



The importance of leisure when living with a life threatening disease:

From on a serious leisure perspective

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Abstract

The purpose of this study is to focus on the perception of the importance of leisure activities by those confronted with a life threatening disease as well as their caregivers. This hypothesis building research was conducted through semi-structured interviews with individuals who were and still are confronted with a life threatening disease as well as their caregivers. Results tend to lead towards the fact that patients still viewed leisure as a very important part of their life. Caregivers would favor acute health care to leisure activities in seeking the highest possible level of wellness for terminally ill patients.

Keywords: leisure, life threatening disease

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Introduction

It is quite difficult to see your life come to an end, yet we do not know what can truly help someone accept or facilitate death unless one has previously experienced near death. Confronted with my own death, I started reflecting as to what was important in my life. Living with cancer at age 21 and undergoing extensive chemotherapy and radiation treatments, I was seeking a significant purpose in life. I then realized the importance of leisure in maintaining a sense of balance while dealing with this life threatening condition. In light of the scarce abundance of background work in this area, I decided to pursue this exploratory research.

Theoretical framework

In today's society, little importance is awarded to leisure, especially in preparation for death. Nevertheless in 1996, Haberkost, Jenkins and Bennett advocated the importance of leisure to maintain wellbeing amongst clients. They also point to the importance of proper leisure involvement to enhance the institution's quality of life, leading to positive impacts both on residents and workers (Haberkost et al., 1996).

At this point literature provides little information on the importance of leisure among individuals confronted with a life threatening disease. What impact does their previous leisure participation profile have when confronted with death? For the purpose of this research the attention has turned to the theory of «Serious Leisure» (Stebbins, 1992, 1998) to help shed light on this subject.

Serious leisure is in contrast to casual or unserious leisure (Stebbins, 1998, 2001). Serious leisure poses bigger challenges while being complex in structure and normally requires a steady commitment to perform it well (Gillespie, Leffler & Lerne, 2002). According to the same author, serious leisure is expressed through three levels of involvement: the "amateur", the "hobbyist" and the "volunteer", whereas casual leisure is referred to as dabblers. Even though each serious leisure structure has its own characteristics, Stebbins (1998) suggests some universal qualities. These qualities are perseverance; opportunity to follow a career, effort on acquiring knowledge, training for skills (at times all three); durable benefits; developing a strong identification with the chosen pursuits and a unique character or spirit. According to this theory, one would

often define itself namely based on personal leisure practices. For example the serious music consumer could define itself based on the type of music preferred, whether it be jazz or classical music.

This exploratory hypothesis building research has two objectives. The first objective is to enhance our comprehension of the importance of leisure for patients with life threatening disease. The second objective is to better understand the perception of caregivers about the importance of leisure activities for individuals confronted with life threatening diseases.

It is therefore hypothesized that leisure maintains its importance for someone who is confronted with personal death. We also stipulate that caregivers of patients dealing with life threatening disease perceive leisure activities as being an important factor to maintain life balance.

Methodology

Sample

For the purpose of this research two palliative care patients, one hospitalized and the other living in the community, three clients with cancer, two in remission and one in terminal phase, all living in the community, were interviewed. Two caregivers, a nurse and a recreation therapist, working in a palliative care setting were interviewed as well. Participants to the study were identified through referrals from hospitals and palliative care institutions.

Questionnaire

Questionnaire to patients

The first question aimed at recording leisure opportunities offered within the patient's actual living environment. The second question aimed at understanding the extent of their interest to participate in structured leisure activities. The third question comprised five statements based on Stebbins' different categories of serious leisure, for which patients could identify, on a scale of 1 to 5, those that represent them best. Patients were provided with time to comment on their choices. This last question aimed at understanding the importance of leisure activities, in respondent's last stages of their life. Participants were encouraged to answer these questions twice, firstly, according to past leisure participation style and secondly based on present participation style.

As participants were interviewed using a semi-structured questionnaire, the frailty of some respondents, namely their lack of energy, made it difficult to undergo a lengthy

process. Because of this limitation, questions were as specific as possible (no more than one sentence) and the duration of the discussion kept short. The questionnaire had three open questions presented in a semi-structured discussion, allowing for the use of a tape recorder. The availability and limits of patients dictated the length of the discussion.

The data contained in the interviews fell into four distinct sections, namely:

1. The socio-economic profile of respondents.
2. The intention of patients to maintain their involvement in leisure as well as the intention of caregivers to offer leisure opportunities to patients.
3. The level of satisfaction with the patient's leisure experience and their participation style, according to Stebbins (1998).
4. The evaluation of participant's present involvement in leisure from a serious leisure perspective.

Questionnaire to caregivers

The initial question for caregivers was about leisure activities offered to patients. The second question aimed at identifying their intention, on a scale of 1 to 7, to offer and facilitate the participation of their patients in structured leisure activities. The third question dealt with the likeliness on their part of considering a possible job offer in a different area of leisure, with salary increase.

