

FORUM

Creativity and Self-Care for Caregivers

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The creative process must be explored not as the product of sickness but as representing the highest degree of emotional health, as the expression of normal people in the act of actualizing themselves. — Rollo May (1)

Paid and volunteer caregiving in a hospice or palliative care setting is rewarding and stressful (2-5). The stress can be attributed to an idealistic philosophy, unmet personal needs, and a lack of emotional preparedness for the reality of the work. The philosophy of the "good death" causes feelings of failure when reality falls short of the ideal (6,7). Hidden agendas and unconscious unmet needs may unduly motivate some workers and influence how they respond to stress (6,8). Most palliative care training for professional caregivers provides clinical and practical skills, but it does not provide adequate preparation for the reality of the emotional demands of this work, nor for methods of self-care (9).

AIDS hospice/palliative care work in North America has some additional and unique issues (10). These are:

- multiple losses
- the relatively young age of most patients
- homophobia
- the stigma attached to the disease
- the complexity and unpredictability of the disease trajectory (2,5,11,12).

Self-care strategies for caregivers are essential to the effective functioning of a hospice (6) and to the longevity of an individual working or volunteering in palliative care (10). Social support groups, personal awareness, and relaxation techniques are among the approaches that decrease caregiver burnout (3,8).

In spite of the acknowledged level of stress and the availability of information about approaches to managing stress, caregivers often neglect their own care (13). They are willing to make the commitment to client care but are less willing to commit to self-care for fear of being viewed as selfish (6). By neglecting their own

needs, they may unwittingly be neglecting their ability to care for their patients (13).

Casey House Hospice had a well structured care for the caregiver program (5,12). Over time it became apparent that, during periods of high stress, paid and volunteer caregivers relied on the management team to "fix things." To counteract this, a workshop was developed that would encourage caregivers to rediscover their own resources through creativity and play. The workshop was designed to facilitate this in a safe and supportive peer atmosphere that would be conducive to risk taking and self-exploration through creativity. Writing, art, and music were chosen as expressive modalities whereby transformation through creative process would be made possible by focusing on the "process" and not the finished "product."

Self-awareness is a critical starting place for self-care. Furthermore, those who understand how they respond to stress, and what mechanisms sustain them and prevent stress overload are the most healthy and effective caregivers (6,14). This was the starting point for the development of *Creativity and Self-Care for Caregivers*.

THE WORKSHOP

Overview

The workshop began at 09:00 and ended at 18:00. Participants met in one large group at the beginning of the day for introductions. At this time, a safe ambiance was established by setting ground rules for playfulness, confidentiality and safety. The group was then divided into three pods. Each pod rotated through all three two-hour modalities during the course of the day, one modality in the morning and two in the afternoon. Each modality session was two hours. At the end of the day, all participants met again in the large group for debriefing, completion of evaluations, and participation in a closing exercise. Self-care was reinforced by the nourishing presence of juice, fruit, and snacks throughout the day.

Journal-Writing Segment

What I can do with words! I just needed to know where to start. — workshop participant

To keep a journal is to write regularly of what is personally significant and meaningful, and to keep this writing private. A journal is often a dumping ground for strong emotions used during a period of great stress. Group journal-writing is an experiential process unlike that in most academic journal-writing classes. In the former, a facilitator guides a group of peers in exploring ways of using personal writing as a stress reducing behavior. A palliative caregiver faces constant stress. If unrelieved, such stress can depress the immune system and make the caregiver more susceptible to illness. Regular journal-writing has been shown to enhance immune function (15).

In these journal-writing workshops, participants were led through a sequence of experiential sensory exercises which elicited immediate responses. They were instructed to write quickly about what they observed. Each exercise used a specific creative writing technique. There was no right or wrong way to write, no need to use correct grammar, spelling or syntax. Writing times were kept short, with little opportunity for the "internal critic" to surface. Simple ground rules established that no criticism would be given by either facilitator or participants, nor was there to be any cross talk. After writing, participants chose whether or not to read out loud what they had written. There was no reluctance to share, since revelations of simple sensory experiences are not threatening or invasive.

Working with journal-writing has some difficulties. Because words are used every day, people have well entrenched verbal patterns. Bypassing these was the challenge. Participants had to be willing to find a "new" language for themselves — a creative way to explore, process, and document what was happening in their inner worlds. Each workshop opened with a verbal check-in that served to alleviate anxiety, provide the facilitator with information about each individual's normal expressive patterns, and allow participants to witness and be witnessed by others.

