

© Copyright 2017

Chieh Cheng

The Process of Symptoms and Coping Strategies Experienced in the Prodromal  
Schizophrenia: A Grounded Theory

Chieh Cheng

A dissertation

submitted in partial fulfillment of the  
requirements for the degree of

Doctor of Philosophy

University of Washington

2017

Reading Committee:

Karen G. Schepp, Chair

Barbara B. McGrath

Elaine Walsh

Program Authorized to Offer Degree:

School of Nursing

University of Washington

**Abstract**

The Process of Symptoms and Coping Strategies Experienced in the Prodromal Schizophrenia:  
A Grounded Theory

Chieh Cheng

Chair of the Supervisory Committee:  
Professor, Karen G. Schepp  
Psychosocial and Community Health Department, School of Nursing

Background: Schizophrenia is a debilitating disorder. Current research emphasizes changing the disease trajectory by prospectively identifying subjects at high risk based on the characteristics shown during the prodromal stage, which is the stage preceding the full-blown psychosis.

However, the process of recognizing the prodromal stage remains unclear. Its non-specific features raise concerns about misdiagnosis, stigma, and unnecessary treatment.

Objectives: The purpose of the dissertation is to demonstrate a theoretical explanation of the prodromal schizophrenia process by describing patients' symptoms, thoughts, feelings and coping strategies.

Participants: Twenty-five adults with schizophrenia in Taiwan were interviewed. A total of 40 interviews were conducted at a medical center, two community settings, and one day care unit.

Selection criteria included adults who were diagnosed with schizophrenia by DSM-IV diagnosis within the previous 5 years and who were in stable mental health status.

Methods: Individual semi-structured interview questions were employed to explore meanings, role shifts, and proximate and ultimate causes. The Grounded Theory method was selected because it is used to explain the disease progression process during the prodromal stage. Constant comparison analysis, memo writing, member checking, and theoretical sampling were adopted.

Results: Two coders analyzed the data. Inter-coder agreement was 95%. Participants' age ranged from 20-40 years with a mean of 27.12 years old. The length of illness ranged from months to 5 years with a mean of 2.88 years. There was equal sex representation of patients (48% female; 52% male). Comparison of these categories led to their being consolidated into a core theoretical explanation in which the prodromal process is described as ranging from manageable to uncontrollable. Four categories emerged from the analysis: (1) something is wrong, (2) boiling up, (3) breaking point, and (4) losing control. Symptoms were either specific to each category or continuous across categories. Symptom severity increased with progression through the process. Before "losing control", there are three corresponding coping strategies within each category: (1) making less, (2) trying to find former self, and (3) control taken away by others.

Conclusions: This study provided a theoretical explanation of prodromal schizophrenia process using four stages with specific symptom manifestations for each. This study is the initial step in directing attention and increasing awareness toward early identification of warning signs that occur before full-blown psychosis.

Keywords: Schizophrenia; Prodrome; Grounded theory

# TABLE OF CONTENTS

List of Figures .....	iii
List of Tables .....	iv
Chapter 1. Introduction .....	9
1.1 Background of Prodromal Schizophrenia.....	9
1.2 Study Purposes.....	11
1.3 Content of The Dissertation.....	11
1.4 Significance and Potential Impact .....	12
Chapter 2. Prodromal Process As Perceived By People With Schizophrenia in Taiwan: A Grounded Theory Study.....	13
2.1 Introduction.....	13
2.2 Methods .....	15
2.3 Results.....	19
2.3.2 Something is Wrong .....	22
2.3.4 Breaking Point .....	26
2.3.5 Losing Control .....	28
2.4 Discussion.....	29
2.5 Strengths and Limitations .....	31
2.6 Conclusion .....	32
Chapter 3. Ways of Coping in Prodromal Schizophrenia.....	34

3.1	Introduction.....	34
3.2	Methods .....	36
3.3	Results.....	38
3.4	Discussion .....	45
3.5	Limitations .....	48
3.6	Conclusions.....	49
Chapter 4. Managing Qualitative Research For Patients With Schizophrenia .....		50
4.1	Introduction.....	50
4.2	Recruitment.....	51
4.3	Interview .....	53
4.4	Data Preparation and Analysis.....	59
4.5	Conclusions.....	60
Chapter 5. Grounded Theory in Psychiatry Nursing Research.....		62
5.1	Introduction.....	62
5.2	Human Subjects Protections .....	63
5.3	Results.....	64
Chapter 6. Conclusions .....		72
Bibliography .....		75
Appendix A.....		86
Appendix B.....		88

## **LIST OF FIGURES**

Figure 1.1. The Diathesis-Stress-Support Model for Prodromal Schizophrenia. ....	10
Figure 2.1. From manageable to losing control. ....	21
Figure 3.1. The process of coping.....	39
Figure 5.1. An Example of Member Checking by Drawing.....	70

## **LIST OF TABLES**

Table 2.1 Participants' psychotic symptoms and quality of life.....	21
Table 3.1. Participants' demographic data (N = 25).....	38
Table 3.2. Comparison of conceptual definitions for coping.....	46
Table 4.1. Practical Interview Questions .....	55

## ACKNOWLEDGEMENTS

Nearly four years ago, I started my journey toward a PhD at the University of Washington. I still remember when I arrived at SeaTac Airport for the first time. The chilly air in the terminal comforted my swollen eyes after saying a hard goodbye to my parents and my lovely home. To Dun-Yu, Efren, Jui Shan Hsu, Olivia, Wan Chian, Su Fang-Yi, April, Christina, Yi-Hsun Yang, Yang-Ho, Joan & Jeff: in those cold, rainy days that followed, you have been my invincible summer.

In my first quarter, I was very anxious because of financial uncertainty and the stress of transitioning to a new place and school. At first, I doubted my decision to turn down other offers with more tuition support and stipends from other prestigious universities in the States. However, through this, my mom reminded me: “You regret the things you don't do, not the things you do.” So I convinced myself that everything was going to be alright, which was true. When I missed home, I chose not to Skype with my parents because seeing their faces would have made the loneliness worse. To overcome this, I went out to visit parts of Seattle beyond campus and compared everything that I saw with what I had in Taiwan. Eventually I found a lot of similarities, such as a Ding Tai Fun restaurant. I realized that it is not about where you are situated, but rather how you allow your mindset to influence how you live. Of course, there were also many differences that I learned about, such as Halloween. I just didn't understand why people would want to decorate their houses with murder scenes. At a pumpkin carving party at Steven's house with my closest colleagues in the PhD program—Minhui, Yuting, Alexa, Claire, Shih-Yin, Musetta, Jenny, Andrea Williams, and Jonika—I learned that it's okay to be afraid, to question the world, and to be frustrated. Having such experiences, and the wonderful companions that you share them with, makes me brave, and trust that someone will pull you up during your toughest moments.

If you were to ask me what I like the most about the UW School of Nursing, the answer would be the people. In a narrow hallway, you can run into three FAANs in 10 minutes and they will all say “Hi” to you like you are a friend, and not some fresh-of-the-boat grad students. That, to me, makes a place special. From the Nursing department, thank you Drs. Cindy Dougherty, Elaine Thompson, Jean Tang, Cynthia Price, Oleg, Kerry, Sue McCurry, Trez Buckland, Hilaire, and Lyn Bond, for giving me opportunity to try and try again, for answering my dumbest questions with mind-blow ideas, and letting me see possibilities far beyond my own dreams and expectations. These outstanding scholars taught me that “you can fail by failing to try.” Even successful people have fear, doubts, and worries. They just don't let these feelings stop them, which was an invaluable lesson for me. Among all these wonderful nursing scientists, I met my lifelong mentor Karen Schepp. She is like a Mazu figure to me: no matter how strong the storms are, she is always the warmest haven and gives me one hundred percent support. Dr. Schepp, thanks for opening my eyes to new stages of opportunity and strength. I will forever be grateful for your guidance and kindness. Additionally, thank you to the other committee members, Drs. Walsh, McGrath, and Eleanor Chen for guiding me towards the right path in my dissertation research. I am glad that Dr. Schepp connected us, as your expertise helped drive me forward.

If the School of Nursing was a family, all of the staff members would be the moms who look after you and clean up after any mess you make. Laura, Betsy, Dayle, Emma, Sunday, Aaron, Ashley Bond, and Janet Lenart: thank you for always listening to me patiently and taking every step with me until I could walk independently.

In my dissertation defense, one of my committee members asked how I performed self-care after listening to so many distressing and traumatic experiences from a vulnerable group of people. I replied, “Knowing that I have the ability to help people makes me strong.” This spirit of helpfulness is something that I value, so thank you to those who helped me. Ben, Susan Landis, Kwankaew, Afnan, Pei-Chin, Sue Han, Pei Lin, Denise, Beth, Yvette, Ashley, SarahAnn, Jillian, all the funding agencies and scholarship donors, my research participants and their caregivers, folks at NTUH : Kristina Lucky, PinPin Hsu, Leo Liu, Dr. Liu and everyone else who has ever helped me: I couldn't have reached this point without your generosity.

In addition to doing research, I am very grateful for having the opportunity to learn from many outstanding educators: Anne, Rizza, Philips, June, Linda Teri, Anita Souza, and Shervin

Churchill. After working with you all, I realized teaching is learning, an art, and an important responsibility to cultivate in the next generation. I have to come to find working with students to be a wonderful experience, which I am sure I will continue doing.

Friends and mentors in Taiwan, thank you for sticking with me. Thank you for cheering me up with those good old memories. Thank you for understanding the time differences and the difficulties of living aboard. I miss all of you! Friends in Seattle, thank you for helping me to settle down. Thank you for sharing all of your experiences. I learned from your stories and avoided many mistakes thanks to you.

And, of course, thank you mom, dad, Fang, A-Ma, Yuan, and Sasa. Thank you for your enormous support and unconditional love. I would not be who I am today without you. I hope you all can be healthy and happy forever! Sorry that I only went back less than ten times in the past three-ish years. Sorry that I forgot to return calls when immersed in work. But thank you for always giving me positive energy and cheering me up. You give me strength to face everything. Finally, thank you to Weichao and Nai-Ching, who helped me have a seamless transition from the end of my PhD program to a new beginning in a faculty position. I love what I am doing after all these years and I now understand that like Sheryl Sandberg said “when life sucks you under, you can kick against the bottom, break to the surface, and breathe again.” I am ready for the next step forward.

## **DEDICATION**

For all those who accompanied, encouraged, critiqued, challenged, and helped me to go on every  
adventure, especially this one.

## Chapter 1. INTRODUCTION

Schizophrenia is a mental health condition affecting society on all levels, from families to governments. About 1% of Americans have schizophrenia, with similar rates occurring in all ethnic groups around the world (Health, 2015). Current research emphasizes early intervention during the prodromal phase of schizophrenia, the period preceding fully-expressed psychosis (Cheng & Schepp, 2016; Mokhtari & Rajarethinam, 2013; Muller, Laier, & Bechdolf, 2014). The prodrome indicates a potential pre-psychotic, at-risk mental state which could be delayed or modified if identified early enough (Yung & McGorry, 1996b).

### 1.1 BACKGROUND OF PRODROMAL SCHIZOPHRENIA

The prodromal stage is a complex and dynamic process (Cheng, Walsh, & Schepp, 2016). Based on a review of the literature, a conceptual framework called the Diathesis-Stress-Support Model (Figure 1.1.) demonstrated major factors relating to the prodromal stage. The complicated characteristics make it challenging for early identification. Current research into identifying the characteristics of the prodrome has predominantly been conducted using quantitative questionnaires completed by patients about their symptoms (Kendler, Lieberman, & Walsh, 1989; Zdanowicz, Mees, Jacques, Tordeurs, & Reynaert, 2014). The items endorsed in screening tools often lack specificity and have a high false positive rate (Cheng & Schepp, 2016; Miller et al., 2003; L. J. Phillips, Yung, A. R., & McGorry, P. D. , 2000; Yung, Nelson, Thompson, & Wood, 2010). Since diagnostic decisions are made based on the data from these tools, the results for using these nonspecific tools could be disastrous, leading specifically to misdiagnosis, exposure to unnecessary and harmful antipsychotic medications (Woodberry et al., 2014), and stigma (Zdanowicz et al., 2014). Information and experiences obtained from qualitative work

could be added prior to establishing both screening tools' conceptual definition and psychometric properties as a method of validation for use in the early identification of patients with schizophrenia (Olsen & Rosenbaum, 2006).

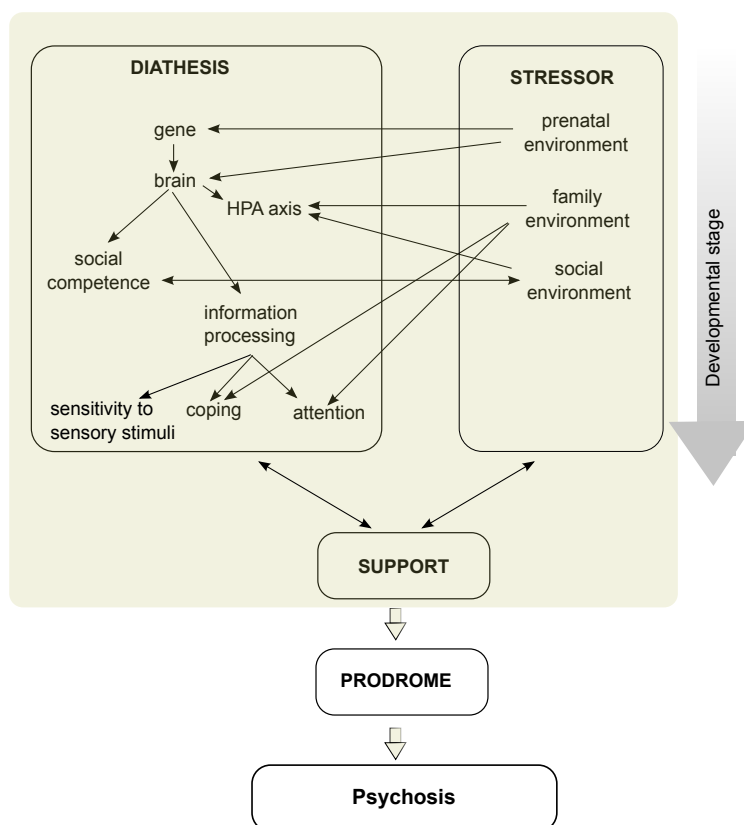


Figure 1.1. The Diathesis-Stress-Support Model for Prodromal Schizophrenia.

Qualitative studies over the past fifteen years have explored common themes pertaining to the period of untreated psychosis through caregiver reports (Bergner et al., 2008; Corcoran et al., 2003; Gater et al., 2014; Muhlbauer, 2002; Wainwright, Glentworth, Haddock, Bentley, & Lobban, 2014) or through participants who met the at-risk mental status criteria but had not been diagnosed (Gronholm, Thornicroft, Laurens, & Evans-Lacko, 2016). However, it is problematic that they ignored symptoms that were perceptible by on the patient, as this leaves out a reflection of the different ways that patients perceived the process (R. G. Bota, Munro, Ricci, & Bota,

2006). Therefore, this study sought to address this issue by using Grounded Theory to focus on patient experiences.

Among different methods in qualitative research, Grounded Theory is used for questions about the dynamic process, when (a) little is known about the area of study, and (b) the generation of theory with explanatory power is the desired outcome (Leavy, 2014; Strauss & Corbin, 1997). These overarching characteristics are all applicable to this study because its focus, the prodrome, lacks an explanatory model to describe its progression toward psychosis.

## 1.2 STUDY PURPOSES

Participants who experienced prodromal symptoms of schizophrenia often struggle to make sense of the changes caused by these experiences (Lester et al., 2011). The main purpose of this dissertation is to understand the prodromal process as described by patients. First, the study aims to use patient perspectives to identify the process before the first onset of psychosis. The research questions are: What symptoms did patients experience prior to their first psychotic break? What was the intensity of the symptoms? What was the duration of the symptoms? What thoughts or feelings did patients experience prior to their first psychotic break? Second, the study seeks to describe patient coping practices before their first psychotic event. Here, research questions include: What strategies did patients use to cope with the symptoms, thoughts and feelings prior to a first psychotic episode?

## 1.3 CONTENT OF THE DISSERTATION

This dissertation consists of six chapters. After describing the background research on prodromal schizophrenia and knowledge gaps in Chapter 1, Chapter 2 provides primary results of the symptoms, thoughts, and feelings experienced by participants with schizophrenia during

the prodromal stage. Next, Chapter 3 illustrates the process of coping juxtaposed with the experiences described in Chapter 2. Chapters 4 and 5 demonstrate how the research was planned and conducted with a vulnerable population. Throughout, working examples for applying Grounded Theory Method (GTM) with schizophrenia patients, as well as participants' feedback on the study, are presented.

