

Original Article

# Family caregivers' perception and response to COVID-19 in caring for older adults with chronic diseases: A qualitative study

Bahtiar<sup>1\*</sup>, Nurlaila Fitriani<sup>2</sup>, Dwi Nopriyanto<sup>1</sup>, Ida Ayu Kade Sri Widiastuti<sup>1</sup>, Arief Andriyanto<sup>3</sup>, Ikkal Fradianto<sup>4</sup>, Eriyono Budi Wijoyo<sup>5</sup>

<sup>1</sup>Department of Nursing, Faculty of Medicine, Mulawarman University, Indonesia

<sup>2</sup>Department of Nursing, Faculty of Nursing, Hasanuddin University, Makassar, Indonesia

<sup>3</sup>Department of Nursing, Faculty of Health Sciences, Bina Sehat PPNI University, Indonesia

<sup>4</sup>Department of Nursing, Faculty of Medicine, Tanjungpura University, Indonesia

<sup>5</sup>Department of Nursing, Faculty of Health Science, Universitas Muhammadiyah Tangerang, Banten, Indonesia

## \*Corresponding Author:

**Bahtiar**

Department of Nursing, Faculty of  
Medicine, Mulawarman University,  
Indonesia

Email:

bahtiar@unmul.ac.id

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## Abstract

**Background:** The older adult is the vulnerable group to infecting COVID-19 and most of them live with their families. The family must take care of them while they face various problems during the pandemic. It will probably tend to more stress and burden so the understanding of their perception and response on dealing with older adults with chronic diseases is vital.

**Objective:** This study explored exploring about perceptions and responses of family caregiver's older adults with chronic diseases about COVID-19 disease.

**Methods:** The study used qualitative descriptive phenomenology by using online semi-structured interviews with family caregivers of older adults with chronic diseases in Samarinda, Indonesia from September to November 2021. Sixteen family caregivers of older adults participated that was using purposive sampling method. The data analysis conducted by Colaizzi technique and rigor process were included peer debriefing with peers, member checking of the outcome, and inquiry audit.

**Results:** After qualitative analysis, three main themes emerged: 1) Views of older adult families on covid-19 disease (positive and negative views on Covid-19 disease); 2) Older adult family caregiver responses in facing covid-19 vaccination of older adult with chronic diseases (negative thoughts about vaccinations, family efforts to facilitate vaccination for the older adult); 3) Families facilitate traditional medicine are an option that is of interest to the older adult to prevent and deal with covid-19 disease (opinions of the older adult to consume herbal medicine, reasons for older adult consuming herbal medicine).

**Conclusion:** This study showed that Indonesian older adult family caregivers have various perceptions and responses to older adults with chronic diseases during the pandemic. The government needs to enhance health promotion regarding COVID-19 and vaccination. Older people commonly use herbal medicine, so information about ingredients and dose must be educated properly.

## Background

Indonesia faces high COVID-19 fatalities with 6.573.805 cases and ranking sixth in East Kalimantan with 5,709 infected patients (Satgas Penanganan Covid-19 Indonesia, 2022). The previous epidemiological data show that older adults have higher proportion on COVID-19 incidence and suffering diabetes mellitus, hypertension, pneumonia, respiration failure was related to higher of mortality rate on COVID-19 (Sujarwoto & Maharani, 2022; Surendra et al., 2023). The elderly population is especially vulnerable to the pandemic in low-income, developing, and highly populated countries like Bangladesh (Alam et al., 2022). Indonesian families prioritize housing and caring for older adults, increasing health risks during COVID-19 pandemic.

People around the world have various perceptions of covid-19 diseases. Previous research shows that people in the middle eastern have a good awareness of covid-19 (Jaber et al., 2021). In Bangladesh, research participants have excellent knowledge, positive attitudes, and practice of COVID-19 prevention (Ferdous et al., 2020). People in Nigeria have good knowledge about COVID-19, but they thought the response of the government and its institutions to the epidemic was poor (Oleribe et al., 2020). The different results show that family caregivers in Canada have felt high fear to infection of covid-19 (Cori et al., 2021). Besides, perceptions about vaccination against COVID-19 are also diverse.

