

# Description of the caregiver's educational needs and the degree of her dissatisfaction

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## Abstract

*This study emphasized the learning needs of caregivers whose husbands have cancer and describes their level of dissatisfaction concerning these needs. A convenience sample of 30 women caregivers was used. The results demonstrate that caregivers possess initial acquired knowledge as learners and have 26 specific learning needs. The existence of a learning need produces a level of dissatisfaction among the female caregivers. Among these learning needs, the most likely to generate the greatest dissatisfaction are the learning needs associated with personal concerns. The results encourage nurses to play a more active role in learning by assessing whether the information the caregivers are receiving is understood well enough to meet their learning needs.*

## Introduction

The ambulatory approach to care is forcing more and more families to take care of loved ones. This situation requires one of the family members, most often the wife, to undertake satisfying the patient's physical and psychological needs in their home. This woman is referred to as a caregiver (Garand & Bolduc, 1990). Without having received any health-related training, the caregiver contributes actively to the care of one of her relations (Brognia, 1996). In this study, the caregiver is the spouse of a man recently diagnosed with cancer who cares for him in the couple's home. She needs to learn in order to deal positively with this reality of life. The caregiver's learning takes place in an informal setting. By its very definition, informal education helps satisfy the learning needs of various populations (Bhola, 1983). Nurses involved in education focus on the learning needs of the patient and family members including the caregiver.

The great majority of studies on caregivers aim to identify the needs of this population. Researchers are unanimous in recognizing learning as a priority need for the caregiver. In fact, Bank, Clark and Longman (1989) as well as Hileman and Lackey (1990) observed that caregivers wish to obtain information on their spouse's health problem and on the instrumental and preventive care to be provided. It is important that research be undertaken in order to provide a detailed description of the caregiver's learning needs and measure the degree of her dissatisfaction in relation to her learning needs.

## Terms of reference

The terms of reference were developed around the learning concepts for adults in connection with a concrete situation, i.e. that of a female caregiver whose spouse has cancer. Thus the caregiver's

learning occurs in an informal adult context (Aucoin-Gallant, 1995). This type of learning is structured, problem-oriented, of short duration and takes place outside educational institutions (Bhola, 1983). In the current health care trend, nurses assume a social responsibility in satisfying the caregiver's learning needs. Through her attitude, the nurse develops a helping relationship characterized by authenticity, empathic understanding and respect (Redman, 1993). Within such a relationship, the nurse demonstrates her cognitive and emotional understanding in order to properly perceive the caregiver's reality (Chalifour, 1989). She encourages the caregiver to express her background as a learner and to share her past experiences. The nurse gives the caregiver the opportunity to express whatever she wants about her cognitive, affective and psychomotor knowledge and about what she thinks she ought to learn (Aucoin, 1998). She helps her become aware of her learning needs in a caring environment (Watson, 1985). A learning need exists when there is a gap to be filled between the caregiver's perception that she has been informed and her desire for information related to the cognitive, affective and psychomotor knowledge areas. It is logical that when confronted with an unfilled learning need, the caregivers should inevitably feel dissatisfaction that is going to be translated into discontent and displeasure (Aucoin-Gallant, 1995).

## Methodology

This descriptive research was conducted with 30 caregivers whose husbands had been suffering from cancer for six to 12 months, were in a stable phase and under chemotherapy or radiation therapy. A convenience sample was used. The data was collected at the caregivers' homes at a time convenient to them. Participation in the study was optional and respondents were asked to sign a consent form. The data was gathered during a single interview at their homes which lasted about 50 minutes. Each interview was recorded on tape. A socio-demographic form and two measurement instruments were used. The selected instruments were the French-language adaptation of Derdarian Informational Need Assessment or DINA, (1995) and the Learning Needs Satisfaction Scale (1995). The French-language adaptation of DINA is intended to identify the learning needs of caregivers whose husbands have cancer. Before it was used, the assessment scale was validated by four experts in relation to its contents and suitability of questions. Pre-tests were completed with caregivers possessing the same characteristics as the subjects in the study. The reliability of the instrument for homogeneity and stability was estimated and correlations of 0.78 and 0.94 were obtained.

