

EVALUATION OF ACCESS TO LONG-TERM CARE SERVICES FOR OLD PEOPLE AGEING IN PLACE IN SLOVENIA

OVREDNOTENJE DOSTOPA DO STORITEV DOLGOTRAJNE OSKRBE LJUDI, KI SE STARAJO V DOMAČEM OKOLJU V SLOVENIJI

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ABSTRACT

Keywords:

access, long-term care, informal carers, aging in place, regression analysis

Theory: The quality of long-term care services has an important effect on the quality of life of their users and their informal carers. By identifying gaps between provision of services and users' needs we can suggest adjustments of the long-term care services and advance their development.

Method: The data from the first Slovenian national survey of social homed care (SHC) users and their informal carers was utilised. Linear regression analysis was used to evaluate factors that affect assessments of five-dimensional concept of access.

Results: On average, affordability was rated the lowest (mean=2.9) and acceptability the highest (4.0), with availability, accessibility and accommodation (mean=3.6) in the middle. Regression analysis explains 15% of variability in affordability, while for other dimensions much less. Caregiver's needs are the most influential predictor of access, negatively influencing the rating of access (availability B=-.127, accommodation B=-.113, acceptability B=-.120, affordability B=-.155). Care recipients' needs also affect the rating of affordability (B=-.132). Family income negatively influences the rating of availability (B=-.115), accessibility (B=-.076) and affordability (B=-.270). Residents of rural areas rate availability (B=-.070) and affordability (B=-.067) less favourable.

Discussion: This study showed that affordability is rated the least favourable among components of access. Adjustment in private out-of-pocket co-payment mechanism is suggested.

IZVLEČEK

Ključne besede:

dostop, dolgotrajna oskrba, neformalni oskrbovalci, regresijska analiza, staranje doma

Teorija: Kakovost storitev dolgotrajne oskrbe vpliva na kakovost življenja uporabnikov in njihovih oskrbovalcev. Evalvacije lahko pokažejo neskladja med ponudbo storitev in potrebami uporabnikov in tako omogočijo korekcije storitev ter spodbudijo njihov razvoj.

Metoda: Podatke prve raziskave uporabnikov socialne oskrbe na domu in njihovih neformalnih oskrbovalcev smo uporabili za evalvacijo petih teoretsko definiranih razsežnosti dostopa. Uporabili smo linearno regresijsko analizo.

Rezultati: Cenovna dostopnost je bila v poprečju najslabše ocenjena (povprečje = 2,9), raven sprejemljivosti pa najvišje (4,0), razpoložljivost storitev, stopnja dostopnosti in ustreznost organiziranosti so bile v sredini (3,6). Z regresijskim modelom smo pojasnili 15-odstotno variabilnost v stopnji cenovne dostopnosti, ostale razsežnosti dostopa pa precej manj. Oskrbovančeve potrebe so bile najbolj vplivna determinanta, ki ima negativen vpliv na štiri razsežnosti dostopa (stopnja razpoložljivosti B = -,127, ustreznost organiziranosti B = -,113, raven sprejemljivosti B = -,120, cenovna dostopnost B = -,155). Na cenovno dostopnost značilno vplivajo tudi potrebe oskrbovancev (B = -,132). Družinski dohodki negativno vplivajo na oceno razpoložljivosti storitev (B = -,115), stopnjo dostopnosti (B = -,076) in na cenovno dostopnost (B = -,270). Prebivalci ruralnih območij nižje ocenjujejo stopnjo razpoložljivosti (B = -,070) in cenovno dostopnost (B = -,067).

Razprava: Pokazali smo, da je cenovna dostopnost najslabše ocenjena razsežnost dostopa. Predlagamo prilagoditev finančnih mehanizmov pri določanju višine plačila storitev.

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1 INTRODUCTION

The purpose of this paper is to examine how informal carers of old people, ageing in place, and using an array of formal long-term services (LTC) in community in Slovenia, evaluate access to formal LTC, used by older people. To this purpose, we explore and operationalise the theoretical five-dimensional (availability, accessibility, accommodation, affordability, acceptability) model of access by Penchansky and Thomas (1, 2). Specifically, we observe perceptions of informal carers of older people, as most often they are the ones who organise and assist access to formal LTC services and are well aware of their characteristics. Their views are especially important regarding the absence of one entry point to LTC services and longstanding division of health and social protection systems in Slovenia, which is pertinent in LTC (3-6). Access to LTC is an important issue in Eastern and Central European countries (3-5), so this study will contribute to understanding the user experience in a broader geographical area. The paper is structured as follows. First, we present major characteristics of Slovenian LTC delivery; this is then followed by a description of the five-dimensional model of access and an outline of hypotheses on the basis of literature review.

