

## The continuity psychiatric nursing care model to enhance medication adherence in schizophrenia patients in Indonesia: Participatory action research

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### Abstract

**Objective:** To develop a continuity of psychiatric nursing care model to enhance medication adherence in schizophrenia patients.

**Method:** The Participatory Action Research study was conducted from 2017 to 2018 in Pekanbaru, Riau, Indonesia, after approval from the ethics review committee of the Faculty of Nursing, Prince of Songkla University, Thailand. The sample included schizophrenia inpatients at a mental hospital, their family members and nursing staff. Qualitative data were gathered through in-depth interviews, observations, field notes, and photo records. Data was subjected to content analysis, while trustworthiness of the model was also determined.

**Results:** Of the 57 subjects, 22(38.6%) were schizophrenia patients, 22(38.6%) were family members, and 13(22.8%) were nurses. The continuity of psychiatric nursing care model consisted of three components: preparing for readiness to live a normal way of life; creating a supportive environment; and, sustaining the continuity of care until the community level care.

**Conclusion:** The continuity of psychiatric nursing care model facilitated holistic nursing care aspects.

**Keywords:** Continuity of care, Medication Adherence, Participatory action research, Schizophrenia.

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### Introduction

Schizophrenia is a mental disorder influencing nearly 24 million people around the world, with an incidence of 7 per 1000 in the adult age group, and most of these adults fall into the age group 15-35 years.<sup>1</sup> The Basic Health Research, which is a unit programme of the Indonesian Ministry of Health (MoH),<sup>2</sup> reported that 0.17% of the total population of 237 million in Indonesia (<1 million) who suffered from a severe mental disorder like schizophrenia were aged >15 years.

Medication has an important role in treating and controlling schizophrenia symptoms.<sup>3</sup> Unfortunately, non-adherence to medication is a huge problem related to continuing schizophrenia treatment. Within a year, 77% patients on medication quit their treatment, and >90% stopped medication within 2 years in a study.<sup>4</sup> The consequences of non-adherence are relapse, suicide attempts, and persistent symptoms.<sup>5</sup> In Indonesia, according to a study<sup>6</sup> there is a 53.3% rate of schizophrenia sufferers being readmitted to a mental health hospital at least once a year because of medication non-adherence. Moreover, the length of hospital stay is extended.<sup>4</sup> Discontinuity of treatment is also associated with an increased rate of mortality.<sup>7</sup>

A study using a mixed method<sup>3</sup> investigated interventions to enhance medication adherence. However, the families were not involved in the intervention. A pilot study on the role of the family showed that the family was an important part of enhancing medication adherence. Understanding, comfortable feelings, and collaboration with the family and the healthcare professionals are three factors for enhancing medication adherence.<sup>8</sup> An experimental study in Indonesia demonstrated that a self-management family participation programme providing clear guidelines for nurses had a better outcome in enhancing medication adherence among schizophrenia patients. However, the nursing care was fragmented, because the study<sup>9</sup> only focussed on the treatment after discharge, and did not clearly explain the continuing role of the nurses with respect to enhancing medication adherence.

Continuity of care (CoC) with its multidimensional concept is a key in mental health care services to respond to the fragmentation between settings of care. Some studies have stated that CoC emphasises the experienced continuity in three ways: relationship continuity, management continuity, and continuity of information.<sup>10</sup> Some studies confirmed the associations between CoC and many outcomes, and showed that medication adherence could be enhanced by CoC.<sup>11</sup>

The current study was planned to develop a continuity of psychiatric nursing care (CPNC) model to enhance medication adherence in schizophrenia patients.

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### Materials and Methods

The Participatory Action Research (PAR) study was conducted from 2017 to 2018 in Pekanbaru, Riau, Indonesia, after approval from the ethics review committee of the Faculty of Nursing, Prince of Songkla University, Thailand. The PAR methodology has distinct phases of reconnaissance, planning, action and observation, and reflection.<sup>12</sup> The reconnaissance step helps in developing a clear understanding of existing nursing practices in a setting.

