

FAMILY CAREGIVING AT THE END OF LIFE CARE

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Abstract

Aim: A study of the relationship between the burden of family caregivers, the overall life quality of caregivers and caregivers' satisfaction in providing care to dying patients.

Methods: This quantitative prospective study used three standardised questionnaires as the means of data collection: Caregiver Strain Index – the assessment of the burden of a caregiver, Caregiver Quality of Life Index Cancer – identification areas of the life quality of a caregiver and FAMCARE – the assessment of the satisfaction with providing care. The research sample consisted of 263 caregivers providing care to dying patients.

Results: The results of the correlation analysis showed a linear relationship between the burden, the satisfaction and overall life quality of caregivers ($p < 0.05$) as well as significant differences among the monitored components in terms of forms of providing care. The caregivers whose relatives have been provided palliative/hospice care indicate the lowest strain, the highest satisfaction with the care and the best overall quality of life.

Discussion: The results of our study accept the conclusion of several studies and systematic reviews. The results confirmed that the caregivers themselves, providing the care for the dying, require care and support of their life quality from the nurses.

Conclusion: Clinical practice should focus on ways of empowering families and public education, as well as intensifying home care, risk assessment, and training practitioners in end of life care.

Key words: caregiver; end of life care, burden; quality of life; satisfaction; nursing

INTRODUCTION

One of the fundamental principles of caring for a dying person is that the patient and family represent the unit of care together (Hudson et al. 2008). Although most patients die in the hospital setting, most of the care prior to dying is carried out at home by family members with the support of health care professionals.

Family members may be called on to provide primary care at home when a patient receives aggressive or disabling

treatment in an outpatient setting or when treatment has transitioned into palliative care. Caregiving to patients with different types of cancer and other terminal diagnoses can create caregiver burden and strain. Extremely high physical and emotional demands are placed on caregivers, and the disease itself creates major cognitive and emotional disruptions of normal patient behaviour (Northouse et al. 2007). Age, gender, cultural background, ethnicity, socioeconomic status, educational level, personal health,

and family dynamics work together as integral factors in predicting the caregiver's reaction to this demanding role (Gaugler et al. 2008, Gourdji 2009, Tamayo 2010). In addition, family caregivers often report an information deficit in providing care to the dying person. Caring for the dying person often involves participation in personal hygiene needs, administration of medication by non-invasive or invasive routes, attention to nutritional needs, psychological support, and emergency management of such problems as pain, dyspnoea, or bleeding (Cameron et al. 2002, Mellon 2002). The heavy physical work of transferring a weak or immobile patient, and meeting other needs (such as laundering or cleaning), is often further compounded by exhaustion due to sleep deprivation as a result of anxious thoughts or patient care needs (Cannaerts 2004). Assessing the family caregivers needs as a system and determining appropriate interventions are important during end of life care. Caregivers' assessments should encompass medical variables, psychosocial concerns, and the adequacy and availability of support, as well as the overall life quality of the caregivers and satisfaction with providing care to dying patients (Peters 2006). Identifying and addressing the numerous variables leading to an improved or decreased quality of life and well-being in caregivers early in the treatment plan would benefit caregivers and patients with terminal diseases (Glozman 2004, Brener 2007). In our socio-cultural context, we find only the quantitative methodology designed to assess the burden on the caregiver in providing care to the dying (Tabaková and Václaviková 2008), although there is an absence of research aimed at assessing the life quality of the caregiver's as well as intervention studies in relation to the role of the caregiver.

Our research is the first study in the Slovak Republic, focusing on the quality of life of non-professional caregivers and brought, despite the limits of the study, original results in our social and cultural context.

As a consequence, the aim of the study was to find a linear relationship between the caregivers' burden, the overall quality of the caregivers' life, the individual areas of caregivers' quality of life and the caregivers' satisfaction with the providing care to the dying.

