

HOPE

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Summary

- I. CF in patients and families**
- II. What is hope?**
- III. Caring with hope to promote hope: Hope strategies in patients and families facing advanced chronic conditions**

I. Families and patients with CF



Ana Filipa, Jorge,
Vanessa



Born different
Progressive disease



Functional decline
Managing the
uncertainty



Living with disability
Facing fear
Awareness of death



New challenges
Psychological
Social



I. Families and patients facing CF



“While there's life,
there's **hope**”.

Cícero

“Life without hope is
not possible” *Ersek,
2001*

“Hope is essential to
cope with disease”

Nowotny, 1991



I. Families and patients facing CF



I am ready to face the winds and storms, with my stubbornness and my willpower. "I will not fall down by a blow" is my motto, and even if a storm comes I'll keep my ideals and keep firm to my will to live ... Because in this world we all have a role and while I did not discover mine, I'm not giving up!!

The strength, the courage and determination with which you struggles to live makes you an enlightened being ... It takes strength to survive, but it takes a lot of courage to live.

Thank you for being my father and above all thank you for being who you are!!



I. Families and patients facing CF



Will power

Love

Strength and courage

Meaning to live



Resilience

Uncertainty

Facing reality

Keep going on

Faith

Goals



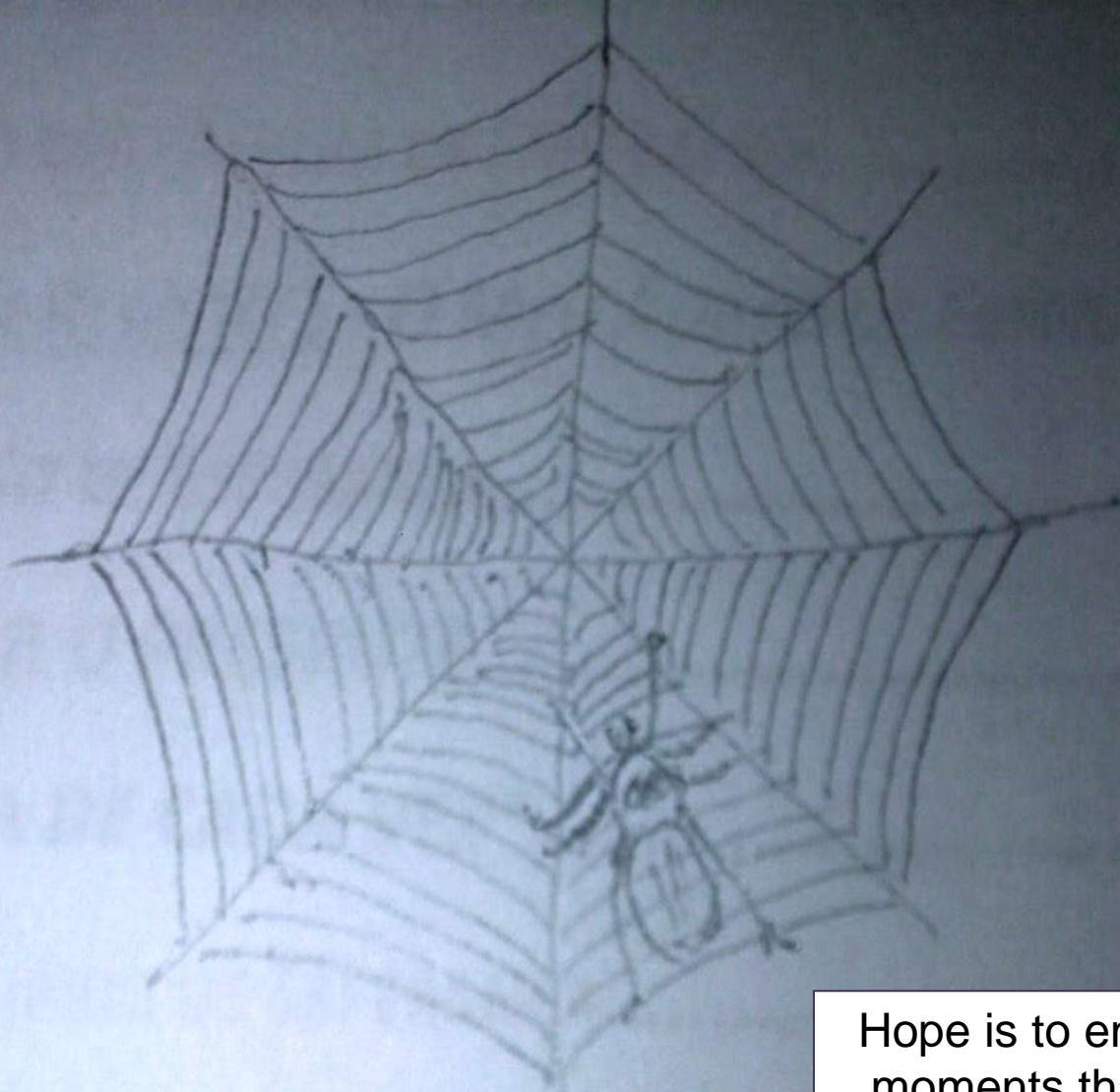
Hope for a cure
Hope to live vs live with hope

What is hope?



Eu e a Fibrose Quística





Hope is to enjoy every single moments that life offers you

A ESPERANÇA É APROVEITAR TODOS OS
BONS MOMENTOS QUE A VIDA OFERECE.

O MEU GUIA DE ESPERANÇA



II. Hope...

Emotion with the specific characteristics: Feelings of having possibilities, trust in others and in future, zest for life, expression of reasons and will to live, inner peace, optimism, associated with setting goals and mobilization of energy. (ICNP 2.0)

Hope is a perceived capability to derive pathways to desire goals and motivate oneself via agency thinking to use those pathways.

