Quality of Life of Caregivers of Children with Cerebral Palsy in Armenia

A cross-sectional study

Master of Public Health Integrating Experience Project

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by

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ABBREVIATIONS

Center	"Ararat" Mothers and Child's Health Center
CFCS	Communication Function Classification System
CP	Cerebral Palsy
CSD	The Center for Epidemiologic Studies Depression Scale
FCG	Family Caregivers
FCS	Family Centered Services
GMFCS	Gross Motor Function Classification System
IRB	Institutional Review Board
MACS	Manual Ability Classification System
NIH	National Institute of Health, RA
PCG	Primary Caregiver
QoL	Quality of Life
RA	Republic of Armenia
SCL-90	Anxiety Symptom Checklist 90
SD	Standard Deviation
SES	Socio Economic Status
USA	United States of America
VIF	Variance Inflation Factors
BP	Bodily Pain

Abstract

Introduction: Family caregivers (FCGs) of children with cerebral palsy (CP) are under higher risks of developing physical and mental health problems, and they encounter greater challenges that may negatively impact their overall quality of life. The enhanced demands of caregiving may affect FCGs dignity and well-being as well. The variety of manifestations of CP may differently impact the health of FCGs: the situation of FCGs of more dependent children may differ from those of more independent ones. The problems of children with CP and their caregivers have not been investigated in Armenia. Thus, the aim of this study was to investigate the associations between the levels of CP severity (i.e., dependence) in children and the pain syndromes, as well as mental health outcomes of their FCGs in Armenia.

Methods: Two hundred CP children and their FCGs were included in this cross-sectional study. Child characteristics were retrieved from medical records at the tertiary care center delivering rehabilitation treatment to children with chronic diseases. Gross Motor Function Classification System (GMFCS) served to classify children as more independent (Levels I and II) and more dependent (Levels III-V). Two hundred FCGs completed phone call interviews (100 FCGs of more independent children and 100 FCGs of more dependent ones). Armenian versions of SF-36, Center for Epidemiologic Studies Depression scale, Anxiety Symptom Checklist 90, and 18-item dignity questionnaires were utilized to measure the pain, quality of life, depression, anxiety, and dignity levels of FCGs. An additional questionnaire was also used to measure the socio-demographic characteristics of FCGs. Multivariable linear regression analysis was conducted with adjusting for identified confounders to explore the association between the health and well-being outcomes of FCGs and the severity of limitations of CP children.

Results: To reach the pre-defined sample size, 999 medical records were investigated and 221 eligible FCGs were contacted (9.5% refusal rate). The groups were similar in most of socio-demographic characteristics. FCGs of more dependent children reported to perceive

higher negative influence of caregiving, feeding difficulties and caregiving demands. There was no association between bodily pain, depression and anxiety of FCGs and the severity of limitations of CP children. FCGs of more dependent children reported significantly lower dignity levels if compared with those of more independent children.

Conclusions: The dignity levels of FCGs was first time analyzed in quantitative study. The health and well-being of FCGs of CP children was first time investigated in Armenia. Strengths and weaknesses related to study design and methodology are highlighted. The needs for interventions and policy setting, as well as the directions for further investigations are described.

"Change is the end result of all true learning"
Leonardo F. Buscaglia

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"The purpose of a doctor or any human in general, should not be to simply delay the death of the patient, but to increase the person's quality of life"

Patch Adams

1 Introduction

The birth of a child with disability can be a sudden and unpredictable event for families. Caring for a child with disability such as the cerebral palsy (CP) requires significant resources and efforts. CP is not a specific nosology with a unique etiology or pathogenesis.[1] It is a group of non-hereditary movement disorders with different etiology and pathogenetic pathways, attributed to discrete and non-progressive damages of the fetal or infant brain.[1–3] It may further be accompanied by mental disorders and seizure syndromes.[2,4–6] Despite the observed decline of prevalence for several types of CP in Europe based on analysis of pooled data from 20 European population-based CP registries (from 1980 to early 2000s),[7,8] the overall prevalence of CP has been relatively stable in the last years (after 1985), and it remains the most common diagnosis of children with disability. [9–12] For example, it is the fourth leading cause of paralysis in the USA (8.3%) amongst 5.4 million overall cases.[13]Currently, the worldwide prevalence of CP is around 2 per 1000 live births.[12] While population based studies indicate no change in the prevalence over the last decade,[9,14,15] it has been shown to fluctuate between 2-4 per 1000 live births by countries and races.[9,14–16]

Disability provoked by CP may change over time. However, it is a permanent disorder, sometimes hard to manage, and requires enormous efforts and resources (e.g., financial and time).[17–20] Even in developed countries social services and supportive policies in the form of appropriate infrastructure and environmental settings are not well established to facilitate mobility and social participation of children with functional limitations, such as CP.[21–23] The responsibility of delivering essential care for CP children, therefore, predominantly lies on the families.[24] This adds to the financial and social burden of the families[25] and may negatively affect caregivers' health[26] and quality of life.[27,28]

Defining the process of how caregiving affects CP caregivers' health is a challenging task. There are numerous pathways and mechanisms of interactions between the health aspects of caregivers and children.[17,29,30] Zhu et al., (2006) have outlined the model of the caregiving process in the pediatric population.[30] The conceptual framework provided by the authors (see Figure 1) describes the main pathways by which the caregiving process may influence the physical and psychological health of family caregivers (FCGs). While it might not be practical to investigate the wide range of determinants, including factors at different levels, such as child, family and community characteristics, which directly or indirectly influence the health of FCGs, research confirms that FCGs of children with chronic disabilities are under higher risks to develop health problems than those of regular children. For example, a large population-based study in Canada compared health outcomes of FCGs of children with chronic disorders and those of regular children demonstrates that FCGs with children having chronic health problems have over two times higher odds of reporting chronic health and well-being concerns.[31]Several studies have further explored this relationship for FCGs of children with CP, specifically, investigating levels of stress[32,33], quality of life (QoL),[34,35] depression,[36] anxiety, and physical health,[37] including different pain syndromes.[38] Higher levels of depression[39,40] and lower quality of life[34,35] have been reported among FCGs of CP children as compared to FCGs of typically developing children.

2 Literature review

CP overview

Appendix A illustrates the most commonly used systems for classification of CP types and subtypes. Although these classifications are crucial to determine the etiology of CP, the functional diagnosis of this disability is equally important in developing the most efficient strategies for CP management.[41,42] The Gross Motor Function Classification System (GMFCS) is the most wildly used tool for functional classification of the severity of CP.[42,43]

The severity of CP classified by GMFCS has 5 levels. Briefly, Level I children have the least movement limitations and can perform all movements that are typical for their age, whereas Level 5 children are practically unable to perform movements without assistance even with supportive devices (e.g., wheelchair). GMFCS provides stable data over time after the age of 2 years.[44] The other widely used classification tools are the Manual Ability Classification System (MACS)[45] and the Communication Function Classification System (CFCS).[46] Both of these tools also distinguish 5 levels of severity, where Level I means the least limitation of function and Level V – the most severe. Detailed description of these classification methods are available elsewhere.[43,45–49] While the life expectancy of CP children is associated with the severity of limitations (e.g., gross motor function, oromotor function and mental function levels), it has increased in the previous years, partly due to the uptake of more effective interventions.[50–53]

CP caregivers' health

Having a child with functional limitations (i.e., CP) is a challenge for each family, despite the social and economic status, racial or religious affiliation.[54] The role of FCGs, on the other hand, is very important in the lives of children with disability. The family-centered services (FCSs), developed and widely disseminated in the last decade, explicitly acknowledge the importance of FCGs in CP child's life.[55,56] FCGs (these may include parents and grandparents, or other household members, who take care, assist and accompany a CP child in everyday life) have a crucial role in daily lives and activities of CP children, as well as in the decision-making processes regarding their healthcare and development of appropriate intervention strategies. While the primary aim of FCSs is to improve the health and the quality of life of children with CP, there are concerns that this focus on children may overlook the possible health risks of FCGs as a result of enhanced burden associated with the caregiving processes.[34,55] On the other hand, health problems affecting FCGs may have further downstream effects on a CP child. For example, a study has shown that FCGs with

less or no symptoms of depression perform more effectively as caregivers when compared to those with more depressive symptoms.[39] Moreover, the adolescents whose FCGs have mental health problems, particularly depression and anxiety, have higher odds to develop mental health problems themselves.[57] Thus, the health of FCGs is not only the outcome of the caregiving process, but also an important factor affecting the child's health.

The health problems of FCGs of children with CP have multiple determinants and long-term impacts. For example, a population based study by Brehaut et al., (2011) have studied the changes of the caregivers' health over the ten-year period among the caregivers of children with health problems, including CP.[58] The study found significant association between the caregivers' general health status and their marital status, income levels, child's age, gender and the number of children. For instance, married caregivers reported better general health as compared to the non-married caregivers. Having only one child or caregiving of boys was also associated with worse general health. The study further indicated the permanence of the health problems among caregivers and the significant role of the severity of the child's health problems in the caregivers' health.[58] Similarly, the study by Murphy et al., (2011)[59] used a convenience sample of 51 FCGs in tertiary care center in the USA. The primary outcome variable was parents' QoL measured with the SF-36 short form. Authors identified statistically significant correlation between QoL of parents and the level of severity of the child's CP symptoms measured with the Gross Motor Function Classification System[60] (GMFCS). Lower levels of QoL were also found to be associated with positive seizure syndromes of the child[28] and the low levels of families' socio economic status (SES).[18] Sawyer et al.,[61] further found that caregivers of CP children have additional time demands. For example, it was found that caring for a child with CP takes over 6 and 8 hours per day for mothers during workdays and weekends, respectively.[61]

Several studies have investigated the pain syndromes amongst FCGs of CP children. Czuprina et al., (2014) have examined back pain amongst 179 mothers caregiving 3-18 years

old children with CP.[62] Authors concluded that caregiving of a CP child leads to back pain of mothers, and that pain is mainly related to child's characteristics (i.e., functional level, the age, and the weight of CP child). The study by Kavlak et al., (2015) amongst 100 mothers of CP children in Turkey found significant association between pain (in lower back, neck and upper limb regions), anxiety and QoL of mothers and the severity of CP of their children (measured with GMFCS).[63] More recently, Terzi et al., (2016)[64] found that mothers of CP children have higher levels of depression and musculoskeletal pain when compared with those with healthy children. Authors also showed that the CP severity and the maternal depression level were independent risk factors for pain in mothers.

In a similar vein, Byrne et al., (2009)[34] have examined QoL (using SF-36) of 161 FCGs of children with CP in Ireland. The study found significant association between bodily pain among FCGs and the level of independence of children: FCGs of more dependent children (defined as those with III-V levels of GMFCS[34]) had significantly higher scores of bodily pain as compared to FCGs with more independent children (defined as those with I-II levels of GMFCS). The lack of control for possible confounders in this association, such as background characteristics of caregivers (i.e., the age, chronic diseases of FCGs), having multiple respondents from one household, as well as the utilized survey method (mail survey) may bias the findings.[34] However, this study provides important exploratory data on the health issues of FCGs highlighting the need for further investigations.

Challenges associated with delivery of care, the complexity of decision making and organization of the best rehabilitation and treatment programs, accompanied with their own unmet expectations and requirements associated with demands of caregiving a child with permanent disability such is CP may have influence on FCGs dignity. Clark (2010) defines dignity as a subjective and multi-dimensional feeling. It is commonly referred to as a fundamental human right, and it is perceived as an experience of "feeling and/or being treated and regarded as important and valuable in relation to others".[65] The dignity in the healthcare

context was examined in several studies in Armenia.[66–68] For example, Mkhitaryan et al (2015) examined dignity of mother caregivers of children with type 1 diabetes and found no difference between them and mothers of healthy children .[68] Several qualitative studies, however, suggest that FCGs, as well as their children with CP may have affected dignity levels.[69–72] This may be associated with the higher caregiving demands for FCGs of children with CP, as well as the severity of CP limitations. Evidence of the association between the severity of limitations of children with CP and the levels of dignity among FCGs may serve as an important indicator of the metal health and overall wellbeing of FCGs.

Finally, most existing studies investigating the impact of caregiving a CP child mainly focus on mothers as primary caregivers,[73] partly because of the available evidence suggesting a higher burden of caregiving among this group.[74] However, to our knowledge, there is no direct evidence showing that mothers are at higher risk of developing health and well-being issues as compared to other caregivers in the family (e.g., fathers).[73,75,76]

Situation in Armenia

In her country-level analytical report, "Children and Disability in Armenia" (2002), Magloutchiants identified over 8000 children in Armenia registered with disability, the majority of whom live in poor families.[77] This suggests 30% increase in the number of children when compared to the official data of 1991 (i.e., 5000 children in 0-16y age range).[77] While data on the prevalence of CP in Armenia are not available for the years 2002 to 2014, the state "Health and Health Care" yearbook (2016)[78] indicates over 1750 CP cases among 0-17 year olds in Armenia in 2016. This demonstrates a slight increase in the number of CP children in Armenia as compared to the years of 2014 and 2015 (see Appendix B). However, in relative numbers, these data represent 259.0, 257.6 and 256.5 per 100,000 Armenian population in 0-14-year age group for the years 2014, 2015 and 2016, respectively.[78–80] More detailed description of NIH data on CP prevalence in Armenia is presented in Appendix B.

Apart from the prevalence data provided by National Institute of Health (NIH) of RA, no further research has been conducted on CP, and, specifically, on health and quality of life of caregivers of children with CP in Armenia. In addition, the available NIH data does not include information about the prevalence and distribution of CP types and subtypes in the country. Moreover, according to the NIH 2017 report[80], almost 20% of the first time diagnosed CP cases were in 15-17 year age group (Appendix C). Given that the verification of CP diagnosis is usually done when a child is 1-3 years old, this data may have two possible explanations: lack of early diagnosis or significant delay of the official diagnosis. However, it is well known that early diagnosis is crucial for effective rehabilitation of children. and, despite the severity of CP, there is always a known range of functions that may be enhanced through early interventions.[81–83] Moreover, without formal diagnosis it would be impossible to claim for governmental and other formal support services, as well as to get appropriate treatment and overall care management suggestions. It should, however, also be noted that, although the caregivers of children with chronic diseases, and, specifically, with CP, have greater health risks, there are no comprehensive social programs or policies addressing this issue in Armenia.

3   Study rationale

FCGs of CP children are at a higher risk of developing pain syndromes or other chronic physical and mental health problems. Situation may be worse for FCGs of children with more severe CP. This issue may not only affect FCGs' QoL, but it may also make them unable to provide necessary care and assistance to children.

To our knowledge no research has been conducted so far regarding the caregiving experiences of CP in Armenia. The studies discussed above, which investigated different aspects of FCGs' health, were mainly conducted in countries with upper-middle or high-

income economies. Moreover, the possible differences in quality and volume of governmental and other social support policies and programs, as well as the geographical and socio-cultural differences limits the generalizability of those findings to the Armenian context. To develop tailored interventions in specific populations and communities, detailed understanding of the determinants of CP caregivers' health and well-being is required in each setting, as experiences may differ across countries due to contextual factors, including socio-economic, socio-cultural, political, epidemiological, geographical, ethical and legal.[84]

Further research is, therefore, needed to examine the health and well-being outcomes of FCGs of CP children in Armenia. This study aims to investigate the associations between the levels of CP severity (i.e., dependence) in children and the pain syndromes, as well as mental health outcomes and QoL of their FCGs in Armenia.

4 Methods

A cross-sectional survey was conducted among FCGs of CP children in Armenia to address the study objectives.

Primary objective

- To compare (bodily) pain between FCGs of more independent (GMFCS levels I and II) with FCGs of more dependent CP children (GMFCS levels III-V).

Secondary objectives

- To estimate the prevalence of pain, depression, and anxiety among FCGs of CP children;

- To explore the association between depression among FCGs and the severity of limitations in CP children;

- To explore the association between anxiety among FCGs and the severity of limitations in CP children;

- To explore the association between dignity among FCGs and the severity of limitations in CP children;

- To describe the distribution of movement and communicational limitations among children with CP.

Target population

The target population of this study includes FCGs of children with CP aged 3-17 years living in Armenia and Artsakh.

Study population

The study population has been selected using the following inclusion criteria:

- having a child with CP 13-17 year of age who has undergone (since 2013) or is currently undergoing treatment in "Ararat" Mothers and Child's health center (Center),

- availability of child's medical records to allow assessment of the severity of CP limitations (as measured by GMFCS),

- ability to speak and understand Armenian.