The first writing exercise used a combination of guided relaxation and visualization to focus participants' attention on their bodies. After writing lists of what they noticed, they chose a particular sensation and wrote a dialogue with it, often using both hands. Writing questions with the dominant hand and answers with the

non-dominant hand helped to bypass the inner critic. For individuals who were right-hand dominant, the left brain (verbal, linear, analytical) controls the right hand, while the right brain (holistic, creative, nonverbal) controls the left hand. Any left-handed individuals were advised that this might not be accurate for them, and were guided to find the best way to work with both hands. Participants became aware of a wide range of body sensations which had often gone unnoticed, learned what these meant, and what they wanted to do with the information. An awareness of tight shoulders led one person to lower his shoulders while a second shrugged hers. How the information was acted upon was personal. New stress-reducing behaviors ensued as a result of enhanced body awareness.

A series of sensory exercises involving taste and smell followed. Eating a peanut or raisin slowly and consciously resulted in descriptive, poetic writing. Sniffing a few drops of vanilla stimulated the limbic brain and memory. This writing was narrative and often described an event from childhood.

Until this point all exercises concentrated on writing about unique personal experiences. In the next exercise, which involved sight, the group was asked to write an objective "catalogue" description of a common object in the room. Before reading this aloud, they were asked to find some other object that appealed to them and to write a similar description of it.

No matter how objective each person strove to be when writing about the first object, the wide range of descriptions was eye opening. Even deliberately factual descriptions were projections of a very personal inner world. No two were alike. There was a perceptible shift in the group as it became apparent that everyone had an individual and unique point of view, even when total objectivity was sought. This realization acted as a stress reducer. Participants noted how much more enjoyable it was to choose what to write about, while admitting that all of their writing gave them information about themselves. A journal is a safe container for emotional catharsis, as well as a place to create and explore.

A major piece of writing, intense and intimate, concluded each session. "Snapshots" is a technique of integrating assumptions and beliefs from a caregiver's past in light of present work. Members were asked to recall and describe some minor childhood illness. They then described each parent's attitude and behavior toward them during this illness. Next they re-

called how each parent reacted to his/her own health and illness and, finally, they looked at how each parent responded to the health and illnesses of their spouse. Group members saw more clearly how their own style of caregiving had been affected, positively or negatively, by their family history.

Feedback from all groups was positive and consistent. Using a journal to document not only the difficult times, but also the more pleasant aspects of their lives, had not occurred to most of them. They were amazed at the vividness of their writing as they turned nonverbal experiences into words. All were surprised to hear that everyone experienced the exercises so differently. They said this helped them feel more comfortable in expressing themselves in their own unique way. One professional, whose initial writing was terse, almost like notes on a patient's chart, and who wanted to talk while many continued to write, said, after hearing some of the poetic and inventive writing of others, "I think I have to take more time with this."

Art Therapy Segment

Being able to express myself in art puts me in touch with feelings I wasn't aware of. — workshop participant

Artwork invites us to communicate naturally about ourselves and with ourselves using the image as a vehicle. Further, artwork embraces the process of creative expression by incorporating it within a structured psychotherapeutic framework. Art therapy is a creative client-centered approach to expressing personal issues, life experiences, and feeling states through the production of artwork. By externalizing an experience in a concrete pictorial form, artwork can act as a vehicle for verbalizing the experience by expressing the significance of colour, symbols, and recurring themes. It is particularly effective for persons who may have difficulty expressing themselves verbally. During art therapy, the act of identifying an experience or feeling state can lead to emotional healing and growth. No artistic skills are required.

The materials used in the art therapy segment included water-based paints, oil pastels, chalk pastels, coloured pencils and felt markers. It is important to offer choices in materials, but not so many as to cause difficulty with selection. Someone who is uncomfortable with the fluidity of paint may be more at ease with more easily controlled materials such as coloured pencils or felt markers. Another may wish to experiment and combine materials. Offering paper of varying sizes can relieve the anxiety of some partici-

pants who find large sheets too extensive and overwhelming, and who prefer to draw on smaller sizes.

The art therapy segment began with the introduction of group members to the materials and the art process. Participants were invited to choose a piece of paper and a colour that was significant to them. They were then asked to draw a line that would illustrate how they were currently feeling. This exercise took only a few minutes. Group members were encouraged not to over-analyze their feelings, but rather to acknowledge and express the dominant emotion at that specific moment. If they struggled to identify the emotion they were feeling, suggestions about various feeling states were made to see if any resonated for them. Or they were asked to choose a colour without saying what they were feeling. After they drew with this colour, they were asked about the significance of their choice. Responses typically reflected anxiety, fear, joy, and excitement. Discussions included the type of line that was drawn, the choice of colour, what it represented to the individual, and how they felt about the overall experience.

