Respect, Dignity and Compassion in Palliative Care

Dr Raksha Balbadhur
MBChB (UCT) DA (SA)

PGDip PallMed (UCT)
MPhil PalMed (UCT)

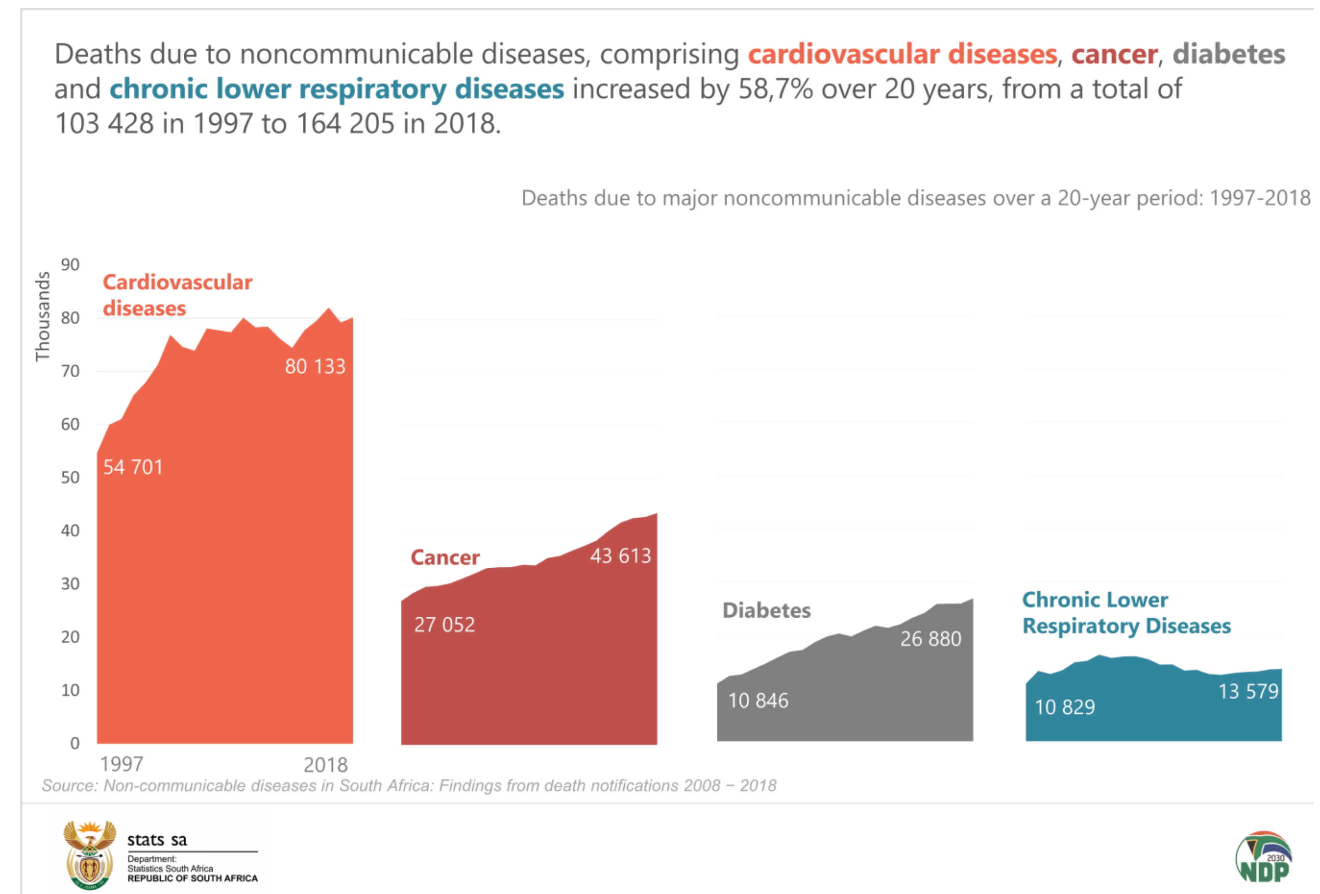
Dr Raksha Balbadhur

- Palliative medicine specialist, practising privately, offering home based care
- Master's degree on understanding the dignity experience of patients with advanced disease - a SA'n perspective
- Board Member PALPRAC
- Founder and Chairperson of VIHASA (the Values in Healthcare Assoc of SA), she has run 100's of experiential workshops across Southern Africa to support healthcare practitioners
- A student and teacher of meditation, she brings meaning and peace to her patients at the most challenging time of their lives

Notable Increase in NCDs Globally

In SA, deaths due to major NCDs increased by 58,7% over 20 years, from 103 428 in 1997 to 164 205 in 2018

This is the population that you are exposed to on a daily basis as family physicians



Role of Family Physicians in Strengthening PHC and PC – creating opportunity from adversity

- The WHA called for Member States to "put people at the centre of health care" by providing "**comprehensive primary care services, including health promotion, disease prevention, curative care and palliative care…**" (WHA 62.12)
- **PC is "an ethical responsibility** of health systems". Integration of PC into public HC systems is essential for the achievement of the **SDG on universal health coverage** (WHA 67.19)
- Yet PC and symptom relief are **rarely accessible** in a number of countries thus suffering on a massive scale remains unrelieved.

Palliative Care – an ethical responsibility

- Those who need PC prefer to remain **at home**, thus, it is medically and ethically necessary that PC be **provided in the community, as part of PHC**.
- **FP with basic training in a PC approach/symptom relief can respond effectively to most PC needs** and arrange for transfer to a higher level of PC when necessary.
- Emphasis should be given to **continuity of care, respect for patients' values, equitable access to services, and attention to the family unit.**

Palliative Care

Palliative Care

Care of the body, mind & spirit: Focusing on, social, emotional, cultural, spiritual & intellectual or knowledge aspects of care supported by an interdisciplinary team and training

Holistic Approach

Patient-centred care incorporating respect for patients' values and preferences, provides information in clear and understandable terms, promotes autonomy in decision-making and attends to the need for physical comfort and emotional support.

Quality of Life

Patients referred to DPH have an expectation of dying, therefore care of the families is included in the care i.e. Care of the infected and affected by the team while the patient is alive and into the bereavement period

Patients & families

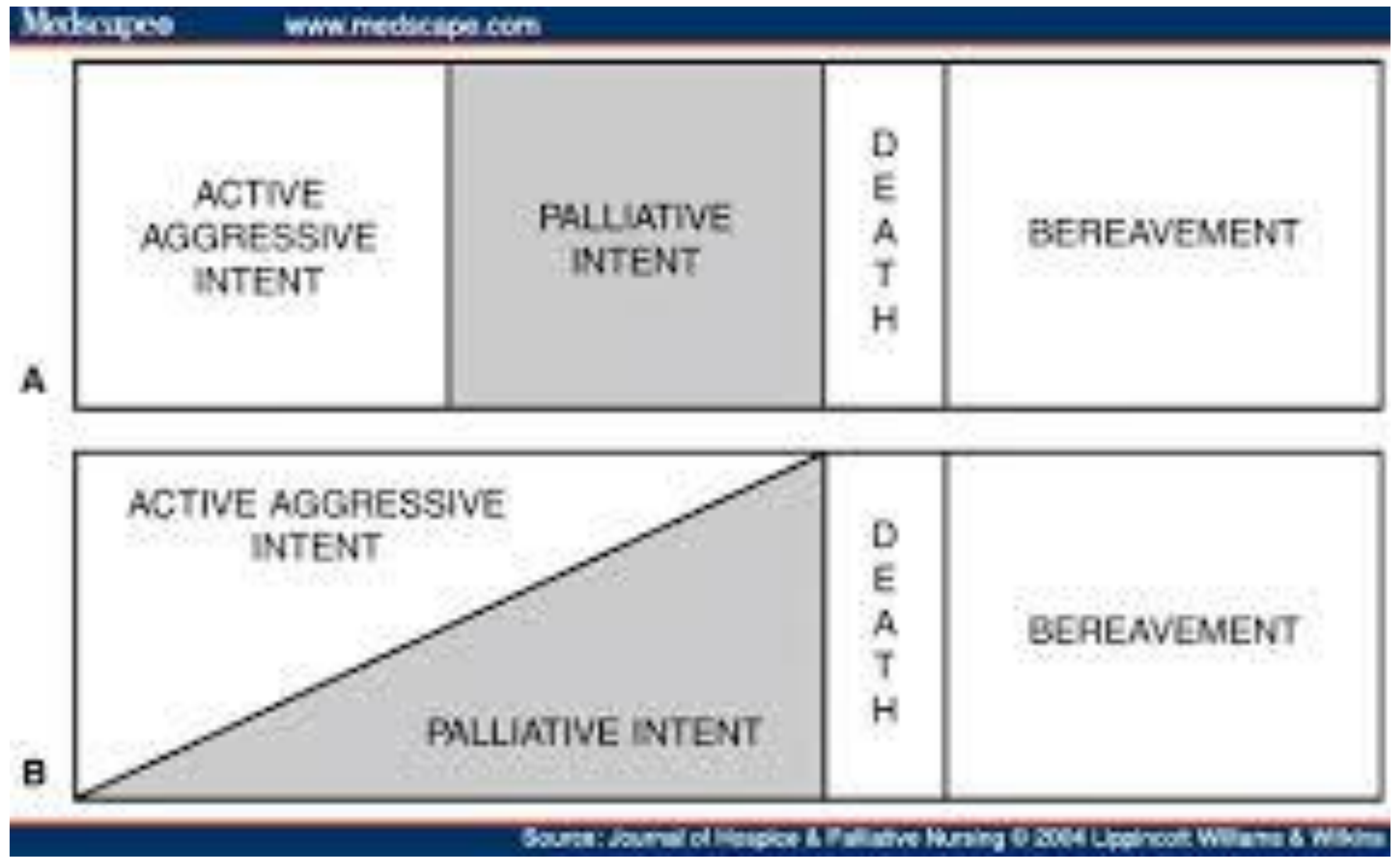
Life-threatening & life-limiting illness

