ABSTRACT
of the dissertation work for the degree of Doctor of Philosophy (PhD) in the educational program "8 D 10101 Public Health"
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Relevance of the research topic

Demographic changes worldwide indicate a steady increase in the proportion of the older-adults. According to the World Health Organization (WHO), the number of people aged 60 and older is expected to reach 1.4 billion by 2030, representing a significant rise from 1 billion in 2020. Projections suggest that by 2050, this number will double to 2.1 billion. Moreover, between 2020 and 2050, the population aged 80 and older is expected to triple, reaching 426 million (World Health Organization, 2024).

This demographic trend is also evident in the Republic of Kazakhstan. According to a study conducted in collaboration with the United Nations Population Fund (UNFPA), the number of people aged 65 and older in Kazakhstan is projected to double by 2050 compared to 2019, rising from 1.4 million to 3.4 million. Furthermore, their share of the total population is expected to increase from 7.5% in 2019 to 14% by 2050 (UNFPA Kazakhstan, 2021).

Kazakhstan actively demonstrates its commitment to the Sustainable Development Goals (SDG) by integrating them into its State Planning System (UNDP Kazakhstan, 2024). A key aspect of this integration is informal caregiving, which plays a crucial role in achieving these goals. Informal caregiving is closely linked to SDG 3, which focuses on ensuring healthy lives and promoting well-being for all; SDG 5, which aims to achieve gender equality and empower all women and girls; and SDG 10, which seeks to reduce inequalities within and among countries. These goals are interconnected, as informal caregiving directly affects health and quality of life, as well as the distribution of caregiving responsibilities between men and women, shaping social and economic disparities.

The rising prevalence of chronic diseases and disabilities among the older adult leads to a decline in quality of life and an increased caregiver burden, making this a pressing issue (Faronbi & Olaogun, 2017). The growing strain on caregivers is closely tied to the increasing number of caregiving responsibilities, which encompass both basic Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) (Riffin, Van Ness, Wolff, & Fried, 2019). This burden is especially pronounced when caring for older adults with chronic illnesses, dementia, or those in terminal conditions (Connors et al., 2020; Perpiñá-Galvañ et al., 2019). Caring for such individuals demands substantial physical effort, as well as emotional and financial resources, significantly intensifying caregiver burden and reducing their quality of life.

Care-related quality of life and burden can also be shaped by demographic and socioeconomic factors. Older age and lower levels of education among caregivers are generally linked to a higher risk of emotional and physical exhaustion (Chien et al., 2024). Women, who are more likely to take on caregiving responsibilities, tend to be particularly vulnerable (Xiong et al., 2020). When a woman is caring for her spouse, her burden can increase significantly due to emotional attachment and social expectations, which add to her caregiving responsibilities (Bom, Bakx, Schut, & van Doorslaer, 2019). Additionally, ethnicity, particularly being part of an Asian ethnic group, may play a significant role in influencing caregiver burden levels. Some studies associate this factor with a higher burden, while others report conflicting findings (Isac, Lee, & Arulappan, 2021; Pan, Chen, & Yang, 2022).

The weekly hours spent on caregiving and the overall duration of caregiving are significant predictors of caregiver burden (Rodríguez-González, Rodríguez-Míguez, & Claveria, 2021). As caregiving demands increase, personal time for leisure, rest, and social activities becomes increasingly limited. This progressive loss of free time often leads to social isolation, reduced activity levels, and, ultimately, a decline in quality of life (Liao, Wang, Zeng, & Zeng, 2024). In this context, the absence of social support—whether from family, friends, or organizations—further intensifies caregiver burden and negatively affects their overall well-being (Del-Pino-Casado, Frías-Osuna, Palomino-Moral, Ruzafa-Martínez, & Ramos-Morcillo, 2018).

Caregiver burden for the elderly is significantly influenced by national context, including socio-economic conditions and sociocultural characteristics. In countries with well-developed support systems, the strain on caregivers is mitigated by the availability of social and medical resources. Conversely, in nations with limited resources, the primary responsibility for caregiving falls on family members, resulting in physical, emotional, and financial strain. In societies characterized by strong familial traditions, caregiving is predominantly provided by relatives, in contrast, in cultures with established collective support mechanisms, the burden of caregiving is more equitably distributed (UNECE, 2019).

