

Coordination Challenges in Collaborative Practices in the Prevention of Mother to Child Transmission of HIV in Tanzania

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Background and Purpose: This paper describes some of the complexities that face health service provision in developing countries, with the motivation to inform design of appropriate information systems. In particular, we are interested in a better understanding of the challenges to coordination and collaboration between health staff that are located in different facilities and employed to work in different health programs.

Methods: The study reported and analyzed in this paper was conducted in two districts in Tanzania. Using ethnographic data collection methods, we studied health workers' practices of coordination and collaboration in Prevention of Mother to Child Transmission (PMTCT) services in Tanzania.

Results: In our study we describe the collaboration required when managing patient trajectories of PMTCT patients across facilities and programs, and how contingencies may change the course of a patient trajectory. We provide a rich empirical description of coordination work in a resource constrained setting and we propose improvements to the design of both computer and paper-based information systems.

Conclusions: The rich empirical description of coordination work in a resource constrained setting and our analysis of coordination challenges contribute to a better understanding that can strengthen collaboration and thus also improve health care provision.

Keywords: Patient-Care Information Systems, Collaborative Practices, Coordination Mechanisms, Coordination Artefacts

1 Introduction

While management information systems have received much attention in the health informatics literature of the developing countries, recently there is a focus on designing and implementing computerized patient information systems that are intended for tracking individual health problems and treatment over time (WHO, 2012). For instance clinical information systems for HIV care in outpatients, and inpatients clinics (Fraser et al., 2007; Kamadjeu, Tapang, & Moluh, 2005; Oluoch et al., 2012; Rotich et al., 2003). However, the design and implementation of computerized record systems is a complicated endeavour with many challenges (e.g. Berg, 1999b; Jones, 2003; Robertson et al., 2010; Safadi & Faraj, 2010; Vikkelsø, 2005). These studies for instance indicate that there is a main tension between existing work practices and new technologies. In this paper we contribute to understanding the challenge of designing patient information system by examining the existing work practices of tracking individual health problems and treatment over time. These practices require collaboration and coordination across facilities, health programs and in time along patient trajectories.

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Collaboration and coordination are key characteristics of health service provision (Berg, 1999a, 1999b; Reddy, Bardram, & Gorman, 2010; Schmidt, Wagner, & Tolar, 2007). Healthcare provision involves many professionals and often different specialties treat a single patient at the same time and location, or across time and locations (Reddy et al., 2010). Patient care develops as a trajectory in time that is partly shaped by the work of health professionals and partly emerges in a contingent way (Fagerhaugh & Strauss, 1997). Thus, the management of patient trajectory is a collective and cooperative effort of health providers where health practitioners not only have to inter-relate their work tasks, but also to know where the process of managing a patient's trajectory is (Berg, 1999b). When many health practitioners are involved in treating patients, patients' records are an important resource used to assess the overview of care provided (Berg, 1999b; Fitzpatrick, 2004). Patient records are repositories of patient information within an institution (Mønsted, Reddy, & Bansler, 2011). They perform a role of communicative artefacts between health providers and configure health care provision services, for instance by organizing consultations between providers and clients (Engestrom, Engestrom, & Saarema, 1988; Heath & Luff, 1996). They also support administrative tasks (Garfinkel & Bittner, 1967). Moreover digitized medical records may have reminders which can prompt providers to perform due health care tasks (Mayo-Smith & Agrawal, 2007; Patterson et al., 2005). Further, Berg (1999b) asserts that both formal and informal aspects of patient records together with the work of clinicians are important for providing healthcare and supporting the collaborative work it entails.

Empirical studies conducted in a developing country context, have address the issue of collaboration in relation to the use of health information systems. For instance, telemedicine supports collaborative practices by facilitating communication between providers (sometimes with patients), the sharing of medical information, and also educational purposes (Bagayoko, Anne, Geissbuhler, & Fieschi, 2008; Bath, 2006; Geissbuhler, Ly, Lovis, & L'Haire, 2003; Mars, 2010; Martínez-Alcalá, Muñoz, & Monguet-Fierro, 2013). Geissbuhler et al. 2003 describe a telemedicine project in Western Africa that facilitated collaboration between Malian practitioners and practitioners at Geneva University (Geissbuhler et al., 2003). Other studies examine collaboration in the context of software development activities for health systems between different ICT specialists located in different settings (Korpela, Mursu, & Soriyan, 2002; Saugene, 2013; Saugene & Kaasbøll, 2013). However, despite the focus on collaboration, researchers in health informatics have given less attention to the understanding of collaborative practices during ordinary health service provision. Health practices in a developing country context often cut across multiple health programs provided in a dispersed and distributed setting and with limited resources, and require complex coordinative and collaborative work in order to be performed.

In this paper we aim to empirically describe and examine the complexities of collaborative work practices. Our study focuses on the work practices of healthcare providers in a cross-setting collaborative practice, and their use of patient-oriented artifacts. Specifically, our empirical material comes from research in the context of prevention of mother to child transmission of HIV (PMTCT) program in Tanzania. In this context we have empirically studied the collaborative practices of healthcare providers and the trajectories of HIV-positive pregnant women. These trajectories develop in time, across facilities and often across other health programs. In our analysis we pay particular attention both to information artefacts used in the facilities to track patients, and to those carried by patients themselves to bring information from one provider to another or to keep track of their visits. Our argument, based on CSCW research, is that the design of patient-care information systems should be based on understanding the collaborative practices of those actually working with patient information during ordinary health service provision and 'doing' the coordination work of patient trajectories. Our aim is to improve the understanding of coordination in collaborative practices and its associated challenges in healthcare provision in a resource constrained context, and to draw design implications for patient-oriented information systems. The following question is addressed in the study: What are the challenges to coordination in collaborative practices and what are the implications for the design of patient information systems as coordinative artefacts?

The rest of the paper is structured as follows. First, we review the relevant literature from CSCW and we present key concepts that are used in this study. Then, in section 3, we present the research context and research methodology. This is followed by the case description in section 4. Section 5 presents our findings and implications for design, and section 6 our conclusions.

