



**5th International Agronursing Conferences**  
*In Conjunction with 1st International Post Graduate Nursing Student Conference (IPGNSC)*

# PROCEEDING

**Chronic Care Management : Bridging Theory  
& Practice In Healthcare Services**



May, 11<sup>th</sup> - 12<sup>th</sup>  
**2023**



5<sup>th</sup> International AgroNursing Conference in Conjunction  
with 1st International Post Graduate Nursing Student  
Conference (1st IPGNSC) 2023  
"Chronic Care Management: Bridging Theory and Practice"

**Jember, May 11<sup>th</sup> – 12<sup>th</sup>, 2023**

**PROCEEDING**

**FACULTY OF NURSING  
UNIVERSITY OF JEMBER**



## REMARK

Bismillahirrohmanirrohim  
Assalamualaikum Wr Wb  
Good morning and greetings

The Honorable, Rector of University of Jember  
The Honorable, All Speakers of the fifth international nursing conference In Conjunction with first International Post Graduate Nursing Student Conference  
The Honorable, Guests, all dean of the faculties in University of Jember, Director of hospitals, primary health center, and other guests.  
The Honorable, Conference Committee  
Dear All oral presenters, poster presenter and Participants of the conference

Alhamdulillahirobbil'alamin, we praise the presence of Allah SWT; because of the blessing, we all can be present here in this auditorium to attend the fifth international nursing conference In Conjunction with first International Post Graduate Nursing Student Conference, Faculty of Nursing. Salawat may always be delegated to the Great Prophet Muhammad SAW.

Ladies and Gentlemen,

As the beginning of this speech, I would like to welcome all of you to the fifth international nursing conference In Conjunction with first International Post Graduate Nursing Student Conference, with the theme " Chronic Care Management: Bridging Theory and Practice". It is an honor to facilitate health professionals from around the world to enhance health sciences.

As a nurse, we can provide holistic care that addresses not just the physical needs of our patients but also their emotional, social, and spiritual needs. By taking the time to listen and understand our patients' unique situations, we can take care to meet their needs best and help them achieve their health goals.

In addition to caring for our patients, it is also important to care for yourself. Nursing can be a demanding and emotionally taxing profession, and it is crucial that we can take steps to prioritize our well-being. This can include things like practicing self-care, seeking support from colleagues or a mental health professional when needed, and taking time off to rest and recharge.

To answer that question, on May eleventh and twelfth of may, twenty twenty-three, we will discuss and enhance this topic with speakers from four countries: Australia, the United Kingdom, Thailand, Taiwan, and Indonesia. Not only that, in the series of international conferences, this time, there will be a guest lecturer in collaboration with community service from Western Sydney University (WSU) Australia. Thanks to Associate Professor Caleb Ferguson and the team who have attended and shared with us. This collaboration can continue and improve the knowledge of the profession we love. We also call the researchers to join not only the conference but also to share their research through oral presentation or poster presentation.



Ladies and Gentlemen

This conference is attended by undergraduate and postgraduate students, lecturer and health care professional from Asia Pacific and Australia. We have more than thousand registrants with two hundred participants able to attend on this room.

This event can be held because of the support and efforts of all parties. Therefore, I would like to thank the Rector of University of Jember, Indonesian National Nurses Association (INNA) and all the committees who have worked hard to carry out this activity.

I sincerely hope that this conference will deliberate and discuss all different facets of this exciting topic and come up with recommendations that will lead to a better and healthier new world.

I wish this conference great success. Aamiinn.

Wassalamualaikum Wr. Wb.

Dean Faculty of Nursing  
Ns. Lantin Sulistyorini, M. Kes



## GREETING MESSAGE

Bismillahirrohmanirrohim  
Assalamualaikum Wr Wb  
Good morning and best wishes

The Honorable, Rector of University of Jember  
The Honorable, Dean School of Nursing, University of Jember  
The Honorable, All Speaker of the International Nursing Conference  
The Honorable, Guests  
The Honorable, Conference Committee  
Dear All, All Participants of the conference

Thank God we praise the presence of Allah SWT, because of the blessing and grace, we all can be present in this place, in order to attend the International AgroNursing Conference. In Conjunction with first International Post Graduate Nursing Student Conference, Solawat and greetings may still be delegated to the Great Prophet Muhammad SAW.

Ladies and Gentlemen,

As the beginning of this speech, I would like to say welcome to the fifth international nursing conference In Conjunction with first International Post Graduate Nursing Student Conference, with the theme " Chronic Care Management: Bridging Theory and Practice".

Chronic care refers to the ongoing, long-term medical care and support provided to individuals with chronic or long-lasting health conditions such as diabetes, heart disease, arthritis, and asthma, among others. Chronic conditions often require ongoing management and treatment to control symptoms, prevent complications, and improve quality of life.

Chronic care may involve a team of healthcare professionals, including primary care physicians, nurses, specialists, physical therapists, and other healthcare providers, who work together to develop and implement a comprehensive care plan tailored to the individual's needs.

The goal of chronic care is to improve the health and well-being of individuals with chronic conditions by providing ongoing, patient-centered care and support that helps them manage their symptoms, maintain their independence, and prevent complications. What is the latest application of chronic care management, bridging theory and practice?

To answer that question, then for the next two days starting from today on 11-12 May 2023 at Auditorium of Universitas Jember, we will discuss the Chronic Care Management: Bridging Theory and Practice with speakers from 5 countries namely:

1. Assoc. Prof. Caleb Ferguson (Australia).
2. Assoc. Prof. Wasana Ruaisungnoen (Thailand)
3. Dr. Asri Maharani, MMRS, Ph.D (United Kingdom)
4. Assoc. Prof. Chi-Yin Kao (Taiwan)
5. Ns. Muhamad Zulfatul A'la, M.Kep, Ph.D (Indonesia)



Ladies and Gentlemen

This conference is attended by students, health department delegates, academics, hospital and community clinic practitioners with a total of 350 participants.

