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What is This?
When Grandparents Have Dementia: Effects on Their Grandchildren’s Family Relationships

Montserrat Celdrán¹, Feliciano Villar¹, and Carme Triadó¹

Abstract
This study aims to identify changes in adolescents’ lives and in the relationships within the family when a family member has a dementia. Grandchildren living in Barcelona, Spain, participated in the study (N = 145). The data, based on both quantitative and qualitative information, showed that if the grandparent moved into the grandchildren’s household, adolescents underwent changes in their daily activities and in their experience of caring for the grandparent. Participants showed mainly positive changes in their relationship with their parents and acknowledged the influences their parents have in their relationships with their cognitively impaired grandparent. Grandchildren experienced a closer relationship with the partner of the person with dementia, although they also mentioned difficulties in maintaining this relationship if this grandparent focuses his or her attention excessively on the care recipient. From a family systems perspective, we discuss the importance of the role of grandchildren in caring for a person with dementia.

Keywords
grandparent, dementia, family relationships, adolescence

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Research on elderly care within the family has traditionally focused on the main caregiver, usually the wife or daughter of the person with dementia or other chronic disease (Dillehay & Sandys, 1990). Few studies have sought to extend the scope of the analysis by exploring how other family members may help to care for the person with dementia, the impact of caring among different members of the family or the changes in their interactions and relationships brought about by the situation (Baum & Page, 1991; Keith, 1995; Penrod, Kane, Kane, & Finch, 1995). For example, if a grandparent has dementia, the situation is likely to have an impact on his or her grandchildren; research has shown that the relationship between grandchildren and their grandparents is significant and developmentally relevant for both parties (Attar-Schwartz, Tan, & Buchanan, 2009; Van Ranst, Verschueren, & Marcoen, 1995).

Some studies of grandchildren who have a grandparent with dementia have investigated how dementia changes the quality of the relationship, the frequency of contact, shared leisure activities, and the involvement of grandchildren in care tasks (Celdrán, Triadó, & Villar, 2009b; Werner & Lowenstein, 2001). Nevertheless, other important issues, such as the impact of grandparents’ health on grandchildren’s lives and their relationships within the family have received hardly any attention from research so far. This study is aimed at filling these gaps, by exploring the changes that grandchildren experience in their lives because of their grandparent’s disease, how they perceive the role of the middle generation in their relationship with their grandparent with dementia, and to what extent their relationship with the healthy grandparent (i.e., the spouse of the person with dementia) has been affected by the disease.

Adopting a family system perspective is crucial to understanding these issues. From within this theoretical framework, grandchildren, as individual family members, are interdependent with other relatives in a continuous and reciprocal influence on one another (Cox & Paley, 1997). Therefore, to understand the changes in the grandparent–grandchildren relationship caused by the onset and development of the disease, it is important to see how the grandparent–grandchild dyad is related to other relatives (for instance, parents or other grandparents) and the overall family system.

**Changes in Grandchildren’s Lives**

The impact of a grandparent’s dementia on grandchildren’s lives may vary according to the grandchildren’s age. The changes may be particularly intense in adolescent grandchildren. In this period of life, adolescents are coping with challenging developmental tasks, such as physical changes,
identity construction, or a redefinition of their relationships with peers and parents, which can make adolescence a particularly stressful life stage (Steinberg & Morris, 2001). The stress caused by these normative adolescence-related transitions may be amplified by the grandparent’s disease and all the modifications in routines and activities that the family as a whole is obliged to take on in order to care for their relative. As a result, research on this issue has reported that grandchildren with a grandparent who has dementia may present poor academic performance, somatic or anxiety problems, lost friendships, or less time for leisure activities or school tasks (Hall, Buckwalter, & Crowe, 1990; Orel & Dupuy, 2002).

The intensity of these life changes also depends on other factors. Among them, where the person with dementia lives seems to be particularly important. If the grandparent with dementia has to move to the grandchildren’s house to receive more continuous care, the disruption of family life is more severe; this cohabitation may fundamentally change the family dynamics or even the space and privacy that each member of the family previously enjoyed (Szinovacz, 2003). In these multigenerational households, grandchildren are more directly exposed to the daily stress that taking care of a person with dementia implies, are more aware of the dementia process, and are more involved in care tasks (Creasey, Myers, Epperson, & Taylor, 1989; Tebes & Irish, 2000). Moreover, the instrumental and social support that adolescents receive from their parents may be reduced as their parents take on more responsibility for caring for the person with dementia (Cañada-Vicinay, 2005). Therefore, adolescent grandchildren who cohabitate with grandparents with dementia are likely to be under more strain, probably need to adapt to more changes in their lives, and must invest more effort in coping with the caregiving scenario (Celdrán, Triadó, & Villar, 2009a; Dellmann-Jenkins, Blankemeyer, & Pinkard, 2000; Howard & Singleton, 2001).

