A Vital and Relevant Life

A Morenian Approach in Palliative Care

Vivienne Pender

Abstract
Moreno's philosophy is considered within the context of palliative care, specifically a Swedish model which illuminates a way of being when a family member is dying. Several examples drawn from hospice experience are described within a framework encompassing Moreno's role theory and the continua of the Swedish model, affinity-isolation, power-powerlessness and continuity-disruption.

Key Words
continua, affinity-isolation, power-powerlessness, continuity-disruption, hospice, Moreno, palliative care, role theory, spontaneity

Introduction

I work with people who are dying. I meet with them and their families as they confront what is truly relevant in their lives. Using four narratives as illustration, I will relate how I combine a Morenian approach with a continua framework accessed from Swedish research. In the process I will discuss related factors, including hospice palliative care, assessment methods and my work as a counsellor and educator.

Existential Crisis

Existential crisis refers to a state of panic or a feeling of intense psychological discomfort concerning questions of existence. When we are facing existential crisis, how do we remember that there is far more to us than the experience of terror, aloneness, helplessness, powerlessness, confusion, doubt, despair or ambivalence that often confronts us? How, as

health professionals, do we keep remembering that there is far more to the lives of the people we are meeting than what we see and experience in the difficulties of crisis, often described in potent metaphors such as:

> *I'm standing on the edge of an abyss, facing non existence. . ...*
>
> *It feels like my whole life is in one of those food processors and I can't work out the different ingredients.*

For families approaching the death of one of their members, there are the moment by moment crucial decisions of care and companionship, the myriad of tasks needing to be done. The experience of intense pain, discomfort, loneliness, isolation and powerlessness often accompany the letting go of all that is valued in life, the disruption of meaning in life and the contemplating of what on earth does life mean now?

Moreno's Philosophy and the Swedish Study

Jacob Moreno's theoretical and experimental work, experiential psychodrama and role theory, the integrative power of the enabling relationship and systems of relationships, together with an innate belief in the resourcefulness and creativity of human beings, shed some light on these questions. When Jacob Moreno created psychodrama as a method of spontaneity, he defined spontaneity from its source, the Latin 'sponta'. This means free will. He further defined spontaneity as "a new response to an old situation, and an adequate response to a new situation" (1953:42), and anxiety as an absence of spontaneity. Mike Consedine (2004) drew a continuum of spontaneity as he diagrammed the dynamic role system - the fragmenting roles showing an absence of spontaneity and an increase of spontaneity in coping roles, through to the fuller expression of spontaneity and life force in the progressive roles.

The social and cultural atom is described as the thinking, feeling and behaviour, the role, of one person responding to another, the counter-role, in a moment in time. It depicts both significant relationships and the nature of the relationship (Moreno 1946). A description which captures the essence of the roles in role relationships, using adjective and noun or a phrase, is known as the cultural atom (Clayton, 1982; Clayton, 1993). For example, the role and counter-role of a couple confronting the woman's dying might be described as *honest confronter of dread* and *frightened and faithful companion*. These role names capture something of the couple's love and companionship, and their fear of separation. It is vital to remember that they are not generic descriptions. They arise in the moment of meeting in the specific situation. Nothing is static. Meaning changes from one moment to another in what can be a highly charged situation of living in the midst of dying. Emotions may travel from despair to hope, rage to acceptance and frank expression, hopelessness to laughter and joy, within brief periods of time.

Role theory, a systems approach, accentuates the dynamic processes of human beings in any context. We respond to people and events from the roles we have developed in

life, and these are constantly changing, developing, expanding as a repertoire of roles and counter-roles. The philosophy and theoretical foundations of Moreno's psychodrama is in accord with a framework established in 2006 by Swedish researchers Susanne Syren, Britt-Inger Saveman and Eva Benzein. Finding that family relational studies were rare in oncology palliative care, they set out to illuminate a family's way of being in the midst of living and dying. Their purpose was to focus on the relational life world of families and to emphasise circular causality, meaning that a change in one part of the family system will inevitably bring about a change in other parts. The researchers interviewed five families who were coping with the dying process of a family member. Circular questioning was focused on being, doing and becoming. The data was organised along three continua and the analysis revealed "dialectic and dynamic processes in constant motion within and between the continua" (Syren et al, 2006:26).