#### 1.4 SIGNIFICANCE AND POTENTIAL IMPACT

By addressing the known gap in understanding with regard to prodromal symptoms for identifying high-risk individuals, this research has the potential to present a definite image of prodromal schizophrenia through patient perspectives. It is hoped that the findings of this study will provide stronger evidence for shifting clinical practice paradigms toward primary prevention for mental illness. More specifically, the findings of this research can be applied to: (1) developing questionnaires for the early identification of warning signs in both schools and medical services where most of the patients show prodromal symptoms; (2) designing a self-management program for slowing down the progression of the illness; and (3) building intervention programs designed to educate and facilitate earlier help-seeking to decrease treatment delay and its associated morbidity.

## Chapter 2. PRODROMAL PROCESS AS PERCEIVED BY PEOPLE WITH SCHIZOPHRENIA IN TAIWAN: A GROUNDED THEORY STUDY

### 2.1 INTRODUCTION

Schizophrenia is a chronic and debilitating brain and behavior disorder affecting 2.4 million people in the U.S. Every year, 100,000 people under the age of 35 experience prodromal symptoms, which are the psychotic symptoms that precede diagnosed schizophrenia (Amminger, Leicester, Francey, & McGorry, 2005). Most nations emphasize early identification of at risk patients based on prodromal symptoms. However, reliable identification of people at high risk for clinical progression of schizophrenia is challenging due to the dynamic variation of the prodromal process combined with substantial individual differences in symptom manifestations (Yung et al., 2010). These nonspecific symptoms used for early identification raise concerns about potential misdiagnoses (Woodberry et al., 2014), prolonged duration of untreated psychosis (DUP), and stigmatization of patients with a false positive diagnosis for schizophrenia (Zdanowicz et al., 2014). In the U.S., early identification and intervention methods have not been broadly adopted in communities or treatment facilities (Addington et al., 2015). For example, the average DUPs, which is the time between the onset of psychotic symptoms and initiation of treatment, ranged from 61 to 166 weeks among US citizens (Birchwood et al., 2013). The longer the DUP is, the poorer the prognosis is.

One study comprehensively traced the stages after the onset of fully-expressed psychosis by discussing chronic patients' retrospective perspectives of schizophrenia over their lifespans (Shepherd et al., 2012). Thirty-two adults aged 50 years and older (mean duration time since

diagnosis is 35 years) were interviewed about changes they perceived in the symptoms of schizophrenia and their functioning. This study showed that, in the developmental course of schizophrenia, heterogeneity exists in the described illness progression for symptoms, general life situations, life goals, and the personal recognition of changes in their illness over time. This study showed the heterogeneity of schizophrenic trajectories. However, for the prodromal stage, this data is less relevant, as not only are the population demographics different, but also the disease process itself as it leads to the onset of psychosis.

To address the challenges in early identification, information and experiences obtained from qualitative work need to be added (Olsen & Rosenbaum, 2006). The main purpose of this study was using Grounded Theory Methodology to explore the process of how patients living with schizophrenia perceive, feel, and experience those symptoms in the prodromal stage. Research found that including patients' experience in the assessment algorithm can increase the homogeneity of the sample and the sensitivity to predicting who will develop schizophrenia (Simon et al., 2006). The theoretical model developed from this study has the potential to present a more comprehensive picture of the prodromal process to improve the validity of screening tools and design appropriate intervention programs for people with early warning signs of developing schizophrenia.

This is, to our knowledge, the first Grounded Theory research that explores the process from patients' perspectives. Grounded Theory Methodology has been used for patients with schizophrenia, but not in the prodromal stage. In the PsycINFO database, when using the keywords "grounded theory" and "prodrome" or "pre-symptomatic" to search for articles between 1997 and May 2015, no articles were found; while using the keywords "grounded theory" and "schizophrenia", 116 articles were found. These articles include topics on patients'

responses to the diagnosis (Henderson & Cock, 2014), the well-being of people with mental health conditions, recovery experiences (Romano, McCay, Goering, Boydell, & Zipursky, 2010), and coping mechanisms (Jalbrzikowski et al., 2014). These all included the individual's inner psychosocial processes as well as environmental factors, such as the availability of resources in the community. Studies on the experiences and perceptions of interpersonal relationships among young people at-risk for developing psychosis, substance abuse (Asher & Gask, 2010), the effectiveness of treatment (Wang & Xiong, 2013), the perspectives of health professional staff (Leutwyler, Hubbard, Jeste, & Vinogradov, 2013), and the siblings of young person with psychosis (Brand, Harrop, & Ellett, 2011) were also prevalent.

## 2.2 METHODS

### 2.2.1 *Aim*

The purpose of this study was to better understand the experiences, symptoms, feelings, and thoughts of patients with schizophrenia in Taiwan when they went through the prodromal stage.

### 2.2.2 *Study design*

A Grounded Theory Methodology (GTM) was used to explore the experiences of patients living with schizophrenia within the past 5 years. GTM, which is informed by the assumptions of constructivism, was chosen to expand knowledge given that the prodromal process is a dynamic and complex phenomenon (Leavy, 2014; Strauss & Corbin, 1997). Patients' own perceptions and daily experiences during the prodrome period were obtained from individual interviews (T. Roberts & Bowers, 2015; Slatyer, Williams, & Michael, 2015). Theoretical sampling and constant comparisons used in data collection and analyses resulted in the generation of a theoretical framework describing the prodromal process.

### *2.2.3 Research Sample, Setting, and Ethical Considerations*

To ensure that the methodological approach used would allow for various perspectives, twenty-five participants with schizophrenia (thirteen men; twelve women) were recruited from a medical center (n= 18), a day care unit (n = 3), and three community rehabilitation centers (n=4). Ethical approval from an ethics committee was obtained before posting research flyers for recruitment in the above sites seeking participants. The participants were age 20-40 years (mean age 27 years) and had been diagnosed with schizophrenia for less than 5 years (mean 2.9 years). All had completed high school education, thirteen were employed, and only one was married. Participants were excluded if they were acutely ill with their illness at the time, had difficulty communicating, or were incapable of signing the consent forms on their own.

Written consent was obtained from all participants for both their participation in the study and audio recording of the interviews. All recordings and transcripts were kept on password secured laptops throughout the collection and analysis of the data. Confidentiality was maintained throughout the study period by the use of a numerical coding system to ensure anonymity of each participant. To protect participants from any potential harm caused by recounting their experience, counseling support by social workers, nurses, and psychiatrists was available if participants experienced any undue distress. During the study, no participants sought or required this support.

### *2.2.4 Data Collection*

Before starting the interview, the researchers developed a semi-structured interview guide to focus on the process associated with the prodromal stage. The interview guide included an exploration of patients' experiences, including symptoms, thoughts, and feelings. The interview

guide was reviewed by the psychiatrist, pre-tested with a patient, revised, and modified before gathering qualitative data related to the topics of interest. Interview questions were for example, *“Tell me what was that like when you start to experience those symptoms?”*

Initially, purposive sampling was used to recruit 10 participants who met the inclusion criteria and were from one of the three aforementioned settings (the medical centers, day care unit, and community institutions). As data were collected and analyzed, the researcher had a detailed provisional model of the process and found the settings did not influence how the participants perceived the process. However, the researcher did not yet understand how the process might vary. For this reason, the researcher theoretically sampled participants from different lengths of illness experience (less than 1 year, 1-3 years, and 3-5 years), age groups (age 30 or younger, or over age 30), and disease status (taking antipsychotic medications or not). Fifteen participants were recruited through this theoretical sampling process. It revealed a considerable richness in how participants talked about their experience. What struck the researcher during the analysis of the second interview was how much their experiences centered on “coping.” For example, participants often commented on what they wished had done differently, or how what they had done was either effective or ineffective. Having this new concept directed the researcher to perform the second interview with some of the participants who were available and more eloquent in describing their experiences. Data collection continued until there were no new or relevant themes emerging. Eventually, following a total of 15 interviews, all the explanations for when the symptoms happened, how they felt, what they thought, and what they did to deal with the situations were sufficiently well developed for the purposes of this study. Data collection continued until data saturation occurred and no new experiences were described by the participants.

By the conclusion of the study, a total of 40 semi-structured interviews were completed. The face to face interview time ranged from 40 minutes to 2.5 hours. Interviews took place in either a private research space within the medical center or the interview room in the community rehabilitation centers. The interviews were conducted in Mandarin and were audio recorded. During the interview, the researcher took memos for the interview context, participants' verbal and nonverbal reactions, researcher's immediate impressions, decisions, information for future research, and emerging questions. These memos acted as a reference and additional data during the analysis. As part of the iterative process of grounded theory, the researcher reflected right after each interview by writing research journals.

In addition to the interview, four questionnaires were administered to understand participants' demographic characteristics, current psychiatric symptoms (Positive and Negative Syndrome Scale; PANSS)(Kay, Fiszbein, & Opler, 1987), quality of life (World Health Organization Quality of Life Instruments Brief version)(Su, Ng, Yang, & Lin, 2014) and social functioning (Personal and Social Performance Scale; PSP)(Wu et al., 2013). PANSS and PSP were filled out by either the primary psychiatrists of the participants or by the researcher who had been trained to evaluate psychotic symptoms and functionality as a psychiatric nurse. These data help to describe participants' characteristics.

### *2.2.5 Data Analysis*

After transcribing the recorded interviews to transcripts, data analysis started immediately, and the results were used to guide subsequent interviews. Since the interviews were conducted in Mandarin, the researcher hired professional translators with bilingual backgrounds to translate interview transcripts from Chinese to English. After translation, the researcher and the co-coder reviewed the translated interviews systematically while reading the original transcript to make

sure the patients words were fully presented in the translated transcripts. Then, all the transcripts were subjected to coding by using Atlas.ti, a software program designed to analyze and edit qualitative data (Muhr & Friese, 2004). The data were analyzed and interpreted according to the coding procedure developed by Strauss and Corbin (1997) through open, axial, and selective coding stages. Team analysis and member checking were used to enhance the credibility. For example, the researcher and the co-coder coded the translated transcripts by using codes in English while coded the same transcript in original language by using codes in Chinese. After coding five transcripts, the researcher and the co-coder met and discussed two things: first the similarities and differences of the codes; second, whether the codes in English could represent the correct meaning in Chinese. In this process, if consensus was not reached, the researcher asked a faculty member who is also bilingual to determine the appropriate terms. In the end, 95% inter-coder agreement rate was achieved. In addition, six participants were asked for feedback to ensure the results accurately captured their experiences. All six participants agreed that the results made sense to them.

## 2.3 RESULTS

### *2.3.1 Participants Characteristics*

The Positive and Negative Syndrome Scale (PANSS) is an outcomes instrument widely used for assessing the severity of schizophrenia symptoms. This 30-item scale includes 3 subscales: positive (7 items), negative (7 items), and general psychopathology (16 items) and the ratings for each item range from 1 (absent) to 7 (extreme). The score range for each subscale is shown in Table 2.1; higher scores indicate greater symptom severity. Results showed that participants had mild to moderate positive symptoms as well as negative symptoms. The

composite score, which is the direction and magnitude of difference between positive and negative symptoms, was positive 0.2. This indicates that participants had predominantly positive symptoms. The reliability of Cronbach's alpha for the overall 30 items is .919.

The World Health Organization Quality of Life Instruments Brief version includes four domains: physical health, psychological, social relationships and environment, such as financial resources. There are 26 items measured with a 5-point Likert scale. Higher scores mean better quality of life. Participants rated their quality of life at a moderate level on four domains and the Cronbach's alpha was .925.

The PSP scale is a 100-point scale consisting of four main areas: socially useful activities, personal and social relationships, self-care, and disturbing and aggressive behaviors. The scoring procedure includes three steps. First, each of the four domains is rated on a six-point severity scale (absent, mild, manifest, marked, severe, very severe). Second, different combinations of severity in the four domains determine a preliminary PSP score in the 10-point intervals. For example, the lowest interval, 1-10, indicates lack of autonomy in basic function with extreme behaviors but without survival risk. Third, clinical judgment scores that are  $>70$  represent mild difficulties known only to those familiar with the person (Patrick et al., 2010). Forty percent of our participants scored 31-70, which means they had various degrees of disability while the majority (60%) of participants scored  $>70$  with mild disability in the four domains. Cronbach's alpha was .77. The findings from this study resulted in a theoretical framework ranging from *manageable* to *losing control* to illustrate the dynamics of the prodromal process. In this process, we identified four core categories that have sequential properties (figure 2.1).

Table 2.1 Participants' psychotic symptoms and quality of life

Distribution characteristics	PANSS				WHO-QOL			
	Positive	Negative	Composite	General psychopathology	Physical health	Psychological	Social relationships	Environment
Mean	12.16	11.96	0.2	25.40	12.62	11.01	12.99	13.62
SD	4.68	5.18	4.93	8.21	2.27	3.62	2.88	2.35
Range (potential)	7-49	7-49	-42- +42	16-112			4-20	
Range (obtained)	7-22	7-27	-17 ~ 10	16-43	9-17	5-16	8-17	9-17
Skewness	.73	1.49	-1.35	.75	-.06	-.004	-.12	-.44
Kurtosis	-.59	2.31	5.79	-.29	-.64	-1.55	-1.48	-.74

Among the participants, the duration of the prodromal stage ranged from 2 months to 5 years. This result is consistent with literature that the average duration of prodromal stage was about 52.7 weeks (1 year) to 98.5 weeks (Loebel et al., 1992).

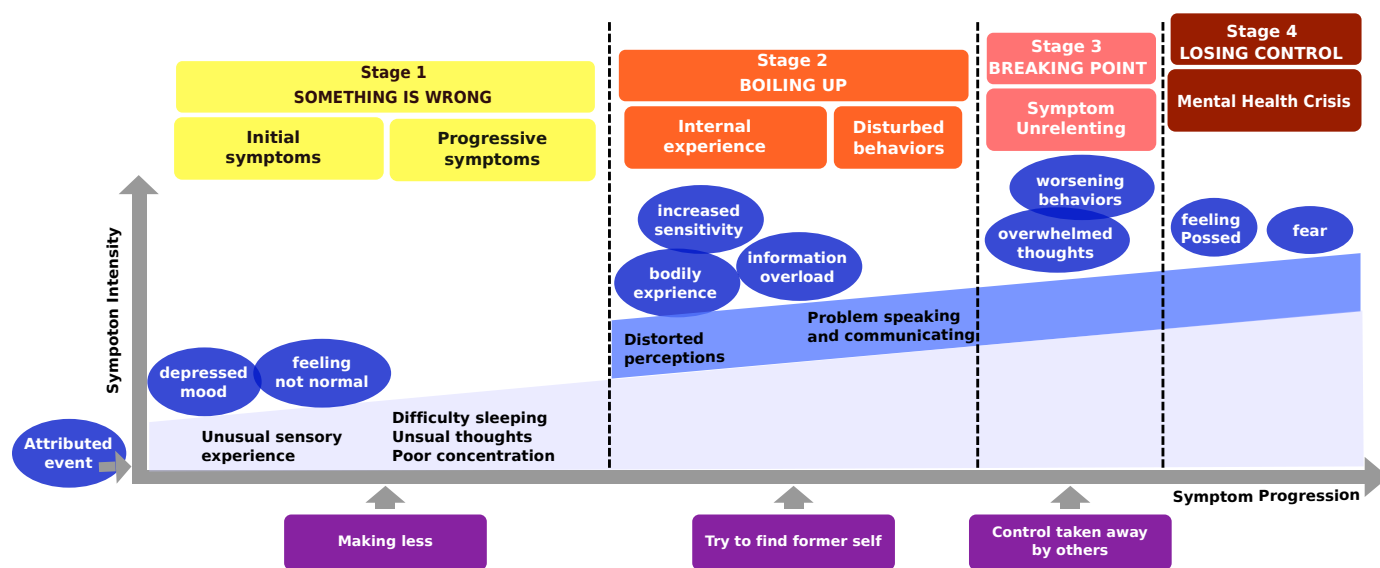


Figure 2.1. From manageable to losing control.

### 2.3.2 *Something is Wrong*

The duration and frequency of the first stage ranged from months to a year. The first stage started with initial symptoms such as depressed mood, feeling not normal, and unusual sensory experiences. Then there were many progressive symptoms that arise, like unusual thoughts, poor concentration and difficulty sleeping. Initial symptoms were related to unusual feelings, emotions, and sensory perceptions. All participants clearly identified the very first event and symptom. For example:

*“I remembered that the first symptom was depression. Depression is like it is raining the whole day.”*

In addition to symptoms, behavioral change was also reported. They felt something was going wrong because they would find themselves doing something they usually wouldn't do.

*“ My friend told me that he couldn't understand what I was talking about. Also, I realized I was becoming abnormal because I couldn't take notes in class. “*

Some participants reported a single significant event that they considered the cause for the onset of the first unusual symptoms.