**Relationships With Parents and Healthy Grandparents**

In addition to the changes in life routines, daily activities, and family tasks experienced by adolescent grandchildren in this situation, other relationships may also be affected, such as their relationships with their parents. Adults obliged to care for their parents may also find their relationship with their own children under stress—especially bearing in mind the normative changes in that relationship during adolescence as children demand more autonomy and redefine the emotional bond with their parents, sometimes leading to an increasing number of conflicts (De Goede, Branje, & Meeus, 2009).
Nevertheless, the direction of these changes is not clear. Focusing on the relationship between adolescents and their mothers, Creasey and Jarvis (1989) did not find that children perceived a worse relationship when mothers were the main caregiver of a person with dementia, and Hamill (1994) and Raphael and Schlesinger (1993) found only a mild deterioration in child–mother communication. Other studies, such as Szinovacz (2003) found a mixed impact, both positive and negative. Among negative changes, children perceived less attention from their mothers and a reduction in the number of activities performed together because of the mother’s caregiver role. Moreover, children reported that the stress and burden generated by caregiving enhanced irritability or impatience behaviors from their mothers toward them. In contrast, among the positive consequences recorded were the children’s empathy toward their mothers, which increased their feelings of support and respect toward them. These positive changes have also been found in previous studies (Beach, 1997; Orel & Dupuy, 2002). The relationship between adolescents and their fathers has been studied only by Creasey and Jarvis (1989), who suggested a deterioration in the relationship, mainly because grandchildren in this study perceived that their fathers were not involved enough in the caregiving tasks and did not give sufficient support to their wives, who were identified as the main caregivers in that study.

Apart from changes in the relationship between parents and their adolescent children, the way parents deal with the grandparent’s disease may also have an impact on family relationships, especially on the relationship between grandchildren and the grandparent with dementia. In families with healthy grandparents, parents influence the grandparent–grandchild relationship directly as they usually act as a bridge or connection between older and younger generations, determining the level of contact and deciding what role grandparents have in their children’s life (Holladay et al., 1997; Kennedy, 1992). When grandparents have dementia, some studies have found that parents can improve the relationship between grandchildren and their grandparent by providing information about the disease and support to help grandchildren understand their grandparent’s behavior (Howard & Singleton, 2001) or by giving advice about how to interact more effectively with the grandparent (Orel & Dupuy, 2002). Nevertheless, this influence is not always positive. For instance, parents who do not talk openly about the disease or who prevent grandchildren from interacting with their grandparent (sometimes as a way to protect them from suffering) may in fact worsen the relationship (Hall et al., 1990; Mace & Rabins, 1999). So far, only Creasey and Jarvis’s (1989) study has looked at the parents’ influence on the grandparent–grandchildren relationship, although they focused solely on how the stress suffered by
mothers caring for a person with dementia negatively affected grandchildren’s perception of their relationship with the grandparent with dementia.

Finally, grandparents’ dementia may also alter the relationships of grandchildren with other members of the family, for instance their relationship with the cognitively intact grandparent, the spouse of the person with dementia. If both grandparents move to the grandchildren’s home, daily life hassles may spur conflicts between the cognitively intact grandparent and grandchildren (Mace & Rabins, 1999). Frequently, this partner is the main caregiver, so the priority of this role may have a negative impact on their relationship with their grandchildren. However, these possibilities have not been studied to date.

Objectives

The aim of the present study is to explore (a) to what degree grandchildren consider that their life has changed because one of their grandparents has dementia; (b) what kind of changes, if any, the grandchildren perceive in their relationship with their parents and their role as an influence in that grandparent–grandchildren relationship; and (c) to what extent grandchildren perceive changes in their relationship with the spouse of the grandparent with dementia.

Method

Participants and Procedure

Data were collected through day care centres and nursing homes in Barcelona, Spain. Families who met the criteria for the study, that is, having a relative with a dementia diagnosis who had at least one grandchild aged between 14 and 21 years, were contacted. If the family caregiver agreed to participate, the researchers sent them the questionnaire along 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. Both parents and grandchildren were clearly informed that the grandchildren’s responses were confidential. The research procedure was approved by the research and ethics commission of the University of Barcelona. No incentives were provided either to the participating families or to the institutions.

A total of 145 adolescents (89 girls and 56 boys) from 106 different families participated in this study. Their age ranged from 14 to 21 years.
(mean = 17.74 years, $SD = 2.35$). This range covers both grandchildren who are experiencing most of the normative changes associated with that life stage (the younger ones) and others (the older ones) who have probably already adapted to most of them. All grandchildren were living with their parents at the moment of the study, although with different family configurations. Significantly, 31 adolescents were also living with their grandparent who had dementia.

