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"Life within the person comes to the fore":

Pastoral workers' practice wisdom on using arts in palliative care

Short title: Pastoral workers' use of arts in palliative care

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Abstract

Background

Pastoral care (also chaplaincy, spiritual care) assists people to find meaning, personal resources, and

connection with self, others, and/or a higher power. Although essential in palliative care, there

remains limited examination of what pastoral workers do. This study examined how pastoral workers

use and consider the usefulness of art-based modalities.

Methods

Qualitative research was used to examine the practice wisdom (tacit practice knowledge) of pastoral

workers experienced in using visual arts and music in palliative care. Two focus groups were

conducted. Thematic analysis was informed by grounded theory.

Results

Six pastoral workers shared information. Three themes emerged. First, pastoral workers use arts as

"another tool" to extend scope of practice by assisting patients and families to symbolically and more

deeply contemplate what they find "sacred". Second, pastoral workers' art affinities inform their aims,

assessments, and interactions. Third, pastoral workers perceive that art-based modalities can validate,

enlighten, and transform patients and families through enabling them to "multi-sensorially" (through

many senses) feel recognized, accepted, empowered, and/or close to God. Key elements involved in

the work's transformative effects include enabling beauty, ritual, and the sense of "home", being

heard, and legacy creation.

Discussion and Conclusion

Pastoral workers interpret that offering art-based modalities in palliative care can help patients and

families to symbolically deal with painful memories and experiences, creatively engage with that

deemed significant, and/or encounter a sense of transcendence. Training in generalist art-based care

needs to be offered in pastoral education.

Key words: art, music, chaplaincy, pastoral care, spiritual care, palliative care, qualitative research

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Introduction

Spiritual care has remained central to palliative care since the fourth century hospice tradition of welcoming travellers and the sick. Attentiveness to spiritual needs was subsequently integrated into the conceptualization of "total pain" in the modern hospice movement.¹ While religion involves common rituals and beliefs related to the sacred practiced communally or privately,² spirituality relates to how individuals seek and express purpose and meaning, and experience connectedness to the moment, nature, self, and others deemed significant or sacred.³ Spirituality can therefore be experienced through relationships, religion, the environment, and arts.⁴ Spiritual well-being and support offered to patients and families positively affects quality of life, mood,⁵ coping,^{6,7} and family satisfaction.⁸

While all palliative care staff are expected to address generalist spiritual issues, those certified by clinical pastoral education programs provide specialist spiritual care and leadership. Specialist spiritual care is widely known as chaplaincy care but, in many areas including Australia, it is also depicted as pastoral care and provided by pastoral workers. Pastoral workers provide a variety of interventions, some of which are described by the "Pastoral Intervention Codings" developed by the World Health Organisation. These are listed under the headings of pastoral assessment, ministry, counselling and education, and ritual and worship. Pastoral care practice standards determined by peak professional bodies, such as the Association of Professional Chaplains (Illinois) and Spiritual Care Australia, are also available. Nonethless, there remains limited data on additional, contemporary pastoral interventions or tasks undertaken by pastoral workers, such as those using artsbased modalities. It is argued that the lack of a widely accepted taxonomy of pastoral care interventions of potentially hinders pastoral workers' communication with interdisciplinary teams and patients' and families' likelihood of receiving pastoral care.

Ettun and colleagues recommend that spiritual caregivers learn and integrate the arts in their work because creative resources create a language for connecting "the brokenness of the body with the wholeness of the spirit" and replace feelings of meaningless with vitality and healing.²⁰ Though art²¹⁻²⁴ and music^{25,26} therapies are well proven therapeutic modalities traditionally offered by

specialist art and music therapists in cancer and palliative care, pastoral workers have also described offering art-based care to patients living with cancer²⁰ and at the end-of-life.²⁷⁻²⁹ Clay work, painting, and/or drawing were perceived to facilitate patients' therapeutic discussions, social interactions, sense of community,³⁰ re-engagement with non-illness identity, and alleviation of pain, boredom, and grief.³¹ This study examined how pastoral workers use visual and musical art-based modalities, and consider their usefulness in palliative care. It examined pastoral workers' practice wisdom which is the tacit practice knowledge that informs how experienced professionals conceptualize and make decisions within daily work.³² Through reflection, professionals' practice wisdom can be articulated and examined to produce findings meaningful to practice.³³⁻³⁶

