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- Palliative medicine doctor, practising privately, offering home based care in Durban and the North Coast of KZN
- Masters degree on understanding the dignity experience of patients with advanced disease - a SA'n perspective
- Board Member Palprac, Steering Committee Member of Palnet KZN, Director of Beacon of Care, Volunteer at Verulam Hospice
- 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 with compassion fatigue
- A student and teacher of meditation, she brings meaning and peace to her patients at the most challenging time of their lives



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Understanding and Enhancing the Dignity Experience of SA Patients with Advanced Disease

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- Dignity is a **core value in palliative care**. A basic principle of palliative care is to help the patient **live and die with dignity**, in conjunction with symptom control, and psychosocial and spiritual well-being in order to achieve the goals of optimizing quality of life
- 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**



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- 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)**
- Based on dignity model model, the dignity intervention - **Dignity Psychotherapy (3)** was generated to enhance dignity in patients with advanced disease.
- There are **no studies to understand the predominant factors that impinge on the dignity experience of dying South Africans from diverse socioeconomic and cultural backgrounds, nor any formal dignity enhancing interventions** that are being practiced in South Africa

Aims:

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

Objectives

- To explore perceived experience of dignity in advanced disease
- To implement Dignity Therapy and Guided Imagery (focused on intrinsic dignity)
- To explore the impact of Dignity Therapy and Guided Imagery
- To explore the relevance and acceptability of Dignity Therapy and 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

Phase 1

Semi - Structured Interview on Dignity Experience

- Thematic Analysis of Qualitative Data

Phase 2

Dignity Therapy (With Production Of A Legacy Document) & Guided Imagery (To Affirm Intrinsic Dignity)

Phase 3

Patient Feedback Questionnaire

- Tabulation of the Quantitative Feedback and Content Analysis of the Qualitative Feedback



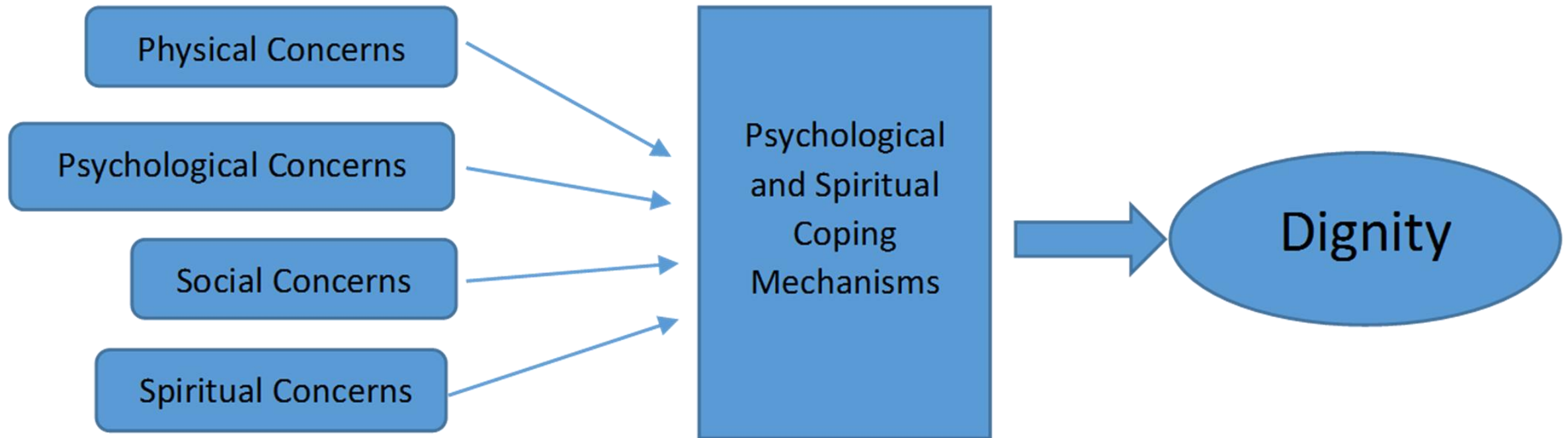
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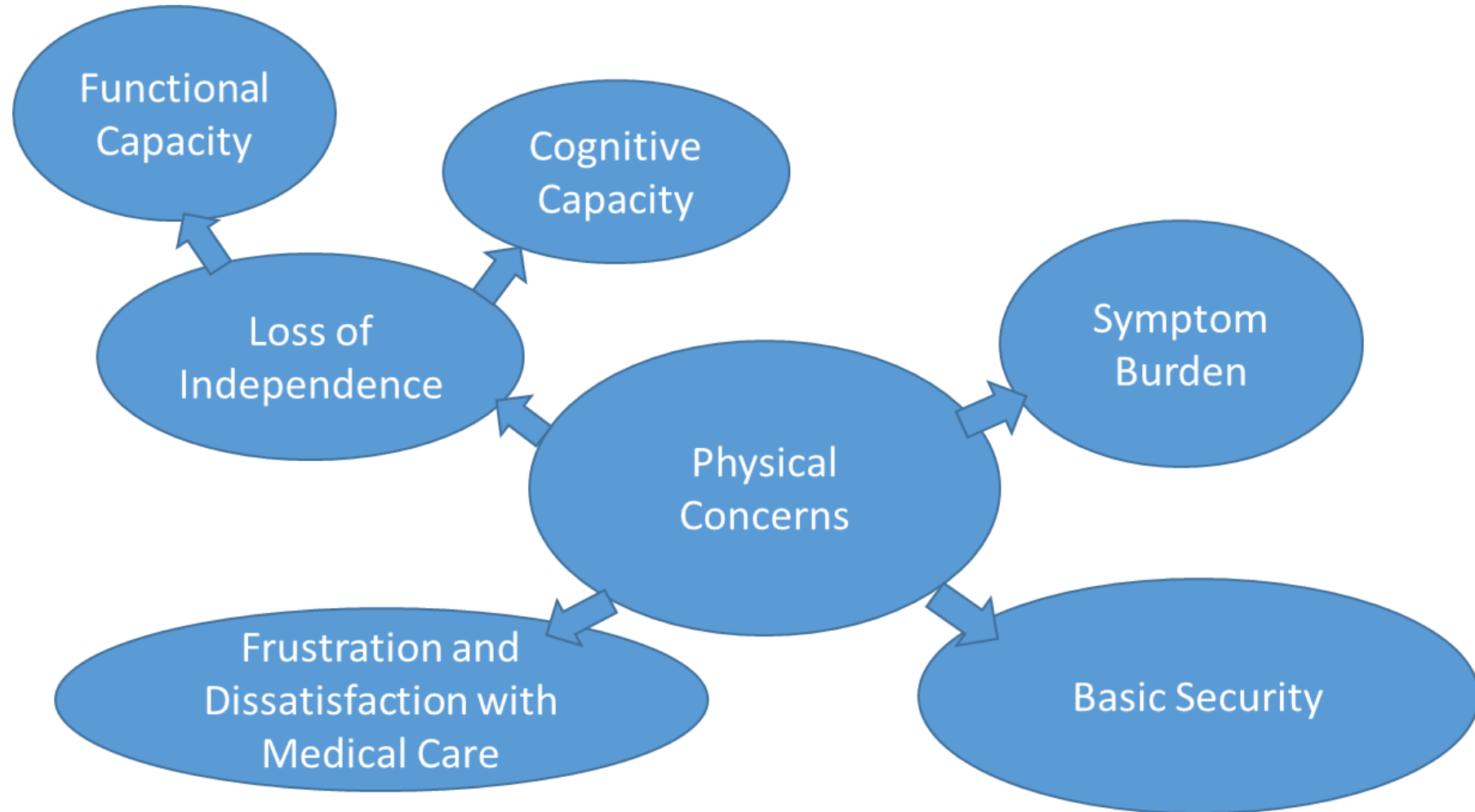