Diagram 1: *The Continua*
Being in the Midst of Living and Dying

AFFINITY ——————————————— *LONELINESS/ISOLATION*

POWER ——————————————— *POWERLESSNESS*

CONTINUITY ——————————————— *CHAOS/DISRUPTION*

Hospice Palliative Care

Hospices are founded on a belief in providing quality in life, as people prepare for death. The ethos is to neither prolong life nor hasten death. Dignity, respect, compassion are the values that sustain hospice work, together with a commitment to a holistic and systemic way of working. Staff and volunteers are disciplined and integrated in their approach. Enjoyment of life and competent care are accentuated. Lightness, order and beauty pervade the environment of the hospice. The multidisciplinary teams attend to physical, psychological, emotional and spiritual needs during the crises of dying and death.

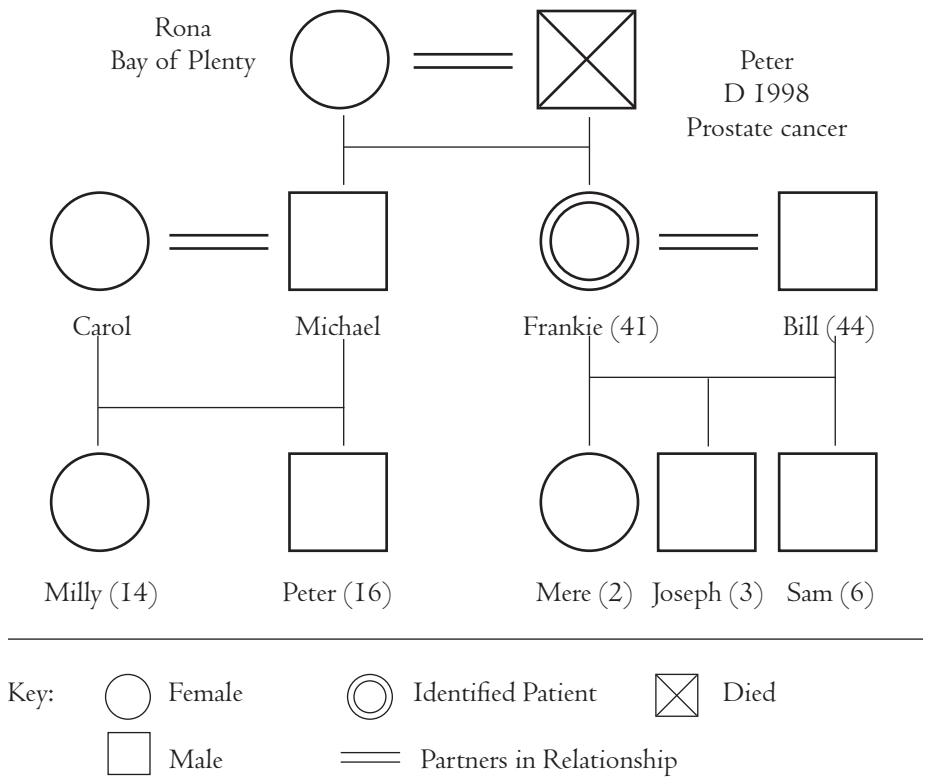
The philosophy of hospice palliative care accentuates the patient's free will and the need for palliative care team members to be tuned into the responses of each patient and family. Role tests arise continually. Which interventions may be the most adequate response and how might the team remain fresh and open? "It is the adequate appropriate response that matters. The response to a new situation requires a sense of timing, an imagination for appropriateness, an originality and a mobility and flexibility of the self" (Moreno, 1946:91).

