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"My Grandparent Has Dementia": How Adolescents Perceive Their Relationship With Grandparents With a Cognitive Impairment

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Abstract

The study examined the grandparent–grandchild relationship when the grandparent has dementia. Grandchildren living in Barcelona, Spain, participated in the study (n = 145). These participants completed a questionnaire that included questions on: (a) the frequency of 15 emotions they may have experienced in this relationship, (b) their current relationship with a grandparent who has dementia (frequency of contact, emotional closeness, and satisfaction with the relationship), and (c) perception of changes in the relationship. Results showed that the dementia process has a negative impact on the relationship between grandparent and grandchildren. However, in some cases, there was also potential for positive changes, which are mainly related to the ability to keep emotional contact and express positive emotions. Findings suggested the need to take into account grandchildren when planning training programs for families caring for relatives with dementia, such as providing information about the disease and improving their coping strategies.

Keywords

intergenerational relationships, dementia, grandparent, adolescent

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The main source of care for older people who have dementia is the family (Wolff & Kasper, 2006). Family care has attracted researchers' attention in the last few decades. Their research has focused mainly on the primary family caregiver and on how caring can negatively affect caregiver's health, mood, and social life (Dillehay & Sandys, 1990; Dunn & Strain, 2001; Schulz, O'Brien, Bookwala, & Fleissner, 1995).

From a systemic perspective, however, within a family context the informal care of older people with dementia could be distributed among several family members with different degrees of involvement (Ablittab, Jonesc, & Muersc, 2009; Keith, 1995; Pruchno, Burant, & Peters, 1997; Pruchno, Peters, & Burant, 1995). Moreover, caring for a person with dementia takes place in a multigenerational context, as not only may the spouse be involved in care tasks but also children, nephews, siblings, or grandchildren, among other family members (Cantor, 1991; Orel & Dupuy, 2002). Studies that examined the care duties of other family members apart from the primary caregiver have usually focused on grown-up children when the partner is the primary caregiver or on sons- and daughters-in-law when an adult child is the primary caregiver (Gaugler, Mendiondo, Smith, & Schmitt, 2003; Lieberman & Fisher; 1995; Penrod, Kane, Kane, & Finch, 1995).

Because of the aging population (and, therefore, the growing number of people affected by dementia), an increasing percentage of grandchildren are likely to experience having a grandparent with dementia. However, the relationship between grandchildren and grandparents who have dementia has received little scientific attention (Celdrán, 2004). For many reasons, having a grandparent with dementia can have a strong impact on grandchildren. This could include the deterioration of previous bonds with the grandparent, the emotional impact of witnessing grandparent's decline (Hodgson, 1992; Kemp, 2005), and the stress on the family system (Lieberman & Fisher, 1995). This impact may be even greater on adolescent grandchildren because it coincides with normative adolescent changes (e.g., physical changes, the redefinition of family and peer relationships, identity construction), which sometimes cause tension and stress among teenagers (Santrock, 2003). Some authors have found that a grandparent's dementia has a negative impact on their grandchildren's academic performances and on the relationships between the grandchildren and their parents (Lieberman & Fisher, 1995; Szinovacz, 2003). However, evidence is far from one-sided, as other studies (Beach, 1997; Celdrán, Triadó, & Villar, 2009) have indicated several positive consequences on adolescent grandchildren, who may learn important lessons from this family situation.

In this sense, the emotions of grandchildren when relating to grandparents with dementia is an issue that has received little research attention. These emotions can

affect how grandchildren cope with the experience of dementia and how they interact with their grandparent (Werner & Lowenstein, 2001). The emotions of the primary caregivers of people with dementia have been studied (e.g., Eloniemi-Sulkava et al., 2002; Robertson, Zarit, Duncan, Rovine, & Femia, 2007), and some intervention programs focused on the grandchildren of grandparents with dementia have included this issue (Hall, Buckwalter, & Crowe, 1990; Magnuson, 1999), as well as brochures, comics, and books containing information for young people about the dementia process (see a review in Manthorpe, 2005). These emotions may be especially relevant for adolescents because, in adolescence, emotional experiences can be particularly intense and the mechanisms to manage and regulate them may not be fully developed (Sadurní & Rostan, 2004).