Understanding the Total Dignity Experience of SA'n Patients with Advanced Disease



- This model suggests that an individual with **under-developed psychological and spiritual coping mechanisms will suffer greater assaults to their dignity.**
- Those patients who had **strong** psycho-existential coping mechanisms seemed **more immune to the assaults on their dignity by bio-psycho-social-existential concerns.**
- However, if the **assaults by these concerns were large enough, this can override psycho-existential coping mechanisms and have a deleterious effect on dignity.**
- Thus, this model proposes that to improve dignity experience in the dying, **psycho-existential coping mechanisms need to be encouraged and bio-psycho-social-existential concerns need to be allayed in the total care of the patient.**

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]

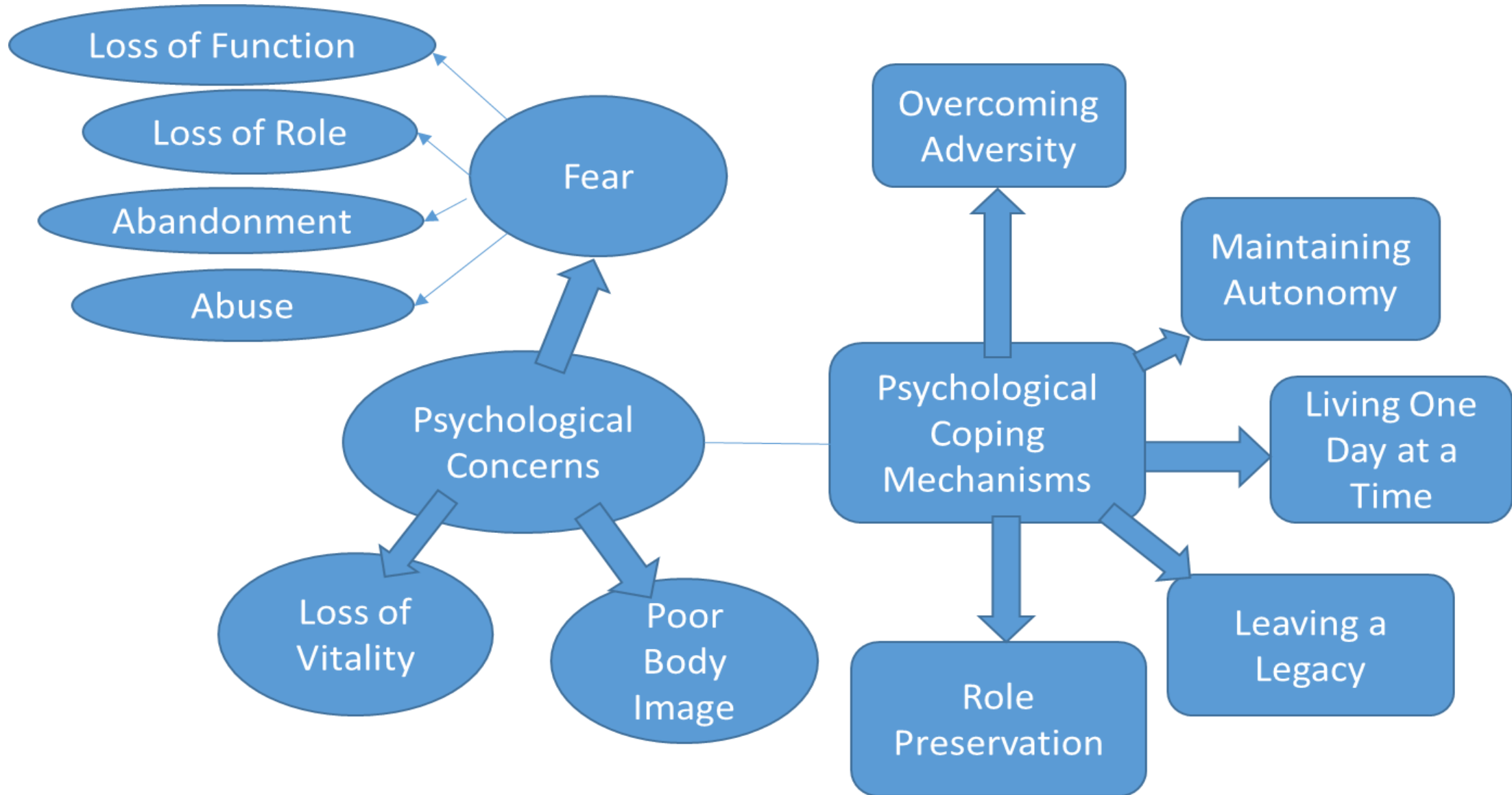
Frustration and Dissatisfaction with Medical Care

- *“When I’m not diagnosed effectively by my doctors or treated effectively 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]*

Loss of Vitality: inherent life force and liveliness and creative power within man which illness, fatigue or depression diminishes. Amongst African participants, the loss of vitality had a severe impact on their dignity experience.