Genograms and Ecomaps

Two assessment tools are used frequently in palliative care, the genogram and the

ecomap. Murray Bowen (Barker, 1998:98) is credited with pioneering the genogram, used since the 1970s by social workers, therapists, nurses and medical staff as an assessment tool to create an immediate picture of a family. It facilitates rapid recording of significant dates and events, and the nature of relationships over two or three generations. The genogram is indispensable in ensuring that valuable information is widely disseminated. Thus staff members are enabled to 'know' patients and develop empathic relationships from shared information at multidisciplinary meetings and staff changeovers. The hospice multidisciplinary team uses genograms to map the significant people in the terminally ill person's life, their emotional closeness and distance and their geographical location. Language, cultural values and beliefs are recorded and actions taken to honour these in relationship with the person who is dying, their family/whanau and friends. An example of a genogram is provided below.

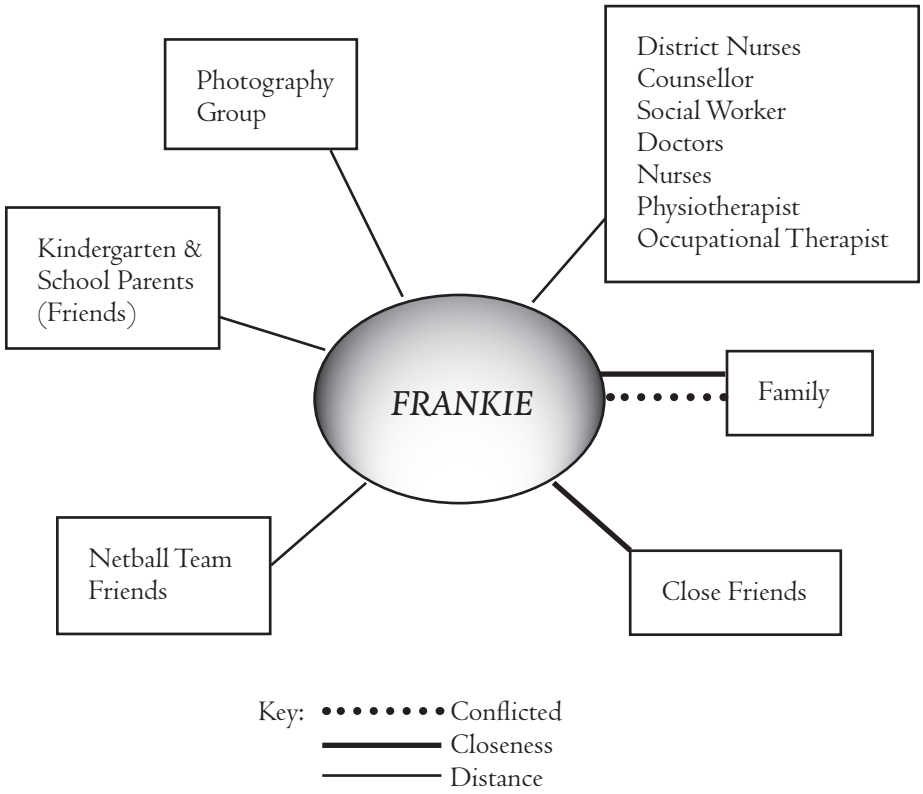
Diagram 2: *Frankie's Genogram*



Frankie loves music, has ipod. Wants visitors monitored by Bill. She is exhausted.
Michael travelling this week to stay with Bill and Rona at Bill's and Frankie's home.

Ecomaps, devised by social worker Ann Hartman in 1978, are visual maps that record in the here and now the significant people in a person's life. They are similar to the psychodramatic sociogram, except that sociograms use action. An ecomap can starkly illustrate how disrupted ordinary life becomes from the time of diagnosis. There are significant social and cultural atom shifts, with many health professionals suddenly becoming involved. Strangers begin to enter the family space providing welcome services but also disturbing the previous continuity of everyday living. The challenge for the professional is to make sure that the best resources are available with the least amount of intrusion, so that the person who is terminally ill stays in charge of their life and the day to day order and continuity they value. Below is an example of an ecomap.

