

# **DESIGN AND EVALUATION OF A LEISURE EDUCATION PROGRAM FOR CAREGIVERS OF INSTITUTIONALIZED CARE RECIPIENTS**

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## **Introduction**

The Canadian Study of Health and Aging (CSHA) (1994) identified that by 2031, 21.8% of the Canadian population will be 65 years and over. The current prevalence of dementia among Canadians was estimated to be just over a quarter of a million elderly people, equally divided between community and institutional placements, with the projected prevalence of dementia expected to triple by 2031.

How does the prevalence of dementia affect caregivers' health and perceived sense of leisure? Could a leisure education program affect their knowledge and behavior regarding self-care? Enhancing quality of life through development of skills and knowledge related to leisure is the essence of therapeutic recreation (TR) when a specialist applies leisure education as a component of the Leisure Ability Model (Peterson & Stumbo, 2000).

The purpose of this study was to evaluate the effectiveness of a leisure education program for caregivers of persons with dementia residing in an institution. The leisure education program entitled "Learn to Take Care of Yourself Too!" was developed based on a review of the literature and the researcher's prior experience delivering therapeutic recreation services to veterans. The leisure education program was designed to assist caregivers to develop a personal knowledge and understanding of oneself in leisure and to develop the knowledge and ability to plan for leisure. The concepts of self-care, societal and personal values/attitudes of leisure, leisure awareness, leisure resources, leisure barriers, and leisure planning were integrated into the program.

The sub-theme is caregivers of persons with dementia who reside in a long-term-care facility.

## **Review Of The Literature**

A primary leisure issue associated with caregivers of persons living in an institution is social isolation (Buckwalter & Hall, 1987; George & Gwyther, 1986). Social isolation is described as a result of lost relationships and activities in order to care for their loved one (Buckwalter & Hall, 1987). It may also be a result of caregivers never having established a leisure lifestyle prior to their caregiving role (Dupuis & Smale, 2000).

Aims and benefits of leisure education programs for caregivers have been varied. They have ranged from: (a) increasing personal well-being (Hughes & Keller, 1992); (b) improving the lives of caregivers (Carter, Nezey, Wenzel, & Foret, 1999); (c) developing coping strategies (Hughes & Keller, 1992); (d) facilitating access to leisure while maintaining caregiver identities and responsibilities (Bedini & Guinan, 1996); (e) addressing social isolation and life satisfaction (Brattain-Rogers, 1999); (f) increasing leisure opportunities, social contacts, awareness of leisure time (Bedini & Guinan, 1996); (g) decreasing emotional and physical fatigue (Bedini & Guinan, 1996); (h) developing a personalized plan of action and identifying resources necessary for implementing the plan (Hughes & Keller, 1992; Keller & Hughes, 1991); and (i) addressing stress (Hagan, Green, & Starling, 1997).

## **Method: Program Design And Evaluation**

### **Program Design**

The program was structured to meet as a group once a week for one and a half hours for 6 weeks. Sessions were held in an enclosed conference room removed from the unit of the long-term care facility to prevent distractions. Weekly topics were addressed primarily with guided discussion, and through paper and pencil completion of predesigned worksheets or projects (i.e., a leisure collage). During each session the following sequence occurred: (a) informal socializing; (b) review of the previous week's topic; (c) sharing and review of 'homework' (a focused journaling exercise) assigned to apply knowledge and skill for the previous week's topic; (d) introduction of the session topic; (e) name tag activity; (f) session activity; (g) discussion with intent to apply new knowledge to each participant's current situation; (h) assignment of homework (journaling); (i) evaluation of learning outcomes using paper and pencil self-reporting; (j) collection of participant's folder that includes their name tag, completed session activities, and completed journal entries; and (k) an opportunity to meet with the facilitator individually.

