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Research paper

“Women in the middle”: An observational study of a generation story in Alzheimer disease in France



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ABSTRACT

Background: It is well known that informal care giving for Alzheimer patients can be a burden and may result in caregivers' distress and stress. Caring for a person with Alzheimer's disease (AD) is a difficult task, which can become overwhelming. Their caregivers need attention as well.

Objectives: The present study examines the socio-demographic characteristics and the quality of health and life of the *sandwich grandparent generation* (SGP) caregivers defined as providing care to both old demented parents and young grandchildren.

Study design: Multicentric, prospective and observational study over a one-year period.

Setting: Eleven voluntary Memory Clinics across the North of France.

Participants: Voluntary SGP caregivers recruited in Memory Clinics who completed an oral questionnaire, during an interview one to one with a physician.

Results: A vast majority of our SGP caregivers were women, mean age 59 years, married, retired, described in the literature as “women in the middle”, feeling stressed and not sleeping well in more than half of the cases. They had three grandchildren, mean age 7 years. The AD patient, mean age 86-years-old, was most frequently the caregiver's mother. Many SGPs had been providing their help for 5 years or even longer. Nevertheless, the SGPs considered themselves satisfied about their health, and said they had a good quality of life.

Conclusion: Although SGP women caregivers reported high levels of perceived burden, they considered that their health and quality of life were good.

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1. Introduction

With more than 36 million people suffering from dementia worldwide, neurodegenerative diseases were the sixth leading cause of death in high-income countries in 2013 [1]. Alzheimer's disease (AD) is the most frequent form of dementia and affects mainly people of over 65. There are only a few drugs for the treatment of AD, which temporarily reduce symptoms including memory problems, behavioural disturbances and the decline in daily functioning. The people who interact most with AD patients are their primary caregivers. US data suggest that 62% of caregivers are women, 23% are 65 years of age and older, 70% are married and

59% are employed [1]. Caregivers of people with Alzheimer's and other dementias provide care for a longer time, on average, than do caregivers of elderly adults with other conditions [1]. Caring for a person with Alzheimer's disease is a difficult task, which can become overwhelming. Their caregivers need attention as well.

The authors are not aware of any published data on the burden and rewards of the caregivers belonging to the so-called *sandwich generation* who care for both their AD old parents and their grandchildren. The expression *sandwich generation* refers to a hamburger made of a minced meat between two slices of bread (old parents and grandchildren) [2–4]. The current study describes the socio-demographic characteristics and the quality of life and health of the *sandwich grandparent generation* caregivers (SGP) defined as providing care to both grandchildren and old demented parents. Our respondents faced care demands from two generations. In the study we describe:

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- the SGP caregivers social, demographic and health characteristics;
- the AD old person's care;
- the grandchildren's care;
- finally the SGP quality of life and health satisfaction ratings.

2. Participants and method

2.1. Participants

The voluntary participants in the study were, after assessment of eligibility, family caregivers simultaneously caring for aging parents with AD all severities and for young grandchildren. One hundred and four SGP voluntary respondents took part in the study. We made five exclusions from the final analysis due to incomplete answers to the questionnaire. Our working sample therefore included 99 subjects.

2.2. Method

We carried out a multicentric, prospective and observational study over a one-year period in 11 voluntary Memory Clinics interested in the study, across the North of France. The voluntary SGP caregivers completed an oral questionnaire devised by the authors and validated by the scientific committee of the Geriatric Society of the North of France. They were therefore invited to take part in a twenty minute structured interview one to one with the physician of the Memory Clinic on the occasion of a follow-up consultation of their AD parent (outside their presence). The SGP caregivers were asked 40 questions about their socio-demographic characteristics, their AD parent and their grandchildren. Their perception and views of their quality of life and health was considered on a numeric intensity scale. We thereby asked the SGP caregivers to assign a number from 1 to 10 to each question (10 was the best they could imagine). The SGPs gave an oral informed consent to the study. The study was approved by our local ethics committee. Privacy and confidentiality rules were respected.

