The Value of Sustainable Protocol to Address Uterine Prolapse in Nepal: Health Camp, Awareness, and Employment Strategy

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ABSTRACT

Pelvic organ prolapse (POP) is a global women's health concern; uterine prolapse (UP), one of the five types of POP, has significant prevalence in Nepal. Studies indicate that over 600,000 women in Nepal are suffering with uterine prolapse and within that group at least 200,000 are in need of immediate surgery. Women with UP often suffer in silence for decades; stigma impacts their personal, family, and social dynamic on physical, emotional, and intimate levels. The degree of prevalence and severity is compounded by lack of awareness of causal and preventative measures, heavy lifting aspects of agricultural and household labor, and insufficient access to health care. A clear, targeted strategy to address UP treatment and cultural causal awareness should integrate income generation for women and address village needs to increase potential for long term success and sustainability.

Keywords: pelvic organ prolapse, POP, uterine prolapse, UP, Nepal

BACKGROUND

Millions of women in every country around the world suffer in silence with pelvic organ prolapse (POP), a chronic health condition that remains shrouded in secrecy despite medical records indicating diagnosis and treatment dating back over 4000 years to the Kahun Papyrus in 1835 BC. A transcription of the Kahun Papyrus states, "Of a woman whose posterior belly and branching of her thighs are painful, say thou it is the falling of the womb" (Griffiths translation).[10]Documentation exists of multiple treatments Hippocrates utilized for POP such as inserting a pomegranate into the vagina to hold the uterus in position or suspending women upside down from a ladder with legs tied together and shaking for 3 to 5 minutes to "encourage" the uterus to return to its normal position.[12]

Nepal has the distinction of being the only county internationally to initiate a government campaign to address prolapse. Nepal's Supreme Court proclamation in the case of Prakash Mani Sharma v. Government of Nepal (Sharma) was the foremost government legal initiative, national or international, which acknowledged that the high incidence of uterine prolapse constituted a violation of women's reproductive rights.[11] No government prior to or since has replicated this action or designated a targeted campaign to address POP.

Pelvic organ prolapse occurs when the pubococcygeus or PC muscle, a trampoline-like muscle which stretches from the pubic bone to the coccyx (tail bone) forming the floor of the pelvic cavity and supporting the pelvic organs, becomes weakened or damaged for a variety of reasons. Once weakened or damaged this muscle can no longer properly support the organs in the pelvic cavity and POP occurs. There are 5 types of POP; uterine prolapse (UP), prevalent in

Nepal, is one of the 5 types. There are 4 grades of severity, differentiated by the degree of downward displacement of organs/tissues into and beyond the outer rim of the vagina.

UTERINE PROLAPSE DYNAMIC

Currently it is estimated that 600,000 women in Nepal have UP, with 200,000 of them in need of immediate surgery.[8] In some cases women suffer with procidentia, a total prolapse of the uterus in which the organ is completely outside the body. The majority of women in Nepal with UP are of reproductive age; 44% of women 20-29 years of age have UP and 14% of women under the age of 20 have UP.[13] While many causal factors for POP are globally universal such as structural damage which occurs during vaginal childbirth, muscle tissue weakness related to estrogen loss in menopause, heavy lifting, chronic coughing, and chronic constipation, multiple social norms exist in Nepal that exacerbate or compound risk factors. There is little awareness among Nepali women about UP as a health condition or its causal factors. Responses of women during focus group discussions indicate they have very limited or no knowledge of UP.[13]

Childbirth practices that occur in Nepal come with multiple risk factors that increase the risk of UP occurring. Women who marry while in their teen years may become pregnant at an early age. Risk for POP increases with each childbirth; lack of adequate birth control methods increases the risk of UP. Applying pressure to the abdomen during delivery is relatively common. "Foot massage", the practice of walking on the abdomen after birthing to expel the placenta, can cause considerable damage. Pulling a large baby out of the vagina because of extended labor can also cause significant damage. Additionally malnutrition, blood loss, and dysentery impact health ballast.

