

# A Case Study of Informal Learning in the Family associated with Very-Late-Onset of Schizophrenia in Female

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## Abstract

*Family is a place of development and informal lifelong learning also in situations of crises, associated with illness or disability of its members. This study is non-clinical, ethno-educational case study of informal learning in Polish family supporting older female, who at age of 76 was diagnosed as having very-late-onset of schizophrenia.*

*Case study I was based on the research no: 195/FES titled "Traces of disability in Polish culture". The field project lasted 13 months, from the beginning of July 2013 – to the end of July 2014. Studies were based on analyzes of the codes and explanations categories of informal learning through family members while supporting female with very-late-onset schizophrenia. The main research question was: what is informally learned by the family in a situation of schizophrenia in female in late adulthood?*

*In the study there were 4 informers, lonely, divorced woman aged 77-78 and 3 members of her family. Personal data research of participants were coded, ensuring anonymity. The woman received a code Prue Patton and her family name Patton. The case study method I leaned on ethnographic field techniques and data collection as: participant observation, in-depth interviews and visual data designing. The analysis was made using techniques of qualitative data analysis: coding and categorization. The results showed three main codes of informal learning in the family such as learning about the schizophrenia, learning about the communication with Prue and learning about changes of support in the family.*

**Keywords:** Informal learning, family learning, care, support, older adult, female, mental illness, very-late-onset-schizophrenia, qualitative case study, participant observation.

## Introduction

Family and kinship are immanent aspects of human existence. Families are permanent place of learning in cultures around the world. Thanks to the joint being in the family, common experiences, entanglement in everyday

life, consisting of: routines, shared values, rituals etc. Families, however, are sometimes involved in various problems of its members. A special situation is the emergence of the disabilities or illnesses in families. The phases of adaptation to the child's disability in the families were described by Kościelska<sup>17</sup> and Obuchowska<sup>26</sup>. The authors suggested elements such as shock, the personal crisis, mourning, grief, aggression, hostility, depression, apparent acceptance and proper acceptance of the accompanying parents.

Namysłowska<sup>25</sup> explains the reorganization of the family in the case of mental illness. The author writes "on the reorganization of the family as a result of mental illness affects a lot of facts: length of stay in hospital - short hospital stays increase the degree of real burden of the family. The patient returns home, still betraying psychotic symptoms that interfere with the functioning of the family; longer psychiatric hospitalization reduces subjective burden of the family, leads to uptake by other family members roles carried so far by the sick person, the frequency of hospital admissions - one or two hospitalizations do not change the functioning of the family; greater number of hospitalizations change the expectations and cause the loss of hope that sick member will be able to function normally, the greater is the degree of worsening of the patient, the more difficult is the adaptation of the family and less is acceptance of the patient".

This case study is not a clinical study but ethno-educational and qualitative research. The aim was to investigate the field, analyze and understand the codes and categories of informal learning in a family in which a female in 2012, at the age of 76, Prue Patton was diagnosed as having paranoid very-late-onset of schizophrenia. The main research question was: what is informally learned by the family in a situation of schizophrenia in female in late adulthood?

I spent in the Polish cultural scene 13 months, in the period from the beginning of July 2013 to the end of July 2014. I carried out researches in the city of Poznan. Explorations were based on the method and techniques of ethnographic participant observation, in-depth interviews and the collection of visual data.

## Review of Literature

**Informal learning:** According to Livingstone<sup>20</sup>, informal

learning, is understood as any activity serving mastered the knowledge or skill which occurs without previously developed program and in any situation. Pierścieniak<sup>28</sup> believes that learning is a kind of informal, natural form of human activity which appears first and is accompanied by a man during life. In the document, the Memorandum<sup>23</sup> of Lifelong Learning, signed in 2000, in Lisbon, "non-formal education (informal learning) is related to the daily activity of human. This type of learning need not to be intentional or purposeful. May just happen naturally to the human throughout life and often may not be considered by him/her to be educational". This definition indicates connections between everyday informal learning and the duration of a lifetime.

I can conclude that informal learning begins in the family home, however the authors did not mention these places. According to publications of European Centre for Development of Vocational Training (CEDEFOP)<sup>5,6</sup> "informal learning is resulting from daily activities related to work, family or leisure. It is not organized or structured in terms of objectives, time or learning support. Informal learning is in most cases unintentional from the learner's perspective. Informal learning can be validated or certified and also referred as experiential or incidental/random learning".

**Schizophrenia:** "Schizophrenia is seen as a serious, chronic and difficult to treat mental illness and experienced as much disturbing the person, difficult to contact, non-controlling their behavior, often aggressive and unpredictable," as written by Tyszkowska and Jarema<sup>32</sup>.

This disease is seen by Warner<sup>33</sup> as "thinking disorder in which the ability to recognize reality, emotional responses, thinking processes, formulating judgments and communication skills deteriorate so much that the operation of a sick person is seriously hampered. There are frequent symptoms such as hallucinations or delusions". Warner<sup>33</sup> after M. Birchwood and C. Jackson<sup>4</sup> and Alanen<sup>1</sup> called schizophrenia, a serious mental illness whose symptoms usually appear during adolescence or early adulthood. Among the features of the disease the author indicated a partial disorganization of mental function, developmental regression and a tendency to withdraw from contacts in the subjective, internal world of ideas, often hallucinations and delusions.

Wciórka<sup>34</sup> and Stasiuk and Baran<sup>30</sup> indicate a wide range of semantic concepts of schizophrenia. The disease in a view of the authors has varied clinical picture and variable course. Jarema<sup>14</sup>, Wciórka<sup>34</sup>, Chilman and McWilliam<sup>7</sup> indicate that schizophrenia can occur almost throughout the human life cycle. Appearing after 60-65 years of age is called very-late-onset of schizophrenia. Wciórka<sup>34</sup> believes that "the disease is relatively common (risk over the life reaches 1%) in all geographic and cultural regions of the world and the characteristics of the course make a

relatively early onset that patients require long-term and comprehensive treatment, comprehensive support social and disability benefits".