*“In early June of 2011, I finished my occupational training and was feeling happy. However, I don't know why, but around mid-June, I started feeling depressed. I felt unhappy, uncomfortable, and I couldn't tell why I felt that way. “*

After the initial symptoms occurred, participants all described sensing more and more unusual feelings and starting to have delusional thinking concurrent with feelings of being confused as to whether the experiences were real. These progressive symptoms made it difficult for participants to concentrate and thus influenced their regular sleep pattern.

*“I felt things around me were sending messages or were monitoring my behaviors. When I was in class, my brain spaced out. It was so difficult for me to focus. I felt distressed, so, I gave up the school. “*

*“I couldn't sleep because I kept thinking. Sometimes I even didn't sleep at all, so I felt exhausted physically. However, my brain was still thinking. “*

In Stage 1, the minor themes or diverse cases found in the data included situations where participants, their friends, or their teachers observed the early signs and brought them to seek help from a health care professional.

*“My friend said I was weird and suggested that I should go to see a doctor. “*

This sub-set of participants described that this early identification and help seeking were very helpful for their recovery.

*“I really appreciated the schoolteacher who told my parents about my situation. Even though my parents at that time did not agree with her, she still brought me to see a*

*pediatrician and then I received much help and treatment, which I think was the key to my recovery and my current situation where I can still have a stable job.”*

### 2.3.3 Boiling Up

Next is the second stage: Boiling Up. In the Boiling Up stage, participants described that they started to feel an increase in severity and frequency of Stage 1 symptoms, thus showing an escalation.

*“After you heard the sound for a week, the volume of the sound started to increase. It's like someone was using a microphone to project the sound. I was very scared. I thought to myself- what the hell was that?”*

Two types of manifestation were identified in this stage: internal experience, something participants sensed inside their body or head, and disturbed behaviors, which are problematic actions that they engaged in when interacting with people.

Almost all the participants mentioned having uncomfortable physical sensations and feeling an increasing sensitivity toward the sensory stimuli.

*“ I felt that some of my senses were amplified. For example, I could hear high-intensity electromagnetic wave sounds just before a phone started to ring. At that time, those normally obscure sounds became very clear and vivid to me. “*

*“ I had a weird feeling in my head. My head and brain were really tight. It was really*

*uncomfortable. I don't know how to describe that. It was like my head was in a crane machine and someone (the crane operator) was pulling on my head.”*

*“ Whenever the symptoms occurred, I would have an uncomfortable feeling in my forehead. It was really strange, only the forehead.”*

Having distorted perceptions toward time and words was one of the most concerning elements for participants, as it made them question reality.

*“ I doubted whether the clock was real. I thought the time was not correct. “*

All these internal experiences escalated and gradually participants started having difficulty processing information and stimuli, which made them feel information overload.

*“The systems I had for filtering information gradually diminished. I couldn't filter the information that was sent to me. I started not being able to read, watch movie, and listen to music because I want to run away from receiving more information.”*

Problems with speaking and understanding and difficulty sleeping are two major sub-categories of disturbed behaviors. When interacting with people, participants feared direct eye contact and even felt afraid of being within others' field of vision. Also, it became increasingly difficult for them to express themselves clearly and interpret conversations.

*“I know it is normal that when we are communicating with people, sometimes we forget a word or use incorrect vocabulary. However, this kind of situation got worse. I found people could not understand what I was talking about. I was really concerned about that. Also, if there is something which has the function of receiving and sending information throughout our body, I think mine must be out of order because I couldn't comprehend information. I couldn't understand what people were talking about.”*

Difficulty sleeping that developed in the first stage continually and intensified in this stage.

*“I couldn't sleep because my brain kept working. I kept thinking: What does the information mean? What is the meaning of those hints?”*

The duration and frequency were shorter and more intense than the first stage. Many participants mentioned one week where the symptoms showed up every day, especially at night.

*“The delusion happened every day. “*

*“All these symptoms were more and more intense and continued about one week.”*

#### 2.3.4 *Breaking Point*

After the accumulation of the progressive symptoms in previous stages, increasingly problematic behaviors and intrusive, overwhelming thoughts all become more difficult. In participants, this was a short and intense period of time right before their mental health crisis

occurred. Most of the participants described it was a continuous 2-3 day process where the frequency of the symptoms was very intense and non-stop.

*“My situation was I only slept less than 2 hours for a continuous 3-day period. I was in the state of immersing in the delusion.”*

In this stage, symptoms were unrelenting, so participants started having some worsening behaviors than in the previous stage. For example, some participants indulged in certain activities continuously without taking a break.

*“I had bad luck in every aspect of my life, including relationships, friendships, family, etc. I went to a temple to perform an exorcism for 2 to 3 hours. After that, I started to have some weird behaviors and say things that I could not control. “*

Not only that, the chaotic picture of their performance became obvious. Impulsive aggression or violence was reported and participants said:

*“Before the onset, I felt like I was becoming braver about doing whatever I wanted to do. I felt I could just do whatever I wanted to. I was not afraid of being embarrassed. I said whatever I liked..... I stole someone’s coat at the gym...I had many distorted behaviors.”*

*“There is always a triggering point before you are sent to the hospital. For example, I had suicidal idea, I was screaming, and I had a fight with my parents.”*

Overwhelming or unusual thoughts, poor concentration, reality distortion, and problem sleeping were commonly extracted from the data.

*“I had a lot of imagination by relating things I have seen...experiences I have gone through.”*

*“I did not sleep well so the thoughts in my head got messy and made me feel overwhelmed.”*

*“I am pretty sure that the day before I was admitted to the hospital, I couldn't focus.”*

### 2.3.5 *Losing Control*

Mental health crisis was the last stage in the prodromal process that patients with schizophrenia described. Feelings of not being able to control themselves, a “possessed feeling,” were frequently brought up.

*“I couldn't stop swinging my body back and forth. “*

*“I was out of control. It's like being possessed. My onset was, like, I couldn't even speak. I couldn't move. It was like my body was not my own. For example, when the psychosis onset happened, I was lying on the floor and couldn't get up. “*

The possessed feeling, those nonstop symptoms, gave participants a deep feeling of fear.

*“I was very very scared.”*

*“It was my first time of losing control. I kept crying. I felt panicked and scared, very scared. I didn't know what I could do. I was helpless.”*

When participants were asked whether they could distinguish a transition point or boundary among the stages, they said the boundary was blurred. The stages were not discrete points but represented periods of days or weeks, or sometimes even months. One of the participants described:

*“I cannot tell you the specific time point for the changes from time to time. The whole process is like a river. The riverbed was not smooth with rocks, particles. As the river move downstream, which is very natural, it turns out I have been diagnosed. All I can recall is to tell you that what have had happened, things that I realized might be related to my diagnosis.”*

## 2.4 DISCUSSION

From the data drawn from the perspectives of people living with schizophrenia, the substantive theory developed here describes and aims to explain the prodromal process of young people with similar circumstances and seeks to inform researchers and clinical practice in the field of early prevention of mental health conditions. It is important to reveal varying

understandings toward this complicated condition from the affected population (Leavy, 2014) by using GTM to present the dynamic illness trajectory and the stage-wise progression of symptoms leading to full-blown psychosis.

#### 2.4.1 *Social cognitive deficits*

Social cognitive deficits, such as facial affect recognition deficits, were present in the prodromal stage of schizophrenia. Current research results have shown some core characteristics of schizophrenia that predate psychosis onset include subtle thought disorder and profound deficits in recognizing emotions in others' faces and voices. Research has identified the correlation between these symptoms and the transition to psychosis. For example, a recent study used functional imaging responses to investigate the neural correlation of processing neutral faces among youth with psychotic-like experience (N=246). The results showed the limbic network's increased response to neutral facial stimuli is potentially a marker to detect brain-related abnormalities in teens before full-blown psychosis (Bourque et al., 2017). The study presented in this paper also showed participants had difficulty having eye contact with people, understanding and interpreting conversation. In order to examine the sensitivity and specificity of these symptoms, which may be important markers of psychosis risk, future research needs to evaluate mechanisms underlying these deficits through the use of neuroimaging and electrophysiology in order to modify clinical paradigms by shifting treatment from individuals suffering from schizophrenia to individuals who are at risk of developing psychosis with the goal of achieving prevention.

#### 2.4.2 *Memory and attention deficits*

Poor concentration shown in Stage One and memory deficits through distorted perceptions found in Stage Two are two major symptom manifestation found in recent studies. For example, a multisite, case-control study and standardized assessment across 8 sites in both the US and Canada found that neurocognitive impairment, especially in attention and working memory abilities and declarative memory abilities, is a robust characteristic of prodromal schizophrenia participants, especially those who later develop psychosis (Seidman et al., 2016).

### 2.4.3 *Sleep problems*

Sleep problems such as insomnia were identified as one of the initial symptoms. It is unclear whether this sleep deficit is present early in schizophrenia, and whether it reflects a core disturbance central to its pathophysiology. More research is needed to examine sleep problems, their relationship to memory consolidation and cognition more generally, and their neural underpinnings in early-course patients with schizophrenia.

## 2.5 STRENGTHS AND LIMITATIONS

In addition to specifying the detailed process by interviewing participants, this research has two strengths: adding evidence to current science, and taking patients' experience into consideration. The research findings presented here provides evidence to support current research evidence and add new findings by describing specific pathways from the earliest unusual symptom to full-blown psychosis. For example, Cannon et al. (2016) conducted a study in which they were able to develop a tool called the Individual Risk Calculator to evaluate the risk levels of developing schizophrenia (Cannon et al., 2016). One of the most interesting findings in this research is that stress levels are not the essential factor for predicting the transition to full-blown psychosis. This is a new argument in discussion with the classic

vulnerability-stress model (Nuechterlein & Dawson, 1984). From participants' perspectives, the sense of control was the main factor in the process. For example:

*“I have more (stress) after being diagnosed because of the financial insecurity, stigma, and uncertainty toward the future. “*

*“The stress at work is mostly from my delusion, or my auditory hallucination, not sure which one has more to do with the stress.”*

The model developed in this study is a human construct and grounded in the experiences of patients with schizophrenia who were diagnosed within 5 years in Taiwan and were stabilized by regular treatment. Results may not be generalizable to persons with schizophrenia in other countries even though it rests on a rigorous approach and analysis of the data aimed at achieving the best possible control for this limitation.

## 2.6 CONCLUSION

It is important to reveal varying understandings toward this complicated trajectory from the affected population (Leavy, 2014). The purpose of this study was to describe and explain the prodromal process of young people with similar circumstances and inform researchers and clinical practitioners in the field of early prevention of mental health conditions. In addition, it acts as another piece of evidence for improving early identification of prodromal schizophrenia and shortening DUP by using GTM to present the dynamic illness trajectory and the stage-wise progression of symptoms leading to full-blown psychosis.

The theoretical framework was developed by categorizing clinical staging, symptoms, and functioning that are commonly experienced in Asian adult patients with newly-onset

schizophrenia (N=25). The framework was innovative in presenting patterns and clinical staging that marked the progression from premorbid stage to full-blown psychosis. Prodromal symptoms were found to be either specific to each stage or continuous across stages. For example, anhedonia is a salient feature that is often present as a prodromal symptom (Gorwood, 2008) among neuroimaging studies. However, researchers have not specified when and how anhedonia has occurred. In this framework, depressed mood and the inability to experience pleasure from activities usually found enjoyable were the very first symptoms. The symptom severity increased with the progression of the stages. The duration of prodromal stage recalled by the participants, 2 months to 5 years, was consistent but much shorter than what has been known in current knowledge. This suggested the importance of providing intervention earlier.

Validation of the accuracy in the theoretical framework may improve the specificity and sensitivity for early identification. Building on these compelling preliminary data, the framework will be examined with diverse participants and by seeking outsider perspectives such as observations from relatives and healthcare providers who witnessed the process. Nurses and other health care providers have a social responsibility for the actions they undertake with people who are vulnerable and at risk of developing into mental illness. This research adds evidence to current knowledge of early identification that will facilitate preventive treatments. For example, a good understanding of the trajectory of a disease can be used to modify existing intervention programs with more individualistic orientations. Above all, this study is an initial step in directing attention towards targeting clinical nursing interventions and assessments for the individuals who are undergoing this process so that they can halt the progression to full-blown disease and restore their functionality.

## Chapter 3. WAYS OF COPING IN PRODROMAL SCHIZOPHRENIA

### 3.1 INTRODUCTION

#### 3.1.1 *Schizophrenia and Prodrome*

Schizophrenia is estimated to be the 8th-ranked cause of life years lost to disability and premature death among people aged 15 to 44. As such, reducing this disease burden is a public health priority (Simon et al., 2017). People with Schizophrenia typically experience the clinical onset in young adulthood, which can derail educational progress and the acquisition of social skills required for independent adult functioning. There is a broad cost to society that accrues on a personal level in the loss of adult productivity and healthy maturation that is also experienced on a socioeconomic level in rising mental health care costs (Cheng & Schepp, 2016).

Accumulating evidence suggests that both preventive interventions prior to the onset of actual psychotic symptoms and early clinical interventions can improve long-term prognosis (Cheng & Schepp, 2016).

However, the period preceding the onset of psychotic disorder—the prodromal stage—is complex, which creates a problem for early interventions. For example, a qualitative study (McCann & Clark, 2003) showed that, at the beginning of schizophrenia's onset, patients and caregivers were not able to distinguish between normal human development and early indicators of psychotic illness. Due to this complexity, there was a significant proportion of people who did not meet the diagnostic criterion of full-blown psychosis still lived in communities rather than inpatient settings or specialized treatment centers. A recent study by Simon et al. (2017) exemplified this by drawing from 5 large health systems serving a diverse and representative population of over 7.5 million people to validate and refine a generalizable algorithm for

identifying first presentations of psychosis (Simon et al., 2017). Results demonstrated that the incidence rates were markedly higher than previously reported rates based on diagnoses. Given this, more research is necessary to understand how these people coped with the putative symptoms before they were diagnosed and sought professional help in order to inform future research and care delivery. Elucidating patients' self-management will move the science closer to targeted preventive interventions that have the potential to improve the outcome for this vulnerable population.

### 3.1.2 *Coping*

Coping can be defined as the cognitions and behaviors that are directed at managing stressful experiences (MacAulay & Cohen, 2013). In patients with schizophrenia who have a recent onset of the illness, findings from several studies indicate that coping styles affect multiple domains of symptoms, levels of self-efficacy, cognitive performance, psychosocial functioning, clinical symptomatology and quality of life (Cooke et al., 2007; Lysaker, Davis, Lightfoot, Hunter, & Stasburger, 2005; Rudnick & Martins, 2009). Given this, it is important to understand patients' perspectives on what works and what does not work for them, and the contributing factors. This is of particular importance due to the limited research investigating patients' experiences of coping during the prodromal stage of schizophrenia (Kommescher, Gross, Pützfeld, Klosterkötter, & Bechdolf, 2017). For example, when searching through literature to find research on the coping styles of individuals at clinical high risk for developing psychosis, it is clear that current research either emphasizes how patients tend to respond to life stressors or how structural contexts, such as stigma, influence help-seeking behaviors, affect them (Cheng & Schepp, 2016; van der Gaag et al., 2012). However, given the heterogeneity within the prodromal stage of schizophrenia, differences in symptoms and behavioral

impairments along with self-appraisal of the situation may influence the type of coping strategy that one employs (L. J. Phillips, Edwards, McMurray, & Francey, 2012).

To address the current knowledge gaps in the literature, this qualitative study aimed to identify what coping strategies these patients with schizophrenia used before they were diagnosed and what outcomes and consequences occurred. By knowing this, the variations in coping can inform typologies of coping that consider contexts of diversity, dynamic symptom manifestations, life situations, and culture. This may ultimately contribute to the development of more effective intervention strategies that will encourage participation and retention by identifying participants' needs and desires in regard to what they need for coping with early psychotic symptoms.

This study is theoretically informed by symbolic interactionism and employs the methodology of constructivist found in Grounded Theory (Corbin & Strauss, 2014). Grounded Theory can be used to uncover the beliefs and meanings that underlie action, to examine rational as well as non-rational aspects of behavior, and to demonstrate how logic and emotion combine to influence how persons respond to events or handle problems through action and interaction. This method has proven to be culturally sensitive and applicable to individuals as well as to larger organizations and societies (Corbin & Strauss, 2014).

## 3.2 METHODS

The aim of this paper was to describe the coping strategies used for prodromal symptoms. This is a qualitative study undertaken in Taiwan. Grounded Theory methodology (GTM), as developed by Corbin and Strauss (Corbin & Strauss, 2014), was the method of choice for this study. This method provides a good starting point for the examination of a phenomenon about which little is known and can lead to the development of a data-based practice theory.