Methods

Design

The constructivist paradigm informed this study because it acknowledges that an individual's construction of social experiences is affected by the ideas, norms, knowledge, and culture that they experience.³⁷ A qualitative descriptive design with grounded theory features^{38,39} guided an examination of the practice wisdom of six trained pastoral workers. Analytic techniques associated with grounded theory that were used included inductive, cyclic, and constant comparative data analysis. A complete set of grounded theory techniques were not used as the intention of the study was to offer thematic insight into pastoral workers' use of arts rather than theory generation. The pastoral worker participants in the study were both co-researchers and co-authors because they helped to design and write-up this work, and their wisdom enabled the study findings. This procedure has been followed in other qualitative studies.^{34,35}

Participants

Snowball sampling was used. XX (first author), an experienced qualitative researcher and non-pastoral care trained, invited involvement of two pastoral workers known to use art, YY and ZZ (third and fourth authors). ZZ recommended other pastoral workers who fitted inclusion criteria, that is, trained pastoral workers who currently or previously used arts (visual and music) in palliative care. Consent was implied.

Data Collection and Analysis

Pastoral workers' demographic and work-life information were collected in questionnaires. XX led pastoral workers in two, 2-hour focus groups, guided by a semi-structured framework (Table 1) which was created by XX and offered to the pastoral workers for feedback/comment. No additional suggestions were made. Pastoral workers later verified focus group transcripts and wrote additional reflections which were included as data. One pastoral worker could not attend the second focus group. Focus groups were used because they facilitate exploration of unanticipated issues.⁴⁰

Thematic analysis of data involved a predominantly inductive, cyclic, and comparative analytic process whereby text was coded (labelled), comparable codes were grouped into categories, and comparable categories grouped into themes. Analysis was supported by qualitative data management software.⁴¹ Initial data analysis was conducted by XX. YY and BB (second author) were involved in qualitative inter-rater reliability⁴² whereby XX, YY, and BB discussed and altered the findings until reaching agreement. Findings were additionally member-checked⁴³ by all pastoral worker participant-co-researchers.

(Name of Hospital) ethics committee approved this study and consolidated criteria for reporting qualitative research⁴⁴ were adhered to.

Results

Six pastoral workers [5 female; mean age 52; (SD 9.0)] participated with religious affiliations stated as: Christian (4), Christian/Zen (2), "love" (1) and "not applicable" (1). They currently (5) or previously (1) worked in: inpatient palliative care (5) and general hospital (1) settings in (city location), and averaged 6 years' experience of both using arts and practicing as pastoral workers.

Table 2 illustrates category and thematic development with text examples. Clarification of three emergent themes follow. To preserve anonymity, all pastoral workers are described as female, identified as #1-#6.

Affinities with Art Extend the Scope of Pastoral Care

When affected by life threatening illness, questions often arise which enhance, enliven, or dampen patients' and families' spiritual lives. Pastoral workers in palliative care aim to help patients and families make sense of what is happening and consider what they find meaningful. Those who have

"affinities with art" are "at home" integrating visual, tactile, creative writing, and/or music modalities into their roles (Table 2, A.1). The arts are "another tool": "The actual work itself doesn't feel any different to pastoral care" (#5).

Pastoral workers with art affinities believe art modalities can facilitate engagement and "deepen contemplation" (#6) with what personally matters or is "sacred". Arts extend the scope "visited" by pastoral workers through enabling an invitational and accepting space where people feel a sense of belonging, and have time to "bring up" important material which may not otherwise be acknowledged:

There was a man there who was aged, a gay man who had been a dress designer. ...

We invited him to do the display for our Easter service. Little be-knowns to us that he had always felt religious and wanted to be engaged but he was excluded ... he was gay. So he was able to do broad things with cloths and that for the display. ... We turned around and there he was bawling (crying) his eyes out that his display was in the centre of the Service, ... he was included He was not only being accepted as an outsider but as a central thing. (#1)

While pastoral workers interact with one person, witnessing bystanders may also have profound encounters (Table 2, A.2). Pastoral workers also facilitate worship through placing icons and/or art objects in hospital sacred spaces.

