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Luka opiekuńcza wśród opiekunów rodzinnych osób starszych z otępieniem we Włoszech i w Polsce

Streszczenie

Wstęp. Potrzeby opiekuńcze istotnie wzrastają z postępem otępienia. Brak wsparcia środowiskowego jest wśród innych powodów przyczyną wczesnej instytucjonalizacji osób z otępieniem.

Cel. Celem badania jest porównanie „luki opiekuńczej" u włoskich i polskich opiekunów rodzinnych osób starszych z prawdopodobnym otępieniem.

Materiał i metody. Badanie stanowi wtórną analizę dany EUROFAMCARE, ograniczonej do polskich (n=113) i włoskich (n=293) opiekunów, którzy świadczyli opiekę wobec starszych i niesprawnych krewnych z zaburzeniami pamięci i zachowania. Opiekunowie, którzy wskazywali podany rodzaj wsparcia jako bardzo ważny w ich przypadku, a jednocześnie nie zaspokojony, definiowani byli jako pozbawieni wsparcia, prezentując „lukę opiekuńczą".

Wyniki. Niezależnie od kraju wykazano znaczące luki między osobami wysoko ceniącymi różne typy usług a korzystającymi z tych usług. Najwyższe deficyty usług odnosiły się do informacji, organizacji opieki i jej planowania na przyszłość oraz wsparcia finansowego. Wyniki potwierdziły szeroko rozpowszechnione zapotrzebowanie na wsparcie w obu krajach, jednakże wielkość poszczególnych luk opiekuńczych różniła się między krajami.

Wnioski. W obu krajach istnieje pilna potrzeba rozwijania usług odciążających opiekuna w sprawowaniu opieki, np. czasowa przerwa w opiece. Szczególne potrzeby opiekunów rodzinnych osób starszych z demencją powinny zostać uwzględnione przez podmioty świadczące pomoc zdrowotną i socjalną oraz decydentów politycznych w działaniach na rzecz obniżenia obciążenia opieką i zwiększenia motywacji opiekunów do kontynuowania opieki.

Słowa kluczowe: opiekunowie rodzinni, usługi, otępienie, niesprawność, luka opiekuńcza.

Support gap in dementia family caregivers from Italy and Poland

Abstract

Introduction. With the progress of dementia, care needs increase substantially. Lack of adequate care support in community is among the reasons of early institutionalization of demented persons.

Aim. The aim of the study is to compare the "support gap" in the Italian and Polish family caregivers of disabled older persons with probable dementia.

Material and methods. The study was a secondary analysis of the EUROFAMCARE data, limited to the Polish (n=131) and Italian (n=293) caregivers who provided care and support for severely disabled relatives with memory impairment and behavioral disorders. The caregivers indicating a given type of support as very important and simultaneously not being met for them were defined as not provided with caring support, i.e. making a "support gap".

Results. Regardless of the country, there were significant gaps between the preferred types of support and low use of these care services. The highest gaps referred to informational and organizational support, planning future care, and financial support. The findings confirmed widespread demand for care support among dementia caregivers in both countries; however the size of relevant support gaps differed between countries.

Conclusions. In both countries there is an urgent need for the development of a respite care services for family caregivers, such as a temporary break from caring process. The special needs of family caregivers of demented older people ought to be taken into consideration by health and social care organizers, as well as policy makers in order to lower the care burden and to enhance caregivers' willingness to continue the care.

Keywords: family caregivers, services, dementia, disability, support gap.

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INTRODUCTION

Due to the aging population, the prevalence of dementia will grow steadily in the next decades [1], effecting increased demand for long-term care services among older persons and their caregivers.

Dementia care is usually provided by a close member of the family: a spouse or child (typically a woman). As indicated, dementia is regarded as the main cause of institutionalization in older persons [2]. With the progress of dementia, care needs increase substantially, causing the necessity of professional services to supplement the care provided by informal caregivers. Lack of adequate long-term care services (unmet needs) in community is among the reasons of final institutionalization of demented relatives [3]. Given the high costs of formal long-term care, recognizing the needs of the dementia caregivers and providing them with the adequate support seems necessary.