Hope is nurtured by positive feelings associated with setting realistic goals, and also the ability to create successful plans to achieve these objectives: past success and its impact on the present makes believing in future capacities. (Snyder, 2002)

Enduring suffering

Transcendence the situation

Coping mechanism

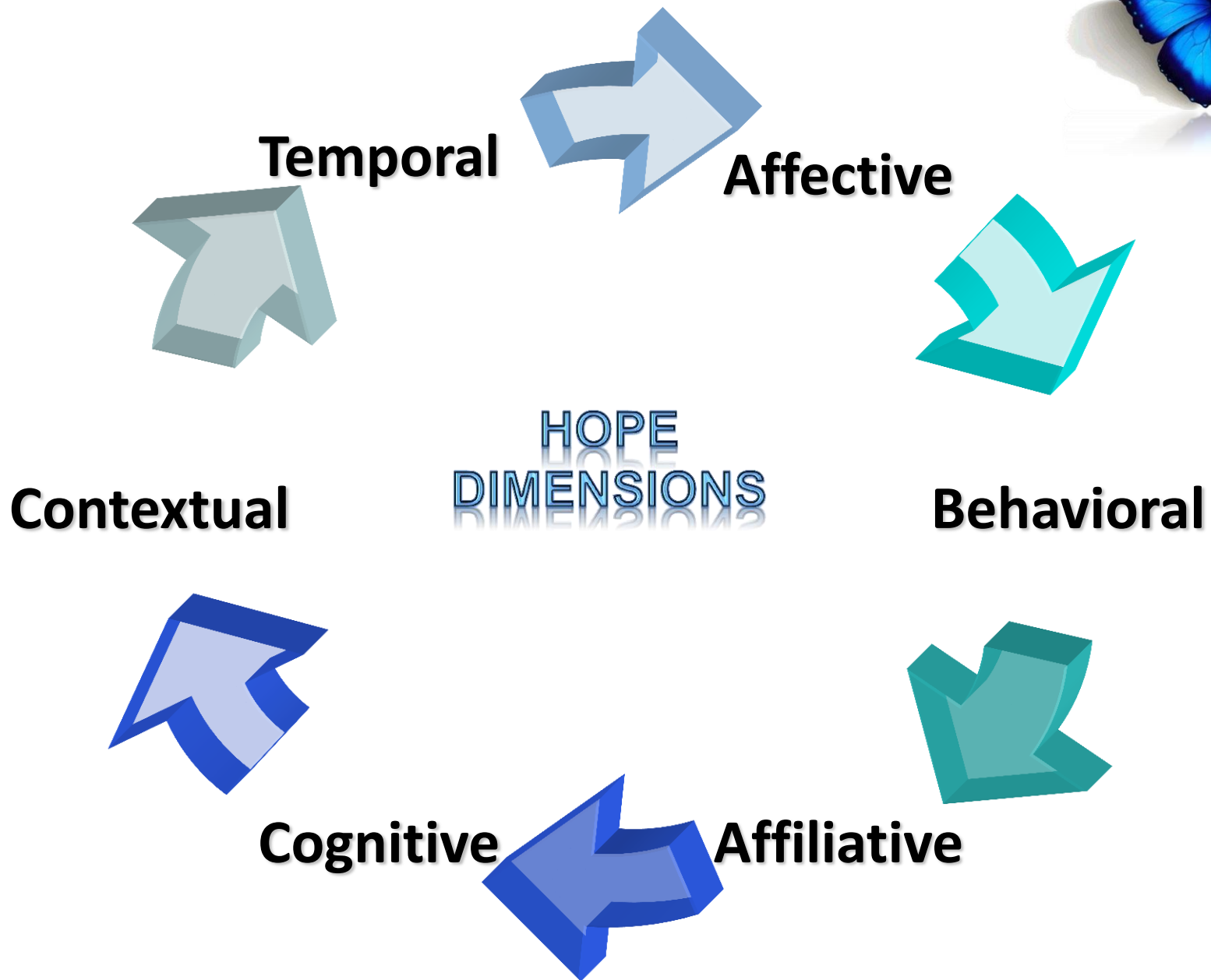
Inner resource of QOL

Incorporates disease experience



Atributos centrais da Esperança





Gives the conditions for the development of particular hope, serves to help the person find alternative hopes, and serves as comfort, when particular hopes are abandoned

Generalized

Relates to a sense of some benefit in the future, the development of which is undetermined. Broad in scope, and is not linked to any object of hope, concrete or abstract

HOPE

Particularized

Related to an object of hope, which can be concrete or abstract, explicit or implicit.

Allows one to perceive what is important, confirm, clarify and prioritize their perceptions, to preserve or reconstruct the meaning of life.

Hope in terminal illness: an evolutionary concept analysis

Sarah Johnson

Abstract

Aims: To clarify the concept of hope as perceived by patients with a terminal illness, to develop hope as an evidence-based nursing concept, to contribute new knowledge and insights about hope to the relatively new field of palliative care; endeavouring to maximize the quality of life of terminally ill patients in the future.

Method: Utilizing Rodgers' (2000a) evolutionary concept analysis methodology and thematic content analysis, 17 pieces of research-based literature on hope as perceived by adult patients with any terminal illness pathology, from the disciplines of nursing and medicine have been reviewed and analyzed. An exemplary case of the concept in action is presented along with the evolution of the concept hope in terminal illness.

Results: Ten essential attributes of the concept were identified: positive expectation; personal qualities; spirituality; goals; comfort; help/caring; interpersonal relationships; control; legacy; and life review. Patients' hopes and goals are scaled down and refocused in order to live in the present and enjoy the time they have left with loved ones.