This event can be held because of the support and efforts of all parties. Therefore, I would like to thank the Rector of University of Jember, Head of School of Nursing- University of Jember, Indonesian National Nurses Association (INNA) or PPNI, Auditorium of Universitas Jember and all the committees who have worked hard to carry out this activity. I also thank to the sponsors who have worked with us so that this event run as expected. Amen.

We as the committee, apologize if there is any inconvenience during this event. Our hope that this activity can increase our knowledge that benefits all of us. Amen.

Before I end my speech, I want to say "when we interpret that today is an ordinary day, then we will come out of this room as an ordinary people, but when we interpret that today is a very extraordinary day, then we will come out of this room as a very wonderful person".

Finally, please enjoy this conference, May Allah SWT always gives blessings to all of us. Amen

Wassalamualaikum Wr. Wb.

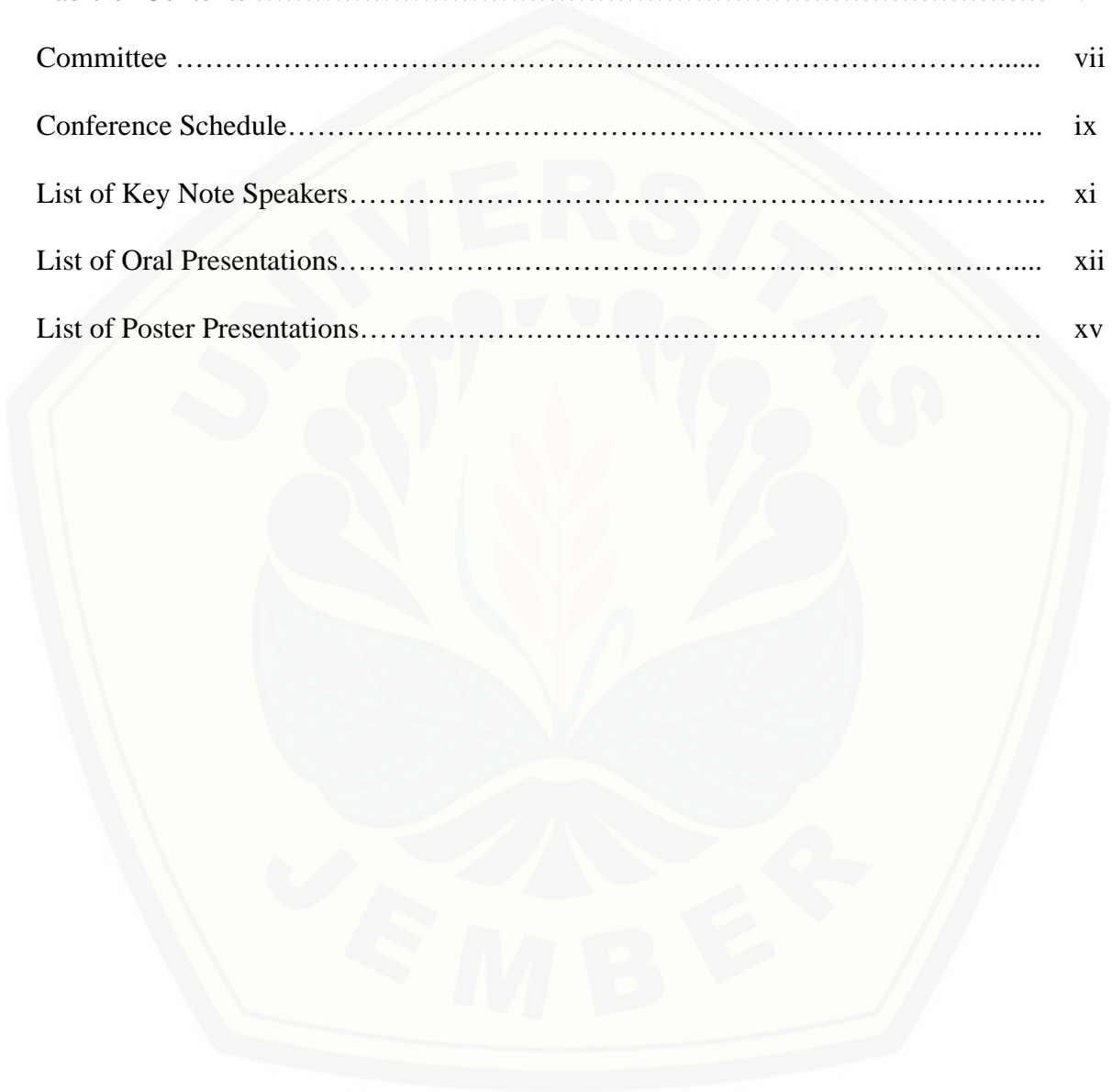
Chairperson

Dr. Ns. Rondhianto, M.Kep.



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Ns. Zaiful Rahman, S.Kep.

**Key Note Speakers**

Associate Professor Caleb Ferguson RN PhD.  
Wasana Ruaisungnoen, PhD RN  
dr. Asri Maharani, MMRS, Ph.D  
Ns. Muhamad Zulfatul A'la, S.Kep., M.Kep., Ph.D



**Conference Schedule**  
**5<sup>th</sup> International Agronursing Conference (5<sup>th</sup> IANC) in conjunction with**  
**1<sup>st</sup> International Post Graduate Nursing Student Conference (1<sup>st</sup> IPGNCS)**  
**“Chronic Care Management: Bridging Theory and Practice**  
**in Healthcare Services”**  
**Jember, May 11-12<sup>th</sup>, 2023**

