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ORIGINAL PAPER

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Select aspects of long-term care provision based on opinions of direct informal caregivers

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Abstract

Introduction. The deteriorating health of persons of advanced age necessitates that essential health care services are provided not only by networks of health care institutions but by informal caregivers as well.

Aim. The aim of this study was to assess select aspects of care provision for persons requiring long-term care on the basis of opinions shared by their direct informal caregivers.

Materials and methods. Surveys were administered to 982 individuals providing informal care for chronically ill persons or for those with disabilities. The survey was conducted in 2017. The questionnaire contained questions concerning the dysfunctions of chronically ill or disabled persons in their daily functioning and addressed related care problems.

Results. Over half of the informal caretakers in the study were over 50 years of age (52.5%), had completed secondary educations (45.8%), and lived mainly in cities with populations under 50 thousand (63.4%). Reconciling care-related duties with one's own professional work or studies was a problem for 43.2% of caregivers. The care tasks which entailed the greatest difficulties for caregivers were washing intimate areas after urination (57.4%) and bowel movements (55.6%) as well as total body bathing.

Conclusions. In the opinion of over half of the surveyed caregivers, the activity posing the greatest difficulty for those providing care for persons partially or completely immobilized and possessing physiological dysfunctions (urinary or fecal incontinence) was the washing of intimate areas of the body.

Keywords. care problems, informal care, sick persons, persons with disabilities

Introduction

The occurrence of both socio-cultural and demographic changes (increasing average lifespans and an aging society) observed in Poland in the past few decades has led to an increase in the demand for long-term care. Increasing lifespans, however, do not always entail their being of high quality. The worsening health and functioning of seniors and the raised incidence rate of chronic afflictions that require long-term care contribute to greater demand for services that are medical, care-related, or social in nature.

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Long-term care encompasses the care and continued treatment of persons who are chronically ill, disabled, or advanced in age in their home environment or, in unique circumstances when the provision of home care is hindered or made impossible, in inpatient health care facilities. Long-term care is designated for persons who are bedridden and chronically ill, who suffer from significant deficiencies in self-care, and who require round-the-clock care and continuation of treatment.[1-3]

The growth rate of long-term care services is slower than both the rate at which society is aging and the rate at which the number of chronically ill and disabled persons is rising. This gives rise to a need for informal caregivers to provide care. Caregivers provide assistance with the execution of daily tasks, offer emotional support, and organize medical services and social aide. Chronic disease, regardless of its nature, interferes in all areas of human functioning and can affect both subjective and objective aspects of the caregiver's life, lowering the quality thereof in many aspects.[4-6]

Aim of the study

The aim of the study was to assess select aspects of care provision for persons requiring long-term care on the basis of opinions shared by their direct informal caregivers.

Material and methods

Surveys were administered to 982 persons, of which 843 (85.8%) were women and 139 (14.2%) were men, all of whom provided care for loved ones afflicted by chronic disease or disabilities. The subjects surveyed represented 11 different localities throughout Poland. The study was conducted in 2017 by trained interviewers and ambassadors of the "Razem Zmieniamy Świat" foundation (*in English:* Together We Change The World), working in cooperation with TZMO S.A. in Toruń, Poland under the nationwide program "Damy Radę" (*in English:* We Can Do It). The participation of the caregivers in the study was voluntary and their consent was made in writing. Purposeful random sampling was employed. With this sampling method, it was possible to select entities whose management agreed to the studies being performed; entities in which there was a possibility of non-problematically establishing contact with caregivers.

The research instrument was a survey designed by the authors. The validation thereof was conducted in one of the centers in which the study was carried out. Sociodemographic questions as well as questions referring directly to the issue under analysis were taken into consideration in the survey. For all categories of sociodemographic variables, percentages were calculated separately in relation to the number of men and women participating in the study (Table 1). Intersexual differences between the categories of sociodemographic variables describing the population of men and women were assessed via a χ^2 test in the form of a G function.[7]

Due to the lack of statistically significant differences between the sociodemographic variables describing the population of men and women, the results of the main part of the survey have been presented in percentages where all persons included in the study, regardless of sex, equal 100%.