Adolescent grandchildren may also experience a range of emotions not only toward their grandparent with dementia but also toward other family members or toward themselves. In a qualitative study (Howard & Singleton, 2001), granddaughters mentioned feeling embarrassed, guilty, sad, or frustrated in their interactions with their grandmother or with the primary caregiver. The emotional experience raised by dementia is far from simple, and contradictory feelings frequently appear together. For instance, positive feelings, such as gratification and satisfaction due to the help grandchildren give to the family, may coexist with negative feelings such as resentment, frustration, sadness, fear, or envy. This complexity sometimes makes it difficult for those involved to express emotions to other family members or friends (Beach, 1994; Orel & Dupuy, 2002).

As well as emotions, the relationship between grandchildren and grandparents who have dementia could also be affected by the disease. Initial studies about that issue date back to the late 1980s, when Creasey (Creasey & Jarvis, 1989; Creasey, Myers, Epperson, & Taylor, 1989) compared a group of these grandchildren with others with cognitively intact grandparents. Their results showed that the frequency of contact and leisure activities and the perceived intimacy were lower in the group with grandparents who have dementia. This tendency has also been found in later studies (Foss, 1998; Werner & Lowenstein, 2001). There also seem to be changes in geographical proximity, usually because the grandparent moves closer to his or her adult children to receive direct care (Orel & Dupuy, 2002). Sometimes grandchildren take greater responsibility for their grandparent's care. Therefore, if many grandparents cared for their grandchildren before the onset of the illness, once cognitive deficits and behavioral changes related to dementia start to appear, grandchildren may provide care for their grandparents as auxiliary or even as primary caregivers (Dellman-Jenkins & Britain, 2003; Fruhauf, Jarrott, & Allen, 2006).

However, beyond this comparison between grandparents with dementia and cognitively intact grandparents, little is known about how grandchildren perceive

the changes, if any, in the relationship with their grandparent during the process of deterioration. Perceptions of changes in relationships with people with dementia have been studied with other family members such as adult children or spouses (e.g., Chesla, Martinson, & Muwashes, 1994; De Vugt et al., 2003). Chesla et al. hypothesized that, though relationships change over time, decline is not always the trend. They found three perceptions of change in the relationship between primary caregivers and people with dementia: a continuous relationship, a continuous relationship that is transformed by the disease, and a discontinuous relationship. De Vugt et al. conducted interviews with the wives of men with dementia in which they asked about their current relationship and their perception of changes in that relationship. The wives perceived deterioration, especially due to the behavioral problems of their husbands.

Briefly, this study had three objectives. First, we examined the emotions grandchildren experience due to having a grandparent with a cognitive impairment. Second, we examined the perception grandchildren have of their current relationship with a grandparent who has dementia, both overall and in three specific areas (frequency of contact, emotional closeness, and satisfaction with the relationship). Finally, we examined what changes, if any, grandchildren noticed in their relationship (also overall and in the three specific areas) and to what factors grandchildren attribute these changes. For each of these objectives, we took into account the effect of sociodemographic variables (age, gender, and family line) and the characteristics of the illness (grandparent's residence and severity of the dementia).

Method

Sample

Our sample consisted of 145 adolescents (89 girls and 56 boys) ranging in age from 14 to 21 years (M =17.74, SD = 2.35). Most participants were living with their parents (n = 17) or with their parents and siblings (n = 76). A total of 31 adolescents were living both with their grandparent who has dementia and their parents.

All grandparents had been diagnosed with dementia, mainly Alzheimer Disease with a moderate degree of severity as assessed by the Global Deterioration Scale (GDS; Reisberg, Ferris, De Leon, & Crook, 1982): 47.9% with GDS 4-5 and 34.5% with GDS 6-7. They lived either in the community (65.5%) or in a nursing home (34.5 %). Their ages ranged from 67 to 96 years (M = 80.39, SD = 5.52). More grandmothers (68.3%) than grandfathers participated in the study. Similarly, maternal grandparents (64.8% of the overall sample) outnumbered paternal grandparents.

Participants were recruited through day care centers and nursing homes in Barcelona (Spain). Users of these centers should satisfy two inclusion criteria: (1) They were diagnosed with dementia, and (2) they have at least one grandchild aged between 14 to 21 years. All participants provided informed consent for the study, which was approved by the research and ethics commission of the University Rovira i Virgili.