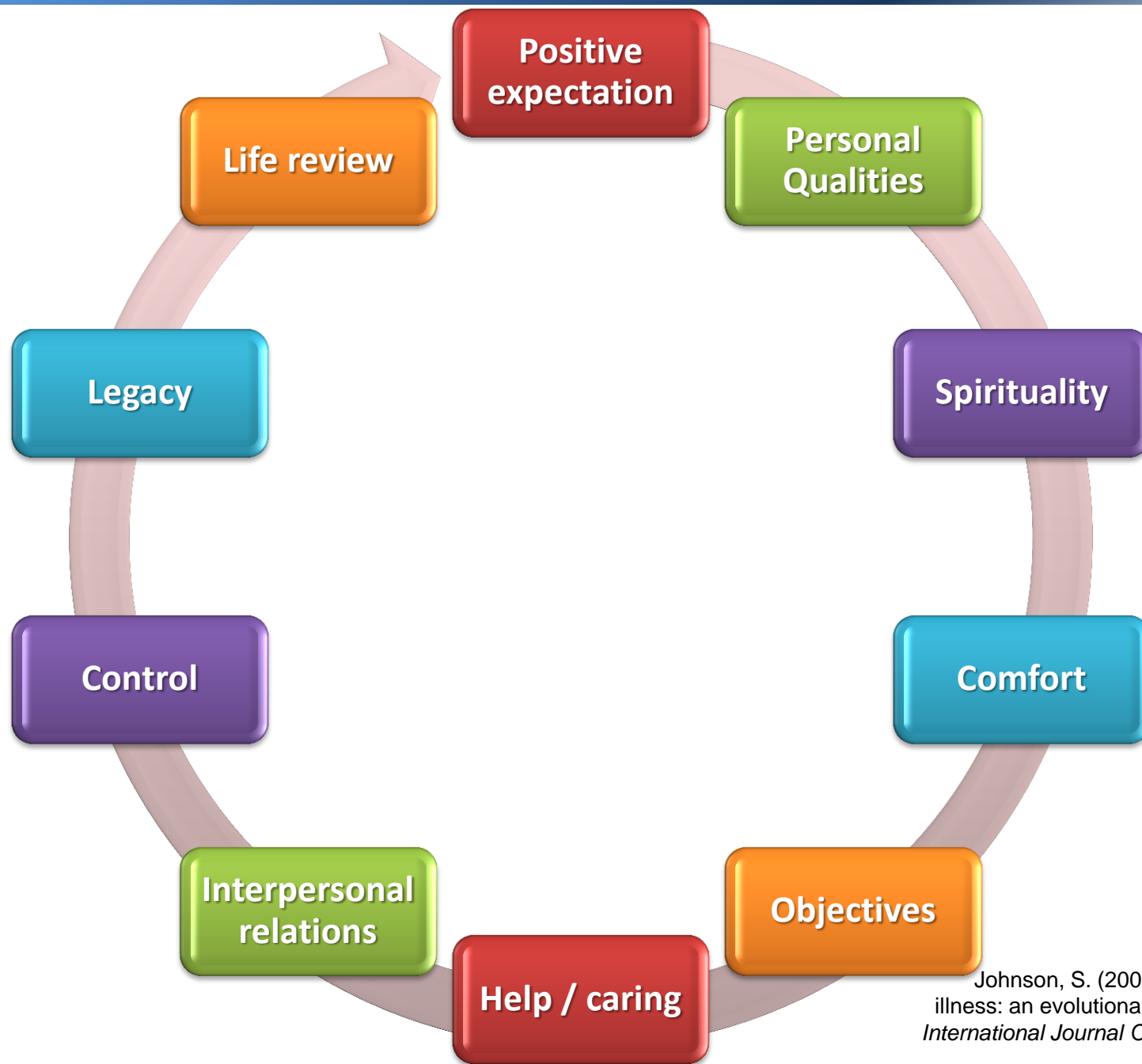
Conclusion: By completing all the steps to Rodgers' (2000a) evolutionary view of concept analysis, a working definition and clarification of the concept in its current use has been achieved. This provides a solid conceptual foundation for further study.

previous attempts at concept development have not produced significant results. Cutcliffe and Herth (2002) agree that in recent years there has been an increasing number of references to hope in contemporary nursing practice, but there remain large gaps. They conclude, 'much of the work on hope neither builds upon previous studies nor adds to this previous substantive knowledge base'.

Background

The terminal phase of an illness is often viewed by Western society as a hopeless situation; and yet, many patients facing such a period make it a time of hope of what can be achieved rather than what is no longer possible (Hockley, 1993). When first confronted with a terminal illness, most patients typically relate hope to a tangible treatment or a cure that can prolong existence despite overwhelming information to the contrary (Rousseau,

Esperança em fim-de-vida – atributos essenciais



II. A esperança em situações de fim-de-vida



1. Hope is **dynamic**
2. Hope is **multidimensional**
3. Hope is **central to life**;
4. Hope is **personalized**;
5. Hope is **future oriented**;
6. Hope is **empowerment**;
7. Hope is related to **faith**;
8. Hope is related to help from others and caring

Olsson, et al 2010; Rustoen et al, 2010; Miller, 2007; Duggleby, et al, 2007; Cutcliffe, 2001; Cutcliffe & Herth, 2005 ; Morse & Doberneck, 1995; Farran, Herth, & Popovich, 1995; Dufault & Martocchio, 1985; Miller, 1983

Hope in chronic conditions

- The focus of hope over time is often modified, realigned and scaled (Eliot et.al, 2009)
- Four stages or phases of hope when facing the advanced disease: **hope of cure; treatment; prolongation of life, a peaceful death** (Farran et.al, 1995)

“A Esperança em cuidados paliativos”

(Querido, 2005)



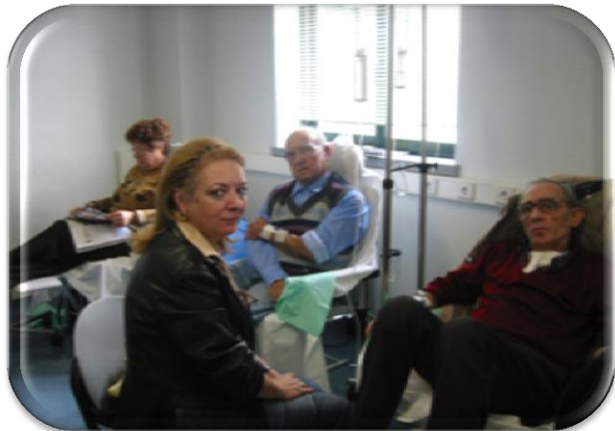
Explore the process of maintaining hope in patients in end-of-life

Hope is part of life and part of disease experience

It's a faith, an inner strength and a way of resistance materialized in hope objects.