The questions contained in the principle part of the survey included issues concerning dysfunction in the daily functioning of chronically ill or disabled persons, care-related problems, and the possibilities of providing such persons with care. The questions concerned the caregivers' subjective evaluation of the independence of those chronically ill or disabled persons under their care as well as their dysfunctions in daily functioning, including the

Table 1. Characteristics of the study population

Sociodemographic traits	Category	Total (n=982)		Women (n=843)		Men (n=139)		G Function
		n	%	n	%	n	%	
Age	up to 24	21	2,1	17	2.0	4	2.9	3.19[#]
	25-30	34	3.5	26	3.1	8	5.7	
	31-40	104	10.6	88	10.4	16	11.5	
	41-50	307	31.3	268	31.8	39	28.1	
	over 50	516	52.5	444	52.7	72	51.8	
Education	primary	36	3.7	27	3.2	9	6.5	5.37
	trade	288	29.3	245	29.1	43	30.9	
	secondary	450	45.8	396	46.9	54	38.9	
	tertiary	208	21.2	175	20.8	33	23.7	
Place of residence	village	188	19.1	153	18.1	35	25.2	4.01
	town up to 50k	623	63.4	542	64.3	81	58.3	
	city 51-500k	141	14.4	121	14.4	20	14.4	
	city over 500k	30	3.1	27	3. 2	3	2.1	

[#] Statistically insignificant differences between the categories of sociodemographic variables describing the population of women and men; (χ^2 test in the form of a G function) severity of their urinary or fecal incontinence. Additionally, respondents were asked about the most frequent problems encountered by caregivers, the duration of care for the chronically ill or disabled person under their care, and the care-related activities that caused the greatest difficulties for caregivers at the beginning period of their care duties. In the case of several survey questions, respondents were able to choose more than one answer, which is why the percentages do not add up to 100%.

Results

The data in Table 1 shows that over half of the informal caregivers who filled out the survey were over 50 years of age (52.5%), had completed a secondary education (45.8%), and resided mainly in towns with populations under 50 thousand residents (63.4%).

The assessment of the independence of the chronically ill or disabled (Figure 1), shows that the majority of such persons moved with the assistance of a cane, crutch, or walker (33.7%). Equally high is the percentage of immobilized or wheel-chair bound persons (23.7%). As many as 24.7% of the persons requiring care were completely bedridden.

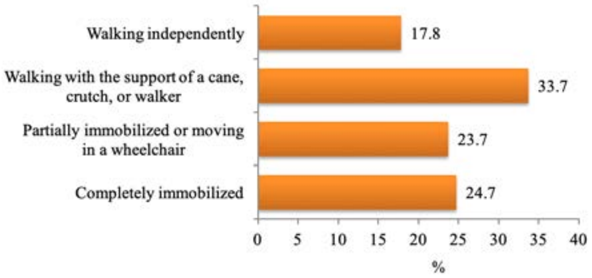

Fig. 1. Assessment of the independence of chronically ill or disabled persons

For 43.2% of caregivers, reconciling duties arising from the care of a chronically ill or disabled person with one's professional duties or studies was a problem (Figure 2). Another significant problem proved to be domicile conditions, particularly apartment size (12.9%) and the distance separating the caregiver's place of residence and the residence of the person requiring care (6.1%).

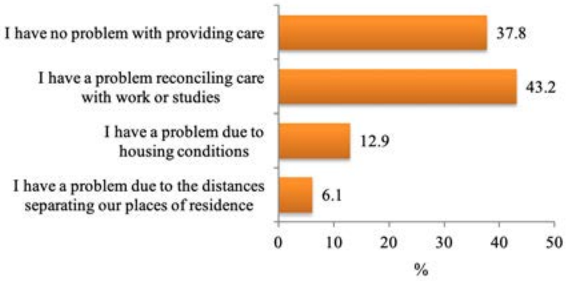

Fig. 2. Problems with providing care for a chronically ill or disabled person

Another important problem for informal caregivers was the urinary incontinence of those under their care (Figure 3). A slight degree of incontinence – characterized by minor leaking in between trips to the bathroom – affected 40% of persons, while moderate and severe degrees of urinary incontinence – the former occurring often and in significant volumes, the latter consisting in a complete lack of control over urination – affected 23.2% and 22.9% of persons, respectively.

