A model of acceptance for family caregivers in the management of severe mental disorders

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ABSTRACT

Introduction: Managing severe mental disorders at home by family members as caregivers is considered the most efficient option compared to hospital care. However, on the other hand, it can lead to the emergence of physical and psychological burdens on the caregiver. To improve their role optimally in caregiving, families will undergo psychological adaptation, reaching the highest level of acceptance. Other factors, such as stigma, social support, social norms, caregiving experience and personal characteristics, influence family acceptance. This study aims to determine a family acceptance model to enhance the role of the family.

Materials and Methods: The research instruments used included The McMaster Family Assessment Device Adaptation, IEXPAC, and S.N.Q. 22, F.Q., P.S.Q., Social Support Questionnaire shortened version, The Family Focused Mental Health Practice Questionnaire and extraversion personality questionnaire. The questionnaire was distributed to caregivers with a population of 175 individuals. The sample size of this study was 133 individuals selected through proportional random sampling. The data were analysed using Structural Equation Modeling Partial Least Square (SEM-PLS) with Amos software v.26.0.

Results: The phase one research showed that intention and satisfaction are the leading indicators of family acceptance that can influence family roles. At the same time, family acceptance is influenced by personal character (p≤0.001), care experience (p≤0.001), social support (p≤0.001), social norms (p=0.004), symptom severity (p≤0.001), and stigma (p≤0.001). Additionally, family acceptance significantly impacted the family's caregiving role (CR=6.573, p≤0.001).

Conclusion: It was found that the family acceptance model to improve the family's role in the care of patients with severe mental disorders focuses on the acceptance that the family has to be able to carry out its role well in patients. To improve family acceptance, families still lack the personal character expected in caring for patients with severe mental disorders at home. It is necessary to increase commitment to care and positive values in life.

KEYWORDS:
Family, caregiver, family acceptance, severe mental disorder

INTRODUCTION

Mental disorder is a medical condition affecting a person's thoughts, mood, emotions and ability to interact with others and perform daily functions.[1] Mental disorders are categorised into mild and severe mental disorders based on symptoms that disrupt an individual's functioning.[2] The number of individuals with severe mental disorders such as schizophrenia, bipolar disorder, major depression, panic disorder and obsessive-compulsive disorder has been increasing yearly.[3]

Severe mental disorders have become one of the 'burden diseases' that are an exciting topic of discussion at the annual conferences of the American Psychiatric Association in Miami, Florida, United States of America since 1995.[4] The prevalence of severe mental disorders is significant worldwide, particularly among the adult population. Individuals with these disorders experience impairments in brain function, involving numerous changes in brain structure, chemistry and genetic factors.[5] As a result, significant clinical symptoms arise, including disturbances in emotions, thoughts and behaviours, leading to distress and suffering.[6]

A report from the World Health Organization (WHO) in 2018 showed that more than 430 million individuals experience mental health problems. In Indonesia, the prevalence of severe mental health disorders is currently around 7 per 1000 people or about 1,652,000 people. In 2013, the number of individuals experiencing mental health disorders in East Java reached around 1.4% of the total 38,318,791 people or about 53,646 people. Meanwhile, in Surabaya, the rate of mental health disorders was about 0.2% of the total population of 1,602,875 people, roughly equivalent to 3,206.[7]

In Indonesia, specifically in the Bantur Primary Health Center area, Bantur District, Malang Regency, the reported number of individuals with severe mental disorders until May 2023 is 225. In that area, all individuals with severe mental disorders receive home-based management or community-based care, known as Community Mental Health Nursing (CMHN), which aims to save costs associated with high hospital care expenses.[8] Individuals with severe mental disorders often experience complex disabilities and require assistance from others to carry out their daily functional activities.[10,11] It burdens various parties, including the

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government, society and families. A burden on the family can occur due to prolonged treatment, frequent recurrence of symptoms, prolonged use of medications and the need for assistance in daily life.[12] The various limitations mentioned ultimately become reasons for families to manage medical care at home under the supervision of the Primary Health Center through the Community Mental Health Nursing program.[13] In this home care management, the family acts as caregivers who are considered experts in mental health, while the responsible doctor carries out the medical treatment management at the Primary Health Center.[12]