2 Literature Review and Theory

Our theoretical approach is based on concepts from studies in Computer-Supported Collaborative Work (CSCW). The aim of the CSCW field is to understand the nature of cooperative work in its natural settings with the objective of designing computer based technologies to support work practices (Schmidt & Bannon, 1992). People engage in cooperative work when they are mutually dependent in their tasks and therefore are required to cooperate in order to get the work done (Schmidt, 1991). However, tasks interdependencies are tractable only if appropriate coordination mechanisms are in place (Schmidt & Simonee, 1996). A coordination mechanism is “a coordinative protocol with an accompanying artifact such as for instance a standard operating procedure supported by a certain form” (Simone & Schmidt, 1998, p. 295). Actors participating in cooperative work are assisted by coordination mechanisms in managing an otherwise overwhelming complexity (Simone & Schmidt, 1998).

In healthcare, collaborative practices are often mediated and supported by artefacts and coordinative protocols (Berg, 1999b). For example, coordinative artifacts support activities such as marking, checking, reading and writing and contribute to coordinate activities of practitioners in time (Berg, 1999a). Many studies in the CSCW tradition have investigated empirically the use of coordinative artefacts in order to draw implications for the design of digital artifact for supporting collaborative work (Berg, 1999a; Bjørn & Hertzum, 2011; Reddy et al., 2010). Bjørn and Hertzum (2011) for example, examined the use of whiteboards in collaborative work practices of health providers, and draw implications for improving the design of digital whiteboards. Likewise, Bardram (1998) reports a study in a large Danish hospital where he studied coordination and planning of patient care, and informed the design of a computer system for planning and scheduling surgical operations, and for requesting and booking diagnostic examination at other departments. These studies show the relevance of understanding the actual work practices of healthcare providers in their work settings in order to draw insights for designing improved collaborative artefacts.

Research in the field of CSCW recognizes that the design and implementation of coordination artefacts is challenging. For example, Cabitza et al. assert that artefacts could be not rich enough to facilitate communication between participants (Cabitza, Sarini, Simone, & Telaro, 2006). The deficit in coordinative artifacts may lead to the development of informal artifacts (Mellini, 2013), or the development of workarounds (Gasser, 1986) or unintended practices (Fitzpatrick, 2004). For instance, Fitzpatrick (2004) describes how clinicians tailored and augmented patient records in order to support their own role and practices. Safadi and Faraj (2010) show how workarounds emerged after the implementation of an EMR system in an ambulatory clinic in Canada. For instance since the software did not allow adding new disease to a list of favorite diseases, clinicians recorded diseases in the medical history of the patient. The study shows how workarounds carry rich knowledge about the needs of the users and the required customizations of artefacts.

While healthcare work has received considerable attention in CSCW studies less attention has been given to studying healthcare work in resource constrained settings. In a recent article reviewing 25 years of publications in CSCW in healthcare, Fitzpatrick and Ellingsen assert that “the developing world presents a very different context for CSCW research and design - reliable infrastructure cannot be depended on, markets are less vendor dominated, and there is significantly lower access to resources than in the developed world” (Fitzpatrick & Ellingsen, 2013, p. 33). However, in CSCW few studies reports from empirical cases conducted in such ‘different’ context. Specifically, in their review Fitzpatrick and Ellingsen have found only three publications reporting studies conducted in Africa (Fitzpatrick & Ellingsen, 2013). In the first study, Cheng and colleagues assess residents’ attitudes toward the use of handheld computers in the collection of HIV/AIDS survey data in Angola (Cheng, Ernesto, & Truong, 2008). They compare residents’ attitudes toward handheld computers with their attitudes toward the standard mode of data collection, paper surveys. The authors conclude that computerized data collection in Sub-Saharan Africa may lead to biased reports of HIV/AIDS-related risk behaviors, when compared to the traditional method of paper-and-pencil surveys due to social-economic factors. In the second study, DeRenzi and colleagues discusses how to facilitate management of child health through the design of software, specifically a Personal Digital Assistant (PDA) system which would help clinicians make decision and adhere to child treatment protocol (DeRenzi et al., 2008). During their study in Tanzania which focused on human-computer collaboration, some features from PDA software had to be redesigned in order to match the observed human-PDA collaborative practices. In the third study, Luk and colleagues describe how pro-

viders collaborate with the use of telemedicine in Ghana and provide principles to inform the design of telemedicine systems in developing regions (Luk, Ho, & Aoki, 2008). The remote system enabled doctors to enter medical case information into a distributed repository and then requesting a consultation from a pool of medical specialists. As illustrated in these three studies, in health care service provision, coordination is important and can be improved by designing and implementing digital information systems. Hence challenges to collaboration and coordination in context with less resources and infrastructures need more attention, empirical research and understanding. In this study, we aim to contribute to understanding challenges to collaboration based on a study of maternal and child health care in Tanzania.

3 Research Setting and Methodology

This study is part of the Health Information System Program (HISP) which is run by the Department of Informatics, University of Oslo. The primary goal of HISP is to enhance the information use behavior of health managers, planners and workers, in the health sector of developing countries, by strengthening local professionals' capacity, for the development of a sustainable HIS (Braa, Monteiro, & Sahay, 2004). HISP has developed software known as DHIS (District Health Information Software), which is used to manage data in various levels of the health sector. Recently, HISP has focused on developing patient-oriented information systems (known as the DHIS Tracker module) which could be used for managing name-based patient data and also for providing reminders and alerts to practitioners and clients (Gizaw, Mukherjee, Lewis, & Sahay, 2012; Saugene, 2013). Our study contributes to HISP by providing an empirical understanding of the existing information practices in order to design patient-oriented information systems.

The study reported and analyzed in this paper was conducted in Tanzania, in Kitangili and Singidani districts¹ in Dodoma Region. The HIV prevalence among pregnant mothers in Kitangili and Singidani districts are 2% and 8% respectively. In Tanzania, primary health facilities (dispensaries and health centers) are responsible for health care provision such as curative, preventive, promotive, rehabilitative and palliative care to the population. Tanzania, is striving to reduce the impact of HIV pandemics by using various interventions, such as, prevention of mother to child transmission of HIV (PMTCT). Within the PMTCT program the aim is to prevent transmission of HIV/AIDS from the HIV positive pregnant women to the children. Based on guidelines from the World Health Organization (WHO), the program offers interventions during pregnancy, birth and breastfeeding period. One of the operational targets to be achieved by the year 2015 by the Tanzanian Government is to have PMTCT services provided to at least 80% of pregnant women, their babies and families. Comprehensive intervention for PMTCT services involves multiple clinics such as maternity care clinics, HIV/AIDS clinics (CTC), tuberculosis (TB) clinics (in case pregnant women develop TB infection), and clinics for children up to 5 years of age.

