

PERSONAL EXPERIENCE OF AGING IN THE CHILDREN OF A PARENT WITH DEMENTIA

DEBBY GERRITSEN

VU University Medical Center, Amsterdam

YOLANDE KUIN

University of Nijmegen, The Netherlands

NARDI STEVERINK

University Hospital Groningen, The Netherlands

ABSTRACT

We investigated whether adults with a parent with dementia experience their personal aging differently than adults whose parents do not have dementia. Semi-structured interviews were conducted with 25 adults who had a parent with dementia and 25 controls. We found that, although in a general sense the two groups were quite similar in their personal experiences of aging, there were specific differences. The children of parents with dementia had a health-concept in which there was substantial emphasis on mental health. Moreover, they linked the dementia of their parent to their own aging and worried about developing a dementia syndrome themselves. They also held different attitudes with regard to end-of-life decisions. Finally, participants having a parent with dementia gave more extensive answers to simple questions. This overall response suggests more involvement with growing older and finitude in the children of parents with dementia.

INTRODUCTION

Growing older is a process that affects multiple facets of life, many of which are normative, such as undergoing physical changes or becoming a grandparent. The way in which people experience aging is, however, highly personal. The personal

experience of aging can be defined as the subjective conceptions that are associated with aging, bearing reference to both the present and the future. A few empirical studies have focused on this personal experience of aging. Connidis (1989), Heikinnen (1993), and Keller, Leventhal, and Larson (1989) found that aging people generally regard their aging process positively, although they may also experience worries, losses, or vulnerabilities. Steverink, Westerhof, Bode, and Dittmann-Kohli (2001) found that the personal experiences of aging not only refer to the experience of physical decline and social loss, but also to personal growth. These studies all stress the importance of objective and subjective health in the evaluation of the personal experience of aging. Apparently, threatened health can have a negative effect. Moreover, the experience of aging was found to have important implications for subjective well-being (Steverink et al., 2001), functional health (Levy, Slade, & Kasl, 2002), and even for longevity (Levy, Slade, Kunkel, & Kasl, 2002).

Given the significance of health status as a determinant of the personal experience of aging, the question is whether it is only personal health status that influences the personal experience of aging, or whether the experience is influenced by the health status of significant others (i.e., parents). Is the confrontation with an aging parent whose health is severely impaired a cause for more negative conceptions of aging and increased fear and concern about one's own future? If so, this would have implications for life satisfaction, well-being, and even for longevity. The results of Neikrug's study (1998) suggest that the health status of others might influence the personal experience of aging. Neikrug found that the employees in geriatric facilities (nurses and nursing aides) had higher scores on a "worry about aging" scale than did others (white-collar clerical workers and middle-class retirees from fraternal associations). Professional contact with the frail institutionalized elderly may lead to increased worry about one's own old age. Gatz, Bengtson, and Blum (1990) studied family stress as a result of the health-related dependency of a parent. They describe a strong emotional effect of the parents' deterioration in health status on all family members, as well as a heightened awareness of their own vulnerability and finitude. This heightened awareness coincides with a phase in life in which people evaluate their personal situations (Neugarten, 1979). Difficult circumstances, such as the health-related dependency of a parent, can greatly influence this evaluation (Duijnste, 1992). Thus, there are some indications that the health problems of others may influence the personal experience of aging.

A striking example of threatened health with aging is dementia, a syndrome that occurs frequently in the elderly (Van Duijn, 1996; Hendrie, 1998). Although having a parent with a physical illness is often stressful, having a parent with dementia is especially difficult. Even though a physically ill parent may need special care, the children of a parent with dementia have to face not only the physical but also the psychological and social deterioration of the parent.

Moreover, the relationship with the parent changes and has to be reshaped and redefined due to the specific features of the dementia syndrome such as a change in personality, deterioration of the ability to interact in the usual way, and a reversal of the roles in the relationship (George & Gwyther, 1986; Zarit, 1996; Zarit & Edwards, 1999). The process of dementia and the resulting change in the parent can cause the children to mourn the loss of the parent long before the parent actually dies (Rando, 1986; Ter Haar, 1992). Difficult enough on its own, this anticipated grief coincides with the child's growing involvement with and intensifying care for the parent. This study investigates whether there is yet another stressor associated with the dementia of a parent. Does the dementia influence the children's personal experiences of aging (i.e., not only their present life in relation to the parent, but also their experiences and conceptions of their own aging and future)?

Most experience-related psychological research on dementia has not focused directly on the personal experiences of aging in the children of people with dementia but rather has been concerned with caregiving, especially the burden of caring for persons with dementia (Farran & Kuhn, 1998; Pearlin, Mullan, Semple, & Skaff, 1990; Zarit & Edwards, 1999). However, some studies on memory concerns can provide information to determine whether having a parent with dementia influences the personal experience of aging. Recently, in their study on the practical memory concerns of older adults, Reese, Cherry, and Norris (1999) found that fear of dementia was a realistic concern for older people in general. The researchers attributed this concern to the increase in public awareness about dementia in recent years. Commissaris et al. (1993) found a growing concern about the possibility of becoming demented in people who were closely related to a person suffering from dementia. Neikrug's (1998) study should also be mentioned in this context. He found that knowledge about aging lessened the worry about the aging process. Dementia is an incurable condition with hereditary features, but little is known about the heredity mechanism of the syndrome (Lovestone, 1999; Van Broeckhoven, 1998). Because dementia is, at least in part, hereditary, the children of a parent with dementia may worry about their own aging and future and, more specifically, about the possibility that they could also develop this syndrome. However, since there are still substantial uncertainties about the precise role of heredity in dementia, it may be difficult for the children of a parent with dementia to lessen their worries by increasing their knowledge about aging or dementia. Moreover, considering that there may be a hereditary component present, knowledge about dementia might actually increase these worries.

