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**Représentations et connaissances des aidants, pharmaciens et préparateurs en
pharmacie concernant le repérage du fardeau des aidants de patients atteints de la
maladie d’Alzheimer en pharmacie d’officine.**

**Caregiver in Alzheimer’s disease, pharmacist, and pharmacy technician attitudes and
knowledge about caregiver burden screening in community pharmacies.**

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Résumé

Objectifs: Explorer les représentations et les connaissances des aidants, des Pharmaciens et des Préparateurs en Pharmacie (PPP) vis-à-vis du repérage du fardeau des aidants en pharmacie d'officine.

Méthodes: Étude descriptive transversale réalisée dans 10 pharmacies d'officine en France. Les PPP et les proches aidants de patients atteints de la maladie d'Alzheimer ont été inclus dans cette étude. Deux auto-questionnaires ont été développés pour explorer les représentations et connaissances des participants à l'égard du repérage du fardeau en pharmacie d'officine et pour évaluer le fardeau des aidants naturels. La version courte de du Zarit Burden Interview (score de 0 à 7) a été utilisée pour le dépistage du fardeau.

Résultats: 52 PPP et 20 aidants ont participé à cette étude. Dans cette étude, 70% des aidants et 96% des PPP ont déclaré que le repérage du fardeau des aidants naturels devrait être effectué dans les pharmacies d'officine ; 65% des aidants ont déclaré mentionner leur statut d'aidants à leur pharmacien ; 82% des PPP ont estimé qu'ils devraient informer les médecins généralistes des aidants du niveau de fardeau détecté. Dix-huit aidants sur vingt avaient une perception de fardeau : le score moyen du fardeau était de $4,0 \pm 1,7$ (modéré à sévère).

Conclusions: Selon les aidants, les PPP représentent des professionnels de la santé de soins primaires accessibles et aptes à repérer le fardeau des aidants naturels. Le repérage du fardeau pourrait être intégré aux activités cliniques au sein des pharmacies d'officine, permettant ainsi d'identifier précocement les aidants à risque d'épuisement.

Mots clés: Aidants, Fardeau, Pharmacie d'officine, maladie d'Alzheimer et maladies apparentées.

Abstract

Objectives: To explore caregiver, pharmacist and pharmacy technician attitudes toward burden screening in community pharmacies and assess caregiver burden in community pharmacies.

Methods: Descriptive cross-sectional study conducted in 10 community pharmacies in France. Pharmacists, pharmacy technicians and caregivers of patients with Alzheimer's disease were included in this study. Two self-reported questionnaires were used to explore attitudes of participants toward the burden screening in community pharmacy and to assess the caregiver burden in community pharmacy. The short version of the Zarit Burden Interview (range 0-7) was used for the burden screening.

Results: 52 pharmacists and pharmacy technicians, and 20 caregivers (61.8 ± 13.7 years) participated in this study. 70% of caregivers and 96% of pharmacists/pharmacy technicians stated that caregiver burden screening should be conducted in community pharmacies. 65% of caregivers reported their caregiver status to their community pharmacist. 82% of pharmacist/pharmacy technicians thought they had to inform the caregiver's General Practitioners (GP) about the detected burden level. Of the 20 included caregivers, 18 had a perception of burden. The mean caregiver burden score detected in this exploratory study was 4.0 ± 1.7 , corresponding to a moderate to severe burden.

Conclusions: According to caregivers' opinion, community pharmacists and pharmacy technicians represent accessible health care professionals in primary care to quantify caregiver burden. The burden screening can be easily incorporated into clinical service offerings in community pharmacy practice. It provides a valuable opportunity to identify high-risk caregivers with the aim of referring them to their GP to prevent the caregiver's frailty.

Key words: Caregivers; Burden, Community pharmacy; Alzheimer's disease and related disorders.

