Investigating the influence of contextual factors in the coordination of chronic mental illness care in a district health system

Stanford Mandlenkosi Phehlukwayo¹, Joyce Mahlako Tsoka-Gwegweni²

1. School of Health Sciences, College of Health Sciences, University of KwaZulu-Natal, Durban, South Africa. Private Bag X54001, Durban, 4000. Tel: +27 31 260 7954 Mobile: +27 73 451 9004; Email: phehlukwayos@ukzn.ac.za
2. School of Nursing and Public Health, College of Health Sciences, University of KwaZulu-Natal, Durban, South Africa. Correspondence: Email: tsokagwegweni@ukzn.ac.za

Abstract

Background: The global shift from institution-based to community-based care for chronic mental illness (CMI) care resulted in the de-institutionalization of clients with CMI. However, health systems which have been originally designed for acute hospital-based care do not seem to be appropriately transformed to manage CMI care at a community level.

Aim: The aim of this study was to investigate how contextual factors influenced care coordination for chronic mental illness care within the eThekwini District.

Methods: This study employed a qualitative multiple case study design with instrumental approach. Maximum variation sampling was used to select five Community Health Centres (CHCs) and 48 health providers who worked with mentally ill clients in the sample CHCs. Framework analysis was used to analyze the results.

Results: Inequitably resourced catchment areas, unclear referral systems, high staff turnover, freezing of posts, chronic staff shortage and adverse working conditions contributed to care fragmentation, poor client care and client loss in the system. On the other hand, limited community support systems constituted barriers for client reintegration into society and relapses.

Conclusion: The study concluded that the eThekwini District health facility settings were not adequately equipped to respond to care coordination demands for chronic mental illness care.

Keywords: De-institutionalization, health facility settings, community support services, chronic mental Illness.

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Introduction

The global policy shift from institution-based to community-based system of care for chronic illness culminated into the de-institutionalization of people with chronic illness, including individuals with chronic mental illness (CMI)¹. However, the health systems which have been historically designed to respond to institution-based acute care seem to be poorly prepared to cope with the demand for community-based chronic illness care. When individuals in need of chronic mental illness care are de-institutionalized, healthcare tasks that were carried out by centralized hospital teams are shifted to a range of health service providers in community-based settings which are often fragmented, under-resourced and uncoordinated. According to the World Health Organization (WHO), the de-institutionalization of people with CMI is a complex process which must be accompanied by a network of alternative support structures outside the psychiatric institution¹². Currently people with CMI, who have been discharged into their community often relapse and get readmitted into hospitals due to poorly planned de-institutionalization and lack of care coordination in community-based settings.
Care coordination is a complex concept in that it is enmeshed in various aspects of health care. In essence, care coordination can be summarized as an integration of different services intended to manage a full range of care continuum across healthcare settings and between health service providers, patients and families. The complexity of care coordination implies that poorly managed patient transitions between healthcare settings and between healthcare providers can result in care fragmentation and an increase in the risk of non-compliance to treatment and re-admissions to hospital. Although empirical evidence shows that care coordination is associated with better managed client transition between healthcare settings and health care providers, there is still limited attention paid to care coordination. Research shows that care coordination leads to compliance to medication, better symptom control, improved mental health, improved functioning and decreased emergency re-hospitalizations.

Worldwide, mental disorders continue to contribute significantly to the burden of disease and disability with alarming statistics which have been projected for the next decade. In common psychotic conditions like schizophrenia, relapses are characterized by acute psychotic episodes which are accompanied by personal risk of self-harm; social risk of danger to others, biological risk of disease progression and deterioration in the level of function. The deterioration in clients’ level of function reduces their capacity to manage the condition which is accompanied by the burden of care.

Statistical records indicate that mental disorders account for nearly 12% of the global burden of disease and it is projected that mental illness will account for about 15% of the disability-adjusted life years (DALY) lost to illness by 2020. In addition, mental disorders which include schizophrenia, mood disorders, substance abuse and dementia are often co-morbid with many physical health problems such as cancer, HIV/AIDS, diabetes and tuberculosis. In cases where mental conditions are co-morbid with physical conditions, mental conditions are often marginalized because they are less overt or perceived as not life threatening. This marginalization of mental illness further exacerbates the burden of illness.