The Learning Needs Satisfaction Scale (1995) helps the caregiver to indicate her satisfaction or dissatisfaction level with each learning need. This instrument was developed by integrating the 15 groups of learning needs identified in the French-language adaptation of DINA. A 5-point Likert scale was added with responses ranging from Not At All Satisfied (1) to Completely Satisfied (5). Contents were validated by four university professors. These four judges declared they were in agreement with the instrument's compliance in representing the 15 learning needs identified in the French-language adaptation of DINA. Then these judges confirmed the capacity of the instrument to measure the satisfaction level for each learning need. In this study, the accuracy for homogeneity and stability of the instrument were 0.80 and 0.84, respectively.

Content analysis was used to discover the learning needs. The interviews were transcribed verbatim in order to underline the situation's constituent sequences. Afterwards, analysis was used to

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find the expressed learning need before translating it to a scientific language. To assess the satisfaction level, central tendency measures, including the median and average, were made so that the data could be illustrated in table form.

## Outcomes

### Description of learning needs

This study identified 26 learning needs for caregivers. These are presented in Table One which also includes some verbatim excerpts. The results indicate that almost all subjects would have liked to learn how to deal with negative social behaviours. Caregivers strive to acquire psychomotor knowledge in order to dispense quality psychological care to their spouses. The great majority of subjects want to obtain information about the psychological impact of cancer and its treatment. Although most of the subjects had been made aware of the evolution of their spouses' disease, it still remained that they wanted to know more precisely the probability of remission or

recurrence. More than three-quarters of the subjects wanted to know whether cancer could have a negative impact on friendships. It does happen that an announcement of cancer can drive some friends away. The majority of subjects wanted to know more about the cancer phenomenon. This study would make it appear as if caregivers have a partial understanding of cancer. Even though almost all of the subjects had been informed about their spouses' test results, one-third of them wished to interpret their signification. Nearly a quarter of the caregivers approached the issue of sexuality. They wonder if sexual activity is contraindicated during cancer therapy.

### The caregiver's level of dissatisfaction with learning needs

The existence of an unmet learning need brings about dissatisfaction in the caregiver. Table Two illustrates the outcomes concerning the central tendency measurements taken for the satisfaction level related to learning needs. The table shows that 12 learning need groups are considered to be unmet by the study

**Table One: A description of the learning needs of women caregivers as perceived by them N=30**

Learning need	%	Verbatim excerpts
1. How to deal with negative social behaviours	96.67	1. He is quite nervous. What can one do to diminish his nervousness?
2. Psychological impact of cancer and its treatment	83.33	2. I would have liked to know that my husband was going to be nervous and impatient, he was picking on me for every little thing.
3. Probability of remission or recurrence	83.33	3. The doctor said he had the situation under control but I would have liked to know about my husband's chances of recovering or the probability of recurrence.
4. Erosion of friendships	80.00	4. We did not know that because of his cancer some friends would no longer visit us.
5. Restrictions on activities caused by cancer or its treatment	70.00	5. My husband wanted to go dancing on Saturday. We went and I would have liked to know that he would be too tired with the treatment. We were not able to stay.
6. Means of fighting stress	66.67	6. When you feel stress inside, what can you do?
7. Understanding cancer	56.67	7. Explain to me the type of cancer, the difference between Hodgkin's and non-Hodgkin's types.
8. How to relieve the spouse's fatigue	46.67	8. What care should be given for him to be less tired?
9. Physical side effects associated with cancer or its treatment	43.33	9. During his chemotherapy, my husband was more tired. And I thought that the cancer was winning.
10. Availability of formal support	40.00	10. I wonder if nurses could come to our home to check on him.
11. Interpretation of spouse's tests	36.67	11. The bone scan was negative. But what does that mean? That was not explained.
12. How to explain to the children their father's disease	30.00	12. I have small children. I would have liked to be informed about what to tell them.
13. Continuing sexual activities	23.33	13. My husband is getting radiation therapy; sexually, we think it is better to wait. Nobody has mentioned anything about that.
14. Available financial resources	20.00	14. We don't have much money. How can we get help to pay for the drugs?
15. Duration of physical side effects	16.67	15. My husband was tired and nauseated. I was asking myself how long this was going to last.
16. Duration of prescribed tests	13.67	16. How long is he going to have to go through tests?
17. How to explain to parents their son's disease	13.33	17. His mother has major cardiac problems. How do you inform her that the youngest of her boys has cancer?
18. How to increase resistance to stress	10.00	18. I have to be strong to help him. What does one do to get stronger?
19. Duration of spouse's sick leave	10.00	19. How long is he going to be without working? The doctor did not say.
20. Duration of treatment	6.67	20. How long is his chemo going to last?
21. Duration of psychological side effects	6.67	21. How long is my husband going to be in a depressed state?
22. How to optimize the spouse's comfort	6.67	22. What can I do to make him more comfortable?
23. Risk factor	3.33	23. I should have been told what can cause cancer of the bowel.
24. Results of prescribed tests	3.33	24. Once tests are done, it would be nice if the doctor called to give you the results.
25. Objective of treatment	3.33	25. Why is he getting radiation therapy? He does not have cancer anywhere else.
26. Alteration of future plans	3.33	26. When your husband has cancer, it changes your life. What plans can you make for the future?