**FIRST DAY (07.00 – 16.00)**

Time (WIB) GMT + 7	AGENDA
<b>REGISTRATION</b>	
07.00 – 08.00	Registration – Log in Zoom Meeting
<b>OPENING CEREMONY</b>	
08.00 – 09.00	Opening Ceremony  Report Speech <b>Dr. Ns. Rondhianto, M.Kep.</b> (The Chairman Committee)  Welcome Speech: 1. <b>Ns. Lantin Sulistyorini, S.Kep., M.Kes.</b> (Dean Faculty of Nursing, Universitas Jember, Indonesia) 2. <b>Dr. Ir. Iwan Taruna, M.Eng., IPU</b> (Rector Universitas Jember, Indonesia)
09.00 – 09.15	Coffee Break
<b>PLENARY SESSION I</b>	
09.15 – 10.15  (ICT)	<b>PLENARY I (Offline) -- (45 + 15 mins Q&amp;A)</b>  <b>SPEAKER I</b> <b>Assoc. Prof. Caleb Ferguson</b> (Western Sydney University, Australia)
<b>PLENARY SESSION II</b>	
10.15 – 11.15  (AEDT)	<b>PLENARY I (Online) -- (45 + 15 mins Q&amp;A)</b>  <b>SPEAKER II</b> <b>Assoc. Prof. Dr. Wasana Ruaisungnoen</b> (Khon Kaen University, Thailand)
11.15 – 12.30	Lunch & Pray



<b>PLENARY SESSION III</b>	
12.30 – 13.30  (BST)	<b>PLENARY III (Online) -- (45 + 15 mins Q&amp;A)</b>  <b>SPEAKER IV</b> <b>Dr. Asri Maharani, MMRS., Ph.D.</b> (The University of Manchester, United Kingdom)
14.00 – 14.30	Coffee Break & Break out Room
<b>ORAL PRESENTATION AND POSTER EXHIBITIONS DAY-1</b>	
14.30 – 16.00 (15 mins/ presenters)	<b>ORAL PRESENTATION</b> <i>6 presenters/room (48 presenters/8 rooms)</i>

## SECOND DAY (07.00 – 13.00)

Time (WIB) GMT + 7	Agenda
<b>REGISTRATION</b>	
07.00 – 08.00	Registration – Log in Zoom Meeting
<b>PLENARY SESSION IV</b>	
08.00 – 09.00  (JST)	<b>PLENARY IV (Online) -- (45 + 15 mins Q&amp;A)</b>  <b>SPEAKER IV</b> <b>Assoc. Prof. Chi-Yin Kao</b> (National Cheng Kung University, Taiwan)
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<b>ORAL PRESENTATION AND POSTER EXHIBITIONS DAY-2</b>	
10.15 – 11.00 (15 mins/ presenters)	<b>ORAL PRESENTATION</b> <i>3 presenters/room (24 presenters/8 rooms)</i>
<b>CLOSING</b>	
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11.15 – 11.30	Closing by MC
11.30 – 13.00	Lunch, Pray, & Certificate Distribution



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## **RECALIBRATING CHRONIC DISEASE MANAGEMENT FOR THE DIGITAL REVOLUTION**

**Associate Professor Caleb Ferguson RN PhD.**

Associate Professor Chronic & Complex Care,  
University of Wollongong & Western Sydney, Australia

We live in an era of increasing chronic disease and multimorbidity. Stroke, atrial fibrillation (AF), heart failure and dementia are increasingly common and burdensome chronic diseases, all associated with increased death and disability, and reduced quality of life. Informal caregivers play a fundamental role in providing ongoing care at home and in the community for these patients. Home based care and virtual care capabilities, including consumer ready wearables, are increasing in their availability and sophistication. It is critical to consider how these impact nursing assessment and care delivery, in the context of increasing chronic disease. There is the potential to revolutionise how vital signs are measured and used in clinical practice, for example. Further, there is potential to disrupt 'nursing work'. Dr Ferguson will provide deep insight into the digital revolution in the context of chronic disease management.



## COMPLEMENTARY APPROACH IN CHRONIC CARE MANAGEMENT

**Wasana Ruaisungnoen, PhD RN**

Faculty of Nursing, Khon Kaen University, Thailand

Complementary and alternative approach (CAA) is commonly used by those suffering from chronic illnesses. Patients with chronic conditions often experience long-term intricate symptoms, either physical or psychological, that only standard therapy may not be able to fully manage. Complementary and alternative medicine (CAM) refers to a wide range of healthcare approaches that are not mainstream treatment and have not been fully integrated into the dominant healthcare system [1]. The complementary method is used in conjunction with standard medical treatment, whereas the alternative approach is employed in place of it. The term integrative treatment is frequently used in the literature, defining a medical approach that combines standard treatment with CAM methods proven to be safe and effective [2]. Both CAM and integrative methods often emphasize the importance of body-mind interaction and holistic aspect of healthcare.

The roles of CAA in managing chronic illnesses can include symptom control, cognitive and behavioral therapy, and mood and emotional problem management [3]. A substantial amount of evidence supports the effectiveness of a complementary strategy in chronic illness care. People with various chronic conditions including hypertension, heart disease, cancer, diabetes mellitus, chronic respiratory disease, and osteoarthritis have been found to benefit from CAA. Chronic pain, dyspnea, fatigue, dyslipidemia, anxiety, depression, and insomnia are some of the frequent problems that CAA has been used to treat. Lifestyle modification, herbal and dietary supplements, meditation, yoga, Tai Chi, acupuncture, massage therapy, reflexology, and biofeedback are common strategies found in the literature pertaining to CAA in chronic illness [2-3]. Although evidence supports the CAA's effectiveness with the fact that majority of the approaches is safe, patients' misconduct may have negative impacts on their health and well-being.

The presentation will cover the nature of chronic condition in relation to the roles of CAA. Subsequently, the definitions of CAM and integrative therapy in comparison to conventional treatment in chronic care will be revealed. In addition, the categories and types of CAA, the major outcomes, and patients' perception and utilization will be presented. Lastly, CAA with its effectiveness in hypertension and diabetes mellitus, two of the most common chronic illnesses, will be discussed.