The data collection for the study was conducted during three periods: August 2011-January 2012, July – August 2012, and November 2013-April 2013². Eleven primary health facilities offering maternal and child healthcare services were researched. The study design was inspired by multi-site ethnographic (see for example Madden, 2010; Marcus, 1995; Blomberg & Karasti, 2013; Nicolini, 2013). This approach was useful for gaining a deeper understanding of the work practices in different places, albeit being difficult to travel to geographically dispersed facilities in the two districts. The main data collection technique employed was participant observation by the first author with her role altering between observer as participant, and participant as observer (Bryman, 2012). In total, 101 sessions of observations were conducted in health facilities with each lasting between 3 to 7 hours. Observations were conducted in antenatal sections, maternity care clinics, children clinics, HIV clinics and one TB clinic. We performed in-situ interviews (Jordan and Henderson, 1995) in Kiswahili language to health providers in facility and Community Health Workers (CHW). In total we encountered 42 nurses, 13 doctors, 5 data clerks, 2 patient-tracing coordinators³, and 6 CHW who were involved in PMTCT services.

We also studied and reviewed artifacts which were used to organize the collaborative work of service providers during health service provision. Artifacts reviewed included clients' cards, clients' folders,

¹The actual district names are not disclosed.

²The fieldwork was conducted as part of PhD work and it required spending at least one year in the field settings.

³Community health workers who coordinate defaulter tracing activities in certain facilities

referral forms, laboratory forms and facility registers. We examined the artifacts to understand how they facilitated collaborative work by making visible work of others and coordinating one’s own work. We also conducted informal interviews with 5 (4 women and 1 man) clients⁴ who gave oral consent first to health providers and then to us. The theme of the interviews was their experience of going to multiple settings carrying coordinative artifacts, as for instance patient cards and referral forms. The efforts to involve more clients did not bear fruits since in some cases nurses disapproved or we sensed that clients were not in good state or unwilling to cooperate. For instance, we arranged some appointments where clients who had agreed to be involved did not show up. Thus, most of our data are based on observation of meetings between nurses and clients in which we listened to their conversations, took notes, and observed information practices when clients’ information was registered or retrieved in different programs and settings. In addition, we reviewed several policy documents such as Tanzanian Health Policy, Reproductive and Child Health (RCH) Strategic Plan, PMTCT guidelines, Home Based Care (HBC) service guidelines, national guidelines for the management of HIV/AIDS and HIV Act and policy. These documents gave us background information about PMTCT healthcare provision protocols.

To get a better understanding of the observed coordination practices, we also interviewed coordinators for the health services supporting maternal and child health and HIV/AIDS services at district, regional and zonal⁵ levels. A summary of the interviewees in relation to their program of affiliation and their work places is presented in Table 1.

Table 1. Summary of interviews at district, regional and zone levels

Location	Type of informant	Number of informants	Total number of interviews (with repetition)
Kitangili	RCH	3	9
	HIV/AIDS	2	4
Singidani	RCH	5	11
	HIV/AIDS	3	8
Regional	RCH	2	3
	HIV/AIDS	1	1
Zone	RCH	1	1
Total		17	37

The empirical study was approved by University of Dodoma⁶’s Research and Publication ethical committee. Ethical concerns were taken into consideration during fieldwork, for example, through gaining written permission prior to the fieldwork from both districts managers, and obtaining oral consent from health workers and clients prior to conducting interviews or observations. We have also changed the name of clients as well as districts and facilities in order to provide anonymity.

The study employed an interpretive approach for data analysis (Walsham, 1995). Notes were taken during fieldworks and later transcribed. Some interviews with nurses were recorded and transcribed. Field notes were read several times in order to obtain an understanding of the data, and concepts of cooperative work, patient trajectory, coordination mechanisms, and coordinative artefacts were used to make sense of the practices observed. Our interest was directed towards identifying and understanding the challenges faced by maternal and child health provision in coordinating their collaborative work. For instance, nurses during care encounters would interrogate or remind clients about attendance in other visits to check their compliance to health programs, but they would not have any formal way to check that attendance actually took place.

In order to organize and analyze the material, we employed both inductive and deductive approaches. For the first level of analyses, we prepared “ethnographic descriptions” (Emerson et al, 1995) of work practices within and across health facilities in order to foreground collaborative practices. We then creat-

⁴ The terms clients, pregnant women and patients have been used interchangeably

⁵ Intermediary administrative level for several regions which is under the national level

⁶ First Author is employee of the university.

ed narrative descriptions (Emerson et al, 1995) of work practices in maternal and child health settings that focused on how information artifacts in different units were used in the collaborative process. To prepare ethnographic description, we have worked with a characterization strategy (Van Maanen, 1988). We have combined the stories of multiple clients into the character of Joyce, obtained from our interviews with clients and our observation of interactions of nurses and clients for successful cases of clients' compliance. In addition, we also used stories from interviews and observations to construct the characters of Prisca and MdalaMatonya. These two women's stories showed different trajectories and exemplify unsuccessful cases of coordination. Van Maanen (1988) argues that this strategy makes it easier to tell fieldwork tales (p. 104). Thus we believe that the narrative descriptions and the way they are constructed improve readers' understanding about the interactions between different units involved in PMTCT care, the use of coordinative artifacts and how they facilitate collaborative work.

4 Case Description

This section describes how PMTCT service delivery is organized in practice and which coordinative artifacts are in use. Tanzania's policies both for HIV and RCH indicate how clients should be attended by different health providers, and health authorities have provided specific coordination protocols. Yet, our description shows how protocols and coordinative artefacts are not always sufficient to coordinate work.

PMTCT interventions include testing and counseling for HIV, antiretroviral prophylaxis for HIV-infected pregnant women (and their partners) in antenatal care and their exposed children in maternity wards, treatment of eligible women, counseling and support for infant feeding, safer obstetric practices and family planning to prevent unintended pregnancies in HIV-infected women. The actual treatment of HIV/AIDS is conducted in cooperation with the general HIV/AIDS Care and Treatment Clinics (CTC). Not all health facilities would offer ANC, PMCTC and CTC services, and patient will then be referred to other facilities for one or more of these services.