In Kazakhstan, traditional family values play a significant role, caregiving for the elderly is predominantly undertaken by relatives, while formal support for caregivers remains insufficient. This gap in research regarding the impact of these factors on the quality of life and caregiver burden limits the potential for developing effective social and medical assistance measures. Investigating the predictors of caregiver burden is a crucial step in shaping policies aimed at supporting caregivers, reducing their burden, and enhancing their quality of life.

Research aim: To conduct a comprehensive assessment of care-related quality of life, identify its determinants, and develop recommendations aimed at improving the quality of life of informal caregivers providing home-based care for older adults.

Research Objectives

1. Examine the legal, medical, and social aspects of support for informal caregivers of the elderly in the Republic of Kazakhstan.

2. Assess the care-related quality of life and burden experienced by informal caregivers.
3. To examine the key factors influencing caregiving quality of life and burden among individuals providing informal care for older adults.
4. Analyze the perspectives of primary healthcare professionals, social service providers, and informal caregivers on existing medical and social support measures.
5. Develop practical recommendations to improve the quality of life and reduce the burden of informal caregivers.

Scientific Novelty

For the first time in the healthcare system of the Republic of Kazakhstan:

1. A comprehensive assessment of care-related quality of life and burden among informal caregivers of older adults has been conducted, along with an analysis of their key characteristics.
2. Significant factors influencing the quality of life and burden of informal caregivers providing home-based care have been identified.
3. Specific challenges, needs, and demands of informal caregivers have been determined.
4. Using a cross-sectoral approach, incorporating the perspectives of healthcare and social service professionals, an analysis of issues related to informal home-based caregiving has been carried out.
5. Scientifically grounded practical recommendations aimed at improving caregivers' quality of life and reducing their burden have been developed and proposed.

Theoretical Significance of the study

This study deepens the scientific understanding of the multifaceted factors influencing the quality of life and burden of informal caregivers of older adults.

By analyzing legal and regulatory frameworks alongside existing medical and social support measures, the research expands current perspectives on informal caregiving. It highlights critical gaps in existing approaches, providing a foundation for the development of more effective strategies.

The findings can be applied to enhance the theoretical training of students in medical and social sciences and serve as a basis for future research aimed at improving caregiver support systems and optimizing home-based care for older adults.

Practical significance of the study

1. The questionnaires for assessing care-related quality of life and burden can be used by general practitioners, psychologists, social workers, and district nurses. These assessment tools have been integrated into the healthcare practice of urban polyclinics in Astana, Almaty, Semey, and Aktobe.
2. The research instruments for evaluating care-related quality of life and burden have been incorporated into the educational curriculum of West Kazakhstan Marat Ospanov Medical University. They are utilized in the Department of General Practice No. 2 for: 7th-year medical interns specializing in General

Medicine as part of the course "Patient Management Algorithms in General Practice." Residents specializing in General Practice and Family Medicine within the course "Mental Health Issues in Family Medicine."

3. A masterclass on "Assessing Caregiver Burden at the Primary Healthcare Level" was conducted for nursing professionals.
4. The developed methodological recommendations are designed to strengthen intersectoral, team-based, and interdisciplinary collaboration to provide comprehensive support for informal caregivers of older adults. These guidelines aim to reduce caregiver burden and improve their quality of life in Kazakhstan.
5. A brochure has been developed for primary healthcare professionals, offering guidance on informal caregiving and providing validated scales for assessing caregiver burden and quality of life.

Statements submitted for defense

1. Despite efforts to strengthen medical and social support for informal caregiving, the "family-based" model continues to serve as the predominant form of elder care in the Republic of Kazakhstan.
2. Individuals providing home care for older adults face physical, financial, and psychological challenges associated with caregiving, which negatively impact their quality of life and contribute to increased caregiver burden.
3. The key predictors influencing the quality of life and burden of caregivers include the health status of both the caregiver and the care recipient, as well as the caregiver's Kazakh ethnicity. Additionally, caregiver burden is further affected by female gender and the number of hours spent on caregiving tasks.
4. Informal caregivers experience social isolation, difficulties in balancing caregiving with employment, and a need for psychological support and formal assistance.