Sample size calculation

To execute the primary objective, FCGs have been grouped by the GMFCS level of their child. Specifically, FCGs of more independent children (GMFCS I and II levels) were assigned to one group, and FCGs of more dependent children (GMFCS III-V levels) were assigned to another. The pain levels of FCGs was measured using the SF-36 questionnaire's pain domain.[85] A similar approach was used in a previous study to detect the difference in mean pain between caregiver groups.[34] The study by Byrne et al. investigated the health status of FCGs of CP children in Ireland and found that the "caregivers of more dependent children had significantly lower mean pain score (indicative of more pain) than the caregivers

of more independent children".[34] The means and the standard deviations from this study[34] were used for sample size calculation.

The sample size was calculated based on the formula for comparing two means:

$$n_1 = \frac{\left(\sigma_1^2 + \frac{\sigma_2^2}{k}\right)(Z_{1-\alpha/2} + Z_{1-\beta})^2}{\Delta^2}$$

$$n_2 = \frac{(k * \sigma_1^2 + \sigma_2^2)(Z_{1-\alpha/2} + Z_{1-\beta})^2}{\Delta^2}$$

Notation:

$$n_1 = sample\ size\ of\ Group\ 1$$

$$n_2 = sample\ size\ of\ Group\ 2$$

$$\sigma_1 = standard\ deviation\ of\ Group\ 1$$

$$\sigma_2 = standard\ deviation\ of\ Group\ 2$$

$$\Delta = difference\ in\ group\ means$$

$$k = ratio = n_2/n_1$$

$$Z_{1-\alpha/2} = two\ sided\ Z\ value$$

$$Z_{1-\beta} = power$$

Based on the study by Byrne et al[34] the means and standard deviations for these two groups of FCGs were as follows: Group 1 mean=52.10; SD=9.8; Group 2 mean=47.77, SD=11.9. Considering equal sample sizes per group (k=1). the sample size with two sided Z value for 95% confidence interval (1.96), and the Z value for 80% power (0.84) will be as follows:

$$n_1 = n_2 = \frac{\left(9.8^2 + \frac{11.9^2}{1}\right)(1.96 + 0.84)^2}{4.33^2} = \frac{1863.176}{18.7489} = 99.37 = \mathbf{100}$$

Thus, to detect the difference in means of body pain (SF-36) between the two groups of FCGs with 95% confidence interval and 80% power, it was required to have 100 FCGs for in each group.

Sampling strategy

Study population was recruited from the 220-beds tertiary care "Ararat" Mothers and Child's health center (Center) that serves around 80 children with CP from all marzes (provinces) of RA and Artsakh each year. The recruitment process started with retrieving and investigating the medical records of all children with CP who attended the center starting from 2013. Records were evaluated in reverse consecution in calendar time (e.g., 2018 then 2017, etc.) to select the participants that potentially met the eligibility criteria. Particularly, the student investigator retrieved information on the severity level of the child, FCG's contact details, and child's age. The age of the child determining the eligibility of the caregiver (3-17 years old) was defined as the age of the child at the time of the interview. In case of multiple attendance of the same child to the Center, the most recent data (both for the FCG contact information and the child characteristics) were used. The data were entered into a journal form (Appendix D). Each FCG was then contacted separately to check the eligibility and to ask for their willingness to participate in the study (see below). This process continued until the planned sample size was achieved.

Data collection

Data collection was conducted by the student investigator and ten other trained interviewers. The volunteers were recruited among friends (3 volunteers), publishing the introduction of the study in Facebook® specific groups, where medical students and young doctors were participating (7 volunteers), the presentation of the project in neurology department of Yerevan State Medical University (5 volunteers). After completing the trainings two volunteers refused to start the interviews due to time restrictions, another one, due to family tragedy, and the last two, based on student investigator decision (lack of trust and willingness to undergo the ethics training).

Training process

The training process included general introduction of the research, it's goals and the details about the interview process and procedure. Next the files containing prepared guideline of call and interview with the empty questionnaire was sent to the volunteers. The link of AUA training course on research ethics (http://chsrd.aua.am/irb/arm/testing/begin.php) was attached to the email. Student investigator highly encouraged all the volunteers to undergo the training and provide the certificates. The Q&A session (via phone, messengers, etc.) followed. Finally, the skype or face to face meeting were organized to discuss all the points. The last stage of training was the interview either via role play or real interview. Two interviewers were recruited to conduct interviews with participants from Artsakh. Special strategies to prevent mistakes and assure the confidentiality were utilized. First, after the interview (successful or refusal), all volunteers deleted the names, and the phone numbers of participants. Second, at the end of the day, each volunteer grouped the done interviews and sent to the student investigator. The report about ongoing interviews and wrong numbers was attached. After first 1-3 interviews of newly recruited volunteers, data entry was conducted and Q&A session followed to verify that everything is clear. Third, if it was not possible to contact with participant (number was not available or did not take the phone) in three calls during first day, 1-2 calls during the next day and 1-2 calls after 2-3 days, the status of participant was defined "not available" and the status was reported to student investigator. Fourth, each week the student investigator reviewed the medical records and journals of participants in the Center to verify the contact numbers or in case of multiple admissions, to find alternative contact information. Updated contact information was sent to the same interviewers for second try. In case of repeating "not available" status, another interviewer was asked to try once again with both numbers. Then the final try was conducted by student investigator. In case if after these procedures it was impossible to reach the participant, the status was defined "Not available".

Additionally, all interviewers underwent the AUA training course on research ethics, "Human participant protections", and successfully passed the test.

Survey procedures

Interviewers contacted the primary FCGs listed in the child medical records to inform them about the ongoing study, provide the oral consent (Appendix E) and ask for participation. In case of a positive answer, the student investigator conducted a phone interview with the FCG either directly at the time of the first call or at the date and time convenient for the FCG (the questionnaire is presented in Appendix F). Taking into account that the interview might have been interrupted due to time constraints and/or CP child or family needs, the participant was given an option to do the interview in parts during few consecutive phone calls. After the interview, the participant was asked for a permission to extract additional data from the child's medical records (Appendix G). In case of a negative answer for participation or for medical records investigation, the reason for refusal was asked. If the reason for refusal was not associated with the study itself (e.g. time constraints, language barriers), a possibility to contact and conduct the same interview with another FCG of the CP child was asked.

If multiple FCGs of the same child were available for an interview, the priority for participation was given in the following order: (1) mother, (2) father, (3) grandmother, (4) grandfather, (5) sister, (6) brother and other relatives who were considered to be FCGs of the child. For this study, only one FCG per child was considered.

Study instruments

The SF-36 short form QoL questionnaire[86] was used in this study, which has been employed in previous studies[34,87–91] as the outcome measurement tool for caregivers of CP children. A validated Armenian version of SF-36 Armenian was used for the study.[85] FCGs' depression level was measured using the Center for Epidemiologic Studies Depression Scale

(CES-D Scale)[92], the levels of anxiety – using the Anxiety Symptom Checklist 90 (SCL-90),[93] and FCGs dignity levels – by the 18-item Human Dignity Scale.[94]

Background information on FCGs was collected through a demographic questionnaire (Appendix F). This questionnaire has been adapted from a similar study investigating the levels of depression, anxiety and dignity in mothers of children with type 1 diabetes in Armenia and further tailored to current study aims.[68] The strategies of scaling social support and socio-economic status (SES) levels are described elsewhere.[68] In the final scale, 3 SES levels were defined (high, middle, and low). FCGs' social support index could have values between 0 and 28, where 0 represents the lowest social support level and 28 – the highest. English and Armenian versions of the questionnaire are presented in Appendices F1 and F2, respectively. The questionnaires were validated via two pilot phone interviews with randomly selected FCGs. This informed appropriate adaptations to the format of the quesionnaire to make it easier to use for interviewers. The pilot interviews did not indicate the need for major changes in the content of questionnaire.

CP children data entry process

Data on children, including the severity of CP, presence or absence of seizures, and demographic characteristics were collected by the student investigator from the child's medical records, after receiving permission from FCGs. Data on the Gross Motor Function Classification System (GMFCS)[43] was used to classify the CP children based on the severity of CP limitations. The Manual Ability Classification System (MACS)[48] and the Communication Function Classification System (CFCS) levels were also used as tools to classify children's functional limitations.[46,95] More detailed information on child's characteristics collected from the medical records is presented in Appendix G.

Study variables

The main dependent variables of this study were pain level, general health, psychological health, overall quality of life, depression, anxiety, and levels of dignity of FCGs. The severity of limitations of CP classified by the GMFCS levels was defined as study independent variable. The list of control variables included FCGs socio-demographic characteristics (including FCG-reported family SES), chronic disease status, the type of CP (according both the ICD classification and the number of limbs involved), child's CFCS and MACS levels, presence of seizure syndromes, age and sex. More detailed information about study variables is available in Appendix H.

5 Data analysis

The student investigator entered the data into SPSS 21.0 in parallel to the data collection, as well as conducted data cleaning through range checking and checking for missing values. Data were analyzed using SPSS 21.0[96] and STATA version 12.[97]

Study population was described using counts and percentages for categorical data and means and standard deviations for continuous data. Differences in characteristics between the two FCG groups were explored using either a standard 2-tailed t-test (for continuous variables) or a χ^2 test (for dichotomous variables). Differences in the outcomes (dependent variables) between Group 1 and Group 2 FCGs were then examined using either a standard 2-tailed t-test (for continuous variables) or a χ^2 test (for dichotomous variables). Further, bivariate regression analyses with the bodily pain as the main dependent variable and factors of interest and potential confounders as independent variables were conducted. Finally, all variables identified as statistically significant in the bivariate analyses (p<0.05) were included in the multivariable regression analyses. Same approach was used for the rest of the outcome variables. Linear regression was utilized in the models with continuous variables (i.e., bodily pain, depression, anxiety, dignity).

6   Ethical consideration

The oral consent form was delivered to all study participants. In case of successful interview, the consent to retrieve child's characteristics from medical records was requested (Appendix E). The questionnaires were filled electronically. After the end of the interview the names and contact information were deleted in journals and contained only the codes of participants. Thus, starting from data entry stage no any personal identifying information was available to investigators.

The study was approved by the Institutional Review Board (IRB) of the American University of Armenia on March 26, 2018 (Protocol #: AUA-2018-008). Any further changes in protocol was reviewed and approved by IRB.

7 Results

Descriptive statistics

To reach the defined sample size, the student investigator reviewed 999 medical records from the "Ararat" Mothers and Child's Health Center. The pre-defined recruitment strategy (i.e., investigation of medical records for years 2018-2013 in reverse order) allowed for only 190 successful interviews. To reach the estimated sample size, further investigation of records was initiated for years 2012 and 2011. Overall, 221 eligible participants were asked to participate to achieve 200 successful interviews (the refusal rate was 9.5%, see Appendix I), which includes 100 FCGs of more independent children (Group 1) and 100 FCGs of more dependent children (Group 2). The mean duration of interviews was 34.7 (SD: 8.2, Range: 20-64) minutes. The mean number of calls to complete the interviews was 1.5 (SD: 0.8, Range: 1-5).

Children's demographic and health characteristics

The characteristics of the children are described in Table 1. Two hundred CP children (140 males and 60 females) were included in the study with the mean age of 10.1 (SD: 3.6). The groups did not differ by age and gender characteristics. There were statistically significant differences between the two groups regarding the type of CP, severity of limitations of hand and communication functions, mental and behavioral problems (p<0.001). Seventy percent of children in Group 1 had bilateral CP as compared to 96.0% in Group 2. There were no statistically significant differences (p=0.692) of the presence of seizure syndromes among the children between Group 1 (16.0%) and Group 2 (14.0%).

FCGs' socio-demographic and health characteristics

FCGs socio-demographic and health characteristics are summarized in Tables 2 and 3, respectively. The majority of FCGs were mothers (88. 0%).The mean age of FCGs was 38.8 years (SD: 8.8). The majority of the FCGs were married (85.0%), reported not to be

employed (77. 0%), and had professional technical education (10-13 years, 44.5%) or university or higher education (24.0%). On average, FCGs reported to live in households with 2.9 (SD: 1.1) rooms and 5.4 (SD: 2.1) people in households. The average number of children in households was 2.2 (SD: 4.8, Range: 1-8). Only 176 participants (88%) responded to the household income question, most of which (51.0%) reported to have 51-100 thousand AMD and 101-200 thousand AMD (20.0%). The majority of the FCGs reported to receive help with the provision of care to their CP child (59.0%) and were recipients of a family poverty benefit program (67.3%). There were no significant (p<0.05) differences of the above denoted characteristics between the two Groups of FCGs (i.e., FCGs of more independent children and the FCGs of more dependent ones).

FCGs of more dependent children reported statistically significantly (p<0.001) more hours daily spend on caregiving their children than those of more independent children (10.3 versus 6.9). FCGs in Group 2 also reported to have significantly more difficulties with feeding their CP children. Likewise, they reported significantly (p<0.001) higher difficulties to handle caregiving demands, when compared to FCGs in Group 1. More than 50.0% of FCGs reported about negative or very negative influence of caregiving on their health, while the positive influence was perceived by 10.0%. FCGs of more dependent children tended to perceive significantly more negative influence of caregiving, when compared with those of more independent children. Study showed that 134 FCGs (67.3%) of FCG families are included in family poverty benefit programs (mainly PAROS), whereas according to SES classification less than 30% of FCGs were classified in low SES group. However, there were no statistically significant differences between the two Groups of FCGs regarding the levels of social support and the SES.

The overall mean for bodily pain in SF-36 was 50.2 (SD: 21.9). There were no statistically significant differences in SF-36 8 domains of quality of life between the two Groups of FCGs. The means and standard deviations of these domains in total and by FCG

Groups are presented in Table 3. The mean scores for the bodily pain (BP) were 51.1 (SD: 22.0) and 49.4(SD: 21.9) in Group 1 and Group 2, respectively (p=0.592), and for general health (GH) 45.2(SD: 13.8) and 48.0(SD: 15.8) in Group 1 and Group 2, respectively (p=0.081). The mean score of depression score according to the 16-item CES-D was 12.6(SD: 8.4 and the mean anxiety score according to SCL-90 10.4 (SD: 5.6). The mean dignity score on 18-item dignity scale was 69.5 (SD: 6.3). There were no statistically significant differences in depression, anxiety and dignity mean scores between two Groups. FCGs reported to have 0-8 chronic diseases/conditions. Fifty-three participants (26.5%) had one or no chronic diseases, 44 (22.0%) had 2, 52 (26.0%)had 3, and 51 (25.5%) had more than 4 chronic diseases. Prevalence of several pain symptoms were calculated. One hundred fifty-six (78.0%) FCGs complained for back pain, from which 70 (70.0%) of caregivers of more independent children and 86 (86.0%) of more dependent ones (p=0.006). Next, most common diseases among FCGs were migraine (45%) and arthritis (37.7%). No significant differences were found in the number and types of chronic diseases between two Groups of FCGs. Many participants did not receive medical support. For example, only 37.8% of FCGs complaining with back pain, 30.0% of those with migraine, and 28.0% with arthritis were diagnosed by physician. More detailed information about the prevalence of chronic diseases in FCGs is represented in Table 4.

Bivariate analyses

To address the study objectives, bivariate analyses of the two Groups of FCGs and the outcome measures (bodily pain, depression, anxiety and dignity) were conducted (Tables 1-8).

Statistically significant association was found between being an FCG of a more dependent CP child and the caregiving hours, caregiving demands, perception of caregiving influence on FCG's health, social support level, as well as the back pain, depression and

dignity in caregivers (see Tables 2-4). Several child characteristics (the type of CP, manual and communication functions of child, mental and behavioral problems) were also significantly associated with being an FCG of a more dependent child (see Table 1).

Bivariate analysis (Pain)

In accordance with the factors described in the Zhu's framework (Figure 1), FCG's and child's characteristics associated with FCG's physical health (Social support, Family function, Child function, Child behavior, Perception of formal care, SES, Caregiving demand) that were statistically significantly different between the two Groups of FCGs, were included in the bivariate analysis for bodily pain (Table 5). The bodily pain in FCGs was statistically significantly associated only with the communication function of CP children and the remaining of SF-36 physical and mental health domains.

Bivariate analysis (Depression)

Factors included in Zhu's framework (Figure 1) which showed statistically significant difference between the two Groups of FCGs were further included in the bivariate analysis for depression, anxiety and dignity.

FCGs' depression level was statistically significantly associated with the severity of CP (child's manual ability level, presence of seizure syndromes, mental problems), family SES and social support levels, feeding difficulty levels and the perceived influence of caregiving (Table 6). Depression was also significantly (p<0.001) associated with anxiety and dignity levels of FCGs.

Bivariate analysis (Anxiety)

FCGs' anxiety level was statistically significantly associated with the level of perceived influence of caregiving on FCGs health and the social support of FCGs (Table 7). From the outcome measures, only FCGs' depression level was significantly associated with anxiety.

