

“My Life as it is has Value:” A Narrative Approach to Understanding Life Course

Experiences of Older Adults with Schizophrenia

Lydia P. Ogden

Submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy

under the Executive Committee of the Graduate School of Arts and Sciences

COLUMBIA UNIVERSITY

2012

© 2012

Lydia P. Ogden

All Rights Reserved

Abstract

“My Life as it is has Value:” A Narrative Approach to Understanding Life Course

Experiences of Older Adults with Schizophrenia

Lydia P. Ogden

This study used thematic narrative analysis to address the question: How do older adults who experience serious ongoing symptoms of schizophrenia understand and express stories of their personal survivorship in the face of life-course and present-time adversities? Framed by the developmental life course perspective and using major constructs of the theory of cumulative adversity and advantage to formulate a line of semi-structured questioning for narrative interviews about the life course experiences of older adults with schizophrenia who experienced ongoing illness symptoms, analysis of 31 interviews with six older adults with schizophrenia yielded findings across five central areas. Shared core themes included: 1) *“My life as it is has value:” Narrating schizophrenia in later life*; 2) *“I have a key and live like a real person:” Homelessness and housing challenges in retrospect*; 3) *“There’s not been jobs:” The meaning of employment*; 4) *“God told me how we’re going to meet back up:” Narratives of relational conflict and loss, adjustment and renewal*. A fifth area of findings developed the theory of cumulative adversity and advantage across the life course with schizophrenia. These results improve our understanding of the subjective experience of a highly vulnerable but grossly understudied and underserved population. Recommendations for focusing future research and development of more effective social work practice and policies are made.

Table of Contents

Acknowledgements	iv
Dedication	x
Chapter 1: Introduction and Study Aims.....	5
Chapter 2: Background	11
Theoretical background.....	11
The developmental life course perspective	11
Cumulative adversity and advantage	12
Schizophrenia across the life course.	14
Life course adversities associated with schizophrenia.....	14
Advantage in schizophrenia	19
Narrative inquiry, gerontology and schizophrenia.	22
Chapter 3: Methods	26
Study design and rationale.....	26
Study sites and recruitment.	28
Sample.....	32
Data collection and analysis.	34
Theme-focused interviews and initial analysis	35
Calendar and time-diary interviews and initial analysis.	36
Member-checking interviews	39
Process interviews.....	41
Field observations.....	41
Data analysis.....	42

Excluded participants.....	46
Quality of the data and analysis.	47
Software.....	49
Ethical issues and protection of human participants.	49
Reflexive analysis.	50
Chapter 4: Findings	58
Characteristics of the sample	58
Shared core themes introduction	64
Theme 1. “My life as it is has value:” Narrating schizophrenia in later life	65
Theme 1 narratives.	66
Discussion of Theme 1.....	73
Theme 2. “I have a key and live like a real person:” Homelessness and housing challenges in retrospect.....	77
Theme 2 narratives.	79
Discussion of Theme 2: Long-term utilization of housing-based social services	94
Discussion of Theme 2: Constructing homelessness and housing challenges as personal metaphors	96
Theme 3. “There’s not been jobs:” The meaning of employment	101
Theme 3 narratives.	102
Discussion of Theme 3.....	116
Theme 4. “God told me how we’re gonna meet back up:” Narratives of relational conflict and loss, adjustment and renewal.	121
Theme 4 narratives.	121

Discussion of Theme 4.....	138
Cumulative adversity and advantage across the life course with schizophrenia..	144
Overview of cumulative adversity and advantage	144
Exploration of patterns of cumulative adversity and advantage.....	145
The adversity of poor health in schizophrenia	148
Identifying advantage in schizophrenia	149
Discussion of adversity and advantage in schizophrenia across the life course ...	150
Strengths and Limitations of the Research.....	151
Chapter 5: Conclusion.....	158
References.....	165
Appendix A: Recruitment flyer.....	180
Appendix B: Demographic form.....	181
Appendix C: Interview guide.....	182
Appendix D: Time diary forms	184
Appendix E: Life history calendar form.....	186
Appendix F: Field observation form	187
Appendix G: Sample information table	188

Acknowledgements

The study participants, Columbia University faculty, dissertation committee members, my family members and my friends have helped me to complete this dissertation. I would like to express my gratitude to some of these groups and individuals for their support and assistance.

I am deeply indebted to the eight participants who shared their life stories with me for the purpose of this project. In line with IRB regulations I have used pseudonyms rather than their names to identify them, but it is my hope that if they chose to read this final report, they would recognize themselves and their stories, and find that their lives, struggles and strengths have been honored. I continue to be humbled by the willingness of those fine people to share so much with me. This dissertation would not exist without them and I will carry them with me throughout my career.

I gratefully acknowledge the faculty of the Columbia University School of Social Work, who provided me with an exceptional graduate education in the MSW and PhD programs. They have taught me to identify and analyze social problems; to marshal creativity and scientific methodology in order to address social problems; and provided me with research opportunities.

I would also like to express gratitude to my dissertation committee as a whole. I managed to assemble a group of highly regarded scholars who are also incredibly kind and thoughtful people. Throughout the course of my dissertation project, I knew I had a committee that believed in my project and wanted it to succeed; who would provide me with thorough, scholarly feedback; and who offered support and encouragement where needed. I deeply appreciate all of your involvement and participation in the project.

More specifically, this dissertation would not have been possible without the support and enthusiasm of my advisor and the dissertation sponsor, Denise Burnette. Her feedback ensured that this project would meet rigorous research standards and, equally important, that it would be a personally meaningful research project that I enjoyed conducting. Through regular meetings, she helped me in wide areas that ranged from developing the right research question to structuring my time, from contextualizing my findings within existing research to terminating research relationships with study participants. I enjoyed our meetings and will miss having her support and insights as I move on to new projects. I couldn't have asked for a better advisor and sponsor.

Ellen Lukens was also an integral part of this dissertation project, served as my dissertation chair, and provided extensive guidance and encouragement throughout the doctoral program as a professor, comprehensive exam committee member and research practicum supervisor. I am particularly grateful for the guidance she provided to ensure I developed a thorough understanding of the current state of scholarship in schizophrenia, as well as for her warmth and amicability throughout the doctoral program.

Fang-pei Chen, also a member of my dissertation committee, provided me with an opportunity to learn qualitative methodology while I was in the early stages of the doctoral program. As she knows, the experience was life altering for me: I discovered that I could pursue powerful research that built upon my intellectual and personal strengths, and that I could happily engage in for a lifetime. I gratefully acknowledge her contribution to the present project and to my research going forward.

Karolynn Siegel, of Columbia University's Mailman School of Public Health, was a member of my dissertation committee, and I was grateful for the public health lens and

gerontological expertise that she brought to the project. I also appreciated the rigor with which she evaluated the research and the results.

Carl Cohen, of SUNY Downstate Medical Center, also served on my dissertation committee, providing psychiatric expertise. I am grateful he was willing to be a part of this dissertation project, as he is one of only a handful of academics engaged in scholarship focused upon the important topic of aging with schizophrenia. His feedback on the substantial area proved invaluable. Additionally, his published work, and in particular his book, are the intellectual shoulders upon which this project stands.

I would like to thank Barbara Simon at the Columbia University School of Social Work for her support throughout the MSW program and for her encouragement as I considered entering the doctoral program. Her high standards for scholarship prepared me for the doctoral program and for this project.

I would also like to thank Sonia Austrian who was my professor and field instructor in the MSW program, and a friend, a mentor and a role model ever after. Her humor and confidence in my abilities kept me going as a social worker in the field, allowed me to think the doctoral degree was a realistic possibility, and kept me going in the early phases of the doctoral program. I hope this project and my future work adequately honor her memory.

I gratefully acknowledge institutional support I received while working on this project. The Columbia University School of Social Work has been incredibly generous in supporting me through scholarships and internal awards, including the Perry Scholarship, the Ruth Fizdale Award, and the Rosenberg Award. I thank the John A. Hartford Society for providing me with a generous fellowship, as well as mentoring, educational opportunities, and career development assistance. This project would not have been possible without it.

My family has provided me with a huge amount of support in this project. My father, John Ogden, has been especially remarkable. In my five years in the doctoral program he has provided me with housing, childcare, and dishwashing services, as well as steadfast emotional support and belief in my abilities. He has been my closest ally and confidant throughout this project. For those reasons and more, this dissertation in part belongs to him.

My mother, Suzanne P. Ogden, has also provided tremendous support. I doubt many people have a mother who is willing and able to proof-read and edit their academic writing, and I am grateful my mother took time away from her duties as chair of her department to do so. Her love and care for myself and for my son were also integral to the completion of the doctoral program and this dissertation.

Few women have as many role models within their families as I have had for pursuing scholarship. I would like to acknowledge and thank my great-grandmother, Elizabeth Peck, PhD; my grandmother, Margaret Ogden, PhD; and of course my mother, Suzanne P. Ogden, PhD, for paving a path for me in academia.

My study of gerontology in general, and this project in particular, has helped me understand the importance of the emotional sustenance provided by one's social network, sometimes called a "moai" among gerontological scholars. I'd like to take this opportunity to thank members of my moai for their assistance and support during this project:

Emily Hardcastle, Jessica Garet, Sara Wicks and Lourdes Astacio have been inspiring colleagues in the field, and their interest in and encouragement of my work in the doctoral program has been deeply appreciated.

Special thanks to Kimberly Keaton, a colleague and a friend, for her willingness to listen to me talk about my dissertation project and for pointing me to some key resources. Special thanks to Johanna Shipman for proof-reading the final draft of this dissertation. Special thanks to Will Ogden for helping with the enormous task of correctly inserting page numbers into the final draft. Special thanks to Henry Ogden for being a vocal advocate of my work.

During the semesters of doctoral coursework, Christopher Pink Bonnstetter provided confidence and assurance that kept me motivated and focused.

While in the doctoral program, Sara Hodges and Johanna Shipman taught me how to play Bridge, which I am certain conditions the brain to achieve academic goals. Thank you ladies.

Cara Weir, my friend since age 5, has provided a lifetime of friendship that has made it possible for me to take risks, weather storms, and forge ahead, including with this dissertation project. For the past few years, Sarah Woods Laurin, Kimberly Keaton, Erin Clark and Sarah Jaxheimer have also been central to my emotional well-being, as well as excellent travel companions, and courteous listeners to the ins and outs of my work in the doctoral program and on this project. Numerous others have been remarkable forces for good in my life and career, which undoubtedly contributed to the completion of this challenging task: Molly Bragdon, Taffy Brodesser-Akner, Todd Florio, Joseph Petrelli, David Wharton, Richard Yoder, and the list goes on.

Thank you all for your love and support.

Finally, I most want to thank my son, Miles B. Ogden-Powers. Where there have been difficulties in completing this project, he has endured them with me. Where there

have been joys, nobody has been happier for me than him. Miles has kept me focused and motivated, and any academic or career success I have had has been in part the result of being his mother. For the duration of this project, he has been patient, loving and generous with the shoulder rubs. Thank you Miles. I could not have done this without you.

I dedicate this dissertation to my parents Suzanne P. Ogden and John V. Ogden, to my son
Miles B. Ogden-Powers, and to the memory of Sonia Austrian.

Chapter 1: Introduction and Study Aims

Schizophrenia is typically considered a disorder of young adulthood, affecting approximately 1% of the population and representing well over 3 million people in the United States alone (Castle & Morgan, 2008). While symptomatic recovery from schizophrenia is possible, and a diversity of courses of illness and recovery and illness definitions are recognized, many persons diagnosed with schizophrenia will experience a course of psychiatric illness with symptoms that extend into older adulthood, affecting up to 0.5% of the population of older adults (Meeks & Jeste, 2008). Current data find that between 50-70% of persons with schizophrenia aged 55 and over experience ongoing symptoms of the illness that require ongoing treatment (Bankole et al., 2008; C. Cohen, personal communication, May 21, 2012). In addition to potentially disabling psychiatric symptoms, schizophrenia is associated with psychosocial disability, cognitive impairment, alcohol and substance abuse, relationship and employment problems, medical problems and social isolation far surpassing that of the general population (Castle & Morgan, 2008; Hafner & Heiden, 2008).

Thus, despite the fact that the prevalence of schizophrenia is lower than other late life mental disorders, individual and societal costs are significant. Further, the cumulative outcome of having lived through adulthood with schizophrenia and its associated challenges is an average lifespan 25 years less than that of adults in the general population (Parks et al., 2006). Moreover, annual Medicare and Medicaid per capita expenditures for older adults with schizophrenia are higher than those for same-aged persons with depression, dementia or medical disorders alone (Bartels, Clark, Peacock, Dums, & Pratt,

2003). A recent analysis of the economic burden of care for persons with schizophrenia in the U.S. suggests that lifetime spending is, on average, 2.306 million dollars per capita (Blomqvist, Leger & Hoch, 2006).

Despite the high costs and marked disparity in areas of wellness and longevity, less than 2% of the current research on schizophrenia focuses on issues facing older adults with the condition, and fewer than 10% of published papers on schizophrenia include older adults in their selection criteria (Jeste & Nasrallah, 2003). The current state of research and the complexity of the experience of aging with schizophrenia preclude its reduction to variables that could reliably inform improved practice and policy (Breier, 1988; Cohen, 2003). For example, instruments to measure relevant phenomena may be inappropriate, since few have been adequately validated for this population (Cohen, 2003).

During the past decade, two expert groups have identified critical research and policy areas to address what they deem to be a crisis in aging for people with schizophrenia. The Medical Directors Council of the National Association of State Mental Health Program Directors (NASMHPD) recommends that persons with schizophrenia and other severe and persistent mental illnesses be designated as a national “priority health disparities population” (Parks et al., 2006). These disparities include higher rates of medical illnesses, greater severity of medical illnesses, and increased morbidity from medical illnesses, many of which are largely preventable and declining in other populations.

There is also growing consensus that to fully appreciate the causes and impact of schizophrenia, we must go beyond symptoms and diagnosis to understand the full spectrum of human experience with the condition, and that to improve services we must

listen to and observe persons with schizophrenia more effectively (Flanagan, et al., 2007; Strauss, 2000; Strauss, 2008). Cohen et al. (2000) present a research agenda that includes the need:

...to establish more clearly which factors determine subjective and objective mental, physical, and social well-being of older persons with schizophrenia so as to provide optimal functioning in the community ...[and] to clarify which factors would improve illness behavior and service utilization of older persons with schizophrenia (p. 25).

It is of particular importance that research goals reflect the participants' view of their problems and strengths and their identification of new research questions (Strauss, 2008; Cohen, 2003). Carefully planned and meticulously executed qualitative studies are thus needed to develop our understanding of poorly understood experiences before reducing these experiences to variables for statistical analysis. Improved services must begin with listening to and observing those with the disorder more effectively and by advancing insights from those who have experienced the disorder first-hand into treatment recommendations that address the full-range of human experiences affected by the illness, making recovery more widely available (Flanagan, et al., 2007; Strauss, 2000).

Research Question

Consistent with the recommendations delineated above, this study is framed by the developmental life course perspective and draws more specifically on the related theory of cumulative adversity and advantage to develop an understanding of the experience of having survived into later life with symptoms of schizophrenia that require ongoing

treatment. Thus, the central research question of this study asks: How do older adults who experience serious ongoing symptoms of schizophrenia understand and express stories of their personal survivorship in the face of life-course and present-time adversities?

Narrative research strategies are best suited to answering questions focused on understanding life experiences as narrated by those who live them (Chase, 2011), therefore the present study has addressed this question through analysis of retrospective life history narratives of older adults with schizophrenia. In this study, thematic narrative analysis strategies were used to add the voices, perspectives and experiences of these older adults to existing research on the topic; to understand shared themes across the life course of older adults with schizophrenia; and to develop an understanding of the relationship between narrative processes, life course experiences and schizophrenia. Improved understanding of the participants' perspectives and experiences focuses recommendations to develop social service practice and policy, and signals new and more focused pathways for research on older adults with schizophrenia. Using a thematic narrative analysis process, transferability of findings will be geared towards developing an understanding of meaning and implications of shared themes (Chase, 2011) and developing theoretical propositions around the orienting theory (Riessman, 2008).

Viewing this study through the developmental life course perspective and framing it with theory of cumulative adversity and advantage also furthers the development of theory by contributing novel and important understanding of subjective experiences of the social and developmental processes it describes, as experienced by study participants. Therefore, in a recursive process, the study will uncover new, stable theoretical concepts to develop theory further (Riessman, 2008). The resulting theoretical development will help to focus

an agenda for future research, and the improved understanding of the study population will inform the development of more effective practice and policies.

In Chapter 2, I will provide the background and a description of the theoretical framework that will guide this study. I then use the study's theoretical framework to organize and present an overview of the current available information on schizophrenia across the life course. The theoretical background and current information provide the context for methodological choices I made in designing and conducting the study. In Chapter 3, I describe in detail the methods used to structure and execute the study, including the design and rationale, recruitment strategies, collection and analysis of the data, and reflexive analysis.

In Chapter 4, I present the findings gathered through thematic narrative analysis of 31 interviews with six study participants. I first describe salient characteristics of the study population, which are also included in the table in Appendix G. I go on to identify four shared themes central to the participants' narratives. In line with conventions around the presentation of qualitative work, I use a format designed to promote the purpose of the research (Ellingson, 2011), by first presenting the context of the narratives, followed by detailed narrative passages from each of the participants. The narrative passages promote the purpose of adding the voice and the experience of the population under study to the existing research while understanding shared themes. This format adds transparency to the analytic and allows the reader to closely follow the development of the findings, and to compare and contrast cases. I then synthesize and discuss the narrative material examining its fit as a whole and with the broader areas to which the narratives speak. Finally, I use what we have learned from examining the shared themes among the narratives to add

constructs that develop the theory of cumulative adversity and advantage as it relates to the life course experience of older adults with schizophrenia, developing a working model. The chapter concludes with an evaluation of the strengths and limitations of the study, focusing upon credibility, transferability, dependability and confirmability of the findings.

In the fifth and final chapter I conclude by making recommendations for future research, policy and practice.

Chapter 2: Background

In this chapter I describe the developmental life course perspective and the connected theory of cumulative adversity and advantage. I then describe how this theoretical framework provides structure to the study by informing methodological choices and is used as an analytical tool for evaluating the study's findings. I subsequently describe the current research on schizophrenia across the life course and into later life, categorizing available knowledge in terms of adversities and advantages. Finally, I review key concepts related to narratives and aging, as well as how studies of schizophrenia have used narratives to date.

Theoretical Background

The developmental life course perspective. This study is framed with the overarching principles of the developmental life course perspective. Through the use of six central principles, the developmental life course perspective provides a common structure for describing and understanding diverse life trajectories, particularly among those who develop mental illnesses (Hutchinson, 2005; George, 2007). These principles include: Long-term temporal patterns in the timing of lives and biography; the intersection of biography and history; linked or interdependent lives; human agency in decision-making; diversity in life course trajectories, and developmental adversity and advantage (Elder, 1994; George, 2007; Hutchinson, 2005). The developmental life course perspective is most effective when used in conjunction with theories that focus upon specific life course principles, particularly those that recognize long-term processes (George, 2007). The sociological theory of cumulative adversity and advantage serves that function in this study, linking

developmental life course perspective with the principles and mechanisms of advantage and adversity (George, 2007; Dannefer, 2003; O'Rand, 2009).

Cumulative adversity and advantage. The theory of cumulative adversity and advantage, sometimes referred to as the theory of cumulative advantage/disadvantage (Dannefer, 2003) is a sociological theory that runs parallel to the psychological theory of stress accumulation and its constructs of risk and resilience (George, 2007). However the theory of cumulative adversity and advantage is differentiated by its incorporation of broader domains of adversity, advantage and outcomes that include and extend beyond the psychological. Adversities can be generally described as demographic factors, social facts, events or mechanisms that worsen an individual's health, mental health, well-being or overall welfare at the time in which they occur and/or in the long run, while advantages do the opposite. Positing that exposure to adversity systematically leads to further adversity and that exposure to advantage systematically leads to further advantage, in ways that create inter-individual and cohort differences across the life course, the theory connects earlier biographical events to multiple domains of later life outcomes (Dannefer, 2003; George, 2007). However it also acknowledges that the interaction of complex social mechanisms may at times change life course trajectories, from adversity-laden to more advantaged, or vice-versa. The interaction of life course trajectories with adversities and advantages has been found in some instances to create unique individual patterns over time (Dannefer, 2003) while elsewhere it is found that specific patterns are visible between cohorts and across individuals (Hatch, 2005).

These patterns of exposure and outcomes may appear similar within historical cohorts that share certain characteristics (Dannefer, 2003; O'Rand, 2009), such as an

adulthood diagnosis of schizophrenia. An accumulation and interaction of adversities or advantages will affect mental health across the life course (George, 2007). For example, adequate resources may circumvent persisting effects of childhood adversities on mental health, while growth in loss-related stressors through later life may lead to worse mental health outcomes (George). In an example more specific to schizophrenia, it has long been established that strong relationships with and support from family of origin serves as an advantage, or source of resilience, leading to better outcomes across multiple domains (Lukens & Ogden, 2011).

In line with cumulative adversity and advantage theory, and supported by prognostic indicators of illness outcomes, the 51% of older adults with schizophrenia who still require treatment for psychiatric symptoms have likely been exposed to more severe adversities across their life courses. At the same time, advantages that have promoted their survival past their foreshortened average life expectancies must also have been present. Developing an understanding of the mechanisms through which adversities and advantages have interacted with the life trajectories of the participants of the present study provides transferable knowledge that can be used to promote the wellness of others in their cohort and future generations.

Mechanisms of cumulative adversity and advantage and the impact of those mechanisms over the life course can be understood in more depth through small-scale studies of individual narratives that illustrate everyday processes leading to the progression or constraint of individual lives (Dannefer, 2003), such as the present study. Major constructs of the developmental life course perspective and the theory of cumulative adversity and advantage have been used to formulate a line of semi-structured questioning

for narrative interviews about the life experiences of the 51% of older adults with schizophrenia who require ongoing treatment. Rather than testing hypotheses based on pre-existing theory, prior theory serves as a resource for development, structuring and interpretation of the narratives, and in a recursive process, new, stable theoretical concepts within and across cases uncovered in analysis will be used to develop theory further (Riessman, 2008).

Schizophrenia across the life course

Life course adversities associated with schizophrenia. A host of late-life and life-course adversities are associated with schizophrenia. Comorbid psychiatric conditions, compromised cognitive functioning, physical morbidity risks, loss of functioning and decreased quality of life and well-being, as well as increased mortality risks, combine to create a picture of cumulative adverse later life circumstances for older adults with schizophrenia.

Co-morbid psychiatric conditions are common among all age-groups of persons with schizophrenia. Depression and post-traumatic stress syndrome are among the most typical, with more than 40% of older adults with schizophrenia showing signs of clinical depression (Bartels & Pratt, 2009). Late-life and cumulative psychiatric comorbidities will also impact late-life outcomes across physical and psychosocial domains as well.

Schizophrenia affects multiple facets of cognitive functioning, including cognitive ability, attention, memory, processing speeds and problem-solving abilities at all ages (Dickinson & Harvey, 2009). Studies suggest that fewer than 30% of clinically stable people with schizophrenia have normal cognitive functioning, a situation which contributes significantly to ongoing disability (Dickinson & Harvey, 2009; Shad, Tamminga, Cullum,

Haas, & Keshavan, 2006). The risks of cognitive decline for older adults with schizophrenia are even greater, since cognitive impairments that accompany the illness are exacerbated by ordinary age-related cognitive functioning declines, as well as lifetime deprivations such as institutionalization and underemployment (Cohen et al., 2000).

Due to these confluent adversities, older adults with schizophrenia experience lower cognitive functioning as compared to older adults in the general population, and as many as two-thirds of older adults with schizophrenia meet criteria for dementia (Arnold, 2001; Cohen et al., 2000). Finally, such cognitive impairment may contribute in turn to suboptimal healthcare in general, to increased lengths of inpatient hospital stays and to early nursing home placement (Andrews, Bartels, Xie & Peacock, 2009; Bartels and Dums, 2003; Bartels and Pratt, 2009). Cognition and its functional and behavioral sequelae are thus particular concerns for older adults with schizophrenia.

For people with schizophrenia, aging also presents physical morbidity and mortality risks beyond those faced by the general population. As many as 75% of all persons with schizophrenia have at least one co-morbid medical illness (Capasso, Lineberry, Bostwick, Decker & Sauver, 2008). An estimated 31% of persons with schizophrenia who are over age 60 are diagnosed with serious cardiovascular or pulmonary health conditions (Kilbourne, et al., 2005). These individuals have ten times the risk of dying from respiratory disease as compared to those without schizophrenia or schizoaffective disorder (Capasso et al., 2008). Rates of diabetes for older persons with schizophrenia are as high as 29% (Kilbourne et al., 2005) as compared to approximately 13% of older adults in the general population (Bertoni, Anderson, Krop & Brancati, 2002). In all age groups, persons with schizophrenia are also more likely than those in the general population to experience

obesity, hepatitis B and C, and cancer (Dixon, et al., 2000; Essock, et al., 2003; O'Day, Killeen, Sutton, & Iezzoni, 2005; Dickerson, et al., 2006; Pandiani, Boyd, Banks & Johnson, 2006). Thus, medical co-morbidities may be equally or more disabling and their management more challenging than the psychiatric symptoms of schizophrenia, representing an accumulation of adverse health consequences.

At all ages the convergence of psychiatric symptoms and physical health issues typically leads to a loss of functioning in more than one important area. Tasks such as sustaining adequate housing through regular rent payment and maintenance, and personal and instrumental activities of daily living such as bathing, cooking, and cleaning, may require training and assistance. Further, inability to maintain housing contributes to high rates of homelessness among persons with schizophrenia. As many as 42% of homeless persons in Western countries have a psychotic disorder like schizophrenia (Fazel, Kholsa, Doll & Geddes, 2008). When basic life skills and subjective sense of well-being are compromised, affected persons are left with lowered self-esteem and self-efficacy, increased vulnerability to life stressors, and social stigma (Mueser, Valentin, & Agresta, 1997).

As with all older adults, a lack of close relationships may affect the length and quality of life during their community tenure (Lubben & Giron, 2003). Community-dwelling older adults with schizophrenia are only half as likely as those in the general population to be integrated into their communities (Cohen et al., 2009). A majority of older adults with schizophrenia have few social contacts and most lack a close family caregiver (Jeste & Nasrallah, 2003). Social isolation may contribute to the loneliness and lower

subjective ratings of well-being among this population, again reflecting an accumulation of adverse circumstances.

While the majority of older adults with severe mental illness live in the community, 85% of institutionalized older adults with severe mental illness live in nursing homes rather than psychiatric care settings (Bartels et al., 2003; Andrews et al., 2009). Despite the poor mental healthcare available in nursing home settings, for older adults with schizophrenia, nursing homes have replaced long-term psychiatric hospitals as the institutionalized locus of care (Bartels et al., 2003; Andrews et al., 2009). Again, poor care options are available to older adults with schizophrenia.

The mechanism for the aforementioned excess mortality in persons with schizophrenia is not fully understood, and may be the result of the cumulative risks and adversities associated with schizophrenia delineated above. Suicide and injury account for up to 30-40% of premature deaths of persons with schizophrenia, and approximately 60% are due to medical conditions including cardiovascular, pulmonary and infectious diseases, diabetes and respiratory disease (Parks et al., 2006). This trend is worsening even as death rates from these often-preventable conditions are rapidly dropping in the general population (Parks et al., 2006).

A final adversity for many older adults with schizophrenia involves the history of the treatment of the mentally ill in the United States, and in particular, the institutionalization and deinstitutionalization of persons with schizophrenia. While deinstitutionalization of persons with mental illness began as early as 1955, federal Community Mental Health Acts and associated funding changed with public, congressional and presidential interest throughout the subsequent decades (Mechanic, 2008).

Throughout the policy fluctuations, persons who were considered “chronically mentally ill,” including those with schizophrenia, were not considered appropriate targets for discharge from the large state psychiatric centers until as late as the 1980s in many areas (Lamb & Bachrach, 2001). Thus, many older adults with schizophrenia have personal histories of dehumanizing treatments, including long-term involuntary hospitalizations and debilitating medication side-effects, perhaps most notably tardive dyskinesia, as the result of treatment efforts (Harvey, 2005; Mechanic, 2008).

Although the central intentions of deinstitutionalization policies were to enhance the civil rights and quality of lives of persons with mental illness through high-quality community-based psychiatric care, for many, homelessness followed shortly after discharge, due to the lack of emotional and instrumental support, social stigma, psychiatric symptoms or vocational skills, (Lamb & Bachrach, 2001; Mechanic, 2008). Homelessness was accompanied by additional adversities, including exposure to violence and lack of access to vital resources including food, medical and psychiatric care. Hopper, Jost, Hay, Welber & Haugland (1997) identified a process whereby persons with serious mental illness often ended-up living on an “institutional circuit,” going between homeless shelters, inpatient stays, and other institutional placements. Although strides have been made to end this cycle through policy changes, accessing housing and effective treatment remains an ongoing challenge for persons with severe mental illness, and of all age-groups of persons with schizophrenia, older adults are the least likely to receive any form of mental health services, even after controlling for gender, ethnicity, living situation, substance use disorder, and insurance status (Jin, et al., 2003).

In summary, sources of adversity for older adults with schizophrenia include physical comorbidities, psychological and cognitive comorbidities, as well as social adversities that include isolation, poor healthcare and psychiatric treatment options, and poor social supports. Personal histories of long-term institutionalizations, problems in access to care and quality of care upon discharge, and resulting homelessness may have, in some cases, contributed to a picture of cumulative adversities across the life course. How older adults with schizophrenia manage these vulnerabilities and adversities is not fully understood, and existing research suggests that they experience lower rates of subjective well-being than younger persons with schizophrenia or older adults in the general population (Sciolla, Patterson, Wetherall, McAdams, & Jeste, 2003). When Shibusawa and Padgett (2009) asked older adults with a range of serious mental illnesses, histories of substance abuse and histories of homelessness to reflect on their experiences of aging, findings captured an overall sense of having experienced small gains amidst many serious losses.

At this time in the U.S., schizophrenia is both a disabling and a deadly illness as the result of the multiple adversities that surround it as much as, if not more so, than the symptoms of the psychiatric disorder itself. The multiple interwoven cumulative adversities typically faced by older persons with schizophrenia, and their associated costs for society at large, such as loss of human capital and the accretion of health and medical health expenditures, provide an important part of the context for the proposed study.

Advantage in schizophrenia. While the previous section illustrates the depth and complexity of adversities experienced over the life course by many persons with schizophrenia, lessons learned from longitudinal studies, qualitative research and the

recovery movement point to specific advantages leading to better outcomes across multiple domains for persons diagnosed with schizophrenia. The domains of these advantages include illness factors, demographic factors, the nature of the social environment and of social supports, and treatment factors.

Illness factors associated with better symptom outcomes include acute onset of illness; hallucinatory and delusional content; brief duration of the active phase symptoms with good functioning between illness episodes; minimal residual symptoms; absence of structural brain abnormalities; and normal neurological functioning (APA, 2000). Further, and perhaps more importantly, lesser severity of symptoms has been associated with improved self-concept and greater satisfaction with life (Bradshaw & Brekke, 1999). Thus the illness presentation itself may have advantageous features.

Demographic advantages are related to gender, age of onset, socio-economic status, and race. Women appear to have a better illness course than men, with fewer lifetime hospitalizations of shorter duration, better work and social functioning, and better response to neuroleptics (APA, 2000). A later age of onset, more often female, is associated with less cognitive impairment and better functional and symptom outcomes (APA, 2000). Persons in higher socio-economic status (SES) groups are more likely to experience financial security and informal support, leading to continuous insurance coverage, and more consistent higher-quality psychiatric care, which in turn is associated with better symptom and functional outcomes (APA, 2000; Seng, Kohn-Wood, & Odera, 2005; West, et al., 2005; Wilk, West, Narrow, Rae, & Regier, 2005). In terms of race, in the United States being White is associated with increased access to and use of psychiatric services that tend to be of higher quality than services for minorities of the same SES status, leading to better

illness outcomes (Bresnahan, et al., 2007; U.S. Department of Health and Human Services, 2001).