Vaccination against COVID-19 is triggering several perceptions. Research result shows that vaccination against COVID-19 is a serious public

health issue. Vaccines are safe and effective, benefit the community and recommend to family and friends (Bennett et al., 2022; Islam et al., 2021). US population faces most hesitation in COVID-19 vaccination, with Black, African Americans, pregnant women, and low-sex males (Yasmin et al., 2021). Inadequate knowledge and perception severely reduced vaccine willingness overall in Bangladesh (Bari et al., 2021). An online survey throughout India found that almost 3 out of 10 persons were unwilling to receive the COVID-19 vaccine (Kishore et al., 2021). Ageism in health policy leads to age discrimination in vaccination prioritization (Lloyd-sherlock et al., 2022). Besides, perception about the usage of herbal medicine is rising.

Herbal medicine is the complementary therapy for COVID-19 disease. Herbal remedies for COVID-19 prevention and treatment in Lithuania may be inspired by ethnopharmacological preferences and archival materials (Pranskuniene et al., 2022). Worldwide research trends at the COVID-19 junction demonstrate that most include traditional Chinese medicine and vitamin D supplementation (Ng, 2020). Nevertheless, several COVID-19 patients utilized complementary and integrative medicine, but few sought advice from their doctors (Parvizi et al., 2022).

Previous research shows that people have diverse perceptions and opinions about COVID-19 diseases, vaccination, and herbal medicine. The perception and opinions from family caregivers of older adults with chronic diseases is still unknown properly especially from low-middle income countries. Therefore, exploring older adult families with chronic diseases regarding perception and responses, especially in the Indonesian context, needs to be studied further using a phenomenological study approach to getting deep information on how they are caring and dealing with to crisis situation. In addition, the urgency of research needs to be carried out qualitatively because there is still a lack of research with this approach and perspectives and the response of older adults' family caregivers from developing countries such as Indonesia. This study aimed to explore how family caregivers of older adults with chronic diseases perceived and responded to COVID-19 in Samarinda, Indonesia.

## Methods

### *Study Design*

The study employs a qualitative descriptive methodology with Husserlian philosophical approach and constructivist paradigm. The selected approach and paradigm influenced using semi-structured interviews that allow the participant to lead the narrative, actively "bracketing" personal opinions to listen for the essence, and also using thematic analysis for the analysis data. This study adhered to the Standards for Reporting Qualitative Research (SRQR) (O'Brien et al., 2014).

### *Participants*

Purposive sampling was used to gather data from 16 older adult families (ages 17 to 60) that cared for older adults with chronic illnesses in Samarinda City, East Kalimantan Province, Indonesia, during the Covid-19 outbreak. The study's population comprised older adult families who cared for loved ones with chronic illnesses. The following conditions must be met for study participants to be included aged between 18 and 59, willing to participate as a research subject, respondents must also meet the following criteria: (1) They must be Older Adult family members with a chronic illness; (2) They must have an Older Adult family member who has had the illness for at least three months; and (3) They must be able to convey their feelings by sharing personal experiences. The exclusion criteria were: (1) Older Adult families are unable to cooperate when communicating; (2) The Older Adult family has suffered from an acute illness that prevents them from participating in interviews; (3) The family abruptly declines to participate in the interview.

