



Being the child's companion at the end-of-life: Weaving meaningful pathways

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**INTERNATIONAL CONFERENCE
ON CHILDREN AND DEATH**

**30 October - 3 November 1989
Athens, Greece**

Second Announcement



*1st International Conference on Children and Death,
Athens, Greece,
30 October – 3 November, 1989*

"Companion"

Latin root

Com= *with* + **Pan**= *bread*

*Companion is someone who breaks bread
with a person, while listening to stories*



Weaving is a process through which we assemble and interlace different threads into a fabric. The color & quality of the threads, and the process by which they are inter-woven, affect the tapestry that emerges among endless possible options.

Weaving meaningful pathways to the borders of life

In pediatric palliative care, **we weave meaningful pathways** to the border of life which can contain both the child's and family's suffering as well as their vitality - "*joie de vie*".

Art by Rashmisingh

“Pathways”

Family trajectory through the child’s illness

1. A pathway through **major disruptions** at diagnosis
2. A pathway **into a new Normal**
3. A pathway in **Liminality**
4. A pathway through **Separation**
5. A pathway through **grieving** and **relearning the world** in the child’s physical absence

A pathway through Liminality

“Limen” in latin = **threshold**

Children and families between two worlds: life and death

- The child is **not well enough** to lead a normal life but is **not dying** either
- Family members perceive the child as **physically present** **YET psychologically absent** due to changes in physical condition, psychological well-being & ways of relating to others.
- Family members may feel they have “**lost**” the child who is **still alive** and wants to be perceived as such

Boss, P. (2000) *Ambiguous loss*. Oxford: Harvard University Press

Living between two worlds:

The mermaid queen *Sophia*, 15 years old



Advance Care Planning

- Redefinition of goals of care
- Consideration of alternative options, potential scenarios, with no definitive plans. **Keep all options open.**

Beecham, et al., 2017 – Keeping all options open: parents' approaches to advance care planning. *Health Expectations*, 20: 675-684.)

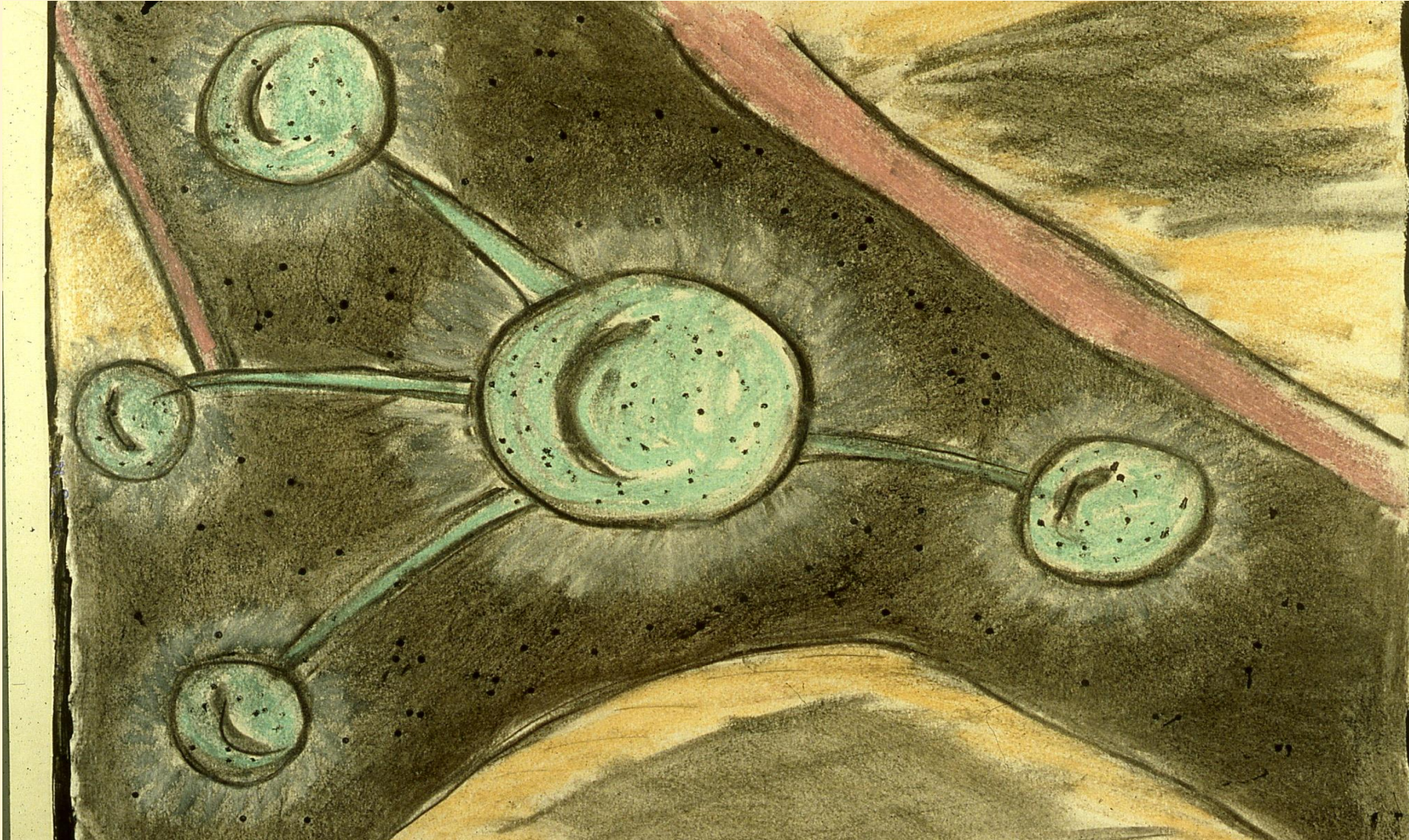
- Guidance about handling communication issues with seriously ill children and siblings
 - How to address “difficult” topics?
 - What to disclose?
 - How to share information?
 - When to engage in discussions?

