PhD Dissertation

尼泊尔减少残疾老年人家庭照顾者照顾负担的教育项目效果

Efficacy of Educational Program for Reducing Caregiving Burden of Family Caregivers of Older Adults with Disability in Nepal

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Efficacy of Educational Program for Reducing Caregiving Burden of Family Caregivers of Older Adults with Disability in Nepal

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尼泊尔针对家庭照护者照护残疾老年人负担的教育项目有效性研究

摘要

引言：人口老龄化已成为全球性的公共卫生问题，残疾和慢性疾病老年人的比例不断上升。尼泊尔老年人口也正在迅速增长，75 岁及以上人口年增长率为 3.8%。随着慢性疾病和伤害的增加，残疾的风险也随之增加。老龄化本身也增加了残疾和严重残疾的患病率。由于生育率下降、潜在支持比下降、家庭规模缩小、缺乏正式的卫生保健设施以及对家庭照护者的支持不足，家庭照护者照护残疾老年人成为日益严峻的挑战。家庭照护者是向慢性病、绝症或残疾家庭成员提供家庭照护的支柱，也是最具挑战性的照护体系。他们需要直接参与日常生活活动 (ADL) 支持、疾病相关症状的照护以及必要照护的管理。照护本身可能会影响他们作为主要家庭照护者的就业状况、继续教育、财务和社会生活，因为持续照护的责任。照护残疾老年人可能是一种极具压力的经历，尤其是照护负担感。研究表明，长期的负担可能导致情绪压力、照护者倦怠、精神问题、免疫力下降、身体健康状况变差、与健康相关的生活质量下降、死亡率上升、工作参与度下降、经济问题、社会隔离，甚至影响将受照护者机构化的决定。

与老年人相关的增加照护负担的因素包括：在 ADLs 上高度依赖、需要更长的 ADLs 提供时间、在四项或更多 ADLs 项目或 IADLs 方面存在障碍、存在认知障碍，特别是痴呆及其行为和心理症状、存在抑郁和行为问题等。同样，与家庭照护者相关的可能增加照护负担的因素包括：在 ADLs 或 IADLs 或在舒适、医疗或情感支持方面照护时间更长、身体健康状况差、患有严重的抑郁和焦虑、为女性、存在经济问题、教育程度低、是配偶或其他与老年人有关系的人以及与老年人同住。

尼泊尔政府无法应对老年人日益增长的照护需求，因为其现有的卫生保健系统有限，因此，开发减轻家庭照护者照护负担的教育干预项目非常重要。世界卫生组织 (WHO) 建议的由训练有素的非专业人士提供的心理教育干预，可以代表像尼泊尔这样的低收入国家应对老龄化人口卫生需求的一种可行且有效的替代方案。对于像尼泊尔这样

时间有限、信息通信技术不发达、缺乏喘息或支持小组的国家，基于罗伊适应模型的结合知识技能的心理教育干预对照护者家庭完整性是有效的。在像尼泊尔这样不发达的国家提供心理教育干预的最佳方法是通过面对面地进行多次个人互动。

目的：识别与家庭照护者照护残疾老年人负担相关的因素；在分析家庭照护者经历并审查尼泊尔不同级别课程的基础上，开发心理教育干预措施；并确定心理教育项目对减轻家庭照护者照护残疾老年人负担的有效性。

方法：题为“尼泊尔针对家庭照护者照护残疾老年人负担的教育干预有效性研究”的研究分四个阶段完成。第一阶段：工具验证和预试验。英语版本的六项认知障碍测试 (6-CIT) 和社会支持评定量表 (SSRS) 在专业翻译和研究者本人的帮助下翻译成尼泊尔语。然后，五名护理专家（一名精神科护理讲师、一名退休教授和一名研究专家）独立测量工具的内容效度指数。由马哈拉杰冈杰护理学院的护理学院、成人健康护理学院和护理研究学院院长组成的专家审查委员会审查了翻译版本并讨论了每个组成部分。在所有专家达成共识后，产生了尼泊尔语版本 6-CIT 和 SSRS 问卷的预最终版本。然后，使用描述性横断面调查，通过非概率目的抽样技术，对居住在托卡市的 60 名照护残疾老年人至少一项 ADLs 和四项 IADLs 达 3 个月以上的家庭照护者进行预试验，其目的是识别 SSRS 的可靠性以及确定其余部分的可行性。数据通过结构化访谈问卷收集，该问卷包括尼泊尔语版本的老年人和社会人口学特征、ADLs 和 IADLs 障碍状况、六项认知障碍量表、社会支持评定量表、照护相关变量、扎瑞特负担访谈问卷和生活质量问卷（SF 36），数据收集时间为 2021 年 9 月至 10 月。第二阶段：描述性横断面研究。使用非概率目的抽样技术，对居住在加德满都区的塔拉凯什沃尔市和戈卡尔内什沃尔市的 430 名家庭照护者进行描述性横断面调查，时间为 2022 年 1 月至 3 月，目的是识别与照护负担相关的因素。第三阶段：心理教育干预项目的开发。通过一系列研究和与专家的咨询以及 3 名家庭照护者的反馈，开发了心理教育干预项目。使用非概率目的抽样技术，对 7 名参与预试验的家庭照护者进行一系列深入访谈的定性研究，时间为 2022 年 2 月至 3 月，以探索家庭照护者的照护经历。研究者还审查了尼泊尔从小学到高中的课程内容。在深入访谈的结果和审查尼泊尔学校教育体系内容的基础上，研究者对已发表的文章进行了范围审查，重

点关注老年人的发展任务、可能存在于老年人中的老龄化变化、老年人心理变化的早期识别和预防措施以及在不同生活情况下使用的各种减压活动，这些文章来自不同的文献来源，特别是 Google Scholar、Hinari、PubMed 以及不同的网站。研究者用英语和尼泊尔语开发了教育干预项目的结构和内容。通过与专家的多次咨询，开发了心理教育干预项目的内容。然后，研究者还对参与预试验、照护负担评分超过 20 分且能读写尼泊尔语的 3 名家庭照护者提供了 5 次教育干预。根据英国医学研究委员会 (BMRC) 的指南，通过进一步的专家咨询以及来自三名家庭照护者的反馈，对心理教育干预项目进行了最终确定，时间从 2022 年 9 月到 2023 年 7 月。第四阶段：心理教育干预。进行了随机对照试验的真实验研究，以评估心理教育干预项目的有效性。为此，从描述性横断面研究中照护负担的 281 名参与者（163 名来自塔拉凯什沃尔市作为干预组，118 名来自戈卡尔内什沃尔市作为对照组）中，通过简单随机抽样技术选择了每个市的 30 名家庭照护者。使用验证的教育项目，在 2023 年 8 月至 9 月期间，向干预组的 30 名家庭照护者提供了 5 次心理教育干预。在心理教育干预 3 个月后，研究者使用与描述性横断面研究相同的访谈问卷，在 2024 年 1 月从干预组和对照组收集数据。在 2024 年 1 月至 2 月期间，向控制组的所有参与者提供了心理教育干预项目。

结果：由于本研究分四个阶段完成，因此研究结果按以下顺序进行：第一阶段：预试验的结果，第二阶段：横断面调查，第三阶段：通过定性深入访谈、审查尼泊尔教育体系（特别是基础教育体系）和范围审查，开发和完善心理教育干预项目的过程，第四阶段：使用心理教育干预项目对干预组进行干预，对照组不进行干预，进行随机对照试验研究。

预试验第一阶段的结果显示，23.3% 的家庭照护者经历了照护负担。同样，大多数（80.0%）家庭照护者表示社会支持程度为中等。百分之百的家庭照护者对所有问卷项目都做出了回应，这意味着问卷清晰易懂。预试验中尼泊尔语版本社会支持问卷的克伦巴赫 α 值为 0.794。

横断面调查第二阶段的结果显示，74.7% 的老年人患有三种或以上的身体疾病，20.0% 的老年人记忆力受损。同样，60.9%、26.5% 和 12.6% 的老年人分别有 1-2、3-5 项 ADLs 障碍和完全障碍，27.9% 的家庭照护者患有至少一种健康问题。除此之外，家庭照护者照护负

担的平均得分为 24.73±10.14，34.7% 的家庭照护者没有或只有轻微的照护负担，而 57.9%、6.5% 和 0.9% 的家庭照护者分别有中度负担、中重度负担和重度负担。与老年人相关的照护负担的可能因素是老年人的疾病状况 {COPD (0.017)、高血压 (0.000)、瘫痪 (0.000)、泌尿问题 (0.041)、胃肠道问题 (0.001)}、他们的健康问题类别 (0.000)、记忆状况 (0.003)、ADLs 障碍状况 (0.000) 和 IADLs 障碍状况 (0.008)。与家庭照护者相关的照护负担的可能因素是他们的职业 (p=0.015)、经济状况 (p=0.047)、居住类型 (0.006) 和家庭类型 (p=0.001)、家庭规模 (p=0.038)、感知到的额外压力 (p=0.000)、照护者的健康状况 (p=0.000)、照护持续时间 (p=0.042)、每天照护时间 (p=0.000) 和夜间睡眠时间 (p=0.000)。照护负担的预测因素是患有高血压的老年人，其调整后优势比为 1.96 (CI: 1.12-3.43; p=0.09)，患有胃肠道问题的老年人，其调整后优势比为 3.33 (CI: 1.35-8.21; p=0.009)，与部分障碍状况相比，完全障碍的调整后优势比为 0.37 (CI: 0.16-0.87; p=0.022)，与一年或更长时间足够相比，经济状况不足一年的调整后优势比为 1.79 (CI: 1.05-3.05; p=0.031)；与三年或更长时间照护相比，照护 3-35 个月的调整后优势比为 0.60 (CI: 0.36-0.98; p=0.043)，与每天照护时间少于 8 小时相比，每天平均照护时间 8 小时或更长时间的调整后优势比为 2.84 (CI: 1.14-7.06; p=0.025)。

研究的第三阶段包括通过进行定性深入访谈、审查尼泊尔的教育体系（特别是基础教育体系）和范围审查，开发和完善心理教育干预项目的过程。对七名家庭照护者进行的定性研究的结果发现，残疾老年人家庭照护者的照护经历是复杂的。一些人认为积极的经历是自我满足和自我激励、学习新技能、感受到良好的家庭支持以及亲戚或邻居对照护行为的赞赏。然而，他们也认为一些消极的经历是身心疲惫、社会隔离、家庭支持不足、照护男性老年人压力更大以及认为生活方式发生了变化，例如辞职、中断教育甚至压抑自己的愿望和抱负。此外，大多数家庭照护者面临经济困难。除此之外，在社会文化方面，他们表示大多数老年人更喜欢儿子而不是女儿。研究结果还表明，家庭照护者对生理和心理老龄化变化的认识较低，并且对老龄化变化存在一些误解。研究者还发现，在修订的学校教育课程中删除了与老年人相关的内容，并且至今还没有开设选修课程。在对不同来源的文献中可用的不同发表文章进行范围审查后，研究者用英语和尼泊尔语开发了题为“照顾我的老年家庭成员和我自己”的心理教育干预项目的

结构和内容，共五个部分。心理教育干预的内容包括：1) 回顾上一节（从第二节开始）；2) 描述本节内容；3) 本节总结；4) 家庭作业；5) 讨论任何疑问。第一节的内容是老年人的发展任务、可能的生理变化和 Om 吟唱的意识以及本节总结和家庭作业。第二节的内容是了解可以帮助克服老年人可能的生理变化的不同活动、正念冥想意识、练习 Om 吟唱以及练习 Om 吟唱的家庭作业。第三节的内容是心理问题的危险因素和迹象以及遗忘的管理、家庭作业是练习 Om 吟唱和正念冥想。第四节的内容是痴呆及其管理、阿尔茨海默病及其管理，特别是沟通技巧，以及继续练习 Om 吟唱和正念冥想的家庭作业。同样，第五节的内容是老年人的心理社会问题、支持有心理社会问题的人的策略以及情绪及其管理的意识，以及练习 Om 吟唱、正念和情绪自我管理的家庭作业。在本阶段研究的最后，研究者通过咨询专家、与家庭照护者分享以及尼泊尔语专家，开发了尼泊尔语的心理教育干预项目。

在第四阶段的研究中，研究者通过随机对照试验选择了 30 名参与横断面调查的家庭照护者，他们对干预组和对照组都有照护负担。研究者使用随机对照试验，仅对干预组的家庭照护者进行了 5 次个人教育干预。在干预 3 个月后，研究者发现，与对照组相比，干预组的照护负担较低，干预组的照护负担平均得分为 14.6±5.96，而对照组的照护负担平均得分为 28.70±5.62。比较照护负担的平均得分，曼-惠特尼 U 检验和威尔科克森 W 检验的 p 值均小于 0.01，具有统计学意义。

结论：基于三个阶段的研究结果，研究者得出了本研究的结论。描述性横断面调查研究表明，超过四分之一的家庭照护者存在健康问题，所有家庭照护者都认为社会支持程度为中等，但近五分之一的家庭照护者每天需要照护 8 小时或更长时间。除此之外，近五分之一的家庭照护者白天无法得到休息时间，甚至有五分之二的他们晚上无法获得充足的睡眠。本研究还表明，近三分之二的家庭照护者有照护负担。照护负担的可能因素是老年人的多种共病状况（COPD、高血压、瘫痪、泌尿和 GI 问题）、心理状况、ADLs 和 IADLs 障碍状况；以及家庭照护者的职业和经济状况、居住地、家庭类型和规模、感知到的健康状况以及感知到的额外压力，包括照护持续时间、每天照护时间和睡眠时间。照护负担的预测因素是患有高血压、胃肠道问题的老年人，与部分障碍状况相比，完全障碍的老年人，经济状况不

足一年，与三年或更长时间照护相比，照护 3-35 个月以及每天照护时间（≥8 小时）。

定性深入访谈研究的结果表明，残疾老年人家庭照护者的照护经历中存在一些积极和消极的经历，他们对老龄化变化的认识较低，并且仍然对老龄化变化存在一些误解。缺乏关于老龄化变化的意识项目，因为在学校教育中没有包含相关内容。然后，范围审查的结果有助于用英语和尼泊尔语编写心理教育干预项目的结构和内容，并通过与专家咨询、对参与定性研究的 3 名家庭照护者进行教育干预，最终确定了文化上可接受的教育项目。

同样，第三阶段研究的结论是，在家庭照护者自己的家庭环境中，通过提供多组分的个人心理教育干预，可以有效减轻残疾老年人家庭照护者的照护负担，因为干预组在接受连续 5 天的教育干预后，照护负担低于对照组。

基于以上结论，建议尼泊尔政府需要在学校课程中重新加入关于老龄化变化及其相关管理的内容，以减少对老龄化家庭成员的误解，根据家庭照护者的经济状况拨付预算，并通过地方当局和地方卫生机构实施并持续开展针对所有老年人家庭照护者的意识项目。

关键词：照护负担；照护经历；教育项目的有效性；家庭照护者；残疾老年人

分类号：

Efficacy of Educational Program for Reducing Caregiving Burden of Family Caregivers of Older Adults with Disability in Nepal

Abstract

Introduction: The Increasing ageing population with disability and chronic illness has become a global health problem. The population of older adults aged 75 years and above is also rapidly growing in Nepal. The prevalence of chronic diseases, injuries, severity of disability, and risk of disability are increased because of ageing. High migration rates of youth, low fertility rates, a reduced potential support ratio, and small family sizes are possible reasons for the increasing caregiving burden. Besides these, a shortage of institutionalized health services and a lack of formal support to family caregivers may also increase the caregiving burden.

Family caregivers are the pillar of providing care to those members who are chronically ill or disabled. They need to be directly involved in performing activities of daily living (ADL), care for disease-related symptoms, and manage necessary care. Continuous caregiving responsibility may affect their employment status, further education, finances, and social life. Caring for older adults with disabilities may be a highly stressful experience. Evidence shows that prolonged burden may lead to emotional stress, burnout, and psychiatric problems. Long-term burden may compromise an individual's immunity, poor physical health, worsening health-related quality of life, and increased mortality. It also deteriorates work participation, financial problems, and social isolation, and may influence decisions to institutionalize care recipients.

The Government of Nepal could not address the rapidly increasing care needs of older adults with its limited health care system. Therefore, it is important to develop an educational intervention program for reducing caregiving burden. To meet the health demands of the ageing population, psycho-educational intervention is a feasible and effective method for low-

income countries like Nepal. With limited time, underdeveloped information and communication technologies, and the absence of respite or support groups, educational interventions based on Roy's Adaptation Model, combined with knowledge and skills, are effective in reducing the care burden of family caregivers. The best method for delivering educational intervention is the individual multiple sessions' interaction through face-to-face.

Objective: To identify factors associated with caregiving burden of family caregivers of older adults with disability; to develop psycho-educational intervention, and to determine the efficacy of psycho-educational program for reducing caregiving burden of family caregivers of older adults.

Methods: The study entitled "The efficacy of educational intervention for reducing caregiving burden of family caregivers of older adults with disability in Nepal" was followed mixed-method study. A descriptive cross-sectional survey design was used for conducting a pilot study and identifying factors associated with the caregiving burden of family caregivers of older adults with disability. For a qualitative study, a phenomenological study design was used. To determine the efficacy of educational intervention for reducing the caregiving burden of family caregivers, a randomized clinical trial study was used. For the pilot study, phenomenological study and pretesting of psycho-educational intervention, Tokha Municipality was the research setting, and the family caregivers of older adults with disability were the sampling population. Similarly, Tarakeshwor and Gokarneshwor Municipalities and family caregivers of older adults residing in these two municipalities were the sampling population of this study. For educational intervention, those family caregivers who had a caregiving burden were identified in the descriptive study.

The sample sizes for the pilot study were 60 family caregivers of older adults with disability; for the descriptive cross-sectional study was 430 family caregivers; for the phenomenological study, 7 family caregivers; and for the randomized clinical trial, 60 family caregivers (30 in intervention and 30 in control groups). The inclusion criteria were 1)

Family caregivers of older adults who were aged 60 years and above and have disability at least in one ADLs and unable to perform more than three IADLs (cooking, shopping and using telephone); family caregivers who were most of the care or assistance for their older adults at least three months. The exclusion criteria for this study were family caregivers who could not communicate clearly, as measured by the Six-Item Cognitive Impairment Test (Score ≥11) and formal caregivers who were paid by family members for taking care of their older adults.

A structured interview questionnaire in the Nepalese language was used for the pilot study, descriptive cross-sectional study, and randomized clinical trial. The structured interview questionnaire consists of five sections. Section I: Socio-demographic characteristics of older adult and family caregiver; status of impairment in ADLs and IADLs, status of care provision related variables, section II: Nepalese version of six-item cognitive impairment test scale; section III: Nepalese version of Social support rating scale; Section IV: Nepalese version of 22-items Zarit Burden Interview Questionnaire and Section V: Nepalese version of quality of life questionnaire (SF-36). For a phenomenological study, an in-depth interview guideline in the Nepalese language and an audio-recorder, and field notes were used.

First phase: Instrument validation and pilot study. The English version of the Six-Item Cognitive Impairment Test (6-CIT) and Social Support Rating Scale (SSRS) were translated into the Nepalese language with the help of a bilingual translator and the researcher herself. A nursing experts group comprised of one lecturer from psychiatric nursing, two associate professors from adult health nursing, one retired professor, and one research expert independently rated the content validity index of the Nepalese version of 6-CIT and SSRS. After that, a pilot study was conducted using a descriptive cross-sectional survey through a non-probability purposive sampling technique among 60 family caregivers of older adults with at least one ADL and four IADLs for ≥3 months residing in Tokha Municipality with the objectives of identifying reliability of SSRS and also identifying feasibility of remaining parts of instrument.

Data were collected through the Nepalese version of a structured interview questionnaire from **September to October 2021**.

Second Phase: A Descriptive cross-sectional survey was conducted among 430 family caregivers of older adults with disability through a non-probability purposive sampling technique, residing in Tarakeshwor and Gokarneshwor Municipalities of Kathmandu District. Data were collected by using the Nepalese version of a structured interview schedule **in January 2022 to March 2022** with the objective of identifying factors associated with caregiving burden.

Third Phase: Evidence Generation and Development of Educational Intervention Program. **Evidence was generated through a phenomenological study, revision of the basic education system of Nepal, and a narrative review. The phenomenological** study was **conducted among 7 family caregivers** of older adults with disability, who participated in a pilot study by using a non-probability purposive sampling technique **in February 2022 to March 2022 to** explore caregiving experiences of family caregivers. Likewise, by **reviewing the curriculum** of primary to higher secondary level education in Nepal, **older adults-related course contents were missing** in the new curriculum. Based on the findings of a phenomenological study, the structure and contents of the extensive narrative review were done based on published articles available in different sources of literature, especially Google Scholar, Hinari, PubMed, and from different websites. Based on evidence collected from a phenomenological study, review of the education system of school-level curriculum, and narrative review, a first draft of the Nepalese and English versions of educational intervention was developed by following British Medical Research Council (BMRC) guidelines from September 2022 to July 2023.

Fourth Phase: A Randomized Clinical Trial study was conducted to evaluate the efficacy of the educational program. For this, 60 family caregivers who had been caregiving were included in a descriptive study. Thirty family caregivers out of 163 of Tarakeshwor as the intervention group and 30 out of 118 of Gokarneshwor municipality as the control group were selected by using a simple random sampling technique. Educational

program was delivered to 30 family caregivers of Tarakeshwor Municipality in 5 sessions by using the Nepalese version of the validated educational program from August 2023 to September 2023. For the control group, no intervention was rendered. After 3 months of educational intervention, the data were collected by using the same interview questionnaires used in a descriptive cross-sectional study from both the intervention and control groups in January 2024. The educational program was also given to 30 family caregivers of Gokarneswhor Municipality as an intervention group, which was in 5 sessions from January 2024 to February 2024.

Results: As the current study was completed in 4 phases, the findings of this study were in the following sequence: findings of pilot study, cross-sectional survey, phenomenological study, narrative review and educational program, and randomized clinical trial.

First phase: Instrument validation and pilot study. The findings of the content validity index provided by 5 experts on the Nepalese version of 6-CIT and SSRS were 0.90 and 0.75, respectively. Similarly, 23.3% of family caregivers had experienced caregiving burden; 80.0% of family caregivers expressed a moderate level of social support. Cent percent of family caregivers gave responses to all items of the questionnaire as which means the questionnaire was clear and understandable. The Cronbach's Alpha value of the Nepali version of the social support questionnaire found in the pilot study was 0.794.

Second Phase: Descriptive cross-sectional survey. The findings of a descriptive cross-sectional survey depicted that the mean score of caregiving burden of family caregivers was 24.73±10.14, 34.7% of family caregivers had no or mild, 57.9%, 6.5%, and 0.9% had moderate, moderate to severe, and severe burden, respectively. Older adults' related possible factors of caregiving burden were diseases of older adults {COPD (0.017), hypertension (0.000), paralysis (0.000), urinary problems (0.041), gastrointestinal problems (0.001)}, their health problems category (0.000), memory status (0.003), impairment status of ADLs (0.000) and impairment status of IADLs (0.008). Family caregivers' related possible factors of caregiving burden were their occupation (p=0.015), economic status

(p=0.047), residency types (0.006) and types of family (p=0.001), family size (p=0.038), perceived extra stress (p=0.000), caregivers' health status (p=0.000), duration of care providing (p=0.042), daily care providing hours (p=0.000), and sleep duration at night (p=0.000). The predictors of caregiving burden were older adults with hypertension as its adjusted odds 1.96 (CI: 1.12-3.43; p=0.09), with gastrointestinal problems as its adjusted odds 3.33 (CI: 1.35-8.21; p=0.009), complete impairment with its adjusted odds 0.37 (CI: 0.16-0.87; p=0.022) as compared with partial impairment status, insufficient economy for less than 1 year with adjusted odds 1.79 (CI: 1.05-3.05; p=0.031) as compared with sufficient for equal or more than one years; the caring duration for 3-35 months with adjusted odds 0.60 (CI: 0.36-0.98; p=0.043) as compared to 3 year or above and the average daily caring hours for 8 or more with adjusted odds 2.84 (CI: 1.14-7.06; p=0.025) as compared to daily caring hours less than 8 hours.

Third Phase: Evidence gathering and Development of educational program. As evidence gathering, the findings of a phenomenological study revealed that family caregivers had mixed experiences. Some perceived positive experiences as self-satisfied and self-motivated, learned new skills, perceived good family support, and received appreciation. Some perceived negative experiences as physical or mental exhaustion, social isolation, insufficient family support, more stress while caring male older adult, and perceived lifestyle changes, quitting a job, discontinuation of education, or even suppression. Likewise, most of the family caregivers faced financial difficulties. Besides these, socio-culturally, they expressed that most older adults preferred a son over a daughter. The finding also showed that they had low awareness of physiological and psychological ageing changes, and also had some misconceptions about ageing changes.

While reviewing school school-level curriculum found that older adult-related contents were deleted from the environment, health, and population course book of grade IX, while the Government of Nepal only added older adult-related curriculum in the +2 curriculum as an elective course, but still now this course has not started. This review showed that lack of awareness of ageing.

Based on evidence generated from phenomenological study, review

of education system of school level curriculum, further narrative review was done on following sequences: developmental task of older adults, ageing changes that could exist among older adults, early identification and preventive measures of the psychological changes of older adults, caring for older adults having dementia and Alzheimer's diseases and different stress management activities for family caregivers.

The first draft of the educational program was written in both Nepalese and English. Then, this first educational intervention program was further reviewed by 5 expert committee. Suggestions were adapted in the educational program.

Three family caregivers who participated in a phenomenological study introduced 5 sessions of an education intervention. After one week of intervention, verbal and written feedback from them was collected.

At the end of this phase of research, the researcher developed a psycho-educational intervention program in the Nepalese language with the consultation of experts, sharing with family caregivers and a bilingual expert. The final version of an educational program entitled "Care of My Older Family Member and Myself" in both English and the Nepalese language was developed after further review by the expert team.

The structure and sessions of the educational program were 1) review of the previous session (from the second session), 2) description of the content of the session, 3) summary of the session, 4) exercises at home, and 5) discussion about any doubts. The contents of psycho-educational intervention were developmental task of older adults, possible physiological changes, awareness on different activities that can overcome the possible physiological changes of older adults, risk factors and signs of psychological problems and management of forgetfulness, dementia and its management, Alzheimer and its management especially communication techniques, psychosocial issues of older adults, strategies for supporting people with psychosocial issues and awareness on emotions and its management and awareness and home assignment on practice of Om chanting and mindfulness meditation.

Fourth Phase: Conducting a Randomized Clinical Trial Study

The findings of the randomized clinical trial depicted that after 3 months of educational intervention for 30 family caregivers residing in Tarakeshwor Municipality in 5 sessions of an individual educational program for an intervention group, data was collected from 30 family caregivers of each group residing in Tarakeshwor and Gokareneshwor municipality, respectively. The findings of caregiving burden of the intervention group were low as compared with the control group, with the mean score of caregiving burden being only 14.6±5.96 intervention group, while in the control group the mean score was still as high as 28.70±5.62. In comparing the mean score of caregiving burden in both groups, it depicted statistically significant association was found p-value of the Mann-Whitney U test less than <0.01. To further quantify the magnitude of the intervention effect, the calculated value of Cohen's d was 2.43. This represents a very large effect size, indicating that the educational intervention had a substantial impact on reducing the caregiving burden of family caregivers of older adults with disability.

Conclusion:

Through expert review, the content validity index of the Nepalese versions of 6-CIT and SSRS were 0.90 and 0.75, respectively. The pilot study showed 23.3% of family caregivers had experienced burden. The Cronbach's Alpha value of the Nepali version of the social support questionnaire was 0.794.

The findings of a descriptive cross-sectional survey study conclude that nearly two-thirds (65.3%) of family caregivers have a burden. The predictors of caregiving burden are hypertension, gastrointestinal problems, complete impairment in ADLs of the older adults and low economic status, continuous caring for 3-35 months, and daily caring hours (≥8) of the family caregivers.

The findings of a phenomenological study conclude that family caregivers have positive and negative experiences, have low awareness of ageing changes, and still have misconceptions regarding the perception of ageing changes. There is a lack of awareness programs regarding ageing changes, as no content is included in up to school-level education. Then, the findings of the narrative review help to write the structure and contents

psycho-educational intervention program in both English and Nepalese language and finalize a culturally accepted educational program by consulting with experts, delivering educational intervention to 3 family caregivers who participated in the phenomenological study.

Likewise, the findings of the randomized controlled study conclude that after providing educational intervention in five sessions at their home setting, the caregiving burden is found to be low compared with the control group.

Based on conclusion, it is recommended that Government of Nepal need to include contents of ageing changes and its related management in school level curriculum again to reduce misconception towards ageing family members, allocate budget for the needy family caregivers based on their economic status and implement and continue awareness program to all family caregivers of older adults from local authorities as well as local health institutions.

Keywords: Caregiving burden; caregiving experiences; efficacy of educational program; family caregivers; older adults with disability
Category number

PREFACE

Understanding the existential issue of increasing care needs of an ageing population, the single family concept, and limited funds to use health care facilities, their family caregivers experience caregiving burden as I perceived from my high school. This work before you is the result of this passion and my desire to discover ways to reduce caregiving burden. From interacting with family members of aged persons and my own family experience, I continuously thought about why family members expressed burden and neglected their seniors. Over the years, I have followed and put in many years of research and hard work to find answers to my queries. Thus, as a doctoral degree candidate, I get an opportunity to select the research entitled "Efficacy of Educational Program for Reducing Caregiving Burden of Family Caregivers of Older Adults with Disability in Nepal". Engaging family caregivers in sharing experiences, and also my engagement in the nursing profession, gave me the necessary wherewithal to start thinking of this research work.

As I exited this challenging journey, I learned many things that have enhanced this study. From steering the difficulties of data collection to balancing academic commitments, each step taught me valuable instruction in determination and critical thinking. This would not have been possible without the encouragement and support of many people.

I am deeply grateful to my mentor and supervisor, Professor Dr Siyuan Tang and his entire team, for his guidance and support throughout this project. His expertise and encouragement were invaluable in my research. A special thanks to all my colleagues who teach in Maharajgunj Nursing Campus, Institute of Medicine, for their support and for providing me with an enriching research environment. Lastly, I am grateful to my family and friends for putting up with my long working hours and often distracted self. I hope my work will inspire others to take up further

research and study in this field.

Raj Devi Adhikari Ghimire

Xiangya School of Nursing, CSU, Changsha; May 2025

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English abbreviations used in this study

Abbreviations	English full name	Chinese full name
ADLs	Activities of Daily Living	
IADLs	Instrumental Activities of Daily Living	
WHO	World Health Organization	
GoN	Government of Nepal	
6-CIT	Six-item Cognitive Impairment Test	
SSRS	Social Support Rating Scale	
ZBI	Zarit Burden Interview	
PCS	Physical Component Summary	
MCS	Mental Component Summary	
SLC	School Leaving Certificate	

Chapter 1 Background and Significance and Value of the Study

1.1 Background of the Study

1.1.1 Increasing number of older adults with disability and chronic diseases

Worldwide, people are living longer, drastically changing population demographics [1] and increasing the caring needs of older adults [2, 3]. Aging itself increased the risk of dementia, osteoarthritis, cardiovascular disease, mobility disabilities, and stroke among older adults [4].

The increasing population of older adults with disability and chronic illnesses globally is becoming a public health problem [5] . The population of older adults in Nepal is also rapidly increasing. The estimated population of Nepal is more than 2.5 million older adults, with the annual growth rate of those aged 75 years and above being more than 3.8% [6]. The prevalence of disability at the age of 60 was 40% and increased by 75% at the age of 80[7]. The prevalence of severe disability is only 20% at the age of 60 years, but is 50% at the age of 80 and above[8]. As people get older, they may experience increasing risks of chronic diseases, including physical/mental health problems, and multimorbidity. Nearly two-thirds of older adults have multi-morbidity in most countries, and 90% of them may have at least one chronic disease [9].

As people live longer, they are more likely to experience health challenges associated with ageing, such as physical frailty, cognitive decline, and chronic illnesses. These conditions require assistance and support mainly from family members to provide care. Family caregivers may face heightened expectations because older relatives require more intensive and prolonged assistance as they age [10]. Older adults have multifaceted care needs that usually require complex treatment in the community or healthcare institutions [11]. This type of care is usually provided by family members, mostly adult children or spouses [12]. In Nepal, also, persons having chronic diseases utilized 80% of outpatient health services for medical follow-up and treatment [13].

Family caregivers are unpaid non-health professionals who assist their family members with functional limitations in various tasks that enable them to perform personal care, activities of daily living, transportation, and access to community and health care services [14].

1.1.2 Increasing caregiving burden

Providing continuous long-term care at home to older adults with disabilities is becoming a stressful condition for family members. The reasons behind these are youth migration[15], decreased total fertility rate[15], declining potential support ratio [5] and having a small family size. Other possible reasons are limited governmental or private health care facilities[15] and a lack of a formal support system for family caregivers[15]. Thus, family caregivers are the pillar a long-term home-based care for their chronically ill or disabled, though this is the most difficult part of the health care system [16-19]. The scope of caregiving for older adults includes providing support in ADLs, care of disease-related symptoms, and management of care [18] Caregiving can affect their employment status, educational prospects, finances, and social life of the key family caregivers because of continuous care provision for their disabled family members[20]. The physical, psychosocial, or financial hardships of family caregivers are known as the caregiver burden [21, 22]. Prolonged sense of burden may lead to emotional stress [23], psychiatric problems [23-26], poor physical health [22-27], and worsening health-related quality of life [22, 23, 27, 28]. It may lead to financial problems [23-25], compromised immunity [22, 27], and also increased risk of mortality [22,27]. Prolonged feeling of burden may increase feelings of social isolation [22,27], caregiver burnout [29], and deteriorate work participation [28]. Prolonged burden may influence decisions to institutionalize care recipients [23,29].

Informal care is defined as unpaid support provided by family members, close relatives, friends, and neighbors, and is essential. Informal caregivers perform a variety of tasks, and informal caregivers rarely receive training for these responsibilities [30]. Family caregivers are unpaid non-health professionals who assist their family members with functional limitations in various tasks that enable them to perform personal care, activities of daily living, transportation, and access to community and health care services [14]. Informal caregivers perform a variety of tasks, provided by family members, mostly adult children or spouses [12]. But informal caregivers rarely receive training for these responsibilities [30].

The caregiver burden refers to the multifaceted strain that a caregiver experiences over time while caring for others, and if high, can have negative consequences such as decreased quality of care, decreased caregiver quality of life, and poor physical and psychological health of the caregiver [31, 32].

1.1.3 Factors associated with caregiving burden

Some conditions that may affect the caregiving burden include dependence on the daily activities of the older person, providing care for long hours, having a lower level of education, conflicting relationships between the older adult and caregiver, living in the same house as the care recipient, being socially isolated, experiencing financial stress, and having no choice to be a caregiver [33, 34]. The consequences of the caregiver burden include negative impacts for both the caregiver and the care recipient. This burden threatens caregivers' physical, psychological, emotional, and functional health and may adversely impact their overall well-being. Caregivers facing this burden may reduce the level of care they provide and neglect the support for older adults [32]. However, strengthening the support network and receiving guidance on care are described as protective factors that minimize the burden [32].

