The role of occupational therapy groups in an Australian hospice

Sky Dawson

Abstract

The hospice philosophy plays an important role in the delivery of health services that focus on the biopsychological needs of people with a terminal illness and their environment. Occupational therapy in hospice can provide an environment which will enable people to discover and respond to their own inner needs. The occupational therapy setting creates an environment which provides people with the opportunity to carry out activities which they are interested in, to socialize with others, and to experience the philosophy of hospice. The purpose of this study was to examine the role of groups with occupational therapy in hospice. A literature search, participant observation, interviews and discussion indicate that music, massage, and beauty treatment are important aspects of care for the dying person.

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Introduction

The role of hospice

The hospice movement developed in Australia as a new and innovative approach to the delivery of care for those with a terminal illness. It was viewed as a movement away from the technological and scientific approach of modern medicine with its goal of cure at all costs. The literature emphasizes that hospice is characterized by:

- Care for the individual rather than treatment of the disease.
- Palliative rather than curative measures.
- Pain management and symptom control as high priorities.
- Equality between the patient and family and the health care professionals.
- Concern for interpersonal, over technical, aspects of medical care.[1-3]

The hospice movement has changed the concept of care for those who are dying of a terminal illness, by supporting the idea of staying at home, and providing support, pain management, and dignity to die peacefully. The emphasis in hospice is to meet the needs of the whole person.

The role of the occupational therapist in hospice care

Occupational therapists are often employed as part of the hospice team working with home care, in the inpatient setting, and/or with clients who attend a day hospice program.[4-6] The occupational therapist in hospice care assists each individual to attain the occupational roles that are perceived by the individual and the caregivers to be important, given the limitations of time and physical ability.

Occupational therapists see clients individually or in groups, in the hospice or in their own homes. In an inpatient setting, the occupational therapy de-

partment is often where many clients spend a large part of their day. The use of groups may be a major focus of occupational therapy. Groups can provide an ideal environment for the therapist to enhance interacting, sharing, caring, remembering, and to decrease feelings of helplessness and isolation.

Little has been written in the literature about the role of occupational therapy groups in hospice. Michael Pizzi addresses the role of occupational therapy groups in hospice with AIDS patients by what he calls, "beginning the conversation."[7] He suggests that occupational therapists focus not on pathology but on positivity, productivity, ability and wellness, "within the value system and on the occupational choices of human beings."[7] To work in this field requires a move away from the traditional medical model. Occupational therapists must be able to assist people to make the major life transition from the occupational roles of living to the role of a person receiving palliative care. The occupational therapy group setting provides an opportunity to create a social support system to assist people to adjust and adapt to the changing roles.

The purpose of this study was to explore the use of groups in occupational therapy in a hospice setting. The goals were:

1) to gain an understanding of the use of occupational therapy groups in hospice,

2) to describe and document different groups observed in an occupational therapy department,

3) to describe and document the value of groups as perceived by the participants,

4) to make recommendations for improving occupational therapy groups in hospice situations.

Groups in hospice

Methodology

Research design

A qualitative study was conducted using an ethnographic approach. Ethnography is defined as a process whereby the researcher attempts to gain a comprehensive understanding of a human group or subculture.[8] Ethnography field methods included participant observation, informal and semi-structured interviews and literature reviews.

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Subjects

The subjects were inpatients and day clients who attended occupational therapy one pay per week at a metropolitan hospice. They were a "convenience sample."[9] Convenience samples consist of participants who are typical of the target populations and who are easily accessible but are not statistically projectable to the entire population being studied. One day-hospice-client was interviewed weekly at one stage of the study for a case study, and consent was formally obtained from him and from the hospice personnel.

Procedure

The ethnographic study of occupational therapy group work was conducted over five months using participant observation, informal and semi-structured interviews and discussion with staff and patients at a hospice in Australia. This is a freestanding hospice with 26 beds. There is one occupational therapist and one occupational therapy assistant, each employed thirty hours per week. At the hospice, there are a variety of groups which are organized by the occupational therapists. The researcher had no input to the program, and simply observed whatever had been organized for that day. Each of the groups usually involved between four and 10 of the hospice participants.