The percentage of private, out-of-pocket expenditure for formal LTC services in Slovenia is ranking the fourth in Europe, as 24% of all costs for the services consists of private out-of-pocket contribution (3). LTC expenditure represents 1% of GDP and 70% of the budget is allocated to health care (7). Altogether, 6.7% of population aged 65+ receives LTC, and among them, the majority (75%) receives institutional care (3). Compared to other European countries, this is a unique situation, as in all countries for which data is available, the majority of users receive LTC at home (3). This specific composition of Slovenian LTC may be partially explained by historical reasons, as institutional care has a long tradition in Slovenia (4), and formal services for old people aging in place became available more recently (3-6). How users of Slovenian LTC services and their informal carers perceive its quality is so far known only from descriptive comparative research (3). European Quality of Life Survey (EQLS) shows that Slovenia is the third country in Europe, ranking in difficulties to the access to long-term care (3). Nearly all users of LTC services state that they encounter difficulties with access (89% - report affordability as an issue, 84% availability (waiting lists, lack of services) and 60% accessibility - distance or opening hours as a source of barriers to access). Quality of care is rated more favourable, as only 46% report quality as difficulty related to LTC services, which is about EU average. It is therefore important to explore in detail how users of formal LTC services and their informal carers perceive their quality.

The theoretical model of five dimensions of access has been proposed already in 1980s (1, 2), and often utilised in research on the quality of LTC or individual services (13-26). Access is broadly defined as fit between peoples' (users or patients) needs and expectations, and services (e.g. health or LTC) that are offered to them in their community or region (1, 2). Availability refers to the relationship between volume and types of services and resources that are offered by the system and users' needs (1, 2). We refer to formal LTC services as the system in this study. Accessibility is fit or distance between location of service and location of users (1, 2). It includes geographical distance between service provider and users' homes, and includes all resources that are needed for users to reach the facilities, such as transfer costs and time spent on the voyage (1, 2). Waiting time between the initial contact between service provider and user and the date of actual service is also included in accessibility (1, 2). Accommodation refers to the quality of the organisation of the services, such as parking spaces, appointment system (phone, in person, the Internet), opening hours, time spent in the waiting room. Satisfaction of users with accommodation shows how suitable these characteristics of service provision are and how much they are a match to expectations of users (1, 2). Affordability refers to fit between total costs of the system and users' ability to contribute to the costs either via insurances, taxes, or with direct out-of-pocket private co-payment (1, 2). Acceptability measures the fit between characteristics of service providers, such as their race, ethnicity, gender, attitude, professionalism, language, etc. (1, 2). Problems with access will influence users as well as the services in three ways, namely: the usage of the services will be lower, users will be less satisfied with services and provider practice patterns may be inadequate or less than optimal (1, 2).

Very often, the usage of services of LTC, access and barriers to access are evaluated from the point of view of users and their informal carers at the same time (13, 14, 18, 22, 23). Quite often, access is evaluated from the perspective of users of services of LTC (16, 18, 21) or informal carers (24-26) or even from the perspective of professional carers (19). Both qualitative (18-20, 22, 25, 27-30) and quantitative (15, 17, 21, 31) approaches were found in the literature, and we tried to take into account evidence from both types of studies to postulate our hypotheses about access to long-term care services for older people, ageing in place in Slovenia.

At the end of each following paragraph we outline a hypothesis, based on literature review of articles presented in this paragraph. Rural areas are characterised by lower availability and accessibility of services (15, 29, 31-33). Low awareness and lack of information about

services among potential users and their informal carers, and reluctance to use formal services were also identified among barriers (16, 29). Insufficient public transport in rural areas was found to be a significant barrier to access to health services, which is important for older people aging in place and their informal carers (32). Gaps in services provision were related to timing of the service or to the ways service was organised around an individual user (16, 29, 33). This accumulation of barriers to access to LTC in rural areas would result in systematic perception of lower access to services across all five dimensions of access also in the Slovenian context.

