



CAREGIVING EXPERIENCE IN A SPOUSE WITH SCHIZOPHRENIA: A SCOPING REVIEW

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ABSTRACT

The problem of schizophrenia will be felt by several couples in the Childbearing age. So the role of caregivers is very important for the recovery process of schizophrenia sufferers. The symptoms that appear in schizophrenia patients will affect the quality of life of the partner as caregiver. Spouse will experience various impacts physically, psychologically, socially and spiritually. This scoping aims to determine the experiences of couples of childbearing age in caring for partners with schizophrenia. This research uses a scoping review method research design. Articles were obtained based on research results through several electronic databases such as SagePub, Ebsco, Pubmed, Google Scholar and Scopus. Articles were selected from 2018 - 2023 and 10 article was found that matched the theme raised.. The results of the analysis in this scoping review illustrate that spouse of childbearing age who care for patients with schizophrenia experience subjective and objective burdens. Apart from that, patients with schizophrenia experience sexual dysfunction due to taking drugs, this can trigger a breakdown in relationships, because biological needs cannot be met. financial problems, confusion in caring for a partner and obstacles in carrying out activities are also things that many couples experience. So it can be concluded that caring for a partner with schizophrenia will cause various problems both biologically, psychologically, sexually and financially.

Keywords: caregiving; childbearing age; schizophrenia; spouse

First Received 19 January 2024	Revised 28 January 2024	Accepted 31 January 2024
Final Proof Received 18 April 2024		Published 01 June 2024

How to cite (in APA style)

Annisa, V., Suryani, S., & Sriati, A. (2024). Caregiving Experience in A Spouse with Schizophrenia: A Scoping Review. *Indonesian Journal of Global Health Research*, 6(3), 1527-1538. <https://doi.org/10.37287/ijghr.v6i3.2894>.

INTRODUCTION

Schizophrenia is also a disease associated with brain damage so they experience emotional disturbances, perceptions, thinking, and strange behavior (Videbeck, 2018). According to APA (2020), Schizophrenia patients experience unrelated thoughts, behave and have strange ways of communicating, and experience hallucinations. According to WHO (2022) schizophrenia affects 24 million people or 1 in 300 people (0.32%) in the world. Or it can be assumed to be 1 in 222 people (0.45%) among adults. According to Basic Health Research data Indonesia in 2013, the incidence of schizophrenia in Indonesia reached 400,000 people or 1.7% million per 1000 Households. This number increased in 2018 from 1.7% to 7%. So it can be interpreted that the prevalence of mental disorders has increased by 28,000 people so the number of people suffering from mental disorders in Indonesia is 428,000.

People with schizophrenia will experience symptoms that are different from one another. A schizophrenia survivor will usually experience several typical symptoms such as hallucinations that are not real, delusions, distorted thoughts, difficulty in using good grammar, incoherence, lack of motivation, and the emergence of unconscious behavior. From the symptoms mentioned above, the role of caregivers is needed to help the recovery process of schizophrenia survivors. One of the roles and functions of the family is caring for family members who are sick (Edwar et al., 2020). One of the closest people in the family is the partner. According to BKKBN (2019) Husband or wife couples aged 15-49 years and still experiencing menstruation or couples whose wives are less than 15 years old but already experiencing menstruation can be said to be couples of childbearing age. Apart from that, if the wife is more than 50 years old but still menstruating then she can be called a Childbearing Couple.

Childbearing age in Indonesia in 2018 was 38,343,931 people (BAPPENAS, 2018) experiencing an increase in 2021, namely 39,655,811 couples. Couples of childbearing age will have a better capacity to provide care for sick family members when compared to families with an age range of 41-60 years (Ningsih, 2019). However, in a different case, the partner who cares for a partner with schizophrenia will experience changes influenced by the process of caring for the patient (Pauji, 2021). In other research, it was stated that the high caregiver burnout score was influenced by the length of time caring for the survivor (at least 6 months) and the length of care for people with Schizophrenia causes caregivers to experience emotional and economic stress (Yulianti et al., 2018). The heavy burden felt is closely related to the duration of the disease, the frequency of recurrence, interactions between survivors and their families, and employment status (Sarwendah et al., 2022)

