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Ageing and frailty: a spiritual perspective of the lived experience

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Narrative, the individual and culture



Since we lack a 'culturally viable ideal of old age, our civilization does not really harbor a concept of the whole of life' (Erikson 1997 p.114)



Our stories define who we are as we interact with others in our families and the wider society



Somehow there is a disconnect between the individual older person and others, especially where the older person becomes frail or has dementia.



This presentation will focus on the experience of frailty



How do we make sense of frailty?

- What is the experience like?
- From the perspective of the onlooker?
- From the perspective of the frail person?
- How might we respond to people who are frail?

What does frailty look like?



Facing one's own frailty

Frailty and dependence is feared by many (MacKinlay 2001, 2006, 2017)

Can be the hardest part of life to navigate effectively (Erikson 1997). Issues of suffering loom large for people who have always believed they could change society and many of the expected experiences of later life. (9th stage of life - written when Joan Erikson was 95)

Yet, can also be a time of spiritual growth as human 'doing' changes to human becoming and being.

What is frailty?

'Frailty is recognised clinically as a geriatric syndrome that arises due to multiple deficits to body systems.' (McPhee et al 2016 p. 569).

Frail people are likely to engage in low physical activity, have few social interactions and several chronic diseases requiring medical care.

'Around 10 % of people aged 65–75 years and half of all people aged over 80 years suffer from frailty, which is aggravated by a lower social status, comorbidities, medication use and lowered immunity

(Ashfield et al. 2010; Clegg et al. 2013; Syddall et al. 2010; Yao et al. 2011; cited by McPhee et al 2016 p. 569).

What is frailty?

But there is more to frailty than bodily problems

A holistic perspective on frailty takes account of physical, mental, social and spiritual dimensions.

That is, how do older people who experience increasing physical losses and disabilities respond to these losses?

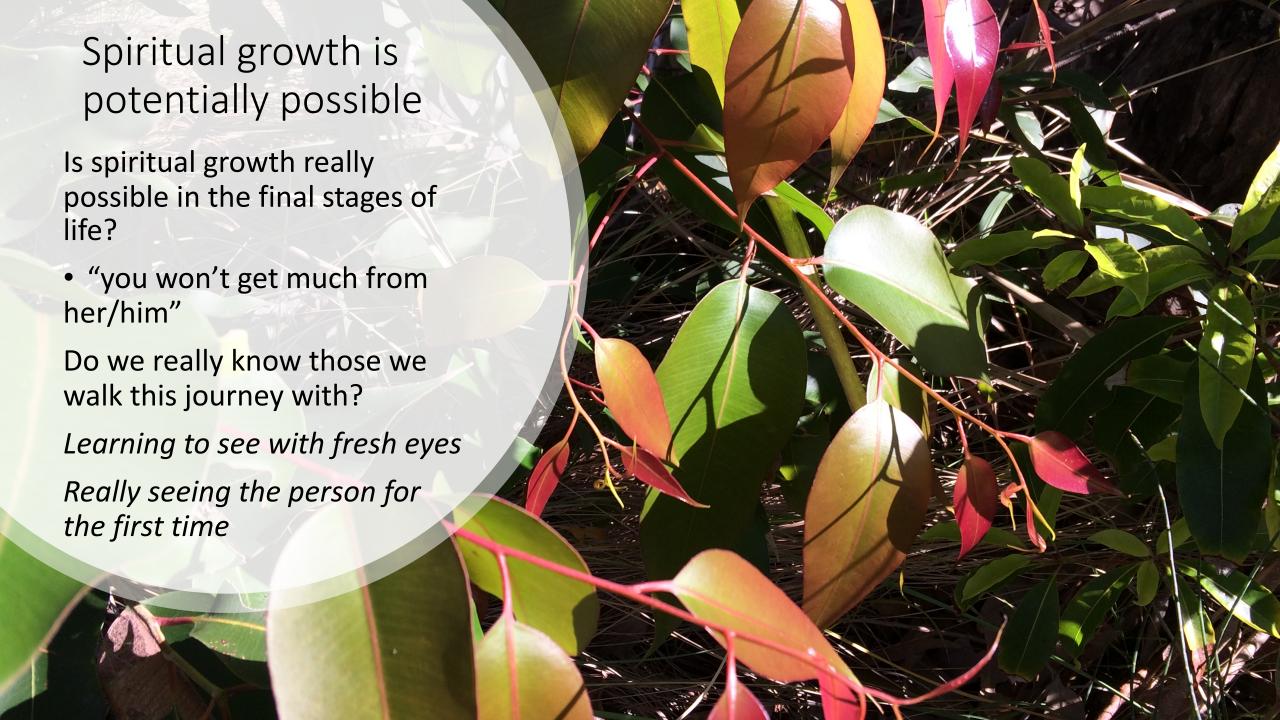
That perspective takes in the psychosocial, emotional and spiritual aspects of the person.