Diagram 3: *Frankie's Ecomap*



Counselling and Educating: My Roles in Palliative Care

In my work as a counsellor in a multidisciplinary palliative care team, I meet with individuals and families who are deep into the crisis of living with the diagnosis of

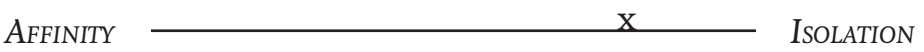
terminal illness. I also meet with family members in bereavement. In another role, as an educator of health professionals, my purpose is to enable reflective practice. I use the continua and Moreno's concepts and techniques in this work. Interactive teaching assists integrative learning. Together, we may set out an ecomap in action. This is the moment of reality when participants begin to relate from their thinking, feeling and behaviour. It is through entering the action that participants gain a different experience. They develop systemic thinking, consider the dying person in relationship to the many dimensions of their lives and learn to reverse roles. A high degree of spontaneity and intelligent critical thinking emerges during and after these enactments. In the sharing, people often comment that they think and feel in a more expansive way about themselves and the families with whom they work.

Narratives, Continua and Role Descriptions

So how do I use the framework of role theory alongside the continua, to encourage enabling solutions for the families I meet in the hospice? The following narratives will be used to describe and illustrate. They are drawn from a compilation of patient experiences, and the names used are creations. The psychodramatic analysis of fragmenting, coping and progressive roles as a means of diagramming dynamic change in a role system (Clayton, 1993) relates well in the context of the continua.

The First Narrative: Tiata

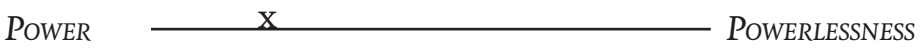
Soon after I arrive to work at the hospice, I am intrigued to see a series of drawings of a waka (Maori canoe) in the staff base. I ask "Who is the artist?" I am told that the artist is a patient, Tiata, who has recently arrived. Seeking solitude, he has been living on the streets and in the bush. He has a diagnosis of terminal cancer and now, needing hospital care, a community agency has assisted him to enter the hospice. Tiata hides beneath a duvet most of the time. The multidisciplinary team respect his space, his need to have great privacy. Staff members have heard from the community agency that he does not want contact with family. He had, from time to time, come into their agency for a meal and was sometimes seen drawing. A nurse places paper and coloured pencils near Tiata's bed, where they stay untouched for several days. He is given medication and gentle, competent nursing care to relieve his intense pain and discomfort. This is his position on the affinity – isolation continuum at this stage.



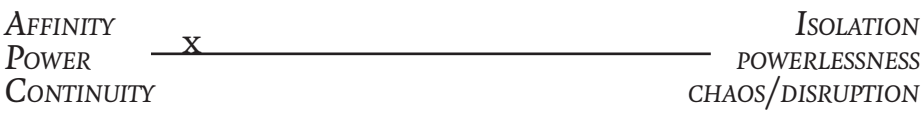
One day a nurse notices that Tiata has done several drawings. She draws closer, and he shows her a series of waka with the same repeating name written on them. It is the name of his turangawaewae, the place of his birth, his place of standing. Does he want to go there? He shakes his head. He gives her the drawings. She places them in the staff base.

The team become connected to Tiata in a different way. He has potently shown what is relevant for him at this moment. His position on the continua is shifting.

Over the next week, Tiata continues to draw the waka and write the name of his turangawaewae. He begins to talk haltingly with his nurse. He talks of an older brother that he used to be close to. He has not seen him for years. Did he want his brother contacted? "No". Tiata continues to move on the continua.



A week later Tiata says yes, he does want to see his brother. His brother is traced. He arrives by plane several hours later. They draw close and talk and talk.



Tiata travels with his brother to their turangawaewae. A hospice nearby is contacted to continue medical care. A few weeks later, Tiata dies at his birthplace with his whanau present.

I thought a lot about how that nurse had doubled Tiata. She brought in the art materials. His space, his silence were respected. She approached quietly and did not move in too close. She respected his cues and responded. Her ability to mirror and role reverse enabled him to spontaneously express what he wanted. No one tried to make decisions for him. He decided on his companions and the timing of events. The staff acted as enablers. At the same time medical staff ensured that he was well informed about medication and what medical treatment was possible.

