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MURO DE LAS LAGRIMAS (WALL OF TEARS): Living with dementia and family experiences of loss and grief.

Elizabeth Tindle (QUT), Trish Carroll (Elder Matters) and Patricia Shuter (QUT)

This brief paper will introduce a new theoretical framework or model which may be useful for putting a structure around the theme of ageing and its accompanying grief and loss. It is especially appropriate in the context of counselling families living with dementia, including those individuals with a diagnosis of alzheimers disease.

The paper describes the origin of the Spanish expressions of the `wall of tears` and `house of tears` and involves an historical narrative of the first author as context to the framework.

Historical narrative as context

http://il.youtube.com/watch?v=we_Fkxgdfeature-related

We loaded three burros (donkeys) with all our camping gear including tents, tarpaulins, utensils crockery, water and food for a few weeks and started off on our 25 kilometre trek from Puerto Villamil, Isabela Island in the Galapagos Islands, Ecuador. This was 1976.

Accompanied by Senior Tupiza, a National Park Officer carrying a loaded rifle to stave off packs of wild dogs or feral pigs, we set off southwards toward Quinta Playa, Fifth Beach where we had been informed that the flamigoes were displaying in preparation for pair selection, mating and nesting. We were studying the breeding biology of the Greater flamingo in the Galapagos Islands so it was important for us to be there to witness and record the spectacle.

Some distance into our journey through the dry barren country interspersed with giant opuntia cacti and other drought resistant vegetation, we encountered a large lava rock wall almost blocking our way. This wall had been constructed in the 1940s by prisoners who resided at the penal colony at Puerto Villamil on the South east coast of Isabela one of the largest of the Galapagos Islands. Isabela is made up of five volcanoes joined together by their lava flows.

The convicts were sent from the South American mainland to spend time in this 'hell hole' where it was impossible to escape. Surrounded by lava fields, volcanoes and ocean there was no escape. Dogs assisted the warders in the control of the prisoners and since the penal colony closed in the late 1950s, the animals had become feral, roaming in packs to eek out a meagre existence. Prisoners carried heavy, rugged rocks for great distances to build the wall and it is said that many died during its construction. Because of the hopelessness and despair that accompanied those who were compelled to collect rocks and carry them with their bare hands to build a wall, it is known as "Muro de las Lagrimas" – the wall of tears. It served no purpose other than to keep them busy and out of trouble.

Introduction

Muro de las Lagrimas was the theme used by the second author to capture the loss and grief experienced by families living with dementia at a recent presentation for the APS College of Counselling Psychologists and the Women and Psychology Group Queensland. The presentation was given in conjunction with the third author and entitled: *Living with Dementia - Family Experiences of Loss and Grief: Insights for the Counselling Professional*.

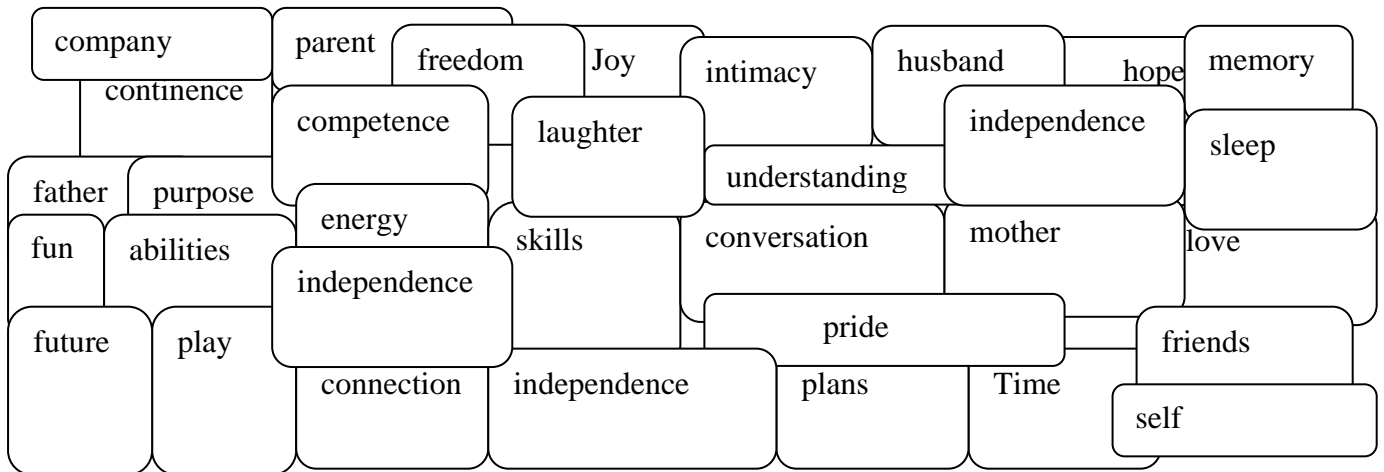
The approach builds on a counselling technique of capturing and naming the losses for an individual, then portraying the losses as an impenetrable wall – their Wall of Loss (De Campo, 2004) – so clients can visualise and have validated their many losses as a precipitant to more in depth discussion of those losses in a counselling context.

Approach to presentation

For the purposes of this presentation, the participants at the workshop, many of whom had personal experiences of caring for a loved one, readily contributed words of loss and grief related to the experience of dementia in the family. Each loss was written up on the white board and was then represented as a lava rock in a larger rock wall - the wall of tears which was then entitled Muro de las Lagrimas and the origin of this title was explained to the group for personal and professional impact. Figure 1 portrays the losses offered by the group which was then portrayed as their Muro de las Lagrimas.