Advantageous social factors include the nature of the social environment and of social supports. Lower experience of stigma of mental illness in the social environment has been associated with improved self-esteem (Bradshaw & Brekke, 1999; Lysaker, Roe & Yanos, 2007) and hopefulness (Lysaker et al., 2007). Lesser experience of relational conflict, particularly anger on the part of social supports, whether clinical staff or family, has been associated with improved self-esteem, life satisfaction and illness outcomes (Bradshaw & Brekke, 1999). Much research has been done on the importance of family as a source of social support and its association with improvement across various domains. When family support is positive, family can act as advocate, encouraging and facilitating appropriate care and improving outcomes related to illness and functioning (Lukens, 2001; McFarlane, Dixon, Lukens & Lucksted, 2003). Overall, it is well established that meaningful relationships and activities are important to the mental health recovery of persons with schizophrenia of all ages (Bradshaw, Armour & Roseborough, 2007; Davidson et al., 2001).

Intertwined with demographic and social factors, treatment factors can provide significant advantages to the course and outcome of illness symptoms and related outcomes. In the last two decades, the consumer-driven mental health recovery movement has played an important role in the development of a growing base of evidence-based treatments and macro- and micro-level policies that place meaningful activity and relationships, as valued and defined by the individual in treatment, as the goal of pharmacological and psychosocial treatments (Bellack, 2006; Davidson et al., 2005; Deegan & Drake, 2006). Although very few programs have been developed or evaluated specifically

for their effectiveness in older adults (Bartels & Pratt, 2009), research on existing group-based psychoeducation programs for older adults with schizophrenia has found measurable improvements in social skills and everyday functional skills, cognitive insight and comprehension, and in access to healthcare and medical problem detection by participants (Cohen et al., 2009). Although access to these programs is not widely available, those who have been able to participate will have experienced the advantage of recovery-oriented treatment.

Thus, while there is a host of adversities associated with schizophrenia, distinct advantages are associated with better outcomes across various domains, ranging from symptom and functional outcomes, to a deeper sense of hope and self-worth. While undoubtedly the study participants have experienced adversities related to schizophrenia, sources of advantage and resilience, external and internal, have allowed them to survive in the face of those adversities. Understanding their experience of these advantages, and how they were marshaled in the face of adversity, is central to the purpose of the present study.

Narrative inquiry, gerontology and schizophrenia

The final piece of background against which the present study is situated is the field of narrative inquiry, and its application to the areas of aging and schizophrenia. Although narrative inquiry has been used to examine the areas of aging and of schizophrenia, the two areas have not served as the focal point of a narrative study until now. In the present study, several key concepts from narrative gerontology dovetail with the study of narrative in schizophrenia.

Key concepts from narrative gerontology, and more broadly of narrative inquiry, contribute to the background of the present study. Narrative inquiry is differentiated from

other qualitative traditions through its focus upon biography and the personal meaning-making processes connected to creating a narrative sense of self (Chase, 2011). These key concepts in narrative gerontology include: narrative integration, narrative identity, biographical capital, autobiographical memory as metaphor, and narrative foreclosure.

In narrative gerontology, aging is viewed as a time of increased internal activity when changes to daily activities, roles, and brain functioning support the developmental task of “narrative integration,” wherein one interprets meaning from life experiences and stories, and continues to develop a coherent sense of self (Randall, 2011). This biographical sense of self across the life course is termed “narrative identity.” “Biographical capital” refers to the idea that autobiographical material is amassed over the life course, becoming most dense in later life, when it is most needed to fulfill the developmental task of narrative integration (Randall).

“Autobiographical memory as metaphor” refers to the process through which autobiographical material is used in narrative integration and the development of narrative identity (Randall, 2011). Autobiographical material is interpreted and prioritized through the lens of other life experiences, culture and values which put autobiographical stories into relief, so that the stories serve as metaphors for meaning and for self. It can be used to reframe negative experiences into positive ones, or, in a process called “instrumental reminiscence,” to cope with the added challenges typical of later life, such as physical infirmities, role and status changes, and loss of loved ones. Finally, “narrative foreclosure” refers to the sense that one’s life story has essentially ended and has been largely devoid of significant, positive, or meaningful experiences (Freeman, 2011). It is considered a breakdown of narrative functioning .

Issues of illness-related narrative impairment and narrative coherence (Lysaker & Lysaker, 2001; Raffard, D'Argembeau, Lardi, Bayard, Boulenger & Van der Linden, 2010; Saavedra, Cubero & Crawford, 2009) and development of narrative identity (Lysaker & Lysaker, 2001; Lysaker et al., 2005; Saavedra et al., 2009) have been examined in studies of persons with schizophrenia, although until now none have focused upon older adults with schizophrenia. Although there are complexities surrounding the interaction between symptoms of schizophrenia and personal narratives (Lysaker & Lysaker, 2001; Lysaker et al., 2005), persons with active symptoms of schizophrenia across cognitive, negative and positive dimensions of schizophrenia are usually capable of constructing meaningful and coherent autobiographical narratives (Saavedra, Cubero & Crawford, 2009; Roe & Davidson, 2005).

To date, the examination of narratives of persons with schizophrenia has been used to advance our understanding of the experience of living with and recovering from schizophrenia. The recovery movement in schizophrenia has emphasized using a more holistic approach to treating and viewing the illness (Deegan & Drake, 2006; Deegan, 2007). Narrative studies have supported this approach, finding that the possibilities of recovery are unnecessarily foreclosed when treatment is focused on clinical symptoms to the exclusion of the whole person, including the narrative sense of self (Davidson, 2003; Roe & Davidson, 2005). Roe et al.'s (2008) examination of narrative illness-insight in schizophrenia suggests that clinical insight only shows part of the picture as to how persons with schizophrenia understand their illness, while study narratives reveal a more complicated and nuanced understanding of their illness experience. Initial studies suggest that the process of developing a personal narrative through the treatment process

mediates some challenges associated with schizophrenia, such as problems in social cognition and social withdrawal for persons with schizophrenia (Lysaker, Erikson, Macapagal, Gilmore & Ringer, 2012).

In sum, in narrative inquiry it is both the process of participants' narrative development and the content of the narrative material that is investigated (Chase, 2011). Narrative inquiry, as it has been applied to both gerontology and studies of schizophrenia, completes the compendium that provides the background of the present study.

Chapter 3: Methods

As described in the background, the developmental life course perspective and the related theory of cumulative adversity and advantage frame the present study. The methodological choices described below, ranging from sample definition to data collection and analysis, were nested within this theoretical framework. In narrative studies, narrative content and processes are both examined (Chase, 2011) and the methods of this study were therefore designed to examine each of those components within and across narratives.

Study Design and Rationale

In order to develop an in-depth understanding of how participants' express and understand their personal survivorship in the face of life-course and present-time adversities, I conducted semi-structured interviews with six study participants who experience serious ongoing symptoms of schizophrenia. Although interviews were the primary unit of analysis, systematic field observations about participants' homes, neighborhoods, and treatment environments were conducted to add to the richness of the data. Thematic narrative interviewing processes, calendar and time diary methods, ethnographic methodologies, and reflexive tools were used to structure and enrich the data collection process and to analyze the data.

The primary methodological strategy used in this study was thematic narrative analysis, which is well-suited to understanding retrospective views on life histories and illness narratives (Riessman, 2008). As with all qualitative methods, this study is geared towards developing an understanding of the subjective and inter-subjective experiences of individuals (Denzin & Lincoln, 2005). Narrative analysis in particular focuses on

understanding narrative content and processes, as they relate to meaning-making and identity across the life course (Chase, 2011; Randall, 2011). Therefore of the range of potential qualitative approaches, thematic narrative analysis is best suited to understanding persons' narrative construction and meaning-making around events in the context of their own lives and was chosen as the primary approach for the present study.

The analytic strategies used in thematic narrative analysis are informed by the social constructivist approach of grounded theory methodology but have some key differences. Rather than using theoretical sampling and inductive data analysis to further novel theoretical development, I geared sampling toward the development of themes informed by a-priori theory, and which would develop that theory. Analysis was primarily case-centered as each narrative developed. I used constant-comparison analytical methods to allow for both flexibility and rigor in developing themes in-depth within each participants' narrative (Riessman, 2008). Subsequently, my use of constant comparative analysis methods allowed for explorations and explanations of similarity and variation across narratives, which were used to strengthen understanding of core themes, narrative development, and case-based theoretical development (Riessman). The phenomenological strategy of "imaginative variation," described in detail below, was also used to identify and develop core themes (Caelli, 2001).

In the present study, I used life history calendar and time diary methods to structure narrative development and collection. Life history calendars are used to structure and strengthen reporting of events that have happened in the past; time diaries are used to report on recent events, such as the previous day or week. These methods have been demonstrated to improve the quality, credibility and transferability of life course research

by systematically encouraging participants to include temporal changes in the reporting of events, improving the fullness and accuracy of participant recall (Belli, Alwin & Stafford, 2009). Through their use, researchers gain insight into the causes and consequences of events over the life course and present time. In this study, these tools served the additional purpose of helping to focus and develop narrative accounts provided in the context of ongoing psychiatric symptoms.

Study sites and recruitment. Three sites collaborated with me to recruit participants. They include an inpatient psychiatric unit, an outpatient treatment program, and a psychosocial clubhouse. Two of the three sites produced participants. The Columbia University Institutional Review Board (IRB) approved the use of all three sites and the recruitment, sampling and data collection strategies of this study.

In all three of the sample sites, staff screened potential participants based on inclusion criteria and gave eligible persons a recruitment flyer and gave assistance in contacting the study upon request. Receipt of the flyer indicated confirmation of the participant's current clinical diagnosis as being that of schizophrenia or schizoaffective disorder, and other inclusion criteria, by the staff at the sampling site. The flyer stated that financial compensation for participation was \$25 per interview.

The first site from which participants were recruited is an acute-care inpatient psychiatric center that is part of a larger teaching hospital in New York City. The unit from which the participants were recruited is a smaller 10-bed unit inside the psychiatric center, which specializes in treating older adults with mental illness. This site did not produce any study participants.

The second site from which participants were recruited is a personalized recovery-

oriented service (PROS) program (The Program) that is part of a larger non-profit organization in New York City that serves the persons with serious mental illness through the provision of housing, mental health treatment, drug rehabilitation and/or other services. The Program offers its services to diverse clients from multiple age groups under federal Substance Abuse and Mental Health Services Administration (SAMHSA) guidelines, and with federal, state, and private funding. It should be noted that until the time in which I began my study, The Program was considered a “continuing day treatment program” and had a long-term maintenance-oriented approach to treatment. The Program’s transition to the PROS model represented development towards a recovery-oriented model that would be more time-limited.

I first presented the study at The Program to the executive leadership of the organization. The study was then approved by the organization’s IRB. I subsequently presented the study to case management staff in their weekly staff meeting. I provided the staff with recruitment flyers and an explanation of the study. I explained the recruitment strategy permitted by Columbia’s IRB, asked that they followed it, and asked that they ensure study recruitment flyers only went to eligible program members. The staff indicated understanding and agreed to meet my requests.

When The Program case managers met with their clients throughout the next few weeks, they gave eligible clients study recruitment flyers (included in Appendix A) and made a brief statement about the study, such as, “This is a flyer for a research project. A doctoral student at Columbia University may be interested in interviewing you for a study on life stories. If you are interested, you can call the number on the flyer for more information.” Upon request, the case managers assisted the clients in calling the study. This

sample site produced four participants.

The third site from which participants were recruited is a permanent housing program for adults with serious mental illness who are over the age of 55 (The Senior Residence). It is part of a larger non-profit organization serving persons with mental illness in New York City, by providing ongoing social services through a psychosocial clubhouse model (The Clubhouse). The Clubhouse provides employment, education and wellness services, as well as membership in a caring community of persons with mental illness and staff members. Psychiatric care is facilitated as needed. The Clubhouse also provides housing across several sites, including at The Senior Residence. The Senior Residence provides government-subsidized studio and one-bedroom apartments; 24-hour staffing that includes case managers and paraprofessional social service providers; and social services including entitlement assistance, medication management and medication monitoring.

This study was presented first to the executive leadership at The Clubhouse, and then to the organization's IRB. The organization's IRB consists of multidisciplinary staff members and members of The Clubhouse. The board provided IRB approval, but due to the organization's policy of including its members in every aspect of its programming, we agreed to use a different recruitment process than the one I used at The Program.

To introduce the study to The Senior Residence, I presented the study to all of the staff and residents at the same time during a regularly scheduled meeting at The Senior Residence. Residents and staff were encouraged to ask questions during this presentation, and to speak with residential staff if they were interested or had more questions. Contact information for the study was provided to the social service staff, in the form of study

flyers, which were the same as the ones I used in the other sites. Staff gave the study flyers to residents who expressed interest after the meeting and who met the inclusion criteria, as well as to those who may not have attended the meeting but were eligible for the study. They also offered and assisted interested residents in calling the study. This site produced four study participants.

Potential participants who called the study were screened over the telephone to further establish that they could provide a generally coherent narrative. As noted earlier complexities surround the interaction between symptoms of schizophrenia and personal narratives (Lysaker & Lysaker, 2001; Lysaker et al., 2005), however sufficient evidence suggests that persons with active symptoms of schizophrenia are nonetheless capable of constructing meaningful and coherent autobiographical narratives (Saavedra, Cubero & Crawford, 2009; Roe & Davidson, 2005). I did not find significant problems with any of the potential participants during the telephone screening.

During the screening, I also explained the nature of the study and reiterated the study criteria during the telephone screening. If the potential participant was interested in joining the study and seemed able to relate a generally coherent narrative, I scheduled an interview with her or him. In the first meeting and prior to beginning the interview, I screened each participant for competency to provide informed consent, and went through the informed consent procedure.

I held interviews at a location of each participant's choosing. During the telephone screening, I suggested that I would interview participants wherever would be most comfortable, private and convenient for them, such as their home. I refer to this location as the "customary environment" below. All but two participants chose their apartment as the

interview location. One participant from The Senior Residence chose to have the first and third interview in the Residence's shared living room, but we had the second and fourth interview in his apartment. A participant from The Program chose to have his first interview in one of The Program meeting rooms, but his subsequent meetings were held in his apartment. When a participant identified a customary environment that was not his or her home environment, I assessed whether and how privacy and confidentiality could be maintained in that environment through discussion and agreement with the potential participant.

Sample. The sample of this study was focused upon on the 51% of older adults with schizophrenia who experience ongoing symptoms of schizophrenia for which they required ongoing treatment (Bankole et al., 2008). I recruited 8 older adults who meet these inclusion criteria: 1) aged 55 +; 2) diagnosis of schizophrenia or schizoaffective disorder, any sub-type, as confirmed through the recruitment process described above; 3) English speaking; and 4) receiving treatment for schizophrenia.

Exclusion criteria were defined as: 1) Psychiatric disorders other than schizophrenia or schizoaffective disorder; 2) cognitive impairment or symptom severity that precludes ability to provide a generally coherent narrative or provide informed consent; 3) late-onset schizophrenia, documented as occurring after age 45. Since understanding cumulative adversity and advantage across an individual's life course was the central purpose of the study, it was important to use broad criteria that would include experiences that varied currently and historically by demographic factors such as gender and ethnicity.

Two participants' narratives were ultimately excluded from the final analysis. The first was excluded because she did not provide thick description about her personal history, although she was coherent and willing to speak about her present life. The second was excluded because he was lost to follow-up, and thus did not participate in the member-checking process. The final sample size for this project was 6.

Narrative analysis requires multiple interviews with few participants, and the small sample of 6 in this study reflects that standard (Riessman, 2008). The small sample is expected to be able to provide thick description around the phenomenon under investigation, and the data collection process continues until saturation is reached. Saturation in qualitative research refers to the point at which no new codes are developed, themes and subthemes have been fully explored, and thus no additional data collection is needed (Padgett, 2008). The term "codes" refers to the categorization of data segments with a label that "summarizes and accounts for each piece of data" (Charmaz, 2006, p. 43). Codes select, separate, and sort data; mark the beginning of the analytic accounting; and are used as analytical tools throughout the research process. Codes are refined through the creation of "memos," which describe, define and develop the themes that the codes identify. Memos also delineate the analytic process. In thematic narrative analysis, saturation is case-centered and occurs when codes, themes and subthemes within each individual narrative have been fully explored and refined, and no new themes arise upon further data collection (Riessman, 2008).

Saturation is generated through the sampling process. Similar to "theoretical sampling" in grounded theory, case-based theoretical (or "thematic") sampling in thematic narrative analysis is the process through which themes within the data are identified as

most salient to the development of the emerging narrative (Charmaz, 2006). Further data is then collected to deepen, elaborate upon, and refine the narrative and its core themes. In the present study, the data was collected through multiple methods and sources, described below in more detail. Sampling questions were generated around each participant's narrative and were both chronological and theory and theme-focused. Cross-case comparisons informed some choice of questions in the subsequent interviews. For example, if I became aware of an absence of a theme in one participant's narrative that was salient in another, then I would ask more about it with both participants. I continued interviewing until saturation was reached in each case. Saturation meant that the participants did not have new stories to add to their life narratives. In the present study, case-based saturation was achieved in 4-6 interviews. In all, 31 interviews were conducted.

Data collection and analysis. Consistent with typical qualitative research processes, data collection and analysis were intertwined (Creswell, 2007). Interviews were the primary source of data, although systematic field observations were also made. I conducted and audio-recorded all of the semi-structured interviews in-person in the chosen customary environment of each participant. In the first interview, I assessed for competency, went through the informed consent process, and completed a brief form with each participant that collected basic information around demographics, education level, psychiatric service utilization, and physical health (attached in Appendix B). I conducted four different types of interview with each participant: "theme-focused interviews;" "calendar and time-diary interviews;" "member-checking interviews;" and "process interviews."

Theme-focused interviews and initial analysis. The first 1-3 interviews were “theme-focused interviews,” consisting of semi-structured interviews, framed by exploratory questions related to domains identified in the literature on life course research, including participants’ thoughts and feelings about 1) their housing and current living situation in general; 2) their work and activities; 3) their health; 4) their past and present relationships, with additional questions focused upon social service providers and psychiatrists; 5) significant physical environments and spaces; 6) their identification and perception of significant or meaningful past events; 7) their perceptions of schizophrenia and its meaning their lives past and present; 8) to what participants attribute their personal survival and strengths. See Appendix C for the general interview guide.

During these interviews, participants were encouraged to discuss aspects of their current lives and personal histories that were most salient to them rather than what I assumed to be most important. Inquiries about the temporal sequencing of events were made, but were not the focus of these interviews.

A pilot theme-focused interview was completed with the first referred participant in order to focus and sharpen the questions. However the findings of the pilot interview later appeared to have been idiosyncratic: That participant refused to speak in any detail about her personal history, choosing to focus intensely on the present. I therefore planned to adjust my inquiry to focus more on present time concerns, adjusting my questions to begin by asking for an overview of participants’ daily lives. However, the next participant ignored the question first question about his daily life, and instead began relaying a story about the conditions of his childhood. He went on to relay an almost entirely linear account of his life from birth through the present time, with minimal guidance from me.

Over the course that first interview with the second participant, I returned to my original interview questions. Although many of the questions had failed to produce thick description in the pilot interview, I found they yielded thick description from the second participant. From that point forward, I considered each first interview as a pilot interview for each particular case. I used the guiding theory of the study and the data as it emerged from each participant through the interviews to shape the interview questions. In that way, interviews were tailored to explore the unique experiences of each participant. It took between 1-3 interviews to complete the theme-focused interviews.

After each of the theme-focused interviews was complete, I listened to the recordings. I wrote notes and memos about the important themes and developed initial codes while listening. At the same time I developed questions to clarify the content and to develop depth around the relevant themes.

Some codes were developed a-priori. For example, I knew that “housing” would be a code for most of the participants due to the high rates of homelessness among the seriously mentally ill, and also because I was interviewing most participants in their homes and would have data from field observations about current housing. Other codes came directly from transcript texts, sometimes using the in-vivo language of participants, such as the code of “exposed,” which represented a sense of agoraphobia and need to return home for one of the participants.

Calendar and time-diary interviews and analysis. Time diaries and life history calendars were created after the theme-focused interviews were complete, in order to structure the core narrative. The calendar and time-diary materials were also used in subsequent interviews as a visual aid to develop consistency and clarity in the

retrospective reporting of time and place of life events (George, 2007; Scott & Alwin, 1998; Stafford, 2009). Three types of these calendars were used with each participant: A daily time diary, a monthly time diary, and a life history calendar.

Although information about daily life was available in the participants' narratives, I printed out empty daily and monthly diaries to fill out with each participant nonetheless. Gathering information by using these empty forms caused participants to add detail and depth to their accounting of their daily lives, confirming or altering information they had previously provided. An example of both types of time-diary forms is included in Appendix D.

For the life history calendar, I used an Excel spreadsheet to create timelines of each participant's life narrative. The timeframe in which events occurred were marked on the horizontal axis and the thematic categories (identified through coding) were marked along the vertical axis. For the first three participants' calendar interviews (including the pilot interviewee), I typed in summaries and direct quotes from the interviews that spoke to the theme and its temporal ordering in the cells. I then presented the life history calendars, reviewing them with participants, checking for accuracy, clarification, depth, and additional information to fill-in the gaps represented by empty cells on the spreadsheet. I found varied responses to the process among the participants:

The pilot-interviewee, whose data was later excluded from analysis, refused to look at her timeline, preferring to focus only on present-time matters. Participant 2 had a clear linear ordering of his narrative, and when I showed him the timeframe he was willing to "help me fill in the blanks" in my understanding of his life story. He was able to engage in

this with ease, providing narratives with thick description when cued to the themes, the time period, or both.

The temporal ordering of Participant 3's narrative was confusing to me. When listening to and coding his theme-focused interviews, I was not clear as to where to place many events within the life history calendar. Therefore I created an empty chart for him. As in the original calendars, timeframes were listed on the horizontal axis, and themes were on the vertical axis. However, all of the cells in the calendar were left empty. Then together we filled in the blank cells with summaries (words or phrases) of events in that domain of his life at that time.

This strategy was successful with Participant 3. In his theme-based interviews, he often had his eyes shut as he spoke, rocking slightly, and getting lost in his own responses to questions as he jumped from topic to topic in order to provide an answer. Consistent with the literature on calendar interviewing, the introduction of the visual cue helped him to focus, organize and clarify his retrospective account of his life, confirming some events and developing his description of others (Belli, Alwin & Stafford, 2009). I realized that completing the calendars beforehand was not necessary, and using blank calendars would provide added confirmation of significant events. Therefore, I used a calendar empty of events with all of the subsequent participants. See Appendix E for an example of an empty life history calendar.

The time diary and life history calendar interviews thus provided clarification around temporal ordering, as well as clarification and depth to the initial narrative, and developed case-based thematic saturation that assisted in narrative and theoretical development. The focus of the calendar and time-diary interviews was establishing the

temporal sequencing of events. I guided the interview process through my understanding of the participant's life themes, with many questions focused on the timing of events, while also asking follow-up questions that sought clarity and more depth in some of the categories.

After the theme-focused and calendar and time-diary interviews were completed for each participant, I transcribed and coded all of the text from all the participant's interviews up to that point. In the coding process, I selected segments of text and identified which of the previously established themes it related to, finding new themes as well. These themes were usually connected with a time-period in that participant's life, although some were more abstract. After the texts were coded, I cut and pasted excerpts into the life history calendar cells that represented a given code or theme and timeframe.

When the charts were filled, I used the data, now placed in the correct temporal ordering, to compose a core narrative for each participant. To the extent possible, I used the participant's own words to describe the significant events in their lives.

Member-checking interviews. The third interview type was "member checking." In qualitative research, member checking is done to ensure the relevance of data to each participant (Padgett, 2008; Creswell, 2007). In the member-checking interviews, I read the participant's narratives aloud to them, pausing frequently to check that the material in the narrative was correct and asking additional questions to clarify, confirm and seek depth. Additionally, I presented elements of my developing analysis, including the emerging themes that I had identified within their narratives and my understanding of what the theme meant in that persons' life. Diagrams and models were presented and discussed.

I was concerned that some participants would be hesitant to correct me as I read their narratives and presented my thoughts. To address this, I might introduce a section that had been unclear by saying, “I may have this wrong, but you tell me....” I also tried to follow closely their body language and facial expressions, asking “Is that not quite right?” if I noticed a shift. All of the participants corrected me at several points during my reading of the narratives and provided clarifying details, promoting the subjective accuracy of the narrative accounts that we co-created.

Participants were open to and interested in my analyses as well. Some seemed to find my insights revelatory, responding with enthusiastic agreement: I captured the ambivalence one participant felt towards The Program in a way that seemed to help him understand it more clearly himself. Another was pleased that I had understood how social workers and doctors had discredited themselves by disputing the word of God.

Others were willing to argue with the way that I had represented and interpreted their lives: I had made one appear “physically infirm” where she felt “robust” despite many physical health issues, and she asked me to adjust her narrative accordingly. As I discussed the theme of relational losses and adjustments, one participant disagreed that close friends were not a part of his current life, explaining that his social worker and I were his close friends now. I had excluded an account of childhood sexual molestation from one participant’s narrative, and she explained to me why it was important to her life narrative and needed to be included in the account.

Following the member-checking interviews, I reviewed my notes from the interviews and listened to the audio-recordings. Revisions of the core-narratives were

made where necessary and participants' insights informed further analysis of the narratives and development of the core themes.

Process interviews. The fourth type of interview was a process interview. I used it to check-in around changes I had made to the text based on the member-checking interview and to describe further the themes I had focused upon in my analysis. I also described how I thought cumulative adversity and advantage related to the participant. In that way, these interviews had an additional member-checking component. However the primary purpose of the process interviews was to provide closure for the participants around their participation in this project, since they had provided large amounts of intimate information to me. I asked them to reflect on the project's process, and describe what they enjoyed about it, and provide feedback about how it could be improved. These interviews were where we said our good-byes and I thanked the participants for their involvement in the project. The participants all wanted copies of their narratives and so I made arrangements for that as well.

Field observations. The final component of data collection was of my own observations of participants, the interview settings, the neighborhood walks, and my own responses to the interviews. These observations were made on an ongoing basis. After each interview and visits to The Program and The Clubhouse, field observations were recorded. I also wrote memos that recorded my personal impressions of the interview, participant and environment. To complete the data collection, I walked around the neighborhoods of each participant's home and treatment program and recorded my observations of those areas as well. These field notes and memos serve as a record of the research process and aided in the analysis of the evolution of data collection, narrative arch development, and

the coding scheme, and furthered the data saturation process. I used a field observation form (attached in Appendix F) to systematically record my observations about the participant's customary environment although often additional observations were made beyond just filling in the form.

As noted earlier, I met with participants between 4 and 6 times each, for a total of 31 interviews. The average number of meetings was 5.1, with a median of 5. Interviews lasted between 18 minutes (for a brief member-checking follow-up to clarify some material while finalizing a narrative) and 137 minutes (for a time diary and life history calendar interview). The average duration of interviews was 68 minutes, with a median of 68.3 minutes.

Data analysis. As delineated above, analysis began after the first interview and was ongoing throughout the study. Creswell (2007) describes qualitative data analysis as occurring in a spiraling, rather than linear order. Although data collection and analysis occurred in a step-wise fashion, the non-linear nature of the component strategies caused elements to occur and recur at various points throughout the study. For example, despite saturation having been met, new data was obtained in all of interviews, including in the finalizing "process" interviews. For example I observed a participant experiencing an increase in psychotic symptoms in a final interview; in another I was informed that I was a "friend" of the participant and was invited to his birthday party.

Theme-focused and time diary and life history calendar interviews were transcribed verbatim. They were coded using principles and protocols of thematic narrative analysis (Riessman, 2008) and incorporating strategies from calendar and time-diary research (Belli et al., 2009; Stafford, 2009). Member-checking interviews were not transcribed, since

they largely involved my reading from the narrative text. I made notes during the interviews, listened to the audio recordings and made changes to the text according to feedback from the members. Any new information gathered in those interviews was noted. The process interviews were typically quite short and were not transcribed, but I took notes and wrote memos around feedback and the participant experience.

Case-centered constant comparative methods were the primary analytic method (Riessman, 2008). Chronological sequences were developed for each narrative and preserved during the coding process, rather than extracted into coding segments. The narrative segments and categories found within each participant's interview were initially isolated as a story (Creswell, 2007). Consistent with the developmental life course model that frames the proposed study, I focused on life-stages, events, turning points, linked lives and other significant aspects of the individual participants' trajectory that created each story.

Suspected symptoms or delusional material were accepted as part of the participants' reality and I included them within the narratives. I maintained an ongoing log of analytic abstracts, or "memos," that highlighted my processes and progress throughout each participant's narrative; compared aspects of the biography to the framing theory of cumulative adversity and advantage, and the developmental life course perspective; and examined aspects of each life story that made it both typical and unique.

The core narrative was constructed, or reconstructed, as the researcher, along with the participant, identified the most significant aspects of the narrative. Time diaries and life history calendars helped ensure that the narrative of each participant was sufficiently organized for interpretive purposes (Belli et al., 2009; Riessman, 2008). Once the core

narratives were constructed I examined them for larger patterns and meanings (Creswell, 2007). I did this through coding the final narrative accounts using again a combination of a-priori codes from the theoretical framework and my working knowledge of the population, and open coding strategies. I wrote memos on the salient themes for each narrative. Although these narratives were coded as individual sets of data, my knowledge of the other narratives at that stage of the research sensitized my coding.

I then made cross-case comparisons to develop case-bound analysis, and by exploring commonalities and differences between cases, strengthen case-based narrative and thematic and theoretical development (Riessman, 2008). For example, the 2nd participant's strong sense of well-being seemed to stem from his early life origins in a culture in which deep spirituality was a form of success and wherein his friends and family spoke to God in a way similar to his own. Therefore when I looked at Participant 4, who had similar mental and physical health symptoms but seemed to have a lower sense of well-being, I examined the cultural difference to see if cultural factors might be connected. A comment that Participant 4 made in passing came into relief. He had stated, "I think I am trying to punish myself for not being more like my brother," who had gone to college and had a business career. The comment reflected how his cultural values defined success as occurring through educational and vocational attainment, rather than a spiritual life as in Participant 2's narrative. I therefore included that comment in his core narrative, and discussed it in more depth with him; checked-in with both participants in order to understand their perspectives on the material and its meaning to them; and considered cultural context as I considered the role of cumulative adversities and advantages in the participants' narratives.

Finally, I made cross-case comparisons to understand core themes shared by all of the participants. I re-coded core narratives of the participants as if they were a single unit, again using the theoretical framework to inform the process. I considered narrative content, process, and relationship to the theoretical framework in the coding process. I examined overlaps, differences and parallels between the narratives in a process of constant comparison that determined the core shared-themes between the narratives, creating analytic memos that described my emerging analysis.

In the cross-case analysis, I also used imaginative variation to sharpen the sense of which experiences were core themes among the group of narratives. Imaginative variation is a process borrowed from phenomenological analysis. It is used to determine which themes are incidental and which are central parts of a narrative, whereby the text is imagined without an identified theme (Caelli, 2001). If a theme's absence does not appear to significantly alter the meaning or structure of the narrative, then the theme is not essential and omitted from the narrative. Otherwise, it is considered essential, maintained in the narrative, and subject to further analysis. I again used reflection and constant comparison to discern what each theme revealed about the narrative content, process and guiding framework, maintaining analytic memos on these emerging themes.