Grandparents’ age ranged from 67 to 96 years (mean = 80.39 years; $SD = 5.52$). More grandmothers (68.3%) than grandfathers participated in the study. Similarly, maternal grandparents (64.8% of the overall sample) outnumbered paternal grandparents. All grandparents had been diagnosed with dementia, mainly Alzheimer’s disease, with a moderate degree of severity 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%).

**Instruments**

The data collected for this study were extracted from a larger research project that examines several spheres of the relationship between grandchildren and grandparents with dementia: how grandchildren attribute changes in this relationship, the care that grandchildren provide for their grandparents, and the impact of the disease on their own processes of maturation and learning. In the first section of the questionnaire, adolescents provided sociodemographic information, including their age, gender, and family composition, and grandparent’s age, gender, side of family, marital status, and residence.

An open question asked grandchildren to compare their life with that of their friends or peers and to state whether their life is different because they have a grandparent with dementia (“Do you think that your life is different from that of other boys or girls of your age because your grandparent has dementia?”). If the participant answered affirmatively, space was provided for him/her to explain the ways in which his/her life has been affected.

To explore the relationship between the participant and their mother and father, two similar questions were designed. First, participants had to indicate the extent to which dementia was affecting their relationship with their mother and with their father on a scale that ranged from 0 (no change) to 3 (a great deal). Again, if the participants answered affirmatively, they answered a second question regarding the direction of change (positive or negative).
Parents’ influence on the relationship between the grandchildren and grandparent with dementia was assessed by two questions. First, participants rated this influence on a 4-point scale (from no change to a great deal), and then wrote down the reason for their answer (whether or not they perceived an influence).

Finally, participants were asked to rate their relationship with the partner of the grandparent affected by dementia. Three different questions were designed. The first one asked to what extent the dementia affected this relationship on a 4-point scale (from no change to a great deal). The second question asked about the direction of the change, positive or negative, and was only answered by participants who perceived that their relationship had changed. In the last question, participants wrote down the reasons for the perceived changes in this particular relationship.

Data Analysis

Results extracted from quantitative questions were analyzed using the statistical package SPSS Version 15. After running descriptive analysis, relationship with the dependent variable of the study was carried out using the t test or Kruskal–Wallis, chi-square test of independence or Mann–Whitney U test, depending on the nature of the variables. The answers to the open-ended questions were analyzed thematically. This qualitative analysis technique is designed to explore people’s lived experiences through a clear description of the topic studied (Boyatzis, 1998) and is particularly useful in exploratory studies in which the goal is to describe people’s experiences rather than to develop theory frames (Gubrium & Sankar, 1994). The researchers first read all the responses to the same question. Afterward, ideas (or units of meaning) in each response were identified. These ideas were then condensed into categories based on the repetition or similarity between threads of meaning or key words, phrases, or sentences contained in the unit. To increase the reliability of the results, this second step was conducted independently by two researchers. The categories obtained by each one were compared and the differences negotiated until a consensus was reached on the category system. Once categories were obtained and defined, another researcher who had not participated in the previous process rated each participant’s response within the category system given. Comparisons between researchers were used to refine the category system and to obtain reliability indexes. This process was repeated for the three open questions (changes in grandchildren’s life, parents’ influence on the grandchildren–grandparent relationship, and changes in the grandchildren–healthy grandparent relationship).
Results

Changes in Grandchildren’s Life

Only 26.2% of the sample (38 grandchildren) perceived that their life was different because they had a grandparent with dementia. Among characteristics to do with the family, the grandchildren themselves or dementia, the only variable related to these results was cohabitation with the grandparent: Grandchildren who lived together with the grandparent were more likely to perceive their life as different from that of their friends or peers, $\chi^2(1) = 7.878; p < .01$.

All these 38 grandchildren answered the open question asking why their life was different. The answers tended to be quite short: the average length was 25.3 words ($SD = 16.3$, range 7-90). Three categories emerged from the thematic analysis: family routines, personal changes, and change in the grandparent–grandchildren relationship (see Table 1). Cohen’s kappa reliability index of the category system was .76.

The most frequently identified category was family routines, which reflected changes in habits and family activities or in common activities for

<table>
<thead>
<tr>
<th>Variable</th>
<th>Category</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes in grandchildren’s life ($n = 38$)</td>
<td>Family routines</td>
<td>51.8</td>
</tr>
<tr>
<td></td>
<td>Personal changes</td>
<td>25.2</td>
</tr>
<tr>
<td></td>
<td>Grandparent–grandchildren relationship’s change</td>
<td>23.0</td>
</tr>
<tr>
<td>Change in the mother–child relationship ($n = 145$)</td>
<td>No change</td>
<td>68.1</td>
</tr>
<tr>
<td></td>
<td>Some change</td>
<td>25.7</td>
</tr>
<tr>
<td></td>
<td>A fair amount</td>
<td>4.8</td>
</tr>
<tr>
<td></td>
<td>A great deal</td>
<td>1.4</td>
</tr>
<tr>
<td>Type of change in the mother–child relationship ($n = 46$)</td>
<td>Improvement</td>
<td>65.1</td>
</tr>
<tr>
<td></td>
<td>Worsening</td>
<td>34.9</td>
</tr>
<tr>
<td>Change in the father–child relationship ($n = 140$)</td>
<td>No change</td>
<td>80.0</td>
</tr>
<tr>
<td></td>
<td>Some change</td>
<td>15.7</td>
</tr>
<tr>
<td></td>
<td>A fair amount</td>
<td>4.3</td>
</tr>
<tr>
<td>Type of change in the father–child relationship ($n = 28$)</td>
<td>Improvement</td>
<td>60.0</td>
</tr>
<tr>
<td></td>
<td>Worsening</td>
<td>40.0</td>
</tr>
</tbody>
</table>