Thus, because of the multifaceted nature of the syndrome and its consequences, having a parent with dementia could influence the personal experience of aging in children. This, in turn, would have implications for the health care system. Health professionals may need to not only focus on the heavy care-burden that children of

a parent with dementia could suffer (i.e., the children who are providing the care), but may also need to focus on the thoughts and worries that all children may have about their own aging and future. The aim of the present study is to investigate: whether the personal experience of aging for adults with a parent with dementia is different from that of adults whose parents do not have dementia and, if so, how it is different. Apart from the study by Commissaris et al. (1993) about reasons for worrying about becoming demented, no other studies have investigated the possible influences of having a parent with dementia on children's experience of aging. Therefore, we chose an exploratory study design and conducted in-depth interviews to gain information about how children of parents with dementia experience their own aging process.

METHOD

Participants

Fifty middle-aged and older adults participated in the study. Twenty-five participants (M age = 55, range 52-65 years) still had or previously had a parent with dementia (the PD group) and 25 participants (M age = 58, range 51-73 years) did not (control group). The PD group consisted of 21 females and four males, and the control group had 19 females and six males. All participants had completed high school, and residents of urban and rural regions were equally represented in both groups. The majority of participants were married, but four were living alone after either a divorce or becoming widowed.

To recruit participants for the PD group, an advertisement was printed in the newsletter of the Dutch Alzheimer Foundation inviting adults with a parent with dementia to participate in a study to investigate how they experienced their own aging. Members of the control group were recruited by purposeful sampling (Maxwell, 1996). An acquaintance of one of the authors, who did not have a parent with dementia, was first asked to participate. She was then asked whether she knew other people who did not have a parent with dementia who might be interested in being interviewed about their aging experience. After these people had been interviewed, they were, in turn, asked whether they knew someone else who would be interested in participating. This continued until the required number of subjects were interviewed.

It should be acknowledged that the recruitment procedure for the PD group might be subject to selection bias, because the group probably is a selective sample in that it only contains people who have some connection with the Dutch Alzheimer Foundation. The method used to recruit the control group might also have had some effect on the selection. Because the primary aim of the study was exploratory, these methods were considered generally satisfactory for the present purposes.

Procedure

The first author conducted and audio-taped all interviews which were in-depth semi-structured interviews concerning the participants' personal experiences of aging. The interviews took place within a period of three months, and each interview lasted for approximately one-and-a-half to two hours. The interviews contained 10 open-ended questions aiming to elicit statements about the personal experience of aging. They started with more general issues (e.g., Do you think about growing older? What is it about?) and progressed to more specific questions (e.g., focusing on health, independence, and the end of life), because these topics represent a direct connection with the threatened health and frailty of parents with dementia. Other issues such as wisdom, time, and plans for the future were also addressed. When these topics were not mentioned spontaneously, the interviewer referred to them in order to obtain information about all aspects from all participants. The interview schedule can be found in the Appendix.

With respect to the question about end-of-life decisions, it is worth mentioning that in the Netherlands, where this study was conducted, this topic is widely debated in daily life. Although only recently legalized, physician-assisted death (i.e., euthanasia and physician-assisted suicide) has been tolerated in the Netherlands since the 1980s as long as the requirements for prudent practice were met. These requirements stipulate that the suffering must be unbearable and hopeless, and that the request for physician-assisted death must be voluntary, persistent, and well-considered (Van der Wal & Dillmann, 1994). The patient must be competent, and the physician must be willing to grant the request and also obtain a second opinion before physician-assisted death can be carried out. Patients with dementia, however, are usually no longer competent to make such a decision, and no one has the legal right to make it for them. In recent years, there has been not only a lot of publicity, but also substantial research concerning end-of-life decisions (Onwuteaka-Philipsen & Van der Wal, 2001; Van der Maas et al., 1996; Van der Wal et al., 1996).

The audiotaped interviews were transcribed and analyzed. Data-analysis was performed according to the procedure proposed by Baarda, De Goede, and Teunissen (1995). First the non-relevant text was removed from each interview (i.e., text not relevant for the research question). The remaining excerpts of text, in which the various issues of study were mentioned, were labeled in order to make a comprehensive list of uniformly formulated interview topics. The labeling procedure consisted of three steps: 1) the first author labeled five randomly-selected interviews from each study group; 2) the second author labeled another five randomly-selected interviews using the topics formulated by the first author, but critically considering their completeness and accuracy; and 3) the two authors discussed the topics, changed, and/or extended them where necessary, and reached consensus on the correct wording. It should be noted that several topics might be mentioned in one excerpt of the text. Moreover, a topic could be mentioned more

than once during an interview. For instance, when a topic was mentioned in three different excerpts of the text, that topic received a frequency count of three. The result of all interviews labeled in this way was a total list of 58 topics (see Table 1).

