



Saint John of God Hospitaller Services

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**Early Intervention Service for psychosis in Northern Malawi.
Is it needed? Is it feasible?**

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Part 1

1.0 Executive summary

Introduction: First episode studies of schizophrenia have indicated that longer duration of untreated psychosis (DUP) has poorer response to antipsychotic medication (Loebel et al 1992). These findings have led to the development of early intervention services in developed countries (Killack and Yung, 2007) with a view to reducing the DUP. Early intervention services are said to improve outcome in first episode psychosis because there is a reduction in DUP. Studies in developed countries, however have persistently and consistently found that many individuals with first episode psychosis delay significantly before they access and receive effective treatment. Whether these findings apply to Malawi is not known. We however have observed that people accessing mental health services at Saint John of God Community Services do so very late. Whether this delay impacts on clinical outcome or not, we do not know.

This study therefore examines the duration of untreated psychosis, defined as the interval from first psychotic symptoms to first effective treatment and evaluates factors that are associated with DUP. It also examines the impact of prolonged DUP on clinical outcome. The study also examines the attitude of the population at risk and their families to the concept of early intervention service.

Objective: (1) Assess the average duration of untreated psychosis in Mzuzu, Malawi and assess whether there are factors associated with duration of untreated psychosis. (2) Determine whether DUP impacts on clinical outcome and (3) establish the attitudes of people at risk and their families to the concept of early intervention services

Methodology: The study is conducted within Mzuzu city, Mzimba and Rumphi districts with a population of 1,022,417. All individuals and their families who presented to the service or to the research officers in the community with first episode psychosis were approached to participate in the study. 140 patients were recruited and assessed using structured clinical interview for DSMIV TR diagnosis (SCID), Schedule for the Assessment of Positive Symptoms and Negative Symptoms to determine severity of symptoms, Quality of Life Scale, Beiser Scale to determine DUP (Beiser et al 1993), and Global Assessment of Functioning Scale. The same number of subjects were followed up at 18 months and assessed with SCD, SANS, SAPS and GAF. The second assessment was to determine whether there had been changes in the severity of symptoms after starting effective treatment and if there was any improvement in the Global Assessment in Social Functioning. Clinical outcome was defined as the reduction in the severity of symptoms and the improvement in the Global assessment of functioning. The population at risk and their families were also asking to provide their confidential opinion on the establishment of an early intervention service. The data was analysed using Statistical Package for Social Sciences (SPSS)

Results: 140 subjects were recruited and 135 analysed. The mean duration of untreated psychosis is 51.70 months. Level of education, employment, diagnosis, global assessment of functioning (GAF) and negative symptoms were all found to be associated with DUP. however, marital status, sex and whether the patient decided to seek for help or not were found not to be associated with DUP. The size of follow-up data varied according to variables, however on average 79% follow-up rate was achieved. We did not find DUP to be associated with improvement in severity of symptoms and improvement in Global Assessment of Functioning paired differences SAPS 1 and SAPS 2 $t=17.573$ $df=104$ $P=0.000$; SANS1 and SANS2 $t=5.781$ $df=106$ $P=0.000$; GAF1 and GAF2 $t=11.597$ $df=106$, $P=0.000$. The means of the differences of

SAPS 1 and SAPS2; SANS1 and SANS 2 and GAF1 and GAF 2 are all positive and significant at 1% significance level. The confidential opinion on the development of an early intervention service was very positive. People talked of inaccessibility of mental health services, poverty as leading to prolonged suffering to both the population at risk and their families

Conclusion: Although these findings requires replication in other epidemiologically based first episode admission samples, the findings support the suggestion that individuals with first episode psychosis in Mzuzu delay to seek for effective treatment and that several factors are associated with this delay. Further to that, there is sufficient information to suggest that DUP does not directly impact on clinical outcome independently. There is also evidence that mental health services are not accessible to the population at risk and that prolonged suffering without effective treatment has caused a lot of miseries to individuals and their families.

Implication

Since the study was conducted in the northern part of Malawi there is need to replicate in other parts of Malawi so that the finding can be generalised to represent Malawi as a country. Areas of knowledge gap have been identified by the research, for example many clients visit traditional healers for consultation when mentally ill. As a result of these findings, a community based service in a form of early intervention service has been suggested within the Saint John of God service to address the gaps that have been identified, emphasis being placed on improving mental health literacy to the general public through educational programs.

The results of the study may also help the government in particular Ministry of Health to include mental health activities in their essential package for primary health care workers and this will help in the promotion of early detection and intervention of common mental health problems and psychosis through community programs.

The study also exposed the influence traditional healers have in the provision of alternative care to people with psychosis. This may assist the policy makers on formulating programs that would allow health personnel to monitor their activities and identify areas of collaboration.

The following points need to be considered by policy makers:

There must be clear policy to integrate mental health services into Primary Health Care (PHC) to make it more accessible and affordable to the population at risk and their families.

Include mental health in the essential health package as an essential health service and ensure that all essential psychotropic or neuroleptic drugs are procured and available in all health facilities

Through collaboration with other stakeholders, educate the general population on the signs and symptoms of first episode psychosis and its treatment

Part 2

2.1 Introduction

Saint John of God Community Service (SJOG) has been providing mental health services for about eighteen years. During this period it has been observed that individuals with first episode psychosis delay to seek for help. The reason for the delay is not known. With the current health system in Malawi which emphasises on integrated primary health care, one would think or assume that individuals with any illness should access service at a community level and have their illnesses treated as close to their homes as much as possible. However the situation at the moment and observations made at Saint John of God Community Services (SJOG) indicates that people with first episode psychosis still delay to access effective treatment. *The question is how long is this delay? And what is causing the delay?* And how does this delay impact on clinical outcome.

First-episode studies of schizophrenia have reported that the longer the Duration of Untreated Psychosis (DUP), the poorer the response to antipsychotic medication and treatment outcome. The findings of these studies have led to the assumptions that by reducing DUP, treatment outcome for schizophrenia and other related psychoses might be improved significantly; hence the need for early recognition and intervention in first episode psychosis has become very important. Shortening of DUP would also reduce the unnecessary burden and sufferings families and patients go through. The determinants of DUP in our culture are likely to be multi-factorial, and yet still unknown to primary health care workers.

Also the belief that mental illness cannot be treated by western type of medicines may contribute to delays in seeking help from hospitals. In Mzuzu the Tumbuka culture believes that hearing voices is a transition to become a traditional healer; this is sometimes called ‘‘Kuthwasa.’’ There are also culturally related conditions which could cause conflict in help seeking behaviours for example ‘‘vyanusi or vinthenda or vimbuza’’. These conditions have symptoms similar to psychosis and traditional healers are believed to be experts to managing them. These beliefs have a huge influence on help seeking behaviours. A traditional healer is highly respected and consulted in most cultures. When one hears voices it may be interpreted as a blessing as it may be interpreted as a process or transition of becoming a traditional healer and hence leading to delays in seeking effective treatment.

In our study, we measured the duration of untreated psychosis and examined the socio-demographic, social and clinical correlates of DUP in patients with first episode psychosis; an attempt to determine the factors that contribute or were associated to a prolonged DUP was done. Predicting the outcome of patients with a first episode psychosis is crucial to clinicians, patients and their families. Studies have continued to suggest that DUP is prognostic, Thomas et al (2008); Crow et al (1998); Loebel et al (1992); Marshall et al (2005); Perkins et al (2005). More recently there has been suggestions that psychosis may be ‘‘biologically toxic’’ implying that longer DUP may adversely affect long-term outcome. In other words, some researchers have found an association between long DUP and poor outcome, Wyatt et al (1997).

2.2 Back ground

Malawi is located south of the equator, in the eastern part of Africa to the south of the Republic of Tanzania, east of Zambia and to the south-west of Mozambique where it is separated and

bordered by Lake Malawi, the third largest lake in Africa. The country has three administrative regions – the Northern region, the central region and the southern region. Each region is divided into districts and there are twenty eight districts altogether. The country's economy is based primarily on agriculture, which accounts for 30% of the gross domestic product (GDP). The country's population is approximately 13.1 million (2008 census). The annual growth rate is 2.8%. Saint John of God provides services in the Northern region.

prevalence of mental disorders as established from studies in other developing countries show that mental disorders are as common in rural communities of developing world as infectious diseases and that severe mental disorders are likely to affect at least 1% of the population at any time and up to 10% at some time in life. Less severe mental disorders affect up to 10% of the population. The national mental health policy (2001) says that between 10-18% of adults and 11-29% of children seen in primary health facilities have varying forms of mental disorders.

