# Gayle's autoethnography and academic achievements despite having a schizoaffective disorder

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**Abstract**

*The focus of this paper is to inspire mature-age students with a mental illness to return to higher education study. Being involved in education can give them an academic purpose, boost self-esteem and contribute to a fulfilling lifestyle. The attainment of a university degree can lead to increased wellness. I intend to outline my story as an example of what can be achieved. The methodology I have utilized in this paper is autoethnography. This approach connects the personal to the culture. It is usually written in the first person where the "subject" is the researcher. Readers are asked to "relive" emotional happenings by referring to intimate narratives and journal entries of the author. A schizoaffective disorder or psychosis is the mental illness I have been diagnosed with which will be highlighted in my research. It includes the concurrent symptomology of schizophrenia and a bipolar disorder. Detrimental life experiences are recognized to accompany this severe psychiatric disability. Therefore, a protective medical plan is necessary to reduce the risk of future total relapses. This regime includes psychotropic medications, psychotherapy, hospitalizations in times of crises and electroconvulsive therapy (ECT). Of significance here is the importance of my story of educational success.*

## Introduction

The key purpose of this research paper is to inspire other mature-age students who have a psychiatric disability to return to study in a tertiary setting. However, it is realized that not everyone would be eligible to enter a university environment. As an orientation to the topic I will include an abstract of my life history. This will give you some insight into who I am and the difficulties I have encountered to date.

## Gayle's life history

I am now a 65 year old Disability Support Pensioner with two children and three grandchildren. Psychological and physical abuse as a child by my mother was a feature in my upbringing. Both personal development and my schooling were restricted. I was taken out of a selective high school at fourteen years of age and sent to Secretarial College. When I decided to go to university, I had to go back to Technical College in 1975 to complete a mature-age Higher School Certificate. I have spent the rest of my life compensating for these factors with devastating results. A schizoaffective disorder was the outcome of existing with these debilitating circumstances.

When a mature-age student with such a mental illness as I have is aspiring to return academically, there is the possibility of having a more fulfilling lifestyle where resilience to adversity can be developed. It is uplifting and rewarding to complete a degree with all the excitement that this entails. Acquiring letters after your name can overcome some of the stigma associated with having such a severe condition.

Rehabilitation techniques in adults with a mental illness illustrate that they have a "realistic chance of re-entering their communities and re-establishing meaningful and productive lives" (Mowbray 2000:1355). Hence rehabilitation practitioners have been able to recognize that "helping individuals restart their post-secondary educational pursuits which is a desirable, valid and viable option". Therefore, "supported education programs contribute to positive outcomes such as graduation, acquisition of marketable skills, employment and positive self-esteem" (Mowbray 2000:1355). Strategies are illustrated in this paper as how to cope with this experience.

Being in touch with the Disability Support Office at your university is a helpful beginning for consideration concerning your specific disability. Keeping contact with your

supervisors, family, friends, practitioners and rehabilitation staff are all support networks, which are necessary to study successfully in higher education.

In my thesis I will encompass the autoethnographic genre for collecting and analyzing personal narratives and journal entries together with my B.Teach. (Primary) degree. I eventually graduated from The University of New England (UNE) Armidale, NSW in 2006. The following research questions will guide my research and data collection.

## Research Questions

1. What is my experience of living with a schizoaffective disorder?
2. What is the role of learning in my life?
3. How have my educational pursuits contributed to my resilience with living a day-to-day existence and achieving considerable academic success at university?

I will analyze personal narratives and journal entries for meaning and emerging themes using the Leximancer analytic software that is available at my university. Kivunja, (2007:1) describes below, "What is Leximancer?"

> Leximancer is text analytic software that can be used to analyze the content of large volumes of qualitative textual documents, extract information at super-electronic speed and display the results visually in a bird's eye view of the content. The results of the analysis are displayed by means of a concept map which summarizes the key themes, the concepts in each theme as well as the absolute and relative frequencies of the concepts.

In a comparative study, Crowsey, Ramsted, Gutierrez, Paladino and White (2007:1) explored qualitative software suitable for analysing unstructured text files. The five software suites these authors reviewed were Leximancer, SAS Enterprise Miner, several products from SPSS, Polyanalyst and Clarabridge. Pricing, learnibility, data presentation, software pluses and minuses and results were all considered.

The reasons for selecting Leximancer were –

1. Pricing, with Leximancer the most cost-effective text mining software at the present time.
2. A demo version, tutorials, user's manual, sample solutions and on-line help were all available components of Leximancer.
3. Leximancer focuses on extracting concepts along with relationship strengths.
4. Leximancer provides several help topics describing how to accomplish certain text mining functions within its architecture. (Crowsey et al 2007).

