

From artmaking to changemaking:
exploring the development of the

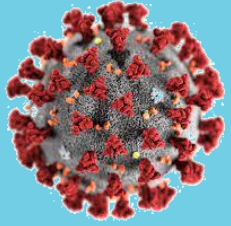
(palliative care patient-led
change) programme

PATCH

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JCECC International Conference
Community End-of-Life Care: Sustainable Development and New Frontier
June 17-18, 2021

Context



Closure of hospice-based day therapy services



Development of *Live well, die well*, an arts-based online support programme



Evaluation of *Live well, die well* programme



What might be the relationship between:

- palliative care patients' sense of identity
- their moral purpose
- their agency
- their illness
- their leadership of change



Individual's leadership of change – influencing something they care about



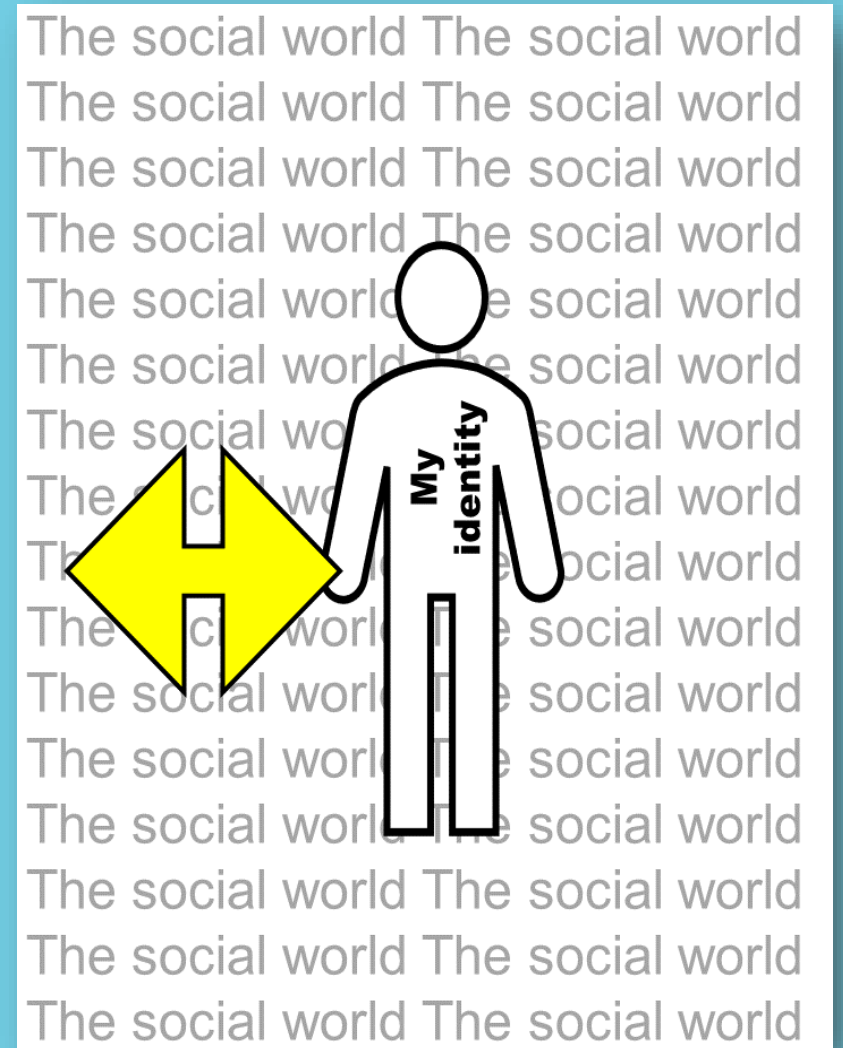
- sense of identity disrupted by illness
- diminished sense of value to family and society
- link to decreased sense of agency – the ability to make a difference to your own life and that of others (Bandura, 1989)



