

# Experiences of Family Members of Dying Patients Receiving Palliative Sedation

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There was no conflict of interest in the presentation of this study nor is there any sponsorship of any product

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### **Learning objectives:**

The learner will be able to:

- Define palliative sedation
- Discuss some of the ethical issues associated with palliative sedation
- Describe the results of a study that investigated the experiences over time of family members of dying patients who received palliative sedation
- Discuss the implications to nursing practice, policy and education related to the results of this study





# Background

## **Refractory symptoms**

- Severe symptoms (physical and psychological) (Van Dooren et al., 2009)
- Treatment for prolonged periods leads to uncontrollable side effects

## **Palliative care**

- Improve the quality of life of all patients and their families, including the dying
- Relieve their suffering

The recommended treatment for a dying patient suffering from refractory symptoms is palliative sedation

(Maltoni et al., 2009)



# Background (con't)


## **Family Centered Care**

- Treatment for the dying patient and family members
- Physical and psycho-social state
- Provide emotional and physical support, medical advice and education

## **Family members**

- Remain with the patient in his last days
- Are involved and influenced by medical treatment
- Suffering of dying family member causes distress to family members

(Cherny & Radbush, 2009; Namba et al., 2007; Bruinsma et al., 2012)



Family members feel:  
Distress, fear, helplessness, and exhaustion  
before the initiation of the sedation treatment  
(Cherny & Radbush, 2009; Namba et al., 2007; Bruinsma et al., 2012)

**These experiences can be the trigger to start palliative sedation**  
(Rietjens et al., 2007)

- **Improve the patient's quality of life**
- **Relieve the stress on family members watching the suffering of their loved one**  
(Rietjens et al., 2007)

- **Family members may feel guilt and anxiety over making the decision to initiate treatment**
- **Palliative sedation thought to hasten death**  
(Bruinsma et al., 2012; Lawson, 2011)



# Study Objectives

Few studies investigated the experiences of family members of terminal patients receiving palliative sedation and none were found that investigated these experiences over time.

## **The objectives of this study were to:**

- ☐ Describe the experience of family members of patients receiving palliative sedation at the initiation of treatment and after the patient has died
- ☐ Compare these experiences over time.





# Method

**Design:** Descriptive, comparative longitudinal study

**Sample:** \* Convenience sample

\* 34 family members of dying patients  
receiving palliative sedation

\* Oncology ward in Israel



## Data collection:

Institutional Ethics Review Board approval

Data collection: T1: Interview while patient was  
receiving palliative sedation

T2: Telephone conversation 1-4  
months later



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graph TD; A[38 Recruited] --> B[T1: 34 participants<br/>(90 %)]; A --> C(4 Refused to participate); B --> D[T2: 26 participants<br/>(76 %)]; B --> E(8 lost to follow up);
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38 Recruited

4 Refused to  
participate

T1: 34 participants  
(90 %)

8 lost to  
follow up

T2: 26 participants  
(76 %)

# Instrument

## Experiences of Family Members of Patients Receiving Palliative Sedation (Morita et al., 2004)

### Four Components:

- a. Demographic and background data of the family member
- b. Demographic and background data of the patient receiving palliative sedation
- c. Participant's experience concerning the palliative sedation
- d. Experiences related to regret and satisfaction with the use of palliative sedation.



# Instrument Reliability and Validity

- Content validity by experts in palliative care
- Small changes were made to increase the questionnaire's sensitivity
- Reliability:

Cronbach's Alpha: T1 =.87 and T2 =.84.

Test retest reliability between T1 and T2 :  $r = .70$



# Data Analysis

Descriptive statistics

Differences between T1 and T2 :

- McNemar test for a dichotomous variable

- Marginal Homogeneity test for a nominal variable

- Wilcoxon Signed Ranks test for an ordinal variable

- Paired Samples T-test for continuous variables

# Results

Family members: Mean: 50.9 years (range 19-77; SD=15.4)

Most children or spouses

Patient age: Mean: 62.27 years (range 21-89; SD=15.54)

All Oncology patients

Primary symptoms: agitation, pain and dyspnea.

