Summary of Depec workshop Kilimanjaro, Tanzania 2017

(5th October Arusha, 6th October Moshi)

This workshop took place as part of Tanzanian Mental Health week events

Senior clinicians/decision makers in attendance

Regional mental health coordinators x 2

District mental health coordinators x 3

Regional non-communicable disease coordinator x 1

Representative from the Ministry of Health (non communicable disease NCD) x 1

Acting Regional Medical Officer (Arusha district) x 1

Total attendees (outwith Depec team) Arusha - 37

Total attendees (outwith Depec team) Moshi - 21

Professions represented

Occupational therapy - 1

physiotherapy - 1

lab technology - 1

Nursing (general)- 12

Nursing (psychiatric)10

MBBS doctor psychiatrist -1

Psychiatric Clinical officers (Bsc Mental Health, working as doctors/ clinical officers with some psychiatry experience)- 8

Psychologist- 4

Local government representatives - 2

Physicians/assistant medical officers (3 year course)/ clinical officers (2 y course) - 3

Radiologists - 3

Workshop summary

In both the Moshi and Arusha workshops participants came from a wide variety of healthcare facilities. Many had travelled very long distances - a number of people described 14 hour bus journey home for example.

Workplaces varied from rehab departments and clinics at urban centres to very isolated rural clinics and delivery of monthly rural/remote mental health outreach clinics.

Each workshop commenced with a keynote introduction by the senior local representative present (this was the acting regional medical officer in Arusha, and the ministry of health representative/minister for non-communicable disease in Moshi).

This was followed by an introduction to the DePec project by Prof Walker and Dr Dotchin, and a summary of previous research work on dementia in Tanzania led by Dr Paddick.

The remainder of the workshop consisted of training sessions/lectures requested by attendees, and stakeholder discussions on priorities for dementia care.

Workshop outcomes/Outputs

1. Whatsapp group of Tanzanian clinicians interested in dementia and attending these workshops set up by Dr Paddick. This group is already active and discussing dementia risk factors and stigma related to mental health. Includes most clinicians attending the Moshi and Arusha workshops.

2. Formal request made by ministry of health representative attending meeting for us to host a further stakeholder meeting reviewing the current Tanzania mental health guidelines in 2018.

3. We have been in contact with Alzheimer's Disease International and are hoping to form a the first voluntary organisation for dementia care and support in Tanzania. ADI can offer a two year support and mentoring programme to help organisations for dementia to set up, under the umbrella of ADI until they can become true branches of ADI. They were very interested in the workshops and level of enthusiasm.

4. Stakeholder discussions on approaches to diagnosis and care currently for people with dementia in their local clinics and healthcare services.

5. Stakeholder discussions on barriers to dementia diagnosis, where resources should be focussed, current areas of strength and weakness in services as well as barriers to delivery of cognitive stimulation therapy (CST) for dementia.

6. Invitations for our team to visit the National Psychiatric Hospital in Mirembe and offers to collaborate on psychiatry projects

7. Plan for a follow-up smaller workshop in early 2018 to roll out dementia screening to other clinics in Tanzania (and set up voluntary organisation for dementia in Tanzania under ADI umbrella)

8. Formal meeting with District medical Officer (DMO) and approval to carry out DePec activities within the Hai district.

9. Meeting with Provost of KCMCollege and verbal agreement for Memorandum of Understanding with Newcastle University (which is in progress)

Other activities which took place during the workshop but were not directly related to Depec included a lecture and interactive session on depression in Old Age (Dr Paddick) and update on epilepsy (Prof Walker). These were provided at the request of the Regional Medical Officer who felt they were priorities for current staff development.

A presentation was also delivered by the local neuroimaging department at Mount Meru hospital during the workshop showing typical neuroimaging (CT/MRI) in different subtypes of dementia.

Stakeholder discussions on dementia

Moshi workshop

Current care pathways were explored through use of three case vignettes based on a rural setting. Participants were asked the following questions.

1. What do you think might be wrong?

2. what else might you want to know?

3. what will you do next.

It was stressed that answers were not a test or exam, and answers were used to explore available resources locally and challenges

Arusha workshop

At the Arusha workshop, participants were placed in smaller groups and asked a series of focussed questions on dementia care

1. What are the current barriers to dementia diagnosis

2. What do you feel your team or service do well in terms of dementia care

3. What do you feel could be improved in terms of dementia care/what does not work so well?

4. What resources are most needed or should be focussed on?

5. Are anti dementia drugs available locally?

6. Are any psychosocial interventions i.e. CST available locally for dementia? What would be the barriers to implementing this type of dementia treatment (if any)

Summary of Arusha discussion

Summary of main points raised in Arusha workshop/stakeholder meeting (this was held at a regional hospital with a psychiatric and rehabilitation department)

Awareness of dementia in the community and amongst healthcare workers is low. In specialist centres, staff do see people with dementia, but often for one appointment and at a time of crisis with severe behavioural disturbance. Families bring the patient wanting medication to calm them.