Aldridge et al., 2017 – “I can’t tell my child they are dying;. Helping parents have conversations with their child. *Arch Dis Child Educ Pract Ed* (on line)

Lito, 9 years old: "Evil eye: The bad things that happen to people"



Lito, 14 years old "The metastases of my disease"



*“My
victory”*


*Lito, 14
years old*



"Pathways"

Family trajectory through the child's illness

1. A pathway through **major disruptions** (diagnosis)
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Anticipatory grief: A process involving an active adaptation to the reality of impending death

manifested through....



- Worries about deterioration & prospect of death
- Separation anxiety
- Emotional withdrawal (except from few relations)
- Concerns about location of care and death
- Direct or indirect communication of farewells

Coelho, A. & Barbosa, A. (2017). Family anticipatory grief. *Am J Hospice & Palliat Care*, 34, 774-785.

Adolescence & Dying

- **Both** are transitional periods
- **Both** evoke losses and a grieving process
- **Both** involve a process of redefinition of the Self **now** (Who Am I?) & in the **future** (Who I want to become?)
- **Both** trigger an active search for meaning
- **Both** involve major inner psychic reorganizations

Papadatou D. (1988). Adolescents dying from cancer. *Acta Oncologica*, 27, 837-839.

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- Who am I? (present)
 - Who was I? (past)
 - Who would I like become
but will never be? (imagined future)
 - Where am I going
after death? (immediate future)
 - How I wish to be remembered (long-term future,
immortality)

Papadatou D. (1988). Adolescents dying from cancer. *Acta Oncologica*, 27, 837-839.



Experiences “Worth Living”

involve

ordinary activities

and

ordinary relationships

with siblings, parents, relatives, peers, lovers etc,

which are experienced

as

extra-ordinary

and lived with an acute vitality that creates
a revived sense of existence into the world

Eva: These are stairs leading up into the sky.

Danai: Who is going up into the sky?

Eva: People..... Me.

Danai: What is up there?

Eva: The sun, the clouds, the moon

Danai: And what are you going to do up there?

Eva: I will be watching you.

Danai: Will I be able to see you?

Eva: No. You will be able to see me only in your heart.

Danai: You will always have a very special place in my heart.

Papadatou, D. (2021). Weaving meaningful pathways through the end of a child's life. *Rivista Italiana di Cure Palliative*, 23, 27-35.

Eva
5 years old

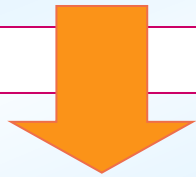


Being fully present at the end of life

Create a

HOLDING SPACE

which provides a sense of safety and predictability in the face of separation



Ability to

CONTAIN

the suffering, love, affirmations and ability to remain invisible

Provide a

SECURE BASE

that opens up possibilities to consider alternative options, decision-making, risk-taking



Ability to

**encourage & facilitate
EXPLORATIVE pursuits**

In unfamiliar situations



"The house is named Danai"

"The wild jungle"

Elli, 7 years old

"With lots of love, your friend, Elli
To my beloved Danai"