The development of mental health services has not been able to keep pace with the growth of the population and national development in other aspects of health care. Although the government has been providing mental health services to its citizens since 1910 and has been operating legislation on mental health treatment since 1948, there has been no formal functioning policy framework defining the scope and future direction of these services in line with national development and national aspiration as reflected in the constitution and national health plans of the country.

Existing mental health services are mainly urban based. They are neither decentralised nor integrated into the national primary healthcare delivery system. This is in spite of the fact that the majority of the population live in the rural areas. The lack of integration of mental health services into health care delivery system has limited the scope of services available to the population of Malawi and has not facilitated the development of the necessary skills for the management of mental health problems by general health care workers.

The mental health available at the moment are provided in one referral government mental hospital in Zomba with 332 bed capacity, one psychiatric unit of 30 beds in Lilongwe and Saint John of God community Services in the Northern region which is a nongovernmental facility with a 32 bedded unit. These mental health facilities constitute just 0.3% of the health facilities available in the country. It has been noted with great concern by the majority of Malawi population, patients and health providers that the quality of public health care service is poor. The quality of care in the mental health sector is below the acceptable standards. Mental health services are housed in very old and poorly maintained buildings and environments that do not promote therapy. The resources in these facilities, both material and human are often inadequate.

2.2.2 Saint John of God Community Services

In 1993 the Brothers of Saint John of God arrived in northern Malawi city of Mzuzu to start Saint John of God community Service. They started work in developing a community based service in partnership with others to promote quality of life of people suffering from mental health problems. In keeping with the mental health policies, ethos and values of the Order and mindful of the recommendations of World Health Organization (WHO) they decided to plan the new mental health service on the following principles:

- Mental health to be developed as a component of primary health care
- Priority was to be given to the promotion of mental health rather than to the treatment mental illnesses per se
- An adequate health care service which was to produce not just freedom from disease but promote an individual and community sense of mental and psychological wellbeing
- It was to be an indigenous system of mental health promotion and care which embraced what was positive in the traditions, beliefs, customs and cultural heritage of the local community
- Time and resources were to be invested overtime in the training and professional preparations of Malawian personnel so that they could be central to the development of new service.

2.2.3 Service vision

Consolidate mental health services. Providing a comprehensive integrated community approach emphasis being placed on prevention, promotion, treatment interventions and rehabilitation.

Develop a formalised community integrated follow-up system within the catchment area

Develop appropriate management structures and clinical teams in situation to meet the developing needs of the community in conjunction with local stakeholders.

Influence the development and implementation of the Malawi mental health policy and improve standards of mental health promotion and care through professional training in the Northern region in particular and Malawi in general.

2.3 Literature review

Studies in developed countries have highlighted a significant delay in accessing treatment for psychosis even in countries with well established psychiatric services Larsen et al (1996), Danny et al (2005). This time period between the onset of frank psychotic symptoms and receiving effective treatment is known as 'duration of untreated psychosis' (DUP). There is consistent evidence that an average delay in obtaining treatment is one year or more (1-2years). In Ireland it has been demonstrated that the duration of untreated psychosis before first effective treatment is one to two years Clark et al (2006). This delay may be influenced by a number of factors, these factors some of which cannot be changed or influenced. Eadbhard et al, (2009) has indicated that being younger and having negative symptoms were associated with carers being involved in help seeking. This sometimes leads to delays in accessing effective treatment. Carers may be trying to observe first before appropriately seeking for help or they may be trying traditional healers first. Individuals with psychosis may have impaired help seeking behaviours because of the nature of the factors associated with the illness such as social withdrawal and lack of insight Eadbhard et al (2009). Many patients who present to psychiatric services with psychosis will have been to several other sources seeking for help before referral, Lincoln et al (1998) and even when they do attend early with psychosis at a health facility, early psychotic symptoms may be missed by primary health workers.

Aniehue Patricia Nonye and Ekwueme Christiandolus Oseloka (2010) have indicated that misconceptions regarding the cause of mental illness are still huge among mentally ill patients in Nigeria. Consequently, psychiatric consultations are not usually sought. In Malawi the cause of most illnesses or misfortunes is believed to be demonic or witch craft or ancestral spirit forces. These beliefs have influence on help seeking behaviour as many will be distressed and psychologically affected. Catherine et al (2008) found that substantial proportion of attendees of traditional healers suffers from psychological distress and that associated factors such as poverty, number of children in the family, polygamy and poverty were common.

Early intervention services in psychosis are currently being applied in the developed world to reduce DUP Killackey and Yung (2007). In Norway, an early detection program reduced DUP in a two year sample of first episode psychosis from median of twenty six weeks to a median of five weeks Melle et al (2004). Furthermore the reduction in DUP was associated with better clinical status at baseline that was maintained after three months Melle et al, (2004)

Delays to effective treatment for even any disease for example tuberculosis, heart disease, diabetes, hypertension are common and lead to poorer clinical outcome. Recent studies have indicated that longer duration of untreated psychosis (DUP) is associated with poorer recovery Marshall et al (2005). However Beng-Choon et al, (2000) indicate that untreated initial psychosis was not prognostic of poor outcome. Beng-Choon et al, (2000) continues to point out that duration of untreated psychosis is difficult to ascertain since the onset of psychosis is often subtle and insidious. However Chow et al, (2005) has suggested that there is an association between DUP and adherence to treatment, such that DUP less than six months were associated with better adherence to treatment than DUP greater than six months.

2.4 Objective

In this project we tried to:

1. Assess and measure the average duration of untreated psychosis
2. Determine if the duration of untreated psychosis (DUP) predicted outcome
3. Establish the attitudes of the population at risk, their families and health workers to the concept of early intervention service.

2.5 Methodology

The study was carried within the Saint John of God Community Services Catchment area in Mzuzu city, Mzimba district and Rumphi district with a population of 1,037,717 inhabitants. Mzimba is one of the biggest districts in the Northern region with a population of 724,873 inhabitants with one general district hospital, and Rumphi has a population of 169,112 inhabitants with one general hospital serving this population. Mzuzu city where Saint John of God Service is based has a population of 128,432 inhabitants. Saint John of God is the only mental health facility in the Northern region.

From June 2009 educational materials adopted from DETECT were translated into the local language (Tumbuka) and an extensive educational training program started within the research catchment area (Mzimba, Rumphi and Mzuzu city). This program consisted of educational campaigns about early psychotic symptoms and their treatment directed to the general population through organized meetings, workshops and distribution of educational materials. There was also targeted information campaigns directed at general health workers, schools, organizations

dealing with young people and families. The research team also acted as a community-care team and could be reached by a single phone from potential patients, families and community structures e. g., traditional leaders in the community. The research team acted as a community care team because mental health services are not well developed in the remote areas and lack of awareness or prejudices about mental illness and treatment. Relying on local health centres could delay treatment because many do not have medications; mental health centres are not accessible to most people in the rural areas. So by assigning research team to respond to the community calls, we made sure that patients were assessed promptly and treatment was initiated immediately. Further to that the tertiary delaying factors such as delays in identifying cases and lack of resources in assigning adequate treatment for first episode was bypassed by this arrangement (research team).

The study included all eligible patients meeting the study criteria for the period of June 2009 through September 2012. Participants were followed up every month for review, supply of medication and to monitor progress.

2.6 Subjects

The inclusion criteria consisted of all individuals living in the districts mentioned above (catchment area) and of the age 18-65 years; meeting the criteria of Diagnostic and statistical Manual of Mental disorders, Fourth Edition (DSM-IV) criteria for schizophrenia, schizophreniform disorder, schizoaffective disorder, brief psychotic episode, delusional disorders, affective psychosis with mood in-congruent delusions and psychotic disorders not otherwise specified; being actively psychotic as measured by the Scale for the Assessment of Positive Symptoms (SAPS) and the Scale for the Assessment of Negative Symptoms (SANS) Scores of 4 or more on at least 1 of positive subscale items for delusions, hallucinations, grandiosity, or suspiciousness/persecution or general subscale item unusual thought content; not receiving previous adequate treatment for psychosis (defined as antipsychotic medication of 300mg chlorpromazine equivalent for 12 weeks or until remission of psychotic symptoms); with organic illness.

During the three years period, 400 patients were referred to our team and 202 were approached to participate in the research and consented to be assessed and 140 were recruited. At the initial

assessment for every client who refused, immediately another was approached to replace him or her.

2.7 Measures/instruments

The research team took responsibility in assessing all the patients sent or referred to the team. The structured clinical interview for the DSM-IV AXIS 1 disorder (SCID) (American Psychiatric Association, 1994) was used for the diagnostic purposes. Symptom levels were measured by means of Schedule for the assessment of positive symptoms (SAPS) Andreason et al, 2001) and Schedule for the assessment of negative symptoms (SANS) Andreason et al, 2001). The score of 3 and above on global rating of symptoms was considered as moderate to severe for negative and positive symptoms.

