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THE SIGNIFICANCE OF CONTINUITY OF CARE IN THE CONTEXT OF CHRONIC ARV CARE IN THE PUBLIC HEALTH CARE SYSTEM

Dr Jan Kuehne

Thesis presented in partial fulfilment of the requirements for the degree of Master of Family Medicine at the University of Cape Town

Promoter: Prof. Steve Reid

October 2012
I, the undersigned Jan Kuehne,
hereby declare that the work contained in this thesis is my own original work and that I have not previously, in its entirety or in part, submitted it at any university for a degree.

Signed by candidate

Signature

Date

2012/10/16
ABSTRACT

Continuity of Care (COC) is a fundamental concept in Family Medicine. The rollout of antiretrovirals in the primary care setting of the public health care system in South Africa was 'vertically' isolated from the other clinics. This isolation provides a rich environment to research COC. The present project describes the longitudinal COC in the Ubuntu ART/TB Clinic in Site B, Khayelitsha, which is one of the oldest clinics with a total of 6000 patients on ARVs since May 2001.

An observational period of the last five visits of patients to the clinic was used to measure the COC as a simple Continuity Fraction (CF) (alternatively called the Usual Provider Continuity/UPC), which was compared with more complex formulas for measuring COC including the K-index, SECON, COC-index and Alpha-index. The nature of the appointments was also explored, in terms of whether the patient was attended to by a nurse or a doctor and whether it was a proxy visit. Since viral loads are a very good indicator of adherence, they were compared to the COC over the observation period of the last five visits.

The data showed a nurse-driven clinic achieved a CF below 50% (0.5). The 0.5 COC score seems to be a benchmark for good COC, yet it is difficult to statistically verify. The CF scored higher than the other COC formula scores, yet correlated well with other COC formulae. The CF scores with nurses were more positively related to better virological outcomes than the other COC formulae, though none were statistically significant. Un-scheduled and proxy visits were not associated with higher VLs. The statistical test of General Linear Modelling with Poisson Regression with robust error variance could be an alternative way of proving that better COC has a measure of impact on the outcomes. Due to the different role of doctors, doctor visit(s) resulted in higher sequentiality scores, but a decrease in suppressed VL.

These COC scores also do not completely explain the good virological outcomes in this clinic, which is considered a well managed public sector clinic in Khayelitsha. The CF places a simple tool in the hands of a clinician at the primary level to measure individual provider continuity; however there is need to test its reproducibility in other contexts of chronic care in order to develop standards. The K-index emerged as a simple measure of the dispersion of the longitudinal COC within the nurse team managing the stable chronic patient. In a broader perspective, this study has put the measuring of COC onto the 'radar' of the public health system in South Africa.
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## NOMENCLATURE

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<tr>
<td>ARV</td>
<td>Anti-retrovirals, commonly used abbreviation for the drugs used in ART</td>
</tr>
<tr>
<td>ART</td>
<td>Anti-retroviral therapy, is an abbreviation used interchangeably with ARV</td>
</tr>
<tr>
<td>COC</td>
<td>Continuity of Care</td>
</tr>
<tr>
<td>Club</td>
<td>Refers to patients who are part of the Adherence Clubs of the Ubuntu Clinic</td>
</tr>
<tr>
<td>COC Scores</td>
<td>Refers to the scores of the CF, K-index, SECON index, COC-index, and Alpha-index as calculated by means of COC formulae</td>
</tr>
<tr>
<td>Continuous</td>
<td>The patient attended all five visits</td>
</tr>
<tr>
<td>Non-club</td>
<td>Refers to the majority of patients in the Ubuntu Clinic i.e. those who are not members of an ‘Adherence Club’</td>
</tr>
<tr>
<td>OI</td>
<td>Opportunistic Infection e.g. Tuberculosis</td>
</tr>
<tr>
<td>Proxy visit</td>
<td>The patient was absent from the visit and sent a family member/friend/neighbour to fetch his/her medication</td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>VL</td>
<td>Viral Load is the name of the test that determines the number of viral copies/ml of blood. ‘Suppressed VL’: The definition used in this study is below 1000 copies/ml (unless otherwise stated); ‘Raised VL’: Any single VL that is more than 1000 copies/ml</td>
</tr>
</tbody>
</table>
1. INTRODUCTION

Background

Continuity of Care (COC) is a 'fundamental' concept of Family Medicine\(^1\), yet it has not been a concept that has been easily measured or standardised to be generalisable\(^2\). The context of this research is the Ubuntu (Site B) ART/TB Clinic in Khayelitsha, which is a peri-urban resource-limited settlement outside Cape Town. The clinic has been rolling out Antiretroviral Therapy (ART) since May 2001, i.e. several years ahead of official sanction by the *National Health Policy* in 2004\(^3\). The feasibility and effectiveness of ART had been proven in the Khayelitsha context\(^4\); however the new challenge is to expand the programmes within and beyond 'saturated'/or 'high patient burden' clinics was stated in the *Khayelitsha Report 2009*\(^5\), i.e. developing strategies to keep patients remaining in care. By mid 2006, the numbers enrolled in the three Community Health Centres (CHCs) in Khayelitsha began to plateau and the numbers of people 'lost to follow up' (LTF) was increasing. Both are indicators of service saturation\(^6\). At the end of 2007, the Ubuntu Clinic, which is the largest ART clinic in Khayelitsha, initiated the development of the 'Adherence Club' concept\(^7\). The ‘Adherence Clubs’ were to fulfil a number of objectives: increase clinic fast-tracking; maintain retention; continue and increase knowledge; increase adherence; increase openness and mutual support. The ‘Adherence Clubs’ were designed for patients who had achieved VL suppression at or after 18 months of ART, had a good clinic visit record and no concomitant opportunistic infections (OI). The validity of the ‘adherence club’ as a model for retaining ‘stable’ patients in Ubuntu is being investigated by *Médecins Sans Frontières (MSF)*, and enrolment was stopped to assess it. According to MSF, “The greatest challenge for the scale-up now is how to retain patients in care over the long-term, while at the same time increasing enrolment on ART”\(^8\). However, to date only a minority of ART patients at the Ubuntu clinic are members of an ‘Adherence Club’; most of the patients in Ubuntu are still

---

* “Adherence clubs are group clinic visits run by lay health workers who dispense pre-packed ARVs. Adherence Clubs are available on a voluntary basis for adult patients stable on ART for 18 months or more and with the two most recent viral load results being undetectable. Clubs comprise a maximum of 30 patients who meet every two months. On club days the group meets in a room, where members are weighed and asked for any signs and symptoms of opportunistic infections or adverse events. A talk is given from a list of topics prepared in advance; in some cases, the group will ask for a particular topic to be discussed. If safety bloods are required, patients are first referred to the nurse for bloods, and then given their pre-packed medications. The aim of the clubs is for patients to be in and out of the facility within 2 hours. Should a person develop a problem, whether an opportunistic infection, a serious adverse event or a detectable viral load, or in the event of a person missing 2 or 3 consecutive club dates, they are referred to a clinician for more intensive follow up.” (Khayelitsha Report 2008-2009:20)
non-club members. The Ubuntu Clinic in Khayelitsha therefore has two different management strategies for patients who are in need of chronic care. In this regard, the majority of patients of the Clinic most probably experience a chronic care management that is reflective of the majority of patients on ART in the South African public healthcare system.

Problem
The goal of chronic ARV care is to create adherence to ARVs which results in viral suppression. As will be shown below, various international studies suggest that there is a positive relationship between COC and outcomes of care. However, literature from the African context on this topic is extremely scarce, and no studies on longitudinal COC exist in Africa in relation to HIV. Only one study internationally measures longitudinal COC in a HIV setting but even that study does not relate COC explicitly to VL outcomes.

The present lack of knowledge in the context of the South African public health system on this topic is problematic, given the potential of COC. The lack of knowledge seems to derive from three interrelated problems. Firstly, the level of continuity of care in the public health care system in South Africa in general, and at the Ubuntu clinic in Khayelitsha in particular, is not systematically measured. Secondly, there are a number of competing indices for measuring COC, some of which have a level of complexity that may be considered prohibitive for their application in a primary health care setting. Thirdly, and likely as a consequence of the foregoing, in current discussions on changing the landscape of public health care in South Africa, COC hardly features.

Without the development of a feasible tool to measure COC in the context of the public health care system in South Africa, and without concrete evidence of the relation between COC and outcomes of care, it will be difficult to substantiate arguments in support of COC in the ongoing development of the public health care system in this country, from high-level policy down to the day-to-day running of a clinic.

Justification
The Ubuntu (Site B) Clinic in Khayelitsha, with its two different management strategies for patients in chronic care, therefore provides a rich environment to test the feasibility of a COC measurement tool. Provided that the rollout of anti-retrovirals (ARVs) in South Africa has been implemented in a vertical system separate from the normal health system and the fact that ARVs demand COC in so many different ways e.g. pre-ARV initiation by counsellors, the
nurse-based care, and problem-based care by doctors, studying COC in an ARV clinic provides an opportunity for developing a greater understanding of COC in this context. Since the goal of an ARV clinic is to create an environment in which adherence to ARVs results in viral suppression, it also creates an environment to test the feasibility of a COC Measurement Tool or Index as a potential measure of COC and its relation to adherence.

The Statement of Consensus on Family Medicine in Africa⁷, establishes a professional imperative to ‘articulate’ the principles of COC into the health systems in Africa. The South Africans’ Rights Charter states: ‘No one shall be abandoned by a health professional worker or a health facility that initially took responsibility for one’s health⁸. As Bresick notes though this ‘does not necessarily imply individual continuity, it alludes to an ongoing relationship with a health service and a health professional as a patient’s right⁹. Measuring the practice of continuity in Ubuntu clinic is in recognition of this right and hopefully influences interventions in the development of the Khayelitsha district health care system, in keeping with WHO strategies for comprehensive disease care in the developing world¹⁰,¹¹.

The future of the re-engineered primary health care system should focus on a chronic care model that favours continuity. As the clinic increases in size, patient choice regarding continuity of care with a single health professional will be challenged. However, patient preference for a specific practitioner should not be prevented⁹,¹². This will require a greater emphasis on existing COC within the clinic, and adapting our clinic systems in line with this, to encourage optimal continuity with the same provider. The creation of practice teams as proposed by Bresick could also improve continuity⁹. Furthermore, policy should be developed for defining standards that are generalisable for district health systems in South Africa. The need for life-long regular follow-up due to the challenge posed by stable patients on ART¹³; this is an opportunity to invigorate the health system in South Africa with the principles of Family Medicine.

To describe COC in the context of chronic ARV care in the public health system need not focus on a universalistic abstract approach; rather it can focus on the empirical setting of traditions that measure COC. The concept of COC is contested and thus different methodologies have evolved to measure it¹⁴,¹⁵. This study aims to describe the use of an ‘easy-to-do’ mathematical fraction for continuity with one provider. Hence, the focus of this research is on using a simple ‘Continuity Fraction’ as an index of continuity that measures the
maximal visits to a single provider in the last five visits. In international COC literature, this formula is typically called the Usual Provider Continuity Index (UPC). Other formulae of COC either analyse sequential visits or the sum of Continuity Fractions in various ways. This potentially increases the complexity of the methodology.

In order to verify the use of the Continuity Fraction (CF) it will be compared to other known continuity indices, namely the K-index, SECON, Alpha-index and COC-index. However, all these formulae do not measure what is called Relational Continuity or Interpersonal Continuity in terms of the nature the relationship including aspects such as loyalty and trust. Since limited research on COC has been conducted in the South African public health system, this project will focus on the longitudinal dimension of COC. "What proof is there that a continuous longitudinal relationship improves the quality of health care?" is a question posed by the protagonists of COC. The use of a primary care measuring instrument of the Continuity Fraction is precisely motivated out of the understanding that clinics on a primary level are busy. The literature consistently shows a positive relationship with COC, but standards are neither set nor are they generalisable. It is therefore the intention of this research to test the Continuity Fraction as an index of COC in the chronic care setting of Ubuntu ARV Clinic.

Research Aim and Questions

The aim of this study is to describe COC in the context of chronic ARV care in the public health system with specific reference to the Ubuntu clinic in Khayelitsha. The main research question guiding the research is: What is the most feasible indicator by which continuity of care can be measured in the South African public health sector? In addition, related subsidiary questions seek to determine the following:

- Is there a significant difference in COC between Adherence Club members and those not in Clubs?
- Are VL outcomes related to COC?
- Is there a significant difference in COC between nurse-based and doctor-based care?

The study also explores certain other factors that may influence COC and VL outcomes.
Structure of the Thesis

This chapter has introduced the background, problem, justification and research aim and questions of this study. In the next chapter, the literature review focuses on the how the burden of HIV/AIDS is impacting and shaping public health systems, including a review of strategies that are evident to deal with the related challenges. The concept of COC in the public health system is highlighted in terms of how increased government concern and intervention into health systems may be at odds sometimes with the concept of COC. Though COC is highly regarded, it seems not to be gaining traction in the public health system. The review also considers different definitions of COC, which have been debated in family medicine and have contributed to different kinds of research and measuring instruments. Various indices of COC are presented. And finally, literature on the relationship of COC with improved outcomes is discussed.

Chapter 3 presents the clinical setting of the study and chapter 4 looks in detail at the methodology. The study is designed as a descriptive cross-sectional study using a review of patient records in the clinic. The chapter further presents the research aims and questions, key definitions, key issues related to the sampling of records, data capturing, data management, analysis and interpretation.

The analysis and results of the data is presented in chapter 5. The analysis is structured according to different sub-samples, and includes an analysis of descriptive data, COC scores, VL outcomes, the influence of doctors, appointment dates and proxy visits. The analysis uses graphs, correlation tests, means and medians, binary analyses, and general linear modelling.

The results are discussed in more depth in the final chapter. Here, the research aims and questions are considered in the light of the existing literature on the topic and the findings of this study.
2. LITERATURE REVIEW

The literature review will survey chronic care in relation to the HIV/AIDS epidemic and the public health care system. This serves as a backdrop for research in continuity of care in the public health care system, particularly an enquiry into past literature on the definition and measurement of COC. Additionally how the concept of COC relates to adherence is investigated.

HIV/AIDS and the Public Health Care System in South Africa

Since the start of ART rollout in sub-Saharan Africa, it is estimated that 60% of patients were retained at the end of two years; the loss of 40% of patients is being attributed to LTF (lost to follow-up) and death. South Africa comprises 0.7% of the world's population yet has the greatest known number of people with HIV/AIDS: 5.5 million people representing 17% of the South African population. South Africa now has the largest ART program in the world, with 871,914 patients in chronic care by July 2009, who are going to need life-long regular follow-up. The related challenge is well articulated by van Damme:

"AIDS poses a challenge for health systems that is fundamentally different from all of the other health problems ever faced. Transforming a deadly disease into a manageable chronic one turns millions of people into chronic patients, in need of life-long regular follow-up. This implies that present efforts and commitments will have to be continuously increased for many years to come."

Therefore a new kind of care is required in Africa involving a chronic disease model which does not focus merely on the acute management of patients.

"How will health systems adapt?" is the question in relation to the scaling up of ART in Southern African where there is also a scarcity of health professionals. Presently the ratio of health care workers to population in South Africa is low (doctors 77/100,000 and nurses 408/100,000). On the one hand, this compares favourably with the WHO minimum standard (doctors 20/100,000 and nurses 100/100,000). On the other hand there are huge disparities within South Africa: there is an urban/rural and public/private mismatch, the latter is indicated with 79% of doctors working in the private health care sector according to a 2009 Lancet series on the Health in South Africa.
Among the adaptation strategies described in the literature is 'task shifting'. Dolvo describes task shifting as delegating from professional health workers to non-professional cadres, with some of the functions and roles normally kept for internationally acknowledged health professionals such as doctors, pharmacists and nurses. Task shifting is not only a strategy to deal with the scarcity of health workers, but it is even considered a way to improve adherence and quality of health services. Thus, the delegation of tasks required for the initiating and maintaining ART to health workers with lower qualifications has been mooted as a solution to the poor distribution of doctors in Africa and South Africa. According to the Khayelitsha Report 2001-2011 Activity Report, in UBUNTU ARV/TB Clinic the process of task shifting has only progressed as far as that the management of the bulk of stable patients on anti-retrovirals has been shifted to nurses, including the nurse-supported community health worker-driven Adherence Clubs.