Locally, the KwaZulu-Natal Province (KZNP) still faces the task of uniting the structurally, functionally and geographically fragmented health care system inherited from the previous health care system. In the KZNP, psychosis alone ranks number 15 in the leading diagnoses seen in the public health facilities. A combination of the marginalization of mental conditions which are co-morbid with physical conditions and the historical backlog of fragmented care continues to contribute to the insidious increase in the burden of mental illness and the burden of disease.

The above background indicates that health systems do not seem to be adequately prepared to cope with de-institutionalized clients in community settings. The de-institutionalization process seems to be poorly planned and community based settings do not seem to be adequately resourced to cope with chronic illness care. Chronic mental illness care seems to be fragmented and poorly coordinated with resultant increase in the relapse rate, hospital re-admissions, burden of care and the burden of disease. This is indicative of a health system gap for chronic mental illness care at a DHS level. The purpose of this study was to investigate how contextual factors influenced care coordination for chronic mental illness within a DHS.

This paper constitutes Paper 2 of the main dissertation which investigated the healthcare system elements for CMI care coordination in the eThekwini District. The health care settings and the community support services constituted the care coordination context in this study.

Methods

The Study area

This study was carried out in the e-Thekwini District which is located in the KZNP of the Republic of South Africa. The high population density, the historically fragmented healthcare services and the geographically diverse catchment areas served by the District provided the unique contextual elements for investigating CMI care coordination in this District.

Study design

A descriptive instrumental multiple case study design
was utilized for this study. Purposive maximum variation sampling strategy was used to select the Community Health Centres (CHC’s) and the key informants for this study. Maximum variation allowed the selection of a combination of key informants from diverse geographical settings with diverse professional background that was likely to impact on participants’ views on contextual factors which influenced care coordination. A sample of five CHC’s which serviced geographically diverse catchment areas in the North, South and West sub-Districts was selected as illustrated in Table 1.

Table 1: CHC Profile

| SUB-DISTRICT          | SAMPLE SIZE | CONTROL AUTHORITY             | GEO. LOCATION                        |
|-----------------------|-------------|--------------------------------|---------------------------------------|
| South Sub-District    | 1           | Provincial & Local Authority   | Semi-Urban & Informal Settlement       |
| North Sub-District    | 3           | Provincial Authority           | Urban & Semi-Urban                    |
|                       |             | Provincial Authority           | Semi-Urban & Rural                    |
|                       |             | Provincial Authority           | Semi-Urban & Informal Settlement       |
| West Sub-District     | 1           | Provincial Authority           | Semi-Urban & Rural                    |

A sample of 48 key informants was drawn from various health disciplines who worked with CMI clients in the five CHC’s. The sample size for key informants was based on the minimum sample size guidelines for reaching saturation in qualitative research which ranged from 12-30 participants. See Table 2.

Table 2: The Key Informant Sample Profile (N= 48)

| SERVICE PROVIDER (n= % N) | CHC A Semi-Urban & In. Settlement (n= 10) | CHC B Urban & Semi-Urban (n= 11) | CHC C Urban & Semi-Urban (n= 10) | CHC D Semi-Urban & Informal Settlement (n= 10) | CHC E Semi-Urban & Rural (n= 7) |
|---------------------------|------------------------------------------|---------------------------------|---------------------------------|-----------------------------------------------|---------------------------------|
| Clinical psychologist    | 1                                        | 1                               | 1                               | 0                                             | 0                               |
| Community caregiver       | 7                                        | 6                               | 6                               | 6                                             | 5                               |
| Medical officer           | 0                                        | 0                               | 1                               | 0                                             | 0                               |
| Nurse                     | 1                                        | 2                               | 2                               | 2                                             | 1                               |
| Occupational therapist    | 1                                        | 1                               | 0                               | 1                                             | 1                               |
| Social worker             | 0                                        | 1                               | 0                               | 1                                             | 0                               |