1.1.4 Educational program

The Government of Nepal (GoN) could not address the increasing caring needs of older adults with disability by utilizing its existing limited health care systems; therefore, the educational program is crucial for reducing the caregiving burden of family caregivers of older adults with disability [5]. For meeting the health demands of ageing, educational interventions delivered by trained non-specialists could be a feasible and effective measure for low-income countries like Nepal. Educational interventions delivered through face-to-face individual in multiple sessions are shown to be effective [5]. Likewise, knowledge and skill-based educational intervention [35]. Based on Roy's Adaptation Model [36, 37] is effective for maintaining the integrity of family caregivers who have limited time, underdeveloped information communication technologies, absence of respite or support groups [37,38]. The best method for delivering education intervention is individual multiple sessions' interaction through face-to-face[5].

1.2 Significance of the Study

(1) This study found factors associated with the caregiving burden of family caregivers of older adults with disability in Nepal.

(2) This interventional program might be the first educational program based on training for local people delivered through face-to-face individual intervention for reducing caregiving burden.

(3) This educational program could reduce the caregiving burden of family caregivers of older adults with disability.

(4) This educational program might be a reference material for nursing professionals working in nursing education and nursing services.

(5) This educational program might be a reference material for the government of Nepal to develop a short-term training program for family members.

Chapter 2 International and Domestic Research Status and Developmental Trends

2.1 International Research Status and Development Trends

2.1.1 International Research Status on Caregiving Burden

2.1.1.1 Older Adults and their Family Caregivers

The global population of older adults is expected to reach nearly 2.1 billion in 2050, while in 2017, their population was only 962 million. Among them, the aged 80 years or over persons are projected to increase more than threefold between 2017 and 2050 (from 137 million to 425 million)[38]. Older adults gradually become dependent on family members to maintain their personal hygiene, optimal well-being and health care, social life, and financial activities[39, 40] either by ageing itself or the prevalence of chronic diseases. About 23% of the total global burden of diseases is shown among them[41].

Likewise, aging itself declines the health conditions and increases the prevalence of chronic diseases among older adults[42, 43] . Aging also increases the prevalence of disability among them[8]. Major causes of disability are unipolar depressive disorders; hearing loss; back and neck pain; Alzheimer's disease and other dementias; osteoarthritis; falls, chronic obstructive pulmonary disease, and diabetes mellitus [44].

As family is the main institution for home-based care for older people[17], family members are providing home care for older adults have disability without any training and remuneration because of technological advancements, shorter hospital stays, and the expansion of homecare technology[45]. They assist in ADLs[46, 47] (bathing, grooming, dressing, transfers, eating or communication, meal preparation, home safety, community mobility, and financial management)[48, 49] and other health care activities[50]. High demand and continuous heavy load of caregiving for older people at home has become a challenging issue for family caregivers[51], because besides caregiving, the family members have additional responsibilities, such as working or looking after other family members[46]. Globally, more women are facing problems while involved in caring roles and breadwinner roles[23].

The trends of research in the academic field have been increasing since 2006, as Nepal gave priority to older adults; still, only limited articles are available for review.

Evidence shows that few studies have been conducted among family caregivers of persons having different chronic diseases or conditions in Nepal. They were the burden of family caregivers of persons with psychiatric or mental illness [52-55], persons with maintenance hemodialysis[56, 57], spinal cord injuries [58], autism disorder[59], and older adults[60]. Among them, two-thirds of studies show that almost all (95.13%-100%) caregivers had of burden [55-59]. However, only one study was done among family caregivers of older adults shows that only 12% of them had a care burden, as this study included the majority (70%) of family members of older adults with no limitation in ADLs [60].

For two decades, the Government of Nepal (GoN) has initiated older adults-related welfare activities. The GoN has provided a non-contributory pension [61] for older adults age 68 years and above, or widows aged 60 years and above, pension for civil servants, free health services, and financial support for the treatment of fatal chronic diseases for older adults aged 75 years and above [62] and financial support for old age homes. The GoN endorses a 50% discount on travel costs and reserving seats for older adults in public transportation. The GoN has coordinated activities with the United Nations or international organizations working for the welfare of older people. A geriatric health-related course has been included in graduate-level health programs [63-65].

2.1.1.2 Factors associated with caregiving burden

The researcher explored factors associated with the caregiving burden of family caregivers of older adults through an extensive literature review. Evidence shows that factors that increase caregiving burden are categorized into two groups:

(1) *Older adults' related factors*

Evidences show that any chronic diseases or conditions that make older adults more dependent on ADLs [22,66-70]; demanding a longer time for caring for ADLs [22, 27, 28, 71, 72]; decreasing functional status [53, 73, 74]; having a higher degree of disability[28,75]; or decreasing or impairing IADL [75-77]; and having impairment in four ADLs[78]. Besides these, decreasing or impairing the cognitive functions of older adults[71,79-81] or having dementia [71,74,82,83] and its behavioral and psychological symptoms[71,77,80]; having depression with behavioral problems [51,69,74,75,77]; having severe neuropsychiatric symptoms [81]; Parkinsonism [28], and cerebrovascular diseases[28] are also known factors of caregiving burden among family caregivers. Likewise, other disease conditions: cancer [22,72]; heart failure [22]. Chronic obstructive pulmonary

disease [22]; fracture [74] or have a risk of falls [75]; end-of-life care [72]; needs of intensive care [85]; insomnia and incontinence [28]; as well as a history of previous hospitalization [75]; or in care transitions stages [72] of older adults also an increase in caregiving burden. The known socio-demographic factors of older adults that increase caregiving burden are gender [75]; younger age (between 60 to 74 years) [69,72]; retired [82]; and being a head of family [70].

(2) *Family caregivers' related factors*

Those family caregivers who are engaging for longer hours of caregiving in ADLs or IADLs or in comfort, medical or emotional support [66,67,68,78,81, 84]; not getting any training [72]; having heavy care load [49] or providing nocturnal care [82]; and providing intensive care [49] for the older adults. Other family caregivers' related factors are poor physical health, as compared with before caregiving started [27,49,72,79]; have higher degrees of depression and anxiety [49,71, 73]; have a feeling of social isolation [72] ; have a lack of choice in being a caregiver [72]; have lower life satisfaction [72] ; poor health-related quality of life [86]; and poor self-efficacy [39]. Likewise, socio-demographic factors related to family caregivers that increase caregiving burden include being female [23, 39,49, 50 72, 85]; having financial stress [25,40,51,70,72]; having a low educational status [25,51, 72, 84]; being a spouse [23, 72, 84] or relationships with older persons [41,82]; living with older adults [51,72]; gender [41]; age [27] or younger [82] ; married [51]; their employment status [41]; ethnicity [72]; and lack of help [84] or poor family functioning [51].

In the context of Nepal, deeply rooted sociocultural structures such as the caste system and traditional gender roles significantly shape the dynamics of family caregiving. Individuals from lower castes often face systemic discrimination, limited access to healthcare resources, and economic marginalization, which can exacerbate the emotional and financial burden of caregiving. Similarly, caregiving responsibilities are predominantly assigned to women, reflecting entrenched gender expectations that prioritize women’s roles within the household. This unequal distribution of care work not only places a disproportionate burden on female caregivers but also limits their opportunities for education, employment, and personal well-being. Understanding how these cultural and social factors influence caregiving roles is essential for developing targeted interventions that alleviate caregiver burden and promote equitable healthcare support systems in Nepal.

2.1.1.3. Intervention programs for reducing caregiving burden

2.1.1.1.1 Historical development of family caregivers' support interventions

According to Griffin et al (2015), in the 1990s, most of the educational interventions were focused on supporting family caregivers of persons having dementia[86]. The contents of educational interventions were problem-solving skills for managing behavioral problems of patients and reducing environmental hazards but excluding the psychosocial needs and support for the family caregivers [86]. Later, educational interventions focused on patients' safety and behavior problems through skill training and a problem-solving approach, as well as training of family caregivers on cognitive behavioral techniques for managing their stress and burden [86]. Nowadays, most educational interventions are becoming more disease or condition-specific to the persons who are suffering and their family caregivers [86].

2.1.1.1.2 Major classification of interventions

The report critically reviewing the interventional research used for the family care givers of persons with dementia by Gaugler et al. (2017) recommended seven themes that were identified from qualitative content analysis were as follow: (1) contents of the interventions were case management, education, cognitive stimulation, psychosocial support, physical activity intervention, relaxation-yoga, respite and skills building; (2) face-to-face, through computer or telephone, video or web-based platforms were used for delivering; (3) audience were individual or dyadic or group; (4) contents were standardized or tailored; (5) multi-domain or singular content; (6) intensity of sessions were fewer than six or more than six; and (7) delivering source were professional or peer-led [87] .

2.1.1.1.3 Scoping review for identifying the effectiveness of the family caregiver support program

The findings of a scoping review (WHO, 2017) revealed that the effective interventions were psychotherapy and multicomponent interventions based upon educational interventions, support, and skill training [5]. Likewise, the educational interventions and psychotherapy were beneficial for reducing caregiving burden, depression, subjective well-being of family caregivers, and enhancing their knowledge or skills for symptom management of care receivers. However, psychosocial interventions produce small to moderate effects [5]. Multicomponent interventions were more effective than single-component interventions: either support or training [5].

Similarly, respite care services were not found to significantly reduce the caregiver's burden, depression, or anxiety [5].

The report of a systematic review conducted by McGuigan et al. (2024) [88] titled "Effectiveness of interventions for informal caregivers of individuals with end-stage chronic illness" found that most of the interventions were delivered face-to-face, at home by involving both the patient and caregivers. Interventions delivered at home may be reflective of the preference of patients at end-of-life to be cared for, and to die, at home [89]. Although significant changes were reported in both dyad and caregivers-only interventions, dyad interventions were more frequently associated with favorable outcomes for caregivers [90-94]. These findings emphasized the need for improvement in educational interventions [95] and highlighted the need for tailored, culturally appropriate psychosocial interventions [96, 97]. The Interventions delivered face-to-face at their home environment showed mixed results [92]. Although significant changes were reported for dyad interventions and caregivers' only interventions, dyad interventions were more frequently associated with favorable outcomes for caregivers [90-94]. The psychosocial interventions were more likely to bring positive outcomes in reducing caregiving burden/strain, depression, anxiety, self-efficacy, and distress [91-94, 98, 99] while the psychoeducational interventions could not significantly improve psychosocial outcomes, except for quality of life [90, 100].

2.1.1.1.4 Evidence of theoretically based educational intervention programs

Evidence showed that educational programs that were based on nursing models, especially, Neuman System Model[101] and Roy's Adaptation Model[26, 36] were effective for reducing the caregiving burden of family caregivers. Educational intervention combined with training and support group service based on the Neuman System Model, delivered through face-to-face interactions for family caregivers of persons with dementia, was significantly effective for reducing the caregiver burden of family caregivers [101]. Likewise, Roy's Adaptation Model was also effective for reducing the caregiving burden of family caregivers of people with chronic diseases [36] and parents of cancer children [26]. Based on these results, theory-based intervention programs may broaden the scope of nursing theories in nursing practices.

2.1.1.1.5 Points to consider while developing educational programs

In many low- and middle-income countries, formal systems of long-term care are poorly developing; or both [103, 104]. The most effective interventions were created by

combining evidence and theory [104]. Interventions adapted from other disease conditions (oncology and dementia) [96, 105, 106] did not yield the desired outcomes for family caregivers, with only one study reporting a significant reduction in caregiver burden [96]. This review suggested that interventions should be developed based on evidence, with psychological framework-based psychosocial interventions delivered at home by involving the patients and caregivers' dyad [107, 108]. The intervention program needs to be selected after identifying the most effective one for the targeted population [93], while also considering gender-specific aspects in the developmental process due to differences in coping styles [109, 110].

2.1.1.1.7 Review of commonly used techniques for reducing caregiving burden

The researcher found two most used educational intervention techniques for reducing caregiving burden were OM Chanting and Mindfulness Meditations.

OM Chanting

The sound of Om plays an important role in our nervous system, as Om is the creation of the universe. Om meditation is easy to practice, as it is less time-consuming and does not require an expert or trainer to assist during performance; it has advantages over other meditation techniques [137]. Om is also called AUM. AUM introduced three sounds, "Aaaaa, Uuuuu, and Mmmmm". When we sound "Aaaaa" part of AUM, we feel the vibration in our stomach. When we sound "Uuuuuuu", we feel vibration at our chest. And when we sound "Mmmmmm," we feel the vibration at the head or mind. If we practice Om chanting in a normal pitch and regularly, our body and mind feel very stress-free and are ready to concentrate on our next work [138]. Chanting Om is equal to the supreme consciousness. Om chanting is widely used [139, 140]. Om chanting is a brain stabilizer; by practicing Om, one can enter deeper and deeper into own natural state, which is also an energy medicine for human beings under stress [141].

Effective 'Om' chanting is associated with the experience of vibration sensation around the ears, which is also transmitted to the vagus nerve through the auricular branch. It is believed that 'Om' chanting produces limbic deactivation like transcutaneous vagus nerve stimulation [142]. Evidence showed that even only Om listening was reported to activate the cortical areas related to cognition and cerebellum [140].

When the sound Om is chanted, it vibrates at the frequency of 432 Hz, which is the same vibration frequency found throughout everything in nature. Chanting Om connects us to this nature and the whole universe. It again proves that what we give to

nature, it returns to us. Evidence found that Om chanting reduces hypertension, resolves skin problems, and improves health [138].

How to Chant OM?

1. First, sit comfortably in a position with eyes closed.
2. Take a deep breath and start first Aaaaa is chanted with the mouth wide open. Don't focus on frequency and the vocal of sound, just open the mouth wide, and air comes naturally.
3. Uuuuu is chanted by forming a circle with the mouth. Again, don't try to make a specific sound, just form the circle with our mouth, and the sound produced naturally.
4. Mmmmm is automatically created when the mouth closes and just makes a sound with a closed mouth.
5. Feel vibrations of three different sounds naturally; don't force it. Sounding an Om in normal pitch always gives us faster results than low or high pitches.
6. While chanting OM, do not think about when and how it works. It Just Works [138].

Mindfulness Meditation

Mindfulness is the moment-to-moment awareness and is trained through meditation exercises adapted from Buddhist traditions [143]. Mindfulness meditation is defined as a non-judgmental awareness and attention on the present moment experience as a means of self-regulation to promote mind-body calmness and relaxation [144, 145]. It is also a skill to non-judgmentally observe emotions, sensations, or cognitions [146]. Mindfulness is not only the attention focused on the present moment and nonjudgmental awareness, but also an acceptance of experience with an attitude of openness and curiosity. It includes formal: mindful movement, the body scan, sitting meditation, and informal practices: incorporating mindfulness into everyday life [147]. The characteristics of meditation are clearly defined as a specific technique of muscle relaxation during the process, logical relaxation, self-induced state, and use of self-focusing skill [148].

Mindfulness is cultivated in formal meditation practices: sitting meditation, walking meditation, or mindful movements [145]. The practice of mindfulness meditation involves focusing attention on the emergence of thoughts, emotions, and body sensations while observing them as they arrive and pass [149].

A meditation may be active, passive or mixed techniques, Winbush, Gross, & Kreitzer [158] Mahmood, Hophthrow, and de Moura [149] found that as little as 5 min of

mindfulness can be beneficial for the study participants [150] is a contemporary mind–body intervention, it may be concentration meditation or mindfulness meditation. Mindfulness promotes an individual's ability to focus their awareness on the present moment [151].

Mindfulness is used to describe a variety of practices and processes [146]. The process of mindfulness is composed of a two-component process that includes attention to the present-moment experience and an attitude that is open, non-reactive, and accepting of things as they are, regardless of their reactiveness and desirability [144, 153, 154].

Evidence showed that meditation reduces stress [155], controls anxiety [156], promotes emotional health [138], enhances self-awareness or more creative problem solving skills [157]; lengthens attention span [154], may reduce age related memory loss [151]; can generate kindness [158], may help fight addiction [159]; improves sleep; helps to control pain [155]; can decrease blood pressure [160]; accessible anywhere [161]. Besides this, recent evidence shows that mindfulness-based educational programs are an effective technique for reducing the burden or stress of family caregivers of older adults with dementia [162-164]. A meta-analysis review determined that mindfulness techniques are being used in interventions based on psychosocial, educational, and counseling programs [164]. Interventions based on mindfulness techniques show significant effects on the reduction of depression and the burden of family caregivers [164]. Likewise, mindfulness-based stress reduction (MBSR) is a treatment for psychological distress, depressive symptoms, and anxiety for people with chronic disease, developed by Kabat-Zinn [145, 162].

Mechanism of Action of Mindfulness Meditation

(1) **Attention regulation**: During focused attention meditation, distracting external events and memories, or thoughts about future events. These are ignored while the practitioner concentrates on meditation. Attention is supposed to rest on a single object. Instructions for focusing entire attention on the incoming and outgoing breath. Try to maintain attention without distraction. If a person gets distracted, calmly return attention to the breath and start again". A sufficient degree of attention regulation is necessary for staying engaged in meditation [149].

(2) **Body awareness**: Body awareness is the ability to notice subtle bodily sensations [122]. In mindfulness practice, the focus of attention is an object of internal experience: sensory experiences of breathing, sensory experiences related to emotions, or other body sensations. Body sensations are

a common object of attention during mindfulness meditation, and practitioners report improved body awareness [149].

a. **Emotion regulation**: Evidence demonstrated improvements in emotion regulation associated with mindfulness. A mindfulness practice leads to increases in positive reappraisal and these increases mediate an improvement in stress levels [122].

b. **Exposure, extinction (elimination), and reconsolidation**: During mindfulness, practitioners expose themselves aware in external stimuli, body sensations and emotional experiences. They let themselves be affected by the experience, refraining from engaging in internal reactivity toward it, and instead bringing acceptance to bodily and affective responses. Practitioners are instructed to meet unpleasant emotions (such as fear, sadness, anger, and dislike) by turning towards them, rather than turning away. Those who are new to meditation may discover the process of releasing unpleasant emotions and experience a sense of safety or well-being in their place [149].

(3) **Change in perspective on the self:** The principle of Buddhist psychology lies in the teaching that there is no such thing as a permanent, unchanging self [165]. The perception of a self is a product of an ongoing mental process. This perception recurs very rapidly in the stream of mental events, leading to the impression that the self is a constant and unchanging entity. The self is experienced as being the one who inhabits the body, being the one who is thinking the thoughts, being the one experiencing emotion, and being the agent of actions: having free will. [149].

Steps of Mindful Meditation

(1) **Get comfortable:** find a quiet place where the person won't be disturbed. Ideally, this would be a room in a house where he/she can be alone and at peace.

(2) **Get in position:** Try to sit cross-legged on a low cushion on the floor, or upright in a chair. Some people prefer to meditate in a sitting position, a lying down position, walking meditation, or mindful movements

(3) **Get relaxed:** Close your eyes, set a timer for five minutes if you are just starting, and begin by taking a few deep, cleansing breaths. Breathe in deeply (but naturally) through your nose, and out through either your nose or mouth, whichever feels more comfortable to you. Let the breaths flow down into your abdomen.

(4) **Focus on your breaths:** Become aware of the sound of your breaths as you inhale and exhale. As you inhale, you breathe in all the peaceful and joyful things around you. As you exhale, you rid your mind and body of all the stress and toxins that

have been bothering you. Let your mind become mesmerized (hypnotized) by the rhythmic pattern of your breathing.

(5) **Bring thoughts back to the center:** The Mind may wander (walk). While you notice your thoughts wandering off from your breath, do not correct yourself; it is normal. Simply acknowledge it and bring your focus back to the center, back to your breaths. Take in your immediate surroundings. What do you hear? What do you feel right now, at this moment? Try not to reflect on the past or worry about the future but be present in this pure moment.

(6) **Commit:** Like exercise, meditation takes practice. And the more we practice, the better we get and the stronger that mindfulness muscle becomes. Even just five to ten minutes per day has been shown to make an enormous difference to well-being after just eight weeks of meditation practice [164].

2.1.2 International Status of Older Adults and their Family Caregivers

The global population of older adults is expected to reach nearly 2.1 billion in 2050, while in 2017, their population was only 962 million. Among them, the aged 80 years or over persons are projected to increase more than threefold between 2017 and 2050 (from 137 million to 425 million)[56]. Older adults gradually become dependent on family members to maintain their personal hygiene, optimal well-being and health care, social life, and financial activities[26, 57] either by ageing itself or the prevalence of chronic diseases. About 23% of the total global burden of diseases is shown among them[58].

Likewise, aging itself declines the health conditions and increases the prevalence of chronic diseases among older adults[59, 60]. Aging also increases the prevalence of disability among them[4]. Major causes of disability are unipolar depressive disorders; hearing loss; back and neck pain; Alzheimer's disease and other dementias; osteoarthritis; falls, chronic obstructive pulmonary disease, and diabetes mellitus [61].

As family is the main institution for home-based care for older people[9], family members are providing home care for older adults have disability without any training and remuneration because of technological advancements, shorter hospital stays, and the expansion of homecare technology[62]. They assist in ADLs[63, 64] (bathing, grooming, dressing, transfers, eating or communication, meal preparation, home safety, community mobility, and financial management)[47, 65] and other health care activities[66]. High demand and continuous heavy load of caregiving for older people at home has

become a challenging issue for family caregivers[34], because besides caregiving, the family members have additional responsibilities, such as working or looking after other family members[63]. Globally, more women are facing problems while involved in caring roles and breadwinner roles[15].

2.2 Domestic Research Status on Caregiving Burden and National Activities

The trends of research in the academic field have been increasing since 2006, as Nepal gave priority to older adults; still, only limited articles are available for review. Evidence shows that few studies have been conducted among family caregivers of persons having different chronic diseases or conditions in Nepal. They were the burden of family caregivers of persons with psychiatric or mental illness [54-57], persons with maintenance hemodialysis[58, 59], spinal cord injuries [60], autism disorder[61], and older adults[62]. Among them two-thirds of studies show that almost all (95.13%-100%) caregivers had of burden[57-61]. However, only one study was done among family caregivers of older adults shows that only 12% of them had a care burden, as this study included the majority (70%) of family members of older adults with no limitation in ADLs[62].

For two decades, the Government of Nepal (GoN) has initiated older adults-related welfare activities. The GoN has provided a non-contributory pension[64] for older adults age 68 years and above, or widows aged 60 years and above, pension for civil servants, free health services, and financial support for the treatment of fatal chronic diseases for older adults aged 75 years and above [64] and financial support for old age homes. The GoN endorses a 50% discount on travel costs and reserving seats for older adults in public transportation. The GoN has coordinated activities with the United Nations or international organizations working for the welfare of older people. A geriatric health-related course has been included in graduate-level health programs[65-67].

2.3 Summary of Literature Review

Increasing population of older adults is a global phenomenon, more formal and informal health services are utilized by this age group as they have a higher prevalence of disability as a result of higher rates of chronic diseases and their complications. Worldwide, the provision of home-based long-term care, especially in ADLs and IADLs for older adults with disability, is becoming a challenging situation for family caregivers as they have other family or social responsibilities, especially for women. Factors associated with the caregiver burden of family caregivers of older adults with disability are older adults' related factors and family caregivers' related factors. Older adults demanding more care or family caregivers who are providing long duration in ADLs or IADLs or in providing comfort, medical or emotional support without any training as well as family caregivers with poorer physical health; higher degrees of depression and anxiety; socially isolated; limited opportunities; lower life satisfaction; poor quality of life; and low self-efficacy are known major factors of increasing caregiving burden. On the other hand, family caregivers having a larger family support network, greater social support, good family functioning, self-efficacy, and more caregiving experiences are factors that decrease the caregiving burden among them.

Though evidence shows that most of the intervention programs were developed and implemented in high-income countries, especially focusing on family caregivers of persons with dementia. There is still a lack of evidence to suggest which types of interventions are effective for those family caregivers of persons having specific diseases, even in high-income countries. In addition, there is a lack of evidence to suggest which type of intervention is effective for low-income countries like Nepal. Though limited theory-based intervention programs are seen for reducing caregiver burden in high-income countries, in low-income countries like Nepal, there is no evidence that depicts the effectiveness of educational interventions based on nursing theories. As almost all population of Nepal belongs to the Hindu and Buddhist religions, the researcher found OM Chanting and Mindfulness Meditations were an effective educational program for reducing caregiving burden.

Chapter 3 The Main Research Ideas, Research Content and Academic Innovation Points

3.1 Objectives of the Study

(1) To identify factors associated with the caregiving burden of family caregivers of older adults with disability residing in two municipalities of Kathmandu district, Nepal.

(2) To develop an educational program based on the Nepalese context to reduce the caregiving burden of family caregivers.

(3) To determine the efficacy of an educational program for reducing the caregiving burden of family caregivers.

3.2 Research Questions

(1) Which factors are associated with the caregiving burden of family caregivers of older adults with disability?

(2) Does this educational intervention program reduce the caregiving burden of family caregivers?

3.3 Research Hypothesis

(1) Family caregivers of older adults with more disabilities have a greater caregiving burden.

(2) Educational intervention can reduce the caregiving burden of the family caregivers of older adults.

3.4 Conceptual Framework

3.4.1 Family caregiver from the perspective of Roy's Adaptation Model

According to Roy's Adaptation Model, different stimuli, whether focal, contextual, or residual, trigger the systems of regulatory and cognitive coping, triggering behaviors that, in turn, will define the level of adaptation to the role of family caregiver. The main focal stimulus of family caregivers is the responsibility to give care to older adults with disability who depend partially or totally on the family caregiver to meet his/her needs. The focal stimulus is responsible for activating the available coping mechanism of the family caregiver to seek physical and psychological resources to cope with this

responsibility. Contextual stimuli that contribute to the effects of focal stimuli on the family caregiver's situation include gender, race, kinship, relationship, care demands, stressful life events derived from care, as well as available social support. The social role of family caregiver includes the responsibilities or functions beyond his/her role as caregiver, towards other people in other aspects of life, e.g. worker, parent, or volunteer[112].

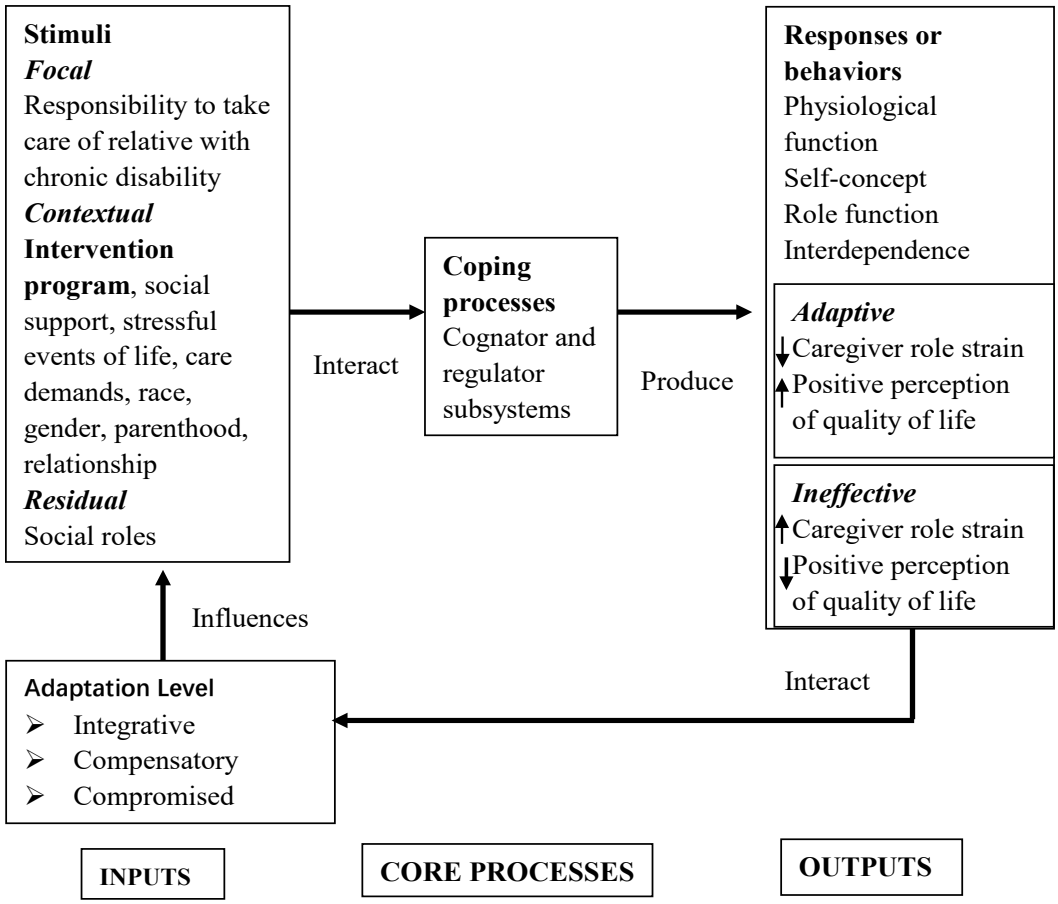

Figure 3-l Effect of Educational Intervention for Reducing Care Burden of Family Caregivers based on Roy Adaptation Model (Diaz & Cruz, 2017)

The environmental stimuli of the family caregiver are processed by the regulatory and cognitive subsystems that act in the adaptive modes. The adaptive or ineffective response of a family caregiver may suggest changes in his/her four adaptive modes: physiological function, self-concept, role function, and interdependence. These changes determine the caregiver's level of adjustment[112]. The family caregiver's adaptation to the care for his/her older relative with disability is a complex process involving internal or external factors that influence his/her responses and level of adaptation[121].

3.4.2 Conceptual-theoretical-empirical structure of the research

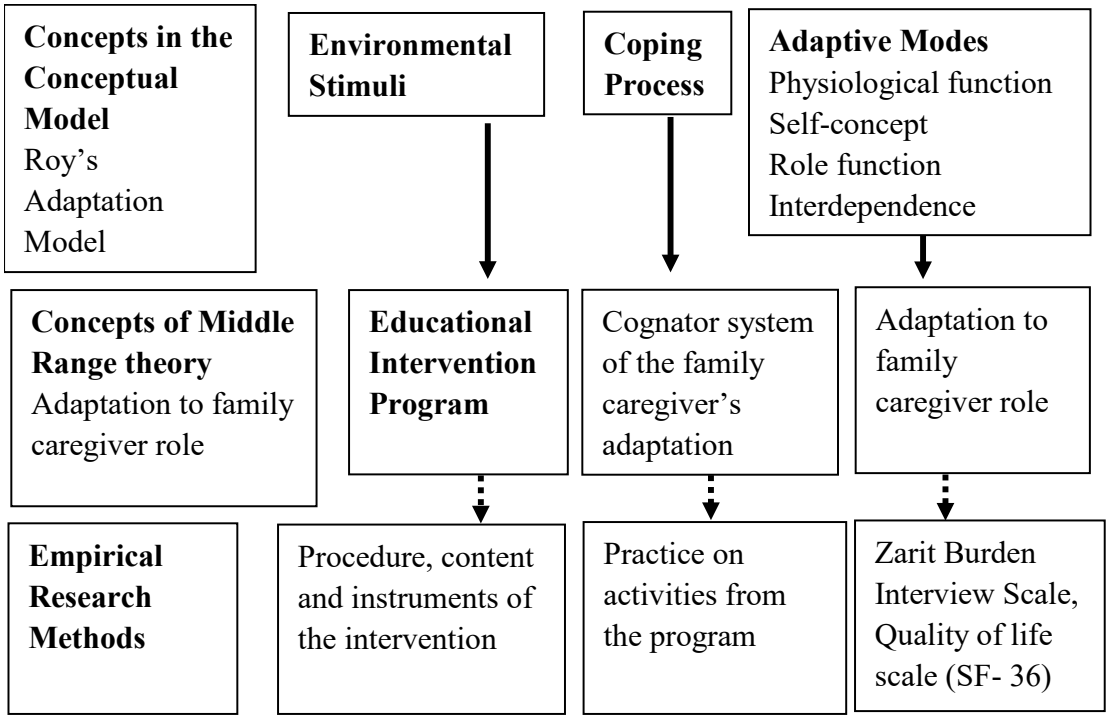

Figure 3-2 Conceptual -theoretical -empirical structure based on Roy's Adaptation Model developed by Diaz & Cruz, 2017

Conceptual-theoretical-empirical structure will guide to assess the effectiveness of educational intervention program to promote the adaptation of family caregiver of older adult with disability with caregiver role strain or burden is elaborated deductively, moving from the more generic conceptual model to the empirical indicators, being the more concrete elements of the structure, the conceptual- theoretical-empirical structure is proposed[112] as in figure 2.

Chapter 4 Research Methodology and Road Map

4.1 Research Methodology

This study followed four phases: 1) pilot study; 2) cross-sectional survey; 3) development of educational program; and 4) evaluation of educational program by using a Randomized Clinical Trial.

4.1.1 First Phase: Instrument Validation and Pilot Study

Instrument Validations:

First of all, original English version of Six-Item Cognitive Impairment Test (6-CIT) that was developed by Katzman, et al. in 1983 as short orientation memory concentration test questionnaire that can be used for those persons who cannot read and write, and Social Support Rating Scale (SSRS) developed by Xiao in 1995 in English language were selected in this study. The English version of the Six-Item Cognitive Impairment Test (6-CIT) and Social Support Rating Scale (SSRS) were translated into the Nepalese language with the help of a bilingual translator and the researcher herself. A nursing experts group comprised of one lecturer from psychiatric nursing, two associate professors from adult health nursing, one retired professor, and one research expert independently rated the content validity index of the Nepalese version of 6-CIT and SSRS. The findings of the **content validity index** provided by 5 experts on the Nepalese version of **6-CIT and SSRS** were **0.90 and 0.75,** respectively.

Pilot Study

The researcher conducted a pilot study [113] among 60 family caregivers of older adults with disabilities residing in Tokha Municipality, Kathmandu, from September to October 2021.

4.1.1.1.1 Objectives of Instrument Pilot Study

The objectives of the pilot study were as follows:

(1) To identify the reliability of the Nepalese version of the Social Support Rating Scale.

(2) To measure the feasibility of the interview questionnaire and select for conducting a cross-sectional study

4.1.1.1.2 Methodology

The pilot study was conducted using a descriptive cross-sectional survey through a non-probability purposive sampling technique among 60[113] family caregivers of older adults with at least one ADLs and four IADLs disability for ≥3 months residing in Tokha Municipality with the objectives identifying reliability of Nepalese version of Social Support Rating Scale, feasibility of impairment status of ADLs and IADLs; six-item Cognitive Impairment Scale, care provision related variables, Zarit Burden Interview Questionnaire and quality of life questionnaire (SF 36) for assessing over all feasibility of interview questionnaire before conducting cross-sectional study. In the personal interview technique was used for selecting data from September to October 2021.