### 3.2.1 *Data Collection and Data Analysis*

Interviews were conducted in Mandarin by the researcher whose first language is Mandarin. The collection and analyses of data occurred simultaneously. Data collection methods included: semi-structured, in-depth interviews, taking notes during interview, and field notes. The interviews were audio recorded, conducted in a relaxed and private environment, and transcribed verbatim. Pseudonyms were used throughout. The constant comparison method and theoretical sampling were used, where transcriptions were analyzed immediately after their completion, and the results were used to guide the course of subsequent interviews and the selection of topics to be further addressed. The researcher took notes throughout the entire study and kept logbooks. Thoughts, decisions, and emerging questions were all recorded and served as additional data. Data collection continued until saturation was reached, which meant that no new concepts arose from the data.

The data were systematically analyzed and interpreted according to the coding techniques developed by Strauss and Corbin (1998), and with help of ATLAS.ti (Muhr & Friese, 2004), a software program designed to analyze and edit qualitative data. Sampling was continued until theoretical saturation of the data was achieved. In the end, 40 interviews were collected, each lasting between 45 and 120 minutes. The transcribed data were coded and analyzed. Beginning with open coding, conceptual labels were then linked to more abstract categories, and the properties and dimensions of the categories were identified. Axial coding ensued, where the data were put back together in a different way through categorizing the data and making links between categories and subcategories. Finally, selective coding took place, with the aim of identifying a core category or basic social psychological process

### 3.3 RESULTS

#### 3.3.1 Demographic Characteristics of the Participants

A total of 25 participants were recruited (Table 3.1). Their ages ranged from 20-40 years. The length of illness ranged from months to 5 years with a mean of 2.88 years. Additionally, there was equal gender representation of patients (48% female; 52% male).

Table 3.1. Participants' demographic data (N = 25)

Item	Number of persons (percentage)	Range	Mean $\pm$ standard deviation
Length of Illness			2.88 $\pm$ 1.32
<1 year	3 (12.5%)		
1~3 years	12 (48%)		
3~5 years	10 (40%)		
Gender			
Female	12 (48%)		
Male	13 (52%)		
Age (years)		20-40	27.12 $\pm$ 4.99
Location			
NTUH	18 (72%)		
Community	4 (16%)		
Day Care	3 (12%)		
Marital status			
Single	24 (96%)		
Married	1 (4%)		
Education			
High School	4 (16%)		
College/University	18 (72%)		
Graduate School	3 (12%)		
Employment			
Unemployed	12(48%)		
Employed	13(52%)		
Religion			
None	10 (40%)		
Christianity	9 (36%)		
Buddhism	3 (12%)		
Taoism	3 (12%)		

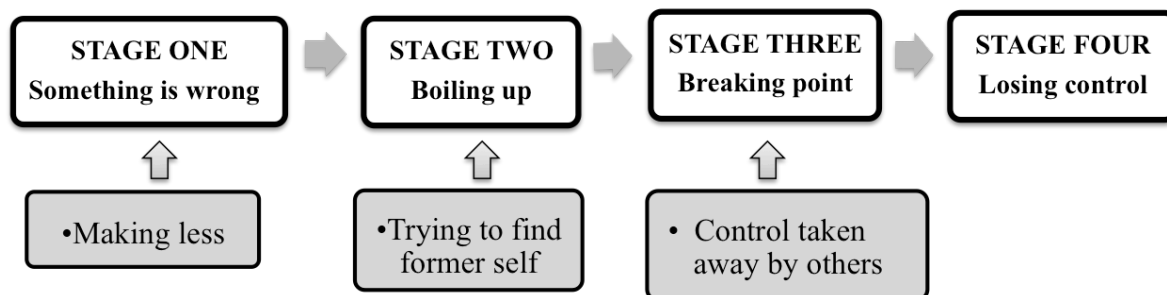


Figure 3.1. The process of coping.

The overall process of coping is shown in Figure 3.1. All of the participants appeared to shift continuously among three coping stages for the prodromal symptoms.

### 3.3.2 *Stage One Coping: Making Less*

Two types of coping activities were described by participants. These activities can be interpreted as attempts to compensate for the initial stage where symptoms just started to emerge. The first activity involved some of the participants trying to avoid the attributed causes. Here they stopped doing things that they thought were the cause of those initial symptoms and uncomfortable feelings.

*“The only way to deal with those stimuli was to leave the environment. So I dropped out of school. After I dropped out of school, the feeling of receiving hints and reminders from the environment disappeared.”*

A second activity was ignoring. Participants decided not to do anything with the symptoms because the denial was, at times, helpful, as it allowed them to carry on with their daily routines by blocking distressing thoughts.

*“I didn't deal with it because it didn't influence my daily life. I could still manage to have a regular daily routine.”*

### 3.3.3 Stage Two Coping: Trying to Find Former Self

In an attempt to manage the accumulation of symptoms, participants engaged in a process called “trying to find former self”. For participants, finding their normal self allowed them to regain self-control after they began to lose self-confidence. They all had the expectation that they would become their former and normal self. The stage of trying to find their former self consisted of three aspects: avoidant coping; active problem solving; and reaching out for help. The first two aspects occurred in participants themselves. The remaining aspect was prominent when people such as patients’ main caregivers became aware that their affected love ones began acting differently.

Avoidant coping consisted of conscious (withdrawal from the environment) and unconscious (distracting oneself from the distorted perception) coping. Psychologically, participants made adjustments for their heightened sensitivity to environmental stimuli or symptoms by drawing their attention toward something else in order to distract themselves from the symptoms or problems.

*“I would just draw attention away from the symptoms or things that made me feel worried.”*

*“The more I focused on the trivial sound, the more I would think that maybe it was my auditory hallucination, so I avoid focusing on the sound by drawing attention to*

*something else.”*

Participants were actively choosing to withdraw as a coping strategy. Although being withdrawn is one of the characteristics of negative symptoms in psychotic diseases, it was triggered here by the concern of being embarrassed due to their disturbed behaviors or showing any deteriorations in front of their peers, friends, and loved ones. They were distressed by their own responses in these situations and were left with immense feelings of guilt.

*“I thought there were too many conspiracies, but I couldn't keep confirming whether those were real or not. In order to avoid embarrassing myself in front of people, I gradually withdrew from the social connections that I had. Well, as time went by, I became more and more isolated.”*

*“At that time, I just wanted to leave the crowd. There was a place on campus where people seldom visited, so I went and sat there. I listened to the stream sounds, which made me feel comfortable. In terms of why I would want to withdraw from people, I, I felt I made some mistakes because of the strange behaviors I did.”*

Active problem solving includes confirming reality. They began to ask someone else to help with confirming whether their experiences were real or not as they realized that they could not believe in themselves and a third party may provide some evidence. This was a double-edged sword as it confirmed their suspicions about whether the symptoms were real, but at the same time did not address their confusion in future situations. They continued to face false realities

and needed to repeatedly search for an answer to explain what was going on.

*“I thought I was monitored, so I hired a private investigator to check whether there were monitors in my house.”*

*“I knew I was weird, so I checked with my friends about my situation at that time. My friend told me that I had flying ideas so she couldn't understand what I was talking about.”*

*“When I had a distorted perception of time, I turned on the TV news because it always has a small clock in the news channel. That clock should be correct, so I could confirm what time it was.”*

The use of self-management approaches, the second aspect of this stage, was a trial-and-error process where participants utilized a variety of strategies based on their habits or beliefs when they experienced unusual sensory experiences.

*“I would go for jogging during midnight when I couldn't fall asleep.”*

*“I tried to wear headphone to block the voice in my head.”*

*“I tried to make a list of things I needed to do in order to organize myself. I bought a notebook to take records of what I have done, and to list what I need to do on an hourly basis.”*

Coping styles were often related to participants' socioeconomic factors, education, and religious beliefs. In Taiwan, the Duo religion often attributes being unwell to the actions of bad spirits. For many, religion provided escape and support and became part of their daily routine. Many participants mentioned their immediate thoughts about religious attributes and, moreover, believed that religious activities such as exorcism or sacraments could restore their mental and physical well-being.

*“When I heard the sound, I thought I was possessed by some evil spirits, so I went to the temple.”*

In the beginning, religion was a valued resource as was physical exercise, but participants reported they became numbed toward these and thus did not find them helpful anymore.

*“(This participant had tried several religious activities)” After the voice showed up, I was scared and I think that was because I was possessed by some bad spirit. So my mom suggested that I should go to a temple near where I live to chant daoism sutra and worshipping. However, it got worse. Agh, I shall have seen the doctor at that time. It got worse because I did not go to see the doctor in time. And then I tried other traditional spiritual practices. There were some masters in the temple who can help people possessed by bad spirit. However, doing that did not help at all and it made (the symptoms) much worse.”*

Social support played an important role in pushing these participants to seek professional

help. Participants' interactions with their community, which included changes in established relationships with friends, schoolteachers, or family members, alerted their social network and caused them to seek help for the patient. Some participants' communities sought help from health professionals whom they trusted.

*“My friend asked his friend who was also a psychiatry nurse for advice when they felt I had been behaved weird for a while.”*

*“My grandma felt there was something wrong with me, so she took me to see the doctor.”*

#### 3.3.4 Stage Three Coping: Control Taken Away From Others

In the last stage, participants were unable to manage distress by familiar means, so participants experienced being overwhelmed when they became embroiled in a crisis situation, especially those involving aggression or violence. Some participants described the aggression as a behavior that sometimes resulted in unwanted.

*“When we sat at the dining table, I kicked my mom's legs underneath because I felt very uncomfortable, but I didn't know what to do. My mom had no response toward my kicking, so I pull her hair to hit the wall. That was when my dad called the police and I was sent to the emergency room.”*

However, at this stage, their caregivers or people around them were frightened by the aggression or were overwhelmed by having to manage the participant's recurring disruptive

behaviors. This disrupted their support network, placing them in an even worse situation. Participants also resorted to seeking professional help for themselves as they realized that they could not manage alone what was happening after utilizing so many established coping strategies without success.

### 3.4 DISCUSSION

Differences in the conceptualization of coping have led to a number of methods for classifying coping strategies. Lazarus and Folkman (1984) offered a widely used definition of coping: “constantly changing cognitive and behavioral efforts to manage specific external or internal demands”. Subsequently, Higgins and Endler (1995) (Higgins & Endler, 1995) grouped coping strategies into three main classes: task-oriented, emotion-oriented, and avoidance-oriented. The task-oriented strategy is problem-focused. It involves taking direct action to alter the situation itself to reduce the amount of stress it evokes. In the emotion-oriented strategy, efforts are directed at altering emotional responses to stressors. It also includes attempts to reframe the problem in such a way that it no longer evokes a negative emotional response and elicits less stress. Finally, avoidance-oriented coping is characterized by the absence of attempts to alter the situation (Melamed, 1994). It includes strategies such as avoiding the situation, denying its existence, or losing hope. It also includes the use of indirect efforts to adjust to stressors by distancing oneself, evading the problem, or engaging in unrelated activities to reduce feelings of stress (Roth & Cohen, 1986). The task-oriented and emotion-oriented approaches are associated with better adjustment. Although avoidance-oriented coping may initially be an appropriate reaction to stress, studies have shown that it is associated with poorer adjustment (Cotton et al., 2013; Ponizovsky et al., 2013), and in the long run, task-oriented coping is the most efficacious strategy.

The present study was compared with these three main classes of coping strategies (Table 3.2). This suggested that participants did adopt avoidance-oriented coping in the initial steps, but this alone did not lead to poorer adjustment, as they had yet to figure out the source of their problems. A qualitative study (Gronholm et al., 2016) using thematic analysis to analyze twenty-nine interviews discussing the coping preferences of young people at risk of psychosis lends support to the result of this study. The study defined a theme in the data known as “conditional disclosure”, a concept reflecting the rules and prerequisites that influenced how/whether participants sought help. Recognition of the problem was followed at times by a rise in task-oriented, coping self-management strategies by the patient. Our research supports that self-perceptions of one’s ability to cope with stressful situations, along with the appraisals of the symptoms experienced, can influence the type to coping that one employs.

Table 3.2. Comparison of conceptual definitions for coping

Stage	Category	Currently used conceptual definition
Stage 1	Ignoring	Avoidance
Making less	Avoiding the attributed cause	Emotional- oriented
Stage 2	Avoidant coping: Distract and withdraw	Avoidance
Trying to get normal again	Active problem solving: Confirming and self-management	Task-oriented
	Reaching out for help	Task-oriented

Note:

Emotional oriented: altering emotional response to problems with attempts to reframe the problem

Task oriented: taking actions to solve the problems

Avoidance: Avoiding the attributed events, denying the existence of the problem, directing efforts to adjust problems through distancing or engaging in unrelated activities.

The findings in this study are also consistent with the results of Kommescher et al. (2017) (Kommescher et al., 2017), who reported that coping strategies and the stages of psychosis are correlated, and that coping is not simply a personal factor that is stable across all stages of the illness. Overall, the use of avoidant coping strategies has been linked to greater distress and negative symptoms, while greater use of task-oriented coping strategies has been associated with

reductions in positive symptoms in the later stage of prodromal schizophrenia. Specially, avoidant coping strategies, such as behavioral disengagement and ignoring, are associated with heightened reactivity to stimuli and shorter attention span (Olf, Langeland, & Gersons, 2005). This is consistent with the study result as well as other research findings.

In addition, better attention performance was related to less avoidant coping strategies (Green et al., 2004). However, this study found that when participants had difficulty paying attention and experienced memory impairments during the prodromal stage, they used active problem solving in order to find their former self. Therefore, before patients' cognitive function deteriorated, they actually had the potential to adopt active problem solving, which gave them the insight necessary to support early intervention practices.

Most research is an investigation of the coping styles in people at risk of psychosis that utilizes existing questionnaires (Jalbrzikowski et al., 2014; Kommescher et al., 2017). For example, in the Stress Coping Questionnaire, 114 items are used to evaluate positive coping, which includes devaluation (e.g. trivialization and downplaying), distraction (e.g. diversion from situations, search for self-affirmation), (Kommescher et al., 2017) and negative coping (e.g. escape, social withdrawal, continued mental preoccupation, etc.) Results showed that clinically high-risk individuals adopt pronouncedly more negative coping methods than positive ones. In addition, with positive coping strategies, at-risk individuals have been shown to prefer distraction to devaluation. The data in this study showed that both were used and the frequency was determined by its effectiveness and patients' preference.

Similarly, another study used the Brief COPE questionnaire to identify the types of coping styles employed by at-risk individuals and to assess whether these coping strategies were different from their same-age peers (Carver, 1997). It revealed that, relative to healthy controls,

at-risk youth reported using significantly fewer adaptive coping methods (e.g., choosing to reinterpret the event in a positive fashion) and more maladaptive coping ones (e.g., blaming one's self for the occurrence of the event). However, it also found that over time, there were significant decreases in reported maladaptive coping strategies. Participants expressed that they evolved in how they reported their coping methods to health care professionals because they quickly learned what kinds of coping were considered "adaptive" and thus positive, from health care professionals' standards. Therefore, using self-report questionnaires should be done with care in case there is any unintended coercion, where participants think their responses are related to the treatment they are receiving.

All of the above discussions suggest that, like those diagnosed with schizophrenia, those who are at-risk of psychosis do attempt to cope using strategies that may be detrimental to their functioning or exacerbate symptomatology. They may not possess the skills to effectively cope with stressful situations. Although, overall, coping strategies were associated with better concurrent outcomes, developing interventions while considering awareness and individual differences is important.

### 3.5 LIMITATIONS

There is one key limitation to the study. The results are context bound to the participants and the settings in which the study was carried out. Even though participants were recruited from various settings and cities and the findings are verifiable, the results cannot be generalized beyond this study at this point because of the small sample size. However, the findings have shed light on the process that patients with schizophrenia experienced before they were helped by health care professionals. As such, the findings constitute a starting point for further validation with diverse population as well as the development of adequate support for these vulnerable

individuals.

### 3.6 CONCLUSIONS

The substantive theory of coping in prodromal schizophrenia describes the process participants' shift through using avoidance and ignoring, to adopting self-help methods and trying to find their former selves, to a situation where established coping strategies were no longer effective. When not understanding their own condition, participants developed a variety of strategies with the hopes that they would force their symptoms to go away. Avoidant coping strategies such as ignoring or avoiding possible trigger events were utilized. When in the stage of symptom accumulation, participants lost their sense of mastery, and wanted to regain their self-control in order to return to their former state. The movement to this process was greatly affected by personal belief, knowledge, and the level of support they experienced from their community. Efforts and attempts were made to return to their normal selves, but the non-stop and recurring symptoms made participants distressed and frightened to the point that they gradually lost control of themselves. In the end, someone in the community had to take control by calling the justice system (i.e. police) or bringing patients to the hospital for help.

Participants felt alone in expressing their symptoms, as not many people understood what they were going through either because of they themselves could not communicate well or because of a lack of understanding about schizophrenia and its early stages by the community. By participating in this interview, participants expressed that they wanted to make a difference by sharing their personal experiences. They said they were able to stay positive with an optimistic mindset and remained appreciative for the help that came after people finally understood. In the end, it was clear that the patients were all aware of warning signs, but did not receive effective interventions and professional help at an early enough stage.

