Psychoeducation for patients with Bipolar Disorders in Rwanda

“Sinds mijn medische opleiding ben ik gepassioneerd door samenwerkingsprojecten” aldus Caroline Juhl Arnbjerg-Nielsen, Deense arts en promovenda. Ze vertelt dat haar interesse in het bijzonder werd gewekt door die projecten waarbij “Noord-Zuid”-partnerschappen betrokken zijn met als doel beide partners te versterken en langdurige positieve veranderingen teweeg te brengen.

Haar motivatie is altijd gericht geweest op het bestrijden van armoede en het verminderen van ongelijkheid; tekortkomingen die ze ziet als gevolg van onrechtvaardigheden en scheefgetrokken machtsstructuren in een samenleving. Naar haar mening is er één gebied dat treffend een voorbeeld is van deze maatschappelijke tekortkomingen en dat ook een van de meest verwaarloosde mondiale gezondheidsproblemen van onze tijd is: geestelijke gezondheid.

Toen haar voormalige afdelingshoofd van het Competence Center for Transcultural Psychiatry (CTP) - (een polikliniek in Kopenhagen die zich toelegt op het diagnosticeren en behandelen van complexe trauma-gerelateerde psychische problemen bij migrantenpatiënten) haar voorstelde een samenwerking in een promotietraject met een jonge Rwandese psychiater aan te gaan, was ze direct geïntrigeerd was.
Ze herinnerdt zich dat ze aan boord van de vlucht ging en dacht: "Dit moet de vreemdste onderzoeks-blind-date-opzet ooit zijn." In Rwanda ontmoette ze Dr. Emmanuel Musoni en binnen 3 weken hadden we een projectvoorstel opgesteld voor toepassing aan de Universiteit van Aarhus, Denemarken. Emmanuel is een expert in de lokale omstandigheden en de uitdagingen bij de behandeling van mensen met psychische stoornissen in Rwanda. Hij wist dat ze probeerden een psycho-educatieprogramma op te starten voor patiënten met een bipolaire stoornis, maar dat de effecten onbepaald waren. Dat werd ons uitgangspunt.

In november van dit jaar hopen Musoni Rwililza Emmanuel - een Rwandese psychiater en Caroline Juhl Arnbjerg-Nielsen - een Deense arts dan ook te beginnen met het verzamelen van gegevens in Rwanda in het kader van hun twin-promotietraject met als onderwerp "*Psycho-educatie voor patiënten met bipolaire stoornissen in Rwanda".* Uiteraard kan dit alleen als COVID-19-situatie in Rwanda stabiel blijft.
Geestelijke gezondheid en neurologische aandoeningen vormen 13% van de wereldwijde ziektelast (1). Het is alarmerend dat deze last de afgelopen 20 jaar met 41% is gestegen (2). In 2016 gingen 18,5 miljoen jaar verloren door een handicap als gevolg van psychische problemen in de Afrikaanse regio. Ter vergelijking: de ziektelast van infectie- en parasitaire ziekten in Afrika was in datzelfde jaar 13,1 miljoen jaar verloren door invaliditeit (3). Momenteel leven drie op de vier mensen met psychische problemen in lage- en midden- inkomenslanden, waar minder dan 1 op de 50 mensen met ernstige psychische stoornissen een evidence-based behandeling krijgt en in de meeste landen minder dan 1% van de jaarlijkse gezondheidsbudgetten wordt toegewezen aan geestelijke gezondheid (4–6).
Het algemene doel van dit project is het bepalen van het effect, de haalbaarheid en de aanvaardbaarheid van psycho-educatie voor patiënten met een bipolaire stoornis in Rwanda op districtsniveau en op het niveau van het verwijzingsziekenhuis. Bovendien zal de studie de huidige kennis en praktijk van zorgverlening aan personen met een bipolaire stoornis onder zorgverleners in Rwanda onderzoeken.