In this context, PMTCT providers have three main information and coordination needs. First, as the PMTCT program covers the pregnancy and the first 18 months of a children's life, PMTCT providers need to keep track of information over time. Second, during pregnancy HIV-positive women may also develop other diseases, for instance TB and may need to enroll in and comply with other health services providing testing, visits and counseling. In such cases PMTCT providers need to be informed about these services in order to adjust their treatments accordingly or to check that clients attend them. Third, attending PMTCT services often requires women to travel because many facilities do not host all sections. For instance a woman may attend services in a facility that has a maternity care clinic but not a CTC clinic. In addition a woman may prefer to attend a CTC clinic that is not in her residential area to avoid meeting familiar people. In these cases, health providers need to be informed also of the services delivered in other facilities. Thus PMTCT services are not delivered at the same point of care but across facilities and over a period of some years (from pregnancy and until the child is 18 months of age, and can continue to family planning services in the family planning section). The information and coordination needs are addressed by using various coordination artefacts, protocols and procedures. However, breakdowns in how information is recorded, updated, transmitted undermine coordination.

To show the complexity of PMTCT service delivery we have organized our case material according to the chronological order of events (HIV diagnosis, pregnancy, delivery and postnatal care) and we have used the stories of three women enrolled in the PMTCT program: Joyce, Prisca, and MdalaMatonya. Our main character is Joyce, a woman who is tested HIV positive and is enrolled in CTC services. Afterwards she becomes pregnant and is enrolled in ANC and PMTCT services. Next Joyce develops tuberculosis and is enrolled in TB services. In addition we use vignettes of other characters - Prisca and MdalaMatonya - two HIV-positive pregnant women who are enrolled in the PMTCT program but have a different trajectory than Joyce. In our description we focus on movements across programs and facilities, on instances of coordination work needed to deliver PMTCT services, and on information artefacts used to coordinate work. We also include in our description instances of breakdowns that we have observed during fieldwork. Our aim is to make visible the complexity of clients' trajectories, the structure and use of coordinative artefacts, the coordinative work performed by health providers and the coordination challenges leading to breakdowns.

4.1 Diagnosis: from Outpatient to Voluntary Counseling and Testing (VCT) to Care and Treatment Clinics (CTC)

Joyce is a housewife living in the catchment area of H facility. In the year 2006 her health condition deteriorated and she decided to seek help. Joyce decided to go to the outpatient clinic at facility D, which was not located in her residential area but offered higher level services. The doctor at facility D suspected that she could be infected with HIV and referred her to the voluntary counseling and testing (VCT) section within the same facility. After a counseling session, Joyce was tested and diagnosed HIV positive and referred to the CTC unit (i.e. the HIV clinic) within the same facility. The providers suspected that she might not be well prepared psychologically to deal with the diagnosis and that she could opt out of the service. Thus, one nurse personally escorted her from the VCT room to the CTC section.

At the CTC section she was given a CTC client retained card (CTC card) with a unique identification number. Then a patient folder (CTC folder) was created for her, with her name and the unique CTC number written on top of the folder. The folder was stored in the facility's archive. The folder contained Joyce's residential tracking form with contact information such as her treatment supporter name, community health workers name and phone contact, residential area, household leader, facility name and district name. Over time, whenever Joyce attended her visits, information about specific HIV care provided was recorded chronologically on the CTC2 patient record form, and doctors' notes about diagnosis and treatment (usually written on plain paper) were added in the CTC folder. In the folders, the clients would have multiple CTC2 forms and it is likely the clients will have multiple client retained cards since HIV requires life long service provision. This folder stored also results from lab test that were prescribed when required, for instance TB or malaria tests (one paper sheet per test conducted).

The CTC folder is a central artefact for coordination on various levels. First, some information is used for coordinating activities across services: some forms are used to record– and thus make visible – information about services from other sections involved in treating the client. For example, in the CTC2 form client's status with respect to pregnancy and TB services are recorded. Second, the patient folders' information is used for tracing defaulters (i.e. clients who do not show up for their appointments): the folders contain forms that trace attendance of clients in the CTC clinic and they can be browsed in order to identify clients who had missed their appointment. Once the clients are identified, the folders can be sorted according to reasons for missed appointments.



Fig. 1. Example of patients' folders grouped according to their status.

For instance, figure 1 shows how patient folders are stored on a shelf in one of HIV clinic section. The folders are organized in three groups: deceased, transferred, and missed appointments (called “lost to follow up”). This sorting of the folders makes visible the load of patients not coming to appointments and that need to be traced. Nurses can trace them by using the contact information form. They may call mobile phones or ask the community HBC provider to contact them.

Third, information contained in the clients’ folders is also used as a resource for reporting both locally and across levels. For instance, aggregated reports are created on quarterly basis and sent to district coordinators for monitoring, evaluation and planning purposes. In addition, facility reports are used locally for coordinating health service provision within the facility. For instance Figure 2 shows a report with the overview on clients’ appointments and registered attendance in one facility. The local reports are used by facility management for getting overview of defaulter tracing activities and coordinating appointment and attendance of clients.

RIPOTI YA MWEZI ~~2012~~ 2012

S/NO.		ARV STATUS						GRAND TOTAL
		ADULT CTC		TOTAL	PAEDIATRIC CTC		TOTAL	
		V	N		V	N		
1.	Scheduled Clients (Adult and Children)	1212	117	1329	50	51	111	1440
2.	Scheduled Attended	1064	74	1138	20	22	93	1241
3.	Unscheduled Enrolled Attended	251	27	278	11	4	15	293
4.	Unscheduled New cases	0	24	24	0	1	1	25
5.	Unscheduled Transfer In	11	3	14	1	1	2	16
6.	Unscheduled On transit	22	4	26	4	0	1	27
7.	Total attended	1452	144	1596	53	29	112	1662
8.	Transfer Out	18	0	18	1	0	1	19
9.	Missed Cases	136	20	146	1	0	1	147
10.	Clients returned in this month	19	2	19	0	0	0	19
11.	DEATH							
12.	PMTCT			3				3

SCHEDULED TIME AS REBLOCKING SYSTEM 1157
 UNSCHEDULED TIME 84 = 1041
 1157 / 1041 * 100 = 92.21 ≈ 93%

F. Planning Exp
 Reblocker - 2
 on steps
 New case - 113

Fig. 2. Sample page of a report used locally in one facility

The above description illustrates how the patient folder functions as a coordinating artefact for treatment, as well as a resource for tracking and reporting. The description also shows how providers may need to engage in additional coordination work in the form of extra activities to take into account contextual issues and support the collaboration between services. For instance, Joyce was not sent alone with the referral form to the CTC section, rather a nurse chose to escort her so that she should not abscond. The act of escorting implies extra use of resources: the nurse escorts the client instead of attending clients sitting in the waiting area.