Note: The number in parentheses refers to the number of grandchildren who reported this variable.
grandchildren (e.g., leisure activities or homework). For instance, one participant said: “I cannot do lots of things I should or want to do, such as studying, doing my homework, going out with my friends or with my family or other activities” (Participant 130, granddaughter, 17), whereas other one responded, “I cannot do many things because I have to stay at home with my grandfather. Leaving him alone might be dangerous” (Participant 56, granddaughter, 21).

Other changes included in this category were those that express how their lives were different because they had to devote time to their grandparent and take part in daily-care tasks: “I think it is different, as we have to take care of him and make sure he is all right, and that keeps me busy part of the week” (Participant 49, granddaughter, 15). In this sense, caring, at least partially, for the grandparent becomes a responsibility for some participants, a responsibility that is not shared by most of his/her peers:

Now . . . because you have a responsibility that your friends do not have, and sometimes they do not understand you. I’m never alone at home, she’s always there; and that restricts my freedom and both my personal and mental space. (Participant 38, granddaughter, 21)

Other grandchildren also reported changes in family structure and dynamics, especially in situations where the cognitively impaired grandparent has moved into grandchildren’s house. In multigenerational households, aspects such as routines or time dedicated to other family members have been modified by the presence of the grandparent: For instance, one participant said, “Since my grandmother has been sick, the family atmosphere has got worse, there’s more stress and I was even on the edge of a nervous breakdown. Sometimes we cannot go out as she cannot be left alone at home” (Participant 131, granddaughter, 20). In other cases, even the physical space at home is mentioned in the responses: “The fact that my grandmother has dementia and lives in our home has influenced our family life a great deal. My brother and I have to share a room, and my parents cannot go anywhere alone any more” (Participant 38, granddaughter, 21).

The second most frequent type of answer was related to personal changes. Interestingly, all the grandchildren who mentioned this category were female. This category reflected alterations grandchildren perceived in their personality, values, emotions, and attitudes. For instance, some participants reflected on their maturity, responsibility, and the suffering they were going through, which sets them apart from their peers: “I guess it is different as I think things that may not even have crossed my friend’s mind” (Participant 13, granddaughter, 19). Sometimes the personal changes are overtly positive, for
instance: “I feel that in many ways I am more mature than my peers” (Participant 2, granddaughter, 15). However, other times the situation makes some participant feel sad or frustrated: “You have a person with dementia who you love, and you feel so helpless because there’s nothing you can do” (Participant 97, granddaughter, 20).

Other grandchildren stated that the worries that came from the experience of having a person with dementia in the family made them think about themselves, their relationships, and the life they want to lead. Moreover, participants also emphasized the new values they had learnt from caring for a family member, which include greater respect for older people and their care: “[I feel different] because of the way I think of older people. The contact with my grandmother has given me values that other people with healthy grandparents do not have” (Participant 27, granddaughter, 19). The irreversible and degenerative nature of the illness is also mentioned as a factor that spurs changes: “You see the progress of the disease. It changes the way you think about things and life” (Participant 116, granddaughter, 21).

Last, the category change in the grandparent–grandchildren relationship involved answers in which grandchildren compared how the relationship was before the dementia and how it had changed since the onset of the disease. Deterioration in communication, affection, and a decrease in shared leisure activities were mentioned,

She has a disease that means she is unable to talk intelligibly or write. She doesn’t even recognize us. So, I can’t have a conversation with her or know what she needs or wants. I can’t make her listen to me or understand me (Participant 141, granddaughter, 18)

In the comparison with friends or peers, some grandchildren highlighted how their lives were different as other friends still had a relationship with their grandparents: “The rest of my friends have a relationship with their grandparents” (Participant 21, grandson, 15), and some participants missed the relationship they had with their grandparent: “I cannot rely on my grandfather as I could before” (Participant 9, granddaughter, 17). However, other grandchildren reported the opposite, as their peers did not see their grandparent so often: “My friends do not have so much contact with their grandparents and they are not forced to live with them” (Participant 99, grandson, 15)

**The Relationship Between Grandchildren and Their Parents**

As for the participants’ relationship with their mothers, only 32.4% of grandchildren ($n = 46$) perceived a change because of the grandparent’s dementia
More grandchildren perceived a change if the grandparent with dementia was from the maternal line, $\chi^2(1) = 14.015; p < .001$. Of these 32.4%, more than half said that this change had been for the better, whereas 15 grandchildren, roughly a third, thought that the relationship is worsening. As regards the participants’ relationship with their fathers, only 28 grandchildren said that this relationship had changed because of the dementia.