Het Deense onderzoek wil graag samenwerken met een lokale partnerinstelling in Rwanda ten behoeve 'capacity building', in dit geval met de Universiteit van Rwanda. Bovendien zal dit onderzoekzoals eerder genoemd een ‘tweelingmodel’ PhD-project (17) zijn met twee promovendi: Musoni Rwililza Emmanuel - een Rwandese psychiater en Caroline Juhl Arnbjerg-Nielsen - een Deense arts. Het tweelingmodel is gebaseerd op de principes van lokale 'capacity building' om hoge wetenschappelijke normen en participatie van lokale belanghebbenden te garanderen en voorkomt extractief(?) onderzoek en wetenschappelijk kolonialisme (17,18). Dit is in overeenstemming met de VN-agenda voor duurzame ontwikkeling, doelstelling 17 over partnerschappen (19). Het project brengt drie academische instellingen samen in een partnerschap: Aarhus University (AU), University of Rwanda (UR) en Copenhagen University (Competence Center for Transcultural Psychiatry).

Project aim

The overall aim of the project is to determine the effect, feasibility and acceptability of psychoeducation for patients with bipolar disorder in Rwanda at district level and referral-hospital level. Moreover, the study will explore current knowledge and practice of caregiving for individuals with bipolar disorder among care providers in Rwanda.

Project background

Mental health and neurological disorders constitute 13% of the global burden of disease(1). Alarmingly this burden has risen by 41% in the last 20 years(2). In 2016, 18.5 million years were lost to disability due to mental health problems in the African region. In comparison, the disease burden of infectious and parasitic diseases in Africa was 13.1 million years lost to disability that same year(3). Currently, three out of four people with mental health problems live in low- and middle- income countries, where fewer than 1 in 50 people with severe mental disorders receive evidence-based treatment and in most countries less than 1% of the annual health budgets is allocated to mental health(4–6).

Bipolar disorder (BD) is characterized by periodic episodes of elevated moods and depression, which co-occur with changes in activity or energy and is associated with cognitive, physical, and behavioral symptoms(7).

It is estimated that severe mental disorders (i.e. severe depression, BD, schizophrenia and other psychotic disorders) have a two to three times higher average mortality compared to the general population(8). Treatment rates for these disorders are low in low-and-middle-income countries (LMICs), where treatment gaps of more than 90% have been documented(9,10). This might explain why a considerable proportion – up to 50% - of individuals seeking care for mental disorders in Africa consult traditional and religious healers in their pathway to mental health care(11).
One of the major barriers in decreasing the treatment gap is the lack of human resources. In response to the shortage of health professionals, experts and WHO advocate that mental health care must therefore be delegated to non-specialist health workers, who are trained to deliver interventions for specific mental disorders(12,13).

In Rwanda, a Sub-Saharan country the size of Jutland and with around 12 million citizens, the total number of medical doctors specialized in mental health is 13 in the year of 2020. So far, no treatment

guidelines on mental health disorders including BD exist in Rwanda. To date, there is no data on incidence, prevalence or prognosis for BD in Rwanda.

The efficacy of psychoeducation as an add-on treatment to pharmacotherapy is well documented in the treatment of symptoms and in relapse prevention initiatives with respect to BD in western countries(14). Psychoeducation is believed to empower the patient to take an active role in the therapeutic process, thereby potentially reducing stigma, guilt, and helplessness, as well as improving medical adherence and to engage caregivers(15). Yet, no studies on psychosocial interventions for BD have been conducted in a low-income country(16).

Given the enormous shortage of skilled mental health professionals in Rwanda the question that emerges is whether simple interventions such as psychoeducation could potentially be decentralized from the referral hospitals and be at least as effective and acceptable as those delivered by specialist health workers at the referral hospitals.

Objectives and hypothesis

Specific objective 1: To collect descriptive data on inpatients at the only inpatient neuropsychiatric hospital in Rwanda as well as to collect data on the number of patients with BD receiving outpatient care at the referral hospitals in Rwanda. This descriptive information is crucial for understanding the service provision at the referral hospitals and the accessibility to intensive mental health care in Rwanda for patients with BD.

Hypothesis 1: We hypothesise that admission data and outpatient data will demonstrate a considerable unmet need for mental health in Rwanda.

Specific objective 2: To determine the feasibility, acceptability and effect of manual-based psychoeducation for patients with BD at the two national referral and teaching hospitals in Rwanda.

Hypothesis 2: We hypothesise that the psychoeducation at the top level of mental health care for patients with BD will improve outcomes.

Specific objective 3: To determine whether the establishment of a psychoeducation program for patients with BD at district level facilitated by district nurses, will be feasible and will show the same change over time as the psychoeducation provided by staff at hospital level.

Hypothesis 3: We hypothesise that psychoeducation conducted by district mental health nurses are feasible and will have a positive effect on patient outcome.