Building a conceptual framework

Identity

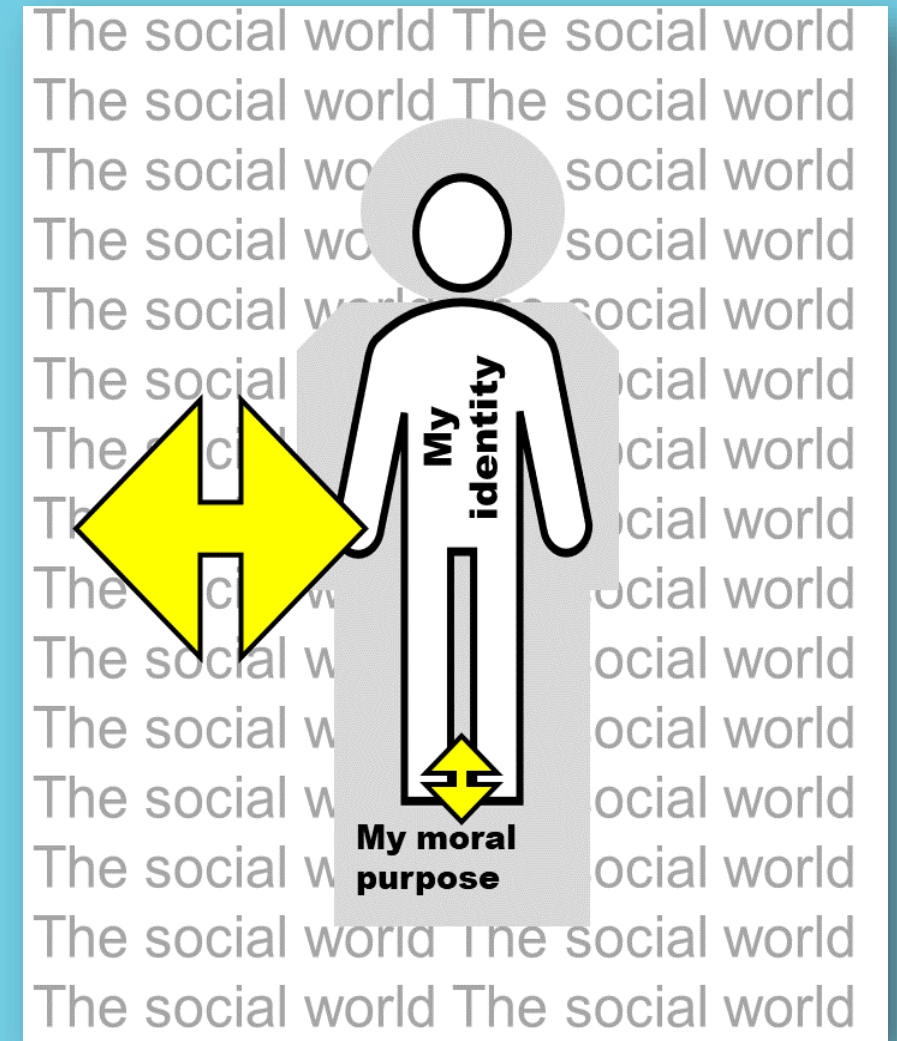
- Identity - 'the kind of person one is recognised as being, at a given time and place' (Gee, 2001:99)
- Context of the social world – identity formed and re-formed by interaction with others
- Identity as a work in progress, a process of development rather than a fixed, life-long state (Erikson, 1975)
- Palliative care patients' experience of identity shift