Sub-narratives that represented the shared core themes were extracted from each participant's narrative as narrative vignettes, and compared again to the others. To deepen the understanding of the fit of the narrative vignettes to the content, a review of existing research was made. Comparisons were then made across cases and across studies, and results from these comparisons were added to existing memos, which became the outlines for and initial drafts of the findings section presented below. The final product includes the

narrative vignettes related to the shared core themes, and an explanation of the narratives' relationships to one another and to the existing literature on the theme.

Excluded Participants. As noted above, I excluded two of the 8 original participants since one was lost to follow-up and the other refused to speak about her past, providing only very thin description of her present time. Nonetheless, having met and interviewed each of those participants 3-4 times respectively, my understanding of their narratives sensitized my analysis as I engaged in imaginative variation and cross-case comparisons. Participant 1, who I met with four times, and who refused to speak about her past made a statement that stuck with me as I continued in the analysis. When asked how schizophrenia had affected her life she responded:

"I would have achieved what I wanted to achieve... I would have all my degrees. And I would have been able to buy anything I wanted because I'd have the money and I'd have bank accounts, credit cards, whatever you name it I'd have it... I would have been in a big home for myself and... the man of my dreams. I ain't gonna lie. The man of my dreams. And we have a beautiful home with everything nicely done in it and everything. And I probably would have been singing too. Something like that... But anyway, I probably would have been all that. And then I would have said I was successful. And not just say I was successful, I'd say we was successful—I would not exclude him! Now we are successful! Now we've made it. Now we have it all. And then we would return our minds over to our religion. Then we would go into our religion, which I'm not going to go into right now. But then when [we]... have everything then we can go into our religion and live a nice quiet life. You know? A quiet peaceful life... But I don't really want to go into that."

Throughout our four meetings together, that statement was the only one that gave me insight into her understanding of her experience of adversities and advantages, and yet it embodied much of what I heard from the other participants: Relationship, work, and housing had all been the biggest casualties of schizophrenia in her life. She coped by focusing intensely on the present, so I never heard about these dreams again—When I tried to follow-up a later interview, she laughed and said, “I told you about that?” She wouldn’t discuss it further.

The other participant, who was lost to follow-up after three interviews, provided an incredibly complicated narrative that was challenging to follow such that I could not have portrayed adequately or understood it fully without thoroughly using the member-checking process. However one piece of his narrative was clear. When asked about the best times in his life he said they were of the times when he was “a member of a small team.” He said this referred to his career and to his work at The Clubhouse. Those reflections stayed with me as I considered the role of family and work, or lack thereof, in the other narratives.

Quality of the data and analysis. The study employed the following strategies to maximize the quality of data (Creswell, 2007; Padgett, 2008):

1) *Multiple sources and thick description.* Data came from multiple sources. In thematic narrative analysis, central data sources are interviews with participants. In line with the purpose of this study, the collected data were focused upon establishing a thorough understanding of their perspective. The data sources included the interviews of which there were at least four interviews per participant and which generated: one monthly and one daily time-diary per participant; one life history calendar completed with each participant; one brief demographic form per participant; several field observation

forms for each participant. Field notes and reflective memos about each interview, including observations of the participants' self-presentation and home-setting, neighborhood, and elements that could not be captured in the recordings or the forms, provided a second source of data. In later stages of analysis, existing research on the population and emerging themes was used in constant comparison with the present study's findings, and as such served as a third source of data.

Thick description refers to the ability of collected data to provide detail, context, focus and emotion in a full way, such that it deepens first the researcher's, and later the reader's, understanding of the phenomena under investigation by revealing participants' voices, feelings, meanings, intentions and actions as well as the contexts and structures of their lives (Charmaz, 2006; Creswell, 2007). Generating thick description is a critical element of all qualitative research in general in that it generates the depth of understanding sought after by qualitative research questions. Additionally, its presence in the final research product allows for the researcher to determine whether the findings are transferable to other settings or populations (Creswell, 2007).

2) *Triangulation*. Triangulation in qualitative research is used to verify the credibility of the data, and refers to using multiple sources and/or multiple methods of gathering data (Creswell, 2007). Since thematic narrative analysis is case-based, and since this study sought to understand the perspective of its participants, triangulation came in part through the use of different methods used in the interview process. Participants were asked to talk about their lives in three ways: through theme-focused interviews; calendar and time-diary interviews, and member-checking interviews. Field observations were a

method of data collection as well as a source of data. The sources of data, as described above, were also triangulated.

2) *Reviews and debriefing.* Members of my dissertation committee, in particular the dissertation sponsor, critically scrutinized and provided regular feedback about methodology, meanings and interpretations throughout the course of the study.

3) *Audit Trail.* I maintained a clearly organized audit trail, from the first interview to the final product, such as members of the dissertation committee might follow it to examine the process and product.

4) *Member-checking.* As described above, I solicited participants' views of the credibility of the developing account of the core narrative and invited suggestions for changes.

Software. I used Express Scribe to store and organize the interviews. I used Microsoft Office as the primary program. I used Microsoft Word to transcribe and code the interviews, as well as to help locate texts associated with themes within cases, and to assist with coding, comparative analysis, and memo-writing. I used Excel and Powerpoint software to aid in visual mapping. I used Excel to create the life history calendars and tables. The time diaries were created in Google Calendar. Although excellent qualitative software programs exist, they are most helpful with large databases (Creswell, 2007) and are geared towards larger-scale studies. The key functions of the programs could be easily replicated through use of the programs noted above. Thus, the scope of the present study did not necessitate the use of qualitative software.

Ethical issues and protection of human participants. This study presented minimal risks to participants. However due to the vulnerability and marginalization of the

study population, I worked closely with the Columbia IRB and the IRBs of the sample sites to ensure that the study maintained ethical standards. Upon the first meeting, the study description was reiterated and the informed consent procedure was followed.

Because of the nature of the vulnerabilities of mentally ill populations, the participants' capacity to provide informed consent was assessed prior to the first interview using assessment standards delineated by Moser (2006) and DeRenzo et al. (1998). As a New York State licensed clinical social worker (LCSW) with a master's in social work from the Columbia University School of Social Work and approximately six years field experience with the population under investigation, I had the experience and qualifications to conduct these procedures. Participant competency screening included checking to ensure each participant was alert and oriented, understood the nature of the study, was aware of potential risks and knew what to do in the case of distress during an interview. The informed consent procedures and confidentiality protections included both a written and verbal explanation of the study, and a signed and verbal consent process, which occurred just prior to the first interview. Columbia University IRB approval was received prior to beginning recruitment.

Reflexive Analysis

This study grew out of my experience in the field as a social worker, and out of my belief in the importance of understanding more fully the persons we serve as social workers, with the hope that this will guide more effective and more empathic clinical work and decision-making, and inform program development and mental health policy and research. In addition to the current research delineated in the introductory chapter, the substance of the study was also informed by my professional experience with the study

population, in outpatient psychiatric care, inpatient psychiatric care, and supportive housing settings. My interest in the topic developed as I gained familiarity with the study population in those settings. This research is therefore considered “practice close” which has both advantages and disadvantages (Lykkeslet & Gjengedal, 2007).

Advantages of the practice close nature of this study included the fact that, as a licensed clinical social worker with experience with the study population and with the study settings, I was comfortable entering the field and interacting with and interviewing persons who sometimes exhibited signs and symptoms of schizophrenia. Also, my clinical license allowed me to examine for consent, therefore allowing me to be the only contact person with the study participants, streamlining the research process. Further, perspectives gained from professional experience enriched my analysis and interpretation of the data and added to my findings around the strengths and needs of older adults with schizophrenia.

I was also aware of the disadvantages of practice-close research while conducting the present study. A primary concern was that biases of which I am not aware may have caused me to “see” or “not see” important themes (Lykkeslet & Gjengedal, 2007). I addressed this issue through the use of field observations and self-reflective notes and memos, critical feedback from members of my dissertation committee, and through the methods of ensuring data quality described above.

The rigorous nature of the data collection and analysis process allowed oversights to be self-corrected. For example, I did not include questions about alcohol or substance abuse in any of the questionnaires or prompts that I developed. However three of the study participants informed me of significant alcohol or substance abuse histories

throughout the course of the data collection process. Recognizing my oversight, I later asked the other participants about alcohol and substance abuse histories. Upon exploration, the participants who had not talked about using drugs or alcohol did not have significant histories for drug and alcohol use, indicating that oversights were being corrected through the data collection strategies.

Conversely, due to the aforementioned concerns around morbidity and mortality of the study population, I asked participants questions about health diagnoses and concerns on the demographic form and returned to the topic frequently throughout the interviews. However the results were inconsistent. For some the topic garnered thick description and for some it produced little narrative talk. Ultimately it was omitted from the shared core themes, despite its centrality to some of the narratives and my own interests.

It should be noted that in developing awareness, the goal was to monitor my influence as a researcher, rather than remove it from the process. From the developmental life course perspective, narratives are viewed within their social context, a context that extended into my work as researcher. How older adults reminisce about their lives to others depends in part on who is listening, and on the relationship that they and their listeners establish (Randall, Prior & Scarborn, 2006). As far as the social context of this study, I found that my role as a social work researcher interested in narratives affected the relationships I developed with study participants.

From the beginning of the study I was aware that I was relating to the participants differently than I had to my clients as a social worker in the field, and differently than I had expected to as a researcher. As a social worker, my work had typically been goal oriented. As a psychiatric inpatient social worker, I had focused on after-care planning. In housing, I

had focused upon assuring their stability in their homes. However, as a researcher using narrative methodology, I found that I got to know the participants in a different way than I had when I was working with them in the field. Since I was there to evoke and elicit narrative talk, I did not feel pressured to move the conversation in any particular direction. I was able to sit and listen, admire their strengths and be moved by their accounts of challenges and losses. The time for those activities had rarely been available in the field settings where I had been employed as a social worker.

Nonetheless, participants knew I had been a social worker, and I found that they sensed that even in the capacity of a researcher, there was something about me that seemed like a social worker to them. One explained to his roommate that I was there as his social worker; another asked if I knew of employment resources; another showed me a new hand tremor and asked what he should do about it; and another asked about my career goals.

Further, I found that challenges I faced as a social worker based on my personal values and beliefs were evident in my work as a researcher. As an atheist, when clients in the past had told me about their spiritual beliefs I had often struggled to assess whether those beliefs were part of a religion or part of a delusional system; and whether the expression of religious beliefs indicated an increase of psychiatric symptoms or spiritual growth. I relied heavily upon co-workers from various religious backgrounds to help me understand what it meant when a client saw signs from God, spoke to God, or when God spoke to them.

Many of the participants in the present study told me of their religious beliefs, and for some religion was a central part of their daily lives, sense of self, and contributed to

their well-being. However, there were times when they spoke about religion in a way that did not make sense to me. One participant in particular had symptoms characterized by religiosity, including auditory hallucinations that he interpreted as the voice of God and the Devil; ideas of reference wherein he interpreted ordinary occurrences as signs from God; and beliefs that he had the power to heal and predict the future. However since his family of origin shared many of his religious practices and beliefs, and since he did not receive psychiatric treatment until he had been ill for a lengthy period of time, it was unclear to me when he was following ordinary religious practices and when he was, in his narrative, beginning to experience psychiatric symptoms. Instead, I put my clinical knowledge to use and relied upon functional markers of schizophrenia: disruptions in work, relationships, and ability to maintain activities of daily living, to approximate when his illness began. Even this was not entirely foolproof, as his work history was probably also influenced by his limited education and training, which in turn may have led to a more transient lifestyle and transient relationships even without the onset of schizophrenia. However the lack of specificity around this detail ultimately mattered very little, since I primarily sought his interpretations and accounting of his illness and other biographical material, rather than an understanding of the clinical course of his illness.

In the National Association of Social Workers (NASW) Code of Ethics (2008), understanding the “importance of human relationships” is listed as a central social work value. As a social worker, and as an individual, I also value highly the role of personal relationships as they contribute to meaning, sense of belonging and sense of well-being in my own life, and as I understand them to contribute to the lives of others. Early on in the present study, I was startled by the loss of relationships and isolation experienced by

participants. Identification of other themes was initially over-shadowed by the power that theme held for me personally. Self-monitoring through response memos and regular reviews with my dissertation sponsor were critical in moving from my “gut response” to refined analysis contextualized within existing research, and on to other core themes.

Perhaps also related to my position as a social work researcher, participants reported that they found participation in the project was “helpful” to them. One participant said she felt the project helped her “get some things off [her] chest.” Another said she felt the project helped improve her self-esteem, finding the analyses that I shared with her to be encouraging. Yet another said he found the project useful, helping him to organize his memories, remember who he is, and gain perspective through seeing his life as a whole. Perhaps more significantly, he said the project helped him remember good times and think about all the positive parts of his past and present, and realize his life had not just been about having schizophrenia.

While I had expected my role as researcher to entail impartial observation and detached questioning, I found instead that I was involved as an active participant listening to and guiding the formation of the participants’ accounts of their narratives through the use of the methodological tools. At times, I couldn’t resist providing feedback (I suggested that the man with hand tremors speak with his case manager about it, for example). At the same time, the participants were more eager to see me than I recalled my clients in the field had been. This may have been partly because of the financial incentive of participation, but participants also enjoyed being involved in the project, often calling between meetings to see when I would be coming next. One participant continued to call me every month or so, even after the conclusion of our meetings: She just wanted to say hello and see how the

project was doing, and how I was doing. Even the most negatively symptomatic of the participants called between appointments with the help of his case manager because he wanted to make sure he had the time and date right for our next meeting. Later, he invited me to his upcoming birthday party.

As I wrapped up the last meeting with one participant, he explained that the “study money” was good, but that he was glad to have the chance to write his autobiography since “everybody else” did. In the process interviews participants agreed that they would participate in a narrative project again, having enjoyed the present one, and would participate even if they were not paid. However their articulation of the utility of the process allowed me to understand that, in fact, the \$25 per session reimbursement was not enough, and that each should also have a final copy of their “biography.” I made arrangements to provide copies to each of them.

The participants’ motivation to provide a socially desirable narrative seemed to have been balanced by their interest in having their stories heard and recorded. While perhaps some important details were embellished or omitted, the narratives went beyond a sociable recounting of stories, as will be evident in the findings. In short, I found that the relationships I developed with participants, coupled with their interest in the study, promoted narrative development and clarity.

As such, I found that the greatest challenge in the analytic process was in advancing the best way to honor the study’s participants through the presentation of my findings. On the one hand, I found that the participants had all experienced unimaginable adversities and carried wounds from those experiences with them into later life, where they often faced new challenges. On the other, the participants had also shown remarkable fortitude

in their ability to face those adversities; to adjust, adapt, cope, grow and learn from them; and to maintain hope. I believe I was able to capture these dialectical elements of the narratives in my findings around the shared core themes. What was harder to capture was how much I liked the study participants. I enjoyed their company and I looked forward to our meetings together. I believe the positive regard with which I viewed the participants enhanced rapport-building that promoted the co-construction of rich narratives.

Chapter 4: Findings

Characteristics of the Sample

The table attached as Appendix G provides detailed information about each of the six study participants: Hank, George, Harry, Evelyn, Bernard and Hope. In this section I describe key features of that table and provide additional key information about the participants that is beyond the scope of the table. I begin with an overview of the demographics and move on to a discussion of the participants' mental health histories, housing histories, and physical health.

Of primary concern to the present study was the age of the participants. The six study participants had a mean age of 65.8 years, with a median age of 67.5 years and ages ranging from 56 to 73. Four of the participants were men and two were women. In terms of race and ethno-cultural backgrounds, Harry, Hope and Evelyn were White and from Queens, NY. Hope and Evelyn held Italian-American Catholic heritages. Harry was from an Irish Catholic background. Hank, George and Bernard were Black men. Hank was from the rural southern U.S., Bernard was from the Harlem area of New York, and George was an immigrant from the Caribbean.

None of the participants were from wealthy families. Hope and Hank both described themselves as having been from "poor families." Hank was raised by sharecroppers in the pre-civil rights movement rural south and was expected to work in the cotton fields from the age of 3 to help his family. Hope described periods of time as a child when her family could not adequately feed her, and the smell of neighbors' cooking caused her to cry. George, Bernard and Harry appear to have been from working class families. While they did not face the harsh conditions experienced by Hope and Hank, they nonetheless had little in

the way of material comforts or available resources. Evelyn was the only participant from a middle class family and engaged in such activities as spending summers in a rental house on the beach, and although she received academic merit scholarships to support her attendance, was financially able to attend private high schools and university and encouraged by her family to do so. Harry and George also graduated from high school, although George was later required to obtain a GED since his education was in the Caribbean. Bernard, Hope and Hank all left high school prior to completing it. Although the reason Bernard left is unclear, both Hope and Hank left so that they could work and help support their families of origin.

In terms of diagnostic category, five reported diagnoses of schizophrenia and one, Evelyn, reported a diagnosis of schizoaffective disorder, bipolar type. However two other participants, George and Harry, reported taking antidepressants, and Hank reported taking a mood stabilizer. Thus mood disorders, and depression in particular, played a significant role in the lives of the participants even though schizophrenia was the primary diagnosis, findings which are in line with current research of schizophrenia in later life (Harvey, 2005). Participants were not screened for schizophrenia sub-types or assessed in-depth for current symptomatology.

Histories of mental health treatment varied. Some of the participants appeared to have experienced psychiatric symptoms for many years prior to receiving mental health treatment, and were in and out of treatment even after the initial contact. Often the only care they received was inpatient hospitalizations, or as part of a homeless shelter or housing program.

Hope appears to have had an onset of illness some time in her mid to late 30s. However she did not receive treatment until several years later when she attempted suicide. Although she was psychiatrically hospitalized at this time, she did not remain in outpatient treatment afterwards because she “couldn’t afford it.” Untreated, she eventually became homeless and only received treatment after receiving housing through The Psychosocial Clubhouse when she was in her late 50s.

Bernard began experiencing psychiatric symptoms at about the age of 17. He was soon after hospitalized at a large state hospital for several years, although he is not clear what his treatment was there besides “pills.” He had three subsequent hospitalizations, each lasting anywhere from 2-8 years, and he says his treatment was always “pills.” In between hospitalizations he did not receive outpatient psychiatric care until he received housing through The Psychosocial Clubhouse in his 60s.

Hank’s illness onset is unclear, clouded by fluidity between the religious nature of his symptoms and the way religion was expressed in his family of origin. Nonetheless, he appears to have been experiencing ideas of reference (“signs from God”) at age 17 and auditory hallucinations (the voice of God and the Devil) at about age 21. His symptoms, as well as his self-reported abuse of alcohol, affected his ability to maintain work, housing, and relationships. He began receiving psychiatric care at about the age of 35 when he was psychiatrically hospitalized while living in a homeless shelter. He has remained on medication since that time and reports no subsequent psychiatric hospitalizations.

Evelyn began receiving outpatient psychiatric treatment at the age of 16 and had her first inpatient psychiatric hospitalization at the age of 18, wherein she received electroconvulsive therapy as well as medications. She reports 19 lifetime hospitalizations since

that time, many rounds of electroconvulsive therapy (ECT) and treatment with mood stabilizers (lithium in particular) and anti-psychotic medication, with which she had been moderately compliant as an outpatient. She had also used long-term talk therapy relationships with psychotherapists, the Psychosocial Clubhouse, and a 12-step program for over-eaters to manage her health and mental well-being.

George's illness onset appears to have been at the age of 22 when he was discharged from a naval academy for fighting, and wherein he described a conspiracy against him. He did not receive treatment until 3 years later, when he was arrested for violence against his family. He was committed for several months at this time, and was discharged with a prescription for Thorazine. He remained on the Thorazine for some time, despite the fact that the side effects for him were debilitating, causing such extreme drowsiness that he could not keep a job. He discontinued his medication and was hospitalized under similar circumstances in his mid-30s. After this point, he became homeless and did not receive consistent psychiatric treatment again until The Program housed him in 2001.

Harry began first experiencing auditory hallucinations when he was about age 23. Although terrifying and disruptive, he tried to "let it go." He didn't receive psychiatric care until age 29, when he was brought to a psychiatric emergency room after his behavior was brought to the attention of the police. He was treated with medication, but did not continue to take it. After a period of homelessness, at the age of 34 Harry was brought to a psychiatric hospital again and hospitalized for 8 ½ months. When he was discharged it was to a psychiatric residence run by The Program where his psychiatric medications would be monitored, and he has received psychiatric treatment at The Program ever since. He estimates that he has been psychiatrically hospitalized 7 times over the course of his life.

Three of the participants, Evelyn, Harry and Hope, had histories of suicide attempts. Hope's attempt was by overdose of pills in her late 30s-early 40s, in the context of increased mood and psychotic symptoms and family conflicts. Evelyn's attempt was also by overdose, she was also in her 40s when it occurred. She said it was triggered by increased symptoms, conflict with her family and stress at work. Harry's attempt was by cutting himself with broken glass from a lamp he had broken in a period of increased psychotic symptoms and insomnia while living in a psychiatric residence at about age 46. Each of these attempts was followed by an inpatient psychiatric admission, although the hospitalization was not necessarily followed by ongoing treatment.

While participants differed in their presentation of psychiatric symptoms, even participants with more negative symptomatology were able to provide informed consent and thick description around subjectively important themes. Three of the men, Harry, Hank, and Bernard, reported histories of alcohol and/or substance abuse, although all now abstained from alcohol use and had for at least a decade.

For treatment at the time of this study, as noted earlier, three participants, Evelyn, Bernard and Hope, came from The Senior Residence and three-- Harry, Hank and George-- came from The Program. All of the participants from The Senior Residence actively participated 2-3 times each week at The Clubhouse. Participants from The Program participated in The Program 3-4 days per week. All of the participants were currently receiving medications that included at least one anti-psychotic medication.

Although participants were not recruited on the basis of housing status, all of the participants' current living arrangements included housing provided by a social service agency. The participants from The Program lived in housing provided by The Program. One

lived in The Program's psychiatric residence, with 24-hour staff and nightly meals provided, among other services that included medication monitoring and money management (rent and utility bills were paid by The Program from participants' Social Security checks, and the remainder was given in cash to the participant). Two lived in scatter-site housing that offered off-site case management services, such as money management and assistance in apartment maintenance.

Five of the six study participants had experienced at least one episode of homelessness. This higher than expected rate of homelessness was likely due to the fact that both recruitment sites had housing programs connected to them. Four of the participants received medication monitoring through their housing programs, wherein social service staff would observe them taking their psychiatric and medical health medications at least one time each day. The study participants lived either alone or with roommates. Of the three who lived with roommates, only one had what appeared to be a friendship with his roommate, in that they shared meals, household responsibilities and had a knowledge of each other's lives and interests. The other two had cordial relationships with roommates but acted more as neighbors than living companions or friends.

I asked multiple questions to identify and explore concerns around and coping with physical health issues. All participants had high blood pressure and were taking medication to control it. Many had experienced serious illnesses or conditions, such as breast cancer, pneumonia, heart attacks, and heart disease that required open-heart surgery. When asked about diabetes there was some confusion. Only two participants, Hank and Bernard, stated that they had diabetes. Hank believed God had cured his diabetes. Staff at his residence monitored George's blood sugar level twice daily, and he took metformin, a medication that

treats diabetes, on a daily basis. The others all took metformin, but did not believe they had diabetes. Harry explained that blood sugar was an ongoing problem, but that he did not have diabetes or “pre-diabetes.” Evelyn believed she had “pre-diabetes” in the past but that she had been able to manage her blood sugar so she no longer had it, and she continued to take metformin. Despite the range of health conditions and confusion around them, the extent to which health issues were salient concerns for participants varied. Ultimately health concerns were not considered a shared core theme among the participants.

Shared Core Themes

Introduction. In the following section I will present the shared core themes identified through thematic narrative analysis of the participants’ life history narratives. I identified four core themes common and central across diverse life trajectories: 1) *“My life as it is has value:” Narrating schizophrenia in later life*; 2) *“I have a key and live like a real person:” Homelessness and housing challenges in retrospect*; 3) *“There’s not been jobs:” The meaning of employment*; 4) *“God told me how we’re going to meet back up:” Narratives of relational conflict and loss, adjustment and renewal*. The first theme describes how participants shared narrative strategies that situated the role and meaning of schizophrenia in their lives. The three subsequent themes are of shared challenges faced by the study participants, and the strengths they marshaled to address them.

I introduce each section by briefly contextualizing each theme within the existing literature and the process through which the themes came into relief during the course of the present study. I then present each participant’s narrative as it relates to that theme analyzing its features within the case of that participant and to a lesser extent, comparing

across narratives. I maintained within theme chronology in the narratives for each participant, and included full summaries that used participants' own words to provide evidence of thick description and promote the overall trustworthiness of the findings. By including participants' own words, I also extend the understanding of how they "expressed" their life narratives, in response to the central research question.

After each participant's narrative has been presented, I analyze across cases, discussing between case parallels, variance, and the relationship of the present study findings to existing research relevant to each theme.

Theme 1. "My life as it is has value:" Narrating schizophrenia in later life.

Illness insight is a paradox in schizophrenia, serving as both an advantage and disadvantage to affected persons. Clinical insight is generally defined as belief in and awareness of meeting the clinical criteria of the illness and its related symptoms, behaviors and other consequences. While on the one hand, increased insight is associated with improved treatment adherence that lead to better symptom outcomes (Buckley et al., 2008), insight is also associated with undesirable outcomes such as increased depression and lowered self-esteem (Drake et al., 2004). As many as 50-80% of persons with schizophrenia lack clinical insight into their illness (Lincoln et al., 2007). However Roe and Kravetz (2003) have argued that narrative insight differs from clinical insight, broadening the definition of insight to include the story that persons tell about their illness, rather than belief in the applicability of clinical criteria to themselves. This allows for a more nuanced view of how persons with schizophrenia understand their illness experience.

Roe et al. (2008) have examined narrative insight in psychosis, finding that psychosis appears in narrative accounts with four distinct profiles. Participants in their study: 1) accepted the illness but rejected the illness label; 2) rejected the illness but searched for another name for their experience; 3) accepted the illness and label passively; and 4) integrated the illness and its label into a narrative that had insight into the illness and its impact on life. Those whose narratives fell into category 2 were significantly older than those in the other categories, although the sample consisted largely of men in their forties, suggesting that age plays a role in the development of narrative insight.

The first theme of this study is therefore that of illness insight in later life, and is encapsulated in Evelyn's statement, "My life as it is has value." At the end of the semi-structured interviews, I asked participants to reflect upon schizophrenia: Whether and how the term "schizophrenia" applied to them and how they would summarize its effect on their lives. These questions consistently yielded thick description. The theme was initially developed through analysis of those responses and then furthered through examining additional statements made by participants throughout the interviewing and member-checking processes. The theme elucidates how schizophrenia was a highly individualized experience, with each participant providing unique interpretations of how the label applied to them. At the same time, in the context of a full life course of experiences, the older adults in this study generally found the illness label was irrelevant. Beyond a diagnostic label, they often shared Evelyn's sentiment that they were not defined by their diagnoses and that "life as it is has value."

Theme 1 narratives.

Evelyn. Evelyn was a 66-year old Italian-American woman from a middle-class family, who was born and raised in Queens, New York. Evelyn's experience of schizophrenia was episodic, and in between episodes of acute illness she felt she has "done well." Evelyn's illness had a mood component and she had received multiple and divergent diagnoses. Her current therapist, a 12-step recovery specialist, did not believe she has a psychotic illness and attributed her problems to addictive personality patterns. However her current psychiatrist treated her for symptoms of schizophrenia and a mood-disorder, asserting that her diagnosis was schizoaffective disorder, bipolar type. Evelyn agreed that she had a psychiatric disorder, adding, "Being in the hospital and being acutely ill was a tremendous amount of suffering." Denying her illness would have amounted to denying the tremendous suffering. Perhaps because of the varying diagnoses she received across her life, and in the face of 19 lifetime hospitalizations and one suicide attempt, she had put a great deal of thought into what her illness was and what it meant:

"I've been told that I'm not schizophrenic. I've been told that I am. I don't know.... I can remember... being psychotic. I can remember that... I feel that the distinction between mind and body and feelings... they're all artificial distinctions. So, my best belief is that there's an organic basis to what's wrong with me. There's a biological component but there's also childhood experiences, which may have triggered this biological component. I think there's more to be understood. I think the current medical model of mental illness-- which is... pills [are] supposed to solve everything... hasn't solved everything.

"...I myself have had a lot of shock treatments. And they were seen as helping and sometimes when I was so deeply depressed, perhaps they did help. But, I just don't know....

I remember my [former] psychiatrist saying... 'That schizoaffective...that disorder-- you've got it.' And my [current] therapist... says, 'Don't make yourself a patient and a victim... be someone who contributes to life rather than takes from life, takes from others.'

"...So, at this point in my life, it's really irrelevant what label you would put on me-- it's irrelevant.... You're not supposed to recover from schizophrenia. But I do recover and I function well. So do I have it? And I recover? Or is it something that's episodic... or something with acute episodes? Or do I not have it-- but have learned how to buy into illness? And do I have all kinds of shame around the way I've lived my life and my feelings and my rage?

"...There's nothing I can do about my past.... I've had always this fear that I'll be locked up because of my illness, and now I feel that I've probably demonstrated that I can recover and that I have recovered... A psychiatrist said to me once, 'But it always comes back....'

"The recovery always comes back, too."

Evelyn later added, "I've come to accept responsibility for my life.... As I look back over my life now, I see certain things that were joyful, and that were accomplishments... In elementary [school], in high school, in college and in graduate school I had scholarships. I was a good student. And I got my master's in my 40s and went back to school and worked.... I guess I've come to accept that my life as it is has value. And I don't define myself by a diagnosis. I define myself by what I do."

Hank. Hank was a 61-year old Black man who had been told his primary symptom of schizophrenia is that he hears the voice of God. However there was fluidity between his expectations around spiritual experiences from his culture of origin and his manifestation

of symptoms. Born and raised by sharecroppers in the rural South of the pre-civil rights era, Hank belonged to a people who spoke to God and experienced miracles. At the age of 3, God dislodged a marble from his throat thanks to a prayer from his grandmother. At 12, he was filled with the Holy Ghost and lifted from his knees by God, in an episode that was later verified by two deacons and “saved” his soul from “burning in hell.” Later, he and his siblings healed his ill mother through prayer and song. He recalled times in his adulthood when he, his wife, and his mother spoke in tongues from joy. From his perspective schizophrenia was the same as being saved.

He explained, “Everyone that gets saved feels the Holy Ghost-- don’t you know that they label them as schizophrenic? ...I say you go into church, you gonna call all of them schizophrenic? ...If you’re saved, you’re schizophrenic.”

Nonetheless, Hank was aware of the stigma attached to schizophrenia, having experienced unpleasant consequences stemming from his diagnosis. Most notably, he was over-medicated at one point, leading to side effects of unbearable stiffness and “feeling like a zombie”—an experience he was sure was the devil’s work. Because of that experience, he associated the term “schizophrenia” with the side effects. Therefore he rejected the label of schizophrenia to describe his mental illness while also accepting that he was different—he was “saved.”

Hank’s experience of schizophrenia had not been as an illness, but as a deepening of his spiritual life. The familial and cultural sanctions of his spiritual life and experience with God added to the richness and purpose of his life by placing him on a spiritual mission. Like Evelyn, the illness label was less important to him than the illness experience: The fact that he chose to use his time in life in service of God was more important to him than whether

doctors and social workers believed his spirituality was an illness or what that illness was called.

George. George was a 70-year old Caribbean immigrant who had lived in New York City since he was 21. George explained that his diagnosis of schizophrenia described how, “When you’re angry... very angry and violent... got a quick temper to fight.” George’s experience of schizophrenia had been a disruptive one, causing him to have a short-fused temper and get into physical altercations with others. The “fights” first occurred in the context of a brief stint in the military at the age of 22, and lead to his “dishonorable” discharge. Later, he had more than one episode of physical violence with his family, which eventually led to their refusal to house him, and in turn, his homelessness.