Kepiński<sup>15</sup>, Alanen<sup>1</sup>, Wciórka<sup>34</sup> and Czernikiewicz<sup>11</sup> write about a variety of contexts and manifestation of the disease and ways of schizophrenia. In some cases, the disease starts early and rapidly, in other gradually increases and its symptoms disappear or become chronic to varying degrees. Kepiński<sup>15</sup>, Wciórka<sup>34</sup>, Czernikiewicz<sup>11</sup> point to the multi factorial etiology of the disease which has not been still completely examined in science. According to the authors in the creation of schizophrenia hereditary factors are involved, acquired, depending on the nervous system and other systems of governing and environmental conditions. Czernikiewicz<sup>11</sup> believes that today, in accordance with the definitions shall apply American Psychiatric Association "we say that schizophrenia is a serious disease of the brain, giving periods of remission, allowing patients to return to normal life. We walked away from the stigmatization of patients".

**Very late onset of schizophrenia:** In opinion of Chilman and McWilliam<sup>7</sup>, "Schizophrenia has always posed diagnostic and management problems for clinicians, particularly in elderly patients. Recent research has helped differentiate between different types of late onset schizophrenia and distinguish them from early onset types and other causes of late onset psychosis. Demographic changes, however, have led to increased numbers of ageing late onset schizophrenics (LOS) in the community and resulted in an increase in burden on health and social care resources. Management is complicated by the heterogeneous nature of the illness, co-morbidity, concerns over safety of medication and an increasing prevalence of cognitive impairment".

Arora and Prahara<sup>3</sup> indicate that "the term 'late-onset schizophrenia' (LOS) was first mentioned by Manfred Bleuler in 1943 to describe a group of schizophrenia patients with an onset after 40 years; these late-onset cases constituted 15% of the patients, of whom 4% had an onset after 60". The authors continue that "the consensus of the international late-onset schizophrenia group has suggested two divisions of these patients: 1 late-onset (onset after 40) schizophrenia and very-late-onset (onset after 60) schizophrenia-like psychosis (VLOSLP)". The authors also noticed that "ICD-10 and DSM-IV-TR, the two major diagnostic guidelines, have no codable diagnosis for LOS. Inconsistency in diagnostic systems and nomenclature, coupled with a tendency among researchers to ascribe late-onset psychoses to organic factors, has led to such cases occupying an ambiguous position. This case is intended to draw attention to a case in which the age of onset of schizophrenia was in the late eighties".

Perera and Yogaratnam<sup>27</sup> wrote paper about very-late-onset of schizophrenia (VLOSLP). Authors indicate after

Almeida et al<sup>2</sup> that very late onset schizophrenia-like psychosis has a incidence of 1.5% in all patients diagnosed with schizophrenia.

Chilman and McWilliam<sup>7</sup> indicate characteristic features of very-late onset schizophrenia (VLOSLP) as: "Compared with early- or late-onset schizophrenia, very-late-onset schizophrenia is characterised by associated sensory impairment, social isolation, a greater likelihood of visual hallucinations, lesser likelihood of formal thought disorder, a lesser likelihood of affective blunting, a lesser likelihood of family history of schizophrenia, a greater risk of developing tardive dyskinesia, the significantly higher number of females affected than males".

**Mental Illness in the Family:** Czernikiewicz<sup>11</sup> indicates that the most recent statistics show that on schizophrenia suffer 2% of the population but about half of this person never has been diagnosed. Such disease is usually mild and people living in a tolerant environments can cope". Chrzastowski<sup>10</sup> writes that mental disorders in the perspective of the family have the interpersonal dimension. It follows that schizophrenia affects not only the sick person, but also the wider environment and family environment. Chuchra<sup>9</sup> argues that "the family in terms of the system is a whole and what happens to the individual members thereof, affects also the functioning of the entire system, while functioning of the family as a whole contributes to the development, behavior and health of its members".

De Barbaro and Ostoja-Zawadzka<sup>12</sup> suggest that the family at the onset of mental illness with one of the members is in contact with the following problems to solve as to establish good communication and cooperation, an unfavorable attitude and excessive overprotection, excessive emotional entanglement with relatives or parents, aggression and criticism, in addition to the problem there is also the need of reconstruction of the social network and the support of optimal level of stimulation for a family member with a diagnosis of schizophrenia.

**Clash and Burden of Mental Disease:** Chuchra<sup>8-9</sup> argues that the "clash" with the disease affects in a greater or lesser extent, each member of the family. The author draws attention to the fact that the first reactions close to the appearance of a mentally ill family depends on how she will reveal suddenly or secretly. Chuchra<sup>8-9</sup> writes that in the case of the first relapse family soon realizes that their family member has a mental disorder. The family in this situation is forced to take immediate decisions and actions. However, when schizophrenia develops slowly, it is difficult to immediately notice the symptoms. Disturbing behaviors occur from time to time, by which family members interpret them as such as fatigue, work or study, the occurrence of some somatic disease, "difficult" sometimes caused by various circumstances etc. Sometimes the disturbing symptoms can be perceived the people

around the patient such as a teacher, employer, a neighbor who is objective judge of the disturbed behaviors. It also happens that when mentally ill person visits, a psychiatrist exposes themselves to negative emotions on the part of the patient's relatives with, that is why in most cases it is advisable to visit a psychologist first.

Chuchra<sup>8</sup> noted that in the case when a child is ill, parents feel a deep sense of guilt, which sources are associated with the blame themselves for the lack of the early support while emerging failure symptoms. Besides parents tend to blame themselves for sense of parenting mistakes. The author, however, did not indicate the burden of disease in the case of very late onset of schizophrenia.