## Chapter 4. MANAGING QUALITATIVE RESEARCH FOR PATIENTS WITH SCHIZOPHRENIA

### 4.1 INTRODUCTION

Recruitment and data collection for research with a vulnerable population are often challenging (Lee & Schepp, 2013). In the case of schizophrenia, this issue is compounded by the fact that only about 1 in every 100 people has the disorder. In addition, schizophrenia is a condition that affects thinking, feeling and behavior, so patients may be less articulate. This creates issues for capturing previous experiences because it might be difficult for them to find the appropriate terminology to express a particular feeling and describe their experiences. As a result, sometimes patients' responses may be vague, fragmented (Graor & Knapik, 2013) and contain off-topic content.

As for researchers, doing intensive interviews or observations for patients' past experience, especially in emotionally charged situations, can be draining. It is important from an ethical standpoint that, when a researcher begins to feel overwhelmed or too emotionally involved, he or she put aside the research for a short time to care for themselves. Keeping a diary of the research process can help a researcher take a critical look at the self and also serves as a release for some of the stress (Corbin & Strauss, 2014).

The aim of this chapter is to give a practical guide based on the experience conducting a qualitative research to elicit descriptions of experiences among young adults who, by their diagnosis, have disordered thinking processes. More specifically, what are the difficulties with recruiting and interviewing patients with schizophrenia, what appeared to encourage recruitment and retention, and how to invite patients to participate in the interviews are discussed.

## 4.2 RECRUITMENT

### 4.2.1 *Collaboration and Mutuality*

It is important to identify the key person whose permission and assistance is needed to enter into the research setting and advertise for recruitment. Examples include the psychiatrists, social workers, and staff nurses in the hospital where the research takes place and the directors of community mental health rehabilitation organizations. Establishing this interdisciplinary collaboration had several considerations. For example, when an application was made for the IRB review at the clinical site, the collaborator was listed as the primary investigator and provided oversight and consultation about research taking place at the facility. This ownership was fostered by involvement and consultation at every stage, from protocol development to publication of the results. Clinical staffs members were involved as consultants in order to gain a better understanding of how to contact the participants, which was based on their long-term partnerships. In the communication process, researchers and clinical staff members assured participants' confidentiality via anonymous email conversations, discussions in private settings, and a focus on only discussing research-related questions.

In clinical settings, usually there are several ongoing clinical trials that might share similar inclusion criteria. To overcome potential conflicts, communication about the recruitment strategies is important. This ensured that recruitment procedures ran alongside routine practices, thus making it easier for everyone. For example, when both parties recruited the same participant, research activity can be scheduled on the same day, assuming it worked for the participants' schedules. The use of Google calendar to share scheduled appointments helps to avoid any confusion.

When conducting the study in different settings, it is helpful to provide the same recruitment script (Appendix B) to the staff. Having the same script made recruitment consistent as well as gave the clinical staff a guideline to follow. The script in the appendix included a step-by-step research process that listed the inclusion criteria. This made the staff feel more comfortable when explaining the research.

#### *4.2.2 Relationship Building with Participants*

As soon as the researchers approached the potential participants, they entered the relationship building stage with the participants because the research aimed to ask the participants to share their life stories and private information. It was important for researchers to place themselves in the shoes of the participants and consider what concerns they may have about the study. The researchers made sure to be honest with potential participants about our research purposes and goals, what it was we were doing and why, and how they would handle the information gathered. This initial approach was helpful in putting people at ease and assured them of how researchers would assure the confidentiality.

Being honest is the first step to present oneself and to minimize the distance with participants. For example, when studying patients' symptoms in order to gain an understanding of the frequency and severity of their symptoms, some became concerned that they were being evaluated on whether or not they were taking their medication regularly. They were afraid that the assessment would make them seem worse off than they believed, which created a situation where the researchers needed to emphasize their purely research-based intent.

#### *4.2.3 Other Facilitators*

Several factors appeared to encourage recruitment and retention in the study. First, participants with direct experience of schizophrenia helped to modify the data collection process when a pilot study was performed to go through the steps of recruitment and the interview process. Participants used their own words to post the research study recruitment information in their own social media groups. This ensured that the language that researchers used was appropriate for this population. One participant told the researchers that he decided to join because a participant who joined the pilot study was his friend in the church. This points to how both researchers and participants who had past or current experience of using services themselves can allay people's fears about being judged, especially when an individual might be paranoid. Second, putting emphasis on participants' role as assisting with research in order to help future patients yielded positive results. In addition, participants were thanked for their time spent completing the research with a \$30 incentive. Rewards, both monetary and self-esteem building, are encouraging. Third, after each interview, participants were reassured that they could contact researchers with questions or concerns before the end of the study. This helped the researcher to prevent a power imbalance with the participants and gave them an opportunity to evaluate any potential side effects from the study that may have stemmed from recalling traumatic events.

## 4.3 INTERVIEW

### 4.3.1 *Where to Conduct Interviews*

When asking people to share their experiences, it is important to make them feel as comfortable as possible by allowing the participants to decide where the interviews be conducted. For example, for the participants in the community, the researchers went to

participants' institutions to meet with them. It does help, however, to request a space that will assure privacy and confidentiality so that the participant feels free to share sensitive information. At the hospital, this was achieved by serving candies and waters and sitting with the participant at 90-degree angle, which is thought to be the best interview position. The researcher would sit near the door in case there were any angry, hostile, or euphoric reactions during the interview. When thinking about the location, transportation and accessibility need to be considered. Fortunately, in the case of this study, Taiwan is a country with convenient public transportation. When scheduling an appointment with participants, the team would confirm that they knew the directions and had the access to transportation. The participants mostly used bus, subway, and rode scooters.

#### 4.3.2 *What Gets Patients to Talk?*

Establishing rapport is the first step. Before beginning interviews, the researcher would open with topics that patients found interesting, comfortable, and easy to answer. For example, when patients arrived, the researcher would welcome them and ask about the traffic. After entering the interview room, the researcher started with what they were currently doing in school or in work. Following this, the researcher carefully explained to participants the purpose of the interviews, the process for the next 45 minutes, and how they would treat the information gathered. The team offered the interviewee the option to ask questions and to have his or her concerns addressed before proceeding. Forming a collaborative atmosphere in which the interviewee is viewed as an active participant, rather than a passive subject of an interview, is important.

The main purpose of the interview was to understand the process of the illness and the explanatory model, which is the patients' explanation of their illness. Therefore, the first questions asked for patients' words for how they named their diagnosis, which were used

throughout the interviews. For example the researcher asked “What brought you here to the clinic?” and “How did you come to be in the hospital?” During the interviews, they would clarify meanings, role shifts, proximate and ultimate causes, focus on here and now, and allow patients to use graphic or metaphorical explanations to organize their thoughts. Examples of how the team conducted these are in the table below:

Table 4.1. Practical Interview Questions

Clarify meanings	<p>“You just said xxx, I am not sure what they meant, can you explain a little bit for me?”</p> <p>“ You said you had the symptom- spaced out.” Can you tell me what that was feeling like?”</p>
Role shifts	<p>“ What happened to your lives after those symptom occured? “</p> <p>“What have you been doing for those symptoms/problems?”</p>
Proximate and ultimate causes	<p>“What did you think were the causes of those symptoms?”</p> <p>When patients said “why me? “, listen and show empathy. Provide disease model when appropriate</p> <p>Patient” “ I think the evil spirits were the cause”</p> <p>Interivewer: “What makes you think that”?</p>
Here and now	<p>Interviewer: “I have a sense that you are not feeling very comfrotable when talking about that. I was wondering if you might be willing to share how you are feeling right now.”</p> <p>Interviewer: “I can see it upset you terribly”.</p>

Other counseling skills such as eye contact, active listening without making judgment, paraphrasing, encouragement (i.e. “uh-hum”), resonating (i.e. “tell me more about that”), and speaking plain language were used. The researcher also showed compassion by saying things like “I would feel sad as well if my friends stopped talking to me”. In addition, respecting the interviewee’s style and self-pacing increased their relaxation into the interview. Forty-five minutes might be long to some of the participants, so the researcher paid attention to signs of fatigue or any difficulty in paying attention. Often, they would ask whether the participant needed a break before moving on. They also checked whether the fatigue was due to any side

effects of medications or due to lack of sleep last night. Overall, the team found that being respectful and flexible was beneficial to conducting successful interviews.

#### 4.3.3 *Challenges During Interviews*

There were three major challenges in the study: tape recording, participants' off-topic thoughts or lack of insight into illness, and emotional effects that the interviewer had on the interview. Interviews were recorded, which participants agreed to as part of the informed consent. There was concern about having to ask people to allow themselves to be taped due to the negative reactions it might incite. However, tape-recording interviews is an important part of the interview process so that the researchers can later go back and analyze the interviews. Participants were informed of this and reassured the confidentiality and protection for those recordings. Most of the participants understood. In case the tape recordings failed, the researcher can review field notes taken during the interview process.

The next challenge occurred with short attention spans and off-topic ideas with interviewees. Since some of the questions were open-ended (i.e., How was it like when you first sensed the symptoms or changes in your life?), the interviewees would occasionally lose track of their ideas or talk about off-topic situations. To handle this, the researcher allowed them to speak freely, but took note of the topic that they were supposed to be focusing on, and then guided the interviewee back once there was a pause in the conversation with a neutral reminder of the focus of the question. For example, the researcher would say *“I really appreciate the story you told me. We were talking about how you xxx earlier. Is there anything you wanted to add? I'd love to know more about that.”* However, despite the tangent, these off-topic moments were useful in assessing whether the questions were unclear, which allowed the team to reformat them. When it was because of feeling embarrassed about an experience, questions were modified slightly to

normalize their negative experience with comments such as *“I heard other people your age had problems getting along with their peers. Did you have this experience?”* and *“I learned in nursing school that patients would have that situation, how about you? Some of my patients have said xxx. Did you have the same experience?”*

Some of the potential participants had a lack of insight, which is a common characteristic of the disorder. For example, they would say *“I don’t know. Everything is just fine.”* In this situation, the researcher avoided being confrontational because the lack of insight may, in some cases, serve as a defense against stigma and other persona attacks. Instead, the researcher acknowledged them and tried to sort out whether it was an issue of vocabulary that was limiting their expression. On the other hand, for enrolled participants who believed what they perceived was correct, as long as their perspectives were within their explanatory model, the researcher would not get angry or anxious about their failing to elicit the required information.

The last challenge was the researchers’ emotional safety and reflexivity. When interviewing patients’ traumatic experience, this might cause a secondary trauma that influences the interviewers’ emotions. However, it is critical that the researcher maintain their objectivity. Having a research journal was important, as it enabled researchers to reflect, to validate emotions rather than evaluating the facts, and to tolerate discomfort, disconnection, and strong emotions from participants. This made the researcher accountable because the researcher became more aware of the emotions and provided an opportunity for self-observation, thoughts, and reactions.

Reflexivity refers to researchers being part of, rather than separate from, the data. Here the researcher acknowledged her prior knowledge and was aware of her own personal preconceptions, values and beliefs. For example, in the research journal, the researcher asked:

*“Does that thought originate from my knowledge, experience or beliefs or does it belong to*

*the interviewees?”*

#### 4.3.4 *Field Notes and Memo Writing*

Field notes allow for invisible data to become visible. The question to ask oneself while writing them is simply “What do I notice?” This includes what one hears, sees, smells, tastes, and feels. In order to facilitate this process, it is helpful to immediately record what is noticed and when that occurs. Sometimes the researchers would discuss their observations with participants, allowing them to be involved in the research process. The field notes later become the data that we analyzed.

Each memo included a title, properties of codes, the conditions under which a code emerges, the supportive quotations for the code, and tracked ideas and audit trails. The memos were sentences, paragraphs or a few pages. As in the example below, the researcher used memos to generate explanations of the emerging concepts and to discern some of the interrelationships that exist among the codes. Since this study aimed to understand the process, the use of arrows was informative for researcher to tie together different pieces of data into a recognizable cluster of states.

---

#### **Sample memo- describing how the symptoms started**

---

Participant #12

##### A. FIRST TIME:

Stress (interpersonal+ love)-->being monitored--> withdraw, depressed, spaced out, cry and quit the school because family thought that is her problem getting along with people--> also had the feeling of out of control--> drop the school

*“Yes, last year. It was ...it was obvious that I had accumulated much pressure within one year. September, October, and November. And... just before I became ill...it was about the same (with much pressure). It might have been during my menstruation... Oh, actually, never mind. It wasn't during my menstruation. But I could feel that before my menstruation phase, I always get defeated easily... feel depressed... Seemed like I have been suffering from this condition for a long time. I often felt upset days before my menstruation phase.”*

---

---

## B. SECOND TIME:

Stress accumulated (work)--> notice to detail, sensitive --> A/H, doubt whether it is real, notice odd things, did not know why that happened--> quit seek for doctor (no psychiatry doctors) ->symptoms not alleviated, added thought problems, relate drug side effect to suspicious thought --> flash back-->seek for religious help no use lose herself, odd behaviors can't control, automatic body movement -->can't stop and out of control-->sent to the hospital and stay for 7 days.

-----Onset: 2015 Nov. -----

- Researcher's other thoughts: frontal lobe was injured. Afterwards, when the symptoms came, she would feel pain at that area.

---

## 4.4 DATA PREPARATION AND ANALYSIS

### 4.4.1 *Documents*

Documentation refers to materials such as transcripts, videos, diaries, manuals, memos, case records, and memorabilia of all sorts that can be used as additional information to supplement observations and interviews (Farber, 2006). For example, the researchers had patients' drawings that expressed their experiences. This provided insight into how they perceive and experience their world. Additionally, sometimes participants texted the researchers about their post-hoc feedback or things they wanted to add into the interview. The team used screen shots to capture those communications and saved them as a part of the data. There were also opportunities in local events to gather documentation. For instance, at the time the study was conducted, there was a patient with schizophrenia [not a study participant] who killed a five-year-old girl randomly on the street during the day. Many participants talked about their concerns that society might have more misunderstandings and biases toward them based on this event. The researcher

saved the news document to help reveal patterns about how information was communicated and whether there were any influences on patients' interviews.

#### 4.4.2 *Coding*

Qualitative research studies typically produce very large amounts of data that need to be managed efficiently. Computer packages can improve the efficiency of data management (Al-Busaidi, 2008). For example, the researcher used the Atlas.ti program to label and manage codes easily during the analysis process. As noted earlier, while a qualitative researcher is never entirely bias-free, utilizing multiple individuals to code the data can enhance the objectivity of any study. Therefore, it is helpful to involve other interested colleagues in the coding process. Having different people search through the data to look for themes and then coming together to discuss findings increased the credibility. One challenge when working with different coders is how to define segments of quotations as the unit of analysis. Communicating and discussing were useful to determine the length of quotations to be the unit of analysis and to develop the codebook. All the decisions, changes, and codebooks were saved in records.

### 4.5 CONCLUSIONS

This chapter described how to approach different challenges with conducting a qualitative research on patients with schizophrenia. Applying these experiences was very valuable and encourages internal collaboration and capacity building for more research with participants with mental illness. Establishing an altruistic, honest, and forthright working relationship with each person is the key to getting a study off the ground. It is important to be honest with participants, establish rapport, discuss confidentiality, discuss the interview purpose, remain open to the unknown, be flexible, and address any concerns/questions the interviewee may have. It is also

important to be sure to consider in advance the sort of barriers for patients with mental illness that may be a challenge for recruitment. Because researchers are interacting with the study participants, it is important to be aware of biases researchers bring to the study (Farber, 2006). Writing a self-reflective journal and using a team of coders increased the credibility of the codes the team developed. Additionally, maintaining audit trails for every decision made, member checking, and debriefing with colleagues were helpful in ensuring a self-aware research study. Efficiency in communicating with other staff about recruitment and scheduling, data management, coding, and the documentation of all related issues require a robust computerized system. Google calendar, internal email systems, and Excel spreadsheets for tracking attendance and questionnaires were found to be effective in the study.

## Chapter 5. GROUNDED THEORY IN PSYCHIATRY NURSING RESEARCH

### 5.1 INTRODUCTION

Psychotic states are primarily experiences of the self (G. Bota & Ricci, 2007). Patients themselves perceive a dynamic nature of action-interaction within the illness, so they make constant adjustments for keeping pace with the changes in conditions. In clinical settings and in research, patients as a source of information are relatively neglected, leading to a void of information from the first-hand perspective. For example, there is a tendency, especially in busy acute psychiatric units, to treat the patients and discharge them without ever reconstructing the patients' personal experience of becoming psychotic (Yung & McGorry, 1996a). Because of the above factors, qualitative study offers an important framework to examine firsthand experience and affords an opportunity for participants to be partners in the generation of meaningful research findings (Leavy, 2014).

