

Doctoral thesis for the degree of Doctor of Philosophy (PhD) in Medical Science

**CHALLENGES IN PREVENTION AND TIMELY
CARE OF UTERINE PROLAPSE IN NEPAL**

Binjwala Shrestha

**Department of Internal Medicine and Clinical Nutrition
Institute of Medicine,
Sahlgrenska Academy at University of Gothenburg**



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Binjwala Shrestha

Department of Internal Medicine and Clinical Nutrition, Institute of
Medicine, Sahlgrenska Academy at University of Gothenburg, Gothenburg,
Sweden

Challenges in prevention and timely care of uterine prolapse in Nepal

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binjwala.shrestha@gu.se

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This work is dedicated to those who are doing their bit to preserve, promote and identify how to “prevent reproductive health” of women and improve the care of uterine prolapse.

To my loving mom, who lost her life at an early age during her fifth child delivery.

ABSTRACT

Background: Uterine prolapse is a common reproductive health problem in low-income countries like Nepal. Physical symptoms of this condition influence women's quality of life. Current data insufficiently determine women's awareness of this condition. Health care seeking practices for uterine prolapse in Nepal are inadequate.

Aims: This Thesis aimed to assess women's knowledge of uterine prolapse and its associated factors, explore how this affects quality of life, and describe health care seeking practices. We also aimed to determine the prevalence of UP in both rural and peri-urban settings of Nepal.

Methods: This Thesis used cross-sectional descriptive studies. The mixed-method approach included quantitative interviews with 115 respondents and qualitative in-depth interviews with 16 UP-affected women in rural Nepal. Nationally, we conducted structured interviews with 4,693 married women aged 15–49 years in 25 districts that represent all 5 administrative regions and 3 ecological zones of Nepal. To assess how uterine prolapse affects quality of life, we conducted structured interviews with 3,124 women during a household survey in the peri-urban Jhaukhel-Duwakot Health Demographic Surveillance Site outside Kathmandu and also with 48 attendees at a screening camp for uterine prolapse. A community-based case control study traced self-reported cases identified by a previous household survey and in a control group (women not having uterine prolapse) from the screening camp.

Results: Most participants (>85%) described major physical discomforts, including difficulty with walking, standing, working, sitting, and lifting. Compared to stage I, women with Stage III uterine prolapse suffered adverse effects on quality of life. They endured humiliation, harassment, torture, and

severe emotional stress from their husbands and other family members due to their inability to perform household chores or fulfill their husband's sexual desires. The prevalence of uterine prolapse in our peri-urban setting was 2.11%, where more than 53% of our participants had comprehensive knowledge of uterine prolapse (compared to only 37% in a national survey). Contributing factors included parity, education, and family structure. Knowledge gaps in the national survey associated with geography, age group, education, caste/ethnic group, and media exposure. Possible factors that influenced women's health care seeking practices for uterine prolapse included access barriers, low socioeconomic status, gender inequality, a culture of silence, lack of autonomy for health care, and lack of regular community-based services.

Conclusions: Major challenges for the prevention and timely care of uterine prolapse include knowledge gaps and associated factors such as geography, caste/ethnic group, education, and media exposure. Key barriers include socioeconomic status, gender inequalities, and women's knowledge and perception regarding accessibility to quality health services.

Keywords: Uterine prolapse, health seeking practice, prevalence, quality of life, health demographic surveillance site, Nepal.

SAMMANFATTNING

Bakgrund: Livmoderframfall (LF) är en vanlig komplikation inom reproduktiv hälsa i låginkomstländer som Nepal. De fysiska symptomen som uppstår påverkar kvinnors livskvalitet. Det är ännu okänt hur stor medvetenheten om LF är bland kvinnor, samtidigt som de drabbade sällan söker medicinsk behandling eller annan hjälp för detta tillstånd.

Syfte: Avhandlingen fokuserade på att både i urban och rural miljö i Nepal kartlägga kunskapen om LF och dess relaterade faktorer, att undersöka kvinnors erfarenhet av LF och dess effekt på livskvalitet samt att kartlägga faktorer som bidrar både till utvecklingen av LF och kvinnors möjlighet att söka medicinsk behandling för tillståndet. Vidare har förekomsten av LF kartlagts.

Metod: I denna avhandling användes en deskriptiv tvärsnittsstudiedesign med mixed-method (blandad kvalitativ och kvantitativ metod). För studier i rural miljö tillämpades strukturerade kvantitativa intervjuer med 115 kvinnor med LF och kvalitativa djupintervjuer av 16 kvinnor. För den nationella studien i 25 nepalesiska distrikt, som representerar samtliga fem administrativa regioner och tre ekologiska zoner i landet, användes strukturerad kvantitativ intervju med 4 693 gifta kvinnor i åldrarna 15-49 år. Samma metod användes även för undersökning i de urbana hushållen i undersökningsområdet Jhaukhel-Duwakot utanför Katmandu samt för att bestämma livskvalitet hos kvinnor med LF som deltog i en medicinsk behandlingskampanj för LF. En fall-kontroll studie utfördes med deltagare med självrapporterad LF vid hushållsundersökningen och en kontrollgrupp som hade diagnostiserats som fria från LF i samband med den medicinska behandlingskampanjen.

Resultat: De flesta studiedeltagarna (>85%) rapporterade omfattande fysiska obehag av LF som svårighet att gå, stå, arbeta, sitta och lyfta. Livskvaliteten var avsevärt försämrad hos kvinnor som hade LF i stadium III i jämförelse med stadium I. På grund av kvinnornas oförmåga att utföra hushållsuppgifter eller bemöta sina mäns sexuella önskemål, fick kvinnorna utstå förödmjukelse, trakasserier och tortyr av både sina män och andra familjemedlemmar. Detta ledde till allvarlig känslomässig stress och påfrestning. Förekomsten av LF i urban miljö var 2.11% och bidragande orsaker till detta var antal graviditeter, utbildningsnivå och familjestruktur. Mer än 53% av kvinnorna i reproduktiv ålder i urban miljö hade omfattande kunskap om LF, men endast motsvarande 37% i den nationella undersökningen. Kunskapsgapet i den nationella undersökningen berodde på geografiskt område (urban kontra rural miljö), åldersgrupp, utbildning, kast/etnisk grupp och vilken typ av medial exponering som använts för att förmedla information om LF. Faktorer som påverkade kvinnors möjligheter att söka behandling för LF var svårigheten att nå kompetent hjälp, låg socio-ekonomisk status hos kvinnorna, ojämlikhet mellan könen, kulturellt betingade faktorer som att inte tala om reproduktiva hälsoproblem, avsaknad av möjlighet att själv bestämma över sitt liv och bristande tillgång i samhället till medicinsk vård relaterad till LF.

Konklusion: De största utmaningarna för att förhindra LF i framtiden är kunskapsgapet vad gäller LF och de faktorer som bidrar till tillståndet: geografi, kast/etnisk grupp, utbildningsnivå och kommunikationsvägar för att förmedla kunskap om tillståndet. Kvinnors låga socio-ekonomiska status, könsdiskriminerande traditioner samt kvinnors kunskap och uppfattning om tillgång till medicinsk behandling för LF utgör hinder för både prevention och behandling i god tid för att förhindra komplikationer relaterade till LF.

LIST OF PAPERS

This Thesis is based on the following papers, which are referred to in the text by their Roman numerals.

Paper I

Binjwala Shrestha, Sharad Onta, Bishnu Choulagai, Amod Poudyal, Durga Prasad Pahari, Aruna Uprety, Max Petzold, Alexandra Krettek.
Women's experiences and health care-seeking practices in relation to uterine prolapse in a hill district of Nepal.
BMC Women's Health 2014, 14:20.

Paper II

Binjwala Shrestha, Bhimsen Devkota, Badri Bahadur Khadka, Bishnu Choulagai, Durga Prasad Pahari, Sharad Onta, Max Petzold, Alexandra Krettek.
Knowledge on uterine prolapse among married women of reproductive age Nepal.
International Journal of Women's Health 2014, 6:771-779.

Paper III

Binjwala Shrestha, Sharad Onta, Bishnu Choulagai, Khadga B Shrestha, Max Petzold, Alexandra Krettek.
Knowledge, prevalence and treatment practices of uterine prolapse among women of reproductive age in the Jhaukhel-Duwakot Health Demographic Surveillance Site, Bhaktapur, Nepal.
Journal of Kathmandu Medical College. 2014, 3:136-143.

Paper IV

Binjwala Shrestha, Sharad Onta, Bishnu Choulagai, Rajan Paudel, Max Petzold, Alexandra Krettek.
Uterine prolapse and its impact on quality of life in the Jhaukhel-Duwakot Health Demographic Surveillance Site, Bhaktapur, Nepal.
Glob Health Action 2015, 8:28771.

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ABBREVIATIONS

ANC	antenatal care
GoN	government of Nepal
ICPD	international conference on population and development
IoM	Institute of Medicine
JD-HDSS	Jhaukhel-Duwakot health demographic surveillance site
MDG	millennium development goal
PHCC	primary health care centers
POP	pelvic organ prolapse
QOL	quality of life
UNFPA	United Nations population fund
UP	uterine prolapse
VDC	village development committees
WHO	World Health Organization

BACKGROUND

Women's reproductive health and uterine prolapse

The International Conference on Population and Development (ICPD) Program of Action, held in Cairo, Egypt in 1994 represents landmark recognition of the importance of women's health. Since then, international communities have included women's reproductive health in policymaking and programs for a key development agenda [1]. Whether or not they have children, women are vulnerable to reproductive health problems throughout their lives, from adolescence through the end of their reproductive years, but those who give birth need essential care to protect their reproductive health [2]. Although not necessarily a consequence of reproduction, reproductive health problems include all conditions that affect the reproductive system. Such problems result not only from biological factors, but also from women's poverty, powerlessness, and lack of control over resources [3]. Obstetric morbidities include conditions that occur during pregnancy, delivery, and the post-partum period, whereas gynecological problems encompass conditions of ill health unrelated to pregnancy such as reproductive tract infections, cervical cell changes, uterine prolapse (UP), malignancies, and sub-fertility [4].