In order to investigate the specific wording that participants used when referring to a topic, the excerpts of the interview texts were also retained for further analyses. This would provide both further specification of the topic, and also information about each participant's specific opinion of the topic.

To establish the reliability of the labeling, a colleague of the authors (blinded for the goals of the study) independently labeled all the excerpts of text on the basis of the final list of topics. The level of agreement of the first author and the colleague was established by dividing the number of agreements by the total number of labels per interview and subsequently calculating the mean percentage of agreement per group (Nunnally & Bernstein, 1994). In the PD group, an agreement of 95% (range 89% through 99%) was found, and in the control group, there was an agreement of 96% (range 92% through 98%). This was considered to be satisfactory. Before the analyses were performed, all disagreements were resolved by consensus.

It should be noted that some topics were already included in the open-ended questions asked in the interviews. These are indicated in bold type in Table 1. Moreover, as can be seen from the interview schedule in the Appendix, the last interview question differed for the two groups (PD group: "What happens when you forget something; do you think about dementia?"; control group: "Are you familiar with dementia in your environment?"). This led to different frequencies with regard to the topic "forgetting something."

RESULTS

Table 1 presents a list of the topics, along with the number of participants who mentioned each topic, for the two separate groups of participants. Also shown is the total frequency with which each topic was mentioned, and the range of how often a topic was mentioned in each interview. In studying the topics, four major themes became apparent: health and independence, (personal) growth, coping with growing older, and finitude. For the sake of clarity, the results herein are described according to these four major themes. Moreover, it was decided to structure the results of each major theme along two lines. First, a topic was considered to be important when at least 12 (i.e., approximately 50% or more) of the participants in one of the groups mentioned it. Differences between the groups in the number of participants mentioning a topic are also described in Table 1. However, as a topic could be mentioned more than once, the frequency with which it was mentioned by each group could also indicate its importance. Therefore, these frequencies are also considered and reported in Table 1. Second, there were some specific details found either when looking more closely at the precise wording of the topics or examining how extensively some topics were discussed

by the participants. These extra details provide insight into differences between the two groups in both the specific ways of talking about the topics and/or the nuances in emphasis.

Health and Independence

All participants in both groups talked about “dementia,” “dependence,” and “health in general.” Dementia was discussed by all participants in the PD group without their being asked about it. The control group was explicitly asked about dementia, so all participants talked about it although with a much lower frequency than in the PD group (35 vs. 92, respectively). Although all participants were asked about dependence and health in general, the importance of these topics is clear. Many participants in both the PD and the control group talked about these topics more than once (dependence: 61 PD vs. 65 control; health: 54 PD vs. 64 control). All participants in the PD group discussed “forgetting something,” but this was because they were specifically asked about it.

All except one person in the PD group mentioned the possibility of developing dementia themselves (“heredity of disease”) and this topic was mentioned 50 times in total. In the control group, only 13 participants talked about a possible heredity of their parents’ disease, with a total frequency of 15 times. This pertained to diseases other than dementia, most frequently cancer ($n = 8$).

“Declining abilities” was an important topic in both groups ($n = 18$ in the PD group vs. $n = 18$ in the control group). Mental health, however, was mentioned by twice as many in the PD group as in the control group ($n = 14$ vs. $n = 7$, respectively). The possibility of having to go to a “residential or nursing home” was mentioned by more participants in the control group than in the PD group ($n = 18$ vs. $n = 14$, respectively) and was also more frequently mentioned in the control group (32 control vs. 19 PD). “Walking inability” was mentioned as often by participants in the PD group as by those in the control group ($n = 10$ vs. $n = 12$ respectively). With respect to the remaining topics, it is remarkable that cancer was mentioned by many more participants in the control group ($n = 19$ vs. $n = 8$). Being a burden was also mentioned by more participants in the control group ($n = 12$ control vs. $n = 9$ PD), and the same pattern applies to being ill or having a disease in general ($n = 13$ control vs. $n = 6$ PD).

Growth

Next to “wisdom,” which was an interview question, “undertaking activities” (e.g., traveling, gardening, new hobbies) and “freedom, more free time, and restfulness” were also important topics for both groups (undertaking activities: $n = 22$ PD vs. $n = 23$ control; *freedom*: $n = 21$ vs. $n = 18$, respectively). Interestingly, “undertaking activities” was mentioned somewhat more frequently in the control group than in the PD group (56 vs. 45, respectively), whereas “freedom, more free time and restfulness” was mentioned more frequently in the

Table 1. Number of Participants Who Mentioned a Topic and Total Frequency with Which Topics are Mentioned (and Range) for Adults with a Parent with Dementia (PD Group) and for the Control Group