Nurse-based services as a strategy to increase access and adherence have been shown to be feasible in poor resource setting in Lusikisiki in rural South Africa, in Lesotho, and in Malawi. This approach has resulted in a more rapid coverage of service provision. This rapid coverage approach was not taken in Khayelitsha; rather a decentralisation of services was implemented step wise from 3 big clinics to all City-run TB clinics in 2006 involving also a shift to more doctor-supported nurse-based care. Thus, nurses are playing an important role in this decentralisation in Khayelitsha and since 2010 nurses have began initiating ART in the primary care clinics. Moreover, in some rural areas innovative 'de-medicalised' delivery models, which are based mainly in the community and draw on the capacity that exist in communities of community health workers with professional backup, have already been initiated. Three such initiatives have been reported from rural Kenya; from a small ART programme in a poor rural community in Haiti; and from Mozambique. This decentralised model of care also promotes increasing patient participation in chronic care. This could therefore be a next step in a progressive model of care in Khayelitsha.

The Lancet Health in South Africa series clearly shows the "collision of four excessive health burdens: communicable disease (especially HIV/AIDS), non-communicable disease, maternal, neonatal and child deaths, and deaths from injury and violence" and calls for "strong leadership and stewardship". Initially the South African government's response to HIV and AIDS was delayed due to HIV denialism. Medecins Sans Frontieres (MSF) in collaboration with Western Cape Provincial Government launched the Khayelitsha
Programme to prove the feasibility of ART in poor settings in South Africa in 2001\(^5\). Eventually, in November 2003, the South African government announced that there would be a national rollout of ARVs. In light of the Millennium Development Goal 6 which is to “Combat HIV, AIDS, Malaria and other diseases”, the target is to place 1.5 million people with HIV infection onto ARVs by 2011, but sadly HIV is still also delaying the achievement of other MDG goals\(^34\). The challenges faced by the South African health care system cannot warrant the continued development of ARV services separate from ‘a functional district health system’\(^34\).

The concept of COC in the Public Health Service

The need for research into COC in South Africa has been identified as long ago as 1983\(^35\). Continuity of Care should be a major factor of the public health care system, and it has been advocated by reformers of the public health care system worldwide\(^9,11,14,36-38\). On the one hand, there is an international trend whereby governments are increasing their control over health delivery, for example, as noted in the 2005 World Health Assembly on *Sustainable health financing, universal coverage and social health insurance*\(^39\). Even in developed countries this trend can be observed, as the objective of US President Barak Obama shows, who wants to “guarantee health coverage for every American” for basic health\(^40\). On the other hand, these potential health system changes occur against an underlying pessimism that the doctor-patient relationship is being ‘compromised’ in the UK public health care system\(^41\), the actual failure of primary care provision in the US\(^42\) and even a conclusion that the doctor-patient relationship was ‘going out of style’\(^43\). In short, there are opportunities and threats as to the future of COC and its place in public health systems.

The ruling political party in South Africa, the African National Congress (ANC), has envisaged a fundamental change in the Health System since 1994 in *A National Health Plan for South Africa*\(^44\), which ten years later issued in the *National Health Act* in 2004\(^45\). The follow-through to the envisioned institutional systems such as a National Health Insurance (NHI) has been slow. However, the ANC 52\(^{nd}\) National Conference in 2007 put renewed emphasis on change in the health system and resolved that government “must accelerate all our programmes in pursuit of the Millennium Developmental Goals”, including reaffirming “the implementation of the National Health Insurance System”, further strengthening the public health care system, and ensuring adequate provision of funding\(^46\).
And yet, little emphasis has been placed on the essential ingredients of such a new public health care system, and the envisaged reforms could take insight from Starfield's Four Cardinal Cs of Primary Care: First Contact Accessibility, Coordination, Comprehensiveness, and Continuity. Starfield envisages continuity (or longitudinality) to be person-focused, not disease-focused. With the 'new start' for primary health care since the Alma-Ata there is a need to link the degree of continuity, however defined, with clinical outcomes. In a multidisciplinary review in the BMI, there is a "call for the enhancement for continuity in health care delivery", whereby the present ineffectiveness in the management of chronic diseases is seen as an argument for emphasising continuity of care in the reform of the health care system. Moreover, studies on COC keep on establishing a positive relationship with outcomes. Even though the models of health care in the developing world have reacted to the health challenges around them and particularly the acute presentation of diseases, they have failed to "acknowledge a sustained partnership between patient and provider as a core value". Again, the kind of care required is based on a chronic disease model which does not focus merely on the acute management of patients (Kishaba 2002), but which is incorporated within a functional district health systems (Chopra 2009: 3027). This is also in keeping with the WHO Strategy for Comprehensive Chronic Disease Care in the Developing World (see Table 1).

**Table 1 WHO Strategy for Comprehensive Chronic Disease Care in the Developing World**

<table>
<thead>
<tr>
<th>WHO Strategy for Comprehensive Chronic Disease Care in the Developing World</th>
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<tbody>
<tr>
<td>• Shift emphasis from acute, episodic care to provide continuity of care with planned visits and regular follow up</td>
</tr>
<tr>
<td>• Develop health policies, collaboration, legislation, and healthcare financing to support comprehensive care strategies</td>
</tr>
<tr>
<td>• Emphasise delivery of services at primary care level to assure broadest access to effective care</td>
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</tbody>
</table>

In the South African context, Chopra highlights the need to integrate all chronic diseases into a functional district health system in light of the collision of four excessive health burdens in South Africa: communicable disease (especially HIV/AIDS), non-communicable disease, maternal, neonatal and child deaths, and deaths from injury and violence. There is a perception that ART services are well-resourced, well-staffed compared to other services to non-HIV patients, as stated: "generally a great deal of attention and resources have been
absorbed by selected health programmes at the expense of developing a functional district health system. The integration of well-run ART services into Integrated Chronic Care Units on the primary level in the Khayelitsha Health District in 2012 provides an opportunity for infusing COC concepts into the district health system.

Promoting the concept of COC in Africa will most probably come from the emerging specialty of Family Medicine in Sub-Saharan Africa, especially when one notes the Statement of Consensus on Family Medicine in Africa, established at the 2nd African Regional WONCA (World Organisation of Family Doctors) Conference in Rustenberg, South Africa in October 2009. The development of this consensus statement shows how synonymous Family Medicine and Primary care are in the future health care of Africa, including translating their principles into health systems. Its first statement concerns “The contribution of Family Medicine to equity in health care”, and outlines a goal of delivering better health outcomes for all. More especially, point 5.3 of the fifth statement on “Quality of Family Medicine practice in Africa” states that “appropriate tools and systems for the evaluation of Family Medicine practice need to be developed, and indicators defined to benchmark practice in Africa. This should be based on key domains of quality, which include cost effectiveness, safety, equity, continuity of care and patient satisfaction”. The rationale for this is provided by Reid who argues that since the discipline of Family Medicine that evolved in the West, and now subsequently spread in Africa, it also needs to be framed within the African context.

Given that the role of a family physician in Africa is performed within a context of poor resources, different patients’ belief systems, different health burdens, and understaffing, to name a few, it will be different to that of a family physician in developed countries, and needs to be realised within community-orientated primary care. The World Health Report for Primary Health in 2008 calls for care that is “comprehensive, continuous and person-centered with the responsibility of the primary care team for the health of the community served and not just the patient in front of them”. Likewise almost all of the data on measuring COC, particularly its measurement is only found in developed countries, except for the data in one unpublished South African study. Therefore, there is a need to measure primary care interventions such as COC in order to show their effectiveness in the African and South African context. This provides an argument for reform of primary care in South Africa.
**Definition of Continuity of Care (COC)**

The concept of COC has been described in different ways:

**Table 2 Different Conceptualisations of COC**

| Henren 1975⁹ | Five dimensions of continuity: interpersonal, chronological, geographic, interdisciplinary, and informational |
| McWhinney 1997¹ | Continuity in the sense of an enduring relationship between doctor and patient |
| Haggerty 2003¹¹ | Three types of continuity: informational e.g. the use of information, management e.g. a consistent and coherent approach to the management of a health condition, and relational e.g. an ongoing therapeutic relationship |
| Saultz 2003¹⁵ | A hierarchy of 3 dimensions: informational e.g. organised collection of medical and social information, longitudinal e.g. coordinated care, and interpersonal continuity e.g. the nature of the therapeutic relationship |

These different conceptual dimensions and understandings of COC show involve agreements as well as disagreements; moreover, they explain the wide variety of methodological approaches that has emerged to date¹⁴¹⁵. Haggerty, in particular, argues that for COC to exist, two elements are required: i) care of an individual; and ii) care delivered over time¹⁴¹⁵. Haggerty would argue that this care 'delivered over time' is the same as the 'longitudinal' care mentioned by Saultz. Research in COC has mainly focused on the longitudinal/management continuity to show how it improves patient outcomes⁹ and cost of care⁹. Patient satisfaction has mostly been used as a means to try to measure the relational or interpersonal aspect of continuity. Hence, Saultz calls for “future inquiry that should focus on a better understanding of interpersonal dimension of COC”¹⁵.

**Measuring Instruments of COC**

The quest for an appropriate universal measuring instrument for COC is born out of the fact that family medicine practitioners would like to empirically prove that the positive benefits of COC have rigorous evidence of effect. In this regard, Saultz asks “What proof is there that a continuous longitudinal relationship improves the quality of health care?”¹². On the one hand, his review of literature consistently shows a positive relationship between COC and patient outcomes and cost¹. On the other hand, he laments that: “persistent methodolog...
challenges regarding the definition and measurement of continuity of care... concluded that there was insufficient evidence that such continuity uniformly improves care\textsuperscript{12}. Saultz\textsuperscript{15} identified 21 measurement techniques in a systematic review of defining and measuring COC. Most of the measurement techniques focused on longitudinal nature of CDC, rather than the interpersonal nature of COC.

The task of this research is to find an indicator of care that is ‘user-friendly’ to the clinician in the chronic care context of the South African public health service; an indicator that is amenable to easy statistical analysis.

**Table 3 Different Indici of Longitudinal COC**

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Usual Provider Continuity/UPC (Breslau 1975\textsuperscript{15})</td>
<td>The maximum visits to a specific health provider divided by the number of visits. The simplest measure of longitudinal COC. The focus of the measurement of the UPC is the individual provider.</td>
</tr>
<tr>
<td>A formulae that includes all the providers</td>
<td>Measures COC dispersed amongst the whole health team by including the sum of all the proportions to each health provider. Mathematically it is $COC\text{ index} = (x_1+x_2+1+x_3+1+...+x_n+1)/n(n-1)$.</td>
</tr>
<tr>
<td>Continuity of Care Index (Bice 1977\textsuperscript{15})</td>
<td>This index only measures the proportion of sequential visits. Therefore $s_1 = (1$ if visits $i$ and $i+1$ are to the same provider, 0 otherwise). The formula $SECON = (s_1 + s_2 + s(n-1))/(n-1)$.</td>
</tr>
<tr>
<td>K-index (Ejlersson 1985\textsuperscript{13})</td>
<td>Mathematically it is written $K\text{-index} = (n-1)/(n-1)$.</td>
</tr>
<tr>
<td>Alpha index (Lou 2000\textsuperscript{10})</td>
<td>The logarithmic formula is a combination of both the sequentiality and concentration of providers which is weighted by prioritising either the sequentiality or concentration of providers. This weighted factor is called alpha, which is...</td>
</tr>
</tbody>
</table>
predetermined by the researcher in relation to the specific context in which COC will be measured e.g. An ill patient would most probably require more sequential continuity than a stable chronic patient. Mathematically it is written Alpha-index = \( \alpha^*(\log M + ((x_i/n)\log(x_i/n) + (x_j/n)\log(x_j/n) + \text{etc})/\log M) + (1 - \alpha)^*\text{SECON} \)

The complex statistical formulae propose to be better measures of the dispersion of COC amongst the whole team rather than measuring the proportion of visits to an individual provider. Hence a better measure of 'management continuity'\(^{15}\). Ejertsson compared four different statistical formulae in a Swedish health district and concluded that the K-index was easier to calculate the COC amongst the whole health team and had similar results to the other three formulae: UPC, COC-index and SECON\(^{17}\). Among the limitations of a statistically complex approach is that it requires a biostatistician and knowledge of computer programmes, which does not lend itself to quick analysis. Another limitation is the time it takes to input the raw data. One unifying factor is that all the calculations can be scored on a range from 0 (zero continuity) to 1 (complete continuity) due to the fact that they are all proportions. These proportions are often presented as percentages.

A simple proportion (i.e. UPC) is a better reflection of the best continuity the patient has had with a specific provider in that setting of care, and an 'easier strategy in attempting to measure continuity of care' with a selected provider\(^{58}\). A simple proportion has been used in research with a systematic review that examined 17 studies\(^{15}\). There is no consensus on what constitutes 'good continuity' and 'satisfactory continuity ratios' or a 'good' UPC continuity score\(^{58}\). In different studies it has been variably defined as above 0.5\(^{59,60,61}\) or above 0.75\(^{62,63}\) or above the median\(^{64}\) or not defined at all. The only COC score measured in the context of HIV is a COC-index score of 0.14 found in a New York HIV Clinic\(^{6}\). In this New York HIV Clinic, only 7% of patients had a score over 0.5, – suggesting maybe that 0.5 is a marker of 'good' continuity. In the South African public health care context in a non-HIV situation, Bresick\(^{9}\) records, that if 80% consultations with the same doctor constitutes 'good continuity' then continuity with the same provider was less than 9% (CI 4-16.9) and if it was defined as 66% of consultations then continuity with the same provider was 21.4% (CI 13.4-31.3). Almost all the 17 studies listed by Saultz\(^{15}\) recorded the UPC results as a mean, except one study which mentioned a median\(^{64}\). It is unclear from the review of the 17 studies whether the data was
normal or non-parametric. Almost all studies on COC continuity scores have occurred in the developed world, except for the unpublished study in Cape Town. Therefore in order to develop a feasible tool to measure COC in the South African public health system and thereby seeking to provide "evidence of the benefits of a primary care-led health system", the UPC or 'continuity fraction' (CF), as it will be called in this study, is the pragmatic choice to explore COC in this ARV clinic.

'Adherence' and COC

According to Haggerty, "Continuity is mostly conceived in terms of improving information and management continuity, with the hope of more relational continuity in the future". In contrast, adherence is typically defined as "the extent to which a person's behaviour — taking medication, following a diet, and/or executing lifestyle changes — corresponds to agreed recommendations from a health care provider". The relationship between adherence and better outcome is known in diabetic chronic care. Maintaining a high level (95%) of adherence is critical to a successful ART programme since only this high adherence will suppress the virus, boost CD4 counts, improve well-being, and avoid the development of drug resistance in patients. Four main methods of measuring adherence to ART have been described: patient self-reporting (e.g. questionnaire), pill counts, drug assays, and electronic monitoring systems. While the main limitation of the first two methods is a potentially higher reported adherence than actual adherence; the last two methods are expensive. Fortunately in the South African public health system, we do have viral load assays, which are a very good measure of adherence. No studies were found that correlated COC with VL/CD4 outcomes.

Rosen notes that "Programs that have achieved higher retention rates can serve as models for future improvements". In this respect, the 'Adherence Club' system of the UBUNTU Clinic in Khayelitsha has been mooted as such a model. Literature reviews on adherence clubs/chronic-care clinics is very limited with regard to the concept of a 'club' as a health delivery mode, particularly in the manner organised in UBUNTU. Some innovations do exist under a variety of labels for example: "self help groups", "support groups for people with chronic illnesses like Diabetes", and the "good life club intervention for diabetes self management", all of which support the view that self management will improve wellbeing and strengthen patients' self-determination and participation in health care, while reducing health care utilisation. However, there appears to be no literature yet that conceives of a 'club' in the manner as the ones designed and operative in Ubuntu with a fixed unit number.
of patients, as a mode of health delivery; rather groups similar to those ones typically get labelled 'support groups'.

**Interpersonal COC and satisfaction**

The Continuity Fraction or CF does not measure the nature of the interpersonal relationship; patient satisfaction surveys are the closest approximation to measuring the interpersonal patient/health care provider relationship in the South African HIV/ART sector. A number of factors have been established as challenging ART adherence in Africa. Thus, recent research shows that levels of satisfaction are negatively affected by human resources shortages and long waiting times.\(^1\)\(^,\)\(^2\) Other factors challenging ART adherence in Africa, include hunger and transports costs.\(^3\) Higher continuity is still important, such as, creating an environment of higher trust and satisfaction, but might not be the overriding factor in good adherence. Guilliford tested an experience-based questionnaire of COC in type 2 diabetes mellitus which measured patients' experience of "longitudinal continuity, flexible continuity, relational continuity, team- and cross-boundary continuity."\(^4\) Bresick's study had a similar approach in the South African public health sector. Interpersonal COC is not the focus of this study.