### REFERENCES

1. World Health Organization. WHO traditional medicine strategy 2014–2023. Geneva: World Health Organization; 2013.
2. National Cancer Institute. Complementary and Alternative Medicine (National Institute of Health, March 21, 2022), <https://www.cancer.gov/about-cancer/treatment/cam>.
3. Edwards E. The Role of Complementary, Alternative, and Integrative Medicine in Personalized Health Care. *Neuropsychopharmacol* 37, 293–295 (2012). <https://doi.org/10.1038/npp.2011.92>



## **APPLICATION OF SMARTHEALTH, A MULTIFACETED MOBILE TECHNOLOGY- ENABLED PRIMARY CARE INTERVENTION, TO ENHANCE CARDIOVASCULAR DISEASE RISK MANAGEMENT IN RURAL INDONESIA**

**dr. Asri Maharani, MMRS, Ph.D.**

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Cardiovascular diseases (CVD) are the leading cause of death in Indonesia. However, less than one-third of Indonesians with moderate to high cardiovascular risk were not receiving appropriate treatment. This study aimed to evaluate the impact of SMARThealth (Systematic Medical Appraisal Referral and Treatment), a mobile technology–supported, multifaceted primary healthcare intervention on CVD care provision in Indonesia. This study was a quasi-experimental study involving 6579 high-risk individuals aged 40 years and older in four intervention and four control villages in Malang district, Indonesia, conducted between 2016 and 2018. We found that 30% (3494 of 11647) and 28% (3085 of 10988) of respondents in the intervention and control villages, respectively, had high CVD risk. After the intervention, the proportion of individuals with high CVD risk taking the BP lowering therapy was higher in the intervention villages (56.8%) than in the control villages (15.7%). The mean systolic blood pressure reduction from baseline was 17.2 (0.4) mmHg among high-risk participants in the intervention villages and 9.2 (0.4) mmHg among those in the control villages (adjusted mean difference, –8.3 mm Hg; 95%CI, –10.1 to –6.6mmHg). We further found that despite the higher primary care and pharmaceutical costs among individuals who received the intervention, they were projected to experience fewer major CVD events and incur lower hospitalization expenditures. In conclusion, multifaceted mobile technology–supported primary healthcare intervention was associated with greater use of preventive CVD medication and lower BP levels among high-risk individuals in this rural Indonesian population. Relative to usual care, the intervention was a cost-effective means to improve the management of CVD in the population.



## **HEALTH SYSTEM STRENGTHENING THROUGH COMMUNITY VOLUNTEERING SYSTEM QUALITY ENHANCEMENT**

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Health system strengthening (HSS) is one of the essential strategies for improving health outcomes. Improving the quality of health financing, developing human resources, health information, service delivery and leadership can increase a country's cost-effectiveness in providing health services to the public. Strengthening the health system can be done from several approaches or one of the components of the health system from the WHO framework. WHO formulates six building blocks in a health system framework that can be used in various country conditions. The building blocks are service delivery; health workforce; information; medical products, vaccines, and technologies; financing; and leadership and governance (stewardship). Several interventions have been carried out to strengthen health systems worldwide: health insurance, service integration, decentralization, contracting, hospital autonomy and routine health information systems. This intervention still needs other developments and innovations so that the cost-effectiveness of health services can be more optimal.



In supporting HSS, we conduct literature reviews and empirical research regarding community volunteering systems. The community volunteering system could be one of the strategies in HSS. In that case, service delivery can be optimized, budgeting for health can be optimized, information systems can run optimally, and leadership will also be optimal. Volunteering and volunteers are part of the health system. Volunteering in the health context is defined as an activity given free of charge, which benefits from prolonged processes through formal organizations.

Cancer is the condition we chose in an empirical study related to the community volunteering system because cancer is a complex condition with a high mortality rate. Moreover, a phenomenon in our research setting is the urgent need to help people with cancer in the community by optimizing the volunteering system, which needs to be explored more deeply. This research was conducted in Jember, Indonesia, from June 2022 to May 2023. This research approach uses a qualitative approach and ethnographic methods. Researchers believed that the phenomenon of the community volunteering system is complex and requires a multi-perspective lens to see the problem. This study involved 63 informants using observation methods, in-depth interviews and focus group discussions. This study concluded that there are six subsystems in the community volunteering system. There are PwC conditions, health budgeting, healthcare service delivery, volunteer organization management, community systems, and healthcare innovation. In a further study, researchers recommend seeing the effect of optimizing six subsystems of the community volunteering system in improving the quality of health services and cost-effectiveness for cancer patients and other conditions.



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## A SYSTEMATIC REVIEW OF FAMILY CAREGIVERS' BURDEN HAVING PARENT LIVING WITH MENTAL ILLNESS

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### ABSTRACT

**Background:** Family caregivers play a crucial role in providing care and support for people with mental health conditions, such as schizophrenia. The purpose of this study was to integrate and summarize the current studies of family caregivers' burden having parents living with mental illness. **Method:** This systematic review followed Cochrane Collaboration and PRISMA guidelines. Three databases were searched using relevant keywords relating to parents, mental illness, burden, and family members. Three Databases included SCOPUS, Science Direct, and, PubMed. The expanded version of Critical Appraisal Skills Program was used to assess the article quality. Thematic synthesis was conducted on the included papers. **Result:** Fifteen papers were identified. Most of Family caregivers of parents with mental illness experiences medium to high burden. The study identified 10 sub-themes associated with burden to substitute care. These themes were divided into five themes: Caregiving burden, emotional burden, social alienation, school/work performance difficulties, and economic burden. **Conclusion:** This review found that additional research is necessary to understand the family caregiver of parent with mental illness experience and how healthcare teams can support them. Further, the findings may help to inform health care policymakers to shift of treatment focus from the patient to the entire household that support family caregivers.

**Keyword:** Children; Family burden; Family caregiver; Mental disorder

### INTRODUCTION

Mental disorders have become a global problem. Data showed that 970 million people around the world struggle with some mental illness or drug abuse and the prevalence of all mental disorders increased by 50% worldwide from 416 million to 615 million between 1990 and 2013 (Hopechest, 2022). Along with the increasing prevalence of psychiatric

diseases, the care for psychiatric patients who are treated at home compared to getting treatment at the hospital is also higher, which can inadvertently increase the burden on caregivers for these psychiatric patients.