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Bivariate analysis (Dignity)

FCGs' dignity level was statistically significantly associated with caregivers' age, marital status, perceived feeding difficulties, caregiving demands, and social support, as well as the type of CP by ICD (Table 8). From the outcome measures, only the level of depression was statistically significantly ($p<0.001$) associated with FCGs' dignity level.

Testing for confounders

Based on the bivariate analyses (Tables 1-8), factors associated with both being an FCG of a more dependent CP child and the outcome measures (pain, depression, anxiety, and dignity) were defined as confounders. The factor, associated both with being an FCG of a more dependent child and the FCGs bodily pain level was only child's communication level (the CFCS level). Therefore, in the final regression model to explore the association between the bodily pain of FCGs and the severity of limitations in CP children adjustment for the level of CFCS was made. Factors, associated with both being an FCG of a more dependent child and the other outcome measures were as follows: perception of feeding difficulties and caregiving influence on FCGs health, social support, as well as the MACS level and mental problems in children for depression; perception of caregiving influence on FCGs health and social support for anxiety; feeding difficulties, caregiving demands, social support of FCGs and the type of the CP for dignity. These characteristics were considered as confounders in the multivariable linear regression analyses for depression, anxiety and dignity, respectively.

Multivariate analyses

The final models are presented in Tables 9-12. There were no statistically significant differences in bodily pain ($p=0.470$), depression ($p=0.822$), and anxiety ($p=0.270$) after adjusting for the identified confounders. Statistically significant ($p=0.001$) difference was found in the dignity levels of FCGs of more dependent children compared to FCGs of more

independent ones, after adjusting for confounders (Table 12). Collinearity analyses were
performed via variance inflation factors (VIF) calculation.

8 Discussion

This study did not detect significant association between bodily pain of FCGs and the severity of limitations of CP children (i.e., dependence). This finding is controversial to the previous findings of Byrne et al. (2009),[34] which show the significant difference in the mean bodily pain between this two Groups of FCGs in the Irish population. However, the findings indicated that FCGs of more dependent children had significantly higher rates of perceiving more severe feeding difficulties, higher caregiving demands, longer caregiving time (10.3 versus 6.9 hours per day), and more negative influence of caregiving on their health. Therefore, several factors that could have influenced the results have to be recognized, such as recall bias, instrument bias, interviewer bias, possible unidentified intervening factors, when claiming about the absence of differences in bodily pain between groups. However, it should be noted that this study utilized standardized questionnaires and followed classification approach (i.e. defining groups of more dependent and independent children) from previous successful practices. Furthermore, as described above, a careful and systematic training for all interviewers was organized.

FCGs of more dependent children had significantly higher rates of back pain. This can be associated with enhanced load and pressure on spine of FCGs due to the specifics of the caregiving demands and needs (e.g. heavy lifting, assisting, hugging, holding, feeding) related to movement and occupational restrictions of CP children.

Over one fifth of FCGs were depressed and over 43% of FCGs had anxiety symptoms. In addition, over 70% of FCGs reported to have 2 or more chronic diseases, whereas the overall rate of diagnosis by physician was around 40%. A previous study by S. Mkhitaryan et al., (2015)[68] investigated the mental health of caregivers (mothers) of children with type 1 diabetes in comparison with the caregivers of regular children in Armenia, utilizing the same outcome measures. A comparison of the prevalence of depression, anxiety

and chronic diseases among the participants of that study with the results of the current study is illustrated in Appendix J. Although the prevalence for depression and anxiety were only slightly different between the caregivers of CP and diabetic children, FCGs with CP children had twice higher rates of having 2 or more chronic diseases. This can be attributed to complexity and specifics of caregiving demands for those having a child with CP. However, the prevalence of depression, anxiety and having 2 or more chronic diseases were higher in FCGs of CP children if compared with those of regular children (see Appendix J).

Strengths and Weaknesses

This study has both strengths and weaknesses. This is the first study conducted in Armenia regarding the health and well-being of FCGs and the distribution of limitations of their CP children. However, a few points need to be described that may limit the generalizability of the findings, specifically, regarding the prevalence of the mental health problems (i.e., depression and anxiety). First, the sample size was not defined to provide a representative number of participants for prevalence calculation. Secondly, the majority of the participants reported to be poverty benefit program recipients (67.3%); therefore, the study sample may not adequately represent families with CP children in Armenia with different levels of SES. Thirdly, to meet the project deadlines, 11 interviewers conducted data collection, which may add further variability to the study findings. However, a structured protocol and clear guidelines for interviewers were developed and training and everyday reports and feedbacks were conducted for data collection to minimize the distortion of results due to this factor.

Despite these limitations, it should, nevertheless be noted that the investigated two groups of participants (i.e., FCGs of more dependent children vs. those of more independent children) were homogeneous in most of socio-demographic characteristics. Moreover, the mandatory functional diagnosis employing the classification systems used in this study (i.e. GMFCS, CFCS, MACS) was available only in the chosen center: all the CP children were,

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therefore, classified by the same team of trained therapists and doctors, which enhances the comparability of the participant groups.

Recommendations

This study points out the risks of undertreatment of FCGs. Appropriate health care and social policies have to be implemented to address this issue. The study also indicates the need for further investigation of problems related to back pain to define the needs for health care interventions. Health care specialists and policy makers have to be aware about the health and well-being risks of FCGs caregiving a child with CP and plan appropriate intervention strategies. Psychosocial and financial support programs for FCGs have to be implemented. More careful attention has to be placed for FCGs of more dependent children, as they tend to have more physical health problems and lower dignity levels. Further investigation of the prevalence and severity of back pain among caregivers is needed to discover the magnitude of this problem and for development of adequate intervention and preventive strategies. Qualitative studies are also needed to understand FCGs' specific needs and challenges of the caregiving process, as well as to find an answer as to why and how some FCGs are able to effectively face the caregiving demands with less consequences to their health and quality of life, while others not.

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10 Tables and Figures

Table 1. Characteristics of the children

Characteristics	Total n=200	Exposed group (GMFCS Level I-II) n=100	Unexposed group (GMFCS Level III-V) n=100	p-value
Age (years), mean (SD)	10.1 (3.6)	10.4 (3.5)	9.8 (3.7)	0.228
Sex (n, %)[*]				0.758
Male	140 (70.0)	69 (69.0)	71 (71.0)	
Female	60 (30.0)	31 (31.0)	29 (29.0)	
The type of the Cerebral Palsy (CP) (n, %)				0.000
Spastic quadriplegic (G80.0)	82 (41.0)	24 (24.0)	58 (58.6)	
Spastic diplegic (G80.1)	47 (23.5)	29 (29.0)	18 (18.2)	
Spastic hemiplegic (G80.2)	33 (16.5)	30 (30.0)	3 (3.0)	
Dyskinetic (G80.3)	10 (5.0)	4 (4.0)	6 (6.1)	
Ataxic (G80.4)	8 (4.0)	3 (3.0)	5 (5.1)	
Other/Mixed CP syndromes (G80.8)	4 (2.0)	0	4 (4.0)	
Unspecified (G80.9)	15 (7.5)	10 (10.0)	5 (5.1)	
CP type (sides involved)				0.000
Unilateral	34 (17.0)	30 (30.0)	4 (4.0)	
Bilateral	166 (83.0)	70 (70.0)	96 (96.0)	
Manual Ability Classification System (MACS) levels (n,%)				0.000
Level I	41 (20.5)	37 (37.0)	4 (4.0)	
Level II	61 (30.5)	47 (47.0)	14 (14.0)	
Level III	43 (21.5)	14 (14.0)	29 (29.0)	
Level IV	34 (17.0)	2 (2.0)	32 (32.0)	
Level V	21 (10.5)	0	21 (21.0)	
Communication Function Classification System (CFCS) levels (n,%)				0.000
Level I	57 (28.5)	47 (47.0)	10 (10.0)	
Level II	59 (29.5)	38 (38.0)	21 (21.0)	
Level III	28 (14.0)	9 (9.0)	19 (19.0)	
Level IV	31 (15.5)	4 (4.0)	27 (27.0)	
Level V	25 (12.5)	2 (2.0)	23 (23.0)	

[*] The percentages were calculated after excluding missing values: 1 missing value for "The type of the Cerebral Palsy", 1 for "Mental retardation", and 1 for "Behavioral problems".

Presence of seizure syndromes (n, %)	30 (15.0)	16 (16.0)	14 (14.0)	0.692
Mental retardation (n, %)	118 (59.0)	36 (36.4)	82 (82.0)	0.000
Behavioral problems (n, %)	91 (45.5)	27 (27.3)	64 (64.0)	0.000

Table 2 Characteristics of the family caregivers (FCGs)

Characteristics	All n = 200	FCGs of more independent children Group 1, n=100	FCGs of more dependent children Group 2, n=100	p-value[†]
Relationship to child, n (%)[‡]				0.313
Mother	176 (88.0)	90 (90.0)	86 (86.0)	
Father	6 (3.0)	1 (1.0)	5 (5.0)	
Grandmother	16 (8.0)	8 (8.0)	8 (8.0)	
Other	2 (1.0)	1 (1.0)	1 (1.0)	
Age (years), mean (SD)	38.8 (8.8)	38.8 (8.9)	38.7 (8.8)	0.954
Education level, n (%)				0.295
School (less than 10 years)	9 (4.5)	5 (5.0)	4 (4.0)	
School (10 years)	54 (27.0)	26 (26.0)	37 (37.0)	
Professional technical (10-13 years)	89 (44.5)	46 (46.0)	43 (43.0)	
University-Postgraduate	48 (24.0)	28 (28.0)	20 (20.0)	
Marital status, n (%)				0.157
Single	5 (2.5)	3 (3.0)	2 (2.0)	
Married	170 (85.0)	84 (84.0)	86 (86.0)	
Divorced	16 (8.0)	7 (7.0)	9 (9.0)	
Widow	9 (4.5)	6 (6.0)	3 (3.0)	
Job status, n (%)				0.169
Employed	27 (13.5)	15 (15.0)	12 (12.0)	
Self employed	19 (9.5)	13 (13.0)	6 (6.0)	
Not employed	154 (77.0)	72 (72.0)	82 (82.0)	
Number of people in household mean (SD) Range	5.4 (2.1) 2-15	5.1 (2.0) 2-15	5.6 (2.1) 2-14	0.128
Number of children under 18 in families, mean (SD) Range	2.2 (4.8) 1-8	2.16 (1.1) 1-7	2.26 (1.0) 1-8	0.496
Caregiving time (hours/day), mean (SD)	8.6 (5.6)	6.9 (4.6)	10.3 (5.9)	0.000
Providing care to another individual with chronic	34 (17.0)	13 (13.0)	21 (21.0)	0.132

[†] In this univariate analysis the independent sample t-test was utilized for means, and χ^2 analysis for proportions.

[‡] The percentages were calculated after excluding missing values: 1 missing value for "Receiving support from family poverty benefit program", "Caregiving influence on caregiver's health", and 10 missing values for "SES".

conditions, n (%)				
Receiving help with provision of care to CP child, n (%)	118 (59.0)	56 (56.0)	62 (62.0)	0.388
Receiving any support from family poverty benefit program, n(%)	134 (67.3)	70 (70.7)	64 (64.0)	0.313
Feeding difficulties, n (%)				0.046
All of the time	21 (10.5)	7 (7.0)	14 (14.0)	
Most of the time	17 (8.5)	10 (10.0)	7 (7.0)	
Some of the time	43 (21.5)	15 (15.0)	28 (28.0)	
A little bit of the time	29 (14.5)	15 (15.0)	14 (14.0)	
None of the time	90 (45.0)	53 (53.0)	37 (37.0)	
Caregiving demands, n (%)				0.001
It is impossible to handle it	5 (2.5)	3 (3.0)	2 (2.0)	
I can hardly handle it	56 (28.0)	19 (19.0)	37 (37.0)	
I successfully handle it, but it requires extra efforts	118 (59.0)	60 (60.0)	58 (58.0)	
I successfully handle it, without any extra efforts	21 (10.5)	18 (18.0)	3 (3.0)	
FCGs perception of caregiving influence on their health, n (%)				0.001
Very positive	1 (0.5)	1 (1.0)	0 (0.0)	
Positive	19 (9.5)	16 (16.2)	3 (3.0)	
Neither positive, not negative	79 (39.7)	46 (46.5)	33 (33.3)	
Negative	80 (40.2)	30 (30.3)	50 (50.5)	
Very negative	19 (9.5)	6 (6.1)	13 (13.1)	
Child health change compared with the last admission year to the tertiary center, n (%)				0.237
Much better	17 (8.5)	8 (8.0)	9 (9.0)	
Better	91 (45.5)	51 (51.0)	40 (40.0)	
The same	73 (36.5)	33 (33.0)	40 (40.0)	
Worse	17 (8.5)	6 (6.0)	11 (11.0)	
Much worse	2 (1.0)	2 (2.0)	0 (0.0)	
SES, n (%)				0.680
High	67 (35.3)	35 (37.2)	32 (33.3)	
Middle	67 (35.3)	34 (36.2)	33 (34.4)	
Low	56 (29.5)	25 (26.6)	31 (32.3)	
Social Support, mean, SD	17.4 (3.5)	17.9 (3.4)	16.9 (3.5)	0.047

Table 3. Quality of life, mental and physical health characteristics of caregivers by CP children groups

Characteristics	Total n=200	FCGs of more independent children Group 1, n=100	FCGs of more dependent children Group 2, n=100	p-value
Quality of Life (QoL) (based on SF-36)				
Physical functioning (PF), mean (SD)	68.6 (23.8)	69.7 (23.7)	67.55 (23.9)	0.525
Bodily pain (BP), mean (SD)	50.2 (21.9)	51.1 (22.0)	49.4 (21.9)	0.569
General Health (GH), mean (SD)	46.6 (14.9)	45.2 (13.8)	48.0 (15.8)	0.179
Role physical (RP), mean (SD)	36.1 (39.4)	37.8 (40.1)	34.5 (38.9)	0.561
Social Functioning (SF), mean (SD)	66.3 (24.3)	66.5 (24.8)	66.4 (23.9)	0.971
Vitality (VT), mean (SD)	47.1 (19.8)	47.9 (19.6)	46.4 (20.1)	0.582
Role emotional (RE), mean (SD)	53.6 (19.1)	55.5 (18.6)	51.7 (19.5)	0.139
Mental health (MH), mean (SD)	38.7 (41.4)	43.0 (41.4)	34.3 (41.2)	0.160
Depression (based on CES-D), mean (SD)	12.6 (8.4)	11.4 (7.8)	13.8 (8.9)	0.045
Depressive symptoms (cut-off 18/19), n (%)	43 (21.5)	17 (17.0)	26 (26.0)	0.123
Anxiety (based on SCL-90), mean (SD)	10.4 (5.6)	10.3 (5.8)	10.5 (5.5)	0.831
Anxiety symptoms (cut-off 10/11) n (%)	86 (43.0)	40 (40.0)	46 (46.0)	0.391
Dignity (based on 18-items Dignity Scale), mean (SD)	69.5 (6.3)	71.1 (5.9)	67.8 (6.3)	0.000
Chronic diseases, n (%)				0.555
≤1 chronic disease	53 (26.5)	29 (54.7)	24 (45.3)	
2 chronic diseases	44 (22.0)	24 (54.5)	20 (45.5)	
3 chronic diseases	52 (26.0)	22 (42.3)	30 (57.7)	
≥4 chronic diseases	51 (25.5)	25 (49.0)	26 (51.0)	

Table 4. The prevalence of chronic diseases among family caregivers (FCGs) of children with cerebral palsy (CP)

Chronic disease[§]	All n = 200	FCGs of more independent children Group 1, n=100	FCGs of more dependent children Group 2, n=100	p-value[**]
High blood pressure, n (%)[††]	55 (27.5)	24 (24.0)	31 (31.0)	0.268
Diagnosed by doctor, n (%)[‡‡]	26 (49.1)	12 (52.2)	14 (45.2)	
Myocardial Infarction, n (%)	1 (0.5)	0	1 (1.0)	0.316
Diagnosed by physician, n (%)	1 (100.0)	-	1 (100.0)	
Other hearth diseases, n (%)	19 (9.5)	11 (11.0)	8 (8.0)	0.469
Diagnosed by physician, n (%)	10 (52.6)	4 (36.4)	6 (75.0)	
Diabetes, n (%)	11 (5.5)	8 (8.0)	3 (3.0)	0.121
Diagnosed by physician, n (%)	10 (90.9)	8 (100.0)	2 (66.7)	
Stroke, n (%)	1 (0.5)	0	1 (1.0)	0.316
Diagnosed by physician, n (%)	1 (100.0)	-	1 (100.0)	
Migraine, n (%)	90 (45.0)	45 (45.0)	45 (45.0)	1.000
Diagnosed by physician, n (%)	27 (30.0)	18 (40.0)	12 (26.7)	
Gastro-Intestinal problems, n (%)	39 (19.5)	24 (24.0)	15 (15.0)	0.108
Diagnosed by physician, n (%)	19 (48.7)	10 (41.7)	9 (60.0)	
Back pain, n (%)	156 (78.0)	70 (70.0)	86 (86.0)	**0.006**
Diagnosed by physician, n (%)	59 (37.8)	28 (40.0)	31 (.36.0)	
Arthritis, n (%)	75 (37.7)	33 (33.3)	42 (42.0)	0.207
Diagnosed by physician, n (%)	21 (28.0)	11 (33.3)	10 (23.8)	
Cancer, n (%)	3 (1.5)	2 (2.0)	1 (1.0)	0.561
Diagnosed by physician, n (%)	3 (100.0)	2 (100.0)	1 (100.0)	
Mental and psychological health problems, n (%)	26 (13.0)	14 (14.0)	12 (12.0)	0.674
Diagnosed by physician, n (%)	3 (11.5)	1 (7.1)	2 (16.7)	
Disability, n (%)	7 (3.5)	4 (4.0)	3 (3.0)	0.690
Diagnosed by physician, n (%)	7 (100.0)	4 (100.0)	3 (100.0)	
Other chronic disorders, n (%)	45 (22.5)	25 (25.0)	20 (20.0	0.397
Diagnosed by physician, n (%)	26 (57.8)	14 (53.8)	12 (46.2)	

[§] One FCG could report about multiple chronic conditions

[**] In this univariate analysis the χ^2 analysis was utilized for proportions.