Specific Objective 4: To explore the perceptions and experiences with the mental health system among patients with BD as well as their relatives to obtain information that can identify different treatment practices, and their efficacy including the use of traditional healers.

Hypothesis 4: We hypothesise that patients with BD may have sought help other places than in the health care system for reasons like accessibility, stigma and culture. Moreover, we assume that they did not receive formal and evidence-based treatment before reaching the tertiary level of the health system and that the use of psychosocial interventions was limited.

Specific Objective 5: To assess the experience, knowledge and practice of caregiving for individuals with BD among traditional and alternative healers (TAH), community health workers (CHWs) as well as the mental health nurses at the district hospital. The assessment will contribute to an understanding of the feasibility of providing treatment for patients at the district and community level.

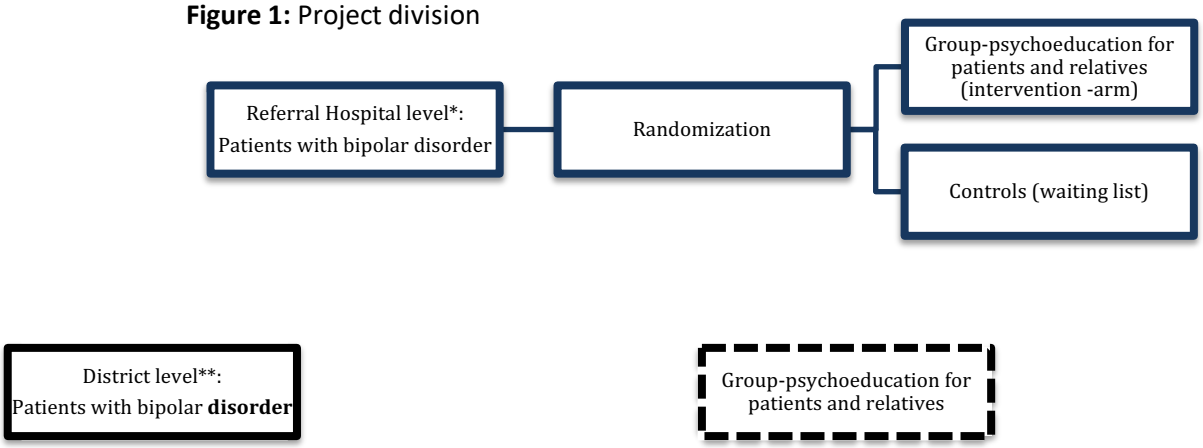
Hypothesis 5: We hypothesise that TAH as well as religious leaders are willing to collaborate with the formal health system. Moreover, we hypothesise that the CHWs and nurses want to provide evidence-based care including psychoeducation for patients with bipolar disorder but may lack the knowledge and skills

Study design

The study consists of **a quantitative part** and a **qualitative part.**

The quantitative part is divided into a prospective randomized controlled trial (RCT), and a district trial (Figure 1)

Figure 1: Project division



* A psychiatric nurse and either a psychologist or a psychiatric resident will conduct the psychoeducation.

** Two district mental health nurses will conduct the psychoeducation

____ RCT

-----The district trial

Study participants will be randomised to one of two groups 1) group-psychoeducation; 2) a waiting list. The RCT will take place at a referral hospital and a psychiatric nurse and either a psychologist or a psychiatric resident will conduct the group-psychoeducation.

The district trial compares the impact of psychoeducation given at district level with psychoeducation conducted at referral hospitals-
The primary outcome is reduction in symptom severity, incidence of relapse and hospitalization. Secondary outcomes include, improved quality of life and medical adherence and knowledge, as well as reduced self-stigmatization.

The qualitative part consists of focus group interviews and in dept interviews with patients, relatives and care providers. Data will be analysed to explore the experience, knowledge and practice of treatment for patients with Bipolar Disorder.