Approbation of the work

The key findings of this study have been discussed and presented at the following conferences:

III International Scientific and Practical Conference "Family Medicine Residency: Achievements, Challenges, and Prospects" with the presentation "Current State of the Regulatory and Legal Aspects of Medical and Social Assistance for Informal Caregivers of Older Adults in the Republic of Kazakhstan" (Aktobe, 2023).

XVI International Scientific and Practical Conference named after B.A. Atchabarov "Ecology. Radiation. Health," dedicated to the 70th anniversary of NAO "Semey Medical University," with the presentation "Gender Differences in Informal Unpaid Care Among Adults Providing Home-Based Care for Older Adults" (Semey, 2023).

XVI European Public Health Conference with the presentation "Perception of Informal Care for Older Adults by Healthcare and Social Care Workers in Kazakhstan" (Dublin, Ireland, 2023), indexed in the Web of Science database, with the abstract published in the European Journal of Public Health (IF: 3.7; Q1) and Scopus (CiteScore: 5.6; 76th percentile).

Publications

As part of this dissertation research, eight scientific papers have been published, including: Two publications in the international peer-reviewed journal Frontiers in Public Health, indexed in Web of Science (IF: 3.0, Q2) and Scopus (CiteScore: 4.8, 70th percentile); One publication in the international scientific journal Sustainability, indexed in Web of Science (IF: 3.3, Q3) and Scopus (CiteScore: 6.8, 88th percentile); Three publications in scientific journals recommended by the Committee for Quality Assurance in Education and Science of the Ministry of Science and Higher Education of the Republic of Kazakhstan; Two conference abstracts published in the proceedings of international scientific conferences, including one indexed in Web of Science (IF: 3.7, Q1) and Scopus (CiteScore: 5.6, 76th percentile).

Compliance with scientific development priorities or state programs

The dissertation research was conducted as part of the scientific and technical project "Comprehensive Assessment of Informal Caregivers for the Elderly at Home," funded by the Non-Profit Joint Stock Company West Kazakhstan Marat Ospanov Medical University (Order No. 13/2-18-142-N/Q, dated March 14, 2023). It aligns with the priority areas of scientific development outlined in state programs, particularly the "Life and Health Sciences" initiative, approved by the Higher Scientific and Technical Commission for 2022–2024. This area is a key focus of national policy aimed at strengthening the country's scientific competitiveness.

Implementation of Research Findings

The findings of the study have been integrated into practical healthcare at the following institutions: State Municipal Enterprises (SME) on the Right of Economic Management (REM): Primary Healthcare Centers No. 2, 4 and Clinical and Simulation Center at West Kazakhstan Marat Ospanov Medical University (Aktobe); Primary Healthcare Center No. 15, "Alatau" City Hospital and "Smart Health city" (Almaty); Primary Healthcare Center No. 2, Medical Centers: "Pobeda" and "Zhan-Yer" (Abay Region, Semey); Primary Healthcare Center No. 7 (Akimat of Astana). Additionally, the research results have been incorporated into the educational and methodological work of the Department of General Medical Practice No. 2 at West Kazakhstan Marat Ospanov Medical University.

The doctoral candidate's contribution includes organizing and conducting data collection, statistical processing and analysis of the results, as well as their interpretation and discussion. The author independently wrote all sections of the dissertation, obtained authorship certificates, and ensured the implementation of the research findings in practice. For each publication, the candidate contributed to formulating and interpreting the results and key conclusions, discussing their significance, and preparing the manuscript for publication.

Volume and Structure of the Dissertation

The dissertation consists of the following sections: introduction, literature review, materials and methods, research results, conclusion, findings, and practical recommendations. The reference list includes 269 sources. The total length of the dissertation is 116 pages of computer-generated text and is supplemented by 16 tables, 14 figures, and 9 appendices.

Materials and Methods

Study Design: This dissertation employed a mixed-methods design, which included a quantitative cross-sectional study using the structured iMTA Valuation of Informal Care Questionnaire (iVICQ) and a qualitative thematic study involving semi-structured interviews.

For Objective 1 (Scoping Review)

Study Object: Scientific publications from the Medline/PubMed, Web of Science Core Collection, Scopus, and Google Scholar databases, as well as the "Adilet" legal information system of the Republic of Kazakhstan https://adilet.zan.kz/rus.

Study Subject: The existing medical and social support measures for caregivers of older adults in the Republic of Kazakhstan and abroad.