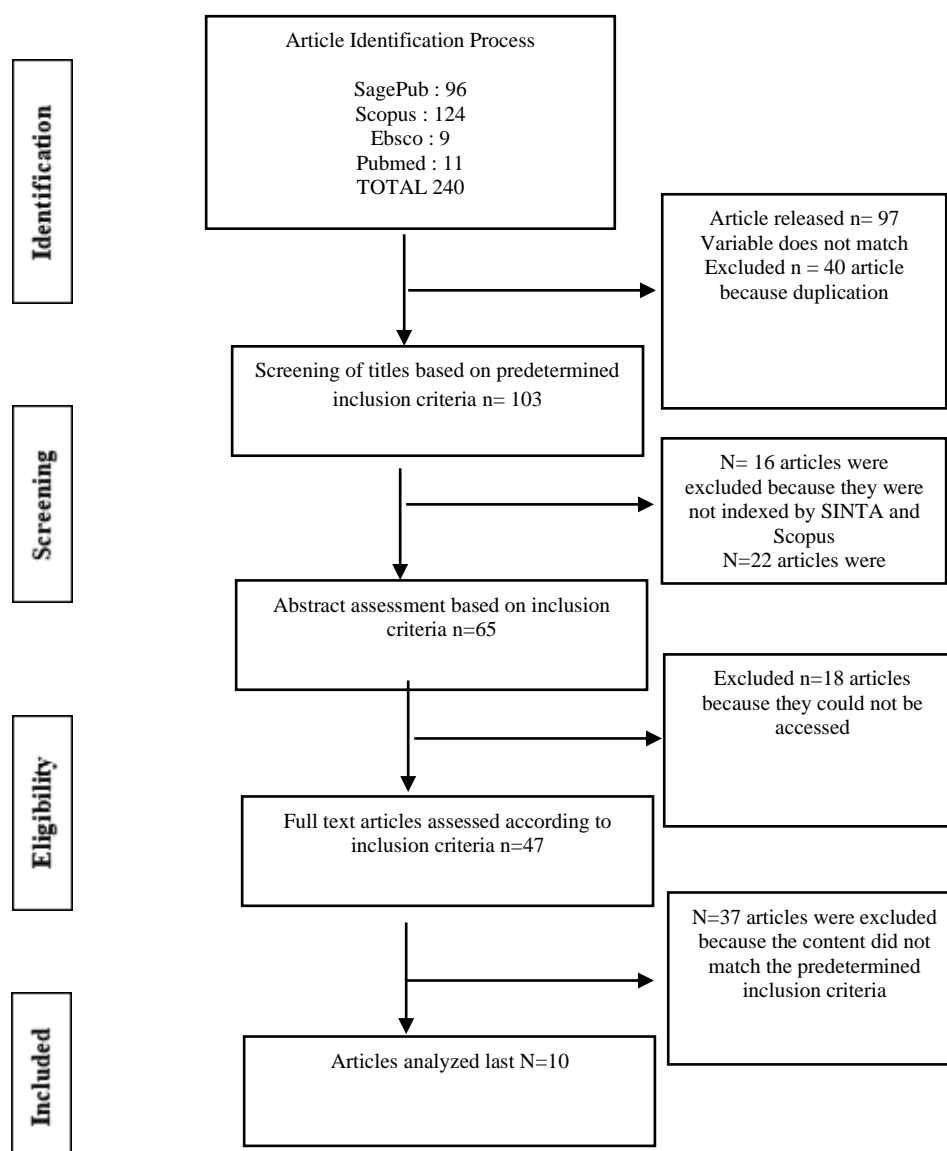
Spouses of childbearing age who caregiving with schizophrenia survivors often feel injustice, shock, and frustration with the condition they are experiencing because they lack knowledge in caring for partners with mental health problems. Many couples feel that they do not have support in carrying out their relationship, do not experience a romantic relationship, and feel that the relationship they are in is an unstable and non-reciprocal (Izon et al., 2022) From the background, it can be seen that it is important to know the experience of caring for people with schizophrenia from various developmental age ranges. This is because each individual's developmental range will have different characteristics and experiences when caring for people with schizophrenia. Especially in couples of childbearing age, partners will spend more time with their partner and become the main caregiver. In addition, couples of childbearing age are at a stage in the development of families that are still sexually active, and there is not much research that highlights sexual problems in couples caring for schizophrenia. Therefore, researchers are very interested in finding out about the experience of caring for couples with schizophrenia in the childbearing age range.