Chrzastowski<sup>10</sup> writes about the burdens, as one of the aspects of family relationships in situations of mental illness. Author refers to the parental burden and defines it as "a sense of mental load each of parents associated with contact with their own child. The burden is manifested by the negative feelings that were awakened by the child's behavior (sadness, disappointment, sense of guilt, anger), fear of the emergence of difficulties to tolerate the behavior of a child (for example, outbursts of aggression), conviction of not dealing with them, the need to exercise care, dominate the child's own life problems, lack of support from the social environment and the difficulty in organizing and ensuring the proper care of the child".

Chuchra<sup>9</sup> pointed out another arrangement of sources of burden in mental illness after Lowyck, de Hert, Peters, Gilis<sup>21</sup> and Magliano et al.<sup>22</sup> The authors indicate that family burden are associated with poor social functioning of ill people, long time presence of the disease, the presence of negative symptoms, frequent hospitalizations, intensification and kind of disturbed patient's behavior.

Bogdan de Barbaro and Ostoja-Zawadzka<sup>12</sup> have drawn up a more complete structure of the burden of the family to put the problem in four dimensions. Author mentioned psychotic patient behavior, survival of people associated with the illness of one of the members of the family, the social consequences of the disease and the treatment process itself. Chuchra<sup>8</sup> after Magliano et al<sup>22</sup> indicates the most aggravating hallucinations and delusions, as compared to other psychotic symptoms. Kępiński<sup>15</sup> believes that particularly difficult times for the family members are considered those that involve them in the system of delusions by mentally ill person.

Concluding, I want to note that in the specialized literature, the researchers refer to the parental burden (Chrzastowski<sup>10</sup>, Chuchra<sup>8-9</sup>, de Barbaro and Ostoja-Zawadzka<sup>12</sup>). It is more difficult to find in the specialist literature scholars reference to the burden of the extended family (nephews, nieces) acquiring care and support of patients with very-late-onset schizophrenia.

## Methodology

**Purpose of the Case Study:** The aim of the study was to investigate informal learning in a family in which an elderly woman fell ill with paranoid schizophrenia. Research question was: what is taught informally to family in a situation of mental illness female in late adulthood? Study leaned on the concept of case study Strumińska-Kutra and Kołodkiewicz.<sup>31</sup>

**Sampling:** The sample was chosen purposively, based on relatively good access to the field. In the case study were interviewed 4 persons. Female with very-late-onset of schizophrenia Prue, a divorced and retired cardiac nurse and three members of her family: nephew, niece and her husband. Prue lives for 20 years alone in own flats or home, has no children of their own.

**Prue:** Prue Is Pole, elder female coded as Prue Patton, age 77-78. In 2012, during the first psychiatric hospitalization Prue at age 76, was diagnosed with paranoid schizophrenia. Until the end of July 2014 Prue was hospitalized in psychiatric hospital twice. Last hospitalization lasted six weeks and was held in July-August 2013, against the will of Prue, although according to the law. After leaving the hospital in 2013 to the present, Prue is monitored by psychiatrist and treated pharmacologically.

After hospitalization in the end of August 2013, she received an injection of Rispolept every two weeks and since January 2014 the amount was reduced to receiving one injection every 3 weeks. In opinion of the family members and informers, pharmacological therapy has had positive effects. Turning to the characteristics of a female's life, I want to mention that Prue was happily married for 19 years and since 1984 has been divorced because of her husband's betrayal. Divorce was painfully survived by her because Prue's ex-husband had an love affair with a woman who gave birth to the child of ex-husband. Since that time, for recent 20 years Prue lives alone. She could never have their own children, even though in the 70's of the twentieth century, was treated in Polish infertility clinics.

Prue characterized by members of the family as before the mental illness, was for years a warm, cheerful, overly emotional and extremely hardworking person. She performed for years also all the technical chores at home. Throughout her professional career, she worked as a nurse in various Polish medical facilities, first, in urban hospitals and then health clinics. She achieved cardiac nurse specialization. She was perceived as always caring for healthy food, clean clothes and elegance. Prue did not smoke cigarettes, rarely allowed herself to alcohol. She always emphasized the role of sexuality and sex life. Sometime after the divorce in 1984, Prue had fleeting affairs with 3 men.

Prue, while her professional career and time of work was electrocuted due to defects in specialized equipment, has

not received her due compensation from the state. For many years Prue cultivated a sense of regret to the people and in particular to medical administration. The female from around 2005 swept away many times, on impulse, contacts with the family which then were renewed.

Most likely under the influence of developing the disease twice she sold her own flats since 2007 because of reason of alleged harassment by neighbors and her complaints of feeling robbed by them, poisoned and tossed some unknown clothing or objects by them to Prue's flats.

Prue as a dynamic female in the course of disease but before the second hospitalization in 2013, by herself hired a construction company and built a small but functional single family house (with the garden) with an surface of approximately 70m<sup>2</sup> in Poznań. My meeting with Prue, as a researcher, took place at a time when she was admitted to the psychiatric hospital in Poznan for observation in July 2013. Because, for years I am a friend of the family and well known to Prue too, I had the opportunity to participate at least once a week in Prue's life and achieve comprehensive observations of phenomena, events and relationships, over the 13 months as well as make interviews or informal friendly talks.

## Other participants of the case study

**Niece:** Age 44, married, 3 children, higher level of education, lives in Poznań.

**Nephew:** Age 48, married, 4 children, secondary technical education, lives in the vicinity of Poznań.

**Niece's husband:** Age 47, higher level of education, lives in Poznan.

## Data collection techniques

Studies were based on participant observation for 13 months from the beginning of July 2013 to the end of July 2014. During this time, I collected audio-recordings of rich verbal data. I realized 11 in-depth interviews, lasting from 30-60 'minutes with each of family member and with Prue. Besides I regularly made informal, non recorded talks with the family members FTF or by phone, which were base for rich field notes and diary.