If the family caregiver agreed to participate, a questionnaire was sent together with a postage-paid reply envelope addressed to the researcher and two introductory letters—one for the parents and one for the grandchildren—explaining the objectives of the study. Parents and grandchildren were clearly informed that the grandchildren's responses were confidential. Only a code number on the questionnaire was used to identify to which centre the questionnaire came from. Of the 250 questionnaires that were sent, 145 (58% response rate) were returned and included in the analysis, a response rate similar to the ones achieved by studies using that data-gathering procedure.

On the basis of information provided by participant institutions, two main reasons account for the lack of response: (1) The main caregiver refused to participate to protect grandchildren, or (2) grandchildren refused to participate because they did not want to talk about the issue or did not have a relationship with that grandparent.

Instruments

The data collected for this study were extracted from a larger research project that included several spheres of the relationship between grandchildren and grandparents with dementia, the care that grandchildren could provide to their grandparents, the impact of the disease on other relationships grandchildren have, and on their own vital process of maturation and learning. The first section of the questionnaire asked adolescents to provide sociodemographic information, including their age, gender, and family composition, as well as grandparent's age, gender, family line, marital status, and residence.

Emotions were measured through 15 items expressing a set of emotions grandchildren could experience (see Table 1).

Participants indicated how frequently those emotions were generated by the relationship with their grandparents who have dementia on a 5-point scale ranging from *never* to *always*. Because no studies have specifically addressed this issue, we selected emotions included in the questionnaire by reviewing emotions identified by brochures, papers, or documents addressed to grandchildren in caregiving families (Alzheimer's Association, 1997; Alzheimer Society of Canada, 2001; Hall et al., 1990). We identified terms referring to emotions that were mentioned

Table 1. Factorial Components of Emotions Experienced by Grandchildren

Item	Loss and threat	Satisfaction	Jealousy	Incomprehension	Guilt
I feel sad when I see how my grandparent is changing because of the disease.	0.85	—	—	—	—
I feel sad when I remember how my grandparent was.	0.80	—	—	—	—
I miss the relation I had with my grandparent.	0.78	—	—	—	—
I fear that in the future I or my parents will suffer the same disease.	0.63	—	—	—	—
I am upset because grandparent's illness has changed my life.	0.40	—	—	—	—
I am satisfied with the help I give to my grandparent.	—	0.90	—	—	—
I feel useful when I can help my grandparent's primary caregiver.	—	0.81	—	—	—
I am satisfied because I manage to understand what my grandparent is trying to tell me.	—	0.66	—	—	—
I am jealous of my grandparent because of the less attention I receive from my parents.	—	—	0.91	—	—
I feel lonely because of the less attention my family gives me.	—	—	0.88	—	—
I am ashamed of some of my grandparent's behaviors.	—	—	—	0.80	—
I am confused because I don't understand my grandparent's behaviors.	—	—	—	0.66	—
I get angry when I have to repeat the same things to my grandparent.	—	—	0.40	0.66	—
I feel bad because I don't want to spend time with my grandparent.	—	—	—	—	0.72
I feel bad if I get angry or shout at my grandparent.	—	—	—	—	0.71

in these sources and grouped together the terms referring to similar emotions. The label chosen for each group was included in the questionnaire. In addition, we made sure that both primary emotions identified by Izard (1977; for example, joy, sadness, anger, fear, shame and guilt) and social emotions (e.g., pride, loneliness or jealousy; Etxebarria, 2008) were included in the questionnaire.

The relationship between grandparent and grandchildren before the onset of the disease was measured by two variables. First, participants were asked to describe the general nature of the previous relationship by choosing from three categories (great intimacy, standard, or distant/cold). This variable had been used in a study examining the prior relationship between primary caregivers and older people with a reduced level of autonomy (Instituto de Mayores y Servicios Sociales, 2005). Second, grandchildren were asked to rate their overall satisfaction with the relationship before the onset of the illness on a scale from 0 (*no satisfaction*) to 10 (*highest satisfaction*). Current relationship between grandparents with dementia and grandchildren was assessed by asking grandchildren to rate their in-person frequency of contact with their grandparent on a 5-point scale ranging from *daily* to *less than once per month*, their emotional closeness on a 5-point scale ranging from *very distant* to *very close*, and their overall satisfaction with the relationship with their grandparent on a scale ranging from 0 (*no satisfaction*) to 10 (*highest satisfaction*).