Observations were made of morning groups, using participant observation techniques. Denzin[10] explains the value of participant observation:

> "It simultaneously combines document analysis, interviewing of respondents and informants, direct participation and observation, and introspection."

Informal interviews were conducted with five participants. One participant was interviewed using a semi-structured interview format, and these interviews were transcribed and analyzed.

Data analysis

Observations were briefly recorded. The material was examined for themes or ideas. Content analysis[8] is useful for studying qualitative data because:

- It can be used with unstructured material such as diary notes of participant observations, and semi-structured interviews.
- It is sensitive to the context in which the study occurs. The results of this analysis were checked with findings from the literature.

As the researcher was a participant and not merely an observer, she needed to record her own thoughts and feeling, and note any biases that may have been present. One bias that was important to recognize was that the researcher is an occupational therapist and this may

have influenced her perceptions of the groups. A diary was kept and the researcher recorded thoughts and feelings as well as intuitive ideas that arose from the data. These were discussed with peers and a field work supervisor and incorporated into the final analysis.

Results

Through weekly observations and interviews the researcher developed an understanding of particular groups in occupational therapy by sharing intimately the life and the activities of the people involved. This included the death of some of the participants and the associated grieving. As Patton[11] explains, "the evaluator not only sees what is happening but *feels* what it is like to be part of the program."

Many different groups were observed. Some were unstructured or had a simple activity base that resulted in social sharing. These group situations allowed some communication, choice, and leisure. Others were more structured and were usually organized around a theme or activity. All groups were open and involved whoever felt well enough or motivated enough to attend. This is an important consideration when working in a hospice. Groups included music, beauty treatment, social outings, picnics, massage, exercises, craft activities, and the celebration of popular festivals.

It was noted that by the time many people are admitted to hospice, there may be little that they can actually do or participate in. Music can always be used, and it remains accessible throughout the disease process. The music flows down the corridors so that those patients who cannot go into the occupational therapy department can still share in the music. There were several visiting musicians, and tapes were also played for relaxation, stimulation, communication, and pain relief.

One man who attended the day-hospice had a strong voice and had sung professionally as a youth. At the time of the study, he had only limited vision and was unable to read or participate in many activities. He experienced great joy when he was able to sing his favorite songs and share his love of singing in the groups. He explained that he loves to come to occupational therapy to be part of the groups, "just to be with others who understand what you are going through. You're not treated as a leper as you are in general society."

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Music therapy was observed to be a stimulus for reviving memories and feelings. It was observed that music provides a non-threatening group experience. People would sometimes choose music that reflected the feelings they wanted to get in touch with. Ruth Bright[12] describes how "music from a particular phase of one's life takes one back very vividly to that time, and it can be of great assistance to making a life review." As people recall these times, they remember friendships, happy or painful situations, and feelings surface easily.

Beauty therapy was observed as another example of a group activity. Traditionally it has been seen as a time of relaxation and sharing. Hawks describes how "the loss of an ability to cope with their (the patients) own personal hygiene and grooming is a devastating aspect of terminal illness."[13] As well as the assessment of a patient's competence with self-care, the provision of aids or equipment, and the teaching of techniques to maintain energy and independence, there is the sensitive issue of beauty therapy. "Well-groomed hair, facials, manicure and pedicure, the selection of a wig, massage, encouragement to get dressed every day can be very therapeutic."[13]

The facial cosmetics group was observed to be a highly social aspect of care for the women. All the women interviewed listed the beauty treatments as the most popular aspect of occupational therapy. They stated that having their hair done, their nails manicured and a foot massage were the most wonderfully energizing activities. There are important positive effects from applying eye make-up and eyebrow color that can move attention away from hair loss. Often patients are unable to go out themselves to attend to their beauty needs. The women were able to organize with the occupational therapist to ring the hairdresser and make an appointment for her to come to the hospice. This provided a sense of control over one's life and the ability to fulfill a need that most women take for granted.

A deeper side to the beauty groups is the use of touch. This was often introduced in beauty sessions and then further explored through massage. For many patients there is little physical contact other than with nursing care. Yet, touch and sexuality are important issues for most people regardless of their state of health. In our generally no-touch society, massage may be the only way that people can show intimacy, and give and receive sensual pleasure. The researcher participated in several massage sessions and found the depth of sharing to be enlightening.