Inadequate attitude by formal carer or physician, her/his lack of communication skills or failure to provide information was also identified as a factor that has a negative effect on the perception of access for all dimensions of access (15, 33). Considering that the quality of LTC was rated as relatively good by EQLS, we expect favourable evaluations of quality of service provision in Slovenia, measured as acceptability and accommodation, as opposed to other dimensions.

Need of care recipient and informal carer, taking into account both illnesses and disabilities as well as psychological impairment, such as problems with memory, would increase the usage of formal services (15, 21, 31, 33). We hypothesise that informal carers with higher amount of illnesses and disabilities rate access to LTC services across all dimension of access lower than respondents with lower amount of illnesses and disabilities.

Financial constraints are an obvious barrier to the access to any kind of service that requires out-of-pocket private contribution, both in rural and urban areas, as well as taking individual or household income into account (15, 26, 29, 31-33). The type of relationship between informal carer and care recipient(s) is also important, as children are more often found to facilitate the usage of formal services than spouses (16, 26, 31, 33), and male carers more often than female carers (16, 26, 33). Education also fosters the usage of formal services (21, 31), and more educated carers may have higher expectations about service provision and service quality, and thus rate access less favourably than informal carers with lower education. We hypothesise that affordability of the LTC services rates the least favourable among all components of access, and that the evaluations will be negatively associated with higher care needs of care recipients and caregivers with lower income and higher education.

2 METHODS

2.1 Subjects and Procedure

Data for this study were drawn from the first Slovenian national survey of social homecare (SHC) users in 2013. Stratified random sampling was applied to obtain a representative sample of service users and service providers. At the same time, informal carers of users of SHC were invited to participate in the survey. 1151 informal carers participated in the survey. The partial non-response is related to self-administered paper and pencil data collection and is explained in more detail in (9). The subjects of the paper are informal carers of old people who age in place and use formal LTC services.

2.2 Instruments

In the present study, we analysed the perception of accessibility of Slovenian LTC services from the perspective of informal carers of users of formal LTC. We designed a multi-item questionnaire according to the theoretical model of access defined by Thomas and Penchansky (1, 2), and examined its multidimensionality with factor analysis (principal axis, oblimin rotation). The questionnaire measures five dimensions of access, evaluating availability, accessibility, accommodation, affordability and acceptability. Likert indexes were calculated on the basis of dimensionality shown by factor analyses, resulting in five indexes of interval measurement scale as dependent variables. Respondents were prompted to consider all LTC services used by the care recipients (i.e., health services, such as visiting the general practitioner or some other specialist, visit of community nurse or social home carer).

2.3 Hypotheses

All hypotheses were elaborated on the basis of literature review, presented in theoretical introduction. We considered findings from available quantitative and qualitative studies on access to LTC services and applied them to Slovenian LTC.

H1: Among dimensions of access, acceptability should be, on average, rated the highest and affordability the lowest.

H2: Increasing need of informal caregivers and care recipients would decrease satisfaction with access to LTC services across all dimension of access.

H3: Personal characteristics of informal caregivers will affect mostly affordability. Having difficulties to manage with family income, higher education, younger age, being partner carer as opposed to child carer would all decrease perception of access.

H4: Across all dimensions of access, informal carers from rural settlements would rate access less favourable.

2.4 Dependent and Independent Variables

The dependent variables are Likert indexes of five conceptual dimensions of access to LTC services (availability, accessibility, accommodation, affordability and acceptability on an interval scale, ranging from 1 to 5). Independent variables were selected according to theoretical and empirical studies presented in Introduction. Owing to limitations in the questionnaire, some were assessed as proxies (e.g. income). We included care recipient's (CR) subjective perception of impairments, illnesses and disabilities that limit daily life activities and problems with memory. We also included informal carers' (IC) perception of their own health, their demographic characteristics, the number of care recipients (informal caregiver may provide care to multiple care recipients) and scope and intensity of care provided to care recipients across 22 activities of daily living (personal, instrumental and advanced activities of daily living), the type of settlement and geographical distance between informal caregiver and care recipient. Ordinal variables were transformed to dummy variables, in order to estimate multiple linear regression analysis.