George used the term “schizophrenia” interchangeably in our interviews with “quick temper,” demonstrating how the clinical label was irrelevant to him and at the same time, the term signified his subjective understanding of his illness experiences. Speaking about schizophrenia in his present life, he said,

“I can’t control it on my own but I’m better... when I’m using medication. It helps me a lot... Calms me down. It calm my nerves. And I’m able to sleep at nights... I’m satisfied whatever it is the consequences. I feel all right.”

His temper and sleep were for him are the most important symptoms, and in turn, the most important treatment outcomes. While the label was irrelevant to him, the label consequences were not. He shared Evelyn’s sense that “the consequences” of his illness were nothing he could do anything about at the present time but, stabilized in his current life, he felt “satisfied” and “all right.”

Harry. Harry is a 56-year old White man from a working class family, raised in Queens, New York. Harry's illness description matched most closely the DSM IV criteria—and most closely approximates clinical insight into his illness. Of all the participants in the study, he appeared to have been the most impaired by positive symptoms of schizophrenia, even though he adhered strictly to a medication regimen that includes two types of anti-psychotic medication, an anti-depressant and an anti-anxiety medication. Although he lived in scatter-site housing that did not provide medication monitoring, he continued to use daily medication monitoring forms to monitor his own adherence. However, even though all of the study participants were receiving active psychiatric treatment, Harry was the only participant who required psychiatric hospitalization during the course of the study.

Harry believed the term schizophrenia applied to him, and was certain it had affected his life. Over his life course, he had felt suicidal at times and had attempted suicide once. On a day-to-day basis, schizophrenia had prevented him from doing things he enjoyed:

"I can't do a lot of things I probably could normally do... before I got sick I used to run around the city and do things all the time. Go to museums, go places, go to the beach. Now I don't go anywhere... I want to go again—do it on my own. But it's too hard.... I like all this stuff. I just don't do any of it. I don't give myself the things I want.... I think I'm trying to punish myself... for not being successful. Like my brother."

Varying from the others' perspectives of "life as it is" having value, Harry saw himself as metaphorically being "in the dead of winter." While this was a painful place to be emotionally, he maintained hope, believing "things change" and "spring comes out... all

over again.” He felt his life had value not because of what he had done or whom he was, but because of what he hoped to do and become.

Additionally, he believed in his own ability to cope with his illness symptoms, and to know when he needed to be psychiatrically hospitalized. While he expressed an ongoing sense of disability, he was adamant in his assertion that his disability stemmed from his physical ailments, of which he had many.

Bernard. Bernard was a 73-year old Black man who was raised in Harlem by a working class family. Bernard presented with negative features of schizophrenia, answering questions with a flat affect and in as few words as possible. His answers to questions about his illness were vague and his perspective on the role of schizophrenia in his life varied. At one moment he said of schizophrenia, “It applies to me, yeah.” And in the next he said, “I don’t have schizophrenia... Never happened to me.”

However he also told me of three life-time psychiatric hospitalizations, each lasting between 5-8 years. He explained these resulted from “a nervous break-down” which made him “moody” and generally “not feeling well.” He also remembered the illness caused him to “lay down on chairs.” Like other participants, upon exploration he ultimately rejected the label “schizophrenia” saying, “I was just sick.” In reflecting upon how schizophrenia affected his life he stated that there’s “no way it could have been any different” and at the same time said his present life was “going pretty good,” sharing with the other participants a sense of acceptance of his *life as it is*.

Hope. Hope was a 69-year old Italian-American woman who was one of 12 siblings raised in Queens, New York, by what she described as a “very poor” family. Like Bernard, Hope presented in her interviews with mostly the negative features of schizophrenia, and a

deep inattentiveness. She would often get lost in thought after a brief response to a question. Her experience of schizophrenia was that it gave her demeaning auditory hallucinations and caused her to “space out” all the time. Through the use of medication and willpower, she said, “I think I’m cured” although at other times she modified that assertion with “mostly.” The voices were gone, and she felt better able to focus than in the past. Less verbally expressive than some of the other participants, she captured the sense of her life having “value as it is” in fewer words—when I asked what she was most looking forward to, her answer was, “just my every day life.”

Discussion of Theme 1. Findings from the present study develop our understanding of narrative insight by adding a new narrative insight profile with distinct features that connects to the narrative insight profiles described by Roe et al. (2008). In terms of the label of “schizophrenia,” the present study’s participants understood that their lives had been affected by something sometimes called “schizophrenia” and sometimes called other things: “being saved,” “quick temper,” “addictive personality,” “spaced out” or “just sick.” The label “schizophrenia” was accepted as one of several labels that had been used to describe their experiences. Although clearly Hank preferred “saved” and Bernard felt he had been “just sick,” the participants shared a general sense that the label did not matter as much as the consequences of their symptoms did. The alternate labels were usually tied to those consequences.

As to whether they “accepted the illness,” the participants in the present study found clinical descriptions of symptoms were less relevant than their own unique experiences of the symptoms, and again, more importantly, they were less relevant than

what they considered the consequences of those symptoms. They accepted the clinical description of schizophrenia only so far as far as it mirrored their experiences.

Although their acceptance of the illness and its label was tentative and subjective, their acceptance of the illness experience was far from passive. Participants in the present study integrated their mental illnesses into their narratives through a process of accepting the clinical criteria as it related to their experience and examining its consequences across their life courses. They actively interpreted the illness label, symptoms and its applicability to their own lives, integrating their understanding of the illness and its consequences into their narratives, as in the fourth profile described by Roe et al. (2008). The illness experience had been integrated into the narratives with more personal, subjective definitions of the illness experience, rather than traditional clinical insight. As a fifth narrative profile, it could be called: Accepting the illness label as one of many possibilities; accepting the illness as it matched personal experience; and actively integrating the label(s) and illness into a narrative.

This process is consistent with addressing the narrative tasks of aging. Narrative gerontologists view tasks of aging as utilizing the increased internal activity of later life to review and value life experiences and assimilate or recontextualize painful or problematic parts of a narrative into positive experiences, through instrumental reminiscence (Randall, 2011). In fact, Hildon, Smith, Netuveli & Blaine (2008), in a mixed methods investigation into resilient outcomes of a diverse group of non-mentally ill older adults, found that resilient outcomes depended upon constructing narratives that reinterpreted past adversity in light of recent events. As Evelyn stated, "there's nothing I can do about my past." Bernard and Hope echoed Evelyn's sentiment in their suggestions that schizophrenia

may or may not have been the reason for past problems, but the past “couldn’t have been different” and now they have their daily lives to enjoy. Even for Harry, who accepted the clinical description and label of his experience, saw his ongoing impairments as coming from physical infirmities rather than the stigmatizing illness label. The participants had lived their lives with the illness, whatever it is called and, having found a way to live with it in to later life, it was not as important as other challenges and joys, past and present.

These findings align with those that find development of a cohesive personal narrative to be an integral part of recovery from schizophrenia (Roe & Davidson, 2005) and may help explain why age was a significant factor related to narrative types in the study by Roe et al. (2008). In the case of the participants in the present study, the consequences of the illness were adapted into complex coherent life histories and present-time narratives, wherein the illness label and its associated stigma held less value. The participants in the present study were able to profit from their accumulation of biographical capital, using it to make sense of their illness in way where it did not diminish their sense of self worth. Internal tasks of later life, particularly instrumental reminiscence, provided a new opportunity and domain for recover from schizophrenia.

Further, the narrative insight shared by the participants seemed to resolve the insight paradox. All participants reported treatment adherence with a regimen that included medication. Although most took their medication with monitoring from onsite staff, which likely advanced their medication adherence, they could also identify ways in which their medication regimens helped improve their specific symptoms or their life. All participants were also active members of The Clubhouse or The Program. Although participants at times expressed unhappiness or seemed dysphoric over the course of the

study, this was not consistent across all study participants who shared this narrative insight profile, and therefore was not likely tied to their narrative insight strategies but to other factors. Participants generally seemed to have found an optimal narrative insight profile that promoted adherence to individualized treatment plans, honored and explained past suffering, but did not consume their identities with stigma.

The shared narrative strategy of this group of survivors shows how they resolved issues around insight into illness through understanding and appreciating the value in their lives and activities, in the face of the illness experience and its attached label and stigma. They were able to integrate their illnesses into their narratives in a way that the damage from the label and illness could be minimized. The decreased importance of the illness label, and integration of the fact of the illness into their narratives represents the participants' moving beyond the constraints of the illness so that they could, as Harry said, experience life anew in their later years.

The participants' acceptance of their lives *as they are* did not exclude the reality of the adversities they faced in the past and present. There was little sugarcoating in their expression of the hardships they had each endured, which ranged from loneliness to years and years of homelessness. Any sense of self-acceptance was hard earned through perseverance in the face of almost unimaginable adversities, including shared adversities that extended beyond their diagnoses. These shared adversities, and how they were expressed, addressed and reflected upon in retrospect, will be presented in the next three sections.

Theme 2. “I have a key and live like a real person:” Homelessness and housing challenges in retrospect. The foremost adverse consequence of schizophrenia shared among participants was that of homelessness and housing challenges. As noted in the introduction, an estimated 42% of homeless persons in Western countries have a psychotic disorder, such as schizophrenia (Fazel et al., 2008). Other common correlates of homelessness and housing challenges include serious medical illnesses and substance abuse histories (Levitt et al., 2009; Shaw, 2004). While mental illness is more likely to predate homelessness, other correlates, such as health conditions, may be caused or worsened by challenges of homelessness that include exposure to the elements, violence, trauma and malnourishment (Shaw, 2004). As with persons with schizophrenia, persons who have experienced homelessness face a decreased life expectancy (Parks et al., 2006; Shaw, 2004), placing participants in the present study doubly at risk for physical comorbidities and early mortality.

Understanding the participants of the current study in light of the data on homelessness, mental disorders, and morbidity and mortality conveys the particular impressiveness of the present study participants’ survival into later life, in some cases decades beyond average life expectancies of persons with their condition and life experiences. In the present study most, but not all, considered the experience of homelessness the greatest challenge of their lives. Evelyn was the only participant who did not experience extended periods of homelessness or quasi-homelessness, but she joined the other participants in identifying housing-related challenges as a significant obstacle in her life.

Gurney (1997) found that the experience of home is constructed in relation to climactic events in people's life histories. Homes were experienced as the setting for identity-forming events and patterns, as well as a sense of fulfillment: Moving to new homes stood as a retrospective marker for significant life changes including "getting a fresh start" or leaving an abusive relationship.

In the present study, the importance of home and housing was signified in the data collection process, wherein participants could readily affirm where they lived during specific time frames when recall on other topics from the same time was hazy. Further, recalling housing type and issues helped the participants to focus on identifying other events and daily activities during that period. Housing conflict, loss of housing, and gaining new and improved housing were significant life events around which their narratives could be organized. Housing was not only a core shared-adversity, but also an organizing principle for the participants' narratives.

In the following section, narratives of housing-challenges and homelessness demonstrate how participants experienced this shared challenge in unique ways. Subsequently the discussion centers upon two ways in which the narratives fit with each other and with current research on homelessness, housing challenges and schizophrenia. The first part of the discussion identifies the process through which long-term social services were viewed as central to participants' ability to obtain and maintain housing after homelessness or housing challenges. The second part of the discussion focuses upon how participants interpreted their experiences of homelessness and housing challenges into narrative metaphors that restored their narrative identities and illuminated the value of their current living situations.

Theme 2 narratives.

Hope. When asked about her greatest life challenge, “homeless” was Hope’s single word answer. When asked about the worst part of being homeless, she replied, “Hungry.” The process through which she lost contact with her family and then lost her housing is something she could not recall. Her sense of time and ability to recollect details from this period of her life were hazy, despite vivid descriptions for times when she was housed. When I asked whether the problem in her ability to recollect is that she couldn’t remember or rather that she didn’t want to, she confirmed my hunch by responding that she didn’t want to remember. She acknowledged that her psychiatric symptoms, the demeaning voices in particular, were bothering her at the time she became homeless. She estimated that she became homeless in her late 40s or early 50s, and that the period of living in the streets lasted for just over a year, and followed by an undetermined period of time living in a shelter.

“If I have to go back and think now, how that I become homeless, that was it. And I couldn’t tell my family because they didn’t believe me. They still don’t believe those voices... so, I just stayed on my own in the streets....”

When I asked how she survived living in the streets for so long, she again could not or would not remember. Consistent with other participants’ recollection of times of acute psychosis, much was lost, disorganized and unclear.

“Part of that time, I went to Atlantic City... There was a woman who cooked for homeless people there... And she made good food, boy! And sometimes the hotels, some of the casinos, used to send over food too. So... just for a while, I was without food.... I used to

beg.... I used to go and say, 'I didn't eat at all today, and I can't afford it, could you spare something?' And some people did. And some people didn't....

"I don't know how I did it. A couple of times I'd fall asleep with my bag next to me. And I'd wake up and it was gone... That was in Atlantic City... And that was all my ID I had. There wasn't any money, just ID. So, I had to go and report it to the police station. And they gave me a paper, which had my ID on it. So that's in case the cops stop me, you know, I would have ID on me...."

It was more than a year before Hope entered the shelter system, "[I] slept on the streets... Just find a stoop that I could crawl on and go like this and slept.... I just walked the streets... that was hard being in the streets, being hungry, and no roof over your head."

She decided at one point that she might be able to start a better life in Philadelphia: "When I was homeless, I walked from New Jersey to Philadelphia. I walked... Stayed right on the highway. It took me straight there... But then when I got there, there was the toll bridge. So I had to pass it and there's cops there. So I thought I got through, but I didn't. The cop car came right over to me, told me I couldn't go to Philadelphia. And that was Philadelphia's boundary line... I had to walk all the way back again."

In summary she said, "That was a bad part of my life.... I remember it. It was just a hard time in my life.... Thank God I got help."

Hope was uncertain for how long she had been homeless in the streets, but believed it was just over one year. By her early-mid 50s she had made her way back to New York City and was living in a small shelter run by nuns for homeless women in mid-town Manhattan:

"I can't remember [how I got there].... I didn't like it.... I think that they were prejudiced... against Italians.... Like when we had time for breakfast, the woman who made the breakfast, she was very nasty and mean... to me. I didn't notice if she was like that with everybody... But, after I found [The Clubhouse], they got me out of there right away."

She "found" The Clubhouse through a little bit of luck: "I met somebody that was a member here. And he got me in there. I was lucky... Just on the street, talking, I was having coffee... I must have looked like a homeless for him to take me." Soon after, in roughly the year 2000, she moved into a residence run by The Clubhouse for people who have mental illness and have been homeless. Several years later, she moved to her current housing in The Senior residence.

Hope's current apartment was a cozy studio in The Senior Residence. The furniture provided by The Senior Residence had a homey feel, and Hope had decorated the apartment with photographs of family and friends, prints of landscapes, and religious statuettes. The phone often rang while we meet, sometimes a neighbor knocked, and sometimes she left the TV on. Although she was not supposed to smoke in her apartment, she occasionally did, and in our last meeting she told me she was no longer permitted to even bring cigarettes into her apartment. Her cigarettes had to be checked at the front desk. Nonetheless, Hope described many friendships with neighbors and staff at The Senior Residence. Her apartment felt like the home of someone who was loved, and Hope expressed contentedness with her present living situation.

Harry. Harry has had two episodes of homelessness. As with Hope, and many of the other participants, Harry couldn't give a clear account of how he became homeless on either occasion. On both occasions he was experiencing acute episodes of psychotic

symptoms, including auditory hallucinations. In the first period of homelessness, Harry had been living with his brother, who went on a business trip for one week, and somehow Harry ended up homeless as a result, sleeping in the parks. Also unclear was the duration of the episode—at one point he said it lasted just one week, and at another point it lasted an entire summer.

Although he wasn't sure how he got there or for how long he remained, details of the experience stood out for him. The benches where he slept were uncomfortable and he had trouble sleeping at night because he was afraid of what might happen to him if he let down his guard. But the police checked on him, and people brought him meals and coffee. After a minor earthquake he became afraid of "being swallowed-up by the street," and called his brother, who by then had returned from wherever he had gone. His brother came to the park in a patrol car and took him in, providing him with housing, cigarettes and an allowance for several years after.

How he again became homeless was also a mystery. His best recollection was that he had been living in the apartment with his brother, but that his brother moved out and over time the building somehow became derelict. He stayed in the building for two years from around 1987 to 1989, the period when his symptoms were at their worst:

"I was in a very bad situation psychiatric-wise. I was hallucinating like crazy. Voices everywhere. I would be yelling out the window at the voices... [The apartment had] no heat, no electricity... no water. Nothing."

"I barricaded myself in my brother's room, old rooms. The police were outside... I went inside, there was a little lock... inside the door. I tried to lock it, the lock came off, and I was pressing my shoulder on the door.

“I heard the policeman say, ‘He’s blockading the door with his shoulder. He won’t come out.’ And he says, ‘Come on out. Come on out.’

“... I had to come out. I was trapped. I came out. I thought a monster was there... That made me really scared.”

The police brought him to a psychiatric hospital, and after an 8½-month psychiatric commitment in 1989, Harry was discharged to a psychiatric residence run by The Program. At the residence, his medications were dispensed and monitored by staff, and he was required to participate in chores, activities, meetings, and attend psychiatric treatment. He was given a weekly allowance out of his Social Security money, but most of the money went to pay his “rent” in the residence. A certain amount of “freedom” was lacking, making him feel like an “invalid” for having to do those chores, not having a key to his own apartment, needing staff to let him in and out, and having to sign-in guests. Nonetheless, he believed living there “put organization into” his life and he was grateful that he had people to turn to there.

Harry lived in the psychiatric residence for 20 years before moving, in 2009, at the age of 55, to the scatter-site apartment where he lived now and which was run by the same organization that runs The Program. Of his current housing, he said, “I’m free... I have key to my own apartment and live like a real person... I needed some independence.”

His current apartment was far from the neighborhood where he had lived in the residence for twenty years, and he still spoke of missing the old neighborhood. The furniture that had been provided by the social service organization was spare and institutional. The couch in his living room was the same make and model as the one that had been on the psychiatric inpatient unit where I used to work. Two chairs surrounded a

small table where we would meet and a dead plant sat on a windowsill. The shades were usually drawn. Aside from a brightly colored quilt he had bought himself and kept on his neatly made bed, there were few personal items in the apartment. His roommate's bedroom was down a long narrow hall, and their interactions seemed to be that of neighbors rather than living companions. His roommate was always surprised to see me and curious about the nature of my relationship with Harry. It seemed that Harry did not have many other visitors.

Throughout our time together, Harry expressed an ambivalence that encompassed feelings of gratitude and a sense of being beholden to The Program and the larger organization that runs it. Harry expressed tremendous gratitude for the organization that provided him with housing and psychiatric care since 1989. "I especially love the [organization] because... they're housing me... and that's a lot.... The [organization] came along and saved me." At the same time, he imagined the organization might "die away" so he could "be a butterfly and fly away." However he did not feel ready to fly away just yet.

Bernard. Bernard informed me that any hard times in his life were eased because his father was "always there" for him, however he spent over a decade homeless, sleeping in the streets and in a large men's shelter with a reputation for violence. He had lost touch with his father when he was psychiatrically hospitalized, and says his father had never known about his hospitalizations. Bernard first became homeless after his discharge from a second long-term psychiatric hospital stay, at about age of 40. He acknowledges this time was difficult:

"It was something. I didn't know where everybody was at [or] where I was. I, I couldn't tell where I was... I was sick.... I could have bust my tail you know.... I was in a daze

walking.... I got drunk... so I would feel better... I started drinking—alcohol. Drinking wine. Half and Half... that was its name... I started drinking Half and Half to get steady. [When it didn't work] I started drinking Night Train. You've heard of Night Train."

To eat he would get "a meal ticket" and "get on line for food" and he usually slept in the large men's shelter. As he said, he was "in a daze" during this period of his life, accounting for the brevity of the description despite the length of the experience. Whatever caused the daze also likely limits his recollection of the period.

He eventually "found" his mother again and lived with her until she died. Her death led to another lengthy episode of homelessness, followed by another years-long inpatient hospitalization at about age 50 in the state hospital. When he was discharged, he lived in a transitional shelter, then another housing program for five years, finally moving to The Senior Residence in 2007, at 69, because "they said it would suit me better-- if I stayed here." He quit smoking at that time, since it was not permitted in the new residence.

Bernard's apartment was a spacious one-bedroom apartment with a small kitchen and a large bathroom. It came furnished by The Senior Residence and had some of the same furniture as Hope's apartment. He kept a collection of animal figurines over his TV and stuffed animals on the windowsill that he explained were gifts from his friend who worked at the nearby pawnshop. Landscapes with Bible passages decorated two of the walls. Since he moved in, a home health aid had come every morning to cook him his meals, clean his apartment, do his laundry, and escort him to any medical appointments, although he could walk down the block to The Clubhouse and the pharmacy on his own.

I learned throughout the course of our meetings that “alright,” “fine”, and “pretty good” were high praise coming from Bernard (“just ok” was a criticism). Of his current housing he said, “It’s fine.” Later he added with a sense of satisfaction, “I live alone.”

George. George provided the clearest explanation of how he became homeless as well as the most detailed account of how he spent his time in that period, despite the presence of psychiatric symptoms. In about 1989, after a final episode of violence with his family, the police brought George to a psychiatric hospital, where he was admitted for a second time in his life, and kept for about a month. While he was in the hospital the family determined that he could not return to live with them and they moved from their home to ensure that he could not find them:

“Then straight up I went my ways and they went their ways. I left and went on my own. It was their decision. Where they went to I don’t know, but I was on my own since 1990. They didn’t explain why, maybe because of the misunderstanding between us. But I haven’t seen them since.”

He was discharged from the hospital to a shelter and shortly after moved into a rented room in Brooklyn. However, after his radio was stolen he became “suspicious” of his surroundings and “worried for” his other belongings. So he left the room to sleep on the subway.

For the next 12 years or so, George was homeless. Sometimes he slept on the subway, sometimes in churches with two chairs pulled together, and other times he stayed in shelters—including two longer stays at a shelter with connections to a psychiatric hospital, although he says he was untreated for schizophrenia most of this period. Of homelessness he said, “I have it rough but I take it easy.”

He objected to the fighting and “incivilities” he found in the shelter, but says that his experience as a cadet, from which he was discharged for fighting, helped him adjust to shelter living. It was a challenge to live in the shelters, but George felt that he “took the challenge,” having made it through.

At the age of 52 he moved from a shelter to a “psychiatric residence,” much like the one where Harry lived for 20 years. As it had been for Harry, George’s rent was paid from his social security check, his medications for medical and psychiatric issues were dispensed and monitored, and he received one meal every night. The rest of his meals he received at The Program, which his residence required him to attend 4 days per week. After several years, the first residence closed for funding reasons, but he was moved to another psychiatric residence run by the same organization and he continued to live there.

Our meetings were held in his apartment in the residence, which was small and partially furnished. It appeared as if someone had just moved in, although he had lived there for about four years. There were two small kitchen tables and three wooden chairs set around one of them, none around the other. There was a coffee table with an end table stacked on top of it, and a floor lamp, but there were no couches or armchairs. Sometimes he placed a fan in the middle of the living room floor, and for a while his roommate’s stereo was there, but he never turned on either item. His bedroom had a twin-sized captain’s bed and a TV at the far end. Papers and personal effects were stacked on the dresser and night table. Although our meetings took place in the living area, I often heard the radio playing in the bedroom and saw the TV was simultaneously running with no volume. He explained that he liked to “watch TV” and listen to the radio at the same time.

He expressed mixed feelings about his current residence. On the one hand, he said, “I am contented,” referring to the apartment and his living situation. At the same time, he had been told he would be living in the psychiatric residence for just a few years, yet had seen people come and go in the decade-plus that he had remained in psychiatric residences. Although he relied on and seemed to appreciate care from the residence staff—for meals, medication monitoring and money management—he craved more independence. He explained:

“I just came here to live, they told me, up to 3 years. They’ll send me to live somewhere else or for independent living. I dreamt of some place of my own without a roommate, all by myself... They told me yes, they have that too-- A place all by yourself with kitchenette and so on. A studio.... I’d like a room alone. That would be my lucky day. I go from here.... But I am waiting on whatever it is. I’m waiting on it. Because they still have to take care of everything... Some of them move out already—went to a place to live on their own. I don’t only want with The [Program] but I mean independently, like a studio... I would like to live in Brooklyn for a change... a long time since... since I lived in Brooklyn... I like to live there. I have had enough of Manhattan for now.”

Although stably housed for over ten years, his history of homelessness continued to bother him: “That’s what makes me feel a bit off the track. I feel very ashamed about it. It’s not a disgrace because... people live there and so on, but you know, it’s just so bad. It make you feel that you’re a bum when you live in a shelter... It was so fast the way it happened-- It was so fast. I didn’t expect that. I never heard of a shelter before or since. It happened that because the situation between my family I began to be acquainted with the shelters.”

Hank. Hank's experience of homelessness had two unique features. First, his housing was marginal for many years before he became homeless. From the age of ten on, he moved back and forth between New York City, where his mother lived, and the rural South, where the rest of his family was. In the South, Hank explained that the houses were uninsulated cabins, which relied on wood-burning stoves for heat. In the North, he stayed with various family members, but rarely had his own apartment. The last apartment where he lived before entering the shelter system was in poor condition, and he appeared to have been "squatting" there rather than living there with a formal lease agreement with a landlord:

"[The building] had nothing but crack head people smoking in there.... And they was trying to get rid of them, get them out of there. They didn't know how. But God was getting a place, was planning a place for me and my wife to go, so that way... we can do the work. So after we moved out the place and God moved us out... the whole marshal and the police department... they came, and they had a big dumpster out there. And they got all that furniture and stuff they had in there and throwed it in the dumpster...."

He seemed to have been more bothered by the conditions of the housing he left than of having to be in the shelter system. He made few complaints about the shelters in which he had lived. For Hank, leaving his last apartment was a spiritual experience—God told him and his wife to leave so he could do God's work. However God sent his wife and daughter to a woman's shelter and he went to a men's shelter, and after a certain point he never saw either of them again. Like George, Hank had a clear sense of how and why he became homeless, and what he did in that time. However his experience varied from George's in that having this experience didn't negatively affect his current sense of well-being, since he was doing "the work" for God.

Hank remained in the shelter system for about 4-5 years moving into a psychiatric residence run by The Program's organization, and then moved into their more independent housing programs, first in scatter-site and then in "graduate" housing. In his current "graduate" apartment, a case manager visited on an as-needed basis. He and his roommate shared household responsibilities, and the apartment invariably smelled like dinner that one or the other of them was making. One or the other of them would also usually be playing music from his bedroom. If it was Hank, the music was gospel. If it was his roommate, the music was oldies. The living room consisted of two deep-cushioned easy chairs and a matching couch, all of which were comfortable although worn, and situated around a coffee table that was covered in carefully stacked piles of papers and books.

There were some maintenance problems in the apartment that Hank said he was managing. There was a roach problem, a tub that wouldn't stop running hot water, dark black mold running up the bathroom walls, and a smoke alarm that never stopped making the low-battery sound. However those problems remained throughout our ten months of interviews in the apartment.

Adding an additional weight to the value of housing in his narrative, Hank often said he was "waiting to go home." By this he was referring to the home where he once lived in Brooklyn with his wife, where he would occasionally visit after he left. The last time he saw it, the "crack head people" were gone and a woman was in the yard gardening. He believed God was going to sell to him his former building in Brooklyn for \$1 as part of the reward for the work he has done for Him:

“...The only reason I’m here at [The Program] cause God got it like this way. Because when I was leaving from [the shelter], I thought I was going back to Brooklyn. But God put a song in my heart, said this is the way God planned it. This is the way God planned it.”

Evelyn. Evelyn was the only participant in the study who did not experience any episode of homelessness. Nonetheless, her experience with housing had challenges related to her illness. For over 20 years she lived in a rent-controlled apartment in Queens, New York. Despite the housing stability, there were problems in her home environment due to her mental illness. During one episode of increased symptoms, she “trashed” her apartment before she was admitted to a hospital, but her family was able to repair most of the damage.

Although she recalled some pleasant experiences, for the most part her experience in her neighborhood in Queens was wrought with tension, a sense of being stigmatized and excluded:

“Because I acted out in the neighborhood, people had me labeled as mentally ill. And it just was very uncomfortable.... When I walked in... I remember one store owner said, ‘Now take a walk....’ Dunkin Donuts when I walked in and they called the cops and the cops sat down and one cop said, ‘Get out. Now....’ People were afraid. They’re afraid of mental illness. And I was known to the police.

“At one point I went through the streets screaming, ‘We’re living in a police state! Wake up!’ And I woke people up and I was screaming... People don’t realize that mental illness can be acute... and those kind of symptoms are acute symptoms that go away. People think you’re quotes “crazy” and that it’s something that is permanent and continual.

“And I overheard someone at the bank once... saying, ‘Well she seems so alert.’ And I heard one of the staff say, ‘Crazy-- she’s crazy.’

“...It was terrible.... I guess I have to take some responsibility for that.... What did I expect when I went through the streets screaming? But... I felt that I had been labeled by the police because they’d come to the house and brought me to the hospital and things.... When I was moving out, I heard one of the neighbors go, ‘Thank God.’ And I felt the same way.”

In late 2010, Evelyn left her Queens home of 20-plus years and moved into The Senior Residence. She did this to improve her ability to get to The Clubhouse, which always made her feel better when she was depressed, and which was impeded by a long commute from her old apartment.

The improvements that came with the new living situation were extensive:

“One of the things which I resisted, but perhaps it’s turned out to be an advantage, is that they give me my medication in the morning and at night.... I really didn’t want to do that, but at times I have played around with my medication because it annoys me to be sleepy from the medication and it’s probably an advantage for me to not mess around with it.

“...Also, I used to have periods when I would lie around all day in bed and not go out and just be depressed. And now someone would notice... And I would at least have to get up and take my medication... If I’m physically ill, someone’s noticing. And... there’s people to talk to... I have my own apartment, so I have my own privacy, but I can go downstairs and there’s people.

“...I feel safe in this neighborhood... It’s a safe building. I don’t have to worry about that. And the neighborhood is only getting better... I feel very safe. The building is very well maintained... and [The Clubhouse] has been [in the neighborhood] for 60 years. So, as I walk in the neighborhood, I’m always seeing people from [The Clubhouse] saying ‘Hello’ to me and that’s nice.

“...I don’t know how many of the neighbors who aren’t from [The Clubhouse] are happy to have us here. There’s always some people who probably aren’t happy. But... I recently got food stamps. I was able to get them. And I wanted to use them at the corner store. I didn’t know whether or not they accepted them. And I went there and I gave them my card and the cashier said, “I’m sorry, we don’t accept those.” And there was a man standing right there, a young guy, and he said, “I’ll take of it.” And he handed his card in. I couldn’t get over that... How nice it was.

“....And then there was someone else, I was walking down the street and my shoelace wasn’t tied and I was kind of heavier and he said, “You having trouble doing that?” And I said, “Yes.” And he said, “I’ll tie it for you.” And he tied my shoelace.... And then I said, “Do you mind doing the other one?” And he said, “Of course.” And he wasn’t a [Clubhouse] person. So, there’s nice people all over.... Living here has helped.... This was probably a good move for me.”

Evelyn received additional housing support from a cleaning person whom she hired privately to clean her apartment and do her laundry. Evelyn was able to shop and cook on her own, and she enjoyed those activities. The rent was HUD subsidized, and she felt she could live comfortably on a combination of food stamps, her income from social security, a small annuity from a clerical job she once held, and a larger pension check from her decade

at the public library. While she was able to live without social services, she appreciated the few key supports The Senior Residence Provided.