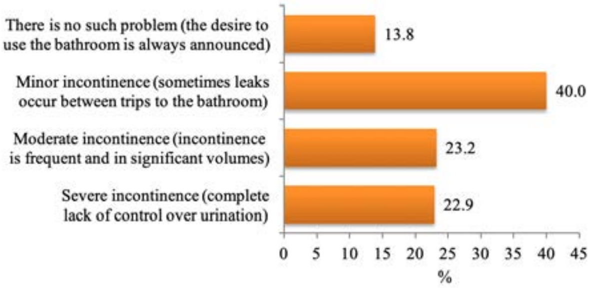

Fig. 3. Degree of urinary incontinence affecting persons requiring care

An equally significant problem proved to be fecal incontinence. A complete lack of control over bowel movements was reported by 27.8% of persons requiring care (Figure 4). For close to half of the caregivers surveyed (47.5%), difficulties related to fecal incontinence were an accidental occurrence, yet for another 27.4%, such difficulties were insignificant, for those under their care always voiced a need to have a bowel movement.

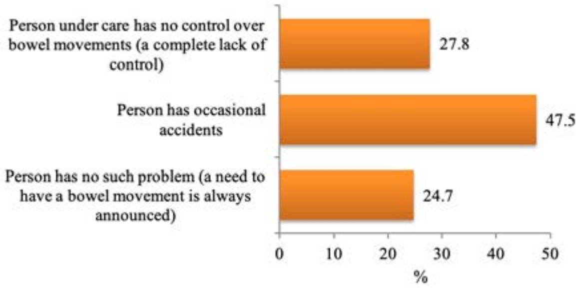

Fig. 4. Degree of fecal incontinence in persons requiring care

For 24.4% of the caregivers surveyed, the chronically ill or disabled person they cared for had been under their care for more than one 12 months, while for close to 60%, this time did not exceed 6 months (Figure 5). Care-related activities which caused caregivers the most problems during this time were washing intimate areas after urination (57.4%) and bowel movements (55.6%), followed by total body bathing (35.7%) and the washing of the person's head (23.6%). The fewest difficulties were caused by oral hygiene maintenance (5.3%), the selection of proper absorbent underwear (6.2%), and changing bedding (7.4%).

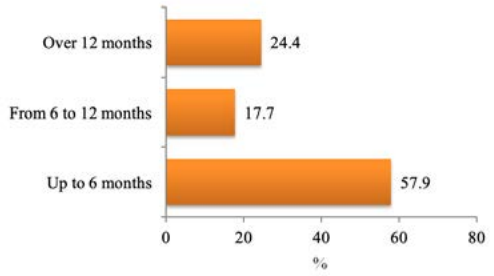

Fig. 5. Duration of care for chronically ill or disabled person

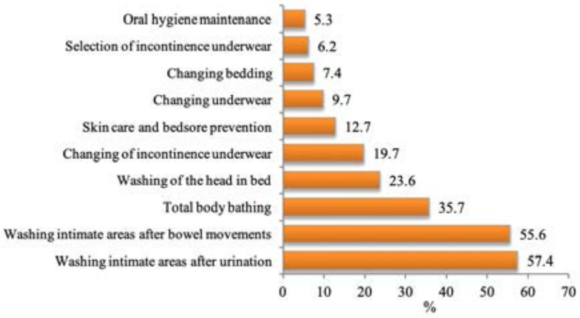

Fig. 6. Care-related activities causing the most difficulties for caregivers in the first 6 months of care

Informal caregivers' knowledge about caring for chronically ill or disabled persons was acquired in similar percentages from nurses and physicians (Figure 7), with there being a slightly greater dependence on the former (65,6% vs. 64,5%). Respondents also indicated other sources as significant in terms of acquiring caregiving knowledge: unlicensed assistive personnel (29.9%), the Internet (22.7%), handbooks and professional medical books (18.9%). The least amount of interest was directed towards radio and television (5.3%).