4.1.1.1.3 The findings of Pilot Study

TABLE 4-1 Socio-demographic Information of Older Adults (n = 60)

Characteristics	Frequency	Percentage
Age in years		
60 – 69	4	6.7
70 - 79	20	33.3
80-89	21	35.0
90 or over	15	25.0
Mean Age	**82.58 ± 8.34**	
Gender		
Male	22	36.7
Female	38	63.3
Types of Residencies		
Own house	48	80.0
Rented house	12	20.0
Marital Status		
Unmarried	4	6.7
Widow/Widower	39	65.0
Married and living with a couple	17	28.3
Governmental allowance		
Not obtained	7	11.7
Obtained	53	88.3
Status of Alive Children		
No child	4	6.7
Have child/ren	56	93.3
Currently living with		
Own family	50	83.3
Others	10	16.7
Current health problems		
One or two problems	33	55.0
Three or more problems	27	45.0
Current psychological status		
Intact memory	55	91.7
Memory deficit	5	8.3

Table 4-1 shows socio-demographic information of care receivers. The oldest older adults, with a mean age of 82.58 ± 8.34, cover the maximum percentage, i.e., 60%.

Among them, 63.3% were female. Eighty percent of them stayed at their own home, and 65% were widows/widowers. Likewise, 83.3% of them obtained governmental support, either pension or senior citizen allowances. Almost all (93.3%) of them had alive child/ren and 83.3% of them were currently living in their own family. Similarly, more than half (55.0%) of them had one or two health problems, and only 8.3% had memory deficit.

TABLE 4-2 Status of Abilities of Older Adults on ADLs & IADLs (n = 60)

Abilities of Older Adults		**Unable**	**Able**
		Number (Percent)	**Number (Percent)**
Abilities of ADLs:	Eating food	11 (18.3)	49 (81.7)
	Changing clothes	39 (65.0)	21 (35.0)
	Taking shower	53 (88.3)	7 (11.7)
	Using toilet	24 (40.0)	36 (60.0)
	Controlling voiding	26 (43.0)	34 (56.7)
	Walking around	23 (38.3)	37 (61.7)
Abilities of ADLs of older adults			30 (50.0%)
	1-2 ADLs impairment		
	3-5 ADLs impairment		23 (38.3%)
	Complete impairment		7 (12.6%)
Abilities of IADLs of older adults			
	Cooking food	59 (98.3)	1 (1.7)
	Washing clothes	60 (100.0)	0 (0.0)
	Eating medication	28 (46.7)	32 (53.3)
	Doing household work	60 (100.0)	0 (0.0)
	Going to market	59 (98.3)	1 (1.7)
	Using telephone	35 (58.3)	25 (41.7)
	Managing finance	51 (85.0)	9 (15.0)
	Use of transportation	57 (95.0)	3 (5.0)
Abilities of IADLs	Partial Impairment	40 (66.7%)	
	Complete Impairment	20 (33.3%)	

Table 4-2 shows the status of older adults performing activities of daily living and instrumental activities of daily living. Half (50%) of the older adults had 1-2 activities impairment, 38.3% had 3-5 activities impairment, and 11.7% had complete impairment on activities of daily living. Likewise, 66.7% had partial and 33.3% had complete impairment in instrumental activities of daily living.

TABLE 4-3 Socio-demographic Information of Family Caregivers (n = 60)

Characteristics	**Frequency**	**Percentage**
Relationship		
Spouse	5	8.3
Son's family	45	75.0
Daughter or son-in-law	7	11.7
Blood relative	3	5.0
Age in Years		
18 – 39	25	41.7
40-59	27	45.0
60 and above	8	13.3

Continued TABLE 4-3 Socio-demographic Information of Family Caregivers (n = 60)

Characteristics	Frequency	Percentage
Gender		
Female	45	75.0
Male	15	25.0
Religion		
Hinduism	59	98.3
Buddhism	1	1.7
Marital Status		
Married and living with spouse	48	80.0
Widow (er)/single	8	13.3
Unmarried	4	6.7
Educational status		
Unable to read and write	8	13.3
Informal education	10	16.6
Formal education	42	70.1
Current Occupation		
Unpaid Job	42	70.0
Paid Job	15	25.0
Not working	3	5.0
Economic Status		
Sufficient for less than 12 months	34	56.7
Sufficient for 12 months and more	26	43.3

Table 4-3 shows the socio-demographic information of caregivers. Seventy-five percent of the caregivers were living with their son's family members (son/daughters-in-law/grandchild). Likewise, a majority (75%) of family caregivers were female, with age groups of 18-39 years (41.7%) and 40-59 years (45.0%). Similarly, 53.3% of family caregivers belonged to Brahmin/Chhetri, and almost all (98.3%) followed the Hindu religion, 80.0% were married and living with their spouse, and 61.7% had SLC or above education. The majority (70.0%) were home managers, and more than half (51.7%) of them had sufficient economic resources for more than six months.

TABLE 4-4 Family Status and Responsibility of Family Caregivers (n = 60)

Variables	Frequency	Percentage
Type of family		
Joint	54	90.0
Extended	4	6.7
Single	2	3.3
Number of Family Members		
2-5	38	63.3
6- 11	22	36.7
Head of Family		
Spouse	24	40.0
Self	16	26.7
Other family member	20	33.3
Having extra responsibilities		
Social responsibilities	6	10.0
Family responsibilities	16	26.7
Responsibilities of under 5 children	25	41.7
Currently had extra stress	4	6.7

Table 4-4 shows the family status and responsibilities of family caregivers. Almost

all (90.0%) of family caregivers were from a joint family, 63.3% of families consisted of 2 – 5 members in their family. Similarly, one fourth (26.7%) of family caregivers were the head of the family, a few percentages (10.0%) of family caregivers had social responsibilities, 26.7% of them had family responsibilities, and 41.7% of them had also responsibilities for under 5 children at home. Likewise, few (6.7%) had current stress in their life.

TABLE 4-5 Care Provision, Sleeping, Resting Time and Social Support Status of Family Caregivers (n = 60)

Socio-demographic Characteristics	Frequency	Percentage
Duration of care provision for older adults		
3– 60 months	40	66.7
61– 120 months	13	21.7
121 months and above	7	11.7
Median (Q1 & Q3) 36 months (13.5, 81)		
Duration of sleep at night		
Have good sleep at night	49	81.7
Need to wake up 1 or 2 times	6	10.0
Need to wake up 3 or more times	5	8.3
Duration of rest at daytime		
Have rest time 1-2 hours	37	61.7
No rest time	23	38.3
Social support status*		
Low social support (≤22)	11	18.3
Moderate (23–44),	48	80.0
High (≥45)	1	1.7
Mean and Standard Deviation	**26.88±5.71**	
Range	**18-45**	
Cronbach's Alpha value of SSRS	**0.794**	

Total support score ranging from 12–66

Table 4-5 shows the care provision, duration of sleep, rest, and social support status of family caregivers of older adults with disabilities. Two-thirds (66.7%) of family caregivers had cared for 3-36 months, with a median (Q1, Q2) of 36 months (13.5-81 months). Forty percent of the caregivers are involved in providing care for 3 – 60 months, with a mean duration of 68.38 months. Similarly, 81.7% of family caregivers had good sleep at night, and 80.0% of family caregivers perceived a moderate level of social support. The Cronbach's Alpha value of the social support scale is 0.794.

TABLE 4-6 Status of Caregiving Burden of Family Caregivers

Level	Frequency	Percentage
No burden	46	76.7
Burden	14	23.3
Total	**60**	**100**

Table 4-6 shows the level of caregiving burden of family caregivers of older adults

with disability. More than three-fourths (76.7%) had no burden, and 23.3% had a burden.

TABLE 4-7 Health Related Quality of Life of Family Caregivers (n = 60)

Scale	Mean Score of Respondents
Physical functioning	93.25 ± 13.42
Role limitations due to physical health	88.33 ± 29.99
Role limitations due to emotional problems	93.33 ± 25.15
Energy/fatigue (Vitality)	50.25 ± 17.03
Emotional well-being	70.93 ± 13.45
Social functioning	85.41 ± 22.68
Pain	93.95 ± 1.38
General health	59.58 ± 1.14

Table 4-7 shows the average health status of family caregivers of older adults with disabilities. The average mean scoring of the SF-36 Questionnaire based on physical functioning, role limitation due to emotional problems, and pain is high (more than 93 out of 100). Likewise, role limitations due to physical health and social functioning are also good (score mean more than 85 out of 100), and the score of emotional well-being is also good (score mean more than 70%). However, the general health and vitality are fair on average (score means more than 59 and 50 out of 100).

4.1.1.1.4 Findings of Pilot Study

The findings of this pilot study concluded that 23.3% of family caregivers had experienced a caregiving burden; 80.0% of family caregivers expressed a moderate level of social support. All participants gave responses to all the questions, which means the questionnaire was clear and understandable. The Cronbach's Alpha value of the Nepalese version of the social support questionnaire found in the pilot study **was 0.794**.

4.1.2 Second Phase: Descriptive Cross-sectional Survey

4.1.2.1 Research Design

The researcher used a quantitative, descriptive cross-sectional survey conducted through non-probability purposive sampling techniques among 430 family caregivers residing in Tarakeshwor and Gokarneshwor Municipalities of Kathmandu District in January 2022 to March 2022 to identify the factors associated with caregiving burden of family caregivers of older adults with disability.

4.1.2.2 Research Setting and Population

The research setting was Tarakeshwor and Gokarneshwor Municipalities of Kathmandu District, which has the highest population density[114]. The population of

this study was family caregivers of older adults with disabilities in these municipalities.

4.1.2.3 Selection Criteria

4.1.2.3.1 Inclusion Criteria

(1) Family caregivers of those older adults who were aged 60 years and above and have disability in at least one ADL[115] and unable to perform more than three IADLs (cooking, shopping, and using a telephone) [115] because of complications of chronic conditions, especially decreasing cognitive function [71, 81-83], cerebrovascular disease[28], cancer [22, 58], heart failure[22],chronic obstructive pulmonary disease[22], end of life care[74], pathological fracture [76], any conditions that bring incontinence or insomnia[28] .

(2) Family caregivers who were the key persons currently providing most of the care or assistance for their older adults with disability for more than one month[117].

4.1.2.3.2 Exclusion Criteria

(1) Those family caregivers who could not communicate clearly, as measured by the Six-Item Cognitive Impairment Test (Score ≥11)[118].

(2) Formal caregivers who were paid by family members for taking care of their older adults.

4.1.2.4 Sampling Methods

The researcher used a non-probability, convenient sampling technique for selecting family caregivers of older adults having disability residing in Tarakeshwor and Gokarneshwor Municipalities of Kathmandu District.

4.1.2.5 Sample Size

In Nepal, there was limited evidence in the literature related to family caregivers of older adults with disability. So, researchers found evidence of having caregiving burden among almost all family caregivers (more than 95%) of persons with different chronic conditions [57-61]. Based on the variability of dependency level of older adults with their family caregivers on ADLs as well as IADL, the researcher assumed that half of the family caregivers had a caregiving burden. So, p=0.5, 95%, and at least ±5% precision. A 95% confidence level gives the researcher Z value of 1.96, per normal tables, so the sample size was calculated based on Cochran formula [119] as following: $\{(1.96)^2 (0.5) (0.5)) / (0.05)^2 = 385\}$, considering an attrition rate of 11.5%, the sample

size was 430.

4.1.2.6 Research Instruments: Structured Interview Questionnaire

A structured interview questionnaire was used, which consisted of five sections.

Section I: Socio-demographic Characteristics of Older Adult and Family Caregiver

Socio-demographic characteristics of older adults were included age, gender, type of residency, marital status, status of governmental financial support, status of alive child/ren and status of impairment of activities of daily living and instrumental activities of daily living, including their physical and psychological status. Socio-demographic characteristics of family caregivers were age, gender, marital status, ethnicity, religion, marital status, educational status including economic status. Besides these caregivers' family-related factors were relationship with older adults, family type, family size, having extra responsibilities, feeling of extra stress, social support, duration of providing care, daily caring hours, average time spent, duration of sleep, and duration of daily time rest[120].

Section II: Nepalese version of Six-Item Cognitive Impairment Test Scale

For identifying cognitive status of family caregivers, the enumerator used pretested Nepalese version of Six-Item Cognitive Impairment Test (6-CIT). This instrument was developed by Katzman, et al. in 1983 as short orientation memory concentration test[121]. For the administration of this instrument, only 2-3 minute needed as well as this instrument was also used use for illiterate persons also. It contains items on orientation, attention, and memory with a range from 0 to 28; a score 0-10 indicates no cognitive impairment, but a score ≥11 indicates cognitive impairment [118].

Section III: Social support

Social support as perceived by family caregivers was assessed by the Social Support Rating Scale (SSRS) developed by Xiao in 1995 in the Chinese Language. The SSRS contains 10 items, measuring three dimensions of social support: subjective support (4 items), objective support (3 items), and support-seeking behavior (3 items)[122]. Subjective support reflected the perceived interpersonal network that an individual can count on. Objective support reflected the degree of actual support an individual received in the past. Support-seeking behavior refers to the pattern of behavior that an individual utilizes when seeking social support. Item scores of the SSRS were simply added up, generating a total support score ranging from 12 to 66, a

subjective support score ranging from 8 to 32, an objective support score ranging from 1 to 22, and a support-seeking behavior score ranging from 3 to 12, respectively. Higher scores indicate stronger social support[123].

Section IV: Caregiving Burden of the Family Caregiver

The caregiving burden of the family caregiver was measured by using the Nepalese version of Zarit Burden Interview (ZBI) questionnaire[124] which has good reliability with Cronbach's Alpha of 0.85[61]. ZBI consists of 22 questions on a 5-point Likert scale. Each question has 5 choices given scores as "never (0), almost (1), sometimes (2), often (3), and always (4)". For this study, cut-off points were used for burden, with 0 to 20 points corresponding to low or no burden; from 21 to 40 points corresponding to moderate burden; moderate to severe burden was scored between 41 and 60 points, and, finally, severe burden is found between 61 and 88 points[89]

Section V: Quality of Life of the Family Caregiver

The quality of life of family caregivers was measured by the Nepalese version of SF-36, which has good reliability, with a Cronbach's Alpha was 0.8[125]. The higher the score, the better the quality of life. The SF-36 includes 36 questions in eight domains, which include physical functioning, physical role limitation, emotional role limitation, social functioning, bodily pain, vitality, mental health, and general health[82]. Again, the eight domains provide two summary measures of health-related quality of life: Physical Component Summary (PCS) and Mental Component Summary (MCS)[125].

4.1.2.7 Recruitment and Training of Research Enumerator

Four research enumerators were appointed to conduct a descriptive cross-sectional survey. The selection criteria of the enumerator were a person (1) at least completed graduate level nursing education, (2) had 6 months of experience in NHRC working as an enumerator (3) was interested in working in this study. The researcher provided two days of training for them. The contents of this training were the purpose of study, procedure of obtaining informed consent, techniques of maintaining participant rights, orientation of interview questionnaire, interview technique, their roles and responsibilities in filling out the interview questionnaire before leaving the respondent's house. The researcher provided a written appointment letter for data collectors with legal terms and conditions for data collection.

4.1.2.8 Data Collection Procedure

(1) The researcher obtained ethical approval for this study from the Institutional

Review Board of Xiangya School of Nursing as well as from Nepal Health Research Council, and written permission from the authority of Tarakeshwor and Gokareneshwor Municipalities.

(2) The research enumerator collected data from family caregivers of older adults with disability through home visits with the help of community leaders and community volunteers. Before data collection, each of them provided information for individual family caregiver on following points: (1) the duration of interview as about 45-50 minutes, (2) respondent might experience distress over the nature of questions, (3) might not benefit personally, (4) also included in experimental study, those respondents who had high caregiving burden, (5) maintained rights of individual respondent as he or she could leave interview at any time without mentioning reasons' (6) obtained responses were kept in confidence without recording any identity of respondents, (7) respondent's identity was not disclose in any place of report only analyzed information in group, (8) at the end of report writing the filled interview questionnaire was destroyed confidentially, (9) the participation in this study was completely voluntary, (10) the participant was freed to decline to participate, to end participation at any time for any reason, or could refused to answer any individual question and (11) ensured that refusing to participate involved no penalty or loss or benefits.

(3) The researcher put self-introduction, objectives of the study, and the contact number of the researcher on the front page of an informed consent form. If any confusion arose between the research enumerator and the respondent, the enumerator could call at any time, with the researcher or the participant could directly call the researcher about any confusion. The researcher clarified many times with the respondent individually. If the respondent still refused or denied participating in the study, instruction was given to the research enumerator to quit the interview at any time using appreciative words or polite manner.

(4) If the family caregivers provided the signed informed consent form, the research enumerator interviewed him/her at home by using an interview questionnaire in another room or ensuring away from the older adult so that he/she could express his/her feelings freely.

(5) The researcher supervised and monitored the work of the research enumerator by randomly verifying the data obtained among 5% of the total samples of each data collector and supervised their field work.

(6) After ensuring the completeness of each questionnaire by double-checking

from the researcher and the research enumerator, the researcher collected the filled interview questionnaires from the data collectors.

4.1.2.9 Data Analysis Procedure

The researcher checked the data daily, coded, recorded, and entered it in a statistical package for the social sciences (SPSS) version 25.0 software, and the hired statistician also entered data independently. Before data entry, a database had been formed, mentioning the name, label, value, and criteria of the variables. Then, the entered data were analyzed by using descriptive statistics: frequency, percentage, mean, and standard deviation, and inferential statistics: Pearson's correlation coefficient (p), univariate, and multivariate logistic regression test to measure the relationship between dependent and independent variables of this study. The level of significance was considered as a p-value of less than 0.05 for all the statistical analyses.

4.1.2.10 Findings of descriptive cross-sectional study

The findings of the descriptive cross-sectional study were as follows:

TABLE 4-8 Socio-demographic Information of Older Adults (n = 430)

Characteristic		Frequency	Percent
Age (in years) *	60 – 69	86	20.0
	70-79	176	40.9
	≥ 80	168	39.1
Mean age ±SD		**77.35±9.04**	
Gender	Male	173	40.2
	Female	257	59.8
Types of Residency	Own house	354	82.3
	Rented house	76	17.7
Marital Status	Widow/er/unmarried/single	244	56.7
	Married and living with a couple	186	43.3
Financial support from the government		364	84.7
Status of an alive child:	No child	10	2.3
	Having child/ren	420	97.7
Status of ADLs impairment:	1-2 activities impairment	193	44.9
	3-5 activities impairment	184	42.8
	Complete impairment	53	12.3
IADLs impairment:	Partial impairment	196	45.6
	Complete Impairment	234	54.4

Pour: ***Minimum age 60 and maximum age 105 years***

Table 4-8 shows socio-demographic information of older adults. Most (40.9%) of the older adults fell in between 70-79 years age group, followed by 80 years and above (39.1%) and 60 – 69 years (20%), with the mean age ±SD being 77.35±9.04. More than half (59.8%) were female, 82.3% were staying in their own house; 56.7% were

widows/ers/unmarried or single, 84.7% were receiving old age allowance, and almost all (97.7%) had alive child/ren. Regarding activities of daily living, 44.9%, 42.8%, and 12.3% had 1-2 activities, 3-5 activities impairment, and complete impairment among older adults, respectively. Likewise, regarding instrumental activities of daily living, 54.4% of older adults had complete impairment and 45.6% had partial impairment.

TABLE 4-9 Perceived Health Status of Older Adults (n = 430)

Health problems*		**Frequency**	**Percent**
Mobility problems		347	80.7
Hypertension		184	42.8
COPD / asthma		180	41.9
Diabetes mellitus		123	28.6
Hearing problems		83	19.3
Heart problems		75	17.4
Vision Problems		70	16.3
Urinary Problems		64	14.9
Paralysis		62	14.4
Gastrointestinal problems		53	12.3
Joint problems		29	6.7
Hypothyroidism		15	3.5
Cancer		14	3.3
Other diseases#		24	5.58
Gender specific problems:	Prostate Problems n= 173	23	13.2
	Uterus Prolapse n=257	22	8.5
Health problems:	One or two problems	109	25.3
	Three or more problems	321	74.7
Psychological status:	Memory intact	344	80.0
	Memory impairment	86	20.0

***Multiple responses; # 5 Parkinsonism, 1 convulsion, 9 uric acid, 9 skin problems**

Table 4-9 shows the status of chronic diseases among older adults as most common diseases were mobility problems (80.7%), hypertension (42.8%), COPD/Asthma (41.9%), diabetes mellitus (28.6%), hearing problems (19.3%), visual problems (16.3%), gastrointestinal problems (12.3%), joint problems (6.7%), and cancer (3.3%). In addition, 13.2% of males out of 173 had prostate problems, and 8.5% of females out of 257 had uterine prolapse. The majority (74.7%) had three or more health problems, and one-fifth (20.0%) of them had memory impairment.

TABLE 4-10 Socio-demographic Information of Family Caregivers (n = 430)

Socio-demographic Variables		**Frequency**	**Percent**
Age in year*	18 – 39	139	32.3
	40-59	218	50.7
	≥60	73	17.0
Mean age ± SD		**45.92±14.05**	
Gender	Male	71	16.5
	Female	359	83.5

Continued TABLE 4-10 Socio-demographic Information of Family Caregivers (n = 430)

Socio-demographic Variables		Frequency	Percent
Caste	Brahmin/Chhetri	280	65.1
	Janajati	133	30.9
	Dalit	12	2.8
	Madhesi including Muslim	5	1.2
Religion	Hinduism	361	84.0
	Buddhism	43	10.0
	Christianity	13	3.0
	Kirat	11	2.6
	Islam	2	0.5
Marital status	Married living with spouse	379	88.1
	Unmarried/Widow (er)	51	11.9
Educational status	Unable to read and write	114	26.5
	Informal education	84	19.5
	1–10-year education	73	17.0
	≥ SLC passed	159	37.0
Current occupation	Unpaid work	245	57.0
	Paid work	185	43.0
Economic status	Sufficient for <1 year	213	49.5
	Sufficient for ≥1 year	217	50.5

mean±SD:45.92±14.05 a *minimum age of 18 years to a maximum age of 93 years

Table 4-10 depicts the socio-demographic information of family caregivers. Regarding the age of caregivers, 32.3% of them belonged to the age group of 18-39 years, 50.7% were in the age group 40–59 years, and 17.0% were in the age group of 60 or over, with a mean age ±SD was 45.92±14.05 years. Similarly, 83.5% were female, 65.1% were Brahmin/Chhetri ethnic group, 84.0% were Hindu, and 88.1% were married and living with their spouse. Likewise, 26.5% of them were unable to read and write, 19.5% were only read, and write; 17.0% and 37.0% of them were studying for 1-10 years and SLC or above, respectively. Likewise, 57% of them were not involved in paid occupation, 43% were involved in a paid job or obtaining a pension, and only 50.4% of them had sufficient income for one year or more.

TABLE 4-11 Caregivers' Family Related Variables, Social Support, and Care Variables (n = 430)

Variables		Frequency	Percent
Relationship	Spouse/Son /his family members	405	94.2
	Married daughters/in laws/other relatives	25	5.8
Family type	Joined/extended	405	94.2
	Single	25	5.8
Family size	2-4 persons	100	23.3
	≥5 persons	330	76.7
Extra-responsibilities**	**Social** responsibility	130	30.2
	Family responsibility	205	47.7
	Care of < 5-year child	70	16.3
Feeling of extra stress		252	58.6
Social support:	Moderate level	430	100.0
Duration of care:	3-35 months	154	35.8
	≥36 months	276	64.2

Continued TABLE 4-11 Caregivers' Family Related Variables, Social Support and Caregiving Variables (n = 430)

Family Related Variables		Frequency	Percent
Mean ±SD	**4.43 (±3.93) years**		
Daily caring hours	1-2 hours	192	44.7
	3-7 hours	154	35.8
	≥8 hours	84	19.5
Average time spent weekly	37.31 hours (7-168 hours)		
Duration of sleeping	1-5 hours	162	37.7
	≥ 6 hours	268	62.3
Duration of rest in a day	Mostly no rest	79	18.4
	Having some resting time	351	81.6

****Multiple responses**

Table 4-11 shows family-related variables of the family caregiver. Almost all (94.2%) family caregivers were spouses/sons / his family. Furthermore, almost all (94.2%) were from joint or extended family, and 76.7% had ≥5 members in a family. In addition, they also had social responsibility (30.2%), family responsibility (47.2%), responsibility of a < 5-year-old child (16.3%), and feeling of extra stress (58.6%). Cent percent (100.0%) of them perceived a moderate level of social support. Regarding duration of care provision, 35.8% of them cared for 3 to 35 months, while 64.2% of them cared for 3 years and more, with the mean duration of 4.43 (±3.93) years. Likewise, 44.7% of them cared for 1-2 hours, 35.8% cared for 3-7 hours, and 19.5% cared for 8 hours or more on average per day. Per night, the majority (62.3%) of family caregivers slept for 6 hours or more, and 37.7% slept for less than 6 hours. In addition, 81.6% of them had some resting time during the day, but 18.4% of them had no resting time.

TABLE 4-12 Health Status of Family Caregivers (n = 430)

Health Status		Frequency	Percent
Health problems**	Musculoskeletal	88	20.4
	Sleeping problem	34	7.9
	Hypertension	28	6.5
	Gastritis	20	4.7
	Diabetes Mellitus	9	2.1
	COPD	9	2.1
	Hypothyroidism	7	1.6
	Decreased vision	5	1.2
	Obesity	5	1.2
	High cholesterol	4	0.9
	Uric acid	4	0.9
	Hearing problem	2	0.5
	Prostate enlarged (n=173)	2	1.1
Health problems	No problem	310	72.1
	One or more health problems	120	27.9

Pour: * Multiple Responses

Table 4-12 shows the self-reported health status of family caregivers. The common health problems of family caregivers were musculoskeletal pain (20.4%), sleeping problems (7.9%), hypertension (6.5%), gastrointestinal problems (4.7%), diabetes mellitus (2.1%), or chronic obstructive pulmonary disease (2.1%) etc. The majority (72.1%) of them had no health problems, whereas 27.9% had one or more health problems.

TABLE 4-13 Item-wise Scores of Care Burden of Family Caregivers (n = 430)

Responses	Frequency (Percentage)				
Feeling of. Scores	**0**	**1**	**2**	**3**	**4**
Asking for more help than he/she needs	**191(44.4%)**	44 (10.2%)	69 (16.0%)	57 (13.3%)	69 (16%)
Not having enough time for oneself	**237(55.1%)**	107(24.9%)	54 (12.6%)	17 (4.0%)	15 (3.5%)
Stressed while caring…..meet….	**196(45.6%)**	97(22.6%)	76(17.7%)	44(10.2%)	17(4.0%)
Embarrassed over a relative's behavior	**361(84.0%)**	47(10.9%)	10(2.3%)	9(2.1%)	3(0.7%)
Angry while being around a relative…	**237(55.1%)**	97(22.6%)	70(16.3%)	20(4.7%)	6(1.4%)
Being negatively affected the relationship	**335(77.9%)**	54(12.6%)	27(6.3%)	9(2.1%)	5(1.2%)
Being afraid of the future of relative.	51(11.9%)	11(2.6%)	49(11.4%)	64(14.9%)	**255(59.3%)**
Having dependent relative……	67(15.6%)	47(10.9%)	49(11.4%)	61(14.2%)	**206(47.9%)**
Being strained while being……..	**177(41.2%)**	127(29.5%)	52(12.1%)	40(9.3%)	34(7.9%)
Suffering health status…….	**278(64.7%)**	73(17.0%)	44(10.2%)	17(4.0%)	18(4.2%)
Feeling unable to maintain privacy	**358(83.3%)**	53(12.3%)	10(2.3%)	5(1.2%)	4(0.9%)
Having suffered social life……	**347(80.7%)**	44(10.2%)	23(5.3%)	11(2.6%)	5(1.2%)

Having friends over…..	**366(85.1%)**	34(7.9%)	14(3.3%)	9(2.1%)	7(1.6%)
Being a person whose relative could ….	115(26.7%)	46(10.7%)	58(13.5%)	49(11.4%)	**162(37.7%)**
Not having enough money to care….	**203(47.2%)**	79(18.4%)	60(14.0%)	42(9.8%)	46(10.7%)
Being unable to take care of longer……	**231(53.7%)**	90(20.9%)	48(11.2%)	32(7.4%)	29(6.7%)
Having lost control of own life…	**268(62.3%)**	82(19.1%)	48(11.2%)	19(4.4%)	13(3.0%)
Wishing to leave the care……..	**324(75.3%)**	52(12.1%)	20(4.7%)	26(6.0%)	8(1.9%)
Uncertainty about what to do….	**204(47.4%)**	80(18.6%)	53(12.3%)	33(7.7%)	60(14.0%)
Extra necessary care……	64(14.9%)	47(10.9%)	71(16.5%)	109(25.3%)	**139(32.3%)**
Doing a better job in caring…….	**108(25.1%)**	58(13.5%)	87(20.2%)	87(20.2%)	90(20.9%)
Burden while giving care…….	**311(72.3%)**	41(9.5%)	49(11.4%)	19(4.4%)	10(2.3%)

Table 4.13 shows the item-wise care burden of family caregivers of older adults with disability.

TABLE 4-14 Status of Caregiving Burden of Family Caregivers (n = 430)

Burden Status	**Score**	**Frequency**	**Percentage**
No or mild burden	0 – 20	149	34.7
Moderate burden	21-40	249	57.9
Moderate to severe burden	41-60	28	6.5
Severe burden	61-88	4	0.9
Overall burden	**21-88**	**281**	**65.3**
Mean ± SD	**24.73±10.14**		
Median (Q1 & Q3)	23 (18 & 31)		
Range	4-72		

Table 4-14 shows the status of caregiving burden of family caregivers of older adults with disability. More than one third (34.7%) of family caregivers perceived no burden or mild burden while more than half (57.9%) had moderate caregiving burden, only few (6.5% and 0.9%) of them had moderate to severe and severe caregiving burden respectively. Overall, 65.3% of family caregivers had caregiving burden with minimum and maximum score were 4 to72.

TABLE 4-15 Quality of Life of Family Caregivers (n = 430)

Scale	**Mean Score**	**Median (Q1, Q3)**	**Range**
Physical functioning	87.17 ± 14.61	90 (80, 100)	15, 100
Role limitations due to physical health	58.6 ± 41.76	75 (25, 100)	0, 100
Pain	80.9 ± 20.76	87.5 (65, 100)	0, 100
General health	48.48 ± 14.67	50 (35, 60)	10, 75
Vitality	64.05 ± 14.43	65 (50, 75)	10, 90
Social functioning	60.55 ± 20.38	50 (50, 75)	13, 100
Role limitations due to emotional roblems	62.79 ± 41.66	66.67 (33.33, 100)	0, 100
Emotional well-being	65.98 ± 16.33	64 (56, 80)	12, 92
Physical H Component	71.92±15.62	72.61(61.19, 86.90)	11.90, 94.05

Mental H Component	63.97±14.41	62.85 (51.42, 71.14)	17.14, 90

Table 4-15 depicts the quality of life of family caregivers. The mean score for physical functioning was 87.17± 14.61, with a median score of 90 (80, 100) and ranging between 15 to 100. Likewise, the mean score of role limitations due to physical health was 58.60 ± 41.76 with median score 75 (25, 100) and scores ranging in between 0 to 100 and the mean score for pain was 80.9 ± 20.76 with median score 87.5 (65, 100) and scores ranging between 0 to 100. Similarly, the mean score of general health was 48.48 ± 14.67, with median scores 50 (35, 60) and ranging between 10 to 75, and the mean score for vitality was 64.05±14.43, with a median score 65 (50, 75), with a range between 10 to 90. Besides these, the mean score for social functioning was 60.55 ± 20.38 with median score 50 (50, 75) and ranging from 13, 100; the mean score of role limitations due to emotional problems was 62.79±41.66 with median score 66.67 (33.33, 100) and ranging between 0 to 100 and the mean score of emotional well-being was 65.98 ± 16.33 with median score 64 (56, 80) and ranging between 12 to 92. The overall mean scores of the physical health component and mental health component were 71.92±15.62 and 63.97±14.41, respectively.

TABLE 4-16 Association of Care Burden and Older Adults' Related Factors

Factors of Older Adults		**Burdened (n=281)**	**No burden (n=149)**	**p-value**
COPD	Yes	106 (58.9%)	74 (41.1)	0.017
	No	175 (70.0%)	75 (30.0%)	
Hypertension	Yes	140 (76.1%)	44 (23.9%)	0.000
	No	141 (57.3%)	105 (42.7%)	
Paralysis	Yes	54 (87.1%)	8 (12.9%)	0.000#
	No	227 (61.7)	141 (38.3%)	
Urinary Problems	Yes	49 (76.6%)	15 (23.4%)	0.041
	No	232 (63.4%)	134 (36.6%)	
Gastrointestinal problems				
	Yes	45 (84.9%)	8 (15.1%)	0.001#
	No	236 (62.6%)	141 (37.4%)	
Health problems				
1 or 2 problems		53 (48.6%)	56 (51.4%)	0.000
3 or more problems		228 (71.0%)	93 (29.0%)	
Psychological status				
Intact Memory		213 (61.9%)	131 (38.1%)	0.003
Memory impairment		68 (79.1%)	18 (20.9%)	
Status of ADLs				
Complete impairment		26 (49.1%)	27 (50.9%)	0.000
3-5 activities impairment		140 (75.1%)	44 (23.9%)	
1-2 activities impairment		115 (59.6%)	78 (40.4%)	
Status of IADLs				
Complete impairment		166 (70.9%)	68 (29.1%)	0.008
Partial impairment		115 (58.7%)	81 (41.3%)	

Pour: (p <0.05, significant at 95% CI; #Fisher's Exact Test)

Table 4-16 shows the association of care burden with older adults' related variables. It shows that there is statistically significant association between diseases of older adults especially COPD (0.017), hypertension (0.000), paralysis (0.000), urinary problems (0.041), gastrointestinal problems (0.001), their health problems category (0.000), psychological status (0.003), impairment status of ADLs (0.000) and impairment status of IADLs (0.008) with caregiving burden of family caregivers as p-values of each is <0.05.

TABLE 4-17 Association of Care Burden with Caregivers' Socio-demographic Variable (n = 430)

Caregivers' Related Factors		Burden (n=281)	No burden (n=149)	p-value
Occupation	Unpaid occupation	172 (70.2%)	73 (29.8%)	0.015
	Paid occupation	109 (58.9%)	76 (41.1%)	
Economic status	Sufficient for < 1 year	149 (70.0%)	64 (30.0%)	0.047
	≥ 1 year or surplus	132 (60.8%)	85 (39.2%)	
Residency type	Own house	221 (62.4%)	133 (37.6%)	0.006
	Rented house	60 (78.9%)	16 (21.1%)	
Family type	Nuclear	24 (96.0%)	1 (4.0%)	0.001#
	Joint or extended	257 (63.5%)	148 (36.5%)	
Family size	2-4 persons	74 (74.0%)	26 (26.0%)	0.038
	≥5 persons	207 (62.7%)	123 (37.3%)	

Continued TABLE 4-17 Association of Caregiving Burden with Caregivers' Related Factors (n = 430)

Caregivers' Related Factors		Burden (n=281)	No burden (n=149)	p-value
Perceived extra stress	Having stress	183 (72.6%)	69 (27.4%)	0.000
	No stress	98 (55.1%)	80 (44.9%)	
Health status	No health problem	186 (60.0%)	124 (40.0%)	0.000
	≥1 or more problems	95 (79.2%)	25 (20.8%)	
Caring duration	3-35 months	91 (59.1%)	63 (40.9%)	0.042
	≥ 36 months	190 (68.8%)	86 (31.2%)	
Daily care time	1-7 hours	205 (59.4%)	140 (40.6%)	0.000
	≥8 hours	76 (89.4%)	9 (10.6%)	
Daily Sleeping time	1-5 hours	123 (75.9%)	39 (24.1%)	0.000
	≥6 hours	158 (59.0%)	110 (41.0%)	

Used Chi-squire test; *p<0.05 was considered statistically significant; #Fisher Exact Test

Table 4-17 shows the association between caregiving burden and possible caregivers' related factors. It shows statistically significant association between their occupation (p=0.015), economic status (p=0.047), residency types (0.006) and types of family (p=0.001), family size (p=0.038), perceived extra stress (p=0.000), caregivers' health status (p=0.000), duration of care providing (p=0.042), daily care providing hours (p=0.000), and sleep duration at night (p=0.000) with caregiving burden as p-value of each is <0.05.

