

Amaranth Foundation

“Your Mind does Matter”



Research Project:

Your Mind Does Matter

Whyte, J. (2011)
Department of Health and Ageing ,Local Palliative Care Grants, Program Round 5
Final Report, April 2011

This project was implemented across rural communities in southern NSW over 2009 to 2011. Its purpose was to develop a “Social Work Palliative Care Case Management” approach for the delivery of a “PallCare Packaged” model of care, and to pilot the integration of mental illness into ‘palliative care’ care planning and case management interventions for people with life limiting or terminal illnesses across selected rural communities.

Strategies utilised to achieve this objective:

- Developing a social work palliative care case management model that works with rural communities addressing the complex needs of people with terminal illness and those with a mental illness, either pre existing or developed as a result of the diagnosis and prognosis;
- Developing eight rural outreach social work led primary health care clinics for people with a terminal illness, their families and caregivers;
- Encouraging utilisation of appropriate Chronic Disease and Mental Health Medicare items for bulk billing and involvement of other primary health care professionals in Team Care Arrangements and Multidisciplinary Case Conferencing;
- Developing a Rural Primary Health Palliative Care Resource and Information Guide based on best practice models;
- Researching the needs of people with terminal illness and those experiencing mental illness and psychological distress;
- Delivering appropriate education and training for primary health care clinicians and service providers in mental health issues

- for people with terminal illness, their families and care givers; and
- Utilising an asset based community development approach to plan, develop and coordinate community engagement and education events and training.

Outcomes:

- A social work led primary health care model of psychosocial and supportive care as well as screening and assessment for MI and psychological distress was trialled for over 100 patients.
- An additional 250 family members and care givers were assisted over the 12 month period.
- Outreach clinics from Corowa were established in Leeton, Griffith, Coolamon, Cootamundra, Tumut and weekly Mental Health clinics held in Henty and new clinics are being established in Howlong, Albury, Culcairn, Chiltern (Vic), Wangaratta (Vic) and Beechworth (Vic).
- Screening and Assessment tools were implemented and evaluated.
- Discussions commenced with National bodies regarding Practice Standards for social workers in EOL and PC. Small research project commenced with involvement with OSWA and AASW.
- A “Rural Primary Health PC and MI Resource and Information Guide” based on best practice models was developed.
- Excellent relationships and partnerships with many aged care facilities offering ACP, EOL supportive care, counselling and bereavement support for their clients, their families and care givers were developed and will continue.

Unexpected outcomes:

- Reaching double the number of patients and family members that we set out to

Mental illness in the terminally ill is under diagnosed and undertreated.

Whyte, J

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“Your Mind Does Matter” cont.

support.

- Developing a partnership with the NSW Ambulance Service in a P1 Protocol Care Plan pathway for rural Palliative patients and extending the NSW Ambulance Palliative Paediatric Protocol into the rural communities of Leeton, Griffith and Narrandera.
- Integration of Respecting Patient Choices ACP protocols into the SW suite of options provided for patients, their families and care givers and training of all Amaranth staff as facilitators in ACP.
- Working with Rural Adult Mental Health Teams in supporting their team and clients with suicide ideation and desire for hastened death with people with terminal illnesses and their caregivers.
- Partnerships with Rural Support Workers from Centrelink and Department of Primary Industries in drought affected communities identifying people at risk who are caring for or who have life limiting illness.
- The development of “Compassionate Conversations” that are part of the psychological and supportive care that the Amaranth SW model provides.
- Inclusion of Dignity therapy, Hope and Meaning discussions, Advance Care Planning, Mindfulness and Acceptance and Commitment therapy into the suite of psychological supportive care offered to all patients and their families.
- Support by the AASW for the development of National Competency Standards for End of Life and Palliative Care.
- The development of a Communities of Interest group which was responsible for the organising an Amaranth-led community health expo around ‘Planning for a Positive Future’.