subjects. As demonstrated by Table Two, the lowest mean score corresponds to the learning need associated with the way the caregiver deals with her own situation. This is followed by the learning need related to the psychological impact of the disease or its treatment. Then, we find the learning need related to how she could help her spouse psychologically. It is worth noting that these three groups of learning needs show the lowest mean scores and that these are almost identical to one another ( $X=1.50$ ;  $X=1.53$ ;  $X=1.57$ ).

## Data interpretation

One of the important datum related to this study is the nature of the information these caregivers seek. Even though there are individual differences among the caregivers when it comes to learning, several of their learning needs are identical. Almost all of the caregivers want to learn how to deal with negative social behaviours. A serious problem such as cancer invariably means for the stricken person episodes of sadness, nervousness, anxiety and uncertainty (Smeltzer & Bare, 1996). One of the tasks of the caregivers is to provide psychological care to the patient (Bunting, 1989). According to Carey et al. (1991), the implementation of interventions aimed at minimizing the patient's anxiety is the most difficult task awaiting the caregiver. As they are aware of this difficult problem, nurses must assess the affective and psychomotor knowledge of the caregivers in the light of the patients' reactions. Thus they will help them to better understand their spouses' experience. Nurses may also encourage the caregivers to develop ways of being and doing that will help them to better carry out their role. Thus it is important that health professionals educate the caregivers about the manner in which to provide psychological care. The caregiver's desire to learn how to provide this care to a member of her own family has been evidenced in the work of Hardwick and Lawson (1996).

Most of the caregivers want to be informed about the probability of cancer remission or recurrence. According to Bélanger (1992), searching for this type of information can be risky business. Indeed, the person may obtain information that is likely to remind her of her spouse's suffering and life's finiteness. However, Krupp (1991) affirms that mature adults with a positive outlook about themselves do not hesitate to take risks to acquire appropriate knowledge. Griffith and Leek (1995) emphasize that the question most often asked by patients and families alike concerns the success rate of the selected cancer treatment. Along the same lines, Tringali (1986) declares that

families want to be informed about the evolution of the disease. It is up to the physician to provide information about the patient's response to treatment and indications about the patient's life expectancy. In a caring environment, nurses can clarify the explanations given by the physician, if necessary.

This study demonstrates that the caregivers are better informed about the physical problems their sick spouses may encounter when compared to emotional problems generated by the disease or its treatment. Indeed, the great majority of subjects want to know about the psychological impact of cancer and its treatment. This result concurs with Hardwick and Lawson's ideas (1996). These authors stress that families want to know about the psychological reactions brought about by cancer and its treatment.

More than two-thirds of caregivers want to know that cancer can disturb their relationship with their network of friends. When caregivers are being informed, it is important to specify that cancer can change relations with friends. Indeed, some friends will grow away from the family stricken by cancer and abandon it. On the other hand, others will make an effort to find a way of being at ease with this new situation and will offer their support to the family. In this study, more than half the caregivers want to understand cancer better. Thorne (1985) suggests that families need to demystify cancer before they are able to learn about the process of the disease. Many people still believe that pain and death are the inevitable outcomes of cancer. All authors agree in stating that cancer is a chronic disease that can, in the end, lead to death or not (Richardson, 1995). Within an educational relationship, nurses invite the caregivers to share their perceptions of cancer and their related questioning. They encourage the caregivers to look at their prejudices and clarify them. The caregivers can then demonstrate a better understanding of the cancer phenomenon.