Evelyn brought most of her own furniture and decorations into her apartment at The Senior Residence. The surfaces were covered with photographs of families, friends, babies, past and present therapists, The Clubhouse staff, and politicians to whose campaign she had donated. Books and other reading materials were evident on the coffee table and end-tables, and Evelyn was the only participant who had a computer. Evelyn's apartment accurately evoked the feel of a beloved aunt's home.

Like the other participants, Evelyn's disruptions in past housing were caused by her illness. Her past behavior while experiencing psychotic episodes had lasting consequences, assigning her with stigma in the eyes of many of her neighbors. Although she had not needed social services to help maintain her housing prior to her retirement, with the onset of physical illness the additional help provided in The Senior Residence ensured her wellness, safety and comfort in her home. Moving to the residence also meant an escape from the stigma, access to The Clubhouse, and entrance into an accepting community.

Discussion of theme 2: Long-term utilization of housing-based social services.

Narratives in the current study portrayed a process through which participants: lost their housing during or after an acute episode of psychosis; throughout the period(s) of homelessness did not receiving psychiatric treatment and had no contact with their families; required help from social services to return to stable housing; and remained in treatment and housing accessed through the same social service agencies that first provided them with housing. These findings mirror processes of becoming homelessness delineated in previous research (Belcher, 1989; Wasson & Hill, 1998). What is novel is the

ongoing but complicated relationship participants often went on to have with the social service organizations that provided them with housing. In this study, all participants who had been homeless were still involved with those social service organizations that had initially provided them with housing, and were receiving ongoing housing, psychiatric services and peer and/or staff support from those organizations as well.

The participants struggled with the extent to which they wanted more autonomous housing, and by extension less social service involvement. After a decade in a psychiatric residence, although comfortable and “contented,” George nonetheless felt it would be his “lucky day” to get a place of his own that does not have social service involvement. Harry had felt like an “invalid” while living in a psychiatric residence, but struggled with loneliness and isolation in his current scatter-site housing, which did not have on-site staff. Bernard felt his current housing was “fine,” as did Hank—but Hank was “waiting to go home.” Although she had never been homeless, Evelyn gave up some of her autonomy to move into the Senior Residence. Although initially it was a source of internal conflict, she was eventually convinced the move was the right decision since it ensured her medication adherence, placed her in a more convenient and friendly neighborhood, and reduced her solitude.

The shared ambivalence around housing develops findings of Padgett, Hawkins, Abrams & Davis (2006), whose analysis of retrospective narratives of homeless women found that the needs and wants of formerly homeless women included increased autonomy. The participants in the present study also wanted autonomy. Those who had been in homeless shelters or lived in psychiatric residences for long periods of time often expressed a sense of personal invalidity that developed from the experience. However, for

Harry this sense of invalidity was countered by his isolation in his current living situation. Even George appreciated the security and supports of his current apartment, despite wanting to leave the psychiatric residence. Thus the need for autonomy was counter-balanced by the need for security, creating a shared sense of ambivalence around the desirability of social service involvement, and uncertainty as to what the optimal level should be. Participants from The Senior Residence appeared most satisfied with their living situation overall.

Shaw (2004) states, “Homelessness is experienced by the individual but results from socioeconomic structural inequalities and housing policies” (p. 406). In the narratives of the present study, homelessness was resolved through connections with social service agencies and maintained in part by forging years-long (and in some cases decades long) relationships with those organizations. Housing that includes ongoing social services, such as in Pathways’ Housing First Program and Critical Time Intervention (CTI) Models, have been established as evidence-based housing practices for persons with mental illnesses who have experienced homelessness (NERPP², 2012; NERPP³, 2012). However the duration of services is time-limited in CTI and variable in Housing First. The narratives of the present study identify that one of the challenges social service organizations continue to face is the development of permanent housing programs that balance the promotion of autonomy with the provision of stability and support.

Discussion of theme 2: Constructing homelessness and housing challenges as personal metaphors. Housing problems and homelessness have an impact on measures of mental well-being (Dunn, 2002). Interaction with, response to and interpretation of housing environments can affect sense of well-being and sense of self, and confer a layer of

prestige or stigma on one's identity (Shaw, 2004; Wardhaugh, 1999). Narrative studies such as the present one have the capacity to explore in-depth the meanings attributed to life events, such as housing challenges and homelessness, in retrospective accounts wherein autobiographical memories serve as metaphors, tying together memory and meaning (Randall, 2011). As noted in the introduction to this study, the stories we remember are those that contain metaphors most relevant to our identities, reflecting our senses of self, personal values and the meanings we attach to experiences. We interpret our own inner texts as we remember and re-tell the stories of our lives (Randall, 2011).

Earlier studies have formulated the meaning of housing as that of having an available safe haven or refuge from social forces and psychological stressors (Shaw, 2004; Wardhaugh, 1999). Extending from this, the concept of "ontological security," refers to the sense of security and control that comes from having a "home" that, ideally, provides constancy in a setting wherein life's daily routines are enacted, people feel most in control of their lives, and, free from surveillance, can formulate personal senses of identity (Dupuis & Thorns, 1998; Shaw, 2004).

Through narrative analysis, Padgett, et al. (2006) also found that the need to restore status and a devalued identity was a high priority for formerly homeless women. Padgett (2007) found formerly homeless persons valued the features of ontological security provided in their current housing, and that the experience of homelessness meant that housing was additionally valued as the setting for needed identity re-construction and repair. In the present study, participants varied from those in Padgett's samples by having had the benefit of many years, and sometimes decades, of stable housing post-

homelessness. Their identities, as constructed through the narrative process, showed evidence of the needed repair, identified by Padgett (2007).

In the accounts above, participants' experiences of homelessness became, in retrospective accounting, metaphors for their personal fortitude. In the midst of her description of the many hardships of homelessness, Hope mused, "I don't know how I did it." In his telling, George asserted, "I took the challenge." Hank's narrative conveyed a sense of pride around the work he was able to do for God, noting the reward he will receive. Bernard marveled that he did not "bust his tail." The hardships of days past, and their endurance of them, signified inner strength in their current life narratives.

While for persons who have never experienced homelessness, "being at home" is often and unselfconscious and taken-for-granted state (Wardhaugh, 1999), for these persons who had experienced homelessness and housing challenges, stable and secure housing became a significant metaphor for the value of their current living situation, imperfect though it may have been. As each narrative varied, so did the nuances of the story's meaning in his or her present life.

For Hope, housing was a stroke of luck or gift from God, for which she now feels grateful and thanks God. For Harry, the program "came along and saved" him. For both Hope and Harry, having God to thank and the sense of "being saved" elevated the emotional-status and meaning connected to their living situation, and can only be fully understood when viewed through the lens of their experiences of homelessness. It is the homelessness from which they were saved.

Even in Bernard's narrative, wherein he said in his simple fashion that his current living situation is "fine," the assertion occurred after a lengthier description of his

homelessness, when things were distinctly not fine. He was “in a daze,” “sick,” and could have “bust [his] tail.” The value of current housing was understood through comparison with his experience of homelessness.

For George, rather than representing the value of his current living, his story of homelessness represented why he felt “off track.” It was, in fact, the story of how he fell “off track.” And while he was content in his current living, his continued dream of independent housing, “a room alone,” was metaphor for his continued drive to get back on track. The studio apartment in Brooklyn of which he dreamt would symbolize his story’s resolution.

The marginal housing in which Hank lived prior to entering the shelter system complicated his account of homelessness. In his narrative, moving to the shelter system freed him from living in a drug-ridden building in order that he could do “the work” for God. Housing was deprived while he needed to do “the work.” By understanding housing as a reward from God for his piety, we can understand the meaning of home in Hank’s narrative. When he has become pious enough, God will buy him and his wife a house of their own. For Hank a home was a measure for his own spiritual worthiness.

In Evelyn’s narrative, her former housing is paired with present housing, and more specifically, her present neighborhood: A mostly negative past situation is compared with a remarkably positive present-time situation. Although moving to The Senior Residence involved giving up some independence, her narrative provided explanation as to why it was nonetheless for the better. It provided resolution to an internal conflict.

In sum, as called for by the participants in the Padgett et al. (2006) study and described as part of the value of housing by the participant’s in the Padgett (2007) study,

after many years in stable, secure housing participants in the present study were able to integrate their experience of homelessness into a repaired identity. They could also use narrative development and expression to reconcile problems with their current housing. Perhaps as another indicator of the exceptional nature of the participants in the current study, participants integrated housing into their narratives in such a way that it often contributed to, rather than devalued, their current sense of worth. In that way, surviving housing challenges and homelessness became a metaphor for their personal fortitude and worth. At the same time, safe and stable housing, juxtaposed with housing challenges and homelessness, was valued as an improvement, a reward, and a sign from God. Housing narratives for these older adults were thus narratives of redemption.

Theme 3. “There’s not been jobs:” The meaning of employment. While impairment in functioning across significant life domains, such as work, is part of the diagnostic criteria for schizophrenia (APA, 2000), data from the current study deepen our understanding of the meaning of that impairment for individuals across the life course. Illness-related challenges and losses experienced in the domain of work were universal among the study participants. Participants shared a sense that their work experiences, or lack thereof, had been a primary adversity brought to their lives by schizophrenia. However, despite the shared nature of the challenge, the participants’ work lives were disrupted in unique ways.

In addition to the vocational disruption, participant narratives conveyed a shared sense of perseverance towards vocational goals, even in later life when many older adults are developing goals outside the vocational domain. Some participants adapted previous goals to make them more attainable while others developed new goals. The persistent adaptations and adjustments made by the participants in pursuit of vocational goals revealed its importance in later life for these persons, most of whom were not able to attain these goals earlier.

The ongoing perseverance of many participants towards vocational goals despite years of obstacles further brought this theme within the narratives into relief. Echoing previous research, the vocational narratives below illuminate how work provides a sense of purpose in life and role in the greater world through which a sense of belonging and identity is attained (Marone & Golowka, 2005). Equally important to the human condition,

it provides income with which to survive. The lack of work among participants compromised instrumental reminiscence in their narratives.

Theme 3 narratives.

Bernard. In Bernard's narrative, work was largely absent. He said, "I ain't do too much work." He held a job as a teenager where he said, "I used to help with the janitors you know? Take out the garbage. The coal? Coal in the house. Yeah, I used to help them take that out. I used to take that out [as a teenager]." For four months at 17 he trained as a cadet in the military. However he left the military before training was complete, for reasons he no longer recalled.

His long-term psychiatric hospitalizations prevented him from working early on. In 1959, at the age of 21, he was psychiatrically hospitalized for, he estimated, 5-8 years. Within a short time after discharge, he was admitted again for another 7 years or so. This episode was followed by a years-long period of homelessness and alcohol abuse, and then another psychiatric hospitalization that lasted a few more years. During one of those hospitalizations, and he doesn't remember which one, he was part of a training program where he drilled screws into boards. However he never pursued related work.

In later life, when Bernard had finally received stable housing in the Senior Residence, he was able to work a 'transitional employment' position through The Clubhouse. He worked several months, breaking down boxes in a warehouse. He said the work was "alright" and he was glad to make the money. However this job did not last long, since he had to leave to have heart surgery that same year. He had not worked since.

Nonetheless, Bernard's present life was structured around participation in the horticultural unit at The Clubhouse, which he calls his "work." Although his speech was

marked by paucity and could be disorganized at times, he described his activities in the unit with clarity and specificity. He explained to me how he worked with “Plants. You know, plants? Sweep up. Clean toilets... Members keep everything looking grand.... I prune them [plants], you know. Cut the bottoms off. Then stash them with water, water in the vases... Then the rest goes to [the Clubhouse], across the street, and wherever.”

He told me he liked the routine of getting up in the morning, getting dressed and going to work. I sensed pride when he said that he helps “keep everything looking grand” and the relative clarity in his description of the work unit, as compared to how he handled other subjects, further pronounced the importance of the activity to him. Although it was unclear what, if any, his past vocational ambitions were, the informal work available in the Clubhouse provided him with structure and gave his daily life a sense of purpose.

George. George’s perseverance towards vocational goals throughout his life had been steadfast. When asked about his greatest challenges he replied, “There’s not been jobs.” That this was the response of someone who has faced such a wide range of challenges, including loss of contact with his entire family and 12 years of homelessness, highlighted the importance of work as it extends beyond its provision of income, but also in its ability to provide a greater sense of purpose and meaning.

George’s military career was the first piece of his work life to be affected by his “quick temper” and he was dishonorably discharged for “fighting and drunkenness.” He explained:

“They think I was very malicious and so on. Make me get into fights. Confuse my mind and... I didn’t cause the fights. They did. I had to attack. Had to defend myself. That’s five times it happened to me—I have to fight. And it was said... you blow the five chances

getting into fights. So then they discharge me from the facilities.... They did it to me. It's not my fault.... The petty officers, they don't care... as long as they see you in a fight they dismiss you.... It was in self-defense. I was just trapped. I knew all about it. I knew about things. I left..."

Subsequently, he had trouble keeping jobs. After his first psychiatric hospitalization at the age of 28 he was prescribed Thorazine, which made him so sleepy he would fall asleep on the job or simply not wake-up in time to go:

"I couldn't wake-up on that Thorazine I used to use... it made me couldn't go to a job... I overslept, couldn't go... So I quit many jobs because of that Thorazine I was using... I was working. I had several jobs, but I quiet and sat down on the job. Only spend two or three weeks on jobs... sometimes two months—[then] I quit. Because of the Thorazine... I just sleep on my job... I couldn't handle it."

Becoming homeless in his late 30s contributed to the trouble he had obtaining and maintaining jobs. For one, he was not on medication during that time, and his accounting of his work in this period was infused with remnants of the psychotic symptoms he was experiencing at the time. For example, he believed he worked briefly in a human body part factory located in the subways of New York City:

"Somewhere in Brooklyn, in New York City, I do not know where but they, they were making human beings down there. I don't know how they do it. What kind of scientific going on down there. But they showed me everything and so I was willing to put the parts together and to make humans. I send them through the shoot. So I was there for just like half an hour and I went out. Next day I wouldn't say I went back. I find it very strange."

Also in that time, he worked in what sounded like a sheltered work program, where his job was to put price tags on items. George found the work demeaning. "It is a job for people who are mentally disabled doing things like a woman concerns," He explained. Rather than supporting a vocational identity, the work compromised his masculine sense of self.

George also told me how he played drums with a Caribbean band while he was homeless. He had learned to play instruments as a teenager, and traveled with a band to perform in England at about age 15. Later he played a few times in nightclubs in St. Croix's when he was working in an oil refinery. The story of joining the Caribbean band onstage while living in the shelter system was the highlight of those difficult years. He spoke of the memory repeatedly and with pride, and told me that his memories of performing are his fondest. However he could not remember how he came to be onstage with the band, and at times he recalled playing with them in a nightclub, while at others he recalled that they had played in Madison Square Garden.

Since becoming housed in a psychiatric residence in 2001, George had continued to pursue formal work opportunities. In his last position as a security guard in 2004, he was again thwarted by fatigue:

"The last time I worked it was...[for] a month. I did not go back. It is a very hard job. I've got to climb maybe... 24 stories, step after step. And write what I see and so on... If there's empty bottles of beers I write it down. I warn them about it. I only work three weeks. I never go back. It was too much a strenuous job."

He nonetheless persevered, continuing to seek training and certifications, including a pistol license, to advance his career as a security guard. He had also pursued offers in the

mail to work from home. Upon reflection, he said that if he had never had schizophrenia he would have liked, “some great job, a skilled job like... aviation mechanic.” However he adapted his current goals to what he believed was attainable and that supported his need for a masculine vocational identity: A job as a security guard on an armored truck.

If George were to write his autobiography he said, “Due to my age... I would call that ‘Success.’” He explained that success was “what you want for the future, present and the future—success.... While you are alive... you have something to keep yourself busy, something that... you get to like. Keep you... motivated. Keep you busy.”

George’s continual adjustment and maintenance of his vocational goals in the face of a lifetime of challenges spoke to his capacity for maintaining of hope, and the larger role of work in the life course outside provision of income: the sense of a successful self.

Harry. Harry had worked in a series of low-wage jobs after high school, none of which lasted very long and there were long gaps between his employment periods even in those early days. His symptom onset was in 1978, but his illness experience did not initially prevent him from working. His longest period of work was from 1980 to 1982, when he worked as a security guard while experiencing serious auditory hallucinations and other symptoms of schizophrenia. He was not on medication during this time, and his accounting of his work in this period was infused with what was likely the result of past psychotic symptoms that have interwoven themselves into his personal narrative. Following are two of the stories of he told me about his career as a security guard:

“I was hearing and seeing things. And I got in the elevator. So I went downstairs. I was checking the basement and everything, and water starts flooding the elevator. It’s at my chest. I’m pushing the buttons, and then the elevator went up and the water ran out.

Imagine if it went over my head in the elevator. I would have drowned.... they plunged the basement. And got it all cleaned out.”

“There was a time, these people... went to the police about a \$10,000 bill they had lost. A \$10,000 bill was lost. It was the big people in the store who lost it. And I see this little, this tiny little piece of money sticking out from under the pole where the clothes hang. I reached in, pulled it out, it was a \$10,000 bill. I turned it in. No one could figure out how it got under there.”

By 1984, at the age of 29, his symptoms had become such that he felt unable to work. In addition to the voices, he was unable to sleep and spent the nights wandering the city looking for discarded cigarette butts to smoke. He started panhandling to get money and cigarettes at that time as well. In this way, panhandling replaced work in his life by providing him with a daily purpose and a role in the large world. As Harry explained, “Everyone wants a cigarette and they want change. They want something, you know, to fill the emptiness of their lives.” Once he entered The Program, he met many of the members through panhandling outside of The Program building. Although he was trying to quit when we met, he found the draw of the money and the social interactions hard to resist.

When Harry began receiving treatment at The Program in the 1990s, the topic of work was revisited:

“I had encouragement to work in the coat room.... in [The Program]. I did that for two seasons. But I quit... ‘Cause I was afraid of conflicts.... I don’t get out of the coatroom until 3 o’clock.... When the check comes out on the 8th, the check is handed out at 3 o’clock, so I’m afraid I won’t... get there on time.... Plus... I can’t do it. They wanted people to put coats in plastic bags, like for a Laundromat. I can do ...one of those but I can’t deal with

those plastic bags over and over.... It's too much work... They're only paying me... \$2.85, something like that... It's not worth it."

Additionally, he had a lengthy list of health concerns that ranged from "inability to breathe through his nostrils," to dizzy-spells, to back pain, to a hand tremor. His feeling of physical infirmity led him to conclude, "I can't work like this." In fact, he felt that his physical conditions, more than his psychiatric symptoms, prevented him from working.

In response to his sense of physical disability, he had put aside his vocational ambition, which had been to find work as a security guard at a concert venue or become a nurse's aid. Instead, he now simply hopes to better manage his social security money. This was an extraordinary challenge, when after his rent money was removed from his social security check, he has \$367 per month to live on. When I first met him, the purpose of saving was to be able to save enough money to buy a \$30 pair of pants, some t-shirts, some socks, and new shoes. He explained how he only had one pair of pants, and showed me how his shoes and socks were worn out and full of holes. He was pleased and proud when he was able to buy the t-shirt and socks in January. However there had been no place for him in the store to try on pants, so he bought a new quilt for his bed instead.

Although seemingly small, these items held significance. He explained, "I think once I've been there to buy these things and realize the value of it, and what I'm doing, I'll prove to myself. It will inspire me to excel." Over the holidays he eagerly awaited gift cards to fast food restaurants that his sisters usually sent so he could indulge in his favorite foods, like Big Macs, which would otherwise compromise his careful budgeting.

As noted earlier, Harry once said he felt like he was "punishing" himself for not being "successful" like his brother. While I never saw how Harry was punishing himself, I

did understand that he experienced ongoing emotional pain. His comment that panhandling and its rewards filled “the emptiness” of peoples lives, and his negative comparison between himself and his brother, connected for me his emotional struggles with his lack of vocational activities. Formal work appeared only in fits and starts in Harry’s narrative, and its absence and the monetary consequences weighed heavily on his mind. His past twenty years had been structured through his activities at The Program, leaving him with a sense of having been “schizophrenic bad” rather than what could have been a vocational identity. Harry’s narrative thus demonstrated the loss caused by the absence of work. It varied from others in that rather than adjusting his vocational goals, he put them aside in favor of the related goals of budgeting, health goals, and symptom management. He received some of the benefits of work—income and daily purpose-- through panhandling and participation in The Program, and relied on his sisters’ generosity for anything extra, but these elements were not enough to fill the “emptiness.”

Hank. Hank was able to work for various periods of his life at skilled or unskilled physical labor. His work history included casting tin pots and pans, working in a steel mill, and serving as quality control in a ketchup factory. The symptoms he may have been experiencing while working in those jobs seem to have infused his accounts of vocational activity. For example, he described how God gave him a ‘vision of hell’ while he was working in a steel mill:

“I went to [a steel company]. I was shoveling coal when I got there. And... we had a test about 40 of us. You gotta be a certain weight, certain height. And so we went into the room to do the test and the time we got was a good 3 minutes. And the man come in and said, ‘Alright, everybody put the pens down. Everybody out in the hallway.’

“ So we went in the hallway. Everybody talking about, ‘I know I ain’t passed.’

“Said, ‘I know I ain’t passed neither. I ain’t get to do one question!’

“And so the man called up back in there. We all wondering what is going down. He said, ‘To keep you all from wondering, everybody passed.’

“And I said, ‘Oh Lordy thank ya.’

“...When I started work we had to go up under this thing with the conveyor belt runch, and the coal we’d throw on top of the conveyor belt. And it goes to a big old, it’s about as big as this room where the coals and stuff come in and the steel come out. And I was standing back way out in this thing and this guy had a suit on, a silver suit on. And I felt the heat from way back where I was. And God said, ‘That’s how hot hell is.’

“I said, ‘My god!’

“And so, I worked there, I don’t remember—about a year. Something like that. But anyway, every job I go to, God give it to me. He know I’m a fast learner.”

Since Hank began receiving psychiatric treatment in the 1990s, he had not worked outside short-lived jobs offered as part of The Program. Nonetheless, he believed he was working for God every day. His particular presentation of symptoms, infused with religiosity, altered his self-conception as a worker from one who does physical labor to one who does spiritual labor. He saw himself as employed by a spiritual mission. The importance of work in Hank’s life was evidenced by the fact that even though he was loved by God, he was still required to work. Further evidence was his belief that one of God’s rewards for him will be employment in a church, preaching at a pulpit.

His work for God had included visiting hospitals and praying for the sick, whom he believed he healed; handing out religious tracts to passerby; blessing passerby; fasting

twice monthly; hours of prayer daily; and providing religious counsel and advice to other members and staff of The Program. During the time of our interviews, he was awaiting a sign from God to begin a janitorial position outside The Program, but he planned to continue his religious work whether or not he received that sign. Hank's sense of self in the role of a worker had not been disrupted, but had been adapted to fit the confines of what his illness allowed, which fit within norms of his culture of origin, rooted in the evangelical churches of the pre-civil rights movement South.

Hope. While I had initially thought that, due to gender norms of this study's age cohort, work would not be as important to women as it was to men, this was not the case. When I asked how schizophrenia affected her life, Hope replied, "It just stopped me from getting ahead." She explained further that without schizophrenia, "I'd get somewhere that's for sure... Like working... as a receptionist." Like many of the other participants, she saw work as one of the primary costs of schizophrenia in her life, despite the fact that she had a lengthy work history.

Due to her family's poverty, which left her crying from hunger as a child, Hope quit school at the age of 16 in order to work, first at a telephone company and then as a receptionist, bringing home her paycheck to her mother. After she married at age 17 and had her first child at the age of 18, Hope stopped work as a receptionist, but resumed after the divorce in her late 20s. Later, when she married her second husband, she again stayed home raising their child on his dairy farm. However she started to experience auditory hallucinations after her second husband left her, at some point in her mid-to-late 30s. She nevertheless found work, again as a receptionist, but this time at a funeral parlor. She also worked at this time as an aide on a bus for children with special needs.

However, rather than enjoying the work, as she had in the past, she found, “It was all depressing...You know, seeing all the kids like that and then going to a funeral parlor.” She was daydreaming and hearing voices at this point. “The voices put me down all the time,” She says. When her brother sold the house where she had been living in the basement, she moved to Florida to live with a sister, and worked briefly cleaning condos. However this period did not last long. Hope returned to Queens, and did not work again. Her symptoms, untreated, lead to interpersonal conflicts and eventually her period of homelessness, described earlier.

Nonetheless, like Bernard, Hope structured daily routines around her activities in The Clubhouse work unit, which for her was the “reception” work unit. In fact, she worked five days each week as a receptionist. On Mondays and Fridays, she sat at the front desk of the reception at The Senior Residence, greeting people as they entered and instructing them on how to sign-in and where to go. Tuesday through Wednesday she went to The Clubhouse building, where she could give tours to guests of the Clubhouse, or attend admissions committee meetings.

When I pointed out that she actually had been working reception, despite her experience with schizophrenia, she smiled and told me it was not the same: She was not getting paid. To make ends meet, Hope relied on one of her brothers to send money each month. Despite her need for additional income and for reasons she could not fully explain, Hope was “afraid” to work outside The Clubhouse, although she acknowledged the work she was doing for The Clubhouse could have been paid work elsewhere.

For Hope the structure and sense of purpose provided by work were benefits, and the security of working for The Clubhouse irreplaceable, but a central meaning of work for

Hope was as source of income, and survival. As somebody who had experienced hunger as a child and during her period of homelessness, that aspect of work was not replaced, even by vocational activities that provided all of the other benefits. The lack of independent income left her with the sense she hadn't gone anywhere in her life, and like Harry, she felt that something was missing.

Evelyn. Compared to the other participants in this study, Evelyn had a remarkable career. However it fell short in comparison to her own ambitions. She first saw a psychiatrist at the age of 16 when she felt suddenly and completely unable to do her schoolwork, which was startling since she had won a scholarship to a private high school. She was treated with medication and supportive counseling and was able to attend college on a merit scholarship. However her first year of college ended abruptly with her first psychiatric hospitalization during winter break. She was treated with ECT and finished the academic year taking classes at a university closer to her parents' home. However, she returned to her college the next fall, with ongoing symptoms, treatment and hospitalizations marking the duration of her college career.

Nonetheless, upon graduation she was able to acquire a job in social services, and was on her way to achieving her career goal of becoming a social worker. She enjoyed the work and remained in that position for 2 years until, at the age of 23, she experienced an acute episode of psychosis and was again hospitalized. This time she was sent to a state psychiatric hospital for 6 months, and, as she notes, "This was before the Americans with Disabilities Act." Her long hospitalization meant she lost her job.

This turn of events began a pattern that lasted for several decades. She would obtain a job, become psychiatrically ill, and then lose the job when she had to be hospitalized.

While she had few problems obtaining jobs, her mental illness meant she had difficulty maintaining them.

Initially she was able to find work in her preferred area of social services. But after a work experience marred by her psychiatric symptoms, she was told by an employer, "You'll never work in social services again." Believing the message, she stopped pursuing social service jobs, relying afterward on clerical work to support herself.

Evelyn adapted her ambitions by pursuing work that was less interesting to her in light of the negative message she received about her capacity for work in social services. However she never stopped pursuing work altogether. She attributed her perseverance to two factors. One was the influence of a psychiatrist with whom she was in treatment in her mid-twenties. "He said two things, 'You have to work the rest of your life. And you have to take medication the rest of your life.' And I took both of those things very seriously," She explained.

The other factor that contributed to her work continuity was her family's encouragement. They constantly reminded her that she needed to support herself. Sometimes these reminders went further than she would have liked. One job in her early 40s made her particularly miserable but her family "wouldn't allow" her to quit:

"[My employers] wanted me out. And they were literally torturing me to get me out.... And my family said, 'You can't go on disability, you can't live on it.' So, I made a suicide attempt... I took hundreds of pills. I think the only reason I didn't die was I threw up.... [My family still] wanted me to go back... But I stayed in the hospital until it was too late to go back."

With the encouragement of her family and psychiatrist, Evelyn remained in the work force. She eventually developed new ambitions that matched her clerical skills. In her mid-40s, Evelyn returned to school for a degree in library science. She was able to work part-time and go to school part-time. Evelyn went on to spend a decade working as a children's librarian. This period was the highlight of her working career:

"I was a children's librarian and I loved the children. So, it was nice... I did wonderful programs for the children... I did craft programs. I did picture book and summer reading club and beginning readers and I wrote little plays and had children perform the plays and I was good when I wasn't sick....

"I remember a play I wrote... [with] very simple dialogue... for children to perform. And, this one boy who was older was having problems at school but he was a little older, so he was able to memorize the dialogue better. So, I made him the star of the play.... I tried to give people the parts that they needed to enhance their lives.

"And I remember the parents came to this play with cameras to photograph it.... And it was wonderful and the flashbulbs popping for these kids and I remember... [a] guidance counselor said, 'I wish I could get ten more kids into that group.' That was a very happy memory...."

Although she had chosen a different career, Evelyn adapted her position as a librarian to make it fit better with the career in social services that matched her values—a career where she could "enhance" the life of others.

Evelyn retired at the age of 56. She attributed her early retirement to her physical health problems at the time, which were partly connected to her psychiatric problems. She had an occurrence of breast cancer and suffered a minor heart attack. Worse for Evelyn

was that her years of treatment with lithium had caused her to develop 70% kidney insufficiency and chronic incontinence had resulted. She explained, “I was gaining weight and I was becoming increasingly non-functioning towards the end... I was becoming incontinent and I was just a mess....”

Early retirement meant a decreased social security payment, as well as a smaller pension. Although she adapted her library work to mirror a social service position, she said that if she had not had schizoaffective disorder, “I would have liked a social work career.”

Yet to a certain extent, Evelyn continued to pursue her social work career, even in retirement. As a sponsor in over-eaters anonymous, she continued to provide support and encouragement to her “sponsee,” in the name of treating “food addiction.” Through The Clubhouse, she was trained as a wellness counselor, and began coaching another clubhouse member in healthy living. She provided tours of the clubhouse to visiting guests and has presented trainings in the clubhouse model. All of those activities involve helping others, and were consistent with the career in which she had felt thwarted by her illness. In so doing, Evelyn’s life was embedded with structure and the sense of purpose and meaning that comes through work, despite psychiatric and physical disability, and despite having retired. Her vocational narrative showed in detail how work and mental illness intertwined across her life course. Although she had worked more than the other participants, she too adapted her work and career expectations because of her illness.

Discussion of Theme 3. The limited and/or compromised work histories among this study’s participants suggest that the current cohort of older adults with schizophrenia have not benefitted fully from extensive recovery literature that has shifted the discussion of

employment with schizophrenia (Marone & Golowka, 2005; Russinova, Wewiorski, Lyass, Rogers & Massaro, 2005). In the recent past, the stress-diathesis model of schizophrenia implied that persons with the illness ought to refrain from work lest the stress of work exacerbate symptoms, however employment for persons with schizophrenia is currently touted as a route to better symptom management and outcomes (Marwaha & Johnson, 2004); a key to increased social inclusion (Krupa, 2004; Marone & Golowka, 2005; Marwaha & Johnson, 2005); and a responsibility that is part of citizenship and belonging (Marone & Golowka, 2005).

While employment has been central to psychosocial clubhouse models for decades (NERPP, 2012), none of the participants in the present study had been actively involved with The Clubhouse until later life. Their later-life engagement in the “work units” provided important structure and sense of purpose to their current lives. For Bernard, his transitional work experience and work unit activities stood out particularly in a life that had otherwise been empty of such opportunities. But even for Hope and Evelyn, who had fuller work histories, their work at The Clubhouse provided them the opportunity to continue to pursue their interests.