2.3. Statistical analysis

The statistical analysis is based on descriptive statistics. A Chi² test was also used. We considered *P* values < 0.05 as significant. We performed the statistical analyses with the Windows SAS package. Chi² test was used to examine differences between groups.

3. Results

Ninety-nine SGP caregivers were included in this study. The SGPs' socio-demographic and health characteristics are presented in Table 1. The SGPs were mainly women, 59-years-old on average,

Table 1
Descriptive social and health SGPs' characteristics.

	<i>n</i> = 99	%
Sex		
Female	78	78.8
Male	21	21.2
Age (years)		
Female	59 (45–74)	60.6
Male	63 (56–58)	39.4
Marital status: number of married people	82	82.8
Professional status		
Retired	61	61.6
Still working	38	38.4

SGP: sandwich grandparent generation.

younger than men. The SGPs were married in most cases, their parents were 86-years-old on average (73–97-years-old) and their grandchildren were aged 7 on average. The SGP caregivers were still at work in more than 38% of cases. Seven percent of the respondents had a full-time job in combination with many hours of parents' care and they also looked after their grandchildren at home.

The AD patient was most frequently the caregiver's mother or mother-in-law (68%). The SGP caregivers had been providing their help for 5 years or even longer (58%). A majority of the old people with dementia lived in nursing homes (56%). The frequency of help was daily for 34% and at least weekly for 92%. The help given to parents consisted in time spent with them or doing things for them such as shopping, doing laundry, transportation or clerical work. In 82% of cases, spouses or siblings gave a hand to the main caregiver.

The SGP caregivers had three grandchildren on average (ranging from 1 to 9-years-old). In our study, help for grandchildren meant things like babysitting, dressing or baby feeding at their children's home. Seventy-one percent of the SGP caregivers also cared for their grandchildren during their own holidays. The SGPs had been caring for grandchildren weekly for over 5 years in 71% of cases and in 47% of cases for those who had full-time jobs. Most helpers reported that they liked to help their parents but they nevertheless preferred to care for their grandchildren.

Most SGP caregivers took medications, two daily on average, especially cardiovascular medications (60.3%) and psychotropic drugs (38.9%). The medication consumption was significantly higher, especially for psychotropic drugs, among women and in particular those with full-time jobs (RR: 3.4 [1.5 to 7.6] - *P* ≤ 0.003). Most of the SGP caregivers felt stressed (56.6%), did not sleep well (52.5%) and nearly 30% had lost weight recently. A third of the respondents had had to delay or cancel a medical appointment because of their caregiving. More than two-thirds of the respondents were stressed at the mere thought of getting AD themselves mainly if they were still working (Table 2).

We finally asked the SGP caregivers to assess how happy they felt about caring for their old parents on a numeric intensity scale. The average answer was 6.4/10. We then asked the same question about grandchildren's care and we got a higher average: 8.7. We also asked the SGP caregivers about their perceived health and their quality of life. They gave a mark of 6.9 out of 10 on average to their own health and 7.2 out of 10 on average to their quality of life. We noted that the SGPs who gave help to both parents and

Table 2
SGPs' answers to the questionnaire.

Questions	Answer: yes (%)
Do you take any medication?	73 (73.7)
Do you feel stressed?	56 (56.6)
Do you have sleep disturbances?	52 (52.5)
Have you lost weight recently?	29 (29.3)
Have you ever delayed or cancelled a medical appointment related to your parent or your grandchildren's care?	33 (33.3)
Do you have time to relax?	67 (67.7)
Do you practice sport regularly?	56 (56.6)
Do you drink alcohol daily?	16 (16.2)
Do you smoke?	17 (17.2)
Do you still drive your car?	83 (83.8)
Do you feel stressed at the thought of getting AD?	66 (66.7)
Do you have to pay the nursing home bills?	18 (18.2)

SGP: sandwich grandparent generation; AD: Alzheimer's disease.

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