On the first continuum, Tiata moved at his own pace from isolation to affinity. He accepted assistance when he needed medical attention. He yearned for turangawaewae and when he was ready he moved towards whanau. Tiata was without financial and material resources. He was powerless to take care of his physical health. The continuum of power and powerlessness documented his movement over time. When he agreed to

hospice care he had some power in the decisions he made about medication, contact with other people, space and movement. He eventually developed the power to decide where he wanted to be when he died.

Tiata's illness took away the continuity of day to day living and surviving. He was thrust into a very different place and had to confront much pain and discomfort. The continuum of continuity and disruption recorded how he acted to create continuity, reconnecting with turangawaewae and whanau just before he died.

Table 1: *Dynamic Change in Tiata's Role System*

Absence of Spontaneity		*Full Spontaneity*
Fragmenting Roles	**Coping Roles**	**Progressive Roles**
isolated sufferer	anxious yearner	expressive artist
hider under duvet		decision maker
withdrawn recluse		turangawaewae dweller
disconnected whanau member		connected whanau member
Isolation		*Affinity*
Powerlessness		*Power*
Disruption and Chaos		*Continuity*

The Second Narrative: John

John is an angry man who rants and swears about an organisation he has had dealings with at different times in his life. There is no letup. He goes on and on, a tirade of abuse, repeating himself without cease. "They are Bastards!" He wants the world to know. People listen at first and then slowly withdraw, worn down and wearied. He is more isolated than ever.

His outbursts render him powerless. There is nothing he wants done to rectify the

situation. John is asked if he would like to record his life. He says yes with alacrity. I arrange for a volunteer biographer to meet him. He tells her the same furious story. However, he also begins to talk about other aspects of his life. An interesting, complicated, difficult and adventurous life emerges through the biography. He has wandered the world without family and friends for many years. He wants his biography given to family if they can be found. And they are found.

Before his death, John connects with several members of his family. He has acted for himself in a powerful way and reconnected with the continuity of his life, with what he values, what he despises, and what meaning his life has for him.

Table 2: *Dynamic Change in John's Role System*

Absence of Spontaneity		*Full Spontaneity*
Fragmenting Roles	**Coping Roles**	**Progressive Roles**
raging rejecter	aggressive critic	reviewer of life
angry haranguer	misunderstood withdrawer	revelling storyteller
		expressive philosopher
		emerging reconnecter
Isolation		*Affinity*
Powerlessness		*Power*
Disruption and Chaos		*Continuity*

"Sharing thoughts and feelings generates inner strength and the courage to be even more open. Reciprocity in families also created experiences of comfort, which was related to their will to be available for each other and to protect each other from individual suffering" (Syren et al., 2006:29). John's story led me to think about how, in meeting with patients' families, openness to anything and everything is a good warm up.

I provide safety so that experience and truth can be expressed and vented without harm to another. Individual meetings prepare people to act spontaneously in expressing their experience in family meetings. When there is truthful expression together with goodwill by one or two people, the family system often shifts to an increase in affinity, power and continuity. I would describe this role as the *interested, open, curious approacher* where a cluster of roles, *naïve enquirer, open learner* and *social investigator*, interplay.

The Third Narrative: Frankie, Bill and Rona

A young person, Frankie, is dying. The family gathers. The family is fragmented. The husband Bill, and mother Rona, will not stay in the same room together. Frankie asks if I will meet with them and sort something out. She has no energy left to talk to anyone. She just wants the pain to stop, and the tension in the room to lift. Bill and Rona both indicate that they would prefer to meet with me alone. The lines seem to be drawn. I suggest we meet individually first and then perhaps meet together later.

Bill tells me that Frankie's illness has been quick and ruthless. She has weeks to live. He cares for their small children while moving between home and hospice each day. He wants their time together to be as uninterrupted as possible, but this is proving impossible because his mother-in-law is always there. He talks quickly. The words tumble forth. Bill is exhausted and angry. He adds that before Frankie's illness, he and Rona had got along together well. She has been helping by looking after the children, and he thought she liked him. However, lately she has begun picking on him, criticising the food that he buys, finding fault with the way he dresses the children, any little thing. He says that he has had "a gutsful". He speaks explosively and then his body droops in exhaustion. He cannot imagine that meeting together with Rona will make any difference. She will probably just have another "go" at him.

