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Abstract Title:

Living with Pelvic Organ Prolapse: Experiences from North-West Ethiopia

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Abstract Text:

Hypothesis / aims of study

Symptomatic pelvic organ prolapse (POP) is estimated to affect around 4-10 % of women in studies reported from high-income countries [1]. However little is known about the condition in low-income settings, including prevalence rates, risk factors, and physical, psychological, social and economic consequences of living with this maternal health disorder. Pregnancy and childbirth are important risk factors for pelvic floor disorders [1]. With a fertility rate of 4.8 children per woman, limited access to obstetric care and other health services, poor sanitary conditions, as well as shame and stigma commonly attached to pelvic floor disorders [2, 3], one may assume that POP is a substantial maternal health challenge in Ethiopia, the present study context. As part of a larger study assessing the prevalence and risk factors of pelvic floor disorders among Ethiopian women [3], this sub-study aimed to assess how women living in rural and semi-urban areas perceive and practically handle POP, as well as potential health seeking behaviour related to the condition.

Study design, materials and methods

The study was conducted in the Amhara Region of North-West Ethiopia in 2011 as part of the Dabat Incontinence and Prolapse (DABINCOP) study [2, 3]. The study had a qualitative design and was based on semi-structured in-depth interviews with 13 informants, including women with symptomatic POP; health care personnel and a traditional healer with experience from health seeking women with POP. A female research collaborator well acquainted with the language and customs assisted with the data collection. All interviews were transcribed verbatim. The analyses followed well-established principles within qualitative research.

Results

All informants suffering from symptomatic POP experienced the problem as a severe burden in their lives. Half of the informants experienced mild to moderate degrees of urinary incontinence in addition to POP. Most of the women experienced the condition as extremely shameful, and were afraid of being discriminated against if it was disclosed. They were convinced that they suffered from a rare condition that others would not be able to understand, and that help would be difficult to attain. Half of the informants had in fact not disclosed their problem to anyone despite having lived with it for years, and none of the informants who were currently married had disclosed the condition to their husbands. Some women expressed fear of being evicted by their husbands, and thus prevented from caring for their children. Some of the women had however disclosed to a sister, mother or another person whom they trusted greatly.

Most of the informants experienced the problem as a hindrance in performing the work and social duties expected of them. The challenge was largely experienced as situational. For example, sitting down for use of toilet, walking long distances or lifting heavy items such as water buckets severely worsened the condition. All the women sought strategies for managing such everyday challenges and for maintaining their appearance by for example laying down for short periods during the day to let the prolapse ‘pull back’, or by pushing the prolapse inside with their hand. Delegating work related chores to children or finding excuses for not carrying out particular chores were other common strategies. Some women applied oil

to the prolapse to be able to move more freely and to reduce the soreness and pain. For a majority of the women the pelvic organs retrieved their normal position while lying down and did not cause major discomfort during sexual intercourse. For a few women, however, sexual intercourse could be painful, and a challenge that led to conflicts in the marital union.

Some of the women had visited the health centre for other health problems, but had failed to disclose the condition of POP to the health care personnel. However, a few of the women had received medical treatment of POP in forms of tablets at the health centre without much improvement or been referred to the hospital. A few of the informants were currently admitted to the hospital undergoing surgical treatment for POP. Several of the informants had regularly attended 'holy water' sessions at a local site; a central mode of healing within the Ethiopian Orthodox Church. Others had seen a traditional healer in the local community, however, none of these experienced improvement in their condition. According to the health personnel at the hospital the costs related to treatment was an important factor hampering many women's chances of receiving treatment. They also commonly experienced that women with some formal education would seek help at an earlier stage. Most of the women in this study had never attended school and were illiterate. The health personnel at the health centre had limited experience with women seeking help for POP, and explained that this was mainly due to low trust in health care institutions, especially among people living in rural areas. According to the traditional healer, shame and fear of discrimination prevent women from seeking help at the health care facilities.

Interpretation of results

The findings of the study illustrate how practical, economic as well as socio-cultural circumstances influence how the women perceive and handle their condition of POP. Diverse factors, including perceived stigma and the fear of gossip and discrimination prevented disclosure of the problem. Access to health information and health care were hampered by such perceived stigma as well as by severe economic constraints and lack of trust in the health care institutions. Most of the women interviewed thus kept the condition to themselves, and sought strategies for handling the pain and the discomfort while striving to maintain their role as wives and mothers actively engaged in keeping up the household chores.

Concluding message

It is vital to generate knowledge about women suffering from POP in low-income contexts, such as Ethiopia, in order to improve health care related to neglected maternal health challenges. Through a thorough exploration of how women experience POP in a specific low-income context, this study contributes to potential future development of interventions for this big and often treatable maternal health challenge in Ethiopia.