Global functioning was measured by the use of Global Assessment of Functioning scale (GAF) American Psychiatric Association, (1994). Quality of life was measured using the WHOQOL-BREF. Duration of Untreated Psychosis (DUP)) defined as the time from the onset of psychosis until the start of adequate treatment (defined as antipsychotic medication of 300mg chlorpromazine equivalent per day for six weeks or more), was measured by Beiser scale (Beiser et al, 1993).

2.8 Results

Analyses were performed with the Statistical Package for Social Science (SPSS)

Two hundred and two (202) subjects were referred within a period of three years and were assessed

140 subjects having fulfilled the inclusion criteria were recruited

84 (60%) were male and 56 (40%) were females

Table 1 Age distribution

| Age | frequency |
|--------------|-----------|
| Below 25yrs | 37 |
| 26 to 30 | 21 |
| 31 to 35 | 22 |
| 36 to 40 | 20 |
| 41 to 45 | 14 |
| 46 and above | 26 |

Table 2 Marital statuses

| Marital status | Frequency |
|----------------|------------|
| Married | 68 (48.6%) |
| Widowed | 6 (4.3%) |
| Divorced | 8 (5.7%) |
| Separated | 19 (13.6%) |
| Never married | 39 (27.9%) |

The first analysis of DUP in months showed that the lowest DUP was 0, the highest was 369, and the average was 61.26 with Standard deviation of 85.314. This meant that data varied a lot. The histogram on appendix (figure B) also indicates the presence of extreme values (outliers). This meant that outliers (any value that was 2.5 Standard deviations of the mean) had to be identified and removed.

After the outliers were identified and removed, the number of subjects was reduced to 135 from 140. Of the 135 patients it was found that 37 had short DUP (that is DUP less than or equal 5), and 98 patients had long DUP (that is DUP greater than or equal to 6).

The estimation of DUP was based on this number as a result, the mean DUP is 51.70 (months) with standard deviation 70.14 and median of 18. Although there are still more variation in the data, there is still an indication that, overall, the Duration of Untreated Psychosis in Mzuzu city is high.

It was also discovered that in this catchment area, when people become psychotic many ill patients do not take initiative to look for help by themselves, instead, family members takes responsibility. These family members will decide whether to look for help or not, and if they want to look for help, they will decide where to look for this help. It has been noted that many families will go to traditional healers to seek for help rather than hospitals. Many more will not even look for help because of strong traditional beliefs that mental illness cannot be treated.

Table 3 Mean DUP differences within categorical variables (Kruskal Wallis test was used to establish if the differences were statistically significant)

| | Frequency, n (%) | Mean \pm SD of DUP in Months | χ^2 | df | <i>P</i> values |
|-----------------------------------|---------------------|--------------------------------------|----------|----|--------------------|
| Sex | | | | | |
| Male | 82 (60.74) | 50.45 \pm 69.286 | 0.001 | 1 | 0.982 |
| Female | 53 (39.26) | 53.62 \pm 72.065 | | | |
| Marital Status | | | | | |
| Single (not married) | 68 (50.37) | 56.24 \pm 72.714 | 0.896 | 1 | 0.344 |
| Married | 67 (49.63) | 47.09 \pm 67.661 | | | |
| Level of Education | | | | | |
| Std 8 or less | 49 (36.3) | 83.08 \pm 84.846 | 13.048 | 2 | 0.001 |
| Form I to Form IV | 74 (54.81) | 35.32 \pm 54.26 | | | |
| University or College training | 12 (8.89) | 24.5 \pm 44.494 | | | |
| Employment Status | | | | | |
| Employed | 15 (11.11) | 13.2 \pm 19.702 | 7.463 | 1 | 0.006 |
| Unemployed | 120 (88.89) | 56.51 \pm 72.69 | | | |

| | | | | | |
|--------------------------------|------------|----------------|--------|---|-------|
| Referral pathways A | | | | | |
| Self | 14 (10.37) | 45.57±62.51 | 0.096 | 1 | .756 |
| Did not seek help | 121(89.63) | 52.40±71.171 | | | |
| Referral pathway B | | | | | |
| Family | 132 | 49.09 ± 67.635 | 4.497 | 1 | 0.034 |
| Did not seek help | (97.78) | 166.33±99.123 | | | |
| | 3 (2.22) | | | | |
| Where help was sought A | | | | | |
| Hospital | 5 (3.7) | 35.60±26.51 | 8.966 | 2 | 0.011 |
| Traditional healers | 5 (3.7) | 88.60±88.562 | | | |
| Others | 4 (2.96) | 4.25±3.096 | | | |
| Where help was sought B | | | | | |
| Hospital | 38 (28.15) | 41.37±71.247 | 13.298 | 2 | 0.001 |
| Traditional healers | 81 (60.00) | 58.75±69.02 | | | |
| Others | 13 (9.63) | 11.46±13.22 | | | |
| Diagnosis of illness | | | | | |
| Schizophrenia | 89 (65.93) | 72.19±76.945 | 58.360 | 6 | .000 |
| Schizoaffective disorder | 6 (4.44) | 36.5±38.635 | | | |
| Bipolar I disorder | 12 (8.89) | 13.75±28.185 | | | |
| Schizophreniform disorder | 20 (14.81) | 8.3±19.636 | | | |
| Delusional disorder | 1 (0.74) | 1 | | | |
| Brief psychotic disorder | 5 (3.7) | 0.2±0.447 | | | |
| Psychotic disorder NOS | 1 (0.74) | 2 | | | |

The above table indicates some statistically significant differences in mean DUP within categorical variables. For example, the mean DUP was statistically significant for these variables: level of Education, Employment status, Referral pathways (family help seeking), where help was sought (by either client or family) and Diagnosis of the illness.

It has been found that there is no significant association of mean DUP with Gender, Marital status and whether the patient initiated to seek help or not. However, patients with higher education were more likely to have shorter mean DUP than those with lower education ($\chi^2=13.048$, $df=2$ $p=0.001$), Kruskal-Wallis test). Patients who were employed were also more likely to have shorter mean DUP than those who were unemployed ($\chi^2=7463$, $df=1$, $p=0.006$), Kruskal-Wallis test). Furthermore, patients whose families did not seek help had longer DUP than those that had their families seeking help for them ($\chi^2=4.497$, $df=1$, $p=0.034$, (Kruskal-Wallis test).

There is sufficient information to suggest that individuals with the diagnosis of schizophrenia are more likely to have longer mean DUP than those with other diagnoses ($\chi^2=58.360$, $df=6$ $p=0.000$, (Kruskal-Wallis test). Clients with families seeking help from traditional healers were also associated with longer mean DUP than seeking help from other sources; ($C=8.966$, $df=2$, $P=0.011$, (Kruskal-Wallis test for client help seeking) and ($\chi^2=13.298$, $df=2$, $P=0.001$, (Kruskal-Wallis test for family help seeking)

Table 4: The relationship between DUP and categorical variable (Pearson Chi-square test)

| <i>Variable</i> | Chi-square (χ^2) | df | p-value | comments |
|-------------------------------|----------------------------|----|---------|---|
| <i>DUP and Sex</i> | 0.035 | 1 | 0.851 | No significant linear relationship between DUP and Sex |
| <i>DUP and Marital Status</i> | 1.036 | 1 | 0.309 | No significant linear relationship between DUP and Marital Status |
| <i>DUP and Education</i> | 2.240 | 2 | 0.326 | No significant linear relationship between DUP and Education |

| | | | | |
|---|--------|---|-------|---|
| | | | | |
| <i>DUP and Occupation</i> | 3.146 | 1 | 0.076 | No significant linear relationship between DUP and Occupation |
| <i>DUP and Client Help Seeking</i> | 1.352 | 1 | 0.245 | No significant linear relationship between DUP and Client Help Seeking |
| <i>DUP and Where Client Sought Help</i> | 4.942 | 3 | 0.176 | No significant linear relationship between DUP and Where Client Sought Help |
| <i>DUP and Family Help Seeking</i> | 1.158 | 1 | 0.282 | No significant linear relationship between DUP and Family Help Seeking |
| <i>DUP and Where Family Sought Help</i> | 10.884 | 3 | 0.012 | There is a significant linear relationship between DUP and Where Family Sought Help |
| <i>DUP and Diagnosis</i> | 71.421 | 7 | 0.000 | There is a significant linear relationship between DUP and Diagnosis |
| <i>DUP and GAF</i> | 17.297 | 5 | 0.004 | There is a significant linear relationship between DUP and GAF |