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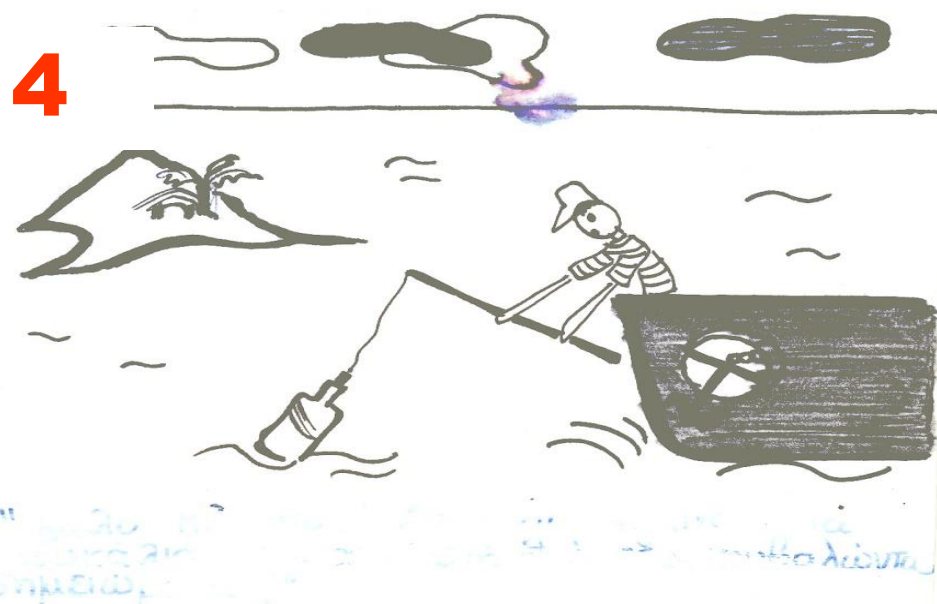
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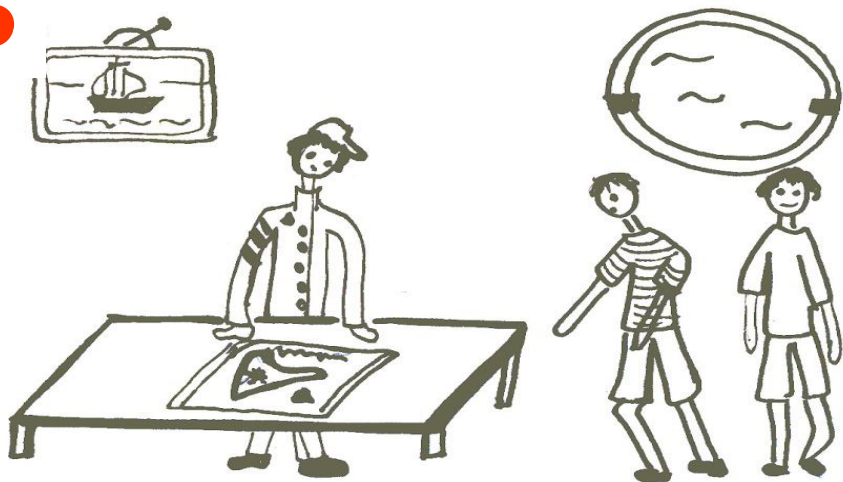
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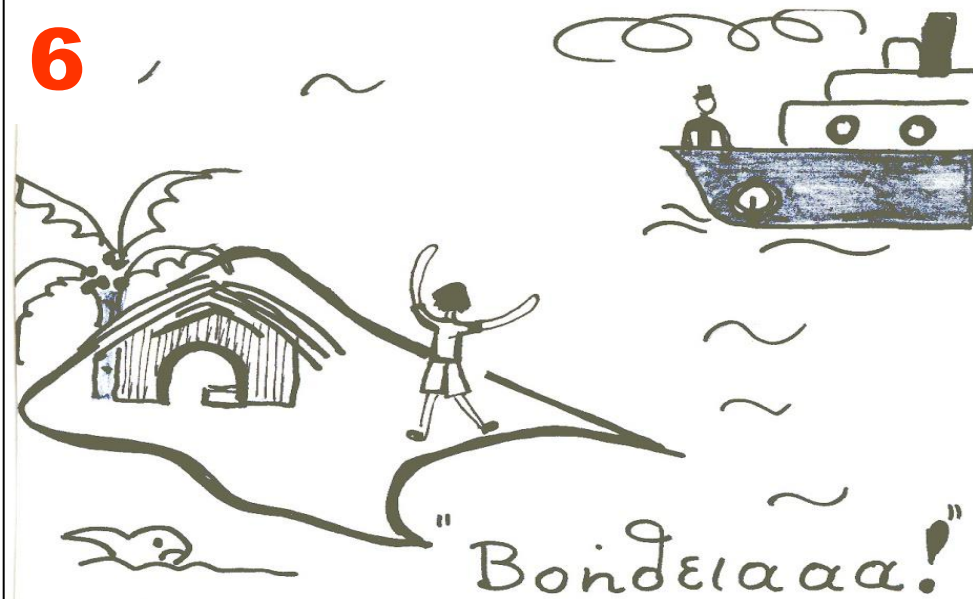