A series of questions were used to assess grandchildren's perception of changes in the relationship with their grandparent. Participants were first asked to rate how their relationship with their grandparent who has dementia had changed since the onset of the disease, according to three options (improvement, worsening, and continuity). Grandchildren were then asked to write down the reasons for their choice in an open-question format. Second, grandchildren rated changes in perceived frequency of contact since their grandparent has dementia on a 5-point scale ranging from *much less contact than before* to *much more contact than before*. Finally, grandchildren assessed changes in emotional closeness with their grandparent on a 5-point scale ranging from *much less closeness than before* to *much more closeness than before*.

Finally, we gathered information about the health of the grandparents. Information about the type and severity of the dementia (Reisberg's GDS) was provided by the centers participating in the study. The grandchildren also rated their grandparents' health on a scale ranging from *very bad* to *excellent*.

Statistical Analysis

All results were analyzed using the SPSS v15 statistical package except for the open-ended question on reasons for changes in the grandparent–grandchild relationship, for which a thematic analysis was used.

As for the emotion instrument, a principal components analysis (PCA) was carried out. The goal of PCA is to reduce the dimensionality of the data, producing a parsimonious set of components that retain as much as possible the variation present in the original dataset. In our case, that components would express commonalities among different emotions, which then could be grouped together. To obtain components that were as independent as possible, we applied a varimax rotation. Before the analysis, the Kaiser–Meyer–Olkin (KMO) index of sampling adequacy and the Bartlett sphericity test were calculated. The KMO index reported a value of 0.65, which is considered acceptable. The Bartlett test reached statistical significance ($p < .0001$), which supported proceeding with the analysis.

Regarding other quantitative data, after running descriptive analysis, relationship with the dependent variable of the study (such as grandparent's residence, health, or family line) were carried out using t test or Krustal–Wallis, χ^2 test of independence or Mann–Whitney U test, depending nature's variables.

Regarding qualitative data, content analysis was employed to investigate grandchildren's reason for a perception of change in their grandparent–grandchildren relationship. This was basically an inductive process involving content comparison with the data (Strauss & Corbin, 1990). The data were first read and reread, identifying ideas (or units of meaning). The units of meaning were then condensed into themes or categories based on repetition or similarity. Finally, an independent researcher assigned responses into categories. These responses were compared to the original ones in order to obtain the intercoder agreement index.

Results

Emotions

Three emotions were mentioned most frequently by the participants in this study. Two of these were related to feelings of satisfaction (for understanding their grandparent or for helping with caregiving) and one was related to their sadness in seeing how their grandparent was deteriorating as a result of the dementia. The least frequent emotions reported were jealousy and loneliness.

To examine the factorial structure of the Emotions instrument, we used principal components analysis (see Method section). The analysis yielded five components with eigenvalues greater than 1, which explained 66.6% of the total variance. Table 1 shows the components and item loadings.

The first component accounted for 19.1% of the variance and comprised five items that reflected *feelings of loss and threat*. This term covered feelings that appeared as a defensive reaction due to the losses suffered in the family during the dementia process, either in the past (feelings of nostalgia), present, or in the