Table 5: relationship between DUP and SAPS and SANS Pearson Correlation coefficient (r)

| Variables | Pearson Correlation Coefficient r | P -value | Comments |
|--------------|-----------------------------------|----------|---|
| DUP and SAPS | 0.106 | 0.221 | No significant linear relationship between DUP and SAPS |
| DUP and SANS | 0.347 | 0.000 | There is a significant linear relationship at the 0.01 level between DUP and SANS |

Table 4 shows that there is significant linear relationship at 5%, and 1% significance level, respectively, between DUP and where the family sought help ($\chi^2=10.884$, $df=3$, $P=0.012$); DUP and diagnosis of illness ($\chi^2=71.421$, $df=7$, $P=0.000$); and DUP and GAF scale ($\chi^2=17.297$, $df=5$, $P=0.004$). It was found that 45.9% of short DUP families sought help from hospitals while 21.4% of long DUP families sought help from hospitals. Furthermore, 40.5% of short DUP families sought help from traditional healers, while 67.3% of long DUP families sought help from traditional healers. For DUP versus diagnosis of illness, it was found that 83.7% long DUP patients had schizophrenia while 18% of short DUP patients had schizophrenia. Moreover, 67.6% of short DUP patients had GAF between 41 and 49 and less, while 43.9% of long DUP patients had GAF between 41 and 49 and less. Also, 18.9% short DUP patients had GAF between 51 and 59 while 36.7% of long DUP had GAF of between 51 and 59. Only 13.5% of short DUP patients had GAF greater than 59 and only 19.4% of long DUP had GAF greater than 59.

Table 5 shows that there is significant correlation between DUP and negative symptoms ($r=0.347$, $p=0.000$) but we found no correlation between DUP and positive symptoms ($r=0.106$, $p=0.221$). The correlation coefficient $r=0.347$ indicates a weak positive linear relationship between DUP and negative symptoms which shows that the values of DUP increase as the values of negative symptoms increase.

Even though there was significant mean DUP differences between levels of education and occupation, DUP was not linearly related with these variables ($\chi^2=2.240$, $df=2$, $P=0.326$; $\chi^2=3.146$, $df=1$, $P=0.076$, respectively).

2.10 Discussion

This is the first study in Malawi which examines the duration of untreated psychosis and its associated factors. Therefore, there are no estimates on duration of untreated psychosis in this country. In this study the mean DUP of the patients was 51.70 months (about 4.3years) which is far longer compared to findings in the developed countries Larsenet al (1996), Clark et al, (2006), Marshal et al, (2005), where the mean DUP has been estimated to be 1-2 years. These results are comparable to other findings from developing countries in Asia Pek et al, (2006). The prolonged DUP could reflect the people's negative perception of psychosis and hence lack of interest in help seeking or the explanatory model of the illness and the distress associated with the suffering the go through or the multiple diverse contradictory models of the illness Das et al, (2006) resulting into visiting the traditional healers to seek for explanation. This we think has had a lot of influence in help seeking behaviours.

2.10. 1 Help seeking

Table 3 indicates that the majority 132 out of 135 families representing 97.8% sought help for their relatives. This seems to indicate that family members are important in help seeking. This concurs with Savanan et al (2005) who found that family members seem to notice the change in behaviour in which the patient has limited insight because of the nature of the illness and, therefore, families seek for help on their behalf. This observation was also noted by Haider et al (2009). Other studies have also indicated that families are very important in the pathway to care Chow et al (2005). We also note in this study that many family members 81% went first to traditional see fig in the appendix). Culturally witch craft is viewed as a cause for many illnesses or misfortunes; this might be the reason for seeking help from witch doctors (traditional healers) and that traditional healer provide important health care alternative for those with first episode psychosis. The current research is unable to give explanations regarding why people go to traditional healers (however issues of accessibility, informality of healers as part of community and affordability may make up for the reasons). Mhwezi and Seggane (2008) have indicated that

a substantial proportion of people attending to traditional healers suffer from psychological distress. Also there are associated factors such as poverty, bigger number of children per household, polygamy in which psychological distress is highly prevalent. These characteristics seem to be similar to our study population as the majority were from very rural areas and were poor.

Out of 135 subjects we recruited only 38 (28%) carers and 5 (3%) clients utilised health facilities. Again this research cannot explain why both carers and clients shied away from using hospitals. Aphrodit and Michael (2010) indicate that stigma is attached to help seeking and that to some, this stigma is harder to bear or face than the illness itself. Further to that, Aniebue and Ekwueme (2009) mentioned that negative perceptions of the cause of mental illness are huge among people and are compounded by ignorance. Explanation for ill health for people in the rural areas compounded by ignorance, can cause huge distress in patients and hence traditional healers are most often than not sought to provide that explanation (Abbo et al, 2008)

2.10. 2 Health service

In this study there was no significant association between socio-demographic factors (gender and marital status) and DUP. We think health service factors, have an influence on DUP. The issue is that people in the rural areas have difficulties accessing mental health service hence alternative services like traditional healers are commonly consulted. Clients and families who sought help from traditional healers were more likely to have longer DUP than those who sought help from either, the hospital, counsellors and church prayers. Also patients who had negative symptoms were more likely to have longer DUP; probably this could be due to the nature of symptoms as patients with negative symptoms are withdrawn not motivated and pose no danger to anyone while those with positive symptoms can be very aggressive and disruptive and therefore perceived to be dangerous and therefore families will take them to police or hospitals for their own safety.

2.10. 3 Level of education

DUP is longer among the uneducated and shorter among the educated subjects and families for several reasons. Both on the part of family and subject, level of education and short DUP may first be linked to the role of the patient in economic survival of the family – ensuring that the

person gets well to continue providing for the family. Secondly it may also have to do with weakening of dependence on traditional system in understanding disease causation by those who are achieving higher education i.e. the higher educated one becomes, the more likely that one's local or tradition value and belief systems weakens and tilts more towards – Eurocentric or western views, which includes weakening of dual causation of disease to mono-causation. Thirdly, due to prevailing Christian views educated family and individuals are more likely to experience cognitive dissonance or inconsistency/conflict between traditional value systems and Christian teachings than the non-educated (they are literate as to read the bible conflict of faith on traditional treatments that use aspects like divination, incision, which are in conflict with biblical teachings – something that may make educated families and individuals seek for help in western/modern health facilities at the earliest time possible. Fourth, it is also possible that the educated families are likely to seek

both at the earliest time possible – while the less educated may either have confidence in just one, or be hindered by lack of assertiveness to violate the mystic power or influence of the traditional healer on the oracle of the illness (the diviner may use some very powerful words that literary holds the mind of non-critical individual and family his or her prisoner and render the person family powerless to leave and seek for other help even when their relative is not improving). Fifth, the majority of the uneducated folks are situated in rural areas where an alternative medicinal system is stronger, affordable and accessible when compared to western medicinal systems which it is weak and compounded by issues of accessibility and affordability.

2.10.4 Employment

Employment is likely to be correlated with education – the more one is educated the more one is likely to be employed. But further to the connection of employment and education is the fact that employment tends to be localised in urban and semi-urban centres – with a relatively stronger modern medical care system than the traditional system. As such, those employed and in urban and semi-urban areas are likely to seek for help in modern health care systems than alternative medicine. In our study, because of change in our methodology where clients were found in their own communities during our campaign, our subjects were more likely to be uneducated and poor and therefore their explanations of illness were more likely to be influenced by cultural values and norms for example spiritual and social explanation (Jeanne et al, 1997)

2.10.5 Diagnosis

Disease pattern in African countries as a social constructive pattern is embedded in cultural understanding of causation. For many non-western cultures the causal component of illness schemas includes spiritual and social factors Jeanne et al (1997) the more difficult to explain the disease the more theories of causation. Illness in this culture is explained by spiritual causes; witchcraft or ancestral anger (Karen Smyth, 1999 and Pulitzer, 1998). Such beliefs have for millennia been reinforced and can cause huge distress in the patient and the family Abbo et al (2008). While psychoanalysts would refer to such events as regressive behaviour and breakdown of the EGO leading to the unconscious dynamics of the individual becoming bear due to breakdown of defence mechanisms. In a non-scientific community, with a world-view constructed on the eternal forces of ancestral spirits, psychosis has been viewed as the first sign towards the road of becoming a diviner a traditional healer, an exclusive domain of non-western medicine. Attribution of mental illness to supernatural possession drives individuals to seek care from traditional healers and other alternative folk practitioners and only when it is not working would they go to hospitals Khoury et al, (2012). These may be some of the reasons that may contribute to delays to access effective treatment.