The sample was raised using purposive sampling technique. Those included were 22 schizophrenia inpatients at a mental hospital, their family members, and 13 nursing staff. The patients were able to communicate in the Indonesian language, were aged 18-60 years, and had a diagnosis of schizophrenia in line with the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)<sup>13</sup> and had a Brief Psychiatric Rating Scale (BPRS) score <31.<sup>14</sup> The nurses were enrolled from the wards as well as the Health Promotion Unit (HPU). The family members enrolled were able to communicate in the Indonesian language, were living with the schizophrenia patient and as a caregiver

before and after discharge, and could be contacted by telephone or mail. Patients and their family members were excluded if the patient had relapsed during the study process. The nurses who were on leave were not included in this study.

Data was collected based on individual interviews, focus group discussion (FGDs), participants' observations, and field notes. The interview guides, demographic data questionnaire, field notes proforma, and observation sheets were verified by 5 experts. Qualitative data was subjected to content analysis, and trustworthiness was established to identify key elements.<sup>15</sup>

### Results

Of the 57 subjects, 22(38.6%) were schizophrenia patients, 22(38.6%) were family members, and 13(22.8%) were nurses. Factors and situations affecting CPNC and medication adherence were identified (Table).

The CPNC model consisted of three components: preparing for readiness to live a normal way of life; creating a supportive environment; and, sustaining the CoC until the community level care (Figure).