Hope is focused in time in a future perspective

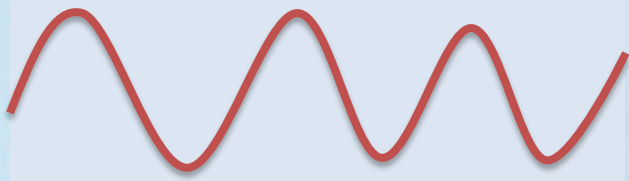
Related with peoples' life cycle



11 Oncology patients on palliative chemotherapy

While facing the disease Living with hope, people use several coping strategies, sometimes paradoxical: believing, resistance, resilience, facing, but also resignation, and just hope.

Maintaining Hope at the end of life

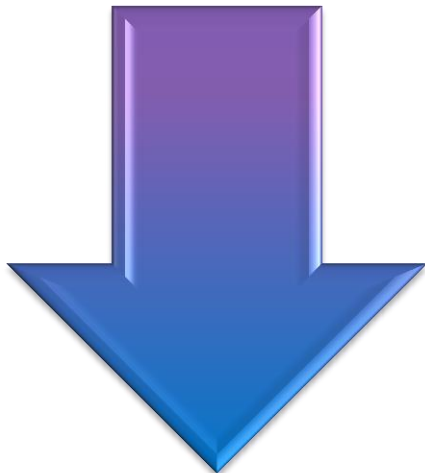


Process of living one day at the time, facing death as a present limit, manage factors that promote and threaten hope, reflecting and analysing them in order to keep going on hoping.

What enhances and decreases hope for people at the end of life



Positive feed-back
Well skilled nurses
Information regarding the disease process
Symptom control
Not being alone facing the disease
To have ways of dealing with suffering
Being remembered



Not being listened to
Abrupt and sharp answers
Hide the truth
Uncontrolled symptoms
New signs or symptoms of disease
Negative influence of others
Loneliness,
Social Isolation



What is known about hope in chronic conditions in Portugal?



Results

n=225 Family (carers) (*Marques, Dixe & Querido, in press*)

n=205 Patients (*Querido & Dixe (2010); Querido, Dixe & Marques, in press*)

Instrument to Measure Hope – Herth Hope Index PT

	Discordo totalmente	Discordo	Concordo	Concordo totalmente
1. Tenho uma atitude positiva perante a vida. (I have a positive outlook towards life)				
2. Tenho objetivos a curto, médio e /ou a longo prazo. (I have short and / or long term goals)				
3. Sinto-me completamente só. (I feel alll alone)				
4. Consigo ver possibilidades no meio das dificuldades. (I can see possibilities in the midst of difficulties)				
5. Tenho uma fé que me dá conforto. (I have a faith that gives me comfort)				
8. Tenho uma profunda força interior. (I have deep inner strenght)				
9. Sou capaz de dar e receber carinho/amor. (I am able to give and receive caring / love)				
10. A minha vida tem um rumo (I have a sense of direction)				
11. Acredito que cada dia tem potencial (I believe each day has potential)				
12. Sinto que a minha vida tem valor e mérito (I feel my life has value and worth)				

