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CLINICAL ARTICLE

Developing a Pictorial Sisterhood Method in collaboration with illiterate Maasai traditional birth attendants in northern Tanzania

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ABSTRACT

Objective: To study whether data on maternal mortality can be gathered while maintaining local ownership of data in a pastoralist setting where a scarcity of data sources and a culture of silence around maternal death amplifies limited awareness of the magnitude of maternal mortality. *Methods:* As part of a participatory action research project, investigators and illiterate traditional birth attendants (TBAs) collaboratively developed a quantitative participatory tool—the Pictorial Sisterhood Method—that was pilot-tested between March 12 and May 30, 2011, by researchers and TBAs in a cross-sectional study. *Results:* Fourteen TBAs interviewed 496 women (sample), which led to 2241 sister units of risk and a maternal mortality ratio of 689 deaths per 100 000 live births (95% confidence interval 419–959). Researchers interviewed 474 women (sample), leading to 1487 sister units of risk and a maternal mortality ratio of 484 (95% confidence interval 172–795). *Conclusion:* The Pictorial Sisterhood Method is an innovative application that might increase the participation of illiterate individuals in maternal health research and advocacy. It offers interesting opportunities to increase maternal mortality data ownership and awareness, and warrants further study and validation.

1. Introduction

The maternal mortality ratio (MMR) has been used to monitor progress toward Millennium Development Goal 5, and is again included in WHO's Sustainable Development Goals. Statistics not only assist monitoring and evaluation of interventions, but also increase awareness around maternal death and action toward health improvement [1,2]. However, the reliability of MMR estimates is a subject of debate. Data collection is often difficult owing to a scarcity of information, human resources, budget, and time. Moreover, local ownership of data is limited: researchers gain insight, but do not share the results with communities [2].

In the Ngorongoro Conservation Area in rural northern Tanzania—predominantly populated by semi-pastoralist Maasai—skilled birth attendants (SBAs) are present at only 7% of deliveries [3]. Maternal complications are a significant cause of death among pastoralist women [4], but gathering data has been difficult owing to migration and a lack of vital registration [5]. Cultural silence about deceased individuals further challenges data collection [4,6]. In 2001, the lifetime risk of maternal death among Maasai women was suspected to be higher than 1 in 33 [6]. In 2005, MMR among women attending prenatal clinics in Ngorongoro was estimated to be 642 per 100 000 live births [3]. On the basis of the population count (81 071) in the catchment area of the local hospital and the rural Tanzanian crude birth rate in 2010 (390 per 1000 individuals), 3162 births would have been expected in this area in 2010 [7,8].

The aim of the present study was to assess whether it was possible to measure maternal mortality in the Ngorongoro Conservation Area while maintaining local ownership of data.

2. Materials and methods

As part of an overarching qualitative participatory action research (PAR) project [9], between March 12 and May 30, 2011, researchers and illiterate traditional birth attendants (TBAs) in the Ngorongoro Conservation Area collaboratively developed and cross-sectionally tested a quantitative participatory approach: the Pictorial Sisterhood Method. Ethical approval for the PAR was provided by the University of Calgary (Calgary, AB, Canada), VU University Medical Centre (Amsterdam, the Netherlands), Tanzanian Commission for Science and Technology, and

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National Institute for Medical Research Tanzania (research code NIMR/HQ/R.8a/VolX./876). Given the illiterate status of TBAs, verbal informed consent was obtained.

Full details of the PAR have been described elsewhere [9]. Briefly, the PAR project stimulated participants to enact solutions to context-specific problems [10], which entailed finding solutions to local problems in maternal health and prevention of mother-to-child HIV transmission. The research took place between 2009 and 2011, and engaged local stakeholders (researchers, Maasai women and men, TBAs, SBAs, hospital management, and community leaders) as co-researchers. Participants were included through expert sampling, including stakeholders who were interested in evaluating, and enacting solutions to, low use of maternal health services [9].

Participants combined their knowledge, whether local experience, or cultural or academic knowledge. Through such a mix of knowledge, called "co-generative enquiry", new knowledge is co-created; this often includes "outside-the-box" solutions that are extremely relevant to the local setting and that would not emerge if stakeholders participate in research in isolation [10]. Additional data collection strategies to enrich and clarify information included naturalistic and participant observation, semi-structured in-depth interviews, and reflexive journaling [9].

Two academic researchers (R.S. and Y.R., a former doctor at a hospital in Ngorongoro Conservation Area), a local research assistant, 19 Maasai TBAs, four hospital management and community leaders, and a supervising team (J.H., M.M., J.v.R., M.Z., and F.S.) participated in the development of the Pictorial Sisterhood Method.

In the overarching PAR project, high maternal mortality was identified as a major local problem; however, silence around it hampered awareness of its magnitude, which contributed to limited use of SBAs [10]. An SBA was defined in accordance with WHO as someone who is "trained to proficiency in skills needed to manage uncomplicated pregnancies, childbirth and the postnatal period, and in identification, management and referral of complications in women and newborns" [11].