### *Data Collection*

During the data collection, Samarinda City, Indonesia, have obstacle on using health services facility, lockdown situation, fear of infection COVID-19 especially for vulnerable group such as older adults that affect on elderly medication regiment program. Many residents of Samarinda City have insufficient knowledge on COVID-19, strong belief on hoax of COVID-19

and also dominant belief on herbal consumption of Kalimantan herbal materials. Sampling saturation was attained if there was information from new participants and repeating statements. Saturation was attained by participant number sixteen which were none of new information and redundant of same information according to interview of the participants. The study used online ZOOM meeting tool for interviews from September to November 2021, using purposeful sampling and data gathering. Before starting the collecting data, the researchers have explained the informed consent by viewing and asking the agreement to involve on the research by online ZOOM meeting. The interview guide or question consist of 9 questions include: explore about point of view, feeling and opinion of caregivers, how to overcome about COVID-19 pandemic, support of family and prevention act of family caregivers of spreading COVID-19. The interviews were recorded by Zoom application and the data were stored at researchers cloud data account with limited access. The probing was conducted with several strategies include: avoid for "why" question which potentially make participants feel defensive, stay neutral while interview session, tell-me-more probe strategy, and clarification probe strategy.

The method used is in-depth interviewing with semi-structured interview techniques. The person that conducted the interviews are four researchers (BB, NF, DN, IAKSW). The researchers have sufficient background and ability on qualitative which are they have conducting qualitative research on health issues. The interviewers had not prior relationships with all of the participants. The researchers was taking interviews and did not give questions in the same order to each participant, depending on the answers and the participants' processes. Researchers allowed participants to express their experiences freely and were guided by interview guidelines. Researchers conducted interviews with an estimated time of between 45-60 minutes.

The interview guide or question consist of 9 questions include: explore about point of view, feeling and opinion of caregivers, how to overcome about COVID-19 pandemic, support

of family and prevention act of family caregivers of spreading COVID-19. Before conducting data collection, the interview guide was pilot-tested among three person of family caregivers' to measure validity and understanding of the question. The interviews were recorded by Zoom application and the data were stored at researchers cloud data account with limited access. The probing was conducted with several strategies include: avoid for "why" question which potentially make participants feel defensive, stay neutral while interview session, tell-me-more probe strategy, and clarification probe strategy.

Based on inclusion criteria, the data collection process began by looking for the responder through an online announcement and word-of-mouth. The researcher then got to know the subjects to establish "rapport" (good relations). The researcher next requested the participant for their consent to record the talk before doing the in-depth interview via online meeting. After the participant interviews, the transcription procedure is carried out using anonymity. Investigator triangulation was used when collecting data to increase the research's credibility. The study's lead or contributing researchers have previous expertise performing qualitative research.

#### *Data analysis*

Collaizi technique steps are employed to process and evaluate data include: (1) familiarization, (2) identifying significant statements, (3) formulating meanings, (4) clustering themes, (5) developing an description, (6) seeking verification of the fundamental structure, (7) seeking verification or member checking (Streubert & Carpenter, 2003). In order to understand the overall significance of participant experiences, the researchers carefully examined the interview transcript. The researcher then did a give-back transcribed interview and culled the actual quotes. The next phase was reviewing the transcript to determine the meaning of the statements and classifying them into codings, categories, and themes using software called Atlas.Ti. The process of data analysis involved various disciplinary background on nursing expertise

such as community health nursing, gerontological nursing, psychiatric nursing and medical surgical nursing. The process of data analysis used member checking, thick description, audit trail, and bracketing to make sure rigor process of analysis data.

#### *Trustworthiness*

The trustworthiness and credibility methodology was carried out by evaluating data using various tactics, including peer debriefing with peers of all researchers and expert, member checking of the outcome to all of participants, and inquiry audit trail with external auditor to give feedback of research include: (1) audit of dependability to examine method of data collection; (2) audit of confirmability to examine the interpretations and conclusions of the research. The researcher then provided the descriptive findings. The study also used the Atlas-Ti program to

organize, analyze, visualize, and present the research findings.

#### *Ethical Consideration*

The protocol of the research has received approval from Health research ethics committee of Mulawarman University, Faculty of Medicine, clearance for this study, No. 95/KEPK-FK/XI/2021, November 10, 2021.

#### **Results**

Two sections make up the results. Table 1 in the first section lists the participant characteristics, and the second portion lists the topics, categories, and coding (table 2).

Participants had diverse educational backgrounds and experienced chronic illnesses like osteoporosis, sinusitis, hypertension, COPD, and autoimmune diseases, with grandparents and biological parents as primary caregivers.