METHOD

In the process of preparing this Scoping Review, researchers used the framework of Arksey and O'Malley (2005) which refers to the Joanna Briggs Institute (JBI). In the framework of Arksey and O'Malley (2005), there are 5 stages in preparing a scoping review. In the first stage of preparation, researchers began to identify several research questions such as 'What is the experience of caring for partners with schizophrenia, especially in couples of childbearing age?'. After the researcher investigates the research questions, in stage 2 the researcher begins to identify relevant literature sources from various existing sources. In this research, researchers used several electronic databases such as SagePub, Ebsco, Pubmed, Google Scholar, and Scopus. In the third step, the researcher begins to carry out literature selection.

Researchers selected literature from 2018 – 2023 (the last 6 years) and obtained 240 articles that were appropriate to the selected topic. 137 were excluded due to the duplication of 103 articles. After that, the researchers re-selected 65 articles that could be fully accessed. In the final stage, researchers began screening by reading the abstract and the entire article. From the screening results, researchers selected 10 articles that were appropriate to the topic raised. In the Fourth step, researchers carry out mapping and collect some literature that will be analyzed. From the results of the mapping that has been carried out, the researcher enters the analysis results into a matrix table. The last step is compiling, summarizing, and reporting the results of the analysis. Researchers discussed the 10 selected articles. Apart from that, the researcher described the article search process using the PRISMA flow diagram to make it easier for readers to understand the article search process

Schema 1
PRISMA (Preffere Reporting Items for Systematic Reviews and Meta Analysis)



RESULTS

The literature search process produced 240 articles, and the researchers removed 137 articles that were duplicates and did not match the predetermined variables, resulting in 103 articles. Of the 103 articles that had gone through screening, the researchers re-screened the articles and produced 10 that were eligible and met the inclusion criteria. This research study comes from several countries, including Indonesia, India, Poland, China, and Oman.

Table 1.
Result

Article Title	Author, Year	Purpose	Respondents	Methods	Result
The Relationship between Social Burden and the Family's Ability to Care for Schizophrenia Patients After Pasung in the Bungo - Jambi Regency Area	Muhamad Pauzi (2021)	This study aims to identify the relationship between burden and the family's ability to provide care for post-pasung patients in Bungo Regency	The research sample was families who cared for schizophrenia patients, 91 respondents were included in this study	<i>Cross Sectional</i>	From the results of the research that has been carried out, it was found that there is a relationship between social burden and family capacity with a p value = 0.000. So it can be concluded that the social burden felt by the family greatly influences the family's ability to care for patients with schizophrenia
Sexual Dysfunction And Marital Seal Dysfnction And Marit Relationship In Women With Schiophrenia In Comparison With Caregivers : A Hospital Based Study	Suvarna Jyothi Kantipudi, Navina Suresh, Poornima Ayyadurai dan Sathianathan Ramana (2020)	This study aimed to assess the nature and incidence of sexual dysfunction in women with schizophrenia compared with male caregivers who do not have serious mental disorders	30 women with schizophrenia were included in the case group and 26 people were included in the control group as caregivers.	<i>Cross Sectional</i>	From the results of the research that has been carried out, it was found that there were significant differences in the Female Sexual Function Index (FSFI) scores and relationship scores between women with schizophrenia and caregiver control subjects. This research states that patients with schizophrenia have better relationship quality compared to caregivers, unlike sexual function
'If He Feels Better I'll Feel Better' Relationships With Individuals At High-Risk Of Developing Psychosis	Emma Izon, Katherine Berry, Heather Law dan Paul French (2022)	This study aims to provide a holistic picture of the exploration of relationships in the families of individuals with At-Risk Mental State (ARMS) by reporting the perceived impact of this	14 families or caregivers participated in the research	<i>Semi structured interview menggunakan thematic analysis</i>	From the results of this research, it was found that parents want to maintain a safe family environment for all family members. This can result in parents spending less time with other siblings, which can have a huge impact on the lives of other siblings. Romantic relationships can also have a negative impact because sometimes there is unclear communication between partners as well as responses and understanding of ARMS.