Life-threatening illness is an illness which could cause a patient to die (cancer, AIDS, old age, MND, terminal diabetes or heart disease) and life-limiting includes conditions which may compromise quality of life (spastic children, metabolic disorders, severe CVA)

Identification, impeccable assessment & treatment of symptoms

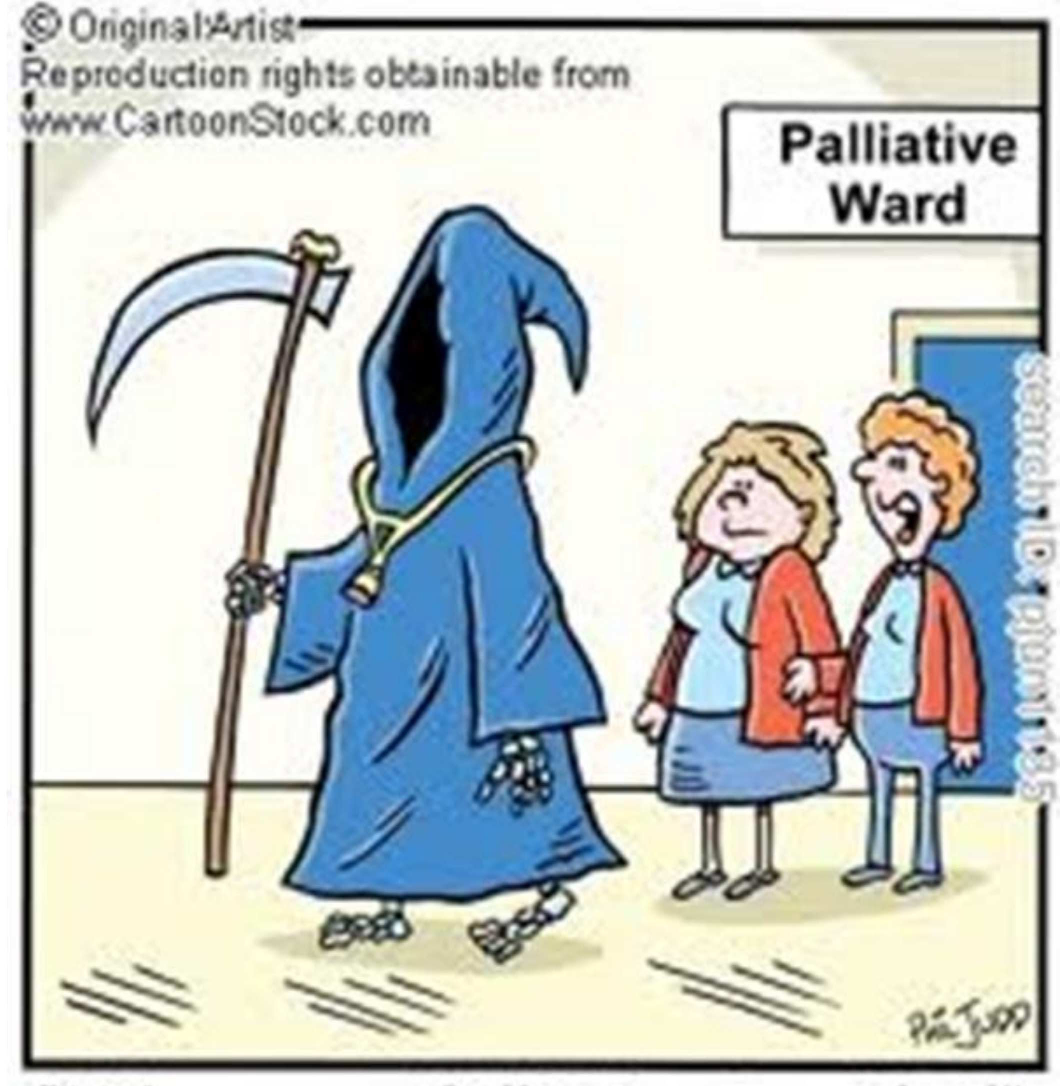
Identification: knowledge & recognition of symptoms.; **Impeccable Assessment:** knowledge based professional evaluation; **Treatment:** Medication management, specialist referral, holistic intervention by **Palliative Trained Team**

- is an **approach** that **improves the quality of life of patients and their families** facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of **pain and other problems, physical, psychosocial and spiritual.**



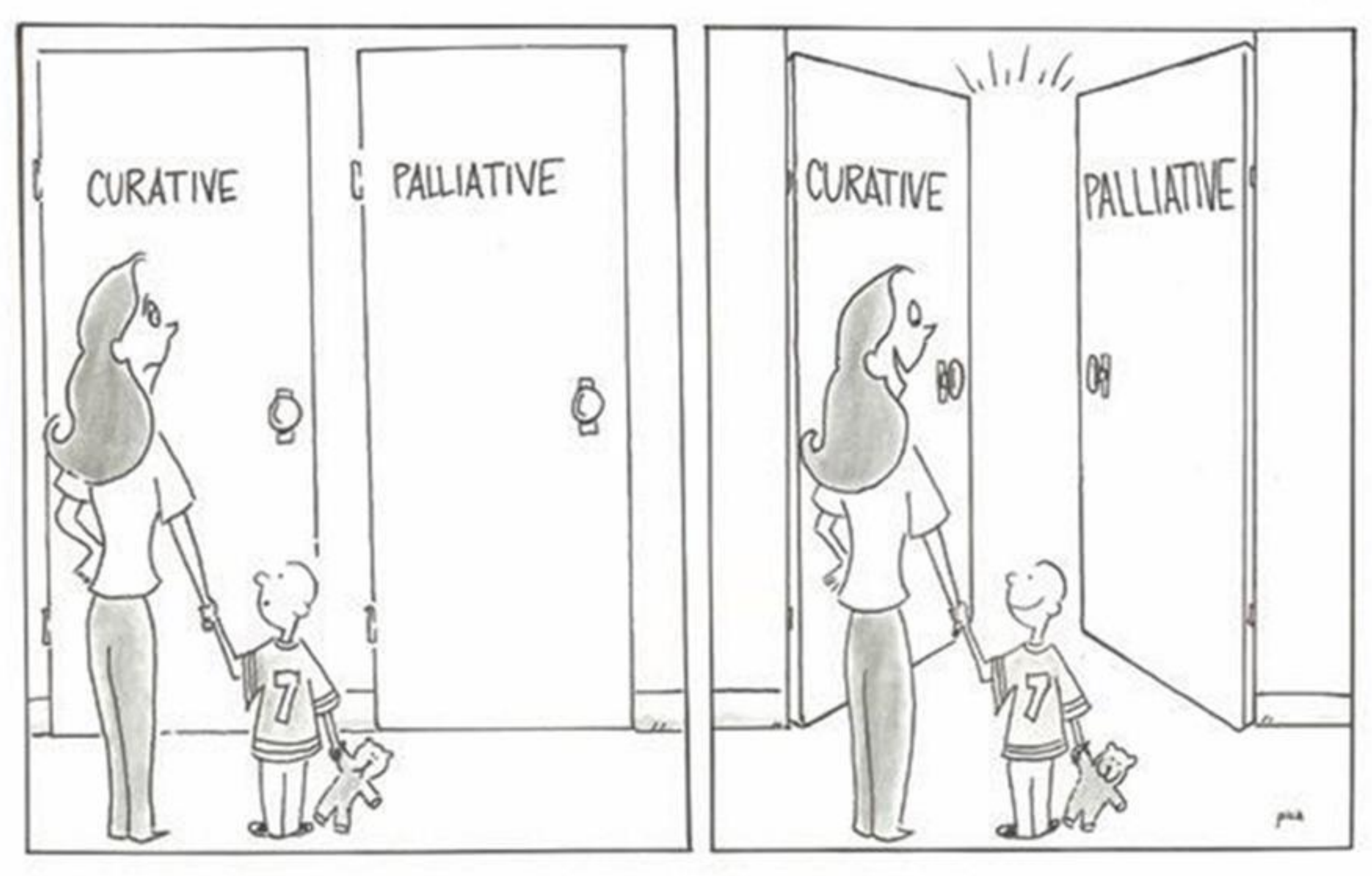
PC is applicable **from diagnosis** of a life-threatening illness (with breaking bad news), **alongside other treatments** to cure or prolong life, and becomes more important along the disease trajectory, incorporating a **multidisciplinary approach**, with **dignity in life and death**, **end of life care and bereavement care**