2.10.6 Global assessment of functioning

GAF and negative symptoms were all found to be significantly associated with DUP. however, marital status, sex and whether the patient decided to seek for help or not were found not to be associated with DUP.

3.1 Duration of untreated psychosis and clinical outcome at 18 months follow-up

3.1.1 Introduction

First episode studies of schizophrenia have indicated that longer duration of untreated psychosis (DUP) has poorer response to antipsychotic medication (Loebel et al, 1992). These findings have led to the development of early intervention services in developed countries (Killack and Yung 2007) with a view to reduce the DUP. Furthermore the reduction in DUP was said to be associated with better clinical status at baseline which was maintained after three months (Melle et al 2004). In Norway, an early detection program reduced the DUP in a 2 year sample of first episode psychosis from median of 26 weeks to a median of 5weeks (Melle et al 2004). Here in

Malawi, we have observed that DUP is longer than that found in the developed countries, but whether this prolonged DUP impacts on clinical outcome as well is not known.

3.1.2 Methodology

As part of the ongoing research, each subject was re-assessed again later at 18 months by the researchers who had done the initial assessment. The instruments used included the structured clinical interview for DSM-IV axis 1 diagnosis (SCID). This was re-administered to ascertain the diagnosis and the symptoms, Scale for the assessment of negative symptoms (SANS) and scale for the assessment of positive symptoms (SAPS) were also administered to determine the severity of symptoms. The global social functioning was determined by administering the Global Assessment of Functioning (GAF).

Clinical outcome was defined as the improvement in the symptomatology both positive and negative and in the improvement of global function as measured by GAF scale. A reduction in the SANS and SAPS score was viewed as an improvement and an increase in the GAF score was also seen as an improvement in the social functioning. we computed the global ratings of SANS and SAPS for every individual subject and found the total global score of every subject at initial assessment and at 18 months follow-up assessment referred to as SANS 1 and SANS 2 and SAPS 1 and SAPS 2 and the scores of initial GAF and GAF at 18 months follow-up referred to as GAF 1 and GAF 2. Then the mean differences were determined and assessed whether these differences were significant or not at 5% significance level.

3.1.3 SAPS and SANS

The SAPS scale has a rating of 0 to 5 where 0 representing no symptoms at all; 1 questionable; 2 mild: symptom definitely present, but occur infrequently, at times the subject may question their existence; 3 moderate: symptoms are vivid and occur occasionally, they may bother the subject to some extent; 4 marked: symptoms are quite vivid, they occur frequently, and pervade the subject's life; 5 severe: symptoms almost occur daily and are very vivid and extremely troubling.

3.1.4 Analysis

Follow-up data were analysed and compared with the findings at the initial assessment. The analysis focused on whether DUP impacted on clinical outcome. Paired sample T-test was used to measure the significance of the differences between SAPS and SANS at follow-up and SAPS

and SANS at initial assessment. The same test was used for GAF at follow-up and at initial assessment.

3.1.5 Results

The size of follow-up data, between SANS, SAPS, GAF and time to treatment response (TTTR) varied. The demographic information with respect to these variables is displayed in tables 6 and 7 below.

107 subjects were re-assessed at 18 months after the initial assessment representing 79% follow-up rate. The number of subjects varied because of accuracy on recording on different variables.

Table 1: Demographic information

| | SANS (N=107) | SAPS (N=105) | GAF (N=106) | TTTR (N=85) |
|-----------------------------------|-----------------|-----------------|----------------|----------------|
| | n (%) | n (%) | n(%) | n(%) |
| Sex | | | | |
| Male | 68 (63.6) | 66 (62.9) | 70 (66) | 54 (63.5) |
| Female | 39 (36.4) | 39 (37.1) | 36 (34) | 31 (36.5) |
| Marital Status | | | | |
| Single (not married) | 55 (51.4) | 55 (54.4) | 55 (51.9) | 46 (54.1) |
| Married | 52 (48.6) | 50 (47.6) | 51 (48.1) | 39 (45.9) |
| Level of Education | | | | |
| Std 8 or less | 37 (34.6) | 36 (34.3) | 37 (34.9) | 27 (31.8) |
| Form I to Form IV | 62 (57.9) | 61 (58.1) | 61 (57.5) | 50 (58.8) |
| University or College training | 8 (7.5) | 8 (7.6) | 8 (7.5) | 8 (9.4) |
| | | | | |

| | | | | |
|-------------------|-----------|-----------|-----------|-----------|
| Age groups | 29 (27.1) | 28 (26.7) | 31 (29.2) | 23 (27.1) |
| <=25 | 16 (15.0) | 17 (16.2) | 17 (16.0) | 14 (16.5) |
| 26-30 | 13 (12.1) | 12 (11.4) | 12 (11.3) | 11 (12.9) |
| 31-35 | 16 (15.0) | 16 (15.2) | 16 (15.1) | 10 (11.8) |
| 36-40 | 11 (10.3) | 10 (9.5) | 8 (7.5) | 9 (10.6) |
| 41-45 | 22 (20.6) | 22 (21.0) | 22 (20.8) | 18 (21.2) |
| 46+ | | | | |

Table 7: Mean Age of Respondents

| | SANS (N=107) | SAPS (N=105) | GAF (N=106) | TTTR (N=85) |
|-------------------|------------------|------------------|-------------------|-------------------|
| Mean Age \pm SD | 35.4 \pm 12.39 | 35.4 \pm 12.46 | 34.88 \pm 12.53 | 35.22 \pm 12.43 |

It is observed that the proportions of subjects in their respective categories are almost the same. In addition, the mean age is approximately 35 years in all the four variables, SANS, SAPS, GAF, and TTTR.

The mean global of SAPS 1 was 7.88 STD deviation 3.333 and std. Error mean was .325. The number of subjects with the entire questionnaire properly completed for this variable was 105 (77.7%) of the subjects initially assessed, while the mean of SAPS 2 was 1.24 std. Deviation 2.525; std. Error of mean .246. This shows that the mean global score at initial assessment is

higher than at follow-up. The paired sample T-test was done to ascertain whether the difference in mean was by chance or real. Mean of the differences is 6.638 std deviation 3.871; t- 17.573; df 104; P=0.000. The same was done for SANS 1 mean 4.13; STD deviation 5.366; STD error .519 and SANS 2 mean 1.52; std. Deviation 4.122; STD error.399. Paired sample T- test is means of differences 2.607; std. Deviation 4.666; t 5.781; DF 106 p=0.000.

The mean GAF 1 was N (106) 52.48 GAF 2 72.21 std 17.077 std error mean 1.659 differences in means of GAF 1 and GAF 2 was 19.726; std 17.512; t-11.597; df 105; p=0.000

The results show that there is a significant improvement in both negative and positive symptoms as well as the global assessment of functioning (GAF) at 18 months. (See the table that follows :)

Table 8: Statistics of SAPS at Assessment (SAPS1), SAPS at Follow-up (SAPS2), SANS at Assessment (SANS1), SANS at Follow-up (SANS2), GAF at Assessment (GAF1), and GAF at Follow-up (GAF2)

| Variable | Mean | Sample size | Std deviation | Std error of mean |
|----------|-------|-------------|---------------|-------------------|
| SPAS 1 | 7.88 | 105 | 3.333 | .325 |
| SAPS 2 | 1.24 | 105 | 2.525 | .246 |
| SANS 1 | 4.13 | 107 | 5.366 | .519 |
| SANS 2 | 1.52 | 107 | 4.122 | .398 |
| GAF 1 | 52.48 | 106 | 9.795 | .951 |
| GAF 2 | 72.21 | 106 | 17.077 | 1.659 |

The number of subjects with the entire questionnaire properly completed for SAPS 1 and 2, SANS 1 and 2, and GAF 1 and 2 was 105 (77.7%), 107 (79.26%), 106 (78.52%), respectively, of the subjects initially assessed. It is observed from Table 8 that the mean of SAPS 1 is greater than the mean of SAPS 2, the mean of SANS 1 is greater than the mean of SANS 2, while the mean of GAF 2 is greater than the mean of GAF 1. Are these mean differences real or by chance? We carry out the paired sample t-test to ascertain whether the mean differences are real or are by chance.