The optimisation of care for severe mental disorders through home-based family management requires a holistic and integrated approach involving mental health services at the Primary Health Center, the community and the family.[14] The home care of individuals with mental disorders by their families emphasises the importance of community strength, family support and the empowerment of the individuals in the care and recovery process. In this program, the family plays a central role in organising the care of the individuals while they are at home,[15] with tasks such as supervising medication intake, providing motivation, involving the individual in social interactions, teaching activities and providing vocational training.[11,16]

Home care management for individuals with severe mental disorders by families is not limited to Indonesia. In Sweden, this type of care is also provided by family members living in the same household, such as partners, children, parents or close relatives. Managing care for people with mental disorders at home has many advantages. In addition to lowering treatment costs, it can improve patients' social skills because they live with their families. However, ensuring that this form of care is complemented by increased resources and a well-developed healthcare service system to support the families and individuals involved adequately is crucial.[17] The role of the family in shouldering the primary responsibility for the healthcare of an ill family member is significant.[18] It will also bring other impacts, namely emotional and economic burdens on the family.[4]

The quality of care the family provides to the person with the illness can indicate the level of family concern. The family's involvement in delivering high-quality healthcare and utilising various available resources for the individual's care is a form of family acceptance.[1,19] However, not all families reach the acceptance stage in the psychological adjustment process. Personal and structural factors can influence family acceptance. Individual factors include demographic characteristics, the relationship with the person with the illness, self-confidence, experience and coping strategies during caregiving. Meanwhile, structural elements encompass social values and norms, social support and social pressure. These factors interact with each other and influence an individual's acceptance of others.[20]

The influence between latent and observed variables in this study will be measured in terms of their direct and indirect relationships using structural equation models (SEM) within the framework of the family acceptance model. The novelty of this research is that a newly developed family acceptance model was found to have a more substantial construction in explaining the family acceptance process, aiming to improve the family's role in caring for individuals with severe mental illness, compared to previously existing models.

Hypotheses

Hypothesis 1 (H1): Symptom severity significantly affects stigma.
Hypothesis 2 (H2): Stigma significantly affects social support.
Hypothesis 3 (H3): Social support significantly affects personal character.
Hypothesis 4 (H4): Stigma significantly affects personal character.
Hypothesis 5 (H5): Social support significantly affects family acceptance.
Hypothesis 6 (H6): Stigma significantly affects family acceptance.
Hypothesis 7 (H7): Symptom severity significantly affects family acceptance.
Hypothesis 8 (H8): Personal character significantly affects family acceptance.
Hypothesis 9 (H9): Personal character significantly affects the caregiving experience.
Hypothesis 10 (H10): Experience caregiving significantly affects family acceptance.
Hypothesis 11 (H11): Social norms significantly affect family acceptance.
Hypothesis 12 (H12): Personal character significantly affects family roles.
Hypothesis 13 (H13): Social norms significantly affect family role.
Hypothesis 14 (H14): Family acceptance significantly affects family role.

Figure 1 represents an image that depicts the hypotheses and the relationships among variables as a structural equation model (SEM).

MATERIALS AND METHODS

Participants and Data Collection

This research was conducted in the Bantur Primary Health Center, Bantur District, East Java Province, Indonesia. The research instrument used was a questionnaire distributed directly to the respondents after checking and verification by the researcher. The research was conducted in April 2023, and all returned questionnaires were checked for data completeness, resulting in 133 respondents.

Sample Size Calculation

The sampling technique used was proportional random sampling, where the researcher obtained the total number of families with family members with severe mental disorders that met the criteria in all villages within the Bantur Primary Health Center area. The study population consisted of families caring for individuals with severe mental disorders and living together with them, providing direct care. The researcher excluded families who were not living together, totalling 175 individuals. After calculating using the minimum sample size formula based on Slovin's recipe, adding a 10% anticipation for dropouts or non-response, the sample size of 133 respondents was obtained. Then, it was

calculated proportionally using the random sampling formula, where ni (the number of sample members per stratum) is Ni (the population size per stratum) divided by N (the total population size) multiplied by n (the full sample size). The proportionate numbers for each village are as follows: Village Bandungrejosari with 36 individuals, Sumber Bening with 27 individuals, Bantur with 41 individuals, Wonorejo with 10 individuals and Srigonco with 19 individuals.