MATERIALS AND METHODS

The research sample consisted of 263 caregivers. Data were collected from January 2009 to June 2010 after obtaining their informed consent. The first group of respondents consisted of 100 caregivers who participate in providing care to dying relatives at home. The second group consisted of 85 caregivers whose relatives have been provided hospice care in a hospice. The last group of 78 respondents were caregivers who provide combined care (home care in combination with institutional hospital care). Items relating to the general identification of the respondents were focused on gender, the age of the caregiver, form and length of providing care and the relationship between family caregivers and a dying patient.

The inclusion criteria were:

1. the age of the respondent is 18 years or more;
2. caregivers who provide care to the dying with a type of cancer for longer than 1 month (Weitzner and McMillan 1999);
3. absence of serious diseases have not been included in the research sample;
4. willingness to cooperate;
5. signed informed consent to participate in the research.

The exclusion criteria were:

1. the age of the respondent is less than 18 years;
2. respondents who provide care to the dying for less than 1 month;
3. respondents with cognitive changes or mental diseases;
4. serious chronic somatic disease in caregivers;
5. unwillingness to cooperate, unsigned informed consent.

Data collection

The administration of questionnaires was carried out by direct contact and individual meetings with non-professional caregivers who have been providing care to the dying in a home environment with a type of cancer, as well as with caregivers during the hospitalisation of patients in a hospice. Filling in the questionnaire was combined with semi-structured interviews due to the more

detailed assessment of the impact of caring for the dying on the life quality of caregivers. Caregivers were given information about the research and signed an informed consent. The time duration of meetings varied in time between 30–45 minutes. Caregivers, whose relatives are provided combined care, were after obtaining informed consent and the provision of adequate information, required to complete questionnaires by the head nurse of the Department of Palliative Medicine in Trstena.

The sample consisted of non-professional caregivers, who provided care for longer than 1 month. This is the boundary length of providing care, since the largest changes in particular life quality areas are seen by primary caregivers (Weitzner and McMillan 1999). A total of 285 questionnaires were distributed and 93% of them were returned.

This quantitative prospective study used three standardised questionnaires as the means of data collection.

1. *The Caregiver Strain Index* is a brief instrument containing 13 statements about strain experienced by caregivers with dichotomous yes/no answers. The total score is the number of yes answers. A total score of 7 or more is considered to reflect a high burden (Robinson 1983).
2. *The Caregiver Quality of Life Index – Cancer* – the evaluation of the quality of life of caregivers providing care to the dying (Weitzner, McMillan, 1999), consisting of 35 items which respondents evaluated on the 5 point Likert scale from 0 (never) to 4 (always). This tool assesses the quality of life in four areas: (1) physical and emotional health (2) social status, (3) social support and positive adaptation, (4) financial concerns. To achieve higher scores in the individual dimensions of quality of life it means a poorer quality of life for caregivers (Weitzner et al. 1999).
3. *FAMCARE* – the assessment of satisfaction with providing care (Kristjanson 1993), which contains 20 items with possible responses on the Likert scale from 1 (very dissatisfied) to 5 (very satisfied with care). Higher average scores indicate the higher satisfaction of the caregiver with the care provided (Kristjanson 1993).

After obtaining user permissions for the questionnaires from the developer of the

original version of instruments, the authors of the study provided two independent translations of the questionnaires into the Slovak language. The first translation was carried out by an expert of nursing; the second translation was carried out by a native speaker in Slovak and fluent in English. After this phase a back translation from the Slovak to English language with native speakers of English and fluent in Slovak was carried out. The authors reviewed the translation of the instrument with the work team – authors of research, doctor, clinical psychology, expert of nursing in the Jessenius Faculty of Medicine, Department of Nursing. The final versions of the instruments were subjected to the same psychometric analysis. Evaluation of internal consistency of the Slovak version of CSI, CQOL-C and FAMCARE through the Cronbach alpha coefficient was based on examining correlations between items. Cronbach alpha values were achieved for the entire range in a group of caregivers from 0.778 to 0.955. Given the results of analysis of reliability and characteristics of the file, we can conclude that all questionnaires are appropriate for caregivers providing care to the dying.

