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PRACTICES OF DISEASE SURVEILLANCE AND RESPONSE IN BURKINA FASO

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Abstract. Efforts to fight communicable diseases in Africa have been harmonized through the Integrated Disease Surveillance and Response (IDSR) framework. Following recent large outbreaks of SARS and Ebola further calls to strengthen disease surveillance and response, for example through information technology, are being made. To avoid parallel systems, data for IDSR is sought to be integrated into countries' existing electronic health information systems (HIS). As experiences in this area are still limited, studying existing practices of disease surveillance and response could serve as a prerequisite for providing such electronic support for IDSR. The paper engages in this question by applying a knowing-in-practice perspective to a case of disease surveillance and response in Burkina Faso. The findings suggest that disease surveillance and response can be conceptualized as two interrelated yet distinct practices; that of surveillance and that of response. Surveillance is being both sustained and developed through everyday practices. It is also similar to routine HIS data collection, and thus seems fairly straightforward to integrate in existing HIS. Response, on the other hand, is both more complex and less sustained in everyday practice due to low frequency and unpredictability of outbreaks. Providing electronic support for IDSR should focus on maintaining a link between surveillance and response, but it would require an IS design flexible enough to also accommodate for situations that are yet unknown.

Keywords: Disease surveillance and response · IDSR · HIS · practice theory.

1 INTRODUCTION

Healthy populations are one of the prerequisites for development. If a population is not healthy, it does not have the capability to engage in work, politics, social issues and other activities that all together generate development in a society, in an economic sense as well as in a human sense [1]. Through delivery of health services by health systems countries ensure healthy populations. Disease surveillance and response is a corner stone of any health system. It is concerned with acquiring and sharing of up to date information about potential cases of communicable diseases to be able to take the necessary actions to fight these diseases. In an African context WHO-AFRO have developed the Integrated Disease Surveillance and Response (IDSR) framework, which unites these two purposes of monitoring and public health action [2].

Recent large scale outbreaks have highlighted the importance of information gathering and sharing both on the events leading to the outbreak as well as evaluation of the response [3]. However, experiences so far with electronic support for disease surveillance and response are sparse [4] and have been mixed [5, 6]. In many countries data that supports monitoring and improvement of health systems is collected on a routinely basis often through electronic health information systems (HIS). As the main storage for health information, a well-functioning HIS could potentially play a critical role in disease surveillance and response.

Providing electronic support for strengthening of disease surveillance could lead to increased sharing of, and use of information for action. However, sharing of health information is likely to involve more than the technology, for example communication, knowledge management, learning and taking action [7]. It can be argued that in order for this to happen the HIS will have to correspond with the social structures surrounding it. Research in information systems (IS) has shown that this is a general issue when it comes to IS. To better understand the interplay between an IS and the social world it is a part of scholars have applied and further developed various practice theories. Practice theory is an umbrella term for several theories used to explain social change through the manifestation of knowledge into action facilitated by practice [8, 9]. An advantage is that it is an approach that is not individually oriented; instead it conceptualizes action as an endeavor dependent on its location, the actors, tools and practices that are part of it. When it comes to understanding disease surveillance and response, which is a collective and distributed task involving multiple stakeholders at a variety of organizational levels, it is likely that there is something to gain from using such a perspective. The paper seeks to contribute to the design for integration of IDSR into HIS by using a practice lens to better understand the distributed practice of disease surveillance and response in a country.

Through a case of the national health system in Burkina Faso the paper presents an analysis of the practices of disease surveillance and response. The paper is organized in the following way; first disease surveillance and response is outlined, second a theoretical lens based on structuration theory is discussed, and third the theoretical lens is applied to the empirical case. The paper concludes with a discussion on the complexities involved in providing electronic support for disease surveillance and response as well as the benefits and limitations of using a practice theory to understand this type of work and inform future design

2 DISEASE SURVEILLANCE AND RESPONSE

Disease surveillance and response is the work that goes into monitoring communicable diseases in order to identify new cases and to control the transmission of these diseases before they spread and develop into epidemics. Surveillance can be done in different ways but it is important that the resulting information is used for public health action [10].

Following severe outbreaks of largely preventable diseases in Africa in the 1990's, the member states of WHO AFRO in 1998 adopted the resolution on integrated dis-

ease surveillance and response (IDSR) as an approach to strengthen disease surveillance in [2, 10]. IDSR has many objectives [10], which are all essential, but those that are of most interest when it comes to HIS are the objectives to integrate multiple surveillance systems, improve the use of information, and improve the flow of surveillance information. More than 45 diseases are included in IDSR, but as the burden of diseases vary from country to country, each country defines its own specific list of priority diseases.