Building a conceptual framework

Moral purpose

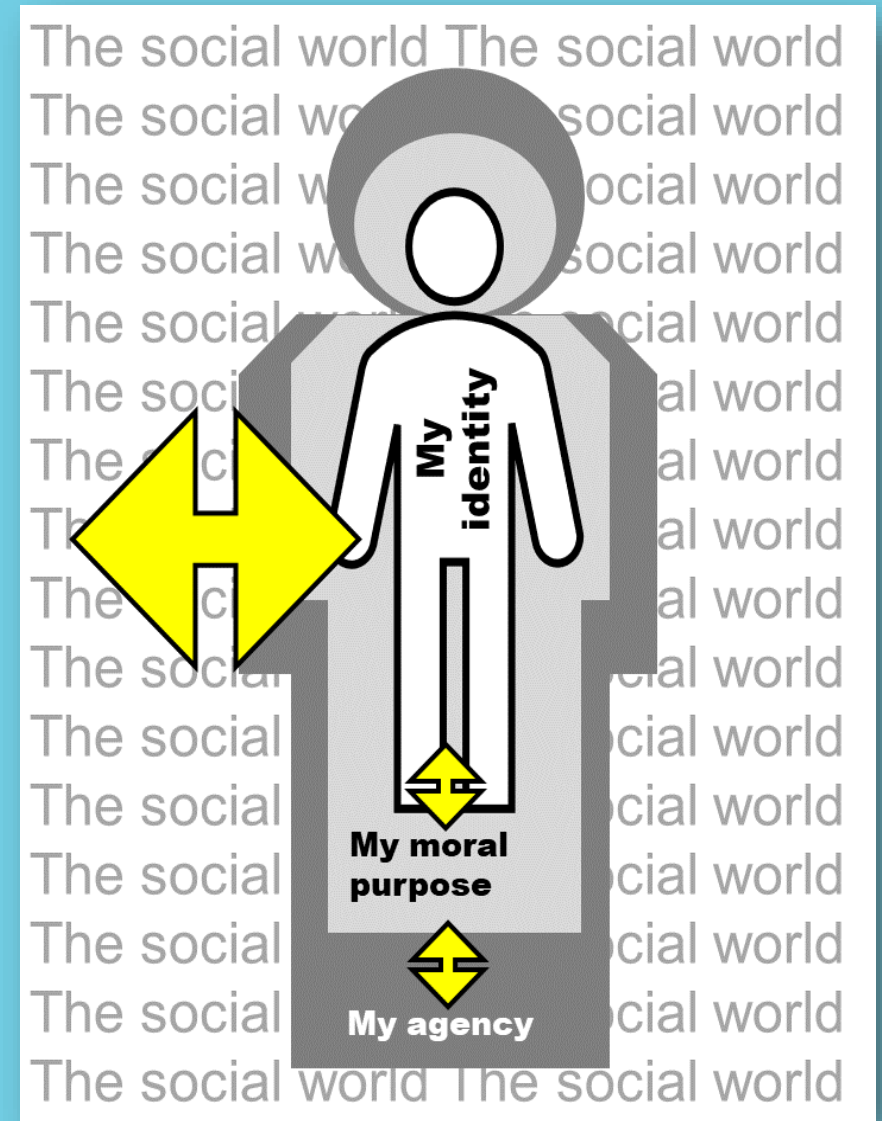
- Moral purpose - the impetus for action brought about by our beliefs and principles
- Our moral purpose is one aspect of our identity, hence it is shaped like it
- Moral purpose influences, and is influenced by, the individual's sense of self
- We do things which support our sense of self and do not do things which challenge it



Building a conceptual framework

Agency

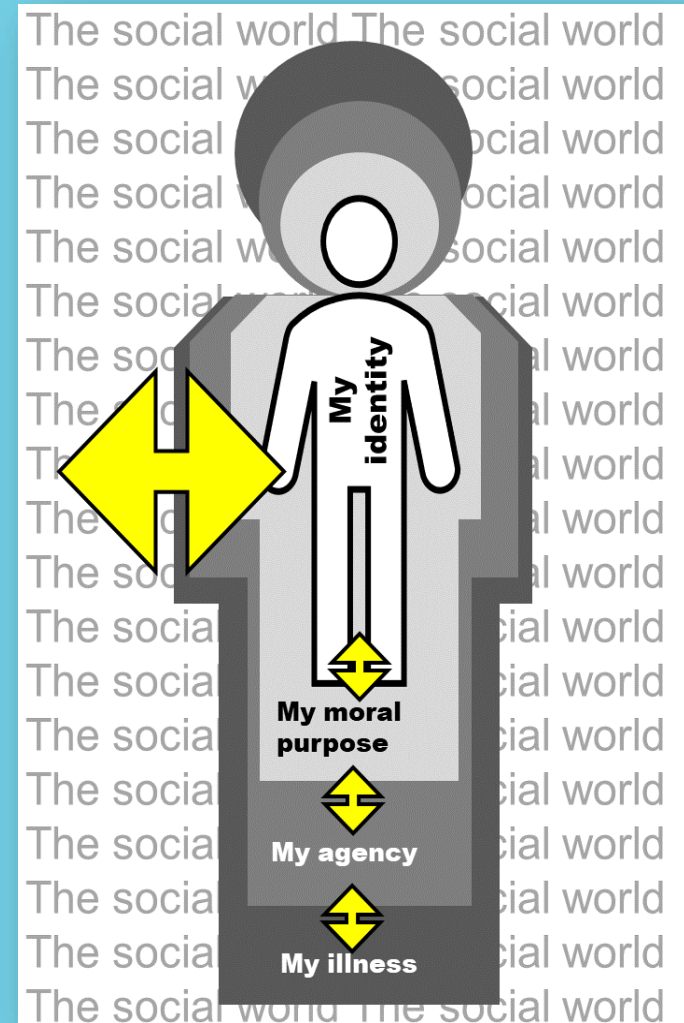
- Agency – human beings' ability to act to change something (Giddens, 1984), to make a difference to one's own life and that of others (Bandura, 1989)
- Structures of the social world - organisational and societal norms, values and practices – can oppose or support agential action
- Our own capacity to act agentially can also shift