Statistics

A statistical analysis was performed with the SPSS 17.00 statistical program version. The total number of respondents who answered the item (n), mean (x), standard deviation (SD), minimum (min.) and maximum scale values of responses (max.) were found for each item of the questionnaires, for the evaluation of the sample. The non-parametric Kruskal-Wallis ANOVA-P (K-W) test statistics H with a significance level of 5% ($p \leq 0.05$) was used for the categorical variables with multiple values (form of providing care – home care, palliative care and combined care). The Spearman correlation coefficients $r(S)$ at the significance level of 5% ($p \leq 0.05$) were used to detect the relationship between the total score values obtained in all three questionnaires and the score in the CQOL-C quality of life questionnaire domains. The evaluation of internal consistency of the Slovak version of CSI, CQOL-C and FAMCARE through the Cronbach alpha coefficient was based on examining correlations between items. Cronbach's alpha values varied from 0.778

to 0.955 for the entire range in a group of caregivers. Given the results of analysis of reliability and characteristics of the file, it can be concluded that all questionnaires are appropriate for the caregivers providing care to the dying.

RESULTS

The study participants ranged in age from 19 to 77 years, the mean age of respondents was 47 years. The research sample consisted of 142 women and 121 men. The mean length of providing care was 26 months. In terms of competent family caregivers providing care to

the dying 86 were spouses, 103 children and 74 other relatives (siblings and grandchildren of the dying patients). Table 1 shows the characteristics of the sample of respondents in terms of forms of providing care (home care/combined care/palliative care). The Chi-squared test revealed statistically significant differences in the length of providing care and in the age of the caregivers ($p \leq 0.05$). No statistically significant differences were founded in the gender of caregivers and in the relationship between caregivers and dying patients.

On the basis of the specific research objectives, the following hypotheses have been formulated:

Table 1. Demographic characteristics of caregivers

| Demographic characteristics | | Home care | Palliative care | Combined care | P(chi ²) |
|-----------------------------|-----------------|-----------|-----------------|---------------|----------------------|
| Gender | Women | 51 | 42 | 49 | 0.664 |
| | Men | 49 | 36 | 36 | |
| Age | x | 52.88 | 43.47 | 47.63 | 0.000 |
| | SD | 13.55 | 14.09 | 14.48 | |
| Length of providing care | x | 38.91 | 2.25 | 37.23 | <0.005 |
| | SD | 17.74 | 1.09 | 10.17 | |
| Relationship | Children | 35 | 28 | 40 | 0.191 |
| | Partners | 35 | 31 | 20 | |
| | Other relatives | 30 | 19 | 25 | |

Legend: Chi-squared test indicates statistically significant differences in the length of providing care and in the age of the caregivers ($p \leq 0.05$).

Hypothesis 1: We assume a linear relationship between the burden of caregivers, the overall life quality of the caregivers, and the individual areas of the caregivers' quality of life (Table 2).

Of the following of the results of statistical analysis we can conclude that **hypothesis H1 is supported ($p \leq 0.05$)**. Items of burden and items of quality of life showed a positive linear correlation. The above table shows that at higher load (increasing scores of burden) worsens the quality of life of caregivers (increasing score of quality of life) as well as each domain quality of life.

Hypothesis 2: We assume a linear relationship between the caregivers' satisfaction with the care provided for the dying, burden and overall quality of life of caregivers (Table 3).

Based on the results of statistical analysis we can conclude that **hypothesis H2 is supported by ($p \leq 0.05$)**. In Table 3 above, we interpreted the correlation between the total burden score, the overall satisfaction score and overall quality of life scores of the caregivers and individual items in the quality of life of domains. For respondents providing care to dying patients, there is an indirect linear relationship at a significant level of 5% ($p \leq 0.05$) between the satisfaction of providing care and level of caregivers' burden and the overall life quality of caregivers, as well as individual domains of life quality. The results show that the increasing burden and quality of life is reduced caregiver satisfaction with providing care.

