Data value and care value in the practice of health systems: A case study in Uganda

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ARTICLE INFO

ABSTRACT

In anthropology, interest in how values are created, maintained and changed has been reinvigorated. In this case study, we draw on this literature to interrogate concerns about the relationship between data collection and the delivery of patient care within global health. We followed a pilot study conducted in Kayunga, Uganda that aimed to improve the collection of health systems data in five public health centres. We undertook ethnographic research from July 2015 to September 2016 in health centres, at project workshops, meetings and training sessions. This included three months of observations by three fieldworkers; in-depth interviews with health workers (n = 15) and stakeholders (n = 5); and six focus group discussions with health workers. We observed that measurement, calculation and narrative practices could be assigned care-value or data-value and that the attempt to improve data collection within health facilities transferred 'data-value' into health centres with little consideration among project staff for its impact on care. We document acts of acquiescence and resistance to data-value by health workers. We also describe the rare moments when senior health workers reconciled these two forms of value, and care-value and data-value were enacted simultaneously. In contrast to many anthropological accounts, our analysis suggests that data-value and care-value are not necessarily conflicting. Actors seeking to make changes in health systems must, however, take into account local forms of value and devise health systems interventions that reinforce and enrich existing ethically driven practice.

1. Introduction

Anthropologists, like others working in global public health have become increasingly interested in numbers; tracing the political-economy through which particular indicators have emerged in the last twenty years (Adams, 2016; Biehl, 2016; Storeng and Béhague, 2014) and their social lives that have unfolded as they assembled in different settings (Crane, 2013; Rottenburg et al., 2015). Many argue that the collection of increasing amounts of data brings great technical promise to global endeavours by bypassing ideology, enabling objective evaluation and allowing money to be traced and better spent. Anthropological interpretations have been characteristically questioning and critical. Anthropologists have been involved in analysing discourses around the promise of numbers. They have attended to the ways in which practices of epidemiology and the requirements of philanthrocapitalists intertwine (Reubi, 2015), showing how increasing collection and use of data forms a fundamental characteristic of the endeavour of global public health (Adams, 2016; Biehl, 2016). They have asked how the collection of data is implicated in the technocratic narrowing of the

goals of global public health (Storeng and Béhague, 2014) and how political decisions are in fact hidden through the insistence on the political neutrality of numbers (Adams, 2016). Anthropologists have challenged the shaky foundations upon which some politically powerful indicators are based (Gerrets, 2015), and the ways in which the collection and use of data ultimately changes and challenges the world in which people provide and seek health services (Crane, 2013).

Where anthropologists have asked a range of questions about the ways in which the reliance upon indicators shapes global health, at the heart of much of the work on low-income settings is a concern with the relationship between data collection and care-giving. Gerrets (2015) for example, asks how care practices shape data and what the relationship is between the ontology of disease objects as they are imagined biomedically and the objects that sit at the heart of the global health data. Others have analysed what happens to caregiving when a deep concern with data collection is pushed out of the core of global public health and incorporated into everyday practice in its peripheries. Case studies show how when political ambition mingles with the need to show the positive impact of a programme, the collection of the right sort of data

can take precedence over the care of patients with profound and worrying effect (Oni-Orisan, 2016). These findings appear part of a broader change in the hierarchy of activity in many low income settings, in which the collection of data has taken primacy over the provision of health services (Adams, 2016; Biehl, 2016).

These accounts provide a thick description of data collection practices but have mostly focused on social relations within vertical programmes and during experiments. The analysis of routinely collected health system data has been of less interest. While the two are not discretely divided in practice, they are rooted in different political economies, with different desires and interests embedded within them. Data gathered for vertical programmes follow direct links to colonial interests in disease burden and provides information for central government, donor agencies and multilateral organisations. In post-colonial states, health information systems (HIS) began with the 1978 Alma Ata declaration and its commitment to ensuring that primary care was shaped and delivered according to local need (World Health Organization, 1978). The establishment of HIS and their successor health management information systems (HMIS) brought with it an imperative that data should be of value to those working within the different social fields (from the Ministry of Health to peripheral health facilities) that make up the health system (Sandiford et al., 1992).

This paper is concerned with the ways in which value is created around HMIS in the different arenas that make up the Ugandan Health System. The analytical frame begins with an understanding that the health system is made up of sites that contain distinct constellations of social relations within which different forms of what is good, useful or ethical are enacted. Our interest lies with the ways in which numbers (numerical values) and the practices through which they are created get caught up with those socially constituted, expressions of what is right or important (ethical or moral values) (Graeber, 2013; Marsland and Prince, 2012; Miller, 2008; Otto and Willerslev, 2013) and how, as these values intertwine, they become implicated in the construction of hierarchies and social orders (Iteanu, 2013).