Palliative care is not just about dying or end of life care…



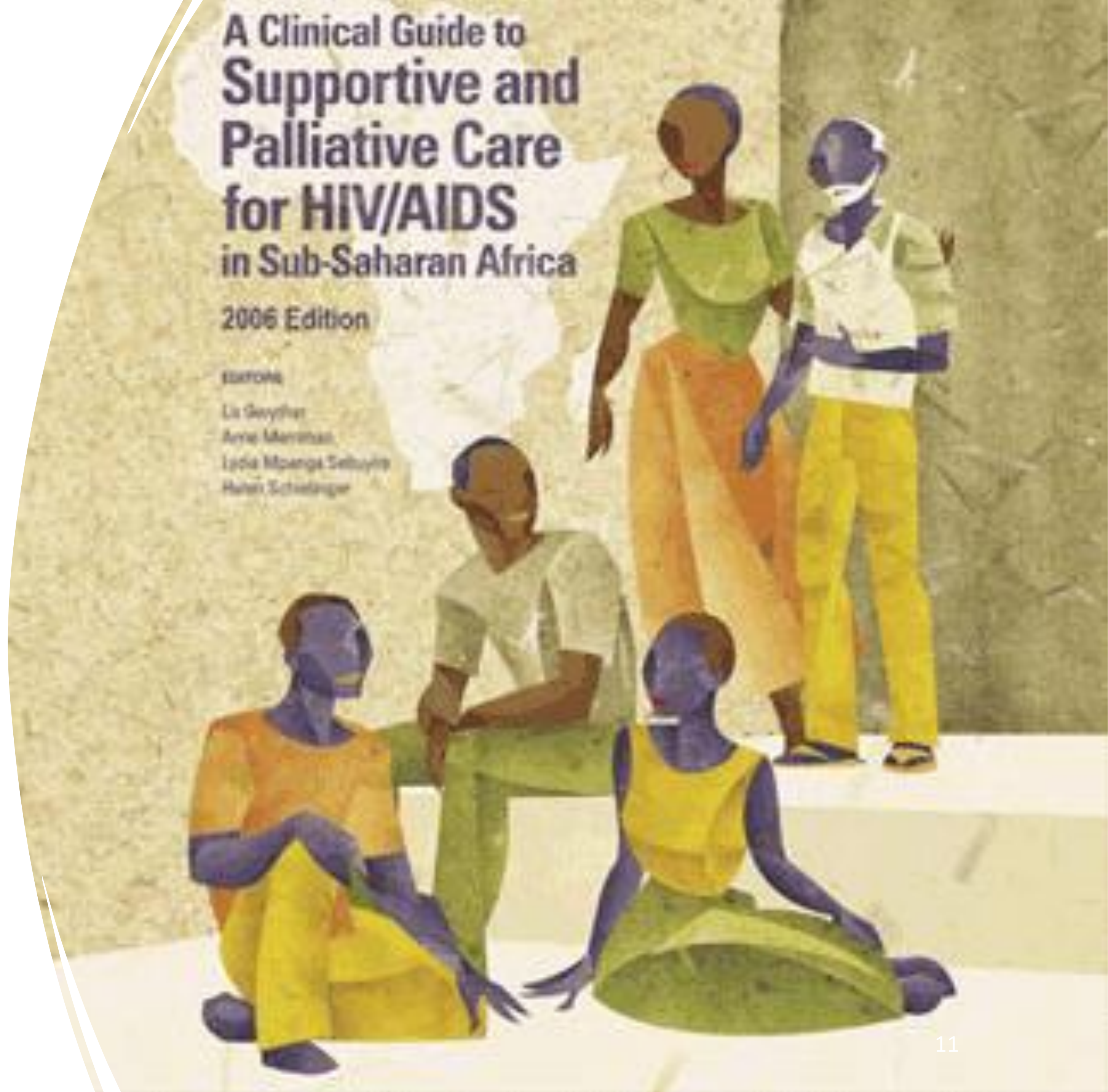
"He's our new Palliative Specialist!"

It is not about having to choose…



It is not about giving up and just about morphine…
but supporting someone at a most crucial time of their life with *active total care*, neither hastening nor postponing death, a normal phase of life

It includes symptomatic relief of suffering in patients diagnosed with chronic illness/NCDs



Aim of this presentation

- Understanding the importance of Respect, Dignity and Compassion through **the lived experience of patients with advanced disease in a study done in KZN with patients from diverse socioeconomic and cultural backgrounds**
- Appreciating the **impact of these values on patient and practitioner outcomes**
- **Practicing these core values**
- **Case studies**

- A basic principle of PC is to help the patient **live and die with dignity** to optimize QOL
- Dignity is an **unconditional inherent worth possessed by ALL living beings – intrinsic dignity (1)**
- Yet there is a **labile extrinsic attributed component: how patients view themselves and how they are viewed by others**
- To understand dignity experience from a patients' perspective, **Chochinov** et al conducted studies to understand the factors that may **support or undermine the dignity of an individual with a life-threatening illness**, and developed a **dignity model** (2) and the **ABCD of Dignity Conserving Care** (3) were generated to enhance dignity

- **Respect** refers to the way of **treating, seeing or thinking** about a patient and the **attitude of regard** for a patient's feelings, wishes or rights
- **Compassionate Care** refers to care offered when interacting with a patient based on a deep awareness of another's suffering and the pure intention to provide relief of this. Patients express appreciation for the **attitude** of kindness, professional **behaviour**, **compassionate** care and valuable **dialogue** expressed by their HCPs
- To provide **total patient-centred care** that improves QOL and relieves suffering of patients with life-threatening illness, respect, dignity and compassion need to be understood from the **patients' experience** and managed.

Aims:

Understanding the Dignity Experience of SA Patients With Advanced Disease From Diverse Socioeconomic And Cultural Backgrounds And Exploring The Impact of Guided Imagery (Focused On Intrinsic Dignity)

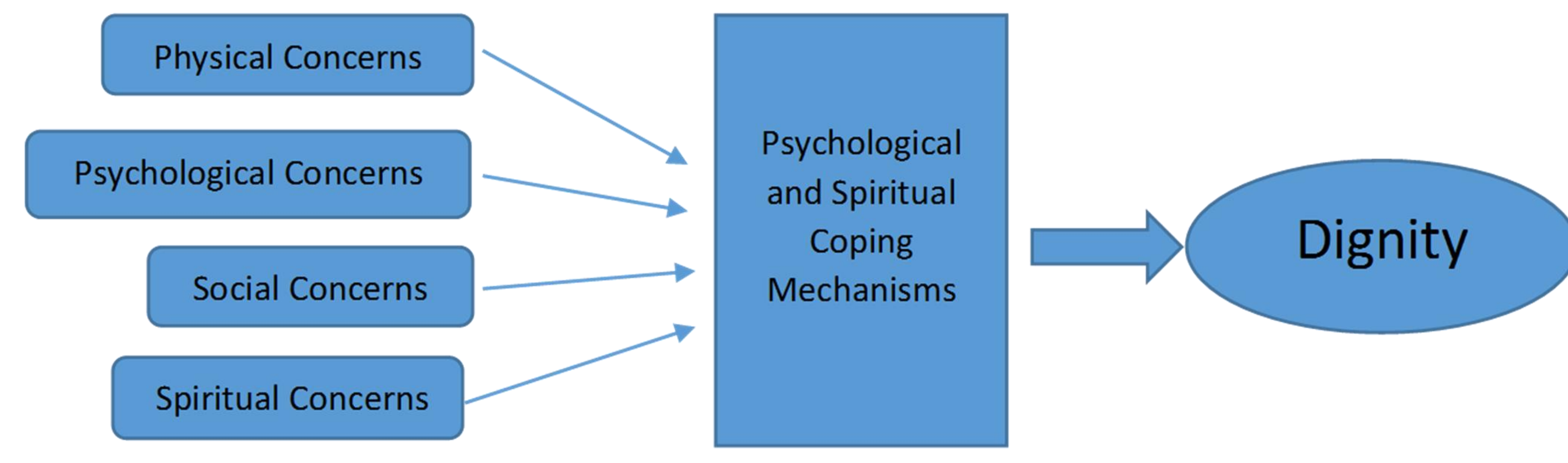
Objectives

- To explore perceived experience of dignity in advanced disease
- To implement Guided Imagery (focused on intrinsic dignity)
- To explore the impact
- To explore the relevance and acceptability of Guided Imagery to enhance dignity in a South African context

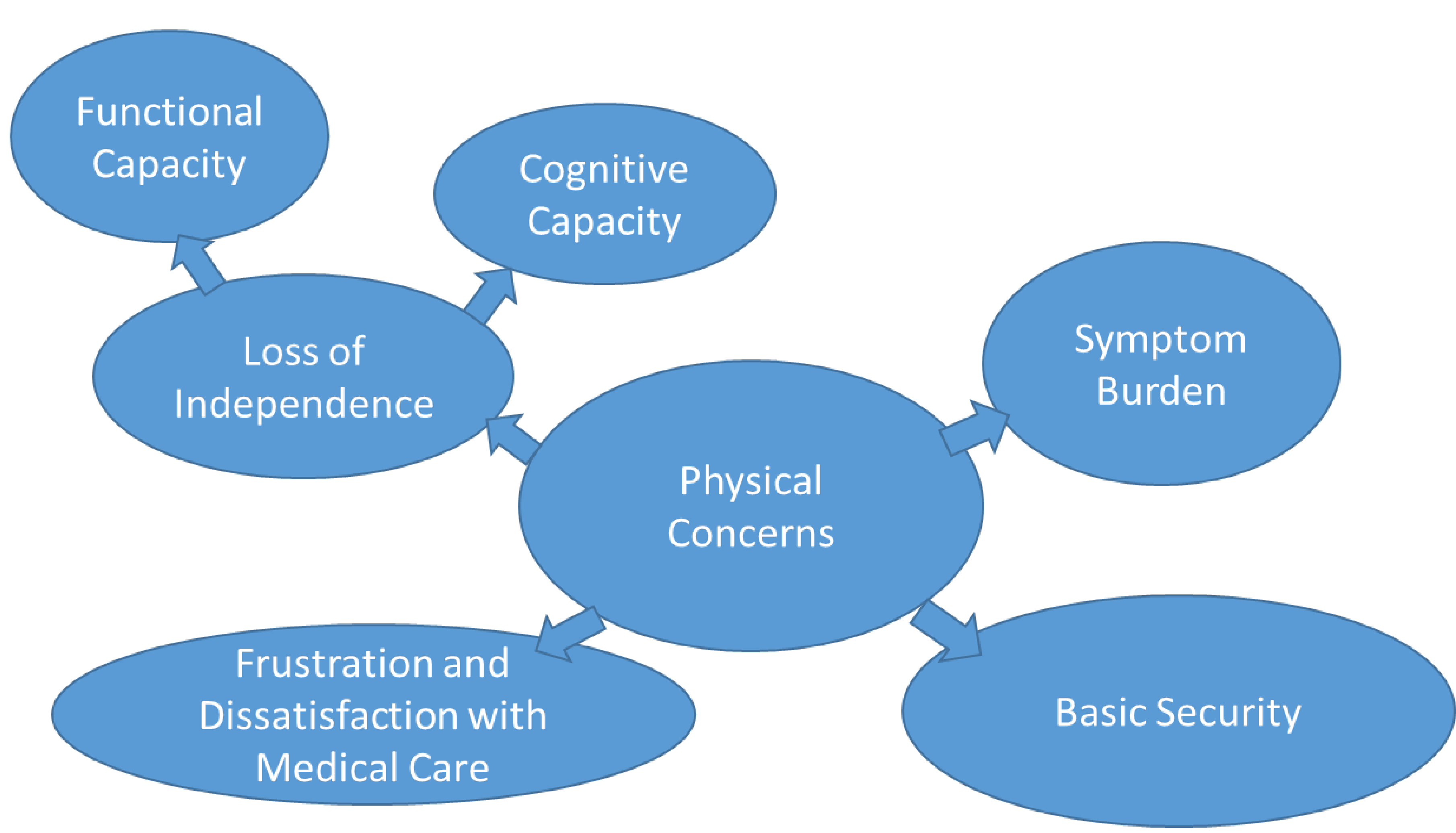
Methodology

- **Descriptive qualitative study**
- Adult patients with advanced disease with no cognitive deficit **enrolled at Verulam Regional Hospice and Dolphin Coast Hospice for home care from diverse cultural backgrounds**
- **Purposive sampling** from diverse cultures – **heterogenous sample that included patients with cancer and AIDS**

Understanding the Total Dignity Experience of SA'n Patients with Advanced Disease



Physical Concerns



Loss of Independence

- Functional Capacity: adapting to being dependent on others impacted their sense of dignity.