Themes	Topics	PD group		Control group	
		Number of participants	Frequency of topic (range)	Number of participants	Frequency of topic (range)
Health and independence	Dementia^a	25	92 (1-9)	25	35 (1-2)
	Dependence^b , needing help	25	61 (1-7)	25	65 (1-5)
	Health in general	25	54 (1-5)	25	64 (1-5)
	Forgetting something, being forgetful^c	25	32 (1-5)	5	8 (0-2)
	Hereditry of disease	24	50 (0-4)	13	15 (0-2)
	Declining abilities, defects, energy loss	18	31 (0-3)	18	36 (0-4)
	Mental health	14	29 (0-4)	7	11 (0-3)
	Residential or nursing home	14	19 (0-4)	18	32 (0-4)
	Walking (in)ability, invalidity	10	16 (0-5)	12	19 (0-3)
	Physical health	10	16 (0-3)	6	8 (0-2)
	Declining of senses (eyes, ears)	6	14 (0-5)	5	5 (0-1)
	Cancer	8	10 (0-3)	19	28 (0-3)
	Being a burden to others	9	9 (0-1)	12	13 (0-2)
	Deterioration	6	9 (0-4)	8	11 (0-3)
	Being ill, having a disease (in general)	6	6 (0-1)	13	16 (0-2)
	Other specific diseases	5	6 (0-2)	7	8 (0-2)
	Growth	Wisdom , experience of life	25	27 (1-2)	24 ^d
Undertaking activities		22	45 (0-4)	23	56 (0-4)
Freedom, more free time, restfulness		21	38 (0-4)	18	29 (0-4)

Growth (Cont'd.)	Being together (partner)	17	22 (0-3)	13	23 (0-2)	
	Relationships with the children	16	32 (0-5)	14	25 (0-4)	
	Relationships in general	15	26 (0-5)	17	25 (0-4)	
	Grandchildren	11	14 (0-2)	9	13 (0-3)	
	Taking things as they come	10	13 (0-3)	11	14 (0-3)	
	Adhering to one's own plans or ideas	6	8 (0-2)	4	5 (0-2)	
	Consciousness-raising, formulating other priorities	6	7 (0-2)	6	6 (0-1)	
	Sense of perspective	7	7 (0-1)	4	5 (0-2)	
	Being content	6	7 (0-2)	3	4 (0-2)	
	Mildness, deliberation	4	4 (0-1)	3	3 (0-1)	
	Being needed	3	3 (0-1)	5	5 (0-1)	
	Weighing up the balance, reorientation	2	2 (0-1)	0	0	
	Being taken seriously	0	0	2	2 (0-1)	
	Coping	Work	18	32 (0-4)	19	33 (0-3)
		Housing	17	23 (0-3)	19	33 (0-5)
		Acceptance, adaptation to (possible future) changes	16	22 (0-2)	20	38 (0-4)
		Health behavior	14	18 (0-2)	11	19 (0-3)
Loneliness, isolation		12	18 (0-5)	6	9 (0-3)	
Staying flexible, active, enterprising		10	16 (0-3)	12	18 (0-3)	
Finances		9	16 (0-4)	10	14 (0-3)	
Continuing life as it is		7	7 (0-1)	11	14 (0-3)	
Keeping occupied		7	7 (0-1)	5	5 (0-1)	
Keeping engaged, interested		6	7 (0-2)	6	6 (0-1)	
Taking it easy, cutting back		6	9 (0-3)	4	4 (0-1)	
Selfishness, hardening, inflexibility, nagging		4	5 (0-2)	6	11 (0-3)	

Table 1. (Cont'd.)

Themes	Topics	PD group		Control group	
		Number of participants	Frequency of topic (range)	Number of participants	Frequency of topic (range)
Coping (Cont'd.)	Keeping fit mentally	4	5 (0-2)	5	8 (0-2)
	Withdrawal	4	5 (0-2)	7	7 (0-1)
	Preparation/anticipation of (possible future) changes	3	3 (0-1)	7	7 (0-1)
Finitude	End-of-life decisions	25	45 (1-4)	25	35 (1-4)
	Dying , end of life	25	35 (1-5)	25	49 (1-4)
	After death	25	28 (1-2)	24	27 (0-3)
	Sense of finiteness	15	24 (0-3)	9	13 (0-3)
	Death is part of life	13	13 (0-1)	9	13 (0-2)
	Pain, struggle, suffering at the end of life	10	13 (0-2)	18	30 (0-4)
	Taking leave at the end of life	10	10 (0-1)	9	15 (0-4)
	Loss of partner	9	13 (0-2)	10	10 (0-1)
	Changing sense of time	8	8 (0-1)	10	11 (0-2)
	No fear of dying	6	6 (0-1)	9	9 (0-1)
	Oldest generation	3	3 (0-1)	2	2 (0-1)

^aQuestion about dementia only asked in control group. ^bTopics in bold type are specifically related to in the interviews. ^cQuestion about forgetfulness only asked in PD group. ^dErroneously, in one interview the question about wisdom was not asked.

PD group (38 vs. 29). In both the PD and control groups, the topics referring to “being together with the partner” ($n = 17$ PD vs. $n = 13$ control), “relationships with the children” ($n = 16$ PD vs. $n = 14$ control) and “relationships in general” ($n = 15$ PD vs. $n = 17$ control) also appeared to be important. Yet, the PD group mentioned “relationships with the children” somewhat more frequently than did the control group (32 vs. 25, respectively).