While having her feet massaged, one woman began to discuss her illness and her interest in alternative therapies. She explained that some had helped her throughout the course of the illness and some had been beneficial in the early stages. She was still continuing to practice meditation and relaxation through

music. She needed a massage daily, for the contact, for the relaxation, and for the release of tension in particular areas which were very painful.

Another aspect of these groups was the communication that developed. Issues such as hair loss or dry skin can lead to the sharing of fears, feelings, and frustrations regarding the cancer, its treatment and prognosis. These issues appeared to be of great importance particularly for those women who were in hospice for respite care or symptom control.

The main themes that were mentioned by the participants were the need to socialize, the need to be accepted by others, the desire to have some control over their lives and the positive aspects of sharing and remembering. One man, when discussing the occupational therapy groups and day-hospice stated, "I love it, absolutely love it ...you meet people that understand what you are going through and what you are suffering from." It was found that groups can provide an environment for the occupational therapist to enhance interaction, sharing, caring, remembering and, thus, decrease feelings of helplessness and isolation.

Discussion

Through observation and participation in the groups, it became apparent that the occupational therapy group environment reaches out beyond the department. The group is open to those patients who wish to come as well as family and friends and staff. Family, friends, and volunteers are involved in the daily activities which are constantly happening in occupational therapy.

Volunteers play a major role and this reinforces involvement from the community, developing social networks and support systems. The statements that people made when interviewed reinforced the need for empathic caring saying that it was wonderful to come and be with others who understood and who cared. Just to be in the hospice and the occupational therapy department, patients felt safe and secure, without expectations. Each person mentioned a need to socialize and to be in a secure and accepting environment.

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It was only after five months of participation that the researcher was able to appreciate the full meaning of the groups and was beginning to experience them as the participants did. Agar[8] suggests that it takes at least three months for an ethnographic researcher to be accepted by the community. One woman was not clear what the researcher meant when asking her about the groups. To her, occupational therapy was a major part of her day, and so there was no separate, structured group as such. The occupational therapy group was a main part of her waking life.

The study suggests that occupational therapy can provide a safe and supportive group environment which assists people to develop the social support necessary to face their future, and to be able to cope creatively with their pain and apprehension. From observations, it appears that occupational therapy groups can help clients deal with feelings as well as develop practical skills toward maintaining a degree of independence.

Tigges, Sherman, and Sherwin[14] explain that being denied the opportunity to engage in occupational roles deprives a person of the benefit of being a contributing member of society and, thus, creates a sense of isolation and alienation. The major difficulties felt by the person with progressive cancer have been identified by Tigges and Marcil[6] as helplessness, hopelessness, and uselessness. These difficulties result in the loss of quality of life associated with loss of control, loss of choices, and loss of options. The ability to develop a sense of control over one's life, to have choices and options, were observed by the researcher to be of great importance. One man in the group stated that it is important, "to be with people who understand my problem and who treat me as an equal."

Howe & Shwartzberg[15] list several aspects of groups in occupational therapy that emphasize the issues raised in this study:

1) Groups support growth and change.

2) Groups can provide feedback and support.

3) Groups can satisfy individual needs and social demands.

4) Groups need to have a common goal and dynamic interaction between members.

Conclusion

It is realized that the results of this study cannot be generalized to other hospice situations; however, some of the observations may be important for other occupational therapists working in the field. Occupational therapy groups in this setting did provide clients with an opportunity to explore and share options and choices and did help develop a sense of control regarding issues such as participation, abilities, and activities. Thus, clients were able to have the opportunity to reconnect with activities that gave meaning to their lives.

It was evident that occupational therapists working in hospice also need to be able to redefine their goals and objectives and be able to work in the immediate present, without a definite future to plan for. Being denied the chance to engage in occupational roles can deprive a person of the opportunity to be a contributing member of society and can result in feelings of isolation

and alienation. Occupational therapists can address these difficulties, as this study has shown. It appears that the most effective therapist is one who has an understanding of the philosophy of hospice and can creatively develop environments to encourage occupational behaviors and satisfy the occupational needs of the individuals to enhance their quality of life.❑

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