[††] The percentages were calculated after excluding missing values: 1 missing value for Arthritis and Disability.

[‡‡] The proportion of FCGs reporting about the chronic disorder, who admitted to physician regarding at least once.

Table 5. Bivariate analysis: Pain is dependent variable

Dependent variable	Independent variable	beta coef	p-value	95% C.I.	
				Lower	Upper
Pain	**Groups**	-1.770	0.569	-7.892	4.352
	Outcome measurements				
	Depression	0.056	0.763	-.309	0.420
	Anxiety	-0.060	0.830	-0.607	0.487
	Dignity	0.249	0.312	-0.235	0.732
	Family caregivers' (FCG) characteristics				
	Marital status				
	Married	1	-	-	-
	Single	14.153	0.155	-5.419	33.725
	Divorced	-7.072	0.218	-18.352	4.208
	Widow	-0.003	1.000	-14.756	14.751
	Job status				
	Employed	-0.431	0.925	-9.435	8.573
	Self-employed	-8.466	0.113	-18.959	2.028
	Not employed	1	-	-	-
	Caregiver's age	0.009	0.960	-0.341	0.359
	Education				
	School (<10 years)	-0.613	0.937	-15.826	14.600
	School (10 years)	-0.946	0.804	-8.448	6.556
	Professional technical (10-13 years)	1	-	-	-
	University/Postgraduate	-2.710	0.493	-10.499	5.078
	Caregiving time (hours/day)	0.001	0.996	-0.551	0.553
	Providing care to another individual with chronic conditions	-3.543	0.392	-11.683	4.597
	Feeding difficulties				
	All of the time	-1.573	0.789	-13.123	9.978
	Most of the time	1.341	0.832	-11.089	13.771
	Some of the time	1	-	-	-
	A little bit of the time	-6.367	0.230	-16.792	4.058
	None of the time	0.569	0.889	-7.474	8.612

Caregiving demands				
It is impossible to handle it	2.449	0.808	-17.361	22.259
I can hardly handle it	-3.265	0.362	-10.306	3.775
I successfully handle it, but it requires extra efforts	1	-	-	-
I successfully handle it, without any extra efforts	-4.408	0.399	-14.684	5.868
FCGs perception of caregiving influence on their health				
Positive	-3.033	0.583	-13.915	7.849
Neither positive, nor negative	1	-	-	-
Negative	-0.330	0.921	-6.888	6.229
Socio economic status				
High	-4.328	0.259	-11.876	3.219
Middle	1	-	-	-
Low	-0.766	0.849	-8.675	7.144
Social support	-0.172	0.703	-1.060	0.716
Child characteristics				
Type of cerebral palsy (CP) (by ICD)				
Spastic quadriplegic	1	-	-	-
Spastic diplegic	-4.890	0.223	-12.778	2.998
Spastic hemiplegic	-4.199	0.353	-13.087	4.690
Other	-9.291	**0.033**	-17.830	-0.752
MACS				
Level I	-4.014	0.364	-12.709	4.682
Level II	1	-	-	-
Level III	-2.905	0.505	-11.478	5.669
Level IV	-4.702	0.316	-13.917	4.514
Level V	7.709	0.164	-3.185	18.603
CFCS				
Level I	1.115	0.780	-6.763	8.993
Level II	1	-	-	-
Level III	-6.378	0.198	-16.113	3.356
Level IV	-5.594	0.242	-15.004	3.816
Level V	11.249	**0.030**	1.126	21.372

	Presence of seizure syndromes	1.884	0.665	-6.691	10.459
	Behavioral problems	-2.248	0.473	-8.415	3.920
	Mental problems	0.317	0.920	-5.945	6.580

Table 6. Bivariate analysis (Depression)

Depression	Independent variable	beta coef	p-value	95% C.I.	
				Lower	Upper
	Groups	2.390	**0.045**	0.057	4.723
	Outcome measurements				
	Anxiety	0.867	**0.000**	0.695	1.039
	Dignity	-0.333	**0.000**	-0.513	-0.152
	SF-36 domains				
	PF	-0.012	0.629	-0.062	0.037
	RP	-0.013	0.404	-0.043	0.017
	BP	0.008	0.763	-0.046	0.062
	RE	0.014	0.324	-0.014	0.043
	VT	0.003	0.925	-0.057	0.062
	SF	0.003	0.888	-0.045	0.052
	GH	0.023	0.573	-0.057	0.102
	MH	-0.024	0.438	-0.086	0.037
	Family caregivers' (FCG) characteristics				
	Marital status				
	Married	1	-	-	-
	Single	-3.106	0.420	-10.681	4.470
	Divorced	1.369	0.537	-2.997	5.735
	Widow	1.272	0.661	-4.439	6.983
	Job status				
	Employed	-0.896	0.612	-4.373	2.581
	Self-employed	-1.896	0.357	-5.948	2.156
	Not employed	1	-	-	-
	Caregiver's age	0.034	0.621	-0.101	0.169
	Education				
	School (<10 years)	-0.851	0.774	-6.698	4.995
	School (10 years)	0.686	0.640	-2.198	3.569
	Professional technical (10-13 years)	1	-	-	-
	University/Postgraduate	-0.754	0.620	-3.747	2.239
	Caregiving time (hours/day)	0.113	0.296	-0.099	0.325
	Providing care to another individual with chronic conditions	-1.303	0.413	-4.435	1.829
	Feeding difficulties				
	All of the time	-2.982	0.172	-7.277	1.312

	Most of the time	0.785	0.738	-3.836	5.407
	Some of the time	1	-	-	-
	A little bit of the time	-3.779	0.056	-7.655	0.097
	None of the time	-5.233	**0.001**	-8.224	-2.243
Caregiving demands					
	It is impossible to handle it	5.985	0.118	-1.535	13.504
	I can hardly handle it	1.281	0.346	-1.391	3.954
	I successfully handle it, but it requires extra efforts	1	-	-	-
	I successfully handle it, without any extra efforts	-3.130	0.115	-7.030	0.771
FCGs perception of caregiving influence on their health					
	Positive	0.125	0.952	-3.980	4.231
	Neither positive, nor negative	1	-	-	-
	Negative	3.349	**0.008**	0.874	5.823
Socio economic status					
	High	0.299	0.836	-2.546	3.143
	Middle	1	-	-	-
	Low	-3.916	**0.010**	-6.897	-0.935
Social support		-0.956	**0.000**	-1.270	-0.642
Child characteristics					
Type of cerebral palsy (CP) (by ICD)					
	Spastic quadriplegic	1	-	-	-
	Spastic diplegic	-0.496	0.746	-3.516	2.524
	Spastic hemiplegic	-0.341	0.844	-3.744	3.063
	Other	2.537	0.128	-0.732	5.807
MACS					
	Level I	1.434	0.397	-1.898	4.765
	Level II	1	-	-	-
	Level III	4.035	**0.016**	0.750	7.320
	Level IV	2.449	0.173	-1.082	5.979
	Level V	3.599	0.091	-0.575	7.772
CFCS					
	Level I	-1.189	0.445	-4.251	1.874
	Level II	1	-	-	-
	Level III	0.024	0.990	-3.760	3.808
	Level IV	2.881	0.122	-0.777	6.539

	Level V	2.921	0.145	-1.014	6.857
	Presence of seizure syndromes	-4.163	**0.012**	-7.411	-0.915
	Behavioral problems	2.014	0.093	-0.338	4.367
	Mental problems	2.501	**0.039**	0.124	4.877

Table 7. Bivariate analysis (Anxiety)

Anxiety	Independent variable	beta coef	p-value	95% C.I.	
				Lower	Upper
	Groups	0.170	0.831	-1.399	1.739
	Outcome measurements				
	Depression	0.384	**0.000**	0.308	0.461
	Dignity	-0.095	0.132	-0.218	0.029
	SF-36 domains				
	PF	-0.016	0.352	-0.049	0.017
	RP	-0.011	0.299	-0.030	0.009
	BP	-0.004	0.830	-0.040	0.032
	RE	0.005	0.610	-0.014	0.024
	VT	-0.018	0.361	-0.058	0.021
	SF	-0.006	0.707	-0.039	0.026
	GH	-0.029	0.282	-0.082	0.024
	MH	-0.008	0.685	-0.050	0.033
	Family caregivers' (FCG) characteristics				
	Marital status				
	Married	1	-	-	-
	Single	-4.565	0.074	-9.581	0.451
	Divorced	-0.877	0.550	-3.768	2.014
	Widow	0.324	0.866	-3.457	4.105
	Job status				
	Employed	-0.298	0.798	-2.601	2.004
	Self-employed	-2.458	0.072	-5.141	0.225
	Not employed	1	-	-	-
	Caregiver's age	-0.013	0.763	-0.101	0.074
	Education				
	School (<10 years)	-0.524	0.790	-4.411	3.362
	School (10 years)	0.994	0.308	-0.922	2.911
	Professional technical (10-13 years)	1	-	-	-
	University/Postgraduate	-0.170	0.866	-2.160	1.819
	Caregiving time (hours/day)	0.003	0.966	-0.138	0.144
	Providing care to another individual with chronic conditions	-1.331	0.208	-3.412	0.749
	Feeding difficulties				
	All of the time	0.566	0.702	-2.344	3.476

	Most of the time	2.703	0.090	-0.429	5.835
	Some of the time	1	-	-	-
	A little bit of the time	-0.250	0.851	-2.877	2.377
	None of the time	-1.390	0.178	-3.416	0.637
Caregiving demands					
	It is impossible to handle it	2.744	0.284	-2.291	7.779
	I can hardly handle it	-1.410	0.122	-3.199	0.380
	I successfully handle it, but it requires extra efforts	1	-	-	-
	I successfully handle it, without any extra efforts	-1.285	0.333	-3.896	1.327
FCGs perception of caregiving influence on their health					
	Positive	-0.192	0.889	-2.914	2.530
	Neither positive, nor negative	1	-	-	-
	Negative	2.183	**0.009**	0.543	3.824
Socio economic status					
	High	0.910	0.350	-1.008	2.829
	Middle	1	-	-	-
	Low	-1.541	0.132	-3.551	0.470
Social support		-0.531	**0.000**	-0.746	-0.316
Child characteristics					
Type of cerebral palsy (CP) (by ICD)					
	Spastic quadriplegic	1	-	-	-
	Spastic diplegic	-0.145	0.888	-2.178	1.888
	Spastic hemiplegic	-0.513	0.659	-2.804	1.778
	Other	-0.850	0.447	-3.051	1.350
MACS					
	Level I	0.666	0.559	-1.578	2.910
	Level II	1	-	-	-
	Level III	0.911	0.418	-1.301	3.124
	Level IV	-0.742	0.539	-3.120	1.636
	Level V	1.173	0.412	-1.639	3.984
CFCS					
	Level I	0.178	0.865	-1.893	2.250
	Level II	1	-	-	-
	Level III	-0.049	0.970	-2.608	2.510
	Level IV	1.044	0.406	-1.430	3.518

		0.835	0.537	-1.826	3.497
	Level V	0.835	0.537	-1.826	3.497
Presence of seizure syndromes		1.849	0.096	-0.333	4.031
Behavioral problems		0.967	0.225	-0.599	2.533
Mental problems		0.142	0.861	-1.452	1.736

Table 8. Bivariate analysis (Dignity)

Dignity	Independent variable	beta coef	p-value	95% C.I.	
				Lower	Upper
	Groups	-3.230	**0.000**	-4.942	1.518
	Outcome measurements				
	Depression	-0.188	**0.000**	-0.290	-0.086
	Anxiety	-0.121	0.132	-0.278	0.037
	SF-36 domains				
	PF	-0.002	0.927	-0.039	0.036
	RP	0.000	0.969	-0.023	0.022
	BP	0.021	0.312	-0.020	0.061
	RE	-0.013	0.233	-0.034	0.008
	VT	0.027	0.227	-0.017	0.072
	SF	0.020	0.284	-0.017	0.056
	GH	0.016	0.597	-0.044	0.076
	MH	0.026	0.262	-0.020	0.073
	Family caregivers' (FCG) characteristics				
	Marital status				
	Married	1	-	-	-
	Single	5.829	**0.041**	0.240	11.419
	Divorced	1.904	0.245	-1.317	5.126
	Widow	4.141	0.054	-0.073	8.354
	Job status				
	Employed	0.046	0.973	-2.569	2.660
	Self-employed	1.307	0.399	-1.740	4.354
	Not employed	1	-	-	-
	Caregiver's age	0.116	**0.023**	0.016	0.215
	Education				
	School (<10 years)	1.805	0.418	-2.583	6.194
	School (10 years)	-0.621	0.572	-2.785	1.543
	Professional technical (10-13 years)	1	-	-	-
	University/Postgraduate	0.055	0.961	-2.192	2.302
	Caregiving time (hours/day)	-0.036	0.661	-0.195	0.124
	Providing care to another individual with chronic conditions	1.611	0.177	-0.735	3.957
	Feeding difficulties				
	All of the time	3.360	**0.045**	0.070	6.649

		Most of the time	2.413	0.180	-1.127	5.953
		Some of the time	1	-	-	-
		A little bit of the time	-0.634	0.674	-3.603	2.335
		None of the time	1.939	0.097	-0.351	4.230
Caregiving demands						
		It is impossible to handle it	6.963	**0.016**	1.318	12.607
		I can hardly handle it	-0.362	0.722	-2.368	1.644
		I successfully handle it, but it requires extra efforts	1	-	-	-
		I successfully handle it, without any extra efforts	1.382	0.353	-1.546	4.310
FCGs perception of caregiving influence on their health						
		Positive	-0.249	0.876	-3.391	2.893
		Neither positive, nor negative	1	-	-	-
		Negative	-0.879	0.361	-2.772	1.015
Socio economic status						
		High	1.418	0.205	-0.780	3.616
		Middle	1	-	-	-
		Low	2.058	0.080	-0.245	4.361
Social support			0.647	**0.000**	0.407	0.887
Child characteristics						
Type of cerebral palsy (CP) (by ICD)						
	Spastic quadriplegic		1	-	-	-
	Spastic diplegic		-0.207	0.858	-2.488	2.075
	Spastic hemiplegic		-0.309	0.813	-2.880	2.262
	Other		-2.496	**0.048**	-4.966	-0.026
MACS						
		Level I	-0.270	0.833	-2.793	2.252
		Level II	1	-	-	-
		Level III	-1.130	0.372	-3.617	1.358
		Level IV	-1.040	0.444	-3.713	1.633
		Level V	-3.008	0.062	-6.168	0.152
CFCS						
		Level I	0.034	0.977	-2.289	2.357
		Level II	1	-	-	-
		Level III	-1.538	0.292	-4.407	1.332
		Level IV	-0.160	0.910	-2.934	2.614

	Level V	-2.246	0.139	-5.230	0.738
Presence of seizure syndromes		-0.837	0.506	-3.314	1.639
Behavioral problems		-1.167	0.197	-2.945	0.612
Mental problems		-1.582	0.084	-3.379	0.216

Table 9. Multivariable linear regression analysis: Final model for pain

Dependent variable	Independent variable	beta coef	p-value	95% C.I.		VIF
				Lower	Upper	
Pain	Groups	-2.704	0.470	-10.075	4.667	1.506
	CFCS					
	Level I	0.627	0.877	-7.373	8.626	1.446
	Level II	1	-	-	-	-
	Level III	-5.506	0.280	-15.539	4.527	1.344
	Level IV	-4.201	0.416	-14.359	5.956	1.498
	Level V	12.774	0.023	1.1819	23.729	1.455