Table 9: Paired Sample T-test for SAPS 1 and 2, SANS 1 and 2, and GAF 1 and 2

| Paired differences | Mean of the differences ± Std deviation | T-test value | df | p-value |
|--------------------|---|--------------|-----|---------|
| SAPS 1-SAPS 2 | 6.638 ± 3.871 | 17.573 | 104 | 0.000 |
| SANS 1-SANS 2 | 2.607 ± 4.666 | 5.781 | 106 | 0.000 |
| GAF 1-GAF 2 | 19.726 ± 17.512 | 11.597 | 106 | 0.000 |

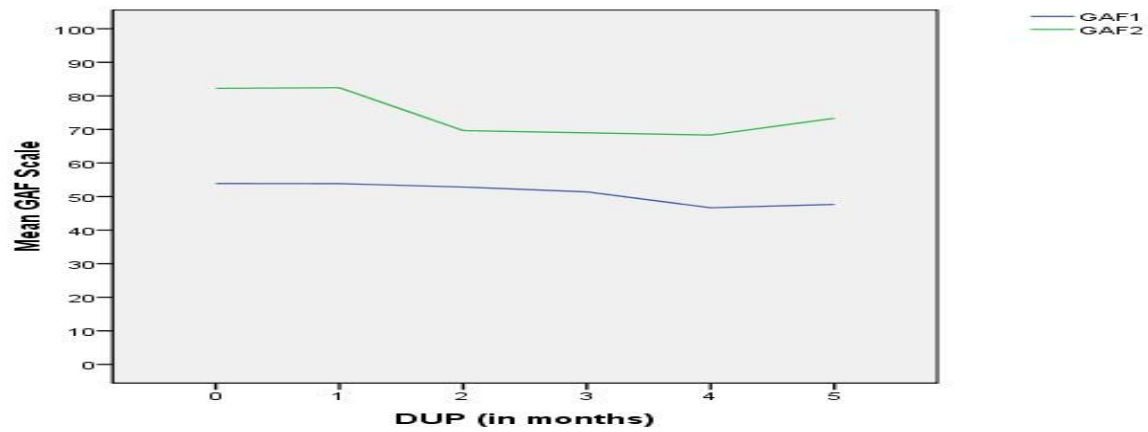
Table 9 shows that the mean of the differences (SAPS1-SAPS2; SANS1-SANS2; GAF2-GAF1) are all positive and significant at 1% significance level. Thus, there is sufficient evidence to conclude that the mean differences are real not by chance. Since the mean differences (SAPS1-SAPS2; SANS1-SANS2; GAF2-GAF1) are all positive, we conclude that there has been a significant improvement in positive and negative symptoms, and in global social functioning.

3.1.6 Changes in GAF scores in relation to DUP

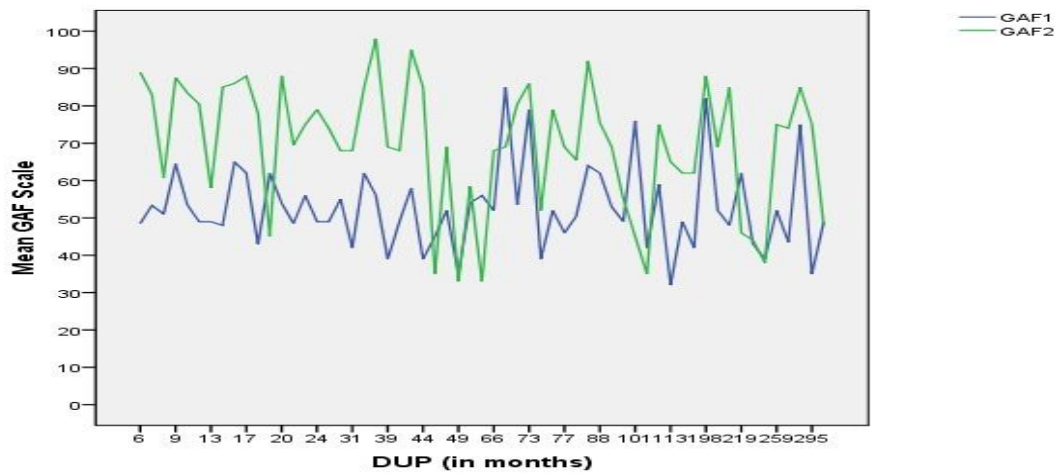
We examined the changes in GAF in relation to DUP. It has been observed that individuals with DUP less than six months had a bigger margin of improvement than those with DUP greater than six months. Furthermore for subjects with long DUP, though they made significant improvement they had frequent relapses than those with shorter DUP

See the graph that follows

(A) Changes in GAF for DUP 0-5 months



(B) Changes in GAF for DUP ≥ 6 months



All subjects with $DUP \leq 5$ months had their GAF improve significantly while subject with $DUP \geq 6$ months had only a few who made significant change in their GAF scale and others had

several relapses (see graph (A) for DUP ≤ 5 months and graph (B) for those with DUP ≥ 6 months). The graph seems to indicate that DUP moderately impacts on social functioning.

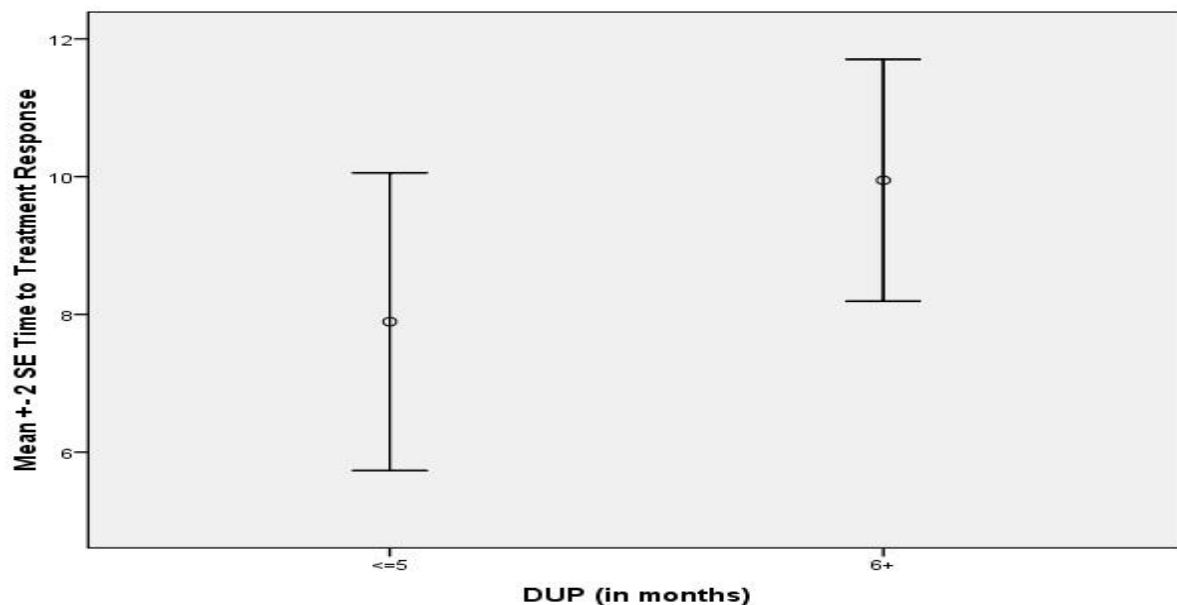
3.1.7 Does DUP impacts on Time to Treatment Response (TTR)?

We carried out an independent sample T-test in order to answer this question.

This test requires that the TTTR data of both Short and Long DUP subjects should be approximately normally distributed with a common variance.

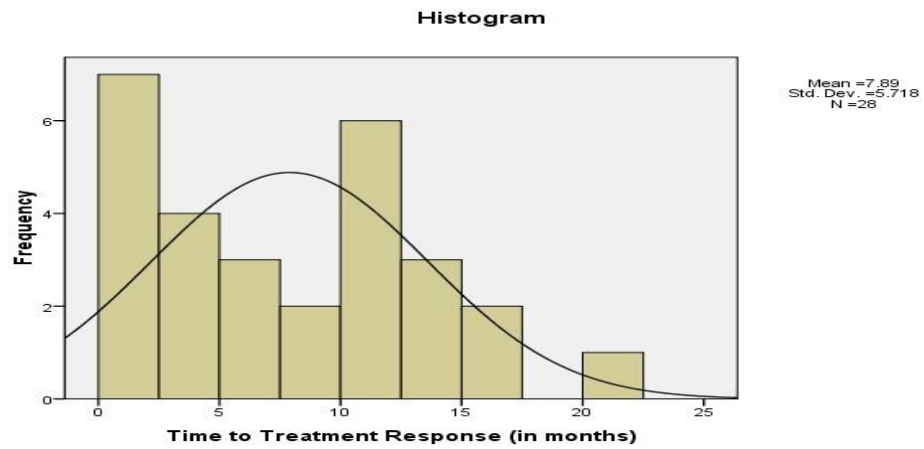
This test requires that the TTTR data of both Short and Long DUP subjects should be approximately normally distributed with a common variance. We construct a standard error graph for two DUP groups in order to see if the TTTR data are approximately normally distributed with a common variance. (See the graph below)