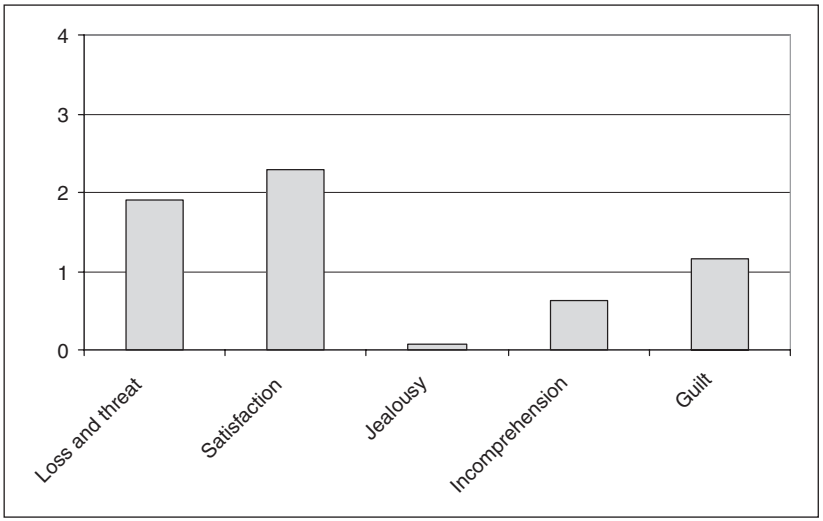

Figure 1. Means of emotion component scores

future (fear of having this disease). The second component accounted for 14.7% of the variance and comprised three items that reflected *satisfaction*. This term expressed positive feelings raised by caring for the grandparent or helping the primary caregiver. The third component accounted for 12.5% of the variance and comprised two items that reflected *feelings of jealousy* caused by the poor attention the grandchild is receiving from their parents due to their grandparent's illness. The fourth component accounted for 12.3% of the variance and comprised 3 items that reflected *incomprehension*. Items in this component included feelings of confusion, anger, or embarrassment caused by lack of understanding of their grandparent's behaviors. The fifth component accounted for 8.0% of the variance and comprised 2 items that reflected *guilt.* This factor included feelings of sorrow and regret caused by a grandchild's desire not to spend time with his or her grandparent or by an angry response to the behaviors of the grandparent.

The means of these components are shown in Figure 1. Emotions included in Component 1 (sadness, nostalgia, and fear) and Component 2 (satisfaction from helping the primary caregiver) were the most frequent. Emotions included in Component 3 (feelings of jealously) were the least frequent.

As two of the five components (4 and 5) did not reach a Cronbach's alpha coefficient of more than .70, caution is necessary due to poor internal consistency. Of the other three components, only one had significant relationships with

Table 2. Percentages and Means of the Variables in Current Grandparent–Grandchild Relationship (n = 145)

Variable	% or *M* (*SD*)
Frequency of contact	
Daily	22.7
Once or twice a week	30.5
At least once a month	35.5
Sometimes during the year	11.3
Emotional closeness	
Nothing	16.6
Some	35.2
Fairly	29.0
A lot	19.3
Satisfaction with the relationship	5.78 (2.52)

variables considered in this study. Caring for a maternal grandparent provided a greater satisfaction for the participants, $t(143) = 3.224$ ($p < .01$).

Current Relationship

Table 2 shows how the participants rated the current frequency of contact, level of emotional closeness, and satisfaction in their relationship with grandparent with a cognitive impairment.

More than half of the sample reported a high frequency of contact (daily or weekly) with their grandparents. Only those living with their grandparent rated their contact as daily. For grandparents living in a nursing home, contact was less frequent, Mann–Whitney U test: $z = –5.414$, $p < .001$.

Perception of emotional closeness was homogeneously distributed between low (*nothing* or *few*, 51.8%) and high (*close enough* or *great*, 48.2%). Perceptions of close relationships tended to be associated with evaluations of better grandparent's health: Kruskal–Wallis test: $\eta = 14.342$, $gl = 3$, $p < .01$; maternal grandparents, $z = –2.207$, $p < .05$; and intimate prior relationship, $z = –3.589$, $p < .001$.

The mean score for the *current level of satisfaction* with their relationship to their grandparent was 5.78 (on a scale from 0 to 10), though nearly 30% of the sample rated their current relationship as more than 7. As with emotional closeness, family line and perception of grandparent's health influenced the scores: maternal grandparents, $t(143) = 2.220$, $p < .05$, and better health perception, $F(4, 145) = 12.133$, $p < .001$, were related to higher scores on current satisfaction with relationship to grandparents.

Table 3. Results of the Grandparent–Grandchild Prior Relationship and Perception of Change in This Relationship (n = 145)

Variable	% or *M* (*SD*)
Definition of the previous relationship	
Great intimacy	37.9
Standard	57.2
Distant/cold	4.8
Change in grandparent–grandchild relationship	
Improvement	11.0
No change	52.4
Worsening	36.6
Change in frequency of contact	
Much less than before	15.9
Less than before	26.2
No change	30.3
More than before	15.9
Much more than before	11.7
Change in emotional closeness	
Much less than before	21.4
Less than before	28.3
No change	43.4
More than before	4.8
Much more than before	2.1
Satisfaction with the relationship prior to the illness	7.44 (1.91)

Perception of changes in grandparent-grandchild relationship. First, the grandchildren were asked to define their relationship with their grandparent before the onset of dementia (see Table 3). In general, they chose a standard relationship—neither very close (55 grandchildren) nor distant or cold (7 grandchildren). A close relationship was more frequently defined by those whose maternal grandparent has dementia: $\chi^2 = 6.016$, gl = 2, $p < .05$.