Affinities with Art inform Aims, Assessments, and Interactions

Assessments evolve with shared conversations, as pastoral workers observe and recognise how art could connect with each person's life narrative, and potentially assist them to engage in a "process which acknowledges ... (and) engages the senses; that takes time and that reminds of something else that is larger and beyond this place in time" (3#). #6 detailed how an assessment informed the integration of multiple art modalities.

God had been central ... and I said to her, "So if you had to pick any of those places you went, where did you most feel God's presence?" And she just burst out, "In the mountains"... and we looked at scriptural references of God and mountains ... psalms and ... I said to her, "Would you like to do a meditation around the mountains?" and

she said, "Yes I'd love it" I want(ed) all her senses engaged so I got beautiful colored images of all of the mountains she had visited and blew them up. ... I brought in the gum leaves, had lighted candles. I wrote a meditation based on what she told me, all her words and I wrote a song called Blue Mountain Blessing I could have gone in and just said, "Let's have a prayer about your experience with the mountains" but taking it to that next level and being engaged in creative art with it. ... I just think it enhanced it.

Aims are informed by pastoral and palliative care literature which promote person-centred engagement with what brings purpose, meaning, spiritual wellbeing, relaxation, and reduces existential distress. Many agreed with #4's statement that, "My role there is to make people feel as much at home as they can If it means having music then that's what they should have" (Table 2, B.1). Art-based methods offered reflect pastoral workers artistic ideas and hospital workplace resources (Table 2, B.2). Materials offered by pastoral workers are in Table 3. Pastoral workers agreed that interpretation of people's art-based work should be avoided as it can be intrusive, disrespectful, a misguided projection, and motivate creators' desire to please rather than work intrinsically. They also emphasized the necessity of referring patients or families to appropriate multidisciplinary team members if art involvement elicited emotions or issues beyond their remit.

Nonetheless, pastoral workers may introduce art when feeling unsure about whether it would be helpful. #3 described 40-year-old "Mary", who had and end-stage cancer. Although advised by team members not to visit Mary as she was confused and "not making much sense", #3 approached her anyway:

This woman grabbed me by the arm and said, "Thank goodness you're here". She gives me her notebook. ... (saying) "I need you to take some notes because I keep forgetting things" And on she went ... I'd use different colored pencils ... but not really understanding what I was doing I stopped taking notes for a while and I started drawing her socks ... letting her see that I was drawing them and after a while she stopped and she said, "You're drawing my socks". "That's right", and ... we,

were, stopped about talking about what was not in the room. She was talking about what is in the room (that is, she was less confused).

On approaching Mary's family after she died, #3 said:

I didn't know what to say ... (sister) had her head on the dead woman's stomach and she was weeping and she looked at me and I said, "Sometimes in these situations art helps", and I felt stupid saying it. ... (The family) nodded and said, "OK let's do that."

Pastoral Care Art-based Interactions Validate, Enlighten, and Transform Awareness

Pastoral workers perceived that art engagement can allow patients and families to physically and

"multi-sensorially" (i.e., through many senses) feel recognized, witnessed, accepted, empowered,
creative, grateful, lightened, closer to God, and healed. Four art-based pastoral care interactions
underpin how patients' and families' lives are creatively validated and/or transformed through this
work:

Enabling beauty. Patients' and families' trusting, supportive relationships with pastoral workers developed as beautiful works were created. One patient with dementia and end-stage cancer selected beach scene pictures for a collage, created with #2. His sisters liked it, requested a copy, and then asked for an introductory meeting with #2, where they discussed care-related concerns unknown to the interdisciplinary team (Table 2, C.1.1).

Bringing home. Through eliciting a sense of being at home where one is living, pastoral workers art-based interactions can bring patients' "identities back": "Illness is less the focus, and life within the person comes to the fore" (#3). Patients often want their names on displayed artworks, reflecting a desire for recognition. Similarly, through art families can acknowledge each other's experiences, as when various members of Mary's family created art for six hours after she died (Table 2, C.1.2).

Listening and legacy. Pastoral workers wait and "listen" non-judgementally at levels beyond what is verbally said, to "recognise what makes (people) tick and what ...you might offer for it" (1). This included a hesitant, anxious Muslim man who feared hell but "lightened" while gradually describing previously experienced war atrocities when creating art legacies (Table C.1.3). Art-based

legacies were described as often humble but precious gifts through which people "poured out themselves" (#1).