Uterine prolapse

Uterine prolapse is characterized by descent of the uterus, with or without the urinary bladder and bowel, into the vagina and results from weakness in normally supportive tissues [5]. Its main clinical symptoms are classified into four groups according to clinical symptoms: (i) vaginal, (ii) urinary, (iii) bowel, and (iv) sexual [6, 7]. Generally, slippage of the pelvic organs (i.e.,

uterus, rectum, and bladder) is described as pelvic organ prolapse (POP) [7]. However, some conditions occur without UP, including *cystocele*, wherein the urinary bladder falls toward the vagina during prolapse, and *rectocele*, wherein the rectum loses support and bulges into the back wall of the vagina [8]. This Thesis defines UP as a condition that occurs when the uterus descends into the vagina with or without the urinary bladder (cystocele) or the bowel (rectocele).

Stages, signs, and symptoms

The level of impairment and disability due to UP are determined by the stages of UP, which are clinically graded as first, second, third and fourth according to the degree of prolapse toward the vaginal opening [9]. Stage I is usually identified during clinical examination because women often do not recognize the symptoms. During stage II, most women experience symptoms, but many do not consider seeking health care. In stage III, almost all women experience difficulties due to severe symptoms as the uterus drops further into the vaginal opening. In stage IV, the uterus drops outside the vagina and requires emergency health care [10].

Global prevalence

The World Health Organization (WHO) reports the global prevalence of uterine prolapse as 2%–20% among women younger than 45 years of age [11]. Compared to UP prevalence in the United States (14.2%) [12], the mean prevalence in low-income countries is 19.7% (range 3.4%–56.4%) [13]. In low- and middle-income countries, UP prevalence ranges from 7.6%–49.8% (7.6% in India [14], 13% in Gambia [15], 22% in Jordan [16], 10% in Oman [17], and 49.8% in Lebanon [18]). These estimates are based on women who attended outreach health clinics or hospitals.

Uterine prolapse in Nepal

Nepal's 2006 National Demographic Health Survey revealed that 7% of women self-reported UP [19]. Self-reported UP prevalence has 95.8% validity with clinically diagnosed UP. Average UP prevalence in Nepal is 10% (N=2,070) [4] among women who participated in screening camps in eight districts representing the hill, mountain and Terai zones. Additionally, UP prevalence varies by ecological zone (20%–37% in the Terai (Plain) area [20], 27% in the Eastern Region [21], 25% in the Far West Hills [22], and 27.4% in the Central and Eastern Hills [23]).

Quality of life

UP is a main contributor to reproductive health problems that influence women's quality of life [4]. UP particularly affects health and social well-being in the reproductive and economically productive age groups [13], causing difficulty in walking, standing, and lifting [20, 22]. Symptoms include pelvic pressure, back pain, urinary and bowel problems, coital discomfort, and drying and cracking of internal tissues exposed outside the vagina [24]. Physical (physical activities, back pain and mobility) and social health (social isolation) and psychosocial stress (emotional stress and sleep energy) associate significantly with frequency of UP symptoms [9]. Prolapse particularly affects women's performance of daily household chores in rural South Asia, where women adopt a squatting posture for most household work [14]. Because these symptoms impair women's ability to work UP threatens their position in the family. Furthermore, women are usually too embarrassed to ask for help [22]. Although women in high- and low-income countries experience similar symptoms of UP, the consequences are usually more severe in low-income countries, largely due to the poor status of women in

traditional societies [13]. In Nepal, women with UP report difficulty in walking, sitting, lifting, and squatting (80%–89%) and often say they have “something falling out” or a feeling of “heaviness” regarding urinary problems (30.7%), and painful intercourse (41.1%). Additional complaints include backache; abdominal pain; burning on urination; white, watery discharge; foul-smelling discharge, and itching (27%–55%) [22].

Risk factors

The definite cause of remains unclear due to the possibility of multiple risk factors [25]. Damage to the pelvic floor can result from one or more of the following: overstretching of the perineum, obstructed labor, delivery of a large infant, and unsafe delivery practices [26]. Risk factors include spontaneous vaginal delivery, body mass index, age, and parity (number of child delivery). Obstetrical conditions include biological risk due to excessive stretching and tearing as well as multiple deliveries [13, 27, 28]. Chronic problems of UP mostly coexist with prolapse of the vaginal wall and urinary and fecal incontinence, leading to pelvic floor dysfunction. These conditions relate integrally to women's reproductive history, especially regarding difficult vaginal deliveries and the trauma that can occur during childbirth [15, 29, 30]. Individual predisposing factors include congenital susceptibility (family history and weak connective tissues), non-obstetric strain on the pelvic floor (overweight, heavy lifting, and constipation), and lifestyle/environment [28]. An association between UP and metabolism of the connective tissues is well established [31]. Additionally, polymorphisms in the alpha I chain of the type III collagen protein-encoding gene (COL3A1) are possible risk factors [32]. Some occupational, sociocultural practices and reproductive characteristics contribute to the severity of UP [33]. A review of

UP in low- middle-income countries revealed contributing factors including regular manual work and frequent heavy lifting, even during pregnancy and shortly after delivery [4, 34].

Prevention and management

Prevention of UP includes different levels of intervention in accordance with the predominant risk factors. Women's empowerment programs and gender-sensitive policies and strategies can improve predisposing factors such as socioeconomic and structural issues (i.e., gender relations and low socioeconomic status of women) [3]. Similarly, reduction of reproductive risk factors (e.g., management of safe obstetric care, postnatal physiotherapy, and family planning to space and limit births) helps prevent the risk factors of UP [22]. In early stage UP, primary care interventions include pelvic floor exercise, pessary insertion, and counseling for lifestyle modification (e.g., weight loss, avoid heavy lifting, bowel management, and pelvic floor muscle exercise). In late stage UP, 10%–20% of women require surgery to improve health-related quality of life [35].

Nepal: An introduction

Nepal is a landlocked low-income country in South Asia, located between China to the north and India to the south, east, and west. Geographically, Nepal is divided into three ecological zones, from east to west: (i) the Northern Range Mountains, which contains eight peaks higher than 8,000 meters, including Mt. Everest; (ii) the Mid-Range Hills, which include high peaks, hills, valleys, and lakes; and (iii) the Southern Range-Terai (Plain fertile land), which includes Kathmandu, the capital city, and the Kathmandu Valley [36]. For administrative purposes, Nepal is divided into five development regions—Eastern, Central, Western, Mid-Western, and Far-Western—and

further divided into 75 administrative districts containing 3,753 smaller units known as village development committees (VDCs) and 99 municipalities. VDCs are political units, mostly located in rural areas, whereas municipalities are located in urban areas [36]. Nepal has 240 electoral constituencies [37].

Health care system

The health post is the first institutional contact point for basic health services in each VDC. More than 48,000 female community health volunteers work as health promoters under the supervision of health posts. Nepal currently has 3,129 health posts (676 upgraded from sub-health posts) and 209 primary health care centers. Primary health care centers represent the first referral center from health posts in each electoral constituency. Most are located in rural parts of the country [38]. For curative services, 65 district hospitals and 10 zonal hospitals represent the second referral health facility from health posts. District hospitals are mostly available in the district headquarters and city areas of the zone (zonal and regional hospitals). District hospitals are located in districts that lack zonal and regional hospitals [39]. Specialized services are provided in central-level hospitals, mostly located in the Kathmandu. Private hospitals, clinics, and community hospitals also provide health services in different parts of Nepal [40]. The Government of Nepal defines its target groups as economically poor households (< 3 month food sufficiency), geographically remote areas, and marginalized (Dalits) and disadvantaged individuals, particularly regarding empowerment, including women who lack access to primary education and health posts and also experience gender inequalities. Nepal requires specific target interventions to end gender inequalities and social exclusion by removing barriers and increasing the access and use of health services by the target groups [41].

Demographic and social cultural dimensions

The total population of Nepal is 26.5 million, with a sex ratio of 94.2 [42]. Among the total female population, 6.7% belong to the reproductive and elderly age groups; about 83% of the total Nepalese population lives in rural areas [43]. Nepal is diverse in geography and religions, with complex social cultures and value systems [44]. Marriage is a universal institution to start family life, and half of the marriages among ever married women < 25 years of age occur before the age of 18 (minimum age for legal marriage) [43]. Mean age at marriage for men is 23.8 years and 20.6 years for women. Compared to men, the tendency of marriage age in women starts and ends earlier (10–14 and 30–34 years of age, respectively), vs. 15–19 and 40–44 years of age, respectively, for men [45].

Twenty-five percent of women give birth by age 18 years and nearly half by age 20 years. The estimated crude birth rate is around 22 per thousand. Similarly, the total fertility rate of a woman throughout her lifetime is around 2.52 children [36]. About one fourth of the population (25.16%) lives below the poverty line, and the Gini-Coefficient, which indicates inequality in income distribution, is 0.328 [46]. According to the 2011 census, Nepal has 125 castes/ethnic groups and 123 different languages and dialects [47]. Nepalese people originate from two major ethnic groups: (i) Tibeto-Burman (Mongoloid groups including Tamang, Rai, Limbu, Sherpa, and Newar) and (ii) Indo-Aryan people of the Terai (Brahmin, Chhetri, and Tharu), who migrated from northern India and participated in the early settlement of Nepal [48].