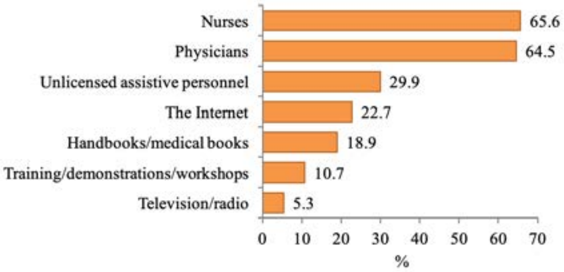

Fig. 7. Sources of knowledge about caring for chronically ill and disabled persons

Discussion

The deterioration in functioning that accompanies aging leads to a greater demand for various forms of care. The increase in the occurrence of chronic afflictions in the elderly and disabled as well as the increasing infirmity that is part of the aging process give rise to specific health and care needs which, in consequence, leads to the elderly and disabled being more dependent on the assistance of others.[8-12]

One's ability to care for oneself – one's self-care efficiency – should be identified with independence in satisfying one's basic life needs. These needs include movement, nourishment, control of physiological functions, and maintenance of personal hygiene.[13,14] The range of essential care is determined by one's level of self-care efficiency, which in turn is contingent upon socioeconomic factors, one's age, and the degree to which one has lost independence, among other things. Results of Fidecki et al.'s study has shown that age and sex are significant factors in determining the functional fitness of seniors as well as one's need for care.[8]

Analysis of the study data indicates a high degree of dependence in functioning (Figure 1). It shows that 57.4% of chronically ill or disabled persons were either persons dependent on the assistance of others, walking with either a cane, crutch, or walker, or persons partially immobilized moving around by means of a wheelchair. Subjects indicated that as many as 24.7% of the persons under their care were completely bedridden. In a study by Pruszyński et al., 77% of patients placed in care facilities displayed severe functional disability, 19.7% qualified as possessing moderate functional disability, while only 3.3 % did not display any functional disability.[15]

Caring for bedridden and chronically ill loved ones residing at home who do not require treatment inpatient care facilities poses a serious challenge for caregivers. However, due to existing health problems, these persons often require systematic and intensive care involving a primary care physician. Home-based care is significantly cheaper when compared to a stay in an long-term inpatient facility, and apart from such financial advantages, this form of care possesses a positive psychosocial dimension as it translates into a better state of being for the patient remaining at home while at the same time strengthening family bonds.[16]

Informal care of the chronically ill or disabled is usually taken up by family members. The problems encountered by direct caregivers are often very complex. Caregivers reported that it was most difficult to reconcile care-related duties with their own work or studies (43.2%) or with housing problems (12.9%) connected with the need to provide the person under their care with an extra room (Figure 2). Analysis of the housing situation of seniors conducted by Doroszkiewicz et al. confirmed the results reported above, as, from the 100 individuals surveyed aged 60 and above in the Geriatrics ward of the MSW Hospital in Białystok, a considerable majority resided with family before being transferred to the ward (46%).[17]

In many cases, when a senior requires constant care, one of the family members is forced to resign from work.

This is often not the result of a conscious, rational decision, but of a lack of alternatives. This is determined by cultural conditioning. Poland belongs to those countries which are extremely conservative with regard to care for seniors. The family was and still is perceived as the main care institution, and, in many circles, it is still believed that, in the situation described above, family members should sacrifice their professional ambitions to take care of the sick or disabled members of their family.[18]

In a study carried out by Sochy et al. concerning the quality of life of family members with terminally ill loved ones, it was shown that illness in the family affects the social and professional situation of those studied, generating a need to verify previously held life plans, which predominantly entailed decisions to shorten one's time of work.[19]

For most caregivers, the duration of care for chronically ill or disabled persons (Figure 5) did not exceed 6 months (57.9%). This relatively short period of caregiving, in combination with the physiological disorders of those needing care such as urinary or fecal incontinence (Figures 3 and 4), resulted in the fact that, even when such occurrences were reported as infrequent accidents, washing intimate areas after bowel movements (55.6%) or urination (57.4%) were reported (Figure 6) as activities causing the greatest difficulties in the initial period of care.