Greater training and access to training materials for healthcare workers, and support from policy makers and local community stakeholders are needed.

Building up of a skill base, by allowing staff to remain in posts they are trained for would help.

Medications for dementia are generally not available and most rely on haloperidol and other antipsychotics.

Family support is good and helpful, but families struggle in more severe dementia.

Mental health workers feel their main role is counselling, but often dont have time for this in their clinics.

Assessment of risk factors and particularly nutrition is felt to be useful

Most would use a dementia screeening app to aid diagnosis

Most if not all felt CST for dementia was a good idea, although resource and transport challenges to implement this were noted.

A summary of answers to specific questions is included below

1. What are the barriers to dementia diagnosis and care in Tanzania

Awareness of dementia is low

Dementia is not taught at undergraduate level

Clinicians see patients with symptoms but they are often not diagnosed

Patients rarely attend follow up and usually present in crisis with behavioural disturbance

There is no time for investigation or long term follow up of symptoms/or to take a long term view

Patients most often attend with physical symptoms such as pain rather than complaining of a mood or memory problem

Very difficult to assess cognition properly outside a specialist service (specialist clinicians pointed out that to identify 'cognitive lowering' they should assess both short and long term memory, other cognitive functions as well as sleep pattern and behaviour.

The most commonly used tools are the MMSE for cognition, and the BDI/BAI for mood and anxiety (within the specialist psychiatry service)

An app or tablet to aid diagnosis would be welcomed and would increase confidence amongst healthcare workers.

Culturally, people expect a cure when they see the doctor, and expect to leave with medication rather than returning for more visits.

A major issue is lack of public awareness of the problem.

People stay at home with dementia and don't access services.

There is concern amongst the public about strange behaviour being evil spirits or a punishment.

In contrast memory problems and slowing down are considered to be due to ageing. (also lack of awareness)

Due to this, people may not present to medical services, preferring to go to traditional or faith healers.

People also tend to present in late stages, rather than as soon as problems present.

Some general healthcare staff (not mental health workers) are worried about patients being aggressive – scared to touch them and tell family to take them to hospital

Mental health workers feel that a large part of their role is counselling, but they often don't have much time for this.

CT scans and MRI are only available in a few locations in Tanzania and are very expensive. Most people cannot access these. This is difficult for both patients and the clinicians trying to make a diagnosis.

What resources are most needed to improve dementia care in Tanzania?

Top down information from senior people/policy makers is important. If workers are asked by the Ministry of Health (MOH) and regional leads to prioritise dementia screening then they will be allowed to fit this in their work. Without involvement of policy makers it is difficult for healthcare staff to change things themselves.

Once dementia is detected, patients are referred to mental health department - There is a mental health department at Mount Meru Hospital in Arusha - but this is not possible elsewhere

Donepezil and memantine cannot be easily obtained - it would be useful if they were possible to obtain

No workshop participant reported access to dementia medications. The only medications available are haloperidol, chlorpromazine and amitryptiline

There should be a named place where these people can be seen, such as a psychiatric or geriatric clinic, or a named day in the medical clinic. At present they just attend general medical clinic.

Availability of trained personnel is difficult. People are trained, but then shifted to completely different departments which are understaffed meaning there is no continuity, and staff with specific training in mental health are lost to the department. Government policy needs to change in order to stop this.

More time in clinic available for counselling patients - often this is not possible due to staff and patient numbers and time constraints.

Transport issues prevent people accessing care in rural areas. This also causes difficulty in getting patients to come to follow up.

Health care workers dealing with mental health are needed generally.

In order to improve dementia care in Tanzania there must be engagement from local stakeholders, particularly local religious leaders and community leaders.

Awareness raising materials, including radio broadcasts and community days

It would be good to identify risk factors and treat these to prevent dementia.

People with dementia are often malnourished and we should intervene to improve nutrition.

What works well in terms of dementia care in Tanzania?

Social support within families

Nutritional support from clinicians when needed

Treatment for aggressive patients. This is Haloperidol/Modecate

We deliver symptomatic treatment based upon behavioural issues

Accidents are probably less common than in other places because people with dementia live with their family and are cared for.

Educating the family is prioritised and is done well where staff have been trained, because we have no access to treatments and no nursing homes

What does not work so well?