Can frailty in some cases be seen as lack of nourishment for the soul?

Can frailty be prevented or reversed?

(Thompson et al 2018) examined prevalence of frailty in four cohort studies in Australia, concluding

- 'If frailty could be prevented or reversed, it would have an impact on a large number of older people' (p 155). They found that 21% of participants were identified as frail with a further 48% as 'prefrail'. Although research into frailty is increasing, recent medical advances are not necessarily going to be able to prevent frailty.
- As yet, little research has focused on issues of frailty and meaning in life. *The Lived experience of frailty* project (MacKinlay & Mordike 2019) seeks to examine issues of frailty from a spiritual perspective, -- the experience of living with frailty may well be different from the frail person's perspective than from a care provider's perspective.



Meaning and the spiritual dimension

Relationship:

Intimacy with others and/or God

Creation / Environment:

Nature, sea, mountains, gardens, human imagination, meaningful activity/work

Ultimate Life Meaning *Mediated through*

Religion:

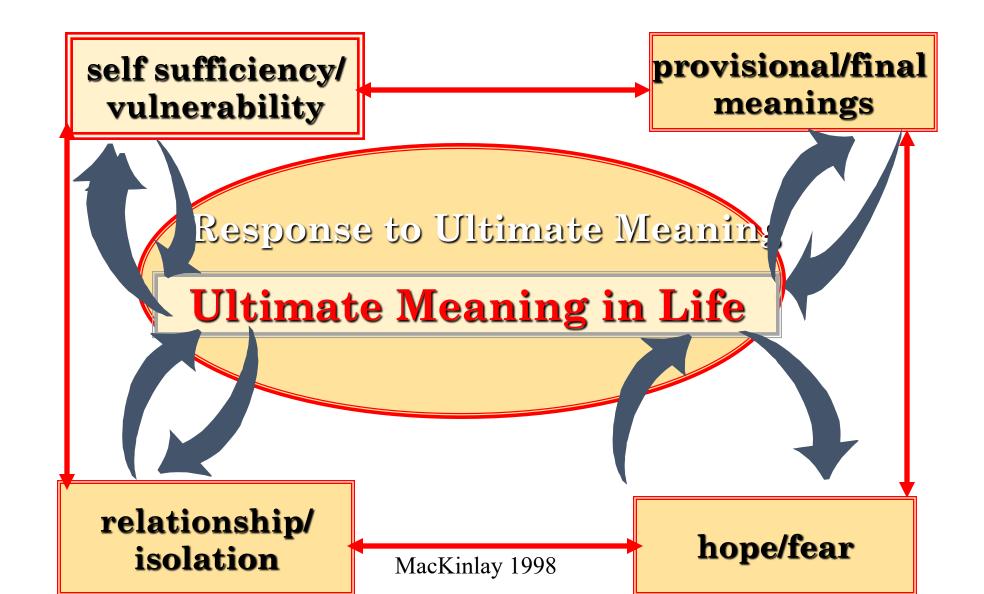
Worship
Prayer
reading of Sacred texts
meditation

The arts:

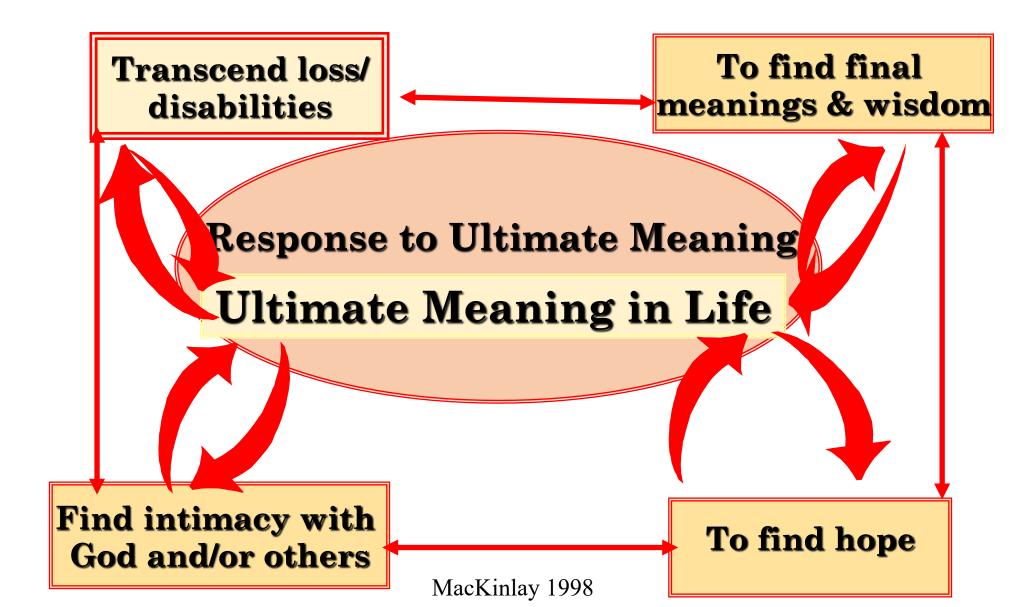
Music, art, poetry, drama, dance

MacKinlay (revised 2017)

Spirituality in Ageing: Themes



Spiritual Tasks & Process of Ageing: A continuing process: a generic model



Finding meaning in the experience of frailty

Aims of the project

- To explore the lived experience of frail older people in the final life journey toward dying and death
- In this presentation focus is on hardest things, meaning and developing inner strength
- Findings will inform aged care practice of nurses, activity officers, pastoral care providers and other aged care providers, for the final life career in palliation and more specifically, end of life care, especially in spiritual care.
- 2 stage study of 24 frail older people (71-102 years) multicultural, multifaith and no faith affiliation, able to speak English, cognitively competent.
- Mixed methods study, survey and in-depth interviews (research sites: Catholic Healthcare. Ethics approved Charles Sturt University 2019)

Findings of study

From the in-depth interviews:

- Loss and disability experienced by all participants, responses varied
- finding *final mean*ing seen in examples of hope and peace and joy which would be linked with inner strength.
- Perhaps the most important theme is the way 'inner strength' is understood by the participants; those who had inner strength seemed able to transcend difficulties and to show greater spiritual wellbeing.

This construct may have important clinical implications in care and for wellbeing; it has already been identified in recent literature in nursing as important to mental health and wellbeing (Boman et al, 2015 & 2017).



What is hardest for you now?

A crucial question as you are getting to know the person – a spiritual question – Hardest things?

Some of the responses:

- Decreasing mobility
- 'Having control of your health' (Jack) all names are pseudonyms

Clement: - give me the strength to be in here. Because I can't change - I can't change things. I can't go out, I can't go for a walk or something like this. I can't do - I can't do anything. But at least - at least I have my brain. I can think the way I want to think.

 Others found it hardest to be alone (in residential care)



 Getting another disability on top of the number of conditions the person already lives with. Sophie lives with neuroma (& its complications) more than 40 years, now has Parkinson's too:

"Well, I suppose at the moment it's - I've tried to live with the neuroma and all that went with that. Now it's trying to live with this new illness, this Parkinson's and all that that entails. I try - and people say, "Oh, take your time. Do this, do that and do that." They just don't know how hard it is to kind of, I am taking my time, as much as I can. But - yes. Maybe yes, that is the hardest thing now."