After this introductory exercise to the art therapy process, there was generally a greater sense of comfort within the group. Participants appeared more at ease and able to progress to the next level. At this point, comments were made about the art materials, how participants might not have used any since childhood, or the joy and freedom they experienced in using them.

When asked to do what appeared to be a simple drawing, group members were often surprised to find their artwork contained information that came from their "creative subconscious." Repressed experiences or emotions may remain trapped in a person due to the lack of a creative outlet. By inviting creative expression, art therapy allowed participants to begin releasing some of these experiences and emotions.

The second directive invited the participants to take greater risks. As a way of introducing themselves to the group, group members were asked to write their names on a piece of paper and illustrate something about themselves that they would like to share. As each person discussed their artwork with the group, anxiety decreased, and sharing and mutual support increased.

The third and final exercise of the art therapy segment involved a close examination of ways in which persons who provide care for others could provide care for themselves. The focus of this exercise was the provision of self-care. This entailed a guided visualization in which group

members were asked to choose a positive affirming word from a list of similar words, or to imagine situations that required introspection about their own needs and the type of care they require. They then created an image to identify their needs and how the type of care could be effected. If members were struggling to visualize this, they were always free to remain in the group, in the hope that this would assist them in some way.

The experience of the participants in the art therapy workshops confirmed that creative approaches can enhance personal wellness and assist persons to maintain a sense of balance in their lives. Comments from participants about what was most helpful in the workshop included feeling uninhibited about expressing themselves in art, experiencing the creative process, the joy of relaxation, and seeing how art touched their feelings and experiences.

Reconnecting to one's creativity was a powerful and emotional experience. Art therapy allowed a dialogue with the artwork to occur, and created the possibility for individuals to take an active role in self-care. By externalizing experiences in a concrete pictorial form, expression and communication occurred. The artwork facilitated communication and self-awareness, which can lead to emotional healing and resolution. As one participant eloquently put it, "I never realized that images I created could say so much ..."

Music Therapy Segment

Music gave me a sense of freedom I had forgotten I ever had. Thank you. — workshop participant

Music — the art of sound — is both personal and universal. It is the language of the emotions, communicating that which is pre-verbal and unformed, as well as that which is beyond words. It conveys celebration and lamentation. It affects us physically, socially, psychologically, and spiritually.

Music has been described as a phenomenological metaphor for our experience. Human identities are "symphonic" in that they are being continuously composed in every moment. Within this metaphor, personality types can be seen not as limitations but as themes in a repertoire of being (16). During creative music improvisation, it is possible to play with different themes and experiment with different ways of being.

The music segment began experientially with movement and movement-sound improvisations during which participants introduced themselves non-verbally. This was followed by verbal introductions of names, work/volunteer

affiliation, and a statement of personal relationship to music. The facilitator's opening remarks conveyed that music is a natural human capacity. Participants were invited to play and explore without judgment. There were to be no "wrong" notes in this experience. All notes would be sounded and heard. The need for confidentiality and safety was restated.

Instrumental improvisation was introduced with individual resonator bars, one pitch per bar. Pitches of the Aeolian mode with added major thirds and no perfect fourths were used singly and in "dialogues" around the circle. This progressed from one pitch to two pitches, then three pitches simultaneously. Participants were instructed to listen and to fit their one sound into the whole group sound.

Resonator bar improvisations followed, preceded by opening verbal instructions and a closed-eye process that enhanced relaxation, focused listening, and de-emphasized formal performance. Half the group improvised together while the other half listened. The listeners then followed with an improvisation in response to what they had heard. All participants permitted these and subsequent improvisations to be tape-recorded.

Participants then explored various musical instruments displayed on tables at the periphery of the room. These instruments provided a wide range of tone color (woods, metals, strings, skins) and dynamic potential. Subsequent improvisations varied according to the characteristics of each group, and often incorporated voice and movement.

Each music segment ended with verbal processing of the experience. Participants were told that a list of music resources would be available at the end of the day. The resource list provided book titles (see Appendix), suppliers of musical instruments, and music schools. Copies of their tape-recorded improvised music would be supplied on request. A song was taught and sung, if time permitted.