Menopause is an additional UP risk factor for Nepali women as it is for all women; inception is between 43.4 and 46.5 years of age. Onset of UP at a young age prior to menopause translates to decades of exacerbation of this condition prior to onset of estrogen and muscle tissue integrity degradation, increasing gravity of the condition.

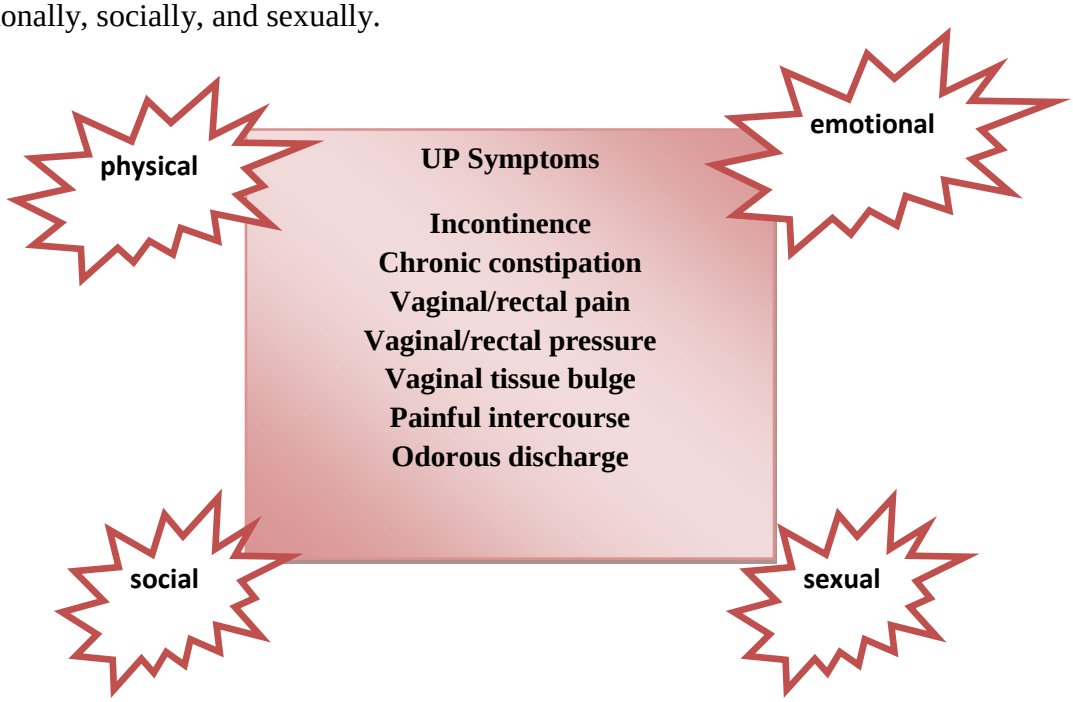
Heavy lifting is a daily norm for the majority of women in Nepal; agriculture is the most prevalent occupation of their women and with it comes a significant amount of heavy lifting. Nepali women have always played an important role in agriculture which sustains nearly 80 percent of the population.[14] Additionally women must transport water for agricultural and household use and wood for cooking fires great distances. Repetitive heavy lifting can cause considerable damage to structural tissues that suspend organs in the pelvic cavity. [10]

Chronic constipation is both a symptom and cause of POP. Bearing down to have a bowel movement because of chronic constipation also pushes organs in the pelvic cavity downward including the uterus.

Chronic coughing can result from smoking; 30% of women in Nepal smoke when pregnant.[1] Additional risk factors such as malnutrition, blood loss, and dysentery, impact health ballast. Every causal factor women experience increases the risk of POP as well as degree of severity; the causal factors for women in Nepal are multiple.

Lack of adequate rest after birthing is also a concern. It typically takes 6 weeks for a woman's body to recapture balance after giving birth; Nepali women return to performing tasks in the field and household duties soon after delivery. The Safe Motherhood Network Federation (SMNF), Beyond Beijing Committee (BBC), Tribhuvan University Teaching Hospital (TUTH) study in 2009 disclosed that 78.79% of the respondents worked one week after delivery.