TABLE 4-18 Determined Factors of Caregiving Burden of Older Adults (n = 430)

Older Adults Variables		Univariate Analysis		Multivariate Analysis	
		Unadjusted OR (95% CI)	p-value	Adjusted OR (95% CI	p-value
COPD	Yes	0.61 (0.41-0.91)	0.017	0.91 (0.54-1.54)	0.741
	No	1		1	
Hypertension	Yes	2.36 (1.55-3.61)	0.000	1.96 (1.12-3.43)	0.019*
	No	1		1	
Paralysis	Yes	4.19 (1.93-9.07)	0.000	1.59 (0.63-4.00)	0.324
	No	1		1	
Urinary problem	Yes	1.88 (1.01-3.49)	0.043	0.79 (0.36-1.71)	0.555
	No	1		1	
GI problem	Yes	3.36 (1.54-7.33)	0.002#	3.33 (1.35-8.21)	0.009*
	No	1		1	
Health problem	1 -2	1		1	
	≥ 3	2.59 (1.65-4.04)	0.000	1.47 (0.83-2.63)	0.184
Psychological health status					
Memory intact		1		1	
Loss of memory		2.32 (1.32-4.08)	0.003	1.33 (0.64-2.63)	0.434
Status of ADLs					
1-2 activities impairment		1		1	
3-5 activities impairment		2.15 (1.38-3.36)	0.026	1.30 (0.71-2.37)	0.388
Complete impairment		0.65 (0.35-1.20)	0.171	0.37 (0.16-0.87)	0.022*
Status of IADLs					
Partial impairment		1		1	
Complete impairment		1.71 (1.15-2.56)	0.008	1.58 (0.88-2.83)	0.120

Pour: N.B. Variables with p<0.25 in the Univariate analysis were included in the multivariable analysis, *p<0.05 was considered statistically significant. 1: reference group; CI: confidence interval; OR: odds ratio

Table 4-18 shows the univariate and multivariate analysis of older adults' related variables for caregiving burden. The adjusted odds of hypertensive older adults were 1.96 (CI: 1.12-3.43; p=0.019) as compared to non-hypertensive and older adults having gastrointestinal problems were 3.33 (CI: 1.35-8.21; p=0.009) as compared to those without gastrointestinal problems. Similarly, the older adults with 3-5 activities of daily living impairment and complete impairment were 1.30 (CI: 0.71-2.37; P=0.388) and 0.37 (CI: 0.16-0.87; p=0.022) respectively. The older adults with hypertension, gastrointestinal problems, and unable to perform activities of daily living were statistically significant. So, the hypertension, gastrointestinal problems, and complete impairment in activities of daily living were the predictors of caregiving burden. However, older adults with other chronic diseases COPD, paralysis, urinary tract problems, and other diseases, their psychological status, and their abilities to perform IADLs were not statistically significant with the caregiving burden of family caregivers. These factors were not the predictors of caregiving burden, as indicated by all p-values being more than 0.05.

TABLE 4-19 Determinate Factors of Caregiving Burden of Family Caregivers (n=430)

Variables	Univariate Analysis		Multivariate Analysis	
	Unadjusted OR (95% CI)	p-value	Adjusted OR (95% CI)	p-value
Occupation				
Paid occupation	1		1	
Unpaid occupation	1.64 (1.10-2.45)	0.015	0.76 (0.46-1.24)	0.275
Economic status				
sufficient for <1 year	1.49 (1.00-2.23)	0.047	1.79 (1.05-3.05)	0.031*
Sufficient for ≥1 year	1		1	
Types of residencies				
Own house	1		1	
Rented house	2.25 (1.24-4.07)	0.007	1.79 (0.88-3.66)	0.106
Types of family				
Nuclear	13.82 (1.85-103.21)	0.010	5.94 (0.64-46.77)	0.119
Joined /Extended	1		1	
Family size				
2-4 persons	1.69 (1.02-2.78)	0.039	1.12 (0.61-2.06)	0.696
5 and more persons	1		1	
Felt extra stress				
Having stress	0.46 (0.30-0.69)	0.000	1.15 (0.91-2.48)	0.104
Having no stress	1		1	
Health status				
No problem	1		1	
Have health problem	2.53 (1.54-4.15)	0.000	1.82 (0.97-3.41)	0.059
Caring durations				
3-35 months	0.65 (0.43-0.98)	0.042	0.64 (0.36-0.98)	0.043*
≥36 months	1		1	

Continued TABLE 4-19 Determinate Factors of Caregiving Burden of Family Caregivers (n=430)

Variables	Univariate Analysis		Multivariate Analysis	
	Unadjusted OR (95% CI)	p-value	Adjusted OR (95% CI)	p-value
Caring hours per day				
1-7 hours	1		1	
8 or more hours	5.76 (2.79-11.89)	0.000	2.84 (1.14-7.06)	0.025*
Sleeping duration				
1-5 hours	2.19 (1.42-3.39)	0.000	1.17 (0.67-2.03)	0.569
6 hours or more	1		1	

Pour: Variables with p<0.25 in the Univariate analysis, included in the multivariable analysis, *p<0.05 was considered statistically significant. 1: reference group; CI: confidence interval; OR: odds ratio

Table 4-19 shows the Univariate and Multivariate analyses of the family caregivers' related variables. The economic status was sufficient for less than 1 year with adjusted odds 1.79 (CI: 1.05-3.05; p=0.031) as compared with sufficient for equal or more than one year. Similarly, the caring duration for 3-35 months with adjusted odds 0.60 (CI: 0.36-0.98; p=0.043) as compared to caring duration for 36 months or above and the average daily caring hours for 8 or more with adjusted odds 2.84 (CI:

1.14-7.06; p=0.025) as compared to daily caring hours less than 8 hours. So, family caregivers with economic status sufficient for less than one year, caring duration 3-35 months, and daily average caring hours of 8 hours or more were the predictors of caregiving burden. Occupational involvement, residency type, type of family, number of family members, perceived extra stress, perceived health status of family caregivers, and sleeping duration were not the predictors of caregiving burden, as indicated by all p-values being more than 0.05.

TABLE 4-20 Model Testing

Omnibus Test of Model Coefficients		**Chi-square**	**Df**		**Significance**
Step		112.578	20		0.000
Model Summary					
Step		-2 Log likelihood	Cox & Snell R Square		Nagelkerke **R Square**
1		442.346[a]	.230		**.318**
Hosmer and Lemeshow Test					
Step		Chi-square	Df		Significance
1		3.727	8		.881
Classification table[a] *a. The cut value is .500			Predicted		
	Observed		Burden categories		Percentage
			No burden	Burden	correct
Step 1	Burden	No burden	78	71	52.3
	categories	Burden	44	237	84.3
	Overall percentage				73.3

Pour: a. Estimation terminated at iteration number 6 because parameter estimates changed by less than .001; b. The cut off value is 0.500.

Table 4-20 shows a multivariate logistic regression was applied for significant variables after using Univariate analysis. According to the Omnibus tests of model coefficients, the chi-square is highly significant (chi-square = 112.578, df=20, p= 0.000), then it is concluded that the model is significant. Moving on Hosmer and Lemeshow goodness of fit suggests the model is a good fit to the data as {chi-square = 3.727, df=8, p= 0.881 (> 0.5)}. According to the classification table, the total accuracy of this model was 73.3%, which is closest to 80%. It means that the prediction model is correct up to 80%. According to Nagelkerke's R-squared, the model explains roughly 31.8% of the variation in the outcome, then it is concluded that this model is significant.

4.1.2.11 Discussion with research findings

This study showed that 74.7% of older adults had three or more physical problems and 20.0% had memory problems. Likewise, 60.9%, 26.5%, and 12.6% of them had 1-2, 3-5 impairment and complete impairment in ADLs, respectively, while a study done by Khanal and Chalise [62] found that 30% of older adults had at least one ADL

impairment. As found in this study, 83.5% were female family caregivers which was consistent with studies reports of Khanal & Chalise [62], Sajeev & John [126], Baysan & Mandiracioglu [127] and Abdul et al, [128] as female were 80.7%, 75%, 81.5% and 66.4% respectively. The current study found that 27.9% of family caregivers had one or more health problems, which was less than a study of Abdul et al [128] as 52.8% had some health problems. Current findings showed the mean duration of care provision was 4.43 (±3.93) years, which was less than the study of Khanal & Chalise [62] , which was 5.18 (±3.51) years. The average caring time of this study was 37.31 hours per week, which was similar to the findings of Brinda et al [28] as 38.6 hours per week.

The mean score of burden of family caregivers in current study was 24.73±10.14 which was lower than the studies of Sajeev & John [126]; Gok Matin, Karadas & Mustafa Cankurtaran, [128]; Baysan & Mandiracioglu [127]; and Naing, May & Aung [130] as 36.4±14.3; 37.59 ± 18.20; 31.95±13.33 and 45.75±16.79 respectively; and was higher than studies conducted by Abdul, et al [128] and Khanal & Chalise [62] as 18.5± 13.6 and 12.89 ±5.7 respectively. The systematic review done by Loo, Yan & Low [131] found that the prevalence of burden was 23.0%-59.2%. This difference may be because of the inclusion criteria and socio-cultural variances.

The current study revealed that 34.7% of family caregivers had no or mild care burden while 57.9%, 6.5% and 0.9% had moderate burden, moderate to severe and severe burden respectively, which was lower than the findings of Tuttle, Griffiths & Kaunnil [132] ; Sajeev & John [126]; Loureiro, et al [86] , and Chandana et al [133] in which 18.8% had no care burden, 43.5% had low-moderate, 30.4% had moderate to high and 7.2% had high burden; 43.33% had mild to moderate burden, 35.83% had moderate to severe and 15% had little or no burden; 61.5% had mild to moderate, 23.1% had moderate to severe and 15.4% had no burden; and 20% had little to no burden and 64.0% had mild to moderate, 14.0% had moderate to severe and 2.0% had severe burden respectively. In contrast to this, a study conducted by Khanal & Chalise [62] found that only 12.0% of family members expressed care burden. This difference may be because of the inclusion criteria.

Factors associated with caregiving burdens

Current study depicted that the older adults' related possible factors of burden were having numbers of health problems (0.000), with their types {COPD (0.017), hypertension (0.000), paralysis (0.000), urinary problems (0.041), gastrointestinal problems (0.001)} and their psychological status (0.003). Another possible factor of

burden in this study was the level of ADLs (0.000), which was consistent with the study of Tuttle, Griffiths, & Kaunnil [132] and Abdul, et al [128] as ADL status of the care recipients (p = 0.003) and their functional independence (P < 0.001). The current study also showed that economic category (p=0.047) is also a possible factor of burden, which was supported by findings of Abdul, et al [128] and Baysan & Mandiracioglu [127] as p=0.034.

The current study depicted that the health status (p=0.000) of family caregivers was a possible factor of burden, which was consistent with the studies of Baysan & Mandiracioglu [127] as physical health problems (p <0.001) and of Abdul et al [128] found that even presence of chronic diseases (p= 0.006). The current study revealed that the other possible factor of care burden was daily caring time (p=0.000), which was similar to the finding of Gok Metin, Karadas, Balci, Cankurtaran Zehra [129]. This finding was also consistent with the study of Tuttle, Griffiths, & Kaunnil [132], as the caring hours (p = .017) were another possible factor of caregiving burden.

The current study findings depicted that the age group of family caregivers was not a possible factor of caregiving burden, but the studies conducted by Naing, May & Aung [130] and Tuttle, Griffiths, & Kaunnil [132] depicted as age group as possible factor of burden as p = 0.008 and p = 0.000 respectively. Other possible factors of caregiving burden were gender (p = 0.023) [128]; home-sharing (p = 0.006), and spending time during the day (p = 0.009) [127]. These results were contradictory to the current study. Likewise, a study done by Lee, Hung, Kim, Chunmi [134] identified as a factor influencing subjective burden was spouse of the older adults (t=2.34, p=.020), a study done by Tuttle, Griffiths, & Kaunnil [132] found that the relationship to the care recipients was the possible factor of caregiving burden as p-value 0.009 which was contradictory to the findings of the current study. In the current study, the educational level of family caregivers was not a possible factor of caregiving burden, while different studies done by Tuttle, Griffiths, & Kaunnil [132] and by Gok Metin, Karadas, Balci, Cankurtaran Zehra [129] found that their education level (p = 0.002) was also a possible factors of burden as p –value less than 0.05.

Predictors of Caregiving Burdens

This study found that older adults with hypertension as its adjusted odds 1.96 (CI: 1.12-3.43; p=0.09), with GI problems as its adjusted odds 3.33 (CI: 1.35-8.21; p=0.009) which was inconsistent with the study done by Sabzwari, et al [134] as the stroke was the predictor of caregiving burden as adjusted odds {3.03 (1.34- 6.86)}. Likewise, this

study also revealed that the older adults with complete impairment were 0.37 (CI: 0.16-0.87; p=0.022). This finding was like the study done by Abdul et al [128] in which their functional independence {–1.1 (–1.6, –0.6); P < 0.001} was the predictor of caregiving burden. This study also found that economic status sufficient for less than 1 year with adjusted odds 1.79 (CI: 1.05-3.05; p=0.031) as compared with sufficient for equal or more than one years; the caring duration for 3-35 months with adjusted odds 0.60 (CI: 0.36-0.98; p=0.043) as compared to 3 year or above and the average daily caring hours for 8 or more with adjusted odds 2.84 (CI: 1.14-7.06; p=0.025) as compared to daily caring hours less than 8 hours.

4.1.2. 10.1 Conclusion of the study

The finding of this study reveals that most of the family caregivers of older adults with disability are female, and more than half of them have extra stress. More than one-fourth of family caregivers have health problems, all of them had moderate social support, and still one one-fifth of them must care for 8 hours or more daily. Besides these, nearly one-fifth of the family caregivers cannot get rest during the daytime and even two-fifths of them cannot get sufficient sleep at night on average.

This study also shows that nearly two-thirds of family caregivers have a caregiving burden. Possible factors of burden are multiple comorbidities status (COPD, hypertension, paralysis, urinary and GI problems), psychological status, ADLs and IADLs impairment status of older adults; and occupation and economic status, residency, family types and size, perceived health status, and perceived extra stress including duration of care, daily caring time and sleep duration of family caregivers. The predictors of caregiving burden are hypertension, gastrointestinal problems, complete impairment in ADLs of the older adults and low economic status, continuous caring for 3-35 months, and daily caring hours (≥8) of the family caregivers.

4.1.3 Third Phase: Development of Educational Program

Psycho-educational intervention program was developed through a series of studies and consultation with experts and feedback from 3 family caregivers after introducing the intervention program based on non-pharmacological intervention Guidelines developed by the British Medical Research Council[135]. The process of developing an educational intervention program has followed the following stages:

4.1.3.1 Stage one: Identification of theories relating to intervention

Two nursing theories (Roy's Adaptation Model and Neuman System Model) were used while developing psycho-educational intervention for reducing the caregiving burden of family caregivers. Roy's Adaptation Model [26, 38] was used in the educational program developed for reducing the caregiving burden of family caregivers of persons with chronic illness, and used for mothers of children under chemotherapy. Likewise, the Neuman System Model[111] was used for reducing the care burden of primary caregivers of patients with dementia. Among these interventional studies, the researcher selected Roy's Adaptation Model.

The researcher also reviewed the contents of the curriculum from the primary level to the higher secondary level education in Nepal. Based on findings of in depth interview and reviewing contents of curriculum of school level education, the researcher conducted scoping review on developmental task of older adults, ageing changes that could exist among older adults, early identification and preventive measures of the psychological changes of older adults and different stress reducing activities used in different life situations for family caregivers from published articles available in different sources of literature especially, Google Scholar, Hinari, PubMed and from different web sites. The researcher developed the structure and contents of the educational intervention program in both English and the Nepalese language. The contents of the education psycho-educational intervention program were developed through a series of consultations with the experts. Then, the researcher also provided five sessions of educational intervention to 3 family caregivers of older adults with disability who had already participated in the pilot study, had obtained a caregiving burden score of more than 20, and could read and write the Nepalese language. The psycho-educational interventional program was finalized with further experts' consultation as well as feedback obtained from three family caregivers by following the British Medical Research Council (BMRC) guideline from September 2022 to July 2023.

4.1.3.2 Stage two: Further Literature Review on Interventions and Modalities

Based on the report of scoping reviews conducted by WHO in 2017 with a group of experts for identifying the effectiveness of interventional programs for family caregivers of care-dependent older people found that most of the interventional studies were conducted in high-income countries, focusing on the caregiving burden of family

caregivers of people with dementia[5]. Evidence showed that psychotherapy and multicomponent interventions based upon educational interventions, support, and skill training are effective interventions[5]. The educational interventions and psychotherapy have beneficial effects on caregiving burden, depression, subjective well-being of family caregivers, and their knowledge or ability for symptom management of care receivers. In contrast, psychosocial interventions produce small to moderate effects on all of the outcomes[5]. Evidence showed that single-component interventions (support or training of care recipients) were less effective as compared with multicomponent interventions[5]. Similarly, active participation of family caregivers of people with chronic diseases in information and communication technology reduced their depressive symptoms and improved their quality of life[5]. Respite care services were not found to significantly reduce the caregiver's burden, depression, or anxiety[5].

Similarly, a report of qualitative content analysis the characteristics of effective interventions were as following (1) use of mixed concepts in contents of the interventions; (2) face-to-face, through computer or telephone, video or web-based platforms were the effectives delivering methods of intervention; (3) intended audience; (4) tailored contents rather than standardized one ; (5) structure/type; (6) intensity: multiple continuous intervention; and (7) individualized intervention as source of delivery[91].

4.1.3.3 Stage three: Evidence collection (In-depth interview and review of curricula used up to a higher educational level of Nepal)

The qualitative study in-depth interview was conducted to explore the caregiving burden of family caregivers residing in Tokha Municipality of Kathmandu District among 7 family caregivers of older adults with disabilities who participated in a pilot study by using a non-probability purposive sampling technique. Then, the researcher obtained informed consent from each family member after explaining the purpose of the interview, duration, and frequency of data collection individually. After that, the researcher conducted in-depth interviews by using interview guidelines and extra probing questions, especially about what they learned, what they found helpful, and what could be done in the Nepalese language in February 2022 to March 2022 to explore caregiving experiences of family caregivers.

After interviewing 5 family caregivers of older adults who had the burden, the obtained information was sufficient as the researcher conducted in-depth interviews

with two family caregivers, but no new concepts were added. The rationale for including only 7 participants was that no new information was added while interviewing the last two participants.

All interviews were audio-recorded, transcribed, and translated from Nepalese language to English by the investigator with the help of a bilingual expert. This study used thematic content analysis, which required the transcription of interview recordings and followed the coding process. Initially, transcripts were read and re-read to identify potential themes while producing overarching elements and higher-level sub-themes.

4.1.3.3.1 The findings of the qualitative study are as follows:

Regarding socio-demographic information of family caregivers, among 7 family caregivers of older adults with disabilities, 4 were from the age group of 25 to 30 years, and 3 were from the age group of 40 to 55 years. Likewise, 6 family caregivers were female and 1 male; among them, one was single, two were unmarried, and 4 were married. Similarly, 4 were Brahman/Chhetri, 3 were Janajati. Two of them had an income sufficient for less than 6 months, 3 of them had an income sufficient for less than one year, and 2 of them had sufficient income for one year or more. Among the seven respondents, 4 were caring for females and 3 were caring for male older adults with disability.

Five main themes and ten sub-themes emerged from the thematic data analysis regarding the caregiving experiences of family caregivers of older adults with disability.

TABLE 4-21 Themes, Sub-themes and Categories of Experiences of Family Caregivers (n=7)

Themes	Subthemes	Categories
1. Caring experience of family caregivers	a. Positive experience	• Self-motivation and satisfaction • Learning skills and enhancing early vocabulary development in the child • Good family support • Appreciation of caring behavior by relatives or neighbors
	b. Negative experience	• Physical and mental exhaustion • Feeling socially isolated • Lack of family support • Feeling stressed in caring for the male older adults • Lifestyle changes: need to leave the job, discontinue education, or suppress own wishes and ambition • Financial issues
2. Socio-cultural beliefs about family caregivers	Preference of son over daughter	• An older adult prefers to stay with a son, and not with a married daughter. • Son and daughter-in-law have crucial roles in the funeral process. • Care provision by married daughters and sons-in-law is a sin for older adults unless they have no alternative.
3. Awareness of aging changes among family caregivers	a. Low awareness of changes in physiological functioning	• Swallowing difficulty or indigestion, stomach pain, or toothache. • Shortness of breath or breathing difficulty. • Decreased vision. • Physically weak, fatigued, unable to walk or work, and unable to perform activities of daily living. • Backache, hands and legs pain, leg spasm. • Headache. • Misconception on changes in physiological functioning among older adults.
	b. Low awareness of changes in psychological functioning	• Suicidal ideation or fear/worry/thought of dying. • Suspicious, irritable, anxious, easily tense, angry, unusual behavior, talkative. • Feelings of insecurity, loss of memory, and forgetfulness. • Overthinking causes psychological changes in older adults. • Misconception on changes in psychological functioning among older adults.

Continued TABLE 4-21 Themes, Sub-themes and Categories of Experience of Family Caregivers (n=7)

Themes	Subthemes	Categories
4. Suggestions for individual family and government/ health institution	a. Suggestions for individual/family	• Every family member should be responsible for providing care for older adults with disabilities. • Older adults are somehow like children and need love, attention, respect, delicious foods, and the presence of family members/relatives or friends. • Children learn to care for older adults from the home environment. • Caring is important when older adults are alive rather than following rituals after their death. • Caring for a single elderly man is more difficult. • Older adults with memory problems need special attention. • Family caregivers must be physically and mentally sound to provide care for older adults with disabilities.
	a. Responsibility of the local government and the health institution	• Conduct awareness programs about the normal changes in older adults. • Appreciation and reward system from local government. • Monitoring the health status and allowance of older adults through home visits. • Provide respite care to family caregivers. • Make a law for older adults' property.
5. Possible reasons for not caring about older adults	a. Behavior of older adults	• Speaking whatever by the older adults. • Showing unusual behavior by older adults.
	b. Increasing dependency of older adults	• Loss of physical strength and memories. • Need help to keep them clean.
	c. Neglecting behavior by the family	• Lack of awareness about changes in older adulthood. • Low emotional attachment of other family members. • Selfish nature of the youth.

<u>Theme 1: Caring Experience of family caregivers of older adults with disability</u>

In the experience of caring for older adults, two subthemes: positive and negative experiences were generated.

a. Positive experiences

The positive experiences explored were self-motivation and satisfaction, learning skills and enhancing early vocabulary development in the child, good family support, and appreciation of caring behavior by relatives or neighbors, respectively.

Self-motivation and satisfaction

Most respondents stated that they were self-motivated to provide most of the care

to their older family members with a disability as respondent 7 stated that "I am self-inspired to care for my mother-in-law". Likewise, respondent 2 stated "I left the job after my mother fell sick. Mother cared for us when we were children and now, we care for her." Though caring requires a great deal of hard work and loss of personal life and time, it gives self-satisfaction. There is no provision of grants or rewards for caring for the elderly, but respondents felt fortunate and gained satisfaction in caring for their older family members with disability. Most of them feel caring for the older adults allows them to repay the debt of love and care they received during their childhood. Respondent 5 stated "When we were small, he cared and loved us to grow but now he needs care, so we should provide care and love to him. My father made me what I am today, so I must care for him, don't I? I have this knowledge so, I am involved in his care, but my other brothers don't have such knowledge, and they don't think about the father".

Increasing in Learning skills and enhancing early vocabulary development among children

Respondent 7 stated, "Caring mother-in-law gave me an idea on how to care for children. I have learned how to change a diaper, how to give a bath, how to care for and love her". Likewise, respondent 3 verbalized "My son started to speak clearly at 16 months. Some children don't speak at 16 months of age, but my son started to mention the names of things, has started conversations, and speaks many words".

Good family support

Only two of the family caregivers stated that they received good family support for caring for older adults with disability. Respondent 5 stated "Sister-in-law cleans home, makes food for all, and washes father's clothes which are not soiled with stool. I am compelled to clean his stool and urine. I wash his soiled clothes. I do all his tasks like bathing him, changing his soiled dress, cleaning, and keeping him in the sun during the daytime". Similarly, respondent 3 said "I don't need to get up at night. At nighttime, my mother-in-law will be with my grandmother-in-law. My father-in-law's sister usually comes in the daytime and spends 2-3 hours with my grandmother. In case of emergency, all our relatives come to meet grandmother."

Appreciation of caring behavior by relatives or neighbors

Respondent 5 stated "Neighbors praise me because I care about my father". Likewise, respondent 4 said, "Other people have observed and appreciated that despite the condition, I am taking care of my father-in-law". Respondent 2 also stated, "I feel

appreciated by neighbors and relatives for taking good care of my mother".

b. Negative experiences

Primary caregivers sometimes were overwhelmed with the care they provided for 7-8 hours a day and having no other members to care for made them feel bad and drained. The negative experiences explored were physical and mental exhaustion, feeling socially isolated, lack of family support, feeling stressed in caring for the male older adults, lifestyle changes: need to leave the job, discontinue education, or suppress own wishes and ambition, and financial issues.

Physical and mental exhaustion

Female respondents mainly daughters-in-law felt overloaded with work in the morning because of different household chores and the caring responsibilities of older adults as respondent 7 verbalized "During morning time, it is difficult for me as I must cook food, send children to school, and at the same time, care for mother". Likewise, all respondents verbalized that caring for older adults with a disability is like caring for children as they need continuous care and supervision. In other words, they expressed that they were not only physically tired but also mentally exhausted with multiple responsibilities. Respondent 1 stated "It is so hard for me to leave her alone. What if something bad happens? What if she falls? Thinking these, I am scared." Respondent 3 also stated, "When I get into the bed, then I realize how tired I am. At the end of the day, as a family caregiver, I become weak and tired both physically and mentally."

Feeling socially isolated

Most of the respondents, who cared about older adults with disabilities, expressed that the frequency of involvement in social gatherings, visiting temples, and getting together with friends has been reduced nearly too a few times a month. Respondent 2 said "After my mother became paralyzed, I didn't get time to visit my relatives and friends often. I rarely visited them; maybe 1-2 times since then." Respondent 5 stated, "Due to the responsibility of caring for my father, I do not get any time to go out. I hardly manage 2 hours to meet my friends". As respondent 7 verbalized, "I am unable to visit my parental home. I must stay here and cannot go elsewhere; I even cannot go to the temple."

Lack of family support

All the family members need to be supportive and take some responsibility in caring for older adults, but some respondents could not get support from family members and relatives. As respondent 6 had said, "Although the father-in-law has relatives, brothers, and sisters, they rarely visit him. They just visit him to give him some goods. Nobody comes to care for him". Likewise, respondent 5 also stated, "Other brothers and sisters-in-law did not show any concern for father. So, I started taking care of him. I feel sad when nobody cares for our father when I fall sick". Likewise, respondent 4 stated, "I have not received any help from anyone within the family. I have done everything myself".

Feeling stressed in caring for the male older adults

Both male and female family caregivers experienced stress while giving care for male older adults. Respondent 5 stated, "There is a great difference between elderly males and females. If there was my mother instead of my father, my sister-in-law would care for her. It is very difficult to care for a father. Likewise, respondent 4 verbalized, "It is difficult for females to care for males but easier to care for females. It is more difficult to care for widower males."

Lifestyle changes: need to leave the job, discontinue education, or suppress own wishes and ambition

Respondents felt a drastic change in their lifestyle, mainly by the youngest caregivers since they were to care for their older adults with disability. Almost all respondents had to leave their work or discontinue their further education, suppress their wishes and ambitions, and stay at home to care for their disabled parents. Respondent 4 said, "I was unable to attend the human rights female program on BBC on time. I was also unable to complete the order of tailoring on time because I must care for my father-in-law." Likewise, respondent 5 stated, "I have completed my school level education, but I could not complete higher education as my father became sick and I have to care for him." Respondent 2 stated, "I used to work in a beauty parlor. I left that job after my mother fell sick." Respondent 7 also stated, "There is no certainty of my future. Till now, I have not done any income generating work. There is no utilization of my qualification. I have not learned anything."

Financial Issues

Most of the respondents were unable to continue their jobs, and because of this,

they had to depend on others for money. However, most of them did not have financial problems when caring for older adults, as they were getting financial help from relatives and friends, and the old age allowance received from the government would cover their daily expenses as well. Respondent 7 said, “There is no certainty of my future till now I have not done any income generating work”. Respondent 5 said, “I don’t get any time to be involved in earning”. Respondent 4 stated, “I feel like I am in a cage. If I don’t work, it will be difficult to join hands and mouth. If I stay caring for my father-in-law, then what to cook and what to eat?” Respondent 2 stated, “I have no earning sources after my mother fell sick. I am staying at home and have no earnings. I feel like my future is ruined and confined to a cage. Being involved in caring for the elderly has affected my personal life.” Respondent 1 stated, “Other older adults face problems due to poor economic status, but my mother is facing problems even though she is economically sound. My father asked me to return all the money to them, but I refused. So, they are angry with me”.

Theme 2: Socio-cultural belief about family caregivers

Preference of son over daughter

All family caregivers believe that other family members should also take caregiving responsibilities of older family members with disability. They claimed that older people prefer staying with their sons and their families, possibly because of the existing patriarchal concept that sons are responsible for their parents’ living and rituals. They stated that the reason behind preferring sons to stay with is strong socio-cultural beliefs that the sons and daughters-in-law have a crucial role in the funeral process whereas caregiving by the married daughters and their families is taken as a sin by the older adults unless they have no alternatives. Caregiving by daughters compared to sons and their families is not much preferred by older adults. Respondent 1 stated, “In her difficulties, she asks to call my brother immediately and I console her saying it will take time to come from his workplace. In case of emergency, he will come immediately. I feel sad when she always asks for my brother when I am the one caring for her”.

Theme 3: Awareness of changes due to aging

The theme summarizes the family caregivers’ awareness of the changes in physiological and psychological functioning due to changes that occur in older people as they age.

***Low awareness of change in physiological functioning*:**

Different changes in physiological function due to aging were explored. Most respondents were not aware of the normal changes of aging rather seemed to be more centered on the problems of aging. The changes in physiological functioning included swallowing difficulty (respondent 1), fatigue, problems in hands and knees, less immunity, decrease in hearing capacity (respondent 2), inability to perform activities of daily living (respondent 6), and stomach pain, toothache, and headache (respondent 7). Further, respondent 4 stated, "Indigestion, asthma, heart problem, hands and legs pain, voiding in random places, leg spasm or paralysis" are the changes in physiological function caused by aging. In addition, breathing difficulty (respondents 1, and 7), decreased vision (respondents 1, and 2), inability to walk or work (respondents 2,3,6, and 7), and loss of physical strength or physical weakness (respondents 2,3,5, and 7) were explored respectively.

Besides these, some family caregivers still had misconceptions about the changes in physiological function among older adults. They find it difficult to believe that older adults with a disability have poor vision, roam here and there, and infer poor vision as the reason for peeing and pooping anywhere.

Low awareness of changes in psychological functioning:

Regarding awareness of changes in psychological functioning due to ageing, almost all have experienced different changes in their older adults with disability. However, the respondents were more focused on psychological conditions rather than the normal changes. Respondent 1 stated, "The older adult had suicidal ideation or fear/worry or thought of dying". Likewise, other explored changes in psychological functioning include being irritable, forgetfulness, easily tense, and talkative (respondent 2); being suspicious, insecure, irrelevant talking, mental instability, and using verbally abusive words (respondent 4); getting angry, scolding, loss of memory (respondent 6); and behaving like a child (respondent 4 and 6). Similarly, respondent 7 stated, "suicidal ideation or fear/worry/thought of dying, getting anxious, and bad dreams" were the changes in psychological functioning.

Besides these, almost all family caregivers still have some misconceptions about changes in psychological functioning such as older adults showing attention-seeking or unstable behavior; even very unusual behavior (respondents 1, 3, 4, 5, 6, and 7).

Theme 4: Suggestions for individual/families and government/health institutions

Suggestions for individual/family

All respondents stated that other family members should take responsibility for caregiving for older adults with disability. Overall, the family caregivers gave the following suggestions for individual families:

(1) Every family member must be aware of the physiological and mental changes of their older family members and the impact of those changes. Understanding these can help older adults with disabilities get the necessary love and care (respondent 1). Older people are like young children; in this phase of life, they need extra love, care, and support from all their family members as they are unable to perform activities of daily living. The needs of older adults are love, attention, respect, delicious and nutritious foods, and the presence of family members/relatives or friends around (respondents 6 and 7).

(2) Home environment and observation of parental behavior affect the children's learning in that respective family. Respondent 1 felt that family upbringing plays a great role. She further added, "Children behave in the way they are brought up. All parents should teach their daughters to look after and care for their older in-laws after marriage. Caring is important while the older people are alive rather than following rituals after their death".

(3) The gender and memory problems of older adults with disabilities make a difference in caregiving. Respondents 4, 5, and 6 stated, "Caring for a single elderly man is more difficult than caring for a single elderly woman". Similarly, respondents 4 and 6 stated, "Older adults with memory problems need special attention. For security purposes, they must be kept under close supervision or locked in a room if they need to go outside.

(4) Family caregivers must be physically and mentally sound to provide care for older adults with disabilities. Respondent 4 claimed, "Stressful and hypertensive people could not be good family caregivers". Different coping techniques can be used to reduce caregiving stress such as being silent (respondent 5), speaking with a loud voice, or forgiving their behavior as well as engage own self to work and forgetting the stress (respondent 4).

Suggestions for the local government and the health institutions

Though caregiving of older adults with a disability is the family's primary responsibility, the government should also provide support to older adults and their families. The government of Nepal provides old age allowances to all older adults aged 68 years and above. For effective care for older adults, the respondents have a few suggestions for the local government and health institutions:

Older adults might not have received effective care as most people are unaware of the changes and impacts of aging, both on older adults and their family caregivers. The presence of disability increases its impact even more. So, the government should conduct awareness programs about the normal changes in aging and its effects on older adults.

