

Omastehooldajate elukvaliteedi ja heaoluhinnangu kaardistamine "Rohkem Sa hoolid Eestis, Lätis, Soomes" MYCELF – More You Care in Estonia, Latvia, Finland Alūksne district, LATVIA

30 people answered the questionnaire. However, not all respondents answered all of the questions.

Main information

- 1) 11 (37%) people were in full-time employment, 5 (17%) in part-time employment, 6 (20%) retired/pensioner and 8 people (26%) were unemployed.
- 2) 1 (3 %) person cared for the spouse, 5 (17 %) cared for their or spouse's elders, 17 (56%) cared for their or spouse's child, 5 (17%) cared for other relative and 2 (7 %) people cared for someone else (friend, neighbour). 1 respondent cared for two children simultaneously.
- 3) 10 (32%) care recipients were 4 17 years old; 16 (52%) were between 18 and 61 years of age (of working age), and 5 (16%) were aged 70 or more. Youngest cared for person was 4 years old and oldest 90 years old.
- 4) With regard to the care needs of care recipients (as described by respondents), they can be divided into 2 groups depending on the required level of care: 50% of care recipients require care and supervision for 24/7, while other 50% need some assistance with activities of daily living (for example, accompanying while going out, help with planning and structuring of the day, assistance with transport, self care and/or communication, supervision of medications etc.).
- 5) 26 people (87%) claimed that they are the guardians of their cared for person.
- 6) Respondents assist their cared for persons daily with housekeeping (26), personal assistance (25), emotional assistance (25), shopping and transport (18), medical assistance (16), repair, construction and gardening works (16), using technical aids (9), providing financial aid (9) and managing paperwork (3).
- 7) 1 (4%) respondent have been caring for less than a year, 9 (30%) respondents for 1-5 years, 3 (10%) for 6-10 years and 17 (56%) for more than 10 years.
- 8) 28 (93%) respondents live in the same household with their care recipient and 2 (7%) live in the same city or municipality.

- 9) 12 (40%) respondents reported that care responsibilities have affected their or their family's economic situation negatively (evaluating the extent of impact as "greatly" (4 respondents) or "somewhat" (8 respondents)), while 18 (60%) carers claimed that there hasn't been any negative impact on their finances.
- 10) 9 (30%) carers receive great support from their family members or friends to fulfil their care responsibilities and 13 (43%) respondents receive some support; however, 8 (27%) respondents have no support or assistance from friends/family.
- 11) 10 (33%) people feel obliged to provide care for their family member, but 20 (67%) do it willingly.
- 12) In a situation, where the cared for person needs constant and intensive care, 15 (50%) people are ready leave employment; in addition, 12 (40%) respondents would be ready to leave employment depending on the circumstances and 3 (10%) carers wouldn't want to leave their employment in any situation.
- 13) Circumstances in which the respondents feel ready to leave or have left from work: mainly due to exacerbation of illness/health issues, crisis situations, doctor or other specialist visits, treatment in hospital.

Work life

- 15) 10 respondents were working in public sector, 6 in private sector.
- 16) 11 (36%) people are regular employees, 2 (7%) are departmental managers and 3 (10%) are members of administration.
- 17) 28 (93%) respondents have talked about their care responsibilities towards their family member or close one at their workplace, but 2 (7%) respondent haven't.
- 18) 14 (47%) respondents have slightly or not at all received support and understanding at their workplace in relation of their care responsibilities.
- 19) In relations of different practices at workplaces when dealing with absence of employee with care responsibilities due to the cared for person's doctor's visit, unexpected illness etc., the most dominant is the arrangement with administration (8), part-time work (8) and flexible working hours (6); also leaving some Annual vacation days for later usage (5), teleworking (4), working based on the schedule or shifts (3), unpaid vacation (3) and additional paid vacation day per month for parents with disabled child (3).
- 20) The health and welfare of employees is an interest for employers at 12 (40%) workplaces; 4 (13%) respondents have experienced negative attitude towards it.
- 21) and 22) Based on the health status or other circumstances, 15 (50%) respondents have thought about early retirement; for 10 of them it is greatly (and for 2 slightly) related to their care responsibilities.

- 23) 12 (40%) respondents have seldom felt that they want to end caring and focus on their work and 18 (60%) people have not felt it.
- 24) The most common situations experienced in the work place due to the care responsibilities, are: having to work part-time (7), giving up new challenges or career opportunities (7) and giving up on work trips/training courses (6). Not being able to take part in work-related events (3), giving up overtime work (3) and difficulties with keeping work agreements (1) are present to a lesser extent.
- 25) Taking in account 2 previous questions, 6 respondents have felt shame; 6 have felt offended and 6 guilty (to a greater or lesser degree) in relation to situations occurring in work life.