“I was so strong...they loved me when I was healthy...When I look at the photo, I see how strong I was...I am holding a lot inside... I feel very bad when I see how I was...and how I am now.” [TA]

Body Image: patients’ perception of their own physical appearance or attractiveness in relation to others or a cultural norm

“(sigh) My nails, my hair...my beautiful hair fell off. My stomach if you look at it, it’s off shape...Now it’s cut down and it’s not... like right. So when I use clothes you can notice my stomach and I feel like ‘Is anybody noticing me?’...I try and cover up, I don’t want anyone to see...” [BA]

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]

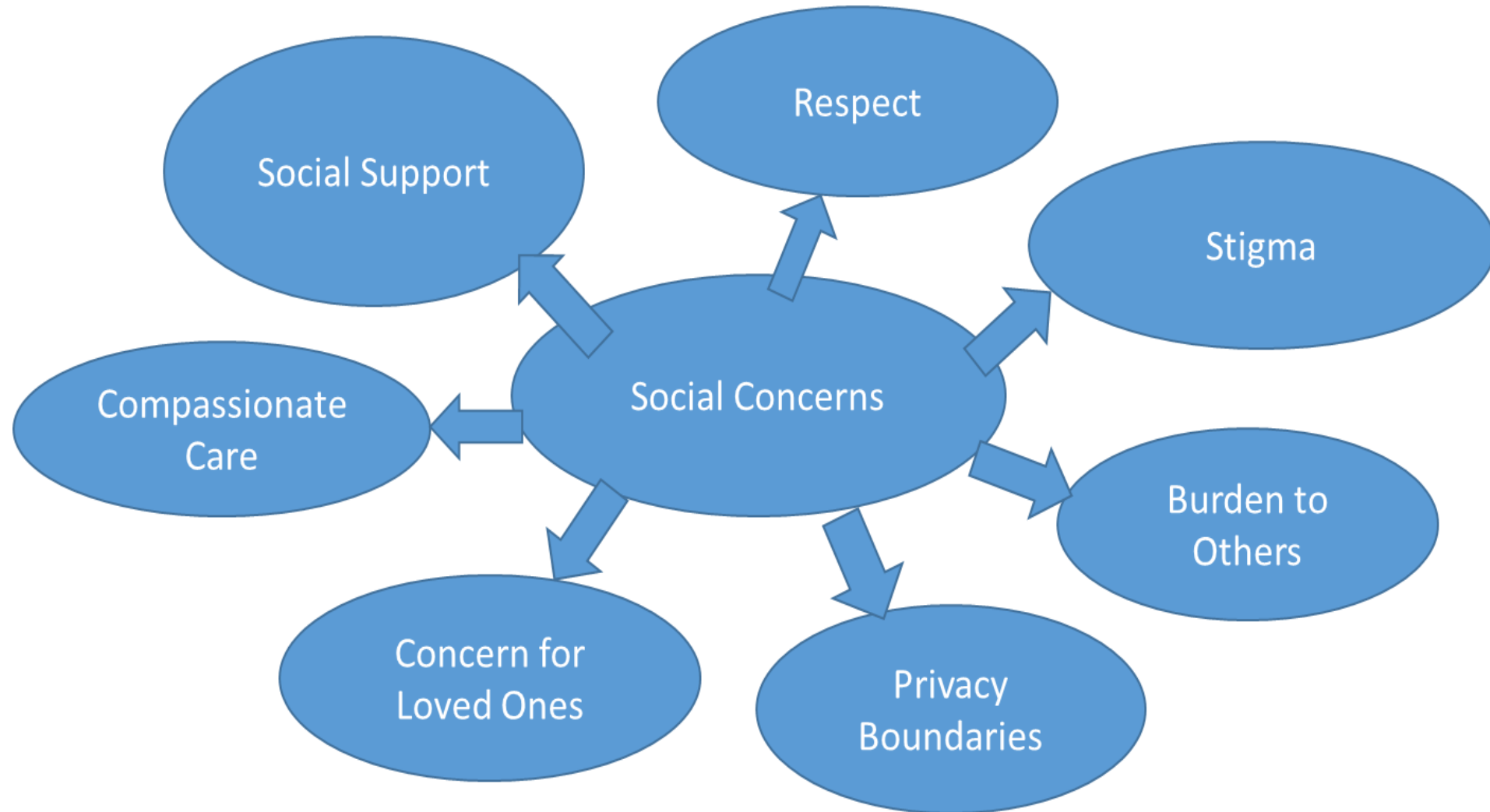
- Leaving a Legacy

“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



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]*

Social Support: *“When my children phoned my extended family to tell them that I am sick, despite being the only female child, not even one person visits.” [TA]*