Perceiving changes in the relationship with one parent was related positively with perceiving changes in the relationship with the other parent ($\chi^2(1) = 30.004; p < .001$).

The majority of adolescents depicted their parents as an active influence in their relationship with their grandparent with dementia; 38.6% denied the existence of this influence. No influence of family, grandchildren, or dementia characteristics was found. All participants were asked to answer a second question in which they could write down the reasons for their previous reply. In all, 103 answers were collected, ranging in length from 3 to 70 words ($M = 15.5$ words; $SD = 11.3$). Seventy-two of these quotations reflected aspects of the parental influence on the relationship between the grandchildren and grandparent with dementia. The qualitative analyses yielded three main categories ($\kappa = .94$): keeping contact, learning, and the grandparent–grandchildren relationship.

As regards the keeping contact category, adolescent grandchildren described their parents as a source of advice and information encouraging them to visit their ill grandparent: “They make me realize how important it is to keep up the visits” (Participant 132, grandson, 20); “Because I go to the nursing home with them and they explain to me what is happening to her” (Participant 18, grandson, 14).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Category</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parental influence ($n = 145$)</td>
<td>Parental influence</td>
<td>61.4</td>
</tr>
<tr>
<td></td>
<td>No parental influence</td>
<td>38.6</td>
</tr>
<tr>
<td>Qualitative answers for parental influence ($n = 145$)</td>
<td>Parental influence</td>
<td>49.7</td>
</tr>
<tr>
<td></td>
<td>No parental influence</td>
<td>21.4</td>
</tr>
<tr>
<td></td>
<td>No reply</td>
<td>28.9</td>
</tr>
<tr>
<td>Presence of parental influence ($n = 72$)</td>
<td>Keeping contact</td>
<td>52.0</td>
</tr>
<tr>
<td></td>
<td>Learning</td>
<td>30.0</td>
</tr>
<tr>
<td></td>
<td>Grandparent–grandchildren relationship</td>
<td>18.0</td>
</tr>
</tbody>
</table>

Note: The number in parentheses refers to the number of grandchildren who reported this variable.
Some participants reported that this contact was influenced by their parents because of the family history, and that this influence had lasted throughout their lives. That is, if parents had always encouraged their children to keep contact with their grandparent, the grandchildren were more likely to maintain this contact in the new situation: “Because they made me go to visit him when I was a child, to pay attention to him . . .” (Participant 110; granddaughter, 21). So, to some extent, the middle generation has acted as a link between grandparents and grandchildren, as some participants expressed: “They have always been my bond with him” (Participant 42, grandson, 21). Nevertheless, the influence that parents seem to exert in grandparent–grandchildren contact was not always positive, as some participants reported, “Because they got me used to visiting her only once a week and not having much contact with her” (Participant 61, grandson, 18). Some participants even seemed to blame their parents for the poor quality of their relationship with their grandparents: “They didn’t take me to visit her much and the relationship has always been quite cold and distant” (Participant 60, granddaughter, 20).

A second dimension of parental influence was the way in which participants learn from their parents how to cope with the disease and take care of the family. For these adolescents, parents were like a mirror in which they look at and copy behaviors and obtain information on the disease: “They talked to me openly about the disease and that helped me to understand my grandmother better, her acts and words, and this has changed my behavior towards her” (Participant 145, granddaughter, 18). Some grandchildren even learn from their parents how to understand the disease so they can cope and deal with it: “Their behavior has helped me to see that my grandmother’s disease is not a drama, but another life event that has to be dealt with without worrying excessively” (Participant 128, granddaughter, 21). Moreover, these statements indicated the importance of this socialization in the form of a series of values and norms that participants saw as influencing the relationship with their grandparent: “Since I was a child my parents have taught me to love and respect her” (Participant 37, grandson, 21). However, not all their peers have this set of norms: “My parents have instilled in me the value of respect for older people in general, which is so important and lacking in people of my age” (Participant 107, grandson, 18).

Last, for some adolescents, the relationship between the two older generations (grandparents and parents) has influenced their own relationship with their grandparents. This influence of the middle generation was less frequently described by the younger grandchildren (14-17 years old), $\chi^2(1) = 5.256$;
This category reflected not only how this parent–grandparent relationship had changed because of the disease but also how it showed a continuity with the past. Sometimes that continuity is framed in positive terms, as in the response: “Because I see the love my mother still feels towards my grandmother and it’s even stronger now, despite the present situation” (Participant 117, granddaughter, 18), but sometimes not: “Because my mum and my grandma never got along and my dad can’t stand her. I have always thought she was unbearable and difficult” (Participant 66, granddaughter, 20).