A different trajectory to CTC services was that of Prisca. Prisca is a client who attended facility S for her antenatal care. She was diagnosed HIV positive and since S facility did not host a CTC unit, she was referred to R for CTC care (5 kilometers away). She was given a referral form. However, Prisca did not accept to be labeled as HIV positive. She stopped going to antenatal care at S and she did not go to R. Unfortunately, her health condition worsened and she decided to seek medical services. Remembering her case at S, Prisca decided to go to R to get treated but acting as a new client, not referred from S. The doctor on duty suspected that she might have HIV, and decided to conduct provider-initiated HIV testing. Prisca then confessed that she had been diagnosed positive earlier at S antenatal care. Through more questions, doctor learned that Prisca had torn the referral form. He further counseled and directed her to CTC unit escorted by a nurse. However, Prisca informed the providers that she would have preferred a distant CTC where she would not meet familiar people. Unfortunately, in that area like in most rural area there was only one CTC and it meant that using other CTC would cost more in transport and time. Later Prisca attended PMTCT unit at S facility after providers at R linked her with provider at S.

This vignette illustrates not only the challenge of tracking patients due to the distributed and fragmented organization of the service, but also how service delivery relies on clients as carriers of information.

Clients take actively part in the coordination of their care trajectories by carrying referral forms between facilities. However, if they do not comply with their schedules and treatments they also hinder coordination practices.

4.2 Pregnancy: from Care and Treatment Clinics (CTC) to Antenatal care and PMTCT

In 2009 Joyce, who had two children, became pregnant again. During one of her visits to CTC in the D facility, the provider realized that she was pregnant and inquired about her adherence to the antenatal care program. The provider learned that Joyce had not been to any antenatal checkups. The D facility had no antenatal care unit, and he advised her to attend antenatal care at her residential area, facility H, in order to facilitate frequent visits with low costs for transportation. The CTC provider then filled a referral form and gave it to her so that she could bring it to the antenatal clinic in her residential area (H). The referral form consisted of two parts on a single page. The first upper part was filled by the provider at CTC: the doctor wrote which health services Joyce needed. He also recorded on the form that Joyce had been on anti-retroviral therapy (ARV).

Afterwards Joyce went to H facility bringing with her the referral form and her CTC card. At H facility she gave the form to the health provider at the antenatal care unit, who, by reading the information on the form, enrolled her into the antenatal care (ANC) program. Enrollment consisted of creating a patient-record in the antenatal register which was kept locally in the unit, and issuing an antenatal card which was given to Joyce to keep it herself. Information from the referral form and CTC card were transcribed in the antenatal register and card, and specifically, her CTC number and information about ARV use. Joyce was also enrolled into the PMTCT program and her information registered into the PMTCT care register which was kept in the PMTCT unit. The unique number from her CTC1 card was transcribed into her record in the PMTCT care register. The alpha-numeric code generated by enrollment into PMTCT (PMTCT code) was also noted on the antenatal card. The presence of the PMTCT code on this card will indicate her positive HIV status to ANC staff. At the end of the visit, the health provider filled in the second part of the referral form and gave the form to Joyce to bring back to the CTC unit at the D facility.

Back at H facility, Joyce then had to undergo some tests related to antenatal care such as urine and blood check ups. Facility H has no laboratory and their clients are usually sent to perform blood and urine checks up at facility J. Joyce was given a laboratory request form and told to go to J facility or any nearby hospital that had a laboratory for analysis. Joyce opted to go to J facility and took the tests. The results were recorded on the laboratory form that Joyce passed back to facility H.

At one time during Joyce's pregnancy, providers at the CTC clinic in facility D suspected her to have tuberculosis (TB) symptoms. She was then referred, using a laboratory request form for TB testing, to another facility which had laboratory and X-ray units for testing TB infection. Joyce went to the TB testing facility, the test was performed and she was diagnosed TB positive. She brought back the form with her results to the CTC unit together with her X-ray picture. Providers at CTC then filled another referral form for TB care, and gave it to her to take it to TB clinic in another facility (the only one with TB services in the area). She then went to the facility with TB services and presented the referral form to the TB clinic providers. There at the TB clinic, she was enrolled into TB care. She was provided with TB1 card (tuberculosis identification card) and a record on her name was created in the TB register. In the TB register was also recorded information about her HIV status, ARV drug dose and pregnancy status. As part of the TB treatment regime, she had also to bring with her a treatment supporter who was given a treatment supporter card for monitoring Joyce's drug adherence during the treatment at home. Lastly, the care provider at the TB clinic completed the second part of a referral form which Joyce took back to the CTC clinic in facility D.

The above description illustrates how Joyce moves between facilities and health programs and related services. For instance when the practitioner saw that Joyce was pregnant, he started the process for enrolling her in both antenatal services and PMTCT services. First of all he interrogated Joyce about her status and her attendance to antenatal services. Then, he used the referral form to inform the antenatal service providers of the need to enroll Joyce, and he used Joyce to carry the form to its intended receiver. Also, clients take actively part in the coordination of their care trajectories by carrying referral forms and laboratory results between facilities. Both referral and laboratory forms are examples of inter-facility coordination artifacts that are used to coordinate service provision across multiple facilities. These forms are particularly important in a context where facilities do not provide all services and do not frequently have

laboratories for analysis. For example, a referral may be sent from PMTCT to CTC or from CTC to TB unit. These forms provide visibility of the services which has been done from the referring units and what needs to be done in the recipient unit. In addition, the forms provide a feedback channel. The second part of the form, which clients return to the referring facility, makes the provider aware that visits and tests have been performed in the recipient units. Thus, some information from the referral feedback form is used to update the client status, for instance regarding pregnancy or TB, in the facility register at the referring unit. Importantly, we saw the crucial role of Joyce for enabling the actual flow of these coordination artefacts. The client's compliance with the requirements and directives are fundamental if the coordinative artefacts shall work.