POP presents with multiple symptoms; the degree of severity and the type of activity mean women's symptoms have aspects of uniqueness and aspects of similarity, with variability day to day and woman to woman. Women may experience vaginal tissue bulge, incontinence or inability to urinate, vaginal, rectal, or pelvic pressure or pain, chronic constipation, pain with lifting, standing or walking, painful intercourse, and when infection occurs foul smelling white discharge.[13] There is significant impact to quality of life; UP impacts women physically, emotionally, socially, and sexually.



Stigma prevents women from disclosing POP; the universal impact of stigma to women's lives has kept pelvic organ prolapse shrouded despite documentation dating back multiple millennium. While women in developed countries remain silent about POP because of embarrassment of symptoms, fear of stigma permeates women's lives in Nepal where disclosure of UP may result in a woman being ostracized from her husband, family, or community. Women may be beaten for refusing intercourse because of pain. Some women fear their husbands will take a 2nd wife. Many women fear the condemnation of their mother-in-law, the matriarch of the

family unit. Women with prolapse can often recall the exact scenario they first felt their prolapse occur, but fear of stigma keeps them from revealing it to anyone.

There is little awareness of UP because of the lack of open dialogue; Nepali women are seldom aware a treatment exists for their condition. Cultural norms related to societal expectations of covering private parts under all circumstances make it difficult for women to discuss this extremely private, personal, condition with healthcare facilitators when access to health camps occurs.

A post-surgical discharge consultation seldom transpires for Nepali women who are able to access treatment for UP and are referred for and receive surgical intervention. The typical surgical intervention for UP is hysterectomy; following discharge from the hospital Nepali women travel long distances to return to their respective villages. Most of Nepal is mountainous and hilly; it was previously believed that UP was more prevalent among women with low socio-economic status from hilly regions but recent studies have shown that it is equally prevalent in women from plains regions as well as in financially secure families.[10]

Complications that can occur are pain, infection, and increased potential for additional types of prolapse; inflammation and damage may result from the long journey home. Additionally, vaginal vault prolapse is a relatively common complication of hysterectomy. Vaginal vault prolapse occurs when the top of the vagina is not properly secured during a hysterectomy and the vaginal walls cave in on themselves.

According to a study by Safe Motherhood Network Federation (SMNF), Beyond Beijing Committee (BBC), and Tribhuvan University Teaching Hospital (TUTH) in 2009, 80% of women received no antenatal check up. Nearly 78% of deliveries were conducted by the mother-in-law or a neighbor and only 8% were assisted by healthcare staff. Women who delivered their

own babies made up 22.73% of this study. A total of 89% of women delivered babies at home; the remaining 11% were hospital deliveries.[10]

There are a few treatments Nepali women utilize to address UP symptoms; nearly 50% of the SMNF respondents sought some sort of treatment such as inserting herbs in the womb or eating herbs and special food or visiting a jhakri (local faith healer). Studies indicate 26% of women utilize a pessary but while pessary use can be very successful in controlling UP, it should be removed, cleaned, and reinserted by a healthcare professional every 3 months. Nepali women may leave a pessary in for 2 years or more, causing infection, discharge, pressure erosion, pain, bleeding, or in extreme cases, fistula formation. Embedded or entrapped pessaries may be coated with hardened urinary salts and need to be surgically removed; erosion and granulation of tissues often make vaginal removal impossible. Some women insert assorted objects such as a sari fabric, stones, bark, mud, or other objects into the vagina as alternate pessaries as well as utilize herbs to self-treat.[10]

GEOGRAPHIC, POPULACE, AND CULTURAL CHARACTERISTICS

Index Mundi indicates the population of Nepal as of 2013 is 29.9 million people with estimates of reaching 35,700,000 by 2025.[6] Administratively, Nepal is divided into 5 development regions, 14 zones, and abundance of villages with 83% rural population. The urban growth rate is one of the highest in the world.[14]