Socioeconomic status of women

Women's status has risen remarkably due to improved education status, health service utilization, economic opportunities, and participation in decision-making positions in formal sectors. To address violence against women, the Government enacted the Domestic Violence (Crime and Punishment) Bill and is developing a gender-responsive budget to formulate gender-sensitive policies and programs in all development sectors in Nepal [49]. However, disparity continues to exist across genders and in rural-urban areas as well as districts and regions [50]. Overall literacy rates increased from 54% in 2001 to 67% in 2011, although female literacy only increased from 43% to 58% during the same period. [50]. Maternal mortality declined > 50% in the past decade [38], but women still face financial challenges: only 20.5% own property [49]. Women's limited economic activity in non-agriculture sectors may result from lack of education, a tradition of working in agriculture, and women's traditional restriction to reproductive activities [49]. Although female-headed houses are increasing due to migration of the male population [50], only 46% of currently married women participate in decisions pertaining to their own health care, major household purchases, and visits to family or relatives [36]. Compared to men, women are home-based informal workers (39% and 61%, respectively [44]. Nepalese women in general and rural women in particular are vulnerable to both domestic and public violence [44]. Nationally, 22% of married women aged 15–49 years have experienced physical violence at least once since they were 15 years old, 9% reported physical violence within the 12 months prior to the survey, and 12% of women aged 15–49 years have experienced sexual violence at least once in their lifetime [36].

Policy and plan for uterine prolapse prevention and care in Nepal

Reproductive health policy and plan

In Nepal, most health policies and programs are linked with Millennium Development Goal (MDG) indicators. For reproductive health services, MDGs include family planning services and maternal health care. All of these services are universally accessible in government health facilities. For the upcoming sustainable development agenda, the Government circulated a draft country report of sustainable development goals to present at the United Nations Summit, which plans to adopt the post-2015 development agenda plan on 25 September 2015. In this draft, Goal 3 mandates universal access to sexual and reproductive health care services, including family planning, information and education, and integration of reproductive health into national strategies by 2030 [51].

Prevention strategies for uterine prolapse

Prevention is a priority program to reduce UP prevalence in Nepal [20, 22, 52]. The Government recognizes that UP associates with reproductive health and rights, sex, equity, and empowerment of women [39]. However, regular reproductive health programs do not recognize UP because preventive activities are not linked with family planning programs and quality maternal health care programs, even though such programs are entry points for initiating UP-related health promotion to improve women's health status. [39]. Key initiatives include awareness programs by various national, international, and nongovernment organizations, which work to reduce UP through outreach camps, health institutions, female community health volunteers, and mass media [52]. Other key initiatives include programs that disseminate information for preventive care management and early treatment

of UP [20]. Since 2007, the media has mobilized to raise awareness of UP by disseminating messages to prevent and treat UP using various approaches [53, 54]. Various national and international networks and nongovernment organizations implement UP awareness programs through outreach camps, health institutions, female community health volunteers, and mass media [55, 56]. Among them, 13 organizations maintain advocacy and awareness programs that focus on increasing women's awareness of early symptoms, possible risk factors, and preventive measures of UP, as well as issues regarding UP-related violence against [57, 58]. In 2009, the Family Health Division of the Ministry of Health developed operational guidelines for UP management that focus on surgical treatment and organizing UP screening camps [59]. Most health promotion programs for UP prevention operate according to the public-private partnership policy. The Government does not fund the UP prevention program [60].

Care and treatment policies and strategies

The 2009 operational guidelines provide free surgical care to UP-affected women who have been diagnosed during a screening program. In compliance with the stages of UP in screening camps and public and private hospitals, the Government reimburses hospital costs and provides counseling services and insertion of pessaries [59]. During September 2008–December 2011, approximately 34,000 women received surgical services for UP in outreach camps and hospitals [39]. However, women who received surgical services at a hospital-organized screening camp and in screening camps themselves reported different levels of care [40]. To ensure quality of care for UP treatment, the Government recently circulated a UP treatment protocol and standardized health institutions and service providers [61].

Sociocultural barriers to prevention and care of uterine prolapse

Access to maternal health care and family planning services for primary prevention

Access to quality reproductive and maternal health care aids UP prevention because multiple risk factors of UP (e.g., unsafe delivery care, early pregnancy, and lack of birth spacing) can be prevented [52, 62]. However, the maternal mortality ratio in Nepal remains at 251 per 100,000 live births: every 12 hours, six mothers die [36]. Regarding indicators of accessibility and availability of maternal health care, only 50% of women make the required four visits to an antenatal care clinic during pregnancy, 36% deliver at health facilities, and only 45% visit health facilities for postnatal care [36]. The risk of suffering from UP is 3.89 times higher among women with multiple pregnancies than women who were never pregnant [13]. Compared to the MDG target (67%), the national contraceptive prevalence rate is 43% [63]. Barriers to accessing maternal health care include distance, cost of travel, culture and tradition, and lack of family support [64]. The inaccessibility of quality maternal health care contributes to the development of UP due to risky and unskilled home delivery practices [22].

Culture, women's position, and gender value

Aside from reproductive factors, UP associates with socioeconomic and cultural factors (i.e., poverty, gender inequalities related to care of reproductive health problems, lack of nutritious diet, workload during postnatal period, and domestic violence) [13]. The Indo-Aryan group is patrifocal and exhibits a strong degree of male dominance and a conservative attitude toward women that involves controlling female sexuality [26]. In Nepal, women engage in hard work, including heavy lifting, with little or no

rest during pregnancy or the postpartum period. Such activity contributes to high rates of UP [4]. Discriminatory gender norms and value systems make women more vulnerable to gender/power relations and place men in a higher position. The entire society considers men's dominant behavior as normal [14].

Accessibility of health services for timely care of uterine prolapse

Barriers to medical help include women's reluctance to seek treatment due to lack of family support; ineffective treatment; and high cost for travel, food, and lodging [64]. Women mostly hide UP due to embarrassment, resulting in problems such as domestic violence [3]. Nepalese women and health workers perceive cultural traditions as risk factors [22]. Women's triple burden of work includes household duties, caring for fields and cattle, and a regularly occurring reproductive role that resumes a few days after childbirth [54]. Among 88.6% of women who received surgical care for UP, 49% and 31% did not go for an immediate checkup due to shyness or lack of knowledge, respectively [40].

Rationale of the Thesis

Despite existing policies and programs for preventing and managing UP, the prevalence of risk factors affects women's quality of life in all parts of Nepal. This Thesis helps explore the challenges to prevention and timely care of UP as well as barriers to accessing care. Therefore, by identifying the gaps between health care and other related development sectors, the results of this Thesis will help develop evidence-based policy and strategies for UP prevention and increase access to health care services for timely care of UP.

AIMS

The overall aims of this Thesis were to

- explore women's experiences of uterine prolapse (UP) and its effects on daily life, perceived causes, and women's health care seeking practices in a rural hill district (Paper I);
- assess UP knowledge among married women of reproductive age, and determine the association between UP knowledge and socioeconomic characteristics (Paper II);
- explore UP knowledge, prevalence, and treatment practices among women of reproductive age in the Jhaukhel-Duwakot Health Demographic Surveillance Site (JD-HDSS) in Nepal's Bhaktapur district (Paper III); and
- identify the contributing factors and stages of UP and its impact on quality of life in JD-HDSS (Paper IV).

THEORETICAL FRAMEWORK

Theory of health and disease

Health status and disease progression is a dynamic process. Human health and disease are defined in terms of the social and ecological environment. Humans attached moral values to their perception of health and disease and share experiences according to their own will [65]. Whereas the clinical concept of health relates to managing health problems and ensuring quality of life, public health uses a holistic approach that aligns with health promotion and disease prevention [66]. This Thesis applied theories of health and disease to describe the progression of health and well-being (i.e., perceived quality of life) vs. the progression, or stages, of uterine prolapse (UP) among affected women.

Theory of prevention

Any effect of health status or disease results from potential risk factors. Although cause and effect interact in time and space [67], it is possible to prevent exposure both before and after effects occur. Prevention encompasses actions taken prior to the manifestation of disease. Prevention research focuses on exploring the potential risk and protective factors of specific health problems [68]. There are four levels of prevention: (i) primordial (i.e., reducing the societal, cultural, and environmental risk factors for health promotion; (ii) primary (i.e., improving personal socioeconomic and behavioral risk factors to prevent disease; (iii) secondary (i.e., improving health seeking behavior and preventing disease complications; and tertiary (i.e., treating disease and improving quality of life) [69].

This Thesis applied the theory of prevention to identify challenges and barriers to UP prevention at all four levels. At the primordial level, it explored personal characteristics and social issues such women's socioeconomic status,

sociocultural norms, and Nepal's gender value system, respectively. At the primary level, potential risk factors for UP included specific reproductive behavior, knowledge, self-perception and accessibility to health information. At the secondary and tertiary levels, the Thesis explored factors affecting health seeking behavior, including accessibility to quality health care services (clinical evaluation) and women's experiences and perception of quality of life due to UP (self-evaluation).

Social cognitive theory

Social cognitive theory (SCT) suggests that human health is a social matter, determined by a casual multi-dimensional structure in which self-efficacy and beliefs function together with goals, outcome expectations, and perceived environmental obstacles and facilitators according to human motivation, behavior, and well-being. Thus, SCT focuses on how people learn from individual experiences, the action of others, and their interaction with their environment [70]. This Thesis used SCT to explore how women's social environment and social system (e.g., the health care system) affect personal factors including emotional states, self-beliefs, and habits regarding UP. Similarly, behavioral factors (e.g., knowledge, perception, and UP prevention practices; early care; and environmental factors) comprise the social, cultural, educational, and geography of women's families and communities.

Theory of health care seeking behavior

Phase IV of the theory of health care seeking behavior, which emerges from Andersen's model (1995), conceptualizes three key factors of health care seeking behavior: (i) population characteristics (predisposing, enabling, and need factors); (ii) behavioral factors (personal and use of health services); and (iii) the outcome of health status (perceived and evaluated health status) [71].