Standard Error graph for DUP Groups

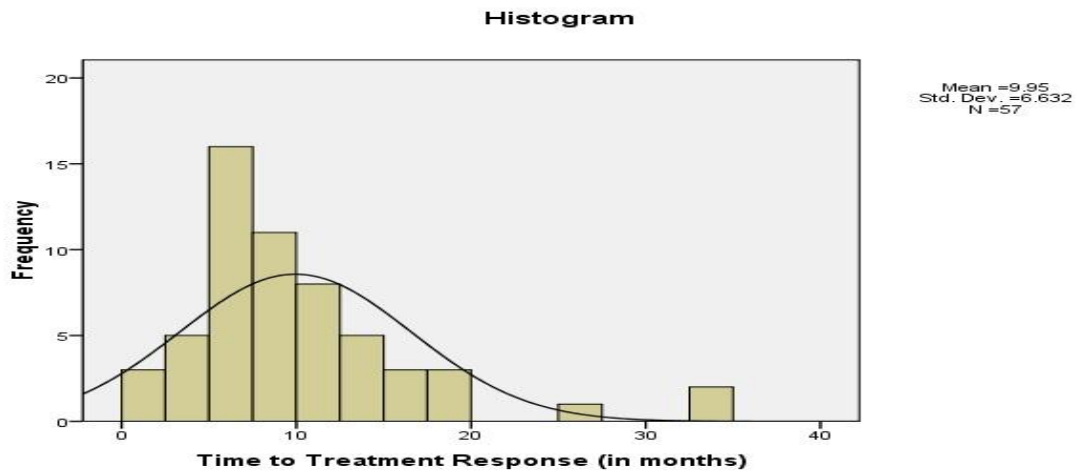


We see that both graphs have approximately the same shape with a mark in the middle dividing both TTTR distributions into approximately two equal halves. The approximately same shape suggests that the TTTR data for the two groups have approximately the same variance. We see the shape again in a histogram

DUP \leq 5 months.



DUP \geq 6 months



Indeed both histograms are suggesting that TTTR data for both DUP groups are approximately normally distributed. Now we test the homogeneity of variances (the condition that the variances are equal)

Test of homogeneity of variance

| Levene statistics | Df 1 | Df 2 | Sig. |
|-------------------|------|------|------|
| .025 | 1 | 83 | .874 |

The value $\text{Sig.} = .874 > 0.05$ in the test of homogeneity of variances indicates that there is significant evidence, at 5% significance level, that the variances of the TTTR for Short DUP and Long DUP subjects are the same.

Now we have seen that the TTTR for Short DUP and Long DUP subjects are approximately normally distributed with equal variance. This condition indicates that we can precede with the independent T-test which tests whether the two means from two independent samples are different.

Independent sample test for equality of means

| T-value | Df | Sig. (2-tailed) | Mean difference | Std-error difference |
|---------|----|-----------------|-----------------|----------------------|
| 1.402 | 83 | .165 | 2.055 | 1.465 |

The value $\text{Sig. (2-tailed)} = .165 > 0.05$ indicate that we cannot reject the null hypothesis that the two TTTR means are the same. Therefore there is enough evidence at 5% significance level that the mean TTTR for both DUP groups is the same. We conclude that DUP does not impact on Time to Treatment Response (TTTR). Therefore there is enough evidence that at 5% significance level the mean TTTR for both DUP groups is the same. We conclude that DUP does not impact on Time to Treatment Response (TTTR). (See the table below)

DUP in Months against Time to Treatment Response (TTTR) in Months

| | Time to Treatment Response (TTTR)-in Months | | | Total |
|----------------------|---|-----|----|-------|
| | 0-3 | 4-5 | 6+ | |
| DUP in Months <=5 | 8 | 3 | 17 | 28 |

| | | | | |
|-------|----|---|----|----|
| 6+ | 5 | 6 | 46 | 57 |
| Total | 13 | 9 | 63 | 85 |

This relationship is not statistically significant as the Pearson Chi-Square test was not significant at the 5% significance level ($\chi^2=5.825$, $df=2$, $P=0.054$).

3.1.8 Discussion

In this study we were interested in knowing what effects untreated first episode psychosis has on outcome at 18 months after starting effective treatment. Clinical outcome was defined as reduction of severity of symptoms and improvement in global assessment of functioning as measured by GAF. Unlike other studies (Loebel et al, 1992, Diana et al, 2005), we did not find longer duration of untreated psychosis (DUP) to be associated with improvement in symptoms at eighteen months (18) after commencing effective treatment. This may be due to methodological differences. In our study we reached out for the patients through our community campaigns on first episode psychosis and clinicians reviewed and treated patients in their own communities (homes). As Javier et al (2012) indicated, being treated at home in ones' own community has the importance of personal interactions in daily routines in the process of recovery. Social interaction in the process of recovery is important; it brings a feeling of being at home and being normal and hence may facilitates quick recovery. However, in this study we notice that those with longer DUP more frequent relapses than those with shorter DUP even though both patents had similar challenges such as shortage of drug supply. We think there are other factors that may impact on clinical outcome but not necessarily DUP per se, for example non compliance to treatment. Further research is probably required. Beng-Choon Ho et al, (2000) also did not find longer DUP to be associated with clinical outcome, a development which they say bodes well with patients.

This study also examined the effect of DUP on 'time to treatment response' (TTR). The findings suggest that DUP does not impact on TTR (See graph on appendix 1). It has been noted that 75% of all subjects responded to treatment within 12 months of treatment regardless of their DUP. However we notice that, in this study DUP has a modest impact on global social functioning in that subjects with shorter DUP had a bigger margin of improvement on GAF scale than those

with a longer DUP. Also that although there were some improvements in the GAF scale subjects with long DUP had more relapses than subjects with shorter DUP. Amminger et al, (2002) found that a long DUP was associated with certain cognitive deterioration in patients with first episode psychosis. Areas that were most affected included, visual motor functioning, processing speed and social functioning. Deterioration in these areas may affect the subjects' motivation to cooperate with clinicians which may lead to non adherence to treatment and hence lead to frequent relapses. Chow et al (2005) also found that DUP was correlated with poor adherence to treatment. It is important to establish whether it is the non-adherence to treatment that impacts on outcome.

4.0 Attitudes of the population at risk and their families to an early intervention concept:

Our main concern in this project is to investigate the duration of untreated psychosis and establish the attitudes of the group at risk and their families towards the concept of early intervention services. We now know that DUP in Mzuzu is long (4.3years) compared to the 1-2 years in the west.

The cultural traditions of people in Malawi provide a rich and diverse source of beliefs about the causes and nature of mental illness, and also appropriate forms of treatment embedded in the diverse forms of social practice. Our questions concern the extent to which these traditions have absorbed "western" or "modern" ideas based contemporary medical and psychiatric knowledge and the comprehensive educational activities provided by our team. Further to that, can these modern ideas simply displace traditional Malawian beliefs or do people in Mzuzu (Malawi) reconstruct these modern ideas in ways that allow them to co-exist with more traditional patterns of thought? We notice in our research that many individuals and their families went to traditional healers to seek for help. These people who seek help from traditional healers are more likely to have longer DUP.

One of the objectives of our research was to assess the population at risk of having a mental illness and their families' attitudes towards an early intervention service. In order to generate as many as individual's feeling' about any early intervention service, we asked people to describe the service that was provided by the research team. Then we asked them about their opinion on an early intervention which was widely discussed during the educational meeting we provided

early in the research. A question to start off the discussion was developed and probing questions were constructed.

“How would you describe the service provided to you by the research team?” “Do you think it is necessary and has it been useful to you and your family?” The interviewer listened to all explanations and recorded them as expressed by the interviewee ‘verbatim’. Answers were expected to provide us with information that we assumed would make us understand the peoples’ attitudes towards an early intervention concept.

During the follow-up we assessed 107 individuals 79% of the recruited subjects. The lost subjects at follow-up were not in any way different from the ones we assessed. Out of 107 we randomly selected 53 families from the sample. We conducted an interview with these families using open ended questions regarding an early intervention service. The question was how would you describe the services provided so far? Follow-up question was do you think an early intervention service is necessary? From these open ended questions clients and their relatives described their feelings about an early intervention service. From these answers we generated themes and subthemes:

Table showing themes generated from the interviews

| Themes | Subthemes |
|-------------------------|---|
| Accessibility | Long distance to nearest health facility Poor attention at health facility Traditional healers near to people |
| Suffering | Sleeping outside the house due to violence Damaging household property Beating any one |
| Poverty | Can’t afford transport to hospital Not seeking help even at traditional healers because of nothing to pay. Already have spent several cows as payment but no change |
| Compliance/side effects | Side effects (not performing at night) Client uncooperative to take medication |

| | |
|--|--|
| | |
|--|--|

4.1 Theme 1: Accessibility

This theme describes about the difficulties families in the rural areas have in accessing health facilities. The subthemes are about long distances they have to travel to a health facility. When they reach health facilities, the stigma they face.