For Objectives 2 and 3

Study Object: Informal caregivers of older adults aged ≥65 years with at least two limitations in performing activities of daily living (ADL).

Study Subject: Caregivers' quality of life and burden related to caregiving, as well as health-related quality of life.

Inclusion Criteria: Individuals aged 18 years or older providing informal care for older adults (≥65 years) with at least two ADL limitation for more than two weeks.

Exclusion Criteria: Individuals under 18 years old; Caregivers of older adults under 65 years old without ADL limitations or providing care for less than two weeks; Individuals with communication impairments.

Sample Size Calculation

To estimate the required sample size for regression analysis, G-Power software was used, accounting for five predictors and an expected explained variance of at least 15%. The calculation was performed with a significance level of $\alpha = 0.05$ and a statistical power of 80% ($1-\beta$). To compensate for potential dropouts or missing data, the sample size was increased by 20%. As a result, the final sample size was set at 396 participants.

Recruitment of participants

The study was conducted in four cities: two metropolitan areas – Astana and Almaty - and two large cities – Semey and Aktobe. Through healthcare facilities: Individuals aged 65 and older with ADL limitations were identified, and their family members were invited to participate via phone calls or during home visits.

Research Tools

The iVICQ questionnaire was developed by the Institute of Health Policy and Management at Erasmus University Rotterdam (iBMG; http://www.ibmg.nl) and the Institute for Medical Technology Assessment (iMTA; http://www.imta.nl). Designed as a robust and structured tool, iVICQ offers a comprehensive framework for assessing various aspects of informal caregiving.

The Informal Care Valuation Questionnaire (iVICQ)

The iVICQ consists of multiple sections and includes:

1. General characteristics of caregivers and care recipients, such as age, gender, education level, employment status, household income, health status (EQ-5D), and level of activities of daily living (ADL) (Barthel Index).
2. Characteristics of the informal care situation, including care-related quality of life (CarerQol-7D) and burden (Caregiver Strain Index, CSI+) (Al-Janabi, Frew, Brouwer, Rappange, & Van Exel, 2010).
3. Assessment of the informal care situation (ASIS) – satisfaction with caregiving (Hoefman, Van Exel, & Brouwer, 2011); Self-Rated Burden (SRB) – subjective burden of informal caregiving; Process Utility (PU) – value derived from the caregiving process (Brouwer, van Exel, van den Berg, van den Bos, & Koopmanschap, 2005); Perseverance Time (Pt) – caregivers' estimation of how long they can continue providing care.

Characteristics of caregivers

The majority of caregivers in the study were women, making up 79.3% (95% CI: 75; 83) of the participants. The average age was 42.7±12.7 years. Most respondents were married (63.7% (95% CI: 58; 68)), identified as Kazakh (63.5% (95% CI: 59; 68)), and had a higher education degree (52.3% (95% CI: 47; 57)). Among those with higher education, 49.3% (95% CI: 44; 54) combined caregiving with employment. Only 30% (95% CI: 25; 34) reported having had the option to choose before assuming caregiving responsibilities.

Characteristics of care recipients

The majority of care recipients were women, with a mean age of 73.5±7.8 years. Age-related health issues were reported in 45% (95% CI: 42; 52), while 31.3% (95% CI: 28; 38) had chronic illnesses. Severe dependence in Activities of Daily Living (ADL) was observed in 42.5% (95% CI: 40; 50). Most older adults (78% (95% CI: 77; 85)) lived with family members, while 22% lived alone. Forty-three and a half percent (43.5% (95% CI: 39; 48)) of caregivers provided care for their own parents or parents-in-law.

Statistical analysis

Statistical analyses were conducted using IBM SPSS Statistics version 22.0 (IBM Corp.) and RStudio version 4.3.1 (Posit Software, PBC). The Shapiro-Wilk test was used to assess the normality of data distribution. Quantitative variables with a normal distribution were reported as M±SD, while those with a skewed distribution were presented as Me (IQR, 25–75%). Categorical variables were expressed as absolute and relative frequencies (%) with 95% confidence intervals (CI).