Coping with Growing Older

“Work” (e.g., terminating or cutting back on working) was found to be an important topic in both groups ($n = 18$ PD group; $n = 19$ control group), and both groups mentioned it an average of twice per interview. Both “housing” (e.g., future accommodation) and “acceptance” (e.g., adaptation to possible future changes) were also mentioned by a substantial number of participants in both the PD and control groups ($n = 17$ vs. $n = 19$, respectively for housing; $n = 16$ vs. $n = 20$, respectively, for acceptance), although the control group mentioned these topics relatively more frequently than the PD group (33 vs. 23, respectively, for housing; 38 vs. 22, respectively, for acceptance). Other topics referring to the major theme of coping and discussed by approximately half of the participants in one of the two groups were “health behavior” ($n = 14$ PD group), “loneliness” ($n = 12$ PD group), and aiming to “remain active and flexible” ($n = 12$ control group). Of these three topics, it is remarkable that “loneliness” only seemed to be an issue in the PD group, where it was mentioned by approximately half of the participants ($n = 12$). It was mentioned by only a quarter ($n = 6$) of the participants in the control group.

Finitude

End-of-life decisions" and “dying” were topics included in the interview questions, and thus were discussed by all participants. “End-of-life decisions,” however, were mentioned more frequently in the PD group than in the control group (45 vs. 35, respectively), whereas for the topic of “dying” the frequency was higher in the control group (49 vs. 35). Interestingly, the topic of “after death” was mentioned by almost all participants in both groups ($n = 25$ PD group; $n = 24$ control group). Other important topics were “sense of finiteness,” “death is part of life,” and “pain, struggle, suffering at the end of life,” but again, there were some remarkable differences between the two groups. Compared to the control group, more participants of the PD group talked both about a “sense of finiteness” ($n = 15$ vs. $n = 9$) and “death is part of life” ($n = 13$ vs. $n = 9$), whereas in the control group, “pain, struggle, and suffering at the end of life” was mentioned by more participants ($n = 18$ vs. $n = 10$) and also more frequently (30 vs. 13).

Some Further Specific Findings

Considering the text excerpts in more detail, a number of specific findings emerged that should also be mentioned. First, further investigation of the topics of health and independence showed that, unlike the control group, all participants in the PD group referred spontaneously to dementia when discussing health. Thus, they directly linked dementia with health. Nine participants in the control group referred to dementia spontaneously. When investigating the topic “forgetting something” in the PD group, it appeared that almost all participants ($n = 21$) mentioned that the possibility of dementia came to mind when they forgot something in daily life. More specifically, more than half of the participants in the PD group ($n = 15$) said that they had this association immediately and frequently, and a quarter ($n = 6$) said that they had it sometimes or regularly.

Second, with respect to the theme of finitude, some specific nuances emerged concerning the topic of “end-of-life-decisions.” With regard to making a decision about the end of one’s own life, all 25 participants in the control group, as opposed to 17 in the PD group, mentioned the possibility that they might consider physician-assisted death under certain deplorable conditions. The other eight participants in the PD group said that they could not make any statement about this in their present circumstances. In the PD group, 15 participants (compared to three in the control group) elaborated on the complexity of the issue by weighing the pros and cons of requesting physician-assisted death. They considered no longer being able to make such a decision (i.e., due to loss of competence), changes in the balance between how to judge what is considered to be acceptable and what is burdensome at the end of life, and wanting to try to live life to the end. Participants in the control group did not elaborate on the complexity of the issue, but discussed reasons for considering such a decision (30 reasons, $n = 18$ control group vs. 13 reasons, $n = 9$ PD group). The control group mentioned mainly physically-related reasons such as pain ($n = 10$ in the control group vs. $n = 1$ in the PD group) and dignity ($n = 5$ in the control group vs. $n = 1$ in the PD group). Those in the PD group who did mention reasons talked mainly about no longer experiencing pleasure or happiness ($n = 6$ PD group vs. $n = 2$ control group).

Finally, data obtained from the interviews gave the overall impression that, when compared to the control group, participants in the PD group were more concerned with growing older and finitude. Although this is not reflected in a large difference between the total number of labeled topics (1100 vs. 1055), the answers given by the PD group were more extensive and more often weighed different factors and aspects of the topics. In addition, when analyzing the excerpts of text it was found that only seven participants in the PD group reacted once or more to the interviewer’s introduction of a topic by saying something like “never thought about it” or “don’t occupy my mind with things like that.” In contrast, a large majority of the participants in the control group ($n = 20$) made this type of remark at least once and often more frequently.

DISCUSSION

The aim of this study was to investigate whether the personal experience of aging for adults with a parent suffering from dementia is different than that of adults whose parents did not have dementia, and in what ways it is different. The study revealed two major findings which are summarized and discussed below.

The first major finding is that the PD group and the control group were on the whole, much alike in their personal experiences of aging. Their statements reflect developments and psychological themes that have been found to be characteristic for their phase of life (see Neugarten, 1979). The participants show an orientation to the present and the future that contains growth on the one side and vulnerability on the other. Growth concerns personal growth and developing new ways in which to organize their lives. Aspects of vulnerability include declining health, possible dependence, coping with growing older, and being concerned with finitude. Health and independence were major concerns in both groups. This is in accordance with the findings of various studies on personal meaning in the second half of life. Dittmann-Kohli (1995) found that desires and worries of the elderly are, to a great extent, concerned with health and independence. Westerhof, Kuin, and Dittmann-Kohli (1998) found health to be a central theme in the personal meaning system of people in the second half of life that becomes even more important with increasing age. Steverink et al. (2001) also found that, in a group of people aged 40 to 85, one of the major dimensions of the aging experiences was (declining) physical health.

