

## Profile of Caregivers Caring for Patients with Cancer Undergoing Oral Chemotherapy

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### Abstract

*Chemotherapy is a type of cancer treatment that uses drugs to destroy cancer cells. Oral chemotherapy is used by cancer patients at home; this requires the role of the family as caregivers in their treatment; this is important considering the complexity of oral chemotherapy drugs with protocols and drug effects. This research contributed to obtaining a profile picture of caregivers of cancer patients. The method used in this research is descriptive quantitative. This research was conducted at a hospital in Yogyakarta. The number of samples in qualitative research was 49. The results of this study were that most caregivers were aged 45-54 years (32.65%), and the majority were female (65.31%). The majority of caregivers are also married (56.10%). Most caregivers hold bachelor's degrees (34.69%), and most caregivers have a husband and wife-relationship with the patients they care for (38.78%). In general, caregivers have many years of experience in treating cancer patients, namely one year or less (38.78%). The most common type of cancer among patients receiving treatment is breast cancer (49.94%). Conclusion: This profile data can be used as a basis for further research regarding patient care at home by the family as caregivers, especially in patients receiving oral chemotherapy treatment.*

**Keywords:** Profile Caregivers; Oral Chemotherapy; Cancer

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### 1. Introduction

Cancer cells that continue to divide can then enter the bloodstream and grow in other parts of the body; this condition is called metastasis ([Indonesia Cancer Care Community 2021](#)). Cancer metastases are the main cause of death due to cancer, so cancer is included in the ten diseases with the most deaths in the world ([World Health Organisation \(WHO\), 2022](#)). Data from the Global Burden of Cancer (GLOBOCAN) states that the number of cases and deaths from cancer up to 2018 was 18.1 million cases and 9.6 million deaths in 2018 (Sung et al., 2021). In Indonesia, cancer incidence data for 2020 are 396,914 cases and 234,511 deaths (Globocan, 2020). The data shows a high incidence of cancer that requires treatment.

Cancer treatment includes radiotherapy, chemotherapy, and surgery. Chemotherapy is one of the treatments that is often given to cancer patients. Chemotherapy is a type of cancer treatment that uses drugs to destroy cancer cells. Chemotherapy stops or slows the growth of cancer cells, which grow and divide quickly ([National Cancer Institute, 2018](#)). The results of the 2018 Riskesdas described as much as 24.9% of cancer patients undergoing chemotherapy ([InfoDATIN, 2019](#)). There are several

ways of giving chemotherapy, including intramuscular, intravenous, oral, and topical chemotherapy that is applied to one area of the body.

Oral chemotherapy is a form of chemotherapy in the form of pills or liquids ([Tang, N., et al 2022](#)). Cancer patients undergoing oral chemotherapy are carried out independently at home or as an outpatient. Problems that often arise due to the use of chemotherapy at home are compliance and safety issues for patients because there is no supervision from health workers which can lead to treatment failure. Research data shows that there is a significant relationship between side effects and adherence to taking medication ([Timmerman, L., et al 2019](#)). This is supported by the statement that patient compliance problems are caused by several things such as cost, dosage complexity, forgetfulness, disruption of daily life, side effects, and misinterpretation of drug instructions ([National Cancer Institute, 2018](#)).

Handling patients at home in their care requires a caring nursing touch carried out by the family as the patient's care provider. Caregiver knowledge, attitudes and practice factors greatly influence the implementation of care ([Zhao, W., et al 2022](#)).

The role of the caregiver is very important in patient care at home. The role of family practice as a caregiver in caring for patients by providing medication in the right preparation, the right dose, preventing events, and managing side effects that may occur. even treatment failure for cancer patients may occur. The profile of the family caring for the patient is very influential, considering the complexity of treating patients with oral chemotherapy at home ([Rahayu, S., & Susilawati. 2018](#)).

Based on the formulation above, it is the basis for the importance of researching the profile of caregivers. This research is expected to be able to improve the quality of care for outpatient cancer patients so that all side effects and the burden of cancer problems can be minimized. The profile of the caregiver is expected to complement effective caring practices in caring for oral chemotherapy patients.

## 2. Method

The research methodology used in this study was used to plan, carry out, and analyze research. includes steps that must be followed by selecting instruments, data collection techniques, data analysis, and interpretation of results. This study also used ethical clearance from Research Ethics Committee (REC) at the University of St. Paul Philippines and from the hospital where the research was conducted.

This research is descriptive quantitative research. This research aims to determine the profile of family caregivers who care for cancer patients undergoing oral chemotherapy. This descriptive quantitative research uses a cross-sectional survey design. The cross-sectional design is carried out by collecting data at a certain time from individuals or groups that represent the population being studied, in this case the family as caregivers.

The participants involved in this study were caregivers who met the inclusion criteria, namely families as caregivers who were/had cared for cancer patients undergoing oral chemotherapy for at least one cycle of oral chemotherapy drugs; Able to communicate well, aged  $\geq 18$  years, able to read/write and use online or hardcopy, and willing to be a participant. The number of participants was 49. The instrument used was an instrument prepared by researchers and tested for content validity and reliability with Cronbach's alpha ( $\alpha$ ) with S-CVI results of 91.67%, and  $\alpha = 0.806$ .

The data collection procedures carried out were as follows: carrying out validation tests of research instruments, obtaining permission from the Research Ethics Committee (REC) at St. Paul Philippines, obtained hospital permission to conduct research, identified research participants according to predetermined inclusion and exclusion criteria, provided informed consent to

research participants, collected participant data using an online form.

The analysis used is a simple distribution that describes the profile characteristics of the participants. The univariate analysis resulted in the distribution of frequency and percentage variables.

