

Feelings of rewards among family caregivers during ongoing palliative care

ANETTE HENRIKSSON, PH.D., C.N.S.,¹ IDA CARLANDER, PH.D., R.N.,² AND KRISTOFER ÅRESTEDT, PH.D., R.N.³

¹Palliative Research Centre, Ersta Sköndal University College and Ersta Hospital, Stockholm, Sweden; Capio Geriatrics, Palliative care unit, Dalens hospital, Stockholm, Sweden; Department of Neurobiology, Care Sciences and Society, Division of Nursing, Karolinska Institutet, Stockholm, Sweden

²Palliative Research Centre, Ersta Sköndal University College and Ersta Hospital, Stockholm, Sweden; Department of Learning, Informatics, Management and Ethics Medical Management Center, Karolinska Institutet, Stockholm, Sweden

³Department of Medical Health Sciences, Linköping University, Linköping, Sweden; School of Health and Caring Sciences, Linnaeus University, Kalmar, Sweden; Palliative Research Centre, Ersta Sköndal University College and Ersta Hospital, Stockholm, Sweden

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ABSTRACT

Objectives: Palliative family caregivers appear to experience the rewards of caregiving concurrent with burdens and negative feelings. Relatively few studies have attended to the positive and rewarding aspects in palliative family caregiving. In addition, most studies on rewards are retrospective and examine the experiences of bereaved family caregivers. The present study aimed at describing feelings of reward among family caregivers during ongoing palliative care. A further aim was to compare the experience of rewards in relation to sex and age.

Methods: The sample consisted of 125 family caregivers and took place in three specialist palliative care units and one hematology unit. Participants answered a questionnaire including demographic background questions and the Rewards of Caregiving Scale (RCS). Descriptive statistics were employed to describe characteristics of the participants and the level of rewards. A Mann–Whitney *U* test was used to compare differences between groups of different sex and age.

Results: Palliative family caregivers reported general high levels of reward. The greatest source of rewards involved feelings of being helpful to patients. This was closely followed by giving something to patients that brought them happiness and being there for them. The smallest sources of rewards were related to personal growth, self-satisfaction, and personal meaning. There was also an association between rewards and age but not between men and women.

Significance of results: Family caregivers experienced the rewards of caregiving during ongoing palliative care despite their unique and stressful situation. Feelings of reward seem to be about handling a situation in a satisfying way, feeling competent and confident to take care of the patient and thereby feeling proud. Support could preferably be designed to improve a family caregiver's ability to care and to facilitate the positive aspects and rewards of caregiving and focus on strengths and resources.

KEYWORDS: Palliative care, Family caregivers, Rewards, Caregiving

BACKGROUND

Family caregivers are central to providing care for patients with life-threatening illnesses (Aoun et al., 2005; Grande & Ewing, 2008). Caregiving has been described as a natural process—something

Address correspondence and reprint requests to: Anette Henriksson, Ersta Sköndal University College, Ersta Hospital—Palliative Research Centre, Stockholm, Sweden. E-mail: anette.henriksson@erstadiakoni.se

done partly out of love, but also out of feelings of obligation and responsibility (Carlander et al., 2010). Being a family caregiver may involve considerable physical, emotional, and social challenges, and the situation is often arduous and exhausting (Hudson et al., 2004; Eggenberger & Nelms, 2007; Grande et al., 2009). It is important to stress the uniqueness of palliative family caregiving in the context of facing the emotional challenges associated with loss and approaching death. Several investigators have identified the negative and distressing consequences experienced by family caregivers in palliative care (Wennman-Larsen & Tishelman, 2002; Brazil et al., 2003; Proot et al., 2003; Hudson et al., 2011). When a patient's illness progresses to more advanced stages, with more symptoms, greater loss of physical function, and more complex care needs, family caregivers are more likely to be distressed (McCorkle et al., 1998; Given et al., 1999; Brazil et al., 2003).