Mental disorders in individuals do not only affect sufferers but also affect those who care for them. Care for people with mental disorders at home is carried out



by informal caregivers which are provided by unpaid non-professional caregivers, most commonly family members (Ignatova et al., 2019). The family caregivers are spouse, children, family members, friends, or relatives of the sick, disabled, and dependent individuals who are not paid for providing care (Hejazi et al., 2021).

Family caregivers play a crucial role in providing care and support for people with mental illness. Caring for an individual with disability is burdensome and stressful to family members (Settineri et al., 2014). Caregiving burden is defined as the stress that derives from caring for others, while caregiver burden is the sensation of emotional or physical tension felt by caregivers. Caregiver burden is defined as a negative reaction to the impact of providing care on the caregiver's social, occupational, and personal roles (Fu et al., 2021). Caregiver burden can be defined as "the level of multifaceted strain perceived by the caregiver from caring for a family member and/or loved one over time (Liu et al., 2020). Caregiver burden includes both subjective and objective aspects (Liu et al., 2020).

Differences in position in a family produce different levels of burden, as previous research has shown that adult children experience a heavier burden in caring for family members with mental

disorders than couples (Chappell et al., 2014). This condition suggests that different types of informal caregivers need to be investigated separately to better characterize the differences that exist in their needs and the challenges they face when caring for family members with mental illness.

Caregivers most disadvantaged are those who indicate as a reason of care the sense of duty rather than the affection. Finally, the sons and daughters, differently from the parents, showed a greater burden of required time and a lower quality of life. The purpose of this study was to integrate and summarize the current studies of family caregivers' burden having parents living with mental illness.

## METHOD

### *Study selection*

This systematic review followed Cochrane Collaboration and PRISMA guidelines. Three databases were searched using relevant keywords relating to parents, mental illness, burden, and family members. Three Databases included SCOPUS, Science Direct, and, PubMed. Databases were searched from inception 2013 to 31 March 2023. Both qualitative and quantitative studies were eligible, so no study design filters were applied during the searches.

**Table 1.** Search terms and strategy used in SCOPUS, Science Direct, and, PubMed

#1	mental illness OR mental disorder OR mental issues OR schizophrenia OR psychiatric disorder OR psych* problem OR bipolar disorder OR psychiatric illness OR depression OR anxiety OR psychotic disorder OR behavior disorder
#2	burden* OR caregiver burden* OR burnout OR exhaustion OR strain OR overload* OR frustrate* OR stress
#3	caregiver* OR family caregiver OR carer*

### *Terminology and definitions*

For the purposes of this review, caregiver burden included objective and subjective burden. The subjective burden refers to the personal perception and personal evaluation of the extent of caregiving burden arising from caring for a

frail or disabled relative can lead to emotional, mental, and physical health problems for caregivers (Fu et al., 2021; Raj et al., 2016). Subjective burden describes the psychological reactions which caregivers experience e.g., a feeling of loss, sadness, anxiety, and embarrassment in



social situations, the stress of coping with disturbing behaviors, and the frustration caused by changing relationships (Raj et al., 2016). The objective burden of caregiving assesses the quantitative aspects that involve tangible currencies (eg, hours of care provided or tasks performed) and finances devoted to care (Fekete et al., 2017; Flyckt et al., 2015).

### ***Eligibility criteria***

The Inclusion criteria for this review included qualitative or quantitative data studies on the experiences of family caregivers to parents with mental illness. Articles were included if they reported data on caregiver burden, as defined above. Studies that report data collected from family caregiver are eligible to this review. Exclusion criteria included: studies not specific to mental disorder; studies discussing family caregiver experience indirectly (for example, data collected from patients or health professionals); studies that contained only data from a second-order analysis. Studies reporting interventions in caregivers were not eligible, as experiences and outcomes may be impacted by the intervention. Articles that were in a language other than English, case reports, editorials, opinion articles and review articles and conference abstracts were also excluded.

### ***Quality appraisal***

Quality appraisal was undertaken independently by two authors (RD and RE). Third author (AY) were reviewed when there are any disagreements. Qualitative studies were appraised using the Critical Appraisal Skill Program (CASP) Qualitative Checklist (Critical Appraisal Skills Programme, 2022). The CASP Qualitative Checklist contains 10 questions based on three broader questions: 'are the

results of the study valid?', 'what are the results?' and 'will the results help locally?'. Quantitative studies were assessed using the Methodological Index of Non-randomized Studies (MINORS) includes eight items for assessment of non-comparative studies (i.e. studies which do not include a control or comparator population) and twelve items for comparative studies.

### ***Data extraction and synthesis***

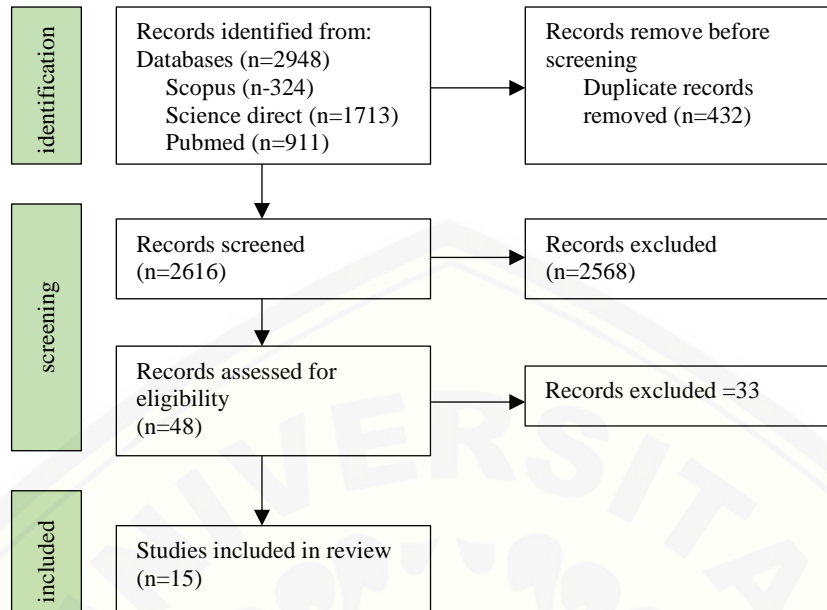
Data were extracted by two authors (RD and RF). The extracted data included study aim, study design, data collection method(s), caregiver age and gender, disease characteristics and data on caregiver experience associated with caregiver burden. RD and AY conducted the data synthesis. The aim of this study is to assess caregiver burden. as such, these key areas formed our themes, using the definitions above, and data was coded using deductive thematic analysis. This analysis has enabled us to provide a summary of the current research available on family caregiver burden in parents with mental illness.