**Conclusion**

The literature review shows that there is an inspection of the public health care system, due to factors such as cost and health care burden. Principles of family medicine and primary care would want to invoke changes that will bring the health system in-line with its thinking, yet there is debate on how to measure COC.
3. CLINICAL SETTING OF STUDY

As mentioned above, the Ubuntu (Site B) ART/TB Clinic in Khayelitsha provides the clinical setting for this research. This chapter outlines the patient numbers, staffing, and health care infrastructure in Ubuntu clinic and Khayelitsha.

Khayelitsha has an estimated population of 500,000 and is located on the outskirts of Cape Town. The health infrastructure for the sub-district of Khayelitsha is managed by the Provincial Government of the Western Cape (PGWC) by means of three Community Health Centres (CHCs), and two Midwife Obstetric Units (MOUs), and by the City of Cape Town with one CHC (Mathew Goniwe), six General Clinics, two Youth Clinics and one Male Clinic.

Ubuntu is the oldest and biggest ART clinic in the Cape Town region, started in collaboration between MSF and the Western Cape Provincial Government in Khayelitsha; it is also one of the first primary care clinics in the public sector to provide antiretroviral therapy (ART) in South Africa (started in May 2001). Ubuntu is one of three large primary care clinics that provided ART in Khayelitsha. The total number of ART patients remaining in care was more than 20,000 in May 2011, of which more than 5,000 were in Ubuntu. According to the Khayelitsha 2001-2011 Activity Report antenatal prevalence of HIV was 26% in 2010 in Khayelitsha. In Ubuntu, patients were initiated with CD4 counts below 250, whereas national guidelines have stipulated 200. A new requirement of a CD4 of below 350 for the initiation of ART in pregnant women and TB patients only came into effect in April 2010.

On a given day, approximately 200 patients pass through the Ubuntu ARV Clinic, and additionally between 1 to 2 Adherence Clubs comprising 25 to 30 patients each. The clinic’s patients are either children below the age of 15 or adults over the age of 25, since a Youth Clinic that targets the age group between 15 and 25 years old has been established at a separate location. The Ubuntu clinic is staffed by four doctors, two clinical nurse practitioners (CNP), four principal nurses (PN), and one enrolled nurse (EN). The clinic has five counsellors who do adherence instruction. The clinic is serviced by its own pharmacy, which is staffed with two pharmacists, and three pharmacy assistants. The doctors also visit the Maternity Unit and Youth Clinic once a week.

b The actual population of Khayelitsha is unknown, and this figure is based on a 2001 census figure of 329002, and is thought to be underestimated, which makes figures difficult to estimate. The 2007 census results still need to be released.
ARV patients' folders have unique records, which have 5 columns on an A3 sheet representing 5 visits. At each visit, the relevant rows prompt the health care provider to provide information on date, weight, TB screening questions, investigations, and a space for history, examination and medication. The very fact that there are 5 columns contributed significantly to the idea of using a CF with a denominator of 5. The possibility therefore arose to develop a 'tool' that at a glance it would be possible to determine the CF.
4. METHODOLOGY

This chapter outlines the design and methods used in this research. It outlines the key study variables and formulae for the calculation of the COC indexes used in the study, and shows how the data was sampled, collected, captured, prepared for analysis and eventually statistically analysed.

Study Design

Descriptive cross-sectional study using a review of patients’ visitation records in the Ubuntu ARV/TB clinic in Khayelitsha to establish COC using a variety of statistical indices.

Study Variables

- ‘Club’ versus ‘Non-Club’
- ‘Continuous’ versus ‘Proxy’ visits
- ‘Suppresses’ versus ‘Raised’ VL
  - The viral load is determined using Abbott m2000 Real-Time HIV-1 assay. The assay measures the number of RNA copies/ml. Linear range is from log 1.6 – log 7.0 (copies/ml);
  - ‘Suppressed VL’: The definition used in this study is below 1000 RNA copies/ml. (unless otherwise stated); ‘Raised VL’: Any single VL that is more than 1000 RNA copies/ml.
  - VL>1000 copies/ml on two occasions, despite intensive adherence counselling is considered the definition for virological failure in South Africa; However below 400 RNA copies/ml is considered suppressed, hence descriptive data tables include the number of patients with VL suppression under 400 RNA copies/ml. (CLINICAL GUIDELINES FOR THE MANAGEMENT OF HIV & AIDS IN ADULTS AND ADOLESCENTS National Department of Health South Africa 2010)
- ‘COC Scores’: refers to the scores of the CF, K-index, SECON index, COC-index, and Alpha-index as calculated by means of COC formulae (see below in Table 4).
  - All COC Scores range from 0 to 1. ‘0’ represents a complete lack of continuity, and ‘1’ presents complete continuity.
Table 4 Mathematical Derivation of Different Indices of Longitudinal COC

**Continuity Fraction (CF):** Mathematically could be written as CF = max visits to a specific health provider/number of visits. The number of visits is 5 in this study.

**K-index (K-index):** Mathematically is written K=(n-i)/(n-1) (i is the number of different health providers seen in a specified time period, n is the number of visits). This easier formula is derived from (x1-1 + x2-1 + ... Xn-1)/(n-1), where

**SECON index (SECON):** Sequential Continuity is measured in the visit pattern. Therefore S1=1 if visits i and i+1 are to the same provider, 0 otherwise. Therefore the formula SECON=(S1 + S2 + S(n-1))/(n-1)

**COC-index:** Mathematically COC index=[x1(x1-1)+x2(x2-1)+...+xn(xn-1)]/n(n-1). Again, x1, is the number of visits to the first provider. It does not take into account sequentiality.

**Alpha-index:** Mathematically is written Alpha-index = (\alpha \log(M) + (x1/n)\log(x1/n) + (x2/n)\log(x2/n) + etc)/\log(M) + (1 - \alpha)\times \text{SECON}. \alpha is a predetermined weighted value which weights the concentration and the sequential components which measure the COC in the formula. M is number of available providers. N is the number of patient visits. x1 is the number of visits to the first provider, x2 to the second provider, etc.

**Sampling**

The target population of the research are chronic care patients on ARVs in the South African public health service. The study population are chronic care patients of the Ubuntu Clinic in Site B, Khayelitsha.

The sample for the research is constructed using periodic sampling of every 10th patient folder, as available from the clinic’s reception after normal clinic hours.

**Inclusion Criteria**

The inclusionary criteria are that a sampled patient needs to be on ARVs for longer than 2.5 years and be over the age of 18, since the area of interest is chronic care and longitudinal continuity of care of such patients. Therefore these patient had ‘continuous’ visits to the clinic.
Why over 2.5 years on therapy? Club members were only eligible for selection for a Club after 18 months of ARV treatment – due to possibility of side effects of Stavudine. 18 months was considered early enough to enter an alternative chronic care model. If the patients care over time is evaluated over their last 5 visits, which could be a visit every 2 months, then in order to assess the observational period, the patients needed to be at least 2.5 years on ARVS. This allows enough time for a Viral Load to be done in the observational period. The patients that were selected were not affected by the change of National ARV guidelines, on the 01 April 2010, when Tenofovir was phased-in the place of Stavudine.

**Exclusion criteria**

The exclusion criteria included any patient who is lost to follow-up (normally 3 months, but in Khayelitsha data it is defined as after 6 months), died, transferred out, or HIV negative (Ubuntu is also a TB clinic, therefore some patients are HIV negative).

Due to LTF and death for non-club patients, only 87.3% of people were alive and on ART at 12 months, 75.2% at 36 months and 65.1% at six years of ART. Lost to follow up and death was a lesser concern for club patients in an evaluation of the clubs since 2008, with 755 patients enrolled into Ubuntu clubs. However it should be remembered that the 'best' candidates were selected to join the clubs. 97.5% of patients were alive at two years of club care over and above their time as non-club patients. The NSP target for retention in care at 12 months of ART is 85%, which Ubuntu clinic achieves. Rosen estimated that about 60% of patients were retained at the end of 2 years in sub-Saharan Africa. This LTF and death do influence the interpretation of the results, especially when only applying a 'lens' at the results of patients with 'continuous' and 'proxy' visits.

**Sample Size**

Originally the sample size was calculated in consultation with a biostatistician, in such a way to ensure that the power would be 100%. It was anticipated that the continuity fraction would be approximately 0.3 in the non-club members and 0.9 amongst club members. However using this approach, using a power of 80% and level of significance at 0.05, results in a low sample number being required, \( n_1 = 13 \) and \( n_2 = 13 \). Since a CHI-SQUARED statistical analysis for 2x2 contingency tables depended on large samples, with expected frequencies greater or equal to 5, it was decided that a 100 folders would be sufficient to derive statistically sound calculations. The power of the test continued to be 1.
However, due to different record keeping and managerial model of COC for Club patients, it would not be possible to calculate COC formulae. The nurse designated to a specific Club would write the medication scripts the day before their visit. Therefore Club patients had only continuity with a Community Health Workers, except on one day year for annual blood investigations by a designated nurse. This placed the original statistical calculation to determine the sample size into doubt, but anymore sampling of folders above 100 folders would diminish the feasibility of using the COC measurement tool in a busy clinic. Therefore the intended sample size was 100 folders.

The potential importance of patients with 'proxy' visits amongst the five visits was observed during the sampling. Since this did not constitute 'continuous' visits, the data could not be used in the COC formula. However, since this information was deemed to be important to describing COC in the clinic, these folders' data was also recorded. This decision, which was taken in the course of the research, was informed by the fact that the concept of 'proxy' visits has a bearing on COC in the South African public health sector. Therefore during the process of sampling the patients with 'continuous' visits, any folders sampled which met the criteria except for having a 'proxy' visits were also recorded. This sampling of patients with 'proxy' visits would continue parallel to the sampling of the intended 100 'continuous' patients who met the criteria.

During the sampling period, the Club folders were removed from the general folder section in the reception into a separate filing area. Therefore the number of Club patients sampled was proportionally smaller.

Pilot

A pilot study using 30 folders was conducted to determine the feasibility of the collection of data in terms of potential difficulties: identifying the health provider from the folder, ease of collecting COC information, sample size determination. The pilot showed that it was possible for an insider to the clinic to identify the relevant health provider, determining the CF was simple, and that sufficient viral loads had been recorded.

The Pilot revealed two interesting factors to consider in this research of COC in Ubuntu: Firstly, conceptually the Adherence Club had continuity with a team of community health care workers, not a nurse or doctor. Therefore it could not be studied in terms of a Continuity Fraction, the primary tool to describe longitudinal COC in Ubuntu. Secondly,
'proxy visits' by patients constituted a conceptual problem. The decision was made to sample patients with 'continuous' as well as 'proxy' visits for the purposes of this study.

**Data Collection and Management**

Patients' folders were sampled from the reception after clinic hours. The information of folders that met the sampling criteria was photocopied by reducing the A3 page to A4 size in reception. The patient records page is an A3 size with 5 columns representing 5 visits. The data entry was done later onto an Excel Spreadsheet. The data was stored on the researcher's laptop and photocopies stored at home, which was more secure than a clinic office.

The data was organised into an EXCEL document with the following baseline information: Folder Number, Baseline CD4, Age, Gender, Club, ARV start date, TB y/n, if the VL was recorded, latest VL result, latest CD4 result, the line of the regime (first or second line⁵) and the actual regime. If the viral load was not available, the laboratory was phoned to obtain the result. The COC data was the last 5 visits, which compromised the name of individual health care professional, the date of the visit, and the variance from the booked date for visit. Then the numbers of nurse visits, the number of doctor visits and the number of proxy visits were recorded into EXCEL. In order to calculate the COC data, firstly, the CF was calculated by viewing the data to determine the highest attendance to an individual nurse and highest attendance to an individual doctor, and secondly, the COC scores were calculated from EXCEL formulae using the data from the last five visits.

**Statistical Analysis**

Data was then analysed using STATA statistical package (StataCorp, Version 11). The Shapiro-Wilk test was used to test for normality.

**Descriptive Statistics**

Descriptive analysis using medians with inter-quartile ranges (IQR) or means with confidence intervals (CI) were used for variables that were normally or non-normally distributed. Analysis using medians with inter-quartile ranges (IQR) was used for variables that were not

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⁵ In South Africa, prior to 1 April 2010, D4T (Stavudine) was the mainstay of the first line regime, including 3TC Lamivudine, and NVP (Nevirapine) or EFV (Efavirenz). AZT (Zidovudine) was used in place of D4T in situations of high BMI and Pregnancy. Since 1 April 2010, TDF (Tenofovir) has replaced D4T and AZT as the premier first line ARV. Second line, used to include DDI (Didanosine) but this has been dropped in favour of continuing with 3TC. AIV (Alluvia - Lopinavir/Ritonavir) is the Protease Inhibitor in the second line.
normally distributed/non-parametric. There is a predominance of using the 'means' in the past literature on COC; the exception is the work of Freeman and Richards which used a median in their research to define 'good' continuity\textsuperscript{64}. It is difficult to assess from the literature if the data was 'normal' to substantiate the subsequent use of the mean. Other problems encountered are that no confidence intervals (or inter-quartile ranges) are given in existing literature.

**Inferential Statistics**

The Continuity of Care data produced COC scores with a range of categorical variables from 0 to 1. Viral Suppression was examined as a binary variable (Suppressed VL vs. Raised VL). The appropriate statistical test was used to test for association e.g. F-exact test, Chi-square test, or Wilcoxon rank-sum test. General Linear Modelling - Poisson Regression with robust error variance was used to test for the strength of association and present the output as a Risk Ratio. The Poisson modified regression to estimate risk ratios in Cross Sectional studies infer the strength of association that was used – to estimate risk ratio at a point\textsuperscript{77,78}. This strength of association is also called the 'measure of effect'\textsuperscript{77}. The F-exact and Chi-test only test for an association, however a Risk Ratio captures the magnitude by which 2 groups are associated. Risk ratios are easier to explain and can be used in the context of high prevalence, unlike Odds ratios\textsuperscript{78}. Therefore, as Barros, states: 'Poisson regression with robust variance and log-binomial regression provide correct estimates and are a better alternative for the analysis of cross-sectional studies with binary outcomes than logistic regression\textsuperscript{78}. The linear modelling was used to control for variables\textsuperscript{77}. This statistical approach fits into public health systems which have data bases which are minimal, and allow for cheap and quick cross-sectional studies which estimates risk at point in time\textsuperscript{77}. A significance level of $p<0.05$ was used for all analysis.
5. RESULTS

The results section is composed of eight sections:

1) Sampling results (5.1)

2) Descriptive data of the different subset of groups (5.2)
   Table 5 and Table 6 compare patients with continuous visits, patients with 'proxy' visits and patient who are in the Club. Table 6 is a more intensive investigation of the patients with continuous visits with at least one visit to the doctor. Table 7 provides a descriptive analysis of the different groups of patients and their time periods over which the five visits occurred. Error! Reference source not found.

3) Interpreting Visit/Continuity of Care Data (5.3)
   A closer analysis of the COC formulae i.e. CF, K-index, SECON, COC-index, Alpha-index in regards to the numerator, denominator, period of time and results.

4) COC Scores and Continuous Visits (5.4)
   These results describe the COC scores in Ubuntu clinic of the patients with continuous visits to nurses only and a mixture of nurses and doctors.

5) COC Scores and VL Outcomes (5.5)
   These results describe the COC scores in relation to the VL Outcomes. This section is divided into four parts: graphs of the distribution of COC Scores and VL Outcomes (5.5.1), tests of association of COC scores and VL outcomes (5.5.2), the measure of the effect of COC scores and VL outcomes (5.5.3), and a tabulated summary of results of association and linear modelling in regards to COC scores and VL Outcomes (5.5.4)

6) COC Scores amongst the 20 Continuous Patients with Doctor Visit(s)
   The Doctor CF was used to describe the patient visit(s) to the doctor(s).

7) Adherence to Appointment Dates
   Patients keeping appointment dates are related to VL Outcomes and CF Scores.

8) Proxy Visits
   Proxy visits are related to keeping appointment dates and VL outcomes.
5.1 SAMPLING RESULTS

Out of 1093 folders sampled 940 folders were excluded. The bulk of patients that were excluded were not yet 2.5 years on ARVs (39%) and TB patients who were HIV negative (23%). 13.9% were found to be lost to follow-up (LTF). 5 folders of patients who had death recorded in their folders were also found.
During the sampling period, the Club folders were removed from the general folder section in the reception into a separate filing area. Therefore the number of Club patients sampled was proportionally smaller with 34 folders.