Table 10. Multivariable linear regression analysis: Final model for depression

Dependent variable	Independent variable	beta coef	p-value	95% C.I.		VIF
				Lower	Upper	
Depression	Groups	-0.354	0.822	-3.447	2.739	2.130
	Feeding difficulties					
	All of the time	3.328	0.102	-0.667	7.322	1.296
	Most of the time	5.758	0.006	1.698	9.819	1.157
	Some of the time	4.063	0.007	1.138	6.988	1.278
	A Little bit of the time	0.733	0.654	-2.487	3.954	1.159
	None of the time	1	-	-	-	-
	Caregiving influence on FCGs health					
	Positive	-1.737	0.384	-5.665	2.191	1.253
	Neither positive, nor negative	-2.018	0.098	-4.413	0.377	1.227
	Negative	1	-	-	-	-
	Social support	-0.872	0.000	-1.197	-0.546	1.128
	Mental retardation	1.199	0.382	-1.501	3.899	1.565
	CFCS					
	Level I	0.931	0.561	-2.220	4.083	1.457
	Level II	1	-	-	-	-
	Level III	2.306	0.181	-1.083	5.696	1.745
	Level IV	0.473	0.820	-3.616	4.563	2.076
	Level V	0.027	0.991	-4.787	4.841	1.965

Table 11. Multivariable linear regression analysis: Final model for anxiety

Dependent variable	Independent variable	beta coef	p-value	95% C.I.		VIF
				Lower	Upper	
Anxiety	Groups	-0.876	0.270	-2.439	0.687	1.120
	Social support	-0.500	0.000	-0.720	-0.280	1.052
	Caregiving influence on FCGs health					
	Positive	-0.296	0.825	-2.930	2.339	1.155
	Neither positive, nor negative	1	-	-	-	-
	Negative	1.724	0.037	0.101	3.348	1.208

Table 12. Multivariable linear regression analysis: Final model for dignity

Dependent variable	Independent variable	beta coef	p-value	95% C.I.		VIF
				Lower	Upper	
Dignity	Groups	-3.290	**0.001**	-5.210	-1.370	1.439
	Social support	0.505	0.000	0.264	0.745	1.080
	Feeding difficulties					
	All of the time	1.529	0.292	-1.324	4.382	1.199
	Most of the time	-0.454	0.769	-3.499	2.591	1.131
	Some of the time	-0.490	0.657	-2.664	1.684	1.249
	A Little bit of the time	-1.911	0.128	-4.373	0.552	1.178
	None of the time	1	-	-	-	-
	Perception of caregiving demands					
	It is impossible to handle it	6.249	0.023	0.862	11.636	1.109
	I can hardly handle it	0.162	0.865	-1.713	2.037	1.110
	I successfully handle it, but it requires extra efforts	1	-	-	-	-
	I successfully handle it, without any extra efforts	-0.311	0.825	-3.093	2.471	1.140
	Type of cerebral palsy (CP) by ICD					
	Spastic quadriplegic (G80.0)	1	-	-	-	-
	Spastic diplegic (G80.1)	-0.528	0.636	-2.723	1.667	1.357
	Spastic hemiplegic (G80.2)	-1.896	0.160	-4.547	0.754	1.517
	Other types of CP	-2.929	0.014	-5.254	-0.605	1.277
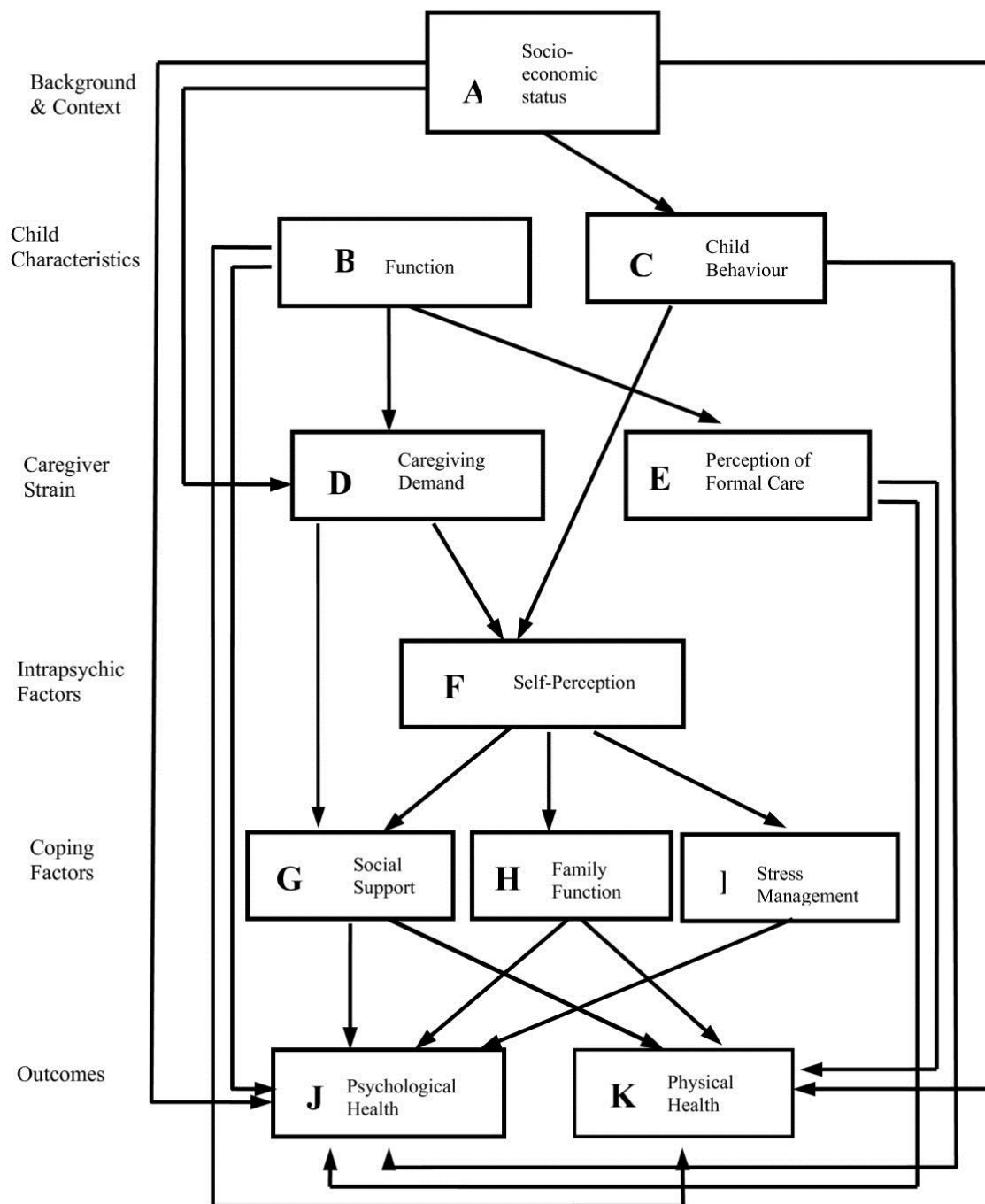
Figure 1. Conceptual model of the caregiving process among caregivers of a pediatric population, taken from Zhu et al., (2006)[30]

11 Appendices

Appendix A. Common classifications of Cerebral Palsy (CP)

Classification of CP by ICD-10-CM[98]	
G80.0	Spastic quadriplegic cerebral palsy
G80.1	Spastic diplegic cerebral palsy
G80.2	Spastic hemiplegic cerebral palsy
G80.3	Athetoid cerebral palsy
G80.4	Ataxic cerebral palsy
G80.8	Other cerebral palsy
G80.9	Cerebral palsy, unspecified

The most frequent used systems of classification of topography of spastic CP subtypes (Goldsmith, et al.; 2016)[41]		
Europe	Australia	North America
• Unilateral • Bilateral	• Monoplegia • Hemiplegia • Diplegia • Triplegia • Quadriplegia	Both of this systems

Appendix B. The Prevalence of cerebral palsy in Armenia

Year	Age group (y)	Absolute number	Prevalence per 100,000 Armenian population
2016[80]	0-14	1,519	256.5
	15-17	253	248.8
	Total	1,772	
2015[78]	0-14	1,509	257.6
	15-17	248	235.1
	Total	1,757	
2014[79]	0-14	1,500	259.0
	15-17	266	239.0
	Total	1,766	

Appendix C. First time diagnosed cerebral palsy in Armenia:

2016[80]

Age group	Neurological diseases (G00-99)	Cerebral palsy (G80)

(*year olds*)	Absolute number	Per 100000 resident	Absolute number	Per 100000 resident
15-17	1074	1056.0	45	44.2
0-14	3181	537.1	181	30.6

Appendix D. Journal form

Date (DD/MM/YYYY)	____/____/2018				
ID:* _____	Phone number _____				
The years of attendance	□ 2018 □2017 □2016 □2015 □2014 □2013				
Child diagnosis**	□ CP □ Other				
Child age (y) at the time of study					
GMFCS Level	1 □ Level I				
	2 □ Level II				
	3 □ Level III				
	4 □ Level IV				
	5 □ Level V				
Study group	1 □ Group 1 (FCG of more independent child)				
	2 □ Group 2 (FCG of more dependent child)				
First contact Date (DD/MM/YYYY)	___/___/2018	Time (HH/MM)	___/__		
FCG's relation to the CP child	1. Mother 2. Father 3. Grandmother 4. Grandfather				
	5. Brother 6. Sister 7. Other relative 8. Other				

Interview status	1. Successful interview	2. Refused to participate	3. Refused during interview
		2a. Reason _____ _	3a. Reason _____

Date of the end of Interview (DD/MM/YYYY)	___/___/2018	Time (HH/MM)	___/__		
Overall duration of interview in minutes	I	II	III	IV	∑
	___	____	___	___	____

* The ID will be the same for FCG and the child and will include 5 numbers: the first 2 numbers will represent the year of last attendance, and the last 3 numbers will indicate the order. For example, second participant who attended last time at 2018 will be coded as 18002.

** All characteristics will be retrieved from the medical records at the last attendance

Appendix E. Phone call procedure and Oral Consent.

English version:

Hello. My name is Hovhannes Hakobyan. I'm a neurologist and graduate student at the School of Public Health at the American University of Armenia. As a thesis project we are conducting a phone-based survey among FCGs of children with CP in Armenia to investigate their health and well-being. This phone number with around 200 other numbers, was provided to me by "Ararat" Mothers and Child's Health Center as a contact number of the primary caregiver of a child with cerebral palsy. If this is true, who are you for the child with cerebral palsy?

Possible answer: mother, father, any other

If not related to the child, finish the survey, if is a caregiver, continue…

There are no direct benefits from participation in this study. However, we believe that this survey, will provide us important evidence to better understand the health and quality of life caregivers of children with cerebral palsy in Armenia, and further inform healthcare decision-makers in the country about caregivers concerns and needs. The questionnaire contains sections to measure the depression, anxiety and quality of life amongst caregivers of children with CP. We will not collect any identifying data from you. The participation to this study is voluntary. There is no penalty if you refuse to participate in this study. You can skip any questions you don't want to answer. You can stop the interview any moment you want. All the information provided by you will be grouped with the hundreds of other caregivers' data and will not include any identifying information about you. Moreover, only the research team, including myself and my two supervisors will have access to the data provided by you and other participants. We assume the interview process will take around 55 minutes. Participation in this study includes only this survey and we will not contact you again. If you agree to participate, we can start the interview right now or any time that is acceptable for

you. You can always stop the interview, whenever you fill not comfortable or for any other reasons without any consequences for you. We also can divide the interview process to sequences and do that in more than one phone calls, if you feel time that is more convenient for you.

If you have any questions regarding this study you can contact the Principal investigator, Ani Movsisyan via Email: ani.movsisyan@wolfson.ox.ac.uk or call the Dean of the School of Public Health Varduhi Petrosyan at +374 60 612592. If you feel that you have been hurt by participating in this study, you can contact the Human Participants Protection Administrator of the American University of Armenia Varduhi Hayrumyan by phone +374 60 61 26 17.

Do you agree to participate? Thank you.

If yes, shall we continue or schedule time for interview?

In case of the successful interview:

To have more clear understanding of the health and well-being of caregivers we also need the information about CP child's health. Thus we need your permission to retrieve your child's health information (i.e. type of CP, severity, presence of seizure syndromes, the history of the disease) from his/her medical records at "Ararat" Mothers and Child's Health Center. The information will not include any identifying data about your child and you. In case if you accept we will add the information to the data provided by you. This procedure does not include any risks or benefits for you and your child. Do you agree to allow us to retrieve the medical information of your child?

Thank you.

Armenian version

Բարև Ձեզ: Իմ անունը Հովհաննես Հակոբյան է: Ես նյարդաբան եմ և հանդիսանում եմ Ամերիկյան համալսարանի հանրային առողջապահության ֆակուլտետի ավարտական կուրսի ուսանող: Մագիստրոսական թեզի շրջանակներում մենք անցկացնում ենք հեռախոսային հարցում ՄՈՒՊ երեխաների խնամակալների շրջանում Հայաստանի Հանրապետությունում (ՀՀ)՝ նրանց առողջության և բարեկեցության ուսումնասիրման նպատակով: Այս հեռախոսահամարը, ինչպես նաև մոտ 200 այլ հեռախոսահամարներ, մեզ է տրամադրել «Արարատ» մոր և մանկան առողջարանը՝ որպես մանկական ուղեղային պարալիզով (ՄՈՒՊ) երեխայի առաջնային խնամակալի կոնտակտային համար: Եթե սա ճիշտ է, ո՞վ եք հանդիսանում դուք ՄՈՒՊ երեխայի համար:

Հավանական պատասխան. Մայր, հայր, այլ

Եթե կապ չունի երեխայի հետ, ավարտել հարցումը, եթե հանդիսանում է
խնամակալ, շարունակել….

Հետազոտությանը մասնակցելուց ոչ մի ուղղակի օգուտ չկա: Այնուամենայնիվ, մենք կարծում ենք, որ այս հարցումը մեզ կտրամադրի կարևոր փաստեր ՀՀ ՄՈՒՊ խնամակալների առողջությունն ու կյանքի որակն ավելի լավ հասկանալու համար: Հարցաշարը ներառում է բաժիններ, ՄՈՒՊ երեխաների խնամակալների դեպրեսիայի, անհանգստության և կյանքի որակի գնահատման համար: Մենք չենք հավաքելու որևէ անձը բացահայտող տեղեկություն ձեզանից: Սա, հետագայում, կօգնի նաև տեղեկացնել երկրի առողջապահական ոլորտում որոշում կայացնողներին խնամակալների անհանգստությունների և կարիքների մասին: Հետազոտության մասնակցությունը կամավոր է: Մասնակցությունից

հրաժարվելու դեպքում Ձեզ ոչինչ չի սպառնում: Դուք կարող եք չպատասխանել ցանկացած հարցի, որին չեք ուզում պատասխանել: Ավելին, դուք կարող եք ընդհատել հարցազրույցը ցանկացած պահի: Ձեր տրամադրած տեղեկատվությունը խմբավորվելու է հարյուրավոր այլ խնամակալների տվյալների հետ և չի պարունակելու մասնակիցների անձը բացահայտող որևէ տեղեկություն: Ավելին, ձեր և այլ մասնակիցների տրամադրած տվյալները հասանելի են լինելու միայն հետազոտող խմբի անդամներին` ինձ և իմ երկու ղեկավարներին: Հարցումը, կարծում ենք, կտնի մոտ 55 րոպե: Այս հետազոտության մասնակցությունը ներառում է միայն այս հարցումը, և մենք չենք նախատեսում կրկին կապվել Ձեզ հետ հետազայում: Եթե Դուք համաձայնեք մասնակցել, մենք կարող ենք սկսել հարցազրույցն այժմ կամ Ձեզ համար առավել հարմար ցանկացած ժամի: Դուք կարող եք ընդհատել հարցազրույցը ցանկացած պահի, եթե որևէ անհարմարություն զգաք, կամ ցանկացած այլ պատճառով:Հարցումն ընդհատելը որևէ բացասական հետևանք չի ունենա Ձեզ համար: Մենք կարող ենք նաև բաժանել հարցազրույցը մասերի և կատարել այն մի քանի հեռախոսազանգերի ընթացքում` Ձեզ համար հարմար ցանկացած ժամի:

Եթե Դուք ունենաք հարցեր այս հետազոտության մասին, Դուք կարող եք կապվել հետազոտության ղեկավար` Անի Մովսիսյանի հետ հետևյալ էլեկտրոնային հասցեով` ani.movsisyan@wolfson.ox.ac.uk, կամ զանգահարել հանրային առողջապահության ֆակուլտետի դեկան Վարդուհի Պետրոսյանին` +374 60 612592 հեռախոսահամարով: Եթե Դուք զգաք, որ Ձեր մասնակցությունն այս հետազոտությանը Ձեզ վնաս է պատճառել, Դուք կարող եք զանգահարել

Հայաստանի ամերիկյան համալսարանի Էթիկայի հանձնաժողովի համակարգող Վարդուհի Հայրումյանին +374 60 612617 հեռախոսահամարով:

Դուք համաձա՞յն եք մասնակցել: Շնորհակալություն:

Եթե այո, շարունակենք, թե՞ նշանակենք հարցազրույցի ժամը:

Հաջողված հարցազրույցի դեպքում.