"There is no dignity. My soul is being sliced away. Coz of the way I feel. It affects me very dramatically. Can't go to the loo by myself. Got to get a nurse to take me. I can't walk…got to get a nurse to take me.… not being able to get up in the morning." **[GSR]**

- Cognitive Capacity: This was feared by some participants as the worst insult to their dignity.

"The worst thing for me will be… if I lose my mind that is if I forget what I have been and what I want to do." **[PHR]**

Symptom Burden

***"Not being able to cope effectively with the pain, not being mobile. The happiest moment is when I can just sit here and I have no pain. So a lot of my time is spent in pain, a lot, a lot, a lot."* [RA]**

"That is another thing losing control. I can't accept it! I battle with that! I can't sit here and make a mess in my nappy and then call ___to change me…" [BDM]

"Chemo, it kills you slowly. I just needed a gun, I just wanted to shoot myself and get over with it because of so much of pain… It was unbearable!" [BN]

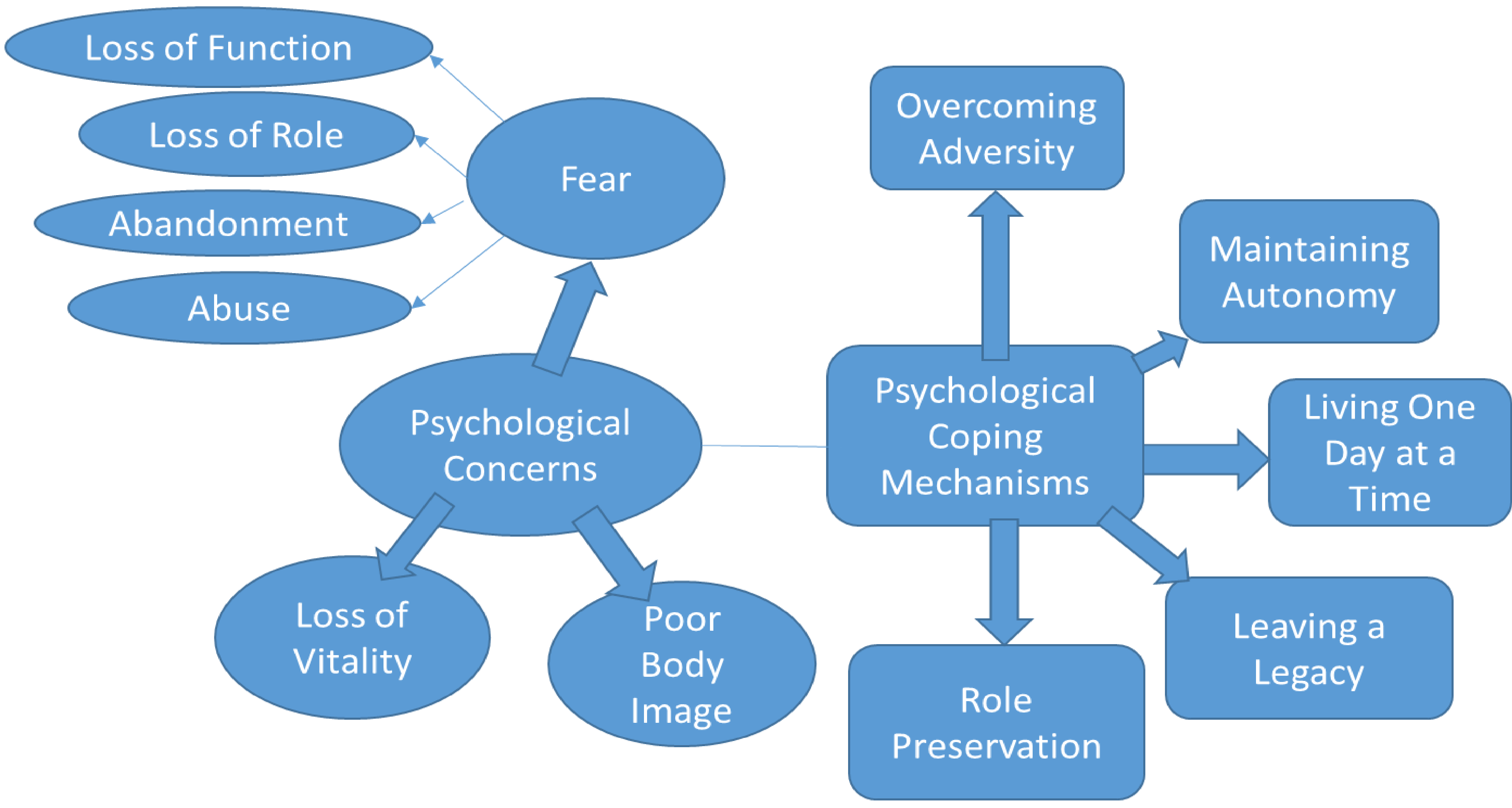
Frustration and Dissatisfaction with Medical Care

- *"When I'm **not diagnosed effectively by my doctors or treated respectfully by them.** I will have a consultation with one of my doctors and he'll be clearly **very much in a hurry, and I always feel absolutely lost.** I complain about the **pain. They don't take me seriously. They poo-poo it. …he called me a drug addict.** I felt completely **undermined, devastated, this is my doctor! Who else can I appeal to? I don't trust him anymore. .……then I feel I have no support.** That undermines me completely! I put my life in their hands!"* [RA]

Basic Security - **concerns that arises in providing for the basic physiological human needs** of food and shelter, and financial and medical needs - predominant concern for lower socioeconomic backgrounds – adversely affected dignity

- **Food and Money:** ***"… I was working and now I can't, and so I can't get an income for the children…I am sick… (teary). I am the breadwinner in the family and this affects my dignity as my children are hungry." [ND]***
- Shelter: *"the place we live in (one bedroom for four children and patient) is also not big enough…"* [TA]
- Transport/Access to Medical Care: *"My son leaves me at the taxi rank and I struggle to push my wheelchair (to get to the hospital)"* [ZO]
- Access to Basic Medication: *"When I take my pain tablets, I feel better but at the moment I don't have...the hospital did not have"* [ZO]

Psychological Concerns and Coping Mechanisms



Anxiety and Fears of **dependency** due to loss of functional and cognitive capacity and of being **abandoned** by medical professionals, of **loss of function/ role** and being **victimized/abused in their vulnerability.**

- *"... I'm scared of that, being bed ridden. I'll be absolutely dependent on who? I don't know…"* [RA]

- ***"...being abandoned by doctors. They can't treat me anymore. That would crush me completely!"*** **[RA]**

- *"Some people want to take over my place because I am sick and they are also taking my things that I used to work with. I worry…"*[ZO]

Psychological Coping Mechanisms

- Resilience/Overcoming Adversity

"So when I was diagnosed, for a couple of days it hit me, and then realization hit me that 'look, you have got it now, now you have to try and fight it!' So, that is what I try to do, I try to be strong and fight it because if you give up and sit down, it is going to overtake you." [SU]

- Maintaining Autonomy/Control

"…. the doctor wanted to do an operation to insert pins in my knees… when it happened, I felt a bit shaken, and I was not so confident anymore so I told him I just need time to build trust in my body…" **[SG]**

- Living One Day at A Time

"I go to my friends and we talk and laugh and I forget about the sickness…, I don't worry. I don't let small things trouble me…NO, NO, NO." [BA]

