Papers and Reports

Restoring creativity to the dying patient

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The hospices have largely directed their attention towards maintaining excellence in nursing care and control of symptoms, providing counselling and spiritual support, setting up and running home care services, providing bereavement support, and caring for the carers. Much less attention has been paid (by the medical profession) to the question of what should be done with the patient when he is symptom free, or nearly so, and expertly nursed in the appropriate environment. How do we put flesh on the phrase "living to the end" for those who for reasons of temperament, lethargy induced by disease, or emotional preoccupation cannot rise above their circumstances?

Bringing art to hospices

Some hospice units employ occupational therapists, who work in various ways to help patients to occupy their time and keep their faculties alert. Entertainment is arranged, usually of a high standard, through individual contacts and through the auspices of bodies like the Council for Music in Hospitals. Sharing favourite melodies and old time songs aids reminiscence and reflection, helping to tie life together in all its years of diversity.

Music therapy has begun to find a place too, and a wide variety of techniques demanding a good deal of ingenuity and improvisation have been studied in one unit.^{1,2}

In the state of Connecticut, United States of America, the approach is more comprehensive. The public health code (1980) states that "The hospice shall provide extensive opportunities for experiences in arts to patient and family. . . . The arts shall be available to hospice patients both on a scheduled and intermittent basis. . . . The artistic experiences shall be directed and coordinated by a qualified representative of the arts with a graduate degree and clinical experience in a hospital based setting in the arts or pastoral care. . . . The director of the arts shall be considered a fully fledged member of the health care team. . . ." In view of this it is not surprising to find in the philosophy statement of the Connecticut Hospice, Branford, that the "Hospice affirms life and focuses on the quality of life. To this end Hospice embraces and views the arts as an important and essential component of care. Hospice believes that the arts can enhance and enrich the personal living and working environments of patients, families and caregivers."

In Britain the inclusion of arts in hospitals is beginning to draw attention from health professionals and administrators. The Manchester hospitals arts project has set a high standard that is being carefully watched, and a study by one of their research psychologists on "the healing role of the arts" is soon to be published (Linda Moss, personal communication).

Maintaining a feeling of self worth

At St Joseph's Hospice we have begun to experiment with an approach to the creative use of the arts not unlike that established in Connecticut. Carers tend to have a preoccupation with treatment of one sort or another, things done to the patient or for the patient for his benefit. Terminally ill patients already have to have so much done for them that often they have lost all sense of purpose and worth. Our aim is to help them whenever possible to restore their own inherent self esteem, getting them working creatively in whatever ways are appropriate to them. As most of us have experienced in ourselves and in others, having a sense of purpose and a feeling of self worth is in itself therapeutic, leading us to venture further in developing our own potential and expressing our own personality. Perhaps too it frees us to look more positively at deeper questions about meaning and purpose in living and dying, questions which become more insistent with the approach of death.

Having the emphasis on the patient "doing" rather than "being done to," however worthily, must therefore break some of the moulds of the sick role and help him to live and die as a whole person, restoring to him his own inherent dignity. It must be said, however, that, as in other medical specialties, the passive invalid persona has its attractions and there are many patients who do not want to keep or to regain responsibility for their own lives. Here we must be careful not to infringe their rights as individuals and attempt to push them into creativity which they do not want. But in many cases a little gentle and imaginative encouragement to an apathetic patient is all that is needed to entice him into an activity that leaves him with an increased sense of wellbeing.

There are, too, those who seem able to continue their naturally active and creative lifestyle almost to the end without any more help than control of symptoms and nursing support. These avid readers, letter writers, needleworkers, artists, and autobiographers are most rewarding to work with. They make such good use of the comfort we can bring them and are, to us, an inspiration.

For the most, time hangs heavy. Skills and opportunities may have been lost, physical disability may make former hobbies inappropriate, or there may never have been any space for recreation in their lives not occupied by the ever present television.

An added complication is that the inertia of the patient frequently means that it is difficult to get him to leave his bedside, and there are, of course, some patients who are totally bedfast. At St Joseph's we have a well equipped and happy day centre, but few of the terminally ill patients will go there. In any one day usually not more than one in eight will visit the day centre, and it is usually the same ones who go down each day. It therefore seems necessary to bring activity to the patient in an attractive and not too demanding way rather than wait for him to make the move.