Introduction

Cognitive impairment, functional autonomy loss and behavioral disorders caused by Alzheimer's Disease (AD) may lead to an increase in caregiver burden (1,2). The caregiver burden is the burden felt by the caregiver in relation to the accompaniment and assistance in the daily living activities provided to their illness relative. The caregiver is often a spouse or an adult child providing assistance with daily living activities, managing the relative's behavioural symptoms, coordinating supportive services, facilitating healthcare visits, and making financial and healthcare decisions (3). Caregivers thus play a central role in the care of people with AD. Therefore, the burden of care may have physical, psychological, emotional, social and financial consequences (4). Caregivers are exposed to higher risk of hypertension, heart disease, and mortality, sleep disorders, mood disorders with a greater use of psychotropic drugs, and lower quality of life (5–10). In the PIXEL study focusing on family caregivers of patients with Alzheimer's disease, one in three caregivers had to postpone or give up a medical appointment, a hospitalization or medical care for themselves to stay with their relative (10). This decline in care is more marked when the caregiver is a spouse. Yaffe et al. showed that a higher caregiver burden was associated with an early institutionalization of the patient (11).

The APhA (American Pharmacists Association) Foundation's White Paper on Expanding the Role of Pharmacist in Caring for Individuals with AD concluded that increased pharmacist involvement in the care of individuals with AD and their caregivers could improve clinical outcomes and their quality of life (12). According to the APhA Foundation, the pharmacist could support caregivers to manage their own chronic health conditions, provide them with medication consultation and education to ensure medication compliance, provide them with support and information about community resources including information about respite care.

In 2010, the French Health Authority published guidelines regarding the screening of caregiver burden by general practitioners (GPs) or community pharmacists in order to improve the caregiver support in primary care (13). However, these guidelines are not well known and not implemented in practice. In France as in most countries, community pharmacists are on the frontline to screen caregiver burden. In France, pharmacists and pharmacy technicians are in contact with patients and their caregivers and can deliver drugs. The activities of the pharmacy technicians are under the responsibility of the pharmacists. To our knowledge only one observational study in the community pharmacy setting in Spain has been conducted to quantify caregiver burden and to identify any signs of psychopathology (e.g. anxiety and depression) (14).

This study was conducted to (1) explore caregiver, pharmacist and pharmacy technician attitudes toward burden screening in community pharmacies and (2) to assess the burden in caregivers of patients with AD in community pharmacies.

Methods

Study Design, Population, and Setting

This cross-sectional study was conducted in 10 community pharmacies between November 2016 and February 2017 in Lyon, France. Community pharmacies in Lyon were recruited on random, practicality and voluntary basis. In each community pharmacy, pharmacists and pharmacy technicians (P/PT) willing to participate in this study were included. The selection criteria for the caregivers were: non-professional caregivers who provided consent and managing patients with known AD or patients with AD treated by antimentia drug (cholinesterase inhibitor and/or memantine). Caregivers were excluded if they could not speak, read or write French.

The study was introduced to caregivers during the community pharmacy drug dispensing process. Oral consent was obtained among caregivers and health professionals for their participation in the study. They could decline to participate in the study. Before the distribution of the questionnaire, a verbal comprehensive description about this study was introduced to caregivers by the P/PT and supplemented with an information letter explaining that caregiver burden screening in primary care is recommended by the French Health Authority (13). Caregivers could decline to answer the questionnaire or withdraw at any time after inclusion. They were assured that the answers were kept confidential and the questionnaires would be anonymous with the assignation of a code to each one.

Data collection

A self-reported questionnaire developed for the study by the authors was distributed during the community pharmacy drug dispensing process to caregivers by P/PT (table 1). Caregivers could directly complete the questionnaire in the community pharmacy or complete the questionnaire at home and return it to the pharmacy during the study period (the next month

during medication refill). This questionnaire included: (i) the scale to assess caregiver burden (validated instrument); and (ii) items about caregiver attitudes toward support and burden screening in the community pharmacy practice setting (yes/no questions). The scale used to assess caregiver burden was the validated short version of the Zarit Burden Interview (ZBI), which was previously developed for routine medical care (15,16). The 7-item scale consists of an interval score ranged from 0 to 7. This score represents the sum of the answers to 7 questions to which the caregivers answered “never” (0 point), “sometimes” (0.5 point) or “nearly always” (1 point). Caregiver burden can be classified as no or mild burden ([0-1]), mild to moderate ([1.5-3]), moderate to severe ([3.5-5]), and severe ([5.5-7]).