In reaction to such a high number of learning needs (26), it is important to generate a few hypotheses to explain the influence factors in the personal, professional and organizational areas. At a personal level, even though caregivers want to be informed, they may not bring their desire to learn to the forefront. They may not necessarily take the means to obtain the information. If caregivers do not ask questions of health professionals, the latter may think that the learning need has been met. Thus it is relevant to give more importance to the desire to learn. Moreover, one should make sure that the written documentation given to caregivers corresponds to their reading ability.

On the professional front, Wright and Dyck (1984) suggest that physicians tend to provide caregivers with fragmented information. They put forward the idea that physicians exert a certain control over the information to be transmitted to the patient and family. They also indicate that physicians expect nurses to collaborate with them in that respect. The nurse must play a more active role in the care-related learning. She should also collaborate with the multidisciplinary team to make sure the caregivers receive all the necessary information including understanding the disease process and the treatment received by their spouses.

With regards to the organizational front, ambulatory oncology clinics are receiving more and more patients and their stay is brief. It may well be that, pressed as they are for time, health professionals are not aware enough of the caregivers as learners. It would be appropriate to have a local phone line put in place for cancer patients and their families including the caregivers. This telephone service could be managed by a group of nurses with a thorough knowledge of oncology. This way, nurses could communicate information clearly by choosing words

**Table Two: Average and median values for the 15 items in the Caregiver Learning Needs Satisfaction Scale N=30**

Description of scale items: Learning needs related to...	Average*	Median*
1. The spouse's disease	3.57	3.50
2. The way to inform the children	1.90	2.00
3. The way to inform his parents and our friends	1.97	2.00
4. The treatment followed by the spouse	4.27	4.00
5. The tests taken by the spouse	3.57	3.00
6. The physical side effects	3.17	3.00
7. The psychological impact	1.53	1.00
8. The means to help the husband physically	3.00	3.00
9. The means to help the husband psychologically	1.57	1.00
10. How to deal with the situation	1.50	1.00
11. The husband's roles	2.47	2.00
12. The husband's relationships	2.07	2.00
13. The husband's work for pay	3.21	3.00
14. The progression of the disease and the couple's future plans	1.93	1.50
15. Resources available in the community	3.13	3.00

\* Possible ratings are between 1 and 5: (1) Not At All Satisfied (2) Little Satisfied (3) Satisfied (4) Quite Satisfied (5) Very Satisfied

that are understood by their audience (Chalifour, 1993). They could then perform an evaluation to see if the information was understood by the caregivers and if their learning need was met (Hardwick & Lawson, 1996).

This research study demonstrates that caregivers express some dissatisfaction regarding learning needs mostly related to personal concerns. In particular, the caregivers' dissatisfaction is aimed at the psychological aspect of care. But caregivers report satisfaction about their learning needs connected to their spouses' health problems. It is possible that health professionals give more importance to the learning regarding the physical aspect of care compared to the psychological. In addition, it would appear that the information provided is aimed more at the patients than at the personal concerns experienced by their caregivers. This study demonstrates that the learning needs most frequently expressed by caregivers are associated with a higher dissatisfaction rating.

## Conclusion

This study demonstrates that caregivers did not acquire enough cognitive knowledge, affective knowledge and psychomotor knowledge regarding the cancer phenomenon and the care they are expected to provide to their spouses. In this research, it is obvious that caregivers want to learn. One can feel they have an open mind to express the information they are after. It may be that the caregivers do not bring their desire to learn to the forefront. They

do not necessarily take justifiable actions to obtain information. Then the information may not have been given or it may not have been understood. This study presents the limitations that ought to be stressed. This study favored the convenience sampling. Therefore the results only apply to the studied sample and are impossible to generalize. The instruments used were adapted and validated after being translated from English into French, thus limiting the scope of the study. Data collected from the subjects are influenced by their own capacity to describe their reality. Learning needs were assessed selectively via a single interview.

Due to the high number of learning needs observed in caregivers, several research trails merit future exploration. One such study could focus on the personal, professional and organizational influence factors associated with caregivers' learning needs. Another study of a phenomenological nature could undertake the exploration of the perceptions of nurses and physicians regarding the caregivers' learning needs and identify the importance given to these by health professionals. The new ambulatory approach to care may incite researchers to direct their attention more toward informal education. Numerous research avenues beg to be explored regarding supporting caregivers in a learning situation.

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