Personal health and coping ability

- 26) 2 respondents evaluated their health status as very good in comparison with their peers, 8 people marked it as good, 17 people as average and 3 as poor.
- 27) 29 people have more or less experienced stress in relation to the care responsibilities. 14 respondents are under frequent stress.
- 28) The current life moment with the cared for person is easy for 1 (3%) person, bearable for 13 (43%) respondents, however, 15 (50%) respondents marked it as difficult and 1 (3%)— as extremely difficult.
- 29) 6 people felt like they have enough time for themselves beside the care responsibilities. It is stressful on one way or another for 26 people to cope with care responsibilities in addition to taking care of their family and fulfilling their work responsibilities. 14 respondents feel irritated at times when being with cared for person. 5 respondents feel that the cared for person is impacting negatively their relationships with other family members and friends. 10 people do not feel tired in the company of the cared for person. 18 respondents feel that their health has suffered due to the care load. 20 respondents feel that the care load limits their freedom of choice and 17 respondents feel that their socializing is limited due to the care load. 16 respondents feel frequently that they have lost control over their life due to the illness of their family member or close one. 20 respondents feel insecure towards their cared for person and 22 respondents feel that they have to improve their caring skills.
- 30) The most important item, when taking in account the carer's coping ability, is the support of family very important for 25 people and important for 5. "One day at a time" mentality (25), work (22), friends (22), faith and spiritual assistance (20), hobbies (17), information and experience groups available through NGOs (13) and counselling (12) are also marked as important or very important.

Social services

- 31) Satisfaction with services offered to the cared for person.
 - Homecare service provided by local municipality is not used by 14 respondents; 11
 people have not heard about the service and 5 people are satisfied with the service.
 - Support person's service is not used by 16 respondents and 12 people have not heard about the service; 2 people are satisfied with the service.
 - Personal assistant's service is not used by 14 respondents and 8 respondents haven't heard about it; 5 people are very satisfied and 3 are satisfied.
 - Daycare service is not used by 16 respondents, 6 people have not heard about the service, 4 people are very satisfied and 4 respondents are satisfied.
 - Physical therapy is not used by 15 respondents, 11 people have not heard about the service, 1 person is very satisfied, 2 people are satisfied and 1 person is not satisfied.
 - Respite care is not used by 16 respondents and 14 people have not heard about the service.
 - Other privately paid services are not used by 15 respondents, 4 people have not heard about these services, 4 people are satisfied and 1 person is not satisfied.
 - NGO services are not used by 16 respondents, 7 people have not heard about these services, 1 person is very satisfied, 5 are satisfied and 1 respondent isn't satisfied.
 - Social transport service is not used by 17 respondents, 9 people have not heard about the service, 1 respondent is very satisfied, 1 is satisfied and 2 are not satisfied.
 - Educational services are not used by 12 respondents, 5 people have not heard about the services, 4 people are very satisfied, 6 are satisfied and 3 people are not satisfied.
 - Medical services are not used by 3 people, 3 people have not heard about these services, 2 people are very satisfied, 19 people are satisfied and 3 people are not satisfied.
 - Rehabilitation services are not used by 9 respondents, 10 people have not heard about the services, 1 person is very satisfied, 8 people are satisfied and 2 people are not satisfied.
 - Other services are not mentioned.

Health

32) 1 (3%) respondent has evaluated his/her health status as very good, 26 (87%) people marked their health as satisfactory, and 4 people marked their health as poor.

- 33) 4 (13%) respondents evaluate their health status as being better compared to the last year, for 21 (70%) people the health status is similar, and 5 (17%) people evaluated their health as worse than last year.
- 34) 9 (30%) respondents have permanent health issues or disabilities that limit their daily life, like back pain, diabetes, epilepsy, headaches, high blood pressure, gastritis, high cholesterol, poor vision, neurological disorders, varicose veins and stress.
- 35) 13 (43%) respondents use medications daily. None of the respondents clarified how many medications they are taking.
- 36) 10 (33%) respondents are concerned about their health specifically about back pain, psychological balance, sleep disturbance, migraines, stress, neurological disorders and fear from traumas.
- 37) How the carers evaluate their mood?
- 19 respondents are happy with their life, 23 people have given up on some activity or hobby, 1 person thinks his/her life is meaningless, 9 people often feel sad, 19 people are usually in a good mood, 12 people fear that something bad may happen to them, 21 people are satisfied with their life, 13 people often feel helplessness, 21 people think that now is a good time to live, 2 people feel that they are not fit for anything, 23 people think they are full of eagerness, 4 people find their situation hopeless, 13 people think that other people are doing better than them.
- 38) When asked about what type of change do carers wish for in their life, the answers were as follows: finding a well-paid job, getting the assistant or respite care service, early retirement, being in good health and not losing hope, doing exercise and self-educating, feeling safe about future, travelling and going to theatre/concert, integrating cared for person in society and finding a suitable work for him/her, improvement of care recipient's health.

Background information

- 39) Questionnaire was answered by 26 (87%) women and 4 (13%)men.
- 40) The carers were between the ages of 36 and 75. 26 respondents were of working-age (under 65) and 4 had reached the retirement age. Average age of respondents was 48 years.
- 41) Level of education Lower secondary education (7), Secondary education (3), Vocational secondary education (10), Vocational education (2), Bachelor's degree (8).
- 42) 10 respondents described a conflict situation between themselves and cared for people. These were specific cases with specific solutions, but common features were communication skills, firmness and patience. 2 of them mentioned that the conflict situations are ongoing and haven't been solved. Another 9 people wrote that there are no conflict situations between them and the care recipients.