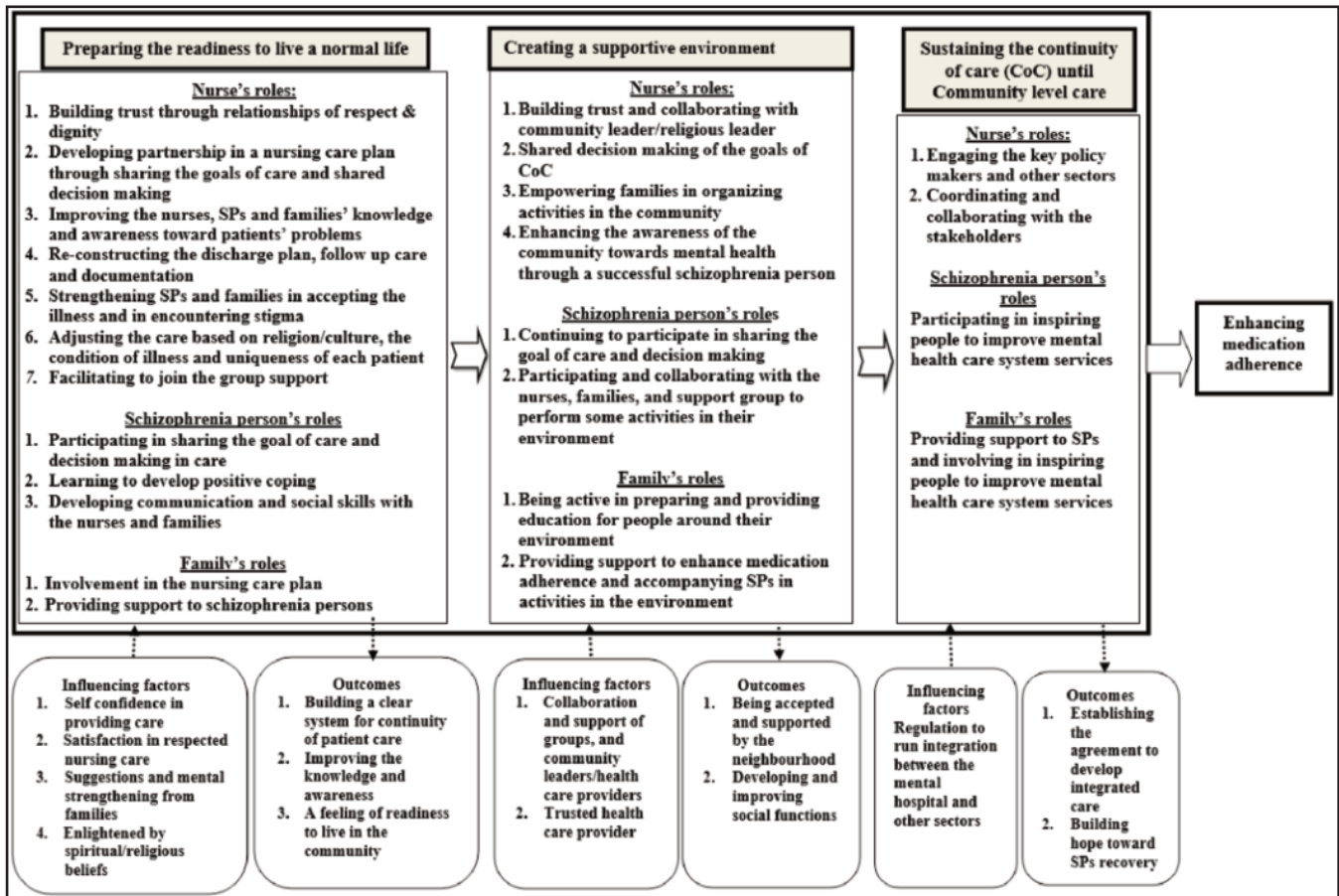


Figure: The continuity psychiatric nursing care (CPNC) model. [nc in Schizophrenia persons in Indonesia]

**Table:** Situations affecting adherence of of schizophrenia patients to the continuity of psychiatric nursing care (CPNC) model.

**The situations of the continuity psychiatric nursing and care medication adherence:**

1. Factors influencing the continuity of psychiatric nursing care
  - 1.1 The promoting factors in continuity of care
    - The monthly meetings of the head of nurses and team leaders.
    - Integrating record of nurses and other health care providers.
  - 1.2 The barriers in the continuity of care
    - Unclear and unplanned process from hospital to home (lack of communication and coordination; lack of resources and unclear regulations).
    - Lack of information about continuity of care for schizophrenia persons (SPs) and families (were not involved in nursing care plans, limited time of nurses or families, less knowledge of nurse, inadequacy in the educating tools)
2. Factors related to medication adherence
  - 2.1 Schizophrenia persons and families' trust
  - 2.2 Schizophrenia persons' unawareness/denial about the illness
  - 2.3 Schizophrenia persons and families' beliefs toward the illness and medication
  - 2.4 Stigma prevented the taking of medication (the medication and its side effects associated with the illness; being treated in a dehumanized way by healthcare providers; and the stigma caused by the attitude of families, societies and religious beliefs)
  - 2.5 The difficulties in accessing the mental health care services.

## Discussion

Among the 3 main of collaborative components identified in the current study, the first one was preparing for the readiness to live a normal life.

In this model, the discharge of schizophrenia patients from the hospital was not decided by the symptoms alone; their readiness to stay in the community was also taken into account. Consistent with some studies, it was found that there were associations between the continuity of nursing care and schizophrenia patients' readiness to manage the care at home.<sup>16</sup> Building trust through relationships based on respect and dignity in this model had an important role that was carried out by the nurses. Studies have mentioned the critical value of a trusting relationship in the context of CoC.<sup>17</sup>

Some action in this regard include calling the schizophrenia patients and their families by their title and name; listening; providing information clearly, directly, and to be understood easily; using appropriate body language, facial expressions, and talking in the patient's language, if possible. Studies have found that a constant therapeutic relationship helped in understanding the illness, the patient's social and family context, as well as becoming better in assessing patients' symptoms and psychosocial problems that lead to better management of the illness.<sup>18</sup>

Developing partnerships in nursing care plan through sharing the goals of care and shared decision-making was the main role of the nurses in this model. The partnership care in this model was developed based on the cultures

and roles of families in Indonesia. Sharing the goals of care and shared decision-making were a collaborative process in which the nurses and the schizophrenia patients with their families working together as experts and partners in exchanging the goals, information, and clarifying values to achieve decision-making in medication management. Understanding the treatment goals was important while discussing treatment options to clearly explain the possible treatment associated with side effects and to help them select their care based on personal choices.<sup>19</sup> Each schizophrenia patient's goal might be different from the other, such as gatherings with family, sleeping at night, marital status, study, and work.