Evaluations were conducted by the Social Worker, Community Development Worker, SW students and CEO, using a variety of qualitative and quantitative methods. Surveys and semi-structured interviews were conducted throughout the life of the project at regular intervals and after information and education sessions. Semi-structured interviews were conducted with consenting families to elicit the effect and impact that Amaranth’s services had on their family and their experience of living with or caring for a person with an advanced disease. Interviews with health professionals and service providers helped to gather information regarding their perceived impact that Amaranth had on a family compared to how a family seemed to be coping prior to Amaranth engagement.

Qualitative, informal, semi structured interviews with bereaved carers and family members has identified that programs like this should be continued, and they have commented that their distress had been greatly reduced, and their coping in the bereavement period enhanced due to having access to the professional support that the social workers provided.

Patients reported that they benefited from :

- Having someone to coordinate their care
- research project commenced with involvement with OSWA and AASW.
- A “Rural Primary Health PC and MI Resource and Information Guide” based on best practice models was developed.
- Excellent relationships and partnerships with many aged care facilities offering ACP, EOL supportive care, counselling and bereavement support for their clients, their families and care givers were developed and will continue.

FINDINGS:

- Enormous gaps exist in the provision of appropriate, timely and evidence based psychosocial interventions for people with life limiting illness, their families and caregivers across all rural communities
- People with mental health issues or those with psychological distress felt that these issues were not adequately addressed by existing services
- Primary health care professionals stated that they felt unskilled when working with people with terminal illnesses, or with grief, loss and bereavement, and that symptom management was paramount or took precedence in palliative care
- Lack of understanding of the psychological and psychiatric needs of people with terminal illnesses, their families and care givers.
- Lack of knowledge and awareness of appropriate screening and assessments tools to identify psychological distress for people with terminal illnesses, their families and care givers
- Lack of care planning and referral pathways for people requesting hastened death or requesting euthanasia.
- Referrals for psychological support occurred late in the disease trajectory and were then acute or crisis driven
- Advance care planning conversations and recording of statement of wishes was poorly done across all communities. NFR orders were only discussed at end of life and only relevant for each admission.
- Values and issues related to dignity, finding hope and meaning were seldom well addressed.
- Paucity of literature regarding primary health care psychosocial or psychological interventions for people with mental health issues and co existing terminal diseases or conditions.

Persons present with medical comorbidity and dual diagnosis; in reality the person is a whole being coping with both a physical diagnosis as well as a psychological impact. A traditional mental health response cannot be used for this cohort (palliative and end of life), neither the patient or the caregivers, as the problem won’t go away.

The language of the mental health response is often not appropriate.

Julianne Whyte

A Social Work response to end of life

Whilst mental illness does not threaten life or decrease life expectancy of itself, it can have a severe impact on a person's health and wellbeing. Many people carry mental illness into their final years of life.

Having a terminal illness and a coexisting mental illness is a very complex situation and requires a specialised knowledge and skill base, both in the diagnosis and treatment of mental illness and in end of life and palliative care. Applying a generic mental health response and strategy to this population group will not attend to their overarching and immediate issues relating to their terminal or life threatening illness.

Mental illness in the terminally ill is under diagnosed and undertreated. People generally underreport their distress and there is an expectation by health care professionals and the community at large that dying people will and should experience depression, anxiety and sadness.

Whilst existential and psychological care are considered crucial to the provision of quality end of life care, people continually report that theirs, their families and care givers needs in this domain are not addressed.

There have been many advances in end of life and palliative care, with medical and nursing clinical specialities making great improvements in patient care and symptom management. The training and skill base of mental health clinicians and other allied health professionals have not kept up with this change.

Research has shown that GP's and other medical and nursing clinicians face significant challenges in discussing death with their patients and families, exploring the patients emotional responses to terminal illness and also specific outcomes for the patient and family. This has been shown repeatedly in research conducted by the psycho-oncology group and medical practitioners themselves.