In the 2000 Norwegian study known as the *Epidemiology of Incontinence in the County of Nord-Trøndelag* (EPINCONT), the prevalence rate of urinary incontinence overall was 27.6%, reaching 10% for persons aged 20-25 and, for persons over 75, up to 40%.[20] This study concerned outpatient patients, not patients hospitalized due to this disease or long-term care home residents, where, according to estimates, up to 25% of care time is devoted to patients with urinary incontinence.[21]

Very similar results were obtained by Grochowska from 64 persons providing informal care for seniors over 65 years of age. This data shows that 28.13% of persons requiring care did not control urination, while 25% fulfilled their physiological needs in places not designated for this activity. Such a high percentage of persons in this group with physiological dysfunctions manifesting in urinary incontinence translated into a relatively high frequency of caregivers feeling burdened by care. Close to half of the surveyed caregivers (48.4%) at least sometimes felt burdened by care, one third (29.7%) – often, while one fifth (20.3%) reported never feeling burdened. Among those surveyed only one person (1.5%) always felt burdened by care.[22]

What were reported by caregivers as more minor care-related problems during the first 6 months of care were oral hygiene maintenance (5.3%), the changing of bedding (6.2%), and the changing of underwear (9.7%). As survey data shows, however, the selection of proper incontinence underwear in terms of size and absorbency (6.2%) and the changing thereof (19.7%) also constitute significant problems (Figure 6).

The study results presented herein show that the greatest specialist support for those caring for the chronically ill and disabled was provided by nurses and physicians (Figure 7). This is a surprising yet positive finding, especially in the age of universal access to the Internet, which society considers the main source of knowledge – for caregiving information as well – and which was used by merely 22.7% of respondents. Perhaps this modest interest in the Internet as a source of information is related to the age of the caregivers (Table 1), of whom 1 in 2 was over 50 years of age (52.5%) and, as one may surmise, may have had problems with using a computer and/or the Internet. The fact that radio and television enjoyed the lowest level of interest as a source of caregiver knowledge (5.3%) is enlightening.

Conclusions

1. The problems of direct informal caregivers responsible for persons requiring long-term care in the home environment arose both from the need to reconcile care duties with work or studies and from the short, less than 6 month period of caregiving.
2. In the opinion of half of the surveyed caregivers, while caring for persons partially or completely immobilized who possess physiological dysfunctions (urinary and fecal incontinence), the activity posing the greatest difficulty was the washing of intimate areas.

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References

1. Kułagowska E, Kosińska M. Opieka długoterminowa w Polsce. Potrzeby, organizacja, bezpieczeństwo, jakość. Instytut Medycyny Pracy i Zdrowia Środowiskowego, Sosnowiec; 2014: 21-35.
2. Ziembicka DM, Marcinowicz L. Pielęgniarska opieka długoterminowa domowa – stan polskich badań naukowych. *Fam Med Prim Care Rev.* 2015;17(3): 232-236.
3. Nowak-Kapusta Z, Irzyniec T, Franek G, Drzazga B. Pielęgniarki i pielęgniarze opieki długoterminowej domowej. *Piel Pol.* 2017;3(65): 409-415.
4. Janowicz A. Rola opiekunów nieformalnych w opiece u kresu życia. Przyczynek do badań w ramach projektu European Palliative Care Academy (EUPCA). *Piel Zdr Publ.* 2014;4(2): 161-167.