Nepal has a High illiteracy rate, particularly for women; 54.6% of women above 15 are illiterate compared to 28.9% of men of same age.[7] Nepal ranks 157th of 187 countries in the 2011 UNDP Human Development Index and 113th of 146 in the Gender Inequality Index—within the bottom quartile for each index.[14]

Only 1 in 2 households have adequate food sources. Access to water and sanitation remains in a critical state for most families. The majority of households have absentee husbands who work in other regions. Women make up the majority of agricultural labor; 61% of women are not paid for the work they perform.[9]

Nearly 25% of women give birth by the age of 18, half by the age of 20. Physical violence starting at the age of 15 is a fact of life for 22% of women between the ages of 15-49. Sexual violence occurs to 12% of women aged 15-49. Emotional, physical, or sexual violence occurs to 33% of women who are married. Women tell no one of the violence they have experienced in 66% of cases that occur.[9]

PROGRAM DESIGN

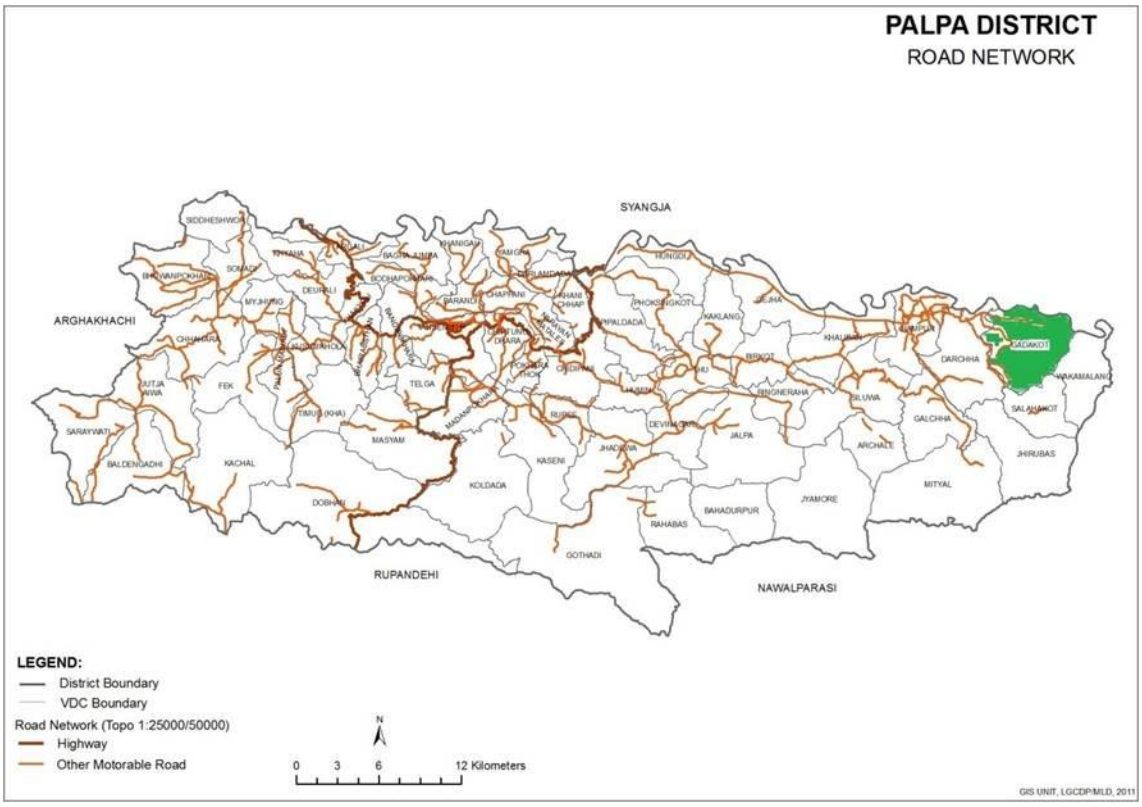
The WHEN program (Women's Health and Empowerment Network) is a multi-phased initiative which will incorporate aspects of health education, stigma reduction, and income generation for women into a base program for uterine prolapse health screening. Phase 1 will engage the village of Bhalayatar; metrics and measurements will address challenges which need to be assessed prior to evolution of Phase 2 where additional village(s) will be engaged.