Model

CR_1 - existence of long-term physical or psychological impairments, illness or disability that limits care recipients in daily life activities (0 - none or one, 1 - more)

CR_2 - problems with memory (0 - none, some, 1 - considerable)

IC_3 - age

IC_4 - gender (0 - female, 1 male)

IC_5 - education (0 - vocational school or less, 1 high school or more)

IC_6 - evaluation of family income (0 - we can (easily) manage with our family income, 1 - it is (very) difficult to manage with our family income)

IC_7 - multiple care provision (the number of care recipients to whom care giver provides informal care)

IC_8 - health problems of IC (Liker scale of reported health issues by caregiver)

IC_9 - scope and intensity of care provided to care recipients across activities of daily living (sum of three Likert scales, one for each of types of activities of daily living; that is, personal, instrumental and advanced activities of daily living; thus, ranging between 3 and 15)

IC_10 - urban vs rural settlement (0 urban, 1 - rural)

IC_11 - geographical distance between care giver and care recipients (0 - the same household, 1 - less than 15 min drive, 2 - more than 15 min drive)

2.5 Data Analysis

Multiple linear regression analysis was used. We examined quality parameters for multiple linear regression analysis.

Standardised residuals were normally distributed, except for acceptability, and in order to keep all five dimensions comparable, we have chosen not to transform the acceptability scale. There were no heteroscedasticity or multicollinearity.

Model 1-5:

$$Y_i = b_0 + b_1X_{1i} + b_2X_{2i} + \dots + b_{11}X_{11i} + e$$

Y_i = access to LTC services

b_0 = intercept

b_i = regression coefficients

X_i = independent variables

e = error

3 RESULTS

Table 1. Descriptive statistics.

	N	Mean	St. Dev.	Min	Max
Availability	698	3.58	.72	1	5
Accessibility	606	3.62	.69	1.25	5
Accommodation	563	3.55	.67	1.25	5
Acceptability	646	4.02	.55	2	5
Affordability	623	2.90	.82	1	5
IC Age	1097	60.20	14.80	20	97
IC Number of care recipients	1151	.97	.73	0	5
IC Scope and intensity of informal care	1033	8.09	3.51	3	15
IC Health problems	1092	2.17	.93	1	5

IC - informal carer

Table 2. Descriptive statistics II.

		N	%
CR Long term disability	0 - None or one	994	36.7
	1 - More		63.3
CR Difficulties with memory	0 - None, some	1005	67.8
	1 - Considerable		32.2
IC Gender	0 Female	1126	62.6
	1 Male		37.4
IC Education	0 - Vocational school or less	961	30.7
	1 High school or more		69.3
IC Evaluation of family income	0 - We can (easily) manage with our family income	933	78.1
	1 - It is (very) difficult to manage with our family income		21.9
IC Settlement	0 -Urban	1039	47.6
	1 - Rural		52.4
Geographical distance between IC and CR	0 - The same household	1003	61.1
	1 - Less than 15 min drive		27.9
	2 - more than 15 min drive		11.1

IC - informal carer; CR care recipient

Evaluations of five dimensions of access considerably vary on average since the mean acceptability is very high (4.02) and affordability quite low (2.90). Informal carers of users of social home care are, on average, 60 years old, in majority they are women (62.6%), in majority they can manage with family income, in majority they have completed high school (69.3%), and they report a lower level of scope and intensity of their own health issues on average (2.17). They provide a substantial amount of informal care to care recipients who mostly reside in their

own households (61.1%). The majority of care recipients have two or more long-term physical or psychological impairments, illnesses or disabilities that limit them in daily life activities, and about 30% have severe memory problems.

Table 3. Results of multiple linear regression analysis.