#### *The program components and their content focus included:*

1. Leisure Awareness with a focus on understanding the definition of leisure (time, activity, state of mind) and how it relates to their own lives.
2. Leisure Benefits with a focus on identifying physical, social, emotional, psychological, and spiritual needs related to caregivers' stress, guilt, relaxation, social support, etc.
3. Leisure Values with a focus on the positive and negative influences that impact an individual's values/attitudes towards leisure.
4. Leisure Barriers with a focus on identifying leisure barriers, and solutions to those barriers.
5. Leisure Resources with a focus on activity opportunities, personal, home, community, and institution.
6. Leisure Planning with a focus on what the participant's plans would be for the next three months in regard to self-nurturance and re-creating time with their care recipient.

#### *Facilitation techniques included:*

- Daily journaling homework with the weekly topic guiding the focus.
- Relating their ability to look after themselves to their continued success as a caregiver.
- Discussions aimed at processing feelings at each session.
- Linking with other health professionals on the interdisciplinary team to encourage initial caregiver participation in the group (nurses, social work).
- Formative evaluation of session content and process.
- Focusing on leisure as a need for respite and time-out.

### **Program Evaluation**

The investigator works as a recreation therapist in a long-term care facility serving 175 Canadian veterans where two of the seven 25-bed units house veterans with

dementia. Any caregiver whose care recipient was a current resident on either of the two 25-bed special care units, and who lived within the county where the LTC facility was located, was invited by letter to participate in the proposed study. Four of 38 existing caregivers who met the selection criteria agreed to participate. Each of the four caregivers' care recipients resided in the institution for a minimum of 8 months. The following evaluation goals were developed:

1. To determine participant knowledge based on the content of the program.
2. To determine modifications related to content and process based on participant and investigator experiences.

The research question was addressed using the following types of data collection instruments: (1) preprogram interview and corresponding participant postsession self-reports (19 performance measures); (2) postsession report forms (Peterson & Stumbo, 2000) completed by the facilitator; (3) participant and investigator journals; and (4) a postprogram interview for participants.

The preprogram interview analysis profiled each participant's leisure knowledge prior to the intervention. The preprogram interview results were compared to the participant's self-reported learning outcomes, which were actually the performance measures of caregivers' leisure awareness and skill. The participant postsession results summarized each participant's knowledge outcome across all six sessions. Each of the six postsession reporting instruments also profiled the 'usefulness' of each session from the participant's perspective. All interviews were tape-recorded and transcribed verbatim. Six facilitator postsession report forms (Peterson & Stumbo, 2000) were analyzed by numerically summarizing responses. This analysis profiled the facilitator's interpretation of each session in terms of program effectiveness and provided direction for future facilitation techniques in interventions with caregivers.

Participants' journals were comprised of six homework assignments where caregivers applied learned session content on a daily basis. They reflected caregiver's ability/desire to apply knowledge and their interpretation of the experience of learning self-care as a leisure activity. The facilitator's journals captured impressions not included in a more 'formal' manner (i.e., in the postsession report form). Both sources of journaling were interpreted based on the literature and judgement of the investigator. The postprogram interview investigated each participant's perception of program effectiveness. Suggestions for program modifications were reported as a narrative (see results).

## **Results**

**Preprogram Interview and Corresponding Postsession Self-Reports**  
Analysis of each participant's preprogram interview compared with their self-reported learning outcomes (participant postsession instrument) determined that each participant was able to meet several objectives before the program (see Table 1). Preintervention knowledge occurred in 8 of the 19 performance measures. The sessions with the highest concentration of preintervention knowledge were: leisure awareness, leisure resources, and leisure planning. Overall results indicated that three participants achieved objectives as a result of the program.