Ritual. Pastoral workers asserted that rituals engage the senses, remind of something existing beyond the present, and connect people with inner worlds, significant others, and shared human experiences. Pastoral workers can facilitate art-based rituals which help patients to feel "alongside their God, or whatever they praise" (#1) or find sacred. Ritual can also enlighten and transform awareness: "If something perhaps isn't processed or dealt with …, we can re-enter that state through symbol … and move through into a different state of being" (#5) (Table 2, C1.4).

Evaluation of pastoral workers work efficacy is informed by observations, and family, staff, and patient feedback, including a note left by Mary to #3 before she died stating, "This (art-based work) has helped with the medicos [doctors]. Thanks so much for everything. Thumbs up" (#3). Feedback also indicated how pastoral workers positively affected ward "vibes" and professional carers (Table 2, C.2).

Discussion

This study illustrates how integrating the arts can significantly extend the scope of pastoral/spiritual care for patients with advanced illnesses and their families by helping them to multi-sensorially connect with who and what matters in their lives. Art involvement elicited pride, confidence, and brought patients' non-illness identities "to the fore" as they connected with their: life-stories through elicited memories; families and friends through legacy creation (that is, left them mementos); or artistic representations of their God. The arts allow people to bypass linear ways of thinking⁴⁵ and access and symbolize aspects of one's personhood that may otherwise be unrecognized and unarticulated.⁴⁵⁻⁴⁷

Pastoral workers interventions can vicariously support patients' families observing patients' artworks, highlighted when two sisters informed a pastoral workers about caregiving fears after requesting a copy of the patient's collage. One third of informal caregivers of terminally ill patients report moderate-severe pre-loss grief, depressive symptoms, and burden scores, and improved provision of support is recommended for this group.⁴⁸ This can evidently include pastoral workers.

Furthermore, given that positive memories of patients' end-of-life care assist family members grappling with bereavement⁴⁹ pastoral workers can also provide valuable pre-loss care for families.

Palliative care staff can experience psychological distress and burnout because of multiple emotional demands involved in caring for dying patients and their families.⁵⁰ In our study, pastoral workers reported incidental well-being effects on staff observing their work, which concurs with effects on oncology staff witnessing music therapy.⁵¹ Future research on staff support interventions should include examination of vicarious benefits potentially gained from observing patient/families' involvement in therapeutic programs.

Work of pastoral workers, art and music therapists overlap, as all involve the use of creative modalities in therapeutic relationships to deal with illness ramifications, and emphasize exploration of feelings and thoughts rather than "quality" of artistic output.⁵² Offering art modalities is based on the principle that words are limited in conveying complex inner worlds, whereas creative activities can offer respite from hardship and direction.^{20,52} Artworks and art-making "show themselves" to the observers and creators, teaching about something that may not already be known.⁵³ Nonetheless, while pastoral workers are specialist, trained spiritual care providers, they only provide *generalist* art-based care, offering art within a suite a interventions/activities, aimed to help people feel "at home" and connected with what they deem significant and life-affirming. Alternatively, *specialist* (expert) art and music therapists respectively focus on art and music-based interventions throughout their work.^{21,54}

Stories by described pastoral workers with patients in this study (including Table 2) affirm how creative arts involvement offers less verbally skilled, literate, or confident people an avenue for expressing fears and concerns more comfortably.⁴⁷ The arts can give symbolic form to the "unthinkable", increase tolerance of the "actual",⁵⁵ and affirm one's sense of feeling heard and known.^{54,56} "Art heals by accepting the pain and doing something with it",⁵⁷ and addressing total pain is central to hospice care. Conversation with pastoral workers may ensue, for example, when the Muslim man's spoke about his fear of hell while making art legacies, or it may remain unspoken with

transformation possibly evident at a non-discursive level, for example, when the man cried watching his artistic display at the Easter service.