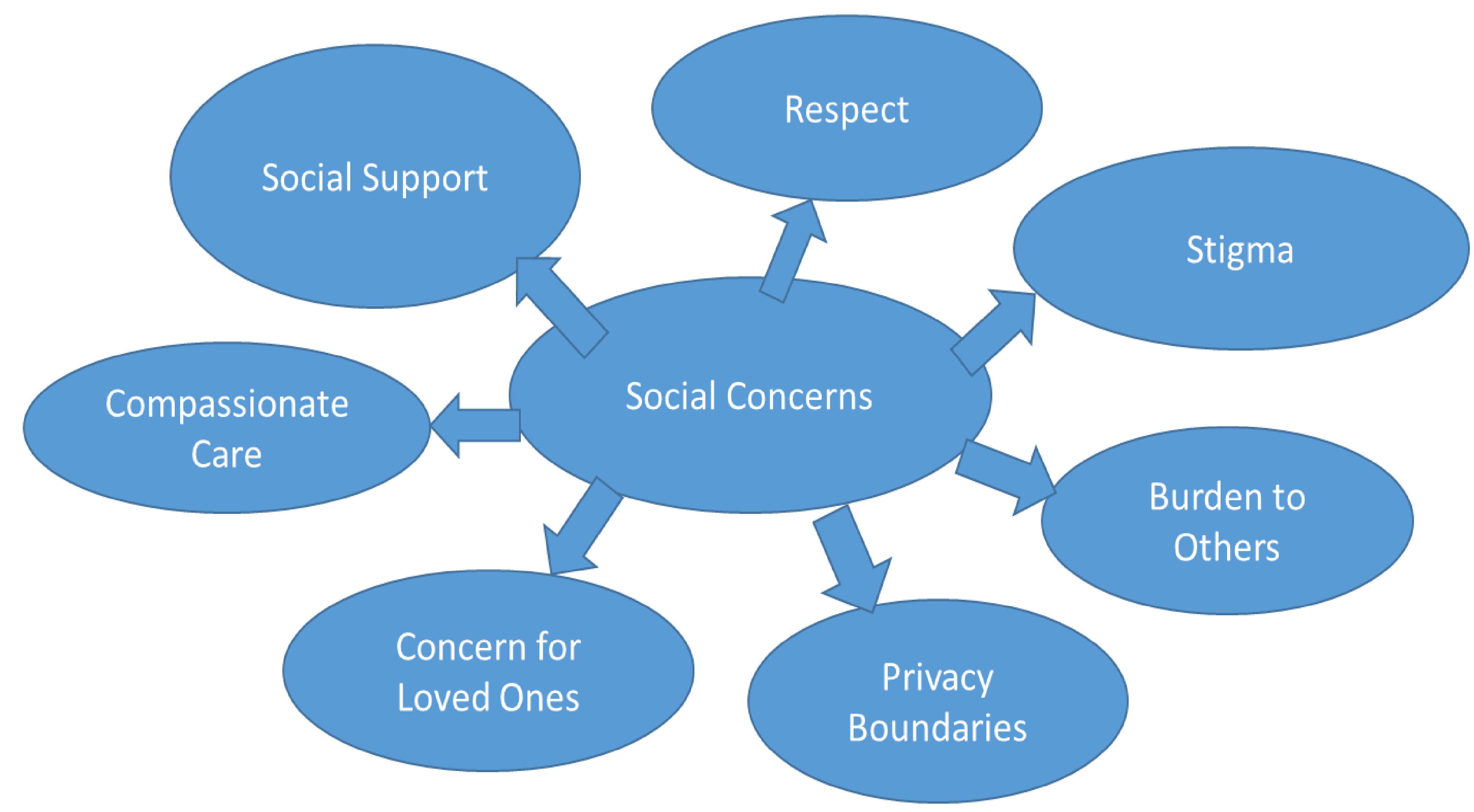
- Leaving a Legacy

"I can tell the children about my life and tell them to respect themselves and respect everyone. I also taught them how to weave grass baskets." [ND]

- Role Preservation

"The ability to work, currently partially, supports my dignity." **[GSR]**

Social Concerns



Compassionate Care: ***"The nurses spoke to me and handled it very professionally. The first time I like passed a stool I was like…. horrified and they said, 'No, these are things you can't help its natural'…and so I sat and thought about it… I actually have excellent doctors who listen to what I have to say and educate us." [SG]***

"I am grateful cos the staff looked after me better than if I was in a private hospital…. I was well taken care of… they made sure I tried to eat, if I could not get up, they bathe me and put me back to bed… they were more than family." [SU]

"I am happy when the hospice comes to visit me because …I open up and tell everything when they come to visit…(smiling). So, I feel my dignity is supported when I can speak and people understand and listen to me." [TA]

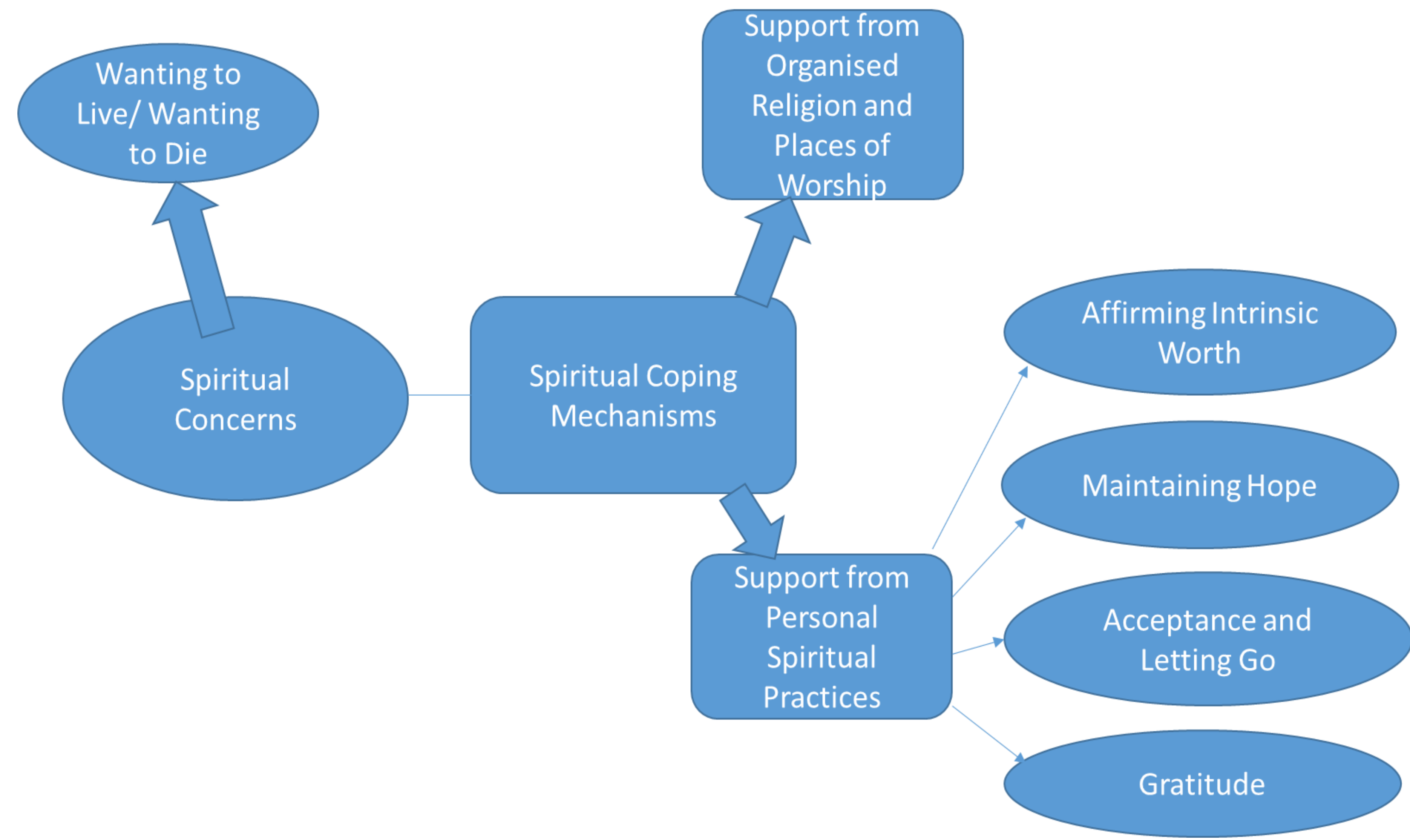
Respect*: "****Dignity can definitely be affected by others, by their behaviour, by how other people treat you… it certainly is deep inside but very vulnerable to outside attack."*** **[RA]**

"They speak roughly… I don't get respect from the doctors at the hospital. The way they treat me, they make me feel like crying." [ZO]

"That is how the nurses and doctors took care of me…. lot of respect and lots of love and so I really appreciate that…" [SU]

Privacy Boundaries: ***"…that was the first time in my life I wore a male nappy. Oh my God! I am unfortunately used to it now, but do you ever get used to that? No! …I had to call the sister to change me, that was the worst thing in my life."*** **[DBM]**

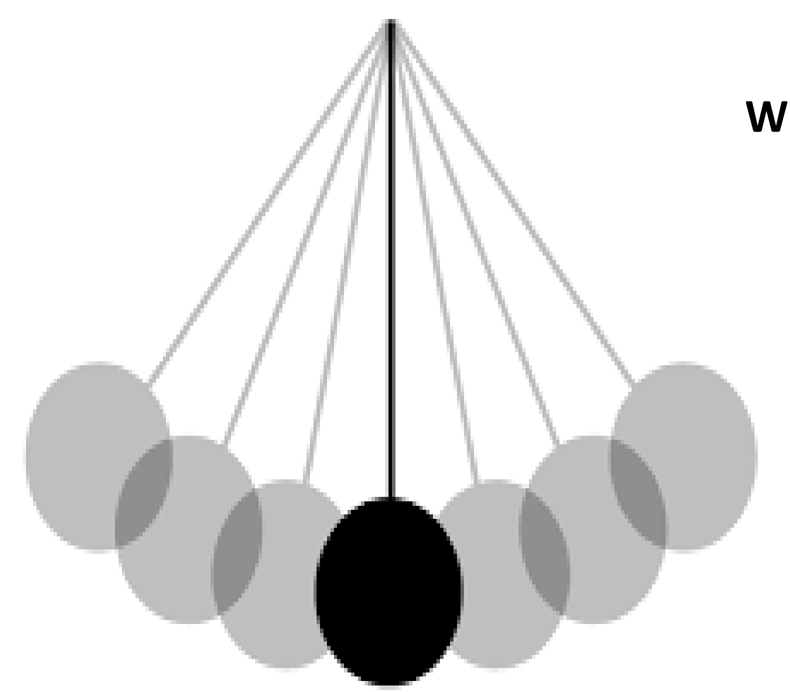
Spiritual Concerns & Coping Mechanisms



Spiritual Concerns

Wanting to Live

Wanting to Die



Good Symptom Control
<u>Respect</u>
<u>Compassionate Care</u>
Social Support
<u>Affirmed Intrinsic Worth</u>
Strong Psycho-Existential Coping Mechanisms

Symptom Burden
Disrespected
Devalued by Society
Burden on Others
Loss of Identity/Role
Psycho-Existential Distress

Spiritual Coping Mechanisms:
a) Support from Personal Spiritual Practices

1. Affirming Intrinsic Worth: ***"I think dignity is something inside you and not something that people can give and take away from you…come the worst situation. You always think of yourself as somebody, a somebody, not a nothing!"*** **[SU]**

2. Maintaining Hope: is associated with an ability to see life as having sustained meaning and purpose defying medical prognosis. *"… when I was asked by my wife, if this is as good as it gets, I said 'no'. The tumour was still there but I was still fighting it."* [GSR]