While the difficulties associated with palliative family caregiving have been extensively studied and recognized, less attention has been paid to the potential for favorable outcomes. It cannot be disputed that negative and distressing consequences exist and are often overwhelming, but research on caring has tended to play down the positive and rewarding aspects (Sinding, 2003). This lack of attention to the positive skews our understanding of the caring experience (Kramer, 1997). In fact, many family caregivers describe mixed emotions regarding their caregiving role and highlight both negative and positive aspects (Smith, 2004). Although palliative care is recognized as being emotionally draining (Payne et al., 1999; Waldrop, 2007), some studies have revealed positive aspects of family caregiving, including increased closeness and strengthened relationship with the person cared for and the experience of caring as a privilege (Hudson, 2004; Jo et al., 2007).

Palliative family caregivers appear to experience positive consequences and rewards concurrent with burdens and negative feelings. The caregiving experience seems to carry the potential for a deepened sense of meaning, greater connection, and accompanying positive effect. Some studies have described how family caregivers experience feelings of satisfaction, thankfulness, and pleasure (Stajduhar & Davies, 2005; Andershed, 2006). Caring can be a way of demonstrating love and partially repaying a patient for what they have previously given (Stajduhar & Davies, 1998; Grbich et al., 2001). Other studies have shown that the caring experience can create personal enrichment, provide a feeling of meaning, and also contribute to increased insights and self-knowledge (Stajduhar, 2003; Oldham & Kristjanson, 2004; Wolff et al., 2007). Caregivers

have reported discovering emotional strength and new physical abilities (Jo et al., 2007). Positive and rewarding aspects may be important and meaningful for family caregivers in their endeavors to reconcile the difficulties and loss they have experienced (Wong et al., 2009). Some studies indicate that experiences of caregiving vary between groups of different sex and age (Diehl et al., 1996; Lockenhoff et al., 2008). However, few studies have examined sex and age in relation to positive outcomes for family caregivers in palliative care.

Of those few studies which have paid attention to the positive and rewarding aspects of palliative family caregiving, most are retrospective and thus examine the past experiences of bereaved family caregivers (Koop & Strang, 2003; Hudson, 2004; Wong et al., 2009). These retrospective studies seem to be more likely to report the positive features of caregiving (Mangan et al., 2003). It is possible that family caregivers may reconstruct their caring experiences as positive and rewarding as a way of attributing positive meaning to the situation and diminishing the negatives.

AIM

The aim of our study was to describe feelings of reward among family caregivers during ongoing palliative care. A further goal was to compare the experience of reward in relation to sex and age.

METHOD

Settings, Sample, and Procedure

Data were obtained from a quasi-experimental study of an intervention for family caregivers of patients with life-threatening illness (Henriksson et al., 2012). The intervention consisted of a psychoeducational group program (six meetings) aimed at increasing preparedness for caregiving and to support well-being among family caregivers. The inclusion criteria were being: (1) over 18 years of age, (2) able to understand Swedish, and (3) identified as a family caregiver by a patient receiving specialized palliative care. All participants were individually approached by caring staff at the study settings and received written and verbal study information from the first author. A total of 125 family caregivers gave their written informed consent to participate and completed the baseline assessment, which was handed out by the caring staff and returned by post to the first author after completion. Data were collected between January and December of 2009. Baseline data from an intervention group and a comparison group were used for

the analyses undertaken. Thus, all the data were collected from both groups before the start of the intervention.

The study took place in four settings. Three of these settings were specialist palliative care units that included advanced homecare and inpatient care for severely ill patients (mostly with cancer diagnoses). The patients had a life expectancy of approximately three months. The fourth setting was a hematology unit that included homecare and inpatient care for patients with malignant hematological diseases and brain tumors at different illness stages. All four settings delivered 24-hour services and were staffed by multidisciplinary teams. Ethics approval was obtained from a regional ethical review board (2008/341).