Predictor variables	Availability		Accessibility		Accommodation		Acceptability		Affordability	
	b	B	b	B	b	B	b	B	b	B
Constant	3.814		3.833		3.797		.143		3.197	
CR Long term disability	.044	.029	.031	.022	-.068	-.048	.003	.002	-.226	-.132 ^c
CR Difficulties with memory	-.081	-.052	-.091	-.062	.013	.009	-.045	-.021	-.069	-.039
IC Gender	.011	.007	-.057	-.040	-.066	-.047	.024	.012	-.039	-.023
IC Age	.000	.004	.001	.012	.001	.025	.002	.023	.004	.077 ^a
IC Education	-.050	-.032	-.040	-.027	-.111	-.076	-.071	-.033	-.070	-.039
IC Evaluation of family income	-.201	-.115 ^b	-.127	-.076 ^a	-.107	-.066	-.039	-.016	-.538	-.270 ^c
IC Number of care recipients	.016	.016	-.009	-.010	.040	.044	.007	.005	.085	.076 ^a
IC Health problems	-.099	-.127 ^b	-.049	-.066	-.082	-.113 ^a	-.129	-.120 ^a	-.137	-.155 ^c
IC scope and intensity of care	.012	.057	-.004	-.022	-.004	-.019	.006	.022	.009	.036
IC settlement	-.102	-.070 ^a	.042	.031	-.036	-.027	.069	.035	-.111	-.067
Geographical distance btw IC and CR	-.041	-.039	-.063	-.063	.072	.073	.023	.016	-.015	-.012
R ²	.039		.022		.036		.017		.148	
F/p	2.229	.012	1.074	.380	1.753	.060	.899	.541	8.674	.000

b - unstandardised regression coefficients; B - standardised regression coefficients; * a ≤ 0.05; ** b ≤ 0.01; *** c ≤ 0.001; IC - informal carer; CR care recipient

Models for five dimensions of access perform differently, as the proportion of explained variance in access varies between 2 and 15 percent. The smallest amount of explained variance was found for accessibility and acceptability, whereas the biggest amount of explained variance was found for affordability.

Perception of availability of LTC services is significantly influenced by evaluation of family income, informal caregivers' health and type of settlement. Informal carers, reporting difficulties with family income, would rate LTC services as less available (unstandardised regression coefficient b=-.201). Similarly, if they reported a higher degree of their own health problems (b=-.127) and if they are living in a rural area (b=-.102), they rate the availability less favourably. Perception of accessibility is only affected by evaluation of family income. Informal carers reporting difficulties with family income would rate LTC services as less accessible (unstandardised regression coefficient b=-.127). Perception of accommodation is only affected by informal carers' health problems (b=-.082), similarly as acceptability (b=-.129). Perception of affordability is affected by a number of variables, including care recipient's health (b=-.226). Perception of affordability increases with informal caregivers' age (b=.004) and the number of care recipients (b=.085). Perception of affordability decreases with informal carers' difficulties with family income (b=-.538), informal carers' own health problems (b=-.137) and living in a rural area

(b=-.111). Among predictors, needs of care recipient and informal caregiver and evaluation of family income are among the strongest predictors of access (as suggested by standardised regression coefficients - B), followed by type of settlement, care recipients' age and number of care recipients.

4 DISCUSSION

The purpose of this study was to evaluate access to Slovenian LTC services for old people residing in community. As predicted, financial access or affordability was rated the lowest. Similarly as in other countries, affordability of the LTC services is an important issue to its users and their informal carers (15, 26, 29, 31-33). Financial resources obviously represent a persistent and universal barrier to the usage of formal LTC.

Disparities which were observed between rural and urban settlements are not surprising, as they are observed in other countries as well (15, 26, 29, 31-33, 35). Financial constraints most likely enhance lower availability of services in rural areas and higher probability of having unmet needs (35). Informal care is related to the lack of financial resources, while the usage of formal services is often related to the financial status of care recipients and their families (34).

Even though financial coverage by insurance reduces financial barriers to LTC services, organisational and geographic barriers will probably persist, similarly as suggested by previous research (15), unless they are specifically addressed by policy makers.

We are less than satisfied with the performance of our appraisal questionnaire, even though all five dimensions of access were addressed explicitly. We acknowledge the lower percentage of explained variability. Quite likely, affordability is an issue that is more important for social care, whereas availability and accessibility are issues that are more important for health segment of the LTC services in Slovenia. This assumption is based on the fact that health care part of long-term care is financed with insurance mechanism, while the social services part of the long-term care requires high out-of-pocket private contributions from users and their families.

5 CONCLUSION

As our findings show affordability as the least favourable aspect of access, we advocate for reconsidering the co-payment policy for social home care in such a way that would consider financial situation of users and their families.