Non-club patients who met the inclusionary criteria, yet with ‘proxy’ visit(s) were collated in a separate subset sample of 61 patients. This sampling of patients with ‘proxy’ visits would continue parallel to the sampling of the intended 100 ‘continuous’ patients who met the criteria. Ultimately 92 folders met the criteria of five continuous visits to nurses and doctors, as on closer examination of folders the patients did not meet the criteria for inclusion. 20 of these folders recorded that the patients had visited doctor(s).
5.2 DESCRIPTIVE DATA OF DIFFERENT GROUPS

The descriptive data reflects the profile of patients in different subsets of groups.

Table 5 compares: all patients with continuous visits (92), patients with continuous visits to nurses only (72), patients with continuous visits with at least one visit to the doctor (20), patients with 'proxy' visits (61) and patient who are in the Club (34).

Table 6 is a more intensive investigation of the patients with continuous visits with at least one visit to the doctor, by sub-categorising these patients into patients with Doctor CF greater or equal to maximum nurse CF (9) and patients where Doctor CF was greater than nurse CF (5). In total there are only 32 visits to doctors out of a possible 460 visits (5 x 92), which is illustrative of a nurse-driven clinic.

Table 7 provides a descriptive analysis of the different groups of patients and their time period over which the five visits occurred. Error! Reference source not found.

Pertinent points are discussed after the three tables.
### Table 5: Descriptive Data of Different Groups of 'Continuous', 'Proxy' and Club folders

<table>
<thead>
<tr>
<th></th>
<th>Patients with 'continuous' visits to nurses only (17 folders)</th>
<th>All patients with 'continuous' visits to either nurses or doctors (92 folders)</th>
<th>Patients with 'continuous' visits with at least one visit to the doctor (20 folders)</th>
<th>Patients with 'proxy' visits (61 folders)</th>
<th>Adherence Club (94 folders)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mean</strong></td>
<td>39 (CI 37 - 42)</td>
<td>39 (CI 37 - 41)</td>
<td>37 (CI 35 - 42)</td>
<td>36 (CI 35 - 38)</td>
<td>40 (CI 36 - 43)</td>
</tr>
<tr>
<td><strong>Median</strong></td>
<td>38 (IQR 34 - 44)</td>
<td>37 (IQR 32 - 44)</td>
<td>34 (IQR 31 - 42)</td>
<td>36 (IQR 31 - 40)</td>
<td>38 (IQR 34 - 41)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Men</strong></td>
<td>26 (56%)</td>
<td>31 (64%)</td>
<td>5 (25%)</td>
<td>20 (30%)</td>
<td>9 (20%)</td>
</tr>
<tr>
<td><strong>Women</strong></td>
<td>23 (54%)</td>
<td>30 (56%)</td>
<td>15 (75%)</td>
<td>42 (67%)</td>
<td>25 (74%)</td>
</tr>
<tr>
<td><strong>Baseline CD4</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mean</strong></td>
<td>126 (CI 110 - 141)</td>
<td>131 (CI 116 - 146)</td>
<td>151 (CI 100 - 196)</td>
<td>129 (CI 102 - 199)</td>
<td>114 (CI 89 - 139)</td>
</tr>
<tr>
<td><strong>Median</strong></td>
<td>124 (IQR 80 - 180)</td>
<td>127 (IQR 80 - 185)</td>
<td>130 (IQR 60 - 212)</td>
<td>110 (IQR 71 - 185)</td>
<td>116 (IQR 63 - 170)</td>
</tr>
<tr>
<td><strong>Min</strong></td>
<td>4</td>
<td>4</td>
<td>35</td>
<td>11</td>
<td>6</td>
</tr>
<tr>
<td><strong>Max</strong></td>
<td>336</td>
<td>437</td>
<td>43/</td>
<td>291</td>
<td>334</td>
</tr>
<tr>
<td><strong>Female</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mean</strong></td>
<td>131 (CI 110 - 152)</td>
<td>137 (CI 117 - 158)</td>
<td>156 (CI 100 - 212)</td>
<td>127 (CI 102 - 141)</td>
<td>116 (CI 66 - 155)</td>
</tr>
<tr>
<td><strong>Median</strong></td>
<td>141 (IQR 79 - 185)</td>
<td>134 (IQR 90 - 185)</td>
<td>128 (IQR 90 - 215)</td>
<td>134 (IQR 89 - 162)</td>
<td>134 (IQR 73 - 173)</td>
</tr>
<tr>
<td><strong>Male</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mean</strong></td>
<td>116 (CI 95 - 138)</td>
<td>119 (CI 97 - 141)</td>
<td>135 (CI 21 - 290)</td>
<td>117 (CI 82 - 151)</td>
<td>82 (CI 34 - 130)</td>
</tr>
<tr>
<td><strong>Median</strong></td>
<td>116 (IQR 81 - 152)</td>
<td>116 (IQR 75 - 127)</td>
<td>183 (IQR 37 - 133)</td>
<td>108 (IQR 55 - 184)</td>
<td>65 (IQR 37 - 126)</td>
</tr>
<tr>
<td><strong>TB y/n</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>TB</strong></td>
<td>34 (57%)</td>
<td>48 (52%)</td>
<td>10 (50%)</td>
<td>40 (66%)</td>
<td>10 (29%)</td>
</tr>
<tr>
<td><strong>- Men</strong></td>
<td>54%</td>
<td>63%</td>
<td>30%</td>
<td>75%</td>
<td>44%</td>
</tr>
<tr>
<td><strong>- Women</strong></td>
<td>54%</td>
<td>44%</td>
<td>70%</td>
<td>69%</td>
<td>74%</td>
</tr>
<tr>
<td><strong>Not TB</strong></td>
<td>35 (52%)</td>
<td>44 (48%)</td>
<td>10 (50%)</td>
<td>21 (34%)</td>
<td>24 (71%)</td>
</tr>
<tr>
<td><strong>VL Recorder</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>VL</strong></td>
<td>47 (65%)</td>
<td>62 (57%)</td>
<td>48 (75%)</td>
<td>74 (71%)</td>
<td></td>
</tr>
<tr>
<td><strong>VL Absent</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Count</strong></td>
<td>Under 1000</td>
<td>63 (88%)</td>
<td>63 (88%)</td>
<td>13 (65%)</td>
<td>56 (22%)</td>
</tr>
<tr>
<td></td>
<td>Under 400</td>
<td>61 (85%)</td>
<td>74 (80%)</td>
<td>13 (65%)</td>
<td>58 (29%)</td>
</tr>
<tr>
<td><strong>Latest CD4</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mean</strong></td>
<td>443 (CI 380 - 507)</td>
<td>443 (CI 387 - 484)</td>
<td>443 (CI 319 - 547)</td>
<td>451 (CI 404 - 507)</td>
<td>508 (CI 445 - 571)</td>
</tr>
<tr>
<td><strong>Median</strong></td>
<td>273 (IQR 259 - 538)</td>
<td>283 (IQR 251 - 557)</td>
<td>267 (IQR 214 - 627)</td>
<td>431 (IQR 333 - 573)</td>
<td>484 (IQR 365 - 683)</td>
</tr>
<tr>
<td><strong>Female</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mean</strong></td>
<td>447 (CI 380 - 513)</td>
<td>447 (CI 400 - 546)</td>
<td>440 (CI 358 - 602)</td>
<td>454 (CI 392 - 517)</td>
<td>528 (CI 449 - 608)</td>
</tr>
<tr>
<td><strong>Median</strong></td>
<td>283 (IQR 292 - 597)</td>
<td>219 (IQR 295 - 597)</td>
<td>510 (IQR 333 - 660)</td>
<td>431 (IQR 339 - 529)</td>
<td>564 (IQR 315 - 104)</td>
</tr>
<tr>
<td><strong>Male</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mean</strong></td>
<td>301 (CI 315 - 485)</td>
<td>382 (CI 301 - 464)</td>
<td>291 (CI 63 - 645)</td>
<td>483 (CI 374 - 532)</td>
<td>453 (CI 359-553)</td>
</tr>
<tr>
<td><strong>Median</strong></td>
<td>340 (IQR 213 - 479)</td>
<td>328 (IQR 249 - 419)</td>
<td>399 (IQR 175 - 720)</td>
<td>432 (IQR 384 - 527)</td>
<td>443 (IQR 376-493)</td>
</tr>
<tr>
<td><strong>ABV Regime</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>1st Line</strong></td>
<td>69 (96%)</td>
<td>86 (93%)</td>
<td>37 (85%)</td>
<td>59 (39%)</td>
<td>34 (100%)</td>
</tr>
<tr>
<td><strong>2nd Line</strong></td>
<td>3 (4%)</td>
<td>6 (7%)</td>
<td>3 (15%)</td>
<td>3 (5%)</td>
<td>9 (10%)</td>
</tr>
<tr>
<td><strong>Treat-period</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mean</strong></td>
<td>4.4 yrs (CI 4.0 - 4.7)</td>
<td>4.4 yrs (CI 4.1 - 4.7)</td>
<td>4.6 yrs (CI 3.0 - 5.4)</td>
<td>4.2 yrs (CI 3.8 - 3.5)</td>
<td>3.9 yrs (CI 3.0 - 4.6)</td>
</tr>
<tr>
<td><strong>Median</strong></td>
<td>4.3 yrs (IQR 3.2 - 5.0)</td>
<td>4.2 yrs (IQR 3.3 - 5.0)</td>
<td>4.2 yrs (IQR 3.4 - 5.0)</td>
<td>4.2 yrs (IQR 3.1 - 5.4)</td>
<td>2.6</td>
</tr>
<tr>
<td><strong>Min</strong></td>
<td>2.5</td>
<td>2.6</td>
<td>2.6</td>
<td>2.6</td>
<td></td>
</tr>
<tr>
<td><strong>Max</strong></td>
<td>8.4</td>
<td>8.6</td>
<td>8.6</td>
<td>8.6</td>
<td></td>
</tr>
</tbody>
</table>

*was not measured*
### Table 6: Descriptive Data of 'Continuous' with Nurse's and Doctor's Visits

<table>
<thead>
<tr>
<th></th>
<th>Patients with 'continuous' visits to nurses only (72)</th>
<th>'Continuous' visits, with at least one visit to the doctor (20)</th>
<th>Patients with Doctor CF greater or equal to maximum nurse CF (9)</th>
<th>Patients where Doctor CF was greater than nurse CF (5)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>Mean 39 (CI 37 - 42) &amp; Median 38 (IQR 34 - 44)</td>
<td>Mean 37 (CI 33 - 42) &amp; Median 34 (IQR 31 - 42)</td>
<td>Mean 37 (CI 31 - 43) &amp; Median 35 (IQR 32 - 50)</td>
<td>Mean 37 (CI 25 - 49) &amp; Median 32 (IQR 32 - 44)</td>
</tr>
<tr>
<td><strong>Gender &amp; Mean Age</strong></td>
<td>Men 26 (36%) &amp; Age 40 (IQR 36 - 45)</td>
<td>Men 5 (25%) &amp; Age 40.4</td>
<td>Men 2 (22%) &amp; Age 41</td>
<td>Men 2 (40%) &amp; Age 41</td>
</tr>
<tr>
<td></td>
<td>Women 46 (64%) &amp; Age 37 (IQR 31 - 43)</td>
<td>Women 15 (75%) &amp; Age 38.4</td>
<td>Women 7 (78%) &amp; Age 38</td>
<td>Women 3 (60%) &amp; Age 34</td>
</tr>
<tr>
<td><strong>Baseline CD4</strong></td>
<td>Mean 126 (CI 110 - 141) &amp; Median 124 (IQR 90 - 180)</td>
<td>Mean 130 (CI 105 - 157) &amp; Median 130 (IQR 78 - 212)</td>
<td>Mean 128 (CI 83 - 195) &amp; Median 128 (IQR 90 - 183)</td>
<td>Mean 132 (CI 27 - 237) &amp; Median 132 (IQR 90 - 183)</td>
</tr>
<tr>
<td></td>
<td>Min 4 &amp; Max 336</td>
<td>Min 35 &amp; Max 437</td>
<td>Min 35 &amp; Max 250</td>
<td>Min 35 &amp; Max 250</td>
</tr>
<tr>
<td><strong>TB y/r</strong></td>
<td>TB Total 34 (47%) &amp; TB Male 54%</td>
<td>TB Total 10 (50%) &amp; TB Male 60%</td>
<td>TB Total 4 (44%) &amp; TB Male 50%</td>
<td>TB Total 2 (40%) &amp; TB Male 50%</td>
</tr>
<tr>
<td></td>
<td>TB Female 43%</td>
<td>TB Female 47%</td>
<td>TB Female 42%</td>
<td>TB Female 50%</td>
</tr>
<tr>
<td></td>
<td>No TB 38 (52%)</td>
<td>No TB 50%</td>
<td>No TB 55%</td>
<td>No TB 60%</td>
</tr>
<tr>
<td><strong>VL Recorded</strong></td>
<td>47 (65%)</td>
<td>15 (75%)</td>
<td>8 (89%)</td>
<td>5 (100%)</td>
</tr>
<tr>
<td><strong>VL Suppressed</strong></td>
<td>63 (88%)</td>
<td>13 (63%)</td>
<td>5 (56%)</td>
<td>2 (40%)</td>
</tr>
<tr>
<td><strong>Last CD4</strong></td>
<td>Mean 443 (CI 380 - 505) &amp; Median 373 (IQR 259 - 536)</td>
<td>Mean 377 (CI 162 - 572) &amp; Median 333 (IQR 229 - 510)</td>
<td>Mean 377 (CI 162 - 572) &amp; Median 333 (IQR 229 - 510)</td>
<td>Mean 285 (CI 164 - 506) &amp; Median 270 (IQR 229 - 342)</td>
</tr>
<tr>
<td><strong>ARV Regime</strong></td>
<td>1st Line 69 (96%)</td>
<td>17 (85%)</td>
<td>7 (78%)</td>
<td>3 (50%)</td>
</tr>
<tr>
<td></td>
<td>2nd Line 3 (4%)</td>
<td>3 (15%)</td>
<td>2 (22%)</td>
<td>2 (40%)</td>
</tr>
<tr>
<td><strong>Treat-period</strong></td>
<td>Mean 4.4 yrs (CI 4.0 - 4.7)</td>
<td>4.63 yrs (CI 3.9 - 5.4)</td>
<td>5.0 yrs (CI 3.7 - 6.3)</td>
<td>5.5 yrs (CI 2.8 - 8.1)</td>
</tr>
<tr>
<td></td>
<td>Median 4.3 yrs (IQR 3.2 - 5.0)</td>
<td>4.2 yrs (IQR 3.4 - 5.5)</td>
<td>4.9 yrs (IQR 4.2 - 5.6)</td>
<td>5.6 yrs (IQR 4.2 - 5.2)</td>
</tr>
</tbody>
</table>
Table 7 Descriptive Analysis of the Patients and the Period of Time over which the 5 Visits occurred

<table>
<thead>
<tr>
<th></th>
<th>51 patients with 'proxy' visits</th>
<th>72 patients with 'continuous' visits to nurses only</th>
<th>20 patients with continuous visits with at least one visit to the doctor</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Patients</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>180 days (CI 170-201)</td>
<td>167 days (CI 172-200)</td>
<td>157 days (CI 135-179)</td>
</tr>
<tr>
<td>Median</td>
<td>192 days (IQR 145-208)</td>
<td>196 days (IQR 147-224)</td>
<td>156 days (IQR 132-186)</td>
</tr>
<tr>
<td>Min</td>
<td>32 days</td>
<td>84 days</td>
<td>55 days</td>
</tr>
<tr>
<td>Max</td>
<td>520 days</td>
<td>450 days</td>
<td>233 days</td>
</tr>
<tr>
<td>Suppressed VL</td>
<td>(56 patients)</td>
<td>(63 patients)</td>
<td>(13 patients)</td>
</tr>
<tr>
<td>Mean</td>
<td>183 days (CI 172-195)</td>
<td>190 days (CI 175-205)</td>
<td>172 days (CI 145-198)</td>
</tr>
<tr>
<td>Median</td>
<td>195 days (IQR 147-211)</td>
<td>196 days (IQR 147-224)</td>
<td>171 days (CI 139-205)</td>
</tr>
<tr>
<td>Min</td>
<td>82 days</td>
<td>84 days</td>
<td>97 days</td>
</tr>
<tr>
<td>Max</td>
<td>258 days</td>
<td>450 days</td>
<td>233 days</td>
</tr>
<tr>
<td>Raised VL</td>
<td>(5 patients)</td>
<td>(8 patients)</td>
<td>(7 patients)</td>
</tr>
<tr>
<td>Mean</td>
<td>154 days (CI 98-210)</td>
<td>163 days (CI 110-216)</td>
<td>130 days (CI 93-167)</td>
</tr>
<tr>
<td>Median</td>
<td>146 days (IQR 114-182)</td>
<td>161 days (IQR 112-196)</td>
<td>140 days (IQR 100-153)</td>
</tr>
<tr>
<td>Min</td>
<td>112 days</td>
<td>85 days</td>
<td>55 days</td>
</tr>
<tr>
<td>Max</td>
<td>217 days</td>
<td>308 days</td>
<td>175 days</td>
</tr>
</tbody>
</table>

Pertinent Points from Table 5, Table 6, and Table 7:

- The descriptive data of the various subgroups of the sample showed little variation in terms of age, gender, baseline CD4, Viral Loads recorded, VL suppression, and the period of treatment since initiation of ARVs.