AIM

The aim of the study is to compare the opinions of Italian and Polish family caregivers of disabled older persons with probable dementia on the most important versus actually used types of support. The disclosure of the gaps between the desired and used support, being a measure of caregivers' dissatisfaction with support, gives a chance to better address family caregivers' needs, as well as to improve their quality of life.

MATERIAL AND METHODS

Study design and sampling frame

This study operates on secondary data collected for the EUROFAMCARE study [4]. This European Community funded project (2003-2005) was carried out in about 6.000 family caregivers of older persons in six European countries: Germany, Greece, Italy, Poland, Sweden and the United Kingdom (about 1.000 per country). The EUROFAMCARE study employed cross-sectional survey methodology. The questionnaire (Common Assessment Tool) was administered by face-to-face interview with the family carer. Therefore, the information about the cared-for people was provided by proxy, i.e. expressed the subjective opinion of the caregivers. The in-depth methodological details were published elsewhere [4]. EUROFAMCARE partners obtained ethical committee approval for the study within their own country.

Participants

A family caregiver was defined as a person who perceived himself or herself to be a caregiver, and who provided at least four hours of unpaid support per week (excluding only financial support or companionship) to an older person aged 65 or more, living in the community or residential/long-term care settings.

For the current study we used the EUROFAMCARE dataset, limited to the Polish and Italian caregivers who provided care and support for severely disabled relatives with memory impairment and behavioral disorders, labeled as 'probably demented'. To identify the subpopulation relevant for the purpose of research, the SPSS 2-step clustering method was employed.

The age of the older persons, memory problems, as well as the mean scores on the Behavioral and Instrumental Stressors in Dementia (BISID) scale [5], and the Barthel Index [6], were chosen as grouping variables. Cluster analysis revealed the existence of four groups. One of the clusters, which was characterized by: memory impairment, high mean score on the BISID scale (indicating frequent behavior disorders), high mean age, and low mean score on the Barthel scale (suggesting substantial physical dysfunction) was defined as the studied group (n=424). In the selected cluster, carers from Italy were in the majority (n=293), whereas carers from Poland constituted a minority (n=131). Uniformity of the Italian and the Polish samples with respect to age, cognitive status and disability of the older persons was ensured, as no statistically significant differences were found for this cluster in the distribution of grouping variables between the countries.

Measures

The questionnaire was developed, comprising a series of items and scales specifically developed by the EUROFAMCARE partners, or selected for use from among a range of validated published instruments [4]. Here, we report brief details of the items or instruments relevant to this paper.

Caregiver and care recipient data. In addition to basic sociodemographic features of the participants, we analyzed the information concerning caregivers' well-being, as well as the care receivers' dependency level. The caregivers' psychological well-being was measured by using the World Health Organization-5 Well-being Index [7]. Higher total scores on this instrument (range 0-25) meant better well-being. The items on the caregiver's quality of life for the preceding 2 weeks, and the caregiver's general health status assessment were taken from the 36-item Short-Form Health Survey (SF-36) [8]. The older person's dependency on basic activities of daily living (ADL) was assessed through the use of the Barthel Index and the instrumental activities of daily living (IADL) scale, Modified Duke OARS assessment [9]. With the use of the BISID scale the disturbances in the older person's behavior were measured.

Support gap. In this article we use the term 'support' in reference to resources and/or services that are provided to older people and their caregivers to help them deal with caregiving. This includes various types of care, such as psychological, social, physical and financial support. For the purpose of the paper, the types of support were arbitrarily grouped into three domains, as follows:

(A) 'Informational and organizational support', including: (1) *Information/Advice about the available support/help and how to access it*, (2) *Information about the older person's disease*, (3) *Help with planning future care*, and (4) *Training for family carer to help develop skills for care*;

(B) 'Respite support', including: (1) *Activities outside of caring*, (2) *Holiday or break from caring*, (3) *Attending carer support groups*, (4) *More time for family*;

(C) 'Support addressing problems resulting from care', including: (1) *Activities for older persons that they enjoy*, (2) *Reconciliation of care & work*, (3) *Talk over family carer's problems as carer*,(4) *More money to provide good care*, (5) *Help with family disagreements*, and (6) *Improvement of the older person's environment*.