Interrogations of the interconnections between these different forms of value are found across anthropological sub-disciplines (Graeber, 2013; Haynes and Hickel, 2016; Marsland and Prince, 2012; Otto and Willerslev, 2013) but have been less in evidence in medical anthropology. Fassin's analysis of the lives of 'others' is a notable exception showing how global health constructs those living at the peripheries of the socio-economic system as being worth less in both economic and moral terms. There is, however, a rich body of work on bioethics in medical anthropology that examines the intertwining of research data (numerical values) with locally constituted moral and ethical positions (values) (Geissler et al., 2008; Molyneux and Geissler, 2008). This work challenges the abstract principles of bioethics that obscure the idiosyncrasies of everyday life within biomedical research projects in low income settings (Geissler et al., 2008; Hoeyer and Hogle, 2014; Kingori, 2013; Kingori and Orfali, 2013). It shows how highly unequal socio-economic relations shape everyday ethics creating novel forms of exchange value (Fairhead et al., 2006; Geissler et al., 2008). Of particular interest for this study is the way that decisions made about whether to ask research questions or fabricate answers are connected to local moralities about the vulnerabilities of research participants (Kingori and Gerrets, 2016).

Drawing on anthropological work on value and ethical practice, this paper explores the relationship between HMIS data collection and care giving within the Ugandan health system. We make the analysis by examining the ways in which global health actors, health workers and volunteers constructed the value of measurement, calculation and narrative practices. The paper follows a pilot project established with the intention of improving health systems data collection in peripheral health centres that began as a new Out Patient Department (OPD) register was introduced by the Ministry of Health. We explore the project as an extended case study during which concerns about the role, position and meaning of care and data were (re)formulated, moving

between project meetings, training sessions and everyday activities and attend to moments when different assemblages of value(s) (the 'data-value' or 'care-value') were used as the basis upon which these practices were evaluated. At each juncture we ask whose authoritative judgement on the form and meaning of measurement, calculation and narrative practice prevailed, and with what consequences.

2. Background

In Uganda, plans for the first national health information system (HIS) were drawn up in the mid-1980s (Gladwin et al., 2003). It was not, however, until 1997, following considerable public sector reform that the collection of health data was transformed away from a model concerned with constructing rates of disease to one that was created to support districts and health centres as they took responsibility for their services (Kintu et al., 2005). Since then, the Ugandan HIS has been through multiple iterations. Responding to concerns about the management of health systems, it was reformulated as a health management and information system (HMIS) through which facilities report to the district and districts report to central government. Within the health facilities, despite a marked increase in data collection, the means of collecting HMIS data has changed little since the 1980s. It continues to be collected by hand in registers (up to 13 per facility) and in specially formulated government tools so that it can be aggregated into weekly, monthly, quarterly and yearly reports. Following the decentralised structure of the health system, these reports are given to the health district and are fed into the national data management system. According to the HMIS manual, the data provided within these registers is expected to be of equal use for all levels of the health system.

> [The HMIS] has been designed for use at the health unit, health sub-district, district and national levels for planning, managing and evaluating the health care delivery system. These critically important tasks are necessary in order to continually improve the quality of health care in Uganda. The HMIS is the Ministry of Health's official routine reporting system replacing all pre-existing routine reporting instructions for health units and districts. Health Facilities are the major contributors to this routine information.
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> (Ministry of Health, 2010, iii)

At national level, HMIS is described as fitting into the reporting structures around the national planning for health. At the health facilities, it is expected to help the health worker who is in-charge of the facility (the 'in-charge') make evidence-based decisions around management, problem-solving, and the quality of care. The manual details practices that overlap: accurate history taking and proper examination, use of instruments, recording of the patient history, the organization of the clinic (including waiting times) and the continuity of treatment (Ministry of Health, 2010).

The 2010 HMIS manual is silent, however, about how its data is shaped by global health research and service delivery. This is despite the fact that Uganda has been the site of significant interest by overseas organisations concerned with improving health (Tappan, 2017) and, since the 1990s, has witnessed considerable economic and intellectual investment by global health actors (Crane, 2013; Meinert and Whyte, 2014; Taylor and Harper, 2014) that has transformed poorly resources health centres into sophisticated research sites (Crane, 2013). As patients move between projects, programmes and research centres located within and parallel to the public system (Meinert and Whyte, 2014), the collection of their data has become a critical site of activity, shaping and challenging the way in which care is provided (Crane, 2013). In 2015, the Ugandan Ministry of Health responded to increasing data demands by making a policy commitment that only government registers and forms could be used to gather data in public sector OPDs. At the same time, the Ministry published a new version of the OPD register. Into this document, the data requirements of global health actors had been inscribed; as a result the data points had more than doubled,