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]*

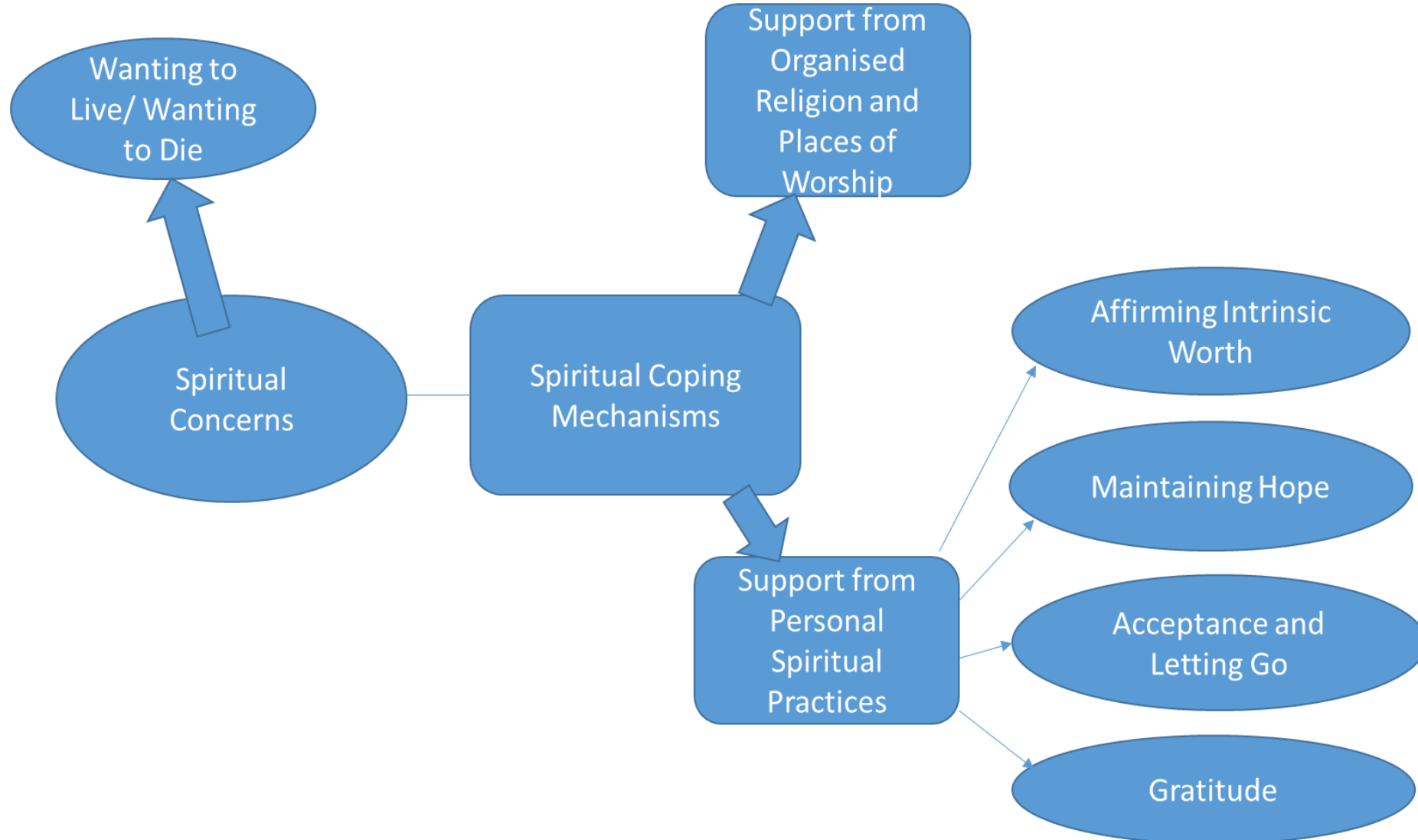
Stigma: *“Some of the Indians they lock themselves in and they don’t live... and they don’t tell others... But there is nothing to hide! And they also isolate themselves...” [SU]*

Burden to Others: *“Sometimes I can’t bathe myself and the neighbours come to bathe me and then I feel life is not worth living.” [TA]*

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]*

Concerns for Loved Ones: *“I am fighting for my children because they are young...18 and 12.” [TA]*

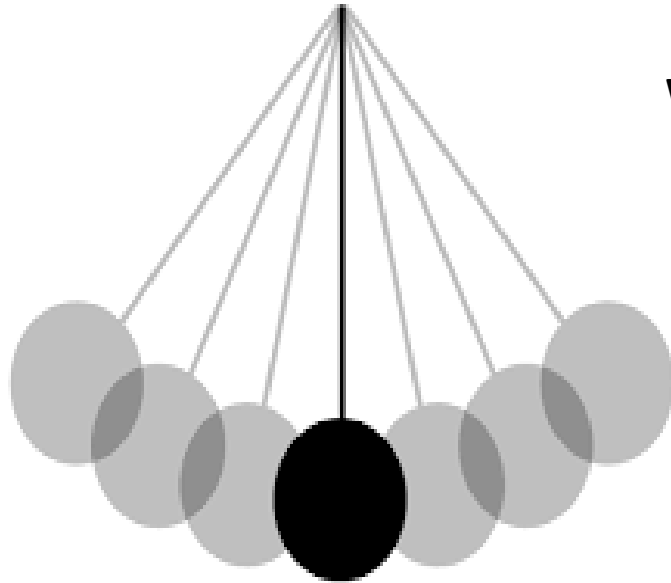
Spiritual Concerns & Coping Mechanisms



Spiritual Concerns

Wanting to Live

Wanting to Die



Good Symptom Control
Respect
Compassionate Care
Social Support
Affirmed Intrinsic Worth
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]

b) Support from Organised Religion and Places of Worship

This was a predominant theme in this South African population. As social structures fail, support is sourced from faith based structures.

“I know no one can help me, only God can help me. Only prayer is boosting me. I pray and God gives me strength. I believe that God is there with me. ... when I go to church the words of God boosts my mind... I feel well and the mind is better.” [ND]



The nature of intrinsic dignity

Frank Brennan
Palliative Care Physician
Sydney, Australia

- 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 this highly abstract and complex concept of one’s innate dignity is lacking**

- Thus, having an **EXPERIENCE** of the “untouchable spirit” and one’s innate **intrinsic dignity and self-worth** can **bolster total dignity** in patients with terminal illness.
- Intrinsic dignity cannot simply be a philosophy but **requires an applied experience for conviction.**
- **Africa : learning through story telling and experiential learning has spanned generations**
- In this study we use a **novel SA 5min intervention of Guided Imagery focused on Intrinsic Dignity** in addition to **Dignity Therapy** which enhances **extrinsic dignity**

Dignity Therapy

1. Tell me a little about your life history; particularly the parts that you either remember most or think are the most important? When did you feel most alive?
2. Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
3. What are the most important roles you have played in life (family roles, vocational roles, community-service roles, etc.)? Why were they so important to you, and what do you think you accomplished in those roles?
4. What are your most important accomplishments, and what do you feel most proud of?
5. Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say once again?
6. What are your hopes and dreams for your loved ones?
7. What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your (son, daughter, spouse, parents, siblings, extended family members)?
8. Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future?
9. In creating this permanent record, are there other things that you would like included?