- Patients with TB had a variation in results: 66% 'proxy' patients had TB as against only 47% of 'continuous' patients with TB who had visits only to nurses. Continuous visits which included doctor's visits only resulted in a slight increase to 52%. However, when the 20 patients who were 'continuous' and had a doctor visit(s) were investigated, 50% have had TB, but with increasing continuity with a doctor, the percentage of patients with TB decreased to 40%. 25% Club patient had TB.

- 100% of the Club patients sampled were virologically suppressed. 88% of the 72 patients with continuous visits to the nurses had a suppressed viral load. As patients had increased continuity with doctors, the percentage of patients with a raised VL increased.

- The patients who only had 'continuous' visits to the nurses had the following results: mean age 39, women represented 64%, mean baseline CD4 was 126, 47% of patients had TB, 65% had VL recorded of which 88% had a suppressed VL, the mean of the latest CD4 taken being 443 over a treatment period that averaged 4.35 years.

- A greater number of visits to the doctors; were associated with more VL's being recorded, as well as decreased VL suppression, and the number of patients on 2nd line therapy increased.
- Five patients out of 92 'continuous' patients had a doctor CF that was higher than the nurse CF.
- There is no significant difference in the period of time from the 1st to the 5th visit between patients with 'proxy' visits, patients with continuous visits to nurses only, and patients who had 'continuous' visits to both nurses and doctors. However, the follow-up time period for the five consultations is less among patients who have had at least one visit to the doctor. The follow-up period is also less for patients with a raised VL. The range of time for each of these three groups is the longest among patients who had 'proxy' visits, and the shortest with patients, who at least had one visit to a doctor.
5.3 INTERPRETING VISIT/CONTINUITY OF CARE DATA

A closer analysis of the COC formulae i.e. CF, K-index, SECON, COC-index, Alpha-index (as presented above in Table 4) showed that they can simply be explained in the following terms:

- Numerator → health providers
- Denominator → number of visits
- Over a certain defined period of time

Results from the formulas

The Numerator and the Nature of a Visit

The conceptual issue of a ‘proxy’ or ‘doctor’ visit had a lot of bearing on this study of COC and on the usage of the formulas of COC. Proxy visits occur commonly with stable chronic patients on ARVs who might be working. Since conceptually the ‘proxy visit’ is not in keeping with the concept of longitudinal continuity of care, it brings to fore an interesting dilemma on how to include ‘proxy visits’ into the COC formulae.

Provided that the intention of this study is to describe COC in the context of chronic ARV care in the public health system none of the five COC formulae can deal with ‘proxy visits’ as a numerator, unless the understanding of a ‘proxy visit’ is re-defined. The potential incorporation of ‘proxy visits’ in the future was considered and the patients with ‘proxy visits’ were also investigated. ‘Proxy visits’ could be seen as ‘discontinuity’ with possibly worse adherence to dates and VL outcomes.

Moreover, during ‘continuous (non-proxy) visits’, it is understood that doctors and nurses perform different roles within the clinic. Broadly speaking doctors’ sort out clinical problems; nurses manage the stable chronic patient. This is important in trying to describe COC in the context of chronic ARV care in the South African public health system. One would suspect that there will be a higher chance of poor adherence and a high viral load if the patient has visited a doctor i.e. any continuity with a doctor would increase the probability of a raised VL. Conversely, patient continuity with nurses would be expected to show a suppressed VL. So a doctor visit is a confounder of ‘good continuity’ in terms of VL outcome in a stable chronic ART patient. This therefore comes to determine which reference sample to investigate in the sets of ‘continuous’ data: either those who visited both nurses and doctors, or those who only visited nurses. For the sake of simplicity, the continuity formulas were calculated on patients with ‘continuous’ visits only – avoiding the issue of the ‘proxy’ visit.

In collecting the visitation data, an anticipated difficulty in collecting the data included the legibility of handwriting to identify the nurse or doctor in attendance, particularly if they did not indicate their
name as part of their record of the visit. Fortunately, in Ubuntu there has been a stable nursing and doctor staff complement. This has made it easier for an ‘insider’ to identify the different handwriting and signatures where necessary. If this tool were to be used by an ‘outsider’, however, identifying the nurse or doctor on the basis of handwriting could become a major obstacle. However, for the researcher who works in this clinic, this was not difficult.

Due to the simplicity of the CF, it belies the potential effect of the other visits to the other health professionals. Hence one of the reasons to using more complicated algorithms to assess the dispersion of COC amongst all health professionals visited by the patient. The K-index and COC-index are variations of measuring the proportions for all health providers visited. The SECON only measures sequential continuity. A quantitative measure of continuity addressing all health professionals visited would increase the complexity of the calculation. However, since COC can be considered a complex system\textsuperscript{16}, the Alpha-index was developed to “reflect both the concentration of providers and the sequential continuity” with the ability to adjust for which aspect is important in the study population, either the concentration of providers or the sequentiality\textsuperscript{16}. In an attempt to address the increasing complexity of COC, the formulae have become increasingly complex. This also requires an understanding on how to develop an EXCEL formula.

**The Denominator**

The default denominator is 5 visits in the CF score; however, the score of the denominator will change as the nature of visits changes. As mentioned earlier, in the context of chronic ARV care, nurses are focused on managing the chronic care patients whereas the doctors focus on sick patients. If a patient has one doctor visit, the maximum Nurse CF score on the denominator is reduced to 4. This is the conceptual nature of the denominator, hence the maximum CF (whether nurse or doctor) would need to be calculated if the denominator would remain 5 in patients who visited continuously. Where a patient has had 5 visits to nurses the denominator is 5. The maximum CF score in these cases was measured of both the nurse and doctor. Therefore, if the focus was COC amongst nurses and the denominator denotes 5 visits, there is the possibility of ‘zero’ continuity if all 5 visits were to doctors.

Conceptually, the ‘proxy’ visit is also a ‘visit’ not necessarily a ‘doctor’ or ‘nurse’ visit. If the ‘proxy’ visit is considered a non-visit, then this will alter the denominator and therefore the result. This is one of the reasons it is not included in COC calculations.
Appointment/Visitation Dates/Duration of the consultations and VL investigations

All visits, including patient and 'proxy' visits, had both the dates of their visit and their expected return date recorded on the clinical sheets. The visit date was written on top of the column and the return date at the bottom of the column. This was an easily observable data on the sheet. Due to the fact that the calculation of the CF was based on a fixed number of visits, the time period over which the visits actually occurred varies between patients. Thus, the method employed here goes against typical COC studies, which tend to stipulate a fixed time period. How this methodological decision will affect the outcome of results of the COC formulae will require further research.

Conceptually, when one seeks to relate the VL to the CF of the last five visits, any relationship between the two measurements cannot be deduced, since the 'input' of the continuity happens at the same time as the 'output' of the virological level. On occasion, the VL result could actually proceed the actual five visits. This is a result of being a cross-sectional design.

Compliance with clinic appointment dates could also be a factor that influences VL outcomes. It may be expected that a patient who has exact date visits will have better VL outcomes.

Results from the COC formulae

Since the number of visits is fixed to five, there is a fixed number of resultant categorical variables for each equation e.g. CF (0, 0.2, 0.4, 0.6, 0.8, 1), K-index (0, 0.25, 0.5, 0.75, 1), SECON (0, 0.25, 0.5, 0.75, 1), COC-index (0, 0.1, 0.2, 0.3, 0.4, 0.5, 0.6, 0.7, 0.8, 0.9, 1). This is in contrast to the Alpha-index which produces complex numbers with numerous decimal points, partly due to the use of logarithms. The Alpha-index takes into account the number of available providers (whether nurses only or a mixture of nurses and doctors). The Alpha-Index thus introduces another variable to the COC formulae calculation which adds to the complexity if there is not a stable population of health providers. Hence, the range of the categorical variables from the Alpha-index with 7 providers was: 0.0864563, 0.1576977, 0.2289391, 0.2826977, 0.3539391, 0.3808288, 0.4789391, 0.5058288, 0.621422, 0.746422, 1; for 13 providers (mixture of doctors and nurses) was: 0.0864563, 0.1576977, 0.1862632, 0.2289391, 0.2403108, 0.2826977, 0.3147584, 0.3539391, 0.3653108, 0.3808288, 0.4193585, 0.4397584, 0.4789391, 0.5058288, 0.5443585, 0.5647584, 0.621422, 0.746422, 0.7774537, 1. These categorical variables detract from creating a simplistic measurement.
5.4 COC Scores and Continuous Visits

These results describe the COC scores in Ubuntu clinic of the patients with continuous visits to nurses only and a mixture of nurses and doctors. Therefore ‘proxy’ visits were not assessed in this section. The data analysis of 72 patients who had ‘continuous’ visits with nurses only as this best represents stable chronic care in the Ubuntu clinic for non-club members. This is potentially true more broadly in the South African public health system with respect for chronic patients on ART. The data analysis of 92 patients includes the additional 20 patients who had visit(s) to doctor(s). As the denominator is 5 in the CF score, the maximum CF score of either nurses or doctors was used (This score, in essence, also represents the maximum CF score to an individual clinician).

This section is divided into two sections:
- A graph of the distribution of COC Scores
- A table of the correlation and median/means of COC Scores

5.4.1 Distribution of Continuity Scores

The analysis presented in Error! Reference source not found. measures the distribution of continuity scores calculated from the different COC formulae using only the data of those 72 patients who had ‘continuous’ visits with nurses only.

Figure 2: Distribution of Continuity Scores (‘Continuous’ Visits to Nurses only)
Graphically, the data is non-parametric; hence the median represents normality better than the mean. The distribution of the each score is not uniform, and all peak below 0.5. Visually, the CF has the most frequent score, that of 0.4 Continuity. The K-index, SECON and COC-index all score zero continuity for a proportion of the sample, whereas the CF did not. The Alpha-index generates a range of 11 variables which have been categorised into each tenth decimal point to help enable comparison with other formulae (e.g., 0.0-0.09999 = 0.0; 0.1-0.19999 = 0.1; etc.). When calculating the distribution of continuity scores from different COC formulae for the subset of patients that had nurse and doctor visits, the graph was similar to the distribution of continuity scores of visits to nurses in Figure 2, since only 20 patients had a doctor visit(s).

### 5.4.2 COC Scores and Continuous Patients

Table 7 outlines the summary of how the scores of the COC formulae compare within one another in terms of: Goal of the formula, calculation ease, range of categorical variables, distribution of scores, correlation tests, medians and means.

<table>
<thead>
<tr>
<th>Table 8 Summary of Results of COC Scores and Continuous Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Goal of formulae</strong></td>
</tr>
<tr>
<td>----------------------</td>
</tr>
<tr>
<td>Individual Provider</td>
</tr>
<tr>
<td>Calculation Ease</td>
</tr>
<tr>
<td>Continuous Visits to Nurses</td>
</tr>
<tr>
<td>No. of Variables</td>
</tr>
<tr>
<td>Distrib. of Scores</td>
</tr>
<tr>
<td>Correlation</td>
</tr>
<tr>
<td>Median (IQR)</td>
</tr>
<tr>
<td>Mean (CI)</td>
</tr>
<tr>
<td>Inclusion of Doctors</td>
</tr>
<tr>
<td>No. of Variables</td>
</tr>
<tr>
<td>Distrib. of Scores</td>
</tr>
<tr>
<td>Correlation</td>
</tr>
<tr>
<td>Median (IQR)</td>
</tr>
<tr>
<td>Mean (CI)</td>
</tr>
</tbody>
</table>

*Italic grey coloured numbers indicate means calculated from non-parametric data
- The easiest formula to use was the CF, since it required no calculator or computer program and could be 'eye-balled'. The easiest formula to measure the dispersion of provider continuity was the K-index which was calculated with EXCEL software. The SECON required time investigating the order of health providers visited for sequentiality and then ultimately calculating with an EXCEL formula. The Alpha-index was the most complex EXCEL formula with the most variables as possible scores. Since the Alpha-index takes cognisance of the total number of health providers in a health facility, the number of variables increases with the inclusion of doctors. The Alpha index has 20 categorical outcome variables, since the total number of possible health providers has increased to 11 (7 nurses plus 4 doctors).

- The correlation between the different COC scores was above 75%. The correlation with the CF was lower with the inclusion of doctors’ visits.

- Means and Medians of COC Scores: The means of the continuity formulae were calculated even though they were non-parametric, except for the K-index. The median were lower than the means; the former is in keeping with the fact that the data was non-parametric and skewed to the left. Thus, in this study, the median is found to better represent normality than the mean. The mean and median was higher for the CF than the other COC formulae. The simplest formula for the dispersion of concentration of providers, i.e. the K-index, had the highest mean and median compared with the more complicated formulae i.e. the Alpha-index, SECON, and COC-index. The mean and median of the Alpha-index was expected to be between the CF and the SECON, since it measures a mixture of sequentiality and dispersion of continuity amongst providers. The inter-quartile ranges of the medians of all the COC scores were not greater than 0.5. The medians remain unchanged with the inclusion of doctor visits.
5.5 COC SCORES AND VL OUTCOMES

These results describe the COC scores in relation to the VL Outcomes. The data analysis of 72 patients who had 'continuous' visits with nurses only as this best represents stable chronic care in the Ubuntu clinic for non-club members. The data analysis of 92 patients, which includes the additional 20 patients who had visit(s) to doctor(s), reflects the mixture of episodic with doctor(s) and consultations for chronic care. As the denominator is 5 in the CF score, the maximum CF score of either nurses or doctors was used (This score, in essence, also represents the maximum CF score to an individual clinician).

This section is divided into four parts:
- Graphs of the distribution of COC Scores and VL Outcomes (5.5.1)
- Tests of association of COC scores and VL outcomes (5.5.2)
- The measure of the effect of COC scores and VL outcomes (5.5.3)
- Tabulated Summary of results of association and linear modelling in regards to COC scores and VL Outcomes (5.5.4)

5.5.1 Graphs of distribution of COC Scores with VL Outcomes

The distribution of COC scores and VL outcomes are presented as graphs, initially for the CF score, and then all the subsequent COC formulae. The graphs for each COC firstly present the results for the nurses-only group and then when doctor(s) were visited.

5.5.1 Graphs of CF Scores and VL Outcomes

These graphs relate the distribution of CF scores and viral load (VL) outcomes.

_Figure 3 Distribution of CF Scores and VL Outcomes of patients with visits only to nurses_

![Graph showing distribution of CF scores and VL outcomes]

<table>
<thead>
<tr>
<th>Frequency of Patients</th>
<th>1/5 Continuity (0-1)</th>
<th>1/3 Continuity (0-2)</th>
<th>2/3 Continuity (0-4)</th>
<th>3/5 Continuity (0-8)</th>
<th>Absolute Continuity (0-10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Virus Load Raised</td>
<td>1</td>
<td>13</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Virus Load Suppressed</td>
<td>5</td>
<td>13</td>
<td>11</td>
<td>5</td>
<td>2</td>
</tr>
</tbody>
</table>

_Fisher exact = 0.826_
In total, 87.5% (63/72) of those who only visited nurses had a suppressed viral load. Error! Reference source not found. and 6 indicate that most patients had a 2/5 CF score, of which, 83% (39/47) had a suppressed VL. With increasing CFs, there was a trend that the patients would more likely be virologically suppressed; however, this 'trend' was not statistically significant (p=0.626).