Although the IDSR guidelines have been adopted in many African countries [4], recent epidemics in West Africa have shown that there's still a need to improve disease surveillance and response in the region. When it comes to information sharing and communication in outbreaks it has been difficult to diagnose fast enough, to provide up to date and accurate information to the highest levels, to coordinate among the many actors involved in the response, and to inform populations about the protective measurements to take [11–13]. Also data on the effectiveness of the response could be strengthened [3].

3 PRACTICE THEORIES AND STRUCTURATION THEORY

The IDSR framework focus on the streamlining of practices of surveillance and response and the integration of those practices across organizational and sectorial levels. Providing technological support for IDSR for example through an electronic HIS needs to take into account the various dimensions of these practices.

Designing IS to support increased knowledge sharing has often been challenging as having knowledge at hand might not being the same as being able to act [14]. Much early IS research built on the rather positivistic assumption that an IS would lead to the change they were designed to bring along. This assumption was challenged by empirical research which argued that technology is not independent of the social world it is part of; instead it is used in a variety of unforeseen ways, which leads to unpredicted changes, sometimes completely different from the desired or expected changes [15, 16]. In ICTD this has also been the case, and it has been described as a design-reality gap [17]. A challenge to both IS and ICTD research has thus been to understand the relationship between technology and the social world it is being used in. In IS studies researchers have been engaged in developing theoretical frameworks that can span both the technical and social aspects of technology as well as the change technology brings about [18, 19]. Since the 1980's different practice theories have been explored as a lens to bridge this gap [20, 21]. Practice theories have also been used in ICTD [22], but much research has been more oriented towards design and less unifying in their use of theory [23].

3.1 Agency, Structure and Practice

Practice theories are characterized by their focus on uniting thought and action rather than separating them [8, 24]. Structure and agency and their relationship of mutual

constitution are central aspects of Giddens' structuration theory, which is one of the most adopted in the IS field [20, 21]. According to Giddens too much emphasis is often put on the structures in society and their potential to shape human action. Instead he argues that structures and agency are mutually interrelated because they influence and are influenced by each other through time and space [25]. To illustrate this interdependent relationship Giddens introduces the concept of duality, which describes a mutually constituting relationship between structure and agency, or knowing and doing.

Structures are the rules and resources that human agents draw on in social actions. To Giddens it is the institutions in society or a social context. The rules – but also more than that; They are not to be understood strictly as rules in for example a game, instead they are defined quite broadly as both social norms or habits, and can therefore be more or less subtle or outspoken [25]. Agency, or human action, is the capability of a person, or an agent, to act in social situations. This capability is both dependent on the knowledge, experience and motivation of the agent as well as the situation where the action occurs [25]. According to Giddens human agents are always knowledgeable but their actions very often have unintended consequences, which can result in an unconscious reproduction of the social system or structural properties of it.

Practice and organizational change is closely linked to knowledge as one key idea of practice theory is that knowledge or theory is inherent in action and that it is manifested in action [24, 26]. An often used example is that of riding a bike; it is hard to explain how to do it in theory but easy to do once you have learned it. This idea is also sometimes referred to as “knowing in practice” [8, 9]. Orlikowski [9] further defines it as knowing rather than knowledge and stresses how knowledgeability that is built through every day practices is a central aspect of distributed work. She further argues that:

“... paying attention to organizational knowing might complement our understanding of organizational effectiveness by highlighting the essential role of situated action in constituting knowing in practice. In particular, we might learn some useful insights about capabilities if we also focus on what people do, and how they do it, rather than focusing primarily on infrastructure, objects, skills, or dispositions” [9, p. 271]

Disease surveillance and response is carried out by many people over time and space, and is an example of a distributed practice. It is a practice that relies on knowledge of what to do and how to do it. In this paper a knowing-in-practice perspective will be applied to understand the distributed practice of disease surveillance and response.