WHEN-NEPAL PROJECT OBJECTIVES

- **Erect permanent multi-purpose structure in Bhalayatar.**
  - **Screening and treatment base for UP.**
    - **UP screening & Pessary fittings.**
    - **Surgical referrals to Lumbini Medical University.**
  - **Micro-financed income generating facility for women.**
    - **Financial benefit to families.**
    - **Improve status in community.**
    - **Reduce reliance on farming heavy labor.**
  - **Health education.**
    - **Shift awareness of UP and causal factors.**
    - **Reduce social stigma**
    - **Reduce improper healthcare practices**
    - **Gender sensitizing programs**
      - **Husbands.**
      - **Mothers-in-law.**
- **Additional considerations being evaluated:**
  - **Water.**
  - **Sanitation.**
  - **Medical equipment & materials.**
- **Product development for income generation; sanitary napkins from plant source.**

Village of Bhalayatar

Phase 1 of APOPS/HCN/GIRHL initiative will be located in the village of Bhalayatar in Palpa district, Gadakot VDC, approximately 25 km from the district headquarters. Local vehicles are available up to Rampur, approximately 10 km from the village.



Bhalayatar has 100 households and is located 25km from district headquarters. The population of the village is 357, average number of children per household is 3. A distinction of the village of Bhalayatar is there are 68 households of Kumals, a shrinking indigenous people who make up 0.44 percent of the population of Nepal. The Kumal are considered a marginalized community. Their traditional occupation is pottery making, likely the reason for their significant presence in the village of Bhalaytar, an area with red mud; however the practice of pottery

making by this culture is nearing extinction (only 3 Kumals in the village continue the indigenous tradition of pottery making) because the open market now supplies plastic and ceramic dishes. As a result of the impact to their livelihood, the Kumals have been compelled to change their occupation.

The houses in the village are of mixed construction, 55% are made of mud and stones with zinc roofs, 7% are cement, the balance are huts. There is no electricity in Bhalayatar; 10% of the houses have solar energy sources. The lack of access to electricity limits villagers' exposure to education, health, and sanitation information. Approximately 12% of the houses in the village have temporary toilets; nearly 60% of the houses have no toilets. There is a high rate of illiteracy in the village, approximately 30%. Discrimination exists regarding preference being given to male children over female to attend school.

The village is particularly poor; agriculture is the main occupation of nearly every household. The village lacks fertile soil; the red mud makes this zone unfavorable for agriculture so corn and soybeans are the primary crops grown along with some vegetables. Animal rearing is also practiced in the village.

Most of the locals work daily wage labor but spend that income for the same day's needs as well as alcohol. Nearly 70% of the households are in debt because loans are necessary to sustain the household during the seasons no work is available. Money is loaned from a community based coop.

Local people are not familiar with health practices or sanitation concerns; illiteracy, lack of access to health practitioners, and prevalence of traditional healing practices translate to poor health status and low life expectancy. Despite access to free health immunizations only 30% of

children are vaccinated. The local health post is a 2 hour walk from the village; the primary health care center is approximately 1 ½ hour walk from the village. The status of women's health is poor with reproductive health being the primary concern. Alcoholism is extremely common in the village.

