1 CLINICAL ARTICLE

A cohort study of functioning and disability among women after severe maternal morbidity

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ABSTRACT

Objective: To assess functioning and disability related to severe maternal morbidity (SMM) via the WHO Disability Assessment Schedule 2.0 (WHODAS 2.0). Methods: In a retrospective cohort study, women with or without a history of SMM who delivered at a tertiary public hospital in Brazil between July 2008 and June 2012, completed the WHODAS 2.0 questionnaire by individual interview between August 2012 and November 2013. General WHODAS scores were evaluated by maternal and neonatal characteristics, and specific domain scores according to SMM event. Results: Overall, 638 women were enrolled (315 with SMM and 323 without SMM). The mean general WHODAS score was higher among women with SMM (19.04 ± 16.18) than among women without SMM (15.77 ± 14.46; $P = 0.015$). Domain scores were also higher in the SMM group for mobility (16.00 ± 20.22 vs 11.63 ± 17.51; $P = 0.003$), household activities (26.79 ± 30.16 vs 20.09 ± 26.08; $P = 0.005$), participation (23.55 ± 21.72 vs 17.27 ± 19.17; $P < 0.001$), and work/school activities for women currently studying or working (20.52 ± 26.64 vs 11.66 ± 19.67; $P = 0.001$). Excluding SMM, a parity of two or more was the only factor significantly associated with higher scores overall ($P = 0.013$) and for domain 4 (getting along with people; $P = 0.017$). Conclusion: By comparison with women without childbirth complications, SMM impaired self-reported functioning among women 1–5 years after delivery.

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1. Introduction

In 2013, there were approximately 800 maternal deaths worldwide every day, most of which occurred in low- or middle-income countries and could have been prevented [1]. However, for every death, approximately 20–30 women survive severe complications during pregnancy, childbirth, and the puerperium [2]. Little is known about the health conditions and quality of life of these women after delivery.

In 2009, the WHO standardized the definition of, and criteria for, potentially life-threatening conditions (PLTCs) and maternal near miss (MNM), which represent a continuum of events on the way to maternal death [3]. These criteria can be used to assess the quality of care provided to a woman during pregnancy, childbirth, and the puerperium [4].

An assessment of pregnancy repercussions—if it occurs at all—normally does not extend beyond one postpartum visit a few weeks after delivery. Nevertheless, some morbidities can occur after this period, impairing quality of life and leading to adverse effects for women and their children [5,6]. In an early study [7], general health status and sexual function were rated worse by women who survived severe maternal complications, and they also sought healthcare facilities more frequently than did control women. A more recent study [8] described increased symptoms of post-traumatic stress disorder among women surviving SMM. Analogous to the long-term consequences of trauma [9], any PLTC or MNM that a woman survives during pregnancy, childbirth, or the puerperium is likely to modify their medium- and long-term functioning.

The WHO International Classification of Functioning, Disability and Health [10] describes functioning and disability in an individual in relation to health conditions. It identifies what a person can or cannot do in daily living, and takes organ and/or system functions and body structures into account, as well as activity limitations and social participation in the environment [10]. The second version of the WHO Disability Assessment Schedule (WHODAS 2.0) was developed to evaluate the functioning and/or disability of an individual to participate in or develop six main life domains—cognition, mobility, self-care, getting along, life activities, and participation—irrespective of

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their medical diagnosis [11]. To our knowledge, this instrument has not been used to evaluate capacity and functioning limitations secondary to SMM episodes.

In general, long-term complications that limit a woman's functional status after pregnancy, especially regarding routine activities [12], remain largely unknown for women affected by an SMM event. The aim of the present study was therefore to apply the WHODAS 2.0 to a cohort of women with and without an SMM episode to identify potential long-term repercussions on functional status.

2. Material and methods

The present retrospective cohort study included women who delivered between July 1, 2008, and June 30, 2012, at the University of Campinas Maternity Hospital, São Paulo, Brazil, where an obstetric intensive care unit (ICU) is available to manage the multiple aspects related to high-risk pregnancy care. The local institutional review board approved the study protocol (approval number 447/2009). Between August 2012 and November 2013, eligible women were contacted and asked to participate in the study. All participants provided informed consent.

The study cohort was identified via the computer-based hospital information system. Initially, a list of all women admitted to the ICU due to an obstetric cause was obtained from the database. Women who experienced SMM during pregnancy or within 42 days of delivery with a diagnosis of a PLTC and/or any criteria for MNM according to the WHO definition [3,4] were eligible for the "exposed" group [3,4]. For each woman in the exposed group, a woman without severe maternal complications who delivered at the same institution in the same year was recruited to the "not exposed" group. A second list containing a random sample of these women by year of childbirth was generated from the system. The clinical records of this second group were checked electronically to verify that they had no severe complications during childbirth before they were invited to participate.