Similarly, the respondents expected appreciation and monetary rewards from the government. Most respondents (respondents 2, 3, 4) requested the government to provide unemployment allowance for those family caregivers of older adults with disabilities who were not engaged in any income-generating work. For example, respondent 2 stated, "It would help a little if the government provides financial help to those family caregivers involved in the care of elderly people". Further, respondents 3 and 4 stated, "Local government needs to develop a reward system for the best family caregivers". Respondents also highlighted the need for respite care for family caregivers as caring for older adults with disabilities is not an easy task. Respondents 4 and 7 stated that the local government needs to mobilize youth volunteers to care for older adults and provide leave to the family caregivers from caring responsibility at least once a month.

Even though older adults with disabilities are cared for in their home settings, their status should be regularly monitored. According to respondent 3 "The local government needs to monitor how the old age allowances are being utilized by older adults and their families". Likewise, respondents 2, and 5 stated, "Health institutions need to conduct home visiting programs for older adults with disabilities to assess their health status and provide education for family caregivers on time". Respondent 4 added, "Health institutions should monitor the care provided by family caregivers to their older adults with disabilities". Likewise, respondent 6 recommended that the nation should make a law that property such as land should be in the name of the older father or mother until his/her death. In addition, make a law that only family members caring that older adults would get that property after his/her death; other people could not claim it.

Theme 5: Possible reasons for not caring about older adults

Older adults with disabilities might not get the proper care that they deserve. While exploring the possible reasons for older adults not getting adequate care and attention, three sub-themes emerged, including the behavior of older adults, increasing dependency, and the neglectful behavior of the family.

Behavior of older adults

The behavior of older adults with disabilities is sometimes troublesome for caregivers. As respondent 6 stated, "I become angry because my father-in-law speaks whatever he likes while changing dresses, bathing, cleaning urine and stool". Older adults sometimes show unusual behaviors. Respondent 5 stated, "Same as other older people, my father also sometimes speaks good and sometimes bad, sometimes he wakes up early in the morning and sometimes he doesn't sleep for a whole night." Respondent 1 claimed that "I get angry when she asks me to help her stand, sleep in the bed, help with toileting while I am busy in the kitchen. She always disturbs me while I am busy. I feel her behavior is very unusual".

Increasing dependency of older adults

The conditions of older adults with disabilities make them dependent on their family caregivers. Increased dependency might burden the caregivers, which may cause inadequate attention and care to the older adults. In the same theme, respondent 5 stated, "The reason behind not caring for older adults is they lose their physical strengths and memories". Respondent 6 added "While old people spit anywhere, drool, soil dress with stool and urine, family members need to help them clean, so it might be the reason for not providing care."

Neglect by the family

Due to different reasons, older adults are neglected by their families. Respondent 5 stated that "My brothers are uneducated and have no idea about physiological changes, and mental changes during late adulthood. I think a lack of education is the main reason for not taking care of my father. The low emotional attachment of other family members with the older adults could be another reason for not caring for them". Respondent 3 added, "Older adults do not get care from their family members because of a lack of awareness about aging changes". Likewise, respondent 3 added "Nowadays, youth are being selfish and only think about self-happiness". Similarly, respondent 6 stated that "Because of social distortion, sons and daughters do not care about older adults as

people have a habit of showing off and staying at home maintaining hygiene." In addition, respondent 1 claimed that "My sister-in-law's parent didn't teach her well about obligations for caring for her parents-in-law".

Summary of Findings:

Family caregivers perceived mixed experiences while caring for older adults with disabilities. Some perceived positive experiences such as self-satisfaction and self-motivation, learn new skills, perceived good family support, and receiving appreciation of caring behavior by relatives or neighbors. However, they also perceived some negative experiences. They were physical or mental exhaustion, social isolation, lack of family support, more stress while caring male older adult, and perceived lifestyle changes: leaving a job, discontinuation of education, or even suppressing their wishes and ambitions. Likewise, most of the family caregivers faced financial difficulties. Besides these, socio-culturally, they expressed that most older adults preferred a son over a daughter. Family caregivers had low awareness of physiological and psychological ageing changes and had some misconceptions of these changes.

Recommendations from Family Caregivers

(1) Family is the main responsible organization for providing necessary care for the older family members.

(2) Local government needs to monitor the utilization of allowances provided for older adults.

(3) Local government needs to provide some remuneration in the form of a non-employment allowance for family caregivers who have low economic status.

(4) Local government needs to create and supervise a caring environment for family caregivers.

(5) Local government and local institutions need to arrange educational programs related to older adults.

(6) Local health institutions need to start to respite care services for those family caregivers who are responsible for caregiving.

The researcher also reviewed the general education system up to the higher secondary school curriculum. Since 2009, in grade 9 on health and population, all students had to study about global and national scenarios of older adults as a demographic change, their physical, psychological, and social changes, as well as caring of the ageing population till 2019. In 2020 AD, this course was removed from grade 9. In 2022 AD, the curriculum development center of Nepal had developed a

curriculum on geriatric health as an optional course for higher education, but till now, no course has been developed.

Based on the findings of a qualitative study and review of the education system of secondary level curriculum, including course contents, the researcher identified a gap in age-related changes in physical, physiological, psychological, and social functioning and the needs of older adults. So, the researcher herself developed the contents of the educational program through the critical synthesis of literature reviews in both English and the Nepalese language. The researcher distributed the draft of an educational program for reviewing the contents of the educational program in Maharajgunj Nursing Campus, including experts from the faculties of adult and geriatric nursing, and two family caregivers of older adults with disability who could read and write in the Nepali language and participated in the qualitative study. For this, the researcher followed following procedure: a) conducting series of face-to-face meeting with all members of expert groups; b) systematically listing of intervention options as well as modules from the available interventional package or modules in the literature review; c) the criteria was developed for prioritizing contents of educational program based on pre-defined criteria which includes acceptability, feasibility, and effectiveness as recommended by Child Health and Nutritional Research Initiative (CHNRI)[54]. After obtaining written as well as verbal feedback from all members, the researcher further revised by selecting understandable and practicable words on the contents of the educational program.

4.1.3.4 Stage four: Development of structure and content of educational intervention through narrative review

Based on the findings of in-depth interviews and reviewing the contents of the curriculum of school-level education, the researcher first developed an outline of the structure of the content of the educational intervention program. Based on qualitative data analysis, the researcher conducted narrative review on developmental task of older adults, ageing changes that could exist among older adults, early identification and preventive measures of the psychological changes of older adults and different stress reducing activities used in different life situations for family caregivers from published articles available in different sources of literature especially, Google Scholar, Hinari, PubMed and from different web sites. The researcher developed the structure and contents of the educational intervention program in both English and the Nepalese language. The contents and the structure of the psycho-educational program, both in

Nepalese and

4.1.3.5 Stage five: Quality assessment of the Nepalese and English versions of the educational program

In this stage, the psycho-educational program was further refined through a series of consultations with the experts. Then, the researcher also provided five sessions of educational intervention to 3 family caregivers of older adults with disability who had already participated in the pilot study and had obtained a caregiving burden score of more than 20 and could read and write the Nepalese language and also participated in an in-depth interview. From verbal and written feedback obtained from three family caregivers and conducting a content validity index of the psych-educational program from 5 experts and consultation with a bilingual expert, the psycho-educational interventional program was finalized. By this process, qualitative assessment of acceptability and feasibility of the newly developed intervention program was also established.

4.1.3.6 Stage six: At the end of the sixth stage

The psycho-educational intervention program was finalized based on a scoping review of efficacious interventions, expert opinions, and a formative qualitative study, as well as qualitative feasibility and acceptability in the Nepalese language.

4.1.4 Fourth Phase: Conduct Randomized Clinical Trial

In the fourth phase of this study, the researcher used a randomized clinical trial as the BMRC recommended for non-pharmacological intervention in a community setting[96] to determine the efficacy of an educational intervention program on reducing care burden of family caregivers of older adults with disabilities.

4.1.4.1 Research Setting and Population

The research setting was also in Tarakeshwor and Gokarneshwor Municipalities. After analyzing the report of the cross-sectional study, the researcher identified those family caregivers who had a moderate to severe level of care burden (ZBI Score more than 20) as the sampling population. The family caregivers who obtained burden scores more than 20 were 281 as 163 and 118 from Tarakeshwor and Gokarneshwor Municipalities respectively.

4.1.4.2 Selection Criteria

4.1.4.2.1 Inclusion Criteria

(1) Those family caregivers who still care for older adults with disability.
(2) Those family caregivers who still stayed in the same house as the older adult.
(3) Those family caregivers who could read and write the Nepalese language.

4.1.4.2.2 Exclusion Criteria

Those family caregivers of older adults who need intensive care or are terminally ill.

4.1.4.3 Sampling Method

The researcher made a list of family caregivers who obtained a care burden score of more than 20 from both municipalities in two groups based on setting (that is, 163 from Tarakeshwor as an intervention group and 118 from Gokarneshwor Municipality as a control group). The researcher selected family caregivers by using a probability, simple random sampling technique (lottery method) for selecting family caregivers in both groups of the family caregivers.

4.1.4.4 Sample Size

The sample size was calculated based on the interventional study done by using Roy's Adaptation Model for reducing the caregiving burden of mothers of children under chemotherapy[26]. The sample size was calculated by considering the following conditions as the significance level (α) = 0.05; effect size (β) = 0.20; power of test (P) = 0.80 that was 30 family caregivers of older adults with disability in each group[26,137]. . The total sample size of the experimental study was 60 (30 in intervention group and 30 in control group).

4.1.4.5 Research Instruments

(1) Educational program in the Nepalese language.

(2) Structured interview questionnaire used in a cross-sectional survey.

4.1.4.6 Steps carried out for conducting Educational Intervention for Family Caregivers were as follows

For intervention, the researcher performed the following activities:

(1) Firstly, the researcher made a name list with the contact address of the interventional group of family caregivers who had a caregiving burden (obtained ZBI Score more than 20 in the descriptive study) from Tarakeshwor Municipality.

(2) The researcher herself provided information regarding the purpose of this intervention, frequency, duration of intervention, content, and techniques of instruction before obtaining informed consent from the family caregiver.

(3) After that, the researcher herself provided educational intervention for family caregivers individually in their own homes by using a printed copy of the Nepalese version of an educational program in 5 consecutive days for family caregivers.

(4) The researcher also instructed family caregivers to practice giving knowledge in their daily lives.

(5) On the last day of intervention, the researcher also provided a printed version of the educational program individually.

For the control group, the researcher did not introduce any activities.

4.1.4.7 Data Collection Process

After three months of completion of the educational intervention, the researcher collected data by using the same tool in the descriptive study from family caregivers of both intervention and control groups.

After completing data collection from the control group who were residing in Gokarneshwor Municipality, the researcher herself provided an educational program for them by following the same procedure as in Tarakeshwor Municipality.

4.1.4.8 Data Analysis

The efficacy of educational intervention was measured by using the Chi-squared test and the Mann-Whitney U test between control and experimental groups. In this study, the level of significance was considered as a p-value less than 0.05 for all the

statistical analyses. The magnitude of the intervention effect was calculated by using Cohen's d test.

4.1.4.9 Findings of Randomized Clinical Trial

The findings of the randomized clinical trial are as follows:

Table 4-22 Socio-demographic Characteristics of Older Adults in Two Groups

Characteristics	Intervention Group (n=30) Frequency (percent)	Control Group (n=30) Frequency (Percentage)
Age in years		
60-79	20 (66.7%)	22 (73.3%)
≥80	10 (33.3%)	8 (26.7%)
Gender		
Male	9 (30.0%)	9 (30.0)
Female	21 (70.0%)	21(70.0%)
Types of Residencies		
Own house	26 (86.7%)	18(60.0%)
Rented house	4 (13.3%)	12 (40.0%)
Marital Status		
Unmarried/widow/er	16 (53.3%)	19 (63.3%)
Married and living with couple	14 (46.7%)	11 (36.7%)
Governmental allowance		
Not obtained	4 (13.3%)	7 (23.3%)
Obtained	26 (86.7%)	23 (76.7%)
Status of Alive Children		
No child	1 (3.3%)	1 (3.3%)
Have child/ren	29 (96.7.0%)	29 (96.7%)
Current health problems		
One or two problems	4 (13.3%)	0(0.0%)
Three or more problems	26 (86.7%)	30 (100.0%)
Current psychological status		
Intact memory	24 (80.0%)	11 (36.7%)
Memory deficit	6 (20.0%)	19 (63.3%)

Table 4-22 presents the socio-demographic characteristics of older adults in both intervention and control groups. The two groups were comparable across most variables, including age, gender, marital status, and number of children. However, a higher proportion of participants in the intervention group lived in their own house (86.7% vs 60%) and had intact memory status (80% vs 36.7%), which may have contributed to caregiver burden differences. These variables were considered during the interpretation of post-test results.

Table 4-23Characteristics of family caregivers in Intervention and Control Groups

Socio-demographic Variables		Intervention Group (n=30) Frequency (Percent)	Control Group (n=30) Frequency (Percent)
Age in years*	18 – 39	12 (40.0)	10 (33.3)
	40-59	12 (40.0)	20 (66.7)
	≥60	6 (20.0)	0 (0.0)
Mean age ± SD		**46.56±15.77**	**42.07±5.99**
Gender	Male	3 (10.0)	1 (3.3)
	Female	27 (90.0)	29 (96.7)
Caste	Brahmin/Chhetri	20 (66.7)	12 (40.0)
	Janajati	9 (30.0)	15 (50.0)
	Dalit	1 (3.3)	3 (10.0)
Religion	Hinduism	29 (96.7)	18 (60.0)
	Buddhism	1 (3.3)	10 (33.3)
	Kirat	0 (0.0)	2 (6.7)
Marital status	Married living with spouse	26 (86.7)	27 (90.0)
	Unmarried/Widow (er)	4 (13.3)	3 (10.0)
Educational status	Unable to read and write	10 (33.3)	0 (0.0)
	Only read and write	2 (6.7)	6 (20.0)
	1-8 School year	5 (16.7)	16 (53.3)
	9-12 Class	9 (30.0)	7 (23.3)
	Bachelor and above	4 (13.3)	1 (3.3)
Family type	Joined/Extended	27 (90.0)	24 (80.0)
	Single	3 (10.0)	6 (20.0)
Family members no.	2-4	8 (26.7)	3 (10.0)
	≥5	22 (73.3)	27 (90.0)
Current occupation	Unpaid job	21 (70.0)	10 (33.3)
	Paid job	9 (30.0)	20 (66.7)
Economic status	Sufficient for <1 year	13 (43.3)	30 (100.0)
	Sufficient for ≥ 1 year	17 (56.7)	0 (0.0)

Table 4-23 presents the socio-demographic characteristics of family caregivers in both intervention and control groups. The two groups were comparable across few variables, including gender, marital status, and family type. However, a higher proportion of participants fell in the intervention in age 40-59 years (40.0% vs 66.7%), and from Janajati ethnicity (30.0% vs 50.0%), from Hindu religion (96.7% vs 60.0%), educational status of 1-8 years schooling (16.7% vs 53.3%); five or more members in the family (73.3% vs 90.0%), in unpaid job (70.0% vs 33.3%) and not sufficient income for 1 year (43.3% vs 100.0%) which may have contributed to caregiver burden differences. These variables were considered during the interpretation of post-test results.

Table 4-24 Caregivers' Responsibilities, Social Support and Care Variables in Two Groups

Variables		Intervention Group (n=30) Frequency (Percent)	Control Group (n=30) Frequency (Percent)
Family's Responsibility		19 (63.3)	19 (63.3)
Social Responsibility		19 (63.3)	9 (30.0)
Under 5 Children		7 (23.3)	4 (13.3)
Having extra stress		20 (36.7)	29 (96.7)
Caring duration	1-2 hours	4 (13.3)	7 (23.3)
	3-7 hours	11 (36.7)	20 (66.7)
	≥ 8 hours	15 (50.0)	3 (10.0)
Sleeping hours	1-5 hours	22 (73.3)	0 (0.0)
	≥6 hours	8 (26.3)	30 (100.0)
Daytime rest	No rest	6 (20.0)	9 (30.0)
	Have a resting time	24 (80.0)	21 (70.0)
Social support status: moderate level		30 (100.0)	30 (100.0)

Table 4-24 presents the family caregivers' responsibilities, social support, and caregiving-related variables in both intervention and control groups. The two groups were comparable across a few variables, including caregivers' family responsibility, daytime rest, and social support status. However, a higher proportion of participants in the intervention group had social responsibility (63.3% vs 30.0%); 8 hours or more caring hours (50.0% vs 10.0%), and sleeping at night up to 5 hours (73.3% vs 0.0%). Likewise, a lower proportion of participants in the intervention group had extra stress (36.7% vs 96.7%), which may have contributed to caregiver burden differences. These variables were considered during the interpretation of post-test results.

Table 4-25 Comparison of Burden Scores in Pretest and Posttest of Both Groups

Burden score	Intervention Group		Control Group	
	Pretest	Post-test	Pretest	Post test
Mean ± SD	33.07±9.355	14.6±5.96	24.93±4.38	28.70±5.62
t-value	-10.45		3.86	
d.f	29		29	
P-value	P<0.001		0.001	
Minimum score	22	6	21	22
Maximum score	59	30	43	48
Have Burden	30	5	30	30
No burden	0	25	0	0
Total	30	30	30	30

Table 4-25 shows the comparison of burden scores of pretest and posttests within control and intervention groups, respectively. The mean burden score was significantly decreased from 33.07 ± 9.36 in pretest to 14.6 ± 5.96 in post-test, indicating a substantial reduction in perceived burden ($t = -10.45$, $df = 29$, $P < 0.001$) in intervention group. In contrast, the control group showed an increase in the mean burden score from 24.93 ± 4.38 to 28.70 ± 5.62 in post-test ($t = 3.86$, $df = 29$, $P = 0.001$), suggesting a worsening of perceived burden over time without the intervention. Furthermore, the

proportion of care burden in the intervention group declined sharply from 30 (100%) at baseline to 5 (16.7%) post-intervention, with 25 (83.3%) no longer experiencing burden. Conversely, all 30 (100%) participants in the control group had a burden at both pretest and post-test, demonstrating no improvement. These results indicate that the intervention was highly effective in reducing the perceived burden, whereas the control group showed no such benefit.

Table 4-26 Family Caregivers' Burden Status in Posttests in Two Groups

Burden Status	Intervention Group (n=30)		Control Group (n=30)		P-Value	Cohen's d test
	Number	Percent	Number	Percent		
No or mild burden	25	83.3	0	0.0		
Burden	5	16.7	30	100.0		
Mean ± SD	14.6±5.96		28.70±5.62		<0.01*	2.43
Mean rank	16.83		44.7			
Median (Q1, Q3)	13.5 (9.75, 19)		27 (25, 32)			
Minimum	6		22			
Maximum	30		48			

P value is calculated by the Mann-Whitney U test

Table 4-26 shows the effectiveness of educational intervention for reducing the caregiving burden of family caregivers of older adults with disability. After educational intervention, the mean score of caregiving burden was only 14.6±5.96, while in the control group, the mean score was still as high as 28.70±5.62, as the p-value of the Mann-Whitney U test was less than <0.01. To further quantify the magnitude of the intervention effect, Cohen's d test was calculated using post-test mean scores of both intervention and control groups and dividing by the data's standard deviations. The value of Cohen's d was 2.43, which represents a very large effect size, indicating that the educational intervention had a substantial impact on reducing the caregiving burden of family caregivers of older adults with disability.

Discussion

In Nepal, few studies had been conducted on the caregiving burden of family caregivers of persons with psychiatric or mental illness [57-61]; persons with maintenance hemodialysis[58,59]Spinal cord injuries [60], autism disorder[61], and older adults[62]. Among them, two-thirds of studies show that almost all (95.13%-100%) caregivers had of burden[57-61]. However, only one study was done among family caregivers of older adults revealed that only 12% of them had a care burden, as this study included the majority (70%) of family members of older adults with no limitation in ADLs[62].

However, few studies in Nepal have explored this systematically. A study done by Khanal and Chalise in Nepal found that caregivers of elderly patients reported high levels of burden, especially among female and lower-caste caregivers, but did not include any intervention.

Supporting the current study's finding that psychoeducational interventions significantly reduce caregiver burden, the randomized clinical study conducted in Iran by using a non-blinded randomized control trial design among 66 family caregivers of cancer patients undergoing chemotherapy found that the intervention group showed a significant reduction in caregiving burden. In contrast, the control group experienced a slight increase. Before the intervention, 100.00% of caregivers reported feeling overloaded with care; after the intervention, 76.32% perceived no overload [166] .

Similarly, another non-randomized clinical control trial study was conducted in Tehran among 80 family caregivers of patients under CABG surgery in intervention and control groups. The control group received routine care, whereas the intervention group received additional education sessions at baseline, before surgery, the day after surgery, and before discharge. The caregiver burden was compared at baseline and six weeks post-discharge. A significant difference was observed between family caregivers in the control and intervention groups concerning pre-post differences in mean scores of burden as $p<0.001$ [167].

This study contributes new knowledge by implementing and evaluating an intervention rooted in Roy's Adaptation Model in a Nepalese context, showing that even short-term structured education can significantly improve caregivers' outcomes. The findings are particularly relevant for policy formulation and community health worker training programs in similar low-resource settings.

Although the short-term effects of the intervention were significant, the three-month follow-up period is insufficient to evaluate the sustainability of behavioral and emotional adaptation among caregivers. Caregiving burden is a dynamic process, often influenced by the progression of the older adult's condition and fluctuating social and psychological support. Longitudinal studies with follow-up at 6, 12, or 18 months are recommended to determine whether the reduction in burden is sustained over time or if caregivers' relapse into high-stress states.

Chapter 5 Conclusion and recommendation

5.1 Conclusion

Through expert review, the content validity index of the Nepalese versions of 6-CIT and SSRS was 0.90 and 0.75, respectively. The pilot study showed 23.3% of family caregivers had experienced burden. The Cronbach's Alpha value of the Nepali version of the social support questionnaire was 0.794.

The findings of a descriptive cross-sectional survey study conclude that nearly two-thirds (65.3%) of family caregivers have a burden. The predictors of caregiving burden are hypertension, gastrointestinal problems, complete impairment in ADLs of the older adults and low economic status, continuous caring for 3-35 months, and daily caring hours (≥8) of the family caregivers.

From the findings of phenomenological study, family caregivers have positive and negative experiences, have low awareness of ageing changes, and still have misconceptions regarding the perception of ageing changes. There is a lack of awareness programs regarding ageing changes, as no content is included in up to school-level education.

Then, the findings of the narrative review, consultation with expert and pretesting on 3 family caregivers: help to develop and evaluate a culturally accepted educational program in Nepalese and English languages for Nepal. After providing educational intervention in five sessions at their home setting, the caregiving burden is found to be low among family members intervention group as compared with the control group.

An individualized, multicomponent, multi-session educational program can reduce the caregiving burden of family caregivers of older adults with disability. The primary outcomes of this study are as follows:

The content validity index of the Nepalese versions of 6-CIT and SSRS were 0.90 and 0.75, respectively. The pilot study showed 23.3% of family caregivers had experienced burden. The Cronbach's Alpha value of the Nepali version of the social support questionnaire was 0.794.

The findings of a descriptive cross-sectional survey study conclude that nearly two-thirds (65.3%) of family caregivers have a burden. The predictors of caregiving burden are hypertension, gastrointestinal problems, complete impairment in ADLs of the older adults and low economic status, continuous caring for 3-35 months, and daily caring hours (≥8) of the family caregivers.

From the findings of a phenomenological study, family caregivers have positive and negative experiences, have low awareness of ageing changes, and still have misconceptions regarding the perception of ageing changes. There is a lack of awareness programs regarding ageing changes, as no content is included in up to school-level education. Then, the findings of the narrative review, consultation with an expert, and pretesting on 3 family caregivers: help to develop and evaluate a culturally accepted educational program in Nepalese and English languages for Nepal.

After providing educational intervention in five sessions at their home setting, the caregiving burden is found to be low among family members intervention group as compared with the control group. An individualized, multicomponent, multi-session educational program can reduce the caregiving burden of family caregivers of older adults with disability.

Limitations of the Study

This study began with Pandemic of COVID-19 and its public health issues, as well as psychological issues of individual respondents and the researcher herself made long time for completion of this study.

Strength of the Study

1. The researcher used validated tools: 22 items Zarit Burden Interview Questionnaire and SF-36 Quality of life questionnaire.
2. This study identified caregiving experiences of family caregivers of Nepal.
3. Develop and evaluate culturally accepted educational program for reducing caregiving burden of family caregivers of older adults with disability in Nepal.

5.2 Recommendation

1. The Government of Nepal need to include content of ageing changes and its related management in school level curriculum again to reduce misconception about ageing family members, as previously had.
2. The Government of Nepal allocates a budget for the needy family caregivers based on their economic status to address the economic needs of family members working as informal caregivers of their older relatives as soon as possible.
3. The local municipality and local health institutions need to implement and continue awareness programs for all family caregivers of older adults using this educational program.

5.3 Implications of the Study

1. The findings of this study might be a reference material for future researchers.
2. This interventional program is a nurse-led educational program based on training to deliver intervention programs through face-to-face individual intervention to reduce caregiving burden.
3. This educational program can be used by educated family caregivers to reduce their caregiving burden of older adults with disability in Nepal.
4. This educational program might be a reference material for other professionals working in public health.
5. This educational program might be a reference material for the government of Nepal to develop a short-term training program for family members.

5.4 Dissemination

The findings of this research was disseminated in Tarakeshwor, Gokarneshwor, Tokha Municipalities and Nepal Health Research Council. In addition, the researcher submitted the manuscript to BMC Geriatrics for publication.

5.5 Road Map of Methods

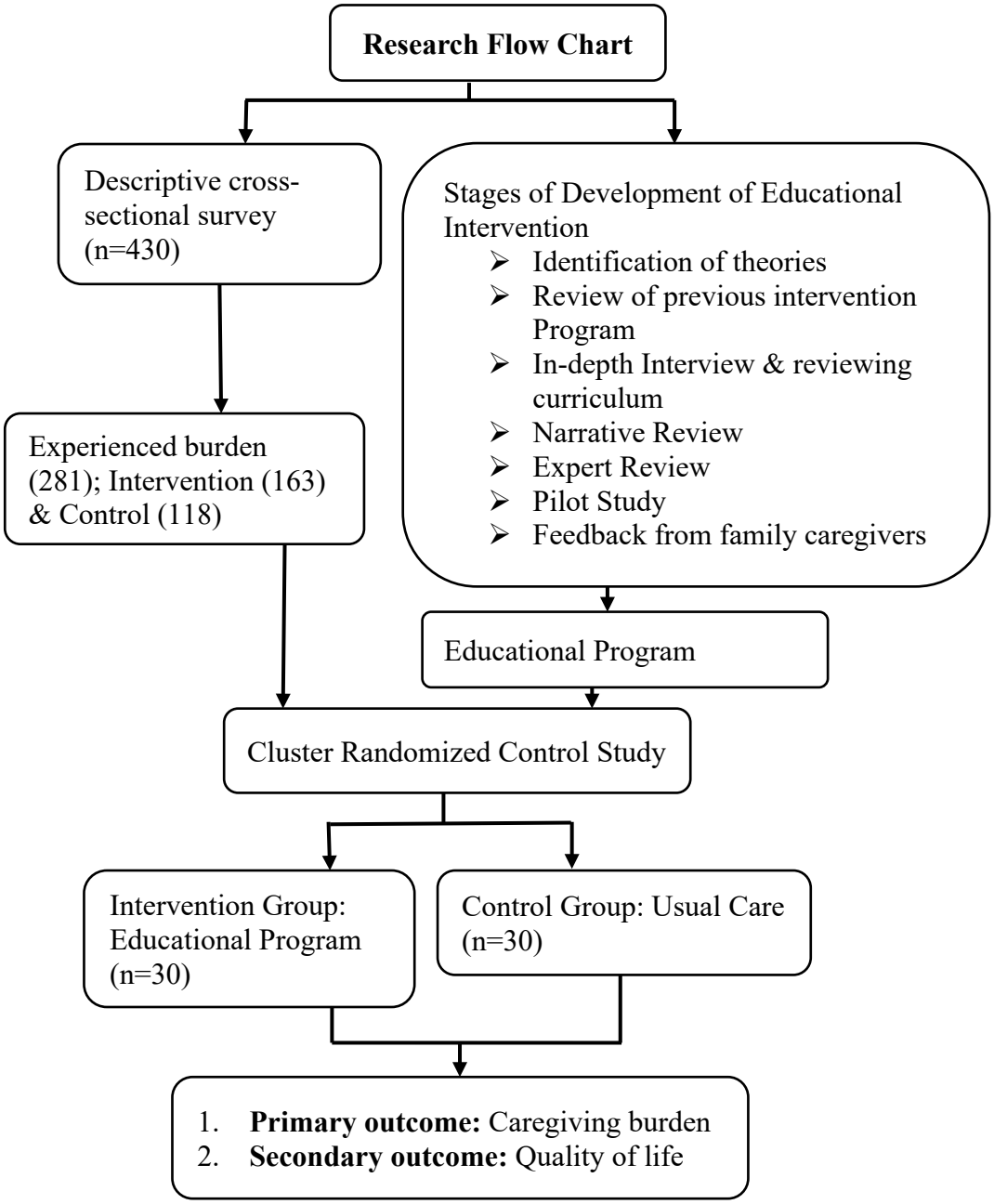

Figure4-1 Roadmap of overall research study

Chapter 6 Ethical Consideration

6.1 Ethical Consideration during Cross-sectional Survey

First, the researcher obtained ethical approval from the Institutional Review Board of Xiangya School of Nursing, Changsha, Hunan, China, and obtained ethical permission from the Nepal Health Research Council. The researcher obtained formal permission from the Tarakeshwor and Gokarneshwor Municipality Office. The data collector explained individual family caregiver about the purposes of the study, data collection, method, and average time duration of the interview as one hour, and requested whether he/she was willing to participate in this study or not. Informed written consent was obtained from the family caregiver who met selection criteria before starting the interview. The data collector maintained the family caregiver's right to withdraw at any stage of the research. Participants were included without any discrimination. Data was collected in the home environment from family caregivers. Confidentiality and anonymity of the collected information were maintained. Results were analyzed based on findings among the total number of participants; therefore, no individual results were reported.

6.2 Ethical Considerations during Experimental Study

The researcher prepared a name list of family caregivers based on the obtained care burden score of more than 20 in a cross-sectional survey, and they were willing to participate in the experimental study. Then, the researcher divided them into intervention and control groups by using cluster randomization. The researcher herself provided educational intervention individually after obtaining written informed consent. Participants of the control group provided care as usual for their older relatives. After three months of completion of the intervention, the researcher again collected data from participants of both groups after obtaining written informed consent as mentioned in the cross-sectional study. Confidentiality and anonymity of the collected information were maintained.

Chapter 7 Timeline and Expected Outcome

7.1 Timelines of the Study

Table 6-1: Timelines of Research Study

Activities	Start Date	End Date
Literature Review	Sep., 2020	March, 2021
Topic selection	Sept., 2020	Oct., 2020
Proposal writing	Nov., 2020	March, 2021
Ethical approval, tool translate in Nepalese language	April, 2021	July, 2021
Proposal Presentation		July, 2021
Pilot Study of Cross-sectional study	Sept. 2021	Oct, 2021
Indepth interview	February, 22	March, 2022
Descriptive study: cross-sectional survey	January, 22	March, 2022
Data analysis of cross-sectional survey	April, 2022	May 2022
Data analysis of In-depth Interview	April , 2022	August , 2022
Educational package: ➢ Development, ➢ Experts review, ➢ Translation into Nepali language ➢ Pilot study, ➢ Publication in Nepali language	Sept., 22	July, 2023
Intervention of educational Program	August, 2023	Sept., 2023
Data collection after 3 months of intervention	Jan, 2024	
Data analysis	Feb, 2024	Feb, 2024
Report writing	March, 2024	March, 2024
Report presentation and submission	November, 2024	
Manuscript preparation	Jan 2025	
Seminar and Articles publication	June, 2025	

7.2 Outcomes of the Study

The primary outcomes of this study were as follows:

(1) This study identified some positive and negative experiences of family caregivers of older adults with disability.

(2) This study identified factors associated with the caregiving burden of family caregivers of older adults with disabilities.

(3) Developed and published the Nepalese version of the educational intervention program for reducing the caregiving burden of family caregivers.

(4) The educational intervention program was found to be effective as the mean score of caregiving burden was reduced in the experience group in three months after the educational intervention.

7.3 Budget Details of the Study

Table 6-2 Budget plan of the Study

Item Description	Cost (RMB)	Expenditure Justification
Development of educational intervention	2,000	Conducting an in-depth interview Conducting a narrative review Writing the first draft of the education program Expert review of first draft
Ethical approval	1,000	Payment for ethical approval
Stationary & printing	1,500	Preparing an interview questionnaire for data collection
Printing of the educational program	3, 000	Preparing for intervention materials
Data collections:		
➢ For pilot study: 3 times	3000	Travel costs for data collection and educational intervention
➢ For a cross-sectional survey	1500x4=6000	➢ Salary for data collectors
➢ Expert review	1000x=2000	➢ Finalization of an educational intervention program
➢ Training for investigators	4000	➢ Stationery, refreshments, remunerations for participants, and rent for the venue
For Experimental study:	1500x4=6000	➢ Salary for interventionists
Data collection	2000	Travel cost
Data entering	1,000	For refreshment
Statistician consultation	2,000	For analysis
Report writing and publication	2,000	Computer designing and Printing
Dissemination	1,000	Give compensation for 1 hour
Publication of an article and a seminar presentation, national or international	5,500	Publication charge and travelling costs
Total		**42, 000/-**

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Overview

Manuscript 1

Manuscript submitted to BMC Geriatrics
Factors Associated with Caregiving Burden of Family Caregivers of Older Adults with Disability, Kathmandu, Nepal

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Abstract

Introduction: The continuous increase in the ageing population suffering from chronic diseases, with difficulty in performing activities of daily living (ADLs) and instrumental activities of daily living (IADLs) increasing their care needs. Because of limited health facilities and support, family caregivers may experience a burden.

Objective: To identify factors associated with the caregiving burden of family caregivers of older adults with disability.

Methods: A Descriptive cross-sectional survey was conducted by using a non-probability convenient sampling technique from 430 family caregivers of older adults with disability residing in Tarakeshwor and Gokarneshwor Municipalities of Kathmandu. Data was collected through personal interviews by using a pretested Nepali version of a structured interview questionnaire consisting of socio-demographic characteristics of older adults and their family caregivers, care provision related variables, social support questionnaire, and 22-item Zarit Burden questionnaire. SPSS version 25 was used for data analysis, especially descriptive statistics (frequency, percentage, and mean as well as standard deviation), and inferential statistics (Logistic regression model: univariate and multivariate) were used to identify factors associated with caregiving burden.