5. Pyszkowska A, Naczyński M. Wsparcie społeczne, samoocena i jakość życia nieformalnych opiekunów osób starszych. *Społeczeństwo i Edukacja.* 2015;17(2): 265-276.
6. Kędra E, Borczykowska-Rzepka M, Wilusz J. Ocena jakości życia rodzin/opiekunów osób chorych na stwardnienie rozsiane dokonana w świetle przeprowadzonych badań. *Piel Pol.* 2017;3(65): 396-403.
7. Sokal RR, Rohlf FJ. Biometry. The principles and practice of statistics in biological research. W.H. Freeman and Co:San Francisco; 1969: 256-258.
8. Fidecki W, Wysokiński M, Wrońska I, Ślusarz R. Niesprawność osób starszych wyzwaniem dla opieki pielęgniarskiej. *Probl Piel.* 2011;19(1): 1-4.
9. Zielińska A, Strugała M, Stachowska M. Ocena funkcjonowania czynnościowego, poznawczego oraz ryzyka rozwoju odleżyn, jako zasadniczych elementów w planowaniu zapotrzebowania na opiekę pielęgniarską u pacjentów w wieku podeszłym. *Probl Hig Epidemiol.* 2007;88(2): 216-222.
10. Kosińska M, Kułagowska E, Niebrój L, Stanisławczyk D. Obciążenie opiekunów osób zakwalifikowanych do opieki długoterminowej domowej. *Environ Med.* 2013;16(2): 59-68.
11. Grabowska-Fudala B, Jaracz K, Smelkowska A, Pniewska J, Buczkowska M. Obciążenie osób sprawujących opiekę nad osobami z chorobą Alzheimera. Wyniki wstępne. *Nowiny Lek.* 2013;82(1): 25-30.
12. Karczewska B, Bień B, Ołdak E, Jamiołowski J. Opiekunowie rodzinni osób starszych z otępieniem lub zaburzeniami poznawczymi w Polsce – czynniki ryzyka obciążenia opieką. *Gerantol Pol.* 2012;20(2): 59-67.
13. Ślusarz R, Beuth W, Książkiewicz B. Ocena czynnościowa chorych z krwotokiem podpajęczynówkowym. *Udar Mózgu.* 2008;10(2): 55-60.
14. Srugała M, Talarska D. Ocena sprawności podstawowej osoby w wieku podeszłym z wykorzystaniem katalogu czynności życia codziennego. *Fam Med & Care Rev.* 2006; 8: 332-35.
15. Pruszyński JJ, Cicha-Mikołaczyk A, Gębska-Kuczerowska A. Ocena wydolności czynnościowej i sprawności motorycznej osób przyjmowanych do pielęgniarskiego domu opieki w Polsce. *Przegl Epidemiol.* 2006;60: 331-338.
16. Markiewicz I, Cebulak M. Sprawność funkcjonalna pacjentów objętych domową długoterminową opieką pielęgniarską. *Probl Piel.* 2014;22(1): 42-51.
17. Doroszkiewicz H, Sierakowska M, Lewko J, Ostrowska A. Ocena stanu funkcjonowania pacjentów geriatrycznych wyznacznikiem zakresu opieki pielęgniarskiej. *Probl Piel.* 2014; 22(3): 258-264.
18. Jurek Ł. Polityka łączenia pracy zawodowej z opieką nad osobą starszą. Acta Universitatis Lodziesis. *Folia Oeconomica.* 2015;2(312): 95-110.
19. Socha B, Kutnohorska J, Zielińska M, et al. Ocena jakości życia członków rodzin pacjentów w terminalnym okresie choroby nowotworowej w warunkach domowych. *J Publ Health Nurs Med Resc.* 2011;2: 20-25.
20. Hannestad YS, Rortveit G, Sandvik H, Hunskaar S. A community-based epidemiological survey of female urinary incontience: The Norwegian EPINCONT Study. *J Clin Epidemiol.* 2000;53: 1150-1157.
21. Tannenbaum C, DuBeau CE. Urinary incontience in the nursing home: practical approach to evaluation and management. *Clin Geriatr Med.* 2004;20: 437-452.
22. Grochowska J. Poczucie satysfakcji oraz obciążenia obowiązkami nieformalnych opiekunów osób starszych w zależności od poziomu sprawności podopiecznych. *Med. Og Nauk Zdr.* 2014;20(1): 46-50.