Talking to patients does not happen as much as it should

Most clients dont have insurance (this only covers working popukation)

Community health fund only allows patients to access rural health post or primary care, not specialist service

Investigations are difficult and family may not be able to pay

Families come in crisis asking for behavioural control and feel pressured to give haloperidol to make the patient calm

Follow up is difficult as we make repeat appointmnts but patients dont come back

Lack of awareness of dementia in the community

There are too few nurses and OTs

There is no medication available locally

There is a lack of knowledge amongst healthcare workers

Who looks after people with dementia in Tanzania?

Family provide most care

It was generally felt that extended family cope well in caring for their elderly relative with dementia, but as the duration of the disease continues they become less able to help, more tired and stressed and their level of care may tail off.

When patients with dementia come to hospital, medical doctors need to refer - not always anyone to refer to

Many patients seek help from traditional healers and spiritual healers as well as alternative medicines.

What are the barriers to conducting CST for dementia?

CST seems to be a good idea

Challenges will the there in remote areas due to transport and infrastructure difficulties

In urban areas, diagnosis is difficult

Cultural diversity (Masaai versus other cultural backgrounds) will mean that design of activities and current affaris discussion will be challenging

People will have different backgorund histories and social status

Availability of trained personnel is difficult. People are trained, but then shifted to completely different departments which are understaffed meaning there is no continuity, and staff with specific training in mental health are lost to the department. Government policy needs to change in order to stop this.

CST is possible in Mount Meru hospital (hospital with psychiatric/rehabilitation department)

Patients and carers would be happy to travel within Arusha area

All felt that cst had the potential to make a big difference in this setting and that community health workers could be utilised with training to deliver this.

Access to training was perceived as being an issue and that an online resource would be most useful, especially with reference guide that could be accessed.

People with dementia may need to travel with a relative- which will depend on the relatives work commitments

In order to implement CST, training will be important.

CST may need to be continued past 14 sessions. Who will implement maintenance CST and how?

Transport and access to materials and a suitable venue (general resource availability) may be problematic.

Summary of main points raised at Moshi workshop

This was held at a tertiary referral hospital (KCMC) but attendees came from all regions of Tanzania rather than from the hospital where the meeting was held.

Three case scenarios were used to guide discussion

These included one vignette of an elderly woman with moderate to severe dementia (undiagnosed, one vignette of a person with recurrent delirium, and one with moderate/severe depression

Attendees were told that these were not tests of clinical ability ot knowledge, but for us to understand together the pathways of care in tanznai

For each vignette, attendees were asked to indicate what they thought might be wrong, what else they would like to know, and what they would do next - with further discussion on challenges and difficulties as appropriate.

It was clear that there was a wide variety of experience and knowledge of these conditions amongst attendees.

The case history of depression appeared most challenging, with the majority not recognising that this was the most likely diagnosis.

General points raised were that patients would not attend follow-up, and would expect medication.

In the majority of cases, attendees felt that there was likely to be more than one diagnosis.

They generally felt that although they might not be sure of the psychiatric diagnosis, they would look for a physical cause within the resources available. For example they would offer blood tests for anaemia, HIV and syphilis.

They would also generally look at other complicating factors such as hypertension and diabetes by examining the patient and offer treatment.

There was a great emphasis on counselling and reassuring the patient and their family.

An important factor was that those attendees working in specialist centres (i.e. occupational therapy, or the national psychiatric hospital in Mirembe) clearly had extensive experience and knowledge of these conditions and were able to differentiate them (OTs as well as doctors/nurses). They were also able to describe a holistic care plan focussing on independence, collateral history from the family etc. Resource issues and lack of follow up attendance sometimes prevented this from being delievred, a problem which they thought might be partially addressed through educating communities.

The vignette of delirium was generally recognised as being due to a physical cause, although some attendees thought the desciption was of psychosis and would treat with haloperidol. It was generally agreed that they would test and/or empirically treat the patient for malaria, carry out other tests if possible such as glucose, HIV and syphilis, and if the patient were to have a fever they would admit or recommend admission.

Around 50% would admit a older person presenting with delirium, but this might be to the psychiatric rather than the medical ward.

The national psychiatric hospital has a medical ward for psychiatric patients with physical illnesses.

It was generally felt that a community mental health service would be helpful, rather than psychiatric care being concentrated in national centres.

Challenges of rural areas were noted. Some mental health nurse/mental health coordinators are covering vast geographical areas alone by attending each area once a month for a local clinic. A lot of work is dealing with patients presenting when very unwell.

As a group it was agreed that training materials with clear instructions on how to approach cases would be useful to standardise care

Inclusion of dementia and mental health prblems of old age in national guidelines would be important - as there are currently no guidelines and treatment varies in different areas.

Online materials that can be accessed at home would be useful.