Participants were not expecting the non-verbal whole-body introduction that opened the music segment, and they responded playfully and with much good-natured laughter. The verbal introductions that followed revealed a pervasive enjoyment of music, and that a small number of participants had skill with a musical instrument. Numerous individuals described unhappy childhood musical incidents — formal music instruction, singing in choir — that had led to the termination of their active participation in music and/or the development of a negative music self-concept (the perception of themselves

as being unmusical). A few participants openly expressed apprehension about their involvement in the music segment.

Initial resonator bar improvisations were quiet, tentative, halting, and of short duration. The pre-music silence (17) was long and laboured. After a reluctant start, participants quickly learned to listen to the group sound while playing their individual tones. This process entailed a symbolic accommodation and integration of group versus individual needs. Participants expressed surprise at the pleasantness and expressiveness of the collective sound.

Subsequent improvisations were longer and used the full potential of all available musical instruments. These musical expressions sounded exuberant, soulful, rhythmical, chaotic, tonal, atonal, integrated, and sometimes several combinations of these within one improvisation. A warm and supportive group ambiance developed. Spontaneous singing and dancing occurred in groups that were most comfortable with each other and with the experience of creative music improvisation.

Gertrude Orff's (18) description of creative music therapy improvisation with children aptly describes the experience of the music therapy segment with caregivers:

[The] experience of community through common activity, the free setting of impulses that arise ... produce this particular atmosphere, whose secret is that it is effective, that it enlivens, that it intensifies, that it mitigates and calms. The atmosphere acquires its particular coloring, its stimulus, and its wholesomeness through the movement, the perpetual, unobtrusive rhythmic flow and the sound colors that are produced in various ways. ... It is always the gift of that particular session. (18, p.162)

Among comments made at the end of the day by participants about the music therapy segment were: "The music group was fun — liberating", and "I even enjoyed the music therapy, which I was a little afraid of."

Evaluation

Participants completed an evaluation form after each workshop answering the following questions:

- what was the most helpful part of this workshop?
- what would you do differently if you organized this workshop?
- any other comments?

Seventy-five evaluations were completed and analyzed. All were positive and indicated that participants had learned about and experienced

valuable aspects of themselves. They appreciated the opportunity to experience all three modalities. No one modality stood out from the others as being more useful. The evaluations overwhelmingly indicated that participants appreciated the nurturing, supportive, non-judgmental climate of the workshop and the skill level of the facilitators. An important benefit of the workshop for a significant number of participants was the opportunity to take time for themselves and to share their experiences of caregiving with other caregivers. Some representative comments were:

"It was very helpful to know what types of therapy I respond to."

"It was very helpful being in a group with others who are involved in caregiving and sharing fun activities."

"It provided a facility for me to get close to who I am, with my many facets, highlight what is important to me, how to let go, relax, experience others."

Some participants felt that the day was too long and too exhausting, and that perhaps breaks could have been longer. Others suggested having the different modalities over three evenings, or in half-day sessions, or having shorter sessions in a one-day period.

A follow-up telephone survey was conducted within two years of the initial workshop. Due to participants having moved, no longer participating in palliative care, or not being available, only 34 of the 75 participants responded to the survey. When asked if they were more aware of the need to take care of themselves as caregivers since taking the workshop:

- 16 said absolutely
- 12 said more so than before
- 5 said somewhat
- 1 said not at all.

When asked if they were better able to take care of themselves as caregivers since taking the workshop:

- 14 said absolutely
- 16 said more so than before
- 2 said somewhat
- 2 said not at all.

These responses clearly indicate that respondents gained insight into the need to take care of themselves as caregivers, and were better able to do so after taking the workshop.

DISCUSSION

The goal of the workshop was to provide an opportunity for caregivers to explore journal-

writing, art therapy, and music therapy as forms of self-care. It was intended that, from this experience, participants would develop a greater awareness of the importance of nurturing themselves. Both initial and follow-up feedback indicate that this was achieved.

For these reasons, Casey House Hospice is continuing to offer the *Creativity and Self-Care for Caregivers* workshop. It has also initiated a Level 2 program to deepen the experience. Based on participant feedback, a Level 3 program is being planned to provide caregivers with information about the benefit of these modalities for their clients.

The arts are crucial to well-being and we cannot afford, even in these economically challenging times, to relegate them to the status of frill. This type of workshop allows for an immediate integration of the body, mind, emotions, and spirit. It provides a holistic experience for the participant. It is not to be discounted.

The observations of the facilitators and the participant feedback from the *Creativity and Self-Care for Caregivers* workshop are evidence that creative play and expression through the arts increase caregiver awareness of the importance of self-care. Research is warranted to quantify these findings and determine long term effects.

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Appendix – Resources

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