Another self-reported questionnaire developed for the study by the authors was used for P/PT to assess P/PT attitudes regarding caregiver burden before the caregiver recruitment (table 1). This 8-item questionnaire (yes/no questions) included items about: (i) P/PT knowledge and skills about caregiver support, and caregiver burden; (ii) P/PT knowledge and attitudes toward caregiver support, and caregiver burden screening in the community pharmacy practice setting.

Demographic variables were also collected: gender for P/PT; age, gender, relation with the patient, duration of caregiving and time spent per day, professional status (retired or with a job) for caregivers.

Statistical Analysis

Descriptive statistics were performed using means \pm standard deviations (SD) for continuous variables and frequencies (percentages) for categorical variables. The data of the two populations (P/PT and caregivers) were analyzed separately.

Results

A total of 20 caregivers (12/20 women) with a mean (\pm SD) age of 61.8 ± 13.7 years (range 40-84) were included to the caregiver burden screening and responded to the survey (table 2). Sixty per cent of included caregivers were adult children of patients with AD (12/20) and 30% were spouses (6/20). No caregiver was excluded from the study. Twenty-two community pharmacists and thirty pharmacy technicians participated in the study. Of the 20 included caregivers, 90% (18/20) had a perception of burden: 15% (3/20) a perception of mild to moderate burden, 50% (10/20) moderate to severe burden, and 25% (5/20) severe burden (table 2). The mean caregiver burden score detected in this pilot study was 4.0 ± 1.7 (range 0-7), corresponding to a moderate to severe burden.

Table 3 presents the P/PT and caregiver attitudes regarding support and burden screening in the community pharmacy. Sixty-five per cent of caregivers reported their caregiver status to their pharmacist. In comparison, fifty-six per cent of P/PT indicated that caregivers easily confide their caregiving status. Eighty-four per cent of P/PT knew the meaning of caregiver burden. Regarding the burden screening, 70% of caregivers and 96% of P/PT stated that it should be assessed in the community pharmacy. However, only 26% of P/PT claimed to be able to assess the caregiver burden. Eighty-two per cent of P/PT thought they had to inform the caregiver's GPs about the detected burden level in the community pharmacy.

Discussion

This study demonstrated the prevalence of caregiver burden and the pharmacy staff's knowledge and perceived ability to screen for caregiver burden in the community pharmacy setting. Ninety per cent of caregivers reported experiencing a burden with 25% of which 25% experienced a severe level of burden. The majority of caregivers and P/PT stated that the caregiver burden screening should be implemented in community pharmacies. For P/PT, the burden level detected should be communicated and referred to the caregiver's GP to optimize the caregiver's and patient's support (i.e. use of appropriate services).

Only one other published study conducted in community pharmacy assessing caregiver burden was found in the literature (14). Of the 25 included caregivers (55 ± 12.8 years) in this study, 28% had a perception of severe burden, 28% a perception of mild burden and 48% had no burden. The proportion of caregivers with severe burden was similar to the results of this present study (28% vs. 25%). However, the proportion of caregivers with no burden was different (48% vs. 10%).