**Table 1.** Characteristics of participants

Participants	Age	Gender	Level of Education	Type of Older Adult Chronic Disease	The duration suffering chronic diseases	Relationship with the Older Adult
P1	33	Woman	Senior High School	Diabetes Mellitus	>6 Months	Biological parents
P2	38	Woman	Magister	COPD and Autoimmune	>6 Months	parents in law
P3	21	Woman	Diploma	Hypertension	>6 Months	grandchild
P4	20	Woman	Senior High School	Stroke	3-6 Months	grandchild
P5	21	Woman	Senior High School	Heart Disease, Post Operation of Hernia	>6 Months	Biological parents
P6	43	Man	Diploma	Diabetes Mellitus	>6 Months	Biological parents
P7	41	Woman	Bachelor	Arthritis Rheumatoid	>6 Months	parents in law
P8	46	Woman	Diploma	Stroke	>6 Months	Biological parents
P9	21	Woman	Bachelor	Heart Disease	>6 Months	grandchild
P10	22	Woman	Bachelor	Hypercholesterolemia	3-6 Months	grandchild
P11	20	Woman	Senior High School	Hypertension	>6 Months	grandchild
P12	49	Woman	Bachelor	Osteo Arthritis	>6 Months	Biological parents
P13	24	Woman	Senior High School	Hypertension	>6 Months	Biological parents
P14	30	Woman	Bachelor	Sinusitis	>6 Months	Biological parents
P15	20	Woman	Diploma	Hypertension and Stroke	>6 Months	grandchild
P16	21	Man	Diploma	Hypertension and Stroke	>6 Months	grandchild

**Table 2.** Themes, Categories, and Codings

Theme	Categories	Codings
1.Views of Older Adult Families on Covid-19 Disease	Positive views on Covid-19 disease	- Comorbid at risk of infection - The Older adult believe Covid-19
	Negative views of the covid-19 disease	- Covid-19 is like the common cold - Disbelief on covid-19 - Indecisive on covid-19
2.Older Adult Family Caregiver Responses in Facing Covid-19 Vaccination of Older Adults with Chronic Diseases	Negative thoughts about vaccinations	- Disbelief in vaccines - Hesitancy of vaccination - Misinformation from neighborhood - The older adult is vulnerable - Misinformation from mass media
	Family efforts to facilitate vaccination for the Older Adult	- Does not meet the requirements - Willing to carry out vaccinations
3.Families facilitating traditional medicine are an option that is of interest to Older Adults to prevent and deal with Covid-19 disease	Opinions of the older adult to consume herbal medicine	- Likes to drink herbal ingredients - Herbal ingredients as a complement to treatment
	Reasons for an older adult consuming herbal medicine	- Recommendations from friends - Free from chemicals - Rarely sick - Save cost

Our results found three themes reflecting family caregivers perception and responses to COVID-19 in caring older adults with chronic diseases:

*Theme 1: Views of Older Adult Families on Covid-19 Disease*

The family caregivers' views about older adults in pandemic covid-19 condition consist of positive and negative views of the disease covid-19. Several participants (participants 4 and 5) have positive views that indicated sufficient knowledge about handling, caring and prevention of covid-19. On contrary, other participants (participants 1, 5, 9, 14) have negative view which reflected lack of knowledge and understanding on covid-19 diseases.

*Sub theme 1.1 : Positive views on Covid-19 disease*

The participants have various positive perceptions on covid-19 diseases include comorbid at risk of infection and their older adult believe Covid-19.

*"This pandemic is dangerous, especially before the discovery of vaccines, especially for people who have comorbidities which can get worse when they are already exposed, when they have other diseases that get worse" (P4).*

*"If there are comorbidities, it is more dangerous if you are exposed to Covid" (P5).*

*Sub theme 1.2 : Negative views of the disease covid-19*

The participants who have negative views thought covid-19 is like the common cold, disbelief and Indecisive on covid-19.