Male members of most households earn the income to fulfill family needs; female members handle the agricultural needs and household work and are not involved in income generation. The rate of illiteracy is higher in the female population as is the rate of health concerns.[4]

PROJECT ANTICIPATED OUTCOMES

- **Uterine prolapse**
  - **Increase awareness.**
  - **Early diagnosis & treatment to prevent progression.**
  - **Post surgical evaluation.**
  - **Tracking of UP repair outcome; metrics and measures.**
- **Village**
  - **Financial benefit to family structure.**
  - **Financial value to village.**
  - **Social value to village.**
  - **Increased respect for female role.**
  - **Improvement in women's reproductive health.**
  - **Reduction in improper health practices.**
  - **Reduction of stigma.**

BARRIERS

Deep rooted socio-cultural perceptions prevent women from capturing full value of programs that have been initiated to date. Birthing practices, awareness, post-surgical follow-up, and pessary monitoring must all be targeted. In order to initiate change to a significant degree, cultural norms must be addressed simultaneously with health screening.[13]

- Sensitivity to women's discomfort regarding being screened for UP by a man must be considered; female assistants should be in screening rooms during pelvic examination.[10]
- Stigma is a significant barrier; 46.97% of women in the 2006 NDHS survey (Nepal Demographic and Health Survey) waited 15-30 years for treatment because of deep rooted socio-cultural norms.[8]
- Women often won't admit to UP because they will be ill-treated by their husbands.[10]

DISCUSSION

UP must be addressed with healthcare, social, anthropologic, awareness, and educational directives to successfully shift the dynamic. Past programs often have treated women with UP but little or no follow-up care occurs; many INGOs set up health camps, treat, take promotional pictures for their own purposes, and leave, with no tracking of outcomes. The 2006 NDHS report contained 6 ½ pages of UP statistical capture, the 2011 NDHS survey contained 2 paragraphs; an indicator of the need to energize the UP initiative on all levels. Globally POP is seldom addressed as the life-altering condition that it is; whether women live in developing or developed zones, the status quo is little awareness and significant stigma. Nepal's initiative to address the pandemic of UP within their borders exemplifies a standard that should be universal.

Pelvic organ prolapse is seldom analyzed from the women's perspective. Impact of POP may be physical, emotional, social, or sexual, but the degree goes far above and beyond what is acknowledged in any country. Pandemic prevalence indicates the need to address this cryptic women's health concern from screening standpoint in all countries.

Regardless what geographic location within Nepal, caste or ethnicity, or educational level, all Nepali women have significant risk for UP. Research indicates that prevalence cannot be associated with any particular group, although lack of rest after child delivery and little access to health care likely increase prevalence and degree of severity.[10]

Women risk emotional isolation, ridicule and shame, lack of economic support, abuse and/or abandonment by husband, violence, and discrimination. Daily household and agricultural duties many of which are load bearing, such as fetching firewood and water, tending livestock, tending young, grinding grain, and field work, with no assistance from male partners, takes its toll on general health and most particularly, reproductive health.[3]

Nepal's Ministry of Health and Population Family Health Division has been providing uterine prolapse surgery free of cost since 2007; approximately 31,000 women have benefited from this program to date. An additional 20,000 have received surgical services through NGOs and INGOs.[3] The 2012 Clinical Protocol for Management of POP addressed the quality of UP treatment and surgery but the protocol is often not adhered to. After surgery, women suffer with complications; guidelines in place are appropriate, but many physicians are not following them. Surgeons should not perform more than 5 surgical procedures daily but some perform up to 25.[5] Additionally, awareness of UP causal factors must be addressed in an attempt to reduce incidence. Specific programs targeted to both husbands and wives conjointly would be of value.

RECOMMENDATIONS

Health treatment and education, awareness, stigma, income generation, and gender disparity must all be addressed in order to achieve success long term in uterine prolapse initiatives. A program that integrates multiple factors and dissects and evaluates the outcome of each aspect is pivotal to achieve long term reproductive health ballast for women in Nepal. There is considerably less value in humanitarian aid than a well balanced program which provides healthcare while educating and empowering women to help themselves and their families.

Randomized controlled studies are considered the "gold standard" of medical research regarding assessment of medical conditions and treatments. It is imperative however to address socio-cultural norms as well as differences in medical practice patterns such as grading of UP when capturing statistical data. Continual long-term follow-up of UP is a necessity regarding both surgical and non-surgical interventions.

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