Consent to Participate and Ethics

All participants in this study voluntarily participated in the research activities and signed informed consent on the questionnaire sheet by providing their signatures directly. The ethical approval for this research has been obtained from the Ethics Committee of Brawijaya University, Malang, Indonesia, through an approval letter with the number No.39/EC/KEPK-S3/03/2023 dated 10 March 2023, following the Helsinki Declaration guidelines.

Instruments

The instrument used in this study is a questionnaire. The first questionnaire measures personal character and comprises 10 items adopted from the Extraversion Personality Questionnaire.[21] The second questionnaire is about social support and consists of six items adapted from the Social Support Questionnaire shortened version.[22] The third questionnaire is about stigma and consists of 12 items modified from the Perceived Stigmatization Questionnaire (PSQ).[23] The fourth instrument is about symptom severity and consists of 15-item questions modified from The Family Questionnaire (FQ).[24] The fifth instrument is a questionnaire about social norms, consisting of 8-item questions modified from The Social Norms Questionnaire (SNQ22).[25] The sixth instrument is a questionnaire about caregiving experience, consisting of six item questions adopted from the Instrument To Evaluate The Experience of Patients With Chronic Diseases (IEXPAC).[26] The seventh instrument is a questionnaire about family acceptance, consisting of 10 item questions adopted from the modified version of The McMaster Family Assessment Device Adaptation.[27] The last instrument is a questionnaire about family roles, consisting of 21 items adapted from The Family Focused Mental Health Practice Questionnaire (FFMHPQ).[28] The instruments used in this study have gone through a process of language adjustment that is easy to understand and adapted to local culture. All instruments were measured using a Likert scale, where "never" is scored as 1, 'sometimes' as 2, 'often' as 3 and 'very often' as 4. The responses were then categorised as follows: poor (<25%), fair (26-50%), good (51-75%) and excellent (>75%). The instruments were also tested for validity using the Pearson product–moment correlation method, which correlates the item scores on the questionnaire with the total scores. The obtained correlation coefficient (r) was compared with the critical value from the Pearson product–moment correlation table at a significance level of 5%. The item is considered valid if the received r is greater than or equal to the table value (0.361, n=30). Furthermore, the reliability of the variables was tested using Cronbach's alpha coefficient, where a value greater than 0.6 indicates reliability. It was found that all questions and variables were both valid and reliable.

Data Analysis

The data analysis consists of descriptive analysis, hypothesis testing and testing the structural model using SEM. The data analysis was conducted using IBM SPSS Statistics 26.0 software. Descriptive analysis presented information about the respondents' socio-demographic data, such as age, education and occupation. Next, a goodness-of-fit test was performed to assess the fit of the observed data to the predicted model. The goodness-of-fit test was conducted using AMOS 26.0 software. Following the goodness-of-fit trial, the indicators were examined to reflect the latent variables through confirmatory factor analysis (CFA) based on the Standardized Regression Weight output. All hands were found to reflect the variables, with estimate values greater than 0.5. The next step was hypothesis testing, which aimed to analyse the relationships within the structural model. The results of hypothesis testing were analysed based on the significance level of the causal relationships between constructs, using the critical ratio (CR) values. A critical ratio value greater than or equal to 1.96 at a significance level of 5% indicated a significant relationship. Finally, the model fit of family acceptance was obtained by testing the Structural Equation Model (SEM).