Table 1. Participants' Postsession Outcomes

Performance Measures	Jackie	Gail	Evelyn	Diane
1. Definition of leisure.	√	√	√	√
2. General leisure interests.	√	√	√	√
3. Personal leisure interests.	√	√	?	√
4. General leisure benefits.	+	+	?	?
5. Personal leisure benefits.	√	+	?	√
6. Personal leisure need.	+	√	?	√
7. Value of leisure in society.	√	-	+	-
8. Personal values in leisure.	+	√	-	+
9. Personal leisure attitude.	√	√	+	√
10. Techniques for changing or reinforcing a personal leisure attitude.	√	√	√	-
11. General leisure barriers.	√	√	√	√
12. Solutions to general leisure barriers.	√	+	-	√
13. Personal leisure barriers.	√	+	√	√
14. Solutions to personal leisure barriers.	+	+	√	√
15. Community resources.	√	√	√	√
16. Facility resources.	√	√	√	√
17. Leisure activity without care recipient.	√	√	√	√
18. Leisure activity with care recipient.	√	√	√	√
19. Leisure plan with and without care recipient.	√	+	√	√

(√) Participant was able to perform the objective before instruction.

(+) Participant was able to perform the objective after instruction.

(-) Participant was unable to perform the objective after instruction.

(?) Investigator was unable to determine score due to lost data or absence.

(√) Participant was able to perform the objective before instruction, but unable to perform the objective after instruction.

The greatest improvement in postintervention knowledge occurred in the sessions that addressed leisure benefits, leisure values/attitudes, and leisure barriers. Conversely, three participants were still unable to meet objectives after the program in the areas of leisure values and solutions to general leisure barriers.

Caregivers' knowledge of the value of leisure in society was the 1 objective out of 19 that had the lowest score. Yet, caregivers' knowledge of personal leisure values was one of the three objectives with the greatest improvement.

#### Facilitator Postsession Report Form

The analysis of the facilitator postsession report form provided direction for revising the leisure education program for caregivers. Only the session on leisure benefits was implemented as designed and five sessions were modified. Some changes or

modifications indicated by the investigator included: (a) participants choosing where to sit during the first three sessions to increase their comfort by being beside someone they knew; (b) incorporating refreshments into the beginning of each session to create a nurturing environment; (c) having them work in pairs to complete a worksheet in the leisure barriers session to develop problem-solving skills among themselves; (d) assigning seating during the fourth, fifth and sixth sessions to balance the “talkers” with the “listeners”; (e) adding ‘delegation’ as a worksheet in the leisure resources session because it developed as a solution to some leisure barriers; and (f) planning to meet earlier than three months after the program because the participants wanted to retain the cohesiveness that had developed among them.

Four out of six sessions had positive unanticipated events/outcomes including: (a) participants building rapport by telling their stories in an unstructured manner, or as a result of being playful together (i.e., creating a leisure collage in Session One); (b) developing an informal support group; (c) deciding to lengthen the session because they wanted to share their caregiving stories as well as fulfill the learning objectives; (d) identifying delegation as a tool for reducing barriers to leisure; (e) participants rallying around a group member when she arrived upset because her care recipient was angry that she was attending and not being with him; (f) locating a more satisfying meeting room; and (g) deciding to meet within one month’s time to reconnect. Three out of six sessions had negative unanticipated events/outcomes including: (a) not starting on time because group members were unsure of the time and location; (b) not having enough time to address guilt; and (c) an unexpected absence.

### **Participant and Investigator Journal**

The analysis of the participants’ journals reflected their ability/desire to apply knowledge and their interpretation of the experience of learning self-care as a leisure activity. One caregiver noted how the journal homework was beneficial: “It opened your awareness.” Debriefing journal exercises as a group enabled participants to help each other by listening to their struggles and what each did that week to look after themselves.

The investigator’s journal provided the following insights into the experience: (a) awareness that careful preparation eased facilitation performance—incorporating worksheets, room set-up, notes about sequencing, introductory words, and refreshments; (b) worrying about starting the group late and not ending on time; (c) discovering that everyone has something important to contribute and feeling that the preplanned agenda did not supersede the evolving group process/dynamics; (d) learning that the journal homework was difficult for participants because it required them to “learn a new language” (i.e., leisure related terminology); (e) recognizing that the dynamics of the group change when a participant is absent; (f) recognizing that group members developed an emotional connection with each other as was demonstrated by the desire to have a combination of teaching and sharing stories; and (g) recognizing that participants are at a different point in their search for self-care because their context of social support and belief systems are unique.