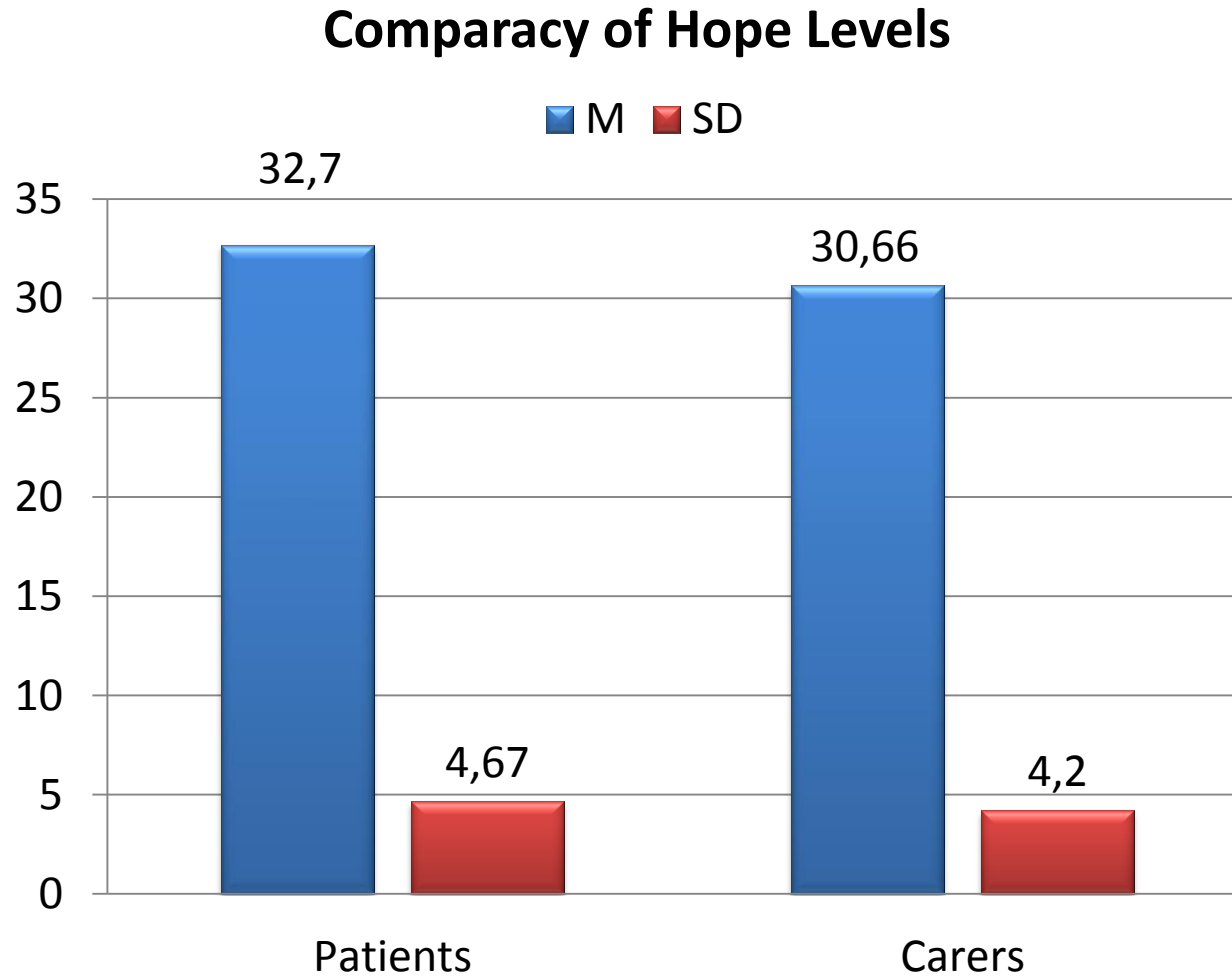


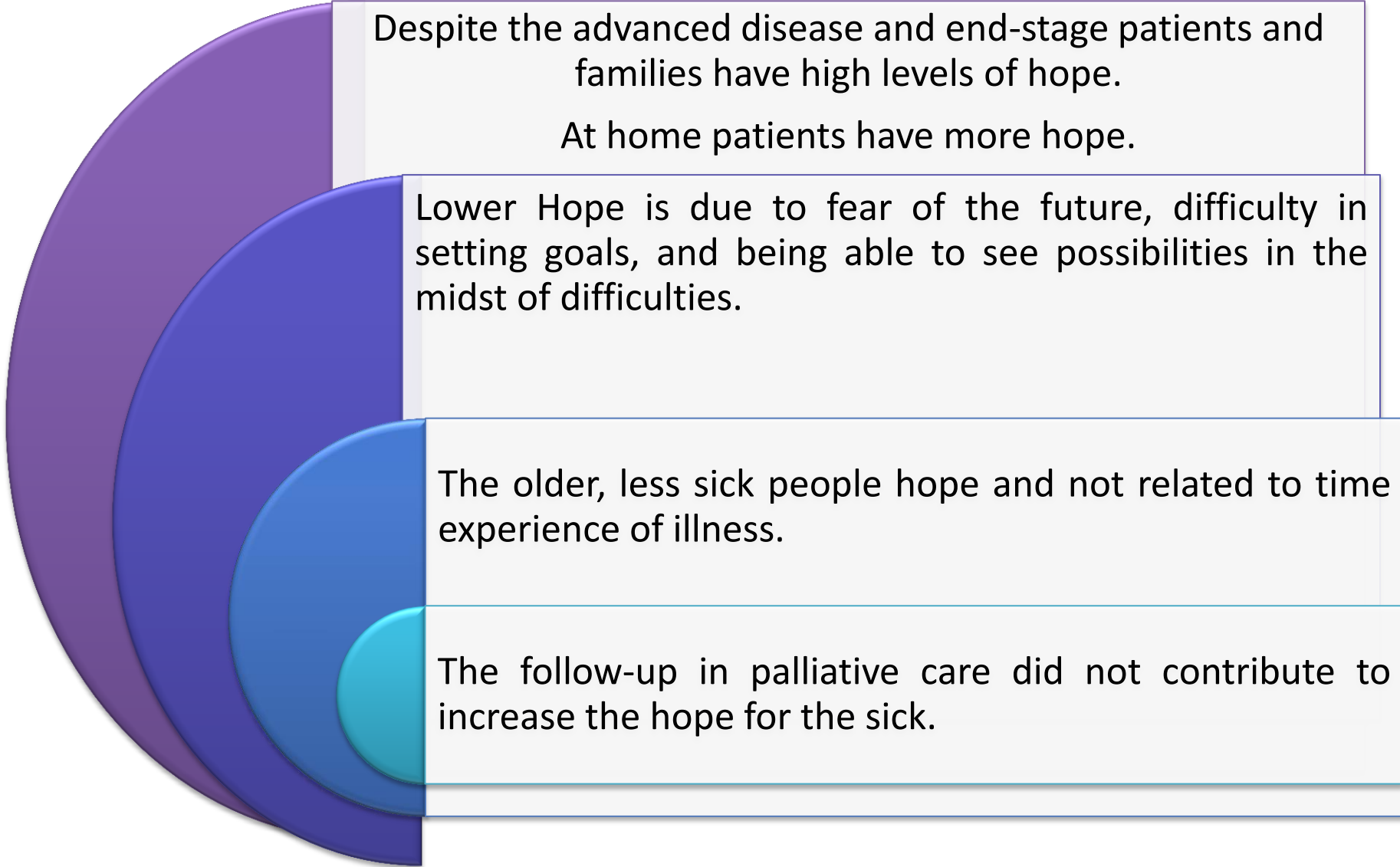
Sample



- Mean Age= 65,4 (+/-12,8); 53,9% ≥65 anos; Me=67 anos
- 57,1% Men
- 69,8% Married
- 72,2% Catholics
- 55,12% 4 years grade
- 85,7% living with family
- 97,6% recognises family support
- 29,76% moderate pain(M=4,97; +/-2,86)
- 62,07% fatigue (M=6,45; +/-=3,4)
- Mean Age= 63,0 (+/-11,7);
- 89,2% women
- 55,3% spouses / living as couple
- 50,7% 4 years grade
- Experience as a carer14,8 months(+/-14,1)
- Carers of partial dependent patients (Barthel <65)
- Facing health problems (M=8,0; +/-1,4)
- Spent 5,68h /day (Mean) caring for the patient (+/-2,1)
- 96% fatigued (M=7,9; +/-1,5)

II. Hope in chronic advanced disease





Despite the advanced disease and end-stage patients and families have high levels of hope.