Figure 1

LOSSES



The impact of using 'Muro de las Lagrimas' as a descriptor of this wall of tears is that it captures the inevitable ongoing and complicated losses experienced by families living with dementia. It also reflects the anticipatory (pre-death) loss so often prevalent in this context, as demonstrated by the third author (Shuter, 2010) through her research findings for her Doctoral thesis.

Once clients are able to name, view and confront/experience the multiplicity of losses, they are then more receptive to working through those losses and identifying which may assist to destabilise the wall to allow them to move forward beyond the wall and address the losses they choose to speak about with the therapist.

This counselling strategy is also helpful when applying Murray's (2005) integrated theory of loss and assist the client move from the 'world that was' to the 'world that is' working as counsellor with Murray's (2007) 'Ten Questions of Loss'.

To ensure participants at the workshop were not compelled to dwell on their experience of loss in living with dementia, the second author explored with the group the characteristic factors that enabled those dealing with such losses to successfully negotiate this challenging period. Asking the group to name that which sustained them was another strategy to name, affirm, share and reinforce their strength and resilience.

Identifying these strengths and resilience was particularly important given the findings of Doctoral research carried out by the third author (Shuter, 2010) which suggested some of the protective factors for families living with dementia, including health of caregiver, subjective caregiver burden, spirituality and degree of mastery and satisfaction with caregiver role.

Broader application of framework

The framework/model of Muro de las Lagrimas has been applied in an aged care setting with family members of residents with diagnoses of dementia, as well as residents and staff who have to cope with ongoing deaths of residents and the accompanying grief and loss. In the latter case the aged care facilities can seem to be – or feel like - “Casas de Lagrimas’ or houses of tears.

This extension of the “Muro de las Lagrimas” model was used in a number of grief and loss sessions conducted with the staff of an aged care facility who worked with and cared for residents, including residents with diagnoses of dementia or alzheimers, and so were affected by a series of deaths of long term residents. It is important to acknowledge for staff that they can understandably sometimes struggle with these bereavements, especially as they are required to continue with their duties and care as new aged residents arrive to fill the vacated beds and rooms. The homes can then be seen by some staff – and residents – as a house of tears for some time.

The Grief and Loss sessions provided an opportunity to name and reflect on the losses through the Muro de las Lagrimas and share treasured memories of residents. It also provided an opportunity to discuss the many and varied ways individuals experience and express grief and loss which led to the metaphor of Casa de las Lagrimas.

Figure 2 below demonstrates how the metaphor of Casa de las Lagrimas is transformed to a positive reflection by capturing the individual characteristics and strengths that enable people to cope and even thrive through these times of loss as the bricks and slabs of the foundation of the house of tears.

Some of the coping mechanisms included: pets, friends, reading, meditation, swimming, music, family, religion craft work and so on. These were the factors that sustained individuals during their experience of loss and acted as a solid foundation giving them strength and fortitude through their loss and bereavement. Reflecting on those strengths and the individual and collective resilience within the group proved to be validating and empowering for many.

This whole framework therefore becomes an individual or a collective metaphor for family members or communities dealing with their loss and can be used as a strategy within individual counselling sessions, family support groups and/or professional development for employees of aged care facilities with a focus on self-care.

Conclusion

In conclusion this brief paper has introduced a theoretical framework enabling a counselling strategy to be applied to the experience of anticipatory or sudden grief or loss experienced by individuals, families or aged care staff living with dementia.

Figure 2

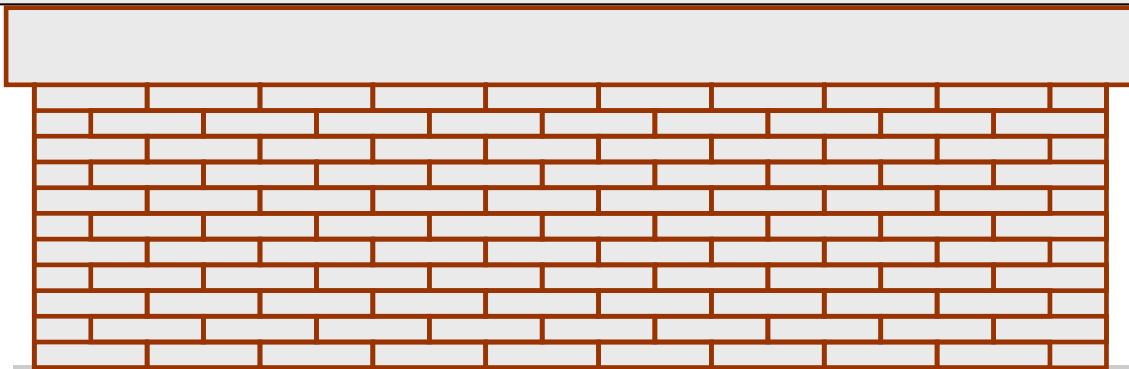
CASA DE LAGRIMAS

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Shock, Disbelief,
Search for understanding,
Sadness, Guilt, Struggle, Anger,
Anticipatory grief
Multiple losses
Bereavement
Despair, Disorganisation
Pain, Fear
(Hope)
Love
Experiences of loss and grief



Music (Listening/Playing)	Confidante Psychologist/ Counsellor	Supervisor Professional organisations	Family/loved ones/ partner	Professional organisations Registration Board
Dance	Friends	Retreats Health Centres	Pets	Projects Passions
Meditation (while walking, swimming, sitting)	Nature, wildlife, bush, beach, mountains	Religion, church, synagogue (for some)	Mosque, prayer, Bible, Talmud, Koran (for some)	Sports Teams
Reading, T.V.	Work teams: management	Technology (information)	Journaling, creating, art, writing, poetry	sculpting, jewellery making, sewing
FOUNDATION OF STRENGTH				

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