## 3. Results and Discussion

Most caregivers who cared for cancer patients undergoing chemotherapy were aged 45-54 years as much as 32.65% of the participants. And the average age of caregivers was 24.5 years ([Tabel 1](#)). This shows that caregiver age is the age category of adults who have fulfilled the requirements in the world of work and responsibilities as caregivers. This age bracket is often associated with the period of active employment and heightened responsibilities ([Abraham, K. G., & Kearney, M. S. 2020](#)). In the context of this study, the age categories reflect different stages of adulthood, professional engagement, and caregiving roles.

Gender. The majority of caregivers are female with 32 or 65.31% of the participants. this is by other studies stated that female caregivers were more numerous than male caregivers ([Maria et al., 2022](#)) and there was a role paradigm in Indonesian society that women are more concerned with caring at home and men play a role in earning income for financial support [Zunaidi, A., & Maghfiroh, F. L. \(2021\)](#) but both genders have a strong role in patient care at home ([Lousada, L. M., et al 2020](#)).

Marital Status. The majority of marital status of caregivers are married with 27 or 55.10% of the participants. Being married is related to the relationship formed between the husband and wife founded on the sense of responsibility towards the partner. This is in accordance with other studies which state that marriage is the most dominant status found considering the various interests in the marital relationship ( [Maria et al., 2022](#)). Educational level. Most caregivers have finished a bachelor's degree, with 17 or 34.69% of the participants. The findings imply that most caregivers have completed a bachelor's degree which would influence their performance as a caregiver due to the ability to make strategic care decisions. Research supports that people with higher education can access information and knowledge to recognize care problems better ([Paudel, P. 2021](#)).

Relationship with patient. Most caregivers are related to their patients either as husband or wife  $n=19$ ; or children= $16$ ; cousin  $n=6$  or parents  $n=6$ . The patient's relationship with the caregiver determines the care activities carried out. Most often than not, the patient's family members are the caregivers. Most of the caregivers are associated with their patients either as spouses or children, parents, or relatives of the caregiver. This is usually associated with family obligation or family responsibility or family bonding. This is confirmed by other research, which states that

the role of the family is vital in providing care to sufferers, mainly when it is carried out by primary caregivers such as a spouse (husband or wife), parents, children, and close relatives who are responsible for caring for and serving sufferers as a strength in kinship ties (Sari, 2022). This study also shows that the relationship with the patient is a child with 32.65%, which supports the statement that primary caregivers have a vital role in patient care.

**Table 1.** Frequency and Percentage Distribution of the Participants' profile.

Profile	Frequency	Percentage
<b>Age</b>		
18 – 24 years old	11	22,45
25 - 34 years old	11	22,45
35 - 44 years old	11	22,45
45 - 54 years old	16	32,65
<b>Gender</b>		
Female	32	65,31
Male	17	34,69
<b>Marital Status</b>		
Single	19	38,78
Married	27	55,10
Widow/Widower	3	6,12
<b>Educational level</b>		
Elementary school	2	4,08
Junior High school	4	8,16
Senior High School	13	26,53
Associate degree	11	22,45
Bachelor's degree	17	34,69
Master's degree	2	4,08
<b>Relation with patients</b>		
Husband and wife	19	38,78
Child	16	32,65
Friend	1	2,04
Cousin	6	12,24
Parent	6	12,24
Cadre	1	2,04
<b>Patient Diagnosis</b>		
Breast Cancer	23	46,94
Colon Cancer	12	24,49
Leukaemia	3	6,12
Multiple myeloma	4	8,16
Collateral Cancer	1	2,04
prostate cancer	2	4,08
lung cancer	2	4,08
Renal cancer	1	2,04
Oropharyngeal cancer	1	2,04
<b>Experience as caregivers</b>		
1 Year old below	19	38,78
2-5 Years	18	36,73
6-10 years	9	18,37
10 Years	3	6,12
Total sample	49	100.00

Year Of Experience in Dealing with Cancer Patients. Most of the participants' years of

experience as caregiver is 1 year and below, with 19 or 38.78% and 2-5-years' experience n=18 or 36.73%. The data imply that the length of care carried out by caregivers is related to the ability of caregivers to pay attention to the factors that support and inhibit patient care. The results of the study affirm other studies which stated that length of care affects the social life of caregivers and their relationship with patients (Maria et al., 2022)

Patient diagnosis. Most caregivers are caring for a patient with breast cancer with 23 participants or 46.94%; followed by colon cancer n= 12 or 24.47%. This data implies that breast and colon cancer incidence in Indonesia is high. Statistics show that the number of new cases of breast cancer in Indonesia has reached 68,858 patients (16.6%) of a total of 396,914 new cases of cancer and occupied the position with the most incidence of new cases. Meanwhile, colon cancer has 17,368, or 4.4% of new cancer cases. and leukemia 14,979 or 3.8% of new patients (Globocan, 2020). Another study assessing the level of knowledge about administering oral chemotherapy for food restrictions (drugs taken with/without food) among outpatients showed the result that the patients who received the most oral chemotherapy were patients with colon cancer, with 45.36% of the entire sample, followed by breast, rectal, and prostate cancer.

#### 4. Conclusions and Suggestions

The conclusion obtained in this profile research is that most caregivers are aged 45-54 years and the majority are female. The majority of caregivers are also married. Most caregivers hold bachelor's degrees and most caregivers have a husband and wife relationship with the patients they care for. In general, caregivers have many years of experience in treating cancer patients, namely one year or less. The most common type of cancer among patients receiving treatment is breast cancer.

This profile data can be used as a basis for further research regarding patient care at home by the family as caregivers, especially in patients receiving oral chemotherapy treatment.

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