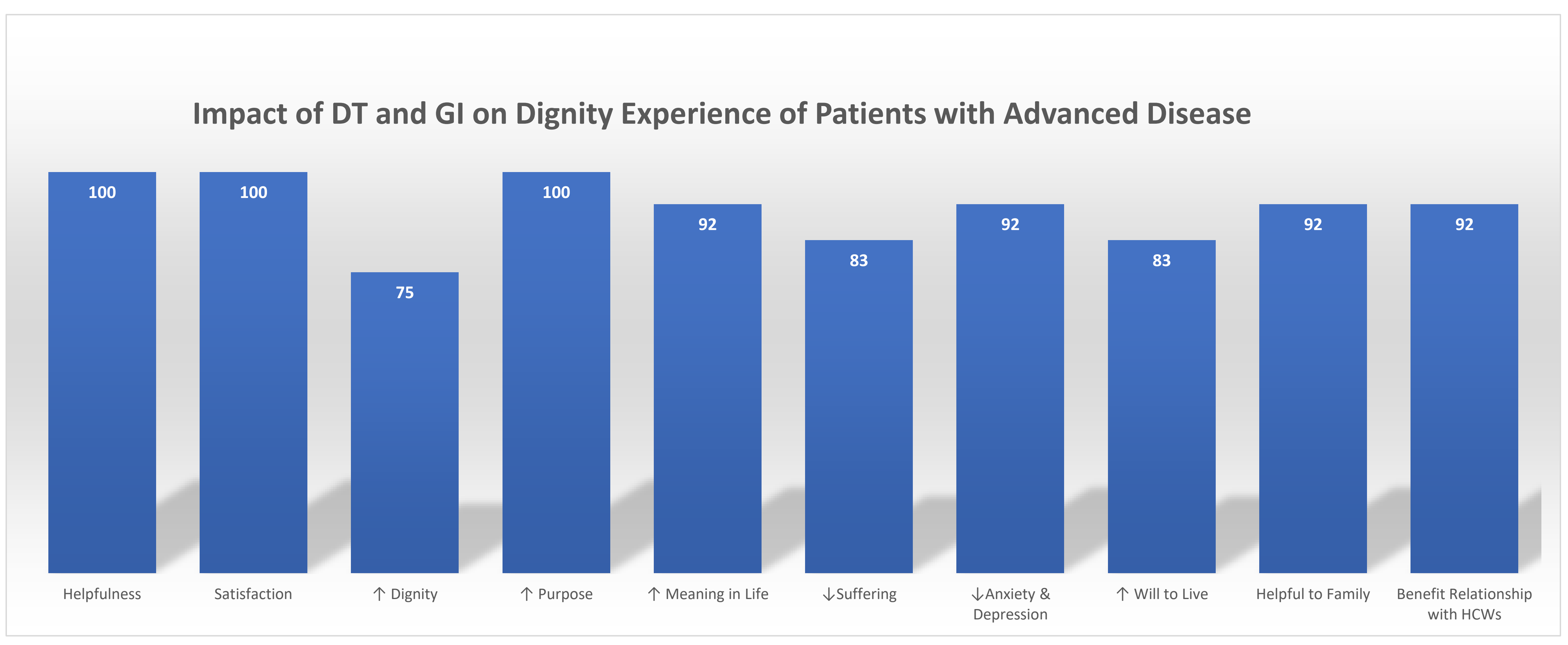
3. Acceptance and Letting Go: *"If you are going through a serious illness at the beginning, it hits you hard when you first hear about it but once you settled in and understand that u have it, then you cope with it, then its fine. Even if they tell you that you have few months to go."* [SU]

4. Gratitude: a quality of being thankful and a readiness to show appreciation for and return of kindness. *"There are people worse off than me so I must thank God that I am in this position where I am better off than a lot of people out there…" [SG]*

- The challenge comes when "…those whose **attributed dignity has been so damaged…** believe that their **own intrinsic dignity has been vanquished:** that they truly have **no worth,** that their **personhood has been forever fractured"**
- Brennan uses the expression, "Joseph – **this disease has done many things to you**. And it will continue to do so. **But it can never take away who you are – your spirit. That is untouchable." (5)**
- Intrinsic dignity is inherent and yet it falters, because **the lived experience of the highly abstract concept is lacking**
- Thus, having an **EXPERIENCE of the "untouchable spirit"** and **one's innate intrinsic dignity and self-worth** can **enhance total dignity**. Intrinsic dignity cannot simply be a philosophy but requires an applied **experience for conviction** thus we used a novel SA 5min intervention of **Guided Imagery** to affirm the experience of intrinsic dignity in this study

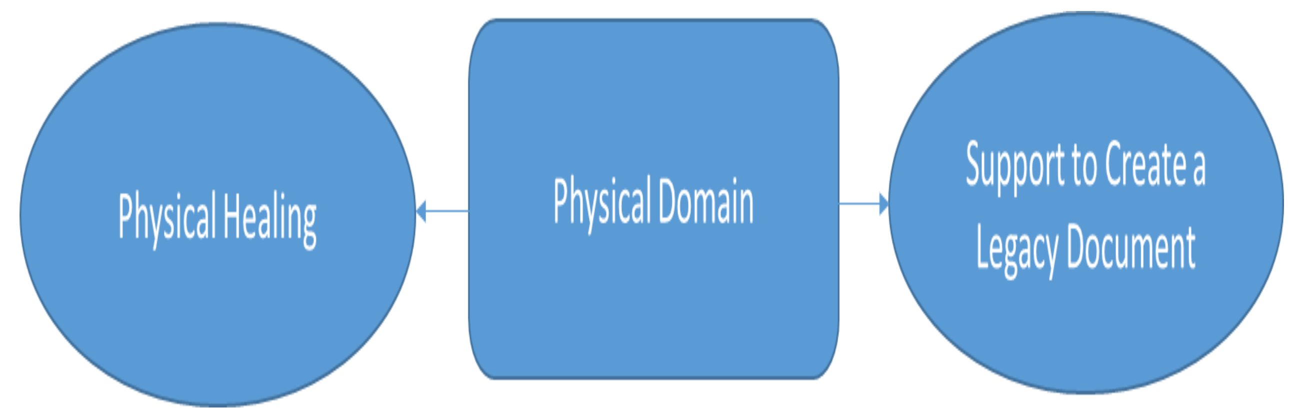
An Experience of Guided Imagery Focused on Intrinsic Dignity

Quantitative Feedback on the Impact of Guided Imagery on Patient Outcomes



Qualitative Content Analysis of Impact

Physical	Psychological	Social	Spiritual
Physical Healing	Feeling Understood and Valued	Beneficial to Family: 1.Sensitising Family to Understanding Patient 2. Sharing Life's Lessons with Family 3. Personal Benefit Will Support Family	Improved Self Esteem/Worth
Support to Create a Legacy Document	Reflection, Learning and Appreciation	Improved Relationship with Healthcare Workers	Self-Awareness
	Lessened Sense of Suffering		Spiritual Healing
	Lessened Anxiety and Depression		Hopefulness and Increased Will to Live
			Greater Acceptance and Letting Go



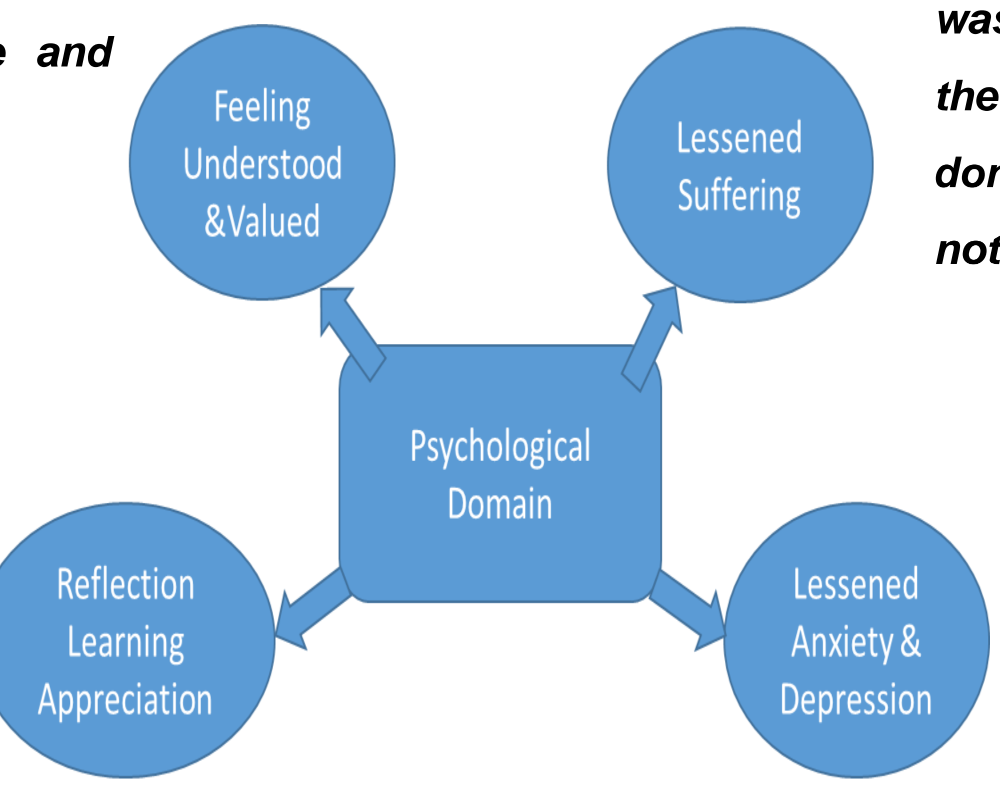
- *“… **my body is feeling relaxed after listening to the therapy… I feel that my legs are feeling strong**…”* **[TA]**

- ***“…the pain has settled in the neck now.”*** [ND]

- *“To me this is meaningful because I have learnt about my life and I have remembered my achievements… and I will keep it at my bedside all the time to remind me of myself and I will forget everything else.”* [ZO]

***"…the thing that encourages me is that the hospital doctor came and knows our needs at home."* [ND]**

*"…**it actually calmed me…I was restless, thinking when the end will come but now you don't worry about it, you are not scared of anything.**"* **[SU]**