Indicators of Model Fit

The goodness-of-fit test was conducted using IBM AMOS 26.0 software. This model-fit test is used to assess the adequacy of the observed input with the predictions from the proposed model. The test yielded the following results: CMIN/DF value of 5.710 (good fit), GFI value of 0.447 (good fit), as a higher GFI value indicates a better model fit, and AGFI value of 0.363 (good fit). Therefore, it can be concluded that the overall model is a good fit, and no modifications are necessary. Other data are presented in Table III.

RESULTS

Characteristic of Participants

Nearly half of the respondents fall into pre-elderly (45-59), with 85 people (64%). Almost half of all the respondents have a distance to the Primary Health Centers ranging from 1 to 4 km, with a total of 39 people (29.3%), while a small portion of them travel a distance of more than 16 km to the Primary Health Center, with a total of 17 people (12.8%).

Furthermore, more than half of the respondents have a family size ranging from 1 to 3 members, with 71 people (53.4%). More than half of the respondents have an income of 1-2 million rupiahs, comprising 75 people (56.4%). Regarding gender, more than half of the respondents are female, with 79 people (59.4%). Most respondents have completed junior high school education, with 82 people (61.7%). Nearly all respondents work in miscellaneous occupations, totalling 95 people (71.4%). Other data are presented in Table I.

Structural Equation Models Analysis

The results of the SEM analysis indicate several significant relationships between variables, with critical ratio (CR) values greater than or equal to 1.96, showing a considerable influence. The positive (+) or negative (–) signs indicate the direction of the result, whereas a negative sign indicates a

Table I: Characteristics of socio-demographic participants (n=133)

Characteristic	Frequency	Percentage
Adult (19-44)	28	21
Pre-elderly (45-59)	85	64
Elderly (>60)	19	15
Total	133	100
Distance to health center		
1-4 km	39	29.3
5-8 km	25	18.8
9-12 km	27	20.3
13-16 km	25	18.8
>16 km	17	12.8
Total	133	100
Number of family members		
1-3 people	71	53.4
4-6 people	60	45.1
>6 people	2	1.5
Total	133	100
Income		
<65.50 USD	53	39.8
65.50-131.00 USD	75	56.4
> 131 USD	5	3.8
Total	133	100
Gender		
Male	54	40.6
Female	79	59.4
Total	133	100
Education		
No formal education	17	12.8
Elementary school (SD)	82	61.7
Junior high school (SMP)	27	20.3
Senior high school (SMA)	6	4.5
Higher education (College/University)	1	.8
Total	133	100
Occupation		
Unemployed	14	10.5
Entrepreneur	10	7.5
Private sector employee	13	9.8
Freelancer	95	71.4
Civil servant	1	0.8
Total	133	100
Ethnicity		
Javanese	131	98.5
Maduranese	2	1.5
Total	133	100
Duration of caregiving		
<1 year	3	2.3
1-3 years	19	14.3
4-6 years	31	23.3
7-10 years	32	24.1
>10 years	48	36.1
Total	133	100
Relationship with the patient		
Husband	8	6.0
Wife	9	6.8
Child	41	30.8
Parent	29	21.8
Sibling	46	34.6
Total	133	100

Note: Age categories according to the Indonesian Ministry of Health, 2019.

Table II: Critical ratio, probabilities and estimate among variables (n=133)

Variable	CR	p-value	Estimate	Influence
Symptom severity (X4) → Stigma (X3)	-0.432	0.666	-0.26	No significant
Stigma (X3) → Social Support (X2)	-0.608	0.543	-0.96	No significant
Social Support (X2) → Personal Character (X1)	5.382	<0.001	0.407	Significant
Stigma (X3) → Personal Character (X1)	5.109	<0.001	0.725	Significant
Social Support (X2)→ Family Acceptance (Y2)	8.206	<0.001	1.795	Significant
Stigma (X3) → Family Acceptance (Y2)	4.289	<0.001	1.465	Significant
Symptom Severity (X3) → Family Acceptance (Y2)	-4.683	<0.001	-0.465	Significant
Personal Character (X1) → Family Acceptance (Y2)	-4.345	<0.001	-1.743	Significant
Personal Character (X1) → Experience caregiving (Y1)	2.171	0.030	0.436	Significant
Experience caregiving (Y1) → Family Acceptance (Y2)	3.512	<0.001	0.205	Significant
Social Norms (X5) → Family Acceptance (Y2)	2.906	0.004	0.167	Significant
Personal Character (X1) → Family role (Y3)	3.714	<0.001	0.451	Significant
Social Norms (X5) → Family role (Y3)	4.971	<0.001	0.283	Significant
Family Acceptance (Y2) → Family role (Y3)	6.573	<0.001	0.380	Significant