Second, the grandchildren rated changes in their relationship with their grandparent since the onset of dementia. Most (76 grandchildren) perceived that the relationship had not suffered major changes; 53 grandchildren perceived that the relationship had worsened, and only 16 perceived an improvement.

When we did a cross-tabulation between the "previous relationship" and "type of changes" categories, we found that 52.7% of grandchildren who described their previous relationship as close perceived a deterioration in that relationship (compared with 27.7% of grandchildren who defined their previous relationship as *standard* and 14.3% who defined their previous relationship as *cold/distant*).

Mentions of *no change* were more common in both of these groups (61.4% and 71.4%, respectively).

Table 3 also shows the percentages and mean scores for three other areas of change in the grandparent–grandchild relationship: frequency of contact, emotional closeness, and previous satisfaction with the relationship. Changes in *frequency of contact* were perceived as negative (there was more contact before the onset of the illness) by 42.1% of the sample. The rest of the sample thought that it had remained the same or that it had increased (27.6%). Declines in *emotional closeness* were also present (41.7%), though stability was higher than in frequency of contact (43.4%). Only 10 grandchildren (6.9%) considered there had been an improvement in emotional closeness since the onset of dementia. Lastly, the degree of *satisfaction with the relationship before the disease* had a mean of 7.44 (on a scale from 0 to 10). Only 9 grandchildren gave this relationship a score below 5. The differences between the means for current satisfaction and previous relationship, tested by a paired-samples t test, were significant, $t(144) = -8.030$ ($p < .001$), which means that current satisfaction was significantly lower than previous satisfaction.

Finally, we analyzed the responses to the open-ended question on the *reasons for change* ($n = 67$) among the grandchildren ($n = 69$) who perceived an overall change in the relationship since the onset of the disease. The answers tended to be quite short: between 2 and 80 words, with an average length of 13.73 words. The responses were divided into two main categories: attribution to dementia ($n = 39$) and attribution to grandchildren's behaviors ($n = 23$). As five answers could not be included in either of these categories, we created a third category called *others*. Cohen's Kappa index was 0.79, which indicates that the system had good intercoder reliability.

Table 4 summarizes the distribution of the answers to the open-ended question in the three categories. A distinction was made between the percentages of these categories in the overall sample, in those grandchildren who ranked the change in the grandparent–grandchild relationship negatively (52 grandchildren) and in those who ranked it positively (15 grandchildren).

More than half (63.5%) of those who considered that their relationship with their grandparent with dementia had worsened ($n = 52$) said the change was directly caused by the illness. This attribution was sometimes made simply by mentioning the name of the illness: "Because he has Alzheimer" (grandson, 20 years old).

Other grandchildren were more descriptive and identified some of the characteristics of dementia, such as their grandparent's inability to recognize them, their difficulties in keeping a normal conversation, and their problems understanding what their grandchildren were trying to say: "Because sometimes he doesn't

Table 4. Frequency and Percentages of the Attribution of Change in Grandparent–Grandchild Relationship

Category	% total	Frequency—worse relationship (n = 52)	Frequency—better relationship (n = 15)
Dementia	58.2	33	6
Self-attribution	34.3	14	9
Others	7.4	5	0
Total	100	52	15

recognize me and when you explain things to him he seems not to be interested" (granddaughter, 21 years old).

Other grandchildren stressed negative changes in the affective bond shown towards them by their grandparent: "He neither talks to me nor caresses me" (grandson, 15 years old); "The relationship is worse; she has taken a dislike to me; she used to love me a lot but now she's against everything I say" (granddaughter, 21 years old).

Second, 26.9% of grandchildren who perceived a worsening in the grandparent–grandchild relationship said they themselves were responsible. Though they referred to certain characteristics of dementia, they highlighted their inability to accept changes that dementia caused in their grandparent and how they react to these changes. These reactions are examples of coping strategies grandchildren employ to stop themselves from getting flustered or angry, feeling sad, or suffering when seeing the deterioration in their grandparent: "We are always arguing about anything; I don't have any patience with her" (granddaughter, 16 years old); "Because it's really hard for me to see her suffering, so I end up avoiding the places where she is" (granddaughter 17 years old); "I always think that I'm busy, but in reality I hardly go to visit her as it hurts me and depresses me a lot" (granddaughter, 18 years old).