Predisposing factors include population characteristics describing age, marital status, education, occupation, caste/ethnic group, gender value, culture, and health beliefs regarding knowledge and perceptions of UP and the health care system. Enabling factors include accessibility to health care (e.g., the regularity and cost of health care, travel, and the extent and quality of women's social relationships) [71]. The need factors are *perceived* and *evaluated* needs. The perceived need for health services include not only women's self-perception of their general health and functional state, but also how they experience symptoms of illness (e.g., pain stress, and health difficulties) and whether they consider their problems sufficiently important to seek professional help. In contrast, evaluated need involves professional evaluation of health status and women's need for medical care.

Both needs relate closely to the type and amount of treatment received when a patient visits a medical care provider. The outcome of health status, either perceived or evaluated, depends on an individual's health behavior. Predisposing factors directly and indirectly determined how individuals practice personal health care or use health services [71]. The theoretical framework is summarized in Figure 1.

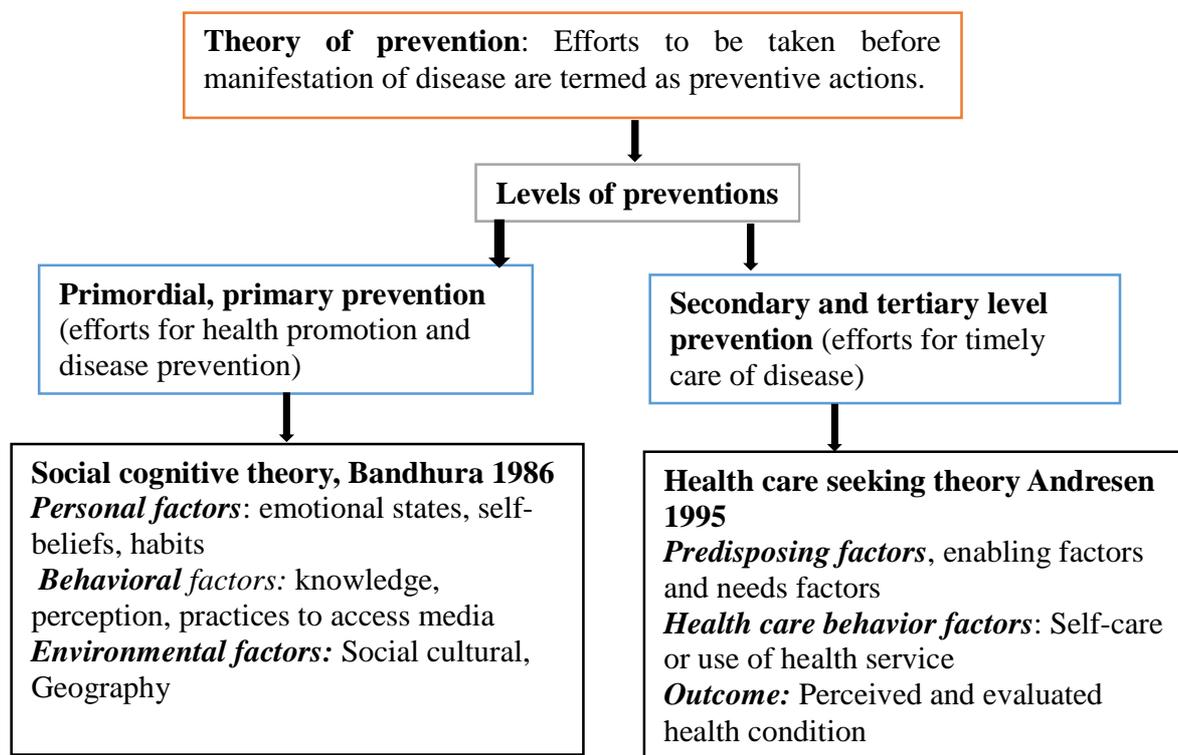


Figure 1: Theoretical framework of Thesis

This Thesis explored possible factors affecting health care seeking practices for UP, categorizing predisposing factors, enabling factors and need factors with identification of risk factors and prevalence of UP (outcome), both perceived and evaluated by clinical examination in rural, in peri-urban settings of Nepal.

CONCEPTUAL FRAMEWORK

This Thesis primarily explored the challenges of prevention and timely care of uterine prolapse (UP) and aimed to identify possible strategies to improve women's quality of life. It groups challenges for primordial and primary prevention in one category. Similarly, secondary and tertiary prevention of UP are grouped in challenges for timely care. Figure 2 details the study population and key areas of each Paper, along with level of prevention. This Thesis further examined UP in terms of women's knowledge and perception of UP in Nepal through the lens of geography, social status of women, cultural values, and gender norms in relation to prevention and health care seeking practices for UP. The challenges are diverse, largely due to differing geography, socioeconomic status, gender value, and the availability and accessibility of health service facilities. This Thesis discusses women's experiences and health care seeking behavior in the rural and urban districts of Nepal. Quality of life due to UP, the prevalence of self-reported and clinically diagnosed UP, and treatment received were identified in a peri-urban setting in Nepal.

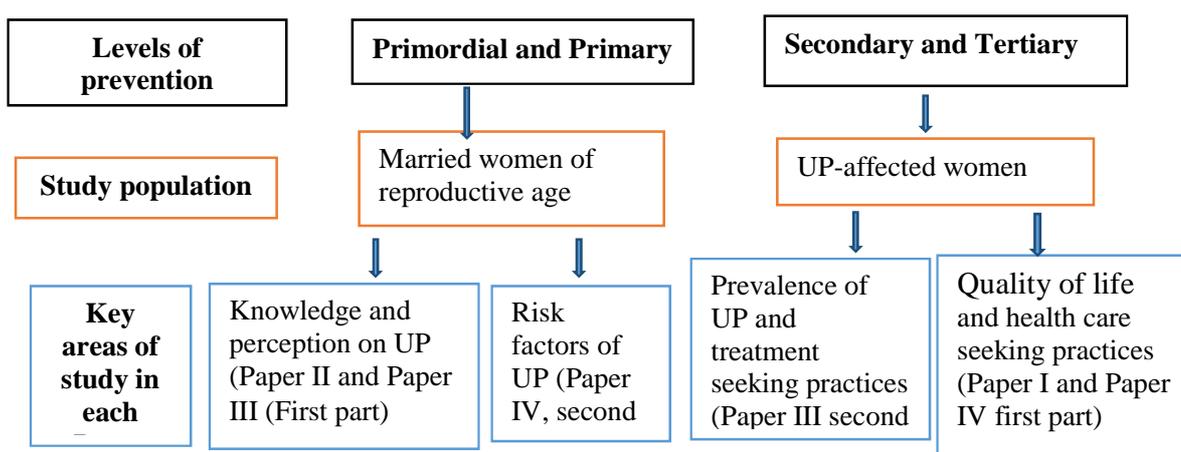


Figure 2: Conceptual framework of the Thesis and Papers

METHODOLOGICAL CONSIDERATIONS

Study design and setting

This Thesis considered mainly cross-sectional descriptive designs and applied both quantitative and qualitative methods for various processes in studies representing a rural district, a peri-urban site, and 25 districts of Nepal (Figure 3). Table 1 and Table 2 summarize the methodological considerations used for all four papers of this Thesis.

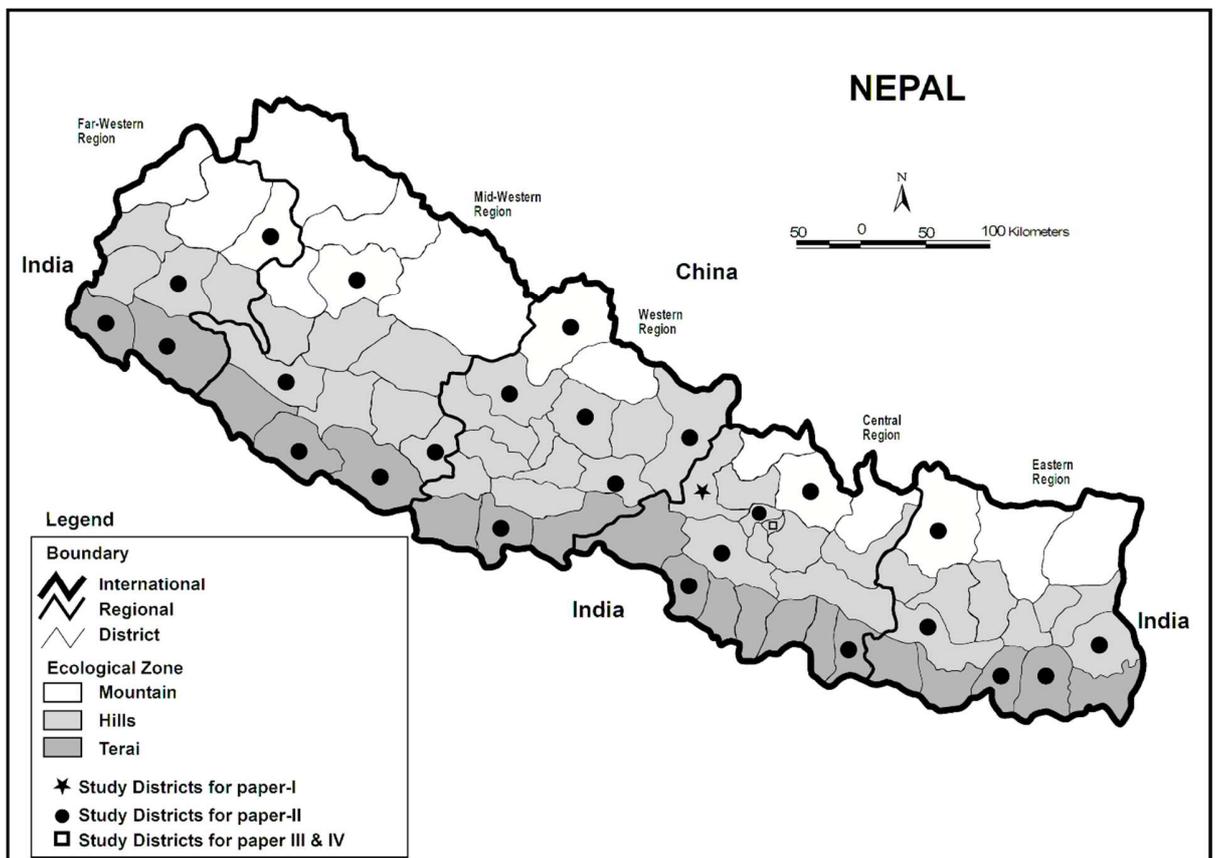


Figure 3: Map of Nepal showing study sites

Table 1: Summary of design, study sites, year of data collection, and tools.