Measurements

The questionnaire included demographic background questions and the Rewards of Caregiving Scale (RCS). The RCS was originally developed in the United States. It consists of three subscales measuring rewards of caregiver learning, rewards of being there, and rewards of meaning for oneself (Archbold & Stewart, 1996). Our study employed an abbreviated version that included 10 items; the learning subscale was excluded due to a focus on caregivers for the elderly. Psychometric testing supported the use of one overall score (Hudson & Hayman-White, 2006). All items were assessed on a five-point Likert-type scale ranging from “not at all rewarding” (0) to “a great deal of reward” (4). A total score ranging from 0 to 40 was calculated by summing the responses for all items, with a higher score indicating more feelings of reward. The 10-item version of RCS has shown good validity and reliability among caregivers of patients in palliative care. A validated Swedish version was used in the present study (Henriksson et al., 2012), which had a Cronbach’s alpha of 0.93.

Data Analysis

Descriptive statistics were employed to describe the characteristics of the participants and levels of reward. Radar charts were created to illustrate the level of attachment for each separate item, and the Mann–Whitney *U* test was used to compare differences between groups of different sex and age. Age was categorized into two groups: younger (<65 years) and elderly (≥ 65 years). The statistical analyses were performed with Stata 12.1 (StataCorp LP, College Station, TX, USA), and the level of statistical significance was set at $p < 0.05$.

RESULTS

The Participants

The sample consisted of 125 family caregivers with a mean age of 58 ± 16 years. Most caregivers were women (61%), partners (58%), employed (48%), cohabiting with the patient (66%), and caring for the patient at home (76%). Further characteristics of the participants are presented in Table 1.

Feelings of Rewards

Palliative family caregivers generally reported high levels of reward (Table 2, Fig. 1). The largest source of reward was a feeling of being helpful to the patient (item 10, mean 3.4 ± 0.8). This was closely followed by a feeling of reward as a consequence of giving something to the patient that brought them happiness (item 9, mean 3.2 ± 0.9) and of just being there for the patient (item 6, mean 3.2 ± 0.9). These aspects of reward are all partially related to the item about making life easier for the patient, which was also a fairly large source of feelings of reward (item 3, mean 3.1 ± 0.9). The smallest sources of reward for the family caregivers in this study were personal growth (item 7, mean 2.3 ± 1.2), self-satisfaction (item 2, mean 2.4 ± 1.0), and personal meaning from caregiving (item 4, mean 2.7 ± 1.1).

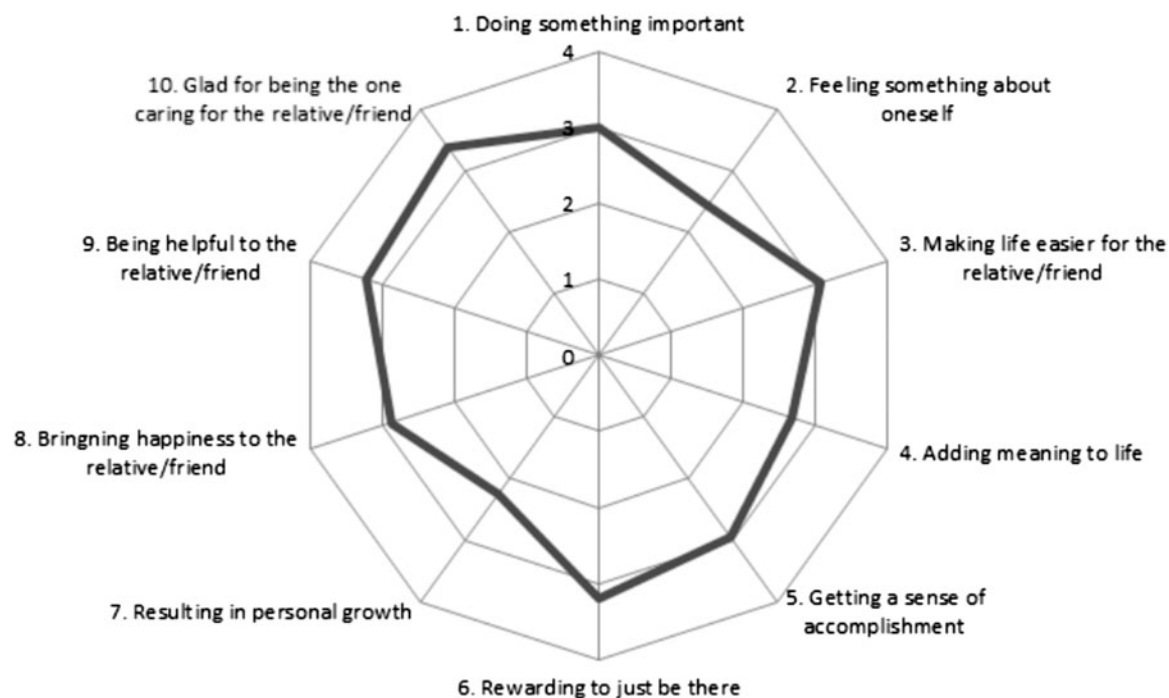
Table 1. Characteristics of participants (N = 125)