**Loved ones in distress  
or great distress before  
starting palliative  
sedation**

T1: 91%, n=31

T2: 92%, n=24

**Satisfied or very  
satisfied with use  
of sedation  
medication**

T1: 88%, n=28

T2: 81%, n= 21

**Start of sedation  
was properly timed**

T1: 77%, n=26

T2: 62%, n=16



# Patient and Family Instruction

## **1. Received instruction about the purpose of the sedation**

T1: 88%, n=30

T2: 92%, n=24

## **2. Patient received an explanation of the treatment**

T1: 32%, n=11

T2: 36%, n=9

## **3. Instructed about the treatment on the day of initiation of treatment**

T1: 74%, n=25

T2: 73%, n=19





# Received Instruction about the Impact of the Treatment on:

## **A. Patient's ability to communicate**

T1: 29%, n=10

T2: 23%, n=6

## **B. Patient's prognosis**

T1: 38%, n=13

T2: 15%, n=4

## **c. Physical effect on the patient**

T1: 38%, n=13

T2: 15%, n=4

# Ethical Impact

## **1. Palliative sedation was an ethical way to decrease suffering**

T1: 100%, n=34

T2: 88%, n=23

## **2. Very important that the patient did not suffer any longer**

T1: 88%, n=30

T2: 92%, n=24

## **3. Treatment shortened the patient's life**

T1: 32%, n=11

T2: 27%, n=7

## **4. Feared that treatment killed the patient**

T1: 15%, n=5



T2: 19%, n=5



No significant differences were found  
between T1 and T2

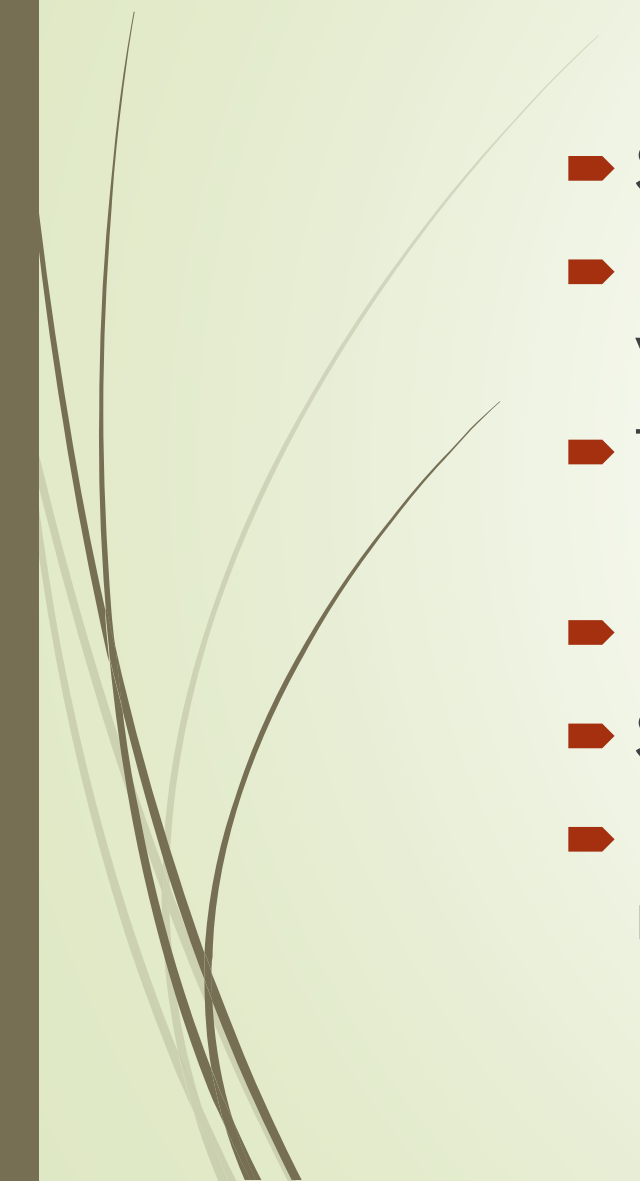
# Discussion

- Most of the families were satisfied with the use of palliative sedation, the relief of suffering, and the support given by staff (Bruinsma et al., 2012; Morita et al., 2004)
- Communication was not as effective as it could have been
  - Partially explained by many who first discussed the use of palliative sedation on the same day it was initiated
- The explanation process might need more time

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- Some felt that treatment may shorten the patient's life but fewer felt that the patient died because of the sedation
  - However, most thought that there were no other means to relieve suffering and most reported that they did not have legal or ethical concerns (Bruinsma et al., 2012; Morita et al., 2004)
  - Suspicions associated with the legal aspects of the therapy remained stable
  - The majority of participants were not conflicted on an ethical level about their decision to administer palliative sedation.



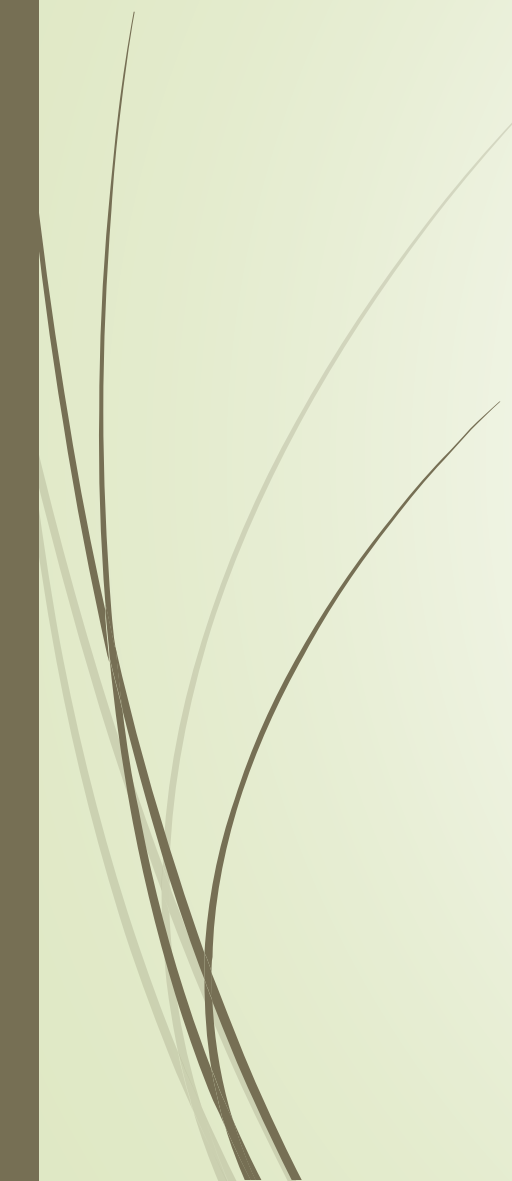
# Limitations

- Small sample
  - Data collector worked as a nurse on the unit where data were collected
  - Translation of questionnaire from Japanese to English to Hebrew
  - Use of two different means of data collection
  - Some of sample were lost to follow up at T2
  - Psychologically difficult to admit that made an ethical misjudgment
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# Conclusion

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1. Importance of providing timely and repeated explanations of palliative sedation.
  2. Treatment should be started early enough to avoid unnecessary suffering of the patient and family.
  3. Ethical conflicts seem less salient than patient suffering.
  4. More research, including qualitative and interventional studies, is needed to investigate this subject.