Results: In this study, 65.3% of family caregivers had caregiving burden in which statistically significant association was depicted with COPD, hypertension, paralysis,

urinary and gastrointestinal problems, health problems, psychological status, impaired ADLs and IADLs of older adults and also occupation and economic status, residency, types and size of family, perceived extra stress, health status, duration of care, daily caring hours, and sleep time of family caregivers. The predictors of burden were older adults with hypertension [AOR:1.96 (CI: 1.12-3.43; p=0.019)]; gastrointestinal problems [AOR: 3.33 (CI: 1.35-8.21; p=0.009)]; complete impairment [AOR: 0.37 (CI: 0.16-0.87; p=0.022)] and family caregivers with low economic status [AOR: 1.79 (CI: 1.05-3.05; p=0.031)]; caring for 3-35 months [AOR 0.60 (CI: 0.36-0.98; p=0.043)]; long caring hours (≥8) [AOR 2.84 (CI: 1.14-7.06; p=0.025)].

Conclusion: As two-thirds of family caregivers feel burdened, the predictors of burden are hypertension, gastrointestinal problems, impairment in ADLs of the older adults, and low economic status, caring for 3-35 months, and long caring hours (≥8) of the family caregivers. The concerned authority of these two municipalities needs to address the economic needs of family caregivers, and local-level health institutions need to develop different activities for supporting family caregivers of older adults with disabilities through home visit.

Key words: Caregiving burden, Family caregivers, Older adults with disability

Background

Ageing is a global phenomenon that results in an increasing population of older adults with disability and chronic illnesses that are becoming public health problems[1]. Nepal is also rapidly growing, with more than 3.8% annual growth of people aged 75 years and above[2]. Not only, the prevalence of disability increase with age (40% at age 60 and 75% at age 80)[3] , but also its severity increases with age (20% at age 60 years and 50% at age 80 and above) [4] . The risk of disability is increased because of the increasing prevalence of chronic diseases and injuries with aging [2]. In Nepal, 80% of outpatient contacts for medical follow-up and treatment in health institutions [5] are utilized by people with chronic diseases. The provision of home-based care for older adults with disability by family caregivers is becoming a challenge due to a shortage of young people, which may be because of a decrease in the total fertility rate [6] , declining the potential support ratio[7], reducing family size as a consequence of youth migration[2] and limited health care facilities[6] as well as a lack of formal support[6].

Family caregivers are the informal workforce for providing care to family

members who are disabled, and the most difficult part of the health care system [8-11] for providing support in ADLs and managing symptoms of chronic conditions [10] . Caregiving can affect the family caregivers' employment status, educational prospects, finances, and social life [12]. Caring for an older adult with a disability is a highly stressful experience (physical, psychosocial, or financial hardships) known as caregiving burden [13, 14]. Thus, a prolonged sense of burden may lead to emotional stress [15], psychiatric problems [15-18], poor health [14-19], worsening health-related quality of life [14, 15, 19, 20], financial problems [15-17], compromised immunity [14, 19], mortality [14, 19], social isolation [14, 19], deteriorate work participation [20], burnout [21] or influence decisions to institutionalize care recipients [15, 21]. Hence, this study was conducted to identify the factors associated with the caregiving burden of family caregivers having older adults with disability.

Methods

Study design and participants

A quantitative, descriptive cross-sectional survey design was used. The population of this study was all the family caregivers of older adults aged 60 years and above with a disability residing in Tarakeshwor and Gokarneshwor Municipalities of Kathmandu District, having the highest population density in Nepal. The inclusion criteria of participants in this study were family caregivers of older adults currently providing care in at least one ADL [23] and four IADLs [24] for more than one month. The calculation of the sample size was based on the following assumptions: prevalence of burden 50%, at a 95% confidence level at least ±5% precision by using the Cochran formula [25] as follows: $((1.96)^2 (0.5) (0.5)) / (0.05)^2 = 385$, considering an attrition rate of 11.5%, the sample size was 430 participants by using a non-probability, convenience sampling technique. After getting ethical approval from the Institutional Review Board of Xiangya School of Nursing and the Nepal Health Research Council, written permission was obtained from the authorities of both municipalities.

Data collection

The study was carried out by appropriately prepared and trained interviewers who conducted direct, pen-and-paper interviews using a pretested Nepalese version structured interview questionnaire at the participants' places of residence. The questionnaire consisted of sociodemographic characteristics of both older adult (age, gender, marital status, family type, number of living children, status of governmental support, type and duration of disability, average required time per day for care assistance, and, history of chronic diseases) and family caregiver (age, gender, marital status, educational background, current occupation, any social role, family income sources with estimated yearly expenditure, relationship with older adult, position, number of family members, caring responsibility of under-five child, provision of care for other family members or relatives and any current stressful conditions); checklist for assessing impairment status on ADLs and IADLs developed by the WGBH Educational Foundation and Massachusetts Institute of Technology in 2008[26] , Social Support Rating Scale (SSRS) was developed by Xiao in 1995[27] for assessing perceived social support of family caregivers and the Nepalese version of the Zarit Burden Interview (ZBI) questionnaire[28] consisting of 22 questions in a 5-point Likert scale. Data was collected from 1st January 2022 to 31st March 2022 using a pretested Nepalese version of the interview schedule.

Statistical analysis

The researcher checked the data daily, coded, recorded, and entered into the Statistical Package for the Social Sciences (SPSS) version 25.0 software. A database had been formed, mentioning name, label, value, and criteria of the variables. Then, the data were entered and analyzed using descriptive statistics such as frequency, percentage, mean, and standard deviation; and inferential statistics such as Pearson's correlation coefficient (*p*), univariate, and multivariate logistic regression tests to measure the relationship of dependent and independent variables. For statistical analyses, a *p*-value less than 0.05 was considered significant.

Results

Characteristics of the population studied

The findings revealed that 44.9% of the older adults had 1-2 activities impairment, followed by 3-5 activities impairment (42.8%), and complete impairment in ADLs (12.3%), respectively. Likewise, 54.4% of them had complete and 45.6% had partial impairment in IADLs. Similarly, 74.7% of older adults had three or more health

problems, and 20.0% had memory impairment. This study also found that the mean age of family caregivers was 45.92±14.05 years, 83.5% and 88.1% of family caregivers were female and married, and living with a spouse. Only 43.0% of them were in earning occupations or receiving financial support from the government, and 50.4% had sufficient income for one year or more. Further, 58.6% of them felt extra stress besides care provision. All of them perceived a moderate level of social support. The mean duration of care provision was 4.43±3.93 years, ranging from 3 months to 30 years. 19.5% of them cared for ≥8 hours per day, 37.7% slept <6 hours, and 18.4% had no resting time in a day. Only 27.9% of the family caregivers had one or more health problems.

Burden status and possible factors associated with caregiving burden

A multivariate logistic regression was applied for the significant variables after using univariate analysis. While calculating model fitness, the chi-square is highly significant (chi-square = 112.578, df=20, p= 0.000) in Omnibus tests; on measuring Hosmer and Lemeshow goodness of fit {chi-square = 3.727, df=8, p= 0.881 (> 0.5)} that suggests the model is a good fit to the data. Likewise, the total accuracy of this model in the classification table was 73.3%, which is closest to 80%, as the prediction model is corrected up to 80%. The value of Nagelkerke's R-squared is 31.8% of the variation in the outcome that this model is significant.

Table 1 shows that 34.7% of family caregivers perceived no burden or mild burden, while 57.9%, 6.5%, and 0.9% had moderate caregiving burden, moderate to severe, and severe burden, respectively, with its mean score of 24.73±10.14. **Table 2** shows that there was statistically significant association between diseases of older adults COPD (0.017), hypertension (0.000), paralysis (0.000), urinary problems (0.041), gastrointestinal problems (0.001), their health problems category (0.000), psychological status (0.003), impairment level of ADLs (0.000) and impairment status of IADLs (0.008) with caregiving burden as p-values of each is <0.05. **Table 3** shows statistically significant association between caregivers' occupation (p=0.015), economic status (p=0.047), residency types (0.006), family types (p=0.001), family size (p=0.038), perceived extra stress (p=0.000), health status (p=0.000), duration of care provision (p=0.042), hours of daily care provision (p=0.000), and sleep duration (p=0.000) with burden as p-value of each was <0.05.

Table 1 Status of Caregiving Burden of Family Caregivers （n = 430）

Burden Status	Score	Frequency	Percent	Range
No or mild burden	0 – 20	149	34.7	4-72
Moderate burden	21-40	249	57.9	
Moderate to severe burden	41-60	28	6.5	
Severe burden	61-88	4	0.9	
Mean±SD	**24.73±10.14**			

Table 2 Association Between Older Adults' Related Factors and Care Burden

Factors of Older Adults		Burden (n=281)	No burden (n=149)	p-value
COPD		106 (58.9%)	74 (41.1)	0.017
Yes				
		175 (70.0%)	75 (30.0%)	
	No			
Hypertension		140 (76.1%)	44 (23.9%)	0.000
Yes				
		141 (57.3%)	105 (42.7%)	
	No			
Paralysis		54 (87.1%)	8 (12.9%)	0.000#
Yes				
		227 (61.7)	141 (38.3%)	
	No			
Urinary Problems Yes		49 (76.6%)	15 (23.4%)	0.041
	No	232 (63.4%)	134 (36.6%)	
GI problems	Yes	45 (84.9%)	8 (15.1%)	0.001#
	No	236 (62.6%)	141 (37.4%)	
Health problems	1 or 2	53 (48.6%)	56 (51.4%)	0.000
	3 or more	228 (71.0%)	93 (29.0%)	
Psychological status				
	Intact Memory	213 (61.9%)	131 (38.1%)	0.003
	Memory impairment	68 (79.1%)	18 (20.9%)	
Level of ADLs				
	Complete impairment	26 (49.1%)	27 (50.9%)	0.000
	3-5 activities impairment	140 (75.1%)	44 (23.9%)	
	1-2 activities impairment	115 (59.6%)	78 (40.4%)	
Status of IADLs				
	Complete impairment	166 (70.9%)	68 (29.1%)	0.008
	Partial impairment	115 (58.7%)	81 (41.3%)	

(p <0.05, significant at 95% CI; #Fisher's Exact Test)

Table 3 Association Between Caregivers' Related Factors and Caregiving Burden （n=430）

Caregivers' Related Factors		Burden (n=281)	No burden (n=149)	p-value
Occupation				
	Unpaid occupation	172 (70.2%)	73 (29.8%)	0.015*
	Paid occupation	109 (58.9%)	76 (41.1%)	
Economic status				
	Sufficient for < 1 year	149 (70.0%)	64 (30.0%)	0.047*
	≥ 1 year or surplus	132 (60.8%)	85 (39.2%)	
Residency type	Own house	221 (62.4%)	133 (37.6%)	0.006*
	Rented house	60 (78.9%)	16 (21.1%)	
Family type	Nuclear	24 (96.0%)	1 (4.0%)	0.001#*

Joint / extended	257 (63.5%)	148 (36.5%)

Continued Table 3 Association Between Caregivers' Related Factors and Caregiving Burden （n=430）

Caregivers' Related Factors		Burden (n=281)	No burden (n=149)	p-value
Family size	2-4 persons	74 (74.0%)	26 (26.0%)	0.038*
	≥5 persons	207 (62.7%)	123 (37.3%)	
Perceived extra stress				
	Having stress	183 (72.6%)	69 (27.4%)	0.000*
	No stress	98 (55.1%)	80 (44.9%)	
Health status				
	No health problem	186 (60.0%)	124 (40.0%)	0.000*
	One or more problems	95 (79.2%)	25 (20.8%)	
Caring duration				
	3-35 months	91 (59.1%)	63 (40.9%)	0.042*
	≥ 36 months	190 (68.8%)	86 (31.2%)	
Daily care time				
	1-7 hours	205 (59.4%)	140 (40.6%)	0.000*
	≥8 hours	76 (89.4%)	9 (10.6%)	
Daily sleeping time				
	1-5 hours	123 (75.9%)	39 (24.1%)	0.000*
	≥6 hours	158 (59.0%)	110 (41.0%)	

Used Chi-squire test; *p<0.05 was considered statistically significant; Fisher Exact Test

Table 4 Determined Factors of Caregiving Burden of Family Caregivers （n=430）

Older Adults Variables		Univariate Analysis		Multivariate Analysis	
		Unadjusted OR (95% CI)	p-value	Adjusted OR (95% CI	p-value
COPD	Yes	0.61 (0.41-0.91)	0.017	0.91 (0.54-1.54)	0.741
	No	1		1	
HTN	Yes	2.36 (1.55-3.61)	0.000	1.96 (1.12-3.43)	0.019*
	No	1		1	
Paralysis	Yes	4.19 (1.93-9.07)	0.000	1.59 (0.63-4.00)	0.324
	No	1		1	
GI problems	Yes	3.36 (1.54-7.33)	0.002#	3.33 (1.35-8.21)	0.009*
	No	1		1	
Urinary problem					
	Yes	1.88 (1.01-3.49)	0.043	0.79 (0.36-1.71)	0.555
	No	1		1	
Health problem status					
1 -2 problems		1		1	
3 or more problems		2.59 (1.65-4.04)	0.000	1.47 (0.83-2.63)	0.184
Psychological health status					
Memory intact		1		1	
Loss of memory		2.32 (1.32-4.08)	0.003	1.33 (0.64-2.63)	0.434
Level of ADLs					
1-2 activities impairment		1		1	
3-5 activities impairment		2.15 (1.38-3.36)	0.026	1.30 (0.71-2.37)	0.38

				8
Complete impairment	0.65 (0.35-1.20)	0.171	0.37 (0.16-0.87)	0.022*
Status of IADLs				
Partial impairment	1		1	
Complete impairment	1.71 (1.15-2.56)	0.008	1.58 (0.88-2.83)	0.120

N.B. Variables with p<0.25 in the Univariate analysis were included in the multivariable analysis, *p<0.05 was considered statistically significant. 1: reference group; CI: confidence interval; OR: odds ratio

Predictors of caregiving burden

Table 4 shows the univariate and multivariate analysis of older adults' related variables of burden. The adjusted odds of hypertensive older adults were 1.96 (CI: 1.12-3.43; p=0.019), as compared to non-hypertensive older adults who had GI problems were 3.33 (CI: 1.35-8.21; p=0.009), as compared to those without GI problems. Similarly, the older adults with 3-5 ADLs impairment and complete impairment were 1.30 (CI: 0.71-2.37; P=0.388) and 0.37 (CI: 0.16-0.87; p=0.022), respectively as compared to impairment of 1-2 ADLs. **Table 5** shows the univariate and multivariate analyses of family caregivers' related variables with caregiving burden. The economic status was sufficient for less than 1 year with adjusted odds 1.79 (CI: 1.05-3.05; p=0.031) as compared with sufficient for equal or more than one year. Similarly, the caring duration for 3-35 months with adjusted odds 0.60 (CI: 0.36-0.98; p=0.043) as compared to caring duration for 3 years or above and the average daily caring hours for 8 or more with adjusted odds 2.84 (CI: 1.14-7.06; p=0.025) as compared to daily caring hours less than 8 hours as in all p-values were less than 0.05.

Table 5 Family Caregivers' Related Factors that Determined Caregiving Burden

Variables	Univariate Analysis		Multivariate Analysis	
	Unadjusted OR (95% CI)	p-value	Adjusted OR (95% CI)	p-value
Occupation				
Paid occupation	1		1	
Unpaid occupation	1.64 (1.10-2.45)	0.015	0.76 (0.46-1.24)	0.275
Economic status				
Sufficient for <1 year	1.49 (1.00-2.23)	0.047	1.79 (1.05-3.05)	0.031*
Sufficient for ≥1 year	1		1	
Types of residency				
Own house	1		1	
Rented house	2.25 (1.24-4.07)	0.007	1.79 (0.88-3.66)	0.106
Types of family				
Nuclear	13.82 (1.85-103.21)	0.010	5.94 (0.64-46.77)	0.119
Joined /Extended	1		1	
Family size				
2-4 persons	1.69 (1.02-2.78)	0.039	1.12 (0.61-2.06)	0.696
5 and more persons	1		1	
Felt extra stress				
Having stress	0.46 (0.30-0.69)	0.000	1.15 (0.91-2.48)	0.104
Having no stress	1		1	
Health status				
No problem	1		1	
Have a health problem	2.53 (1.54-4.15)	0.000	1.82 (0.97-3.41)	0.059
Caring durations				
3-35 months	0.65 (0.43-0.98)	0.042	0.64 (0.36-0.98)	0.043*
≥36 months	1		1	

Continued Table 5 Family Caregivers' Related Factors that Determined Caregiving Burden

Variables	Univariate Analysis		Multivariate Analysis	
	Unadjusted OR (95% CI)	p-value	Adjusted OR (95% CI)	p-value
Caring hours per day				
1-7 hours	1		1	
8 and more hours	5.76 (2.79-11.89)	0.000	2.84 (1.14-7.06)	0.025*
Sleeping duration				
1-5 hours	2.19 (1.42-3.39)	0.000	1.17 (0.67-2.03)	0.569
6 hours or more	1		1	

Variables with p<0.25 in the Univariate analysis, included in the multivariable analysis, *p<0.05 was considered statistically significant. 1: reference group; CI: confidence interval; OR: odds ratio

Discussion

This study showed that 74.7% of older adults had three or more physical problems, and 20.0% had memory problems. Likewise, 60.9%, 26.5%, and 12.6% of them had 1-2, 3-5 impairment and complete impairment in ADLs, respectively, while a study done by Khanal and Chalise [29] found that 30% of older adults had at least one ADL impairment. As found in this study, 83.5% were female family caregivers which was consistent with studies reports of Khanal & Chalise [29], Sajeev & John [30], Baysan & Mandiracioglu [31]and Abdul et al, [32] as female were 80.7%, 75%, 81.5% and 66.4% respectively. The current study found 27.9% of family caregivers had one or more health problems, which was less than a study of Abdul et al [32], as 52.8% had some health problems. Current findings showed the mean duration of care provided was 4.43 (±3.93) years, which was less than the study of Khanal & Chalise [29], which was 5.18 (±3.51) years. The average caring time of this study was 37.31 hours per week, which was similar to the findings of Brinda et al [20] as 38.6 hours/week.

The mean score of burden of family caregivers in current study was 24.73±10.14 which was lower than the studies of Sajeev & John [30]; Gok Matin, Karadas & Mustafa Cankurtaran, [33]; Baysan & Mandiracioglu [31]; and Naing, May & Aung [34] as 36.4±14.3; 37.59 ± 18.20; 31.95±13.33 and 45.75±16.79 respectively; and was higher than studies conducted by Abdul, et al [32] and Khanal & Chalise[29] as 18.5± 13.6 and 12.89 ±5.7 respectively. The systematic review done by Loo, Yan & Low [35] found that the prevalence of burden was 23.0%-59.2%. This difference may be because of the inclusion criteria and socio-cultural variances.

Current study revealed that 34.7% of family caregivers had no or mild care burden while 57.9%, 6.5% and 0.9% had moderate burden, moderate to severe and severe burden respectively, which was lower than the findings of Tuttle, Griffiths & Kaunnil [36]; Sajeev & John [30]; Loureiro, et al [37], and Chandana et al [38] in which 18.8%

had no care burden, 43.5% had low-moderate, 30.4% had moderate to high and 7.2% had high burden; 43.33% had mild to moderate burden, 35.83% had moderate to severe and 15% had little or no burden; 61.5% had mild to moderate, 23.1% had moderate to severe and 15.4% had no burden; and 20% had little to no burden and 64.0% had mild to moderate, 14.0% had moderate to severe and 2.0% had severe burden respectively. In contrast to this, a study conducted by Khanal & Chalise [29] found that only 12.0% of family members had expressed a burden. This difference may be because of the inclusion criteria.

Factors associated with caregiving burdens

Current study depicted that the older adults' related possible factors of burden were having numbers of health problems (0.000), with their types {COPD/asthma (0.017), hypertension (0.000), paralysis (0.000), urinary problems (0.041), gastrointestinal problems (0.001)} and their psychological status (0.003). Another possible factor of burden in this study was level of ADLs (0.000) which was consistent with the study of Tuttle, Griffiths, & Kaunnil [36] and Abdul, et al [32] as ADL status of the care recipients ($p = 0.003$) and their functional independence ($P < 0.001$). Current study also showed that economic category ($p=0.047$) also a possible factor of burden which was supported by findings of Abdul, et al [32] as $p= 0.034$; Baysan & Mandiracioglu [31].

Current study depicted that health status ($p=0.000$) of family caregivers was the possible factor of burden which was consistent with the studies of Baysan & Mandiracioglu [31] as physical health problems ($p <0.001$) and of Abdul et al [32] found that even presence of chronic diseases ($p= 0.006$). The current study revealed that another possible factor of care burden was daily caring time ($p=0.000$), which was similar to the finding of Gok Metin, Karadas, Balci, Cankurtaran Zehra [33]. This finding was also consistent with the study of Tuttle, Griffiths, & Kaunnil [36], as the caring hours ($p = .017$) were another possible factor of caregiving burden.

Current study finding depicted that age group of family caregivers was not the possible factor of caregiving burden, but the studies conducted by Naing, May & Aung [34] and Tuttle, Griffiths, & Kaunnil [36] depicted as age group as possible factor of burden as $p = 0.008$ and $p = 0.000$ respectively. Other possible factors of caregiving burden were gender ($p = 0.023$) (Abdul et al) [32]; home-sharing ($p = 0.006$), and spending time during the day ($p = 0.009$) (Baysan & Mandiracioglu) [31]. These results were contradictory to the current study. Likewise, a study done by Lee, Hung, Kim, Chunmi [39] identified as factor influencing subjective burden was spouse of the older

adults (t=2.34, p=.020), a study done by Tuttle, Griffiths, & Kaunnil [36] found that the relationship to the care recipients was the possible factor of caregiving burden as p-value 0.009 which was contradictory to the findings of current study. In current study, the educational level of family caregivers was not the possible factor of caregiving burden, while different studies done by Tuttle, Griffiths, & Kaunnil [36] and by Gok Metin, Karadas, Balci, Cankurtaran Zehra[33] found that their education level (p = 0.002) was also a possible factors of burden as p –value less than 0.05.

Predictors of Caregiving Burdens

This study found that older adults with hypertension as its adjusted odds 1.96 (CI: 1.12-3.43; p=0.09), with GI problems as its adjusted odds 3.33 (CI: 1.35-8.21; p=0.009) which was inconsistence with the study done by Sabzwari, et al [40], as the stroke was the predictor of caregiving burden as adjusted odds {3.03 (1.34- 6.86)}. Likewise, this study also revealed that the older adults with complete impairment were 0.37 (CI: 0.16-0.87; p=0.022). This finding was similar to the study done by Abdul et al [32] in which their functional independence {–1.1 (–1.6, –0.6); P < 0.001} was the predictor of caregiving burden. This study also found that economic status sufficient for less than 1 year with adjusted odds 1.79 (CI: 1.05-3.05; p=0.031) as compared with sufficient for equal or more than one years; the caring duration for 3-35 months with adjusted odds 0.60 (CI: 0.36-0.98; p=0.043) as compared to 3 year or above and the average daily caring hours for 8 or more with adjusted odds 2.84 (CI: 1.14-7.06; p=0.025) as compared to daily caring hours less than 8 hours.

Limitations

This study also has some limitations. As this study follows a descriptive cross-sectional survey, it does not allow the researchers to make a strict cause-and-effect analysis of the associations between caregiving burden and related independent variables and their determinants. A longitudinal study is recommended to establish such associations. Due to resources and time constraints, the study sample was drawn from only 2 municipalities of Kathmandu District; as such, the sample may not fully represent all the family caregivers of older adults with disability of Kathmandu District. Another limitation of this study was that a few family caregivers denied the researcher for visit their older relatives with disability because of pandemic of COVID 19.

Conclusions

This study showed that nearly two-thirds of family caregivers had a caregiving burden. The older adults' related factors of burden are COPD, hypertension, paralysis,

urinary and gastrointestinal problems, psychological status, ADLs, and IADLs impairment status. Similarly, the family caregivers' related factors are occupation and economic status, residency, family type and size, perceived health status, and perceived extra stress, including duration of care, daily care time, and sleep duration. The predictors of caregiving burden are hypertension, gastrointestinal problems, complete impairment in ADLs of the older adults and low economic status, continuous caring for 3-35 months, and daily caring hours (≥8) of the family caregivers. The concerned authority of these two municipalities needs to address the economic needs of family caregivers and local-level health institutions need to develop different activities for supporting family caregivers of older adults with disabilities through home visiting.

Abbreviations

ADL: Activities of Daily Living; IADL: Instrumental Activities of Daily Living Scale; CI: Confidence Interval; COPD: Chronic Obstructive Pulmonary Disease; HTN: Hypertension, GI: Gastrointestinal, ZBI: Zarit Burden Interview

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Authors' contributions

Study concept and design: Raj Devi Adhikari Ghimire, Prof Dr Siyuan Tang. Data acquisition: Raj Devi Adhikari Ghimire. Data analysis: Raj Devi Adhikari Ghimire, Prof. Dr Siyuan Tang, Lec. Amrita Shrestha. Interpretation of data: all authors. Drafting of the manuscript: Raj Devi Adhikari Ghimire and Amrita Shrestha. Critical revision of the manuscript: all authors. Raj Devi Adhikari had full access to all data in this study and takes responsibility for the integrity of the data and the accuracy of data analysis. The final manuscript has been read and approved by all named authors.

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Availability of data and materials

The datasets used and/or analyzed during the current study are available from Raj Devi Adhikari Ghimire at rajdevi2017@gmail.com on reasonable request. https://drive.google.com/file/d/1mteuuGgF508NXBpCb-udT4ltLFqH3eyb/view?usp=sharing

Competing interests

The authors declare that they have no competing interests.

Ethics approval and consent to participate

Written informed consent and permission for interviews and publication were received from all study participants and their main adult caregivers. Approved from Nepal Health Research Council in 2nd Sep 2021, approved NHRC Number was 455-202-PhD.

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TRAINER MANUAL ON CARE OF MY OLDER FAMILY MEMBER AND MYSELF

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PROJECT

Effectiveness of psycho-educational program for reducing care burden of family caregivers of older adults with disability. The psycho-educational intervention will consist of following parts:

1. Introduction
2. Program description
3. General guidelines
4. First session
5. Second session
6. Third session
7. Fourth session
8. Fifth session
9. Bibliographic references
10. Annexes

INTRODUCTION

The purpose of this manual is to describe and standardize the procedures for the implementation of the proposed program for those family caregivers who experienced care burden because of their caring responsibility of their older family members with disability who will participate in the research "Efficacy of Educational Program for Reducing Caregiving Burden of Family Caregivers of Older Adults with Disability in Nepal".

The researcher assumed that the family caregivers would obtained opportunities for maintaining their quality of life through awareness on normal developmental tasks of older adults, their possible physiological and psychosocial changes and awareness on required activities to deal with these changes for older family members and develop

skills required for dealing with caregiving burden of family members of older adults with disability.

Any comments or suggestions on how to improve this manual are welcome.

PROGRAM DESCRIPTION

GENERAL OBJECTIVE

The general objective of this manual is to promote the adaptation of family caregivers with the nursing diagnosis of having caregiving burden among family caregivers of older adults with disability.

SPECIFIC OBJECTIVES

(1) Offer family caregivers relevant information about the physical, psychosocial changes of older adults including the caring needs of the care of the older adults with disability.

(2) Offer family caregivers relevant information about dealing with tension, and Om chanting and mindfulness meditation as techniques of stress reduction.

(3) Stimulate the development and use of techniques of self-stress reduction according to their caring situation.

EXPECTED HEALTH RESULTS

(1) Decrease the caregiving burden of family members of older adults with disability.

(2) Improve the positive perception of the physical and psychosocial changes and caring needs of older adults with disability.

(3) Practice the tension releasing measures, Om chanting and mindfulness meditation as techniques of stress reduction for family caregivers.

TARGET POPULATION

Family caregivers who have caregiving burden.

ORGANIZATION OF THE PROGRAM

The intervention program will last 5 sessions, at the rate of a 40-50 minute session per day (See table 1).

STRUCTURE OF INTERVENTION SESSIONS

Each intervention session is structured as follows:

(1) Review of previous session (from the second session)

(2) Describe the content of the session

(3) Summary of the session

(4) Exercises at home

(5) Discussion about any doubts.

Information Delivery Method

Individual educational intervention by home visiting.

Table 1 Program Overview of Psycho-educational Intervention

Sessions	Interventions/Activities	Contents
Session One	❖ Introduction and Pretest ❖ Awareness of family caregivers on the developmental tasks of older adults ❖ Awareness of family caregivers of possible physiological changes of older family members ❖ Awareness of Om chanting technique ❖ Summary of the session ❖ Home assignment for practicing Om Chanting	✓ Developmental Tasks of Older Adults ✓ Possible physiological changes in older adults ✓ Theoretical knowledge on Om Chanting ✓ Demonstration of Om Chanting
Session Two	❖ Review of session one ❖ Awareness of different activities that can overcome the possible physiological changes of older adults. ❖ Awareness of mindfulness meditation ❖ Practicing Om Chanting with return demonstration by family caregivers ❖ Summary of the session ❖ Home assignment for practicing Om Chanting and mindfulness meditation	✓ Different activities that can overcome the possible physiological changes of older adults. ✓ Theoretical knowledge on mindfulness meditation ✓ Practice of mindfulness meditation. ✓ Sharing of the experience of Om Chanting.
Session Three	❖ Review of session two ❖ Awareness of risk factors and signs of psychological problems, and management of mild forgetfulness in older adults. ❖ Practicing Om chanting and mindfulness meditation ❖ Summary of the session ❖ Home assignment for practicing Om Chanting and mindfulness meditation	✓ Awareness of risk factors and signs of psychological problems and management of mild forgetfulness. ✓ Practicing Om chanting and mindfulness meditation

Continued Table 1 Program Overview of Educational Intervention

Sessions	Interventions/Activities	Contents
Session Four	❖ Review of session three ❖ Awareness of dementia and its preventive measures ❖ Awareness of Alzheimer's disease and teaching for Family members of Older Adults with Difficulties in Communication ❖ Practicing Om chanting and mindfulness meditation ❖ Summary of the session ❖ Home assignment for practicing Om Chanting and mindfulness meditation	✓ Awareness of dementia and its preventive measures ✓ Awareness of Alzheimer's disease and teaching family members of older adults with communication difficulties. ✓ Practicing Om chanting and mindfulness meditation.
Session Five	❖ Review of session four ❖ Psychosocial Issues of Older Adults ❖ Strategies for supporting people with psychosocial issues ❖ Awareness of emotions and their management ❖ Summary of the session ❖ Home assignment for practicing Om Chanting and mindfulness meditation	✓ Awareness of psychosocial issues of older adults ✓ Awareness of strategies for supporting people with psychosocial issues ✓ Awareness of emotion and its management ✓ Practicing Om chanting and mindfulness meditation.

1 FIRST SESSION

1.1 Developmental Tasks for Old Age by Robert Havighurst

1. Adjusting to Deteriorating Health and Physical Strength
2. Adjusting to Retirement or Reduced Income
3. Meeting Social and Civil Obligations
4. Adjusting to Death or Loss of Spouse
5. Affiliation with Members of One's Age Group
6. Establishing Good Physical Living Arrangement[1, 2]

1.2 Possible Physiological Changes among Older Adults

Nearly half of the people aged 50 to 64 years, while 90% of those aged 75 years and above have chronic conditions: diabetes mellitus, hypertension, stroke or Parkinsonism, or osteo-arthritis[3].

Older adults are at risk of the following conditions:

1. Pneumonia, Chronic Obstructive Pulmonary Disease[4];

2. Constipation, fecal incontinence, malnutrition, postprandial hypotension, dysphagia[5], indigestion[6], diarrhea, abdominal pain, peptic ulcers, heartburn, flatulence, diverticulitis, or hemorrhoids[7];

Hypertension, left ventricular hypertrophy or myocardial ischemia or heart

3. failure[8];

4. Increased the frequency of urination and the high risk of urinary tract infections[9], urinary incontinence among women, urinary retention among men[10].

5. Injury[11], falls, fractures, joint problems, and easily tired[12];

6. Eyelid malposition[13], cataract, glaucoma, presbyopia or dry eyes, visual problems[14-18], so they may have difficulty in recognizing faces and differentiating colors.

7. Reduction in hearing, difficulty understanding high pitch sound[13] or hearing loss by 25%[19].

8. Declining ability of detecting salty taste, and exaggerating the taste of bitter[20],

9. Decreased sense of smell[13], more decrease among men[20].

10. Speech loss because of stroke[21].

11. Chronic pain[22, 23] because of chronic diseases (arthritis, cancer or bone or muscle pain)

12. Suffer from neurodegenerative disorders (Alzheimer's disease/ Parkinson's disease) [24-26], increased risk of stroke[27], declining memory and dementia[28];

13. Reduced cognitive abilities[29] declines in decision making, working memory (particularly task switching), and periodic memory[30], decreased learning and memory, attention, decision making speed, motor coordination[30-32],

14. difficulty in understanding rapid speech, reduced comprehension of complex sentences as a result of cognitive slowing and hearing loss[30],

15. Affect the activities of daily living[33] and difficulty in maintaining gait[11].

1.3 OM Chanting Introduction

The sound of Om plays an important role in our nervous system, as Om is the creation of the universe. Om meditation is easy to practice, it is less time-consuming, as well as does not require an expert or trainer to assist while performing; it has advantages over other meditation techniques[34]. Om is also called AUM. AUM introduced three sounds, "Aaaaa, Uuuuu, and Mmmmm". When we sound "Aaaaa" part of AUM, we feel the vibration in our stomach. When we sound "Uuuuuuu", we feel vibration at our chest. And when we sound "Mmmmmm," we feel the vibration at the head or mind. If we practice Om chanting in a normal pitch and regularly, our body and mind feel very stress-free and are ready to concentrate on our next work[35]. Chanting Om is equal to the supreme consciousness. Om chanting is widely used[36, 37]. Om chanting is a brain stabilizer; by practicing Om, one can enter deeper and deeper into

the own natural state, which is also an energy medicine for human beings under stress[38].

Effective 'Om' chanting is associated with the experience of vibration sensation around the ears that sensation also transmitted to the vagus nerve through auricular branch. It is believed that 'Om' chanting produces limbic deactivation like transcutaneous vagus nerve stimulation[39]. Evidence showed that even only Om listening was reported to activate the cortical areas related to cognition and cerebellum[37].

When the sound Om is chanted, it vibrates at the frequency of 432 Hz, which is the same vibration frequency found throughout everything in nature. Chanting Om connects us to this nature and the whole universe. It again proves that what we give to nature it returns to us. Evidence found that Om chanting reduces hypertension, resolves skin problems, and improves health[35].

How to Chant OM?

7. First, sit comfortably in a position with your eyes closed.
8. Take a deep breath and start first Aaaaa is chanted with the mouth wide open. Don't focus on frequency and vocal of sound. In our normal voice we must just open mouth wide, and it comes naturally.
9. Uuuuu is chanted by forming a circle with our mouth. Again, don't try to make a specific sound, just form the circle with our mouth, and the sound happens naturally.
10. Mmmmm is automatically created when we close our mouth and just make a sound with our mouth closed.
11. Feel vibrations of three different sounds naturally; don’t force it. Sounding an Om in normal pitch is always gives us faster results than low or high pitches.
12. When we chant OM we do not have to think when and how it works. It Just Works[35].