Building a conceptual framework

Illness

- Wellness – ‘harmony with one’s image of self’ (Carlander et al., 2011:11)
- Illness acts on agency, potentially reducing it
- Feeling an active part in shaping the world is key to human flourishing (McArthur, 2011)
- Maslow (1943) conceptualizes this human flourishing as self-actualisation, the fulfilment of human potential

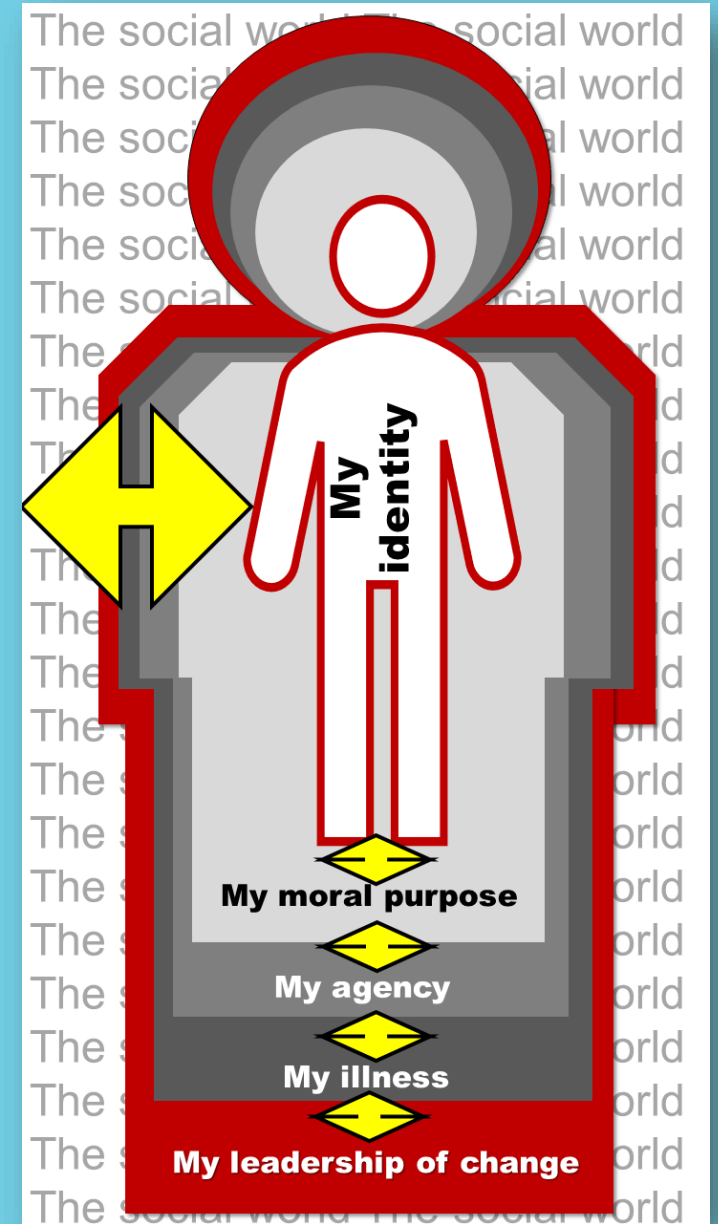


Building a conceptual framework

Leadership of change

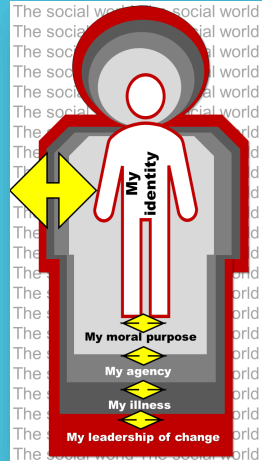
One approach to self-actualisation and the avoidance of illness-induced diminished self:

the leadership of change in an area which matters to the individual



Conclusions

- The link between change leadership and positive self-view
- A challenge to stereotypical views of the dying
- An asset-based approach to individual and societal change



PATCH

- Online collaborative group, 1 hour per week for 6 weeks
- Participants are encouraged to identify an issue they wish to address
- Facilitators support participants to design and execute a change strategy

or



PATCH development team

**We are seeking collaborators! Please contact me if you would like to discuss a potential collaboration:
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References

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- Carlander, I., Ternestedt, M., Sahlberg-Blom, E., Hellström, I. and Sandberg, J. (2011) Four aspects of self-image close to death at home, *International Journal of Qualitative Studies on Health and Well-being*, 6(2), Retrieved 5 May 2021 from <https://www.tandfonline.com/doi/full/10.3402/qhw.v6i2.5931>
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