It was unclear the extent to which participants in The Program had been exposed to the most current ideas about employment and serious mental illness. While all of the participants from The Program expressed ongoing interest in employment, none of them had worked outside of The Program’s internal occupational opportunities in the decade or decades since they had entered the program.

Participants were aware that their compromised employment histories lead to decreased social security payments. Living with extremely low incomes was challenging

and help from family and/or social service agencies, or panhandling, was usually required to make ends meet. Hope expressed gratitude to a brother who sent her extra money each month, and Harry waited eagerly for fast food gift certificates around the holidays, panhandling to make ends meet. Evelyn had benefitted from housing case management services that enabled her to get food stamps. All of the participants lived in subsidized housing and would have been unable to afford market-rate housing with their incomes.

The significance of the lost work experience in their narratives included and went beyond the financial loss. The compromised employment histories were connected to diminished sense of worth, loss and regret among the study participants. Hope saw herself as “not getting somewhere” in life because she was not able to work for extended periods of time and was not financially independent. George stated that the limited employment in his life was among the greatest hardships he has faced. Harry mulled over his past careers and present interests, ultimately shelving them because his sense of disability, while at the same time indicating a sense of emptiness stemming from his feeling that he could not work at present. Even Evelyn, with her lengthy and impressive work history, felt that her career had been compromised by her illness. Dunn, Wewiorski, & Rogers (2008) examined the value of work to persons with serious mental illness finding that work for persons with serious mental illness has the capacity to provide a vocational identity, and a source of pride and esteem. In the narratives of the current study, it appears that the converse is also true.

While participants in the present study had compromised work histories, many had been able to work at some point, even with ongoing symptoms. These findings add to an existing body of research averring that symptom remission is not required in order for

persons with serious mental illness to be able to work (Russinova, Wewiorski, Lyass, Rogers & Massaro, 2005). In fact, the participants in the present study who worked with illness symptoms generally did so without support from social services, and stopped only when symptoms became severe.

Symptoms of schizophrenia were part of the explanation for compromised work histories, but not the entire story: George's medication side effects were as disruptive as his illness symptoms. Evelyn was actively discouraged from pursuing the career of her choosing. For George and Hope, homelessness appeared in their narratives as a significant factor in their foreshortened work histories. For Harry and Evelyn, physical health interacted with mental health, compromising their abilities to work. Evelyn's incontinence, which she believed stemmed from her years of using lithium, led to her early retirement. Harry's tremors, insomnia, and other physical health conditions contributed to his diminished sense of well-being and sense of disability that made him believe he could not work. These narratives add to findings from Dunn et al. (2008) wherein participants only stopped working when their symptoms were at their worst, and wherein additional factors, such as medication side effects, health issues, homelessness and discouragement, also contributed to diminished vocational histories and achievements across the life course.

Nonetheless participants persevered, adapting by continuing to consider and work towards vocational goals. Paralleling previous findings that a flexible goal orientation is facilitative of employment among persons with serious mental illness (Krupa, 2004), findings from the current study add two additional elements.

First, the drive for vocational identity, and willingness to adapt vocational goals, was not foreclosed by mental illness or by entering later stages of the life course for these

older adults, as evidenced by their narratives of ongoing motivation and willingness to adapt their goals in order to work. In fact, rather than narrative foreclosure, participants appeared to have a remarkable reserve of narrative hope and perseverance in this area.

Second, these narratives identified at least one problem in adapting vocational goals. When the participants' vocational goals were adapted to the extent that they were no longer connected to the values and identity that the original goals had stemmed from, a sense of loss and diminished valuation of the work experience resulted. For example, George had wanted to be an aviation mechanic and it came as an assault on his sense of self, particularly his masculinity, when he was employed in a sheltered workshop putting price tags on items. Because of discouragement, Evelyn adapted her goal of becoming a social worker in favor of becoming a librarian. In retrospect it is one of her few regrets in life, because she valued a career wherein she would help others. Nonetheless, George and Evelyn again showed perseverance as they continued to engage in present-time activities that connected with earlier vocational goals. In the past decade George had pursued training and job opportunities as a security guard, a career that fit more closely to the masculine identity that had been compromised in the sheltered workshop, and aligned with the vocational identity that he sought. Evelyn engaged with O.A. as a sponsor, and with The Clubhouse wellness center as a peer counselor, volunteering in both cases to take on helping roles that she had been discouraged from pursuing professionally. Adapting vocational goals in order to make them feasible while not losing sight of the values, meaning and identity that the original vocational goals had embodied thus required a balancing act, which social services in the vocational arena needs to support.

Theme 4. “God told me how we’re gonna meet back up:” Narratives of relational conflict and loss, adjustment and renewal. Problems in social relationships have long been established as part of the criteria and impact of schizophrenia (APA, 2000). In the present study, relational conflict and loss was an integral theme among the subjective shared adversities across the life course for the participants. This fourth theme refers to the shared pain associated with those relational conflicts and losses, as well as the way participants were able to adjust to those challenges and renew the presence of relationships in their lives.

All participants in the present study described relational disruptions. Most had experienced times when they had lost contact with their families and loved ones for extended periods of time; all had experienced conflict resulting from their mental illnesses. Their accounts of having lived through relational adversities across the life course generates an understanding of coping with relational losses and conflict through processes of adjustment and renewal, as well as an understanding of the meaning those losses took on over the life course. While some participants renewed and adapted previously lost and ruptured relationships in later life, others adjusted through the development of new relationships with peers and/or providers that replaced what had been lost with varying success. Following are the narratives of relationships that depict this theme and the unique within case variations.

Theme 4 narratives.

Hank. From 1988 to 2004, Hank lost contact with his family of origin. His mother, who was only 15 years older than him, had been a particularly important to him. He had lived with her off and on throughout his adult years, spending months with her in

California helping her hand out religious tracts to immigrants. Although he attributed their separation to “God’s plan,” he told the story of reunion with his mother that was so joyous they “spoke in tongues.” The story through which God put him “in the computer” so that he could reconnect with his mother was repeated over and over again in our meetings together, highlighting its significance.

Similarly, it was “God’s plan” to separate Hank from his second wife and daughter. While there was little indication that this separation has been an emotional hardship for Hank, the pain of the loss was shown through the expected remedy:

“God told me how we’re gonna meet back up. She gonna be in church in the audience. And I’m gonna be getting ready to preach. And he gonna say, ‘There your wife and daughter, in the audience.’ That’s how we’re gonna meet back up.”

Although he had not seen either his wife or daughter in nearly two decades, he was certain he will recognize them when the time comes.

In the meantime, he had coped with their absence through including others in his life. He had the same roommate since he moved into The Program housing in 1994. Together, they pooled resources for groceries, and took turns cooking and cleaning. He spent his days at The Program “helping” the other members and the staff through provision of religious counsel and advice on smoking cessation.

Although initially I had a sense that he did not care much for The Program, he corrected me. He felt that his role at The Program was important and that God wanted him to spend time with many of the people there. Symbolizing this, when I asked if he would like a copy of his narrative, he said he would like several copies—two would be for program staff, one for his mother, and one for himself.

In the face of relationship losses across his life course, Hank coped by developing relationships with others and believed he contributed to their well-being. In the program he placed himself in the role of spiritual leader. While little in his present life indicated the pain of his past losses, the repetition of the story of his reunion with his mother, and the belief that his reward from God would involve his reunion with his wife and his daughter, demonstrated the significance of the loss of those relationships, and the lost role of husband and father, to his life narrative.

Hope. Hope's relationships were affected by schizophrenia in a number of ways and much of what she said about the challenges she faced in her life were connected to problems in her relationships. The first example of this was Hope's loss of her son. Her son left her home to live with his father around the time he was 12, because, as Hope says, she was "in a pretty bad way." She was hearing voices, depressed, and had recently attempted suicide. Her son wanted the chance to be outdoors and with his Dad. She and her daughter had argued were no longer speaking. Further relational conflict occurred when her siblings did not believe she heard voices. As a result, she cut off contact with them and "left to go homeless."

When Hope reflected on how schizophrenia had affected her life, she spoke about homelessness, lack of work, and relationships. Of relationships, she believed that if it were not for schizophrenia, she would have married again, or stayed married, and also had more children. She felt schizophrenia took from her the willingness to engage in an intimate relationship with a man that would lead to marriage. Her role as a spouse and a parent was compromised as the result of schizophrenia.

“It just stopped me from getting ahead,” She explained, referring this time to relationships rather than work. “I wasn’t open to meeting anybody and I didn’t want to meet anybody. I still feel that way...I don’t want to meet anybody.... I can’t cope with the problems that come with having a husband... [but] I’m sorry I didn’t have any more children....”

Hope expressed reluctance to go to her psychiatrist or The Clubhouse staff with any problems, even physical health concerns. Thus the subjective importance of her interpersonal relationships was highlighted by the fact that a family problem is the only one she has found worth bringing to a psychiatrist: “It had to do with my family... They weren’t calling me,” She said.

Some of Hope’s siblings refused to believe she had a mental illness even through the time of the study, which created a distance between them. Hope adjusted to conflicts of this nature with her siblings by renewing relationships with other siblings (there were 12 total), adapting relationships she had with others through distancing herself and reducing contact, and subsequently embracing her relationships with other more understanding members of her family. She found that one of her younger sisters, to whom she was never close in the past, became a close confidant. When that sister calls, Hope said, “It makes my day.” However because of the long commute between her apartment in Manhattan and her sister’s home in Long Island, she sees that sister only every 2-3 months.

In lieu of having more children, Hope adjusted by embracing her role as a grandmother. At the time of our interviews, Hope hadn’t spoken to her daughter since an argument in the 1980s, because she believed her daughter had babies in order to sell them on the black market. However she remained in close contact with her son and his children,

speaking to them on a weekly basis. During our visits, she showed me cards they had sent her and framed photographs from her windowsill. She planned to visit them out of state next year, despite her fear of flying. “I can’t wait to go see them,” She said.

This year, she spent Christmas with her siblings and their families out in Long Island. Her brother in-law picked her up and drove her to Long Island and her sister Elaine baked 7 trays of lasagna, giving her one to take home. Her narrative’s sense of enduring hope and present day contentment was interwoven with her renewal and adjustment of family relationships, the importance of which balanced, but did not erase, the sorrows and trials of earlier, and sometimes unresolved, family conflicts.

Harry. Harry connected his problems in relationships with the onset of his mental illness. Although his early family life was marked by his parents’ alcoholism and arguments, he had a close relationship with his parents and his older brother. He had fond memories of his mother taking care of him while he was sick, special days with his Dad, and long bike rides and turtle fishing with his brother and their friends. However, beginning with his auditory hallucinations in 1978, at the age of 23, Harry began to experience what he described as “withdrawal” and “estrangement” from others. He explained, “I used to have friends but once I started hearing and seeing things—I didn’t really... communicate.... I don’t know [why]... I was just worried. I was very inside myself.”

Harry’s brother remained close to him, taking on a caretaking role as Harry’s mental illness progressed, although there were also at least two periods when, somehow, they were also estranged. Both times, their estrangement resulted in Harry becoming homeless. Nonetheless, Harry recalled that after his first period of homelessness, his brother found

him in the park, took him home and served him a hot bowl of oatmeal, letting Harry move in.

Later, Harry lost contact with his entire family, including his brother, for two years from 1987 to 1989. However once he was hospitalized, he and his brother renewed contact and his brother visited regularly. When Harry was discharged to a psychiatric housing program after the 8½ month-long psychiatric hospitalization, his brother continued to visit, bringing cash, cigarettes, and clothes. Harry appreciated his brother's company, and needed the additional items. His brother's death 5 years later in 1994 was a turning point for Harry. Upon losing his brother, Harry drank and destroyed property, was subsequently arrested, and became sober from that point forward.

Following his brother's death, one of his three sisters tried to take over his role in Harry's life, but "they were big shoes to fill," He said. "She'd show up like twice a year. And the clothes didn't last that long. And she didn't bring me a lot of clothes anyway—just some. Most of the time my sister, she would just get me coffee and cigarettes, you know. And forty bucks." Over time, this changed: "My sister— She kind of, like, over the first few years lost interest...."

Although one sister rarely visited, another came once a year in the summer with her children to get a fried chicken dinner with him. One sister was minimally involved as healthcare proxy, and for the holidays both sent gift certificates for fast food restaurants. At the time of our interviews, he had not seen his third sister in a decade. He considered his sisters the most important people in his life "because they're family," and he seemed disappointed by their lack of involvement. He said he would call them more, but he wouldn't know what to say.

In absence of close ties to his family, Harry established trusting relationships with staff members at the program, some of whom he had worked with for more than two decades. "They're all reliable people that I've worked with for years.... I'd be worried if I lost them-- to go out on my own." When a staff member had left The Program; when Harry had been transferred to a different caseload; or when a longstanding group had been canceled or altered, it required a period of adjustment for him.

He felt closest with a staff member named P., who he considered a mentor and one of the most important people in his life. "She always talks about us as if we're great or something," He said, explaining what made her stand out. In the decades since Harry began attending the program, P. ran a poetry workshop, through which his poetry had been published in numerous volumes, and she facilitated his support group as well. He often expressed gratitude for her support, encouragement and consistency.

On the other hand, Harry had not developed friendships with peers in The Program outside of the group settings in which they met, and the acquaintanceships he made from panhandling in front of The Program alongside them. He had a roommate in his current apartment, but they stayed in their own rooms interacting more like neighbors than housemates. He spent his time on evenings and weekends alone. He explained his isolation outside The Program was because he became "a little paranoid" and worried he might "feel uncomfortable" around other people, especially if he started to hear voices, which happened frequently. Also, he didn't want to be tempted to drink or smoke, and was afraid he would if he spent time with peers outside The Program.

Despite his long stretches of solitude and his reasons for them, he preferred being at the Program, where "the action happens" to being alone. He said, "I can't wait 'til Monday

morning,” which was when his support group of 20-plus years meets. “Stuff goes on in my life. And I can discuss the problems in group... Sometimes I just feel depressed in my head... I feel a little bit depressed—or just not good. It helps me to sit in there. It helps just to sit and listen...You know and I honestly like to help people out... The clients have their problems, and [I] give them advice.... Give them feedback... I get a lot of feedback and it helps me, [tells] me what to do.” The support group, one of the highlights of his week, was also one of the only places where he had reciprocal relationships with peers in his current life.

In our interviews, Harry still spoke about how much he still missed his brother, having not found a relationship that approximates their bond. “Sometimes I still think my brother’s there though,” He said. “You know. Like he’s in heaven looking down on me... he can see me sober. Not smoking.”

Harry’s brother’s shoes had never been filled and he would have liked somehow to spend less time alone, with friends—and a brother—like he used to have. While Harry adjusted, using his support group and relationships with staff at the Program to substitute for the void of a close family member or other intimate relationship, these replacements did not fulfill his emotional needs completely.

Evelyn. Evelyn was the only participant who never lost touch with her family, yet, and perhaps for that very reason, she experienced the most extensive familial conflicts. While she was able to paint idyllic images of her childhood, with summers by the beach and Christmas feasts in a house filled with toys, those times were contrasted by her memories of the turmoil created by her family’s problems in emotional functioning, which were worsened by her own struggles with mental health. At the same time, Evelyn’s mental

illness kept her family deeply involved in her life throughout her adulthood. Her family carved out a role for her as the “sick child,” which made them simultaneously her adversaries and her support system since Evelyn’s lifelong response to this role wavered between appreciation of the support and rejection of their attempts to control her.

When she reflected back to the early days of her illness, she mused, “I think now of how cruel I had been sometimes to them... I let them understand it was all their fault... One day my mother said to me, ‘You know, every week you go to the psychiatrist and every week we give you \$25 to pay for this psychiatrist and every week you come home and tell us something else that we did wrong.’”

“I was kind of a handful in terms of my family. And there was a lot of anger over the years about my illness... But what I’ve seen... other families that abandon family members who’ve been mentally ill-- my family didn’t do that. But... it’s hard to have a family member... going in and out of hospitals and they would get angry at me, I would get angry at them. We would yell.... When I would get depressed, I would stop functioning. And, they would get angry about that... it was just a mess. It was just a mess.”

When asked why her family didn’t abandon her when, as she said, others abandoned their ill family members, she replied, “Despite all the conflict, there was love in our family... Whenever I would get depressed, my mother would tell me, ‘Bring your dirty laundry and come visit.’” If Evelyn was hospitalized, her family always visited. Troubling as the sick role was for her, the associated emotional support was critical.

Although her parents had died years before our interviews, Evelyn remained closely engaged with her sister and nephews, and had been enjoyed her new role as an aunt. Evelyn outlined “very good relationships” with both of her nephews, one of whom had been

diagnosed with schizoaffective disorder. She had been able to provide him with support, and felt exceptional pride over the life he had made for himself:

“I have a nephew who has had problems and he was able to marry and I’m very happy for him... and he’s never been hospitalized. So... he’s having a better life than I had... He sees me as someone who doesn’t judge him. And I don’t judge him. I love him very much and I feel very positive towards him... He sees me as someone who has had a mental illness but has led a life, and for him that’s encouraging.”

Her definition of a better life for her nephew was partly defined through relationships—being able to marry, having people who don’t judge him, and who feel hold him in positive regard (and staying out of the hospital). At the same time, she had been able to become a role model. While she may have been mentally ill, she saw herself as someone “who has had a life.” In later life, therefore, she was provided with the opportunity to shift from the sick role, to being a role model within her family.

Evelyn felt her romantic relationships across her life had been compromised by her mental illness. She listed two such relationships. The first was in her 20s, with another woman and lasted only one weekend. However when she had tried to discuss her homosexual feelings with her psychiatrist she had been informed she was not a homosexual and that it was her schizophrenia that was making her believe she was. She therefore did not pursue relationships with women, although she considered herself bisexual.

Her other romantic relationship occurred when she was in her 30s and was with her first sponsor in Overeaters Anonymous. Although it lasted a few years, she considered the relationship with her sponsor to have been “abusive” and “perverse.” She said, “I was a fool

and my therapist, when I was describing our activities, he told me to stop... I did.... This guy really had no interest in seeing that I got satisfaction out of the relationship... His interest was his getting satisfaction.... It was mostly sexual.”

Although Evelyn’s romantic relationships did not go as she might have hoped, Evelyn made and maintained friendships throughout her adult years, which endured despite occasional conflicts sparked by her mental illness: “When I was manic, I can remember [K.] saying to me once, ‘I need a little more proof before I come follow you.’ But, you know, I was warm... people like warmth.”

Evelyn characterized herself as hostile and aggressive when she was experiencing episodes of psychosis. In her daily life, that hostility led to conflicts and prevented her from establishing connections that could enhance her life. For example, although she had brief contact with The Clubhouse when she was in her 20s, she stopped participating due to conflicts with a staff member there. In retrospect she felt that if she could have navigated that relationship better, she would have benefitted with Clubhouse involvement throughout her life, particularly in terms of guidance around her career and social aspects of working.

In terms of treatment providers, Evelyn was able to develop a twenty-year long relationship with a psychiatrist who she considered to have been one of the most important people in her life:

“He was wonderful. And he helped me a lot, but he also had some problems, which, everyone has problems... I was too dependent on Dr. [B.] On the other hand, I had a lot of crises in my life and he was there for me. But sometimes I think I enjoyed talking to him so much that every crisis was an opportunity to talk to him. Once, he was on his boat... And I

called him... And I said his wife couldn't say he's not there because they were on a boat... I remember how unpleasant it must have been for him to have his patient call him day and night... He provided me with an intimate relationship...[and] a support structure. And while I was seeing him, I got a master's degree, and I remember going into his office and crying and telling him how tired I was. And I remember he just kept stroking my head.... He was a very warm empathetic person..."

Her treatment with Dr. B. ended when he lost his license to practice after having a sexual relationship with another patient. They nonetheless remained in touch over the years. She was invited to his daughter's wedding, and after she retired, she spent two weeks at his beach house in Italy. She kept a framed photo of him on her coffee table amidst those of her family and friends. Evelyn noted that their relationship's unusual emotional intimacy substituted at times for some of what was missing in the romantic relationships in her life.

When Evelyn was asked to think of the important people in her life, she produced a long list. Her "buddies in O.A." came to mind first. She felt that "O.A. and [The Clubhouse] have, in a way, transformed my life and made me a better person...." Although she had not been deeply involved in either program until she retired, O.A. and The Clubhouse provided her with supportive environments in her later life where she could contribute her talents and warmth, allowing her to marshal her adverse experience to serve to the advantage of others, and acknowledging her value and challenges beyond her psychiatric diagnosis. Of note, the important persons in her life were not from her past, as with some of the other participants, but were present in her current life.

She spent the holidays this year surrounded by family and friends, and her daily life was filled with contact with people who are important to her. She found herself pleased with the way those relationships had improved in the last ten years. Nonetheless, the relational conflicts had been significant throughout her life and support, opportunity, and internal work had been required in order for her to develop the satisfying relationships she now enjoyed. When asked how schizophrenia had affected her life, she saw relationships as having been a large and central part of the illness's toll, "There was a lot of loneliness—a lot of loneliness... I would have liked to have had a family. I would have liked to have done that... And I would have liked, in lieu of a family, to have some sort of decent sex life. That would have been nice."

Bernard. Bernard's relational narrative was marked by his love for his father. His father's nickname for him was "Sonny" and he wore a sterling silver identity bracelet with that name engraved on it. He had his father's name engraved on a gold ring, which he wore around his neck on a chain. However the nature of his relationship with his father, particularly after illness onset, was unclear to me. Like others, he recalled a happy childhood filled with friends and family, and especially of time he spent with his father—driving in his car, spending a week at his house or going to Coney Island. However his father never knew when Bernard was hospitalized and so he never came to visit in all the years that Bernard was on an inpatient unit.

The last time Bernard saw his father was at his sister's funeral, but he couldn't recall when that had been. He could only say it was some time in his adulthood. In fact, initially Bernard told me that his father was still alive, living in Brooklyn, but he that he just hadn't seen him for a long time. Later in the interview he explained, his father was "up there," and

he pointed up, as if at heaven. But, he said, “I don’t believe it anyway... that he died... I wish he didn’t, never died.”

Bernard’s one-bedroom apartment was furnished by the Senior Residence and decorated with personal memorabilia as I described earlier. Among his personal items were name plaques, such as one would see on a corporate executives desk. One plaque had his name engraved, one had his father’s name, and a third had both of their names together. He explained, they “aren’t for when he died” or in memorial—“they’re just plaques.” Although staff referred to him as Bernard, Bernard called himself “Sonny,” his father’s nickname for him, perhaps because being a “son” had been the most important, and successful, role in his life. It was evident that Bernard still mourned the loss of his father, and his loss of the role of “son,” in his present life.

Bernard had adjusted to the death of his father and loss of contact with his surviving family by developing bonds with his treatment providers. His face lit-up when he saw his home health aid, and when he spoke of his residence social worker. He considered his social worker his closest friend. He explained, “She’s my staff—my social worker... Give me my pills. Collect my medication. Prescriptions... She got a real—a real bad accent,” He laughs, “More of one than everybody around.... I can understand it... [We talk about] getting out... I guess the usual stuff for a social worker... how am I feeling.”

He said he did not have friends at The Senior Residence or in The Program. He had run into a friend on the street in his old neighborhood several years ago, and enjoyed catching up. He considered the man who worked at a nearby pawnshop a friend. Over the course of our interviews, he told me that he considered me a friend and invited me to his

birthday party. But otherwise, outside of his social service providers and his daily contact with a home health aid, he was socially isolated and seemed lonely.

Bernard's relational narrative ran particularly close to that of Harry. The loss of his father, like Harry's brother, was something from which he had never recovered because nobody had been able to fill his father's shoes. Additionally, the relationships Bernard had with the mental health and social service providers took on particular importance in his life in the absence of significant peer or family relationships.

George. In George's narrative, once again I found a story of a childhood that started out full of friends and family, filled with "sunshine and... games like cricket... and fiesta and so on," but through several turns, he had found himself in a life full of solitude. However, George did not have confusion about the process through he lost his relationships. Violence that stemmed from his mental illness drove his family away:

"We got in a little dispute and so on, a little quarrel and it went into a fight. And they were outdoors, start crying, and neighbors asked what they were crying about. They say they haven't done anything and I start beating up on them.... The police came. And they took me [in handcuffs] to [the psychiatric hospital]-- Listen to what I have to say and listen to what they have to say. And they told me... I'm crazy to beat up on someone... from nowhere, just like that, without a reason. But I had my reason... why I hit them. So they told me they take me to... [the state hospital] where they give me some medicine to cool my temper... to calm me down... I spent [three] months and a half. And they put me on Thorazine...."

Although his parents took him back into their home after the first incidence of violence and subsequent psychiatric hospitalization in 1977, a decade later, in about 1988,

after another incidence, his parents moved while he was in the hospital in order to ensure he could not return to their lives. He didn't hear from a member of his family for 16 years after that point.

In 2004, three years after he was finally housed again, his sister tracked him down, "[She] contact the social security administration office... and they took up in the computer and they told her where I am at... It was for [about 16] years... she not look... And then she try to locate me... She said she knew I was on Social Security and she check with the Social Security office in the neighborhood to find out about me and my address. That's how she found out... where I was. And she wrote me a letter. I read the letter... She said she would come. I must give her a call. And I gave her a call and she came by. And so it was she and another lady came by to visit me. And my apartment was in a state with letters and newspapers... She helped me fix everything up—how to make this folder of what I need and what I don't need... I felt happy about it... I was glad because she... find out where I was.... Since that time, we were communicating with each other."

George was pleased that his sister found him, indicating the events significance to his narrative through repetition of the story of her finding him. Yet although his sister had invited him to visit her in Florida, where she now resides, he was not sure he was interested. There seemed to be a lingering piece of resentment, as indicated by his comment, "it was for about 16 years she not look" for him. While the relationship had been renewed, there remained physical and emotional distance.

George also repeated many times in his narrative the phrase "I'm on my own." More than the other participants, he seemed proud of his independence and less bothered by long stretches of solitude. In his daily life, he continued to spend most of his time alone,

despite having a roommate, and being surrounded by others in his residence and at The Program. For example, for the nightly dinner provided at the residence, he explained, “Dinner is at six.... I eat separately from them [the other residents]. We go downstairs... [And] when the time come to get my dinner, I come up here to my apartment to eat it... I prefer be by myself and sometimes I have something I don’t want and I throw it away. And they saw me I’d be embarrassed throw away the food... But I eat it in my bedroom.”

In this way, George’s adjustment to the loss of relationships included becoming accustomed to being “on his own.” However, although I initially saw George as standing out from the other study participants in his seeming indifference to social relationships, I discovered through further interviews that this was not entirely true.

First, he was readily able to describe an important treatment provider—his case manager at The Program with whom he had worked for 4 years. He described in detail the nature of their relationship and meetings together, and upon analysis his narrative demonstrated he placed high value on her feedback.

Second, as I entered his residence for one of our last interviews I was stopped by the staff who asked who I was, and whom I was visiting. When I informed them that I was visiting George about a project we were working on together, the staff member asked, “Which one? He’s got so many people coming and going. He’s got so many projects!” She laughed and let me go to his apartment.

George enjoyed his solitude but at the same time, he was more engaged in social relationships than I had initially understood. His acceptance of being “on his own” set him apart from the other study participants, and yet his portrayal of the loss of his family, and his feelings around it, matched that of others.

Discussion of Theme 4. The narratives in Theme Four add to research that has explored the challenges of and recovery from what the APA (2000) terms “social dysfunction” in schizophrenia. Findings from the present study develop an understanding of the personal stories, coping, and meanings which “social dysfunction” takes on across the life course. From the perspective of these participants, loss of relationships and relationship conflicts stood out among the worst of the life course adversities they had faced. The significance of this theme was elucidated by its consistent occurrence across narratives, as well as in the valuation of its importance among persons who had experienced hardships that threatened their survival, such as homelessness and extended periods of joblessness. Relationship challenges and losses appeared to be as important, or nearly as important, as those that compromised survival. The relationship renewals and relational adjustments described by the participants identified long-term strategies and resources that helped study participants address this aspect of their illness. Their willingness to put in the work required to renew and adjust to relationships signified the importance of relationship and social roles to sense of self across the life course and into later life.

While family relationships are often compromised for persons with schizophrenia, family relationships can also be central to recovery. Involved families can lead to better illness outcomes when those families are able to serve as advocates and ensure broader treatment adherence (Lukens, 2001; MacFarlane et al., 2003). However, from the perspective of the participants in the present study, problems with their families were not framed in terms of how it affected their symptom outcomes, but in how it affected their personal senses of well-being.

Among the participants in this study, only Evelyn had a family who was willing to serve as an advocate and provided space and comfort to her in difficult times. However, at other times her relationship with her family had been marked by conflict, when she found them to be overly involved, compromising her independence. When families were either absent, under-involved, or a source of conflict and tension for extended periods of time, as they were for all of the participants, it was marked among the narratives as a loss and a significant challenge.

The significance of the loss of family was often illuminated within the narratives by how important reconnecting with previously disconnected family members had been for the participants. For George, Harry and Hank, family reached out to reconnect with them after lengthy periods of disconnection. Hank spoke in tongues with his mother when he first heard from her again. George repeated the story of his reconnection with his sister over and over. Harry's reconnection with his brother while in the hospital was recalled with a sense of relief, and he noted how his brother provided instrumental support. Hope took initiative and reconnected with her family on her own, overcoming significant negative symptoms and letting go of past conflicts in order to do so.

In renewing family relationships, participants adjusted and altered relationships to improve the fit of family into their present lives. This was done largely through the establishment of more distant or withdrawn ways of relating. Reconnected with his mother, Hank sent her money from his disability check and spoke to her regularly on the phone, but did not spend extended periods of time with her as he had in the past, keeping her physically removed from his life. George spoke with his sister on the phone, and although pleased when she visited on 2-3 occasions in the past 8 years, expressed

ambivalence about visiting her. For Hope, a younger sister replaced contentious relationships she had with other siblings. That sister's phone calls "made her day," but again visits were scarce. After the loss of his brother, Harry found the relationship with his sisters to be less than what he desired both in terms of companionship and instrumental support. However he was able to find value in what they offered instead—an annual visit, yearly gift certificates, and someone to fill the role of health care proxy.

Sells, Staynor & Davidson (2004) interpretation of withdrawal from family life among persons with schizophrenia is that it may serve as part of a recasting a sense of self, a defensive maneuver used to manage the challenges brought on by the mental illness. In that way, they suggest that such withdrawal may serve as an internal strength or coping mechanism. In the current study the initial withdrawal stemmed from varying levels of intent; was often completely involuntary; and often lead to periods with no family contact whatsoever. It did not appear to indicate coping and was experienced as a loss. Reconnection with family on the part of the participants in the current study entailed altered relationships that featured a more withdrawn relational style that seemed to maintain, rather than recast, a hard-earned sense of self and stability as had been developed through non-familial life experiences.

Recovering the self as a "social agent" and developing a renewed sense of social belonging is considered an integral piece of recovery from schizophrenia (Sells et al., 2004; Davidson et al., 2001; Davidson, 2003). In their present lives, each of the participants had been able to meaningfully engage with at least one person. For participants with limited family involvement, such as George, Harry and Bernard, that one person was a social service provider with whom the person had worked in housing or The Program for at least

five years (for Bernard) and as long as twenty years (for Harry). Evelyn, Hope and Hank had more extensive social networks that involved family, peers, and also included social service providers or therapists. Despite the participants' need for ongoing treatment for symptom management, participants in the present study had achieved varying levels of recovery in the social domain, of which long-term relationships with providers were often a key part.