These coping strategies do not always avoid guilt feelings:

> For me [dementia] is the worst end anyone can suffer. So although I am ashamed and I know some day I will regret it, my visits to the nursing home where my grandmother lives are more and more sporadic as I don't want to lose the good memories I have of her when she was healthy. And although it's hard it's something that doesn't have any solution at all. (granddaughter, 16 years old)

Three grandchildren mentioned changes in their relationship with their grandparent due to developmental issues they are experiencing, such as wanting

to spend more time with friends and less time with family members: "I don't see him as before and as I grow up I spend more time with my friends" (grandson, 14 years old).

Finally, five grandchildren answered different aspects from the two categories of dementia and self-attribution, saying only that the relationship was different or nonexistent but did not indicate any reason for this.

For grandchildren who answered that there had been positive changes in the grandparent–grandchild relationship since the onset of the illness (n = 15), the percentages of both categories (dementia and self-attribution) were the opposite of those of the group that mentioned negative changes: More grandchildren attributed the changes to themselves (60.0%) than to the dementia (40.0%). That could be seen as a reflection of how grandchildren could be viewed as active agents in an improved relationship, mentioning actions such as being involved in their grandparent's daily activities or in caregiving duties, trying to keep their grandparents company, and performing affective behaviors such as cuddles or caresses: "I am more involved in her life. Like everyone, I take care of her" (granddaughter, 20 years old); "I love her and cuddle her even more" (granddaughter, 20 years old); "I try to spend more time with her and be her mate to entertain her" (granddaughter, 19 years old).

Some answers stressed other coping strategies, such as having patience with their grandparent: "We live together and I've learnt to deal with it" (granddaughter, 20 years old); "Since I know she's more vulnerable, we both have changed our attitudes; now the relationship is easier. I have more patience with her" (granddaughter, 20 years old).

Other grandchildren reported improvements in their relationship due to their grandparent's illness, referring to emotional aspects related to how their grandparent was still able to communicate with them or to a softening in their grandparent's character due to the disease: "The way she expresses her love towards me, kisses me, caresses me, etc." (grandson, 21 years old); "Because of the medication or the dementia itself her hard traits have mitigated; she's not as stubborn as she was" (granddaughter, 21 years old).

Discussion

This study had three objectives. The first of these was to explore the emotions grandchildren experience in their relationship with grandparents who have dementia. Our results showed that these emotions were mixed. In fact, far from experiencing only negative feelings, the most frequent emotions mentioned were positive. These positive emotions were mainly associated with the satisfaction derived from helping the family to care for the grandparent. According to the

participants, small, everyday actions are important for producing these positive feelings because they allow grandchildren to feel they are an important part of the changes experienced by their family. This result was also found by other studies (Orel & Dupuy, 2002; Pruchno et al., 1995). The presence of positive feelings also suggests that, even in difficult situations such as having a grandparent with a cognitive impairment, family, including grandchildren, may draw some positive lessons (Celdrán et al., 2009; Fruhauf & Orel, 2008).

However, having a grandparent with a cognitive impairment also produced negative emotions. These emotions reflect how a grandparent's situation is relevant to their adolescent grandchildren, with feelings such as loss, sadness, or nostalgia for a previous and richer relationship being generated (Howard & Singleton, 2001; Orel & Dupuy, 2002). A fear that other relatives (or even themselves) may experience the illness in the future was also evident. This was also found in the literature on caregivers of patients with dementia (Roberts & Connell, 2000). Other emotions mentioned were feelings of guilt linked to not wanting to spend more time with their grandparents or reacting in ways deemed inappropriate, such as shouting at them or getting annoyed at their behavior. These guilt feelings also frequently appear in the primary caregivers (Fisher & Lieberman, 1994; Williamson & Schulz, 1990).

The second objective was to describe the relationship between adolescent grandchildren and grandparents with dementia, taking into account aspects such as frequency of contact, emotional closeness, and satisfaction with the relationship. Our data suggest that, despite the illness, these grandchildren maintain contact with their grandparents, see them regularly, feel close to them, and are fairly satisfied with the relationship despite the limits caused by dementia to the kind of activities grandparents and grandchildren can share.