## **RESULT and DISCUSSION**

### ***Search results***

The screening process was detailed by A PRISMA flowchart shown in Fig. 1. The systematic search of three databases returned 2948 citations. Full texts of 48 citations were reviewed after removing duplicates and screening the remainder of articles by title and abstract. Of these, 33 full texts were excluded. Fifteen studies (six qualitative study, seven quantitative study and two mixed-method study) were included in this review.





**Figure 1.** Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram of the literature screening process

### ***Descriptions of the studies***

The fifteen studies were published between 2013 and 2022 (Table 1). A total of 456 and 3013 family caregivers were included in the qualitative and quantitative studies respectively. The studies reviewed were conducted in develop country namely 8 countries: Canada (Herbert et al., 2013; Law et al., 2023), Italy (Roncone et al., 2023), Germany (Bauer et al., 2015; Kettemann et al., 2020; Theurer et al., 2019), Finland (Juntunen et al., 2018), Japan (Kageyama et al., 2021), Swedish (Widemalm & Hjärthag, 2015), United States (Bacharz & Goodmon, 2017), and Denmark (Dam et al., 2018). Four studies were conducted in developing countries namely: Iran (Rahmani et al., 2022), Cambodia (Phoeun et al., 2022), Taiwan (Hsiao & Tsai, 2015), and Indonesia (Buanasari et al., 2018).

### ***Family Caregiver Burden Characteristics***

Family caregiver of parent with mental illness were varied from school age, adolescent and adult children. The range of age was 4-49 years old totally 1,366.

Tristiana, et al (2023)

Children of parents suffering from bipolar or depressive disorder show high levels of burden (Bauer et al., 2015) and reported more burdensome aspects when they were either younger than 11 or older than 20 years old at the onset of their parent's disorder (Bauer et al., 2015). Highly involved caregivers reported less psychological distress than less involved caregivers (Bacharz & Goodmon, 2017).

Family caregiver of parent with mental illness lacked clear understanding of the legal definition and limitation of being a caregiver, and carried out the role intuitively as an extension of their being a caretaker and advocate. Many, though dedicated to their role, often expressed frustration with the lack of authority (Law et al., 2023)

### ***Family Caregivers Burden Measurement***

The caregiver burden measurement used: The family caregiver burden was measured using the version of the Family Problem Questionnaire (FPQ) (Roncone et al., 2023), economic burden (Roncone et al., 2023), The 9-item Patient Health



Questionnaire (PHQ-9; The 7-item Generalized Anxiety Disorder (GAD-7), The 21-item Depression, Anxiety, and Stress Scale (DASS-21) (Phoeun et al., 2022), Child Behavior Checklist (CBCL/4–18) (Kettemann et al., 2020), the COPE Index (Juntunen et al., 2018), The 18-item Caregiver Burden Scale-Brief (CBS-B) (Hsiao & Tsai, 2015), The Chinese version of the 10-item Family Stressors Index and the 10-item Family Strains Index, and The Chinese version of the 20-item Family Hardiness Index (FHI) (Hsiao & Tsai, 2015), the 10-item K10 Psychological Distress Scale (Bacharz & Goodmon, 2017).

### **Family Caregiver burden**

#### *Caregiving burden*

The caregiving burden of children of parent with mental illness in areas such as taking responsibilities (Herbert et al., 2013). A study describe that children were acting as surrogate parents in took care of chores in the home, went shopping and helped with practical matters, and take care of younger siblings (Dam et al., 2018). Children also help to take care parent for their disease: helping their parents to get up in the morning, ensuring that they took their pills (Dam et al., 2018). They spend most of their time to take care of their parents with mental illness. The children had to put aside their own life, especially when the parents had bad days. Then, it happened that they stayed home from school to take care of the family. Also, already in early life, they were fearful of the effect of the mental illness on their parent and on family life (Dam et al., 2018).

There are several different research results regarding gender and the caregiving burden. A study found that the female adult child caregivers had more the negative impact of caregiving than the caregiver mothers (Juntunen et al., 2018). Daughters are more had higher acceptance of the caregiving situation than sons (Theurer et al., 2019). Other study found that there was

no significant differences between gender, role, and location (Roncone et al., 2023).

#### *Emotional burden*

Children of parent with mental illness experience emotional burden (Bauer et al., 2015) such as: feeling sorry and guilt (Dam et al., 2018; Rahmani et al., 2022) for their sick and tired parent, pain (Roncone et al., 2023), feel loneliness (Dam et al., 2018; Herbert et al., 2013), ongoing worries receiver (Phoeun et al., 2022; Rahmani et al., 2022), somatic complaints (Kettemann et al., 2020), having fearfulness and lack of sense of peace and happiness (Herbert et al., 2013). Children of parent with mental illness had a clinically relevant fearful-avoidant attachment style (Kettemann et al., 2020)

Daughters scoring substantially higher across all scale scores than son for depression (Hsiao & Tsai, 2015; Phoeun et al., 2022). a relatively low subjective burden in the caregiver sample, with a statistically significant higher burden for women than men (Roncone et al., 2023). However, a few of children of parent with mental illness reported having positive experiences such as becoming more independent, developed positive relationships in the process of taking and giving help which made them more selfless (Herbert et al., 2013).