Current qualitative research on exploring psychotic disorders, which has a trajectory that generally leads from a pre-psychotic prodrome to full-blown psychosis, relies on descriptive and phenomenological studies. The Grounded Theory Method (GTM) was used to explore common themes pertaining to social or psychological processes (Corbin & Strauss, 2014). GTM goes beyond simple exploration of subjective perceptions toward the illness (Tweed & Charmaz, 2012) because it emphasizes the connections between action and interaction, which have to be linked to the conditions with which patients react. However, the use of GTM in mental health services research have long been regarded as unscientific, largely due to a lack of understanding and experience with such methods (Palinkas, 2014). Essential Grounded Theory consists of the following attributes: simultaneous data collection and analysis, the development of codes from

the data rather than from theory, constant comparison of data at all levels of the data collection and analytic process, theoretical sampling to serve the purpose of theory generation rather than representativeness of the sample, and memo writing to refine and elaborate on emerging categories and the relationships among them. As it became increasingly used in mental health and psychiatry nursing research, the efforts to demonstrate the rigor applied to the collection and analysis of interview data became essential.

## 5.2 HUMAN SUBJECTS PROTECTIONS

In this paper, a working example of how to use Grounded Theory methodology in practice with schizophrenia patients is documented. Before starting the research, the Institutional Review board of the university as well as the hospital approved the project. It was ensured that participation was voluntary and that participants could refuse or withdraw without loss of benefits to which they are otherwise entitled.

When meeting with eligible participants, the researchers provided a copy of informed consent, which was a plain language statement explaining the research and their rights. They guaranteed that anything the participants said or did would be kept confidential and that all identifying information would be removed. All participants were advised of their right to withdraw from the study at any time without jeopardy to their care. Initial meetings with the researcher and the informed consent process are meaningful and have significance for participants with schizophrenia. It is important to note that the informed consent process is not reducible to a single action, sentence, moment, or signature. In fact, it is ongoing throughout various aspects of the research process, as is the researcher's responsibility to advocate for the participant's rights. In the consent process, the researchers told patients that if they witness or

hear about illegal or dangerous behaviors or situations that place a person in a life-threatening situation, they would have to notify the appropriate authorities.

Patients with schizophrenia may have fluctuating cognitive impairment and decision-making capacities (Graor & Knapik, 2013). Therefore, enhanced informed consent considers the sharing of information from the researcher's perspective, which may include an evaluation of the participant's perceived capability to emotionally manage information. Participants signed informed-consent forms and were offered TWD \$900 (USD \$30) honoraria for their participation. Research has shown that monetary or other incentives may be more highly salient for potential participants who have already experienced a decline in functioning than for less impaired individuals with more opportunities for financial income (Morris & Heinssen, 2014). Individuals often volunteer for research for altruistic reasons (Dainesi & Goldbaum, 2014; L. W. Roberts, Warner, Anderson, Smithpeter, & Rogers, 2004) and these participants were just the same.

### 5.3 RESULTS

The fieldwork experience demonstrates how to maintain data integrity data in the process following GTM. Through describing the steps of conducting the research and how these were consistent with Grounded Theory methodology, the results can be used as a detailed model by other researchers.

#### 5.3.1 *Recruitment and Sampling*

The researchers recruited patients from a medical center, a day care unit, and two community centers for patient rehabilitation in Taiwan. The researcher had in-person meetings with staff who provided names and helped to introduce research to the potential participants,

posted research flyers recruiting volunteers, and also used social media. The study inclusion criteria included patients who: (a) were diagnosed with schizophrenia; (b) resided in the inpatient unit at a medical center; (c) were capable of providing informed consent; (d) had sufficient language skills to participate in an in-depth interview; and (e) were 18-40 years old. Regarding the age range, most cases of schizophrenia appear in the late teens or early adulthood; however, it is quite rare in people under 10 years of age, or over 45 (Mueser & McGurk, 2004). On the other hand, patients who had psychotic disorder with affective feature (i.e. major depression), or were using illicit substances, or had medical causes associated with their psychosis were excluded.

### 5.3.2 *Data Collection*

The researcher/interviewer (SCC) traveled to three different towns in Taiwan and conducted the interviews. The 25 participants were interviewed at places convenient for them, such as the family therapy room at a medical center, community centers or the participant's school. One initial interview was scheduled with each participant. Interviews were semi-structured and based on the research questions with the use of an interview protocol, which had been modified based on two pilot interviews before we started the data collection. According to the protocol, the interviewer would first introduce herself, briefly describe the process of the interview, and make sure participants understood what they were going to do by asking them to give a brief description of what they understood after our introduction. Most importantly, the interviewer emphasized that patients had the opportunity to stop and ask questions at any time.

The interviews were conducted in Mandarin. There were four types of questions included in the interview. First, guiding questions such as "Tell me, how would you like me to call the diagnosis that you were given?". In this case, the interviewer wanted to use the term that patients

felt most comfortable with throughout the interview process. Second, sensitizing questions were used, such as “What is the meaning of the experience to the patients? What consequences occurred after patients adopted their coping strategies?” Third, theoretical questions like “How do the symptoms or events change over time? How do all the events play into the onset of psychosis?” Last came practical questions, which provided direction for theoretical sampling, which happened after the analysis. Researchers asked themselves “Which concepts are well developed? Which ones are not?” to achieve this point. Interviews were recorded. All recordings were kept in a secure location throughout the course of data collection and analysis. Because of the need to disseminate the findings, the recordings will be destroyed ten years after completion of the study based on the informed consent form approved by the Human Subjects Division.

In addition to interviews, data also includes field notes and memos. Memo writing and field notes differ in that field notes are data that may contain some conceptualization and thoughts. Writing field notes consistently and copiously helped build the intellectual assets of this study (Leavy, 2014). Memo writing is an intermediate stage between data collection and write up and involves the detailed capturing of the researcher’s thoughts, hunches, interpretations, and decision making throughout the analysis (Tweed & Charmaz, 2012). The early memos were case-based, tentative, and exploratory. They were filled with empirical information to check and questions to pursue. The memos included titles to easily sort definitions and properties from data, delineation conditions under the code or categories, representative quotations as evidence to support the code or categories, and ideas for future references. Later memos were more spread across cases, abstract, and sophisticated. The associations and relationships between codes and categories were demonstrated. The researcher used these memos to record our thinking about the meaning of codes and to record our thinking about how and when processes occurred, how they

changed, and what their consequences were. The researcher also used memo-writing to track fleeting ideas that they had not noticed before coding (i.e. family factors, patients' suggestions for early interventions).

### 5.3.3 *Data Analysis*

Before translating the recorded interviews into English, interviews were transcribed in full and read over systematically in order to carefully review their contents. The process of review involved reading through the transcribed interviews while listening to the audiotapes at the same time. This helped identify any errors in transcription. Field notes and memos were dictated into a word processor following each interview. Transcripts, field notes, and memos were read and re-read before coding commenced in order to become thoroughly familiar with the data. Atlas. Ti software (Muhr & Friese, 2004) was used to assist in the analysis process.

Two coders with graduate-level qualitative research experience, clinical experience working with patients with cognitive disorders, and with language fluency in both English and Chinese independently read and coded a sample of five interviews using a line-by-line, open-coding process. When doing the open coding, researchers selected the quotations and assigned conceptual codes. The coded data were then grouped into a coding scheme based on the conceptual codes identified. Different researchers coding the same data may generate new insights because perspectives and social locations affect how code is made. The two coders made repeated comparisons and modifications to reach consensus. The validity in this stage was confirmed between the coders by meeting a consensus. If consensus was not met, the team consulted experienced researchers. Although there were variations in the labeling of some codes, there was a 95% consensus after several discussions regarding the main emerging categories. A codebook was developed to guide the rest of the coding. Catalyst online survey software was

used for the inter-coder reliability process, which was beneficial in that it allowed for record tracking and was free for university users.

The second step was to elevate concepts to provisional categories. The team grouped the initial codes according to their respective properties (Corbin & Strauss, 2014). This used a set of procedures that refine the open coding grid by identifying of patterns and relationships during the process of category development. This stage is called axial coding. The next step, selective coding, focused on identifying a core category and attempting to establish links and sequence among categories. The code categories began to emerge only after constant comparative analysis with the data, persistent questioning and painstaking analytical thinking. The core category recurred frequently in the data and represented the processes that patients had in responses to the prodromal stage. Once the core category was identified, the researcher concentrated on clustering around four phases. The phases, in turn were embedded within two domains of wellness-illness transition: from manageable to losing control.

In coding, using line-by-line coding was found to be particularly informative during initial data collection. It helped to identify gaps in the transcripts and spurred a comparison of data and codes. It also aided in pursuing subsequent data collection and ideas.

#### 5.3.4 *Theoretical Sampling*

Theoretical sampling is a strategy designed to sample new cases or data actively in order to develop, refine, and elaborate the emerging theory (Tweed & Charmaz, 2012). After the initial data collection and analysis, the researchers used theoretical sampling for the next stage of data collection through a process of concurrent analyses that continued cyclically until categories were fully developed or saturated (Corbin & Strauss, 2014). For instance, at one point in the cyclical process of data collection and analysis, the issue of stressful experience was mentioned

among all the participants. The temptation was for the researcher to claim that the data was saturated with this particular issue. However, the researcher persevered, using the flip-flop technique, which means turning the concept in order to view it from different perspectives (McCann & Clark, 2004). For example, when participants recalled stressful feeling from the work or school in the prodromal stage, researchers asked “What was the stressful feeling like?” However, some participants could not answer that question, so researchers simply asked the opposite: comparing with your stressful feeling right now in work, is the feeling similar with what you had before the diagnosis? Eventually a group of patients voiced that the stressful experience was more worrisome after they were diagnosed. Before they were diagnosed, they would find success with different ways to solve the stress. After they were diagnosed, the stress was caused by external factors as well as not being able to go back to their “normal self”. This resulted in a competing category where stress was not necessarily the inducer for the onset of psychosis. Thus, the flip-flop technique helped demonstrate that more data needed to be gathered on that particular issue.

All elements of the analysis—data, codes, categories, and concepts—were constantly compared within and between each other. The comparative process entails looking for similarities, differences, and nuances between all the able elements in order to generate a more clear understanding of the material (Silverman, 2013; Tweed & Charmaz, 2012). Constant comparison makes it more likely that analysts can discover variation as well as a general pattern. In the end, theoretical saturation occurs when no new codes are identified in later rounds of data generation that pertain to a particular category (Corbin & Strauss, 2014).

### 5.3.5 *Member Checking*

Member checking involves checking and commenting upon the data with the aim of validating the findings. For patients with schizophrenia, there is a dilemma when considering member checking because member checks might endanger trust relationships. Patients might think that other participants had access to their comments or that the researcher doubts their responses. There is also the potential harm caused by reminders of past traumatic experiences. Do member checking whenever is appropriate. See this as a validation and show respect toward patients. The researchers in this study found it useful to use drawing as a form of member checking (picture 2.1). Here they were checking with a female participant about a commonly shown feature, information overload, and she drew this picture to show arrows as how the information comes from all directions into her head (the circle) as well as how she coped with this overwhelming information by inserting her own will and to breaking the limitation she set for herself.

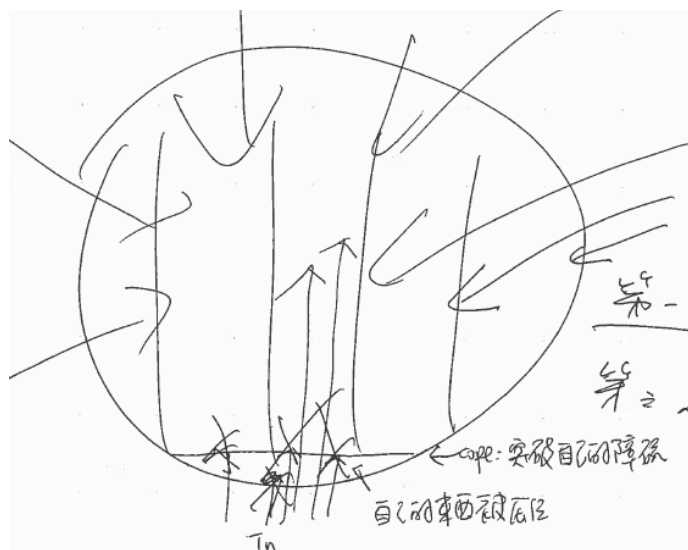


Figure 5.1. An Example of Member Checking by Drawing.

The researchers shared their interpretation of the data with six participants in an effort to ensure that it reflected the participants' experiences. These participants were chosen according to their availability and whether there were willing to take extra time to read through the transcripts.

The participants received the transcripts as well as a summary of the interpretation of the data and were invited to respond. The team met again with them to discuss whether the grouping of categories accurately reflected their own words and experiences. They found that the codes and categories were accepted by and resonated with these six participants.

## Chapter 6. CONCLUSIONS

From Chapter 1, the background of this dissertation showed that the prodrome is potentially important for early diagnosis and management of psychotic disorders. However, early identification of schizophrenia is a long-standing and perplexing problem because prodromal signs have been largely nonspecific to psychosis outcome. As such, it is important to understand the course of symptom changes for improving early identification of schizophrenia.

Chapter 2 of this dissertation presented the way patients with schizophrenia experienced the dynamic course of the disease while in the prodromal stage. The major categories from “something is wrong” to “losing control” emerged from patient interviews through the use of GTM. Under these categories, four distinct stages emerged from the data. The first stage, *something is wrong* related to the process where patients first experienced symptoms. This stage contains two sub-categories. The first phase, “initial symptoms”, portrayed how patients described the very first unusual experience. The second phase, “progressive symptoms”, described how the accumulated symptoms started influencing daily activities, such as difficulty sleeping. The second stage *boiling up* portrayed the increased frequency and severity of the symptoms. There are also two distinct sub-categories from patients’ experience: internalizing and externalizing psychopathology. Here, patients suffered from the overwhelming internal information and started having problems communicating externally with people. The third stage *breaking point* showed the unrelenting and escalated symptoms from previous stages. This stage leads to the last category *losing control*, where patients lost self control over those non-stop symptoms.

Chapter 3 described the coping strategies that participants used before they sought

professional help. In all cases, the decision to initiate coping behaviors was a matter of an appraisal of the situation. Initially, when participants recognized that something was wrong, they became preoccupied with the fact that they did not know what was wrong. This preoccupation consumed their time and impacted their ability to accomplish planned life goals. As a result, participants were unable to effectively respond to their established obligations, such as focusing on lectures at school. Participants reported that their established life patterns changed when those unusual sensations or disturbed behaviors became pronounced. In an attempt to manage the accumulation of symptoms, participants engaged in a process called “trying to find former self”.

The other focus of this dissertation was to disclose practical examples for initiating, planning, executing, monitoring, analysis and reporting a clinical qualitative study in a vulnerable population. Chapters 4 and 5 provided a general understanding to ensure the success and credibility of conducting a GTM study in clinical settings.

Psychotic disorders typically have their clinical onset in young adulthood, and often derail educational progress and interfere with the acquisition of social skills required for independent adult functioning. Both of these outcomes lead to a negative impact on society through the loss of healthy, productive adults and the socio-economic costs that accompany that detriment. Hence, this dissertation could be the basis for improving the validity of screening tools for early identification and on developing suitable intervention programs for people with early warning signs of developing schizophrenia. Implications of this research will result in recommendations for strengthening actions by practitioners, researchers, and policy makers.

Verification and extension of this substantive theory is warranted due to the limitation of including only patients with schizophrenia in Taiwan. These preliminary results are pending validation by interviewing more participants and including outsider perspectives such as

observations from relatives and healthcare providers who witnessed the process. Recent research shows that cultural perceptions toward mental illness have an impact on the duration of untreated psychosis (Devi Thakoor et al., 2016), which is an important factor for prognosis.

## BIBLIOGRAPHY

- Addington, Jean, Heinssen, Robert K, Robinson, Delbert G, Schooler, Nina R, Marcy, Patricia, Brunette, Mary F, . . . Penn, David. (2015). Duration of untreated psychosis in community treatment settings in the United States. *Psychiatric Services, 66*(7), 753-756.
- Al-Busaidi, Zakiya Q. (2008). Qualitative research and its uses in health care. *Sultan Qaboos University Medical Journal, 8*(1), 11.
- Amminger, G., Leicester, Steven, Francey, Shona, & McGorry, Patrick D. (2005). The prodromal course. *Juvenile Onset Schizophrenia: Assessment, Neurobiology, and Treatment, 199-219*.
- Asher, Carolyn J., & Gask, Linda. (2010). Reasons for illicit drug use in people with schizophrenia: Qualitative study. *BMC Psychiatry, 10*. doi: 10.1186/1471-244X-10-94
- Bergner, E., Leiner, A. S., Carter, T., Franz, L., Thompson, N. J., & Compton, M. T. (2008). The period of untreated psychosis before treatment initiation: a qualitative study of family members' perspectives. *Compr Psychiatry, 49*(6), 530-536. doi: 10.1016/j.comppsy.2008.02.010
- Birchwood, Max, Connor, Charlotte, Lester, Helen, Patterson, Paul, Freemantle, Nick, Marshall, Max, . . . Amos, Tim. (2013). Reducing duration of untreated psychosis: care pathways to early intervention in psychosis services. *The British Journal of Psychiatry, 203*(1), 58-64.
- Bota, G., & Ricci, F. (2007). Empathy as a method of identification of the debut of the prodrome of schizophrenia. *Bulletin of the Menninger Clinic, 71*(4), 312-324.
- Bota, R. G., Munro, J. S., Ricci, W. F., & Bota, D. A. (2006). The dynamics of insight in the prodrome of schizophrenia. *CNS Spectr, 11*(5), 355-362.