1.4 Practice of Om Chanting

2. SECOND SESSION

2.1 Instructions for Family Caregivers of Older Relatives with Ageing Changes in Physiological Conditions

2.1.1 Nutritional Needs and Dietary Advice

The older adult is at risk of malnutrition and deficiencies of iron, folic acids,

vitamins A, C, D, B_{12}, calcium, zinc and riboflavin.

1. Serve whole grains, high fiber foods, avoid white foods such as bread rice and potatoes.

2. Serve variety of lean animal and plant sources of protein e.g. lean animal meat or fish and variety of beans.

3. Serve green leafy vegetables, yellow and orange fruits.

4. Serve diet high in calcium: milk, curds, cheese, broccoli, green vegetables, or tofu for supplementing calcium requirements and encourage to stay 10 to 30 minutes from morning 10 am to 3 pm, 3 to 4 times per week in sun for vitamin D. In case of any known deficiencies, may supply calcium and vitamin D tablets orally, for vegetarian supplementation of vitamin B12[40-43]

5. Limited salt, sugar, high in saturated fat, fried or spicy foods[44, 45].

6. Encourage to drink fluid at least 2000 ml (per day in the form of water or non-caffeinated, non-alcoholic beverages[40-43].

2.1.2 Exercise

Those older adults who exercise at least 150 minutes of moderate-intensity aerobic physical activity per week, have better physical health and cognitive functioning. If they are unable to perform recommended number of physical activities, they should perform according to their abilities and conditions[45, 46].

1.Encourage your older relatives in deep breathing and coughing exercises[47].

2.Educate your older family members about Kegel exercises. Teach about the technique of Kegel exercises, that is, squeeze the muscles to stop passing gas or holding urine, or stool. Try it for three seconds at a time and then relax for a count of three. Continue the exercise for 10 to 15 times in a row, at least three times a day[40].

3.Getting regular exercise like yoga, meditation, and active passive exercises in a way that's comfortable and discouraging sedentary lifestyles[41, 48].

2.1.3 Encourage following healthy behaviors

1.Sleep at least seven to nine hours[40], daytime rest, and sleep

2.Encourage your older relatives to quit smoking and alcohol consumption[49] if they have a habit of smoking or drinking alcohol, as this substance may add to cognitive and mood deterioration in the long term[45].

3.Make arrangement for limiting environmental pollution, secondhand smoking, dust and other toxins or pollen as much as possible. For this, encourage them to wear masks while moving out in the polluted environments.

4.Encourage your older relative to maintain a healthy weight[40, 47, 50].

5.While moving your relative outside the home, wear umbrella, wear long sleeves clothes, apply sunblock cream, wear sunglasses or a wide-brimmed hat[43], including

walking stick.

6.While moving your older relatives around loud machinery or other loud noises, use earplugs[5]. If he/she has hearing defects, encourage them to use hearing aids; if they have vision problems, encourage them to wear spectacles.

2.1.4 Encourage to follow the daily routine

1.Encourage to empty the bowel daily[40].

2.If your older relatives have urinary urgency, encourage or remind them to go toilet regularly. Consider urinating on a regular schedule, such as every hour[40].

3.Encourage brushing teeth twice a day and cleaning between teeth using dental floss or interdental cleaning as required[40].

4.Encourage to maintain perineal hygiene as well as bathe in warm water using mild soap and moisturizer [40]. Avoid using very hot water as old, aged people may have sensory impairment and might get hurt.

2.1.5 Encourage social interaction by establishing social support

Social networks and interactions promote mental health and prevent mental illness among older adults. Arrange a regular family gathering, arrange for a phone call with relatives or grandchildren. These activities provide a sense of belonging and intimacy as well as promote them to be more competent and self-efficacious [45, 51]. As family caregivers, ensure an environment for social participation so that they can involve themselves in religious activities, groups like the bhajan team.

2.1.6 Arrange and plan a schedule for regular health screening and follow-ups

(1) Arrangement for periodic health checkup for diabetes mellitus, hypertension, and cardiovascular diseases at least once a year; even if he or she is not sick.[49]

(2) If your older adult is suffering from chronic diseases such as diabetes mellitus, high blood pressure, cardiac problems, respiratory problems, follow the instruction and guidance given by the physician and ensure medication compliance, including lifestyle modification [41].

(3) If possible, provide pneumonia or flu vaccine[47].

(4) Eyes and ears checkup with a specialist for glasses or hearing aids, or for timely treatment of other possible problems[43].

(5) Dental or oral checkup regularly with dentist or dental hygienist [43].

(6) If there are any changes in skin, consult with the doctor [43]

(7) Screening colorectal cancer, tests for fecal occult blood, and performing colonoscopy for those over 50 years of age [49, 50].

(8) As the intake of multiple medicines increases cognitive deterioration and other geriatric syndromes, the habit of intake of appetite stimulants, high-calorie nutritional supplements, sleeping medication (benzodiazepines), pain killers, and use of antibiotics without physician prescription should be avoided as much as possible [44, 45].

(9) If your older relatives are using any medicines, consult the physician for any side effects like nausea, diarrhea, constipation, or any other concerns. Ask for a substitute if a medicine has any severe side effects and avoid overusing over-the-counter medication pain relievers [52].

2.2 Mindfulness Meditation Introduction

Mindfulness is the moment-to-moment awareness and is trained through meditation exercises that have been adapted from Buddhist traditions [53]. Mindfulness meditation is defined as a non-judgmental awareness and attention on the present moment experience as a means of self-regulation to promote mind-body calmness and relaxation[54, 55]. It is also a skill to non-judgmentally observe emotions, sensations, or cognitions[53]. Mindfulness is not only the attention focused on the present moment and nonjudgmental awareness, but also an acceptance of experience with an attitude of openness and curiosity. It includes formal (mindful movement, the body scan, sitting meditation) and informal practices (incorporating mindfulness into everyday life) [56]. The characteristics of meditation are clearly defined as a specific technique, muscle relaxation somewhere during the process, logical relaxation, self-induced state, and use of self-focus skill [57].

Mindfulness is cultivated in formal meditation practices (sitting meditation, walking meditation, or mindful movements) [55]. The practice of mindfulness meditation involves focusing attention on the emergence of thoughts, emotions, and body sensations while observing them as they arrive and pass [58].

A meditation may be active, passive or mixing techniques, Winbush, Gross, & Kreitzer[59], Mahmood, Hophthrow, and de Moura [60] found that as little as 5 min of mindfulness can be beneficial for the study participants [60]. Meditation is a contemporary mind–body intervention, it may be concentration meditation or mindfulness meditation. Mindfulness promotes an individual's ability to focus their awareness on the present moment [61].

Mindfulness is used to describe a variety of practices and processes [62]. The process of mindfulness is composed of a two-component process that includes: attention to present moment experience and an attitude that is open, non-reactive, and

accepting of things as they are, regardless of their reactiveness and desirability[54, 63-65].

Evidences showed that meditation reduces stress[65], controls anxiety[66], promotes emotional health [67]; enhances self-awareness or more creative problem solving skills[68, 69], lengthens attention span[65]; may reduce age related memory loss[61]; can generate kindness[70]; may help fight addiction[71]; improves sleep[72]; helps to control pain[66]; can decrease blood pressure[73]; accessible anywhere[74]. Besides this, recent evidence shows that the mindfulness-based educational programs are an effective technique for reducing the burden or stress of family caregivers of older adults with dementia [75-77]. A meta-analysis review determined that mindfulness techniques are being used in interventions based on psychosocial, psycho-educational, and counseling programs [77]. Interventions based on mindfulness techniques show significant effects on the reduction of depression and the burden of family caregivers [77]. Likewise, mindfulness-based stress reduction (MBSR) is a treatment for psychological distress, depressive symptoms, and anxiety for people with chronic disease, developed by Kabat-Zinn [55, 78].

Mechanism of Action of Mindfulness Meditation

(4) **Attention regulation**: During focused attention meditation, distracting external events and memories, or thoughts about future events. These are ignored while the practitioner concentrates on meditation. Attention is supposed to rest on a single object. Instructions for this as "Focus your entire attention on your incoming and outgoing breath. Try to sustain your attention there without distraction. If you get distracted, calmly return your attention to the breath and start again". A sufficient degree of attention regulation is necessary for staying engaged in meditation [58].

(5) **Body awareness**: Body awareness is the ability to notice subtle bodily sensations [79]. In mindfulness practice, the focus of attention is an object of internal experience: sensory experiences of breathing, sensory experiences related to emotions, or other body sensations. Body sensations are a common object of attention during mindfulness meditation, and practitioners report improved body awareness [58].

c. **Emotion regulation**: Evidence demonstrated improvements in emotion regulation associated with mindfulness. A mindfulness practice leads to increases in positive reappraisal and that these increases mediate an improvement in stress levels [80].

d. **Exposure, extinction (elimination), and reconsolidation**: During mindfulness, practitioners expose themselves aware in external stimuli, body sensations and emotional experiences. They let themselves be affected by the experience,

refraining from engaging in internal reactivity toward it, and instead bringing acceptance to bodily and affective responses. Practitioners are instructed to meet unpleasant emotions (such as fear, sadness, anger, and dislike) by turning towards them, rather than turning away. Those people who are new to meditation may discover the pass away of unpleasant emotions and experience a sense of safety or well-being in their place[58].

(6) **Change in perspective on the self:** The principle of Buddhist psychology lies in the teaching that there is no such thing as a permanent, unchanging self [81]. The perception of a self is a product of an ongoing mental process. This perception recurs very rapidly in the stream of mental events, leading to the impression that the self is a constant and unchanging entity. The self is experienced as being the one who inhabits the body, being the one who is thinking the thoughts, being the one experiencing emotion, and being the agent of actions: having free will [58].

Steps of Mindful Meditation

(7) **Get comfortable:** find a quiet place where you won't be disturbed. Ideally, this would be a room in your house where you can be alone and at peace.

(8) **Get in position:** You might try sitting cross-legged on a low cushion on the floor, or upright in a chair. Some people prefer to meditate in a sitting position, a lying down position, walking meditation, or mindful movements

(9) **Get relaxed:** Close your eyes, set a timer for five minutes if you are just starting, and begin by taking a few deep, cleansing breaths. Breathe in deeply (but naturally) through your nose, and out through either your nose or mouth, whichever feels more comfortable to you. Let the breaths flow down into your abdomen.

(10) **Focus on your breaths:** Become aware of the sound of your breaths as you inhale and exhale. As you inhale, you breathe in all the peaceful and joyful things around you. As you exhale, you rid your mind and body of all the stress and toxins that have been bothering you. Let your mind become mesmerized (hypnotized) by the rhythmic pattern of your breathing.

(11) **Bring your thoughts back to the center:** Your mind will wander (walk). When you notice your thoughts wandering off from your breath, do not chastise (correct) yourself; it is normal. Simply acknowledge it and bring your focus back to the center, back to your breaths. Take in your immediate surroundings. What do you hear? What do you feel right now, at this moment? Try not to ruminate (reflect) on the past or worry about the future, but present in this pure moment.

(12) **Commit:** Like exercise, meditation takes practice. And the more we practice, the better we get and the stronger that mindfulness muscle becomes. Even just five to ten minutes per day has been shown to make an enormous difference to well-being after just eight weeks of meditation practice[82].

2.3 Practice of Om Chanting and Mindfulness Meditation

3 THIRD SESSION

3.1 Psychological Problems of Older Adults

The World Health Organization projected that between 2015 and 2050, the proportion of the population over 60 years will double (12% to 22%). Globally, more than 16% of older adults are suffering from some form of mental disorders, depression (7%), dementia (5%), anxiety disorders (3.8%), and substance use (1%)} along with multiple comorbidities at the same time [83]. Mental illness is usually underdiagnosed among older persons, as they are susceptible to depression or other mental problems because of the grief and loss of loved ones, chronic health conditions, or limited functioning that is accompanied by ageing.

3.2 Possible Risk factors for mental health problems among older adults

(1) Declining functional abilities, especially mobility of older adults as a result of chronic pain, weakness.

(2) Increasing experience of bereavement, as well as low socio-economic status, because of retirement or lack of education.

(3) Increasing risk of depression because of social isolation, loneliness, or psychological distress, and being female.

(4) Increasing risk of mental illness as well as physical injuries because of physical, verbal, psychological, financial, and sexual abuse; rejection; neglect or serious losses of dignity and respect [84-86].

3.3 Signs of psychological problems among older adults

(1) Withdrawal from social activities.

(2) Disturbance in intake of food or sudden weight loss or gain.

(3) Confusion or disorientation.

(4) Unexplained physical symptoms: muscular pain, sweating or shaking, digestive upsets, or changes in bowel habits.

(5) Sadness, worthlessness, sorrow, emptiness, lethargy or other depressive mood for 2 weeks or more.

(6) Neglect personal hygiene or being obsessive about cleanliness.

(7) Lose interest in recreational activities.

(8) Increased consumption of alcohol or other substances, including unhealthy foods.

(9) Changed in sleeping patterns (excessive or difficulty in sleeping)[87].

3.4 Mild Forgetfulness

As we age, we may experience mild forgetfulness: difficulty to learn new things or remembering certain words, or finding it time-consuming to find our objects. A person may make a bad decision occasionally, miss a monthly payment, forget the current date day and slowly remember it, forget proper selection, and lose things from time to time.

3.4.1 A person can overcome mild forgetfulness by following these activities

(1) Follow a daily routine.

(2) Use memory tools: calendars, to-do lists, or maintain a diary about your plan.

(3) Always put your wallet or purse, keys, phone, or glasses in the same place.

(4) Participate in volunteer activities (in the community, at a school, or in religious activities).

(5) Plan time for interaction with friends and family daily.

(6) Plan daytime naps, and sleep at least seven to eight hours each night.

(7) Involve in active physical exercise, eat a balanced diet daily, and quit alcohol.

(8) Consult a doctor if you feel depressed for weeks at a time.

3.4.2 A family member can help an older adult with mild forgetfulness

(1) Use large calendars to highlight important dates and events

(2) Remain in use of listed plans daily

(3) Maintain safety in the home

(4) Display written directions for using common household items

(5) If possible, set an alarm on your mobile for medication reminders and set map services on your mobile[88].

3.5 Practice of Om chanting and mindfulness meditation

4 SESSION FOUR Severe Forgetfulness Diseases (Dementia and Alzheimer's disease)

4.1 Dementia

Dementia is a chronic, progressive deterioration in memory, thinking, behavior, and the ability to perform daily activities and communication. Dementia increases physical, emotional, and economic pressure on families and caregivers, so support is necessary for them. Possible risk factors of dementia are age over 75 years, heredity, head injury with loss of consciousness, hypertension, diabetes, stroke, smoking, physical inactivity, high cholesterol, obesity, and low level of education.

Teaching Family Caregivers for Reducing the Risk of Dementia among Older Adults

(1) Serve Vitamin E containing diets: Avocados, almonds, spinach, kiwifruit, broccoli, add foods high in antioxidants (apple, Avocados, mushrooms, green tea, nuts, strawberries) and omega-3 fatty acids (soybean oil, kidney beans, wall nuts, chia seeds), mental and physical activity, and social engagement [89, 90].

(2) Maintain blood pressure; if hypertensive, arrange for antihypertensive drug and a drug that lowers the blood cholesterol level under the supervision of a physician[91].

(3) Encourage the use of hearing aids if hearing problems exist and protect ears from excessive noise exposure[92].

(4) Avoid smoking uptake and support smoking cessation to stop smoking. In addition, reduce exposure to air pollution and passive smoking, which reduces the risk of dementia even in later life.

(5) Prevent head injury.

(6) Limit alcohol use, as alcohol misuse and drinking more than 21 units (630 ml) weekly increase the risk of dementia.

(7) Perform regular exercise to maintain a healthy body weight [92].

4.2 Alzheimer's disease

Alzheimer's disease is the most common form of dementia, a neurodegenerative disease in which a person may have loss of memory and the ability to learn new things,

difficulty in speaking and thinking. It affects one in four people over age 65.

4.3 Teaching Family Members of Older Adults with Difficulties in Communication

Older people may report problems in recognizing faces, differentiating colors, and experiencing pain; such symptoms may be distressing for their family members or friends. Communication difficulties can occur among people with dementia, hearing difficulties, or even a person may have speech loss and serious memory problems. Try some of these tips to help make communication easier:

(1) Make eye contact and call the person by name.

(2) Be aware of your tone, how loud your voice is, how you look at the person, and your body language.

(3) Use other methods besides speaking, such as gentle touching.

(4) Try distracting the person if communication leads to a conflict or makes the person agitated or stressed. For example, look through a photo album together.

(5) When choosing your words, aim to be direct, specific, and positive. Some examples are:

(1) “Let’s try this way,” instead of pointing out mistakes.

(2) “Please do this,” instead of “Don’t do this.”

(3) “Thanks for helping,” even if the results aren’t perfect.

(4) Encourage the person to communicate with you:

(5) Show a warm, loving, straightforward forward and unemotional (matter-of-fact manner).

(6) Hold the person’s hand while you talk.

(7) Be open to the person’s concerns, even if he or she is hard to understand.

(8) Let him or her make some decisions and stay involved.

(9) Be patient with angry outbursts. Remember, it’s the illness “talking” [88].

4.4 Practicing Om Chanting and Mindfulness Meditation

5 SESSION FIVE Psychosocial Issues of Older Adults

The common psychosocial issues of older adults are:

(1) decreased or withdrew from social contact because of the death of friends.

(2) spouse and family members.

(3) settlement with the past as resolving conflicts, losses, and acceptance.

(4) changes in physical appearance.

(5) changes in roles/tasks, they feel they have less to contribute; managing leisure time as they have more free time.

(6) Depression is relatively common.

5.1 Strategies for supporting people with psychosocial issues as the person ages

(1) Some may speak with others to express their thoughts/ feelings or ask questions while some may take a long time to collect their ideas and be better understood if given time before expressing themselves verbally [92].

(2) Provide grief support and encourage existing friendships.

(3) Do life review work/use life story books and use photographs to help person talk about the past.

(4) Help the person with grooming and clothes so they can look their best.

(5) Help the person participate in meaningful ways in daily activities (make a plan for engaging older adults in simple activities such as preparing green leafy vegetables, getting involved in making thread for worshiping god, and rearing with grandchildren) find new roles and have as much control and choice as possible. Help the person in time arrangements.

(6) Facilitate participating in leisure activities such as being involved in Bhajan team (religious singing groups) talk therapy, social gathering, watching television as the person likes.

(7) Facilitate assessment for and treatment of depression.

(8) Advocate for your older family members since it is predicted that social services will not be enough to deal with the increased ageing population.

(9) Consult with geriatric physicians or nurses periodically for identifying and managing anticipated psychosocial problems [93].

5.2 Emotions

For some people, emotions may be distressing, leading to the engagement in self-injury. One or more strong emotions increase the risk of self-injuries (feelings of guilt, sadness, speechlessness or frustration, anger, self-blame, and low self-worth). Emotion needs to be managed by developing healthy strategies to cope with difficult situations. Healthy coping strategies are talking with friends, exercising, writing in a journal, meditation therapy, taking care of oneself when physically ill, getting adequate sleep, taking a break from the job, and paying attention to negative thoughts.

Techniques of overcoming emotions:

(1) Take adequate rest at night, eat healthy foods, and perform exercises daily.

(2) Perform at least one activity that builds a sense of achievement and satisfaction daily.

(3) Change your thoughts, as it is easier than changing feelings. If you feel upset, try to evaluate the thought causing emotion, as there is a relationship among thought, emotion, and our behavior. Find the answer to the following questions for yourself:

a. What specific thoughts trigger the most negative emotions for me?

b. Which emotions are hardest to tolerate for me?

c. Which emotions are easiest to tolerate for me?

d. What behaviors do I tend to use to calm down the feelings?

e. How well do these work in the short and long term? Do I want to use these behaviors again?

f. What are the underlying beliefs about me, others, or life in general that tend to most strongly continue the negative cycles?

g. Equally, what thoughts and beliefs do I have that assist me most in generating positive feelings? [90].

Preventive measures of negative feelings towards other people:

(1) First, you need to stop justifying the rationale for being angry and distressed.

(2) You need to stop making excuses for yourself and others, as well as stop making yourself a victim. Think about whether or not other people have done anything wrong or not.

(3) As you have stopped making excuses, take responsibility for yourself and your actions for being a happy, functionally active person.

(4) You should maintain your self-image and self-worth, as well as stop giving power to others.

(5) You should remove your negative habits, as well as surround yourself with happy and positive people who take joy in life. If possible, stay away from people who are always negative. And, quit activities that may make you angry and depressed.

(6) You should always think ahead about the long-term effects of your anger or upset.

(7) You should always be grateful**,** instead of recalling the bad feelings of life. Start defining your life by the good. Get into this habit by thinking of at least one thing that you are grateful for daily.

(8) You should give credit to yourself, stop placing limitations on yourself. Only say you cannot do if those activities harm you or is beyond your capacity. Always believe that you can do.

(9) You should try and let go of your negative emotions. Though some people are satisfied while complaining or waiting for developing conflict, practice just letting it go as well as staying silent[94].

5.3 Review of Om Chanting and Mindfulness Meditation

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Appendix A Informed Consent Form

Study Title: Efficacy of Educational Intervention for Reducing Care Burden of Family Caregivers of Older Adults with Disability in Nepal

Investigator: I am Raj Devi Adhikari Ghimire, studying doctoral degree in nursing in Xiangya School of Nursing, Central South University, Changsha, Hunan Province, PR China

Funding Source: Self-finance

Purposes of the Study:

(1) To identify factors associated with caregiving burden of family caregivers of older adults with disability in Nepal,

(2) To develop educational program for reducing caregiving burden of family caregivers.

(3) To measure efficacy of educational intervention.

Phases of Research:

This research study will be conducted in three phases.

First Phase: Pilot Study

Second Phase: Descriptive Cross-sectional Survey

Third Phase: Development of educational intervention program through qualitative in-depth interview, review of curriculum of school level education and narrative review, expert consultation, pilot study and feedback from participants.

Fourth Phase: Exploration of efficacy of educational program

Research Procedure:

For this study, I obtained ethical permission from both the Institutional Review Boards of Xiangya School of Nursing and the Nepal Health Research Council. First, to identify factors associated with the caregiving burden of family caregivers of older adults with disability, I will conduct a cross-sectional survey. For this survey, I will use the Nepalese version of the interview questionnaire. As a family caregiver of your older relative with disability, I will fill-up the form based on your responses on the interview

questionnaire. The duration of this interview will be 55-60 minutes. By this, the caregiving burden of family caregivers of older adults with disability will be identified as low, moderate, or severe. Those family caregivers who will experience a caregiving burden of more than 20 can participate in an educational intervention. In this educational program, I will provide knowledge and skills required to reduce the caregiving burden on family caregivers. After 3 months of completion of the educational intervention, the researcher will again assess the care burden of family caregivers of older adults with disability.

Risks and benefits

While participating in a cross-sectional survey, you may experience distress over the nature of questions. Although this phase of study might not benefit you personally. But the findings of this study will be identifying the factors associated with caregiving burden of family caregivers and reducing their caregiving burden by selecting and providing proper educational program.

Confidentiality

All your responses will be kept confidentially and safely by using code numbers as well as without recording your personal identity. Your identity will not be disclosed in any place of report; the responses will be analyzed in group and only used for this study. So, please express your feelings without any hesitation.

Voluntary participation

Your participation in this study will be completely voluntary. You can decide whether you are going to participate or not in this study. If you participate, if you feel you want to leave the interview at any time for any reason, or refuse to answer any individual question, I will not give any pressure. If you refuse to participate, there will be no harm, loss, or penalty.

Finally, I hope you will help me by participating in this study. If you need to explore more information regarding this study, you can contact me.

Name of Researcher: Raj Devi Adhikari Ghimire

Contact No. 014027900, **Mobile No.** 9841251217

Address: Shivanagartole, ward no. 10, Manamaiju, Tarakeshwor Municipality, Kathmandu.

Agreement to participate

I have read all the information given above and I have had the opportunity to ask for further clarification. Finally, I agree to participate in this study. While signing in this study, I do not give my legal authority to the researcher.

Signature _____ **Date** _____

Name of Participant:

Contact No. Mobile No.

Thank you for your participation

Appendix B Screening tool for older adults and family caregivers

The instruments of this study are as follows

1. Checklist for measuring the status of activities of daily living of older adults:

The functional status of older adults in activities of daily living is listed below. This will help to determine his or her level of dependency in the following activities:					
Eating	Able	unable	Grooming	Able	Unable
Toileting	Able	Unable	Dressing	Able	Unable
Walking	Able	Unable	Transferring	Able	Unable
Bathing	Able	Unable	Doing laundry	Able	Unable
Cooking	Able	Unable	Housework	Able	Unable
Managing medication	Able	Unable	Using phone	Able	Unable
Shopping	Able	Unable	Managing finances	Able	Unable

N.B. Older adults with disabilities mean those persons who are unable to perform any one activities of daily living except cooking food, shopping, and using the telephone.

2. Checklist for assessing cognitive impairment among family caregivers:

Instruction: Score 1 error for each incorrect response, to maximum for each item.

S. N.	Questions	Correct Response	Incorrect Response
1.	What year is it now?	0	4
2.	What month is it now?	0	3
	Repeat these phrases Banana; Manamaiju Temple. Bishnumati River; Ram, Cow		
3.	About what time is it? (within one hour)	0	3
4.	Count backwards 20 to 1	0	1 false=2; more than 1 false=4
5.	Say the months in reverse order	0	1 false=2; more than 1 false=4
6.	Repeat phrases just given	0	1 false=2; 2 false=4; 3 false=6, 4 false=8, all wrong=10

N.B.: Only those persons who will obtain score 0=10 will be included in this study.

Appendix C Interview Questionnaire for cross-sectional study

Date of Interview:

Interviewer

Municipality:

Duration of being a caregiver:

Code number:

Duration of ADLs dependency:

Number of ADLs disability:

Number of IADLs disability:

Section: I

A. Socio-demographic information about your disabled elderly relative

1. Age of your relative:
2. Gender: Male/ Female
3. Type of Residency: One house / Rented
4. Marital Status: Unmarried / Married living with spouse / Widow (er)/ Single
5. Source of Income: None / Old Age Allowance / Pension/ other, specify
6. Number of living children……
7. Does your relative have any major medical problem?

a) Respiratory problem / COPD b) Hypertension

c) Diabetes Mellitus d) Heart Problems

e) Cancer f) Paralysis

g) Urinary Problems h) Joint Problems

i) Blindness j) Ear Problem

k) Prostate Problem (if male) l) Gynae Problem

If others, specify…….…….

8. Does your relative have a memory problem? No / Yes

B. Socio-demographic information of the family caregiver

1. Your relationship with the older adult:…….
2. Age:…….
3. Gender: Male / Female
4. Ethnicity: Brahman/Chhetri, Janajati / Dalit / Muslim
5. Religion: Hinduism/Buddhism/ Christianity/ Islam/ Kirat/ Other….
6. Current Marital Status: Unmarried / Married living with spouse / Widow (er) / Single
7. Educational status: unable to read and write; able to read and write, Completed degree of educations…….
8. Current Occupation: No work / Business / Retired / Labor / Home maker / Service / Agriculture / Other, specify……..
9. Economic status:
   a) Sufficient for less than 6 months b) Sufficient for more than 6 months
   c) Sufficient for up to one year d) Sufficient for more than one year
10. Type of family: a) Single b) Join c) Extended
11. How many members are living in your family? …….
12. Who is the head of your family? ……..
13. Do you have any social responsibility? No/ If yes, specify: …….
14. Do you have any other family responsibility?
    a) No b) Another older adults in a family
    c) Have under 5 children d) Have under 10-year children
15. Do you experience any stressful life events currently as a result of continuous provision of care to your relatives such as separation with spouse/ other family members/ loss of job/loss of property/death of any family member or relative/unable to participate in important family or social function? If yes specify ……..……
16. Could you please rate your psychological health? Excellent / neither good nor bad / Poor

C. Care provision status of family caregiver of older relative with disability

1. In average how many hours per day you need to engage in providing care for your older relatives? …….Hours
2. In average how many hours you get sound sleep at night?.....
3. In an average how many hours you can take rest at daytime?.....
4. The status of assisting or performing activities of daily living and instrumental

activities of daily living for you older relative with disability

ADLs/ IADLs	Unable/need assistance	Able to do
Eating food		
Changing clothes		
Taking Shower		
Using toilet		
Self-controlling of stool or urine		
Walking		
Managing medications		
Washing clothes		
Performing Household work		
Cooking		
Shopping glossaries		
Using the phone		
Managing finances		
Managing transportation		

D. Social Support Rating Scale

The following questions are related to what kinds of social support you are getting in during your difficulties of providing care to your older relative with disability based on your experience.

1. How many intimate friends do you have, from whom you can receive support and help?

(1) None (3) 3~5

(2) 1~2 (4) no less than 6

2. Over the past year, you_____

(1) stay away from family, and live alone

(2) often move the residence, and most of time live together with strangers

(3) live together with students, colleagues or friends

(4) live together with family

3. With your neighbors, you_____

(1) have a speaking acquaintance and never care about each other

(2) maybe have a little concern when meeting trouble

(3) are deeply concerned by some of them

(4) are deeply concerned by most of them

4. With your colleagues, you_____

(1) have a speaking acquaintance and never care about each other

(2) maybe have a little concern when meeting trouble

(3) are deeply concerned by some of them

(4) are deeply concerned by most of them

5. Obtain support and help from family members (Draw "√" in the suitable box)

	None	Rarely	Normally	full support
A. couple				
B. parents				
C. children				
D. siblings				
E. others (for example, sister-in-law)				

6. In the past, when you encounter difficulties, what is the source that you ever received either economic support or practical problem-solving help?

(1) no source

(2) the following source (more than one answer is permitted)

a) Spouse

b) Other family members

c) Friends

d) Relatives

e) Colleagues

f) Companies

g) Official or semi-official organizations, such as, parties, leagues and trade union

h) Unofficial organizations, such as, religion, social group and etc.

i) Others——————————— (please list)

7. In the past, when you encounter difficulties, what is the source that you ever received comfort and caring?

(1) no source

(2) the following source (more than one answer is permitted)

A. spouse

B. other family members

C. friends

D. relatives

E. colleagues

F. companies

G. official or semi-official organizations, such as, parties, leagues and trade union

H. Unofficial organizations, such as, religion, social group and etc.

I. others ——————————— (please list)

8. What is the way of talking when you are in trouble? (Exclusive Choice)

(1) never complain to anyone

(2) only complain to 1 or 2 persons who have a close relationship with

(3) will talk to the friend who takes the initiative to inquiry

(4) take the initiative to talk their own troubles in order to get support and understanding

9. What is the way of seeking help when you are in trouble?

(1) just rely on myself, and do not accept the help of others

(2) rarely ask someone for help

(3) sometimes ask someone for help

(4) ask family, friends or organizations for help when facing troubles

10. Organized activities for groups (such as, party and youth league organizations, religious organization, trade union, student union and etc.), you _____

(1) never attend

(2) occasionally attend

(3) often attend

(4) take the initiative to attend and are active with

Section II Zarit Care Burden Interview Questionnaire

The following statements reflect how people sometimes feel when taking care of another person. Please listen carefully while I read each given statement. Then state HOW OFTEN you feel while taking care of your relative. Key: 0=Never; 1=Rarely (few times per month); 2=Sometimes (1-3 times per week); 3=Frequently (4-5 times per week); 4=Nearly always (Almost every day)

How often do you……..					
1. Feel your parent/spouse/relative asks for more help than he/she needs.	0	1	2	3	4
2. Feel you do not have enough time for yourself.	0	1	2	3	4
3. Feel stressed between caring for your parent/spouse/relative and meeting responsibilities of family or work.	0	1	2	3	4
4. Feel embarrassed over your parent/spouse/relative's behavior.	0	1	2	3	4
5. Feel angry when you are around your parent/spouse/relative.	0	1	2	3	4
6. Feel your parent/spouse/relative affects your relationship with other family members in a negative way.	0	1	2	3	4
7. Being afraid of what the future holds for your parent/spouse/relative.	0	1	2	3	4
8. Feel your parent/spouse/relative is dependent on you.	0	1	2	3	4
9. Feel strained when around your parent/spouse/relative.	0	1	2	3	4
10. Feel your health status suffered because of your parent/spouse/relative.	0	1	2	3	4
11. Feel you do not have a much privacy as you would like, because of your parent/spouse/relative.	0	1	2	3	4
12. Feel your social life has suffered due to caring for your parent/spouse/relative.	0	1	2	3	4

How often do you……..					
13. Feel uncomfortable about having friends over.	0	1	2	3	4
14. Feel parent/spouse/relative expects you to care for him, as if you were the only one, he could depend on.	0	1	2	3	4
15. Feel you do not have enough money to care for your parent/spouse/relative.	0	1	2	3	4
16. Feel you will be unable to take care of your parent/spouse/relative much longer.	0	1	2	3	4
17. Feel you have lost control of your life.	0	1	2	3	4
18. Wish you could leave the care of your parent/spouse/relative to someone else.	0	1	2	3	4
19. Feel uncertain about what to do about your parent/spouse/relatives.	0	1	2	3	4
20. Feel you should be doing more for your parent/spouse/relatives.	0	1	2	3	4
21. Feel you could be doing a better job in caring for your parent/ spouse / relative.	0	1	2	3	4
22. Finally, do you feel that care for your parent/spouse/relative is a burden for you?	0	1	2	3	4

Section III: SF-36 Health Survey

Please answer every question. Some questions may look like others, but each one is different. Please listen carefully when I read the following statement or question and answer each question carefully that best represents your feeling.

1. In general, would you say your **health is**

Excellent	**Very good**	**Good**	**Fair**	**Poor**
1	2	3	4	5

2. Compared to one year ago, how would you rate your health in general **now?**

Much better now	**Somewhat better now**	**About the same now**	**Somewhat worse now**	**Much worse now**
1	2	3	4	5

3. The following items are about activities you might do during **A TYPICAL DAY**.

Does your health now limit you in these activities? Yes/No, If Yes, how much?

Activities	**Limited a lot**	**Limited a little**	**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

Activities		Limited a lot	Limited a little	Not limited at all
g)	Walking more than one 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 or your physical health?

Have you had any of the following problems		Yes	No
a)	Cut down the amount of time you spent on work or other activities		
b)	Accomplished less than you would like		
c)	Were limited in the kind of work or other activities?		
d)	Had difficulty performing the work or other activities (for example, it took extra time)		

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)?

Have you had any of the following problems		Yes	No
a)	Cut down the amount of time you spent on work or other activities		
b)	Accomplished less than you would like		
c)	Did not do work or other activities as carefully as usual		

6. During the **PAST 4 WEEKS**, to what extent has your physical health or emotional problems interfered your normal social activities with family, friends, neighbors or groups?

Not at all	Slightly	Moderately	Quite a bit	Extremely
1	2	3	4	5

7. How much bodily pain have you had during the **PAST 4 WEEKS?**

Not at all	Slightly	Moderately	Quite a bit	Extremely
1	2	3	4	5

8. During the **PAST 4 WEEKS,** how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	Slightly	Moderately	Quite a bit	Extremely
1	2	3	4	5

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closes to the way you have been feeling. How much of the time during the **PAST 4 WEEKS**?