We analyzed the caregivers' opinion on whether the following type of support was currently being met for them (response options: 'mostly not', 'mostly yes'). The caregivers indicating a type of support as very important and simultaneously not being currently met for them were considered dissatisfied with caring support. Therefore, the term 'support gap' used in this article is an indication of a gap between the desirable and actually accessed support.

Data analysis

In order to compare the qualitative and categorized variables between the countries, the chi-square test for independence was used, as well as the Shapiro-Wilk test to verify the statistical shape of the tested variable distribution, and the Mann-Whitney U-test to compare non-parametric distribution variables. For all the statistical tests used, a p value <.05 was considered statistically significant. The statistical analysis was carried out by means of the SPSS version 17.0.

RESULTS

Caregiver and care recipient

Table 1 presents the characteristics of the sample. There were few statistically significant differences between Italy and Poland in the main characteristics of caregivers and older persons. Italian caregivers declared lower religiosity compared with their Polish counterparts (85.1% and 96.2%, respectively). Negative self-rated health status was indicated by every fifth carer from Poland, whilst only every tenth in Italy (21.4% vs. 9.3%). Italian older persons (35.2%) were statistically more likely than Polish ones (25.2%) to live with a spouse or partner. With regard to major similarities, caregivers in both countries declared a relatively poor quality of life and older persons showed a similar high disability measured on the Barthel scale. Problems with urinary and fecal incontinence were prevailing, as well as severe functional dysfunctions measured on the IADL scale and frequent behavioral disorders measured on the BISID scale.

Types of support: desirability versus usage

The support gap, which illustrates the share of caregivers rating a type of support as very important but currently being unmet, is presented in figures 1-3.

Informational and organizational support. In general, support referring to this domain was the most desired by caregivers (Figure 1). Out of four types of support within this domain, lack of information about the available support was the most often reported. Almost two-thirds of the caregivers, rating highly such support, declared not having the need met, significantly more often in Italy than in Poland. The need for information about the older persons' disease was much more frequently met in both countries, however significantly more often in Poland. Help in planning future care was very important for every other caregiver in both countries, though only a few caregivers, especially in Italy, admitted having this need met. Training to develop caring skills was not ranked too high, and within those family caregivers who appreciated this support the vast majority had no opportunity to attend such schooling.

TABLE 1.Participant characteristics.

	Italy (n=293)	Poland (n=131)	p
Family caregiver			
Age*	57.1 (12.7)	56.2 (12.7)	.268
Female	234 (79.9)	106 (80.9)	.802
Urban place of residence	227 (77.5)	91 (69.5)	.078
Married/cohabiting	208 (71.2)	98 (74.8)	.447
Low level of education	81 (27.6)	29 (22.1)	.232
Religious	246 (85.1)	126 (96.2)	.001
Currently working	95 (32.6)	41 (31.5)	.882
Poor health status (self-rated)	27 (9.3)	28 (21.4)	.005
Score on 0-25 WHO Well-being Index*	10.5 (5.9)	10.9 (6.4)	.535
Older person			
Age*	84.9 (7.4)	83.2 (8.0)	.061
Female	208 (71.0)	95 (72.5)	.747
Married/cohabiting	103 (35.2)	33 (25.2)	.042
Score on 5-100 Barthel Index*	30.6 (25.9)	32.3 (26.5)	.597
Score on 0-6 IADL scale*	5.9 (0.3)	5.9 (0.4)	.966
Score on 0-9 BISID scale*	4.9 (2.5)	5.2 (2.9)	.173
Urinary incontinence	252 (86.0)	109 (83.2)	.454
Fecal incontinence	209 (71.3)	84 (64.1)	.138