In addition, I collected visual materials - photographs, a total number of 105. I performed the observations and field notes in Prue's home, at least once per week. During 13 months, I conducted notes and regular telephone calls to Prue within a week. Because of ongoing research, I organized even my university didactics in three of the seven days a week to spend 1-2 of the other days for travels and work in the field in Poznań. I had the opportunity to observe the process of informal learning of coping with mental illness in the family as well as participating in the healing process in Prue. I would like to say, that during the observations I appreciated the role of own collected field

notes, after FTF or phone interactions with the family members and with Prue.

### **Ethics of data collection**

A case study and data collection were preceded by obtaining the written consent of Prue and her family members, according to the Rapley<sup>29</sup> and Kubinowski<sup>18</sup>. It was not an easy task, however arduous and possible, in conjunction with prior knowledge of my many years of Prue and her family, before the time of Prue's disease. Prue, accepted such option telling me "so now you all will learn about me". During the implementation of the research report, I assured anonymity of personal data of the female, encoding and changing her name into the English sounding as Prue Patton. Anonymity was also assured to the members of the family Patton. I also encoded and make anonymous the place of the research, which has been encoded as Poznań, a city in Central-West Poland.

### **Data analysis techniques**

Data were analyzed through selective coding and explanatory categorization by the following authors: Gibbs<sup>13</sup>, Konecki<sup>16</sup>, Miles and Huberman<sup>24</sup> and Kubinowski<sup>18</sup>. Miles and Huberman<sup>24</sup> argue that "code" is a "sign, or" label "aimed at assigning units of meaning to descriptive information or inductive data collected during the research. Codes can usually have different size as "segments", "pieces" - words, phrases, sentences or whole paragraphs, associated or not with a particular context. They can take the form of a simple label or a more complex categorization (ex. metaphor).

Konecki<sup>16</sup> identifies two main types of encryption: Encoding factual and theoretical. Encoding factual "means broadcasting labels fragments of empirical material in order to specify the area of the research. It has two main subtypes, namely open, or indication of any data in different ways and that is selective marking only those factors that relate directly to the central category in the research project". In contrast, theoretical encoding "refers to the relationship between the emerging categories, i.e. to generate hypotheses". The second way, which I analyzed the data is explanatory categorization. According to Kubinowski<sup>18</sup>, "categories and subcategories refer to giving the extract data units which in turn are significant segments collected and parsed empirical material". Kubinowski<sup>18</sup> sets out descriptive and explanatory categories, both created by the researcher as well as those posed by the respondents.

### **Triangulation**

In order to enhance the credibility of qualitative research, the process of data collection in the field lasted 13 months and allowed me noticing changes in the informal learning process in the family, in the context of illness of elderly Prue and her recovery. Another way to enhance the credibility of the study was triangulation of data collection techniques. I assured it by using three techniques, direct participant observation with field notes and diary, in-depth

FTF interviews as well as informal phone calls and visual data collection. Moreover, I used triangulation of data sources, gathering them in a group of 4 people: Prue, three members of her family. At the last hospitalization of Prue in July 2013, I also spoke about Prue with two psychiatrists.

### **Results**

Analysis of 11 in-depth interviews, participant observations, field notes, diary and 105 photographs made possible to construct the structure of informal learning in the family of an elderly woman with schizophrenia. After analysis of coding and categorizations I generated the following analytical categories:

**Code 1: Learning about schizophrenia phenomena - explaining category 1.A:** Learning about the themes and contents of delusions.

**explaining category 1.B:** Learning about the effects of delusions.

**explaining category 1.C:** Learning about the phenomena of social contacts of elderly female with schizophrenia depending on contexts.

**Code 2: Learning about communication with Prue - explaining category 2.A:** Learning about the phenomena of communication with Prue while her delusions.

**explaining category 2.B:** Learning about self-reactions in contacts with Prue.

**Code 3: Learning about changes of support in the family -**

**explaining category 3.A:** Decoding needs of Prue as independent person.

**explaining category 3.B:** Learning about monitoring Prue in everyday life.

**Code 1: Learning about schizophrenia phenomena:** One of the most difficult moments for family Patton, was the initial contact with the diagnosis of mental illness and accepting the state of health of Prue. Although the delicate symptoms of the disease appeared earlier in 2007, when Prue was 71 years old and revealed occasionally. Prue blamed visitors in her home for thefts or purposive destructions of property. She also blamed sometimes her neighbors for stealing, drug addiction made to her and poisoning Prue with drugs. Family Patton noticed reported complaints of Prue and her feeling of being oppressed, not treating these comments seriously, perceiving them as false suspicion or minor insults from Prue. Family associated mainly these facts with the age of Prue. During this time, only the Prue's niece tried to persuade her to visit a psychiatrist whose ideas met with explosive aggression from Prue and breaking contacts with the niece and her husband.

Since 2007, Prue as an energetic woman started to think for the first time about changing and selling own apartment, trying to isolate themselves from family as well as from harming her neighbors, by which she allegedly felt robbed. She sold successively two other own apartments and bought herself smaller in other districts of Poznan, for similar reasons - harassment from the neighbors and their alleged thefts. At the same time appeared in Prue at age 77 love-erotic delusions and delusions about her pregnancy.

### Category 1A - Learning about the themes and contents of delusions

**Prue's delusions:** Prue in about 2012 began to reveal the panic at night and acute symptoms of alleged persecution by the suitor, the then Polish Prime Minister. Well she is always nearby health facilities and at times that night went out of own home, drove to the hospital and spent the night there in the waiting room. The hospital was always a safe place for Prue. Prue through the phone of the other niece, went to psychiatric hospital and was diagnosed as having very-late-onset of paranoid schizophrenia.