When I meet with Rona, she cries and tells me that she does not know how she will survive without her only daughter. Bill has been giving her the cold shoulder and the tension is unbearable. She feels unloved, anxious and deeply troubled by her daughter's pain. Her husband, Frankie's father, died ten years ago and she remembers that time with grief. Her sleep is broken. She is so weary. She loves being with the children but tires quickly.

Bill and Rona are both experiencing themselves at the fragmenting end of all three continua.

Isolation

Powerlessness

Disruption/Chaos

In the individual sessions, I describe to Bill and Rona the ground rules that would apply for a meeting, such as listening without interruption, no criticising, no blaming, so that each would have an opportunity to express themselves regarding their current experience.

Tentatively, they agree to a meeting. When we meet up the following week, Bill and Rona agree to stick to the ground rules. Each expresses their deep love for Frankie and the children, the grief and anguish they experience, and both refer to the burden of keeping going with daily life and tasks.

Bill thanks Rona for her help. He appreciates the way in which she cares for the children and the respite it provides. I am surprised. I had thought that Bill's intense anger might prevent him from experiencing anything else. In turn, Rona tells Bill "how stoked" she was when he married Frankie. He is a great son-in-law. Then she cries with shuddering tears. He grabs handfuls of tissues and pushes them into her hand. He wipes tears from his own eyes.

We sit quietly together for some time. Then I ask "What would help both of you? What could you ask of each other that would help you through this time?" Rona speaks first "Bill, please could I have some time alone with Frankie, just by myself? And I want you to have plenty of time with her too. I'll look after the kids whenever you want. I love being with them". Bill replies "Yes, that's easy to do. And yes, I need a lot of time with Frankie myself. And I need you to stop criticising me. I'm knackered. I'm doing my best". Rona withdraws and cries. Eventually she says "I'm sorry. I didn't mean to criticise. I thought it might be helpful if I told you the food the children like. I'll try and think in future before I open my mouth". Bill puts his arm around Rona. Gruffly he says "Thank you". He looks exhausted but relieved.

Bill and Rona are no longer isolated in their separate corners of misery. Small criticisms have ceased and acts of kindness have taken over. They each have alone time with Frankie while the other plays with the children in the hospice lounge. Sometimes a hospice volunteer cares for the children. The family spend a lot of time together with Frankie. Frankie tells me that things are easier now that the tension has gone.

Isolation and loneliness are the bitter fruits of dying. Social and cultural atom repair is achieved and isolation reduced when the people involved are prepared to listen to one another. Power is restored when people attempt to understand one another in their pain, and in their willingness to keep going moment by moment in what is an intense and difficult time for many. The disruption brought on by the shock and anguish of loss and grief is reduced when two or more people weave the necessary threads of continuity in their goodwill towards, and shared love of, the dying person.

The Fourth Narrative: The Bereaved Partners' Group

"Receiving a diagnosis of cancer is described as being pushed out of a helicopter into a jungle war without any training, any familiarity with the terrain or any sense of how to survive" (Lerner, 1994 cited in Syren et al., 2006:26). I co-lead a group for partners of people who have died in the hospice service. Eight tends to be the average number attending per group and there are predominantly more women than men. Our intention is to establish a respectful place where grieving partners meet others with common experiences.

The group participants respect a multiplicity of experiences and meanings. After the roller coaster existence of living in a permanent existential crisis, there is now time for

reflection and integration. No one wants to be 'fixed' or 'changed'. There is a wish to meet others who have endured similar experiences of terminal illness and the death of a beloved partner. The mirroring and role reversal that takes place in the group provide invaluable integrative experiences.

The group members describe the indescribable, that time from diagnosis to death. They talk about the intensity, the hard work of care-giving, the depth of love and discipline that they discover in themselves. They discuss the exhaustion, the sleeplessness, the everyday conflicts, the joy, the surprise laughter, the eruption of intense anger and the bitter loneliness that emerges at times.