- Bourque, J., Spechler, P. A., Potvin, S., Whelan, R., Banaschewski, T., Bokde, A. L., . . .
- Conrod, P. J. (2017). Functional Neuroimaging Predictors of Self-Reported Psychotic Symptoms in Adolescents. *Am J Psychiatry*, appiajp201716080897. doi: 10.1176/appi.ajp.2017.16080897
- Brand, Rachel M., Harrop, Chris, & Ellett, Lyn. (2011). What is it like to be friends with a young person with psychosis? A qualitative study. *Psychosis: Psychological, Social and Integrative Approaches*, 3(3), 205-215. doi: 10.1080/17522439.2010.528562
- Cannon, Tyrone D, Yu, Changhong, Addington, Jean, Bearden, Carrie E, Cadenhead, Kristin S, Cornblatt, Barbara A, . . . McGlashan, Thomas H. (2016). An individualized risk calculator for research in prodromal psychosis. *American Journal of Psychiatry*, 173(10), 980-988.
- Carver, Charles S. (1997). You want to measure coping but your protocol's too long: Consider the brief cope. *International journal of behavioral medicine*, 4(1), 92-100.
- Cheng, S. C., & Schepp, K. G. (2016). Early Intervention in Schizophrenia: A Literature Review. *Arch Psychiatr Nurs*, 30(6), 774-781. doi: 10.1016/j.apnu.2016.02.009
- Cheng, S. C., Walsh, Elaine, & Schepp, Karen G. (2016). Vulnerability, Stress, and Support in the Disease Trajectory from Prodrome to Diagnosed Schizophrenia: Diathesis–Stress–Support Model. *Archives of psychiatric nursing*, 30(6), 810-817.
- Cooke, Michael, Peters, Emmanuelle, Fannon, Dominic, Anilkumar, Anantha PP, Aasen, Ingrid, Kuipers, Elizabeth, & Kumari, Veena. (2007). Insight, distress and coping styles in schizophrenia. *Schizophrenia research*, 94(1), 12-22.
- Corbin, Juliet, & Strauss, Anselm. (2014). *Basics of qualitative research: Techniques and procedures for developing grounded theory*: Sage publications.

- Corcoran, C., Davidson, L., Sills-Shahar, R., Nickou, C., Malaspina, D., Miller, T., & McGlashan, T. (2003). A qualitative research study of the evolution of symptoms in individuals identified as prodromal to psychosis. *Psychiatr Q*, *74*(4), 313-332.
- Cotton, SM, McCann, TV, Gleeson, JF, Crisp, K, Murphy, BP, & Lubman, DI. (2013). Coping strategies in carers of young people with a first episode of psychosis. *Schizophrenia research*, *146*(1), 118-124.
- Dainesi, Sonia Mansoldo, & Goldbaum, Moisés. (2014). Reasons behind the participation in biomedical research: a brief review. *Revista Brasileira de Epidemiologia*, *17*, 842-851.
- Devi Thakoor, J. P., Dong, H., Zhang, X., Wang, G., Huang, H., Xiang, Y., & Hao, W. (2016). Duration of Untreated Psychosis in Chinese and Mauritian: Impact of Clinical Characteristics and Patients' and Families' Perspectives on Psychosis. *PLoS One*, *11*(6), e0157083. doi: 10.1371/journal.pone.0157083
- Farber, Nancy. (2006). Conducting qualitative research: A practical guide for school counselors. *Professional School Counseling*, *9*(4), 367-375.
- Gater, A., Rofail, D., Tolley, C., Marshall, C., Abetz-Webb, L., Zarit, S. H., & Berardo, C. G. (2014). "Sometimes It's Difficult to Have a Normal Life": Results from a Qualitative Study Exploring Caregiver Burden in Schizophrenia. *Schizophr Res Treatment*, *2014*, 368215. doi: 10.1155/2014/368215
- Gorwood, Philip. (2008). Neurobiological mechanisms of anhedonia. *Dialogues in Clinical Neuroscience*, *10*(3), 291-299.
- Graor, C. H., & Knapik, G. P. (2013). Addressing methodological and ethical challenges of qualitative health research on persons with schizophrenia and bipolar disorder. *Arch Psychiatr Nurs*, *27*(2), 65-71. doi: 10.1016/j.apnu.2012.10.006

- Green, Michael F, Nuechterlein, Keith H, Gold, James M, Barch, Deanna M, Cohen, Jonathan, Essock, Susan, . . . Heaton, Robert K. (2004). Approaching a consensus cognitive battery for clinical trials in schizophrenia: the NIMH-MATRICES conference to select cognitive domains and test criteria. *Biological psychiatry*, 56(5), 301-307.
- Gronholm, Petra C, Thornicroft, Graham, Laurens, Kristin R, & Evans-Lacko, Sara. (2016). Conditional Disclosure on Pathways to Care: Coping Preferences of Young People at Risk of Psychosis. *Qualitative Health Research*, 1049732316680337.
- Health, National Institute of Mental. (2015). Schizophrenia. Retrieved August 6, 2015
- Henderson, A. R., & Cock, A. (2014). The Responses of Young People to Their Experiences of First-Episode Psychosis: Harnessing Resilience. *Community Ment Health J.* doi: 10.1007/s10597-014-9769-9
- Higgins, June E, & Endler, Norman S. (1995). Coping, life stress, and psychological and somatic distress. *European journal of personality*, 9(4), 253-270.
- Jalbrzikowski, Maria, Sugar, Catherine A, Zinberg, Jamie, Bachman, Peter, Cannon, Tyrone D, & Bearden, Carrie E. (2014). Coping styles of individuals at clinical high risk for developing psychosis. *Early intervention in psychiatry*, 8(1), 68-76.
- Kay, S. R., Fiszbein, A., & Opler, L. A. (1987). The positive and negative syndrome scale (PANSS) for schizophrenia. *Schizophr Bull*, 13(2), 261-276.
- Kendler, K. S., Lieberman, J. A., & Walsh, D. (1989). The Structured Interview for Schizotypy (SIS): a preliminary report. *Schizophr Bull*, 15(4), 559-571.
- Kommescher, Mareike, Gross, Sonja, Pützfeld, Verena, Klosterkötter, Joachim, & Bechdolf, Andreas. (2017). Coping and the stages of psychosis: an investigation into the coping

- styles in people at risk of psychosis, in people with first-episode and multiple-episode psychoses. *Early intervention in psychiatry*, 11(2), 147-155.
- Leavy, Patricia. (2014). *The Oxford handbook of qualitative research*: Oxford University Press.
- Lee, Heeyoung, & Schepp, Karen G. (2013). Lessons learned from research with adolescents with schizophrenia and their families. *Archives of psychiatric nursing*, 27(4), 198-203.
- Lester, H., Marshall, M., Jones, P., Fowler, D., Amos, T., Khan, N., & Birchwood, M. (2011). Views of young people in early intervention services for first-episode psychosis in England. *Psychiatr Serv*, 62(8), 882-887. doi: 10.1176/appi.ps.62.8.882
- Leutwyler, Heather, Hubbard, Erin M., Jeste, Dilip V., & Vinogradov, Sophia. (2013). 'We're not just sitting on the periphery': A staff perspective of physical activity in older adults with schizophrenia. *The Gerontologist*, 53(3), 474-483. doi: 10.1093/geront/gns092
- Loebel, Antony D, Lieberman, Jeffrey A, Alvir, Jose M, Mayerhoff, David I, Geisler, Stephen H, & Szymanski, Sally R. (1992). Duration of psychosis and outcome in first-episode schizophrenia. *The American journal of psychiatry*, 149(9), 1183.
- Lysaker, Paul H, Davis, Louanne W, Lightfoot, Jeffrey, Hunter, Nicole, & Stasburger, Amy. (2005). Association of neurocognition, anxiety, positive and negative symptoms with coping preference in schizophrenia spectrum disorders. *Schizophrenia Research*, 80(2), 163-171.
- MacAulay, Rebecca, & Cohen, Alex S. (2013). Affecting coping: Does neurocognition predict approach and avoidant coping strategies within schizophrenia spectrum disorders? *Psychiatry research*, 209(2), 136-141.

- McCann, Terence V, & Clark, Eileen. (2003). A grounded theory study of the role that nurses play in increasing clients' willingness to access community mental health services. *International Journal of Mental Health Nursing*, 12(4), 279-287.
- McCann, Terence V, & Clark, Eileen. (2004). Grounded theory in nursing research: Part 3—Application. *Nurse researcher*, 11(2), 29-39.
- Melamed, Samuel. (1994). Life stress, emotional reactivity and their relation to plasma lipids in employed women. *Stress Medicine*, 10(3), 167-175.
- Miller, T. J., Zipursky, R. B., Perkins, D., Addington, J., Woods, S. W., Hawkins, K. A., . . . McGlashan, T. H. (2003). The PRIME North America randomized double-blind clinical trial of olanzapine versus placebo in patients at risk of being prodromally symptomatic for psychosis. II. Baseline characteristics of the "prodromal" sample. *Schizophr Res*, 61(1), 19-30.
- Mokhtari, M., & Rajarethinam, R. (2013). Early intervention and the treatment of prodrome in schizophrenia: a review of recent developments. *J Psychiatr Pract*, 19(5), 375-385. doi: 10.1097/01.pra.0000435036.83426.94
- Morris, Sarah E, & Heinsen, Robert K. (2014). Informed consent in the psychosis prodrome: ethical, procedural and cultural considerations. *Philosophy, Ethics, and Humanities in Medicine*, 9(1), 19.
- Mueser, Kim T., & McGurk, Susan R. (2004). *Schizophrenia* (Vol. 363): Elsevier.
- Muhlbauer, S. A. (2002). Navigating the storm of mental illness: phases in the family's journey. *Qual Health Res*, 12(8), 1076-1092.
- Muhr, Thomas, & Friese, Susanne. (2004). User's Manual for ATLAS. ti 5.0. *Berlin: ATLAS. ti Scientific Software Development GmbH.*

- Muller, H., Laier, S., & Bechdorf, A. (2014). Evidence-based psychotherapy for the prevention and treatment of first-episode psychosis. *Eur Arch Psychiatry Clin Neurosci*, *264 Suppl 1*, 17-25. doi: 10.1007/s00406-014-0538-0
- Nuechterlein, K. H., & Dawson, M. E. (1984). A heuristic vulnerability/stress model of schizophrenic episodes. *Schizophr Bull*, *10*(2), 300-312.
- Olf, Miranda, Langeland, Willie, & Gersons, Berthold PR. (2005). The psychobiology of PTSD: coping with trauma. *Psychoneuroendocrinology*, *30*(10), 974-982.
- Olsen, K. A., & Rosenbaum, B. (2006). Prospective investigations of the prodromal state of schizophrenia: assessment instruments. *Acta Psychiatr Scand*, *113*(4), 273-282. doi: 10.1111/j.1600-0447.2005.00698.x
- Palinkas, Lawrence A. (2014). Qualitative methods in mental health services research. *Journal of Clinical Children and Adolescence Psychology* *43*(6), 851-861. doi: 10.1080/15374416.2014.910791
- Patrick, D. L., Burns, T., Morosini, P., Gagnon, D. D., Rothman, M., & Adriaenssen, I. (2010). Measuring social functioning with the personal and social performance scale in patients with acute symptoms of schizophrenia: interpretation of results of a pooled analysis of three Phase III trials of paliperidone extended-release tablets. *Clin Ther*, *32*(2), 275-292. doi: 10.1016/j.clinthera.2010.02.003
- Phillips, L. J., Yung, A. R., & McGorry, P. D. . (2000). Identification of young people at risk of psychosis: validation of Personal Assessment and Crisis Evaluation Clinic intake criteria. *Australian and New Zealand Journal of Psychiatry*, *34*(s2), 164-169.

- Phillips, Lisa Jane, Edwards, Jane, McMurray, Nancy, & Francey, Shona. (2012). Comparison of experiences of stress and coping between young people at risk of psychosis and a non-clinical cohort. *Behavioural and cognitive psychotherapy*, 40(01), 69-88.
- Ponizovsky, Alexander M, Finkelstein, Irena, Poliakova, Inna, Mostovoy, Dimitry, Goldberger, Nehama, & Rosca, Paula. (2013). Interpersonal distances, coping strategies and psychopathology in patients with depression and schizophrenia. *World journal of psychiatry*, 3(3), 74.
- Roberts, Laura Weiss, Warner, Teddy D, Anderson, Charles T, Smithpeter, Megan V, & Rogers, Melinda K. (2004). Schizophrenia research participants' responses to protocol safeguards: recruitment, consent, and debriefing. *Schizophrenia research*, 67(2), 283-291.
- Roberts, T., & Bowers, B. (2015). How nursing home residents develop relationships with peers and staff: a grounded theory study. *Int J Nurs Stud*, 52(1), 57-67. doi: 10.1016/j.ijnurstu.2014.07.008
- Romano, D. M., McCay, E., Goering, P., Boydell, K., & Zipursky, R. (2010). Reshaping an enduring sense of self: the process of recovery from a first episode of schizophrenia. *Early Interv Psychiatry*, 4(3), 243-250. doi: 10.1111/j.1751-7893.2010.00187.x
- Roth, Susan, & Cohen, Lawrence J. (1986). Approach, avoidance, and coping with stress. *American psychologist*, 41(7), 813.
- Rudnick, Abraham, & Martins, Jennifer. (2009). Coping and schizophrenia: a re-analysis. *Archives of psychiatric nursing*, 23(1), 11-15.
- Seidman, L. J., Shapiro, D. I., Stone, W. S., Woodberry, K. A., Ronzio, A., Cornblatt, B. A., . . . Woods, S. W. (2016). Association of Neurocognition With Transition to Psychosis:

- Baseline Functioning in the Second Phase of the North American Prodrome Longitudinal Study. *JAMA Psychiatry*, 73(12), 1239-1248. doi: 10.1001/jamapsychiatry.2016.2479
- Shepherd, S., Depp, C. A., Harris, G., Halpain, M., Palinkas, L. A., & Jeste, D. V. (2012). Perspectives on schizophrenia over the lifespan: a qualitative study. *Schizophr Bull*, 38(2), 295-303. doi: 10.1093/schbul/sbq075
- Silverman, David. (2013). *Doing qualitative research: A practical handbook*: SAGE Publications Limited.
- Simon, G. E., Coleman, K. J., Yarborough, B. J. H., Operskalski, B., Stewart, C., Hunkeler, E. M., . . . Beck, A. (2017). First Presentation With Psychotic Symptoms in a Population-Based Sample. *Psychiatr Serv*, 68(5), 456-461. doi: 10.1176/appi.ps.201600257
- Slatyer, S., Williams, A. M., & Michael, R. (2015). Seeking empowerment to comfort patients in severe pain: a grounded theory study of the nurse's perspective. *Int J Nurs Stud*, 52(1), 229-239. doi: 10.1016/j.ijnurstu.2014.06.010
- Strauss, Anselm, & Corbin, Juliet M. (1997). *Grounded theory in practice*: Sage.
- Su, C. T., Ng, H. S., Yang, A. L., & Lin, C. Y. (2014). Psychometric evaluation of the Short Form 36 Health Survey (SF-36) and the World Health Organization Quality of Life Scale Brief Version (WHOQOL-BREF) for patients with schizophrenia. *Psychol Assess*, 26(3), 980-989. doi: 10.1037/a0036764
- Tweed, Alison, & Charmaz, Kathy. (2012). Grounded theory methods for mental health practitioners. *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners*, 131-146.
- van der Gaag, M., Nieman, D. H., Rietdijk, J., Dragt, S., Ising, H. K., Klaassen, R. M., . . . Linszen, D. H. (2012). Cognitive behavioral therapy for subjects at ultrahigh risk for

- developing psychosis: a randomized controlled clinical trial. *Schizophr Bull*, 38(6), 1180-1188. doi: 10.1093/schbul/sbs105
- Wainwright, L. D., Glentworth, D., Haddock, G., Bentley, R., & Lobban, F. (2014). What do relatives experience when supporting someone in early psychosis? *Psychol Psychother*. doi: 10.1111/papt.12024
- Wang, Chun, & Xiong, Wei. (2013). Treatment effect of group psychotherapy in inpatients with schizophrenia and mood disorders: A qualitative research. *Chinese Mental Health Journal*, 27(7), 508-512.
- Woodberry, K. A., Serur, R. A., Hallinan, S. B., Mesholam-Gately, R. I., Giuliano, A. J., Wojcik, J. D., . . . Seidman, L. J. (2014). Frequency and pattern of childhood symptom onset reported by first episode schizophrenia and clinical high risk youth. *Schizophr Res*. doi: 10.1016/j.schres.2014.05.017
- Wu, B. J., Lin, C. H., Tseng, H. F., Liu, W. M., Chen, W. C., Huang, L. S., . . . Lee, S. M. (2013). Validation of the Taiwanese Mandarin version of the Personal and Social Performance scale in a sample of 655 stable schizophrenic patients. *Schizophr Res*, 146(1-3), 34-39. doi: 10.1016/j.schres.2013.01.036
- Yung, A. R., & McGorry, P. D. (1996a). The initial prodrome in psychosis: descriptive and qualitative aspects. *Aust N Z J Psychiatry*, 30(5), 587-599.
- Yung, A. R., & McGorry, P. D. (1996b). The prodromal phase of first-episode psychosis: past and current conceptualizations. *Schizophr Bull*, 22(2), 353-370.
- Yung, A. R., Nelson, B., Thompson, A., & Wood, S. J. (2010). The psychosis threshold in Ultra High Risk (prodromal) research: is it valid? *Schizophr Res*, 120(1-3), 1-6. doi: 10.1016/j.schres.2010.03.014

Zdanowicz, N., Mees, L., Jacques, D., Tordeurs, D., & Reynaert, C. (2014). Assessment and treatment of the risk of psychosis in adolescents - a review. *Psychiatr Danub*, 26(2), 115-121.