Paper	Method	Study site	Data collection (year)	Tools
I	Quantitative and qualitative	1 rural hill district, including nine VDCs of Nepal	2012	IoM/UNFPA, 2006 [62]
II	Quantitative	25 districts of Nepal	2012	UNFPA/ GoN advocacy tool 2007 [54]
III	Quantitative	1 peri-urban site of Nepal (JD-HDSS)	2013	Knowledge assessment reliable tool ,Shah, 2008 [72]
IV	Quantitative	1 peri-urban site of Nepal (JD-HDSS)	2013	P-QOL (Digesu, 2005) [73]

IoM, Institute of Medicine; GoN, Government of Nepal; JD-HDSS, Jhaukhel-Duwakot Health Demographic Surveillance Site; UNFPA, United Nations Population Fund, VDC; village development committee.

Table 2: Sampling methods and study participants.

Paper	Sampling unit	Sampling method	Sample size and study participants
I	UP follow-up clinics (rural hill district)	Convenience	115 UP-affected women (semi structured interview)
		Purposive	16 in-depth interviews
II	Household (national)	Multistage stratified	4,693 married women of reproductive age
III	Household (peri-urban site)	All households of study site	3,125 married women of reproductive age and elderly
	Screening camp (peri-urban site)	Screening camp	303 UP screening camp attendees
IV	Screening camp (peri-urban site)	Purposive	48 UP screening camp attendees for QoL study
	Community based (peri-urban site)	Purposive (Tracing case and control group according to Phase I household survey records of Phase I and Phase II screening camp records)	402 UP-affected and unaffected-women for case control study

QoL, quality of life; UP, uterine prolapse.

Data was collected during 2012–2013 for all studies (Table 1). After pretesting in local context, I used standardized tools to assess UP knowledge, perception, and quality of life.

Study participants

Study participants included married women (reproductive age group) for knowledge assessment and UP-affected women both self-reported in household and diagnosed with UP during clinical examination at a screening camp or UP follow-up clinic. While selecting participants in the clinical setting, we excluded women diagnosed with cystocele or rectocele only as well as women without UP. Prior to interview in the UP screening camp and follow-up clinic, a gynecologist and trained medical officer diagnosed participants with first, second, or third stage UP in accord with scoring for the pelvic organ prolapse questionnaire [74]. Trained local female researchers with health background conducted all interviews during the household survey.

Data collection

Paper I

Mixed methods study designs used for research that combine elements of qualitative and quantitative approaches during data collection, process analysis, and reference techniques for the broad purpose of breadth and depth of understanding the phenomenon being explored and investigated [75]. This Thesis used a mixed method design. The quantitative research questions sought to identify the distribution of women's experiences and health care seeking practices among UP-affected women. Similarly, I used the qualitative method to explore issues that could not be explored from a quantitative perspective, such as women's experiences of UP and its impact on quality of life, expressions of emotional stress, perceived reasons for UP, and practical

issues regarding barriers to accessing health. The study was conducted during follow-up clinics for UP care after screening camps in nine rural hilly villages in the Dhading district of Nepal. We used convenience sampling to include participants diagnosed with UP at the follow-up outreach clinics. Random sampling included 115 UP-affected women for face-to-face interviews.

We collaborated with Nepal's Rural Health and Education Trust (RHEST) and the Women for Women Foundation in the Netherlands during data collection. I coordinated and obtained their support for data collection in UP screening camps organized in the Dhading district during December 2012. To me help plan the data collection process, both organizations provided records from previous UP screening camps. To facilitate data collection, both organizations supported my transportation, accommodations, and staff.

Paper II

Paper II included structured interviews with 4,693 married women of reproductive age (15–49 years) in 25 of the 75 districts in Nepal, representing all 5 administrative regions and 3 ecological zones (i.e., Terai, hill, and mountain) in both urban and rural settings. A map of Nepal contains dots denote the study districts (Figure 2). We assessed UP knowledge by asking participants whether they had ever heard about UP, followed by specific questions about symptoms and preventive measures. Descriptive statistics characterized the study population regarding socioeconomic status, assessed how many participants had ever heard about UP, and determined the UP knowledge level of participants who had heard about the condition.

Formulation of validation of questionnaire

We reviewed UP campaign materials [54] and formulated questions to assess participants' knowledge on UP symptoms (5 options) and preventive

measures (7 options). We validated tools by pretesting them in a similar community in Nepali language. We used 12 options as variables for both questions from the campaign material, which expected an increase in knowledge by the campaign program. Regarding the 12 variables (Paper II) and 12 statements (Paper III), we used separate sets of tools with different references, as discussed above. Details on the 12 variables used in Paper II describe them as questions that asked participants to assess UP knowledge and referred to national UP campaign material [54].

We asked women who had ever heard of UP, “*What are the symptoms?*” (Options 1–5) and received multiple responses including

- 1) Difficulty in lifting loads,
- 2) Experiencing lower abdominal pain,
- 3) Having a sagging uterus,
- 4) Feeling pain during sexual activity,
- 5) Difficulty controlling urine and to take preventive measures for UP.

Next, we asked “*What are the preventive measures for UP?*” (Options 6–12) and received multiple responses including

- 6) Not lifting heavy loads during the postnatal period,
- 7) Eating nutritious foods during pregnancy and post natal period,
- 8) Taking adequate rest during the post natal period,
- 9) Practicing family planning and birth spacing,
- 10) Avoiding early pregnancy,
- 11) Using institutional delivery,
- 12) Using safe abortion services.

We used ready-made UP campaign materials to assess knowledge of UP. One message for the prevention of UP (#7) was “*eating nutritious food*

during pregnancy and postnatal period.” This question possibly was included due to the prevalence (35%) of malnutrition among women of reproductive age in Nepal [36]. The UP campaign materials might have aimed to reduce malnutrition by promoting women’s health, especially during pregnancy and the postnatal period.

Paper III

Data was collected in Jhaukhel and Duwakot, two village development committees (VDCs) located in the mid-hills of the Bhaktapur district, 13 kilometers east of Kathmandu, the capital city of Nepal. Jhaukhel and Duwakot are in a peri-urban setting, connected by road and transportation facilities to Kathmandu and Bhaktapur cities. Hospitals and clinics are easily accessible. Paper III was a collaborative effort by the University of Gothenburg and the Nordic School of Public Health NHV, Sweden, and Kathmandu Medical College and Nepal Medical College, Nepal [76]. Our structured survey of 3,124 households in the Jhaukhel and Duwakot Health Demographic Surveillance Site (JD-HDSS) incorporated 60% of all women of reproductive age and assessed their knowledge of uterine prolapse.

Formulation and validation of questionnaire

We reviewed standardized statements to assess UP knowledge [72] and used all 12 statements (Table 3), adapting them to a local context before pretesting and making further adjustments as needed after testing. For clarity regarding the details of 12 variables in Paper III, both papers describe the statements as “a list of statements used exactly as state below to asses knowledge of UP” [72].

We read the statements, as outlined below, to women who had ever heard about UP and asked them to express their views, i.e., “agree,” “don’t agree” or “don’t know”.

1. Carrying heavy loads daily can increase the probability of uterine prolapse
2. Problem of uterine prolapse is more common among women who deliver many children
3. A symptom of uterine prolapse is the feeling of heaviness or pulling in the pelvis
4. The best measure to diagnose the problem of uterine prolapse is to go for a check up to a health worker
5. Women of any age can have the problem of uterine prolapse
6. Regular exercise can prevent the uterine prolapse from becoming worse
7. The best treatment of uterine prolapse is surgery or vaginal hysterectomy
8. The treatment of the symptoms of uterine prolapse can be done by using a ring pessary
9. Problem of pelvic organ prolapse (vaginal swelling, uterus, urine bladder or rectum prolapse) is found more in aged women than adult women
10. Doctors can identify the problem of uterine prolapse by blood testing
11. If the problem of uterine prolapse starts, it cannot be cured
12. An obese woman can have less chance of getting the problem of uterine prolapse

For our UP prevalence study, we used direct questions regarding availability of ever UP-affected women and their treatment seeking practices in each household after completing an interview for knowledge assessment. Next, we organized a 5-day clinical screening camp at JD-HDSS to identify the UP prevalence in attendees including, diagnosis and treatment received thus far.

Paper IV

We conducted structured interviews with women attending UP screening camps in Jhaukhel and Duwakot. We used a community-based case control study design to determine the contributing factors of UP. The study included three phases: a household survey to explore the prevalence of self-reported UP (Phase 1); a standardized tool in a 5-day screening camp, which explored quality of life among UP-affected women (Phase 2); and a 1-month community survey that traced self-reported cases from Phase 1 (Phase 3). To validate UP diagnoses, we reviewed participants' clinical records and used screening camp records to trace women without UP.

Data management and analysis

We used descriptive statistics to analyze quantitative data for all papers. Data were processed in SPSS version 17 (SPSS Inc., Chicago, Illinois, USA).

Paper I

For quantitative data analysis, variables regarding physical and emotional experiences of UP were categorized according to a study on experiences of genital prolapse [77]. For qualitative data analysis, we used a deductive approach to conduct content analysis of our in-depth interviews [78]. The in-

depth interview comprised 16 different stories with various issues. For qualitative data analysis, we used a deductive approach by sorting previously formulated categories. This process involved familiarizing ourselves with the material, identifying a thematic framework, indexing, charting, mapping, and interpretation [79]. After analyzing variables that required qualitative findings supplement and validate quantitative results, we formulated the categories.