Contents of Prue's delusions concerned several topics. They were about delusion of romantic love, sexual relationship and the imaginary pregnancy with the Prime Minister of Poland. The other theme of delusions concerned oppressions by the world and stealing and tossing things into her apartment. The third main theme of delusions was medical manipulation with the body of Prue, cutting and transplantation of organs such as the heart, uterus as well as and the impact on Prue "remote laser."

Prue as a professional and experienced cardiac nurse had knowledge of the human anatomy and its physiology so the challenge for the family became a constant conversation with Prue about the lack of the possibility of such events. Prue could not sleep at nights in fears of "mysterious" people of the Prime Minister from the government.

While in the case of delusions concerning pregnancy, Prue acted mostly calm and was in a good and optimistic mood. I noticed that she behaved like a pregnant woman, because bought loose dresses in pastel colors and even went to fellow nurses to listen to the beating heart of an unborn child. Whereas the delusions of oppressions she mainly felt into anger and was frequent heavily energetic, shaking people and demanding with lot of noises to believe her in what "terror" she experiences.

She was able to get out of the house and threaten their neighbors and throw them on the ground own old clothes, allegedly tossed to her home by them. I witnessed a similar incident when I went to visit Prue, I found a top of underwear that brought the last time behind the fence, on the road. I asked Prue why the orange top is on the way – she said that "X neighbors tossed it." Prue before going to the hospital in 2013 visited often shops with technical supplies, bought herself a huge tarp of black film. She

covered the bed on the top before bedtime to decrease the negative impact of "their laser".

Family of Prue Patton, from her second hospitalization decided constant monitoring of the life of Prue. Niece and her husband and nephew from this time are in constant telephone conversations and visits at Prue's home. Prue regularly is supported financially by her nephew who is doing her larger purchases once for about three weeks. They are providing ready dinners that Prue can reheat, cleaning products and dog food.

Rebuilding a relationship with a niece and Prue took place during visits to the hospital, in which she visited Prue for 2 times or at least 1 time per week. In addition, niece while visiting Prue makes her small purchases too. While bathing, Prue is not fettered by her own naked body and manifests nudity without embarrassment before niece. I think she's looking at own body through the prism of anatomy, medicine and habitus of the nurse. It does not seem that she wanted to shock the family members. Prue cannot put up only with wrinkles on the face. She was always a woman very elegant, neat and attractive, concerned with men attention.

A good way to support Prue, the family divided responsibilities among several family members. Prue is aware that although there are no children of her own nor her husband, she can count on the support of family of at least three people I interviewed.

Methods of communication in the family with Prue manifested delusions, were shortly after hospitalization of two kinds. I noticed that Prue as mental ill person is respected by the family as the human being with living problems. However communication spread over spectrum continuum from initial radical but calm denial of the presence of her imaginary worlds and stories as pregnancy and defrauding by family or neighbors via moderate listening with understanding to the treatment Prue's delusions with delicate sense of humor. Needless to say that delusional content were sometimes such a structure, it was difficult to keep a straight and calm face by the family members, what they reported.

Around January 2014, when the injection dose was reduced, Prue, said on a telephone, that last night "they" made her heart transplant from a pig. The reactions of the family were different from embarrassment and denial, forcing Prue to even greater emotional persuasion to accepting the fact and humorous response. Prue's nephew, a wealthy man 47 years old, with big sense of humor and the confidence of Prue, said by telephone after the sudden news of Prue: "What ? - Auntie you have transplanted pig heart? - Well I just wonder what is the oink sound on the phone?" This statement provoked laughter at Prue on the phone for a while and a short temporary return of critical thinking. It took, however, only a while.

In contrast, Prue's niece agreed with Prue consensus relies on the fact that "every human can have his/her own truth" and therefore Prue can believe that the events about which she says really happened, while the niece does not need to believe in them. Prue accepted such a solution, however, did not feel comfortable with it. Niece every time tried to appeal to the rational basis of discussed phenomena. A means of ensuring communication and conversation about the delusions, Prue was asked to appeal to the own profession as nurse.

**Niece:** "Auntie you know anatomy of the human and the nursing" - said during one of our conversations - "This is absurdity such transplant having at home out of hospital". Prue replied from professional position: "And you never know, how medicine has advanced?!" This fast response somewhat surprised niece. Prue is mainly not aggressive physically to people as well as is not an aggressive person towards members of her family, with one exception - an episode of anger, aggression to her niece, when she approximately tried to persuade her to see a psychiatrist. I also noticed that Prue prefers contacts with the men than women supporters. So she prefers to speak with nephew and the husband of niece, than niece.

#### Category 1B - Learning about the effects of delusions

**A home is Prue's castle:** Prue delusions associated with the oppressions coming from the external world, tended to buy Prue additional supplies and establish more and more security at her home. Each cabinet has a lock and even is still locked with a padlock and chain. The gate of the fence is always closed on the lock and a padlock with chain. The fence also has barbed wire.

Before and after leaving the hospital Prue always took care to all locks and padlocks were closed, sometimes spent 15 minutes at the door before she found the right key in a bundle of them. Prue has two large bunches of keys and without markings, can find the right key to the right lock. None of the family members ever questioned the number of keys. Study participants treated them as collateral for a good well-being of Prue. From approximately March 2014 Prue at all times having proper pharmacological treatment and injections of Rispolept, started to show impatience that everything is closed at home key or padlock. I witnessed how she with impatience struggled with new locks and padlocks which she closed before 1/2 hour.

After some time, about half of April 2014, when I came to her, the closets at home and garden arbor were unlocked. In addition, Prue advised me only to impose a chain on the gate, without closing. Two rooms and the bathroom also were open, which in my mind was a symbol of some well-conducted pharmacological therapy and family support. I had the impression that these factors improved well-being of Prue and her sense of security.