| | |
|--|---------------|
| Age, mean (SD) | |
| Caregivers | 57.7 (15.8) |
| Patients | 65.1 (12.3) |
| Gender, n (%) | |
| Women | 76 (60.8) |
| Men | 49 (39.2) |
| Employment, n (%) | |
| Employed full time | 60 (48.0) |
| Retired | 53 (42.4) |
| Sick leave | 6 (4.8) |
| Other | 6 (4.8) |
| Cohabiting with the patient, n (%) | |
| Yes | 83 (66.4) |
| No | 42 (33.6) |
| Relationship to patient, n (%) | |
| Spouses | 73 (58.4) |
| Adult children | 28 (22.4) |
| Parents | 5 (4.0) |
| Other | 19 (15.2) |
| Place for care, n (%) | |
| Home | 95 (76.0) |
| Care unit | 29 (23.2) |
| Unknown | 1 (0.8) |
| Time since diagnose (weeks), mean (SD) | 169.3 (233.9) |
| Diagnose, n (%) | |
| Cancer | 111 (88.8) |
| Other | 14 (11.2) |

Table 2. Level of attachment in relation to sex and age (N = 125)

| | All, Mean (SD) | Sex, Mean (SD) | | | Age, Mean (SD) | | |
|---|----------------|----------------|------------|-----------------------------|----------------|------------|-----------------------------|
| | | Women | Men | <i>p</i> Value ^a | <65 Years | ≥65 Years | <i>p</i> Value ^a |
| 1. Does caring for your relative/friend help you feel like you are doing something important? | 3.0 (1.0) | 3.0 (1.0) | 2.9 (0.8) | 0.204 | 3.0 (1.0) | 2.8 (0.9) | 0.163 |
| 2. Does caring for him/her help you feel good about yourself? | 2.4 (1.0) | 2.5 (1.1) | 2.3 (0.9) | 0.135 | 2.5 (1.1) | 2.3 (0.9) | 0.182 |
| 3. Is it rewarding because you feel you make life a little easier for your relative/friend? | 3.1 (0.9) | 3.2 (0.8) | 2.9 (1.0) | 0.191 | 3.1 (1.0) | 2.9 (0.8) | 0.052 |
| 4. Does caring for him/her add meaning to your life? | 2.7 (1.1) | 2.8 (1.2) | 2.5 (1.1) | 0.257 | 2.9 (1.2) | 2.3 (1.0) | 0.004 |
| 5. Does caring for your relative/friend give you a sense of accomplishment? | 3.0 (1.0) | 3.0 (1.0) | 2.8 (0.9) | 0.156 | 3.1 (1.0) | 2.7 (1.0) | 0.065 |
| 6. Is just “being there” for him/her rewarding to you? | 3.2 (0.9) | 3.2 (1.0) | 3.2 (0.8) | 0.506 | 3.3 (0.8) | 2.8 (1.0) | 0.005 |
| 7. Have you personally grown as a result of being a caregiver? | 2.3 (1.2) | 2.3 (1.2) | 2.3 (1.1) | 0.816 | 2.5 (1.1) | 1.9 (1.1) | 0.008 |
| 8. Do you feel glad that you are the one who is providing care to your relative/friend? | 2.9 (1.2) | 2.9 (1.2) | 2.8 (1.1) | 0.481 | 2.8 (1.3) | 2.8 (1.0) | 0.566 |
| 9. Is caring for your relative/friend rewarding because it makes him/her happy? | 3.2 (0.9) | 3.3 (0.9) | 3.1 (0.9) | 0.204 | 3.3 (0.9) | 2.9 (0.9) | 0.005 |
| 10. Is it rewarding to know that you are helpful to your relative/friend? | 3.4 (0.8) | 3.4 (0.8) | 3.3 (0.8) | 0.423 | 3.6 (0.7) | 3.1 (0.9) | 0.002 |
| RCS total score | 29.0 (7.8) | 29.5 (8.2) | 28.2 (7.2) | 0.216 | 30.1 (7.8) | 26.4 (7.7) | 0.008 |