*"Covid is like the common cold, like the effect I had yesterday, it rarely just feels like that" (P 14).*

*"We are between sure and not sure. I still think it is still gray. Some believe and some do not" (P 9)*

*"Yes, it is real, or it is not true. Because many are affected, so I think it was really covid" (P 1).*

*Theme 2: Older Adult Family Caregivers Responses in Facing Covid-19 Vaccination of Older Adults with Chronic Diseases*

Responses of older adult family caregivers are included of negative thoughts about vaccinations (participants 2 and 9) and family efforts to facilitate vaccination for the older adult (participants 5,10, and 12).

*Sub theme 2.1: Negative thoughts about vaccinations*

The participants have various negative thoughts of vaccinations such as disbelief in vaccines, hesitancy of vaccination and misinformation from neighborhood.

*"The vaccine, I do not believe it. My parents are scared because their friends around this neighborhood tell them and hear hoaxes" (P 2)*

*"Some still do not have the vaccine because they are still afraid, and my grandmother is also afraid that the mother will be afraid to get the vaccine like that. By word of mouth says that some have died because they ran out of vaccines" (P 9).*

*Sub theme 2.2: Family efforts to facilitate vaccination for the older adult*

The participants have implemented some efforts that lead to facilitate older adult for taking vaccination, but they do not meet the requirements and others willing to carry out vaccinations.

*"I also gave him vaccine information, but he did not want it. Because he is old, he said, he does not need to be vaccinated because he is afraid" (P 10).*

*"Maybe he watches the news. Someone said that after the vaccine was paralyzed, some had been vaccinated" (P 12).*

*"My father wanted the vaccine yesterday, but because there were comorbidities so he could not (take covid 19 vaccine)" (P 5).*

*Theme 3: Families facilitating herbal medicine are an option that is of interest to the older adult to prevent and deal with Covid-19 disease*

The family caregivers have also facilitate older adults by herbal medicine as effort to prevent and handling covid-19. The participants revealed opinions of the older adult to consume herbal medicine (participants 1 and 9) and the reasons for an older adult consuming herbal medicine (participants 5 and 13).

*Sub theme 3.1: Opinions of the older adults to consume herbal medicine*

The participants thought that their older adults opinion like to drink herbal ingredients and herbal ingredients as a complement to treatment.

*"Sometimes he drinks concoctions or something like that. Sometimes I do not know what it is. He says it is a sugar medicine, he says it is good" (P 1).*

*"She often makes it like herbal medicine mixed with honey. My grandmother said that herbal medicine, will prevent from covid disease" (P 9).*

*Sub theme 3.2: Reasons for an older adult consuming herbal medicine*

The participants show that the reason of herbal medicine consumption are recommendations from friends, free from chemicals, rarely sick and save cost.

*"We also often drink herbs for immunity, such as ginger, turmeric, and brown sugar. We mix them and then boil them with water to drink. If it is like a red betel leaf, it is a chlorophyll leaf, or "binahong." He immediately took the initiative and finished off the herbs to calm his anger" (P 1)*

*"For about three to four months, my parents took the medical medicine, so after that, when my parents were still working, they talked with their friends and were advised to take herbal medicine" (P 5).*

## **Discussion**

*Views of Older Adult Families on Covid-19 Disease*

Older adult families hold both positive and negative views on COVID-19, with some believing it's more vulnerable for those with comorbid conditions, while others view it as a common cold. Both views from the participants would influence how the participants respond and handle the COVID-19 problem. Good perspectives on using social media as a source of medical information. The findings show that during the COVID-19 epidemic, social media was utilized to connect with offline friends, family, co-workers, and online networks belonging to the respondents (Saud et al., 2020). Older adults in Swiss generally accepted and adhered to public health measures, especially those with comorbid conditions (Bearth et al., 2021). Television is now a source of pandemic information and stress for certain people due to the contrasting opinions on the epidemic (Winship et al., 2022). Older adults are associated with a higher likelihood of adaptive behaviour due to reduced mobility and intention to stay home during the COVID-19 pandemic (Macy et al., 2021; Spitzer et al., 2022).