4 METHOD

The empirical material for the paper is drawn from a larger on-going qualitative study of health information use from the national HIS in Burkina Faso. As the aim of the

research is to better understand the social structures around the IS, the research approach has been interpretive [27]. The study was conducted over a one-year involvement with the Ministry of Health in Burkina Faso, where the researcher was affiliated with the IT-department in the Ministry of Health. Data for this paper was mainly collected through 22 structured and semi-structured interviews, which focused on health information use and practices of disease surveillance and response. Additional material was gathered through observations, participant observation, as well as documents, such as the IDSR guidelines, reporting templates and surveillance reports.

Table 1. Overview of fieldwork

Level	Organizational unit	Observations	No. of interviews
National	Office for the fight against diseases		Data manager
	Office for statistics		Director Statistician
	Office for health informatics	Participant observation	Director Data base administrator
Regional	Region A: Urban		Director of health programs Data manager (2 times)
	Region B: Rural/semi urban		Director Data manager
District	District A.1: Urban	Observations of daily work	Director Data manager
	District A.2: Urban	Observations of data entry	Data manager (2 times) Data manager assistant
	District B.1: Rural/semi urban		Data manager
Facility	Clinic B.1.1: Semi urban	Observations of data entry	Managing nurse 2 nurses Mid-wife
Other	Academic		Epidemiologist Previous district director
			Total: 22

A weakness of the study, which will be returned to in the discussion, is that while data collection was going on, there were no epidemics taking place. Thus there are no observations from an epidemical situation to support the statements given by the participants. To compensate for this weakness, participants were asked to describe their work during response with reference to a recent epidemic.

All interviews were recorded and transcribed for closer analytical examination. Themes regarding disease surveillance and response, practices and knowledge were extracted from the transcripts and the notes. In addition, data collection and data dissemination flows were mapped out based on the empirical material, which showed a difference between surveillance and response. This difference was further explored in

a matrix-mapping where different aspects of practices were related to the different phases of disease surveillance and response.

5 THE CASE

Burkina Faso shares borders with six other West African countries but was not directly affected by the 2014-2015 Ebola epidemic. However, during the epidemic the alert level was high in the country and procedures for identifying and handling an eventual case of Ebola were integrated into the country-wide system for disease surveillance. Apart from the apparent threats from the Ebola epidemic, Burkina Faso is prone to suffering from outbreaks of meningitis, measles and malaria. In total 14 diseases or conditions are monitored on a weekly basis and the information is collected and transmitted from facilities (CSPS from “Centre de santé et de promotion sociale”) to the district, regional and national level. There are 13 regions, 63 districts and approximately 1,650 CSPS [28].

In Burkina Faso the IDSR guidelines have been adopted into its own country-specific technical guidelines [29]. These guidelines contain detailed information for each disease on how to handle disease surveillance and response at each level throughout the health system. The public health sector, which is responsible for the delivery of the majority of health services, is also responsible for the administration of the national IDSR-guidelines.

6 ANALYSIS OF IDSR PRACTICES

Many of the interviewees distinguished between before, during, and after an epidemic. The work practices and information needs in each of these phases are somewhat different. For the purpose of this analysis focus will only be on the work that takes place before and during epidemics, including the transition between these two phases.

6.1 Surveillance

During the pre-epidemic phase surveillance takes place. All interviewees described a clear, consistent, and well-organized process for the weekly routine surveillance. The managing nurses from the 1,650 CSPS across the country report weekly data to the district health data manager. Once all CSPS have reported in, the data is compiled and aggregated and sent, via e mail or phone, to the regional level. Here, the regional level data manager repeats the process of compilation but also checks data quality, before forwarding to the national level. These initial steps must take place by 10 am every Tuesday. The national office for the fight against diseases produces a national bulletin that is used at the weekly ministerial meeting and also circulated back to the regional and district offices and other relevant partners. Observations confirmed the workload that this process generated on Monday, Tuesdays and Wednesday each week. Data managers were often unavailable for appointments on these days, and where observa-

tion was done, there were a stream of visitors coming in with reports or phone calls to report in with data. All of this information had to be taken down by the data manager. For surveillance, the IDSR guidelines seem to have provided a structure, which is both known and embedded in the work practices concerned with gathering and sharing information on surveillance.

There is one standardized template that is used for the collection of data at all levels. For each disease, aggregate numbers of suspected cases, confirmed cases and deaths are collected. Such standardized tool helps to reinforce the structure of the guidelines. However, small variations of daily practice also help to maintain the structure and keep it functioning. For example, facilities far away from their district can transmit data via phone instead of the form. Similarly, a phone call could be made from districts to regions in case the internet was down. In this way the structure is shaped by adaptations based on the environment within which the daily practice of surveillance is taking place.