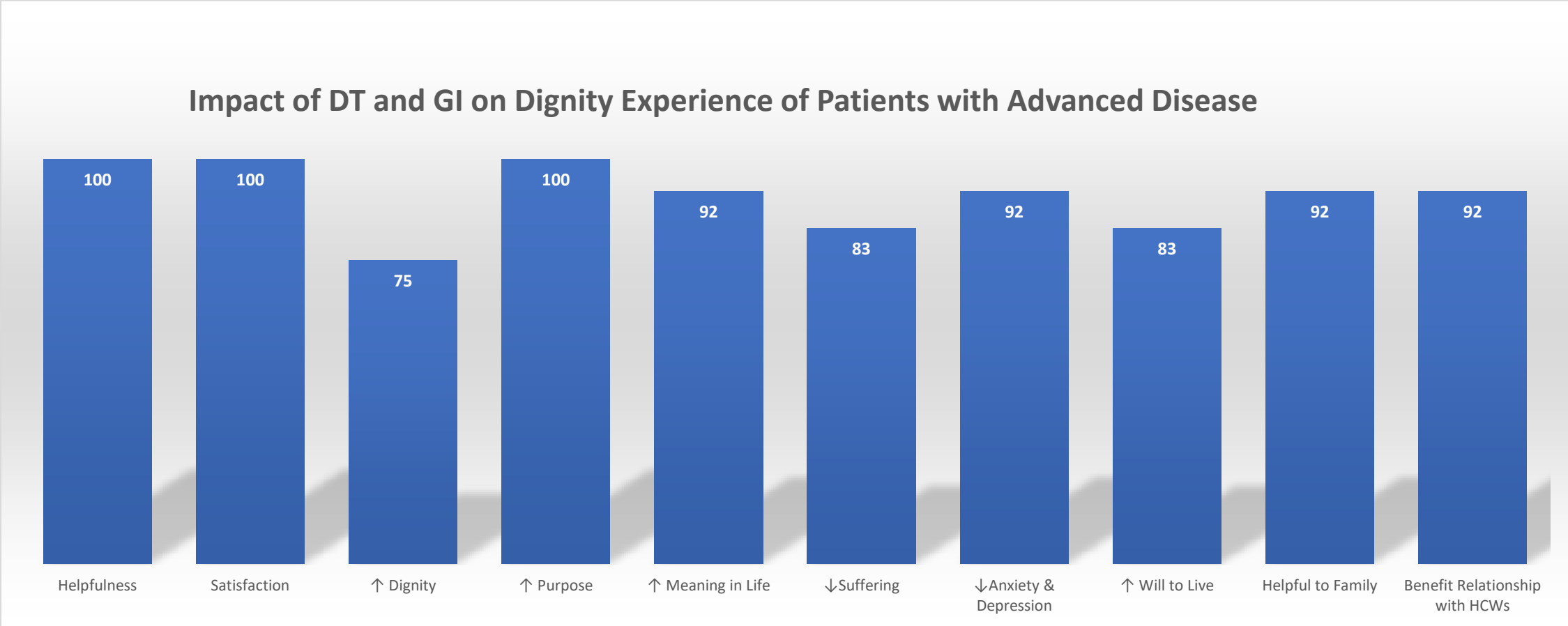
Guided Imagery Focused on Intrinsic Dignity

As I sit here, I relax my body completely...if there is any tension I am holding in any muscles of this body, I relax them...from my toes...I invite the tiny, tiny muscles of my toes to become fully relaxed...and I thank my feet for carrying me on this full journey through this life.... I relax the muscles of my calves...my legs... my buttocks...my back...my spine...my stomach...I take a deep breath in...filling my lungs with peace...and I breathe out...I let go of all the stale air in my lungs.... I do this again.... I breathe in peace and I breathe out...and I allow my breath to find its own rhythm. I relax the muscles of my arms...my fingers...my neck and shoulders...we can hold so much tension here...and I just let them go...I relax them even further...I relax the muscles of my scalp...my face... In this moment... I don't need to pretend...to hold only onto any masks of roles and responsibilities.... I can just be myself...! And in this moment... after reflecting on my unique life's journey... all that matters is the bliss and contentment...that I feel in just being me in this moment.... With my mind... I visualize the radiant living energy that I am... that has journeyed through life...the living being that I truly am, filling this body with light and life.... **I am the untouchable living spirit...and no illness or disability..., no one... and nothing... not even serious illness... can touch this...! I am peace... I am love... I am bliss... I am worthy of esteem and respect...I am free! I am immortal...I am eternal...I am...This is my imperishable intrinsic dignity...! My innate inherent worth...! Not affected by people or situations or circumstances... but this is Who I really am, always eternally! And within this lies my real self-worth! My dignity!**

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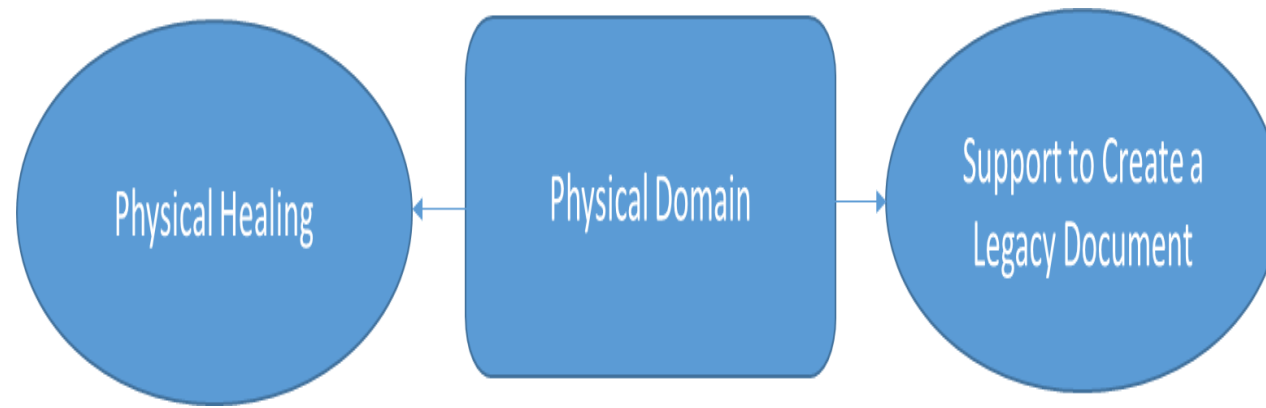
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Quantitative Feedback on the Impact of Dignity Therapy and Guided Imagery on Dignity Experience