Process

This research was conducted in both community and institutional setting, data collected through semi-structured interviews based on the theory of "Serious Leisure" (Stebbins, 1998).

Results

The patients

Patients see leisure activities as the most important daily activity as it helps facilitate the acceptance of their own death. Leisure also brings a feeling of belonging, appreciation, self worth and accomplishment. It is also an opportunity to socialize. As a client confided: "Even though I can't eat anymore, I still go to the restaurant with my family, just for the pleasure of it."

Respondents (patients) perceive leisure activities as important, providing several benefits such as a sense of accomplishment, self actualization, a better self-esteem,

sense of control, evasion, sense of appreciation, a link to life, acceptance of their life conditions and a feeling of empowerment.

All respondents stated having maintained their leisure lifestyle towards the end of their life as per Stebbins' theory. They also believe that leisure activities have more importance at this stage of their lives than ever. As one interviewee said: "I used to love reading, and I still do, but now, reading has a new meaning and I feel it is more important to me because I can escape every day's hardship."

It is essential to note the importance that leisure activities take in the lives of patients faced with life threatening diseases. For patients, leisure activities help deal with depression, shown when one of them said: "I participate in leisure activities because I can." As well, "Leisure helps me feel life is important again." According to Kübler-Ross (1975), depression is part of the grieving process, but must be kept to a minimum. According to responses provided and their nonverbal language, each interviewee seemed to have accepted their diseases and did not display signs of anger or depression. These observations were supported by patient's referral sources to the researcher.

The caregivers

Caregivers see leisure activities as very important for palliative care clients. As one said: "Leisure activities are so important but not everyone realizes it. It should be part of every institution, especially with the ill and dying." Both caregivers have intentions to facilitate participation in structured leisure activities and think that leisure activities should be part of the treatment directed at palliative care patients. As the other interviewee said: "Leisure activities can enhance quality of life, allow for socialization and alleviate the feeling of loneliness and solitude."

Even though caregivers admit enjoying their present employment, they stated that they would change position if offered an enhanced pay. They expressed a need for change and new challenges.

Discussion and Conclusions

The importance of leisure activities for patients suffering from a life threatening disease appears to be eminent. Conducting such research is quite challenging, but tends to point towards the fact that both patients and caregivers recognize the importance of leisure towards the last stages of life. Results suggest that leisure participation styles as defined by Stebbins (1998, 1992) do not change significantly

when faced with a life threatening disease. In this situation, leisure activities take a much greater place in one's life and it would be very important to offer these activities in order to facilitate the grieving stages.

A number of challenges surrounded this study. For instances the analysis was conducted on a small sample often limited by physical and cognitive depleting conditions. This limitation had an impact on the type of questionnaire used, the time spent with the subject and the quality of their answers. Although aware of this, respondents verbalized effectively their thoughts, feelings and beliefs.

To overcome these limitations participants were provided with an opportunity to freely discuss questions. The fact that I have had a life threatening disease is an asset since I know what the interviewees are going through. This has made us more sensitive to their needs and helped in the forthcoming of the questions and length of interviews.

This exploratory pilot study had three objectives; firstly, to enhance comprehension on the importance of leisure when faced with a life threatening disease. Secondly, to better understand the perception of importance of leisure activities of caregivers. Thirdly, to help define future research topics on leisure activities for people living with a life threatening disease.

What does this all mean to us as researchers? Keeping in mind that leisure activities are important for people living with a life threatening illness and that the leisure participation styles as defined by Stebbins do not change significantly when faced with a life threatening disease this research opened the door to numerous possibilities. Where do we go from here? Following this research it is recommended:

1. To further investigate the role of therapeutic recreation for the well-being of individuals living with a life threatening disease. This study could compare patients living in a community and in an institutional setting.
2. To study the importance of leisure from a multidisciplinary perspective. For instance to study the views of the medical doctor, nurse, primary caregiver or personal support worker.
3. To record and assess leisure opportunities within a community for individuals dealing with a life threatening disease. Such research would provide insight as to the accessibility of leisure opportunities for these individuals.
4. To further investigate why for some individuals their serious leisure lifestyle does not change even when living with a life threatening disease?
5. To study to what extent serious leisure help evolve through the grieving

stages?

6. To investigate how serious leisure involvement can help patients avoid denial and better accept their disease.

Recommendations

Researchers working with this population should adapt questions to the clientele keeping in mind that the potential participant can be frail and suffering from possible cognitive impairment. Therefore, the language used must be adapted to the condition and capacity of comprehension of participants.

Adapt the data collection strategy to the participants. An approach centered on interviews and discussions could be favored over a written questionnaire for example.

When interacting with terminally ill patients, one must be conscious and open-minded towards their own apprehensions of death. Researchers should be working within interdisciplinary teams providing emotional support allowing for extra help in dealing with feelings experienced when confronted with death. If well planned, this process will become for the researcher a learning experience like no other.

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