Խնամակալների առողջության և բարեկեցության մասին ավելի պարզ պատկերացում կազմելու համար անհրաժեշտ է նաև ՄՈՒՊ երեխայի առողջական վիճակի մասին տեղեկություն: Այդ իսկ պատճառով մեզ անհրաժեշտ է Ձեր թույլտվությունը՝ Ձեր երեխայի առողջական տվյալներն (մասնավորապես՝ ՄՈՒՊ տեսակը, ծանրության աստիճանը, ընցումային համախտանիշների առկայությունը, հիվանդության պատմությունը) "Արարատ" մոր և մանկան առողջարանի հիվանդության պատմագրերից ուսումնասիրելու համար: Այդ տեղեկությունները չեն ներառելու Ձեզ կամ Ձեր երեխայի անձը բացահայտող տվյալներ: Համաձայնության դեպքում՝ մենք ավելացնելու ենք այդ տեղեկությունը Ձեր տրամադրած տվյալներին: Այս գործողությունը չի ներառում ոչ մի ռիսկ կամ օգուտ Ձեր և Ձեր երեխայի համար: Դուք համաձա՞յն եք թույլ տալ մեզ հավաքել ձեր երեխայի բժշկական տեղեկությունները:

Շնորհակալություն:

Appendix F1. Questionnaires (English version)

Participant ID _____			

<table>
<tr><td colspan="4" align="center">Questions about CP Child and Caregiving
<i>(Now I want to ask a few questions related to the child with cerebral palsy)</i></td></tr>
<tr><td rowspan="5">1</td><td rowspan="5">How is your child's health now, if compared with the period of his/her last admission in "Ararat" Health center</td><td>□ 1</td><td>Much better</td></tr>
<tr><td>□ 2</td><td>Better</td></tr>
<tr><td>□ 3</td><td>The same</td></tr>
<tr><td>□ 4</td><td>Worse</td></tr>
<tr><td>□ 5</td><td>Much worse</td></tr>
<tr><td rowspan="5">2</td><td rowspan="5">Are you having difficulties with feeding your child?</td><td>□ 1</td><td>All of the time</td></tr>
<tr><td>□ 2</td><td>Most of the time</td></tr>
<tr><td>□ 3</td><td>Some of the time</td></tr>
<tr><td>□ 4</td><td>A little bit of the time</td></tr>
<tr><td>□ 5</td><td>None of the time</td></tr>
<tr><td>3</td><td>For last 4 weeks, on average, how many hours per day did you spend on caregiving your child? (e.g. dressing, playing, feeding, taking to therapy, exercising)</td><td colspan="2" align="center"><i>Please tell the approximate number</i>

___ <i>hours per day</i></td></tr>
<tr><td rowspan="4">4</td><td rowspan="4">How do you feel about the overall demands for caregiving to your cerebral palsy child?</td><td>□ 1</td><td>It is impossible to handle it</td></tr>
<tr><td>□ 2</td><td>I can hardly handle it</td></tr>
<tr><td>□ 3</td><td>I successfully handle it, but it requires extra efforts</td></tr>
<tr><td>□ 4</td><td>I successfully handle it, without any extra efforts</td></tr>
<tr><td rowspan="5">5</td><td rowspan="5">Finally, How do you feel about the influence of caregiving a CP child on your health?</td><td>□ 1</td><td>Very positive</td></tr>
<tr><td>□ 2</td><td>Positive</td></tr>
<tr><td>□ 3</td><td>Neither positive, nor negative</td></tr>
<tr><td>□ 4</td><td>Negative</td></tr>
<tr><td>□ 5</td><td>Very negative</td></tr>
<tr><td colspan="4" align="center">SOCIO-DEMOGRAPHIC CHARACTERISTICS</td></tr>
<tr><td>6</td><td>Can you please tell me your age?</td><td colspan="2">_____</td></tr>
<tr><td>7</td><td>Please indicate the highest level of education that you have completed</td><td colspan="2">1. □ School (less than 10 years)
2. □ School (10 years)
3. □ Professional technical education (10-13years)
4. □ Institute/University
5. □ Postgraduate</td></tr>
<tr><td>8</td><td>What is the total number of people living in your household (including yourself)?</td><td colspan="2" align="center">Please specify the number _____</td></tr>
<tr><td>9</td><td>How many children do you have?</td><td colspan="2" align="center">Please specify the number _____</td></tr>
<tr><td>10</td><td>How many children do you have who are less than 18 years old</td><td colspan="2" align="center">Please specify the number _____</td></tr>
</table>

11	Tell please the genders and ages of children («+» to answer)	1.	☐ Male ☐ Female	**please, specify the age ____**
		2.	☐ Male ☐ Female	**please, specify the age ____**
		3.	☐ Male ☐ Female	**please, specify the age ____**
12	When did you learn about the diagnosis of your child?	*Indicate the age of the child in months _____*		
13	Please answer, which one of these arguments fits your current employment status. («+» to answer)	1. ☐ Employed 2. ☐ Unemployed 3. ☐ Self-employed		
14	What is your current marital status? («+» to answer)	1. ☐ Single 2. ☐ Married 3. ☐ Divorced 4. ☐ Widow		
15	Do you currently provide any care to an individual with a chronic condition/s (elderly person, dementia patient, children with disability)? («+» to answer)	1. ☐ Yes *1a. If Yes, please specify whom* _____ 2. ☐ No		
16	Does anyone help you with the provision of care to your child? («+» to answer)	1 .☐ Yes 1a. *If Yes, please specify whom* _____ 2. ☐ No		
17	Does your family currently receive any support from a family poverty benefit program (e.g. PAROS)? («+» to answer)	1. ☐ Yes 2. ☐ No		
18	Do you pay rent for your living place? («+» to answer)	1) ☐ Yes 2) ☐ No		
19	How many rooms does your house (apartment) have?	_____		
20	**20. Please note whether this household has the following working items:**			

#	Items	Yes	No
1	Hot water tank/supply (uninterrupted)	☐ 1	☐ 2
2	Automobile	☐ 1	☐ 2
3	Auto washing machine	☐ 1	☐ 2

	4	Personal computer	□ 1	□ 2
	5	Satellite/cable TV	□ 1	□ 2
	6	Vacation home/villa	□ 1	□ 2

21	How many members of your household (including yourself) are currently employed (including self-employed, seasonal worker or other regular work)?	Write the number _____

22	What is your approximate household's monthly income? *(Please, check one that applies)* *(«+» to answer)*	1 □ Less than 50,000AMD 2 □ 51,000-100,000AMD 3 □ 101,000-200,000AMD 4 □ 201,000-300,000AMD 5 □ Not sure 6 □ Refuse to answer

23. CHRONIC DISEASES

23 Do you suffer from any of the following chronic diseases?
(Note: check whether it was diagnosed by physician or self-diagnosed)

#	Name of disease	a. Year of onset	b. It was	1=Diagnosed by physician 2=Self diagnosed
1	High blood pressure			
2	Myocardial infarction (MI)			
3	Heart diseases (excl. MI)			
4	Diabetes			
5	Stroke			
6	Migraine			
7	Gastro-intestinal diseases			
8	Back pain			
9	Arthritis/joint pain			
10	Cancer			
11	Mental or psychological problems			
12	Disabilities			
13	Other, specify:			

24. QUALITY OF LIFE

24 **INSTRUCTIONS:** **This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.**

If you are unsure about how to answer a question, please give the best answer you can.

(«+» to answer)

1	In general, would you say your health is:	Excellent	1	
		Very good	2	
		Good	3	

			Fair	4	
			Poor	5	

	2	Compared to one year ago, how would you rate your health in general now?	Much better now than one year ago	1
			Somewhat better now than one year ago	2
			About the same as one year ago	3
			Somewhat worse now than one year ago	4
			Much worse now than one year ago	5

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(«+» to answer)

#	Activities	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
a	**Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
b	**Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
c	Lifting or carrying groceries	1	2	3
d	Climbing **several** flights of stairs	1	2	3
e	Climbing **one** flight of stairs	1	2	3
f	Bending, kneeling, or stooping	1	2	3
g	Walking **more than a mile**	1	2	3
h	Walking **several blocks**	1	2	3
i	Walking **one block**	1	2	3
j	Bathing or dressing yourself	1	2	3

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(«+» to answer)

#		YES	NO
a	Cut down on the **amount of time** you spent on work or other activities	1	2
b	**Accomplished less** than you would like	1	2
c	Were limited in the **kind** of work or other activities	1	2
d	Had **difficulty** performing the work or other activities (for example, it took extra effort)	1	2

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

#		YES	NO
a	Cut down the **amount of time** you spent on work or other activities	1	2
b	**Accomplished less** than you would like	1	2
c	Didn't do work or other activities as **carefully** as usual	1	2

6	During the <u>past 4 weeks</u>, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?	*«+» to answer* Not at all 1 Slightly 2 Moderately 3 Quite a bit 4 Extremely 5
7	How much <u>bodily</u> pain have you had during the <u>past 4 weeks</u>?	*«+» to answer* None 1 Very mild 2 Mild 3 Moderate 4 Severe 5 Very severe 6
8	During the <u>past 4 weeks</u>, how much did <u>pain</u> interfere with your normal work (including both work outside the home and housework)?	*«+» to answer* Not at all 1 A little bit 2 Moderately 3 Quite a bit 4 Extremely 5

9. These questions are about how you feel and how things have been with you <u>during the past 4 weeks</u>. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the <u>past 4 weeks</u> -

(Circle one number on each line)

#		All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
a	Did you feel full of pep?	1	2	3	4	5	6
b	Have you been a very nervous person?	1	2	3	4	5	6
c	Have you felt so down in the dumps that nothing could	1	2	3	4	5	6

			cheer you up?				
		d	Have you felt calm and peaceful?	1	2	3	4	5	6
		e	Did you have a lot of energy?	1	2	3	4	5	6
		f	Have you felt downhearted and blue?	1	2	3	4	5	6
		g	Did you feel worn out?	1	2	3	4	5	6
		h	Have you been a happy person?	1	2	3	4	5	6
		i	Did you feel tired?	1	2	3	4	5	6

10	During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?	*(+ to answer)* All of the time　　　　　1 Most of the time　　　　2 Some of the time　　　　3 A little bit of the time　4 None of the time　　　　5

11	How TRUE or FALSE is each of the following statements for you?
	Give one answer to each question

#		Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a	I seem to get sick a little easier than other people	1	2	3	4	5
b	I am as healthy as anybody I know	1	2	3	4	5
c	I expect my health to get worse	1	2	3	4	5
d	My health is excellent	1	2	3	4	5

25. DEPRESSION

25	Next I will name the ways you might have felt or behaved. Please answer how often you have felt this way **during the past week.**
	(«+» to answer)

#	Questions	Rarely or none of the time (<1 day)	Some of the time (1-2 days)	Moderate amount of time (3-4 days)	All of the time (5-7 days)
1	I was bothered by things that usually don't bother me.	□ 1	□ 2	□ 3	□ 4

#		Complains			
2	I did not feel like eating; my appetite was poor.	□ 1	□ 2	□ 3	□ 4
3	I felt that I could not shake off the blues even with help from my family or friends.	□ 1	□ 2	□ 3	□ 4
4	I had trouble keeping my mind on what I was doing.	□ 1	□ 2	□ 3	□ 4
5	I felt depressed.	□ 1	□ 2	□ 3	□ 4
6	I felt that everything I did was an effort.	□ 1	□ 2	□ 3	□ 4
7	I thought my life had been a failure.	□ 1	□ 2	□ 3	□ 4
8	I felt fearful.	□ 1	□ 2	□ 3	□ 4
9	My sleep was restless.	□ 1	□ 2	□ 3	□ 4
10	I talked less than usual.	□ 1	□ 2	□ 3	□ 4
11	I felt lonely.	□ 1	□ 2	□ 3	□ 4
12	People were unfriendly.	□ 1	□ 2	□ 3	□ 4
13	I had crying spells.	□ 1	□ 2	□ 3	□ 4
14	I felt sad.	□ 1	□ 2	□ 3	□ 4
15	I felt that people disliked me.	□ 1	□ 2	□ 3	□ 4
16	I could not get "going".	□ 1	□ 2	□ 3	□ 4

26. ANXIETY

How much were you bothered or distressed over the <u>past 4 weeks</u> by:

(«+» to answer)

26	#	Complains	Not at all	A little bit	Moderately	Quite a bit	Extremely
	1	Nervousness and shakiness of inside	□ 0	□ 1	□ 2	□ 3	□ 4
	2	Trembling	□ 0	□ 1	□ 2	□ 3	□ 4
	3	Suddenly scared for no reason	□ 0	□ 1	□ 2	□ 3	□ 4
	4	Feeling fearful	□ 0	□ 1	□ 2	□ 3	□ 4
	5	Heart pounding or racing	□ 0	□ 1	□ 2	□ 3	□ 4
	6	Feeling tense or keyed up	□ 0	□ 1	□ 2	□ 3	□ 4
	7	Spells of terror or panic	□ 0	□ 1	□ 2	□ 3	□ 4

	8	Feeling so restless you couldn't sit still	□ 0	□ 1	□ 2	□ 3	□ 4
	9	Feeling that familiar things are strange or unreal	□ 0	□ 1	□ 2	□ 3	□ 4
	10	Feeling pushed to get things done.	□ 0	□ 1	□ 2	□ 3	□ 4

27&28 Social support relationship and activities

27	**Within the last 3 months, how many times did you go to the following places?** (**Note: ask to** *INDICATE FOR ALL OPTIONS*) *(0 if none)*	1	Theater	_____
		2	Concert	_____
		3	Church	_____
		4	Party	_____
		5	Other entertainment	_____

By selecting the most suitable response option for next questions, please, indicate, how satisfied are you with:

#		Very dissatisfied	Dissatisfied	Neither dissatisfied nor satisfied	Satisfied	Very satisfied
1	… your relationships with your family members	□ 0	□ 1	□ 2	□ 3	□ 4
2	…how much you see your family or friends	□ 0	□ 1	□ 2	□ 3	□ 4
3	…your ability to help others	□ 0	□ 1	□ 2	□ 3	□ 4
4	…your leisure time activities	□ 0	□ 1	□ 2	□ 3	□ 4

Please, indicate:

		Not at all	A little	Moderately	Very much	Extremely
5	How alone do you feel in your life?	□ 0	□ 1	□ 2	□ 3	□ 4
6	To what extent can you count on your friends and relatives when you need them?	□ 0	□ 1	□ 2	□ 3	□ 4

29. DIGNITY

(«+» to answer)

	#	**Please, indicate how much you agree or disagree with each of the following statements concerning yourself:**	Strongly disagree	Disagree	Neither desagree nor agree	Agree	Strongly agree
29	1	I have control over life decisions and choices, such as where to work or when I can	□ 1	□ 2	□ 3	□ 4	□ 5

		leave home.					
	2	I am free to act on my beliefs.	□ 1	□ 2	□ 3	□ 4	□ 5
	3	I feel that others look up to me.	□ 1	□ 2	□ 3	□ 4	□ 5
	4	I make an important contribution to my community.	□ 1	□ 2	□ 3	□ 4	□ 5
	5	Till now, I am pleased with what I have accomplished so far.	□ 1	□ 2	□ 3	□ 4	□ 5
	6	I try to overcome adversity.	□ 1	□ 2	□ 3	□ 4	□ 5
	7	When I am suffering physically, people (other than my family) around me usually do not know it.	□ 1	□ 2	□ 3	□ 4	□ 5
	8	When I make a mistake, I take responsibility for it.	□ 1	□ 2	□ 3	□ 4	□ 5
	9	When things go wrong around me (loss of job, broken relationship…), I usually do not blame others.	□ 1	□ 2	□ 3	□ 4	□ 5
	10	Other people treat me with respect	□ 1	□ 2	□ 3	□ 4	□ 5
	11	I have a high sense of self-respect.	□ 1	□ 2	□ 3	□ 4	□ 5
	12	I have the freedom to exercise my rights as a human being.	□ 1	□ 2	□ 3	□ 4	□ 5
	13	I feel that I am not a burden on my friends/family members.	□ 1	□ 2	□ 3	□ 4	□ 5
	14	I do not feel I need to depend on other people around me to get things done.	□ 1	□ 2	□ 3	□ 4	□ 5
	15	I treat people the same way I like to be treated by them.	□ 1	□ 2	□ 3	□ 4	□ 5
	16	I respect other people.	□ 1	□ 2	□ 3	□ 4	□ 5
	17	People around me (family, friends, coworkers) appreciate what I do for them.	□ 1	□ 2	□ 3	□ 4	□ 5
	18	People come to me for advice or for counsel when making decisions.	□ 1	□ 2	□ 3	□ 4	□ 5