Table III: Model fitness index

Index	Recommended values	Value of model	Meaning
Chi-square	<341.95	5.7	Good fit
Probability level	≤0.05	0.000	Good fit
CMIN/DF	<2.00/3.00	5.710	Enough fit
GFI ≥0.90	0.447	Enough fit	
AGFI	≥0.90	0.363	Enough fit
RMSEA	≥0.90	0.189	Bad fit
TLI ≥0.90	0.453	Enough fit	
NFI ≥0.90	0.454	Enough fit	

Note: χ2, chi-square; GFI, goodness of fit index; AGFI, adjusted goodness-of-fit index; CFI, comparative fit index; df, degrees of freedom; NFI, normed fit index; PGFI, parsimony goodness of fit index; NFI, normed fit index; RMSEA, root-mean square error of approximation

reverse effect. The significance level between variables is determined by values with a significance level of <0.05, marking a significant relationship. (Table II)

Based on the standardised regression weight, in the family acceptance model, it is known that symptom severity does not have a significant influence on stigma (CR= -0.432, p=0.666), stigma does not have a significant effect on social support (CR = -0.608, p=0.543), social support has a significant influence on personal character (CR = 5.382, p<0.001), stigma has a significant effect on personal character (CR=5.109, p<0.001), social support has a significant influence on family acceptance (CR=8.206, p<0.001), stigma has a significant influence on family acceptance (CR=4.289, p<0.001), symptom severity has a significant effect in the opposite direction on family acceptance (CR= -4.683, p<0.001), personal character has a significant effect in the opposite direction on family acceptance (CR= -4.345, p<0.001), personal character has a significant influence on caregiving experience (CR=2.171, p=0.030), caregiving experience has a significant effect on family acceptance (CR=3.512, p<0.001), social norms have a significant influence on family acceptance (CR=2.906, p=0.004), personal character has a significant effect on family role (CR=3.714, p<0.001), social norms have a significant influence on family role (CR=4.971, p<0.001) and family acceptance has a significant effect on family role (CR=6.573, p<0.001).

DISCUSSION

This study aimed to identify the influence of social support, personal character, stigma, social norms, caregiving experience, symptom severity, family acceptance and family caregiving roles on caring for individuals with severe mental disorders in Bantur, East Java, Indonesia. The research findings indicate that all the mentioned variables have a significant relationship with family acceptance and caregiving roles, except for the relationship between symptom severity and stigma and between stigma and social support, which were not found to be significant (Figure 2).

The figure above explains the statistical model of family acceptance. It is an analytical approach to understanding the factors that influence families of people with severe mental illness. This model seeks to identify the relationship between various independent variables or predictive factors, including social norms, social support, stigma, personal characteristics, and symptom severity, with the dependent variable, family acceptance. The aim is to provide a deeper understanding of these factors in influencing family acceptance to improve the role of the family. This structural model is built by correlating the variables through hypothesis proving, which is discussed as follows:

1. **The Influence of Symptom Severity on Stigma**
   In the final model, symptom severity does not influence stigma in family acceptance.29 Stigma is one of the main reasons families caring for individuals with severe mental disorders do not seek help. This fact can explain the