Identified women were initially contacted by telephone by trained interviewers. If the woman was not reached by telephone, an invitation letter was mailed to her. Those who accepted the invitation were asked to attend a face-to-face interview performed by healthcare professionals specifically trained for the study.

In the face-to-face interview, participants underwent a multidimensional assessment regarding reproductive health, quality of life, post-traumatic stress disorder, sexual function, daily functioning, and disability, along with an assessment of the physical growth, and neurological and psychomotor development of their child. The data from women with severely complicated pregnancies (exposed group) were compared with those from women with uncomplicated pregnancies (not-exposed group) [13].

For each woman, the time between childbirth and the interview was recorded. Clinical information on patient hospitalization was extracted from medical charts. The 36-item form of the WHODAS 2.0 instrument was completed for each participant by a trained interviewer (the 32-item form was used for participants who were unemployed and no longer in school). The instrument had been previously translated and culturally adapted to Brazil [14]. Women in either group might have had another delivery since the index delivery considered in the present study. In this case, the women were exhaustively oriented to answer the questions and forms thinking specifically in the context of the index childbirth.

The WHODAS 2.0 is designed to measure activity functioning and participation in daily living activities in the previous 30 days. Both functioning and disability have a dynamic interaction with health conditions and contextual factors. The instrument provides a common way of measuring the impact of any health condition in terms of functioning. It is not targeted to a specific disease, so it can be used to compare disability due to different conditions. It also allows assessment of the impact on health and of health-related interventions [10].

The first domain of the instrument, "cognition" (six questions), evaluates communication and thinking activities, including concentration, memory, problem-solving, learning and communication. Domain 2, "mobility" (five questions), evaluates activities such as standing up, moving around the house, going outside the house, and walking a long distance. Domain 3, "self-care" (four questions), evaluates hygiene, getting dressed, eating, and staying alone. Domain 4, "relationship with people" (five questions), evaluates interaction with others and difficulties that could be encountered owing to adverse health conditions. Domain 5, "life activities" (eight questions), evaluates difficulty with daily living activities (i.e. activities that individuals do most days, including those associated with household responsibilities, leisure, work, and school). Domain 6, "participation" (eight questions), assesses social dimensions, such as joining in community activities, barriers and obstacles in the world surrounding the respondent, and other issues including maintenance of personal dignity. The total score ranges from 0 to 100, and a high score indicates major daily living limitations [11,15].

Interviews were initially recorded on paper charts and then in a virtual database specifically built for the study using the LimeSurvey platform (https://www.limesurvey.org/). Subsequently, the data were transferred to SPSS version 20.0 (IBM, Armonk, NY, USA) for analysis. The logical consistency of data was checked, and information was updated via manual charts, clinical records, and additional telephone contact when necessary. The research group and statistician met to discuss the analytical approach to be used and prepared a detailed plan of analysis.

Sociodemographic, obstetric, and perinatal characteristics were compared between groups with and without SMM, and differences were assessed by χ^2 test. Mean and median WHODAS 2.0 scores were evaluated by maternal and neonatal variables, and domain scores were evaluated by exposure to SMM. The nonparametric Mann–Whitney test was used to assess differences in scores between the groups. Multivariate analysis was performed by using generalized linear models, which included all predictors for the total score and for each domain score separately. $P < 0.05$ was considered to be statistically significant.

3. Results

In total, 840 women were eligible for the study, and 638 were enrolled (Fig. 1). Among the participants, 315 with SMM formed the exposed group (246 [78.1%] with PLTC, 67 [21.3%] with MNM, and 2 [0.6%] who did not fully answer the WHODAS 2.0) and 323 without SMM formed the not-exposed group. Overall, 297 women were employed or studying, and were able to answer the full 36-item instrument. For these women, the outcomes measured were the WHODAS 2.0 domain scores.

Table 1 shows demographic, obstetric, and perinatal characteristics of the study women by SMM occurrence. Only age 35 years or older was significantly more common in the SMM group ($P = 0.001$). Neonatal death was two times higher among women with SMM, but the difference between groups was not significant. Table 2 shows the mean and median WHODAS 2.0 scores for 636 women who fully answered the 32-item instrument by maternal and neonatal characteristics. Only parity showed a significant difference in scores ($P = 0.030$).

Across the whole cohort, mean general and specific domain scores for the 32-item WHODAS 2.0 were evaluated by SMM status (Table 3). The mean general score was significantly higher among women with SMM than among those with no morbidity ($P = 0.015$); within the SMM group, there was no difference between PLTC and MNM. Mean domain scores were significantly higher in the SMM group for domains 2 (mobility; $P = 0.003$), 5a (household activities; $P = 0.005$), and 6 (participation; $P < 0.001$).

Table 4 shows the mean general and specific domain scores for the full 36-item WHODAS 2.0 among women who were currently studying or working. Among these women, the general scores were similar, but