Table 2. Correlations between burden, the life quality of caregivers, and the areas of the caregivers' quality of life

| n=263 | | Quality of life | Physical/emotional health | Social domain | Social support/positive adaptation | Financial concerns |
|------------------------------------|--------|-------------------|---------------------------|-------------------|------------------------------------|--------------------|
| | Burden | r | 0.850 | 0.762 | 0.806 | 0.563 |
| | p | <0.0005 | <0.0005 | <0.0005 | 0.000 | 0.000 |
| Quality of life | r | | 0.960 | 0.959 | 0.449 | 0.763 |
| | p | | <0.0005 | <0.0005 | 0.000 | 0.000 |
| Physical/emotional health | r | | | 0.894 | 0.279 | 0.709 |
| | p | | | 0.000 | 0.003 | 0.000 |
| Social domain | r | | | | 0.352 | 0.713 |
| | p | | | | 0.002 | 0.000 |
| Social support positive adaptation | r | | | | | 0.222 |
| | p | | | | | 0.004 |

Legend: The table rows contain data on the affinity (correlation – Spearman's correlation coefficient) between the individual scales of quality of life with items for assessment for overall quality of life and overall burden. Data are evidential on the maximum level of significance of 5% ($p \leq 0.05$).

Table 3. Correlation between burden, quality of life of caregivers and satisfaction with providing care of caregivers

| n=263 | Satisfaction | |
|------------------------------------|---------------|--------------|
| | r | p |
| Burden | -0.450 | 0.008 |
| Quality of life | -0.580 | 0.000 |
| Physical and emotional health | -0.596 | 0.000 |
| Social domain | -0.551 | 0.001 |
| Social support/positive adaptation | -0.279 | 0.004 |
| Financial concerns | -0.488 | 0.000 |

Legend: The table rows contain data on the affinity (correlation – Spearman's correlation coefficient) between the individual scales of quality of life, overall quality of life, and overall burden with items for assessment for satisfaction with providing care. Data are evidential on the maximum level of significance of 5% ($p \leq 0.05$).

In addition to the identified correlated pairs between burden, satisfaction and quality of life, the linear relationship in three components in terms of forms of providing care were confirmed in the study. We can interpret the correlation between the total burden score, the overall satisfaction score and overall quality of life scores of the caregivers and individual items of quality of life of nonprofessional caregiver domains that provide care to dying patients in the home

environment. The above results indicate that a higher burden worsens the life quality of caregivers in all domains of life quality. Caregivers in this group reported problems with managing symptoms of the dying (especially pain), social support and optimising the actual performance of patients. In this group caregivers did not show a statistical significance of direct/indirect correlation between the degree of burden, quality of life and satisfaction with providing care. Next,

we present the results of correlation analysis between the three components of caregivers whose relatives are the services of hospice and palliative care. A direct linear relationship was observed between the overall quality of life and emotional domain of quality of life and financial concerns. These caregivers said that the multidisciplinary team of palliative care especially help them with the management of symptoms and reduce their physical burden. The results show that the incidence of symptoms in the dying may influence the incidence of emotional and financial problems, and thus the overall life quality of caregivers.

For caregivers whose relatives are in combined care services (home care in combination with palliative/hospice care) a positive linear relationship is shown in correlation to the total score and the score of the social domain of emotional and physical health. Positive linear relationships observed the overall burden on physical and emotional health domains. The results indicate that a higher burden worsens the life quality of caregivers in these quality of life domains. Statistically significant correlations were found between the burden score and overall score of satisfaction with providing care, in that the increasing burden of caregivers of this group decreases their overall satisfaction.