The role that providers took in facilitating this aspect of recovery was significant. In line with findings of Ware, Tugenberg & Dickey (2004) and Green et al. (2008), participants in the present study often articulated the value of their present treatment in terms of the relationships and social connections it fostered, whether they were treated through The Program or The Clubhouse models. Professional alternates to family and peers did not adequately filled this role. Harry viewed family relationships as the most important, so despite his high valuation of the providers in his life, he continued to mourn the loss of his brother and regret his sisters' inability or unwillingness to engage with him more extensively. While Evelyn had found her relationship with a psychiatrist was so fulfilling that it precluded the need for other intimate relationships in her life at the time, she ultimately regretted never marrying. Thus the close bonds many of the participants had with social service professional alternates were not adequate to replace completely the need for other social and/or family ties.

One aspect of relationships missing between the study participants and social service providers was reciprocity. Reciprocity in relationships, in which both parties are able to add to the others life and well-being, has been identified as a key component as recovering from the elements of social dysfunction, and its related loss of social roles and

isolation, for persons with schizophrenia (Davidson, 2003; Ware et al., 2008). Without labeling them as such, when study participants described reciprocal relationships they tended to place those relationships among their most valued. Evelyn spoke in detail of the personal importance of her involvement in O.A. and her relationship with her mentally ill nephew. Hank found reciprocity in his relationships with other members and staff of The Program to whom he provided spiritual counseling, and in his relationship with his roommate with whom he shared household responsibilities. Harry provided thick description of the process of mutual support in his 20-year old support group at the Program, the importance of which was evident in his statement, "I can't wait 'til Monday morning" when his support group meets.

Prior research indicates that social relationships and social inclusion is a treatment priority for persons with schizophrenia (Davidson et al., 2001; Davidson, 2003; Ware et al., 2008). This was also true of the participants in the present study, for whom the importance of social recovery was often indicated by the effort to engage socially despite ongoing psychiatric symptoms and other challenges. This study adds that social recovery remains a priority across the life course of persons with schizophrenia, despite significant disruptions to social and family relationships in the past; seeming disinterest in social engagement; and entering a phase within the life course where social contacts often become more sparse (Lubben & Gironda, 2003). Further, despite illness presentations, illness severity and age, the willingness to renew, adjust and replace relationships to meet their needs was maintained by the participants.

The primacy of social connection links to a principle of narrative gerontology, wherein part of a coherent identity is in creating a meaningful narrative and in sharing it

with an actively involved other (Randall, 2011). The participants in the present study had engaged in a great deal of the internal work of later life as evident in the complex narratives presented above. They had integrated seemingly disparate pieces of their life histories into stories that promoted a cohesive sense of self; a remarkable task when considering the challenges to cohesiveness provided by their illnesses. Developing a relationship with someone with whom to share personal narratives is therefore a task of both aging and recovery. The participants in the present study held remarkable capacity for and drive towards addressing this task.

Cumulative Adversity and Advantage Across the Life Course with Schizophrenia

Overview of cumulative adversity and advantage. As I described in the background section, the present study is framed by the theory of cumulative adversity and advantage and the connected developmental life course perspective. Principles and concepts from the framework informed methodological choices and analysis. The recursive nature of qualitative research suggests that study findings will also develop its orienting framework. The findings above tell of the shared core subjective adversities as experienced and narrated by six older adults with ongoing symptoms of schizophrenia: Homelessness and housing challenges, vocational challenges, and relational conflict and loss. They also tell of advantages and strengths marshaled to face those adversities.

The theory of cumulative adversity and advantage proposes that differences in broad life course outcomes can be explained by differences in hardships and stressors faced by individuals across their life courses as they interact with resources, advantages and sources of inner resilience (Hatch, 2005; George, 2007). Demographic factors, social facts, events or mechanisms that worsen an individual's health, mental health, well-being or overall welfare at the time in which they occur and/or in the long run are considered adversities. Advantages have the opposite effect. Adversities and advantages may be intrapsychic or external. The theory connects earlier biographical events to multiple domains of later life outcomes (George, 2007).

Hatch (2005) identifies three processes through which adversities and advantages may accumulate over the life course. In the first, a single factor may provide persistent and continuous effects. In the second, a chain of contingencies can occur, wherein each hardship is surpassed by the next. In the third, there is a cascading series of events in which

small effects amass into larger consequences. Dannefer (2003) suggests that patterns are unique across individual lives. The data from this study allow us to examine which process most closely mirrored that experienced by study participants.

Exploration of patterns of cumulative adversity and advantage. In considering life course patterns of adversity and advantage, I first considered the single factor model, since many of the shared adversities identified in the present study were at least in part attributable to a single factor, which was the shared diagnosis of schizophrenia. The small yet diverse sample had little else in common with one another in terms of demographic factors as noted in the table that describes the sample in Appendix G.

Early life course experiences varied greatly among participants. Among the three Black participants, Bernard was from Harlem, Hank was from the rural South, and George had emigrated from the Caribbean. Evelyn and Hope were both Italian American women from Queens, but their socio-economic status varied. Evelyn came from a solidly middle-class background with an entrepreneurial father and a mother who also worked. Hope, one of 12 children, had been raised in severe poverty and endured hunger in her childhood. Evelyn had been encouraged to pursue education through college, even in the face of her psychiatric symptoms, while Hope had been encouraged to leave school at the age of 16 in order to work and contribute to her families' income. Harry was the only White male participant.

However as I tried to map the single factor model for each participant, I found that although schizophrenia was central to the participants' shared adversities, direct effects of schizophrenia were not simply "persistent and continuous" as described in the Hatch (2005) overview. Rather there were also chains of effects, and there were opportunities

that served as advantages, such as housing with a social service agency, that altered the disadvantaged course even if it did not re-set it entirely.

I then considered whether the data fit the cascading model, but it did not. Although adversities often existed in the early lives and onward for the participants, a build-up of smaller stressors was not evident in the narratives. Schizophrenia appeared to have been a turning point for all of the participants, regardless of early life history and demographics.

The data fit the chain contingency model better, but again, not perfectly. Schizophrenia remained a central, disruptive role, more so than what could be represented by a simple link on a chain. At the same time I found that not every contingency or condition was linked to each other, and the relationships between contingencies and conditions were not always straightforward.

By way of example, in Bernard's narrative, despite a mix of adverse and advantageous circumstances in his early life, schizophrenia acted as a filter through which a narrative of adversities developed. Schizophrenia led to his homelessness, joblessness, and lost contact with his family. Lengthy inpatient hospitalizations directly stemmed from the single factor of schizophrenia, and both the illness and the hospitalizations were connected to his loss of contact with family, his homelessness, and his joblessness. Those adversities also had relationships amongst each other that appeared to create a cluster-effect, rather than a simple chain wherein each sub-adversity individually stemmed off from the central adversity of schizophrenia. Within the clusters there were secondary chains and cross relationships. Bernard's drinking was connected to his homelessness, joblessness and loss of family. For many factors, including his problem drinking, the effects

were also not necessarily in any one direction of causality, but simply appeared to have all been connected.

In Bernard's narrative, a host of adversities later interacted with a second, primary advantageous factor, which was Bernard's involvement with the social service organization that provided him with housing, treatment and social support. The chain of adversities was filtered through his access to resources via The Clubhouse organization, altering his narrative into one that included both advantageous and adverse outcomes. His receipt of housing through The Clubhouse organization lead to his vocational pursuits in The Clubhouse work unit, and provided him with opportunities to make connections with staff, if not peers. In Bernard's case, a central adversity led to a chain of adverse contingencies; but overtime a central advantage led to small gains, which, coupled with his remarkable resilience, lead to his survival into a life that, if not ideal, had many comforts and fulfilling characteristics.

As I considered the other participants, despite differences amidst the details, I found that many of their life course chronologies of adversity and advantage took on the same general pattern. Demographic factors, early life events and early life circumstances were filtered through schizophrenia, which led the previously diverse and divergent life trajectories of participants onto parallel trajectories. Engagement with a social service organization that provided access to housing, mental health care, health care, and to varying extents access to employment was a second filter, but leading to a more advantageous trajectory.

Still, not all participants' narratives fit the model. Hank's narrative was one that was poorly captured by it. First, Hank had been able to work for long periods, maintain housing

and relationships for many years into the onset of his psychiatric symptoms, even though they coincided with heavy drinking. As I noted earlier, his symptoms had religious overtones, where he saw signs from God in his ideas of reference, and he heard the voice of God in his auditory hallucinations. As he explained to me, most members of his family heard the voice of God, and spoke back to Him. Most of the members of his family had been “saved.” Most saw signs from God in their daily lives.

Hank was from a Southern U.S. evangelical Christian culture that understood spirituality differently from the one wherein he was treated by psychiatrists in New York. Although, like the other participants, he eventually lost the ability to maintain formal work, housing, and relationships, I noted that his sense of wellness and self-esteem did not appear to have been compromised in the same way as the others. Harry, for example, felt he was “punishing himself” for failing to meet his family’s New York City-based standards of success. For Hank, the culture-bound normalcy of the nature of his symptoms seemed to have allowed him to remain in the work force and sustain relationships with his family for longer. He appeared to have only lost his ability to work and maintain relationships when his illness worsened, but from his perspective, this was when he was called to do God’s work. Most importantly, his sense of wellness and self-worth was maintained despite the losses, because of the value he and his family placed in a spiritual life and his “success” in that domain.

Although I tried to create a graphic representation of his individual “pattern” of adversity and advantage with all of the factors available, the visual image was not meaningful. The unique elements at play in his narrative were often not straightforward enough to be dichotomized as an adversity or advantage, and relationships were more

complicated than worsened/improved outcomes. For example, although the culturally-sanctioned religious nature of his delusions delayed his receipt of treatment (an adversity), it maintained his sense of self, and kept him from facing the same social exclusion faced by his peers (an advantage). Such complexity prevented his life course experience from fitting well into any of the Hatch (2005) models or the one that I described above. While his narrative shared all the features of the model I created, the model I created did not have room for all the features of his narrative. As suggested by Dannefer (2003), his model took on unique patterns.

Identifying advantage in schizophrenia. In the theory of cumulative adversity and advantage, advantage is typically framed in terms of a combination of demographic factors (such as social-economic status and gender), protective resources (access to care) and social support (Hatch, 2005). The theory of cumulative adversity and advantage has been criticized for focusing on sources of adversity and social inequities at the expense of understanding ways in which such gaps can be addressed, and for neglecting the role of personal agency (Dannefer, 2003). Other internal processes that contribute to resilient outcomes have also been understudied in relation to this theoretical framework (Hatch 2005). The narratives from the present study allow an understanding of subjective experiences, providing insight into the content of adverse experiences, as well as internal and external contributors to gains, resilience and recovery.

The present study formulated the participants as “survivors” of life course adversities related to schizophrenia, and those adversities are well documented above, developing earlier literature on schizophrenia. This study also contributes uniquely to the

understanding of the subjective experience and identification of advantage, which was analyzed in-depth.

Internal processes identified in the above discussion of the shared core themes included 1) narrative integration of the illness experience into the context of the life course and narrative identity work; 2) perseverance towards work and meaningful activity across the life course; and 3) the willingness and ability to renew adjust, adapt and persevere in the face of relational challenges and losses. External opportunities were identified as 1) obtaining and maintaining apartments with connected social services; 2) vocational opportunities (at The Clubhouse for those engaged there); 3) the presence of peers, family and/or providers with whom to engage in social relationships.

Discussion of cumulative adversity and advantage in schizophrenia across the life course. Models of life course narratives of adversity and advantage in the present study fell short when individual narratives were closely examined. Although single-factor and chain contingency models could explain part of the narrative in most cases, inclusiveness of important single-case based details consistently produced unique patterns as Dannefer (2003) suggested.

Findings around advantage in the present study are aligned with those from Hildon et al. (2008) whose investigation of the resilience of a diverse group of non-mentally ill older adults found that advantageous internal processes included constructing narratives that reinterpreted past adversity in light of recent life circumstances; relying upon lifelong coping strategies, and gaining support from close, ongoing relationships. Adverse or vulnerable outcomes were connected with more severe adversities, and practical support could moderate outcomes.

Overall the theory of cumulative adversity and advantage provided a useful framework for developing and analyzing study results. The development of our understanding of cumulative adversity and advantage across the life course with schizophrenia provides clinicians and researchers with insights into the effects of schizophrenia across the life course, as well as resilient living with schizophrenia, and in turn, its treatment. However in line with Dannefer (2003) unique attributes of the participant narratives meant that despite some conforming patterns between narratives, patterns of adversity and advantage held unique characteristics across individual life trajectories.

Strengths and Limitations of the Research

I conclude the findings section with an evaluation of the strengths and limitations of the study. In constructivist qualitative research, strengths are framed in terms of trustworthiness established through the presence of four components: credibility, transferability, dependability and confirmability (Denzin, 2009). In narrative research, credibility refers to the demonstration that findings reflect the experience of the participants and is established through prolonged field observation, persistent observation, triangulation, peer debriefing and member-checks (Denzin, pp.330). Transferability refers to the ability to generalize findings beyond the sample group and is established through the generation of thick description in interview and observational material. Dependability in narrative analysis refers to whether the experience is being evaluated consistently within and across cases and is enhanced through the use of step-wise replications, overlapping methods, time-triangulation and the use of well-informed participants. Confirmability suggests that the same data presented to other researchers would garner comparable

results and is developed through the use of audit trails, field notes, memos, a field diary, process and personal notes, and a reflexive journal.

Strengths of the research. I rigorously applied features of credibility to the research process and presentation of the findings. Interviews with participants were held over periods of time that ranged from 5 to 10 months. Field observations were made around the primary environments in participants' current lives, including their homes and neighborhoods, treatment facilities and treatment neighborhoods. Triangulation of data collection methods was established through the use of four interview types, as well as from field observations. Since my interest was in the subjective experience of the study participants, I chose not to ask for alternate perspectives from treatment providers, family or friends that could compromise establishment of the subjective perspective. However field observations and later-stage comparisons to existing literature on the core themes added to the data generated by the interviews to create a triangulation of sources. Further, over the course of 21 months, I debriefed with the project's sponsor every two to six weeks, depending upon the phase of the project. I also presented narrative accounts to the participants, as well as my analysis of their accounts, to the study participants through the member checking and process interviews. I accepted their corrections to their narrative accounts, considered their suggestions around the analysis, and adjusted the findings accordingly. In the presentation of the findings, I included long chronologically ordered passages that further promote the credibility of the findings. Credibility of the findings was therefore well established.

I engaged strategies that would enhance transferability of the findings. I developed and used interview questions that were framed by the theoretical background of the study,

but adjusted for each participant as narratives, case-bound and cross-case analysis unfolded. The use of these interview strategies and detailed field observation notes garnered thick description across participants. When interviews failed to yield thick description around a full life course narrative, despite multiple interviews, the participant's data was eventually excluded from the findings.

I established dependability through the use of a step-wise process. The step-wise process is described in detail in the methodology section, and included overlapping methods that involved field observations, use of a demographic data form, and four interview types. The first participant, noted above, who refused to speak about her past was also not willing to engage in building a life history calendar, leading to her narrative's exclusion from the findings. Another participant was lost to follow-up prior to the member checking and process interviews, and therefore his data was also excluded. Furthering dependability, time-triangulation was also deployed, with multiple interviews occurring over 5-10 months, adjustments were made to narratives as the participants' accounts developed nuances, ambiguities, and increased expression of ambivalence about events and relationships.

Additionally, the recruitment strategy was focused and strategic, ensuring that participants were currently diagnosed with schizophrenia or schizoaffective disorder, receiving treatment for ongoing symptoms, and were over the age of 55; each participant was considered an expert in his or her own life. My willingness to go to homes and treatment facilities of participants meant that even persons significantly disabled by psychiatric or medical symptoms could participate. Varying levels of psychiatric illness presentation and medical comorbidities among participants suggest that the sample was

not limited to more well or able persons. The recruitment and data collection strategies therefore created a well-informed sample. Overall, the use of the study procedures ensured dependability in the results.

Confirmability of data was developed through the use of audit trails. The audit trail developed for this study includes field observations, a field diary, interviews, coded interviews, life history calendars and time diaries, memos, and process and personal notes. The project's sponsor informally followed this trail in our regular meetings throughout the course of the research. In the presentation of the findings in this report, I described the process through which themes and processes became evident, and included lengthy narrative passages from each participant that would allow for the reader to confirm or challenge the findings. Member-checking allowed for participants to confirm or alter the findings.

Additionally, I added the fourth interview type, the "process interviews" to check reflexive responses to the research with participants' experience of participation in the research. The social constructivist underpinnings of this type of qualitative research in general (Denzin, 2009) narrative research in particular (Randall et al., 2006) suggest that the social context of research includes the unique features of the researchers, and in particular, the interviewers. Therefore all research is subject to idiosyncratic results. However the methods used in designing the study, collecting, organizing and analyzing the data, suggest that the same data presented to other researchers would in fact garner comparable results.

Limitations of the research. As a clinician and a researcher, I have often had a challenging relationship with the recovery movement. On the one hand, I was familiar with

statistics that clearly showed persons with schizophrenia and other serious mental disorders can and do symptomatically recover from mental illness before later life (Harding, 2005; Bankole et al., 2008). I also share the values and person-centered principles of the recovery movement whole-heartedly. However, my perspective was sensitized by clinical experience that told me that there exist persons with serious mental illness, particularly schizophrenia, who do not make a symptomatic recovery by later life and would benefit from social services specialized to meet their unique needs. I found myself aligned with those who were concerned that the emphasis on recovery marginalized those who were sicker; those who did not experience episodic or complete symptom remission; and those who, for whatever reason, were not able to function meaningfully in the life domains identified by the recovery movement. This research was thus framed by a desire to present the voice and understand the experience of those persons who required a lifetime of psychiatric treatment and social service support. A limitation of the study was therefore the exclusion of those older adults who no longer required treatment, having made complete or nearly-complete symptomatic recovery. At the same time, the experience of older adults who continue to endure ongoing symptoms, but do not receive psychiatric treatment or social services, was not captured in the present study.

Additionally, although ongoing symptoms for which participants required treatment was part of the inclusion criteria and was confirmed through the referral process, I did not specify or screen for what type of symptoms, among the broad array of possible schizophrenia symptoms, were ongoing. Treatment with anti-psychotic medications, which tend to be geared towards alleviating positive symptoms of schizophrenia, was universal among the participants. My own clinical impressions were the only other source of

evaluation of ongoing symptoms, and would have been enhanced through the use of a standardized measure. However I was concerned that a standardized measuring process would detract participants' from the focus of the study, erroneously focusing it upon discussion of schizophrenia. I was also concerned standardized symptom measures would inhibit the establishment of a researcher-participant rapport focused upon narrative development, instead creating a more clinical rapport. Nonetheless, type of symptoms, particularly cognitive and negative symptoms, may affect a broad range of factors that influenced findings, including narrative construction, motivation and willingness to participate in a study such as the present one, and competence to participate. Lack of symptom screening therefore limits transferability of the findings.

I did not consider domains of recovery beyond illness symptoms in defining my sample inclusion criteria. These domains are identified in recovery literature as including housing, relationships, vocational, and spiritual domains (Davidson, O'Connell, Tondora, Staeheli & Evans, 2005). However the diversity in recovery across those domains by participants allowed for an examination of shared and varying processes of recovery. As reflected in the conclusion below, the project moved me towards a closer alliance with the consumer-driven recovery movement as I found that, regardless of symptom level or presentation, all participants described subjective experiences of recovery across at least some domains and perseverance towards greater recovery in those domains and others.

Given the high mortality rates of the study's population (Parks, et al., 2006; Fazel et al., 2008) and the fact that the study participants had outlived the average life expectancy of persons with their condition and experiences, the participants were framed from the beginning as "survivors." Although comparisons to existing research found unique and

shared characteristics between the sample group and others with schizophrenia, case comparisons with “non-survivors” was not possible using this methodology. Retrospective case comparison using treatment chart data and reporting from family and service providers or longitudinal narrative studies might yield interesting results in this area. Narrative case comparisons between persons who achieve symptomatic recovery and those who do not may provide novel insights, but run the risk of further marginalizing those who have more severe forms of the illness.

Overall, limitations of the study were generally related to inclusion and exclusion criteria of the study population, and methodological limitations as might appear in any study. However the focused definition of the study population promoted depth in the findings and richer understanding of the phenomenon under investigation. The methodology was successful in answering the study’s research question. The central strength of the present research was the use of multiple strategies that ensured a rigorous process produced trustworthy findings.

Chapter 5: Conclusion

Through the lens of the developmental life course perspective and the overarching framework of the theory of cumulative adversity and advantage, this study explored how older adults with schizophrenia understand and express their narratives of survival in the face of life course and present time adversities. Using thematic narrative analysis, narratives of six participants relating to four shared core themes were developed: 1) *"My life as it is has value:" Narrating schizophrenia in later life*; 2) *"I have a key and live like a real person:" Homelessness and housing challenges in retrospect*; 3) *"There's not been jobs:" The meaning of employment*; 4) *"God told me how we're going to meet back up:" Narratives of relational conflict and loss, adjustment and renewal*. In the findings, each participant's narrative as it related to the shared core theme was presented, demonstrating the unique characteristics of their experience and story. Subsequently, cross-case comparisons and discussion of fit within the existing research around schizophrenia, narrative and aging were made. Taken as a whole, the recursive process allowed development of our understanding of cumulative adversity and advantage as subjectively experienced through older adults with schizophrenia. I conclude now by presenting the finding's implications for future research, policy and practice.

In the first theme, participants used narrative insight that integrated the adversity of experiencing symptoms of schizophrenia for extended periods with other life course experiences. Older age served as an advantage to participants wherein the process of instrumental reminiscence allowed problems associated with their psychiatric illnesses to be interpreted in the context of biographical capital that contextualized and lessened the importance of the illness, its label, and the associated stigma, without denying the

adversities they had endured. Considered with parallel findings from previous research (Lysaker et al., 2012; Roe & Davidson 2005; Roe et al., 2008); findings in Theme 2 about identity reconstruction post-homelessness; and findings from the reflexive analysis in this study, the present study's findings around narrative suggest that social service provision to older adults with schizophrenia could be improved by assisting in the development of cohesive personal narratives, particularly those that develop a narrative understanding of schizophrenia across the life course. Such assistance may promote resilient aging (Hildon et al., 2008) as well as recovery from schizophrenia (Roe & Davidson, 2005). Research that evaluates the effectiveness of narrative interventions with older adults with schizophrenia, and across age groups, is needed to understand how social service providers can best provide support in the area of narrative recovery.

In the second theme, participants described the adversity of homelessness and housing challenges. The assistance of social services was required to obtain stable housing and participants remained in housing that was provided through those same social service agencies, and in treatment facilitated by those same agencies, for long periods of time. However The Program participants expressed ambivalence as to whether they wanted more independence in their housing or more security and support, while The Senior Residence participants expressed more contentedness with the levels of independence and support. In later life, when medical issues may compound social and psychiatric problems for older adults with schizophrenia, long-term housing settings that provide a balance of autonomy and support may be optimal environments to support broader outcomes of improved health, mental health and well-being, or at the very least, decrease social isolation. Although current evidence around housing support for formerly homeless

persons with mental illness promotes more autonomous housing via Pathways' Housing First Program, and shorter duration of housing-related social services via CTI (NERPP², 2012; NERPP³, 2012), research that more fully evaluates optimal housing environments for older adults with schizophrenia is needed. Policy-makers and program developers should be wary of a one-size-fits-all approach to housing for members of this population and consider other factors, such as age, when developing housing models. Participant satisfaction with The Senior Residence suggests it may be a promising prototype. Further research is needed to evaluate the unique benefits of The Senior Residence to older adults with schizophrenia.

Findings from Theme 2 also included participants' narration of current living situations through the lens of their previous experiences of homelessness and housing challenges. In creating such narratives, despite issues with compromised autonomy, all participants were able to identify positive aspects of their current living situations. Many developed narratives of enduring the challenges of homelessness that allowed their sense of personal worth to expand as they recognized their own resilience. However at least one participant continued to struggle with the meaning in having been homeless as related to his sense of self. These findings, coupled with those of Padgett (2007) suggest again that narrative interventions that support the internal work required after episodes of homelessness may help develop an improved sense of well-being and repaired identity. Further research is needed to understand how social service providers in housing settings can best provide support in this area.

In Theme 3, the adversity of vocational disruption in earlier life was addressed through perseverance towards work and volunteer activities in later life. Narratives

consistently included ideas about finding employment and/or accounts of meaningful participation in other vocational activities, despite age, psychiatric symptom types, and physical infirmities of the study participants. Although the age of the study participants extended past where development of new careers is ordinarily found, some participants expressed an interest in doing just that. Alternately, some were interested in involvement in activities that fulfilled the deeper sense of purpose provided by engaging in constructive and meaningful activities. This finding of perseverance towards work and volunteer activities in later life has two important practice implications. First, organizations providing vocational services to persons with serious mental illnesses, such as through the psychosocial clubhouse and PROS models as in this study, should be sure to offer such services to participants regardless of age or co-occurring physical infirmities. Second, adjustments to vocational goals that improve their feasibility, as is often facilitative of employment (Krupa, 2004), must not lose sight of the values and identity that the original vocational goals had embodied. Providers of vocational services to persons with schizophrenia and other serious mental illnesses must have an understanding of the persons with whom they work that goes beyond goals, skills and experience to include consideration of the needs met and values enacted through vocational employment.

In Theme 4, narratives poignantly illuminated the meaning of relational adversities across the life course. The participants countered these adversities with various adaptation and adjustment strategies, although the pain of some losses endured. Long-term relationships with peers and providers proved invaluable to participants in countering these challenges. As such, one policy recommendation stemming from this theme is that agencies providing social services to persons with schizophrenia of any age should

implement measures that will ensure lengthy staff tenures. PROS models, which are designed to be shorter-term than the treatment received until now by persons in the Program, may benefit from adding longer-term treatment options for more severely symptomatic and for older adults, who typically face more social challenges, including higher rates of isolation (Hafner & Heiden, 2008). Additionally, although current research supports clubhouse model effectiveness in addressing areas of employment, quality of life, and perceived recovery from mental illness (NREPP, 2012), further research that develops an understanding of how the model addresses relational recovery would help improve replication of this model.

Theme 4 also has practice implications. Although there is a growing body of evidence-based practices for families of persons with serious mental illnesses (Lukens & Ogden, 2011), none of the participants in the present study had been involved in family programs, although their narratives suggest such programs would be useful. Participants often did not know what to say to their families or how to engage with them more generally. Participation in programs that involve family, such as family psycho-education, could have improved their quality of their relationships, and of their life overall. As such, across settings wherein persons with schizophrenia are treated and/or housed, programs that promote family involvement should be offered to participants across the life course including in later life.

While advantages related to schizophrenia have often been connected to other factors, findings from the present study noted that participants' abilities to integrate adversities into coherent and meaningful narratives was a key to internal resilience for the participants in this study. Each adversity experienced by the participants was not only

countered by social service interventions and/or family involvement, but also by intrapsychic attributes, such as fortitude, perseverance and the ability to integrate adversities into a meaningful narrative. These remarkable attributes were in turn bolstered by the presence of social services. Improvement of social services focused on addressing ongoing challenges faced by older adults living with ongoing symptoms and other challenges in living related to schizophrenia would allow recovery in these areas to rely less on intrapsychic functioning, making it more broadly available. Recovery is not only possible in later life, but due to the increased internal activity that characterizes this life phase (Randall, 2011), may be an ideal time to address unresolved issues from earlier in the life course.

To date the study of older adults with schizophrenia has been limited, but represents a growing field. This study compliments the existing research, adding to it the voices and subjective experiences of the population, which were presented throughout the findings. It represents the first study to use thematic narrative analysis to develop an understanding of the subjective experience of older adults with schizophrenia. The unique contribution of this study is in its discerning of the subjective understandings and expressions of personal survivorship, adversities faced, and advantages marshaled across the life course and present time, by older adults with schizophrenia. The recommendations herein for practice, policy, and future research come from the study population in a direct way not previously present in the literature on older adults with schizophrenia.

The consumer-driven mental health recovery movement has identified key areas of recovery from serious mental illnesses that include home, purpose and community (SAMHSA, 2012). Critics of the recovery movement have argued that the consumer leaders of the recovery movement do not represent the majority of persons with serious mental

illnesses and that emphasis on recovery marginalizes those who are sicker and therefore less able to recover symptomatically or regain functioning in the meaningful life domains identified by the recovery movement (Davidson, 2003). However the findings from the present study add to a growing body of research that refutes these claims (Davidson). The sample of the present study was defined by age and ongoing symptoms of schizophrenia that required treatment into later life. All of the participants had experienced substantial illness-related hardships across their life courses. Despite the obstacles presented by psychiatric symptoms, age and physical infirmities, the participants in the present study eloquently expressed their personal stories of gains, adjustments, renewals, perseverance, fortitude and ongoing hopes for recovery across life domains.

References

- APA (2000). *Diagnostic and statistical manual of mental disorders test revision (DSM-IV-TR)* (4th ed.). Washington DC: American Psychiatric Association.
- Andrews A.O., Bartels S.J., Xie H. & Peacock W.J. (2009). Increased risk of nursing home admission among middle aged and older adults with schizophrenia. *American Journal of Geriatric Psychiatry*, 17(8), 697-705.
- Arnold, S.E. (2001). Contributions of neuropathology to understanding schizophrenia in late life. *Harvard Review of Psychiatry*, (9)2, 69-76.
- Bankole, A., Cohen, C.I., Vahia I., Diwan, S., Palekar N., Reyes, P., Sapra, M. & Ramirez, P.M. (2008). Symptomatic remission in a multi-racial urban population of older adults with schizophrenia. *American Journal of Geriatric Psychiatry*, 16(12), 966-973.
- Bartels, S.J., Clark, R., Peacock, W.J., Dums, A.R. & Pratt, S.I. (2003). Medicare and Medicaid costs for schizophrenia patients by age cohort compared with costs for depression, dementia and medically-ill patients. *American Journal of Geriatric Psychiatry*, 11(6), 648-657.
- Bartels, S.J. & Dums, A.R. (2003). Mental health policy and financing services for older adults with severe mental illness. In C.I. Cohen (Ed.) *Schizophrenia into later life: Treatment, research and policy* (pp. 177-194). Washington, DC: American Psychiatric Publishing.
- Bartels, S.J. & Pratt, S.I. (2009). Psychosocial rehabilitation and quality of life for older adults with serious mental illness: Recent findings and future research directions. *Current Opinion in Psychiatry*, 22(4), 381-385.
- Bellack, A. S. (2006). Scientific and consumer models of recovery in schizophrenia: Concordance, contrasts, and implications. *Schizophrenia Bulletin*, 32(3), 432-442.

- Belli, R.F., Alwin, D.F. & Stafford, F.P. (2009). Introduction: The application of calendar and time diary methods in the collection of life course data. In Belli, R.F., Stafford, F.P. & Alwin, D.F. (Eds.) *Calendar and time diary methods in life course research* (pp. 1-10). Thousand Oaks, CA: Sage Publications.
- Belcher, J.R. (1989) On becoming homeless: A study of chronically mentally ill persons. *Journal of Community Psychology*, 17, 173-185.
- Bertoni, A.G., Anderson, G.F., Krop, J.S. & Brancati, F.L. (2002). Diabetes-related morbidity and mortality in a national sample of U.S. elders. *Diabetes Care*, 25(3), 471-475.
- Blomqvist, A.G., Leger, P.T. & Hoch, J.S. (2006). The costs of schizophrenia: Lessons from an international comparison. *Journal of Mental Policy and Economics*, 9(4), 177-183.
- Bradshaw, W. & Brekke, J.S. (1999). Subjective experience in schizophrenia: Factors influencing self-esteem, satisfaction with life, and subjective distress. *American Journal of Orthopsychiatry*, 69(2), 254-260.
- Bradshaw, W., Armour, M.P. & Roseborough, D. (2007). Finding a place in the world: The experience of recovery from severe mental illness. *Qualitative Social Work*, 6(27), 27-47.
- Breier, A. (1988). Small sample studies: Unique contributions for large sample outcomes studies. *Schizophrenia Bulletin*, 14(4), 589-593.
- Bresnahan, M., Begg, M. D., Brown, A., Schaefer, C., Sohler, N., Insel, B.,... Susser, E. (2007). Race and risk of schizophrenia in a US birth cohort: Another example of health disparity? *International Journal of Epidemiology*, 36(4), 751-758.
- Buckley, P.F., Wirshing, D.A., Bhushan, P., Pierre, J.M., Resnick, S. A. & Wirshing, W.C. (2007). Lack of Insight in Schizophrenia: Impact on Treatment Adherence. *CNS Drugs*, 21(2), 129-141.