Analysis Framework

Our content analysis considered only predetermined categories. Table 3 describes the frame of data analysis.

Table 3: Frame of quantitative and qualitative data analysis

Components of quantitative data		Components of qualitative data	
Variables for quantitative analysis		Main themes	Categories
(i)	Socioeconomic characteristics (i.e., age, education, occupation caste/ethnicity, and income);	1. Women's experiences due to UP	1.1. Physical discomfort 1.2. Sexual discomfort
(ii)	Reproductive characteristics of women and stages of UP;	2. Emotional stress	2.1. Spousal behavior after disclosure of UP 2.2. Domestic violence after disclosure of UP
(iii)	Decision making for health care;	3. Perceived cause of UP	3.1. Past experiences of work load in postnatal period 3.2. Past experiences of obstetric complications
(iv)	Experiences of physical discomfort;	4. Care-seeking practices for UP	4.1. Type of practices 4.2. Coping with the problem 4.3. Reasons for delay in seeking health care
(v)	UP-related sexual discomfort;		
(vi)	Review of records detailing UP-diagnosed cases.		
(vii)	Spousal behavior after disclosure of UP;		
(viii)	Experiences of domestic violence following disclosure of UP;		
(ix)	Self-perceived reasons for UP; and		
(x)	Health care seeking practices for UP.		

UP, uterine prolapse.

Since most of the results were described in quantitative tables, we used relevant data where required to support by women's experiences with emotions. Two case studies presented demonstrate the complete scope of women's experiences and emotions in relation to UP and their quality of life.

Paper II

Paper II used descriptive statistics to characterize the study population regarding socioeconomic status and to assess participants' knowledge level about UP. We performed univariate and multivariate logistic regressions to determine the association between ever heard about UP, satisfactory knowledge of UP, and background variables (e.g., urban rural setting, developmental region, ecological zone, caste/ethnic group, age group, and education level).

Paper III

Paper III used household data to assess knowledge of UP for 12 variables. As recommended, we classified the level of knowledge categories to assess knowledge of POP, scoring correct answers as "1" and "incorrect" or "don't know" answers as "0" [72]. Next, we calculated the proportion of ever heard answers and satisfactory level of UP. To identify prevalence and treatment seeking practices, we used information from the household data, analysing it separately and detailing the socioeconomic characteristics, UP prevalence (self-reported), and treatment practices. Self-reported UP prevalence was calculated using the total number of women who reported UP symptoms in the household survey. Clinically diagnosed UP prevalence was calculated using the total number of UP and POP diagnoses among women who attended the UP screening camp. Both calculations excluded women who had undergone surgical treatment for UP (i.e., hysterectomy).

Paper IV

To assess quality of life in nine domains for analysis, we developed a scoring system according to questions used (Table 4).

Table 4: Scoring system for quality of life assessment in uterine prolapse-affected women in the Jhaukhel-Duwakot Health Demographic Surveillance Site, Bhaktapur Nepal

Domains	Variables	Scoring system			
		"No effect"	"Some effect"	"Little effect"	"Bad effect"
General health perception	1. Perceived general health condition	0	0	1	1
	2. Effect of UP in daily life	0	0	1	1
	3. Lower back pain <ul style="list-style-type: none"> • Effect of back pain in daily life 	0	0	1	1
UP impact	5. Vaginal symptoms <ul style="list-style-type: none"> • Something coming out from vagina • Heavy thing putting in the lower abdomen or vagina • Uncomfortable during sitting • Something coming out from vagina during defecation 	0	0	1	1
	6. Urine symptoms <ul style="list-style-type: none"> • Continues urination • Urine drop after urination • Urine leakages • Urine leak during coughing • Difficulty in urination 	0	0	1	1
	7. Bowel symptoms <ul style="list-style-type: none"> • Constipation • Feeling on incomplete stool pass after defecation • Discomfort during defecation • Digitization on stool pass 	0	0	1	1
	8. Sexual symptoms <ul style="list-style-type: none"> • Something coming out during sexual intercourse • Effect of something coming out during sexual intercourse 	0	0	1	1

		Scoring system			
Role limitation	9. Effect on doing household work	0	0	1	1
	<ul style="list-style-type: none"> • Effect on doing outdoor work • Effect on doing physical work 				
Physical limitation	12. Effect on walking	0	0	1	1
	<ul style="list-style-type: none"> • Effect on sitting and sleeping • Effect on standing 				
Emotional stress	15. Loneliness	0	0	1	1
	<ul style="list-style-type: none"> • Sadness • Self-blame 				
Sleep energy	18. Bad dream	0	0	1	1
	<ul style="list-style-type: none"> • Tiredness 				
Social limitation	20. Effect on social work	0	0	1	1
	<ul style="list-style-type: none"> • Effect on meeting friend circles • Effect on family life 				
Personal relationship	23. Effect on spousal relation	0	0	1	1
	<ul style="list-style-type: none"> • Effect on sexual relationship 				
Severe measure	24. Need to use pad or other material	0	0	1	1
	<ul style="list-style-type: none"> • Pulling up uterus • More pain from uterus prolapse 				

UP, uterine prolapse.

We used descriptive statistics to describe participants' socioeconomic characteristics. To score quality of life, we characterized all answers to the questionnaire and the related probing questions as individual variables (Table 4). Additionally, we used descriptive statistics and analysis of variance (ANOVA) to determine all nine domains of total quality of life among three groups of women diagnosed with UP (stage I–III). Finally, we applied bivariate and multivariate logistic regression analysis to determine the factors associated with UP.

Validity, generalizability, and benefit

For the UP knowledge assessment study, we used national UP campaign materials to assess the national level UP knowledge. To assess UP knowledge in peri-urban sites, we adapted a standard tool to the local context after

pretesting the tools. We validated tools for all Papers by translating them back to English from Nepali and pre-tested them in a similar community in Nepali language. Interviews were conducted with UP-affected women after diagnosis by a qualified medical team in the clinical setting. Trained female researchers conducted all interviews in the community and in clinical settings. We modified flow and wording of questions after pre-testing the questionnaire. The entire process of data collection was closely supervised. I conducted and analyzed all in-depth interviews for qualitative data using an audio recorder.

Because this study was conducted in a specific sociocultural geography of Nepal, the results of Paper I might not reflect the condition of all women suffering from UP across the diverse socioeconomic strata. The results of Paper II can be generalized at the national level in Nepal. The findings of Paper III and Paper IV can be generalized in peri-urban sites of Nepal and in a similar context in other low-income countries.

In the context of women's lives, findings associated with women's health-related quality of life, care practices, and access issues might enable early identification and management of potential health risks that may remain into older age (Paper I and Paper IV). The results of Paper II can be considered as baseline data for future studies of UP knowledge assessment. Overall results of UP knowledge assessment could be useful for planning evidence-based UP prevention and care programs in various socioeconomic cultural settings.

Trustworthiness

To maintain the trustworthiness of both quantitative and qualitative studies, we applied various approaches during data collection, analysis, and reporting. For qualitative data collection, participants in the in-depth interviews included

only UP-diagnosed women immediately after clinical examination. We used open questions to explore experiences, emotions, and problems encountered during health care seeking practices. Demonstrating my confidence with qualitative methodology, I conducted all in-depth interviews, constantly checking and updated the interview guideline to cover any issues that emerged during each interview. Interviews with study participants were conducted only until saturation of the issues occurred. Regarding categorization and abstraction, categories reflected the results of quantitative findings, and issues were focused to elaborate and validate the quantitative results. I reviewed both qualitative and quantitative results carefully, interpreting them to describe, elaborate, and discuss the depth and breadth of information. Each table and all transcriptions were checked carefully to identify the representative issues, using a thematic framework analysis. To deepen the understanding and coherence of our findings, all results were presented and connected with quantitative data.

Methodological issues

We encountered various methodological issues during data collection. A clinical study does not provide a good representation of the general community. However, in this case the clinical setting helped validate the inclusion of UP-diagnosed participants. Managing a qualified medical team and enabling the clinical environment with necessary logistic supplies for diagnosis, treatment, and management of UP in an outreach camp is challenging and it entails a substantial amount of resources. All research activities were made possible due to available resources for PhD education and collaborative efforts with national and international partners who were working for UP prevention and management in Nepal. Time for in-depth

interviews (Paper I) was limited, but they were possible due to the support of two staff members who screened patients exiting clinical examination and referred them to me according to the inclusion criteria for study participants.

Assessing UP knowledge in the population-based study allowed interpersonal variation among interviewers as well as variation in participant's level of comfort to freely express their feelings about reproductive issues during their interview. In the Nepalese culture, women usually consider it highly shameful and degrading to talk about reproductive issues. Because we could only capture responses to framed questions, we might have missed including women's perception of the concept of UP, and the variance in social and cultural environment might have caused misunderstanding.

Compared to estimating the prevalence of morbidity, interviews provide a more accurate measurement of reproductive morbidity because they can explore useful information about disability or adverse effects of reproductive health and illness [80]. UP is a common reproductive health problem in Nepal [4]. However, community-based studies present many challenges because most women consider reproductive issues a personal matter that burdens them with social stigma and cultural norms [3]. Various studies report UP prevalence in Nepal at 20%–37% [4, 20-22]. UP prevalence is calculated among women diagnosed with UP out of the total women with reproductive morbidity in the screening camp. Paper III identified UP prevalence at only 2.11%. We calculated UP prevalence among the self-reported UP during household survey and also among women of reproductive age and the elderly population. Our different results could be due to a difference in methodology.

We considered self-reported UP prevalence because an earlier study from Nepal reported that clinical examination confirmed UP in 207 of 216

self-reporting women, indicating a high degree of correlation between self-reported and clinically diagnosed cases [4]. Self-reported UP prevalence was based on face-to-face interviews. A systematic review confirmed that an interview-based survey provides valid information for estimating the prevalence of reproductive morbidity [80].

