SCHIZOPHRENIA OUTREACH IN LARKANO (SOUL):

Home based psychiatric services for Schizophrenic patients at Larkano Sindh, Pakistan

Joint project of Sindh Doctors Association (SDA) UK and Psychiatry Department, Shaheed Mohtarma Benazir Bhutto Medical University (SMBBMU)

Visit report by Dr Safi Afghan 27th November – 1st December 2011

The SOUL project has finally taken off the ground and my recent visit to Larkano when I met the patients and their family members, SOUL outreach nurse (Aurangzeb) and psychiatry department team led by Dr Badar Junejo; I was able to see vivid glimpses of a dream come true. The visit lifted my spirits and energy levels manifolds and I left Larkano as a rejuvenated and contented person.

It was during my earlier visit to Psychiatry Department Larkano in February 2010 that we first conceived the idea and dream of a developing an outreach service for schizophrenic patients. The broad framework of the project were agreed and announced on 25th December 2010 at the end of stakeholder consultation meeting organised by the Psychiatry Department of SMBBMU at Larkano and these were:

a) Recognition and treatment of identified patients with diagnosis of schizophrenia through stepped care approach – initially home based outreach treatment and stepping down to out patient based treatment.

b) Social recovery of patients through facilitating their inclusion in local employment / labour market by working closely with local agriculturists and businesses.

c) Provide education and awareness about schizophrenia to the immediate care givers, family members and local community

d) Generate clinical, functional and economic evaluation outcomes
We agreed to name the project as SOUL, which stands for ‘Schizophrenia Outreach in Larkano’. The abbreviated name is a passionate expression of the innovative work in the neglected area of mental health care provision in a region which carries legacy of selfless devotion to the cause of poor and downtrodden, martyrdom and courage in the face of oppression.

**27th November 2011**

Arrived at Moenjodaro airport which is located about 20 miles from the main city of Larkano. At the Airport, I had a chance meeting with Professor Akbar Haider Soomro, Vice Chancellor of the Shaheed Mohtarma Benazir Bhutto Medical University who was on his way to Karachi. During the meeting, I shared salient features of the SOUL project and its potential benefits to the local population in the Larkano region as well as academic and clinical profile of the University. Later in the evening, I was received by Dr Badar Junejo and team in Larkano, where we discussed the progress of SOUL project, schedule of meetings over the next three days.

**28 November 2011**

**Departmental training on outcome measures - BPRS, CGI and GAF**

Dr Junejo had organised a training session at his department in the morning on 3 rating scales, which are being used as clinical and social functioning
outcome measures in the SOUL project. These scales are Brief Psychiatric Rating Scale (BPRS), Clinical Global Index (CGI) and Global Assessment of Functioning (GAF). The training was jointly delivered by Dr Junejo and myself and was attended by most of the psychiatry department doctors as well as Aurangzeb, who works as an outreach nurse for the SOUL project. The first session was devoted to the BPRS, its layout, elements and clinical benefits. It was agreed to hold a second session to cover CGI and GAF as well as pilot the scales on couple of patients to give opportunity to the team doctors to become familiar with these scales.

It was agreed that I will send BPRS training PPT presentation to Dr Junejo so that this training is repeated for at least two more times (on 6 monthly intervals) for the benefit of department doctors and for new doctors and PG trainees.
Visiting patients and carers

The afternoon was devoted to visit some of the patients in their homes in the company of Aurangzeb, our outreach nurse. I was particularly impressed with Aurangzeb’s devotion, his rapport and communication skills with patients and carers as well as sensible record keeping and progress notes. I was able to visit 5 patients in their homes and spent time with them as well as family members. These visits helped me understand the magnitude of work in the area, need for further refinement and improvement in the project. The visit also helped review the patients progress and suggest changes in the treatment.
Lecture on Schizophrenia and evidenced based treatments to SMBBMU Consultants and local GPs

I had the privilege to spend the evening of 28th November to offer an interactive session on current concepts of recognition, diagnosis and biological and psychosocial treatments of schizophrenia with most of the senior consultants affiliated with SMBBMU, Larkano and about 5 local GPs. My presentation was followed by Q&A session. The meeting was hosted by Dr Badar Junejo and also joined by members of psychiatry department.

Presentation to Consultants and GPs on Schizophrenia

29th November 2012

Meeting with patients, care givers and representatives of NGOs / Media

The main event of my 3 day trip was to see the impact of the SOUL project as seen through the patients and family members through an interactive meeting for which preparations and date had been fixed in advance. The meeting started with brief address from Dr Junejo, providing an overview as well as progress on the project and encouraging the audience to give their feedback and suggestions for further improvement in the work. Dr Junejo also acted as a facilitator to get feedback from some of the patients as well as most of the care givers. The overall feedback was extremely positive in terms of improvement in the quality of life of patients and reduction in the burden of care for the family members. Dr Zulfiqar Rahujo, another active member of the department and
some NGO representatives also spoke on the occasion and gave valuable suggestions. Some of the photographs of the event have been included in the report. We intend to place the short edited version of the video on the website as well.

Photographs of the meeting with patients and caregivers held on 30th November 2011

With Dr Badar, Aurangzeb and others at Family and Carers Meeting on 29th November 2011
With Dr Junejo

Audience
**30th November 2011**

**Followup training session on BPRS, CGI and GAF**

Dr Junejo organised a followup training session on Wednesday 30th November 2011 for the psychiatry department doctors to pilot the rating scales on some of the in-patients of his department. This was a morning session that lasted from 10.00 AM to 12.30 PM and was extremely productive for the team doctors in better understanding and utility of the rating scales in capturing clinical and functional outcomes.