At home patients have more hope.

Lower Hope is due to fear of the future, difficulty in setting goals, and being able to see possibilities in the midst of difficulties.

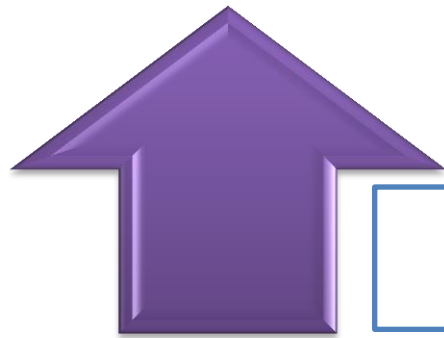
The older, less sick people hope and not related to time experience of illness.

The follow-up in palliative care did not contribute to increase the hope for the sick.

Can hope to determine quality of life and comfort?



Hopeful Patients have better quality of life



Quality of Life

Existential
 $\rho = 0,56; p < 0,01$

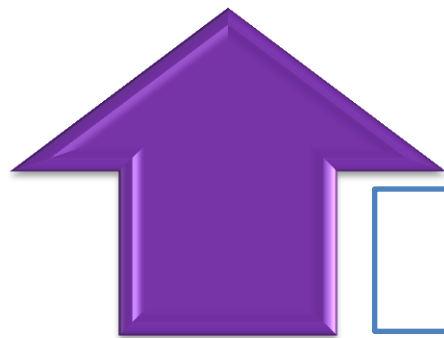
Total
 $\rho = 0,66; p < 0,01$



Hope

Hope can help to live with Quality of Life

Hopeful patients has more comfort



Comfort

Relief
 $\rho = 0,65; p < 0,01$

Trancendence
 $\rho = 0,53; p < 0,01$



Hope



Why working to enhance hope?

Palliative care in the **affirmation of life by supporting the goals of the patient and family, including their hopes for cure or prolongation of life as well as his hopes of peace and dignity during the course of the illness, the dying process and death.**

The purpose is to lead and assist the patient and family in decision-making processes, in order to allow working its objectives during the period of time they have left.

This assumption based standards of good clinical practice in palliative care include the evaluation and promotion of hope as a criterion for quality care
(NATIONAL CONSENSUS PROJECT, 2009).

III. Caring with hope to promote hope



- It is done through the presence, time to talk, and provide help.
- The way information is transmitted interferes with hope.
 - honesty
 - respect
 - compassion
- Attitudes and behaviors that demonstrate intent to care are:
- 'gestures', 'showing warmth and being genuine, nice and polite', helped to increase life expectancy of patients

(Querido, 2005; Koopmeiners et al, 1997).

III. Carinf with hope to promote hope



Hope promotion strategies

Nursing Interventions and activities to promote Hope

RESOURCES AND THREATS TO HOPE

Focuses on awareness of emotions and feelings associated with the final stages of life, and the interpretation of the meanings as opportunity paw test hope.

Focused on perception. It addresses the cognitive and contextual dimensions of hope.

Hope Coat -of-arms ; Hope Inspirator

REMEMBER MEMORIES OF PAST HOPES

It focuses on the life experience, the positive memories of the past, and their interpretation, which can be used for the present and projected future.

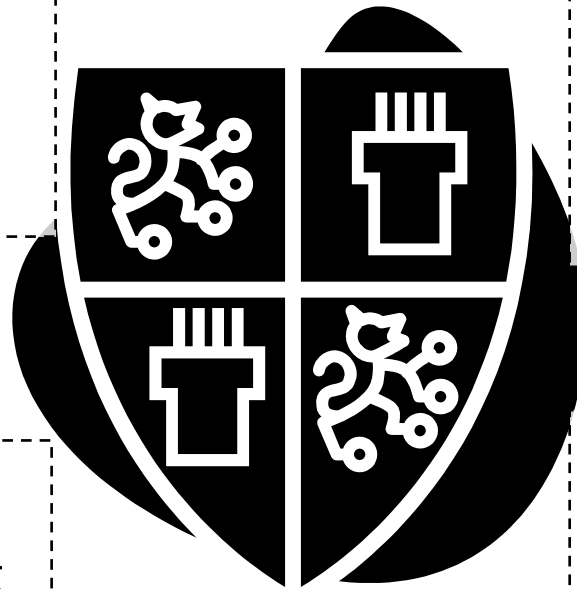
Focused on the temporal dimension of hope. Addresses the cognitive dimension of hope and affiliative, using reminiscence.

Hope Album; Hope Kit

Activity 1- Hope Coat-of-arms

Someone
close that
gives you
hope

A feeling that
gives you the
sense of hope



Something
or someone
that you
believe that
gives you
hope

Na experience
of hope from
the past

“About me collection”

HOPE ALBUM

- *Of the happier stories can select books, postcards, photographs that most enjoy and / or have greater meaning for you;*
- *From the messages it receives significant motivation and that convey a positive message of courage and hope;*

*Put these photos in an album,
poems,
images of his past,*

*Give a name (label)
every memory of hope*



My Hope Story...

You can count on your life path referring to the high and low points, starting as soon as possible and the way you prefer.

The postcards, photos, images, objects significant help to portray this route.

You can put your story in a notebook, make a newspaper / book, recording video or voice so others can learn from you





Hope Kit

- The "Hope Kit" represents his "Hope treasure box" where you can store objects that represent reality or something that feeds your hope.
- Choose objects that represent things that may not be achievable but that are important to hope
- Choose a box, folder or other storage material for your Kit

- You can personalize your kit. Decorate it to your liking with colors, drawings, collages, messages ...
- Give a name to your kit.