- Caelli, K (2001). Engaging with Phenomenology: Is it more of a Challenge than it needs to be? *Qualitative Health Research*, 11, 273-281. doi: 10.1177/104973201129118993
- Capasso, R.M, Lineberry, T.W., Botswick, J.M., Decker, P.A., & St. Sauver, J. (2008). Mortality in schizophrenia and schizoaffective disorder: An Olmstead County, Minnesota cohort: 1950-2005. *Schizophrenia Research*, 98(1-3), 287-294.
- Castle, D.J. & Morgan, V. (2008). Epidemiology. In K.T. Mueser & D.V. Jeste (Eds.) *Clinical handbook of schizophrenia* (pp.14-24). New York, NY: Guilford Press.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage Publications.
- Chase, S.E. (2011). Narrative inquiry: Still a field in the making. In N.K. Denzin & Y.S. Lincoln (Eds.) *The Sage handbook of qualitative research* (4th ed.) (pp. 421-434). Washington, D.C.: Sage Publications.
- Cohen, C.I. (2003). Toward the development of theory and research in aging and schizophrenia. In C.I. Cohen (Ed.) *Schizophrenia into later life: Treatment, research and policy* (pp.177-194). Washington, D.C.: American Psychiatric Publishing.
- Cohen, C.I., Cohen, G.D., Blank, K., Gaitz, C., Katz, I.R., Leychter, A.,... Shamoian, C. (2000). Schizophrenia and older adults: an overview: Directions for research and policy. *American Journal of Geriatric Psychiatry*, 8(1), 19-28.
- Cohen, C.I., Pathak, R., Ramirez, P.M. & Vahia, I. (2009). Outcome among community dwelling older adults with schizophrenia: Results using five conceptual models. *Community Mental Health Journal*, 45(2), 151-156.
- Creswell, J.W. (2007). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches* (2nd Ed.). Thousand Oaks, CA: Sage Publications.

- Dannefer, D. (2003). Cumulative advantage/disadvantage and the life course: Crossfertilizing age and social science theory. *Journal of Gerontology: Social Sciences*, 58B(6), S327–S337.
- Davidson, L. (2003). *Living outside mental illness: Qualitative studies of recovery in schizophrenia*. New York, NY: New York University Press.
- Davidson, L., O'Connell, M.J., Tondora, J., Staeheli, M. & Evans, A.C. (2005). Recovery in serious mental illness: Paradigm shift or shibboleth? In L. Davidson, C., Harding & L. Spaniol (Eds.) *Recovery from severe mental illnesses: research evidence and implications for practice* (Vol. I) (pp. 5-26). Boston, MA: Center for Psychiatric Rehabilitation, Boston University.
- Davidson, L., Stayner, D. A., Nickou, C., Styron, T. H., Rowe, M. & Chinman, M. L. (2001). "Simply to be let in": Inclusion as a basis for recovery. *Psychiatric Rehabilitation Journal*, 24(4), 375-388.
- Deegan, P. (2007). The lived experience of using psychiatric medication in the recovery process and a shared decision-making program to support it. *Psychiatric Rehabilitation Journal*, 31(1), 62-69.
- Deegan, P., & Drake, R.E. (2006). Shared decision making and medication management in the recovery process. *Psychiatric Services*, 57(11), 1636-1639.
- Denzin, N.K. & Lincoln, Y.S. (2005). Introduction: The discipline and practice of qualitative research. In N.K. Denzin & Y.S. Lincoln (Eds.) *The Sage handbook of qualitative research* (3rd Ed.) (pp.1-32). Thousand Oaks, CA: Sage Publications.
- Denzin, N.K. (2009). *Qualitative inquiry under fire: Toward a new paradigm dialogue*. Walnut Creek, CA: Left Coast Press.

- DeRenzo, E.G., Conley, R.R. & Love, R. (1998). Assessment of capacity to give consent to research participation: state-of-the-art and beyond. *Journal of Health Care Law and Policy*, 1(1), 66-87.
- Dickerson, F. B., Brown, C., Daumit, G., LiJuan, F., Goldberg, R., Wohlheiter, K.,... Dixon, L.B. (2006). Health status of individuals with serious mental illness. *Schizophrenia Bulletin*, 32(3), 584-589.
- Dickinson, D. & Harvey, P.D. (2009). Systemic hypothesis for generalized cognitive deficits in schizophrenia: A new take on an old problem. *Schizophrenia Bulletin*, 35(2), 403-414.
- Dixon, L., Weiden, P., Delahanty, J., Goldberg, R., Postrado, L., Lucksted, A. & Lehman, A. (2000). Prevalence and correlates of diabetes in national schizophrenia samples. *Schizophrenia Bulletin*, 26(4), 903-912.
- Drake, R.J., Pickles, A., Bentall, R.P., Kinderman, P., Haddock, G., Tarrier, N. & Lewis, S.W. (2004)
- The evolution of insight, paranoia and depression during early schizophrenia. *Psychological Medicine*, 34, 285-292.
- Dupuis A. & Thorns, D.C. (1998). Home, home ownership and the search for ontological security. *Sociological Review*, 46(1), 25-47.
- doi: 10.1111/1467-954X.00088
- Dunn, J. (2002). Housing and inequalities in health: a study of socioeconomic dimensions of housing and self reported health from a survey of Vancouver residents. *Journal of Epidemiology and Community Health*, 56(9), 671-81.

- Dunn, E.C., Wewiorski, N.J. & Rogers, E.S. (2008). The meaning and importance of employment to people in recovery from serious mental illness: Results of a qualitative study. *Psychiatric Rehabilitation Journal*, 32 (1), 58-62.
- Elder, G.H. (1994). Time, human agency, and social change: Perspectives on the life course. *Social Psychology Quarterly*, 57(1), 4-15.
- Ellingson, L.L. (2011). Analysis and representation across the continuum. In N.K. Denzin & Y.S. Lincoln (Eds.) *The Sage handbook of qualitative research* (4th ed.) (pp. 595-610). Washington, D.C.: Sage Publications.
- Essock, S. M., Dowden, S., Constantine, N. T., Katz, L., Swartz, M. S., Meador, K. G.,... Rosenberg, S.D. (2003). Blood-borne infections and persons with mental illness: Risk factors for HIV, hepatitis B, and hepatitis C among persons with severe mental illness. *Psychiatric Services*, 54(6), 836-841.
- Fazel, S., Khosla, V., Doll, H., & Geddes, J. (2008). The prevalence of mental disorders among the homeless in western countries: Systematic review and meta-regression analysis. *Public Library of Science Medicine*, 5(12), 1670-1681.
- Flanagan, E.H., Davidson, L. & Strauss, J.S. (2007). Issues for DSM-V: Incorporating patients' subjective experiences. *American Journal of Psychiatry*, 164(3), 391-392.
- Freeman, M. (2011). Narrative foreclosure in later life: Possibilities and limits. In G.M. Kenyon, E. Bohlmeijer & W.L. Randall (Eds.) *Storying later life: Issues, investigations, and interventions in narrative gerontology* (pp. 1-18). New York, NY: Oxford University Press.

- George, L.K. (2007). Life course perspectives on social factors and mental illness. In W.R. Avison, J.D. McLeod & B. A. Pescosolido (Eds.) *Mental health, social mirror* (pp. 191-218). New York, NY: Springer.
- Gurney, C. M. (1997). “Half of me was satisfied”: Making sense of home through episodic ethnographies. *Women’s Studies International Forum*, 20(3), 373–386.
- Green, C. A., Polen, M. R., Janoff, S. L., Castleton, D. K., Wisdom, J. P., Vuckovic, N., & ... Oken, S. L. (2008). Understanding How Clinician-Patient Relationships and Relational Continuity of Care Affect Recovery from Serious Mental Illness: STARS Study Results. *Psychiatric Rehabilitation Journal*, 32(1), 9-22. doi:10.2975/32.1.2008.9.22
- Hatch, S.L. (2005). Conceptualizing and identifying cumulative adversity and protective resources: Implications for understanding health inequalities. *Journals of Gerontology: Series B*, 60B(Special Issue), 130-134.
- Hafner, H. & Heiden, W. (2008). Course and Outcomes. In K.T. Mueser & D.V. Jeste (Eds.) *Clinical handbook of schizophrenia* (pp. 100-116). New York, NY: Guilford Press.
- Harvey, P. (2005). *Schizophrenia in late life*. Washington, DC: American Psychological Association.
- Harding, C.M. (2005). Changes in schizophrenia across time: Paradoxes, patterns, and predictors. In L. Davidson, C., Harding & L. Spaniol (Eds.) *Recovery from severe mental illnesses: research evidence and implications for practice* (Vol. I) (pp. 27-48). Boston, MA: Center for Psychiatric Rehabilitation, Boston University.
- Hildon, Z., Smith, G., Gopalakrishnan, N. & Blane, D. (2008). *Understanding adversity and resilience at older ages. Sociology of health and illness*, 30(5), 726-740.

- Hopper, K., Jost, J., Hay, T., Welber, S. & Haugland, G. (1997). Homelessness, severe mental illness and the institutional circuit. *Psychiatric Services*, 48(5), 659-664.
- Hutchison, E.D. (2005). The life course perspective: A promising approach for bridging the micro and macro worlds for social workers. *Families in Society*, 86(1), 143-152.
- Jeste, D.V. & Nasrallah, H.A. (2003). Schizophrenia and aging: No more dearth of data? *American Journal of Geriatric Psychiatry*, 11(6), 584-588.
- Jin, H., Folsom, D.P., Lindamer, L., Bailey, A., Hawthorne, W., Piedad, G. & Jeste, D.V. (2003). Patterns of public mental health service use by age in patients with schizophrenia. *American Journal of Geriatric Psychiatry*, 11(5), 525-533.
- Kilbourne, A., Cornelius, J., Han, X., Haas, G., Salloum, I., Conigliaro, J. & Pincus, H.A. (2005). General-medical conditions in older patients with serious mental illness. *American Journal of Geriatric Psychiatry*, 13(3), 250-254.
- Krupa, T. (2004). Employment, recovery, and schizophrenia: Integrating health and disorder at work. *Psychiatric Rehabilitation Journal*, 28(1), 8-15.
- Lamb, H.R. & Bachrach, L.L. (2001). Some perspectives on deinstitutionalization. *Psychiatric Services*, 52(8), 1039-1045.
- Lincoln, T.M., Lullmann, E., & Rief, W. (2007). Correlates and Long-Term Consequences of Poor Insight in Patients With Schizophrenia: A Systematic Review. *Schizophrenia Bulletin*, 33(6), 1324–1342.
- Levitt, A. J., Culhane, D. P., DeGenova, J., O’Quinn, P., & Bainbridge, J. (2009). Health and social characteristics of homeless adults in Manhattan who were chronically or not chronically unsheltered. *Psychiatric Services*, 60(12), 978-981.
- doi:10.1176/appi.ps.60.7.978

- Lubben, J. & Gironde, M. (2003). Centrality of social ties to health and well-being of older adults. In B. Berkman and L. Harootyan (Eds.) *Social work and health care in an aging society* (pp. 319-350). New York, NY: Springer Publishing.
- Lukens, E. (2001). Schizophrenia. In A. Gitterman (Ed.), *Handbook of social work practice with vulnerable and resilient populations* (pp. 275-304). New York: Columbia University Press.
- Lykkeslet, E. & Gjengedal, E. (2007). Methodological problems associated with practice close research. *Qualitative Health Research*, 17(5), 699-704.
- Lukens, E. & Ogden, L. (2011). "Psychotic Conditions." In N. Rovinelli Heller and A. Gitterman, (Eds.) *Mental Health and Social Problems: A Social Work Perspective*. New York: Routledge.
- Lysaker, P.H., Carcione, A., Dimaggio, G., Johannesen, J.K., Nicolo, G., Procacci, M. & Semerari, A. (2005). Metacognition amidst narratives of self and illness in schizophrenia: Associations with neurocognition, symptoms, insight and quality of life. *Acta Psychiatrica Scandinavica*, 112(1), 64-71.
- Lysaker, P.H., Daroyanni, P., Ringer, J., Beattie, N., Strasburger, A., & Davis, L. (2007). Associations of awareness of illness in schizophrenia spectrum disorder with social cognition and cognitive perceptual organization. *Journal of Nervous and Mental Disease*, 195(7), 618-621.
- Lysaker, P.H., Erikson, M., Macapagal, K.R., Tunze, C., Gilmore, E. & Ringer, J.M. (2012). Development of personal narratives as a mediator of the impact of social deficits in social cognition and social withdrawal on negative symptoms in schizophrenia. *Journal of Nervous and Mental Disease*, 200(4), 290-295.

- Lysaker, P.H. & Lysaker, J.T. (2001). Psychosis and the disintegration of dialogical self-structure: Problems posed by schizophrenia for the maintenance of dialogue. *British Journal of Medical Psychology*, 74(1), 23-33.
- Lysaker, P., Roe, D., & Yanos, P. (2007). Toward understanding the insight paradox: Internalized stigma moderates the association between insight and social functioning, hope, and self-esteem among people with schizophrenia-spectrum disorders. *Schizophrenia Bulletin*, 33(1), 192-199.
- Marwaha, S. & Johnson, S. (2004). Schizophrenia and employment: A review. *Social Psychiatry and Psychiatric Epidemiology*, 39, 337-349.
- Marone, J. & Golowka, E. (2005) If work makes people with mental illness sick, what do unemployment, poverty and social isolation cause? In L. Davidson, C., Harding & L. Spaniol (Eds.) *Recovery from severe mental illnesses: research evidence and implications for practice* (Vol. I) (pp. 451-463). Boston, MA: Center for Psychiatric Rehabilitation, Boston University.
- McFarlane, W. R., Dixon, L., Lukens, E., & Lucksted, A. (2003). Family psychoeducation and schizophrenia: A review of the literature. *Journal of Marital and Family Therapy*, 29(2), 223-245.
- Mechanic, D. (2008). *Mental Health and Social Policy: Beyond Managed Care* (5th Ed.). New York, NY: Pearson Education.
- Meeks, T.W. & Jeste, D.V. (2008). Older Individuals. In K.T. Mueser & D.V. Jeste (Eds.) *Clinical handbook of schizophrenia* (pp. 390-397). New York, NY: Guilford Press.
- Moser, D.J. (2006). Determining capacity to consent to research in cognitively impaired individuals. Department of Psychiatry, University of Iowa, Carver College of Medicine

- Bioethics Forum, March 3, 2006. Retrieved from:
<http://research.uiowa.edu/hso/downloads/educational/DMcapacitytoconsent.ppt>
- Mueser, K. T., Valentiner, D. P., & Agresta, J. (1997). Coping with negative symptoms of schizophrenia: Patient and family perspectives. *Schizophrenia Bulletin*, 23(2), 329-339.
- NASW (2008). Code of ethics of the National Association of Social Workers: Ethical principles. Retrieved from: <http://www.socialworkers.org/pubs/code/code.asp>
- NERPP (2012). ICCD Clubhouse Model. Retrieved from:
<http://nrepp.samhsa.gov/ViewIntervention.aspx?id=189> on 4/13/2012
- NERPP² (2012). Critical Time Intervention. Retrieved from:
<http://nrepp.samhsa.gov/ViewIntervention.aspx?id=125>
- NERPP³ (2012) Pathways' Housing First Program. Retrieved from:
<http://nrepp.samhsa.gov/ViewIntervention.aspx?id=155>
- O'Day, B., Killeen, M. B., Sutton, J. & Iezzoni, L. I. (2005). Primary care experiences of people with psychiatric disabilities: barriers to care and potential solutions. *Psychiatric Rehabilitation Journal*, 28(4), 339-345.
- O'Rand, A.M. (2009). Cumulative processes in the life course. In G.H. Elder & J.Z. Giele (Eds.) *The Craft of Life Course Research*. New York, NY: Guilford Press.
- Padgett, D.K. (2007). There's no place like (a) home: Ontological security among persons with serious mental illness in the United States. *Social Science & Medicine*, 64(9), 1925-1936.
- Padgett, D.K. (2008). *Qualitative Methods in Social Work* (2nd Ed.). Thousand Oaks, CA: Sage Publications.

- Padgett, D. K., Hawkins, R. L., Abrams, C. & Davis, A. (2006), In their own words: Trauma and substance abuse in the lives of formerly homeless women with serious mental illness. *American Journal of Orthopsychiatry*, 76(4), 461–467.
doi: 10.1037/1040-3590.76.4.461
- Pandiani, J. A., Boyd, M. M., Banks, S. M., & Johnson, A. T. (2006). Elevated cancer incidence among adults with serious mental illness. *Psychiatric Services*, 57(7), 1032-1034.
- Parks, J., Svendsen, D., Singer, P. & Foti, M. (2006). Morbidity and mortality in people with serious mental illness. National Association of State Mental Health Program Directors (NASMHPD) Medical Directors Council, Alexandria, VA 22314. Available at: http://www.nasmhpd.org/general_files/publications/med_directors_pubs/Mortality%20and%20Morbidity%20Final%20Report%208.18.08.pdf
Accessibility verified April 20, 2012.
- Raffard, S., D'Argembeau, A., Lardi, C., Bayard S., Boulenger, J.P. & Van der Linden, M. (2010). Narrative identity in schizophrenia. *Consciousness and Cognition*, 19(1), 328-340.
- Randall, W.L. (2011). Memory, metaphor and meaning: Reading for wisdom in the stories of our lives. In G.M. Kenyon, E. Bohlmeijer & W.L. Randall (Eds.) *Storying later life: Issues, investigations, and interventions in narrative gerontology* (pp. 18-36). New York, NY: Oxford University Press.
- Randall, W.L., Prior, S.M. & Skarboen, M. (2006). How listeners shape what tellers tell: Patterns of interaction in lifestory interviews and their impact on reminiscence by elderly interviewees. *Journal of Aging Studies*, 20, 381–396.

- Roe D. & Davidson L. (2005) Self and narrative in schizophrenia: Time to author a new story. *Medical Humanities*, 31(2), 89 –94.
- Roe, D., Hasson-Ohayon, I., Kravetz, S., Yanos, P.T. & Lysaker, P.H. (2008). Call it a monster for lack of anything else: Narrative insight in psychosis. *Journal of Nervous and Mental Disease*, 196(12), 859-865.
- Roe, D. & Kravetz, S. (2003) Different ways of being aware of and acknowledging a psychiatric disability: A multifunctional narrative approach to insight into mental disorder. *Journal of Nervous and Mental Disease*, 191(7), 417– 424.
- Riessman, C.K. (2008). *Narrative methods for the human sciences*. Thousand Oaks, CA: Sage Publications.
- Russinova, Z., Wewiorski, N.J., Lyass, A., Rogers, E.S. & Massaro, J.M. (2005). Correlates of vocational recovery for persons with schizophrenia. In L. Davidson, C., Harding & L. Spaniol (Eds.) *Recovery from severe mental illnesses: research evidence and implications for practice* (Vol. I) (pp. 464-478). Boston, MA: Center for Psychiatric Rehabilitation, Boston University.
- Saavedra, J., Cubero, M. & Crawford, P. (2009). Incomprehensibility in the narratives of individuals with a diagnosis of schizophrenia. *Qualitative Health Research*, 19(11), 1548-1558.
- SAMHSA (2012). SAMHSA's definition and guiding principles of recovery. Retrieved from: <http://blog.samhsa.gov/2011/12/22/samhsa's-definition-and-guiding-principles-of-recovery---answering-the-call-for-feedback/>
- Sciolla, A., Patterson, T., Wetherall, J., McAdams, L.A., & Jeste, D.V. (2003). Functioning and well-being of middle-aged and older patients with schizophrenia: Measurement with the

- 36-Item Short-Form (SF-36) Health Survey. *American Journal of Geriatric Psychiatry*, 11(6), 629-637.
- Scott, J. & Alwin, S. (1998). Retrospective versus prospective measurement of life histories in longitudinal research. In J.Z. Giele & G.H. Elder (Eds.) *Methods of life course research: Qualitative and quantitative approaches* (pp. 98-127). Thousand Oaks, CA: Sage Publications.
- Sells, D.J., Stayner, D.A. & Davidson, L. (2004) Recovering the self in schizophrenia: An integrative review of qualitative studies. *Psychiatric Quarterly*, 75(1), 87-97.
doi: 10.1023/B:PSAQ.0000007563.17236.97
- Seng, J. S., Kohn-Wood, L. P., & Odera, L. A. (2005). Exploring racial disparity in posttraumatic stress disorder diagnosis: Implications for care of African American women. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 34(4), 521-530.
- Shad, M.U., Tamminga, C.A., Cullum, M., Haas, G.L., & Keshavan, M.S. (2006). Insight and frontal cortical functioning in schizophrenia: A review. *Schizophrenia Research*, 86(1-3), 54-70.
- Shaw, M. (2004) Housing and public health. *Annual Review of Public Health*, 25, 397-418
doi: 10.1146/annurev.publhealth.25.101802.123036
- Shibusawa, T. & Padgett, D. (2009). The experiences of “aging” among formerly homeless adults with chronic mental illness: A qualitative study. *Journal of Aging Studies*, 23, 188–196.
- Stafford, F.P. (2009). Timeline data collection and analysis: Time diary and event history calendar methods. In Belli, R.F., Stafford, F.P. & Alwin, D.F. (Eds.) *Calendar and time*

- diary methods in life course research* (pp. 13-30). Thousand Oaks, CA: Sage Publications.
- Strauss, J.S. (2000). The interactive developmental model revisited. *Acta Psychiatrica Scandinavica*, 102(suppl. 407), 19-25.
- Strauss, J. S. (2008). Prognosis in schizophrenia and the role of subjectivity. *Schizophrenia Bulletin*, 34(2), 201-203.
- U.S. Department of Health and Human Services (2001). *Mental health: Culture, race and ethnicity--A supplement to mental health: A report of the surgeon general*. Retrieved from: <http://www.surgeongeneral.gov/library/mentalhealth/cre/>
- Wardaugh, J. (1999). The unaccommodated woman: Home, homelessness and identity. *The Sociological Review*, 47(1), 91-109.
- Ware, N.C.; Tugenberg, T. & Dickey, B. (2004). Practitioner Relationships and Quality of Care for Low-Income Persons With Serious Mental Illness. *Psychiatric Services*, 55(5), 555-559.
- Wasson, R. R. & Hill, R. P. (1998), The Process of Becoming Homeless: An Investigation of Female-Headed Families Living in Poverty. *Journal of Consumer Affairs*, 32, 320-341.
doi: 10.1111/j.1745-6606.1998.tb00412.x
- West, J. C., Wilk, J. E., Olsson, M., Rae, D. S., Marcus, S., Narrow, W. E.,... Regier, D.A. (2005). Patterns and quality of treatment for patients with schizophrenia in routine psychiatric practice. *Psychiatric Services*, 56(3), 283-291.
- Wilk, J. E., West, J. C., Narrow, W. E., Rae, D. S., & Regier, D. A. (2005). Access to psychiatrists in the public sector and in managed health plans. *Psychiatric Services*, 56(4), 408-410.

Appendix A: Recruitment Flyer

Have you ever been told you have schizophrenia?
Are you 55 years or older?

Whether or not you agree that the term “schizophrenia” applies to you, chances are that being given that diagnosis at some point has affected your life.

I am a doctoral student at Columbia University. The purpose of my study is to improve understanding of and services for older adults who have been diagnosed with schizophrenia.

The purpose of my study is to improve services for older adults who have been diagnosed with schizophrenia by helping social workers and other professionals to better understand their needs and strengths.

Participants will receive \$25 per interview.
They will be asked to share their life stories.
Interviews will last 30-90 minutes.

Participants Needed for Interviews

If you are interested in participating, please contact: Lydia Ogden
917-656-8764

Appendix B: Demographic form
Demographic Information Collection Form

Gender:

Date of birth:

Place of birth:

Race/ethnicity:

Marital Status:

To the best of your recollection, what is your history of inpatient psychiatric hospitalizations (number, length)?

To the best of your recollection, what other psychiatric or social services have you used?
What are you using now?

Do you have any medical conditions? What are they?

Appendix C: Interview Guide

I would like to begin with a few questions about your day-to-day life now:

PRESENT FOCUSED QUESTIONS:

HOUSING

- Could you tell me a little about your current living situation?

Probe for perceptions about apartment, living companions, neighborhood/community, safety and security. How long have they lived here and where did they live before. How did they get to their present housing.

WORK/ACTIVITY:

- What about your usual activities? What sorts of things do you spend your time doing?

HEALTH:

- As people get older, they often become concerned about their health. Is this a concern for you?

Probe for why or why not this is a concern, how they manage what concerns them in this area, and what they might do to prevent the development of new health concerns.

RELATIONSHIPS—PAST and PRESENT:

- When you think about the important people in your life, who comes to mind first?

Probes might include: Could you tell me a little bit about your relationship with that person? What kinds of things do you do together? How did this person come to be important to you? In what ways would you say that you are able to contribute to this person's well-being?

Do any social workers stand-out as especially helpful or good?

Do any stand out as unhelpful or bad?

What about psychiatrists?

PERSONAL HISTORY FOCUSED QUESTIONS:

ENVIRONMENT:

What about important places in your life?

Probes: Where did you grow up?

What was your neighborhood like at the time?

EDUCATION

What was school like for you?

Probes: Did you enjoy school? How has education influenced your life? Having already asked about level of education, also explore decisions to leave and return/pursue more training.

EVENTS:

Now I am going to ask you to please think back with me for a time in your life, up to the present

moment:

- What would you say has been the best time? Fondest memories?

Probe: What made it special?

- What do you think was the most difficult time in your life?

Probe: What made it especially trying? How did you manage to get through it?

What have your major challenges been?

Probe: Ask for past or present challenges. Also use the word “concerns” or try “hardest times.”

MENTAL ILLNESS PERCEPTION—PAST & PRESENT

Do you recall the first time you were told you have schizophrenia?

What were you told? What was the treatment? How did you feel about it?

Do you believe the term schizophrenia applies to you?

Do you receive any treatment for schizophrenia now? What is it? How do you feel about it?

Overall, consider all the ups and downs in your life up to now, how would you say that the experience of being diagnosed with schizophrenia has affected your life?

In what ways might your life have been different without it?

SURVIVAL/STRENGTHS

What would you tell a young person who has recently been diagnosed with schizophrenia?

Probe: How did you learn this? Is that how you have gotten through hard times?

Many people believe that wisdom comes with age. Do you believe this is true for you? How so?

What should the title of your biography be?

Appendix D: Time Diary Forms

Dec 2011 (Eastern Time)

Sun	Mon	Tue	Wed	Thu	Fri	Sat
27	28	29	30	1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31

Calendar Print Preview

Participant Time Diary

Thu Dec 1, 2011 (Eastern Time)

6a m	
7a m	
8a m	
9a m	
10a m	
11a m	
12 p m	
1 p m	
2 p m	
3 p m	
4 p m	
5 p m	

Print Range:

Thursday, Dec 1, 2011 ▼

Font size:

Normal ▼

Orientation:

Auto ▼

Show events you have declined:

☒

Black and white:

☐

Print

Save As...

Cancel

Appendix E: Life History Calendar

Participant							
		Age 1-12	Age 13-17	Age 18-26	Age 27-35	36-45	46-50
	1942	1942-1954	1955-1959	1960-1968	1969-1977	1978-1987	1988-1992
Daily Life							
Other Events							
Poverty							
Relationships: Family							
Relationships: Social							
Relationships: Provider							
Housing/homelessness							
Education/Work							
Health							
Mental health Treatment							
Religion							

Appendix F: Field Observation Form

Interview location/type of location:

Neighborhood comments:
(accessibility, safety)

Observations on interview space:
Who else is there?

Tidiness/Cleanliness/clutter/organization?

Safety?

What are the hallways like?

What are the floors like?

Is there a kitchen? Does it look used?

Are there any odors?

Are there basic appliances like TV, coffee maker and toaster?

Does it appear that appliances and plumbing in good repair and working?

Is there adequate heat or a/c?

Would this place be accessible if the participant became injured? Could a home health attendant or visiting nurse work here?

Appendix G: Sample Information Table
Page 1

Sample Information					
Participant	Number of interviews	Duration of data collection	Year born	Age at start of study	Gender
Hank	6	10 months-- May 2011- Feb 2012	1950	61	Male
George	6	10 Months-- June 2011- March 2012	1949	70	Male
Harry	6	11 Months-- June 2011- April 2012	1955	56	Male
Evelyn	5	7 Months-- Oct 2011- April 2012	1945	66	Female
Bernard	4	5 Months-- November 2011-April 2012	1938	73	Male
Hope	4	5 Months-- November 2011-April 2012	1942	69	Female
	31	7 3/4 months		65.8	
	= total # of interviews	= average duration		= average age	
	5.1 '= average number of interviews				

Sample Information Table
Page 2

Sample Information					
Participant	Race/Ethnicity	Marital status	Living situation	Housing type	Sample site
Hank	Black, from rural South	Divorced	Roommate; shares responsibilities and meals	"graduate"	The Program
George	Black, Caribbean immigrant	Divorced	Roommate; limited interactions	"psychiatric residence"	The Program
Harry	White, Irish Catholic, from Queens	Single	Roommate; limited interactions	"scatter site"	The Program
Evelyn	White, Italian American, from Queens	Single	Lives alone	The Senior Residence	The Senior Residence
Bernard	Black, from Harlem	Single	Lives alone	The Senior Residence	The Senior Residence
Hope	White, Italian American, from Queens	Divorced	Lives alone	The Senior Residence	The Senior Residence

Sample Information Table
Page 3

Sample Information					
Participant	Current Mental health treatment	History of homelessness	History of Substance Abuse	History of lost contact with family of origin	Current contact with family
Hank	PROS/Medication including an antipsychotic	Yes	Yes	Yes	Yes
George	PROS/Medication including an antipsychotic	Yes	No	Yes	Yes
Harry	PROS/Medication including an antipsychotic	Yes	Yes	Yes	Yes
Evelyn	CLUBHOUSE, Private therapy, 12-step program, Medication including an antipsychotic	No	No	No	Yes
Bernard	CLUBHOUSE/ Medications including an antipsychotic	Yes	Yes	Yes	Yes (but immediate family all deceased)
Hope	CLUBHOUSE/ Medication including an antipsychotic	Yes	No	Yes	Yes

Sample Information Table
Page 4

Sample Information					
Participant	Diabetes/Takes metformin	Other health	Smoke: past or present	History of suicide attempt; number of attempts & method	Current mood stabilizer or antidepressant
Hank	Diabetes	Hypertension	Past	No	Mood stabilizer
George	Metformin	"Smoker's cough" & hypertension	Present	No	Antidepressant
Harry	Metformin	List of other minor conditions: tremors, constipation, insomnia, etc.	Past	Yes; 1; Cutting wrists with broken glass	Antidepressant
Evelyn	Metformin	History of breast cancer; two heart attacks	Past	Yes; 1; pills	Mood stabilizer
Bernard	Diabetes	History of open heart surgery	Past	No	No
Hope	Metformin	"Smoker's cough" & hypertension	Present	Yes; 1; pills	None, but reported recent episode of depression
				=1/2	

2

3

2

3

2

3