Below are three photos made by me - with artifacts as

symbolic image of the need for security by Prue short before diagnosis, while mental illness and during recovery. These are artifacts associated with the effects of delusion.

**Photo 1: The Locks on the Doors to the Garden Arbor next to Home**



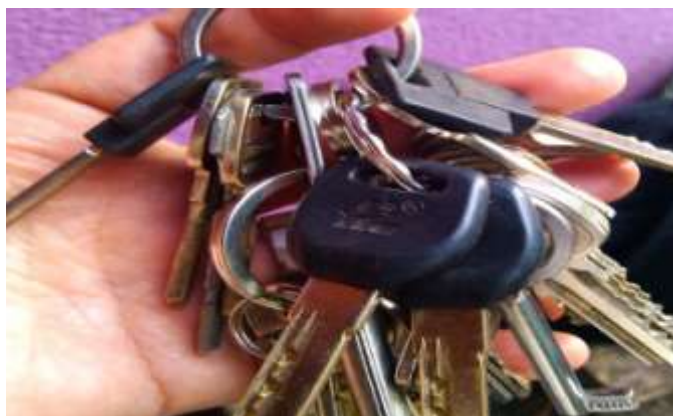
Source: Photo by Beata Borowska-Beszta

**Photo 2: The Padlock with a Chain on the Doors to the Closet in the Little Living Room**



Source: Photo by Beata Borowska-Beszta

**Photo 3: The Keys used at Home and Garden Arbor. Bunch One.** Source: Photo by Beata Borowska-Beszta



### **Category 1C - Learning about the phenomena of social contacts of older female with schizophrenia depending on contexts**

**Prue in the hospital:** In July 2013 Prue was admitted for six weeks, against her will but according to the law, to psychiatric hospital in Poznan. She was dissatisfied with such oppression in her opinion and manifested openly during visits by her niece and me that her human rights were violated and she will write about it to Commission of Human Rights in Strassbourg. However it was surprising for members of the family that Prue, who lived alone for 20 years, quickly adopted rules of hospital ward. Easy and quickly she accepted the routine of the hospital which possibly reminded her working hours in other Polish hospitals. During my visits she was cheerful, talking to other women on the psychiatric ward and also telling me about the difficult cases: either female who jumped out of the window or another slitting wrists. One of the leading male psychiatrist gave her even the nickname Prue "Our Sunshine." Prue aroused the sympathy of doctors.

The surprise for the family was a good mood of Prue, her well-being on the ward, in spite of involuntary treatment. It may be possible that contacts of Prue with seriously ill females caused her recall of the "nursing habits" on the hospital ward. Prue in the hospital felt comfortable but she missed her autonomy and spoke lot of her home and garden. After 5 weeks of stay, Prue persuaded doctors to this that she must collect cherries in the garden. Finally she got a pass to the house for entire day.

Being on psychiatric ward Prue took part in psychotherapy but did not want to participate in occupational therapy, despite the fact that she is manually skilled and likes implied homework or crafts. Cheerful and smiling Prue received a pass for a few hours and was taken home by niece and me around 1PM to 8 PM. The surprise for me and niece was a complete change of her cheerful behavior, after getting to the house. She felt calm and silent and began to do all the steps in silence mechanically associated with plucking their course and making preserves and accompanied me and niece.

All conversation were initiated by me or niece. All conversation had to be encouraged and supported by us. Before 8pm without objection, she went with us back to the psychiatric ward. I had the impression that Prue knew exactly how to take the role of "a recovering patient" on the ward, how to talk to doctors and how to convince them to go on pass for home. It was also possible that her behavior changed, because of injection she had about noon at ward. Prue was for many years before the disease and is still now highly independent person and every visit with her need to be first announced by the phone in order to not to ruin her personal plans, as she used to say. The second pass from psychiatric ward held on 1. August 2013.

**Field note - 01/08/2013:** "We went home. On the way Prue

bought cleaners, liquid for washing greasy things, a few wipes, etc. When we entered, Prue again fell silent as if she moved to a different "mode" of acting. She had changed and began opening sequence of locks, padlocks and chains in closets in the rooms and kitchen cabinets. Prue takes a lot of time to find the right key in two bunches of keys. But after a while she is error-free. I put water on the stove to heat. I decided to clean up the bathroom and do laundry. Prue was busy doing something in the garden. Niece cleaned living room. Prue took a hose and began to water the garden, washing the dog, took it slow and long. Prue moved slowly and almost mechanically. Her face looked slightly worried and somehow expressionless. I had always initiated the talk. She paused busy work, established a dialogue with me. About 4:00pm I asked if she was hungry, she answered, she was not. Upon arrival to the house we gave Prue roll and two natural yoghurt. She ate. Approximately it 5:30pm I heated up ready-made meatballs and we all ate them on the yard. I said that I admire Prue that she combats with the garden, cherries, earth and mud after rain".

I suggested her that rubber boots she should took off before entering the house and put on the house slippers, because of the damage a beautiful floor. I did not even think that she will listens to, but she surprised me, because while going to the house took off waders and put flip flops. Prue not changing any muscle of her calm face said today, she was calm, without yelling at the neighbors.

This day niece and I noticed that Prue still felt oppressed by her delusions of "dangerous them".

### **Code 2 - Learning about communication with Prue**

Family members, research participants, agree that Prue disease caused the need to modify their way of communicating with Prue. Nephew can naturally pass on communication style saturated with humor, like the husband of Prue's niece. Niece was characterized by calm, serious but friendly communication style. I noticed that the more successful the communication refers nephew, who often uses to communicate with Prue, a sense of humor. It happens that Prue smiles shortly too. The members of the family agree that Prue wants to be listened too. Her speaking style FTF or on the phone also evolved into the calmer at this moment by the end of July 2014.