Inner strength a summary of responses

Faith

God, belief in God

Family

Control – out of control

Interior tranquility – it's been with me the whole time

Maybe God, hard to believe

I don't know, I just do it

God gives the strength

Often self awareness of increasing vulnerability stimulates the growth of inner strength and self-transcendence

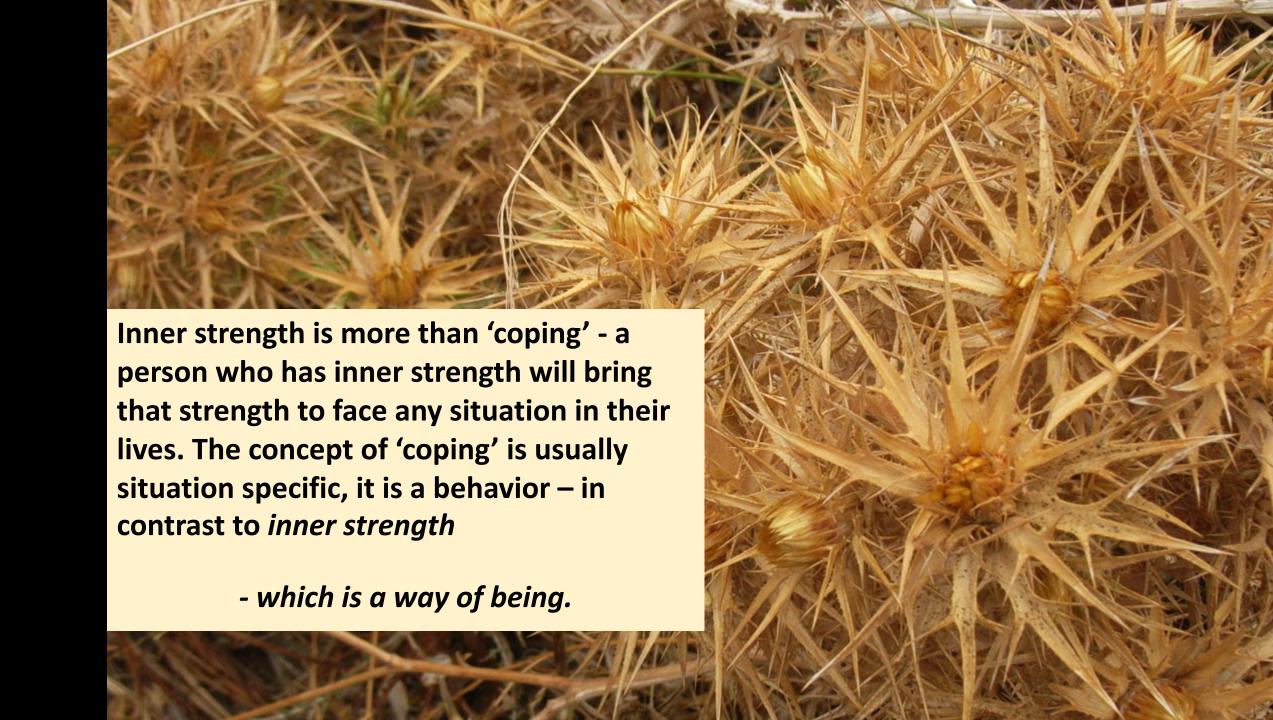
It can take various shapes as worked through by the individual.

- Margaret: "I suppose basically just trusting God, I mean he's there all the time and you know that God the Father's, he loves us, he's not going to test us beyond our means. So whatever happens, you just trust, and I think you can get through it."
- Helen: But I guess, I've really accepted the fact that I'm dying, and I feel very comfortable with that. So now I'm just enjoying the trip.
- Xanthe: But it was not that hard. I was laughing about it because in Holy Koran there is a chapter this is in English also, you can read it - that God never gives you that much burden which you are not capable to carry.

What does inner strength look like?