The following graphs include the patient(s) who had visit(s) to the doctor(s). The maximum CF is compared with the comparative CCC scores.

*Figure 4 Distribution of CF Scores and VL Outcomes (Percentages)*

*Figure 5 Distribution of Maximum CF (of either Nurse or Doctor) Scores and VL (92)*

\[
\text{Fishers Exact } = 0.641
\]
There is still no significant association of VL outcomes and the maximum CF ($p=0.641$). The most frequent CF score remains 2/5. The inclusion of doctor visits meant that at higher CFs scores there were now patients with a raised VL. A record with a CF score of 3/5 had a raised VL with the inclusion of a doctor’s visit. The distribution of CF scores has not been done from the perspective of the maximum Nurse CF, since the inclusion of doctors resulted in 1 visit with ‘zero’ continuity (the case where all 5 visits were to doctors). This illustrates the conceptual nature of the numerator and denominator. The distribution between the Nurse CF (92) and the Maximum CF (92) showed an 88% correlation.

5.5.2 Graphs of other COC Scores and VL Outcomes

These graphs relate the distribution of COC scores of the other COC formulae and viral load (VL) outcomes. Again, the graphs for each COC firstly present the results for the nurses-only group and then when doctor(s) were visited.

Figure 7 K-index Scores and VL Outcomes with nurses only

Fisher Exact = 0.671
Figure 8: K-index Scores and VL outcomes with inclusion of doctor visits

Fisher's Exact $= 0.696$

Figure 9: SECON Scores and VL Outcomes with nurses only

Fisher's Exact $= 0.054$

Figure 10: SECON Scores and VL outcomes with inclusion of doctor visits

Fisher's Exact $= 0.243$

Figure 11: COC-index Scores and VL Outcomes with nurses only

Fisher Exact $= 0.615$
Graphically there is evidently a trend of no raised VL over a COC score of 0.5, except when doctors are included in the Alpha-index scores. The association between the various COC formulae and VL outcomes for nurses-only visits is not statistically significant, although it is close in the SECON COC formulae (p=0.054). It becomes significant when doctor visit(s) are included in the Alpha-Index scores.
5.5.2 Measuring Association of COC Scores and VL Outcomes

The association between the COC scores and VL outcomes was determined by: fisher exact tests, binary analysis using a COC score of 0.5 and VL outcomes, comparison of means and medians in regards to VL outcomes.

The fisher exact test results on the distribution of COC scores and VL outcomes were presented with the graphs in the previous section. These results are presented again in the table which is a summary of all the tests of association and linear modelling. The following two tests of association are a binary analysis of COC Scores and VL Outcomes (5.5.2.1) and COC Formulae Score Means/Medians and VL Outcomes (5.4.2.2).

5.5.2.1 Binary analysis of COC Scores and VL Outcomes

The CF scores were reformulated to perform binary calculations, as indicated below, in Error! Reference source not found.. A COC score of 0.5 was deduced from the graphs to be an appropriate point to divide the scores. Binary analysis was initially applied to nurse-only visits:

<table>
<thead>
<tr>
<th>Continuity Fraction (CF)</th>
<th>CF &lt;= 2 out of five</th>
<th>CF &gt;= 3 out of five</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Viral Load Suppressed</td>
<td>45</td>
<td>18</td>
<td>63</td>
</tr>
<tr>
<td>Viral Load Raised</td>
<td>9</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Total</td>
<td>54</td>
<td>18</td>
<td>72</td>
</tr>
</tbody>
</table>

*Fisher Exact = 0.104

Variations of binary tables with the CF categories reconfigured into binary variables showed no statistical significance. Binary analysis of the more complicated COC formulae showed a trend towards significance at a lower benchmark of 0.25 continuity score (K-index p=0.283, SECON p=0.1, COC-index p=0.1, Alpha-index p=0.256) but not at a 0.5 continuity score. This binary analysis was applied to all patients with continuous visits:

<table>
<thead>
<tr>
<th>Continuity Fraction (CF)</th>
<th>CF &lt;= 2 out of five</th>
<th>CF &gt;= 3 out of five</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Viral Load Suppressed</td>
<td>55</td>
<td>22</td>
<td>77</td>
</tr>
<tr>
<td>Viral Load Raised</td>
<td>14</td>
<td>1</td>
<td>15</td>
</tr>
<tr>
<td>Total</td>
<td>69</td>
<td>23</td>
<td>92</td>
</tr>
</tbody>
</table>

*Fisher's exact = 0.204

Variations of Binary Tables with the CF categories reconfigured into binary variables showed no statistical significance. Binary analysis of the other COC formulae showed a trend towards
significance at a lower benchmark of 0.25 continuity score (K-index p=0.107; SECON p=0.177; COC-index p=0.158).

5.4.2.2 COC Formulæ Score Means/Medians and VL Outcomes

The rank-sum test for non-parametric data was utilised.

### Table 11 COC Score Means/Medians and VL Outcomes (72 patients)

<table>
<thead>
<tr>
<th>Formulæ</th>
<th>VL Suppressed</th>
<th>VL Raised</th>
<th>Mean (T-test)</th>
<th>Median</th>
<th>Rank-sum</th>
</tr>
</thead>
<tbody>
<tr>
<td>CF</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.1240</td>
</tr>
<tr>
<td>K-index</td>
<td>VL Suppressed</td>
<td>0.37</td>
<td>(0.32 - 0.47)</td>
<td>0.75</td>
<td>(0.25 - 0.5)</td>
</tr>
<tr>
<td></td>
<td>VL Raised</td>
<td>0.28</td>
<td>(0.16 - 0.39)</td>
<td>0.25</td>
<td>(0.25 - 0.25)</td>
</tr>
<tr>
<td>SECON</td>
<td>VL Suppressed</td>
<td>0.25</td>
<td>(0.19 - 0.34)</td>
<td>0.25</td>
<td>(0.0 - 0.5)</td>
</tr>
<tr>
<td></td>
<td>VL Raised</td>
<td>0.22</td>
<td>(0.16 - 0.29)</td>
<td>0.25</td>
<td>(0.25 - 0.25)</td>
</tr>
<tr>
<td>COC-index</td>
<td>VL Suppressed</td>
<td>0.11</td>
<td>(0.06 - 0.16)</td>
<td>0.1</td>
<td>(0.1 - 0.1)</td>
</tr>
<tr>
<td></td>
<td>VL Raised</td>
<td>0.34</td>
<td>(0.30 - 0.39)</td>
<td>0.35</td>
<td>(0.16 - 0.48)</td>
</tr>
<tr>
<td>Alpha-index</td>
<td>VL Suppressed</td>
<td>0.79</td>
<td>(0.22 - 0.35)</td>
<td>0.28</td>
<td>(0.28 - 0.35)</td>
</tr>
<tr>
<td></td>
<td>VL Raised</td>
<td>0.47</td>
<td>(0.42 - 0.51)</td>
<td>0.4</td>
<td>(0.4 - 0.6)</td>
</tr>
</tbody>
</table>

Error! Reference source not found. shows that the medians were not different between groups of patients with a suppressed VL and patients with VL raised. Rank-sum test for non-parametric variables were therefore also found not to be significant. Higher continuity scores' association with VL suppression is not statistically evident, except for the fact that the upper border of the interquartile range for VL suppression is higher than that for VL raised.

### Table 12 COC Score Means/Medians and VL Outcomes (92 patients)

<table>
<thead>
<tr>
<th>Formulæ</th>
<th>VL Suppressed</th>
<th>VL Raised</th>
<th>Mean (T-test)</th>
<th>Median</th>
<th>Rank-sum</th>
</tr>
</thead>
<tbody>
<tr>
<td>CF</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.1093</td>
</tr>
<tr>
<td>K-index</td>
<td>VL Suppressed</td>
<td>0.34</td>
<td>(0.30 - 0.39)</td>
<td>0.25</td>
<td>(0.25 - 0.5)</td>
</tr>
<tr>
<td></td>
<td>VL Raised</td>
<td>0.31</td>
<td>(0.21 - 0.42)</td>
<td>0.25</td>
<td>(0.25 - 0.5)</td>
</tr>
<tr>
<td>SECON</td>
<td>VL Suppressed</td>
<td>0.18</td>
<td>(0.14 - 0.22)</td>
<td>0.1</td>
<td>(0.1 - 0.3)</td>
</tr>
<tr>
<td></td>
<td>VL Raised</td>
<td>0.15</td>
<td>(0.07 - 0.23)</td>
<td>0.1</td>
<td>(0.1 - 0.2)</td>
</tr>
<tr>
<td>COC-index</td>
<td>VL Suppressed</td>
<td>0.34</td>
<td>(0.30 - 0.38)</td>
<td>0.2</td>
<td>(0.1 - 0.4)</td>
</tr>
<tr>
<td></td>
<td>VL Raised</td>
<td>0.31</td>
<td>(0.25 - 0.37)</td>
<td>0.2</td>
<td>(0.1 - 0.3)</td>
</tr>
</tbody>
</table>

Using the Maximum CF, according to the rank-sum test (non-parametric) there was a significant difference between VL suppressed and VL raised groups. This was not evident when patients only visited nurses, but once a doctor visit is included the sample it becomes significant. This finding was only evident with the CF and not reproducible with the other COC formulæ. The median scores
still remain unchanged for all the formulae when doctor visits are included. All the scores show an inverse relationship between VL and continuity scores.

5.5.3 The measure of the effect of COC scores and VL outcomes

The measure of the effect of COC scores and VL outcomes was measured with General Linear Modelling with Poisson Regression with Robust Error Variance. Modelling was done to control for the following factors: age, gender, baseline CD4, TB, visitation date continuity, the follow-up period of 3 consultations, the ARV regime and the time period since when they were started on ARVs. Firstly, the effect of continuity on VL outcomes is measured (5.5.3.1) and secondly, the effect of suppressed VLs on continuity is measured (5.5.3.2).

5.5.3.1 The Effect of COC Scores on VL Outcomes

Table 13 Risk Ratios of COC Exposure on VL Outcomes (72 Patients)

<table>
<thead>
<tr>
<th></th>
<th>CF</th>
<th>k-index</th>
<th>SECON</th>
<th>COC-index</th>
<th>Alpha-index</th>
</tr>
</thead>
<tbody>
<tr>
<td>IRR</td>
<td>1.51</td>
<td>1.47</td>
<td>1.12</td>
<td>1.55</td>
<td>1.38</td>
</tr>
<tr>
<td>CI</td>
<td>(1.06 - 2.56)</td>
<td>(1.01 - 2.36)</td>
<td>(0.68 - 1.41)</td>
<td>(1.11 - 2.19)</td>
<td>(1.10 - 1.90)</td>
</tr>
</tbody>
</table>

*The VL outcomes were reconfigured to VL suppressed = 1, VL raised = 0

IRR is a Risk Ratio

The results show that there is a relationship between increasing COC scores and an increased chance of having a suppressed VL. The confidence intervals of the SECON and Alpha-index overlap 1, indicating no significant chance of suppressed VLs. However, the CF, k-index and COC index do indicate a significant chance of a suppressed VL. As the CF score increases, there is a 51% increased chance for a patient to have a suppressed VL, if the patient visits nurses continuously in the clinic. The following Table examines the effect of the inclusion of doctor visits.

Table 14 Risk Ratios of COC Exposure on VL Outcomes (92 Patients)

<table>
<thead>
<tr>
<th></th>
<th>CF</th>
<th>k-index</th>
<th>SECON</th>
<th>COC-index</th>
<th>Alpha-index</th>
</tr>
</thead>
<tbody>
<tr>
<td>IRR</td>
<td>1.68</td>
<td>1.36</td>
<td>1.15</td>
<td>1.51</td>
<td>1.36</td>
</tr>
<tr>
<td>CI</td>
<td>(1.03 - 1.77)</td>
<td>(0.97 - 1.93)</td>
<td>(1.08 - 1.57)</td>
<td>(1.11 - 2.06)</td>
<td>(1.03 - 1.84)</td>
</tr>
</tbody>
</table>

*The VL outcomes were reconfigured to VL suppressed = 1, VL raised = 0

These results of all patients with continuous visits compared to those of patients who visited only nurses are similar in that with increasing COC scores, there is an increased chance of having a suppressed VL. But this is reduced, except the SECON. The k-index, SECON and Alpha-index are now not significant. The CF and COC continue to indicate a significant chance of a suppressed VL with increased COC scores. The SECON index has a slightly increased likelihood with a suppressed VL with the inclusion of doctors visits i.e. provider sequentiality. The maximum CF has a marked drop in the chance of a suppressed VL when compared with the results with patients with only visiting nurses.
5.5.3.2 The effect of Suppressed VLs on COC Scores

Since CDC cannot be assumed to cause VL outcomes, there is the possibility that suppressed VL ('exposure') results in higher COC ('outcome'), whereas a raised VL resulted in lower COC scores, since the patients might be referred to doctors, resulting in a lower dispersion of CDC scores calculated by the complicated CDC formulae.

<table>
<thead>
<tr>
<th></th>
<th>CF</th>
<th>K-index</th>
<th>SECON</th>
<th>COC-index</th>
<th>Alpha-index</th>
</tr>
</thead>
<tbody>
<tr>
<td>72 Patients with nurse visits only</td>
<td>IRR 1.25</td>
<td>1.49</td>
<td>1.16</td>
<td>2.016</td>
<td>1.29</td>
</tr>
<tr>
<td></td>
<td>CI (1.07–1.45)</td>
<td>CI (1.08–2.04)</td>
<td>CI (1.06–1.88)</td>
<td>CI (1.18–2.95)</td>
<td>CI (1.19–1.61)</td>
</tr>
<tr>
<td>92 Patients including doctor visits</td>
<td>IRR 1.20</td>
<td>1.34</td>
<td>1.27</td>
<td>1.75</td>
<td>1.17</td>
</tr>
<tr>
<td></td>
<td>CI (1.04–1.37)</td>
<td>CI (1.00–2.15)</td>
<td>CI (1.02–1.96)</td>
<td>CI (1.24–2.46)</td>
<td>CI (1.05–1.45)</td>
</tr>
</tbody>
</table>

*The VL outcomes were reconfigured to VL suppressed = 1, VL raised = 0

With the inclusion of doctors, the chance that a patient with VL suppression has a higher COC score is evident when using all the formulae, yet it was lower than the results when patients only visited nurses. The exception was the SECON, which showed an increase due to more sequential visits, when doctors were included in the visit(s). Only, the CF produced a significant result, but it was lower than the result for continuous patients with only nurses visits. In general, including doctors visits in the sample thus lowered the likelihood of a higher CDC score. In the case of the complex formula, this finding could be a case of the 'dispersion' of concentration of CDC with a greater number of providers.
## 5.5.4 Summary of results of association and linear modelling in regards to COC scores and VL Outcomes

### Table 16: Summary of Results of Continuous Patients in relation to VL Outcomes

<table>
<thead>
<tr>
<th>Continuous Visits to Nurses</th>
<th>CF</th>
<th>K-index</th>
<th>SECON</th>
<th>COC-index</th>
<th>Alpha-index</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goal of formulae</td>
<td>Individual Provider</td>
<td>Dispersion of concentration of providers</td>
<td>Sequential providers</td>
<td>Dispersion of concentration of providers</td>
<td>Weighting between dispersion and sequentiality</td>
</tr>
<tr>
<td>Distribution of Scores and VL Outcomes</td>
<td>0.626</td>
<td>0.571</td>
<td>0.054</td>
<td>0.615</td>
<td>0.11</td>
</tr>
<tr>
<td>Binary Analysis of CF&gt;0.5</td>
<td>0.1</td>
<td>1</td>
<td>1 (but if &gt;0.25 then 0.983)</td>
<td>1 (but if &gt;0.25 then 0.1)</td>
<td>0.515 (if &gt;0.25 then 0.256)</td>
</tr>
<tr>
<td>Ranksum</td>
<td>0.1246</td>
<td>0.1998</td>
<td>1</td>
<td>0.13908</td>
<td>0.5581</td>
</tr>
<tr>
<td>General Linear Modelling with VL suppression as the outcome and the COC score as the exposure</td>
<td>IRR 1.51 (CI 1.05 - 2.16)</td>
<td>IRR 1.47 (CI 1.01 - 2.11)</td>
<td>IRR 1.12 (CI 0.94 - 1.31)</td>
<td>IRR 1.56 (CI 1.11 - 2.13)</td>
<td>IRR 1.38 (CI 1.07 - 1.90)</td>
</tr>
<tr>
<td>General Linear Modelling with COC as the outcome and VL suppression as the exposure</td>
<td>IRR 1.25 (CI 1.07 - 1.43)</td>
<td>IRR 1.49 (CI 1.08 - 2.04)</td>
<td>IRR 1.19 (CI 0.79 - 1.81)</td>
<td>IRR 2.02 (CI 1.38 - 2.95)</td>
<td>IRR 1.29 (CI 1.03 - 1.62)</td>
</tr>
</tbody>
</table>

### Inclusion of Doctors

| Distribution of Scores and VL Outcomes | 0.641 | 0.596 | 0.243 | 0.706 | 0.04 |
| Binary Analysis of CF>0.5 | 0.104 | 0.594 (if >0.25 then 0.708) | 0.587 (if >0.25 then 0.177) | 0.594 (if >0.25 then 0.167) | 0.545 (if >0.25 then 0.158) |
| Ranksum                    | 0.1093 | 0.2693 | 0.91014 | 0.2118 | 0.9958 |
| General Linear Modelling with VL suppression as the outcome and the COC score as the exposure | IRR 1.08 (CI 1.01 - 1.17) | IRR 1.36 (CI 0.97 - 1.83) | IRR 1.15 (CI 0.82 - 1.61) | IRR 1.51 (CI 1.12 - 2.06) | IRR 1.30 (CI 1.07 - 1.54) |
| General Linear Modelling with COC as the outcome and VL suppression as the exposure | IRR 1.26 (CI 1.04 - 1.57) | IRR 1.34 (CI 1.00 - 1.79) | IRR 1.27 (CI 0.82 - 1.96) | IRR 1.75 (CI 1.21 - 2.46) | IRR 1.17 (CI 1.05 - 1.39) |
5.6 COC SCORES AMONGST 20 CONTINUOUS PATIENTS WITH DOCTOR VISIT(S)

To describe the patient visits to the doctor, the formulation of the Doctor CF was used. Therefore amongst the 20 patients with continuous visits, including doctor visit(s), the formulation of the Doctor CF was used to describe the patient visit(s) to the doctor(s). The denominator of the Doctor CF was fixed, however the conceptual dilemma has been discussed in 5.3. Amongst the 20 patients with doctor visit(s) the mean was $0.26$ (CI $0.19-0.33$) and median was $0.2$ (IQR $0.2-0.3$).