Nevertheless, the second major finding herein was that there are specific differences between the two groups. The three that are especially striking are described in more detail below. The first intriguing difference concerns the meaning of the concept of health. The control group primarily associated health with health or sickness in general, or more specifically with cancer, and thus referred to health on a more general and physical level. The children of a parent with dementia, however, often referred to mental health, especially dementia, as an aspect of health. More specifically, dementia was a major topic for children of a parent with dementia when discussing the experience of growing old. Participants in the PD group often related their ideas and opinions about health to dementia, and they wondered whether they would become demented as well. For most of them, forgetting something was associated with dementia and worried them to the point where these worries intruded upon them regularly in daily life. This means that a large majority of children of a parent with dementia regularly experience a "dementia alarm." As people in the second half of life often report forgetfulness (Salthouse, 1991; Sugar & McDowd, 1992), and their capacity for memory may decline with age (Balota, Dolan, & Duchek, 2000; Perlmutter & Hall, 1992; Willis & Schaie, 1999), the frequency of the dementia alarm will be substantial.

This finding is in accordance with the results of the study carried out by Commissaris et al. (1993), who found that worries about cognitive deterioration

are related to having a relative who suffered from dementia. Reese et al. (1999) found that the general population also worries about becoming demented, and indeed, several participants in the control group also mentioned forgetfulness and dementia. Yet, in the children of parents with dementia, the finding is especially striking because the participants in the PD group mentioned thinking about becoming demented when they forget ordinary things in daily life, such as groceries when shopping. This implies that thoughts about becoming demented can occur daily or even several times a day in the children of parents with dementia and may have a considerable influence on their daily functioning and well-being. Worrying about dementia may therefore be an important issue that needs to be addressed when providing health care to people with dementia and their families.

The second striking difference between the groups concerns the way in which the two groups discussed end-of-life decisions. The control group was very outspoken about the possibility of physician-assisted death, whereas the PD group was not certain whether this issue could be considered adequately at this stage of life. Apparently, having a parent with dementia may trigger thoughts about end-of-life decisions and may influence the way in which people think about the end of their lives. The groups mentioned different reasons for considering these decisions. The control group mentioned mainly physically-related reasons, whereas the relatively few reasons mentioned by the PD group concerned psychological well-being. This difference forms an intriguing parallel with the process a nursing home physician goes through in making end-of-life decisions. Onwuteaka-Philipsen et al. (2001) and Hoogerwerf (1999) point out that the immediate cause for nursing home physicians to *start* a decision-making process concerning the termination of life (in competent patients) or withholding treatment is the medical status of the patient, while the aspects related to psychological well-being are the most important considerations that actually lead to reaching a final decision. This might contribute to explaining the difference in orientation between the two groups in this study, which seems to reflect the two phases in end-of-life decisions, a deplorable medical status is the starting point in this process, but then the central issue becomes the psychological well-being of the patient. This fascinating analogy calls for further research, not only quantitative research into the personal experiences of aging in various populations, but also research into the mental process through which an individual arrives at an end-of-life decision.

A third remarkable difference between the two groups refers to the more specific statements about health and the end of life made by the PD group as compared to the control group. These statements, about end-of-life decisions, for example, are more differentiated and represent a high level of consideration. This, as well as the fact that the control group more often said that they did not concern themselves with any specific topic, reflects a central and crucial tendency in the interviews; the PD group appears to be more involved with growing older and finitude. Apparently, experiencing the serious health problems and end-of-life

situations of a parent contributes to developing an attitude toward one's own aging whereby aging and finitude become more tangible, thus influencing the personal experience of aging. However, this involvement does not necessarily lead to increased worry about growing older and finitude. For instance, with regard to the theme of finitude, it appeared that the PD group was not particularly afraid of dying, whereas the control group was more concerned with and worried about their end-of-life situation.

These findings raise the question of whether similar results will be found when investigating the personal experiences of aging in the children of elderly people who suffered from other chronic geriatric diseases, or whether it is only the dementia syndrome with its especially striking features (i.e., behavioral changes, cognitive deterioration) that has such an influence on the personal experiences of aging in significant others.

Some critical remarks and recommendations for further research have to be mentioned. First, this study was an initial investigation; therefore, no specific assumptions about relationships with other factors or variables were formulated. Further research could investigate possible factors that influence the relationship between the personal experience of aging and the aging of significant others (i.e., the parent with dementia). Such factors might include personality characteristics such as neuroticism and the tendency to worry, the quality of the relationship with the parent with dementia before the parent became ill, the level of involvement in the daily care of the parent, and whether this influence fades with time after the death of the parent. Second, the selectivity of the samples must be considered. Members of the Alzheimer Foundation may concern themselves more directly or differently with dementia than adults having a parent with dementia might in general. The control group was also potentially biased due to the selection method. Further research with a larger and more representative sample is needed to confirm the generalizability of the present results. Finally, as was discussed above, there is probably a heredity component in several forms of dementia. Given the significant worries the PD group had about dementia, it is advisable to conduct further research into the causes of these worries and how they can be limited. Comparing the worries of children of parents with a type of dementia known to be hereditary to the worries of children of elderly parents with types of dementia in which the relative importance of heredity is still unclear may also provide more insight.