#### *Social alienation*

Children of parent with mental illness experiencing some problems in social life such as fear of discrimination, prejudice and stigma (Rahmani et al., 2022), lacking close relationships (Dam et al., 2018), and had negative experiences while going out with parents or guests visiting them (Herbert et al., 2013). They also feelings of embarrassment and shame (Rahmani et al., 2022), feelings of helplessness in relation to health care (Widemalm & Hjärthag, 2015), and being ignored, bullied and laughed (Dam et al., 2018). Children of parent with mental



illness spent less time with their friends, had no leisure time (Widemalm & Hjärthag, 2015)

#### *School/work performance difficulties*

Children of parent with mental illness could not concentrate in school, and their grades dropped (Widemalm & Hjärthag, 2015). Their parents did not visit the school or talk to teachers, being bullied, forgetfulness, absenteeism, arriving late for school, and academic deterioration (Kageyama et al., 2021). Children feel lack of support and guidance in studies and emotional support from their parents (Herbert et al., 2013) and aware of teachers' prejudice, discriminatory behavior, and lack of consideration for privacy. and had an inadequate consultation environment or were unprepared to consult (Kageyama et al., 2021) during the school.

#### *Economic burden*

Children of parent with mental illness experience burden because of direct costs (professional, alternative medicine, drugs, and all non-reimbursable expenses) which range for professionals (psychiatrists, neurologists, psychologists, nurses) and other services (Roncone et al., 2023). The majority of children of parent with mental illness experienced severe financial issues (Phoeun et al., 2022)

#### **CONCLUSIONS**

This systematic review sought to identify reported burden experiences of children when a parent had mental illness. Majority of children reported spend most of their time to take care of their parents with mental illness and had to put aside their own life, though a few others experienced positive experiences such as becoming more independent and developed positive relationships. Children were emotionally impacted by family disruption and their parent behavior when had bad days. Children experience lack of support on their study and had academic deterioration, some

problems in social life and also financial problems.

Children caregivers who had role as primary caregiver or secondary caregiver tend to place their caregiving role as a higher priority than other life goals. Caregivers tend to place the needs of others before their own and need to be educated about the importance of preventive self-care (Champlain, 2012). Although many studies illustrate that caring for parents with mental illness has reduced children's time in activities and also increases children's burdens, there are two studies which illustrate that children have positive experiences while caring for their parents.

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**Table 2.** Study characteristics of eligible studies

Title (author, year)	Method	Result
“Everyone means well but the one person who’s really going to go to bat” - experiences and perspectives of substitute decision makers in caring for their loved ones with serious mental illness (Law et al., 2023)	D: qualitative research S: 13 interviews with 14 family member SDMs (with one joint parent interview). V: <i>experiences and perspectives from acting as an SDM for people with serious mental illness</i> I: interview guidance A: thematic analysis	1) Varied subjective understanding of the responsibility and authority of the SDM role; 2) Varied role demands and impact on SDMs' lives; 3) Challenges in dealing with the mental health system; 4) Leveraging decision making status to promote patient care; and 5) SDM role impact on family relationships.
Family functioning and personal growth in Italian caregivers living with a family member affected by schizophrenia: Results of an add-on study of the Italian network for research on psychoses (Roncone et al., 2023)	D: add-on study S: 136 caregivers V: socio-demographic data; Family functioning; Burden of care I: Family Problem Questionnaire (FPQ) A: Chi-squared test and <i>t</i> -test	low objective burden in the sample of caregivers. No statistically significant differences were found based on gender, role, and location. Subjective burden: relatively low subjective burden with a statistically significant higher burden for women than men
Caregiver or care receiver: Adolescents' experience of caregiving to a parent with severe mental illness: A qualitative study (Rahmani et al., 2022)	D: A qualitative research S: 18 caregiving adolescents V: experiences of living with and providing care to a parent with a severe mental illness I: interview guideline A: thematic analysis	(1) emotional exhaustion with associated subthemes of ‘ongoing worries’, ‘fear of loneliness’, ‘feeling of shame and guilt’ and ‘fear of discrimination and stigma’; (2) being trapped in a difficult situation with subthemes of ‘living a compromised life’, ‘alienating from peers’ and ‘caregiver rather than care receiver; and (3) adapting to the situation with subthemes of developing new skills and growing accountability
‘I feel hopeless’: Exploring the psychosocial impacts of caring for mentally ill relatives in Cambodia (Phoeun et al., 2022)	D: a convergent mixed-methods study design S: The FGDs included 37 participants (6–9 per group), and 115 participants provided quantitative survey data (20 children and age 18–19=16) V: qualitative= problems impacting caregivers of people with serious mental illness; Demographic data; I: A semi-structured FGD guide. The 9-item Patient Health Questionnaire (PHQ-9); The 7-item Generalized Anxiety Disorder (GAD-7); e 21-item Depression, Anxiety, and Stress Scale (DASS-21) A: multiple linear regression models.	Financial burden: her lost their job or cannot work because their caregiving and help-seeking responsibilities are too time-consuming. encompassing a range of physical, somatic, psychological, and emotional symptoms Burden of distress among relative caregivers
Burden of Children of Patients with Mental Illness-A High Risk Population that Needs Selective and Indicated Prevention? (Kettemann et al., 2020)	D: cross sectional S: 399 children 4-18 years V: Child Behavior I: Child Behavior Checklist (CBCL) A: SPSS	Children of mentally ill parents showed significantly more behavioral problems than children of healthy parents. behavioral problems were similar with respect to “social problems” (4–11 year-old boys, 12–18 year-old girls) and “somatic complaints” (12–18 year-old boys and girls)
Perceived burden among spouse, adult child, and parent caregivers (Juntunen et al., 2018)	D: cross-sectional study S: 2 388 caregivers V: Caregiver burden I: COPE Index	No significant differences were observed between daughter and son caregivers. significant factors of burden were being bothered by depressive symptoms, poor perceived health, care recipient’s low level of