### **Category 2A - Learning about the phenomena of communication with Prue while her delusions**

Nephew, featuring a natural sense of humor, takes the content of delusional Prue as harmless eccentricities. It bothers him only when strongly "screwed" some imaginary situation Prue tries to pour his torrent of words by phone or at immediate meeting. Nephew excluded himself from listening off or made clear: "Auntie, we are close to the psychiatric hospital, I can immediately turn the car". After stroke of delusional contents such response of the nephew resulted in calming down of Prue. Nephew relationships



with the delusional contents does not make him terrifying vision of disease but mostly humorous retorts. Often silently nods absurdity for achieving peace, he was able, however, to deal with the determination of the boundaries listening complaints of Prue on the telephone and severe her aggression against delusional pursuers, to put aside the enabled phone because he was not able to "break" the spewed by Prue issues.

Prue after several minutes of laud and expressive talking waited for the conclusions of nephew who raised finally the phone and ended the conversation constructively. Niece presents a different style of speaking FTF or on the phone with Prue. Initially Prue flooded niece with lot of delusional content expected nod. Niece pointed out calmly the absurdities in the way of Prue thinking. In the situation when it came to delusion theme as being pregnancy by Prue - niece said: "Auntie is a nurse, after all - pregnancy at the age of 77? - The menopause starts around 50 years of age". Prue replied that "medicine went ahead and it is possible."

I watched her in 2013 frequent insulting herself by Prue and sudden ending by her calls, when she heard that the niece does not believe in facts about which Prue speaks. A breakthrough happened in the display by niece limits of their own sentences. Prue convinced that everyone has a right to their own opinions and to believe in it what he/she wants. Thus, Prue has own truth as well as niece. Since January 2014, talks initiated or participated by Prue with niece FTF or telephone are calmer with very little appearance of delusional content in their common dialogues.

### **Category 2B - Learning about self-reactions in contacts with Prue**

Below is a fragment of the niece interpretation of one of phone call with Prue after she went home from the psychiatric hospital on September 28 2013: "In the morning at 10:22 AM she called and almost screaming declared that once brought a cute plaid from Germany and now someone in her home, is laundering it wrong and it is rough and tough. I said that when I was cleaning with her, there was no nice and soft blanket but same old and scratchy blankets. She did not find out, just screamed allegedly, that nice and soft blanket was destroyed by someone who has a key to her home. These persons still destroy her stuff in Prue's opinion. Many of her clothes in her opinions were wrongly laundered. She claimed that he knows how to wash.

I remembered that my aunt was in Germany in the 80's, when I was in school. These time in 80's Prue bought a cute plaid which now has about 30 years. Although my aunt took care of their stuff, blanket just got old naturally. I listened and listened to her loud arguments, until finally I said - "Aunt, no one does not break to your home. Your eyesight deteriorated greatly and imagination creates such

reality". - "If this is my imagination - it's goodbye!" - Prue said, clearly offended. Quickly hung up the phone." Niece explained to Prue logically why the blanket, which was cute and fluffy is now rough.

However Prue has not accepted the argument and in opinion of niece, was angry and annoyed. Niece mentioned that during telephone conversations with Prue, tried to be calm and not raise voice, even when Prue's narrative is close to scream. Niece reacts differently than nephew who deposits the phone aside on the table. The niece is trying to change the attention and way of Prue's thinking. In situations stimulated by Prue, such action succeeded very rare, but is possible. Both nephew and his sister – niece and her husband, were overloaded by delusional contents during Prue's recovery.

Delusions were expressed FTF or by the phone calls. In the opinion of the nephew, niece and her husband these were difficult and aggravating moments. The idea was to withstand tensions during communication and the same time to manifest the respect and acceptance to the ill family member. This is also difficult to cope with delusions because as I noticed, that many of delusional contents of Prue were related to her incorrect, visual recognition and interpretation of phenomena and staff in her everyday reality. Concluding I would like to say, that these three, indicated members of the family, participants of the research, felt common responsibility for elder Prue. They perceive the mental illness in Prue rather as family situation, demand of life, but not as a fate.

### **Code 3 - Learning about changes of support in the family**

Family Patton, learned to flexibly adopt further changes in the support associated with the process of Prue's healing. These changes required vigilance and segregation of duties and non-invasive support given the support of high need for self-autonomy in Prue. Changes in the support tended to decrease gradually intensified monitoring which is observable from about April 2014. Currently, support is given for the following areas: finances, shopping, cleaning, laundry and occasional current and urgent intervention for Prue's requests. In addition, emotional support is provided by FTF and telephone conversations. Prue also visits her niece in her home, meets one single, female neighbor, visits church.

### **Category 3A - Decoding needs of Prue as independent person**

Back from the hospital occurred in late August 2013. Prue initially manifested general aversion to what has happened about the way of her forced hospitalization but she had a feeling that after talks with her figured persons that her further "treatment is necessary." Prue had to take injections, reimbursed by the National Health Fund. The price of one injection without a refund is equal to about half the pension Prue as retired nurse. Niece repeatedly talked about the

need for treatment of Prue. She watched that Prue after the hospital has become more prone to accept the words and suggestions of the family. Prue knew the treatment important and necessary.

However, initial dose every 2 weeks of Rispolept injections, slowed down and immobilized Prue's activity. Prue has seen it herself who felt helpless and weak, niece and me as well noticed the situation. Most irritating for Prue was concept that she has so much to do in the garden and nothing can do, feeling so weak. Prue asked psychiatrist for a reduction in dose which her doctor considered positively. She takes currently injections regularly to the present. Paradoxically, some encouragement was in a price of injection, when Prue noticed that finally she receives something from the state, which has deprived her of compensation for an accident at work. One injection after refund costs about 0,94 EUR and no refund is the half of monthly paid retirement pensions of Prue.