Ethical approval and ethical consideration

Ethical approval for this study was obtained from the University of KwaZulu-Natal Biomedical Research and Ethics Committee (REF: BE 323/14). Gatekeeper permission to conduct this study was obtained from the eThekwini District Manager, the KwaZulu-Natal Province Health Research Committee (REF. HRKM 294/14) and the Health Facility Managers from all the CHCs who formed the study sample. All prospective participants were invited to participate in the study and provided with information on what the study entailed, which included the study benefits, their rights to participate or refuse to participate or withdraw anytime from the study as well as issues regarding privacy, confidentiality and anonymity. Prior to the commencement of data collection, all participants were required to sign an Informed Consent Form.
confirming their willingness to participate in the study. During data collection all interviews were conducted in an isolated room to ensure privacy. The study sample CHCs were allocated alphabetic codes and Key Informants were allocated numerical codes to ensure anonymity. During the interviews, all identifying information directly linking CHCs or key informants to the content of interviews was omitted or deleted from the transcripts, audio recording, the main report and all publications or presentations of this study to ensure anonymity. During data analysis, all hard copies of transcripts, field notes, CHC Health documents accessed during data collection and electronic data were kept in a locked cupboard and stored in a password protected computer respectively to ensure privacy and confidentiality.

All hard copies electronic raw data used for this study will be deleted or shredded after a period of five years of completion of this study.

**Trustworthiness**

In order to ensure research rigor in this study, the research adopted the four criteria for addressing trustworthiness as proposed by Guba in Shenton (2004) namely, transferability, dependability, confirmability and credibility. In this study design, transferability was ensured by a detailed description of the study setting (See Table 1 above) and a clear description of the study sample (See Table 2) using ‘thick description’. During data collection, dependability was achieved by a detailed documentation of the processes employed in the study and by developing the case study data base which could be reviewed by others to enable future researchers to emulate the same study. In order to ensure confirmability, the researcher took necessary steps to demonstrate that the findings had emerged from collected data and not from own predispositions. During data analysis credibility was achieved by looking for patterns in the data and across the data through pattern matching, and by comparing and contrasting data across respondents and data sources through triangulation. The recognition of the study limitations and their potential influence on the results, the in-depth description of the research methodology to allow for scrutiny of the research results integrity and the use of a diagram to illustrate the audit trail of the research process was used to reduce the researchers’ bias.

**Data collection**

Data collection was conducted by the Principal Investigator (PI) using one-on-one semi-structured interviews. Each interview lasted up to 45 minutes and data was collected over a period of one month from 08 December 2014 to 15 January 2015. Prior to data collection, the Interview Question Schedule was piloted on the key informants in a similar CHC which was not included in the study sample. All interviews were audio-taped and backed up with a summary of participant responses, field notes and direct observations of physical settings which were compiled immediately after each interview as outlined in Table 3.

**Data analysis**

Framework analysis (FA) using deductive reasoning was used to analyze the results. FA involves five stages of data handling namely, familiarization; development of an analytic framework; indexing and charting; summarizing data in an analytic framework and synthesizing data by mapping and interpreting. A total of three sub-themes emerged from the health facility settings theme namely, poor referral system and client cross-border migrations; poor health facility design and poor working conditions; and, high workloads. Poor Social Welfare support services; crime and emergency service disruption; socio-cultural and socio-economic factors constituted the community support services sub-themes.
Table 3: Data Collection Plan

| CARE COORDINATION DOMAIN | Care Coordination Contextual Factors |
|--------------------------|--------------------------------------|
| STUDY OBJECTIVE          | To investigate the influence of contextual factors on the care coordination of chronic mental illness care in a District Health System |
| DATA COLLECTION METHOD   | • Semi-structured interviews  
                            • Audiorecording  
                            • Observations & Field notes |
| DATA COLLECTION SOURCE   | Mental Health Service Providers |

| SEMI-STRUCTURED INTERVIEW SCHEDULE | Health Care Settings & Community Support System |
|------------------------------------|-------------------------------------------------|
|                                    | 1. **Health Care Settings**                      |
|                                    | • What is your opinion on your community based health settings for chronic illness (CMI) care in the District? |
|                                    | • Please describe the procedure followed when clients are discharged from Hospital into community. |
|                                    | • What do you understand by care coordination?  |
|                                    | 2. **Community Support System**                  |
|                                    | • What support services are available for CMI clients in your community? |
|                                    | • Do you get adequate support from management to adequately care for clients with CMI after discharge? |
|                                    | • What service delivery challenges have you experienced in caring for clients with CMI after discharge? |
|                                    | **Concluding Questions**                         |
|                                    | • What would you change about current facility settings and or care for clients with CMI in the District? |
|                                    | • Are there any other issues that you would like to comment on regarding CMI care? |

**Results**

This section presents results on the contextual factors which influenced the care coordination for chronic illness care based on the objectives of this study. The results are presented according to matching care coordination context elements from the study conceptual framework namely, the health facility settings and community support systems.