> *It's like living in another world parallel to the everyday world, with people living normal lives not realising what I am experiencing . . . intense loneliness and anguish.*
>
> *If only they (friends and work colleagues) would realise how precious life is and stop the banal, the petty bickering, worrying about the small things . . . and yes I used to, too. Now I realise how precious life is. It means a lot more. It's deeper. I can't be bothered with superficial talk.*
>
> *I wouldn't wish this experience on my worst enemy (if I had one) and yet I wouldn't trade the strength I've found, my ability to live my life every day in a new way. I appreciate it far more deeply.*

A paradox!

We find that similar themes emerge, time and time again. These themes and experiences substantiate the findings of Syren et al. (2006). Movement on the continua in the direction of affinity, power and continuity seem to prepare families for enduring the changed and challenging life situation, and give them a kind of repose. Existential and emotional suffering emerges when movement is in the opposite direction. Individuals then embody experiences of depression and anxiety.

Power to express what is previously inexpressible, and the meaning of the continuing relationship with the lost partner, is established as the group deepens in trust. The deeply endured absence is expressed fully. Photos, music, letters, writing and drawings are shared. Tears and sorrow, anger and laughter often coexist in small enactments. When a relationship is not within the cultural conserve, the significant person is often invisible. A partner may die during the formation of a new relationship before the new meanings are woven into the continuity of a full life. Grief is thus voiced by disenfranchised ex-partners, or new partners not yet acknowledged.

We explore the changed roles and the missing roles when a partner dies. The reality of powerlessness, not knowing how to be and what to do in new circumstances, is

expressed. Reconnection with the past and the present occurs and tentative future plans emerge. The consistent movement from loneliness to affinity continues as new friendships are forged in the commonality of the experience of group participants.

TABLE 3: *ROLES EXPRESSED IN THE BEREAVED PATRNERS' GROUP*

Absence of Spontaneity				*Full Spontaneity*
Fragmenting Roles	**Coping Roles**			**Progressive Roles**
	best can do under stress			
distraught despairer	quiet withdrawer	angry venter	agreeable pleaser	expressive griever
bitter rejecter	ruminating brooder	fierce criticiser	passive obeyer	acknowledger of strength
disconsolate isolate	wisecracking distracter	sarcastic critic		laughing comic
invisible griever				warm relater
exhausted sufferer				enjoyer of friendship
				loving narrator
				courageous continuer of life
Isolation				*Affinity*
Powerlessness				*Power*
Disruption and Chaos				*Continuity*

Conclusion

Health professionals working in palliative care teams benefit from reflective practice and a systemic approach. When they listen to multiple meanings and consider the many dimensions of family narratives, they will assist families to experience belonging and connection, power of choice and continuity through life and death. Meanwhile, Moreno's techniques of doubling, mirroring and role reversal assist everyone in a system. The use of genograms and ecomaps is a culturally acceptable warm up to enactment, which then further expands the experience of self and the understanding of others within family systems. The three continua, affinity-isolation, power-powerlessness and continuity-disruption illuminate the dynamic movement within families in the midst of living and dying. Together with role analysis, this is a useful framework to think about, and bring about, enabling solutions.

Epilogue

There is a universal story related by David Kuhl (2006) in his book, *What Dying People Want*.

> *An elder approaches death and draws extended family around.*
> *"I have a small stick for each of you. Take it and break it".*
> *Each person in this large extended family takes a stick and some, with great difficulty, break their sticks. Finally each stick is broken.*
> *"This is how it is when a soul is alone and without anyone. They can be easily broken".*
> *The elder then gives each person another stick.*
> *"This is how I would like you to live after I pass. Tie your sticks together in bundles of twos and threes".*
> *The elder waits quietly as the extended family and friends tie the sticks together. There are many bundles, some of two sticks, some of three sticks.*
> *The elder instructs "Now break these bundles in half".*
> *No one can break the sticks where there are two or more in the bundle. The elder smiles.*
> *"We are strong when we stand with another soul".*

I acknowledge and thank all of the families, staff and volunteers with whom I work, and Virginia Lee, social worker, who co-led the groups for bereaved partners with me.

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