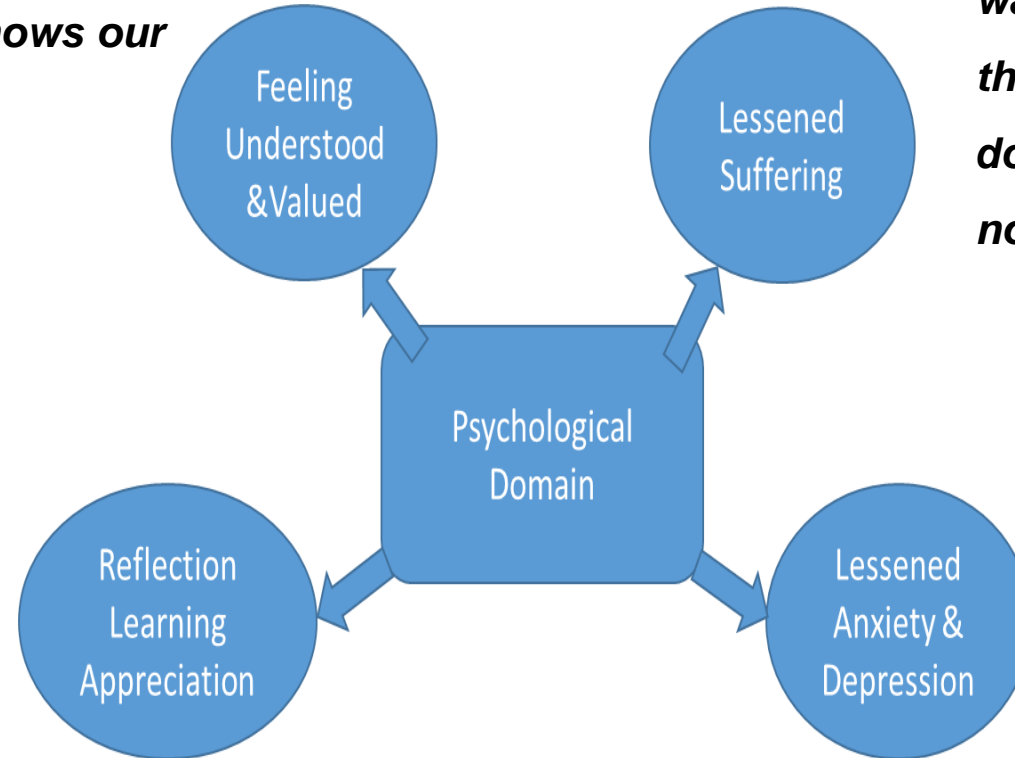
Qualitative Content Analysis of Impact

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]

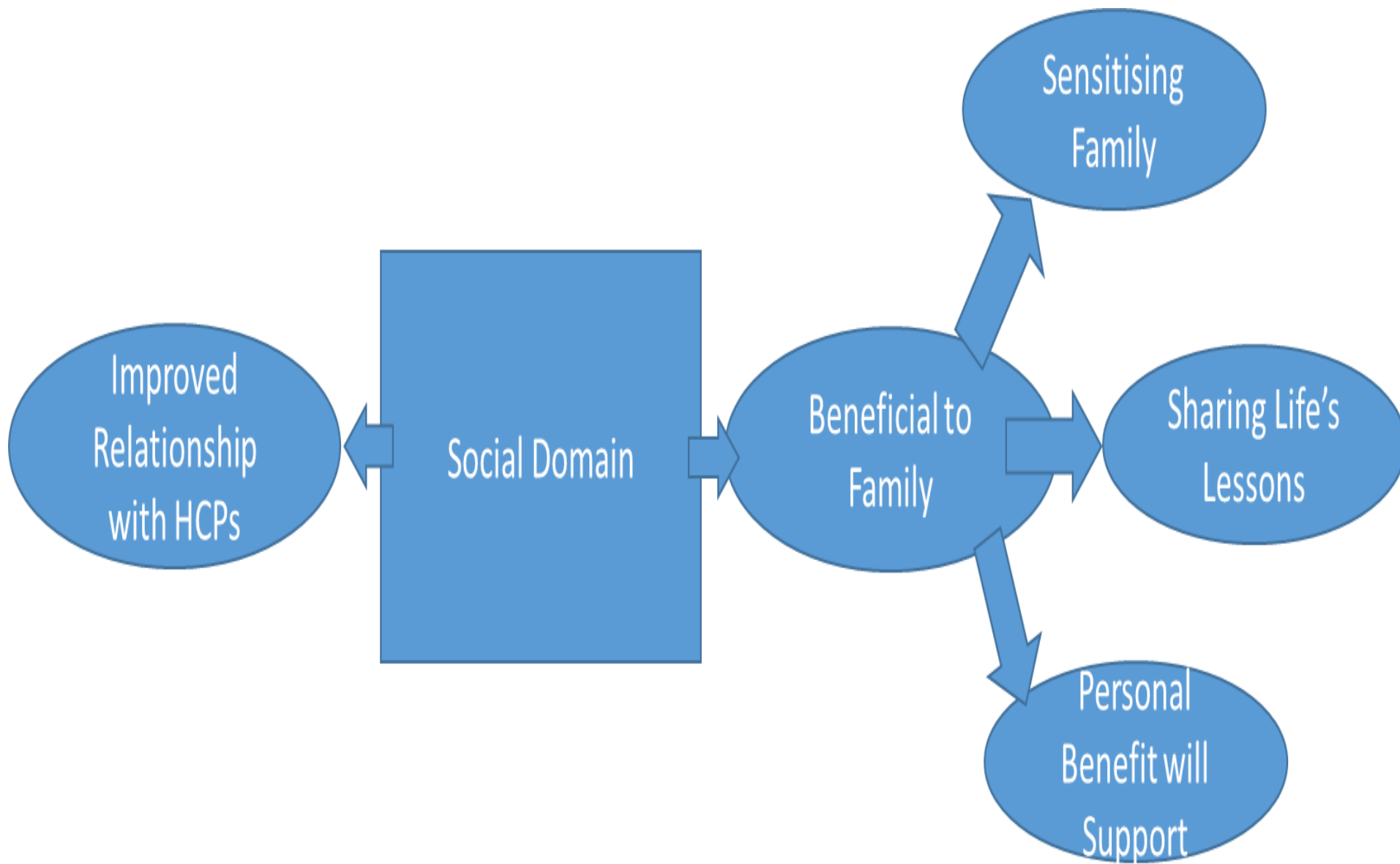
“It opens up my mind. You feel sorry for yourself, and then ... you think these other things mean life!” [DBM]