Ethical considerations

UP is still a taboo topic in Nepalese society. Because women fear that others will know their problems, they may be reluctant to share personal information. Women also may fear the consequences of sharing personal experiences and exposing themselves to potential harm by their spouse and other family members. To address these ethical dilemmas, we ensured the autonomy of all participants to respond to each question; we also discussed and ensured both anonymity and confidentiality prior to each interview. Further, the study participants directly benefitted from the UP screening camp and its medical and counseling services. The overall benefits to participants include the development of evidence-based policies and strategies for UP prevention health care programs. This study was granted ethical approval by the Nepal Health Research Council (Reg. no. 56/2012). In response to a written request letter, I also received verbal consent from local community stakeholders and health workers.

We explained the importance of the study to each participant and conducted interviews only after obtaining informed consent. We also discussed and ensured respondents' autonomy and confidentiality prior to each interview. We received special permission to record voices during in-depth interviews. We ensured the participants about privacy and confidentiality regarding their information and identification.

RESULTS

This section presents the key results of the Thesis, based on the individual Papers. Description of participants' socioeconomic characteristics, key results according to the research objective, and statistical analysis are described in percentages and association with risk factors are described using suitable statistical tools, where appropriate. The symbol “±” denotes standard deviation after the value of specific findings in all papers. In Paper IV, odds ratios are presented as 95% confidence interval (CI) while computing the associated factors of knowledge of uterine prolapse (UP) (Paper II) and associated factors of UP in Paper IV. Key findings for each Paper are described as follows.

Paper I: Women’s experiences and health care-seeking practices in relation to uterine prolapse in a hill district of Nepal

Socioeconomic and reproductive characteristics of participants

A total of 115 UP-affected women were from 10 rural VDCs in Nepal’s Dhading district. Most women (67%) belonged to an advantaged ethnic group (i.e., Brahmin, Chhetri, or Newar). Participants’ ages ranged from 23 to 82 years (mean age 54 ± 15 years), 82% were married and currently living with spouse, 11% were widows, and 6% were separated. Eighty-four percent of women’s main occupations were farming or household chores. The average number of pregnancies per woman was nine, and 47% (N=107) had experienced pregnancy during her teen-age years.

Physical discomfort

Among the total UP-diagnosed participants (N=15), 11% were stage I, 60% were stage II, and 25% were stage III. Three percent of participants had vault

prolapse. Participants experienced multiple physical discomforts and emotional stress due to UP, and physical discomforts were often accompanied by vaginal symptoms. Most (>85%) participants described a bulging sensation and heaviness in their vagina due to UP. Affected women also reported difficulty walking, sitting, and doing manual work. Sixty-eight percent of participants said they suffered from urinary incontinence. During in-depth interviews, some women reported suffering from urinary incontinence for long durations, resulting in severely impaired quality of life that led to other reproductive health problems. A 55-year-old said: *“I was suffering from dripping urine with foul smell for 16 years with occasional vaginal bleeding.”* Forty-two percent of participants reported suffering from various types of bowel symptoms and 71% had multiple symptoms, including the need to manually reduce and hold the uterus during defecation, constipation and painful defecation, and fecal leakage. During an in-depth interview, a 68-year-old woman said: *“I had difficulty on defecation; the pessary will come out while defecating so I need to hold the pessary and I am frequently suffering from diarrhea and constipation but have not done health check up till now.”*

Sexual discomfort

Most participants (74%) mentioned that they had discontinued sexual activities due to (i) lack of sexual desire due to old age (36%); (ii) pain and difficulties during sexual intercourse (7%); (iii) conflict and separation from spouse (13%); and (iv) multiple other reasons, including conflict with spouse and fear of spousal awareness of UP (29%). The remaining UP-affected participants (26%) said they had periodic sexual relationships with their spouse. Among those, one fourth experienced painful sexual intercourse. During an in-depth interview, one 50-year-old participant said: *“I don’t have any sexual desire it is painful but I must fulfill my husband’s desire, can’t get*

any support from my husband. I am forced to tolerate the painful sexual relation....”

Spousal behavior after disclosure of uterine prolapse

Most (60%) spouses of women who had disclosed UP were not bothered by the diagnosis. Twenty-three percent of spouses were caring and supportive, but 16% harassed their wives by threatening to remarry or separate. Twenty-four percent of spouses remarried after their wives disclosed a UP diagnosis.

Domestic violence after disclosure of uterine prolapse

About 50% of participants did not wish to respond to questions relating to violence. Among those who did respond, 30.4% reported that they had experienced domestic violence (psychological) after disclosing UP to their spouse. Additionally, in-laws humiliated and harassed them because they could not perform the expected level of household work. Participants also reported that they had experienced violence, including physical assault and verbal abuse, specific threat of remarriage, and food deprivation. During an in-depth interview, one 55-year-old woman said: *“Before operation I was facing various problems from my family. My sister-in-law used to scold me and insulted me by using abusing words because I was incapable to do household chores. I was excluded in many social functions because I could not maintain hygiene. Many times my sister-in-law scolded me by saying “leave home”; I was about to leave home but the neighbor rescued me. Now after operation, I am also harassed by my husband and sister-in-law because my working capacity is still not restored.”*

Box 1 highlights a case study on UP-affected woman’s experiences regarding quality of life after hysterectomy.

Box 1: Recurrent post-hysterectomy prolapse and impact on quality of life

Kanchi Shrestha (name changed), a 55-year-old resident of a village in Nepal's Dhading district, is an illiterate farmer. She suffered from uterine prolapse for 16 years. Last year, she had a hysterectomy, but still has difficulty walking, sitting, performing daily household chores, and farming. Before the hysterectomy, she faced humiliation and harassment by her husband and family members because she could not perform daily household work. Her husband shouted at her because she could not manage her personal organ. Surgical treatment resolved her personal hygiene problems, but she still has continuous pain in her lower abdomen and a small piece of her uterus protrudes from her vagina. She shared this problem with her husband and family members, but no one helps her. All family members scolded her, saying that “*after treatment you should work, it should be fine, and you are just pretending to escape from work.*” On many occasions, her husband and family members asked her to leave the house. Somehow, her neighbors protect her from her family members. Her family life is very uncertain.

Women's perception of reasons for uterine prolapse

Self-perceived reasons for UP included repeated pregnancies and childbirth (40%), lack of rest during the postnatal period (31.3%), and heavy lifting in daily housework (18%). Among affected women, 77% resumed household chores within 6–20 days of delivery, 13% resumed work within 1–5 days, and 8% began working again within 21–30 days. During in-depth interviews, participants mentioned that they did not have any opportunity to rest because tradition requires the daughter-in-law to do all household chores. Daily chores included carrying water, caring for cattle, cleaning, washing clothes, cooking, and doing agricultural work. Similarly, 37% of participants had experienced obstetric complications (e.g., postpartum hemorrhage and obstetric labor that lasted more than two days). About 19% of participants faced both types of obstetric complications. Almost all participants of in-depth interview said that they delivered children at home. Some were referred to a health facility or called a health worker if they encountered complications. Most had faced

multiple obstetric complications, including prolonged labor (> 5 days) or heavy bleeding with or without retained placenta.

Health care seeking practices

Mean age at first perception of UP was 34±10 years and mean duration of suffering from UP was 23±15 years. Among study participants, 23% immediately communicated their UP problem to their relatives or health workers. However, 35% hid their UP problem for more than 10 years. Prior to visiting the outreach clinics, participants had not visited health facilities for various reasons, including shame (48%); feeling unnecessary (12%); and multiple responses (29%) including shame, having no one to share the problem with, male service provider, fear of stigma and gender bias, and a perception that UP is normal for childbearing women. Forty-eight percent coped with UP by manually reducing the uterus, 9% consulted local health workers, and 42.5% used multiple practices such as Bethi (an herb that resembles a green vegetable) and eating nutritious food (e.g., meat, eggs, milk, fruits). After intervention at an outreach clinic, participants began using health services as instructed by experts. Among 115 women, 62% used a pessary, 13% had surgical treatment, and 20% used pelvic exercise and herbal medication. During in-depth interviews, participants further explained their reasons for using services in follow-up outreach clinics and health facilities. The most pertinent symptom that causes women to seek health care was urinary incontinence. One 40-year-old woman reported: *“I am using pessary since 4 years. The doctor recommended surgical treatment, there is free treatment. However, I have to manage travel and other additional costs for patient visit and food. I cannot afford these additional costs. My son is not taking care of me; maybe God will take care of me....”*

Box 2 highlights a case study on UP-affected woman's experiences during pre- and post-hysterectomy.

Box 2: Pre- and post-hysterectomy experiences of women with uterine prolapse

Sunita Shrama (name changed), a 49-year-old woman from a village in Nepal's Dhading district, was living with her second husband and four other family members and earning money by doing daily labor. Sunita had completed seven pregnancies. She first noticed uterine prolapse (UP) problems during her second pregnancy and recalled that she had lived with UP for 26 years. She experienced complicated labors (2 days) and all her deliveries were conducted at home by an unskilled birth attendant. She almost died after each delivery because she could not get proper rest and food during the postnatal period.

Past experience with uterine prolapse (before hysterectomy): Sunita had difficulty walking, sitting, and standing. While walking, she had to use her fingers to reduce her prolapsed uterus manually. She had to hold a pessary while defecating and could not sit for urination; most of the time she passed urine in a standing position. Her husband never showed concern about her problem during sexual relations, and she had to surrender to painful intercourse. She continuously experienced problems with abdominal pain. Her husband did not support her health care.

Treatment received: Sunita used a red rubber pessary for 17 years, but she never told family members. Last year, she received a clinical checkup at an outreach camp organized in her village. When she recently received surgical treatment for UP in Kathmandu, the Government paid for her treatments. She borrowed NRs. 10,000 loan to pay for the cost of travel and other logistics. After recovering from surgery, she was satisfied with the treatment. However, she still worries about repaying the loan.