A poet at the bedside

From the beginning of 1985 we have had a poetry graduate working at St Joseph's Hospice, at first in a voluntary capacity and then funded by a grant from the Sir Halley Stewart Trust. She had

become interested in death as a subject for poetry, and thence for her BA (Hons), for philosophical reasons related to its being an experience "outside" life and hence a non-verbal reality.

The involvement in death and dying in the hospice has transformed an academic interest into a valuable tool for the patients' benefit. During the four days a week that she spends here she is inevitably drawn into wider areas of patient support such as reading to those who wish it and finding taped books and music appropriate to a wide variety of tastes. Some patients are referred to her by the medical or nursing staff, either because they feel the patient has a natural aptitude for "that sort of thing" or because there are perceived to be underlying problems and conflicts which the patient is not resolving successfully. Others are, in effect, self referred—patients who show an interest in what she is doing with others nearby in the ward.

Because the focus is not solely on poetry the pressure to begin to write is minimised, but a surprising number of patients are willing to make the attempt. As an art form poetry has a number of advantages for its use in a hospice setting. It is not messy; it can be very short; and most patients have not tackled it before, so have no previous experience with which to compare their current efforts. It is also possible to "write" poetry by dictation if the hand cannot hold a pencil. In fact some of our best poetry has been written this way. Once patients have discovered that poetry does not have to rhyme and that thoughts set down on paper and then typed up and put in short lines under each other often scan fairly well, then they have a vehicle for the thoughts and emotions they are experiencing.

In fact poetry seems to be a vehicle for conveying significant impact in relatively few words. One reacts, not just to what is written but to what seems to hover around it unwritten. Though a professional poet can express in very fine verse what it must be like to die, the inexpert poem of the dying person may end up speaking more clearly to the heart.

Afraid

I am afraid of death;
death rather than dying;
fear of the unknown.

Nothing is worse than death.

Life is terribly important.
ANY sort of life—
just being alive. . . .

Life is important even if
the importance of life
is sometimes hidden. . . .

Life is important because
I am afraid of death.

One of the most important things about poems is that they teach us about dying and disability, and this is often the most helpful aspect to explain to a patient who may be thinking of trying his hand. To feel that his own experience might help health professionals and clergy to work more effectively and sensitively with other patients is a tremendous motivating force. The effectiveness of this was demonstrated to me by the poem "I can't talk" written by a man who had suffered an almost totally disabling meningoencephalitis. I cannot now walk past him or any other aphasic patient without being reminded of the importance of verbal communication and acting accordingly.

I can't talk

I can't talk
but that does not mean
my thinking process
is a "has been."

When we meet
please don't be afraid
it's just that my brain
had a raid,
from a virus
that left parts dead:
legs, arms;
and my speech asleep.

When we first meet
be not withdrawn
Please speak,
don't let your thoughts be torn
by my limitations
though tough it may be
to ignore my silence
when first you see me.

I can't talk
but you can.

Sometimes we can express in words things we find hard to say. In this way poems have had a part in journeys of reconciliation—such important events when approaching death threatens to leave open forever, for the bereaved, wounds from the past. Then too it can be a way of saying goodbye and so leaving a legacy more precious than a photograph because it so fully expresses the personality of the patient. Having a third party such as our poet to work with and to show such a poem to opens up many opportunities to talk through the pains and joys, frustrations, and disappointments of life.

We have found too that it can be a way of off loading frustrations about disability or about problems with care which can sometimes be corrected or at least talked about. As one articulate lady said, "I had that poem inside me for ages. I couldn't get it out until I got my electric typewriter. I couldn't have dictated it to *anyone*, it was too personal. When I could at last type it out I actually felt a burden roll off me. There was still the pain, but the burden had gone." This was the poem.

Stricken

Turn your face away. Do, hide your face away.
Let's keep the conversation at a purely superficial level,
Using words as walls to keep each other out;
Mouthing repetitious formulas to guard against their meaning.