In conclusion, the results of this study show that having a parent with dementia probably influences the personal experience of aging in two distinct ways. On the one hand, the dementia of the parent causes the children to assign great importance to mental health, and in most cases also causes them to worry about becoming demented themselves. This is an aspect that has implications for healthcare professionals. The onset of the parent's dementia will often occur when the children are in middle-age. That is when the personal experience of aging of all the children needs to be a focal point for care-providers, as it appears to be

characterized by considerable daily worries and uncertainty. Yet, on the other hand, the dementia of the parent seems to cause the children to regard their own finitude and age-related health and independence in highly differentiated ways. Thus, although the dementia of a parent has several threatening influences on the well-being of the child, it also appears to cause the child to become more consciously occupied with growing older, which need not be considered a negative phenomenon.

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APPENDIX

Interview Questions

(not necessarily asked in this order)

1. Do you think about growing old? What do you think about specifically? What is growing old about? (If not mentioned spontaneously, specific questions about four subjects are asked: is it about health, about dependence, about time, about wisdom?) Do you have concerns about growing older?
2. Do you think about the future? What do you think about specifically? Do you have concerns about the future? When you think about the future, can or will there be changes in your daily life?
3. Do you have plans and ideas for the coming years? What do you want in the coming years, what don't you want, what do you hope, what do you fear?
4. Could you sketch an ideal picture of growing older? Do you think it is possible for you?
5. Do you want to grow older?
6. Do you talk to others about growing older?
7. Do you think about dying? What do you think about specifically? Can you tell me what dying is about for you?
8. Have you ever thought about end-of-life-decisions? What do you think about them?
9. Would you say the aging process of your parents influences the way you experience your own aging? Can you tell me something about that? Does it influence the way you see your own future?
10. a) Dementia-group: What happens when you forget something; do you think about dementia?
b) Control group: Are you familiar with dementia in your environment?

REFERENCES

- Baarda, D. B., De Goede, M. P. M., & Teunissen, J. (1995). *Basisboek Kwalitatief Onderzoek: Praktische handleiding voor het opzetten en uitvoeren van kwalitatief onderzoek* (Basic book qualitative research: Practical guide to constructing and carrying out qualitative research). Houten: Stenfert Kroese.
- Balota, D. A., Dolan, P. O., & Duchek, J. M. (2000). Memory changes in healthy older adults. In E. Tulving & F. I. M. Craik (Eds.), *The Oxford handbook of memory* (pp. 395-409). New York: Oxford University Press.
- Commissaris, C. J. A. M., Jolles, J., Verhey, F. R. J., Ponds, R. W. H. M., Damoiseaux, V., & Kok, G. J. (1993). Vergeetachtig of dement? Wie maakt zich zorgen en waarom? (Forgetful or demented? Who cares, and why.) *Tijdschrift voor Gerontologie en Geriatrie*, 24, 144-149.
- Connidis, I. (1989). The subjective experience of aging: Correlates of divergent views. *Canadian Journal on Aging*, 8, 7-18.
- Dittmann-Kohli, F. (1995). *Das persönliche Sinnsystem: Ein vergleich zwischen frühem und spätem Erwachsenenalter* (The personal meaning system: A comparison of early and later adulthood). Göttingen: Hogrefe.
- Duijnste, M. S. H. (1992). *De belasting van familieleden van dementerenden* (Caregiving stress in family of patients with dementia). Nederlands Instituut voor Zorg en Welzijn. Doctoral dissertation, University of Nijmegen.
- Farran, C. J., & Kuhn, D. R. (1998). Finding meaning through caring for persons with Alzheimer's disease: Assessment and intervention. In P. T. P. Wong & P. S. Fry (Eds.), *The human quest for meaning: A handbook of psychological research and clinical applications* (pp. 335-358). Mahwah, NJ: Lawrence Erlbaum Associates.
- Gatz, M., Bengtson, V. L., & Blum, M. J. (1990). Caregiving families. In J. B. Birren & K. W. Schaie (Eds.), *Handbook of the psychology of aging* (3rd ed., pp. 407-426). San Diego: Academic Press.
- George, L. K., & Gwyther, L. P. (1986). Caregiver well-being: A multidimensional examination of caregivers of demented adults. *The Gerontologist*, 26, 253-259.
- Heikinen, R. (1993). Patterns of experienced aging with a Finnish cohort. *International Journal of Aging and Human Development*, 36, 269-277.
- Hendrie, H. C. (1998). Epidemiology of dementia and Alzheimer's disease. *The American Journal of Geriatric Psychiatry*, 6, S3-S18.
- Hoogerwerf, A. (1999). *Denken over sterven en dood in de geneeskunde: Overwegingen van artsen bij medische beslissingen rond het levenseinde* (Thinking about dying and death in medicine: Physicians' reflections on medical decisions at the end of life). Utrecht: van der Wees.
- Keller, M. L., Leventhal, E. A., & Larson, B. (1989). Aging: The lived experience. *International Journal of Aging and Human Development*, 29, 67-82.
- Levy, B. R., Slade, M. D., & Kasl, S. V. (2002). Longitudinal benefit of positive self-perceptions of aging on functional health. *Journal of Gerontology: Psychological Sciences*, 57B, P409-P417.
- Levy, B. R., Slade, M. D., Kunkel, S. R., Kasl, S. V. (2002). Longevity increased by positive self-perceptions of aging. *Journal of Personality and Social Psychology*, 83, 261-270.
- Lovestone, S. (1999). Early diagnosis and the clinical genetics of Alzheimer's disease. *Journal of Neurology*, 246, 69-72.