Apart from general evaluations of long-term services, there is need for additional exploration of this field in Slovenia. Little is known about respite care or other services designed for informal carers in Slovenia, regardless of their beneficial effects on informal carers of LTC recipients (14, 17), and we encourage in-depth evaluations of services that are available in Slovenia. There is very little known about different experiences in accessing services of male and female family carers (27) and more research is needed to better understand their caring experiences. There is persistent encouragement for co-ordination and integration of LTC services (20, 22), as integrated services guarantee better care to end users and their informal carers.

CONFLICTS OF INTEREST

The authors declare that no conflicts of interest exist.

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ETHICAL APPROVAL

Informed consent to participate principle was applied.

REFERENCES

1. Penchansky R, Thomas JW. The concept of access: definition and relationship to consumer satisfaction. *Med Care*.1981;19:127-40.
2. Thomas JW, Penchansky R. Relating satisfaction with access to utilization of services. *Med Care*. 1984;22:553-68.
3. Anderson R, editor. Quality of life in Europe: impacts of the crisis. Luxembourg: Publications Office of the European Union, 2012.
4. Colombo F, Ana LN, Jérôme M, Frits T. OECD health policy studies. Help wanted? Providing and paying for long-term care. Paris: OECD Publishing, 2011.
5. Gennet N, Boerma W, Kroneman M, Hutchinson A, Saltman R. Home care across Europe: current structure and future challenges. Copenhagen: The European Observatory on Health Systems and Policies Supports, 2012.
6. Nagode M, Zver E, Marn S, Jacovič A, Dominkuš D. Dolgotrajna oskrba - uporaba mednarodne definicije v Sloveniji. Ljubljana: UMAR, 2014.
7. European Commission. Adequate social protection for long-term care needs in an ageing society. Accessed June 18th, 2014 at: http://ec.europa.eu/health/ageing/docs/ev_20140618_co04_en.pdf.
8. Mali J. Social work in the development of institutional care for older people in Slovenia. *Eur J Soc Work*. 2010;13:545-59.
9. Hlebec V, Nagode M, Filipovič Hrast M. Kakovost socialne oskrbe na domu: vrednotenje, podatki in priporočila. Ljubljana: Založba FDV, 2014.
10. Lebar L, Kovač N, Nagode M. IRSSV. Izvajanje pomoči na domu - analiza stanja v letu 2014. Accessed June 30th, 2015 at: http://www.irssv.si/upload2/pnd/IRSSV%20izvajanje%20pomoci%20na%20domu%20-%20analiza%20stanja%20v%20letu2014_koncnocno.pdf.
11. Hlebec V. Contextual factors of home care utilization in Slovenia. *Zdr Varst*. 2012; 51:120-7. doi: 10.2478/v10152-012-0014-z.
12. Hlebec V. Individual and contextual determinants of social homecare usage in Slovenia. *Zdr Varst*. 2014;53:311-7. doi: 10.2478/sjph-2014-0034.
13. Hare R, Rogers H, Lester H, McManus RJ, Mant J. What do stroke patients and their carers want from community services? *Fam Pract*. 2006;23:131-6. doi: 10.1093/fampra/cmi098.
14. Jeon Y-H, Brodaty H, Chesterson J. Respite care for caregivers and people with severe mental illness: literature review. *J Adv Nurs*. 2005;49:297-306. doi: 10.1111/j.1365-2648.2004.03287.x.
15. Niefeld MR, Kasper JD. Access to ambulatory medical and long-term care services among elderly medicare and medicaid beneficiaries: organizational, financial, and geographic barriers. *Med Care Res Rev*. 2005;62:300-19. doi: 10.1177/1077558705275418.
16. Arksey H, Glendinning C. Choice in the context of informal care-giving. *Health Soc Care Community*. 2007;15:16575. doi: 10.1111/j.1365-2524.2006.00671.x.
17. Ng GT. Support for family caregivers: what do service providers say about accessibility, availability and affordability of services? *Health Soc Care Community*. 2009;17:590-8. doi: 10.1111/j.1365-2524.2009.00858.x.
18. Newbould J, Burt J, Bower P, Blakeman T, Kennedy A, Rogers A, et al. Experiences of care planning in England: interviews with patients with long term conditions. *BMC Fam Pract*. 2012;13:71. doi: 10.1186/1471-2296-13-71.
19. Joseph GM, Skinner MW, Yantzi NM. The weather-stains of care: Interpreting the meaning of bad weather for front-line health care workers in rural long-term care. *Soc Sci Med*. 2013;91:194-201. doi: 10.1016/j.socscimed.2012.08.009.