4.3 From Antenatal to Delivery to Postnatal Care and Enrolling the Infant in the PMTCT and Vaccination Programs

Antenatal care is scheduled with four visits during the course of a pregnancy. Whenever Joyce attended antenatal care at H facility, providers were alerted of her HIV status through the PMTCT code written on her antenatal card and they would remind her to attend the PMTCT clinic, located in the same facility. Also, whenever Joyce attended PMTCT services, the provider would inquire about her attendance to CTC at facility D. And whenever she attended visits at the CTC unit in facility D, the care provider by reading her pregnancy status from CTC2 form in the patient folder, would inquire about her attendance to antenatal clinic at H clinic. At one time, the care provider even asked Joyce to show her antenatal card in order to ascertain that she was attending antenatal visits as required.

At Facility H, the Reproductive and Child Health (RCH) service had no delivery unit. Thus, Joyce had to deliver at facility E. The nurse at E facility, by recognizing her PMTCT code on her antenatal card asked about ARV drug treatment. Joyce showed her the CTC card and the nurse read on her CTC card about her visits and ARV drug administration. The nurse concluded that according to the Tanzanian PMTCT protocol, Joyce would not need to take ARV during labor since she was already on ARV treatment. Joyce delivered safely a baby boy who was provided with ARV syrup. The nurse recorded into the delivery register the following information (but not limited to): ARVs dispensed during labor, infant's ARV doses, newborn feeding practice, and linkage to CTC. Joyce's antenatal card which had a section to record information about the delivery and child conditions was filled in. Finally, the nurse filled a referral form with information about the delivery and gave it to Joyce to bring it back to the CTC unit at facility D.

After the delivery, Joyce attended postnatal care at her residential facility H. The nurses used her antenatal card to copy information and fill her postnatal register including her and child's PMTCT and delivery information. Following the protocol, after six weeks the child was enrolled into the child health clinic in facility H. The child was registered into the children register and issued with a child health card. The providers on duty after recognizing PMTCT code in Joyce's ANC card also filled information related to PMTCT services to children. The child was also enrolled into PMTCT child follow-up health services and a record created in the PMTCT child follow-up register. Some information from Joyce's ANC card delivery section was transcribed into the PMTCT register. The child health card also contained a code (generated in children clinic) which communicate that the child is in PMTCT services (HIV exposed child).

The services of the children health clinic are offered for five years and include services such as vaccination, vitamin A, growth monitoring, and mosquito net distribution. Whenever Joyce attended the clinic as scheduled, providers by seeing the child's PMTCT code would remind her to attend also the PMTCT clinic. In PMTCT services, infants are tested for HIV infection at age of 4-6 weeks, 9 month and 18 month. Children are supposed also to continue with ARV drugs during breastfeeding time. In the PMTCT room, providers would also enquire about Joyce's attendance in CTC clinic. Sometimes they would ask her to show her CTC card so that nurses could verify what Joyce told them.

Joyce's baby was tested and diagnosed HIV negative at the first test. The PMTCT services were also challenged by resource shortage including shortage of referral forms which is one of coordinative artefacts. However, during the time when the second test was supposed to be performed for Joyce's baby at facility H, there was neither HIV testing kits nor ARV drugs. This implied that Joyce had to be referred to another facility for her treatment. This was combined with shortage of referral forms. The breakdown was resolved by the nurse who instructed Joyce to tell the provider what services she needed at the other facil-

ity. Thus, Joyce went to the other facility where she was attended, and brought back the feedback to facility H.

The description above illustrates how providers articulate the collaborative work through various coordinative artifacts (e.g. PMTCT codes and CTC cards). The health workers practice of interrogating and reminding is an example of how coordinative work can be supported through coordinative artifacts. For example, PMTCT codes provide awareness of the HIV status and the linkage with CTC and PMTCT services. The patient card offers an overview of activities that have to be performed or that have already been performed in either this provider's section or in another section. The PMTCT code also facilitated nurses' awareness of tasks to be done in their location, e.g. in the delivery ward, and trigger coordinative practices such as reminding or inquiring clients. We also see how PMTCT information is recorded into different facilities' registers: antenatal, delivery, postnatal and children. Information recording in registers provides an overview of clients' usage of other health services: nurses can know that clients are attending PMTCT services or vaccination/antenatal services by using facility registers.

A different trajectory about reminding practices was that of MdalaMatonya. MdalaMatonya is a mother of twin boys who are PMTCT clients. She was diagnosed HIV positive during her pregnancy in the antenatal section of facility P and was enrolled into their PMTCT program. However, facility P offered limited PMTCT services due to lack of training to providers and does not have an HIV clinic, hence referring their clients to facility Q. MdalaMatonya was referred to Q and was enrolled into their HIV clinic, meanwhile she was attending PMTCT services at antenatal section of Q. After delivery, her boys were enrolled into the children clinic program in facility P and into PMTCT program in facility Q. In the meantime since pregnancy, MdalaMatonya had been attending facility Q for CTC services. One day when MdalaMatonya was attending CTC, a nurse (who also was responsible for PMTCT) inquired about the boys' attendance in PMTCT services. The nurse learned that the boys had not done a third HIV test and instructed the mother to bring the boys to PMTCT services the next day. The boys' children's card showed that they had attended all children visits in facility P. However, at the age of 20 months the boys had had only two HIV tests, while according to the PMTCT protocol they should have had three HIV tests. MdalaMatonya explained that no one had told her to bring the children for a third test. Through our studies in four children clinics (including facility P) and HIV clinics, we learned that nurses might forget to remind clients about their visits and tests due to high workload, and this may create breakdowns.

4.4 Enrolling the Infants in the HIV Program

Joyce's baby was due for a third test and was diagnosed HIV negative. Because by the third test Joyce's child was 18 month, the nurse recorded 'discharged' on the remark column in the register. This meant that the child would no longer need to visit PMTCT. The nurse also informed Joyce that whenever nurses in children's clinic would ask her about PMTCT service, she was supposed to inform them that the child had been discharged from PMTCT services and that he resulted negative in all three tests. Nurses at the children's clinic used the child card to record the results.