5.6.1 Graphs of Distribution of COC Scores with VL Outcomes

The distribution of the frequency of Doctor CF Scores and other COC scores with VL Outcomes was graphed.

5.6.1.1 Graphs of Doctor CF Scores and VL outcomes

Graphs of the Doctor CF Scores and VL outcomes are presented below in Figure 15 and 16. Amongst the 20 patients, 9 patients had a Doctor CF greater or equal to the maximum Nurse CF, and 5 patients had a Doctor CF greater than the maximum Nurse CF. The maximum CF score for the patient does not describe the nature of the mixture of the nurse and doctor visits.

![Figure 15 Distribution of Doctor CF Scores and VL](image)

*Fisher's Exact = 0.329*
75% patients had one visit to a doctor. Doctor CF scores above one visit have a higher percentage of raised VLs. No patients have absolute continuity or 4/5 continuity. The overall percentage of patients visiting a doctor with a raised VL is 35%. The relationship between COC including doctors' visits and VL is not statistically significant (p=0.329). And yet, when all 'continuous' visits are included, the Doctor CF relationship was significantly related to a raised VL (p=0.023).

5.6.1.1 Graphs of other COC Scores and VL outcomes
The K-index, SECON, COC-index and Alphie-index were calculated for the dispersion of continuity amongst all the providers (see Figure 17 to Figure 20).
Figure 19 Distribution of COC-index Scores and VL Outcomes (20 patients with a doctor visit)

Fisher’s Exact = 0.615

Figure 20 Distribution of Alpha-index Scores and VL Outcomes (20 patients with a doctor visit)

Fisher’s Exact = 0.77

The graphs of ‘dispersion’ of concentration of providers and/or sequentiaity reflect the fact that patients with a raised VL are visiting a specific doctor more often or sequentially. In these cases, when the COC score is above 0.5, there is an increased chance of a raised VL.

5.6.2 Mean and Medians of Doctor CF and VL Outcomes

<table>
<thead>
<tr>
<th>Table 17 Mean and Medians of Doctor CF and VL Outcomes (20 Patients)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor CF (20 patients)</td>
</tr>
<tr>
<td>-------------------------</td>
</tr>
<tr>
<td>VL suppressed</td>
</tr>
<tr>
<td>VL raised</td>
</tr>
</tbody>
</table>

The VL outcomes and the Doctor CF were not significant in the analysis with the 20 patients who only had visits to doctors. When one looks at the CF scores amongst the patients who only visited doctors, and assumes that the denominator of the CF is 5 visits, the following graph reflects the distribution of Doctor CF for patients.
5.7 COC AND ADHERENCE TO APPOINTMENT DATES

Other factors determine the management of patients visiting the clinic, including scheduled and unscheduled visits. This section describes keeping appointment dates and VL Outcomes for nurses-only (72 patients) and then patients who had at least one visit to a doctor (20 patients). Firstly, visits are reviewed in terms of how the patient kept their scheduled date to visit the clinic, from ‘exact’ date to increasing period of grace for unscheduled visits. Secondly, a binary analysis of CF Scores and Date Continuity is presented.

5.7.1 Nurse Visits, Keeping Appointment Dates and VL Outcomes (72 Patients)

In order to determine whether keeping appointment dates would be a good indicator for better VL outcomes, the COC data is analysed to determine, whether there is any association between keeping appointment dates and VL outcomes. Due to the fact that a patient might not keep the ‘exact’ appointment date, a three-day grace period was included for a patient who could not make it on the exact date, but came the next day or after the weekend. The grace period was extended to include any visit prior to the appointment date and 3 days later, thereby accommodating patients who might come earlier if they have a problem. The groups of patients are analysed separately below.

![Figure 21: 'Exact' Date and VL Outcomes](image)

*Figure 21: 'Exact' Date and VL Outcomes*

<table>
<thead>
<tr>
<th>Number of exact visits adhered by the patient</th>
<th>Number of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

Fisher Exact = 0.932

24% patients kept exact dates. Between 10-20% of patients with 2- to 5 exact-day visits had a raised viral load. Interestingly, among patients with no date adherence (representing 6% of the patients) there was no raised viral load. Therefore, there is no significant association with VL outcomes evident in this data.
54% of patients visited five times within the grace period of the exact dates of the appointments. 86% of patients had at least 4 visits within this time period. There is no significant association with VL outcomes.

With increasing 'grace' periods, patients are less likely to come late for their date. The majority of patients (78%) came within the 'grace'-period five times. 99% of patients maintained this three times. However, there is no significant association between keeping appointment dates that include grace periods and VL outcomes.

5.7.2 Nurse CF Scores and Date Continuity (72 patients)

The question considered here is whether patients with higher CF scores also have higher date continuity in terms of keeping appointment dates. Binary analysis was performed by categorising the categorical data into binary data, by using a cut-off of '2.5' date continuity (i.e. representing 50% of a 5 times data continuity) and '0.5' CF COC score (i.e. the CF only has results of 0.4 and 0.6, but 0.5 is a mid-point). Date continuity is not associated with improved CF Scores (p=0.262).
Similarly, binary analysis was performed testing the association of Date Continuity and VL Outcomes. It is found that Date Continuity is not related with increased VL suppression (p=1).

5.7.3 Doctor Visits and Keeping Appointment Dates and VL Outcomes (20 Patients)

The analysis above was replicated with patients who had continuous visits with both, doctors and nurses.

**Figure 24 'Exact' date and VL Outcomes**

![Graph showing number of patients and VL outcomes](image)

*Fisher Exact = 0.149*

**Figure 25 Grace'-period of 3 Days with Appointment and VL Outcomes**

![Graph showing number of visits and VL outcomes](image)

*Fisher Exact = 0.483*

**Figure 26 'Grace'-period Anytime before Appointment day till 3 Days later and VL Outcomes**

![Graph showing number of visits and VL outcomes](image)

*Fisher Exact = 0.138*

It is found that keeping appointment dates is not associated significantly with VL outcomes. Fewer patients keep their times as visualised in the 3 day grace period graph.
5.7.4 Doctor CF Scores and Date Continuity (20 patients)

The same question is now posed to Doctor CF scores and its relation to date continuity, in terms of keeping appointment dates. Again, Chi-square analysis was performed by categorising the categorical data into binary data, by using a cut-off of '2.5' date continuity (i.e. this 50% of a 5 times date continuity) and '0.5' CF COC score (i.e. the CF only has results of 0.4 and 0.6, but 0.5 is a mid-point). Date Continuity is not related with improved CF Scores (p=0.479). Patients do not keep appointment dates with 'their' doctor. Similarly, Chi-square analysis was performed with Date Continuity and VL outcomes. Again, Date Continuity is not related with more VL suppression (p=0.642)
5.9 ‘Proxy’ Visits
As noted above, ‘proxy visits’ refers to visits to either nurse or doctor of a family member, friend, or neighbour of the patient who was sent as a ‘proxy’ to fetch the patient’s medication. Overall, 61 patients with ‘proxy’ visits were in the sample. The analysis here seeks to determine whether ‘proxy’ visits are related to keeping appointment dates and VL outcomes.

5.9.1 ‘Proxy’ Visits and VL Outcomes
Figure 27 represents the number of proxy visits and VL outcomes.

Figure 27 Number of ‘Proxy’ Visits

<table>
<thead>
<tr>
<th>Proxy Visits and VL Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients</td>
</tr>
<tr>
<td>35</td>
</tr>
<tr>
<td>30</td>
</tr>
<tr>
<td>25</td>
</tr>
<tr>
<td>20</td>
</tr>
<tr>
<td>15</td>
</tr>
<tr>
<td>10</td>
</tr>
<tr>
<td>5</td>
</tr>
<tr>
<td>0</td>
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</tbody>
</table>

Fisher Exact = 0.710

Perhaps contrary to expectation, an increasing number of proxy visits is not related to a raised VL. The association between VL suppression and more than two ‘proxy’ visits was not significant (p=0.575).

5.9.2 ‘Proxy’ Visits and ‘Exact’ Date Visitation
The association between ‘proxy’ visits and ‘exact’ date visitation was not significant (p=0.147), but if one allowed for a 3-day grace period then ‘proxy’ visits significantly occurred in the grace period (p=0.046).

5.9.3 ‘Proxy’ Visits within Expected Time Period and VL Outcomes
In this analysis only the proxy visits which occurred within the expected timeframe that the patients were supposed to come to an appointment, was measured against VL outcomes. The analysis shows that there was no significant result for ‘proxy’ visits on ‘exact’ date and VL suppression (p=1); including using binary variables for ‘proxy’ visits above 2 ‘proxy’ visits (p=0.641). Furthermore, there was no significant result for ‘proxy’ visits within three days of
grace of visitation date and VL Suppression ($p=0.723$), including using binary variables for 'proxy' visits above 2 'proxy' visits ($p=1$).

### 5.9.4 Keeping Appointment Dates and VL Outcomes

Lastly, the analysis seeks to determine whether keeping appointment dates is related to VL outcomes. Figure 28, Figure 29, and Figure 30 consider both, 'exact' date appointments as well as appointments within the stipulated grace-periods.

**Figure 28** Proxy Visit with 'Exact' date and VL Outcomes

![Figure 28 Proxy Visit with 'Exact' date and VL Outcomes](image)

Fisher Exact = 0.745

**Figure 29** Proxy Visit with 'Grace'-period of 3 Days with Appointment and VL Outcomes

![Figure 29 Proxy Visit with 'Grace'-period of 3 Days with Appointment and VL Outcomes](image)

Fisher Exact = 0.284
Fisher Exact = 0.056

The analysis reveals a pattern that is similar to that of the 72 ‘continuous’ patients, in that there is no significant association with VL outcomes evident in this data.
6. DISCUSSION

6.1 Descriptive Data

The descriptive data reflects the profile of patients in the clinic: more women than men, women with a higher baseline CD4, which is the clinical experience within the clinic. This is mostly due to women being initiated earlier during pregnancy at the Maternity Unit. Patients below the age of 25 are started on ARVs at the Site B Youth Clinic. The descriptive data of the various subgroups of the sample showed little variation in regards to the age, gender, baseline CD4, Viral Loads recorded, and the period of treatment since initiation of ARVs.

Patients with TB had a variation in results: 66% 'proxy' patients had TB as against only 47% of 'continuous' patients with TB who had visits only to nurses. Continuous visits which included doctors' visits only resulted in a slight increase to 52%. However, when the 20 patients who were 'continuous' and had a doctor visit(s) were investigated, 50% have had TB, but with increasing continuity with a doctor, the percentage of patients with TB decreased to 40%. It is unclear why this trend is occurring, except that it is understood that there is a higher frequency of patients who are being initiated on ARVs whilst on TB Treatment. 50% of patients starting ART at Ubuntu Clinic have TB and 70% of TB patients have HIV26. 29% Club patients had TB; this is expected due to the eligibility criteria of Clubs which require that patients do not have an OI at the time of selection.

100% of the Club patients sampled were virologically suppressed. However, a suppressed VL is a criterion to remain in the Adherence Club. A raised VL would result in the patient being removed from the Club and placed back with the 'mainstream' patients in the Clinic. 88% of the 72 patients with continuous visits to nurses had a suppressed viral load. This result is similar to the 86% virological suppression found in an analysis of virological outcomes after 5 years at the original 3 ART centres in Khayelitsha87. As patients had increased continuity with doctors, the number of patients with a raised VL increased. This would be expected.

At least 54% (33) patients had a VL within the last 5 visits. Whether the VL was taken in the period of the 5 consultations or not did not have a significant association with the VL Outcome (p=0.653).
6.2 COC Data

6.2.1 COC Scores

This study was a 'thermometer' of the clinic's longitudinal COC. The researcher's experience of using the formulae was that the CF was the easiest method to calculate COC. The K-index was the easiest to calculate for the dispersion of COC amongst the providers. The SECON, COC-index, and Alpha-index required more thought in creating the formulas in EXCEL. The Alpha-index was the most complicated and generated variables with numerous decimal points due to its logarithms. The use of the formulae needed to be restricted to 'continuous' patients who visited the clinic; and excluded patients with 'proxy' visits. An 'insider' would have a greater ability to identify the clinicians' handwriting in order to confirm who the patient had visited.

The distribution of scores was non-parametric and skewed to lower COC scores. Statistically the data would then need to be presented as medians with inter-quartile ranges, yet all the studies on the UPC or other COC formulae presented their data as means. It is difficult to verify from the published research on the UPC whether the data was 'normal'. The only research that utilised a median was Freeman\(^64\) in order to define good continuity at 0.58, part of the 17 Studies reviewed by Saultz\(^15\). The means will be used in this discussion only to compare to previous literature, though medians better represent the actual situation.

The CF scored continuity higher than the other more complicated formulas, with a correlation above 75% with the K-index, SECON, COC-index and Alpha-index. In the Ejlertsson study\(^7\) the mean score of the formulae were: K-index 0.28, UPC/CF 0.27, COC-index 0.23, and SECON 0.25 (no confidence intervals in the study). The score for patients' only visiting nurses was: K-index 0.34(CI 0.31–0.41), UPC/CF 0.46(CI 0.42–0.5), COC-Index 0.18(CI 0.15–0.23) and SECON 0.23(CI 0.19–0.30). However since the Ejlertsson study included acute and scheduled visits, this was also compared with the Ubuntu patients who had doctor visits: K-index of 0.34(CI 0.3–0.39), UPC/CF 0.46(CI 0.42–0.5), COC-index 0.18(CI 0.14–0.21) and SECON of 0.23(CI 0.18–0.28). In the Ubuntu Study, it is the CF score that scored higher than the UPC (the CF equivalent) in the Ejlertsson study, though it is difficult to comment on any significance in the comparison. When comparing the CF with the UPC in international literature, the UPC is measured in varying situations: 'Community hospital based family practice residency' with 0.59 for 2\(^{nd}\) year doctor/residents and 0.54 for 3\(^{rd}\) year doctor/residents\(^75\), UK 'combined list' general practice with a median 0.58\(^64\) or mean of 0.49,
0.52, and 0.58\textsuperscript{80} or 0.52\textsuperscript{81} and 'personal list practices' with a median of 0.9\textsuperscript{84} and mean of 0.83\textsuperscript{80} and 0.82\textsuperscript{81}, 'outpatient primary care setting' in the USA was 0.79 and in the UK it was 0.72\textsuperscript{74}, 'primary care district' with a UPC of 27.3\textsuperscript{17}. This range of contexts makes it difficult to compare. In the Bresick study\textsuperscript{9} of the South African public health sector context in Cape Town, the mean UPC was 0.43 (CI 0.38–0.47) and median UPC was 0.33 (IQR 0.33–0.5). Bresick used a UPC with a denominator of 6. The Ubuntu CF mean of 0.46 (CI 0.42–0.5) and median of 0.4 (IQR 0.4–0.5) could then be considered adequate scores for the Ubuntu clinic. Both South African studies had a median of 2 visits. Both Bresick's UPC and Ubuntu's CF possibly represent the situation in the South African public health system. In the HIV setting, the New York Community Based ARV Clinic\textsuperscript{6} had a mean COC-index score of 0.14 amongst 653 patients over 24 months period, whereas in this study for the 72 patients with visits to nurses-only, the mean COC-index score was 0.18 (CI 0.15–0.23) over an average duration of 180 days. The median COC-index score in the Ubuntu study was 0.1 (IQR 0.1–0.25), and from the New York Community Based ARV Clinic it was approximately 0.06 or 0.07 as estimated from their distribution graph. It seems that the longitudinal COC in Ubuntu is similar to the New York clinic.