RCS = Rewards of Caregiving Scale

^aMann-Whitney *U* test**Fig. 1.** Mean levels of rewards of caregiving for all caregivers.

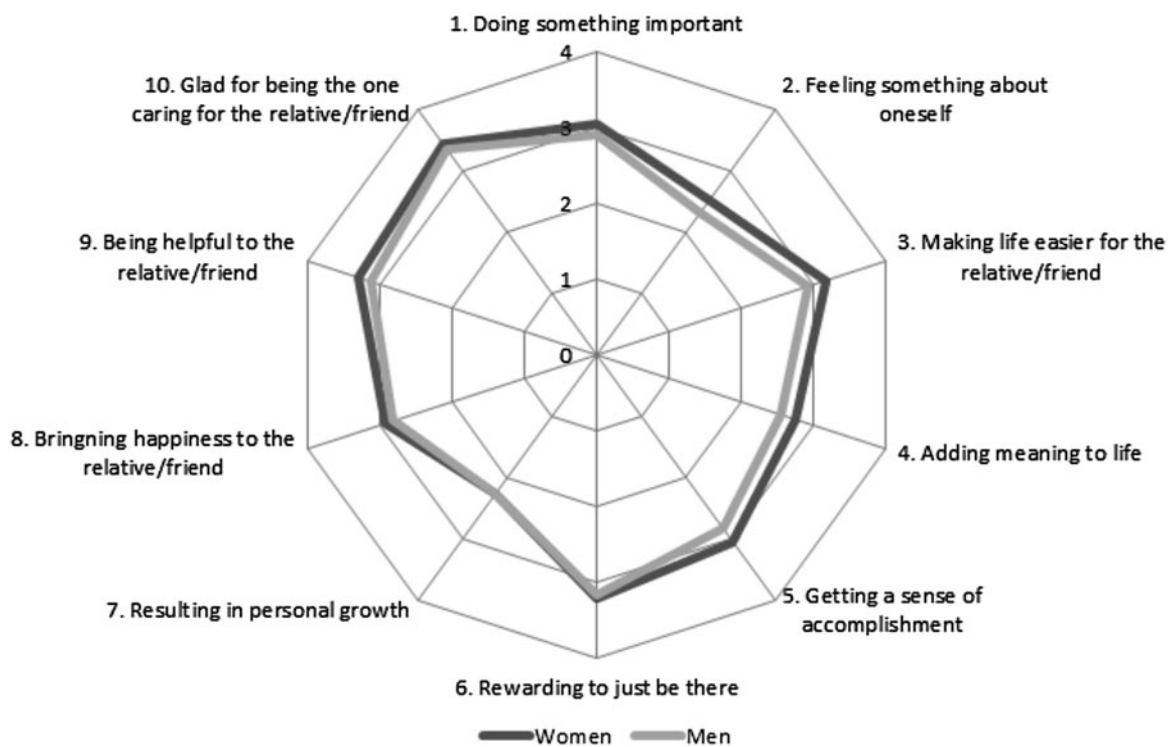


Fig. 2. Mean levels of rewards of caregiving for women and men.