The different trajectory was observed on the same day where another child (Baraka) of nine months tested HIV positive. This information was recorded in the child register and in the PMTCT child follow-up register. In addition, the nurse filled an infant referral form from PMTCT to CTC services. In the same town area there were four CTC units whereby one was just half a kilometer from H facility. Nurses advised the mother of the child who tested HIV positive to attend CTC in the clinic nearby. In this way she could conveniently combine children and CTC clinics on the same day. However, the mother disapproved of using the nearby facility since she would probably meet people she may be familiar with. She preferred to attend a more distant facility where she would also receive her CTC services. She proposed to ask the provider to combine her and child CTC clinics dates.

However, there was a problem regarding the infant referral form due to a mismatch between its design and existing work practices. The infant referral form had no feedback part, such as what the general referral form had. Figure 3 shows a form with a feedback part (on the left), and the infant referral form without a feedback part (on the right).

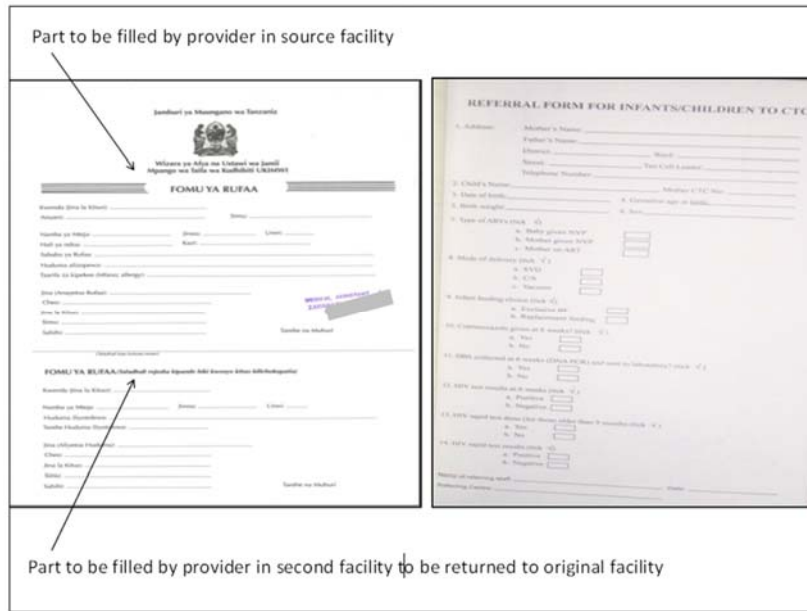


Fig. 3. General HIV form (left) and infant referral form (right).

The infant referral form has specific information about PMTCT services. The absence of a second part for feedback was not supporting collaborative practices. Despite the form not supporting it, feedback was assumed to happen; the registers had space for recording CTC number which would make visible that a client had been enrolled into HIV care. In Baraka’s case, the providers told the mother to come back with the CTC card so that information could be recorded in the register. The mother passed the infant referral form to the CTC unit and she came back with the child CTC card. Information such as CTC unique number was transcribed into the PMTCT child follow up register. From that time nurses in PMTCT were also inquiring about child attendance in CTC unit by seeing her records in PMTCT register.

As a result of this lack of feedback section in children’s referral form, in one urban facility with high number of clients, new information practices emerged. The health workers started to record all referred clients and their enrollment into the HIV/AIDS clinic even though these were recorded on papers. One health worker explained: “Some mothers do not come back to ascertain that they have joined the HIV/AIDS clinic. We have started to record their names so that we can make a follow up of their enrollment to HIV/AIDS clinic”. Figure 4 shows a page of referred clients in one register.

WATO WAUFATA RUDA				CTC			
TARUHU YA RUFUA	NAMBA YA DBS	TARUHU YA KUTOKA	MACHO YA MOTO	MACHO YA KIDINI	NAMBA YA KIMWIJAZILI	NAMBA YA RUDATA	BAWA AMBAWA
15/02/2013		27/11/2012			22/02/2012		10 BAWI
21/01/2013		02/10/2011					KE
03/02/2013		26/09/2012					KE
22/02/2013		11/02/2012					MTC

Fig. 4. A local registry to support tracking of children from PMTCT to the HIV clinic.

In other two facilities (located in the outskirts of the town), the practice was to combine in one register information about home based care services (for HIV/AIDS clients) and PMTCT information so that all

children clients born from HIV positive mothers would be tracked in the community across time, along schedules of PMTCT services in case they do not show up to the original facility.

5 Discussion

In the previous sections we have described several trajectories of HIV-positive pregnant women and how information is collected, organized, stored and eventually retrieved by health providers. In the different stages of the trajectories, whenever a woman contacts or is contacted by a health provider, information is produced and correlated with previous collected information. For health providers is critical to be able to track women and monitor how their pregnancies and their HIV conditions are developing, and how well they comply with the PMTCT program. For instance, health providers check if women are attending their counseling sessions and periodical visits, if they are regularly tested, and if they are taking the prescribed drugs.

We have also described challenges in tracking women along their trajectories. Specifically we have focused on two main challenges. First, we have described how women visit several facilities when attending PMTCT services. This happens for different reasons. For instance in the case of Prisca, her home facility did not have a CTC unit and she was referred to another facility 5 kilometers away. In the case of Joyce her home facility did not have an antenatal care unit and again she was referred to another facility. In another case, MdalaMatanoya was referred to another facility because her home facility did not have a HIV clinic and trained personnel. Second, we have described how women receive care services from different programs. It is rare, especially in rural areas, that care facilities provide comprehensive services for CTC, TB care, antenatal and postnatal care, vaccinations and dispensation of ARV drugs. A pregnant woman who is tested HIV positive would need to be enrolled in both PMTCT and ANC, and perhaps other programs, such as TB. For instance Joyce was already enrolled in PMTCT services but needed also TB care. Her case illustrates how the work of tracking women's trajectories is usually performed within programs, and that there is little coordination across programs. In addition once the child is born he would also need care which belongs yet to another care program that may be offered in few facilities. This implies that women's information gets distributed across facilities and programs, and tracking becomes difficult. In this situation, health providers need to keep an overview of how services are interrelated, and where are they offered. For instance when possible they escort women to other parts of the facility offering another service. The case of Joyce describes how she was escorted from the VCT to the CTC section. Or they also give the option to choose a facility that is closer to the home area of the woman. In addition, women themselves collaborate in coordinating and supporting the communication across facilities and programs. As our analysis illustrates women carry referral forms, test results, and personal cards with them. They participate actively in the coordination of their own trajectories.