Article Title	Author, Year	Purpose	Respondents	Methods	Result
		condition on other family members including siblings and partners who have romantic relationships.			
A Comparative Study Evaluating The Marital And Sexual Functioning In Patients With Schizophrenia And Depressive Disorders	Shivali aggarwal, Sandeep Grover dan Subho Chakra barti (2019)	This study aims to assess marital function, marital quality, marital forgiveness, sexual dysfunction and sexual satisfaction between patients with schizophrenia and their partners and to compare with patients with depressive disorders and their partners.	78 patients were married and had a partner with schizophrenia and 58 patients were married and had a partner with depressive disorders	Cross Sectional	The results of research that has been conducted, it was found that couples with schizophrenia reported poor marital adjustment (in the consensus and satisfaction domains of the DAS or Dyadic Adjustment Scale) in addition to having poor marital quality. Compared with patients with depressive disorders, patients with schizophrenia report significantly lower sexual satisfaction. However, in this study there were no differences in the prevalence of sexual dysfunction between groups. Poor marital adjustment in patients with schizophrenia was associated with lower sexual satisfaction but not with sexual dysfunction
Love And Romantic Relationships In The Voices Of Patients Who Experience Psychosis: An Interpretive Phenomenological Analysis	Magdalena Daria Budziszewska, Małgorzata Babiuch-Hall dan Katarzyna Wielebska (2020)	This study aims to determine the patient's perspective in adjusting to illness, the hospitalization process, stigmatization, obstacles in love, lack of self-confidence and difficulties in maintaining relationships.	5 women and 5 men who had experience serious mental health problems and had been diagnosed with schizophrenia	Qualitative interpretive phenomenological analysis	From the research results, it was found that the results really highlight how a person experiences adjustment to illness and hospitalization turns out to have an isolating or alienating effect on social relationships due to stigma. Apart from that, schizophrenia can cause psychological obstacles in love, increase self-confidence and other people's confidence and have difficulty maintaining social relationships. Moreover, the results of this study show how patients experience changes in sexuality and the risks involved in it
Caregiving Experience And Marital Adjustment In Spouses Of Patients With Schizophrenia	Shipra Singh, Deoraj Sinha dan Nitin B. Raut (2019)	This research aims to study the experiences of parenting and marital adjustment in couples of schizophrenia patients	100 patients with schizophrenia at the Tertiary Care Teaching Institute	Cross Sectional	From the research results, it was found that the average total positive Experience of Caregiving Inventory (ECI) score was higher, namely (2.56) than the negative score. Meanwhile, the highest Dyadic adjustment scale (DAS) or marital adjustment score was for consensus (3.07) and the minimum for the affect expression scale (1.66). Better marital adjustment with a p-value <0.001) with increasing age of the current partner and at the time of marriage, as well as