Note.*Values are mean (SD); all other values are n (%)

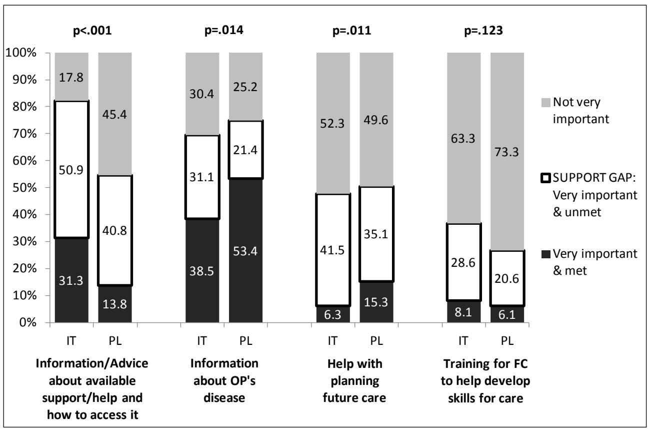

FIGURE 1. Gaps in informational and organizational support. FC=Family carer; OP=Older person; IT=Italy; PL=Poland.

Respite support. Out of four forms of support from this domain, namely: the willingness to have more time for family, a break from caring, and opportunities to enjoy activities outside of caring were most commonly mentioned by the caregivers in both countries, more frequently in Poland (Figure 2). Just one-fourth of the caregivers appreciated attending carer support groups. A greater number of carers with such need did not receive any support.

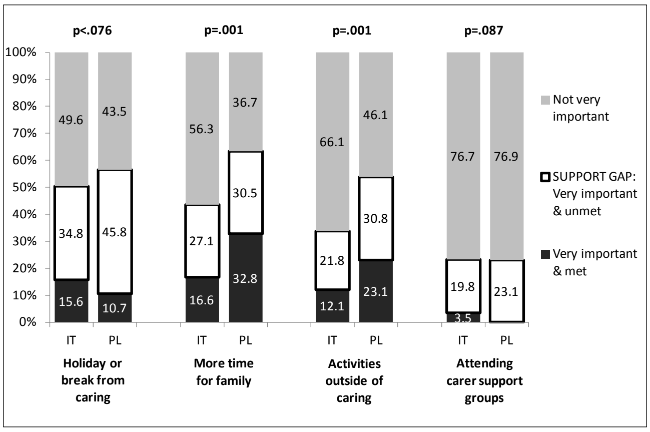

FIGURE 2. Gaps in respite support. IT=Italy; PL=Poland.

Support addressing problems resulting from care. Out of seven different types of support in this domain (Figure 3), two were especially emphasized by caregivers in both countries: the possibility to combine caregiving with paid employment (56% in Italy; 66% in Poland), and financial help to provide good care (51% in Italy; 63% in Poland). The former was met to a much lower degree in the Italian caregivers compared with the Polish ones (21.5% and 40%, respectively). More money for better help was a demand of almost half of the Italian and Polish carers, significantly more often in Poland. As many as 88% of the caregivers in Poland and Italy reported not having this need met. Opportunities for older persons to undertake activities they enjoy and help to make their environment more suitable for caring were very important for almost every third carer in both countries, slightly more often for the Polish carers. Nevertheless, in the majority these forms of support were unmet for caregivers from both countries.

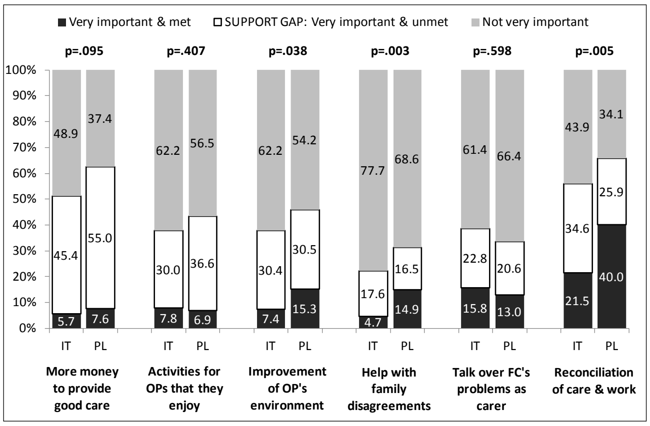

FIGURE 3. Gaps in support addressing problems resulting from care. FC=Family carer; OP=Older person; IT=Italy; PL=Poland.