20. Close H, Hancock H, Mason JM, Murphy JJ, Fuat A, de Belder M, et al. "It's somebody else's responsibility"- perceptions of general practitioners, heart failure nurses, care home staff, and residents towards heart failure diagnosis and management for older people in long-term care: a qualitative interview study. *BMC Geriatr.* 2013;13:69. doi: 10.1186/1471-2318-13-69.
21. Chou Y-C, Kröger T, Pu C. Models of long-term care use among older people with disabilities in Taiwan: institutional care, community care, live-in migrant care and family care. *Eur J Ageing.* 2014;12:95-104. doi: 10.1007/s10433-014-0322-z.
22. Browne S, Macdonald S, May CR, Macleod U, Mair FS. Patient, carer and professional perspectives on barriers and facilitators to quality care in advanced heart failure. *PLoS One.* 2014;9:e93288. doi: 10.1371/journal.pone.0093288.
23. Greenwood N, Habibi R, Smith R, Manthorpe J. Barriers to access and minority ethnic carers' satisfaction with social care services in the community: a systematic review of qualitative and quantitative literature. *Health Soc Care Community.* 2015;23:64-78. doi: 10.1111/hsc.12116.
24. Singh P, Hussain R, Khan A, Irwin L, Foskey R. Dementia care: intersecting informal family care and formal care systems. *J Aging Res.* 2014;e486521. doi: 10.1155/2014/486521.
25. Greenwood N, Holley J, Ellmers T, Mein G, Cloud G. Qualitative focus group study investigating experiences of accessing and engaging with social care services: perspectives of carers from diverse ethnic groups caring for stroke survivors. *BMJ Open.* 2016;6:e009498. doi: 10.1136/bmjopen-2015-009498.
26. Greenwood N, Smith R. Barriers and facilitators for male carers in accessing formal and informal support: a systematic review. *Maturitas.* 2015;82:162-9. doi: 10.1016/j.maturitas.2015.07.013.
27. Suurmond J, Rosenmöller D, el Mesbahi H, Lamkaddem M, Essink-Bot M-L. Barriers in access to home care services among ethnic minority and Dutch elderly - a qualitative study. *Int J Nurs Stud.* 2016;54:23-35. doi: 10.1016/j.ijnurstu.2015.02.014.
28. Merrell J, Kinsella F, Murphy F, Philpin S, Ali A. Accessibility and equity of health and social care services: exploring the views and experiences of Bangladeshi carers in South Wales, UK. *Health Soc Care Community.* 2006;14:197-205. doi: 10.1111/j.1365-2524.2006.00610.x.
29. Innes A, Blackstock K, Mason A, Smith A, Cox S. Dementia care provision in rural Scotland: service users' and carers' experiences. *Health Soc Care Community.* 2005;13:354-65. doi: 10.1111/j.1365-2524.2005.00569.x.
30. Drainoni M-L, Lee-Hood E, Tobias C, Bachman SS, Andrew J, Maisels L. Cross-disability experiences of barriers to health-care access consumer perspectives. *J Disabil Policy Stud.* 2006;17:101-15.
31. Hong S-I. Understanding patterns of service utilization among informal caregivers of community older adults. *Gerontologist.* 2010;50:87-99. doi: 10.1093/geront/gnp105.
32. Douthit N, Kiv S, Dwolatzky T, Biswas S. Exposing some important barriers to health care access in the rural USA. *Public Health.* 2015;611-20. doi: 10.1016/j.puhe.2015.04.001.
33. Phillipson L, Jones SC, Magee C. A review of the factors associated with the non-use of respite services by carers of people with dementia: implications for policy and practice. *Health Soc Care Community.* 2014;22:1-12. doi: 10.1111/hsc.12036.
34. García-Gómez P, Hernández-Quevedo C, Jiménez-Rubio D, Oliva-Moreno J. Inequity in long-term care use and unmet need: two sides of the same coin. *J Health Econ.* 2015;39:147-58. doi: 10.1016/j.jhealeco.2014.11.004.
35. Hlebec V, Srakar A, Majcen. Determinants of unmet needs among Slovenian old population. *Zdr Varst.* 2016;55:78-85. doi: 10.1515/sjph-2016-0011.