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					with the presence of high social support positively correlates with positive parenting experiences with (p-value = 0.010, r = 0.257, p-value = 0.04, r = 0.202, p<0.001, r = 0.610 respectively Negative parenting experiences were related to joint family, Positive and negative syndrome scale (PANSS) scores.
Female Sexual Dysfunction and Schizophrenia: A Clinical Review	Pragya Lodha dan Avinash De Sousa (2020)	This study aims to discuss various aspects of sexual dysfunction in women and their relationship to schizophrenia	20 patients in Harbin, China were undergoing inpatient and outpatient treatment at a mental hospital	<i>Qualitative Study</i>	In this study, 3 main themes and 10 sub-themes were found, namely (1) Barriers to sexual activity, first, symptoms and side effects of antipsychotics which cause disturbances in sexual function, then rapid changes in the environment that make it difficult for patients to communicate with the opposite sex and not have a private space to carry out sexual activities, and the last sub-theme is the stigma received by ODS so that sexual needs are always neglected (2) The importance of sex, some people think that reproduction is the main goal in having sexual relations, besides that sexual activity is also a medium in expressing forms of love and increasing the ability to regulate emotions in everyday life and the last theme is (3) Conditions for fulfilling sexual needs resulting in themes regarding professional sexual knowledge, space for sexual activity and objects of sexual activity
A cross-sectional study on spouse and parent differences in caregiving experiences of people living with schizophrenia in rural China	Yu Yu, Tongxin Li, Yilu Li, Dan Qiu, Shijun Xi, Shuiyuan Xiao dan Jacob Kraemer Tebes (2020)	This study aims to determine the differences in the experiences of caregivers of parents and partners, as well as to determine the impact of caring for people living with schizophrenia patients in China.	264 samples of caregivers of people with schizophrenia in the community were involved in the research	<i>Cross Sectional</i>	The research results show that both types of caregivers are involved in caregiving activities and there are differences in the level of caregiving burden. Where parent caregivers reported experiencing a higher subjective burden compared to partner caregivers (b = 7.94, 95%CI: 2.08, 13.80, P < 0.01). Apart from that, the level of depression experienced by parental caregivers was also higher (b = 3.88, 95%CI: 1.35, 6.41, P < 0.01), anxiety (b = 2.53, 95%CI: 0.22, 4.84, P < 0.05), and lower family functioning (b = -1.71, 95%CI: -2.73, -0.49, P < 0.01)
Exploring the experience of relatives living with individuals	Aziza AL-Sawafi, Karina Lovel,	This study aims to explore the experiences and needs of relatives	20 relatives of inpatients in Oman	<i>Qualitative semi-struct</i>	This research produced 4 main themes, namely (1) Burden, where relatives complain about physical, emotional, social and financial problems. The second theme is (2)

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diagnosed with schizophrenia in Oman: A qualitative study	Laoise Renwick dan Nusrat Husain (2021)	(parents, siblings and partners) living with schizophrenia in Oman.	were involved in the research	used interviews	Stigma, where caregivers experience pressure and anxiety due to the stigma they receive, which forces them to keep the disease a secret. The third theme is (3) violence, where caregivers feel stressed when providing care to ODS who are at risk of committing violence. The aggressive behavior that appears in ODS causes emotional distress in caregivers and increases shame and stigma. The third theme is (4) Need, where caregivers report a lack of knowledge about mental illness, thereby delaying the process of seeking help, in addition to that, partners ask for help in managing emotions and dealing with stress.
Spousal Caregiver Burden and Its Relation with Disability in Schizophrenia	R. Arun, S. Inbakamal, Anna Tharyan, Prasanna S. Premkumar (2018)	This study aimed to explore caregiver burden in People with Schizophrenia and to assess the relationship between disability and partner caregiver burden	A total of 52 schizophrenic patients and their partners visited a psychiatric center	Cross Sectional	From this research, the results showed that the average partner caregiver burden score was 73.5 with a st.deviation of 14.0. In bivariate analysis, disability, duration of schizophrenia, severity of schizophrenia, place of residence, and socioeconomic status had statistically significant associations with spousal caregiver burden. In addition, it was also found that disability is one of the strongest causal factors in the burden of caring for a partner