## Identification Of The Research Problems

### *What is the usefulness and significance of this research?*

There is a need to create awareness of psychiatric disabilities in the community where normality predominates (McKay 2000). When placed in such restrictive environments as in psychiatric hospitals, patients deserve dignity and understanding so they feel comfortable with their treatment regimes. What are useful here are the rehabilitation efforts such institutions put into place while patients are being prepared for recovery and discharge back into their communities. If such measures as the correct psychotropic medications, visits to psychiatric consultants, and integration into the circles of family and friends, this may eventuate in the possibility of pursuing an academic career path.

The significance of utilizing an autoethnographic method is that the researcher is the "subject". Personal and cultural implications include both aspects of adjusting to the

outside world and studying at university. This is complicated by having such a significant mental illness which, in some cases, has lifelong implications.

When looking to the population of individuals with a mental illness and their needs, entry qualifications to university may be relaxed. If this happened, such a population could compete favourably for the restricted opportunities there sometimes are in university placements. Perhaps some form of eligibility examination could be developed. This idea may cover personal, financial, rehabilitation aspects and academic possibilities. Again a supported educational program may allow such individuals to experience open days and preliminary higher education attendance for a few months to acclimatize potential mature-age students with a mental illness. These measures could be exercised for both aspiring and previously experienced students to become familiar with university life. If these concerns could be followed through, such tertiary institutions may attract a new generation of students.

What follows is a review of the literature. First of all, what is it like having a schizoaffective disorder? A definition and treatment regimes are outlined. Then quality of life in families living with an individual with a mental illness is revealed. As an attempt to relate Higher Education to the topic, several categories to be discussed are mature-age students, students with a disability and students with a psychiatric condition. These categories of reference illuminate the difficult journey individuals have to negotiate in their eventual attainment of a university qualification.

## Review of the Literature

### *Schizoaffective disorder –Definition*

A schizoaffective disorder is characterized by a combination concurrently of symptoms of psychotic proportions. These include thought disorders, hallucinations, delusions and paranoid expressions (schizophrenia component). Then there are indications of a mood disorder with swings between mania and depression (bipolar component) (Marneros & Tsuang 1986: Murray 2006).

A schizoaffective disorder is a “perplexing mental illness which is becoming increasingly common in clinical practice” (Murray 2006:109). The symptoms are “highly frustrating, unbearable and dehumanizing with the disability being a potentially crippling illness” (Murray 2006:160). Commencement dates can occur in the late teenage years or as a young adult. One is described as being doubly mad and doubly crazy. When living with this condition, the patients are out of touch with reality on a regular basis. This perplexes the resultant confusion imposed on the individual, family members, friends and practitioners in the wider community. Personal life, work and study commitments are all disrupted as a result of having this psychiatric disability. Next we look at the treatment options inherent in a schizoaffective disorder.

### *Treatment options*

In the management of this disorder, traditionally there are four categories for these psychotic problems. They are psychotropic medications, psychotherapy, hospitalizations in times of crises and electroconvulsive therapy (ECT). These will be discussed in turn below.

The first is psychotropic drugs to treat the illness of severe psychotic patients. Atypical antipsychotic agents are one of the newer medications of choice. An example is Risperdal. The older antipsychotic medications were not as effective in controlling the symptoms of hallucinations, delusions and paranoid manifestations inherent in the schizophrenia component. Lamictal has mood stabilizing effects and has important neuroprotective mechanisms in the brain. This medication is mainly given to treat the mood swings in a schizoaffective disorder. Pristiq is an antidepressant which is given for the depressive cycle that is encountered in this illness.

The first psychotherapy used is “Psychoanalysis” (PA). The second method is “Cognitive Behavioral Therapy” (CBT). Psychoanalysis is “usually developed and refined through clinical observations” (Mace & Marginson 1997:11). Psychiatrists and Clinical Psychologists still adhere to this approach where personal and intimate recollections are discussed. Then reference to the patient’s childhood is brought to the fore. There is the possibility “they may be psychiatrically ill because of a weak reality base” (Winnicott 1971:66). This means that such an individual cannot distinguish between “real” and “unreal” happenings in the outside world.

The second strategy to tackle the symptomology inherent in mental illness is CBT. In psychotic states, people vary in the severity of their symptoms. Both methods involve “talking therapies” but CBT considers behaviour in the here and now to be most important. It emphasises positive reinforcement at following and implementing healthy behaviour.

When discussing the above two psychotherapies, each has its own benefits when treating patients. Currently, psychiatric practitioners use an “integration approach which is likely to be more beneficial when personal analysis is the required outcome” (Mace & Marginson 1997:95). Some patients respond more favourably to one option over the other but these therapies can complement each other as personalities differ and individuals’ behaviour determines the recovery outcome.