Some issues identified from the literature in the treatment of people with a mental illness and who have an advanced progressive disease and are terminally ill include:

- The utility of psychotherapy to this population group needs specialised training and may not work quickly enough to be of primary therapeutic value for patients with limited life expectancy
- Clinicians report that they are uncomfortable in prob-

ing too deeply into the psychological experiences of their patients,

- Clinicians score reasonably well in identifying people who do not have depression, but they miss those that are depressed unless they present with particularly obvious signs and symptoms.
- The consequences of failing to treat depression successfully can lead to greater difficulty in managing the patients physical symptoms and helping to resolve social and existential concerns. For many this leads to an earlier admission to an acute or aged care facility.
- Previous research suggests that terminally ill cancer patients who wish to accelerate their death were more likely to report dissatisfaction with emotional support and communication with their health care providers.
- Chocinov et al (2009) stated that many patients have occasional transient periods of distress or demoralisation during their course of their advanced illness. Although they are usually not considered to be experiencing a mental disorder during these periods, some may qualify for a diagnosis of adjustment disorder. Even if not formally diagnosed with a mental illness or disorder, many people with significant distress may value the opportunity to receive supportive care addressing the source of that distress.
- A life threatening illness is clearly a major stressor that may precipitate an episode of depression in individuals who are particularly vulnerable
- The sense that a person is a burden on one's family members is a common experience among the terminally ill and is consistently associated with depression and suicide ideation.
- Screening for depression does not necessarily lead to better outcomes. The issues related to depression and palliative care are complex when patients may not be screened until too late to introduce an optimal intervention.
- It is important to accurately diagnose anxiety disorders because they have the potential not only to cause extreme distress but also to interfere with appropriate medical management.
- Depressed people were particularly at high risk of suicide ideation and are four times more likely to report a high desire for hastened death than those who were not diagnosed with major depression
- Hopelessness is significantly related to suicide ideation and stronger predictor than severity of depression
- Pre existing psychiatric disturbance increases the risk for the desire for hastened death and suicide ideation.

'You matter because you are you,
and you matter to the end of your life.

We will do all we can not only to help you die peacefully,
but also to live until you die.'

Dame Cecily Saunders

“HOW PEOPLE *Live* MATTERS”

... it really does.

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The data regarding mental illness in Australia is equally relevant to the population living with a life limiting illness as with other members of the community. Having a life limiting illness does not preclude the possibility of also having a pre-existing mental illness or one developing as a result of the psychological impact of the diagnosis or prognosis. Many people experience symptoms of Post Traumatic Stress Disorder as a result of a serious complex medical condition.

Delivering the right care at the right time and in the right place is a challenge the health system needs to meet. There is an emerging understanding of the need to improve the experiences of people as they approach the end of life. Ensuring appropriate, timely and acceptable care is provided to all Australians at the end of life is not just the responsibility of the palliative care community, but rather everyone's business.

Patients that are dying are not just dying ; They are also living.
Whether or not they have the opportunity to live this final human experience
To the fullest – each in their own way
Is influenced in great measure by those that take care of them.



Mind the Gap: a professional development course addressing mental health in palliative and end-of-life care

A new paradigm in health care

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Carrot Kraut

INGREDIENTS

- 650g grated organic carrot
- 1 tbsp Changing Habits Seaweed Salt
- 1/2 tsp organic ginger powder or freshly grated ginger
- 1 tsp Changing Habits Dulse Flakes
- 1/4 tsp Cayenne Pepper or more if you want more spice
- 1 1/2 CUPS FILTERED WATER

METHOD

Combine all ingredients in a bowl, spoon into a 1 litre jar and press down tightly to ensure the carrot is under the liquid. If it doesn't quite get under the liquid, add a splash more water. To ensure the carrot stays under the liquid, if

you have a cabbage leaf lying around then fold it up and press down over the top of the kraut, pushing the carrot under the liquid. Store it away for 3 days (shorter time in warmer climates, longer time in cool), popping the lid open every day to ensure it doesn't bubble over.



This wonderful condiment will stimulate your digestive juices, help you break down your food, will provide you with an array of probiotics and aid detoxification
<http://changinghabits.com.au/recipes-1/carrot-kraut>