Some factors identified in the literature as relevant in the relationship between grandchildren and their cognitively intact grandparents, such as the grandparent's gender or lineage (see Triadó & Villar, 2000; Van Ranst, Verschueren, & Marcoen, 1995), also seem to have an impact when the grandparent has dementia: The relationship is more frequent and closer with grandmothers than with grandfathers and with maternal grandparents than with paternal ones. Also, the relationship is more intense when the bond between the grandparent and the grandchild was already strong before the onset of the illness, which supports the idea of continuity in the relationship despite the adverse circumstances caused by dementia.

Finally, our third objective was to examine how grandchildren perceive changes in their relationship with their grandparents after the onset of dementia. Our results suggest that, although when assessed generally most grandchildren considered that the relationship remained the same despite the illness, several specific aspects did reveal certain changes. These included a perceived decrease

in the frequency of contact, less emotional closeness, and less satisfaction with the relationship, particularly compared to the satisfaction (retrospectively evaluated) before the illness. These results are similar to those of other studies that compared the perceptions of grandchildren with cognitively intact grandparents with those of grandparents who have dementia (Creasey et al., 1989; Foss, 1998; Werner & Lowenstein, 2001). It is also important to take into account, however, that, as was indicated by Chesla et al. (1994), dementia does not always negatively affect relationships with family members. In our study, 11% of grandchildren expressed an improvement in their relationship, which reduces pessimism and highlights the positive changes that may be experienced by caregiving families (see also Cohen, Colantonio, & Vernich, 2002; Kramer, 1997).

One of the variables that had a greater impact on the perceived decline in the relationship was the level of intimacy before the onset of the illness. Grandchildren who remembered having a good relationship with their grandparents tended to perceive a greater decline than did those whose relationship had been rather distant and cold. This result emphasizes the importance of taking into account the quality of the prior relationship when determining the potential impact of dementia on grandchildren. Other studies (e.g., Parrot & Bengtson, 1999) that examined this aspect in relation to generational interchanges between caregiving adults and their parents who have dementia found similar results.

To understand the perception of changes in the relationship between grandchildren and their grandparents, it is also important to determine what the grandchildren attribute these changes to. In our study, the dementia was cited as the main reason for the changes in the relationship: cognitive aspects, such as grandparents who no longer recognize their grandchildren, and non-cognitive aspects, such as behavioral disturbances, were mentioned. It was noticeable how this attribution of changes to dementia was particularly frequent among grandchildren who perceived that their relationship had declined. When positive changes were found in the relationship, grandchildren tended to emphasize how they had made an effort to sustain this relationship. This suggests that being able to exert some kind of control over the situation (employing active coping strategies, for example) may be important to grandchildren to keep a positive view of the relationship and how it is affected by the illness. Information about the illness and how to cope with it should be included in training programs for family members of older people with dementia, and grandchildren should be taken into account for these programs.

We should also acknowledge some limitations of our study. First, the participating grandchildren came from families that use some kind of formal care support such as a daycare center or a long-term institution. This makes it difficult to generalize our results to families or grandchildren who do not receive any kind

of formal support. Changes in relationships and emotions may be different when the families have to cope with the illness without any formal support. Second, some aspects of the study were based on retrospective information (as frequency of contact or emotional closeness before the disease). That kind of memories could be biased or altered, among other factors, by the current situation or emotions that grandchildren are experiencing in relation to their grandparent's disease. Future research should address those limitations. In addition, the cross-sectional design of our study cannot describe the dynamic nature of dementia; therefore, more studies, and particularly longitudinal studies, are needed to explore changes in relationships and emotions as the disease advances.

Despite these limitations, our results shed some light on the role and emotions experienced by grandchildren as relevant members of a family who must cope with the illness and care needs of one of their members in a changing situation as the dementia advances. Giving voice to grandchildren who suffer their grandparent's illness offers a new perspective on family caregiving, which has so far almost completely focused on the primary caregivers. It also highlights the positive or negative impact that the illness may have on them and their role as important actors who should be taken into account—sometimes as a resource willing to participate in family care and sometimes as a potential target for intervention.

Some results of our study could also be applied to improve intervention programs addressed to grandchildren. They highlighted some of the most important emotions and changes in the relationship experienced by grandchildren, and interventions should be aimed at limiting and reducing the negative ones, and, at the same time, using the positive ones as resources that improve coping abilities, as an opportunity to give meaning to that painful situation and, ultimately, to grow.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interests with respect to the authorship and/or publication of this article.

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