Hospitalization is an option when the patient is really sick and can be admitted to a public psychiatric hospital or a private clinic. ECT is a psychiatric procedure which decreases changes in mood and psychotic symptoms. Electrodes are placed on the front of the brain to induce a cerebral seizure, which lasts only for a few seconds. This procedure happens when the patient is unconscious. Once conscious again, there is confusion, sleepiness and cognitive impairment. It takes sometimes three hours to recover enough to be allowed home. Some memory loss is experienced for several days. This is why ECT is a final treatment consideration when all else fails. However, “it is limited by prejudice, fear, ignorance and legislation” (Ottossom & Fink 2004:60).

In the present time, ECT is delivered humanely and sensitively by psychiatrists and anesthetists in an ECT suite in a hospital setting. For my distressing symptoms a fortnightly maintenance ECT regime is the choice or weekly in times of total unwellness. This pattern has negated my hospitalization for a total relapse for some 3 years now.

In the literature, there are many authors who view the diagnosis of a schizoaffective disorder as invalid. These researchers describe it as a psychotic mood disorder (Lake & Hurwitz 2006; 2007; Maier 2007; Mario 2000; Metizer 1984). This is because a psychosis can be evident in both schizophrenia and a bipolar disorder. When these symptoms are concurrently displayed, one way of describing this illness is a separate diagnostic category because of its special symptoms of psychotic proportions. Schizophrenia always has hallucinations and delusions but bipolar disorder can be free of them with only a mood disorder being present in most cases. Because in my instance of being diagnosed with a schizoaffective disorder, I believe in the original classification by Kasanin, which was discovered in 1933. This author called the illness an “acute schizoaffective psychosis”. In some instances this psychosis was displayed by a very sudden onset in a setting of marked emotional turmoil in the outside world (Kasanin 1933).

There are quality of life considerations for families coping with an individual who has a mental illness. In the next section, relevant definitions are explained. Then there is a summary of strategies to bear in mind when faced with these problems.

## *Quality of life for families with mental illness*

The concept of “Quality of Life” (QoL) presumes a “holistic perspective that focuses on the totality of a client’s existence” (Ritsner & Kurs 2006 in Murray 2006:69). The QOL concept has “many definitions varying in the degree of emphasis on subjective and objective aspects of quality” (Ritsner & Kurs 2006 in Murray 2006:69). Maslow, (1943) outlines five needs organized hierarchically; “physiological needs; belongingness and

love needs; esteem needs and needs for self-actualization" (Maslow 1943 in Murray 2006:70).

The concept of "Health Related Quality of Life' (HRQL) is an "important outcome measure in the treatment of severe mental disorders" (Ritsner & Kurs 2006 in Murray 2006:70). HRQL refers to "the physical, psychological and social domains of health seen as distinct areas that are influenced by a person's experiences, beliefs, expectations and perceptions" (Ritsner & Kurs, 2006 in Murray, 2006, p. 70-71). This is an "important outcome measure in the treatment of severe mental disorders" (Ritsner & Kurs 2006 in Murray 2006:70).

Illness in the family, especially mental illness, has an effect on the whole group. If the mother is mentally ill, a child in such circumstances retreats from reality and enters his/her world. Ensuing psychopathology can occur in later life when family equilibrium is disturbed. Also the "level of family interactions are markedly impaired and further deteriorate after each episode" (Anthony 1970:139). This is part of my autoethnography where as a child I was abused by my mentally ill mother. Some 50 years ago, this was not recognized nor talked about amongst her peers or doctors.

My condition was a result of environmental circumstances (schizophrenia) and inherited from my mother (bipolar disorder). In mental illness, "the family must adapt to the restrictions imposed by the disability and the demands of the sick person" (Anthony 1970:132). Evidence of this disruption impacts on individuals re-entering the academic domain. The ensuing issues in the family add to the difficulties encountered by the students. Finally for the family, this can entail a grinding circle of relapse, times of remission, times of hope and times of despair.

References on higher education are important as part of the topic of mature-age students with a mental illness returning to study at a university. Of interest here are the concepts inherent in tertiary institutions where academic aspirations affect life circumstances. Coping in this environment must ensue if graduation with a degree is the desired outcome. Mature-age students, tertiary students with a disability and tertiary students with a psychiatric disability are all covered in the next section.

### *Higher education*

The fostering of higher order intellectual capabilities in students is the "overarching purpose of higher education" (Nightingale & O'Neil 1994:51). For Australian universities, the creation and advancement of knowledge produces graduates who are "able to form and substantiate independent thought and action in a coherent and articulate fashion" (Nightingale & O'Neil 1994:52). My research on mature-age students indicates that some are hesitant to return to study as they do not have the confidence in their academic abilities. Also to leave their safe environments and enter a new domain where future involvements are an unknown quantity instills fear and apprehension.