As indicated early in the report, the issue here is that people in the rural areas have difficulties accessing mental health service hence alternative services like traditional healers are commonly consulted. So when people were asked to describe how they felt with the services provided by our research team and their attitude towards an early intervention service, many clients and their families as expected were very positive. Many family said this: *‘Tavwilika chomene na bovili uwu mwati phatsa, tikayendagha mitunda yitali chomene kuti ti vwilike kweni sono tikuvwilika muno muchikaya, nyengo zinyake tikanyamukanga muma 4 okolo namulenji nakukafika kuchipatala muma 10 okolo panyake 11 okolo kuti tisange bovili. Pala wovwili uwu bungalutula muvikaya vyitu chingawa makola’* ‘we have been helped a lot with this service which was provided right into our communities. We used to walk long distances to find help like this, sometimes we used to start off around 4 AM in the morning and arrive at a health centre 10-11 AM to find help and sometimes such help would not be available’

4.2 Theme 2: Suffering

This theme describes the suffering people go through if they are at home with someone with a mental illness who is not an effective treatment. There psychological suffering, physical suffering social suffering. Sometimes clients are beaten, rocked up in buildings to stop them from wondering around, they considered as outcasts in the community and dangerous people. Most importantly they do not live in peace even in their own homes. Some families said this:

‘Kwambula mankwala palinje chiweme, wa kwambana na muwoli wake pufupi-pafupi na kuchaya’. ‘Without treatment there was nothing good at home, very violent, always urging or quarrelling with his wife and sometimes beating her’.

4.3 Theme 3: compliance

This theme is describing the effect of the treatment we gave to those with mental illnesses (psychosis) and the change in their lives they experienced. However if medication run out and there was no resupply the symptoms would be worse. They need continuity in drug supply so that the sick remain stable for a longer time. The relationship while on treatment was good. Some families described it as follows:

Kwambula mankwala tikawa banthu chala, tikawa mumasuzgo, tikagonanga kuwalo navula, wakatchayanga na kuswa vinthu vya munyumba. Sono tikugona makola, kukhalila lumoza ngati banthu makola yene. Tili banthuko. Without treatment we were not like human beings, we were in trouble; we were sleeping outside the house in the rains. He was violent and was beating and breaking household utensils. This time we are like human beings. Another group of families said this: *Sono ndipo tikukhala ngati banthu. Timanyenge nyengo yeneyila nthena nkhamulondezyani. Takhala mumasuzgo nyengo yitali chomene. Chonde lutilizyani kutivwila.* Now we are living like human beings. Had we know that time we would have followed you wherever you were. We have lived in trouble for a long time. Please continue helping us.

4.4 Theme 4: poverty

This theme is describing how money affects their livelihood. Lack of money makes it very difficult to reach mental health facilities as they are very far from most remote communities and mental health in Malawi is not well integrated into primary health care programs. Even the alternative health care services are very expensive. One family says this: *Ise tindaonepo vinthu ivyo mwachita, kuti chipatala chilondole banthu mphaka muchikaya. Client: Timanyenge kuti banthu ba nthena imwe mulipo, nthena nkhusuzgika yayi kuti nisangike kuno ku n'ganga'. Parent: mwana wane uyu, naluzanayo n'gombe kujumpha seveni kwa a sin'ganga ba kupambana-pambana. Chiuta wabe namwe tikaluwako kuti tizamuwila lumoza mphaka kuyoghoskana. Tikutondeka kuluta kunyumba kwithu chifukwa ntchakuti a ng'anga a kukhumba kuti ti balipile n'gombe*

“We have never seen things you have done, for the services to follow people where they are”; Client: “had we known that there are people like you, maybe I wouldn't have suffered like this”; Parent: “with this child, I have lost more than seven cows paying different traditional healers. God be with you, we forgot all about this child that we would be together again

chatting''. This time we are at a traditional healer, we can't go home because the traditional healers want to be paid''

4.4 Discussion

One of our objectives was to know people's attitudes towards the development of an early detection and intervention service within the Saint John of God Catchment area. From these findings people in the rural areas have no access to mental health services; as a result they either use alternate health services (traditional healers) or stay at home untreated or suffer silently. Almost all the individuals we asked of their opinion regarding the establishment of an early intervention felt that the service would be a welcome development and that people with mental health problems would benefit a lot. The quotes illustrated above are a testimony of how people with mental health problems and their relatives have suffered or suffering without appropriate mental health services. The issue of accessibility of services is complicated with poverty, such that people can't travel to where there are mental health services because they cannot afford. The incorporation of mental health into PHC is the way forward to improving accessibility of mental health services in most rural areas.

4.5 Limitations

The general economic challenge that the nation was going through during the period of research affected some operations of the project for example; recurrent fuel shortages.

Persistent shortage of drugs in government hospitals, which led to clients missing treatment at some stage within the research period posed numerous challenges. This we think had some effect on the definition of effective treatment. The difficult to reach places made it difficult in rainy season and researchers were forced to give medication to guardians and their clients for a long time (three months supply). This made monitoring difficult.

4.6 Strengths

The researchers actually went into the community to enhance referral system to allow even those that had transport problems to access the information and help.

Researchers had a 24 hour telephones to pick up any referral which enhanced prompt and quick assessment of the referred clients.

5.0 Recommendations/ Further research

There is need for further research to find out what domains DUP impacts on other than the clinical outcome

Further research is needed to follow the subjects under study at 24 and 36 months and see how psychosis evolves at different time. A study is again required to see if education can change the beliefs about psychosis and whether pathway to care can change.

There is need to understand the explanatory model of psychosis in this culture.

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8.0 Appendixes

Fig. B

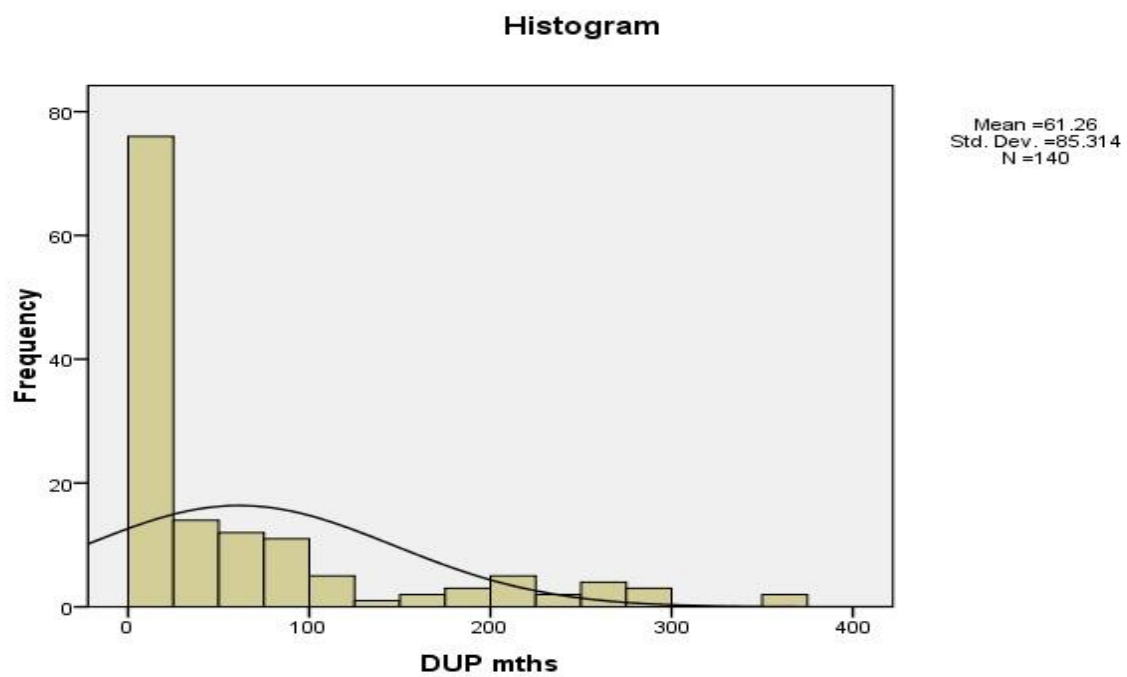


Fig. C