Our results show that relatively similar among older adult family caregivers with the previous studies, which is that participants have positive and negative views on COVID-19 issues. The results of our research and participant experiences align with the previous study in the Indonesian setting. Media dependence and social impact influence trust in COVID-19 news, with uncertainty influencing trust development and accurate perceptions (Asyary et al., 2023; Handarkho et al., 2022; Widayati, 2021). However, previous studies show that more exposure to pandemic news via social media was linked to increased depression (Zhao & Zhou, 2020).

#### *Older Adult Family Caregiver's Responses in Facing Covid-19 Vaccination for Older Adults with Chronic Illness*

Participants face barriers to vaccination for older adults with chronic diseases, including negative thoughts, hesitancy, and misinformation. Support for booster vaccination depends on various factors, including health, family, and media attention. Hong Kong older adults' vaccination resistance influenced by trust, confidence, and social support networks (Siu et al., 2022). Older adults experience vaccine hesitancy due to fear, doubts, and apprehensions (Awijen et al., 2022; Forber-Pratt et al., 2022; Tolstrup Wester et al., 2022).

The participants have negative thoughts about COVID-19 vaccination, like disbelief, hesitancy, and misinformation. Our research results are similar to the previous research. Older adults refused COVID-19 vaccination due to conspiracy theories, superstitions, and fear of dying (Jafarnezhad Dehmiani et al., 2022). Conspiracy theories and skepticism decrease vaccine desire, according to path models (Pakalniškienė et al., 2022). Nevertheless, Older adults support vaccination, highlighting advantages and removing freedom-restricting measures (Fadda et al., 2021). Influencers impact COVID-19 vaccination decisions, including self-protection, avoiding hazards, and trusting information (Light et al., 2022).

#### *Families facilitating herbal medicine are an option that is of interest to older adults to prevent and deal with Covid-19 disease*

Participants face barriers to vaccination for older adults with chronic diseases, including negative thoughts, hesitancy, and misinformation. Most support booster vaccination, while others disagree. Our result is similar to previous research in that participants suggested using conventional, complementary, and alternative medicine to treat and manage viral disorders like COVID-19 (Youn et al., 2022). Vietnamese people used herbal remedies like ginger, honey, garlic, and perilla during COVID-19 (Nguyen et al., 2021). Ethiopian participants used traditional medicine for COVID-19, primarily using "Damakase", garlic, ginger, lemon, seeds, and leaves (Chali et al., 2021; Tegegne et al., 2022). Covid-19 treatment requires respect, complementary communication between traditional and contemporary medicine (Yimer et al., 2021). Traditional medicine and supplements utilized for COVID-19, influenced by professionals and family (Alshammari et al., 2022).

The study's limitations include the fact that the interview was performed online, which made the participants' voices and images indistinct due to the unstable internet connection. This circumstance would impede and halt the interviewing process. The researchers had trouble contacting the participants once again. Thus, member checking required extra time for input.

#### **Conclusion and Recommendation**

Our study shows that perception and response about COVID-19 in three themes: (1) views of older adult families on covid-19 disease; (2) older adult family caregiver responses in facing covid-19 vaccination of older adults with chronic diseases; (3) families facilitate traditional medicine are an option that is of interest to the older adult to prevent and deal with covid-19 disease. Older adult family caregivers in Indonesia have to face positive and negative thoughts about COVID-19 and the vaccination from their older adults. Then, they need to help an older adult with the consumption of herbal medicine during the

COVID-19 epidemic. The government should educate and promote the knowledge of people especially older adults and their family, properly. Also, health professionals in Indonesia could advise and educate about using herbal medicine as complementary therapy to older adults with chronic diseases.

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### Declaration of conflict of interest

The authors declare that the research has no conflict of interest during the research, authorship, and publication process.

### Declaration on the Use of AI

The authors declare that the research has no using AI tools in this manuscript.

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