“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]



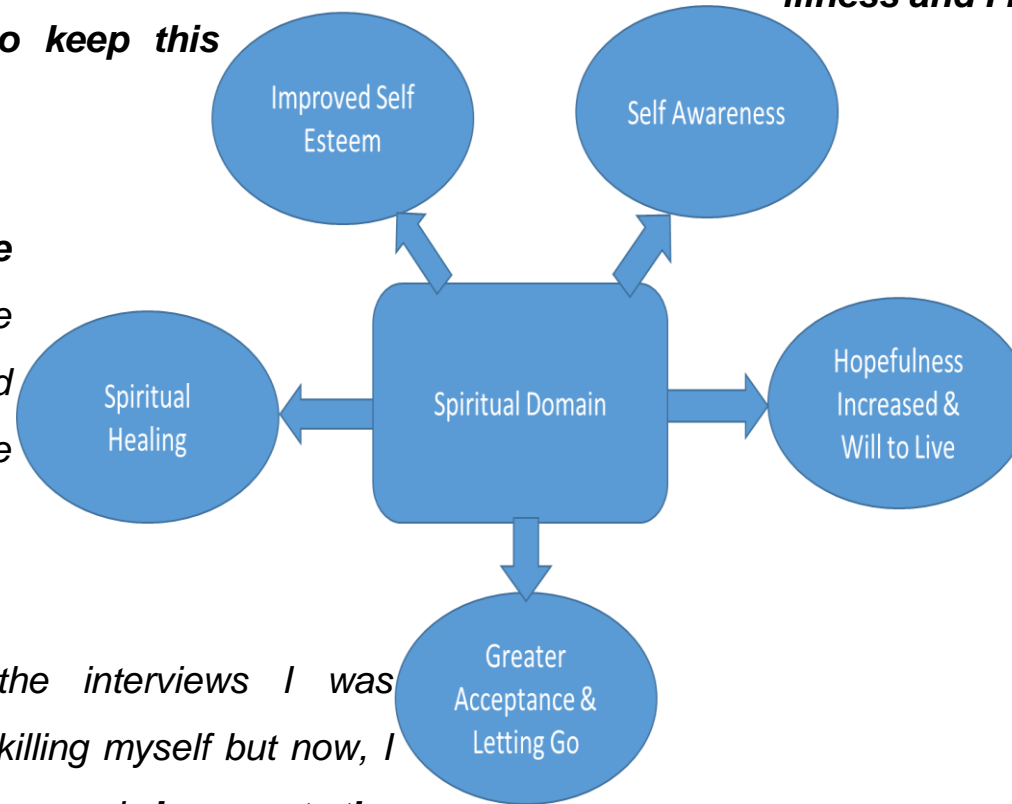
*“And the guided imagery changed my mind, the way I am thinking. I want to be proud of myself now and **have got back my confidence... I feel stronger and I want to keep this dignity.**” [ND]*

*“I **got healed from the spirit** with the whole thing... I used to cry and now I am no more emotional.” [MA]*

*“...before the interviews I was thinking of killing myself but now, I feel stronger and I **accept the situation and how it is now.**” [MA]*

“...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]

*“... I like the guided imagery very much so. It was very peaceful. This improved my sense of self... I realized that **I was more than the body and its illness and I have to get out of this.**” [GSR]*



*“I feel there is more to life than just lying here feeling sorry for myself. I **had purpose and I still have purpose.**” [DBM]*

“... the last bit of 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, purer** and at the end of the day **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]

What Does This Study Imply? What have We Learnt? How Can This Be of Use to Patients with Advanced Disease?

- Some people with advanced disease can retain their dignity and some cannot...
- **“It’s not a weakness. Everyone sees it differently and only one who is in the situation will know what it feels like to be at such a low point.” [SU]**

How can we learn from those who retained their dignity to help those who lost their dignity?

Those who retained their dignity:

- had **strong psycho-existential coping** mechanisms.
- knew how to **accept and let go**
- had a **belief in their intrinsic worth and that nothing can take that away from them, not people and not illness**
- sought nontangible spiritual support**
- sought to find meaning and purpose in their circumstances**

- **DT and GI improved the dignity and will to live of patients in this study, by improving attributed dignity and affirming intrinsic dignity**
- International studies have shown the benefits of Dignity Therapy; **this study in addition shows the benefit of a novel 5min Guided Imagery focused on intrinsic worth as an intervention to enhance intrinsic dignity.**
- To add to the knowledge on dignity research, this study **specifically highlights the need to affirm intrinsic dignity in dying patients, to affirm their personal worth**