*Health facility settings*

Three sub-themes emerged from this theme namely, poor referral system and client cross-border migrations; poor health facility design and poor working conditions; and high workload.

*Poor referral system and client cross-border migrations*

Overall, results showed that the District catchment areas were inequitably resourced, fragmented and poorly planned. This was characterized by health service user (HSU) cross-border migrations between catchment areas and the neighbouring Districts, consultation of more accessible traditional medicine (TM) practitioners or confusion about the referral system amongst the HSUs.

“Our clientele is beyond our catchment areas. We serve clients from different catchment areas including other adjacent Health Districts” [Participant 5]

Poor health facility design and poor working conditions Observations showed that the health facility space was not appropriately designed to cater for service utilization and services provision. Poor signage or lack of signage made it difficult for clients to find their way around the facilities in some CHC’s. Some staff members worked...
under poor and unsafe working conditions which compromised the quality of healthcare. In one CHC, a health professional was allocated a medical examination cubicle as an office which doubled up as the “staff room” during lunch time. In the same CHC, three senior staff members shared a standard size office for one person. [Field Notes].

In at least two other CHC’s female staff held client consultations in confined office with psychiatric patients without any back-up security systems. [Field Notes].

At a community level, the CCG’s indicated that at times they worked with clients who had communicable diseases which were difficult to treat.

“We work under risky conditions. Sometimes the defaulting client has MDR. It’s easy for CCG’s to contract MDR”. [Participant 20]

In another CHC the Psychiatric clinic was located in a separate isolated building which was also not accessible by public transport routes. This was repeatedly articulated as a barrier to the transfer and sharing of client information between healthcare service providers.

“We are one institution in different buildings and that affects our communication. You find that in this clinic we do not have access to client information from the psychiatric clinic [Main CHC]. You only rely on the referral letter from the referring Discipline”. [Participant 5]

High workload
The high staff turnover combined with the freezing of posts frequently came up as a contributing factor for the chronic staff shortage and subsequent high workload. This negatively impacted on the continuity of care and poor quality of care for HSUs.

“Posts are frozen and do not get filled. This makes it difficult for people to stay in public health. This very discouraging and affects service delivery”. [Participant 2]

“Patients are not motivated to attend the clinic……. Patients end up defaulting and getting lost in the system. ….. when we eventually find the patient the patients will start complaining about poor service”. [Participant 19]

Community support services
Deficient basic Welfare Services, Crime and Emergency Service Disruption, Socio-cultural factors and Stigma and Socio-economic factors constituted the sub-themes which emerged from this theme. The findings from this study showed that the community support services necessary for effective integration of clients with mental illness into society were inadequate and not conducive to effective care coordination.

Deficient basic Social Welfare Services
The CCGs often used their personal funds to provide food for clients who were waiting for delayed food parcels from Social Welfare or to assist clients with transport fare to go to the clinic to fetch medication.

“You also find you do not even have food powder to give clients before taking their medication. I sometimes leave money for patients to buy food …….. Due to the delay of the food parcel process” [Participant 23].

Crime and Emergency ambulance Services disruption
The poor ambulance service was also exacerbated by security risks of Ambulance vehicle hijackings and other crime related risks especially in informal settlements.

“Ambulances notify us that their priority is emergencies for injured people…..We do not get any refunds”. [Participant 26] “Ambulance crew is concerned about their safety especially in an informal settlement. We end up using our money to provide transport”. [Participant 27]

Socio-cultural factors and stigma
The client’s capacity to manage own condition was compromised by the nature of mental health condition combined with the clients’ poor insight into the condition itself.

“In terms of carry over … that becomes a problem especially for psych… most of them discontinue treatment because they can’t cope with the change…” [Participant 3]

Some client admission procedures did not seem to take into account some accompanying risk factors which are associated with the mental condition itself.