For group comparisons, the Mann-Whitney U test was applied for non-normally distributed data, while the chi-square test (χ^2) was used for categorical variables, with statistical significance set at $p < 0.05$. Factors influencing quality of life and caregiver burden were examined using univariate and multivariate regression analyses. Quality of life (CarerQOL) was assessed through linear regression, whereas caregiver burden (CSI+) was analyzed using logistic regression. Spearman's correlation was used to detect multicollinearity. The backward stepwise regression method with Wald's criterion was applied in the multivariate model. Regression coefficients (β for linear models, OR for logistic models), p-values, and 95% CIs were reported.

For EQ-5D-5L analysis, the "eq5d" package in RStudio was utilized. The frequency of responses indicating "some problems" across five dimensions (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) was assessed, along with the 10 most common health state profiles. Cronbach's alpha coefficient was used to evaluate the reliability of the scales. Statistical significance was set at $p < 0.05$ for all analyses.

For objective 4

Study object: The study population included primary healthcare professionals (general practitioners, psychologists, social workers, and nurses), social service professionals, and informal caregivers providing home-based care for older adults.

Study subject: The research focused on respondents' opinions, judgments, and perspectives regarding the existing measures of medical and social support for caregivers, as well as their needs.

Sampling method and recruitment of participants: The sample was formed dynamically throughout the study, adapting based on newly emerging questions and data analysis. Data collection was concluded upon reaching the "saturation point," the stage in the research process when no new themes or aspects emerged from further data analysis (Moser & Korstjens, 2018). Key informants, including primary healthcare and social service professionals, were selected through purposive sampling from a randomly chosen list of institutions in Aktobe. Caregivers were recruited from individuals who had previously participated in the survey and reported a caregiver burden score of CSI+ ≥7.

Data processing

Content analysis was applied to examine the collected data, using both inductive and deductive approaches. Audio recordings of interviews were transcribed verbatim into text format using Microsoft Word. The coding of categories was conducted using MAXQDA 2022 (VERBI Software, Germany).

For objective 5

Based on the integration of quantitative and qualitative data, practical recommendations were developed to optimize the support system and improve the quality of life and burden of caregivers.

Results of the study

Results for objective 1

The analysis of regulatory and legal acts governing the provision of medical and social care for caregivers in the Republic of Kazakhstan identified the following key themes: 1) The concept of "informal caregiver", 2) Legislative regulation of elderly care, 3) Social guarantees for caregivers, 4) Balancing professional responsibilities with caregiving duties, 5) Caregiving allowance payments, 6) Healthcare support.

Results for objective 2

The health-related quality of life mean score of caregivers (EQ-VAS) was 84.1±13.4. Additionally, the frequency of “some problems”- indicating moderate impairments in one of the five health dimensions (mobility, self-care, usual activities, pain/discomfort, anxiety/depression) - was analyzed. The findings revealed that 35.8% (95% CI: 31; 40) of respondents reported symptoms of anxiety and depression, while 31.4% (95% CI: 22; 30) experienced pain and discomfort. The average EQ-VAS score, reflecting health-related quality of life in older adults, was 40±14.6. The most significant health issues among the elderly were mobility limitations (99.7% (95% CI: 98; 99)) and difficulties with performing usual daily activities (98.2% (95% CI: 91; 99)).

The mean score for caregiving-related quality of life (CarerQol-7D) was 87.2±49.5, while the mean CarerQol-VAS score was 8.1±1.9. A total of 40.5% (95% CI: 36; 45) of respondents reported high satisfaction with their caregiving role, 49.8% (95% CI: 49; 56) indicated moderate satisfaction, and 9.8% (95% CI: 7; 13) reported no satisfaction. Approximately one-third of respondents reported experiencing challenges in their relationships with older family members, difficulties related to their physical health, struggles with balancing caregiving responsibilities and daily activities, and financial strain. Additionally, about one-quarter of caregivers acknowledged experiencing psychological distress.

The analysis of caregiver burden (CSI+) among informal caregivers revealed the presence of "positive aspects" of caregiving in 52.8% (95% CI: 48; 58) of respondents, "mild to moderate" burden in 32.0% (95% CI: 28; 37), and "significant" burden (CSI+ ≥7) in 15.3% (95% CI: 12; 19) of participants. A more detailed examination of the negative aspects of caregiving showed that nearly half of all respondents reported experiencing emotional and physical strain, as well as additional responsibilities that demanded their time. About one-third of caregivers had to adjust their work schedules and felt completely overwhelmed by their caregiving duties. Furthermore, 40% of participants stated that their caregiving responsibilities-imposed restrictions on them and led to changes in their personal plans, while one-third experienced alterations in their family structure. The average burden level on the Self-Rated Burden (SRB) scale was 3.1±2.8. Notably, 47.3% of respondents scored five or higher, indicating an increased level of caregiver burden.