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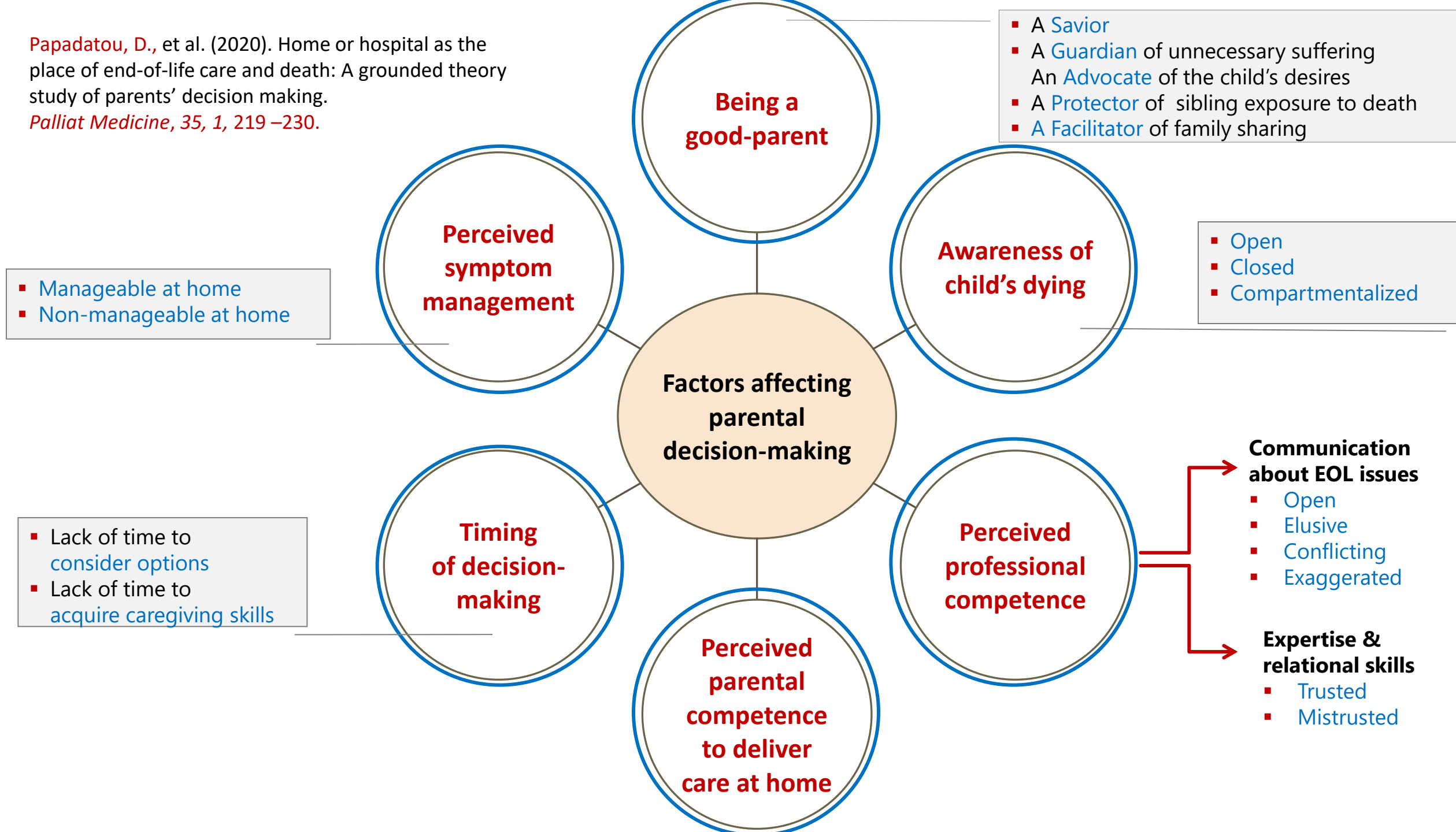
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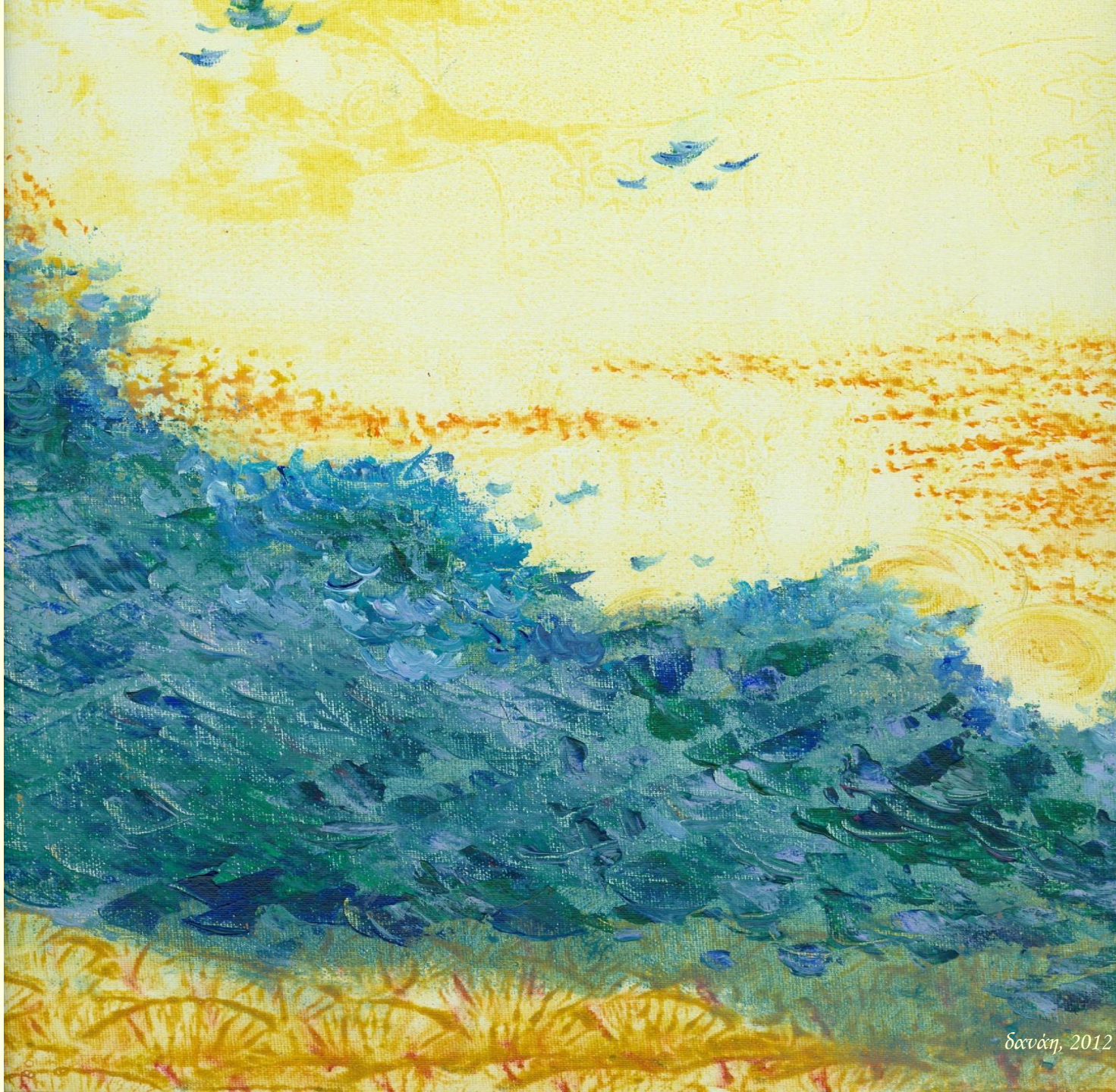


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Papadatou, D., et al. (2020). Home or hospital as the place of end-of-life care and death: A grounded theory study of parents' decision making. *Palliat Medicine*, 35, 1, 219 –230.





To maintain
the illusion that together
we' will carried into
death,

requires
a willingness
to face the
threat of loss

to tolerate the anxiety
and suffering it evokes,

and to recognize that
we will be unavoidably
affected and enriched.



Diego Rivera