Thank You For Participation

Appendix F2. Questionnaire (Armenian version)

Մասնակցի կոդը _____			
Հարցեր ՈւՊ երեխայի և խնամակալության մասին *(Այժմ ես ցանկանում եմ ՈւՊ երեխայի վերաբերյալ մի քանի հարց տալ)*			

1	Ինչպե՞ս է Ձեր երեխայի առողջությունը հիմա, եթե համեմատեք «Արարատ» առողջարան նրա վերջին անգամ ընդունման ժամանակի հետ:	□ 1	Շատ լավ	
		□ 2	Ավելի լավ	
		□ 3	Նույնը	
		□ 4	Ավելի վատ	
		□ 5	Շատ վատ	
2	Դուք ունեն՞ւմ եք դժվարություններ Ձեր երեխային կերակրելում հետ կապված:	□ 1	Ամբողջ ժամանակ	
		□ 2	Ժամանակի մեծ մասը	
		□ 3	Ժամանակի որոշ մասը	
		□ 4	Ժամանակի փոքր մասը	
		□ 5	Ոչ մի ժամանակ	
3	**Վերջին 4 շաբաթվա** ընթացքում, միջինում օրական քանի՞ ժամ եք ծախսել Ձեր երեխայի խնամքի վրա: (օր. հագցնելու, խաղալու, կերակրելու, բուժման տանելու, վարժություններ կատարելու)	*Խնդրում ենք ասել մոտավոր թիվը* ___ ժ/օր		
4	Ինչպե՞ս եք Դուք գնահատում Ձեր ՈւՊ երեխայի խնամքի ընդհանուր պահանջարկը:	□ 1	Դա անհնար է բավարարել	
		□ 2	Ես դժվարությամբ եմ բավարարում	
		□ 3	Ես հաջողությամբ բավարարում եմ, բայց ինձնից հավելյալ ջանքեր են պահանջվում	
		□ 4	Ես հաջողությամբ բավարարում եմ, առանց հավելյալ ջանքերի	
5	Վերջապես, ըստ Ձեզ, ինչպե՞ս է ՈւՊ երեխայի խնամակալությունն անդրադառնում Ձեր առողջության վրա::	□ 1	Շատ դրական	
		□ 2	Դրական	
		□ 3	Ոչ դրական, ոչ էլ բացասաբար	
		□ 4	Բացասաբար	
		□ 5	Շատ բացասաբար	

ԺՈՂՈՎՐԴԱԳՐԱԿԱՆ ՏՎՅԱԼՆԵՐ		
6	Կարո՞ղ եք, խնդրեմ, ասել Ձեր տարիքը	_____
7	Նշեք ամենաբարձր կրթությունը, որ Դուք ստացել եք:	1 Թերի միջնակարգ (10 տարուց քիչ)
		2 Դպրոց (10 տարի)
		3 Միջին մասնագիտական (10-13 տարի)
		4 Ինստիտուտ/Համալսարան
		5 Հետդիպլոմային/Ասպիրանտուրա
8	Քանի՞ հոգի է ապրում Ձեր	Խնդրում ենք նշել թիվը _____

	ընտանիքում (ներառյալ Դուք)			
9	Դուք ներկայում քանի՞ երեխա ունեք:	Խնդրում ենք նշել թիվը _____		
10	Քանի՞ մինչ 18 տարեկան երեխա է ապրում Ձեր ընտանիքում	Խնդրում ենք նշել թիվը _____		
11	Խնդրում ենք նշել երեխաների սեռը և տարիքը **ըստ ծննդյան հերթականության**: *(«+» պատասխանի դիմաց)*	1.	☐ Male ☐ Female	**please, specify the age ____**
		2.	☐ Male ☐ Female	**please, specify the age ____**
		3.	☐ Male ☐ Female	**please, specify the age ____**
12	Ե՞րբ եք իմացել Ձեր երեխայի ախտորոշման մասին	*Նշել երեխայի տարիքը՝ ամիսներով* _____		
13	Խնդրում ենք պատասխանել, թե հենյալ պնդումներից որն է համապատասխանում Ձեր ներկայիս աշխատանքային կարգավիճակին: *(«+» պատասխանի դիմաց)*	1. Աշխատում եմ 2. Չեմ աշխատում 3. Տանն եմ աշխատում		
14	Ներկայումս Ձեր ամուսնական կարգավիճակը *(«+» պատասխանի դիմաց)*	1. Չամուսնացած 2. Ամուսնացած 3. Բաժանված 4.Այրի		
15	Ներկայումս Դուք զբաղվո՞ւմ եք քրոնիկ վիճակում գտնվող անձի խնամքով (օր՝ տարեցներ, դեմենցիա ունեցող հիվանդներ, հաշմանդամություն ունեցող այլ երեխաներ): *(«+» պատասխանի դիմաց)*	1. Այո 2. ☐ Ոչ	*1a. Եթե այո, խնդրում ենք նշել, թե ում* _____	
16	Ձեր երեխայի խնամքի հարցում Ձեզ որևէ մեկը օգնո՞ւմ է: *(«+» պատասխանի դիմաց)*	1 Այո 2. Ոչ	*1a. Եթե այո, խնդրում ենք նշել, թե ով/ովքեր* _____	
17	Այժմ Ձեր ընտանիքն օգտվո՞ւմ է Փարոսից կամ սոցիալապես անապահով ընտանիքների օգնության որևէ այլ ծրագրից: *(«+» պատասխանի դիմաց)*	1. Այո 2. Ոչ		

18	Դուք վարձո՞վ եք ապրում: *(«+» պատասխանի դիմաց)*	1. Այո 2. Ոչ
19	Քանի՞ սենյականոց է Ձեր տունը (բնակարանը)	_____

| 20 | **20. Նշեք խնդրեմ՝ Ձեր ընտանիքն այս հարմարություններից ո՞րն ունի սարքին վիճակում:**

 («+» պատասխանի դիմաց) |||

#	Հարմարություններ	Ունենք	Չունենք
1	Մշտական տաք ջուր	☐ 1	☐ 2
2	Ավտոմեքենա	☐ 1	☐ 2
3	Ավտոմատ լվացի մեքենա	☐ 1	☐ 2
4	Համակարգիչ	☐ 1	☐ 2
5	Արբանյակային անտենա կամ կաբելային հեռուստատեսություն	☐ 1	☐ 2
6	Ամառանոց	☐ 1	☐ 2

21	Ձեր ընտանիքում քանի՞ հոգի է աշխատում (հաշվեք նաև Ձեզ և նրանց, ովքեր աշխատում են տանը, զբաղվում են սեզոնային գործով կամ արտագնա աշխատանքով)	Խնդրում ենք նշել թիվը _____

22	Միջինում, ամսական որքա՞ն է Ձեր ընտանիքի ընդհանուր եկամուտը: *(«+» պատասխանի դիմաց)*	1 ☐ 50,000 դրամից քիչ 2 ☐ 51,000-100,000դրամ 3 ☐ 101,000-200,000 դրամ 4 ☐ 201,000-300,000 դրամ 5 ☐ Չգիտեմ 6 ☐ Հրաժարվում եմ պատասխանել

	23. Խրոնիկ հիվանդություններ			

23	Do you suffer from any of the following chronic diseases? Դուք տառապո՞ւմ եք հետևյալ խրոնիկ հիվանդություններից որևէ մեկով: (Նշում:*Հշտել հիվանդությունը ախտորոշվել է բժշկի կողմից թե ինքնուրույն*)				

#	Հիվանդության անվանումը	a. Ե՞րբ է ի հայտ եկել (**տարին**)	b. Ո՞վ է ախտորոշել	**1**=Բժիշկը **2**=Ինքնուրույն
1	Արյան բարձր ճնշում			
2	Սրտամկանի ինֆարկտ			
3	Սրտի այլ			

	4	Շաքարախտ		
	5	Կաթված (ինսուլտ)		
	6	Միգրեն կամ այլ ուժեղ հաճախակի գլխացավեր		
	7	Մարսողական համակարգի հիվանդություններ		
	8	Մեջքի ցավ		
	9	Հոդացավ կամ հոդաբորբ		
	10	Քաղցկեղ		
	11	Հոգեկան կամ հոգեբանական խնդիրներ		
	12	Հաշմանդամություն		
	13	Այլ (նշեք):_____		

	24. ԿՅԱՆՔԻ ՈՐԱԿ			

òàôòàôØÜºð: ²Ûë Ñ³ñóÙ³Ý Ýå³³ÏÝ ¿ å³ñ½»É Ò»ñ Ï³ñÍùàÁ Ò»ñ ³éáÕçáõÃÛ³Ý í»ñ³µ»ñÛ³É£ ³ ÑÝ³ñ³íáñáõÃÛáõÝ Ïï³ ï»Õ»Ï³Ý³Éáõ ³ÛÝ Ù³ëÇÝ, Ã» ÇÝãå»ë »Ý Ò»½ ½·áõÙ ¨ áñù³Ýáí »ù Ç Ý×³Ï Ï³ñ»É Ò»ñ ³éûñÛ³ ·áñÍ»ñÁ£

°Ã» ¹áõù íëï³Ñ ã»ù, Ã» áñ å³³ëË³ÝÝ ÁÝïñ»É, ÁÝïñ»ù ³ÛÝ å³³ëË³ÝÁ, áñÝ ³Ù»Ý³× ×ÏÇ Ùáï ¿ Ò»ñ Ï³ñÍùÇÝ£

			(«+» պատասխանի դիմաց)	
24	1	Ինչպե՞ս կգնահատեիք Ձեր առողջությունն ընդհանուր առմամբ:	Գերազանց	1
			Շատ լավ	2
			Լավ	3
			Ոչ այնքան լավ	4
			Վատ	5
	2	Ինչպե՞ս կ·Ý³Ñ³ï»Çù Ò»ñ ³éáÕç³õÃÛáõÝÝ ³ÛÅÙª Ñ³Ù»Ù³ï Ù»Ï ï³ñÇ ³é³çÇ Ñ»ï£	Շատ ավելի լավ այժմ, քան մեկ տարի առաջ	1
			Որոշ չափով ավելի լավ այժմ, քան մեկ տարի առաջ	2
			Այժմ գրեթե նույնը, ինչ մեկ տարի առաջ	3
			Որոշ չափով ավելի վատ այժմ, քան մեկ տարի առաջ	4
			Շատ ավելի վատ այժմ, քան մեկ տարի առաջ	5
	3	3. Ստորև թվարկված են մի քանի առօրյա գործողություններ: Արդյո՞ք Ձեր ներկայիս առողջական վիճակը խանգարում է Ձեզ		

կատարել այդ գործողությունները: Եթե այո, որքանո՞վ:

			(«+» *պատասխանի դիմաց*)		
#	<ins>ԳՈՐԾՈՂՈՒԹՅՈՒՆՆԵՐ</ins>	Այո, շատ է խանգարում	Այո, քիչ է խանգարում	Ոչ, ամենևին էլ չի խանգարում
ա	**Ակտիվ գործողություններ**, օրինակ՝ վազել, ծանրություն բարձրացնել, զբաղվել ակտիվ սպորտաձևերով	1	2	3
բ	**Միջին ակտիվության գործողություններ**, օրինակ՝ սեղան տեղաշարժել, փոշեծծիչով մաքրել, սեղանի թենիս խաղալ կամ պարտեզում աշխատել	1	2	3
գ	Մթերքով պայուսակը բարձրացնել կամ տանել	1	2	3
դ	Աստիճաններով բարձրանալ մի քանի հարկ	1	2	3
ե	Աստիճաններով բարձրանալ մի հարկ	1	2	3
զ	Կքանստել, կռանալ կամ ծնկի գալ	1	2	3
է	Քայլել մոտ մեկ կիլոմետր	1	2	3
ը	Քայլել մի քանի հարյուր մետր	1	2	3
թ	Քայլել հարյուր մետր	1	2	3
ժ	Ինքնուրույն լողանալ կամ հագնվել	1	2	3

4. Արդյո՞ք <ins>վերջին **4 շաբաթվա**</ins> ընթացքում ունեցել եք Ձեր աշխատանքի կամ ամենօրյա այլ գործերի հետ կապված հետևյալ դժվարություններից որևէ մեկը կամ մի քանիսը՝ <ins>Ձեր առողջական վիճակի հետևանքով</ins>:

			(«+» *պատասխանի դիմաց*)	
#			ԱՅՈ	ՈՉ
ա	Կրճատել եք աշխատանքի կամ այլ գործերի վրա **ծախսած ժամանակը**		1	2
բ	**Կատարել եք ավելի քիչ**, քան կցանկանայիք		1	2
գ	Ի վիճակի չեք եղել կատարել **որոշակի տիպի** աշխատանք կամ այլ գործեր		1	2
դ	**Դժվարությամբ** եք կատարել աշխատանքը կամ այլ գործեր (օրինակ՝ պահանջվել են լրացուցիչ ջանքեր)		1	2

5. Արդյո՞ք <ins>վերջին **4 շաբաթվա**</ins> ընթացքում ունեցել եք Ձեր աշխատանքի կամ ամենօրյա այլ գործերի հետ կապված հետևյալ դժվարություններից որևէ

		մեկը կամ մի քանիսը՝ <u>որևէ հուզական վիճակի</u> (օրինակ՝ ընկճվածության կամ մտահոգվածության) հետևանքով:		
		(«+» պատասխանի դիմաց)		
	#		ԱՅՈ	ՈՉ
	ա	Կրճատել եք աշխատանքի կամ այլ գործերի վրա **ծախսած ժամանակը**	1	2
	բ	**Կատարել եք ավելի քիչ**, քան կցանկանայիք	1	2
	գ	Սովորականից պակաս **ուշադրությամբ** եք կատարել աշխատանքը կամ այլ գործեր	1	2

6	<u>Վերջին 4 շաբաթվա</u> ընթացքում Ձեր առողջական կամ հուզական վիճակը որքանո՞վ է խանգարել Ձեր առօրյա շփումներին ընտանիքի, ընկերների, հարևանների կամ այլոց հետ:	*(«+» պատասխանի դիմաց)* Ամենևին 1 Թեթևակի 2 Չափավոր 3 Բավականին 4 Չափազանց 5
7	<u>Վերջին 4 շաբաթվա</u> ընթացքում որքա՞ն **ֆիզիկական** ցավ եք զգացել:	*(«+» պատասխանի դիմաց)* Ոչ մի 1 Շատ թույլ 2 Թույլ 3 Չափավոր 4 Ուժեղ 5 Շատ ուժեղ 6
8	<u>Վերջին 4 շաբաթվա</u> ընթացքում որքանո՞վ է ցավը խանգարել Ձեր նորմալ աշխատանքին (ինչպես տանը, այնպես էլ՝ տնից դուրս):	*(«+» պատասխանի դիմաց)* Ամենևին 1 Թեթևակի 2 Չափավոր 3 Բավականին 4 Չափազանց 5

9	9. Հետևյալ հարցերը վերաբերում են Ձեր ինքնազգացողությանը <u>վերջին 4 շաբաթվա ընթացքում</u>: Խնդրում ենք յուրաքանչյուր հարցի համար ընտրել այն միակ պատասխանը, որն ամենից մոտ է Ձեր զգացածին:

(«+» պատասխանի դիմաց)

#		Ամբողջ ժամանակ	Ժամանակի մեծ մասը	Ժամանակի զգալի մասը	Ժամանակի որոշ մասը	Ժամանակի փոքր մասը	Ոչ մի ժամանակ
ա	Զգացել Ձեզ եռանդով լի	1	2	3	4	5	6

		բ	Եղել շատ նյարդայնացած	1	2	3	4	5	6
		գ	Զգացել այնքան ընկճված, որ ոչինչ չեր կարող Ձեզ ուրախացնել	1	2	3	4	5	6
		դ	Զգացել հանգիստ ու խաղաղ	1	2	3	4	5	6
		ե	Եղել շատ առույգ	1	2	3	4	5	6
		զ	Եղել սրտնեղած ու տխուր	1	2	3	4	5	6
		է	Զգացել լրիվ ուժասպառ	1	2	3	4	5	6
		ը	Եղել երջանիկ	1	2	3	4	5	6
		թ	Զգացել հոգնած	1	2	3	4	5	6