Questions	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 nothing could cheer you up?	1	2	3	4	5	6
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
j) Has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives etc)?	1	2	3	4	5	6

10. How **TRUE or FALSE** is each of the following statements for you?

Statements	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

A. In-depth Interview Guideline

Interview date: _____

Interviewer name: _____

Start time: _____ End time: _____

Thank you for agreeing to participate in this research on caregiving experiences to your older relative/parent with disability.

PART I (First Visit)

1. Please, can you tell me a little about yourself?

   Probe: Life before being a caregiver, social dynamics (social activities, friends, etc.)
2. What does it mean to provide care?

   Motivation for providing care
3. How did you become a caregiver of your older relative/parent?

   Probe: What happened before you became a caregiver?

   Who decided that you should become a caregiver?

   Did you like the idea of becoming a caregiver? Probe: Why?
4. What are the reasons why you provide care to your older relative/parent?

   Probe: Obligatory/no choice, reciprocity, benefit from someone else not care receiver etc.
5. Who do you think should provide care for the older adult? Probe: Why?
6. What are the cultural values or beliefs associated with caregiving for the older adults in this community?

PART II (Second Visit)

Caregiving experience

1. Have you ever provided care to a friend or family member who needed care in the past?

   Probe: If yes, who was this person?
2. Are you the main person providing care to your older relative or parent?

   Probe: Do you do it all the time?

THIRD PART (Third visit)

Self-care practices of family caregiver for reducing caregiving burden:

7. How do you try to reduce caregiving burden?

   Probe: Do you use any relaxation techniques: deep breathing, muscle relaxation technique?

   Probe: Do you share your feeling with your other family member or other relatives?

   Probe: Do you try to explore other ways of solving your problems?

   Probe: Do you feel you ignore activities of daily living? Exercise, rest, sleep, eat, social life, spiritual life and caring of younger children or other family members?

   Techniques of taking care of yourselves Probe: How many hours you sleep at night? Did you take rest when you feel tired?

8. In relation to providing care and support to your relative or parent, have you received any support, help or assistance?

   If yes, who provided this support, help or assistance? Probe: What was the reason(s) for providing the support, help or assistance?

   What was the type of support, help or assistance you received? Probe: Financial, emotional, health, physical, personal Perception and other issues

9. In your community, what are people's perceptions of caregiving to the older adults?
10. What more do you wish you had known about while caring for your older adult?

    Probe: Do you know where you can get this information?

11. If you were advising a relative/friend about caregiving, what advice would you give them?
12. Is there any other issue related to your caregiving experience that you feel is important that we have not brought up in this interview

PART FOUR (Fourth Visit)

1. **Changes in nervous system**
2. **Cognition**
3. **Memory, learning and intelligence**
4. **Special senses**
   Vision
   Hearing
   Taste acuity

Smell
Touch

5. **Changes in musculoskeletal system**
6. **Body composition changes in old age**
7. **Obesity in elderly**

Major research achievements during the degree program

Acknowledgement

As I reflect my 7 years of doctorate in nursing journey, I am filled with a mix emotions, fatigue and accomplishment intertwined. The past 7 years have been life changing transformation, and I am grateful for the unwavering support of those around me.

First and foremost, I extend my deepest gratitude to my research supervisor, Professor Dr Siyuan Tang and his entire team. Your care and concerns have been a constant source of motivation, and I am deeply inspired by your modest characteristics, sharp scientific acumen, and tireless pursuit of excellence. It has been honored to be your student.

I am also thankful to Deans of Xiangya School of Nursing for their guidance and support as well as all teachers of nursing department for their companionship assistance over the 7 years. The high-quality teaching from Central South University has laid a solid foundation for my future endeavors.

I appreciate the expert opinion and assistance provided by Lalita Rai, Dr Archana Pandey, Muna Sharma, Tilarupa Bhattarai, Dr. Sarala Joshi and Pratima Sharma and my dear friends Dipshikha Bhattarai, Roshani Tamang, Nabina Paneru and Anisha Koirala offered unconditional help during data collection of descriptive parts of this study, for who I am truly thankful. My seniors and junior sisters under my supervisor's team supported and helped me from the beginning my work. I am also thankful with Nabina Paneru, Bibhav Adhikari and Prem Panta for statistical analysis and interpretation of statistical findings by using SPSS version 25I express heartfelt thanks to Nepal Health Research Council, authorities of Tarakeshwor, Gokarneshwor and Tokha Municipalities of Kathmandu District and all participants participated in my research.

Lastly, I express heartfelt thanks to my family, my beloved husband my son and my daughter and son in laws. Your sacrifices, support and care have been the driving force behind my perseverance. Without your love and encouragement, I would not have had the strength to overcome challenges and pursue my dreams in abroad. Thank you for being my rock throughout this journey.

Thank you for all the supporting hands who have directly and indirectly put their efforts to complete my work. Best wishes to all.

Raj Devi Adhikari Ghimire

Commendation Letters

Date: 2021/07/14

To Whom It May Concern

This letter is to introduce to you Mrs. Raj Devi Adhikari, Ghimire; a Nepalese Female Citizen, who is a student of Xiangya School of Nursing, Central South University in China under Central South University Scholarship, pursuing a four years Doctoral Degree in Nursing Program. This is certified that Xiangya School of Nursing has accepted and approved her research proposal entitled **"Efficacy of Educational Intervention for Reducing Care Burden of Family Caregivers of Older Adults with Disability in Nepal".**

I wish her success in her academic journey.

Siyuan Tang

Professor Dr. Siyuan Tang
Dean, Xiangya School of Nursing
Central South University
Changsha, Hunan, China

Government of Nepal

Nepal Health Research Council (NHRC)

Estd. 1991

Ref. No.: 422

Date: 2 September 2021

Ms. Raj Devi Adhikari Ghimire

Principal Investigator

Xiangya School of Nursing, Central South University

China

Ref: Approval of thesis proposal

Dear Ms. Ghimire,

This is to certify that the following protocol and related documents have been reviewed and granted approval through the expedited review process by the Expedite Review Sub-Committee meeting for it's implementation.

ERB Protocol Registration No./ Submitted Date	455/2021 PhD 23 July 2021		**Sponsor Protocol No**	NA
Principal Investigator/s	Ms. Raj Devi Adhikari Ghimire		**Sponsor Institution**	NA
Title	Efficacy of Educational Intervention for Reducing Caregiving Burden of Family Caregivers of Older Adults with Disability in Nepal			
Protocol Version No	NA		**Version Date**	NA
Other Documents	1. Data collection tools 2. Acceptance letter form the study sites 3. Informed Consent Form		**Risk Category**	Minimal risk
Study Team Member	1. Dr. Minhui Liu			
Expedited Review	Proposal	√	**Duration of Approval** 2 September 2021 to 2 September 2022	**Frequency of continuing review** At least once in a year
	Amendment			
	Re-submitted			
	Meeting Date: 31 August 2021			

Tel: +977 1 4254220, Fax: +977 1 4262469, Ramshah Path, PO Box: 7626, Kathmandu, Nepal
Website: http://www.nhrc.gov.np, E-mail: nhrc@nhrc.gov.np

Government of Nepal

Nepal Health Research Council (NHRC)

Estd. 1991

Ref. No.: 422

Total budget of research	**NRs 7,00,000.00**
Ethical review processing fee	**NRs 10,000.00**

Investigator Responsibilities :

- Any amendments shall be approved from the ERB before implementing them
- Submit progress report every 3 months
- Submit final report after completion of protocol procedures at the study site
- Report protocol deviation / violation within 7 days
- Comply with all relevant international and NHRC guidelines
- Abide by the principles of Good Clinical Practice and ethical conduct of the research

If you have any questions, please contact the Ethical Review M & E Section at NHRC.

Thanking you,

Dr. Pradip Gyanwali
Member Secretary
(Executive Chief)

Tel: +977 1 4254220, Fax: +977 1 4262469, Ramshah Path, PO Box: 7626, Kathmandu, Nepal
Website: http://www.nhrc.gov.np, E-mail: nhrc@nhrc.gov.np

Tokha Municipality

.....2..... No. ward office

.....Tokha....., Kathmandu

Let. No.: 2081-2082
Ref. No.: 1353

Bagmati Province, Nepal
Phone No.:

Date: 23rd January, 2025

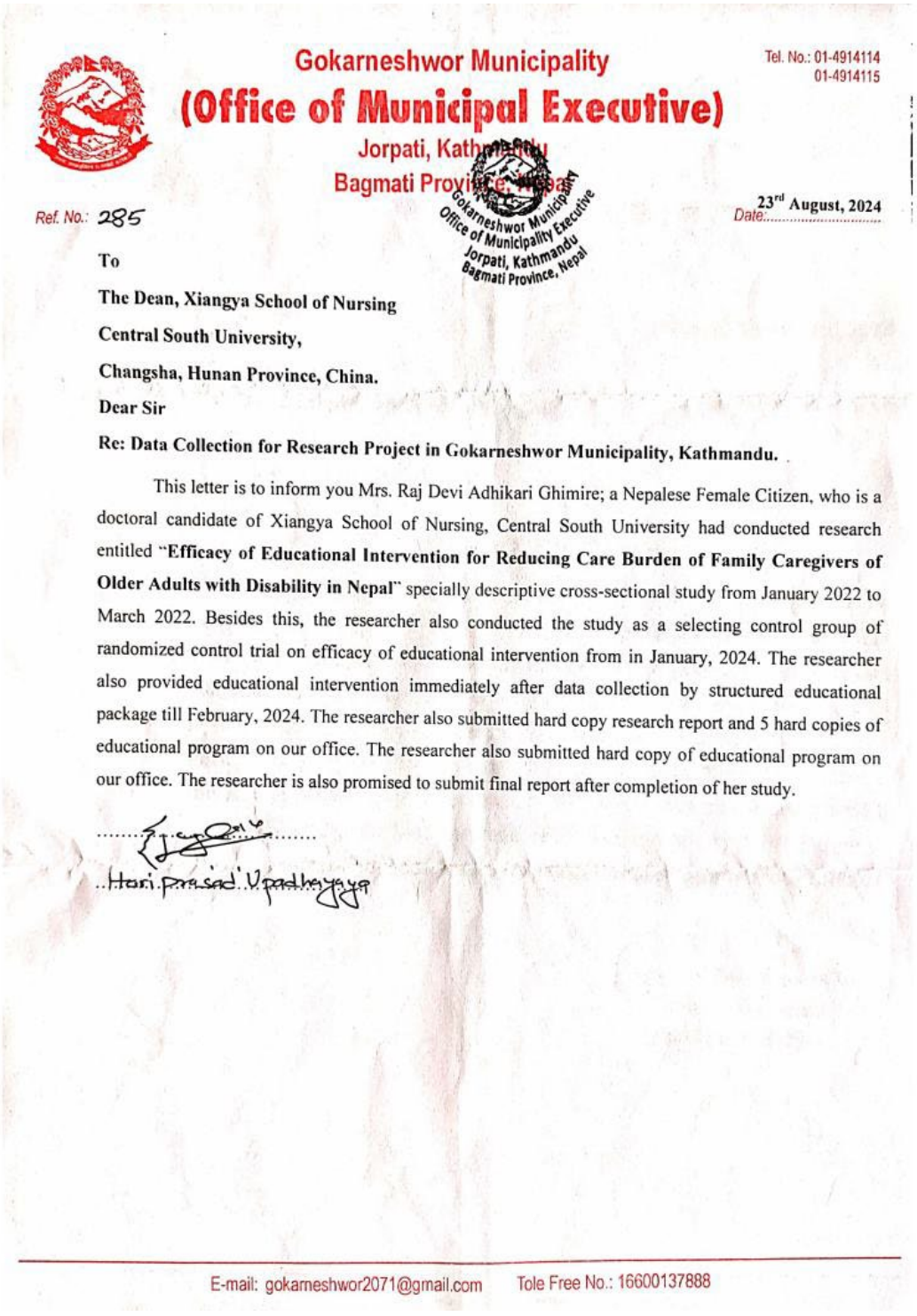
Subject:Completion of the pilot project

To
The Dean, Xiangya School of Nursing
Central South University,
Changsha, Hunan Province, China .

This is to inform you that Mrs. Raj Devi Adhikari Ghimire; a Nepalese Female Citizen, who is a doctoral candidate of Xiangya School of Nursing Central South University had conducted research entitled " Efficacy of Educational Intervention for Reducing Care Burden of Family Caregivers of Older Adults with Disability in Nepal " especially pilot study on factors associated with caregiving burden among family caregivers of older adults with disability was conducted in September to October, 2021 . The researcher also conducted qualitative study on caregiving experiences of family caregivers of adults with disability from February to March, 2022 . The researcher also submitted hard copy research report and 5 hard copies of educational program on our office .

Amar Dangol
Acting chairman

ACTING CHAIRMAN



Gokarneshwor Municipality
(Office of Municipal Executive)
Jorpati, Kathmandu
Bagmati Province, Nepal

Tel. No.: 01-4914114
01-4914115

Ref. No.: 285

Date: 23rd August, 2024

Gokarneshwor Municipality Executive Office of Municipality Jorpati, Kathmandu Bagmati Province, Nepal

To

The Dean, Xiangya School of Nursing
Central South University,
Changsha, Hunan Province, China.

Dear Sir

Re: Data Collection for Research Project in Gokarneshwor Municipality, Kathmandu.

This letter is to inform you Mrs. Raj Devi Adhikari Ghimire; a Nepalese Female Citizen, who is a doctoral candidate of Xiangya School of Nursing, Central South University had conducted research entitled "**Efficacy of Educational Intervention for Reducing Care Burden of Family Caregivers of Older Adults with Disability in Nepal**" specially descriptive cross-sectional study from January 2022 to March 2022. Besides this, the researcher also conducted the study as a selecting control group of randomized control trial on efficacy of educational intervention from in January, 2024. The researcher also provided educational intervention immediately after data collection by structured educational package till February, 2024. The researcher also submitted hard copy research report and 5 hard copies of educational program on our office. The researcher also submitted hard copy of educational program on our office. The researcher is also promised to submit final report after completion of her study.

.....

Hari prasad Upadhyaya

E-mail: gokarneshwor2071@gmail.com Tole Free No.: 16600137888

Tarakeshwor Municipality

Office of the Municipal Executive

Dharmasthali, Kathmandu

Bagmati Province, Nepal

Tarakeshwor Municipality Office of the Municipal Executive Dharmasthali, Kathmandu Bagmati State, Nepal

Ref. No.: ०५५ Date: 25th August, 2024

To

The Dean, Xiangya School of Nursing,

Central South University,

Changsha,Hunan, China.

Dear Sir,

To Whom It May Concern.

This is to inform that Mrs. Raj Devi Adhikari Ghimire, a Nepalese Female Citizen, had conducted research title on **" Efficacy of Educational Inter vention for Reducing Care Burden of Family Caregivers of Older Adults With Disability in Nepal"** in which she collected data among 215 person in January 2022 to March 2022. Besides this she provided health education on 30 persons in August 2023 to September 2023. After 3 months of educational intervention, she again collected data from 30 persons in January 2024. The researcher also submitted 1 hard copy of research report and 5 soft copies of educational program in our office.

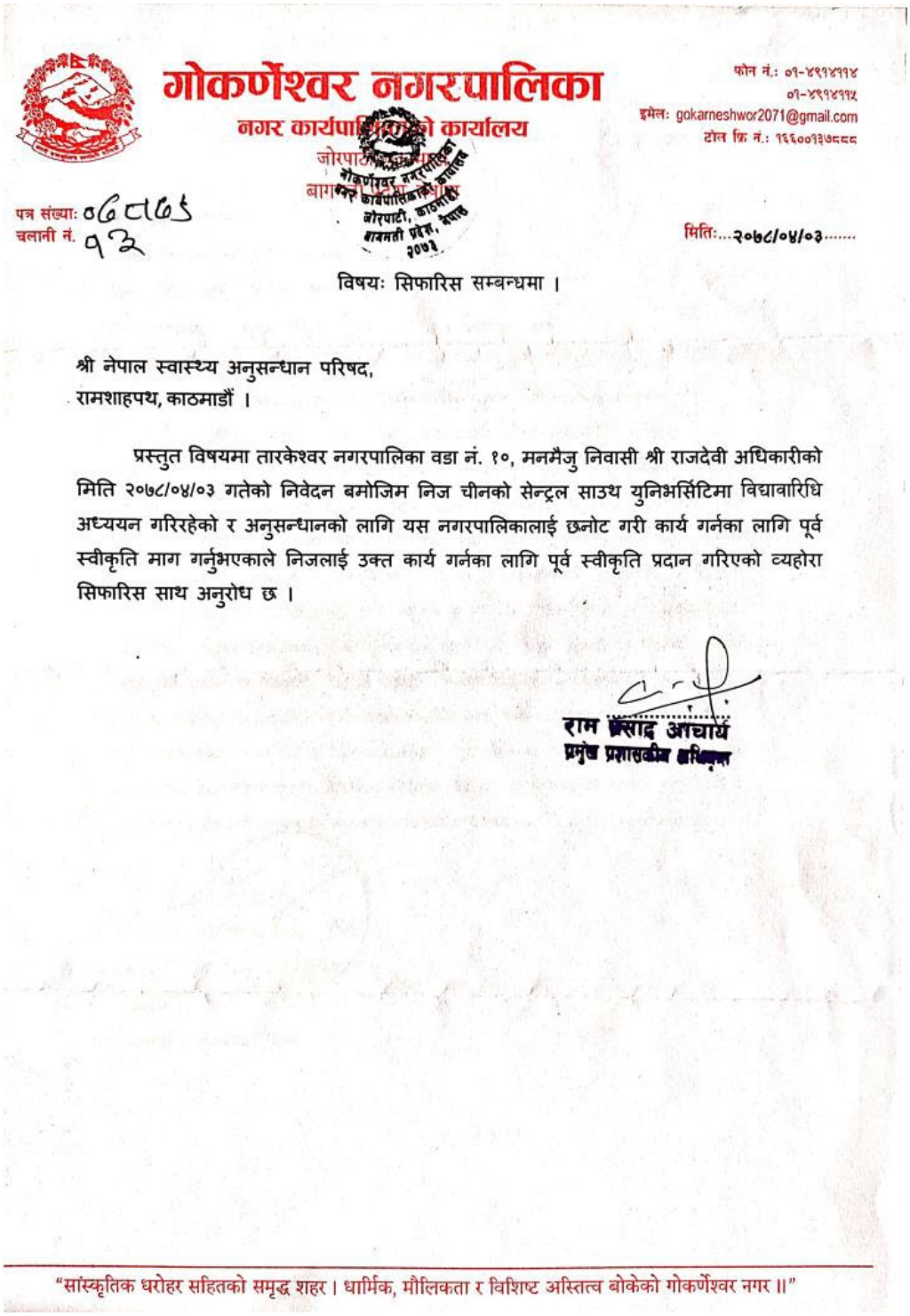
.....

Santosh Khanal

Education Officer

Web: www.tarakeshwormun.gov.np

Phone No.: 01-5168123 | Facebook: Hello Tarakeshwor Municipality, Dharmasthali, Kathmandu | Email: tarakeshwormun2071@gmail.com



गोकर्णेश्वर नगरपालिका

नगर कार्यपालिकाको कार्यालय

जोरपाटी, काठमाडौं

बागमती प्रदेश, नेपाल

फोन नं.: ०१-४९१४११४
०१-४९१४११५
इमेल: gokarneshwor2071@gmail.com
टोल फ्री नं.: १६६००१३७८८८

पत्र संख्या: ०७८/७९
चलानी नं. ९३

मितिः...२०७८/०४/०३.....

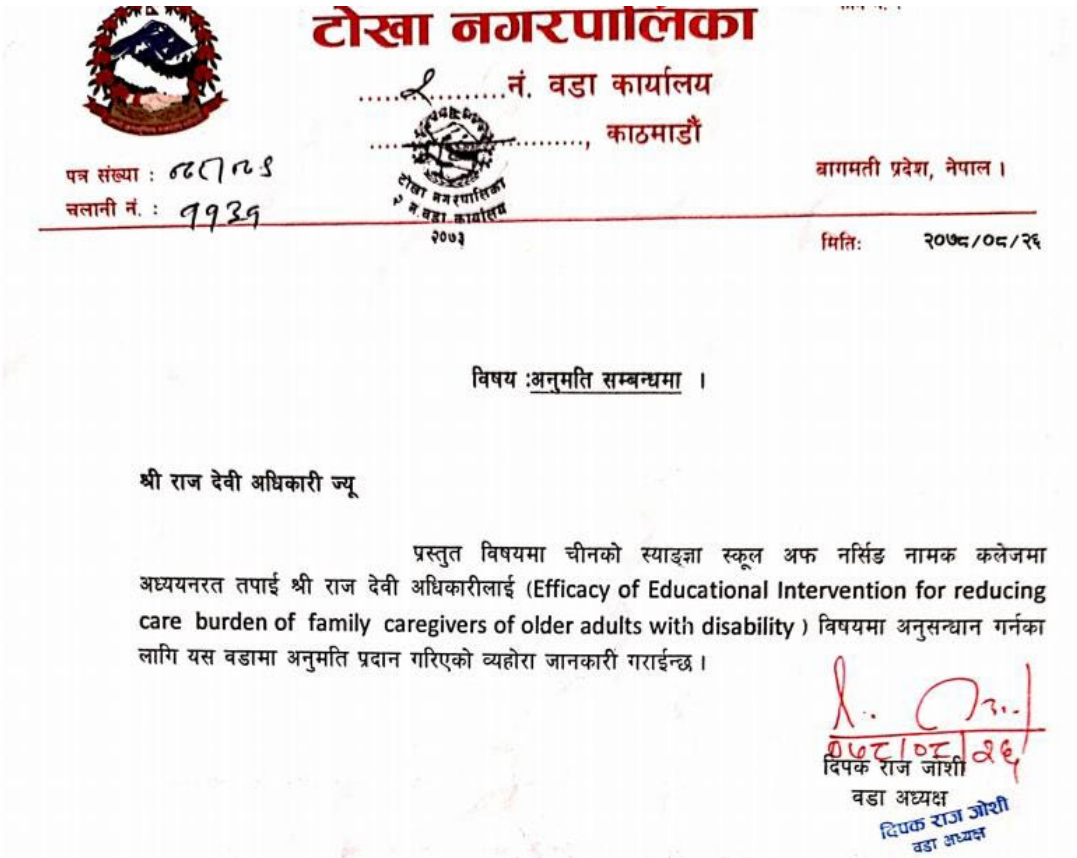
विषयः सिफारिस सम्बन्धमा ।

श्री नेपाल स्वास्थ्य अनुसन्धान परिषद,
रामशाहपथ, काठमाडौं ।

प्रस्तुत विषयमा तारकेश्वर नगरपालिका वडा नं. १०, मनमैजु निवासी श्री राजदेवी अधिकारीको मिति २०७८/०४/०३ गतेको निवेदन बमोजिम निज चीनको सेन्ट्रल साउथ युनिभर्सिटिमा विद्यावारिधि अध्ययन गरिरहेको र अनुसन्धानको लागि यस नगरपालिकालाई छनोट गरी कार्य गर्नका लागि पूर्व स्वीकृति माग गर्नुभएकाले निजलाई उक्त कार्य गर्नका लागि पूर्व स्वीकृति प्रदान गरिएको व्यहोरा सिफारिस साथ अनुरोध छ ।

राम प्रसाद आचार्य
प्रमुख प्रशासकीय अधिकृत

"सांस्कृतिक धरोहर सहितको समृद्ध शहर । धार्मिक, मौलिकता र विशिष्ट अस्तित्व बोकेको गोकर्णेश्वर नगर ॥"



टोखा नगरपालिका

.....१.....नं. वडा कार्यालय

....., काठमाडौं

पत्र संख्या : ८८।८९

चलानी नं. : ९९३९

बागमती प्रदेश, नेपाल ।

मिति: २०७८/०८/२६

विषय :अनुमति सम्बन्धमा ।

श्री राज देवी अधिकारी ज्यू

प्रस्तुत विषयमा चीनको स्याङ्झा स्कूल अफ नर्सिङ नामक कलेजमा अध्ययनरत तपाई श्री राज देवी अधिकारीलाई (Efficacy of Educational Intervention for reducing care burden of family caregivers of older adults with disability) विषयमा अनुसन्धान गर्नका लागि यस वडामा अनुमति प्रदान गरिएको व्यहोरा जानकारी गराईन्छ ।

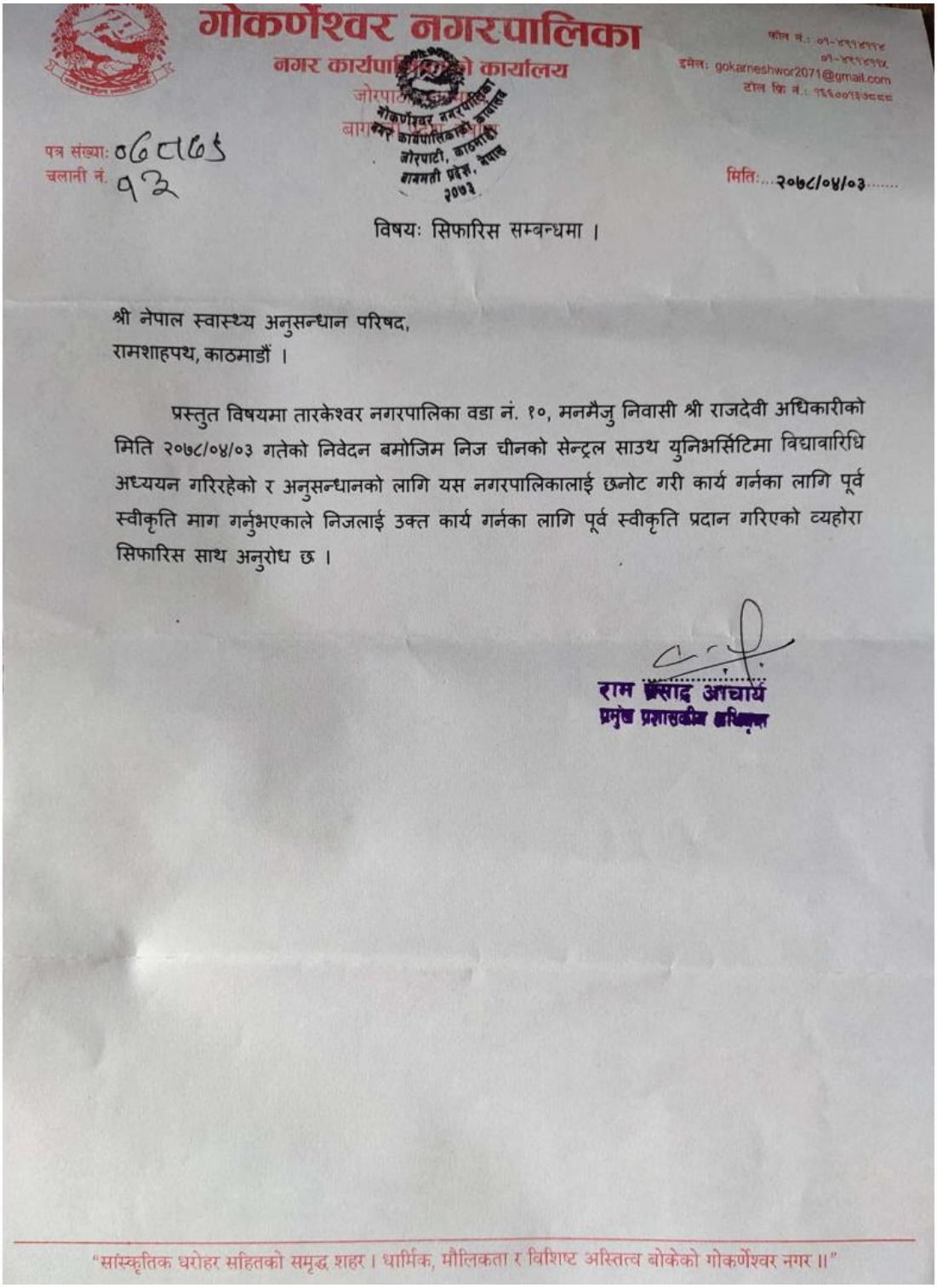
२०७८/०८/२६

दिपक राज जोशी

वडा अध्यक्ष

दिपक राज जोशी

वडा अध्यक्ष



गोकर्णेश्वर नगरपालिका

नगर कार्यपालिकाको कार्यालय

जोरपाटी, काठमाडौं

बागमती प्रदेश

फोन नं.: ०१-४९१४१९४

इमेल: gokarneshwor2071@gmail.com

टोल फ्री नं.: १६६००१३७८८८

पत्र संख्या: ०६८/७३

चलानी नं. ९३

मिति: २०७८/०४/०३

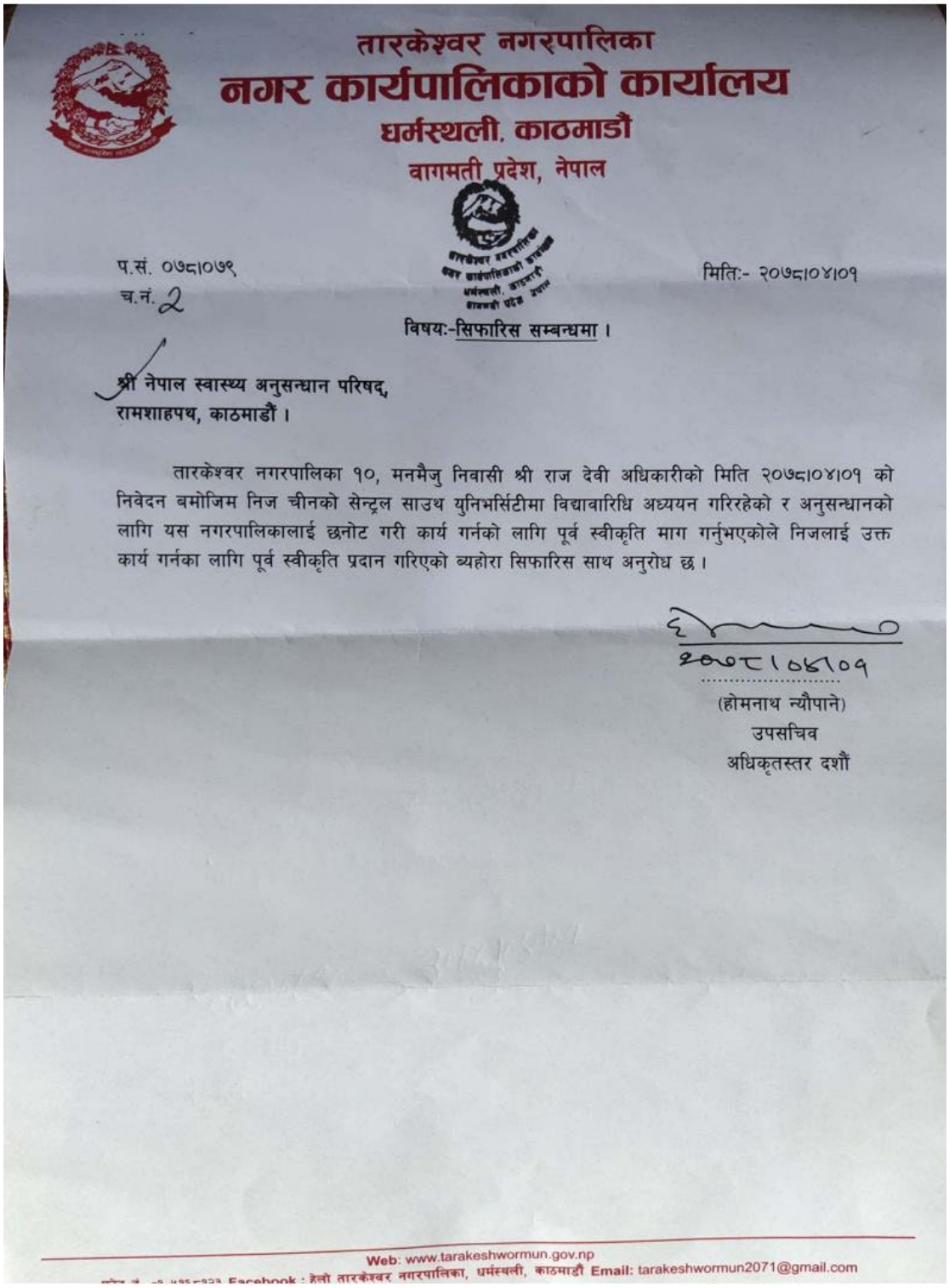
विषयः सिफारिस सम्बन्धमा ।

श्री नेपाल स्वास्थ्य अनुसन्धान परिषद,
रामशाहपथ, काठमाडौं ।

प्रस्तुत विषयमा तारकेश्वर नगरपालिका वडा नं. १०, मनमैजु निवासी श्री राजदेवी अधिकारीको मिति २०७८/०४/०३ गतेको निवेदन बमोजिम निज चीनको सेन्ट्रल साउथ युनिभर्सिटिमा विद्यावारिधि अध्ययन गरिरहेको र अनुसन्धानको लागि यस नगरपालिकालाई छनोट गरी कार्य गर्नका लागि पूर्व स्वीकृति माग गर्नुभएकाले निजलाई उक्त कार्य गर्नका लागि पूर्व स्वीकृति प्रदान गरिएको व्यहोरा सिफारिस साथ अनुरोध छ ।

राम प्रसाद आचार्य
प्रमुख प्रशासकीय अधिकृत

"सांस्कृतिक धरोहर सहितको समृद्ध शहर । धार्मिक, मौलिकता र विशिष्ट अस्तित्व बोकेको गोकर्णेश्वर नगर ।।"



तारकेश्वर नगरपालिका
नगर कार्यपालिकाको कार्यालय
धर्मस्थली, काठमाडौं
वागमती प्रदेश, नेपाल

प.सं. ०७८।०७९
च.नं. 2

मितिः- २०७८।०४।०१

विषयः-सिफारिस सम्बन्धमा ।

श्री नेपाल स्वास्थ्य अनुसन्धान परिषद्,
रामशाहपथ, काठमाडौं ।

तारकेश्वर नगरपालिका १०, मनमैजु निवासी श्री राज देवी अधिकारीको मिति २०७८।०४।०१ को निवेदन बमोजिम निज चीनको सेन्ट्रल साउथ युनिभर्सिटीमा विद्यावारिधि अध्ययन गरिरहेको र अनुसन्धानको लागि यस नगरपालिकालाई छनोट गरी कार्य गर्नको लागि पूर्व स्वीकृति माग गर्नुभएकोले निजलाई उक्त कार्य गर्नका लागि पूर्व स्वीकृति प्रदान गरिएको व्यहोरा सिफारिस साथ अनुरोध छ ।

२०७८।०४।०१

(होमनाथ न्यौपाने)
उपसचिव
अधिकृतस्तर दशौं

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Facebook : हेलो तारकेश्वर नगरपालिका, धर्मस्थली, काठमाडौं Email: tarakeshwormun2071@gmail.com