first I found it very difficult and I thought I was not capable, I was very scared, as I still am ... because I have already taken care of people with lot of different illness, but as in her case, no”. (C6)*

# The feelings experienced by the family caregiver in the course of care

- *"There is anguish, there is sadness, we feel it, there are moments that we distance ourselves from these things a little, but the feelings come and they catch us."* (C10)

# The feelings experienced by the family caregiver in the course of care

- *"... sometimes I say that I am inside a prison, that I can not even go outside ... I do not leave only a minute, because if something happens, I'll blame myself [...]. I take care of her now because in the future I will close my eyes I do not regret thinking that I did nothing for her, right?". (C13).*

# The feelings experienced by the family caregiver in the course of care

- *“Nobody is prepared to lose... nobody thinks about that (...) I know that one day it's going to happen, but nobody will think about it right away. ”(C2)*

# The feelings experienced by the family caregiver in the course of care

- *"I've never had that contact we're having right now. And now, after all, this moment was a moment to unify, to unite, then there is this positive side too, to be closer together, to be closer, so the cool thing is that."(C5)*

# The sources of support to address the situation experienced

- “ (...) *I trust in God, that God gives strength and courage for us to continue.*” (C3)
- *"It has the support, not of physical presence, but a support of help, of visit, of conversation, of giving a support, for example, medical supply etc (...)"*. (C5)

CONCLUSION





# Acknowledgments





*Thank you!*

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