DISCUSSION

As expected and previously reported [10], the most desirable prerequisites for better dementia care are focused mainly on the logistics of the care arrangement. The majority of the Italian and Polish caregivers especially valued the appropriateness of the information and advice on the available support, help with planning for future care, and information about the older person's disease. In this domain, dissatisfaction with support for caregivers, making up a support gap, prevailed over those satisfied, i.e. with their needs met. Our findings are consistent with those of Lamura et al. [4] from the whole EUROFAMCARE sample. Therefore, it may be hypothesized that informational support is strongly desirable for all caregivers, but especially when their care recipients are disabled and demented. The review of intervention studies among dementia caregivers showed that caregivers were likely to benefit from knowledge about the disease and the available support resources [11]. When informational needs were met, caregivers could additionally benefit from other forms of support (e.g. intervention that targets caregivers' emotional responses to care) [6]. However, increased caregiver's knowledge did not consistently produce improvements in caregiver psychological well-being or burden [12].

Another highly desired type of support, especially in Poland, was more money for providing better help. Dementia caregivers are often under heavy financial burden due to high expenditures resulting from care [13] and financial assistance is a frequently reported need with relevance to the caregiver's quality of life [14]. Adequate financial aid is therefore important in building an effective support system that might help in preventing caregiver burnout and premature institutionalization of the care recipient [9].

Both Italian and Polish caregivers seemed to underestimate the importance of receiving help in family disagreements and attending support groups, as these were among the least rated types of support in both countries. This clearly indicates a lack of awareness among Italian and Polish caregivers of the relevance of support (i.e. respite care), which positively contributes to the quality of caregiving and the carer's life. The benefits of support groups, such as more information about the illness and its intervention, how to cope better with difficult situations and feel more comfortable in providing care may not only improve the quality of care but also the carer's psychosocial life by decreasing distress [15].

Summing up, consistently with a study conducted by Lamura et al. [16], our findings seem to confirm a widespread absence of support in Italy and Poland. The usage of all fourteen different types of support was generally low in both countries, especially with regard to support perceived by carers as very important. However, in five cases ('Help with planning future care', 'Information about the older person's disease', 'Improvement of the older person's home', 'Help in family disagreements', and 'Reconciliation of care & work'), the gap between desirability and use was greater in Italy than in Poland, whereas only in two cases ('Information/Advice about the available support/help and how to access it' and 'Attending carer support groups') the situation was opposite. It may be hypothesized that in comparison with Poland utilization of highly valued types of support among the Italian caregivers was relatively worse.

The limited use of care services in both countries may be partially explained by widespread lack of information on the available support. As suggested, one of the reasons for non-utilization of services by dementia caregivers is a lack of information provided for the carers[11,17]. Increased information on the available support (e.g. through media campaigns) may help use of services become more accessible to caregivers. Another possible reason for low utilization of the available support, especially in Poland, may lie in the fact that carers tend to have low expectations in relation to being provided with support [11].

CONCLUSIONS

1. The Italian and Polish family caregivers of demented older people struggle with many unmet care needs, referred especially to the organizational and informational support and planning for the future long-term care, however a size of relevant support gaps differs to some extent between countries.
2. In both countries there is an urgent need for the development of a respite care services for family caregivers enabling them even a short break from caring process.
3. The special needs of family caregivers of demented older people ought to be taken into account by health and social care organizers, as well as policy makers in order to relieve their burdensome life and to enhance their willingness to continue the care.

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