There were no differences in feelings of reward between women and men (Table 2, Fig. 2). In contrast, age was associated with feelings of reward (Table 2,

Fig. 3). Overall, and in 5 out of 10 individual items, younger family caregivers reported significantly higher levels of reward compared to those aged 65



Fig. 3. Mean levels of rewards of caregiving for younger and older caregivers.

and older. The mean differences were largest for reward as a consequence of personal growth (item 7, $\Delta = 0.62 \pm 0.22$) and personal meaning from caregiving (item 4, $\Delta = 0.54 \pm 0.22$). Other items that were scored significantly higher by younger caregivers were just being there for the patient (item 6, $\Delta = 0.50 \pm 0.17$), being helpful to the patient (item 10, $\Delta = 0.49 \pm 0.16$), and being able to give something to the patient that brought them happiness (item 9, $\Delta = 0.42 \pm 0.18$).

DISCUSSION

Discussion of Results

These findings support previous research suggesting that palliative family caregivers experience the rewards of caregiving despite their often arduous situations. The largest sources of rewards concerned experiences of doing something good for the patient; specifically, being helpful and being able to provide something that brought happiness and made life easier for the patient. Similar findings have been reported among family caregivers of patients with Alzheimer's disease, whose largest source of caregiver satisfaction was bringing the patient happiness and pleasure. The same study found that the giving of pleasure was often based on simple acts of kindness, underpinned by previous knowledge of the patient's likes and dislikes (Lundh, 1999). This can be further compared with the findings of Sand et al. (2010), who revealed that family caregivers expressed a strong desire to foster the patient's well-being in the best possible way. These caregivers tried to keep the patient comfortable by maintaining everyday structures, by maintaining hope, and by standing up for dignity. Their actions were taken not only out of concern for the patients but also out of concern for themselves.

Wong et al. (2009) found that meeting the expressed needs of the patient, feeling truly helpful, and gaining the patient's appreciation were all rewarding to family caregivers. Jo et al. (2007) also found that appreciation from the patient was a source of reward and satisfaction for family caregivers. These are important aspects of reward. In addition, some caregivers feel better able to cope with the demands of caregiving when the patient recognizes and appreciates their caregiving efforts, when they do not feel taken for granted, and when the patient treats them with respect (Stajduhar et al., 2008).

The quality of the relationship between caregiver and patient may influence the caregiver's ability to cope with the caregiving situation (Stajduhar et al., 2008), and it seems reasonable that relationship quality would also influence family caregivers' feel-

ings of reward. Illness can change the nature and quality of the relationship between caregiver and patient. It sometimes makes people realize how much they appreciate one another, and this can make the relationship stronger. Family caregivers may experience a profound and positive change in the relationship with the person for whom they care, which can result in feelings of reward as a consequence of caring (Wong et al., 2009). Illness may actually result in deepened relationships within a family, with an increased consciousness of preciousness that creates a feeling of togetherness (Sand et al., 2010). It should be noted, though, that illness does not always affect the quality of these relationships in a positive way. Consequently, family caregivers with a strained or deteriorating relationship might not gain feelings of reward from bringing happiness to the patient. However, it might be possible that they will still feel rewarded as a consequence of standing up for, taking responsibility for, and staying with and caring for the patient despite everything else.

Reward may in some cases stem from doing something important that meets cultural expectations of "doing the right thing" (Wong et al., 2009). For most people, one reason for becoming a caregiver is that we have learned since childhood to commit ourselves to and feel responsibility for our family and friends. Caring for and helping family and friends is mostly seen as a basic human way to act (Sand et al., 2010). There is an imperative to provide the necessary care (Stajduhar, 2003), though the obligation to care is not in itself as negative as it may appear (Wong et al., 2009). Family caregivers may feel rewarded as a consequence of fulfilling social obligations (Zapart et al., 2007). They might experience caring as rewarding since they believe it is important and expected of them; they feel glad to do it because they believe it is the right thing to do. This is an important aspect to consider when undertaking research with scales and instruments. It could be that reward is something that people expect themselves to feel and think that others expect them to feel, and this may have an impact on their ratings.