In the reconstruction of the plan of discharge and follow-up care, the nurses needed to understand schizophrenia illness trajectories that were composed of two phases: hospital setting for the acute phase, and home setting for the recovery/stable phase. The settings of the model were guided by the trajectories of schizophrenia<sup>20</sup> because it is essential to continue the care in all stages of the illness, particularly while the patient is hospitalised in an acute ward.

the follow-up care component was developed based on the evidence, regulations and situation of Indonesian mental health hospitals. Some studies suggested conducting a follow-up after discharge within 7-30 days due to the high vulnerability for problems related to medication and CoC.<sup>21</sup> A study<sup>22</sup> reported that the ideal time to do a home visit was within 48-72 hours post-discharge to prevent relapse. The nurses gave the appointment for a phone call within 3 days, then conducted a home visit within 7-12 days post-discharge in the current study, and the home visit was conducted before the scheduled outpatient appointment on day.<sup>14</sup>

Encouraging schizophrenia patients and their families to accept the illness despite the stigma associated with it required awareness among the nurses. Before educating the schizophrenia patients, families and society at large, the nurses were exposed to interventions aimed at enhancing their knowledge and awareness about the condition.

Since spiritual/religious needs are part of everyday life for most people in Indonesia, the nurses should be sensitive and aware of this dimension in the model, and for it to be considered in a comprehensive nursing assessment and treatment. In the assessment of spiritual needs, the basic knowledge about the traditions of the major world religions should be understood by nurses because spirituality and religion are interwoven in Indonesia.<sup>23</sup> The same principle applies to cultural norms and practices.

The patients were encouraged to join peer groups by the nurses as a way of sharing their feelings and thoughts, and to learn from each other to cope with the medication adherence problem in daily life. However, the encouragement was provided only through social media. Based on a study, creating an accessible group and encouraging such activities enhanced patients' social lives and built a safer foundation for patient recovery.<sup>24</sup>

Furthermore, the tasks of the families in the current study were identified as developing partnerships to provide extending care to the home; to transfer information from one nurse to other nurses or doctors, and also to the schizophrenia patients; and to support flexible and consistent nursing management. The family also had a major role in helping the schizophrenia patients picking up social skills, re-socialisation, and getting a job, as there were no professionals in the system to perform such services.

Among the 3 main of collaborative components identified in the current study, the second one was creating a supportive environment for schizophrenia patients. In this model, building trust and collaborating with the cadre, community leader, or the religious leader in the community was emphasised to help in facilitating schizophrenia patients and their families to live normally in their environment. In the Indonesian culture, taking care of people is considered to be a moral obligation for families and communities. The community would cooperate to share the burdens, which is known as the spirit of gotong royong (collaboration). Therefore, even though there has been a greater stigma in societies, the support from communities is a positive culture for CoC to enhance medication adherence. The communities' support in the context of CoC included helping the families to ask the patient to take the medication, facilitating the process of getting the due treatment, and accompanying the family to the hospital.

Providing education through a schizophrenia patient in recovery phase was also introduced to reduce the sense of stigma, and to strengthen the positive belief among the patients, the families, and the communities. Some studies reported that education and social contact, like meeting and learning from the experiences and life of a recovered mentally ill person, were effective in promoting knowledge and attitude changes toward the stigma.<sup>25</sup>

Among the 3 main of collaborative components identified in the current study, the third one was sustaining CoC until community-level care. This model involved a complex interaction among schizophrenia patients and their families, multidisciplinary health professionals, institutions, communities, and systems. This was in line with literature.<sup>10</sup>

The nurses in the hospital were to be the care coordinator/main care team, and carried out their duties as expected. In addition, due to the stigma of mental health problems, the management continuity was taken as mandatory supervision.<sup>10</sup>

## Conclusion

The CPNC model facilitated holistic nursing care aspects, including physical, psychological, sociocultural and spiritual aspects, to be integrated into a practical setting.

**Limitation:** As the sample size was not calculated for this research, it could influence the power of the study.

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