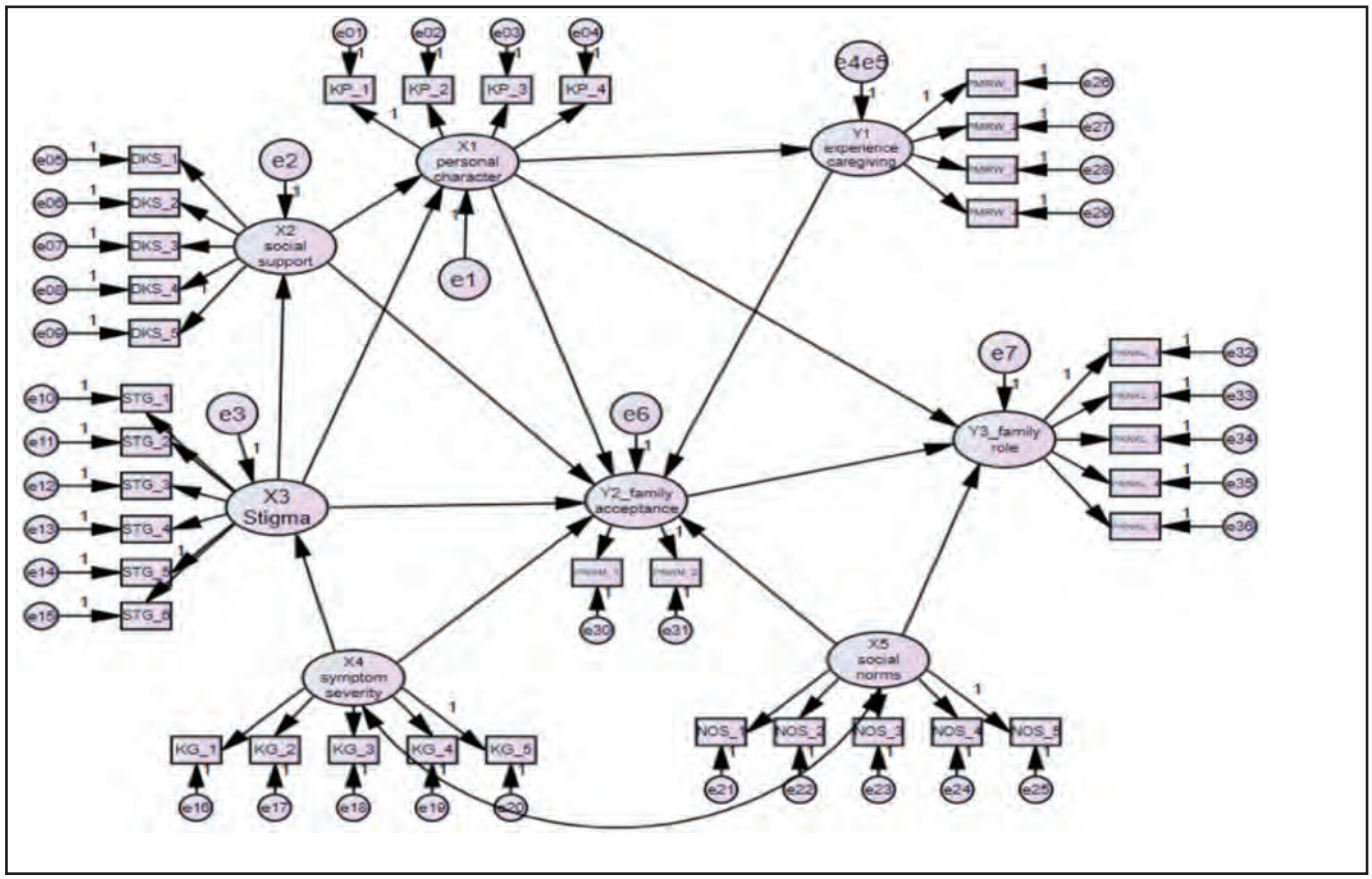

Fig. 1: The original hypothetical model (M1) was performed using IBM SPSS Statistics and Amos 26.0 statistical software.