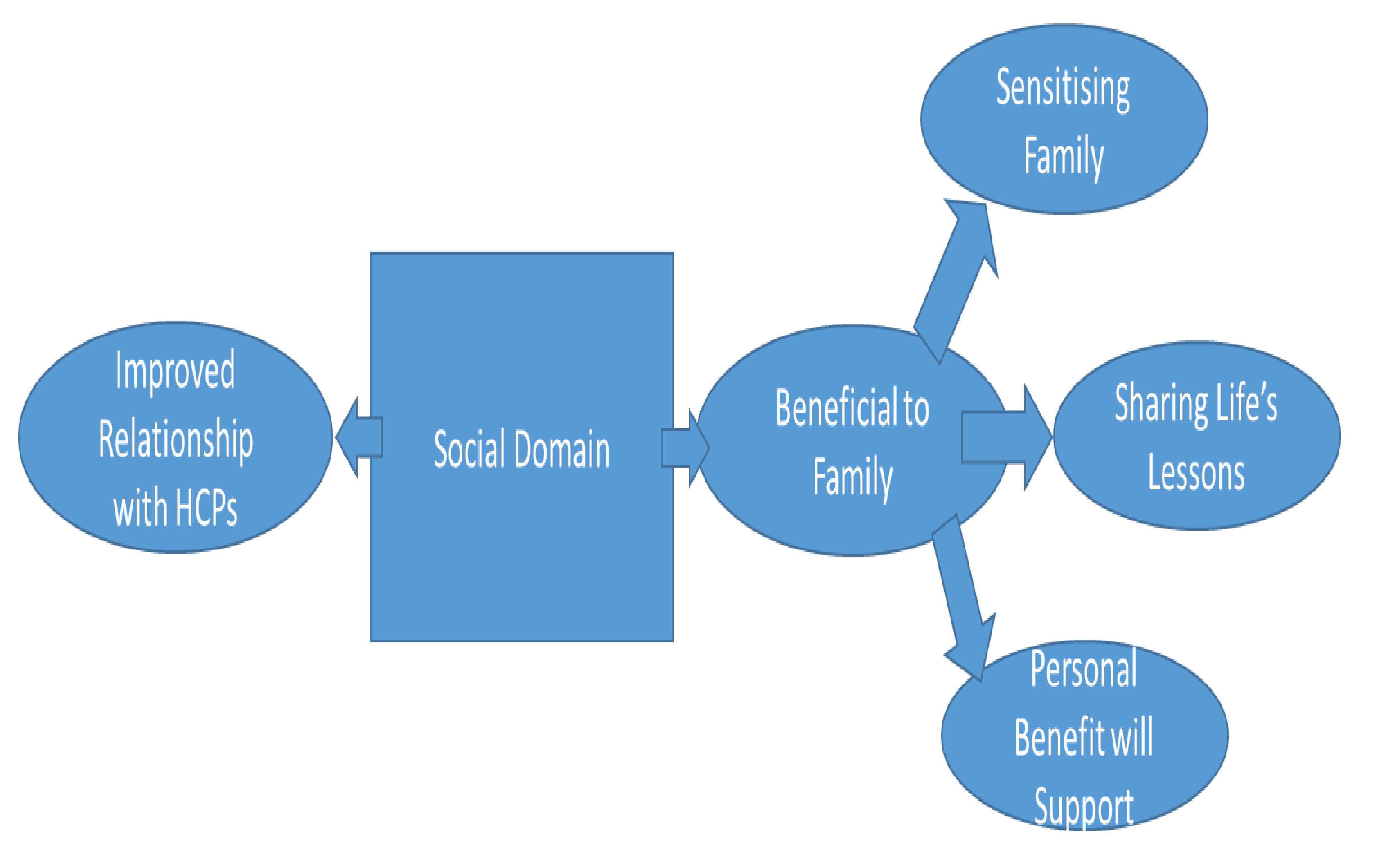
"It opens up my mind. You feel sorry for yourself, and then … you think these other things mean life!" [DBM]

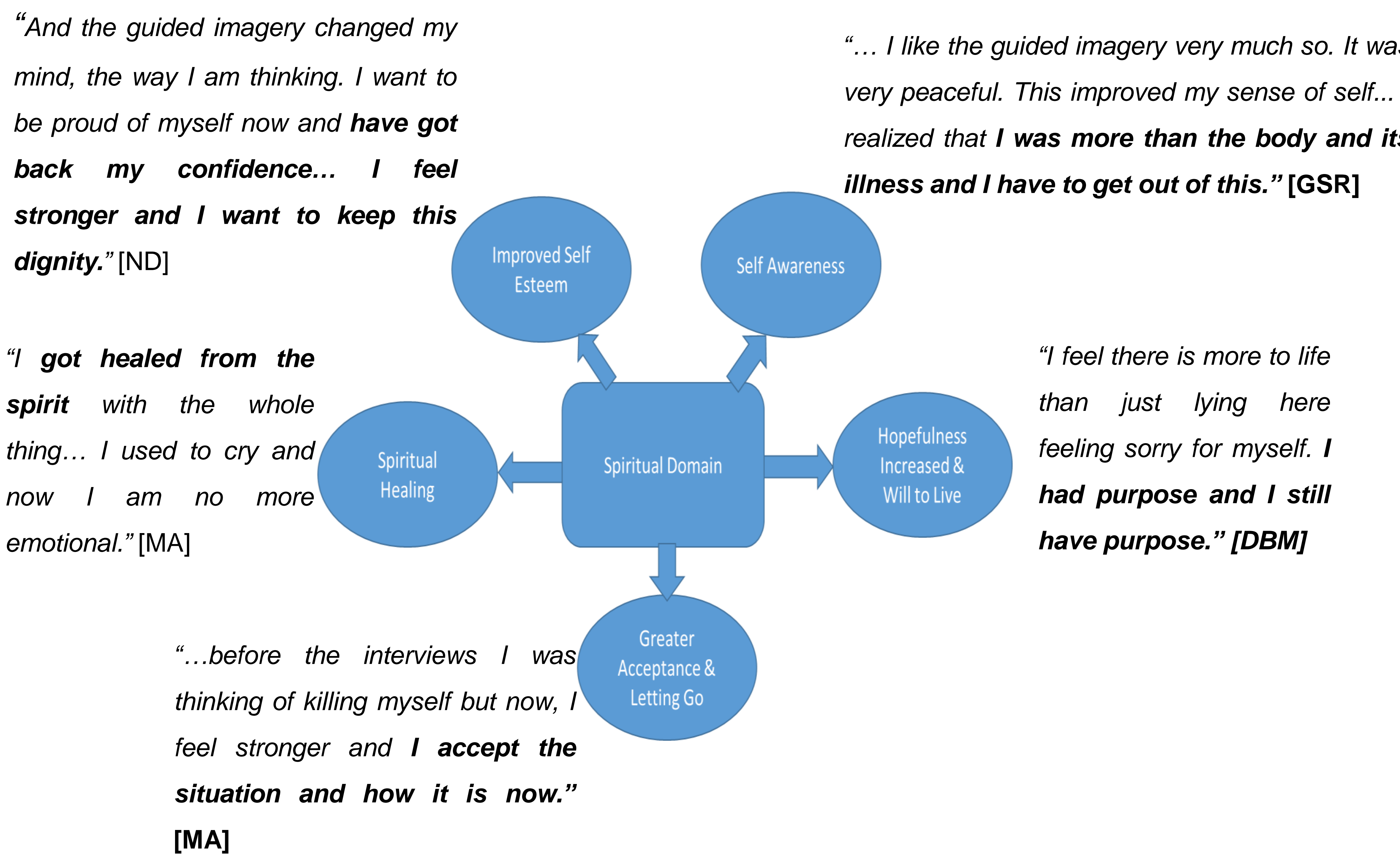
*"**The guided imagery was very appropriate and useful to put things into context…takes one out of oneself."*** **[RA]**

*"…**I don't feel so isolated**."* **[RA]**

"It reminded me to stop being afraid." **[BN]**

"Nothing makes me sad or scared now." [TA]


Improved Relationship with HCPs
Social Domain
Beneficial to Family
Sensitising Family
Sharing Life's Lessons
Personal Benefit will Support



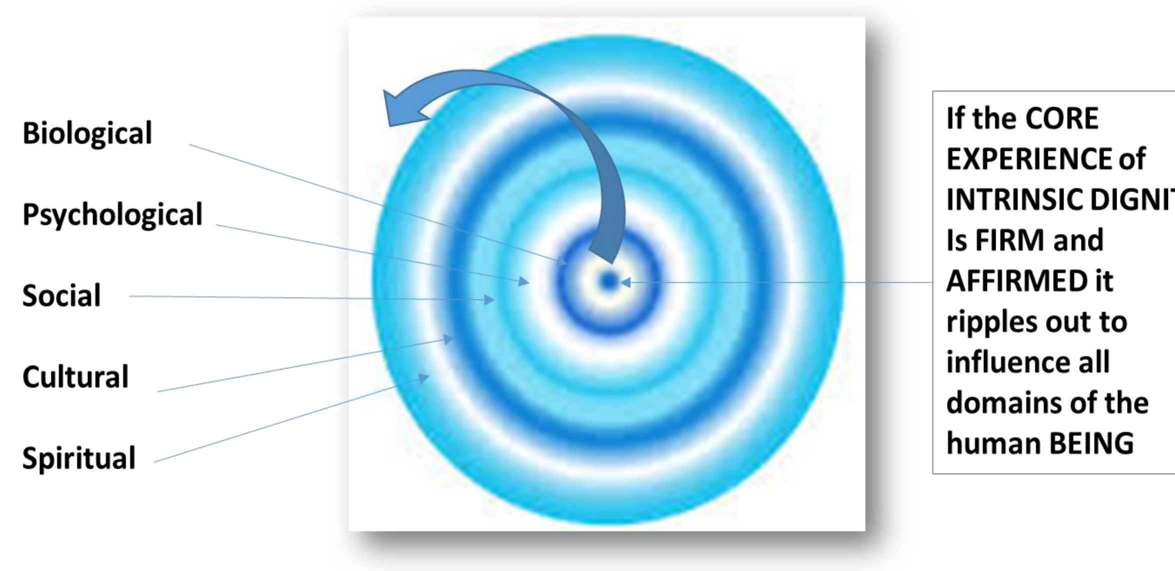
"…now life is more meaningful versus before the intervention. I realised what I achieved and that I am more than what is happening to me… it improved my dignity and worth." [GSR]

"… the guided imagery speaks to me, telling me **who I am, and what I am and telling me how I can make myself feel lighter,** and **not worry about the things outside of me, so it's very inspiring to me** – … the more you read it, **the calmer you feel**. Now I can stand up with **head held high** and say **I am going on; this is who I am** – Now you feel freer and the worldly things mean **nothing even the body means nothing, the spirit goes on…the body can die that is fine, your spirit goes on…. your life." [SU]**

Dignity of the untouchable spirit
Remind patients of their innate worth
See and acknowledge patients as more than their disease

Compassion for the eternal human spirit:
the importance of a compassionate environment, empathetic communication/dialogue and active compassionate listening and emotional support

Respect for the unique human *being*:
kind professional attitude and behaviour, “seeing the person”, respecting patient autonomy/ preferences/privacy boundaries/cultural values.