10	_Վերջին 4 շաբաթվա ընթացքում Ձեր առողջական կամ հուզական խնդիրները_ որքա՞ն ժամանակ են խանգարել Ձեր շփումներին շրջապատի հետ (օրինակ՝ չեք կարողացել այցելել ընկերներին, բարեկամներին և այլն):	*(«+» պատասխանի դիմաց)*			
		Ամբողջ ժամանակ			1
		Ժամանակի մեծ մասը			2
		Ժամանակի որոշ մասը			3
		Ժամանակի փոքր մասը			4
		Ոչ մի ժամանակ			5

11	Ըստ Ձեզ, որքանո՞վ է ՃԻՇՏ կամ ՍԽԱԼ հետևյալ պնդումներից յուրաքանչյուրը:

(Ամեն հարցի համար մեկ պատասխան)   *(«+» պատասխանի դիմաց)*

#		Լիովին ճիշտ է	Հիմնականում ճիշտ է	Չգիտեմ	Հիմնականում սխալ է	Լիովին սխալ է
ա	Կարծես թե ես ավելի հեշտ եմ հիվանդանում, քան ուրիշները	1	2	3	4	5
բ	Ես նույնքան առողջ եմ, որքան իմ ճանաչած մարդիկ	1	2	3	4	5
գ	Ես կարծում եմ, որ իմ առողջությունը կվատանա	1	2	3	4	5
դ	Իմ առողջությունը	1	2	3	4	5

		գերազանց է					

<table>
<tr><td colspan="8" align="center">25. ԴԵՊՐԵՍԻԱ</td></tr>
</table>

| 25 | Նշեք, խնդրեմ, թե վերջին 7 օրվա ընթացքում որքան հաճախ եք զգացել Ձեզ այնպես, ինչպես կնկարագրեմ: |||||||

(«+» պատասխանի դիմաց)

#	Հարցեր	Հազվադեպ կամ երբեք (<1 օր)	Երբեմն (1-2 օր)	Բավական հաճախ (3-4 օր)	Մշտապես (5-7 օր)
1	Ես հուզվում էի այնպիսի բաներից, որոնք սովորաբար ինձ չեն հուզում:	□ 1	□ 2	□ 3	□ 4
2	Ես չէի ուզում ուտել: Վատ ախորժակ ունեի:	□ 1	□ 2	□ 3	□ 4
3	Ես չէի կարողանում ազատվել տխրությունից՝ անգամ ընտանիքիս և ընկերներիս օգնությամբ:	□ 1	□ 2	□ 3	□ 4
4	Ես չէի կարողանում ուշադրությունս կենտրոնացնել արածիս վրա:	□ 1	□ 2	□ 3	□ 4
5	Ես ինձ ընկճված էի զգում:	□ 1	□ 2	□ 3	□ 4
6	Ես ամեն ինչ անում էի մեծ դժվարությամբ:	□ 1	□ 2	□ 3	□ 4
7	Ես մտածում էի, որ կյանքս իզուր է անցել:	□ 1	□ 2	□ 3	□ 4
8	Ես վախս էի զգում	□ 1	□ 2	□ 3	□ 4
9	Ես վատ էի քնում:	□ 1	□ 2	□ 3	□ 4
10	Ես ավելի քիչ էի խոսում, քան սովորաբար	□ 1	□ 2	□ 3	□ 4
11	Ես ինձ միայնակ էի զգում:	□ 1	□ 2	□ 3	□ 4
12	Մարդիկ անբարյացկամ էին:	□ 1	□ 2	□ 3	□ 4
13	Ես լացի պոռթկումներ էի ունենում:	□ 1	□ 2	□ 3	□ 4
14	Ես տխուր էի:	□ 1	□ 2	□ 3	□ 4
15	Ես զգում էի, որ դուր չեմ գալիս մարդկանց:	□ 1	□ 2	□ 3	□ 4
16	Ես չէի կարողանում հունի մեջ ընկնել:	□ 1	□ 2	□ 3	□ 4

<table>
<tr><td colspan="7" align="center">26. ՏԱԳՆԱՊԱՅՆՈՒԹՅՈՒՆ</td></tr>
</table>

| 26 | Նշեք խնդրեմ, թե հետևյալ զանգատներն ի՞նչ չափով են անհանգստացրել Ձեզ վերջին 4 շաբաթվա ընթացքում |||||||

(«+» պատասխանի դիմաց)

#	Գանգատներ (վերջին 4 շաբաթվա ընթացքում)	Ամենևին	Մի փոքր	Միջին չափով	Շատ	Չափազանց շատ

	#						
	1	Նյարդայնություն կամ ներքին անհավասարակշռություն	□ 0	□ 1	□ 2	□ 3	□ 4
	2	Դող	□ 0	□ 1	□ 2	□ 3	□ 4
	3	Հանկարծակի անհիմն խուճապ	□ 0	□ 1	□ 2	□ 3	□ 4
	4	Վախի զգացում	□ 0	□ 1	□ 2	□ 3	□ 4
	5	Սրտխփոց կամ հաճախասրտություն	□ 0	□ 1	□ 2	□ 3	□ 4
	6	Լարվածության կամ կաշկանդվածության զգացում	□ 0	□ 1	□ 2	□ 3	□ 4
	7	Մարսափի կամ խուճապի նոպաներ	□ 0	□ 1	□ 2	□ 3	□ 4
	8	Այնպիսի անհանգստություն, որ անկարող եմ տեղում մնալ	□ 0	□ 1	□ 2	□ 3	□ 4
	9	Ծանրք իրերի տարօրինակության կամ անիրական լինելու զգացում	□ 0	□ 1	□ 2	□ 3	□ 4
	10	Ինչ-որ գործ ավարտին հասցնելու պարտադրանքի զգացում	□ 0	□ 1	□ 2	□ 3	□ 4

27&28 Social support relationship and activities

27	Վերջին 3 ամսվա ընթացքում Դուք քանի՞ անգամ եք գնացել հետևյալ վայրերը: (Նշում. Հարցնել բոլոր տարբերակները) *(0, եթե ոչ մի անգամ)*	1	Թատրոն	_____
		2	Համերգ	_____
		3	Եկեղեցի	_____
		4	Խնջույք	_____
		5	Այլ զվարճավայր	_____

28	Ամեն հարցի համար ընտրելով պատասխանի՝ Ձեզ համար ամենաճիշտ տարբերակը, նշեք, խնդրեմ, թե Դուք որքանո՞վ եք գնի… *(«+» պատասխանի դիմաց)*					
	#		Շատ դժգոհ	Դժգոհ	Ոչ դժգոհ, ոչ էլ գոհ	Գոհ	Շատ գոհ

	1	… Ձեր փոխհարաբերություններից Ձեր ընտանիքի անդամների հետ	□ 0	□ 1	□ 2	□ 3	□ 4
	2	…այն ժամանակից, որ հատկացնում եք Ձեր ընտանիքին և ընկերներին	□ 0	□ 1	□ 2	□ 3	□ 4
	3	…ուրիշներին օգնելու Ձեր կարողությունից	□ 0	□ 1	□ 2	□ 3	□ 4
	4	…Ձեր ազատ ժամանակը և հանգիստը կազմակերպելուց	□ 0	□ 1	□ 2	□ 3	□ 4

Խնդրում եմ նշել			*(«+» պատասխանի դիմաց)*		

		Ամենևին	Մի քիչ	Միջին չափով	Շատ	Չափազանց
5	Որքա՞ն միայնակ եք զգում Ձեզ կյանքում:	□ 0	□ 1	□ 2	□ 3	□ 4
6	Ի՞նչ չափով կարող եք հույս դնել Ձեր ընկերների և բարեկամների վրա, երբ նրանց կարիքն ունենաք:	□ 0	□ 1	□ 2	□ 3	□ 4

29. DIGNITY

			(«+» պատասխանի դիմաց)			
29	#	Խնդրում ենք նշել, թե որքանով եք համաձայն այս պնդումներից յուրաքանչյուրի հետ, եթե դրանք վերաբերում են Ձեզ:	Ամենևին համաձայն չեմ	Համաձայն չեմ	Ոչ համաձայն եմ, ոչ էլ՝ ոչ	Համաձայն եմ	Լիովին համաձայն եմ
	1	Ես եմ կայացնում իմ կյանքին վերաբերվող որոշումները, օրինակ՝ որտեղ աշխատել կամ երբ դուրս գալ տնից	□ 1	□ 2	□ 3	□ 4	□ 5
	2	Ես ազատ եմ գործել այնպես, ինչպես ճիշտ եմ համարում իմ համոզմունքով:	□ 1	□ 2	□ 3	□ 4	□ 5
	3	Ես զգում եմ, որ ուրիշները լավ կարծիք ունեն իմ մասին	□ 1	□ 2	□ 3	□ 4	□ 5
	4	Ես կարևոր չափով օժանդակում եմ իմ շրջապատին:	□ 1	□ 2	□ 3	□ 4	□ 5
	5	Ես գոհ եմ այն ամենից, ինչի համար եմ հասել կյանքում	□ 1	□ 2	□ 3	□ 4	□ 5

		մինչն հիմա:				
	6	Ես աշխատում եմ հաղթահարել անհաջողությունները:	□ 1	□ 2	□ 3	□ 4	□ 5
	7	Երբ ես ցավ եմ զգում, ինձ շրջապատող մարդիկ (բացի իմ ընտանիքից) սովորաբար չեն իմանում այդ մասին:	□ 1	□ 2	□ 3	□ 4	□ 5
	8	Ես հանձն եմ առնում իմ գործած սխալների պատասխանատվությունը:	□ 1	□ 2	□ 3	□ 4	□ 5
	9	Ես սովորաբար ուրիշներին չեմ մեղադրում, երբ իմ կյանքում լինում են անհաջողություններ, օրինակ` գործի կորուստ կամ հարաբերությունների խզում:	□ 1	□ 2	□ 3	□ 4	□ 5
	10	Մարդիկ հարգանքով են վերաբերվում ինձ:	□ 1	□ 2	□ 3	□ 4	□ 5
	11	Ես սեփական արժանապատվության շատ արտահայտված զգացում ունեմ:	□ 1	□ 2	□ 3	□ 4	□ 5
	12	Ես ազատ եմ օգտվել իմ մարդկային իրավունքներից:	□ 1	□ 2	□ 3	□ 4	□ 5
	13	Ես զգում եմ, որ բեռ չեմ իմ ընկերների կամ ընտանիքի անդամների համար:	□ 1	□ 2	□ 3	□ 4	□ 5
	14	Գործերս կատարելու համար ես կարիք չունեմ դիմելու ուրիշների օգնությանը:	□ 1	□ 2	□ 3	□ 4	□ 5
	15	Ես մարկանց վերաբերվում եմ այնպես, ինչպես կուզեի, որ իրենք վերաբերվեին ինձ:	□ 1	□ 2	□ 3	□ 4	□ 5
	16	Ես հարգում եմ մարդկանց:	□ 1	□ 2	□ 3	□ 4	□ 5
	17	Ինձ շրջապատող մարդիկ` ընտանիքս, ընկերներս ու գործընկերներս, գնահատում են այն ամենը,	□ 1	□ 2	□ 3	□ 4	□ 5

		ինչ ես անում եմ իրենց համար:					
	18	Որոշում կայացնելիս մարդիկ իմ խորհուրդն են հարցնում:	□ 1	□ 2	□ 3	□ 4	□ 5

Շնորհակալություն մասնակցության համար

Appendix G: CP child characteristics: retrieved from their medical records in "Ararat" Mothers and Child's Health Center

Characteristic	Values		
1. Age at the time of study	**3-17**		
2. Gender	**1**	**Male**	
	2	**Female**	
3. Diagnosis	**1**	**CP**	
	2	**Other**	
4. Diagnosis of Center	**1**	**CP**	
	2	**Other**	
5. Diagnosis by ICD-10	1	G80.0 Spastic quadriplegic cerebral palsy	
	2	G80.1 Spastic diplegic cerebral palsy	
	3	G80.2 Spastic hemiplegic cerebral palsy	
	4	G80.3 Athetoid cerebral palsy	
	5	G80.4 Ataxic cerebral palsy	
	6	G80.8 Other cerebral palsy	
	7	G80.9 Cerebral palsy, unspecified	
6. CP type (sides involved)	1	Unilateral	
	2	Bilateral	
7. CP subtype (limbs involved)		1	Monoplegia
		2	Hemiplegia
		3	Dipeliga
		4	Triplegia
		5	Quadriplegia
The levels of functional limitations			
Levels (1-5)	8. GMFCS	9. MACS	10. CFCS
11. Seizure syndromes	1	Yes	
	2	No	
12. Mental retardation	1	Yes	

	2	No
13. Behavioral problems	1	Yes
	2	No

Appendix H. Study variables by type, measures and sources

Variable	Type	Measure	Source
Independent			
Severity of children motor limitations	Ordinal	Levels I-V	Medical records: Gross Motor Function Classification System (GMFCS)
Level of movement independence in children	Binary	More dependent/More independent	By GMFCS (Medical records)
Communication level of CP children	Ordinal	Levels I-V	Medical records: Communication Function Classification System (CFCS)
Hands function level of CP children	Ordinal	Levels I-V	Medical records: Manual Ability Classification System (MACS)
Seizures among CP children	Binary	Yes/No	Medical records
Daily time spent on CP child caregiving	Binary	< than 7 hours/ > than 7 hours	Questionnaire
Feeding difficulties of CP child	Binary	Yes/No	
Dependent			
Bodily pain in FCGs	Binary	Yes/No	Armenian version of SF-36
FCGs Quality of life	Continuous	Summative score	
FCGs Depressive symptoms	Binary	Yes/No	Center for Epidemiologic Studies Depression (CES-D) scale (Armenian modified version)
FCGs Anxiety symptoms	Binary	Yes/No	Armenian modified version of Symptom Checklist 90 (SCL-

			90)
FCGs Dignity	Continuous	Summative score	18-items Dignity Scale
Intervening			
FCGs' age	Continuous	Num	Questionnaire
FCGs' marital status	Binary	Single/Married	
FCGs' education level	Ordinal	School/Professional technical education/Institute, University, Postgraduate	
FCGs' employment status	Binary	Employed/Unemployed	
FCGs' socio-economic status	Ordinal	High/Middle/Low	
Number of children in FCGs family	Continuous	Numbers	
Sex of the CP child	Binary	Male/Female	
Age of the CP child	Continuous	Numbers	
Age of the children in FCGs family	Continuous	Numbers	
FCGs chronic diseases	Binary	Present/Absent	
FCGs headache symptoms	Binary	Present/Absent	
FCGs back pain	Binary	Present/Absent	
Child's age at the time of diagnosis	Continuous	Numbers	
Provision of care to individuals (other than CP child) with chronic conditions	Binary	Yes/No	
Presence of other people sharing the caregiving of the CP child	Binary	Yes/No	
Outside help with the provision of the care to the child	Binary	Yes/No	
Variable	**Type**	**Measure**	**Source**
Child's health status change compared to last admission in "Ararat" Mothers and Child's Health	Ordinal	Better/The same/Worse	Questionnaire

Center			
FCGs perception about the influence of caregiving on their health	Ordinal	Positive/None/Negative	
FCGs social support, relationships and activities	Continuous	Numbers	

Appendix I. Study participants' recruitment process.

Year	Number of medical records reviewed	Number of children with CP	Number of CP children under 18 years of age	Number of eligible participants	Successful interviews n (%)
2018	99	73	72	35	35 (100.00)
2017	96	80	78	62	58 (90.63)
2016	101	80	56	44	39 (88.64)
2014	150	104	94	43	37 (82.22)
2015	105	78	12	7	7 (100.00)
2013	142	83	39	20	15 (75.00)
2012	151	90	20	6	5 (83.33)
2011	155	82	20	4	4 (100.00)
Total	**999**	**670**	**391**	**221**	**200**

Appendix J. The prevalence of depression, anxiety and chronic diseases among FCGs of children with CP, type 1 diabetes and regular children.[i]

Characteristic[ii]	FCGs of more independent children n=100	FCGs of more dependent children n=100	FCGs of children with type 1 diabetes n=95	FCGs of regular children n=95
Depression	17.0	26.0	20.0	4.0
Anxiety	40.0	46.0	50.5	20.0
≥2 chronic diseases[iii]	71.0	76.0	36.0	16.0

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[i] Data about the prevalence for FCGs of CP children are retrieved from current study, and for caregivers of diabetic and regular children from the study of S. Mkhitaryan et al., (2015): "Mental Health of Mothers of Children with Type One Diabetes".

[ii] Depression and anxiety were defined utilizing the same instruments and same cut-off levels.

[iii] "≥2 chronic diseases" represents the number of FCGs who reported about having 2 or more chronic conditions. The questionnaires investigating this rate were the same in both studies.