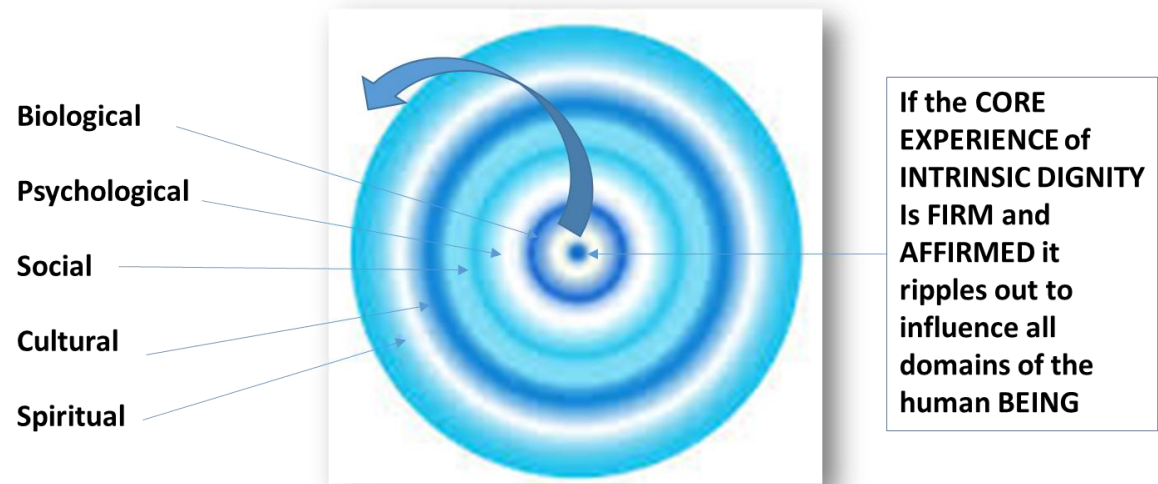


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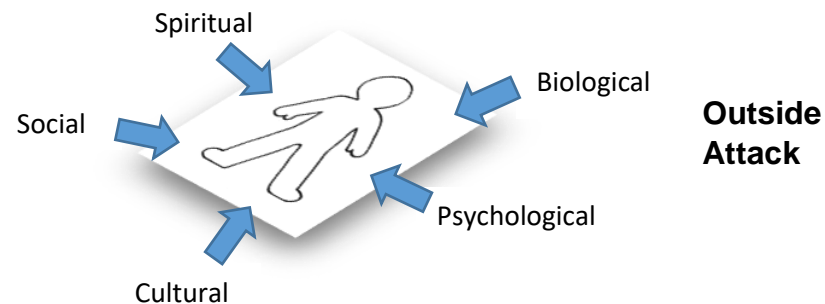
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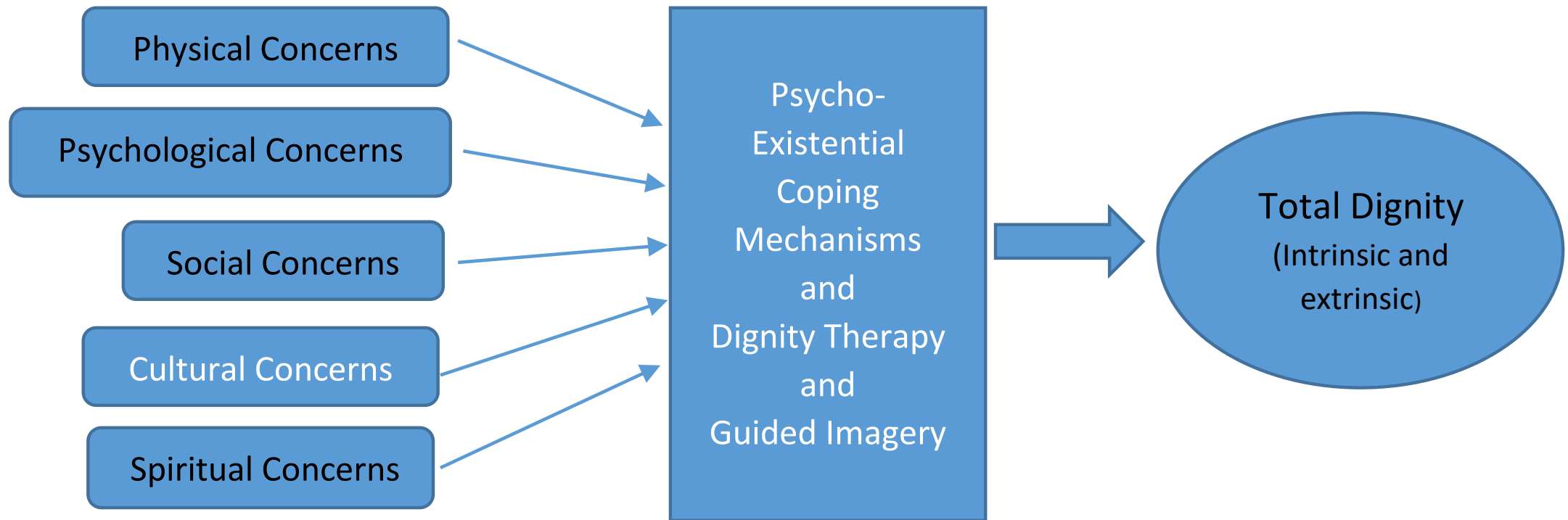


If the core EXPERIENCE of INTRINSIC DIGNITY is FIRM and AFFIRMED this ripples out to influence all domains of the untouchable human BEING.

Dignity Therapy Serves as a Reminder of One's Immortal Worth and Legacy & Guided Imagery Helped Deliver an Experience of the Intangible Intrinsic Dignity



New Model of Influences on Total Dignity



Guided Imagery for Patients with Disease

Reflections and Guided Imagery for People Living with Disease

https://youtube.com/playlist?list=PLRPNeZQYbcCR_XGvKzm7ieNzRSq_zrtOg

Reflections and Guided Imagery to Care for the Carer

<https://youtube.com/playlist?list=PLRPNeZQYbcCT3kc7DD9guGLGoPve9HYtR>

Reflections and Guided Imagery for Times of Crises

<https://youtube.com/playlist?list=PLRPNeZQYbcCQBpHEEX2GjwBP2P4FuMts2>

Reflections and Guided Imagery for Coping with Loss and Grief

https://youtube.com/playlist?list=PLRPNeZQYbcCR_bsnhGI-GleUXQdIWrp7

Link to YouTube channel: <https://www.youtube.com/@drrakshab/featured>

Email: raksha56@gmail.com

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References:

- Assembly UG. Universal declaration of human rights. UN General Assembly 1948.
- Chochinov HM, Hack T, McClement S, Kristjanson L, Harlos M. Dignity in the terminally ill: a developing empirical model. Soc Sci Med 2002;54(3):433-443.
- Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. J Clin Oncol 2005 Aug 20;23(24):5520-5525.
- Chochinov HM. Dignity and the essence of medicine: the A, B, C and D of dignity-conserving care. : University of North Dakota, Division of Biomedical Communications; 2007.
- Brennan F. Dignity: A unifying concept for Palliative Care and human rights. Progress in Palliative Care 2014;22(2):88-96.



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