In this study, pastoral workers described how music, art materials, and private and communal artistic spaces supported and transformed patients and families through enabling them to encounter beauty and a sense of home, and rendered them capable of legacy leaving and participation in ritual. These enabling and capacity building foci could provide a foundation for characterising the purpose of art modalities used by pastoral workers. They are integral to palliative/hospice care as the aesthetic provides a resource that assists with dealing with suffering, ⁵³ and the hospitality of palliative care provides a reponse to indivuals' pain, confusion, and appeal for understanding. ⁵⁸ Creation of legacy enables the expression of core values, exploration of one's meaning, and forms a bridge between existence and nonexistence. ⁵⁹ Rituals allow shared expression of values, emotions, and identity, ⁶⁰ which help people to feel included, safe and, potentially, that they "matter to the last moment of ... life". ⁶¹ Further, engaging the imagination using art within ritual provides a level of sensory engagement that is capable of sustaining people in the liminal space between what has passed and what is still to come. The process offers time, resources, and opportunities for people to acknowledge and adapt to changing life experiences, and to consider what remains possible. ⁶²

Limitations and Future Directions

While this is likely the first study examining pastoral workers' perspectives about art usage in palliative care, findings only reflect experiences of pastoral workers from one city who discussed their use of visual arts and music modalities. Further examination of pastoral workers working elsewhere and using other art modalities would extend understanding of pastoral workers' potential contribution to palliative care. Research on patients' and families' experiences of involvement with pastoral workers and effects of patients' legacy making on themselves and bereaved recipients is also recommended. While no adverse experiences of art involvement with pastoral workers were reported in this this study, potential unintended effects of this work also warrant further consideration.

Conclusion

In this study, pastoral workers illuminated transformative ways in which art-based modalities enabled patients with advanced illness and their families to symbolically deal with painful memories and experiences, creatively engage with that deemed important, and/or encounter a sense of transcendence. Pastoral care educators should consider developing appropriate training for students who seek to engage the arts, and locating the arts within pastoral care intervention codings to improve ways that pastoral workers communicate about their work. Further examination of pastoral workers interactions will enable deeper appreciation of how art enables the possibility a life being lived, heard, valued, and healed until its mortal completion.

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Table 1. Semi-structured Focus Group Question Protocol

What is an art-based modality/ intervention/ or way of caring in pastoral care?

How would you define the use of arts in pastoral care?

How did you come to offer arts in pastoral care?

When and to whom do you offer arts in pastoral care?

 $Each\ participant\ describes \geq 1\ case\ study\ where\ the\ arts\ helped\ a\ palliative\ care\ patient\ and/or\ their$

family. Participants offer further thoughts about the case study.

How do you make decisions about the focus/direction of a session when in progress?

When is pastoral care creative arts contraindicated in palliative care?

How do you: (a) communicate about your work with staff/colleagues, and (b) experience their reactions

to you and your work?

What recommendations do you have for others considering art-based pastoral care?

What recommendations do you have for the World Health Organisation Pastoral Intervention Codings?

Table 2. Themes (Bold) and their Categories (Italics) and Subcategories (Indented) Reflecting Perspectives of Pastoral Workers who Use Art-Based Modalities in Palliative Care Work, with Illustrative Quotes

Themes, categories

Illustrative Quotes

& subcategories_

Theme A. Affinities with Art Extend the Scope of Pastoral Care

A.1. Art-based

I'm not just going to be using this art because it might be good for the patient. I have to feel very comfortable doing it myself and opportunities to creatively its part of me. It's part of my persona. (#6)

engage with what matters

A.2. Art extends the scope

If you've got four people in a ward together and ... you've gone in there to work with one person ... it's unlikely that other people

"visited" by pastoral

are just going to interrupt and chip in, but if you're in there and you've got (art) materials on the beside and you're starting to

grow something or make something it's far more likely that other people will speak about that or comment or get involved with it.

...Some of the most profound encounters that I've had with art weren't with the person who the thing started with. (#3)

Theme B. Affinities with Art Inform Aims, Assessments, and Interactions

B.1. Integrating art into

I think the overarching aim if I think of going and being in the pastoral care space is to be hospitable and for people to feel relaxed and safe and at home (#5).

assessments

B.2. Art-based methods of engaging and working with people

(Working with person with an acquired brain injury and a brain tumour) ... he doesn't communicate very well and I offered art and he was like, "Yeh love to do that", and he really, really engaged with art like we made a collage and he was, he really carefully, cut round the pictures and arranged them really beautifully but then when I tried to engage him on, "Why did you choose these pictures?" He just shrugged and ... (today) we did like a scribble pattern ... he drew a bird and he, he got really excited and, and I did one too and we were coloring in and he started telling me that he had a birthday last week and went to a Vietnamese restaurant ... I was thinking there's a lot more going on than what was first apparent (#2)