DISCUSSION

The first aim of our study was to assess the linear relationship between the burden of caregivers, the overall life quality of the caregivers and the individual areas of the caregivers' quality of life. Progress and the impact of chronic illness on the patient's life can influence their life style, and as such complex chronic illnesses can negatively affect the quality of life of patients as well as primary caregivers (Chrastina et al. 2009). The results of the correlation analysis confirmed a direct relationship between the burden, the overall quality of life as well as various domains of the caregivers' quality of life when providing care to dying patients. The results of several studies (Meyers and Gray 2001, Cohen et al. 2006, Hanson 2007) addressing the issue of caregivers' strain confirmed that caring

for the dying has a negative impact on the physical, psychological, social, economic and spiritual sphere of the caregivers' life quality. The home environment is rich with benefits that enhance patient comfort, but it also provides challenges in providing optimum physical, psychosocial, and spiritual care. We frequently observe the occurrence of these problems for caregivers who are for the first time confronted with death and are not ready to provide care for a dying family member. Cohen et al. (2006) noted the presence of increased depressive symptoms, anxiety, psychosomatic symptoms, restrictions of roles and activities, burden in marital relationships and reducing physical health among family caregivers. Kim and Given (2008) reported that patient symptoms and symptom distress, declined mobility, and dependency with instrumental patient activities were linked to a significant burden on family caregivers. The positive correlations we found among burden, total quality of life and social support and positive adaptation.

Stajduhar (2003) shows, that caregivers report the unmet needs of dying patients associated with social support financial assistance, emotional support and assistance with managing the dying person's symptoms. Activation of social support, not only in terms of cooperation with other family members, who were also contacted to indicate the formal and informal groups, is an important element of support to caregivers after the death of a relative in the prevention of complicated grieving (Gurková 2009).

In our research we focused on finding the burden correlated with the overall life quality of a caregiver, how it affects various aspects of life quality in caring for the dying, and the degree of stress and the caregivers' quality of life being affected by one of the main determinants of life quality – the satisfaction with providing care. The satisfaction of caregivers was assessed as the most important item designed to provide information and satisfaction with the information provided. Satisfaction as one of the main determinants of quality of life significantly affects the life of the individual caregivers. Our results and the results of several studies (e.g. Weitzner et al. 1999, Pinqart and Sörensen 2005, Peters 2006) show that a caregiver's dissatisfaction with the information provided has a direct

impact on caregiver burden and negative evaluation of their quality of life.

Next, we presented the results of correlation analysis between the three components of caregivers who provide home care, palliative and combined care. Because family caregivers have been playing a central role in the wellbeing of most people with a terminal illness, it is important that attention is given to their needs and experiences. However, the principle of regarding the needs of the family and the patient as equally important in care provision is not always upheld, with caregivers' needs usually overshadowed by concerns about the patient's comfort, practical care, information needs, and emotional support (Schumacher et al. 2002, Stajduhar 2003, Harding 2004, Lee and Cameron 2004).

Caregivers in our research and in other studies (Bruera et al. 2003, Salmon et al. 2005, Ferrell and Whitlatch 2007, Lingler et al. 2008), who provided home care to dying patients, suggest the negative impact of care on various aspects of the caregivers' life quality in terms of information deficit, changes in an established way of life, physical and mental burden, the change of roles among family members, which greatly affects the overall quality of life and satisfaction of the caregivers. The needs of patients and family caregivers in home care span the domains of quality of life. Home care needs most often involve physical needs, such as the management of pain and other symptoms, and treatment of the side effects associated with treatment of the illness (Peters 2006). The results confirmed the physical symptoms of caregivers: fatigue, sleep disturbances and loss of appetite. This might be connected to the fact that the recipient of care during illness may experience troublesome symptoms, which may have a negative impact on the provider of health care. The psychological aspects, most frequently described by the caregivers, are emotional distress, nervousness, fear and depression (Goetschius and LaPorte Matzo 2006). Several authors (Hudson 2004, Brener 2007) also show the impact of caring for the dying on family relations and social spheres. Cohen (2006) argues that the life quality of patients with an incurable disease, and their family, is better the smaller the difference between the expectations and perceptions of

individuals about life and the reality of real life. An additional burden of family caregiving, often neglected, are the costs assumed by patients and family caregivers themselves in relation to pain management and home care. Families incur significant expenses related to home care in advanced illness, much of which is not reimbursed. Costs include direct expenses, such as medications, as well as extensive indirect costs such as loss of wages. Most of the cost savings to third-party payers have resulted in increased costs assumed by patients and families (Goetschius and LaPorte Matzo 2006).