The ZBI developed by Zarit et al. (22 items), Translated and validated in several languages, is the most widely used scale in the world in research and in clinical practice (4,17). Short versions of ZBI have been published in different countries for clinical practice (16,18–20). However, other tools assessing the caregiver burden have been validated such as the Caregiver Burden Inventory and the Screen for caregiver Burden (21,22). **In this study, the short version of ZBI was chosen given its convenient use in clinical practice and its recommended use by the French Health Authority during the annual medical consultation of the caregiver(13).**

Pharmacist-initiated screening in cognitive disorders

In the area of cognitive disorders, other screening services, such as memory screening, have been evaluated in community pharmacies. A study conducted by Breslow described patient attitudes toward pharmacist-administered memory screening and assessed patient satisfaction (23). Most participants responded to having community pharmacies offer memory screening because of their convenient locations (100%) and willingness to have an annual screening (92%) performed by a trained pharmacist (80%). A second study conducted by Rickles *et al.* assessed the impact of a pharmacy-based cognitive memory screening using the Mini-cog (combination of the three-Word Recall and the Clock Draw Test) and the Animal Fluency Test (24). Of the 161 included participants, 44.1% experienced at least one cognitive deficiency that required referral to a physician.

The results of the memory screening studies combined with the results of this present study highlight the need to involve the community pharmacists in memory and caregiver burden screening. The purpose of identifying caregivers with a high level of burden is to optimize and to provide appropriate human, material and financial support. However, the implementation of these new services in a community pharmacy practice setting will require close collaboration with GPs and an assessment of the GPs' satisfaction with a referral program. Currently, there is no threshold or guidelines indicating when caregivers should be referred to their GP. Further research could be conducted to propose guidelines regarding this threshold and the means to communicate burden level and to refer caregivers to GPs. Several limitations for the implementation of this new clinical service in community pharmacy have been identified in this study. Indeed, nearly half of P/PT reported that caregivers did not easily confide their caregiving status. Only ten P/PT reported knowing how to measure the caregiver burden (without verification), thus requiring prior training of professionals.

Limitations

Among the limitations of this pilot study, we emphasize the small sample of P/PT and caregivers. The number of caregivers who refused to complete the questionnaire was not collected. The time required to complete the survey - which forced the caregiver to be away from home longer than usual - may have contributed to limiting the sample size.

The narrow selection criteria also prevented the inclusion of caregivers whose relatives were not treated by antimentia drugs or who had not communicated with the P/PT about the patients' AD. The study also did not include caregivers who could not speak, read, or write French. These selection biases potentially excluded caregivers and patients with reduced access to care. In this study, the burden scale (short version of the ZBI) was self-reported by the caregivers. P/PT will require training and qualifications to administer the scale during an interview with the caregiver.

Conclusion

Caregiver burden screenings performed in a community pharmacy by pharmacists and pharmacy technicians provides a valuable opportunity to identify caregivers with a significant burden level. However, larger studies are needed to measure the pharmacists' and pharmacy technicians' ability to assess the caregiver burden, to assess the costs of this new clinical service, and to confirm the benefits of burden screening in community pharmacy (on the burden evolution, the improvement of the caregiver medical follow-up and the implementation of health and social services).

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Table 1. Items of the questionnaire for caregivers and questionnaire for pharmacists/pharmacy technicians

Tableau 1. Thèmes du questionnaire à destination des pharmaciens et préparateurs en pharmacie.

Questionnaire for caregivers	Answer
I am disclosing my caregiver status to my pharmacist	Yes/no
I am disclosing my caregiver status to my GP	Yes/no
I think that pharmacist must be able to screen caregiver burden in community pharmacy	Yes/no
Caregiver burden - validated short version of the Zarit Burden Interview: (1) Does the fact of caring for your relative lead to difficulties in your family life? (2) Does the fact of caring for your relative lead to difficulties in your relationship with friends, hobbies, or in your work? (3) Does the fact of caring for your relative lead to have an impact on your health? (4) Do you have the feeling of no longer recognizing your relative? (5) Are you concerned for the future of your relative? (6) Do you feel you need more help to take care of your relative? (7) Do you feel a burden in taking care of your relative?	Never/Sometimes/ Nearly always
Questionnaire for pharmacists/pharmacy technicians	Answer
I know the meaning of « caregivers »	Yes/no
I find that caregivers easily confide with pharmacists/technicians about their caregiving status	Yes/no
I am currently able to discuss with caregivers about the caregivers' role	Yes/no
I know the meaning of « caregiver burden » If yes, I know how to screen the caregiver burden (tools/scales)	Yes/no Yes/No
I think we will be able to screen the caregiver burden in community pharmacy	Yes/no
I think we must inform the caregiver's GP about their burden level (score to the burden scale)	Yes/no
I know the impact of caregiving on the caregiver's health	Yes/no