Results for objective 3

To assess the impact of key factors on caregiving-related quality of life (CarerQol-7D), a univariate linear regression analysis was performed. According to regression coefficients, being female was significantly associated with a higher caregiving-related quality of life (4.55 (95% CI: 1.08; 8.02)) (β coeff.(95% CI)), which was 4.5 times higher compared to males. As caregiver age increased, quality of life declined (-0.19 (95% CI: -0.30; -0.08)). Caregivers of Kazakh ethnicity reported a significantly higher quality of life (10.64 (95% CI: 5.68; 15.59)) compared to caregivers of other ethnic backgrounds. Living with children was associated with improved quality of life (5.51 (95% CI: 1.93; 9.09)), whereas having children over the age of 18 was linked to a decrease in quality of life (-2.04 (95% CI: -3.62; -0.45)). Better health status in both caregivers (0.37 (95% CI: 0.27; 0.47)) and care recipients (0.26 (95% CI: 0.17; 0.36)) was positively associated with an improved quality of life among caregivers. However, providing care for older adults who were fully dependent in ADL significantly increased the likelihood of a decline in caregivers' quality of life (-5.88 (95% CI: -10.22; -1.54)). Additionally, caregiving duration (-0.01 (95% CI: -0.02; 0.001)), caregiving intensity (-1.04 (95% CI: -1.76; -0.33)), and time spent on caregiving responsibilities (-0.06 (95% CI: -0.10; -0.02)) all had a negative impact on caregivers' quality of life.

In the univariate logistic regression analysis examining factors associated with caregiver burden (CSI+), women were found to have a statistically significantly higher likelihood of experiencing burden compared to men (5.97 (95% CI: 1.82; 19.57) (OR (95%CI)). Caregivers aged 65 and older were also more likely to experience a higher level of burden (5.00 (95% CI: 1.54; 16.19)) compared to younger caregivers. Additionally, caregivers of Kazakh ethnicity had a lower likelihood of developing caregiving-related burden (0.26 (95% CI: 0.11; 0.60)) compared to Russian and other ethnic groups Better health status of both caregivers (0.96 (95% CI: 0.94; 0.98)) and care recipients (0.96 (95% CI: 0.95; 0.99)) reduces the likelihood of caregiver burden. Caregivers supporting for older adults in terminal conditions experienced a significantly higher burden (7.71 (95% CI: 1.47; 40.24)) compared to those caring for older adults with other health conditions. Furthermore, caregiving for older adults who were fully dependent on others for Activities of Daily Living (ADL) was associated with a higher burden (2.89 (95% CI: 1.32; 6.37)). An increase in caregiving intensity (1.16 (95% CI: 1.003; 1.35)) and total time spent on caregiving responsibilities (1.02 (95% CI: 1.008; 1.02)) was significantly associated with a higher likelihood of increased caregiver burden.

Subsequently, a multivariate linear regression analysis was performed to identify statistically significant independent factors. The results of the multivariate analysis CarerQol-7D demonstrated that Kazakh ethnicity ($\beta = 9.86$ (95% CI: 5.12; 14.41)), the caregiver's health status ($\beta = 0.31$ (95% CI: 0.19; 0.42)), and the care recipient's health status ($\beta = 0.13$ (95% CI: 0.03; 0.24)) were statistically significant predictors of caregiving-related quality of life.

In the multivariate logistic regression analysis with CSI+ as the dependent variable, female gender (OR: 4.87 (95% CI: 1.38; 17.10), caregiver health status (OR= 0.96 (95% CI: 0.94; 0.98), and time spent on caregiving tasks (OR= 1.01 (95% CI: 1.002; 1.02) were identified as significant independent predictors of caregiver burden. In contrast, caregivers of Kazakh ethnicity (OR = 0.28 (95% CI: 0.10; 0.73)) had a lower likelihood of experiencing high burden compared to those of other ethnic backgrounds.