Other themes supporting inner strength

- Struggle and faith
- Support in time of crises
- Regrets and forgiveness
- Prayer
- Religious faith
- Relationships
- Hope, joy and fear
- What is God like? A question that provides a window into the individual's sense of inner strength



Embracing suffering

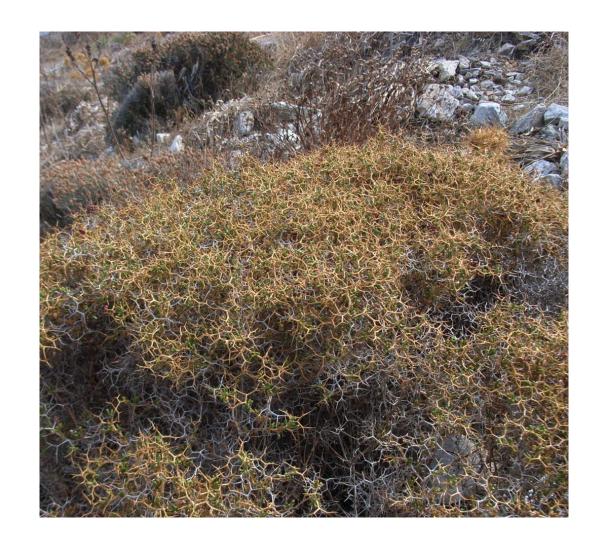
Increase in vulnerability may stimulate change of being and becoming, to work through vulnerability – change in meta-framework of being– more than coping

Encompassing physical, mental, social and spiritual

and embrace the whole life journey

Finding the final life career, learning to see through new lenses, it is through struggle and the loss of previous abilities and relationships that new hope is born

These factors lead to inner strength



Self-transcendence and transformation - Matters of meaning

- Finding meaning in each and every situation of living is essential to flourishing and wellbeing. Potentially, at no stage in life is meaning lost (Frankl 1984). However, numbers of people fail to see meaning in their lives; lack of meaning is a major factor in suicides and especially in late life suicides. It was an important topic to explore with these frail participants.
- Meaning or purpose? Personal meaning or 'what is the meaning of life?'
- Blessings and grace evidence of moving from self-centredness to other centred: Ruby said: "So you know really, I've got a million things to be thankful for, so why would I complain? I'm truly blessed, honestly."

Developing inner strength and self-transcendence

'inner strength' is an important aspect associated with self-transcendence (self-forgetting – Frankl 1984) which is on the pathway towards peace and hope and joy.

The person who has a sense of inner strength, will readily respond in the positive to that question, seeming almost to confirm their deep sense of strength and well-being.



And the greatest of these is love...

Ways participants respond to and show love in their lives -

- Ruby: I adore you, my God. I love you with all my heart.
- Arthur: I love to see the jacarandas when they come out.
- I love the colour. I love the colour of the vestments the priests wear, I love the music the music is just I told you, on Easter day they sung a whole Schubert mass.
- Margaret: I love being with people, with friends.
- Helen: I just know that I'm loved. Not because I've earnt it, it's his free gift.
- Nancy: I love kids.
- Fred: Oh, I love singing, I just definitely love singing.
- Xanthe: And then, in our religion (Muslim), it is true, it is creation of God and God is the creator, so we have to love the creation of God, the creator.



Theme: Self-sufficiency versus vulnerability



Increased disability, losses, multiple chronic conditions, lower energy

Spiritual Task: Transcend losses and disabilities

Humour & laughter

Embrace frailtystimulates spiritual growth Deny frailty-

blocks spiritual growth

Outcomes – finding *meaning* leads to *inner strength*Inner strength produces freedom, hope, love, peace & joy and *increases the likelihood that the person*will be able to face any particular circumstance



The final life career- as important as all of life's stages that have gone before: acknowledging that all of the following may be present

- Struggle
- Inner strength
- Hope
- Peace, love and joy

Searching and finding meaning potentially to end of life Journeying with, seeing each person as they are, open to their possibilities, hopes and fears

Spiritual care and support: Affirming each person in their narrative, being present, resisting judgment of the other, honouring and supporting relationships among these frail elders.

New life may be possible where meaning is found and the final life career may be enhanced beyond all expectations.



References and further reading

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