The information flow described above is very similar to the information flow for collection of routine health information. The main difference is that the IDSR data are collected on a weekly basis where the routine data are collected on a monthly basis. But in both cases it is the data managers under the supervision of the facility, district or regional directors who are the key persons managing and transmitting the information. During interviews and observations with these two groups of people, they all explained how they worked with surveillance based on recent experiences. This similarity to routine data collection provides an additional structure that further strengthens the practice of surveillance.

6.2 Response

Surveillance is done to inform response. Turning to the possible outcomes of surveillance they can roughly be grouped into the following three; no alerts resulting in surveillance going on as usual, an alert resulting in further investigation and control of the situation, or an alert turning into an outbreak.

According to interviewees a level of alert is reached if the notified suspected cases reach a certain threshold. These thresholds are specified in detail in the national IDSR guidelines, but generally speaking it could be a single suspected case of one of the very contagious diseases or a certain amount of cases for other diseases. When this happens, contact is made immediately by phone to the higher level in order to ensure prompt notification of the potential risk. If a suspected case is reported two actions are taken; case confirmation and site investigation. A specimen sample is sent to the closest laboratory for confirmation and further analysis. The documentation of this work is done with a line list, which there is a standardized template for. Furthermore, an investigative team can be formed at district level if necessary. The role of such a team is to go to the site of the case to analyze the nature of the case, how many have potentially been effected, and what protective measures should be taken? The documentation of this work does not follow a strict standard.

The main differences from the collection of routine health information collection is that much more information is being collected, there are differences in information

needs between the diseases, and it is not done on a routinely basis but rather every other month. Many of the interviewees had experience with this type of work for diseases, such as meningitis or measles, which would most often be the ones with cases that needed investigation. Again the structure of the national IDSR guidelines would shape the work on case investigation.

During the epidemic phase surveillance must still be done to monitor the development of the outbreak, however the response takes priority. The type of response is very dependent on the disease, but it could for instance be vaccination campaigns targeting vulnerable populations, awareness campaigns in communities carried out in collaboration with community resource persons, or deployment of specialized treatment centers. A certain challenge here is that contextual factors also influence which actions can be taken. When it comes to known diseases, the national guidelines are very clear on how to respond on each specific disease at each organizational level. But the decision on which type of response to do is based both on the guidelines, the spread of the disease, and the analysis of the situation at the specific site. Some action is taken based on routine while other action is taken based on the actual characteristics of the epidemic. Agency, as in the capacity to take action, is thus not only dependent on the structure provided by the guidelines, but also on unknown structures specific to the nature of the disease. The guidelines recognize this by being specific about how to do the site investigations, but there are no daily routines to reinforce this structure into daily practice or vice versa.

In both the two regions where the study took place actual large scale outbreaks appeared to be quite rare. When asked to describe how response was carried out by taking a recent outbreak as an example, all participants would answer that it had been a long time since there actually were an outbreak.

“Well, luckily we’ve not had epidemics. For a good period of time, we’ve not had an epidemic. Since I’ve been in this office, there has not been any.”

(Regional health manager)

Also during the time spent on site there were no investigative team missions done, nor were there epidemics taking place in the two regions. Response thus appears to be a task that is not routinely performed. This means that although the country specific IDSR guidelines are well known and well adopted there are not many possibilities to exercise them when it comes to response. Although everyone throughout the health system seems to be well aware of what to do and how to do it, routine and experience has not been built or tested.

6.3 Knowing-in-practice

Disease surveillance and response go hand-in-hand, which is logical as surveillance is supposed to trigger response. However, from the case it appears to be important to also recognize that it indeed covers two different practices. The national IDSR guidelines can be seen as a structure for how to do both surveillance and response. Health care workers can rely on this structure to seek knowledge on how to perform this type

of work. However, following Orlikowski's argument that knowledge is not the same as knowing, this might have consequences for the capacity to act based on the guidelines. The table below summarizes how the practices of surveillance and response differ.

Table 2. Summary of practices

	Surveillance	Alert	Response
Knowledge of tasks and procedures	Well-defined and adopted for all priority diseases.	Well-defined and adopted for outbreak prone diseases.	Well-defined and adopted for outbreak prone diseases.
Frequency	High. Done on a routine basis before, and during an outbreak.	Low. Done when an alert level is reached.	Very low. Done during an outbreak.
Knowing-in-practice	Easily obtained due to weekly procedures.	Obtained to some extent due to bi-monthly alerts.	Difficult to obtain due to low frequency of outbreaks.