“The suicidal and psychotic patients are emergency. You feel like you want to “do good” but the system won’t allow you to do that”. [Participant 2]

Socio-cultural factors
Some socio-cultural factors imbedded in some beliefs by certain families featured as the contributing factor in the disruption of client compliance to medication.
As well as [sic] in some households mental illness is regarded as taboo such that the person is hidden; which results in non-adherence to prescribed medication.” [Participant 19]

The extended family bonds in the case of clients from informal settlements necessitated some occasional visits to relatives in remote rural areas for undefined duration of time which was often done without any arrangements with the CCG’s or the clinic. This resulted in loss of clients in the system or non-compliance to treatment.

“After starting Rx with the clinic, some patients go back to their rural areas without notifying the clinic or requesting a referral letter for the local clinic”. The patient ends up defaulting”. [Participant 9]

Discussion

The main objective of this study was to investigate the contextual factors which influenced care coordination for chronic mental illness care within the eThekwini District. This discussion present the synthesis of the findings on the influence of health facility settings and community support services on the coordination of chronic illness care in a District Health System.

Health facility settings

A combination of inequitably resourced catchment areas and confusion about the referral system invariably contributed to care fragmentation and loss of clients in the health system. These findings reflected the challenge still faced by the KwaZulu-Natal Province, of uniting a structurally, functionally and geographically fragmented health care system inherited from the previous healthcare system10. On the other hand, recent research shows that consultation of TM practitioners remains high because it is embedded within contextual cultural and belief systems milieu, free from stigma and easily accessible26. In this study, the loss of clients in the system could be attributed to client consultation of TM practitioners who were more accessible and who understood the client culture.

Observations further indicated that some CHC layout were not appropriately designed to facilitate good quality of healthcare and staff safety. These findings were supported by recent research which showed that limited office space can impact negatively on client quality of care3,27. In spite of the research showing that working in isolation with mentally ill clients predisposed staff members to attacks by clients with mental illness, some staff members still worked in confined spaces without any backup security or support28. On the other hand, the occupational risk exposure to communicable diseases expressed by CCG’s highlighted serious concerns about the working conditions of these healthcare service providers.

The continuous staff turnover and the freezing of posts directly contributed to the chronic staff shortage and high staff workload in the CHC’s. This could be partly attributed to the Health District Human Resource Plan (HRP) which were not aligned to service delivery requirements and policy shift from institution based to community-based care11,29. According to Adnanes (2013), high staff turnover negatively influenced appropriate handover between health providers due to the nature and complexity of mental illness30. Similar studies identified stable services without breaks, seeing the same member of staff and coordination between different health providers as the pre-requisite for continuity of care30,31. A combination of these factors contributed to poor staff morale, the disruption of continuity of care or limited access to health care by clients.

Community support systems

This study further found that community support services (CSS) for chronic mental illness within the eThekwini District were still deficient. In terms of income support, entitlement and crisis response, the CCGs were faced with the burden of providing basic client subsistence and logistic support from their meager stipend due to delays in Disability Grant applications and the supply of food parcels. With regard to crisis support, poor ambulance service, failure to recognize mental illness as a priority and the security risk faced by the ambulance crew in informal settlements seriously compromised emergency response to client needs. These findings were supported by previous research which showed that the de-institutionalization of clients with CMI is often poorly planned and not accompanied by alternative support structures outside the psychiatric institution1,2,3.

Study Limitations

Although the objectives of this study were achieved, researchers were aware of some unavoidable limitations which could be addressed in follow up studies and future research. Even though the findings from a case study can-
not be generalized, the study design was rigorously documented to facilitate possible replication of these findings in similar settings. The scope of this study was limited to service providers perspectives and related support systems due to the critical role of these components in care coordination for CMI. The findings from this study will provide a necessary context for future research on studies incorporating service user perspectives on care coordination for CMI within a DHS.

Conclusion
The study concluded that the historically inequitably resourced catchment areas and poorly communicated referral system contributed significantly to care fragmentation and loss of clients in the eThekwini District system. The poorly planned health facility space and the working environments in client households which posed occupational risks for staff impacted negatively on client quality of care. The continuous staff turnover, the freezing of posts and deficient community support systems contributed to chronic shortage of staff, care fragmentation and poor reintegration of clients into society. This was exacerbated by the socio-cultural factors, socio-economic factors and multiple health service provider consultations by clients which were not coordinated within client treatment milieu.

Overall, this study concluded that the eThekwini District care coordination context was not adequately equipped to respond sufficiently respond to care coordination demands for chronic mental illness care.

Conflict of interest
All authors declare no conflict of interest.

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