Results for objective 4

Following the mixed-methods design of our study, a qualitative study was conducted after the completion of the quantitative phase. This phase included caregivers (n=10) who had previously completed the survey and reported a caregiver burden score of CSI+ ≥7, with a mean age of 40.9±10.8 years. The analysis identified the following key themes: 1) The physical and psychological impact of caregiving on caregivers, 2) Work-Care Balance and Social Isolation, 3) Gender roles in elderly caregiving, 4) Lack of support from healthcare and social services, 5) Caregivers' needs and requirements, 6) Low awareness and knowledge levels.

Additionally, an analysis was conducted on the perspectives of primary healthcare specialists and social service workers regarding the existing medical and social support measures for informal caregivers in Kazakhstan. A total of ten specialists from urban polyclinics and social services in Aktobe participated in the study, with a mean age of 40,3±11,89 years. The analysis identified four key themes: 1) Absence of caregiver identification, 2) Filial responsibility, 3) Healthcare system challenges, 4) Mismatch between formal care and informal caregivers.

Results for objective 5

The integration of quantitative and qualitative data, along with an analysis of regulatory frameworks and a review of best international practices in supporting informal caregivers, provided a comprehensive understanding of existing challenges. This process highlighted critical gaps in the support system and formed the basis for evidence-based recommendations to enhance caregivers' quality of life and improve the effectiveness of social and healthcare support mechanisms.

Conclusions

1. The analysis of regulatory frameworks in the Republic of Kazakhstan indicates a predominant "family-based model" of elderly care, where primary responsibility falls on relatives. Government support for caregivers is only partially regulated, highlighting the need for further improvements in the legal framework governing this area.
2. The mean CarerQol-7D score was 87.2 ± 49.5, and the mean CarerQol-VAS score was 8.1 ± 1.9. However, only 40.5% (95% CI: 36; 45) of respondents reported satisfaction with their caregiving role. The primary factors negatively affecting care-related quality of life included deterioration of physical health (39% (95% CI: 34; 42)), limitations in daily activities (34% (95% CI: 30; 39)), financial strain (32% (95% CI: 27; 36)) and difficulties in relationships with care recipients (27.8% (95% CI: 24; 32)). According to the CSI+ scale, 32% (95% CI: 28; 37) of caregivers experienced mild to moderate burden, while 15.3% (95% CI: 12; 19) reported a significant burden. Additionally, 49% (95% CI: 44; 53) reported emotional difficulties, 37% (95% CI: 34; 42) of respondents experienced physical exhaustion, 29% (95% CI: 24; 33) had to adjust their work schedules, and 29% (95% CI: 25; 34) felt completely overwhelmed by their caregiving responsibilities.
3. Factors positively associated with care-related quality of life included Kazakh ethnicity ($\beta = 9.82$ (95% CI: 5.12; 14.42)), satisfactory self-rated health ($\beta = 0.31$ (95% CI: 0.19; 0.42)), and the health status of the care recipient ($\beta = 0.13$ (95% CI: 0.03; 0.24)). Conversely, caregiver burden was associated with being female (OR = 4.87 (95% CI: 1.38; 17.10)), caregiver health (OR = 0.96 (95% CI: 0.94; 0.98)), and increased time spent on caregiving responsibilities (OR = 1.01 (95% CI: 1.002; 1.02)). At the same time, caregivers of Kazakh ethnicity were less likely to

experience caregiving burden compared to those of other ethnic backgrounds (OR = 0.28 (95% CI: 0.10; 0.73)).

4. An analysis of perspectives from primary healthcare professionals, social service workers, and informal caregivers revealed that the existing medical and social support system fails to fully meet caregivers' needs. Primary healthcare and social services do not have a system for identifying caregivers, and their concerns are handled using standard approaches that do not take the specific challenges of caregiving into account.
5. The findings of the study on the care-related quality of life and burden among informal caregivers, as well as the current measures of medical and social support in the Republic of Kazakhstan, highlight the need for comprehensive actions aimed at strengthening public health. These actions include: the implementation of a systematic mechanism for identifying caregivers and assessing their quality of life and care-related burden; consideration of the possibility of providing temporary disability leave; expansion of access to psychological and informational support; specialized training for healthcare and social workers on interacting with this population group; and the improvement of the integration of primary health care into the caregiver support system