Intervenções e Actividades promotoras de esperança

**ENJOY LIVING
THE PRESENT**

**Living one
day at a
time**

Focuses on the importance of giving meaning to the little things, focus on the positive emotions, cherish the present and determine short-term objectives. Is targeted at the cognitive, behavioral and contextual hope.

**Hope Journal / Gratitude Journal; Clarifying values
Therapeutic letters**

**Enjoying
the
moment**

Focuses on the ability to self-transcendence and as a strategy for dealing with unpleasant symptoms associated with the disease

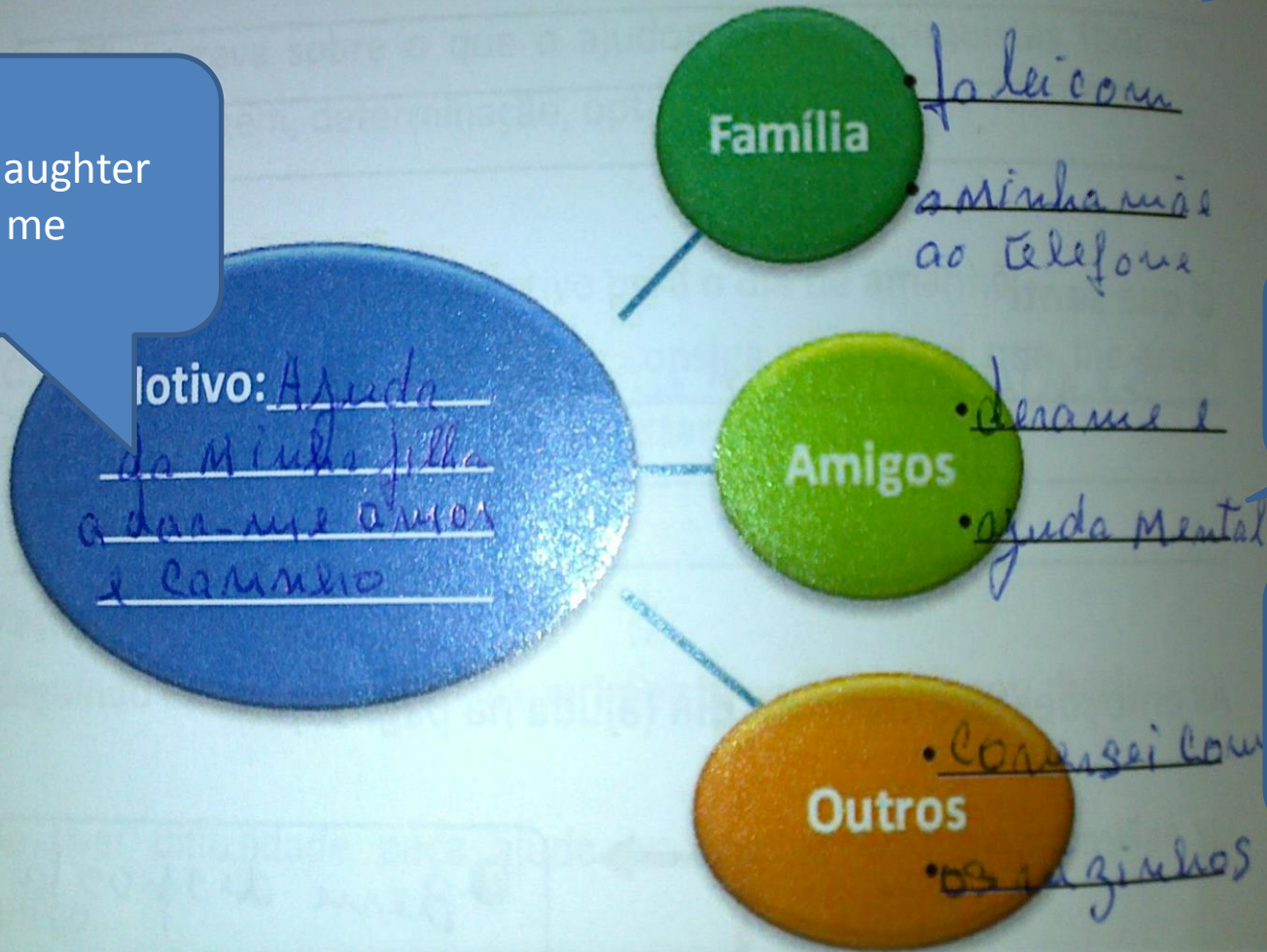
Focused on cognitive and behavioral dimension.

**Personal list of joys
Relaxation Moment / Stress Relief**

Hope Journal

O dia valeu a pena por:

Having my daughter helping me



Speaking to my mother on the phone

Friends help me to cope with my mind

Talking socializing with neighbors

My Talents

Today I was able to....

Sentir _____

Partilhar _____

Fazer _____

Os meus talentos

Assinale com um círculo as capacidades que o ajudaram nas conquistas do dia. Acrescente outras se necessitar.

Hoje fui:

Optimista

Resistente

CORAJOSO

Determinado

Forte

UMA BOA PESSOA

Crente

CARINHOSO

Capaz de aceitar ajuda dos outros

Example from a Hope Journal

Sentir senti-me feliz, por estar
cá mais um dia.

Partilhar Partilhe o meu dia com
a minha família

Fazer fazer as minhas tarefas
diárias, mesmo sem o
poder.

Gratitude Journal

5 things that make the day worthwhile... things for which you feel grateful and that brings you happiness.

08/06/2011

Continuo na cama sem me poder mexer sózinha (nem sequer para coçar o nariz ou para escrever as 5 coisas boas de hoje). Mas vou fazer o esforço...

Hoje o dia valeu a pena porque:

- 😊 *Tive a visita da minha amiga Lena*
- 😊 *Fui capaz de Rir com vontade ao lembrar-me dos velhos tempos com a Lena*
- 😊 *Adormeci após o almoço a ouvir o barulho dos pássaros no jardim*
- 😊 *Ter sentido na cara o fresco da brisa do final da tarde (a Lena abriu a janela do quarto)*
- 😊 *Não estou tão sonolenta e sinto-me com todas as minhas capacidades mentais*

Therapeutic Letters

Querida Teresa:

Hoje que não estás perto de mim, dei por mim a pensar o quanto tenho saudades dos nossos tempos de.....