### **Postprogram Interview**

The analysis of the post-program interview determined participant suggestions for modifying the program and they included: (a) distributing handouts of background

information content for each session; (b) having a ‘refresher’; doing a group activity separate from the leisure education program; (c) keeping the sessions in small groups (between six to eight people); (d) incorporating an opportunity after the care recipient dies to see how the caregiver is doing with the new life; (e) keeping day time sessions because night driving could be a barrier; (f) allowing for storytelling as well as education; (g) keeping sessions at once a week because any shorter wouldn’t give enough time to practice and any longer would make it hard to remember; and (h) looking at availability of leisure resources from a continuum to where the care recipient is now to where he is going to go in terms of declining cognitive status.

## **Discussion**

In general, the leisure education program “Learn To Take Care of Yourself Too!” increased caregivers’ knowledge of leisure. All caregivers reported that the program had a positive effect on their life as a caregiver. They reported that their thinking had changed. They described the parts of the program that helped them to take care of themselves as increasing self-awareness about leisure, increasing confidence, valuing taking time to look after themselves, and reducing guilt.

In essence the nine program objectives could be maintained for the next program delivery. New performance measures could be added if the caregivers had sufficient preintervention knowledge or more depth could be expected when addressing the topics. The intervention will continue to evolve as each program evaluation consistently reveals content and process modifications that strengthen the message for caregivers that self-care is essential in staying healthy.

## **Practical Applications**

In summary, teaching leisure education in a semi-structured group format is an opportunity for participants to learn from each other, to be in a group where others share similar challenges, develop an informal support group, and have a common experience with another in a positive way. As well, it is an opportunity for the facilitator to provide material that focuses on developing self-care practices through leisure, to increase understanding of caregiver experiences, to demonstrate value of a leisure education program for caregivers, to develop a network of caregivers to advocate to other caregivers about the value of the program, and to initiate and facilitate an informal caregiver support network at the facility.

## **References**

- Bedini, D. M., & Guinan, D. M. (1996). The leisure of caregivers of older adults: Implications for CTRS’s in non-traditional settings. *Therapeutic Recreation Journal*, 30(4), 274-288.
- Brattain-Rogers, N. (1999). Caring for those who care: Achieving family caregiver wellness through social support programs. *Activities, Adaptation & Aging*, 24(1), 1-12.
- Buckwalter, K. C., & Hall, G. R. (1987). Families of the institutionalized older adult: A neglected resource. In Brubaker, T.H. (Ed.), *Aging, health and family: Long term care*, (pp.176-196). Beverly Hills, CA: Sage Publications.

- Canadian Study of Health and Aging (1994). Canadian study of health and aging: Study methods and prevalence of dementia. *Canadian Medical Association Journal*, 150(6), 899-912.
- Carter, M. J., Nezey, I. O., Wenzel, K., & Foret, C. (1999). Leisure education with caregiver support groups. *Activities, Adaptation & Aging*, 24(2), 67-81.
- Dupuis, S. L., & Smale, B. J. A. (2000). Bittersweet journeys: Meanings of leisure in the institution-based caregiving context. *Journal of Leisure Research*, 32(3), 303-340.
- George, L. K., & Gwyther, L. P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *The Gerontologist*, 26(3), 253-259.
- Hagan, L. P., Green, F. P., & Starling, S. (1997). Addressing stress in caregivers of older adults through leisure education. *Annual in Therapeutic Recreation*, 7(7), 42-51.
- Hughes, S., & Keller, M. J. (1992). Leisure education: A coping strategy for family caregivers. *Journal of Gerontological Social Work*, 19 (1), 115-128.
- Keller, M. J., & Hughes, S. (1991). The role of leisure education with family caregivers of persons with Alzheimer's disease and related disorders. *Annual in Therapeutic Recreation*, 2(2), 1-7.
- Peterson, C., & Stumbo, N. J. (Eds.) (2000). *Therapeutic recreation program design: Principles and procedures* (3<sup>rd</sup> ed.). Boston: Allyn and Bacon.

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