Training session in progress
Concluding meeting with Dr Junejo and team

At the end of my 3 day visit, I held a very constructive and productive meeting with Dr Junejo, Dr Rahujo, other team doctors and Aurangzeb to strengthen the SOUL project.

Following actions were agreed:

Greater Departmental involvement and ownership in the project

It was agreed to maximise engagement and involvement of the psychiatry department doctors so that the projects is fully owned by all. This will facilitate better coordination and communication among the department led by Dr Badar Junejo, Head of Department. Following initiatives were agreed:

a) Monthly meetings of the department doctors and outreach nurse on first Monday of every month

It has been agreed that Department of Psychiatry at Larkano will hold monthly meetings every Saturday afternoon to look at the progress of the project. I will also try to link up with the meeting via Skype which will provide me with the opportunity to be part of the discussion. The first meeting has been planned for Saturday 7th January 2011.

b) Providing honorarium to the doctors doing home assessments and follow-up

Doctor providing initial full assessment will be paid Rs 200.00 and Rs 100.00 for follow-up visits (they will be expected to complete the case notes, outcome measures and discuss the treatment plan with the patient, care givers and outreach nurse. If the doctor makes a total of 6 home visits in a year, the annual cost of honorarium will be Rs. 200 + Rs 500 = Rs 700.00

The doctors will be aware that the small amount of honorarium is not the exact value of their involvement, but is an attempt to cover the cost of their time and fuel spent in doing home visits (which they would not normally undertake as part of their usual job description).
c) **Record keeping**

i) **Clinical record keeping:**

A person having sound typing skills and computing know how (recording basic patient information, diagnosis, treatment, date of initial assessment with outcome measures (BPRS, CGI and GAF), follow up visits by psychiatrists with 4 monthly BPRS, CGI and GAF scores on XCEL spreadsheet.

ii) **Expenses record keeping:**

Monthly record keeping needs to be inputted by the same person under the heading of:

- Salaries
  - Nurse
  - Record inputting clerk
- Honorarium for doctor
- Cost of medicines
  - Depot injections
  - Tablets
  - Clozapine
- Stationary
- Website for the SOUL project
- Miscellaneous

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d) **Principles of antipsychotic medication prescribing**

One oral antipsychotic medication to be considered at any given time. The SOUL project team have agreed to follow the steps below as guideline:

**Step 1:** The team psychiatrist will initially start the patient on Haloperidol titrating the dose from 5mgs BD to maximum of 30mgs per day.

**Step 2:** In the absence of clinical response, new generation antipsychotics from groups Risperidone, Olanzapine, Aripiprazole or Amisulpiride
may be tried at the maximum prescribing doses only after withdrawing Haloperidol.

Step 3: In cases where patient is not compliant / adherent to oral medication or if the psychiatrist or the outreach nurse in their clinical judgement come to the conclusion that patient is unlikely to take the medication on daily basis, depot injection may be considered. The psychiatrist should aim to optimise the depot against clinical response and avoiding potential EPSE and secondary negative symptoms as well as depot as monotherapy. Rarely, a combination of depot with a low dose of new generation antipsychotic may be considered. In no situation, a patient should be prescribed three antipsychotics at a given time as their no research or clinical evidence that it is therapeutic. Moreover two or more antipsychotics prescribed increase the risk of neuroleptic malignant syndrome (NMS), reduced QT interval and Tardive Dyskinesia (TD).

Step 4: Procyclidine prescription: This should not be routinely prescribed. Initiall Procyclidine could be prescribed in the dose of 5mgs BD in the first month. In the absence of EPSE, it needs to be reduced to 5mgs once a day in the second month and then stopped in 3rd month.

e) Identifying treatment resistant cases for Clozapine prescription

Patients who fail to show adequate clinical response, i.e. 50% reduction in the BPRS scores, even after trial of 2 different combinations of treatments over a period of 6 months may be considered appropriate for the initiation on Clozapine treatment. The costs of Clozapine treatment for the patient will be higher (needs to be calculated and accounted in the SOUL project).

f) Booklet for patients and Carers in Sindhi

I met Pir Mazhar ul Haq, Sindh Minister for Education to discuss the publication of the Sindhi booklet on schizophrenia to be published through Sindhi Adabi Board and got his verbal agreement and approval. Makhdoom Saleemullah Siddiqui who works with Sindhi Adabi Board has already completed the Sindhi translation of the booklet. In case Sindhi Adabi Board is unable to do undertake this task, we have agreed
to undertake this through SOUL project funds. Rs 25000.00 – 30000.00 have been set aside for this purpose

g) **SOUL project website**

Dr Zulfiqar Rahujo has taken on board the responsibility to work towards developing SOUL project website on fast track basis. It is hoped that the website will be up and running within 8 weeks i.e. before 1st February 2012

h) **SOUL project fund raising in Sindh and Pakistan**

Dr Zulfiqar Rahujo has also volunteered to take up the responsibility for the website development. The main features of the website will be to share the salient features of the SOUL project, its activities demonstrated through photographs and video clips. The website will also be used for fund raising through PayPal etc and efforts will be made to link it up with Shaheed Mohtarma Benazir Bhutto Medical University, Larkana, SDA (UK), and the Royal College of Psychiatrists UK

i) **Hosting next assembly for families and care givers**

It was agreed that the next assembly may be held in June / July 2012, which could be held at an accessible community venue, in which patients and their family members will be asked to provide active input. The event should have entertainment and fund raising element as well as strong presence of media and NGOs

End of the report by Dr Safi Afghan

Email: safiafghan@btinternet.com