In our findings, the second smallest sources of rewards were self-satisfaction and finding meaning in life as a consequence of caring, and the smallest source was personal growth. This was somewhat surprising, since the literature suggests that personal growth and finding meaning in life are often significant when it comes to feelings of reward. Caregiving has been described as involving reflection on life's values and existential concerns, including facing one's fears, strengths, and shortcomings. This may not be easy, but it is probably a source of personal development (Sand et al., 2010; Carlander et al., 2011).

One reason for this discrepancy may be that our study was conducted during ongoing palliative care. It is possible that finding meaning in life and experiencing personal growth as a consequence of caring can only be felt retrospectively, not while one is in the middle of the process. Previous researchers have described how the meaning and purpose of caring may only begin to crystallize sometime into the grieving process, when memories and emotions can be sorted through (Hoppes, 2005). However, it should be noted that persons in our study younger than 65 years felt significantly more rewarded as a consequence of personal growth and personal meaning from caregiving. In addition, we found (somewhat in contradiction to other studies) that younger caregivers overall felt more rewarded than their older counterparts.

METHODOLOGICAL CONSIDERATIONS

It is possible that our participants, in light of their agreement to participate in the study, represent a group of caregivers who were coping relatively well and feeling sufficiently supported and therefore experienced high levels of feelings of reward. It could be that caregivers who chose to participate in intervention studies were already naturally engaged in their role, and more likely to find benefit in it, than those who do not participate in such studies. There is also a need to critically examine the Rewards of Caregiving Scale that was employed for data collection. The items in the RCS are posed in a positive manner, which may contribute to higher scoring. However, many measurements are constructed in the opposite way, in order to capture negative aspects of caring. We reiterate that there is a need to focus on positive aspects in the context of palliative care. We believe that our findings highlight an important issue and contribute knowledge about and understanding of the rewards of palliative family caregiving.

CONCLUSIONS AND IMPLICATIONS FOR CLINICAL PRACTICE AND FUTURE RESEARCH

This study demonstrates that our family caregivers experienced the rewards of caregiving during ongoing palliative care notwithstanding their unique and often stressful situations. The largest sources of reward concerned being helpful to the patient and being able to provide something that brought happiness to and made life easier for the patient. The smallest sources of reward were self-satisfaction, finding meaning in life, and personal growth as a consequence of caring.

Although a considerable number of family caregivers experience poor psychosocial well-being, many will experience feelings of reward associated with this role. This does not mean that caregivers do not need support; on the contrary, they should be offered support that will help sustain them in their role and promote optimal psychosocial well-being (Hudson & Payne, 2009; Applebaum & Breitbart, 2013).

Feelings of reward seem, in fact, to be to a great extent about handling the situation in a satisfying way, feeling competent and confident in taking care of the patient, and thereby feeling proud (Salmon et al., 2005; Jo et al., 2007). Support could preferably be designed with the aim of improving family caregivers' abilities to care, facilitating positive aspects of caregiving, and focusing on strengths and resources (Grande et al., 2009; Carlander et al., 2011). Such psychoeducational interventions have already been found to increase feelings of reward (Hudson et al., 2005; 2009; Henriksson et al., 2013). More prepared family caregivers may be able to see the good with the bad, in order to reconcile the difficulties embedded in their caring experiences. However, it is important to avoid trying to explicitly encourage caregivers to think positively, since this might have a detrimental effect on those caregivers already challenged by the demands of caregiving (Stajduhar et al., 2008).

Family caregivers in our study reported feelings of reward during ongoing palliative care even though the patients were severely ill and many were close to death. However, the cross-sectional design of the study did not allow us to take into account the possibility that feelings of reward may change over time. There is a need for future research into palliative family caregiving using longitudinal methodology to offer important insights into the nature and consequences of rewards for family caregivers. This research should examine factors associated with rewards in addition to age and sex, such as relationship to the patient, cohabitation status, duration of illness, and place of care for the patient. There is also a need for knowledge about the associations of rewards with caregiver outcomes such as anxiety, depression, and health.

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