The knowledge created through surveillance, response and evaluation it is not the same type of knowledge. The objective of surveillance is to spot a potential threat in order to be able to roll out the recommended treatment for this threat if it is detected. This is a routine task that becomes integrated in the daily work and where knowing in practice of how to do it is built through everyday activities. In a response phase the objective is to understand the development of a beginning or ongoing outbreak of one disease, the factors that nourish it as well as the effect of the action taken to counter it. When it comes to well-known diseases, where small-scale outbreaks occur more often, the response is to some extent done on a routine basis. But in large-scale outbreaks or outbreaks in a region previously unaffected, there are more unknowns and a higher chance that things may develop in unexpected ways. This can lead to ad-hoc decisions and new non-standardized procedures. Knowing-in-practice only becomes enacted as the outbreak unfolds.

From a practice-based perspective which recognizes a duality between knowing and doing, disease surveillance and response inherits a challenging paradox; that you need to be prepared (know what to do) for something that does not occur on a routinely basis or – as in cases such as Ebola in West Africa – have never occurred before. This is a phenomenon that applies to many aspects of medical practice, such as for instance treatment of life-threatening conditions. In many cases applied medical knowledge is obtained through practical hands-on experience. But there are critical situations, such as heart attacks where it would be unethical to ask a new doctor to practice on the patient [30]. In such cases techniques such as clinical simulation or emergency drills might be used in order for health workers to obtain the skills and experience need to act in an urgent situation. In Burkina Faso one simulation had been done as preparation for an eventual Ebola outbreak, but for other types of outbreaks it is not prioritized due to lack of resources. This might potentially also affect HIS de-

sign as it might be difficult to design a system for a practice that is mainly described in guidelines and where experience from real-life situations has yet to be gained.

7 DISCUSSION

The case discusses how national IDSR guidelines provides a standard for how disease surveillance and response is done in Burkina Faso. It is argued that the guidelines can be seen as the structure that defines and dominate agency through both standardization and contextualization of practice. However, the mutual reinforcing relationship between structure, as knowledge, and agency, as action, is stronger for surveillance than response. This seems to be due to the low frequency of outbreaks and the effects this has on the opportunities to practice response and thereby obtain knowing-in-practice.

This difference also has a methodological implication. For the same reasons that it is difficult to exercise response, it also becomes more complicated to study it and to get solid information on how it is done. Consequently, a recommendation for future research is to consider paying more attention to this challenge both in the framing of the study and in the research design.

The analysis further highlights that the practice of surveillance is very similar to routine data collection in a HIS, while the practice of response is not. As a consequence, response might be overlooked when strengthening disease surveillance and response through existing electronic HIS. Attention should thus be given to keeping the connection between surveillance and response in such work.

The main focus of the paper has been to make an empirical contribution to the understanding of IDSR as a domain of international interest, and to use concepts from practice theory to unfold this understanding. The practice-based perspective, has served as a useful lens to analyze the interplay between the guidelines and the actions health workers need to take action based on both the guidelines and the situation on the ground. It has worked better for assessing the structures in this interplay than the agency itself. This might be due to agency being more a difficult concept to address empirically. As it is within the action the potential for change lies, it could be interesting to explore this part of practice further in future studies. This could also potentially support the calls made within ICTD for strengthening the link with theories of development in order to better assess the consequences of the technology [22]. Structuration theory, has been criticized for not focusing sufficiently on technology itself [21]. In this case the analysis did not provide many leads as to how to improve a technical solution for IDSR strengthening. It is likely that this is due to the practice-lens being less technology focused and thus less strong as a prescriptive tool.

In spite of the practices of surveillance and response being different they should not be separated. With action being an inherent part of IDSR, future research and design strategies should rather focus on reinforcing the link between collecting data and using data for public health action in order to provide electronic support for the whole IDSR concept. This would, however, require a stronger focus on the response part of IDSR. In addition, it would require strategies for doing IS design flexibly

enough to accommodate for situations that are yet unknown – which is especially critical when it comes to countering epidemics in environments where a disease, or a new strain of a disease, occur for the first time. If this is not done, design-reality gaps might persist, and future IS to support IDSR might not hold the ability to support a change towards improving health for all.

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