Overall, the CF scores were higher than the other COC formulae. The concept of a satisfactory ratio for good continuity will be discussed following the discussion relating to VL outcomes and doctor visits.

6.2.2 Is there a significant difference in COC between adherence club members and those not in clubs?

The unique sequestration of 'good' patients with suppressed VLs into the Adherence Clubs meant that these patients experienced a 'managerial' continuity of care\textsuperscript{14}. This was not 'longitudinal' COC with an individual health professional, but rather a health 'team' which comprised a nurse and community health worker. Therefore it would be difficult to compare patients in the Adherence Clubs and those who are not. The development of Adherence Clubs was an adaptation to the dilemma of continuing to provide care for large numbers of well-controlled patients\textsuperscript{5}. The use of a CF has been complicated by a model of care that does not view an 'individual' provider as the emphasis of COC. This could be an example of how COC is 'framed within an African context' and the needs of the patients are realised within community-orientated primary care\textsuperscript{52}.
6.2.3 Are VL outcomes related to COC?

In this section the focus is on the patients with continuous visits to nurses only. The results of two factors, the patient’s ability to keep appointments and proxy visits, are also interpreted in the light of their VL outcomes. How doctor visit(s) influence COC and VL outcomes is discussed in 6.2.4.

Generally VL suppression in Ubuntu Clinic was good: for ‘continuous’ visits only to the nurses it was 88% (CI 78-94) and for all ‘continuous’ visits it was 83% (CI 73-90). This data compared favourably with the 86% virological suppression found in an analysis of virological outcomes after 5 years at the original 3 ART centres in Khayelitsha\(^2\). A systemic review of 89 studies in Sub-Saharan Africa\(^3\) had a 67% virological suppression at 24 months. The New York Community based ARV Clinic did not relate their COC-index to VL outcomes\(^6\). Since the COC scores were skewed to below 0.5, the good VL outcomes are most probably related to other factors in the clinic. These factors may include an activist heritage in the clinic culture, or a good pharmacy, or good clinic management which have not been studied yet in the clinic.

When the distribution of COC scores graphically incorporated VL outcomes, VL suppression appeared related to higher COC scores for all formulae, particularly over 0.5. Patients with continuous visits to nurses showed no significant association between higher COC scores and better VL outcomes. However, with increased sequentiality, as measured by the Alpha-index (p=0.11) and particularly the SECON (p=0.054) there is seems to be an association with raised VLs. Binary analysis that formulated the categorical variables of the COC scores into those of above and below a 0.5 (50%) did not replicate any association. Overall, however the statistical tests for association (fisher exact, binary analysis, Ranksum) between the COC scores and VL outcomes were not helpful to find a potential benchmark for good continuity.

General Linear Modelling with Poisson Regression with robust error variance was used to test for the strength of association proved to be a more suitable statistical test for this cross-sectional study\(^7\). Risk ratios are easier to explain and can be used in the context of high prevalence, unlike Odds ratios\(^8\). This statistical approach fits into public health systems which have data bases which are minimal, and allow for cheap and quick cross-sectional studies which estimates risk at point in time\(^7\). VL suppression as the outcome of the exposure to the COC was significant for the CF, K-index and COC-index. However it was not significant for the formulae which measured sequentiality: SECON and Alpha-index. Higher
CF scores had a 51% increased chance of VL suppression. Conversely, it could be argued that a suppressed VL could result in a better COC. A patient with a suppressed VL has a 25% chance of an increased CF score. Such a patient would have similar increases with the K-index, SECON, COC-index, and Alpha-index, except that it was not significant with the SECON. A suppressed VL improves your chances of better COC scores, but not necessarily sequentiality. This gives an idea that nurses work in teams who are focused on managing the stable chronic patient in the primary care system, rather than individual continuity.

The patient's ability to keep appointments is a form of adherence which could have good VL outcomes, or vice versa, since it is expected that poor adherence to dates results in poor VL outcomes. However graphically it appeared that patients with higher appointment date adherence were more likely to have a high VL, even with increasing the period of grace around the exact appointment date. This association was not statistically significant. Higher CF scores were not related to better appointment date adherence. This shows a clinic with a high number of 'unscheduled' visits; however this is not related to VL outcomes or CF scores. Unscheduled visits are a challenge of planning in the chronic care setting of Ubuntu, yet in this study it does not compromise the virological suppression.

'Proxy' patients had a VL suppression of 92% (CI 82–97) for the 61 patients who had 'proxy' visits. The 72 patients with continuous visits only to nurses had a VL suppression of 88% (CI 78–94). 'Proxy' visits significantly occurred within the grace period of 3 days from the appointment date. Graphically there was a trend that over 2 'proxy' visits there was VL suppression, but this was not statistically significant. There was no association between proxy visits within a grace period of 3 days and VL outcomes. This is also not an uncommon feature of the Ubuntu clinic, when patients send proxies to fetch their medication, and it is encouraging that 'proxy' visits do not have a negative effect on VL suppression.

6.2.4 Is there a significant difference in COC between non-club patients seen by nurses and those seen by doctors?

This section focuses on how the inclusion of doctor visit(s) by the 20 patients who had continuous visits had on the overall understanding of all the continuous visits, increasing the sample analysed from 72 patients with nurse-only visits to 92 patients.

The conceptual understanding of what is a 'maximum' CF score versus maximum nurse CF score or maximum doctor CF score was discussed in the assessment of interpreting COC.
data. CF scores calculated only according to nurse or doctor would alter the interpretation of the denominator, since not all 5 visits would be to either. Unless the denominator was deemed to be equal to 5 visits; unrelated to who was visited. If this were the case, then the nurse will have 1 patient with zero continuity which would not make sense. The other COC formulae did not have a conceptual issue with the denominator, as their scores were measuring the degree of dispersion of provider continuity or sequential continuity, irrespective of whether it was a nurse or a doctor. The Doctor CF scores that were calculated used a fixed denominator of five. Only 2 patients had 5 doctor visits. 75% of the patients who had a doctor visit has a CF score of 0.2 i.e. one visit or 1/5. None of the patients had a CF score above 0.6 (3/5). Graphically with higher doctor CF scores, more patients had a greater percentage of patients with a raised VL. The ‘episodic’ once-off visit patients were mostly VL suppressed (73%). Understandably the VL suppression decreased from 88% (CI 78–94) to 83% (CI 73–90) with the inclusion of the 20 patients who had a doctor visit(s).

Since there were 32 doctor visits out of a total of 460 visits, this had a limited impact on the statistics: the COC score medians were unchanged, the correlation of COC formulae with the maximum CF was slightly decreased, and the majority of patients still had a maximum CF score of 0.4. However the inclusion of doctor visits resulted in raised VL at a higher CF score of 0.6, breaching the 0.5 mark.

Testing of association of VL outcomes and COC scores by binary analysis did not deliver a significant association with a benchmark of 0.5, though the maximum CF score has a trend towards significance (p=0.104). Non-parametric Ranksum tests comparing VL raised and VL suppressed continued to be insignificant. There was no significant association between the distribution of COC scores and VL outcomes, except with the Alpha-index (p=0.04). However the SECON, which also displays sequentiality, does not have a similar result. It is difficult to make sense of these results from these tests of association.

With linear modelling, the inclusion of doctors resulted that the VL suppression was decreased in all the COC Indices, except the SECON. There was an increased chance of a higher SECON score with inclusion of doctors, though not significant. The chance a patient has a suppressed VL with continuity, according to the CF score, had a mark drop down to 8%. This drop in the COC scores of the CF, K-index, COC-index and Alpha-index could be on the basis that the inclusion of a doctor(s) increased the number of providers, hence the
dispersion of continuity. This mathematical phenomenon is a result of adding another numerator as much as it is a reflection of the continuity. The increase in sequentiality could be expected with a patient whose problem is followed up by a specific doctor, which is the normal practice in the Ubuntu clinic, hence the increase in the SECON score.

If best practice towards chronic care needs to be measured, a focus on the nurse based care needs to be observed. Doctor visit(s) sufficiently alter the results by changing the mathematical interpretation of the formulae e.g. increasing the numerator, increasing the dispersion, increasing the sequentiality. Nurses were not focused on providing individual provider continuity with the patient, but 'managing' the chronic patient as a group of nurses. Doctors focus on problems of an individual patient. Therefore correlating COC scores with improved VL outcomes only would be sensible if patients were only visiting nurses: the mainstay of a nurse-driven, doctor-supported clinic.

6.2.5 Is the CF a feasible tool?
To establish a goal for 'good' continuity, in this study, the median is a better measure of COC than the mean. If the operational definition of good continuity were a CF score above $0.5^{59-61}$, then the following results support such a benchmark in patients who only visited nurses: the distribution of COC scores of all formulae 'peak' below 0.5, the upper quartile range of the median CF for 'continuous' patients visiting nurses was 0.5, there are no raised VLs above 0.5, binary analysis for the CF had a trend to significance ($p=0.1$). Though the tests of association did not strongly associate the CF score with improved VL outcomes, general linear modelling test presents an alternative way of measuring 'good' continuity, by measuring the impact of good continuity.

The strengths and limitations of the CF as a COC score:
Strengths of CF:
- It is easy to calculate
- It measures individual provider continuity. Though the goal of nursing care in this clinic is not towards individual provider care, the maximum nurse CF still correlated well with other COC formulae.
- The graphs, medians, binary analysis seem to indicate that 0.5 COC score could be a benchmark for good COC as measured by the CF.
- The CF produced definite results when General Linear Modelling with Poisson Regression with robust error variance was used. Patients with nurse-only continuity
had a 51% chance of being virologically suppressed, which dropped to 8% with the inclusion of doctor(s).

Limitations of CF:

- Sequential continuity and dispersion of continuity scores of all providers has been disregarded by the CF. Therefore it is a poor measure of managerial continuity with a team of nurses. The K-index was the easiest method to measure this continuity.
- Conceptually, a doctor increases the dispersion of continuity amongst the health providers.
- It does not ultimately measure relational continuity\(^{14}\) or interpersonal continuity\(^{15}\).

6.2.6 Strengths and Limitations of Study

Strengths of Study:

- Ubuntu is a nurse-driven doctor-supported clinic with good informational continuity of care.
- The study can become part of a tradition to focus on COC in the public health sector in terms of designing a valid COC measurement tool, thereby building a body of research to set standards for good continuity.
- Longitudinal care in Africa needs to take consideration of proxy visits, and unscheduled visits, which were shown to have no association with poorer VL outcomes.
- The statistical test of General Linear Modelling with Poisson Regression with robust error variance could be an alternative way of proving that better COC has a measure of impact on the outcomes and setting standards.

Limitations of Study:

- The Study was limited to the HIV/ARV field, not other domains of Chronic Care, such as, Hypertension, Diabetes, Epilepsy and Asthma.
- The pilot study failed to identify the difficulty in sampling of the Club patients which resulted in an insufficient comparison with the non-Club patients.
- There are limitations to the use of the COC formulae: that they are restricted to patients with continuous visits, the number of providers in the clinic and the number of providers that is seen by the patients influence the how the COC scores should be interpreted – another reason why COC scores will be contingent on the context, simple formula (CF) are not simple conceptually and complex formulae do not simplify the complexity.
• The cross-sectional methodological design meant that the 'outcome of interest'/VL and 'exposure of interest'/COC-CF were measured at the same time, whereas they are actually separated in time. A more prolonged prospective cohort study might be feasible to overcome this problem.

• The COC scores do not measure relational continuity or interpersonal continuity.

6.2.7 Implications of Study

The study has measured and described COC in the Ubuntu clinic. This study is part of the imperative to 'articulate' the principles of COC into the health systems in Africa. The CF remains an easy formula for measuring COC in a clinic on the primary care level. The K-index is the easiest formula to measure the dispersion of continuity amongst the providers. The question of which COC formulae to use in a given context depends on what aspect of COC the researcher would like to measure. A continued abstract positivist approach is not going to establish a 'universal' level of good continuity. Rather the approach should be to develop a tradition of 'good' continuity ratios that should be empirically re-tested within the context of local conditions. Therefore a rational construct of COC needs to be empirically verified in the traditions that are set in the locality of that public health system. If 'speeding' is defined as going 80km/hr in a 60km/hr zone, then that is how that society has constructed 'not speeding' and 'speeding'. Traffic police do not argue whether speeding has been scientifically tested to verify it. Norms are created in a system through traditions that are contingent on experience of authorities within systems over time. To describe Continuity of Care (COC) in the context of chronic ARV care in the public health system need not focus on a universalistic abstract approach, but rather begin to set traditions on an empirical basis.

The statistical methods used in the study raise the need to test the data for normality. Since the COC scores were distributed non-parametrically, the use of medians and inter-quartile ranges better represented the data. The graphs and medians seem to point to 0.5 COC scores as a good benchmark for 'good' continuity, yet tests of association were not helpful. Risk Ratio's produced by general linear modelling with Poisson Regression with robust error variance could be an alternative way of presenting how improved COC impact on outcomes.

Correlating COC Scores with VL outcomes is more reasonable with nurse only continuous visits. The relative roles of nurses and doctors in the Ubuntu, and wider South African public health system on the primary level, are different. Nurses are concerned with the chronic management of patients and measuring the dispersion of continuity is more important than
individual provider continuity. The dilemma is that the nurses' role in the health system does not lend itself to individual provider continuity. Doctors who focus on patients' problems in this clinic means that sequentiality is more important factor, which do not correlate with improved VL outcomes. Maybe doctors need not to worry about relationships over time in the chronic care setting, expect ensuring COC in regards to a patients' problem. This would describe the principles of COC in the health systems in Africa, firstly, individual provider continuity or sequentiality with a doctor, and secondly, continuity with/in a team of nurses. Proxy visits also illustrate a unique continuity not only with the patient, but their family and community.

6.2.8 Conclusion with Recommendations
Measuring the practice of continuity in Ubuntu clinic recognises the patients' right to COC and influence interventions in the development of the Khayelitsha district health care system. Policies to improve informational continuity, such as an easy A3 patient sheet with 5 columns for visits, could become a template for COC calculations and research. As the clinic, increases in size, patient choice regarding relational continuity of care with a single health professional will be challenged. However patient preference for a specific nurse or doctor practitioner should not be prevented\(^9,12\). This will require a strengthening of existing COC within the clinic, and adapting our clinic systems in line with this, to encourage optimal continuity with the same provider. The creation of practice teams could also improve continuity\(^9\). A focus on a quality cycle improvement using COC scores will aid the management of the clinic. This change might necessitate the use of the K-index or the CF score. Policy should be developed for defining standards that are generalisable for district health systems in South Africa. A 50% (0.5) Score as an operational definition of continuity for individual or team is recommended as a starting point from this research.

Future research in other contexts of chronic care is encouraged with the COC formulae. Since the other indicators of COC were lower with good virological outcomes, more qualitative studies to explore the 'relational continuity' and other factors in the clinic that contribute to adherence needs to be investigated. The failure to manage chronic illness effectively could be countered by policy and charters focusing on the promulgation of COC in health care delivery. The need for life-long regular follow-up due to the challenge posed by stable patients on ART is an opportunity to invigorate the health system in South Africa with the principles of Family Medicine.
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