Rimos tanto que agora também a mim me deu vontade de rir.

Só quero que saibas que apesar da situação ser difícil, ela vale a pena também por ti.

Fazes-me sentir muito amado e isso ajuda a viver esta fase da vida.

Não sei quanto tempo vou cá andar, mas quero que saibas que me fazes muito feliz.

António

Therapeutic Letters - Forgiveness

Forgiveness is synonymous with reconciliation. Not necessarily requires to repair ties with the abuser, excuse it or deny the offense suffered. To forgive is to renounce hatred.

A sheet to write a **letter of forgiveness**. If you need help you can ask your family, friends or even the nurse.

Start detailing the pain suffered

Explain why you feel hurt by the person

Tell us what you would like the person had done instead of what really happened

Grant him forgiveness explicitly showing their understanding

Write a sentence beginning with "**I forgive you ... for ...**" such as:

"I forgive my father for having abandoned me ..."

You can send a letter to someone if you want, but you don't need to do so.

Therapeutic Letters - Forgiveness

PESSOAS A QUEM GOSTARIA DE PERDOAR

Nome / Foto do acontecimento	Motivo

Enjoy Living the moment – Family

Time saving

Most important tasks	Important non urgent tasks

Sparing Hope

Write what you like to do and cannot do due to lack of time;

Put small papers in a box

Whenever someone asks how you can help, ask him to pick a paper from the box

Intervenções e actividades promotoras de esperança

PLANNING THE FUTURE

Focuses on the guidance of action towards achieving the objectives. Identification of important areas of life and setting realistic goals.
Addresses the behavioral dimension, contextual, affiliative hope.

Setting realistic goals

Setting realistic goals

1^o - **Select the field of interest** - an aspect of life that is important to you and who is not satisfied with what you have achieved in this area

2^o - **Identify the level of hope** that has this area of life

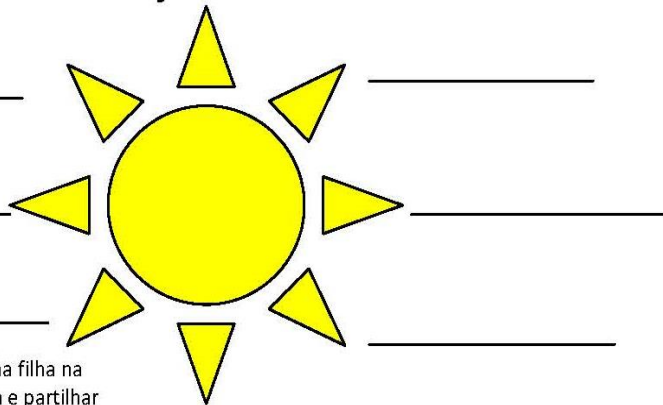
3^o - **Decide what you really want** - what you can do to increase satisfaction in this domain?

4^o - **Determine whether the goal is realistic** - What possibilities has to achieve the objective? (write the questions)

5 - **Determine the pathway you need to achieve the objective** - If you need to ask those who have done it before

6 - Let's **split** the objective

Os meus objectivos da semana são ⁽¹⁾:



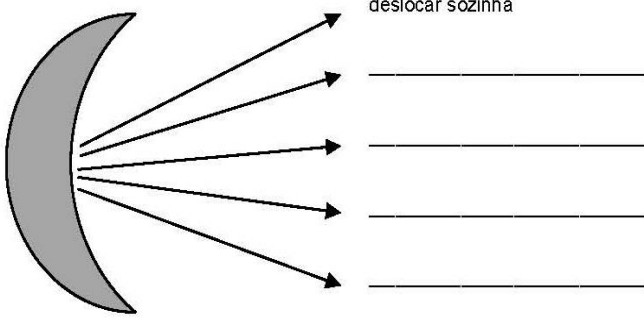
Ex: Visitar a minha filha na próxima 4ª feira e partilhar fotografias antigas

7



Numa escala de 0 a 10, considerando que 0 a ausência de possibilidades para concretizar os seus objectivos, e 10 é o máximo dessas possibilidades, indico um número atribuído a cada um dos objectivos (como no exemplo)

Os obstáculos que podem impedir-me de concretizar os meus objectivos são:



Ex: Não ter possibilidade de me deslocar sozinha

Setting realistic goals

O plano para cumprir os meus objectivos é:

O meu Primeiro Plano

Ex: Pedir à minha filha para me vir buscar a casa

1.º Passo:
2.º Passo:
3.º Passo:

O meu Segundo Plano

Ex: Pedir boleia à minha vizinha

1.º Passo:
2.º Passo:
3.º Passo:

¹⁾ Adaptado de Charepe (2011) e Snyder C. (2000)

Caring with hope in CF...



It is essential in the experience of illness, able to increase the comfort and quality of life

Living with Hope is a choice that each of us can take.

It takes practice, commitment and work:

It is needed to

- 1 - Recognize changes
- 2 - Projecting the future and define objectives
- 3 - Believing in personal skills and reinforce them
- 4 - Believe that every day has a potential - have a positive attitude
- 5 - Define objects of hope and make dreams come true
- 5 - Encourage meaningful relationships
- 6 - Foster spirituality

A close-up photograph of a person's hand holding a blue, textured, egg-shaped object. The object has several small, dark holes along its bottom edge. The background is dark and rocky, with some dry grass or twigs visible. The lighting is dramatic, highlighting the texture of the object and the hand.

The value of things is not the time
they last, but the intensity with
which they occur.

That's why there are unforgettable
moments, unexplainable things and
incomparable people.



The value of things is not the time
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incomparable people.

Fernando Pessoa

Thank you and...



Good Hopes!!!...

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