Table 2. Characteristics of caregivers, pharmacists and pharmacy technicians, and burden screening

Tableau 2. Caractéristiques des proches aidants, pharmaciens et préparateurs en pharmacie – évaluation du fardeau de l’aidant

	Caregivers	Pharmacists	Pharmacy technicians
n (%)	20	22	30
Age (years) Mean - m \pm SD (range)	61.8 \pm 13.7 (40-84)	-	-
Gender Female Male	12 (60) 8 (40)	14 (64) 8 (36)	29 (97) 1 (3)
Relation to the patient Child Spouse Others	12 (60) 6 (30) 2 (10)	- - -	- - -
Caregivers with a job yes no	10 (50) 10 (50)	- -	- -
Cohabitation with the patient Yes No	8 (40) 12 (60)	- -	- -
Time spent per day for caregiving < 6 hours > 6 hours	8 (40) 12 (60)	- -	- -
Caregiving (years) > 5 1-5 < 1	8 (40) 9 (45) 3 (15)	- - -	- - -
Caregiver Burden Screening (ZBI short version) [0-1] – no or mild burden [1.5 - 3] – mild to moderate burden [3.5 - 5] – moderate to severe burden [5.5 - 7] – severe burden Mean ZBI short version – m \pm SD (range)	2 (10) 3 (15) 10 (50) 5 (25) 4,0 \pm 1,7 (0-7)	- - - - -	- - - - -

m \pm SD: mean \pm Standard Deviation; ZBI: Zarit Burden Interview

Table 3. Pharmacists, pharmacy technicians and caregivers attitudes regarding support and burden screening in the community pharmacy practice setting.

Tableau 3. Représentation et connaissances des pharmaciens et préparateurs en officine concernant le soutien et le repérage du fardeau de l'aidant en pharmacie d'officine.

Items	Number of participants who agreed (%)		
Community pharmacists (n=22) and pharmacy technicians (n=30) attitudes	P n (%)	PT n (%)	P/PT n (%)
I know the meaning of « caregivers »	22 (100)	29 (97)	51 (98)
I find that caregivers easily confide with pharmacists/technicians about their caregiving status	15 (68)	14 (47)	29 (56)
I am currently able to discuss with caregivers about the caregivers' role	16 (73)	15 (52)*	31 (61)*
I know the meaning of « caregiver burden » If yes, I know how to screen the caregiver burden (tools/scales)	20 (91) 8 (44)**	23 (52)* 2 (10)**	43 (84)* 10 (26)**
I think we will be able to screen the caregiver burden in community pharmacy	21 (95)	29 (97)	50 (96)
I think we must inform the caregiver's GP about their burden level (score to the burden scale)	18 (86)***	23 (79)***	41 (82)***
I know the impact of caregiving on the caregiver's health	19 (90)*	21 (70)	40 (78)*
Caregiver attitudes (n=20)	Caregivers n (%)		
I am disclosing my caregiver status to my pharmacist	13 (65)		
I am disclosing my caregiver status to my GP	17 (85)		
I think that pharmacist must be able to screen caregiver burden in community pharmacy	14 (70)		

GP: General Practitioner; P: Pharmacists; PT: pharmacy Technicians; P/PT: Pharmacists and pharmacy Technicians.

*missing data for one pharmacist/pharmacy technician; ** missing data for four pharmacist(s)/pharmacy technician(s); *** missing data for two pharmacist(s)/pharmacy technician(s).