DISCUSSION

The family is one of the main roles in the process of providing care to people with mental disorders. There are several factors that greatly influence family motivation in providing care to people with mental disorders, such as the level of family knowledge, attitudes, beliefs, environmental beliefs and health facilities (Twistiandayani & Alifathul, 2016) In caring for patients with schizophrenia, the partner or family who is the care giver will experience several impacts, one of the impacts that usually occurs is a change in dynamics in carrying out family roles. Family members will experience changes influenced by the process of caring for the patient. In the case of schizophrenia, there are several consequences that will be received, not only regarding the patient's quality of life, but also the quality of life of their caregivers (Wijngaarden et al., 2019). Caregivers will usually experience several burdens, namely financial, emotional and quite large activities in caring for patients with schizophrenia (Shipra et al., 2022)

Own burden is an unpleasant feeling from one of the family members, difficulty accessing health facilities and the family's inability to overcome problems among family members. The burdens usually felt by caregivers include objective and subjective burdens. Objective burden is a demand that is visible during the care process, which is very burdensome on family members, such as financial problems, additional daily tasks and disrupted routines. Subjective burden refers to the caregiver's perception of the role burden, emotions and feelings of worry felt by the caregiver (Flyckt et al., 2015) The level of burden that this couple will experience

varies greatly and some of the problems that often arise are disturbed interpersonal relationships. In research (Wijngaarden et al., 2019), the ECI score or Experience of Caregiving Inventory (ECI) was obtained, namely a questionnaire to measure the effects of caregiving/treatment on patients diagnosed with psychotic disorders. The highest score was obtained for 'dependence' followed by 'stigma'. These results really show that most caregivers feel worried about their patients because patients with psychotic disorders are very dependent on them financially, apart from that they also have weaknesses in socializing with the community, so they communicate mostly only with their caregivers.

In research conducted by Amelia and Anwar (2014), the stigma received by families will make families express excessive emotions towards families with schizophrenia. This excessive expression of emotions will usually cause stress in patients with schizophrenia and will cause relapse or relapse in patients. Muhammad Pauzi (2021) obtained data that there is a relationship between social burden and the family's ability to care for post-pasung schizophrenia patients. In research conducted by Carrión (2011) it is stated that the burden felt by families in caring for patients with schizophrenia is the stigma faced by the family, caregivers have limitations in interacting and socializing with other people because they feel inferior about the condition of family members who suffer from it. schizophrenia. Families will feel stigma from their environment so that families will feel isolated, neglected, have no status in society, and even discrimination (Frías et al., 2017). The stigma received by family members will become a burden, because they feel embarrassed by the condition of a family member who has schizophrenia (Corrigan & Nieweglowski, 2019). Families often experience rejection from the surrounding environment, families also experience oppression in the form of rude and aggressive behavior, being treated unfairly, insulted and ridiculed (Hanifah et al., 2021)

Apart from limitations in socializing with society, couples also experience loneliness and frustration with their partners. Individuals feel confused about providing support to their partners and the relationship feels very distant. Apart from that, individuals feel confused because they do not have knowledge about mental health problems and how to support partners who have mental health problems. Many couples feel injustice, shock and frustration with the situation they are facing. Apart from that, they feel they have no support and are isolated in their relationship. They feel like they are not in a romantic relationship. They feel that the relationship is unstable, the support is not reciprocal Schizophrenia patients who are in a romantic relationship will usually experience rejection from their partner because they are diagnosed with schizophrenia. The ongoing relationship usually only lasts temporarily and the partner will easily leave because they know that their partner has been treated in a mental hospital. Even though he chooses partners who can be said to be bad and unattractive, such as (alcoholics, strangers who meet on the street, unemployed and drug addicts). Apart from the problems above, what makes a person experience some rejection is poverty.