For if you were a friend . . .
I might pour out my troubles. I might beg for your help.
And be forced to accept your pity and love.
or . . . I'd bottle it up, for fear of upsetting
The two of us—doubly—vicariously laden.

And if you were my God . . .
I'd make an inverted litany of "Damn. Damn. Damn."
And shout and rant and rave inside me;
And cry the eternal question "Why?"
Then guilty with my misery, feel doubly-laden
By my unacceptance of reply. . . . "I
am all that you have in the land of the living."
Forgive me—It should be—But—it's just not enough.
. . . I would pray, when I know the answer is "No."
. . . Then . . . plead for acceptance and patience and trust.
so, turn your face away—And wait,
Please.

Conflicts about dying can be worked at—often in symbolic language—when direct discussion would be too painful. Then too poetry can be a vehicle for expressing spiritual conflicts or alternatively statements of faith and praise to God when life is drawing to a close and issues of the hereafter loom larger for many. The value for relatives is also great, as shown by remarks such as: "Even after he's gone I'll still have his poems, won't I?" One wife

said of a love poem from her husband, "He never says it, but at least if he writes it down he must think it—a bit."

At the time of writing over 100 poems have been produced by about 20 patients. Though we have not yet had many relatives writing poetry as they watch the patient's slow demise, the poems written to his dying mother by Dr Balfour Mount, physician in palliative care at the Royal Victoria Hospital, Montreal,³ reveal the depth of the heart searching and medical and spiritual conflicts of even a skilled physician in this specialty as he puts on paper things too difficult to express in any other way. Out of grief has come a beautiful gift not only to his mother and his family but to all who work in care of the dying and to the world at large.

Other types of art

Having found so much of value with poetry we are now beginning to work with other art forms, again taking the art to the patient at the bedside if necessary, using a skilled artist and one to one contact. Poetry will of course continue as one of the art forms, our poet continuing with her academic interest concurrently by writing for an MA on poetry from within a hospice.

As funds permit we hope to add artists working with graphic arts and with fabrics, with music, and with flower arranging. We are also beginning to use PAT dogs with patients, relationships with animals being an area where affection can be given and received without complication or obligation. It will be interesting to observe in the course of time the particular place of each type of activity with the patient.

We are also beginning to engage our patients more actively in musical entertainments. Students on a "music communication" section of their course at the Guildhall School of Music visit to play to the patients. Now there are plans for them to write music to one or two of the patients' poems in conjunction with the patients and then perform them either as songs or as poetry read to music for the benefit of all the patients. Not only will this give a boost to the patient, but our previous experience has shown the considerable impact on the students of such contact with some of the painful

realities of life when they attempt to relate their musical skills to them. Similar developments in "Invitation to the Ballet"—an award winning project by the Royal Ballet to take dancers into hospices and hospitals—are being planned at present.

Restoring creativity through art with the help and encouragement of experts is already showing signs of influencing the course of the illness in some patients. For some years there has been an independent "quality of life" study going on at the hospice. In November 1984, soon after the introduction of broader arts activities, positive comments about these began appearing in response to non-directive questions about the patient's perception of his or her quality of life. One patient, rating hers quite high, remarked that preparing posters for a concert gave her a "pride of achieving by doing." Another said that a musical performance "not only gave me an exquisite feeling, but was also a kind of religious feeling." Other comments included being "able to do something to the end of life" and "doing something positive—I'll sort myself out that way" (Beryl Munns, personal communication).

Clearly the potential for applying this experience beyond the confines of a hospice—in the home and in other long term and debilitating illnesses—is considerable.

Personal growth through suffering is something that can be encouraged and stimulated. There is probably a large reservoir of artistic people within the community who with careful training and supervision would willingly use their gifts on a voluntary part time basis both inside and outside hospices. This training we are beginning to work towards.

I should like to thank Ms Jane Eisenhauer (research associate) for her innovative work with poetry described above and for her contribution to the thinking behind the creative arts programme. Help the Hospices (c/o BMA House) is now actively supporting and encouraging arts projects throughout the country.

References

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- 3 Mount B. *Sighting in the valley of the shadow*. Illinois, USA: Inter Varsity Press, 1983.

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