This category of students forms an important part of the overall consideration in Australian universities, mainly studying off-campus (Commonwealth of Australia 2003; Fogarty & Taylor 1993). It can be identified that "broad learning orientations can emerge in populations which may be somewhat deficient in actual study skills" (Fogarty & Taylor 1993:328). However, as they tend to be more self-reliant and possess valuable resources of successful learning, mature-age students "learn more efficiently in relaxed, supportive, co-operative and informal learning environments" (Nightingale & O'Neil 1994:79). It is very difficult returning to study after many years living and working in the wider community.

An important sub-group of mature-age students who return academically is that of individuals with mental illnesses. This group constitutes the focus of the proposed research.

Many institutions have experienced demands on their services, with little or no increase in disability resources or funding (Tertiary Initiatives for People with Disabilities, 1996). When faced with problems disabled people encounter, their impairments exist because society is organized in a way that does not take their needs into account. Tregaskist

2004:104 notes that “the negative attitudes of non-disabled individuals help to maintain disabled people’s exclusion from the cultural environment”. In general, “adopting a strategy of self-revelation with one’s non-disabled peers may be a necessary step towards breaking down the assumptions between them” (Tregaskist 2004:104).

There are two concerns if you have a psychiatric disability when attempting university study:

1. The issue of the effect of mental illness on academic pursuits; and

2. The development of strategies to successfully study at university.

One solution to these problems is using this Disability Support Office at your university. I have taken up this opportunity of being a Registered Disability Support student while studying for my B.Teach. (Primary) degree and M.Ed. (Hons.) degrees at UNE, Armidale. Also help with extensions for assignments are part of their services. Professional help and that of family members together contributes to completing a degree in the chosen field. In my case, this is Education and Health. In this research paper, my key focus is to inspire mature-age students with a mental illness to return to higher education.

The Research Questions centre on my experience of living with a schizoaffective psychosis. Education and learning have had an important role in my life and contribute to my wellness. My existence from day-to-day includes the usual chores of managing a family and finding time to finish my assignments. This balancing act can become very stressful at times and a break is needed to recover. This is especially so when my condition worsens and rest is the only option.

## Summary of Work and Academic Achievements

### *How far have I come?*

Personal and academic learning have led to a fulfilling lifestyle. So far, my qualifications illustrate the fact that I have been awarded two undergraduate degrees and one postgraduate qualification.

I graduated from Macquarie University in Sydney, N.S.W. with a B.A. in 1980 and a M.A. in 1993. During this time I raised a family and worked as a Psychologist/Rehabilitation Counsellor from 1981 to 1995. These vocations were all in disability organizations such as The Spastic Centre, The Epilepsy Foundation and the Department of Developmental Disability in their workshop at Hornsby, NSW.

In 1996, I retired to the Central Coast of N.S.W. as a Disability Support Pensioner. I again had the desire to re-enter the academic domain. So from 2005-2009, I was involved in my M.Ed. (Hons.) degree. If accepted, I have the potential to convert to a Ph.D. candidate in 2009. This would be the pinnacle of my career and give this category of students inspiration to attempt a similar course of action. Over all the years I have still included continual psychiatric treatment for my mental illness.

## Conclusion

Students, including those of a mature-age can succeed in a tertiary setting when suffering from a mental illness. The stability and self-esteem they so rightly deserve in their lives is delivered when they graduate with a degree from their chosen university. It has been divulged that I have a schizoaffective disorder or psychosis. This includes symptomology concurrently of schizophrenia and a bipolar disorder. Detrimental life experiences could be delivered when I was diagnosed with this psychiatric disability.

The schizophrenia component was environmental but the bipolar portion was inherited from my mother. Just living with someone with a mental illness is a real challenge to overcome. Luckily my husband is very understanding and co-operative in managing my daily life.

A protective plan is necessary to combat the risk associated with this psychosis. This includes psychotropic medications, psychotherapy, hospitalizations on a regular basis and ECT. Now with maintenance ECT, my relapses are not as frequent but they still do trouble me on occasions. This is where the Disability Support Office at a university is a wealth of strength. Special precautions have to be in place to treat me in times of crises.

I hope other students with a mental illness will be inspired by my story to attempt academic study. The results of the attainment of a B.Teach. (Primary) degree at UNE in 2006 is interpreted as a way of demonstrating the difference between disabled and non-disabled peers. The Methodology I have chosen here is autoethnography. In this approach the candidate is the "subject" of the research.

Having a schizoaffective disorder is like living in a desolate world where often, reality is not an option. During my regular psychiatric treatment modalities, including ECT, I feel like a punished individual for revealing my disability. Most individuals I come into contact with admire my persistence and resilience under the absolutely horrific circumstances I find myself having to endure on some occasions. There is the hope that future research could centre on trying to find cures for mental illnesses that have been around for centuries.

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