Title (author, year)	Method	Result
	A:t-test; Mann-Whitney	cognitive function, and care recipient's physical immobility. High quality of support was associated with lower caregiver burden
Growing up with a parent having schizophrenia: Experiences and resilience in the offsprings (Herbert et al., 2013)	D: exploratory study S: 45 offsprings of parents with diagnosis of schizophrenia according to ICD-10 V: Resilience I: A semi-structured interview; Connor-Davidson Resilience Scale (CD-RISC) A: Frequency distribution, Mean and standard deviation	they had negative experiences in social aspects of life such as while going out with parents or guests visiting them and difficulties in emotional aspects such as having fearfulness, loneliness, and lack of sense of peace and happiness. Burden in areas such as taking responsibilities and financial and emotional aspects was reported by 66% of them. However, a few of them (2%) reported having positive experiences.
Previous experiences of Japanese children with parents who have a mental illness, and their consultation situation at school: A survey of grown-up children (Kageyama et al., 2021)	D: web-based questionnaire survey S: 120 grown-up children V: experience of grown-up children with parents suffering from mental illness during their elementary, junior high, and high school years, I: survey A: simple tabulation	the respondents provided emotional care, did household chores, most recognized adult fights, and experienced attacks by parents. Signs that others could have noticed included the fact that parents did not visit the school or talk to teachers, being bullied, forgetfulness, absenteeism, arriving late for school, and academic deterioration
The forum as a friend: parental mental illness and communication on open Internet forums (Widemalm & Hjärthag, 2015)	D: survey S: 35 selected forum threads that, in all, contained 301 comments and amounted to 166 pages of text for analysis (13-49 year) V: communication content in forum I:- A: A thematic analysis	a pressure directly related to their parents' illness: his pressure led to different types of stress reactions that affected many areas of their everyday lives, such as education, social networking, responsibilities, and their health. The forum writers often ventilated both the frustration they experienced in regard to the care provided and their frustration with the lack of care that they thought should have been provided for their parent. Many times, they had fought hard for their parent to receive adequate health care, and they often felt powerless when they could not control the situation
Experiences of adults who as children lived with a parent experiencing mental illness in a small-scale society : A Qualitative study (Dam et al., 2018)	D: a qualitative semistructured interviewstudy S: Eleven participants, eight women and three men, aged 18 till 49 years, were recruited. V: experiences I: An interview guide b A: manifest and latent content analysis	these children were acting as surrogate parents.They took care of chores in the home, went shopping and helpedwith practical matters. Those who had younger siblings had to takecare of them too. Taboo as barrier refers to memories that many of the adult childrenrecalled, such as lack of openness in the family, at school and in the society at large regarding their parent's mental illness.
Factors of caregiver burden and family functioning among Taiwanese family caregivers living with schizophrenia (Hsiao & Tsai, 2015)	D: A cross-sectional descriptive study S: 137 primary family caregivers V: caregiver burden and family functioning I: Chinese versions of the Family Stressors Index, Family Strains Index, 13-item Sense of Coherence Scale, 18-item Caregiver Burden Scale, Family Hardiness Index and Family Adaptability, Partnership, Growth, Affection, and Resolve Index	Female caregivers, additional dependent relatives, increased family demands and decreased sense of coherence significantly increased caregiver burden, whereas siblings as caregivers reported lower degrees of burden than parental caregivers.



Title (author, year)	Method	Result
	A: descriptive statistics, Pearson's product-moment correlation coefficients, t-test, one-way analysis of variance and a stepwise multiple linear regression	
Care of parents with dementia: comparison of caregiving sons and daughters (Theurer et al., 2019)	D: survey S: 322 caregiving relatives V: style of caregiving, the feeling of stress and burden and the utilization of support offers. I:- A: t-tests, Mann-Whitney tests and <sup>2</sup> -tests.	Daughters scored on average higher than sons only with respect to the acceptance of the caregiving situation. Overall caregiving daughters and sons did not differ with respect to caregiving experiences as strongly as previously assumed
Burden, reward, and coping of adult offspring of patients with depression and bipolar disorder (Bauer et al., 2015)	D: qualitative study S: 30 adult children V: predictors of burden I: Freiburg Questionnaire of Coping with Disease ( <i>Freiburger Fragebogen zur Krankheitsverarbeitung, FKV</i> ) A: Regression analysis	Predominately, adult children of parents suffering from bipolar or depressive disorder show high levels of burden and are in urgent need of professional support. Emotional burden (reported by 100%), burden due to impaired family life (90%), burden due to the patient's symptoms (76.7%), burden due to dissatisfaction with the patient's therapy/professional staff (73.3%), burden due to impaired free-time activities (63.3%), burden due to impaired functioning in school/job (46.7%), burden due to own health problems (43.3%), and burden due to problems in the child's relationship/own family (30.0%)
The caregiver's burden: Psychological distress in the younger adult caregiver adult caregiver (Bacharz & Goodmon, 2017)	D: Cross-sectional study S: 44 young adult children V: financial support, social support, symptoms of distress I: The 12-item Multidimensional Scale of Perceived Social Support, the 10-item K10 Psychological Distress Scale A: univariate ANOVA	significantly higher distress scores than caregivers who were not financially supporting their loved one. no significant correlation between level of caregiving support and psychological distress or between financial distress and psychological distress.
The experience of adolescents having mentally ill parents with pasung (Buanasari et al., 2018)	D: Qualitative study S: 6 adolescences V: experience in caring for parent with pasung I: The interview guide A: Thematic analysis	economic burden felt by families is greater if it is associated with the decreased of occupational functions of mentally ill parents that hinder them to work and contribute to the fulfillment of the financial needs of the family