## APPENDIX A

### University of Washington Human Subjects Review Approval Letter

PAGE 1 RECEIVED  
 UNIVERSITY OF WASHINGTON  
 Human Subjects Division  
 Box 359470  
 APPLICATION: Human Subjects Review

OCT 30 2015  
UW

BOX FOR COMMITTEE USE ONLY

MASTER  COMM.  INVESTIGATOR

APPLICATION NO. 50737-ED

**I. PRINCIPAL INVESTIGATOR** (Provide all the information requested. Change of PI requires a modification. All paper-based correspondence will be directed to this person. Please list the mailing address for paper-based correspondence. You may designate a contact person other than yourself in section II., below.)

Name Chieh Cheng Title student Position \_\_\_\_\_

Home Institution (or source of paycheck) UW

UW Student? Home institution is UW. \_\_\_\_\_

Home UW Department (if applicable) School of Nursing Division --

UW Position or appointment (choose the most appropriate one):

Faculty:  Regular Faculty Appointment  Research Faculty Appointment  Clinical Faculty Appointment  
 Visiting Faculty Appointment  Dual Appointment with PNNL  
 Other (describe): \_\_\_\_\_

Student:  Matriculated Undergraduate Student  Graduate or Professional Student (matriculated or approved "On Leave")  WWAMI Student

Resident or Fellow at the UW or Local VA  UW Administration or Staff  None

Campus Box # 357260 Other Address if not at UW \_\_\_\_\_

Telephone 2064325117 Fax \_\_\_\_\_ e-mail ccsunny@uw.edu

**II. IRB CONTACT PERSON** (Provide all the information requested. Change of Contact Person requires a modification. If this section is completed, all paper-based correspondence will be directed to this person.)

Name [same as above] Title \_\_\_\_\_ Position \_\_\_\_\_

Home Institution (or source of paycheck) \_\_\_\_\_

Home UW Department (if applicable) \_\_\_\_\_ Division \_\_\_\_\_

UW Position or appointment (choose the most appropriate one):

Faculty:  Regular Faculty Appointment  Research Faculty Appointment  Clinical Faculty Appointment  
 Visiting Faculty Appointment  Dual Appointment with PNNL  
 Other (describe): \_\_\_\_\_

Student:  Matriculated Undergraduate Student  Graduate or Professional Student (matriculated or approved "On Leave")  WWAMI Student

Resident or Fellow at the UW or Local VA  UW Administration or Staff  None

Campus Box # \_\_\_\_\_ Other Address if not at UW \_\_\_\_\_

Telephone \_\_\_\_\_ Fax \_\_\_\_\_ e-mail \_\_\_\_\_

**III. TITLE OF PROJECT:** Using Grounded Theory Method to Explore the Process of Prodromal Experiences Prior to the Diagnosis of Schizophrenia

**IV. SIGNATURES:** The undersigned acknowledge that: 1. this application is an accurate and complete description of the proposed research; 2. the research will be conducted in compliance with the recommendations of and only after approval has been received from the Institutional Review Board (IRB). The lead researcher is responsible for all aspects of this research, including: reporting any serious adverse events or problems to the IRB, requesting prior IRB approval for modifications, and requesting continuing review and approval.

A. Investigator: Chieh Cheng Chieh Cheng 10/30/15  
 TYPED NAME PLUS SIGNATURE DATE

B. Faculty sponsor (for student): Dr. Karen G. Schepp Karen G. Schepp 10/29/15  
 Change requires a modification. TYPED NAME PLUS SIGNATURE DATE

C. The Chair, Dean, or Director acknowledges the researcher is qualified to do the research, sufficient resources will be available, and (if no external funding review occurred) there was an internal review of scientific merit.  
Karen G. Schenn, Chair and Professor Karen G. Schenn 10/29/15  
 TYPED NAME PLUS SIGNATURE DATE

APPLICATION: Human Subjects Review (13-11) (10/23/2015)

**W** UNIVERSITY of WASHINGTON  
HUMAN SUBJECTS DIVISION

Date: December 2, 2015

PI: Ms. Chieh Cheng  
School of Nursing

RE: Human Subjects Application #50737, "Using Grounded Theory Method to Explore the Process of Prodromal Experiences Prior to the Diagnosis of Schizophrenia"

Dear Ms. Cheng,

Human Subjects application #50737, "Using Grounded Theory Method to Explore the Process of Prodromal Experiences Prior to the Diagnosis of Schizophrenia" has been approved by the University of Washington IRB in Subcommittee ED under Expedited Categories 6 & 7. The Subcommittee has determined that this research meets all the requirements for approval outlined in 45 CFR 46.111. In addition, the following waivers and determinations apply:

- Waiver of consent for verbal screening process

This research was reviewed for engagement of the University of Washington only. Activities being performed by agents of other institutions are not covered by this approval unless otherwise noted. UW IRB approval does not eliminate the need to obtain other applicable approvals or permissions.

The approval is valid from December 2, 2015 through December 1, 2018. If you have completed the study, including all data analysis, by December 1, 2018 you will need to close out the application. If you have not completed the project by that date, you will need to submit a Status Report requesting continuing approval six weeks before the expiration date. The Status Report to renew or close your study can be found on the HSD website.

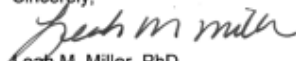
This approval is for 50 subjects. Please note that subject number is part of your IRB-approved protocol. Over-enrollment is considered non-compliance with your IRB approval. Any revisions which need to be made to the IRB-approved protocol, including an increase to subject numbers, must be reviewed and approved by the IRB before they are implemented. This review can be requested by submitting a Modification form, which can be found on the HSD website. Non adherence to the IRB-approved protocol may be considered non-compliance and must be reported to the IRB as soon as it is discovered.

**Note that HSD policy requires that you use copies of the stamped approved consent materials with subjects.** You will find the stamped form at the back of your approval packet. If use of stamped copies is not applicable to your study because you have been approved to obtain oral or electronic consent, you must use the exact script that has been approved.

Please use the IRB application number listed above on any forms submitted which relate to this research, or on any correspondence with the HSD office.

If we can be of further assistance, please contact us at (206) 543-0098 or via email at [hsdinfo@uw.edu](mailto:hsdinfo@uw.edu). Thank you for your cooperation, and good luck in your research.

Sincerely,



Leah M. Miller, PhD  
Team Lead – Team D and IRB D

4333 Brooklyn Ave. NE, Box 359470 Seattle, WA 98195-9470

main 206.543.0098 fax 206.543.9218 [hsdinfo@u.washington.edu](mailto:hsdinfo@u.washington.edu) [www.washington.edu/research/hsd](http://www.washington.edu/research/hsd)

## APPENDIX B

### Recruitment Script

**WHAT:** The purpose of this study is to elicit information directly from individuals with schizophrenia about their experiences prior to the diagnosis.

**HOW:**

Step 1	<p><i>(First, I have a couple of questions to ask you about your medical status):</i></p> <ol style="list-style-type: none"> <li>1. Have you been given a diagnosis of schizophrenia or begun to receive treatment for schizophrenia within the last 5 years ? Can you bring your registry card for major illness for us to screen your eligibility?</li> <li>2. Are you between 20-40 years old and have legal authority to make your own health care decisions?</li> </ol> <p>Persons answering "yes" to both questions are considered medically eligible to participate.</p>
Step 2	<p><i>(Now I want to explain the interview procedures):</i></p> <ol style="list-style-type: none"> <li>1. You will be interviewed twice about your experience before being diagnosed.</li> <li>2. Questions such as "what was it like when you first started experiencing symptoms before the first psychosis onset? What is the process that you went through during this period of experiences will be asked during the interview.</li> <li>3. Each interview will last no more than 45 minutes and will be recorded.</li> </ol>
Step 3	<p>After interviews, three questionnaires will be administered to identify your symptoms, functional level and quality of life of the participants.</p>

- ❖ Persons who are medically eligible and willing to take part in the interviews and complete the questionnaires are eligible to participate in the study.
- ❖ You do not have to be in this research study. You can stop at any time, and it will not jeopardize your right in receiving all the treatments. Information about you is confidential. Your doctors will not have any access to this research information.
- ❖ After the two interviews and complete the three questionnaires, you will receive a \$30 incentive for participation.

## VITA

DATE: July 8, 2017  
 NAME: Chieh (Sunny) Cheng  
 BIRTHPLACE: Pingtung, Taiwan  
 WORK ADDRESS: University of Washington School of Nursing, Seattle, WA 98195  
 TELEPHONE: 206-432-5117  
 EMAIL: ccsunny@uw.edu

### CERTIFICATION AND LICENSURE

Registered Nurse State of Washington #60762078  
 Registered Nurse Taiwan # 208699

### EDUCATION

August 2017 (expected) **University of Washington**, Seattle, Washington,  
 Ph.D., Nursing, Psychosocial and Community Nursing  
 Dissertation: Using Grounded Theory Method to Explore the Process of  
 Prodromal Experiences Prior to the Diagnosis of Schizophrenia  
 2012 **National Cheng Kung University**, Tainan, Taiwan,  
 M.S., Nursing, Psychiatry and Mental Health  
 Thesis: Dose-response Relationships of Multisensory Intervention on  
 Hospitalized Patients with Chronic Schizophrenia  
 2007 **Kaohsiung Medical University**, Kaohsiung, Taiwan, B.S.N.

### PROFESSIONAL EXPERIENCE

2014-2017	University of Washington, School of Nursing Seattle, Washington	Teaching Assistant
2014-2017	University of Washington, School of Nursing Seattle, Washington	Research Assistant
2010-2011	National Cheng Kung University Hospital, Acute Psychiatric Ward Tainan, Taiwan	Registered Nurse

### TEACHING ASSISTANT EXPERIENCE

University of Washington, Seattle, WA

2017 Summer	N METH 403 Introduction to Research in Nursing- Dr. Shervin Churchill
2017 Summer	NURS 407 Culture, Diversity, and Nursing Practice- Dr. Anita Souza
2017 Spring	NURS553 Foundations of Health Systems and Health Economics- Dr. June Strickland & Dr. Linda Teri
2016 Fall&Winter	NURS415 Nursing of Families: Childbearing & Childrearing- Rizza Cea & Anne Kalkbrenner
2016 Fall	NSG557 Physiology & Pathophysiology - Dr. Kerry Reding
2015 Summer	NCLIN500 Comprehensive Health Assessment- Ms. Phyllis Christianson
2014 Summer	NCLIN302 Health Assessment- Ms. Phyllis Christianson

## RESEARCH EXPERIENCE

University of Washington, Seattle, WA

- 2016-present Principal Investigator. Using Grounded Theory Method to Explore the Process of Prodromal Experiences Prior to the Diagnosis of Schizophrenia (Dissertation). International Society of Psychiatry Nursing Foundation, Health and Wellness Research Grant.
- 2015-2016 Principal Investigator. The Disease Trajectory of Schizophrenia Patients in Taiwan. University of Washington School of Public Health, Global Opportunities Health Fellowship.
- 2014-present Graduate Research Assistant. Body-oriented Therapy for Women in Substance Use Disorder Treatment (PI E. Thompson & C. Price). National Institute on Drug Abuse at the National Institutes of Health, NIDA R01DA033324.  
Graduate Research Assistant. Scale of Body Connection: Establishing Scale Measurement Properties and Norms for Interoceptive Awareness Research (PI E. Thompson & C. Price). University of Washington School of Nursing RIFP Grant.
- 2013-2014 Graduate Research Assistant. Anti-Arrhythmic Effects of Exercise after an ICD (PI C. Dougherty). National Institutes of Health/National Heart, Lung, and Blood Institute, R01 HL 084550-01A1.
- National Cheng Kung University, Tainan, Taiwan
- 2009-2012 Graduate Research Assistant. Developing a Healthy Care Environment in Psychiatry: A Study of Dose-response Relationship and the Evidence-based Multisensory Stimulation Intervention (PI M.F. Lin). Taiwan Nursing Association.  
Graduate Research Assistant. The Empirical Study of Cancer Patient-Centered AIICE Program: Promoting Effective Communication Competencies with Cancer Patients (PI M.F. Lin). Taiwan National Science Center.

## PUBLICATIONS

- 2017 **Cheng, S. C.**, Hsu, M.C., Hsu, W.S., Shen, S.H. & Lin, M.F. (2017). Dose-response Relationships of Multisensory Intervention on Hospitalized Patients with Chronic Schizophrenia. *Journal of Nursing Research*, 25 (1), 13-20. doi: 10.1097/jnr.0000000000000154
- Crowell, S.E., Price, C.J., Yaptangco M., Puzia, M.E. & **Cheng, S. C.** (2017). Emotion Dysregulation and Autonomic Responses to Film, Rumination, and Body Awareness: Extending Psychophysiological Research to a Naturalistic Clinical Setting and a Chemically Dependent Female Sample. *Psychophysiology*. doi: 10.1111/psyp.12838
- 2016 Price, C., Crowell, S., Hooven, C., **Cheng, C.**, Puzia, M., Thompson, E. (2016). Interoceptive Awareness Training for Emotion Regulation through Mindful Body Awareness Among Women in Treatment for Substance Use

Disorder. Proceedings, *International Research Congress on Integrative Medicine and Health*, and online in *Journal of Complementary and Alternative Medicine*.

Price, C., Hooven, C., **Cheng, C.**, Thompson, E. (2016). Interoceptive Awareness among Women in Treatment for Chemical Dependency in Response to Mindful Awareness in Body-oriented Therapy. *International Journal of Massage and Bodywork*, 9(2), 9-27.

**Cheng, S. C.** & Schepp, K.G. (2016). Early Intervention in Schizophrenia: A Literature Review. *Archives of Psychiatry Nursing*, 30(6), 774-781. doi: 10.1016/j.apnu.2016.02.009

**Cheng, S. C.**, Walsh E. & Schepp, K.G. (2016). Vulnerability, Stress, and Support in the Disease Trajectory from Prodrome to Diagnosed Schizophrenia: Diathesis-stress-support Model. *Archives of Psychiatry Nursing*, 30(6), 810-817. doi: 10.1016/j.apnu.2016.07.008

#### **AWARDS, SCHOLARSHIPS, HONORS**

2017	STTI Psi-at-Large Chapter research grant
2016	Hester McLaws Nursing Scholarship, School of Nursing, University of Washington
2015-2016	Taiwan Government Study Abroad Scholarship, Taiwan Ministry of Education
2015	Lois Price-Spratlen Research Award, Advanced Practice Psychiatric Nurses Association
2014-2015	Cole Scholarship, University of Washington Shattuck Scholarship, University of Washington

#### **SERVICE, PROFESSIONAL AND COMMUNITY**

##### *Memberships*

2016-present	Sigma Theta Tau International Honor Society of Nursing Member
2015-present	International Society of Psychiatry Nursing Member
2012-present	Taiwan Nursing Association Member <i>Professional Activities</i>
2017-present	Communication Committee, International Society of Psychiatry Nursing Foundation <i>Editorial Boards/Reviewer</i>
2016-present	Reviewer, Archives of Psychiatric Nursing Reviewer, Journal of the American Psychiatric Nurses Association