Our analysis also shows the different artefacts used to manage information in PMCTC services. Codes and unique patient numbers are important coordination artefacts that identify women and their diagnosis, and are copied from cards to referral forms to registers. For instance when Joyce went to delivery unit, the nurse was alerted by her PMTCT code on her card and inquired about her ARV drugs treatment. Other artefacts are referral letters which are used for ordering exams and visits in other facilities or units. These forms may also have a feedback part that is brought back to the health provider. For instance when Joyce was referred to a facility for antenatal care, she brought back the second half of the referral to her home facility. However, while artefacts are usually designed for tracking patients within programs and within a single facility, the design and use of cross-facility and cross-program artefacts meets challenges.

We have also described how breakdowns may happen and health providers may lose track of their clients. Women may intentionally not collaborate. For example, Prisca tore the referral form she was supposed to bring to a facility for PMTCT care. In another example Baraka's referral form did not have a feedback part. Thus the health provider had to ask the mother to come back again with the CTC card in order to register her CTC code and relevant information into the local register.

In the following section we discuss two key set of findings from our analysis of the case. First we discuss the complexities of coordinating work in a resource constrained setting and PMTCT care, and then we formulate implications for the design of patient information systems.

5.1 Complexities of Coordinating Work

As Schmidt states, people engage in cooperative work when they are mutually dependent in their tasks and therefore are required to cooperate in order to get the work done (Schmidt, 1991). In our study we have shown the collaboration required when managing patient trajectories of PMTCT patients across facilities and programs, and how contingencies may change the course of a trajectory. In the descriptions reported in our study it is evident that coordinating work across time (along clients' trajectories), across facilities (different locations), and across health programs (type of services) is crucial to PMTCT service delivery. However, patient trajectories are emergent and contingent, and in a resource scarce setting like in ordinary health provision in developing countries, coordination is challenging and prone to breakdowns. Furthermore, the nature of the disease contributes to the complexity of care delivery in PMTCT services, and to forming more intricate task interdependencies. HIV is a disease burdened with social stigma and some clients would rather travel to a distant facility than receiving care from their home health services. In addition other diseases are likely to develop, and requiring additional care, and the involvement of additional health providers. Thus, in our study we show how the complexity of cooperative work is increased not only by involving additional stakeholders from different health programs (for instance specialists in TB care), but also by stretching the trajectory to other facilities where clients would not be recognized. While the literature recognizes that the involvement of multiple stakeholders and diverse professional groups increases the complexity of cooperative work (Fitzpatrick & Ellingsen, 2013; Hartswood, Procter, Rouncefield, & Slack, 2003), and has examined the complexity of distributed settings (e.g. Hinds & McGrath, 2006; Olson & Olson, 2000), it has not addressed the challenge of unbounded distributed cooperative work. For instance the case of Baraka's mother, being in an urban setting, shows how clients can select one HIV clinic among many. However, the case shows also how it was complicated for the health provider to coordinate Baraka's mother's connection with her home HIV facility.

Coordination work relies on and it is mediated by artifacts and protocols (Bardram, 1998; Berg, 1999a, 1999b; Reddy et al., 2010). Our findings are in line with research showing the shortcomings of coordinative artifacts in complex healthcare settings (Cabitza et al., 2006; Gulube & Wynchank, 2001). In cases when coordinative artefacts fail to support cooperation, this might lead to the development of informal artifacts (Mellini, 2013). Differently, in our case additional coordinative work was needed due to the scarcity of resources (e.g. absence of referral forms, of test kit, of labs). There are cases when coordinative artifacts are just not available, and health providers have to come up with ways to deal with the situation. For example, in Joyce's case the health provider sent her to another facility for PMTCT testing services with oral instructions but without referral letter. Many studies point to similar challenges when discussing collaboration in developing countries (e.g. Geissbuhler et al., 2003).

5.2 Implications for Design

In this study we have foregrounded the complexities of collaboration and coordination. In this section we argue that based on our study we can draw important implications for the design of paper based and digital artefacts, and ultimately for improving health care provision. Specifically, we argue that some coordination breakdowns that we have observed could be avoided by improving those artefacts that are used in PMTCT health delivery.

First, the design of patient information systems should consider how patient artifacts support coordination work between different health programs. For instance, it is important that referral forms have a feedback part in order to support a two way communication between health providers and to ensure visibility between providers in involved facilities. Second, coordination work should be supported by improving coordination protocols and procedures. For instance, reminding practices should be enforced both within facilities and across health programs. This could be procedures where clients are required to show their different health services patients' cards where attendance is registered. Third, in the case of PMTCT services, we have showed how the coordination mechanism of clients carrying information is vulnerable. In this case the coordination breakdowns observed in RCH, can not only be resolved through redesign of patient information systems tools (e.g. infant referral forms) or enforcing protocols (e.g. reminding practices for health workers). We suggest the need for creating complimentary coordination mechanisms based on a computerized patient system supporting horizontal coordination between health facilities. For example, the design of patient information systems would need to afford visibility and communication

between groups involved in treating clients. In the case of the HISP program, the DHIS tracker, which is patient-oriented could facilitate users' communications through mailing lists i.e. queries for patients are sent to a list of all involved health workers in PMTCT care in different health facilities. The DHIS tracker displays (in a list) the email addresses of other users in other facilities so that a worker can find the address of someone and write to ask if the patient has come or not. The same strategy can be implemented at the district and regional levels where health facilities communicate to each other about clients' status on attending maternal and child healthcare.

6 Conclusion

Our study has addressed the following research question: what are the challenges to coordination in collaborative practices and what are the implications for the design of patient information systems as coordinative artefacts? Taking a CSCW approach we have described and analyzed several challenges. We have provided a rich empirical description of coordination work in a resource constrained setting and we have proposed improvements to the design of both computer and paper-based information systems. Our findings have contributed to understanding the coordination work to facilitate collaboration around health care provision. Future research could investigate more concrete solutions to the needs for appropriate coordination mechanisms through participatory design with the end users, in order to generate well-working solutions to the very practical and significant challenges we have started to illuminate in this paper.

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