As for the 31 participants who gave a reason why their parents had not influenced the relationship with their grandparent, in general their answers emphasized the freedom they had to decide what kind of relationship they wanted with their ill grandparent: “They have not influenced me at all, as they trust me, they know I am aware of the situation and act accordingly” (Participant 13, granddaughter, 19). That freedom included not only the nature of the relationship but also the contact that grandchildren had with their grandparents:

My sister and I are free to visit my grandparents whenever we want, although maybe now we visit them less because we are busier with studies and work. To some extent, we are free to choose not to visit our paternal grandparent so much, and my dad more or less accepts our decision. (Participant 34, granddaughter, 16)

Grandchildren and the Spouse of Their Cognitively Impaired Grandparent

Sixty-five participants (44.8% of the sample) had a grandparent with dementia who was married at the moment of the study. These grandchildren were asked questions about the partner of the ill grandparent. Among partners, 30 were male and 35 female; slightly more were from the maternal \((n = 38)\) than from the paternal side \((n = 27)\). More than half of the adolescents reported that this relationship had changed due to the illness of the other grandparent (55.29%), whereas the rest indicated no change (see Table 3). Participants who perceived a change were more likely to report a more positive relationship now than before the disease (57.89%). No influence of family, grandchildren, or dementia characteristics was found.

Thirty-five answers were gathered from an open question regarding the reasons for the changes in the grandparent–grandchildren relationship. The answers were categorized according to whether they reported an improvement
in the relationship \((n = 20)\) or a deterioration \((n = 15)\). Kappa reliability was excellent for both sets of answers (.93 and 1.0, respectively).

**Positive changes.** Fifteen participants’ responses focused on their behavior toward their healthy grandparent and on changes in their relationship, such as frequency of contact and emotional closeness. Grandchildren perceived an improvement in this relationship because they now gave emotional and instrumental support to this grandparent in order to help him or her cope with taking care of his or her spouse. For instance, one participant said: “Because I give her more support, I know that taking care of my grandfather is hard, so I try to help her” (Participant 27, granddaughter, 19). This support implied comprehension of his or her point of view: “Because I understand her a lot and I help her around the house” (Participant 102, granddaughter, 14). Often those actions of support included a feeling of returning to the grandparent the help he or she had given to the grandchild when he or she was young:

### Table 3. Percentages of the Variables in Current Healthy Grandparent–Grandchild Relationship

<table>
<thead>
<tr>
<th>Variable (n = 65)</th>
<th>Category</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partner of the grandparent with dementia</td>
<td>Maternal grandmother</td>
<td>23.1</td>
</tr>
<tr>
<td></td>
<td>Maternal grandfather</td>
<td>35.4</td>
</tr>
<tr>
<td></td>
<td>Paternal grandmother</td>
<td>23.1</td>
</tr>
<tr>
<td></td>
<td>Paternal grandfather</td>
<td>18.5</td>
</tr>
<tr>
<td>Change in grandparent–grandchildren relationship (n = 65)</td>
<td>No change</td>
<td>37.1</td>
</tr>
<tr>
<td></td>
<td>Some change</td>
<td>38.6</td>
</tr>
<tr>
<td></td>
<td>A fair amount</td>
<td>20.0</td>
</tr>
<tr>
<td></td>
<td>A great deal</td>
<td>4.3</td>
</tr>
<tr>
<td>Type of change in grandparent–grandchildren relationship (n = 39)</td>
<td>Improvement</td>
<td>57.9</td>
</tr>
<tr>
<td></td>
<td>Worsening</td>
<td>42.1</td>
</tr>
<tr>
<td>Changes in grandchildren–healthy grandparent—answers of improvement (n = 20)</td>
<td>Grandchildren support to the healthy grandparent</td>
<td>75.0</td>
</tr>
<tr>
<td></td>
<td>Efforts of both member of the dyad</td>
<td>25.0</td>
</tr>
<tr>
<td>Changes in grandchildren–healthy grandparent—answers of deterioration (n = 15)</td>
<td>Caregiver–grandparent role conflict</td>
<td>53.3</td>
</tr>
<tr>
<td></td>
<td>Caregiver–care receiver relationship</td>
<td>46.7</td>
</tr>
</tbody>
</table>

Note: The number in parentheses refers to the number of grandchildren who reported this variable.
Because I am older now and I can help my grandmother. She looked after me and my brothers and sisters, now I try to look after her and if I am not able to go to visit her at least I call her often. (Participant 4, granddaughter, 19)

Second, five participants emphasized the involvement of both members of the dyad in improving this relationship, an aspect that was not included in the previous category in which the grandchild was the only agent of change. These participants perceived the relationship was now closer because of the illness: “Because we feel close to each other we talk about everything. Maybe if we hadn’t had this problem [the illness], we wouldn’t have been so close” (Participant 2, granddaughter, 15). Sometimes, they mentioned that the communication had improved: “He isn’t afraid of talking to me about how he feels toward my grandmother or what it is happening in the family, I think that this situation make us feel closer to each other” (Participant 127, granddaughter, 18).