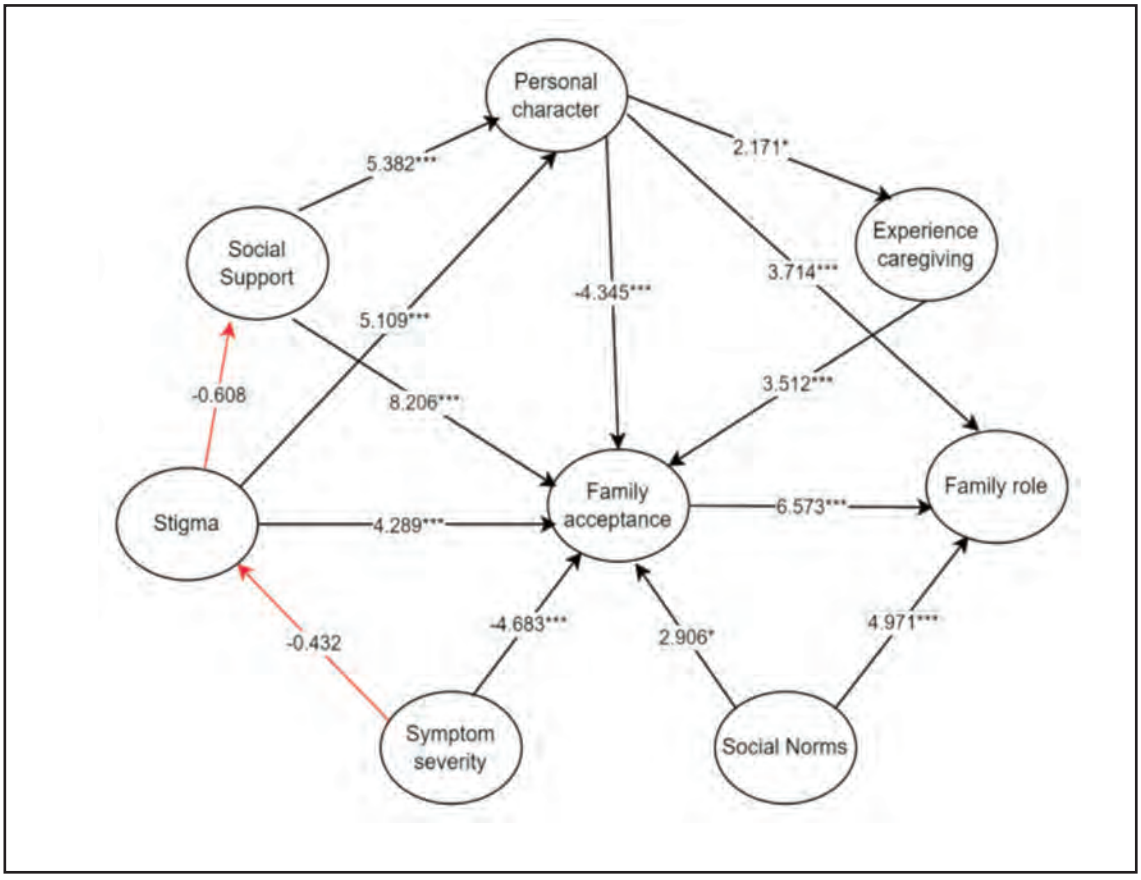

Fig. 2: The final model (M2) with standardised regression weights, ***p<0.001; **p<0.01; *p<0.05

findings of this study, which suggest that families may anticipate and prepare for stigma by considering the symptoms of the affected individuals as tolerable. Thus, it is hypothesised that higher symptom severity experienced by the patients would not necessarily lead to increased stigma. Because the families have already taken anticipatory measures to prevent the occurrence of stigma.[30] This assumption is supported by research findings stating that public stigma in Latin America in 2018 remains high, ranging from 40.5% to 70%. Furthermore, an individual's education level significantly influences their understanding of the severity of severe mental disorders. Education level is associated with a person's ability to recognise signs and symptoms or the severity of severe mental disorders. Therefore, a lack of knowledge and information may lead families to perceive the symptoms experienced by the affected individual as less serious.[31]