Prue performs simple daily chores - during the winter burning in the fireplace, washing the dishes, sweeping the floor. After all, is not able to cope with all items at home. She takes care of personal hygiene and washing, what supports her niece. She knows that while visiting the doctor, while shopping, in the church she must be neatly and cleanly dressed and she is doing it. Since about April 2014 members of family noticed significant reduction of delusional content while communication with Prue. She stopped to share the delusions of love, sexual relations with the head of the Polish government. She rare mentioned the alleged pregnancy.

Prue requires financial assistance, because during the pre-hospitalization received a loan from the bank to build a house that she pays back and the rate is half her monthly pension. After talking with the family, Prue knows not to take any other bank credit without consultation. After own observations and talking with the doctors family members we know that Prue "works" two ways and on two levels. One is everyday goal and the task she performs with needed autonomy. The second track was her delusions. Multiple delusions at the moment appear to be relatively rare.

### **Category 3B - Monitoring Prue in everyday life**

Family monitoring of Prue includes two types of activities: visits and telephone calls. Visits are often initiated by Prue who reports such as the need to buy dog food or some food for her. The division of responsibilities in the family takes into account the financial possibilities of its members. Nephew as the wealthy person, entrepreneur - took over the implementation of major purchases for Prue in supermarkets. Niece and her husband carry smaller purchases and ongoing help in the household in terms of home duties, help in the garden. Prue at the same time, while reduced her dose injection of Rispolept as 1 for every

3 weeks also performs household chores and heats the food for herself.

The family support needs some more deeper than dialogue basis. Some surprise experienced niece, who went with a visit to Prue and she heard that Prue got the trolley after shopping and bought for about 24 EUR. Expecting a full refrigerator, niece thought that Prue bought foods. Shortly before leaving her house, however, looked inside and saw empty fridge. Prue bought for 24 EUR technical materials and paints to paint the house. After talking with niece, Prue promised that she will be buying the food in the first place. This story, in relation of niece gave her a new image of recovery of Prue and the need to monitor deeper her spoken assurance and contents. Prue is eloquent in the opinion of niece, this can make mistakes. Prue as an independent person likes to have a purpose in life. Such current goal is to take care of the garden, the dog, participate in church activities, small home repairs and improvements.

### **Discussion**

From the point of view of family support, Prue is not overly burdensome, since the setting of appropriate pharmacological treatment by doctors. Prue until now accepts Rispolept. Prue has become a more contact, even joyful. Rarely speaks delusional contents. In mid-July 2014 Prue re-engaged herself in activities in the church and these meetings are enjoying her very much.

Since the beginning of January 2014, I observed slow improvement of the functioning of the Prue. Prue knows that she is supported by the family and can count on financial support, help with homework and conversation. I think it gives her a sense of stability, even though the loans are paid off to the bank. Comparing the situation with before the second hospitalization, Prue showed a significant improvement in the return to activity. Family: nephew, niece and her husband survived the surprise at the time of diagnosis for Prue in 2012 and 2013, but I have the impression that they are not burdened with guilt, as indicated in the specialist literature when parents become parents of mentally ill child. One unusual emotional "color" has been also given to the family coping with the unusual content of delusions as pregnancy with the head of the Polish government which was in the family commented humorously as: "Aunt already could not have chosen better".

Looking at the relationships in the family Patton, nephew and niece with her husband feel an inner need associated with loyalty to family and care about Prue and are however, aware that Prue always was a dynamic and independent personality. That is until today. They do not dazzle excessive care, however, regularly support Prue. At the moment - at the end of July 2014, Prue's health condition is relatively stable, but the family does not exclude various contingencies in the health and lives at a slight uncertainty. It is not too uncomfortable condition but rather indicating

awareness, concerning the variability of family knowledge and experiences of mental illness. At the moment, Prue conducts independent activity, is pleased with the work in the home, garden, church activities, visits and phone calls.

## Conclusion

Responding to what the main research question of what learned Patton family at the time of diagnosis of very-late-onset of paranoid schizophrenia in Prue, the family learned to accept the diagnose, cope with emerging delusions of Prue and react to them in various ways. In addition, family learned to communicate with Prue. Family members seem to share the view expressed by Tyszkowska and Jarema<sup>32</sup> that "the patient achieved remission, recovery in schizophrenia does not mean the end of the action - is a continuing struggle to maintain adequate health and its quality." However I never heard from the family rhetoric containing the words associated with: "war", "fighting schizophrenia" or "battle" with disease.

During Prue's recovery family members did not use any support groups or training. They did not try or tried to deny ever Prue's disease, nor disclose guilt in relation to mental illness of elderly family member. They were surprised with the diagnosis of very-late-onset of schizophrenia. They did not show during data collection excessive anxiety, or grief but only impatience, aroused when Prue tried earnestly to convince family to accept her views and truth of her delusions.

Some surprise and sensation in the family caused same delusions and their content. Especially unusual were for them erotic-love and pregnancy delusions in female of 77-78 years old as well as subject of her delusions the head of the Polish government. Family after the second hospitalization of Prue in 2013, decided continuously monitor a living alone Prue and support her. Members of the family are together in constant contact and at times they had communicated by telephone dispositions of what is going on with Prue. Proceedings of the family are characterized by a certain restraint. The family knows that as family cannot impose to Prue because she likes the independence and must always have appointment before the visit.

Family Patton was not overly preoccupied or emotionally entangled with mental illness of Prue, treating her mental state as simply a disease with such a course and such particular however unusual symptoms. Prue goes out as an autonomous person, which is associated with the appropriate pharmacological support and family support. That, what puzzled me most during this research is also pattern of communication with Prue which family had to learn. I noticed that in this case study, cheerful communication, based on humor unloaded tension proved to be better than the rejections of Prue's delusional "facts", tranquil translation or noncompliance with Prue's options. I have the impression that the burden of the family is not

something very burdensome for the family Patton because Prue was also not many times hospitalized, her delusions were almost extinguished and same Prue is now communicative in conversations, not retreating from contacts.

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