**Negative changes.** Eight grandchildren reported a negative impact on their relationship with this grandparent because of the grandparent’s involvement in caregiving tasks. They expressed regret regarding the shift in the grandparent’s attention from them to the care recipient and the fewer activities they share together: “Because my grandfather devotes every minute of the day to my grandmother, we can’t do the things we used to do” (Participant 134, granddaughter, 15), or “Because he has to spend all his time taking care of my grandmother” (Participant 63, grandson, 14).

Finally, seven participants complained about how the healthy grandparent behaved toward his or her partner or the rest of the family. Sometimes they felt that their healthy grandparent should give more support: “This relationship is worse now because I can’t understand some of my grandfather’s reactions. He should pay more attention to her [grandmother with dementia]” (Participant 36, granddaughter, 18), whereas other participants mentioned that the healthy grandparent did not care for or behave correctly:

I think she is angry with my grandfather because he has this disease. She yells at him because he has wet himself or if he eats quickly and my grandfather can’t do anything to stop it and she gets angry, then the situation irritates me and I get angry with her. (Participant 51, grandson, 17)

**Discussion**

This study was designed to explore the impact of having a grandparent with dementia on grandchildren’s perceptions of three different topics: (a) their
own lives, (b) their relationship with their parents, and (c) their relationship with the partner of the person with dementia.

As regards the first objective, when grandchildren compared their lives with their peers who did not have a grandparent with dementia, they generally perceived no or few changes. However, this was not the case for grandchildren who lived in the same house with their grandparents. These multigenerational households made daily life different for young people, changing routines, family relationships, and even the distribution of space in the home. Grandchildren were more aware of the process of deterioration of their grandparent and of the stress the main caregiver was under; they had to deal with it every day and, at the same time, had to continue with their normative daily activities (academic duties, dating, or friends, among others). Those results are consistent with other studies that focus on multigenerational households of this kind (Howard & Singleton, 2001; Szinovacz, 2003).

Moreover, grandchildren who lived with a cognitively impaired grandparent also stressed how involvement in care of their grandparent made their life different. Though none of the grandchildren were the main caregivers, their auxiliary caregiver role often clashed with the need for autonomy, freedom, and independence from the family that adolescents need. In addition to changing routines or responsibilities at home, grandchildren mentioned the ways in which their lives differed from those of their peers, some of them positive: for example, they learnt things that their friends did not, and may be assumed to be responsible or mature as a result. This maturation had also been reported in other studies (Beach, 1997; Celdrán et al., 2009a).

The perception of a different life was not altered by other variables, such as grandchildren’s age. Younger grandchildren might be expected to be under more normative stress because of their age and, in turn, might be affected more by the nonnormative changes in their family (Fruhauf & Orel, 2008). Further research could help to ascertain whether these changes perceived by adolescents who cohabit with a grandparent with dementia also appear when compared with matched adolescents with cognitively intact grandparents, or whether age differences are revealed in this group comparison.

Our second objective was to explore the changes grandchildren perceived in their relationship with their parents because of their grandparent’s illness, and how, in turn, parents might influence the grandchildren’s behavior toward their grandparents. The grandchildren–parent relationship changes over the course of adolescence, and this change often causes problems. Adolescence has been described as a stage in which conflicts with parents increase and the closeness of the parent–child relationship may be affected. Therefore, dealing with the disease of a grandparent can be seen as an extra
strain on the grandchildren–parent relationship (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). However, our results show that perceived changes in the relationship with parents tended to be quite positive. One possible explanation for this result is that in periods of stress, grandchildren use their parents as their first source of support, strengthening communication and their relationship in general (Oliva, Jimenez, & Parra, 2009; Shulman, 1993). However, as our research did not include data on the source of changes, more studies that compare the perspectives of grandchildren and parents are needed to corroborate this finding (see Szinovacz, 2003, for an example).

Moreover, not only does the relationship between grandchildren and their parents change in families with a person with dementia, but parents also appear to influence how grandchildren interact with their cognitively impaired grandparent. It is well known that parents play an important role in the interactions between grandparents and their grandchildren, both in intact families (e.g., Uhlenberg & Hammill, 1998) and in divorce cases (Bridges, Roe, Dunn, & O’Connor, 2007). Our data were consistent with this trend: Participants indicated a positive influence of their parents on the relationship with their cognitively impaired grandparent. Parents served as gatekeepers for the grandparent–grandchild relationship, facilitating interactions of the dyad: they supported and encouraged grandchildren to visit their grandparents, especially if the grandparent lived in a nursing home. Parents’ influence also seemed to follow an indirect route, acting as a model for grandchildren. Specifically, some grandchildren reported having learnt coping strategies and values regarding the care for elderly people from seeing how their parents interacted with their ill grandparent. A third view of the parental influence was that it may be a result of the previous family history of relationships. Some grandchildren stressed that their parents had strengthened their relationship with their grandparents by trying to keep up regular contact with them during their childhood, and that the present grandparent–grandchildren relationship was the result of this parental effort.