2. **The Influence of Stigma on Social Support**
   Stigma does not affect social support; according to theory, stigma is a multifaceted construction built from three separate but interrelated structures: perceived, anticipated and internalised stigma.[13] Perceived stigma is the stigma received based on the past or the family is currently experiencing. Meanwhile, anticipated stigma reflects an individual's prediction of future stigma.[32] Based on this theory, it can be explained by the researcher that the stigma that has been felt or will be felt by the family results in the family no longer expecting support from other people. So, with low stigma, it does not also make the family feel increasing support because there are already limitations from the family itself that there is no hope for support from other people.[33]

3. **The Effect of Stigma on Personal Character**
   As previously explained, stigma in the family, whether it is felt, anticipated or internalised directly, significantly affects personal character. As previously described, stigma makes a person no longer have hope for patient care or recovery. However, this hope is one indicator of personal character. This fact is in line with the results of research that the higher the stigma, the lower the personal character.[31]

4. **Social Support's Significant Effect on Personal Character and Acceptance**
   Social support has a significant effect on personal character and family acceptance. The results of this study indicate that the higher support received by the family can affect the personal characteristics of the family, such as beliefs and expectations for caring for people with severe mental disorders. This statement aligns with Taylor et al.,[34] which states that social support is a material or psychological resource from an individual's social network that can help them face challenges. The social support that the family receives from other people can develop the family's sense of purpose and purpose in caring for others. Further research states that perceived social support can significantly predict one's feelings and expectations in the future. The existence of hope, belief and willingness to care shows that it directly affects family acceptance of patients.[15,35]

5. **Personal Character's Significant Effect on the Experience of Caregiving, Family Acceptance, and Family Roles**
   The Personal character significantly affects the experience of caring for, family acceptance, and family roles. This study's results align with the previous theory that beliefs and individual expectations can increase patients' acceptance. This character also gives the family a positive personal basis in developing themselves to face challenges in caring for patients. A person's ability to use knowledge and other positive self-sufficiency is called experience in caring. This statement is consistent with Metzelthin et al. and Nguyen,[36] which state that the family as a caregiver can feel a loss of role when experiencing changes in responsibility, distance, or other changes that occur. Included in this context is when the family loses the experience of caring for or changes in experience, it will affect its role.[37] It is in line with research results, which show that the experience of managing will affect the function of the family to patients. It is necessary to develop personal character to develop acceptance and a "sense of role".[38]

6. **Social Norms' Significant Effect on Acceptance and Family Roles**
   Social norms significantly affect the acceptance and role of the family. Social norms can help or, on the contrary, burden individuals who are in the environment of these social norms.[36] Actions taken by people with severe mental disorders in the form of collective and individual behaviour allow society to change disliked or liked norms.[37,39] Social norms can reduce a person's autonomy to do or do something. Suppose this social norm is considered discouraging to the family. In that case, it can influence the family not to accept patients, so it can ultimately affect the role of the family in care.[40]

7. **Family Acceptance's Significant Effect on Acceptance and Family Roles**
   Acceptance has a significant effect on the role of the family, and family acceptance is defined as a condition in which the family is voluntarily involved and actively participates in the care of people with severe mental disorders.[39] From this theory, it can be explained that individuals who want to live in the same house and even care for these patients either directly or indirectly cause individuals to take responsibility for the treatment and activities of patients with severe mental disorders every day.40 And conversely, individuals who do not accept patients will lead to reduced family behaviour in administering drugs and involving patients in daily activities.

CONCLUSION

The conclusions from the results of this study focused on variables such as stigma, social support, social norms, personal characteristics, caring experiences, acceptance, and family roles. Stigma and social support have no effect, and social support also has no impact on personal character. What has the most significant effect is social support on family acceptance and personal character, as well as family acceptance of family roles. We can suggest the results of this

study to families to emphasise improving personal character because this personal character can change our perception and mindset to gain social support and reduce stigma. Good personal character will directly affect family acceptance so that the family can carry out its role properly. In addition to supervising taking medication, the family can involve patients in daily activities and teach them to work or be productive.

Application of Research Ethics

This study was approved by The Health Research Ethics Commission, Faculty of Medicine, Universitas Brawijaya, protocol number No.39/ EC/ KEPK – S3/ 03/ 2023

Informed Consent

All participants in this study agreed and signed informed consent.

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