The present participants discussed whether data on maternal mortality could be collected, and if and how the barrier of cultural silence might be respectfully overcome. Four semi-structured interviews with hospital management and local leaders addressed different methods to estimate maternal mortality. Only 68 institutional deliveries took place in 2010, and women experiencing complications of home delivery arrived at hospital in extremis, reflecting the severe underutilization of local health services and leading to limitations in calculating community mortality estimates from hospital figures. Follow-up data of women who attended prenatal clinics were limited. Government vital registration was hardly used by the Maasai community. Participants suggested the sisterhood method [1] as a possible alternative.

Although the sisterhood method is deemed unreliable in populations that migrate [1], participants suggested that it might increase insight into local maternal mortality among the Maasai community itself by breaking the silence. Talking about deceased individuals is restricted to specific people [6], and outsiders can easily take the wrong approach. Maasai TBAs stated that they would be able to appropriately collect these data in their communities. Researchers regarded the involvement of TBAs as crucial, respecting their central role in childbirth and in maternal-health-related research locally [9]. The TBA community that had participated in the overarching PAR project selected 19 TBAs for the present study. Although their illiteracy formed a barrier, active participation in the whole project and statements on motivation to improve maternal health were great motivators [9].

The original indirect sisterhood method consists of four questions (Box 1) [1]. To overcome illiteracy, researchers, a Maasai research assistant, and TBAs collaboratively discussed how these questions might be adapted to the Maasai setting, which led to the Pictorial Sisterhood Method (Fig. 1). Pawns depict the women and their "ever-married" sisters, circles indicate live births [12]. An oval shape was collectively chosen to indicate a pregnant or 6-week postpartum status. Sisters were defined as those from the same biological mother—an important fact in polygamous Maasai marriage. Only after having reached puberty and, by tradition, after rituals including circumcision, young women are considered to be ready for childbearing [13]. Although female circumcision is illegal, "post-circumcision" was used to delineate female sibling inclusion in line with previous Maasai population research after local advice from TBAs. The postpartum period of 42 days, when not clear, was replaced by "*entomonone*," the period of seclusion after childbirth, which varies among families from some weeks to some months [6].

Box 1
Questions in the sisterhood method.[a]

1. How many sisters (born to the same mother) have you ever had (including those who are now dead)?
2. How many of these ever-married sisters are alive now?
3. How many of these ever-married sisters are dead?
4. How many of these dead sisters died while they were pregnant, or during childbirth, or during the 6 weeks after the end of pregnancy?

[a] Reproduced from *The Sisterhood Method for Estimating Maternal Mortality: Guidance notes for potential users* [1], with permission from WHO.

Researchers developed the research form in line with advice from the TBAs and practiced how to use it with the TBAs (Fig. 2). Every line of the form starts with a big pawn that was checked (via a diagonal line), representing the woman interviewed by the TBAs and/or researchers. Consecutively, the adjacent smaller pawns were checked

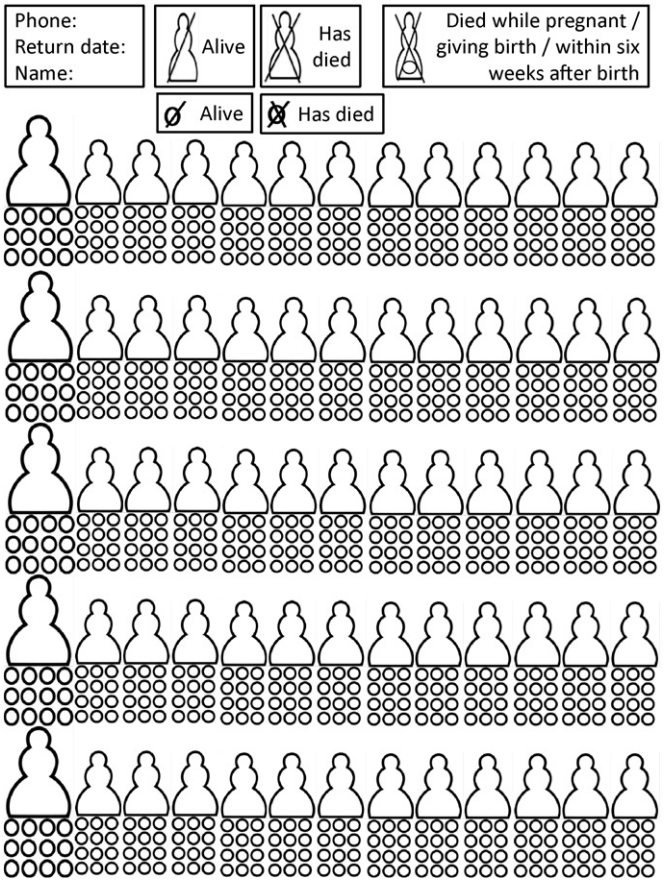

Fig. 1. Empty Pictorial Sisterhood Form (English version). One form could be used to interview five separate women.