Finally, a small part of the sample stated that they had sufficient autonomy to decide how they wanted to interact with the different members of the family, and in this case, with their grandparent who had dementia. This autonomy could be a sign of the increasing independence of the adolescent grandchildren from their parents as part of the normative individualization of values and behaviors, and the increasingly voluntary nature of their relationship with their grandparents (Mueller, Wilhelm, & Elder, 2002).

Our third and final objective was to examine changes perceived by grandchildren in their relationship with the spouse of the person with dementia. Most participants found that the disease had affected this relationship, in
contrast to the minor changes found in the relationship with their parents discussed above. This specific grandparent–grandchild relationship has not been considered before in other studies of caregiving and our data suggest that it may be important for the understanding of family dynamics in the case of dementia. Both positive and negative outcomes were found, although the former were more frequent. On the positive side, grandchildren felt closer to this healthy grandparent and offered them emotional and instrumental support, which may help to relieve some of the stress related to caregiving. They also increased their frequency of contact and emotional closeness. In contrast, according to the normative grandchildren–grandparent literature, these aspects tend to decrease once grandchildren reach adolescence (Kennedy, 1992; Van Ranst et al., 1995). Regarding the negative effects on the relationship between grandchildren and their healthy grandparent, participants underscored the influence on their relationship of the grandparent’s role as main caregiver. For instance, the negative reactions of the healthy grandparent toward their partner may erode their relationship with their grandchildren and the role as main caregiver may restrict contact and reduce the opportunities for shared activities.

In conclusion, our results show the complexity of the different changes in the families with a cognitively impaired grandparent. Young members of the family may see changes in routines, family duties, or family activities, and modifications in their relationship with other members of the family (i.e., parents or healthy grandparents). These changes may be due not only to the grandparent’s illness but also to other aspects, such as the behavior of the middle generation (their parents) or the decision to have the grandparent move into the family home. This complexity emphasizes the importance of using a family systems perspective to address family caregiving that focuses predominantly on the main caregiver.

Analyzing the adolescent grandchildren’s perceptions of the changes in family relationships is of interest both for research in family caregiving and also in grandparent literature. First, the current study breaks new ground in showing how new relationships are created by caregiving experiences, questioning the typical view of the relationship between caregiver and care receiver. It stresses how young people can experience life changes if they live in a multigenerational household with a person who has dementia and how young people in general may feel that their relationships with other members of the family are changing, though not always in a negative way. Those positive changes due to the grandparent’s illness contribute to a more optimistic appraisal of this experience, as previous studies have noted (Beach, 1997,
Second, our data confirm the influence of the middle generation in the interaction between grandchildren and grandparents with dementia and also highlight how the relationship with other grandparents, especially the ones from the same family line, is also affected by the caregiving system.

Our study has certain limitations. First, the participating grandchildren came from families that use some kind of formal care support, such as a day centre or a long-term institution. This means that we cannot generalize our results to families or grandchildren that do not receive support of this kind, since the changes in relationships in this situation may be different. As grandparents of the grandchildren who participated in our study spend part or all their day in care centers, the availability of formal support may have helped grandchildren to perceive relatively few changes in their life. Moreover, the fact that data were collected by post, and the contact was made through the main caregiver, may have limited the number of participating families in which adolescents have a poor relationship with their grandparents or, more generally, the number of families with relational problems.

Finally, at least three practical implications can be drawn from this study. First, grandchildren who live in the same house as grandparents with dementia experience the most profound changes in their lives and are the ones that need most support, in the form of information about the disease and coping strategies. Second, as parents are a key source of influence for adolescent grandchildren, it is important to raise their awareness of how they can facilitate the grandparent–grandchildren relationship. This help can take the form of giving information on dementia or by supporting grandchildren who want to continue to see and interact with their grandparent. Last, since in most cases the relationship between grandchildren and healthy grandparents improves, this relationship could be used as a source of emotional and instrumental support for the healthy grandparent, particularly if he or she is the main caregiver of the cognitively impaired spouse.

In sum, as the family systems perspective suggests, any kind of intervention on older people with dementia should take into account all the members of the family and their interactions and should avoid an excessive focus on the main caregiver. Other members of the family, such as grandchildren, may be affected by the situation, but the experience may also teach them important lessons.

**Declaration of Conflicting Interests**

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