The most frequent changes included the lack of family support, changes in the reallocation of labour between family members, as the roles and responsibilities previously performed by a sick family member are moved to other members, or remain unrepresented. Progressive illness and subsequent home care for family members raises frustration, affects them in many ways, may restrict their life style and perspectives, and may cause disruption of family relationships, because family members may feel that they are not able to handle the situation or may fail to provide adequate care to the dying relative (Glozman 2004, Gourdjii 2009, Tamayo 2010).

Cooperation with the family of the dying requires a comprehensive approach in assessing the role of a caregiver, interaction among caregivers and recipients of care, as well as planning and implementing interventions that result from the evaluation of problems and needs of the family (Hudson 2004, Peters 2006).

Caregivers whose relatives are provided combined care observed a direct relationship between the degree of burden, the overall quality of life and a caregivers' physical health domain. Recognising the results of our study, it can be concluded that the form of care appears to be the least effective. These results explain the frequent changes of care, caregivers' concerns about the worsening health of the patient, as well as the unpreparedness of nurses and other members of a multidisciplinary team to work with families of the dying in a hospital. These differences are in accord with the results of foreign studies (Hudson 2004, Hudson et al. 2008).

The palliative services and hospice care are considered as the most effective form of providing care for the dying. The caregivers in this group reported higher satisfaction with the care, improving their quality of life especially in the emotional domain. The lowest strain, the highest level of satisfaction with the care and the highest score of overall quality of life was found in this group of respondents. Similar results are indicated in the study of Finlay et al. (2001) in a systematic review aimed to assess the quality of life for patients and caregivers in providing palliative care at home, in hospices and hospital. Caregivers, show higher satisfaction with providing the care, lower strain as well as better control of pain and other annoying symptoms for the patient. These caregivers suggest that they were educated about the annoying symptoms of the patient resulting from disease and from treatment by the nursing staff, which resulted in the positive evaluation after being discharged from hospice to home care. Bužgová and Sikorová (2010) using the approach of evidence based practice, found no significant differences between the standard care for dying patients and specialist palliative care and the impact of specialist palliative care on the psychosocial well-being and satisfaction of patients and caregivers. Evidence for the impact of specialist palliative care on the life quality of patients and caregivers was found mainly in qualitative studies where a higher rate of unmet needs and lower quality of life was found in caregivers caring for patients dying of end-stage chronic diseases or dementia patients (Gourdjji 2009).

CONCLUSION

Caring for dying patients is as complex as a result of changing patient and family caregiver characteristics. The assessment of burden and caregivers' quality of life leads to the identification of the problems and needs of caregivers and is an important aspect of planning for effective interventions, based on their specific problems (Tabaková 2011). The results of our study indicate that caregivers providing care for the dying require the care and support of nurses for their quality of life.

Assessing the caregiver can be an opportunity to educate nurses and multi-disciplinary teams of palliative care about the changes that occur in relationships as the family tries to cope. Clinical practice should focus on ways of empowering families and public education, training practitioners and providing strategies and interventions aimed at minimising the burden and improvement of their quality of life. These interventions include a range of suggestions about physical care, including the transfer of information about physical care back to the families, offering validation and support to families for their efforts in home care, and interventions to improve communication. One way to minimise the burden and negative evaluation of a caregiver's quality of life is by using the services of palliative and hospice care, which is confirmed by the results of our research and various other studies.

ETHICAL CONSIDERATIONS AND CONFLICT OF INTEREST

The study was approved by the ethics committee of Comenius University in Bratislava, Jessenius Faculty of Medicine in Martin, and was not proposed for publication in any other professional periodical. The authors declare that the study had no conflict of interest.

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