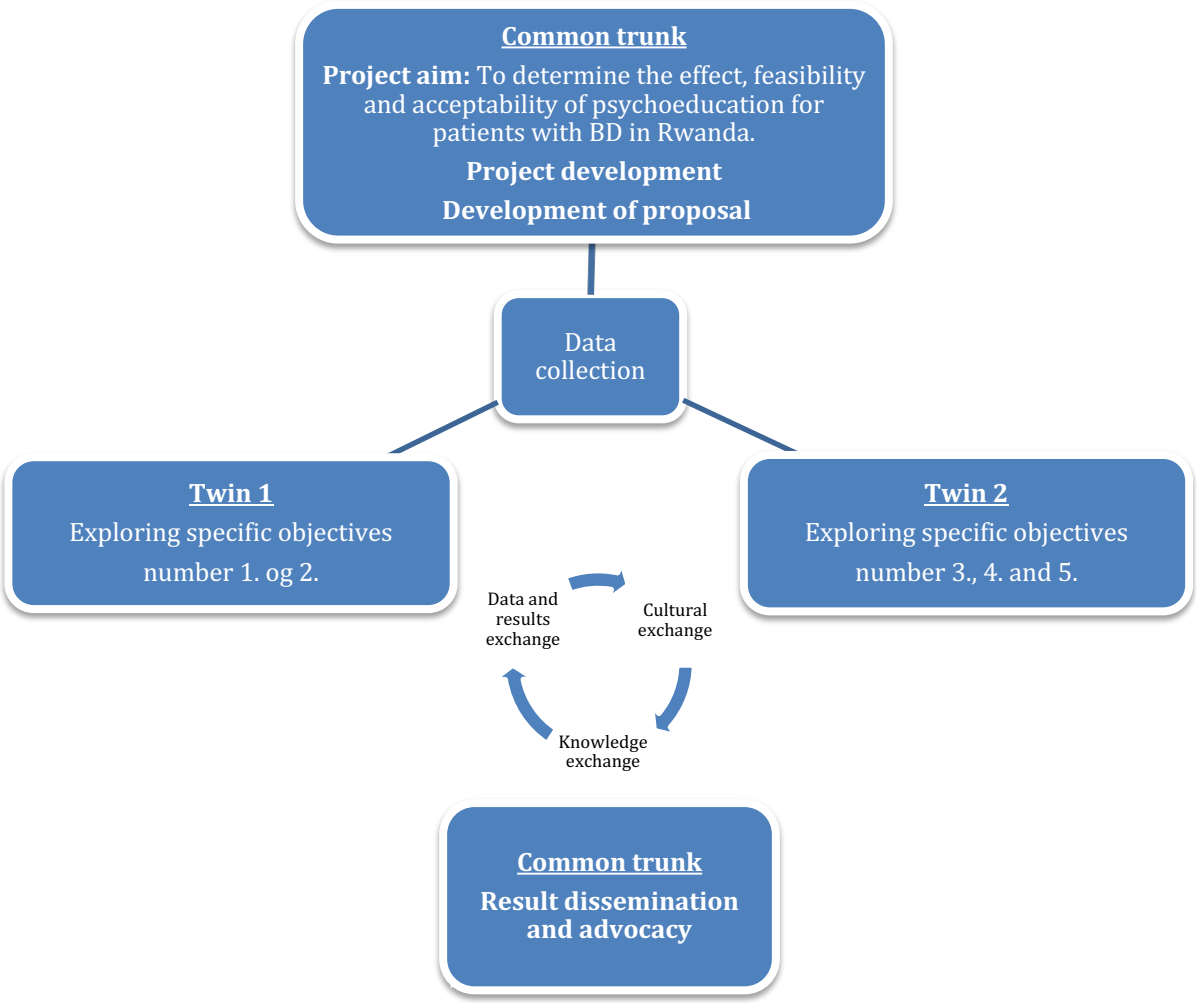
Ethical Approval

The research protocol and study-related documents will be presented to the Rwandan National Ethical Committee (RNEC) for approval prior to study initiation. Informed consent will be obtained from participants after oral and written information.

A "twin model PhD project":

To ensure general capacity building extending further than our research team, we collaborate with a local partner institution in Rwanda – University of Rwanda. Furthermore, this research will be a 'twin model' PhD project(17) involving two PhD-students: Musoni Rwililza Emmanuel - a Rwandese psychiatrist and Caroline Juhl Arnbjerg-Nielsen – a Danish doctor. The twin model is based on the principles of local capacity building to ensure high scientific standards and participation by local stakeholders and prevents extractive research and scientific colonialism(17,18). This is in line with UN's sustainable development agenda, goal 17 on partnerships (19). The project will bring together three academic institutions in a partnership: Aarhus University (AU), University of Rwanda (UR) and Copenhagen University (Competence Centre for Transcultural Psychiatry).

Figure 2: Twin-PhD-model



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