Theme C. Pastoral Care Creative Arts Interactions Validate, Enlighten, and Transform

C1. Interactions

underlying pastoral work

with arts: beauty,

bringing home, listening

and legacy, and ritual

responding to
experiences of what

C.1.1. Enabling and

is meaningful and beautiful

[Gadamer⁶³] suggested that one of the functions of the beautiful is that it creates a bridge between the ideal and the real and so it enables us to find a place of belonging within a real that is less than ideal. I wonder if ... art creates a bridge between what would be ideal in life which is to not be in this place and what's real, and that, somehow, having that bridge enables him (patient who created beach collage with #2) to function without being in one or the other place. (#3)

C.1.2. Eliciting a
sense of home to
bring identity and
people back together

So I brought the materials in and that was about half-past-10 in the morning and that family came and went throughout the day with this (deceased) woman (Mary) in the bed till about half-past-four art held that family for that day and it kind of gave her one more day in a life that was cut short The capacity of the group to do this for one another and together I think was ultimately healing for them. ... They just painted what they thought was needed to be on the plate with brushes and somebody started by putting her name across the middle of it ... the family came back later ... (and said), "thank you so much". (#3) He just watched (others' art activities). A few days. He didn't participate but he really enjoyed the social aspect. ... on the third or

C.1.3. Waiting and listening deeply to enable a coherent life narrative; and legacy

fourth day I encouraged him to just color in a mandala ... Then on I'd show up to work at 9:00 or 9:30 (am). He'd be sitting in the art room, waiting He did all these legacy pieces (for family) ... and they all had a story. They were all about his home the trauma, the atrocities. Near the end ... we started to explore his religion and his spirituality. He had so much guilt. ... I said, "What is it exactly that you're so scared of?" because he was terrified of dying and he said, "I'm scared of hell," and showed me the part in the Koran about hell. ... He hadn't been a perfectly practicing Muslim. ... He said, "My body will just keep reforming and will keep burning over and over", ... I just reflected back what he was saying and he just burst out laughing ... and I had never seen him laugh before. In the three months that I had known him I had known this very closed person who, with art every day, had started to come more and more out of his shell ... It was really transforming for him and he felt a real sense of belonging in that arts space. ... He didn't ever get rid of that guilt ... (but) he lightened. (#5)

C.1.4. Enabling engagement with

(Describing a bereavement program session). They write what has been the hardest part of the whole journey of losing their loved one ... (and) read that out, ... (are) witnessed in that, and then I ask them to draw ... anything that kind of gets that emotion onto a

ritual and symbolism,
inspiring validation,
new awareness,
and/or transcendence

page, ... and then I ask them: "What it would-be like to not be holding that anymore?" and, "What is it that they would like to hope for themselves?" ... (then) They do other pictures that are more positive, you know, more full of peace and hope and life and love, and then they articulate those things to the group, and then they plant those intentions for themselves using rosemary into a pot. ... They kind of do a ritual in terms of what they want to do with their first picture, whether it be folded up and, you know, keep it with them, or tear it up. Some, some have stomped all over it, thrown it in the bin. ..., and the second, they all say, ... "I'm going to put it on my fridge just to remind myself of what I want". So nothing really changes. The grief is still there but somehow their relationship to it changes a little bit. (#5)

C.2. Pastoral workers'
evaluation of their work's
efficacy reflects feedback
and observed changes

A minister ... called in to see a parishioner who was dying at 2 o'clock in the morning and she said to me, "I was really scared to go in there in the middle of the night and I didn't know how I was going to cope with this personally, but I had to be there and then I saw the art and I knew that you had been there and I felt safe and it was ok. (#3)

Table 3. Art-based Materials offered by Palliative Care Creative Arts Practitioners (singularly or combined) in Palliative Care

- A public art room, with paints, crayons, pencils, paper
- Greenware (pottery), glazes and kiln for ceramic program
- Magazines, glue, paper, scissor, for collage work
- Pencils and paper for "scribbling" whereby patient or family and therapist each close eyes and scribble and then describe shapes found in it
- Therapist writing poetry or songs, inspired by what patient shares
- Bringing in pictures for viewing, inspired by what patient shares
- Familiar song singing alongside patients' related memories
- CD library and players to loan