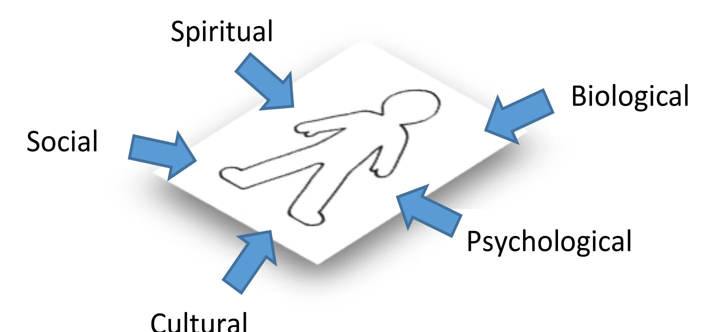
Dialogue

Compassion

Acceptance & Letting Go

Behaviour

Attitude

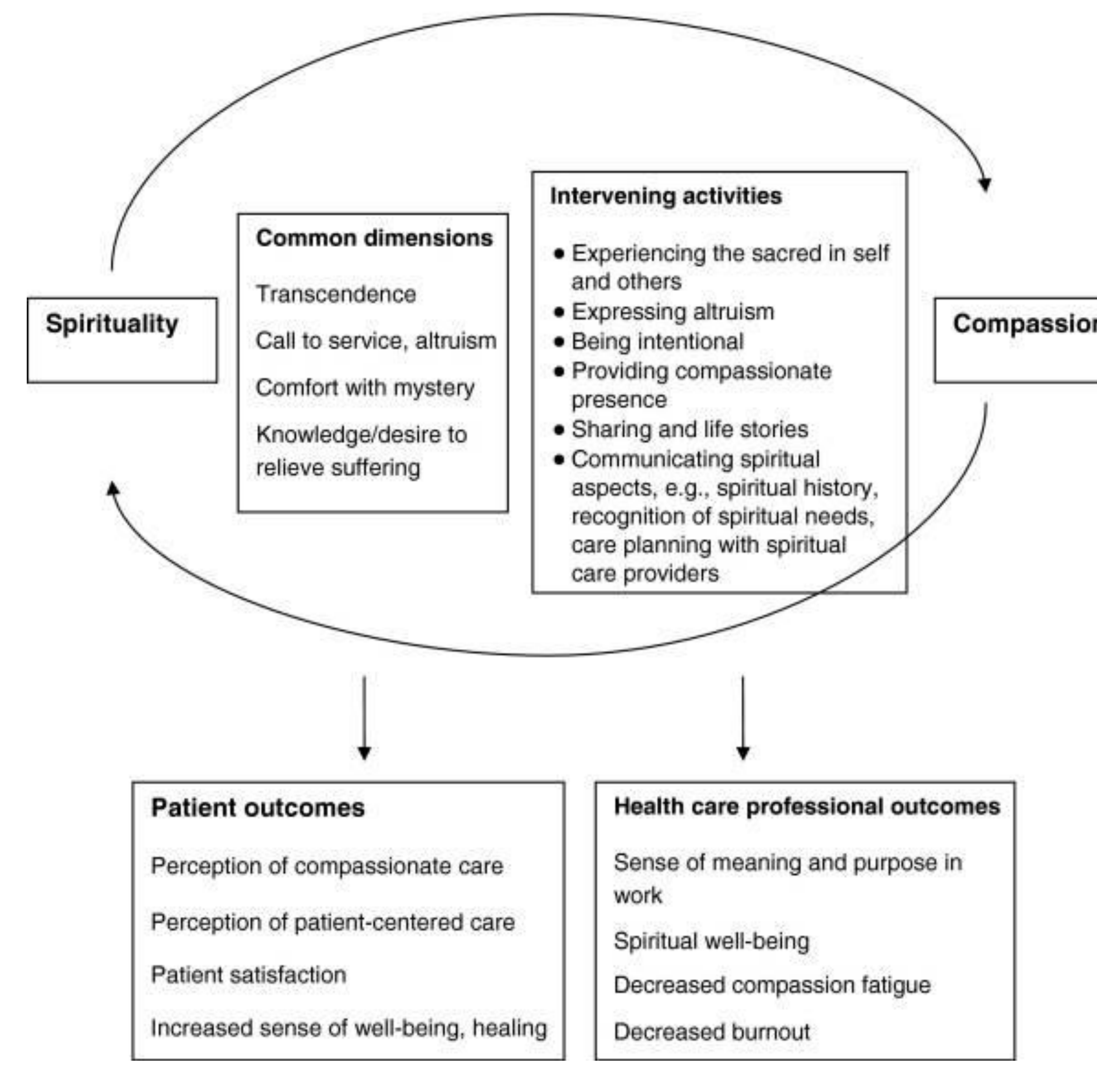


Outside Attack

- **How HCPs view people seeking their care has an influence on the experience of being a patient**. “How patients perceive themselves to be seen” is an influential **moderator of their dignity**.
- HCPs can affirm the individual patient’s value by **seeing each individual as the person that they are, as opposed to just the illness they are seeking care for.**
- Sir William Osler – “**it is much more important to know what sort of patient has a disease than what sort of disease a patient has”.**
- **In DCC the HCP’s affirmation of the patient and the patient’s self-perception** matters – HCPs should attend to Attitude, Behaviour, provide Compassionate care and effective Dialogue with patients

Impact on the HCP

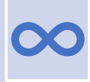
Compassion is a spiritual practice, a way of being and service to others, and an act of love. Thus, spirituality is intrinsically linked to compassion. By being aware of own own spirituality (transcendence, meaning and purpose, call to service, connectedness to others), HCPs are more able to be compassionate with their patients. **We cannot give what we don't have… thus the importance of HCP wellbeing**

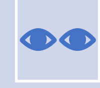


Model of Spirituality and Compassion by Pulchalski, C and Landsford, B

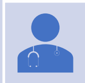
Practice:

Visualise that you are in consultation with a troubled patient


First focus on your own inner stillness, then expand our awareness to a space of infinite peacefulness. Use the idea that we are a still point of light and this greater awareness is like an ocean of light.


Have kind regard and respect seeing the other in front of you as a unique human being/the untouchable spirit in the body

Practice compassionate listening as they share: Being peaceful, attentive and listening from your heart. Remember, we are not analyzing what the person is saying to make some type of assessment but just being there for them.


No matter how challenging/hopeless their medical condition is, can you remind the patient of their intrinsic untouchable worth with your attitude and compassionate words

The feeling of compassion passes through you rather than coming from you. This is key to compassion and the way to prevent yourself from feeling drained. You are detached emotionally whilst keeping the spiritual connection…

Case Studies:

- 60yr old builder – Ca Stomach – partial gastrectomy – dumping syndrome – "Why did they butcher me…?" Biomedical explanations fail to relieve suffering. Reminded him of his innate identity that he is more than his illness… He is a dignified, peaceful and powerful spirit despite his loss of functional capacity… Dignity is restored in dying.
- 11 mo unvaccinated healthy baby in LSP – whooping cough – 2003 – no ventilator available for transfer – 6 hours of ambu-bagging – calling the consultant and referral facilities – compassion and seeing the untouchable spirit – 6 hrs (colleagues frustrated – helpless - not able to cope with inequalities – burnout - breakdown or becoming dissociated from their emotions to protect themselves)

Conclusion:

- HCPs can offer kindness, compassion and respect that **acknowledges and honours the unconditional value/worth of patients beyond the labels placed on them by their body, bodily illness and challenging circumstances**.
- Patients wish to be seen as **living beings, not disease entities that need fixing**, and to be **supported to create meaning and purpose in their last days**. It is not about what they have become but patients wish to be **seen for who they are**.
- Peabody: **It is time that "treatment of disease takes its proper place in the larger problem of the care of the patient."**

Thank you

Email:raksha56@gmail.com

1. Reflections and Guided Imagery for People Living with Disease
YOUTUBE: https://youtube.com/playlist?list=PL4p495j5lhw6sLhEDWIhHyAIZAAi8TQPr
SOUNDCLOUD: https://on.soundcloud.com/58M1y

2. Reflections and Guided Imagery to Care for the Carer
YOUTUBE: https://youtube.com/playlist?list=PL4p495j5lhw467QWH6LK5J4rb6_30Gwv4
SOUNDCLOUD: https://on.soundcloud.com/eqCcS

3. Reflections and Guided Imagery for Coping with Loss and Grief
YOUTUBE: https://youtube.com/playlist?list=PL4p495j5lhw4I4vVPXNIQke0Lzc0jhGxd
SOUNDCLOUD: https://on.soundcloud.com/At1gA

4. Guided Imagery for Times of Crisis
YOUTUBE: https://youtube.com/playlist?list=PL4p495j5lhw5I8mzQFfaoh9c1W3h-ysGf
SOUNDCLOUD: https://on.soundcloud.com/M26en