The poverty experienced by individuals with schizophrenia will make romantic relationships difficult. Romantic relationships usually end because the couple has no money, no work. Another problem that can trigger relationship problems in patients with schizophrenia is physical problems. Where individuals with schizophrenia experience weight gain due to consumption of drugs Apart from that, changes that occur in patients such as hallucinations and emotional changes can become obstacles for someone in maintaining a romantic relationship. Apart from that, many individuals feel that they are sick and have low self-esteem so they leave their partner without talking about the illness they are experiencing. From the results of research conducted by Budziszewska (2020) it is said that apart from patients having to adapt to the disease and getting to know themselves again. There are

several reasons, such as the partner having fears about the future, the partner viewing the patient with schizophrenia as a 'diseased' person. So they decided to end their relationship with each other. This causes individuals to experience social isolation

What needs to be paid attention to by couples of childbearing age is the issue of sexual well-being in the couple, because this problem is very important in maintaining health and has a big impact on the quality of life of couples of childbearing age. WHO defines sexual health as a state of physical, emotional, mental and social well-being in sexuality. The problem that often occurs is that couples rarely have sexual relations because the client's condition is relapsing. Schizophrenia can have a serious impact on sexual activity, in the acute phase, clients will show various symptoms such as not recognizing their partner, having the opinion that their partner will hurt them and clients not realizing what they are doing and saying (Yang et al., 2023) One of the problems that arise in the sexual aspect is sexual dysfunction. Sexual dysfunction is something that typically occurs in patients with schizophrenia. Sexual dysfunction usually occurs in patients with mental illnesses such as depressive disorders, anxiety disorders and schizophrenia (Basson & Gilks, 2018). The prevalence of sexual dysfunction in women with schizophrenia reaches 30% to 80% (Beggaley, 2008). Haddad and Wieck (2014) said that there is a lot of evidence that the use of psychotropic drugs, especially antipsychotics, can cause high levels of sexual dysfunction, or around (30-80%). Data also shows that the incidence of infertility in patients with schizophrenia, especially men, is very low.

Other research states that the side effects of psychotic drugs are impaired sexual function, including low libido, erectile dysfunction, and difficulty achieving orgasm (Yang, 2023). Apart from that, looking at the characteristics of schizophrenia patients which are always associated with emotional and social problems, it turns out that this factor can influence intimacy between partners. Schizophrenia is always associated with high rates of marital failure or divorce (Dominian, 1979). When compared to married couples in general, couples or parents with mental health problems will have a higher likelihood of separation, divorce, and losing custody of their children (Park et al, 2006 dalam Izon 2022). Therefore, professional health workers need to provide holistic support to individuals or couples with schizophrenia. In the schizophrenia group, 40.8% reported that they experienced sexual dysfunction. Meanwhile, in Recurrent Depressive Disorder patients, it was reported that 34.48% of patients experienced sexual dysfunction who had evaluated the relationship between sexual dysfunction and antidepressants (Grover et al, 2012). Another finding in this study was that patients with schizophrenia reported that they experienced a decrease in sexual satisfaction.

This decrease in sexual satisfaction and dysfunction is one of the causes of separation in couples of childbearing age with schizophrenia. So research (Izon, 2022) states that it is very important for couples to consider having children, because the process of having children will create several further changes. According to Wansink et, al (2014) it is said that parents who have mental health problems and have many difficulties will have a big impact on parenting patterns and children's growth and development. When compared to married couples in general, couples or parents with mental health problems will have a higher likelihood of separation, divorce, and are at risk of losing custody of their children (Park et al, 2006).

CONCLUSION

The results of the analysis of several articles above show that there are various problems felt by couples of childbearing age who have partners with schizophrenia. Couples experience several burdens such as emotional, financial and social burdens. Spouses or caregivers receive some negative stigma from society, which has an impact on communication and social interaction processes. Apart from that, due to ignorance of information regarding the mental health experienced by their partners, caregivers are unable to control their emotions, causing their partners to become stressed and experience relapses. Symptoms of psychosis that appear in a partner will also cause a decline in romantic relationships so that the partner feels that the relationship is not reciprocal. Apart from that, sexual needs are also highly emphasized in couples of childbearing age, where couples do not feel sexual satisfaction and well-being because patients with schizophrenia consume a lot of antipsychotic drugs and also the appearance of symptoms such as hallucinations, where this factor greatly affects intimacy between partners. This has led to an increase in the incidence of separation and divorce in couples of childbearing age with schizophrenia

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