Maxwell, J. A. (1996). *Qualitative research design: An interactive approach* (Applied Social Research Methods Series, Vol. 41). Thousand Oaks, CA: Sage.

Neikrug, S. M. (1998). The value of gerontological knowledge for elders: A study of the relationship between knowledge on aging and worry about the future. *Educational Gerontology, 24*, 287-296.

Neugarten, B. L. (1979). Time, age and the life cycle. *The American Journal of Psychiatry, 136*, 887-894.

Nunnally, J. C., & Bernstein, I. H. (1994). *Psychometric theory* (3rd ed.). New York: McGraw-Hill.

Onwuteaka-Philipsen, B. D., Pasman, H. R. W., Kruit, A., Van der Heijde, A., Ribbe, M. W., & Van der Wal, G. (2001). Withholding or withdrawing artificial administration of food and fluids in nursing-home patients. *Age and Ageing, 30*, 459-465.

Onwuteaka-Philipsen, B. D., & Van der Wal, G. (2001). Support and consultation for general practitioners concerning euthanasia: The SCEA project. *Health Policy, 56*, 33-48.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*, 583-594.

Perlmutter, M., & Hall, E. (1992). *Adult development and aging* (2nd ed.). New York: John Wiley and Sons.

Rando, T. A. (1986). *Loss and anticipatory grief*. Lexington: Lexington Books.

Reese, C. M., Cherry, K. E., & Norris, L. E. (1999). Practical memory concerns of older adults. *Journal of Clinical Geropsychology, 5*, 231-244.

Salthouse, T. A. (1991). *Theoretical perspectives on cognitive aging*. Hillsdale, NJ: Lawrence Erlbaum Associates.

Steverink, N., Westerhof, G. J., Bode, C., & Dittmann-Kohli, F. (2001). The personal experience of aging, individual resources, and subjective well-being. *Journal of Gerontology: Psychological Sciences, 56B*, P364-P373.

Sugar, J. A., & McDowd, J. M. (1992). Memory, learning, and attention. In J. E. Birren, B. Sloane, & G. D. Cohen (Eds.), *Handbook of mental health and aging* (2nd ed., pp. 307-337). San Diego: Academic Press.

Ter Haar, H. W. (1992). *Dementie, een vergeten aandoening* (Dementia, a forgotten disease). Houten/Zaventem: Bohn Stafleu Van Loghum.

Van Broeckhoven, C. (1998). Alzheimer's disease: Identification of genes and genetic risk factors. *Progress in Brain Research, 117*, 315-325.

Van der Maas, P. J., Van der Wal, G., Haverkate, I., De Graaff, C. L. M., Kester, J. G., Onwuteaka-Philipsen, B. D., et al. (1996). Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995. *New England Journal of Medicine, 335*, 1699-1705.

Van der Wal, G., & Dillmann R. J. M. (1994). Euthanasia in the Netherlands. *British Medical Journal, 308*, 1346-1349.

Van der Wal, G., Van der Maas, P. J., Bosma, J. M., Onwuteaka-Philipsen, B. D., Willems, D. L., Haverkate, I., et al. (1996). Evaluation of the notification procedure for physician-assisted death in the Netherlands. *New England Journal of Medicine, 335*, 1706-1711.

Van Duijn, C. M. (1996). Epidemiology of the dementias: Recent developments and new approaches. *Journal of Neurology, Neurosurgery and Psychiatry, 60*, 478-488.

Westerhof, G. J., Kuin, Y., & Dittmann-Kohli, F. (1998). Gesundheit als Lebensthema (Health as life theme). *Zeitschrift für Klinische Psychologie*, 27, 136-142.

Willis, S. L., & Schaie, K. W. (1999). Intellectual functioning in midlife. In S. L. Willis & J. D. Reid (Eds.), *Life in the middle: Psychological and social development in middle age* (pp. 233-247). San Diego: Academic Press.

Zarit, S. H. (1996). Interventions with family caregivers. In S. H. Zarit & B. G. Knight (Eds.), *A guide to psychotherapy and aging* (pp. 139-159). Washington, DC: American Psychological Association.

Zarit, S. H., & Edwards, A. B. (1999). Family caregiving. In R. T. Woods (Ed.), *Psychological problems of ageing: Assessment, treatment and care* (pp. 153-193). Chichester: John Wiley and Sons.

Direct reprint requests to:

Debby Gerritsen
VUMC, EMGO-Institute, Dept. of Nursing Home Medicine
Van der Boechorststraat 7
1081 BT Amsterdam
The Netherlands
e-mail: DL.Gerritsen.emgo@vumc.nl