Paper II: Knowledge on uterine prolapse among married women of reproductive age in Nepal

Socioeconomic characteristics of study participants

This study included 4,693 married women in the reproductive age group. Nearly four of every five (78.6%) respondents lived in rural communities; among these, 50.7% lived in the Hill zone. The mean age of participants was 30.0±7.4 years. More than two thirds (67.5%) were educated (26.5% at the

primary level, 51.7% at the secondary level, and 19.2% at the higher secondary level). Forty-eight percent of participants were from the advantaged group (Brahmin and Chhetri) and 22.2% were Janajati from the Hill and Terai zones. Regarding income source, 41.6% worked in agriculture, 23.4% worked in service, 17.6% were employed with wage labor, and 17.5% had foreign jobs.

Knowledge of uterine prolapse

More than half (52.9%) of the participants responded that they had not heard about UP. Moreover, knowledge regarding symptoms and preventive measures of UP varied among the 2,212 participants who had heard about UP. We used 12 variables of UP knowledge assessment questions (both symptoms and preventive measures). The proportion of knowledge varied in four categories grouped according to the 12 variables. Among them, 26.8% had highest knowledge (4–6 types of variables) and 3.8% had lowest knowledge (10 types of variables). The mean score of the 12 variables was 5.3 ± 2.55 (CI, 5.2–5.4). Among the women who had ever heard of UP, 37.5% had a satisfactory level of knowledge (equal to and above average knowledge).

Channel/source used by women and knowledge level

Women accessed information regarding UP from multiple sources/channels, including radio (53.4%), television (47.2%), female community health volunteers (36.2%), friends/relatives (47.2.0%), health workers (19.5%), and newspapers.

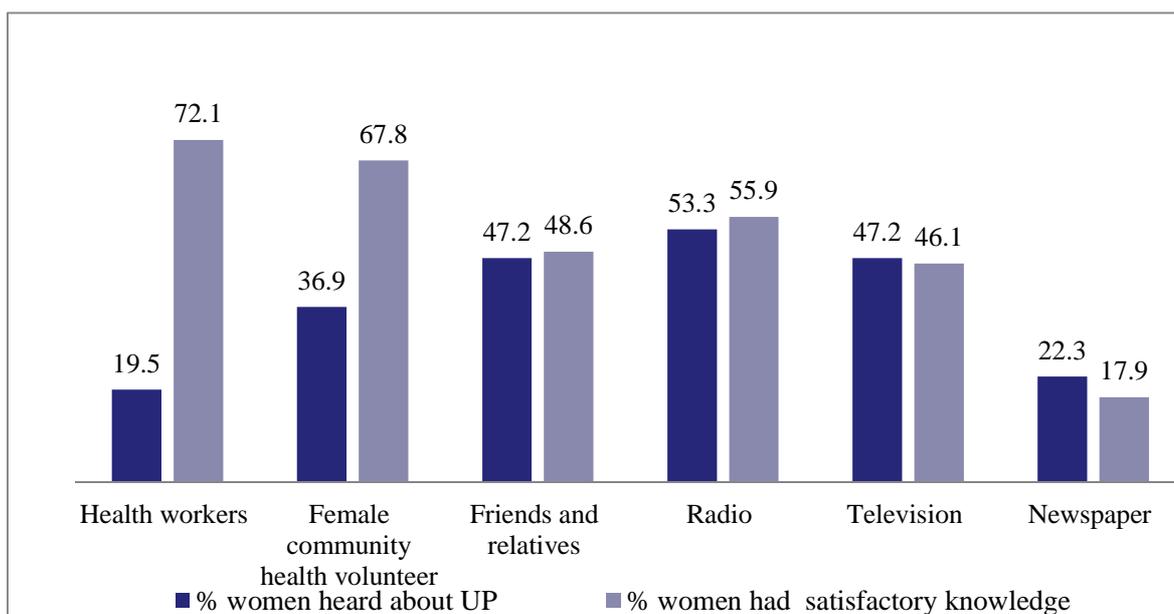


Figure 3: *Distribution of channels used to receive information and level of knowledge on uterine prolapse among the participants*

(22.3%) (Figure 3). The women provided multiple answers regarding the channel/source they used to access information about UP.

“Ever heard about uterine prolapse” and socioeconomic background

We observed differences in association between ever heard of UP participants and other groups (i.e., rural/urban setting, caste/ethnicity, age and education level). Compared to Brahmin and Chhetri women, we found no significant associations between ever heard of UP and other caste/ethnic groups.

Knowledge about uterine prolapse and socioeconomic background

Women residing in the Eastern, Central, Western, and Mid-western developmental regions had higher knowledge of UP than those in the Far-western Region. Indeed, women from the eastern region were 6.7 times more likely to have satisfactory knowledge compared to women from the far-western region. Furthermore, knowledge of UP associated significantly with ecological zone. Table 5 shows the odds ratio in bivariate and multivariate logistic regression.

Table 5: Association of knowledge of uterine prolapse with various socioeconomic factors (N=2,212)

Variables	Satisfactory knowledge of UP (%)	Bivariate odds ratio (CI)	Multivariate odds ratio (CI)
Developmental region			
Far-western	17.6	1	
Eastern	57.0	6.2 (4.5-8.5)	6.7 (4.7-9.4)
Central	45.9	3.9 (2.8-5.4)	5.6 (3.9-8.0)
Western	28.9	1.9 (1.3-2.6)	2.4 (1.6-3.4)
Mid-western	36.3	2.6 (1.9-3.7)	4.6 (3.1-6.6)
Ecological zone			
Mountain	25.5	1	--
Hill	34.7	1.5 (1.2-2.0)	1.4 (1.0-1.8)
Terai	50.7	3.0 (2.2-3.9)	2.9 (2.0-4.1)
Caste/ethnic group			
Brahmin, Chhetri/advantaged	38.2	1	--
Dalit/marginalized group Hill and Terai	20.9	0.4 (0.3-0.6)	0.4 (0.2-0.5)
Janajati/disadvantaged from Hill and Terai	41.0	1.1 (0.9-1.4)	0.6 (0.4-0.7)
Caste/non-Dalit from Terai	52.0	1.7 (1.2-2.5)	0.9 (0.6-1.4)
Muslim/religious minority	15.4	0.2 (0.0-1.3)	0.1 (0.0-0.5)
Newar,Thakali/relatively advantaged	34.1	0.8 (0.6-1.1)	0.6 (0.5-0.9)
Age group (years)			
< 20	31.6	1	
20–35	38.8	0.7 (0.6-0.8)	0.4 (0.2-0.8)
> 35	53.3	0.5 (0.4-0.8)	0.3 (0.1-0.6)

Note: Satisfactory level of knowledge of UP = equal to or above the equal mean of the variables

CI, confidence interval; UP, uterine prolapse

Paper III: Knowledge, prevalence and treatment practices of uterine prolapse among women of reproductive age in the Jhaukhel- Duwakot Health Demographic Surveillance Site, Bhaktapur, Nepal

Socioeconomic characteristics

A total of 3,124 women (60% of all women of reproductive age in the JD-HDSS) participated in the household survey, 60% from Duwakot and 40% from Jhaukhel. The dominant ethnic group in Jhaukhel was Newar (42.5%), compared with Brahmin/Chhetri (43.1%) in Duwakot. Each woman had 2.3 ± 1.3 children. Most women (39.3%) belonged to the 20- to 30-year age group, followed by the 31- to 40-year age group (36.6%). The mean age of the women and their spouses was 31.9 ± 8.2 years and 37.1 ± 8.4 years, respectively.

Knowledge of uterine prolapse

Most (93%) respondents had heard of UP, and 92.15% understood that carrying heavy loads can increase the probability of UP. Similarly, 84%–88.7% of participants had knowledge regarding risk factors (delivering many children), symptoms (heaviness/bulging sensation), and appropriate method of diagnosis of UP (health checkup). Perceived treatment options for UP varied from 49% to 59.5%, including regular exercise (56.4%), vaginal hysterectomy (59.5%), and ring pessary (49.7%). Regarding diagnostic method, 31% of women perceived that a blood test is one method of UP diagnosis, 23.15% perceived that UP is incurable, and 13.8% did not know that obesity is a risk factor for UP (Table 6).

Table 6: Distribution of statements used to assess knowledge of uterine prolapse among women of reproductive age in the Jhaukhel-Duwakot Health Demographic Surveillance Site (N=3,124): multiple responses.

Statements (multiple response)	Knowledge (%)
1. Carrying heavy loads daily can increase the probability of uterine prolapse	92.1
2. Problem of uterine prolapse is more common among women who deliver many children	88.7
3. A symptom of uterine prolapse is the feeling of heaviness or pulling in the pelvis	84.5
4. A best measure to diagnose the problem of uterine prolapse is to go for the check up from health worker	84.4
5. Women of any age can have the problem of uterine prolapse	64.2
6. Regular exercise can control/stop the uterine prolapse to becoming worse	56.4
7. The best treatment of uterine prolapse is surgery or vaginal hysterectomy	59.5
8. The treatment of the symptoms of uterine prolapse can be done by using a ring pessary	49.7
9. Problem of pelvic organ prolapse (vaginal swelling, uterus, urine bladder or rectum prolapse) is found more in old aged women than adult women	41.8
10. Doctors can identify the problem of uterine prolapse by blood testing	30.9
11. If the problem of uterine prolapse starts once, it cannot be cured	23.1
12. An obese woman can have less chance of getting the problem of uterine prolapse	13.8

Prevalence of uterine prolapse and treatment seeking practices

Based on self-reported data from 3,124 women who participated in the household survey, UP prevalence was 2.1% (8.5% when including women who had undergone hysterectomy for UP). Among them, 46% reported receiving UP treatment from hospitals in Bhaktapur and Kathmandu, including surgery (53%), exercise and medicine (35%), and pessary (11%). Among women who attended the UP screening camp (N=303), the prevalence

of clinically diagnosed UP was 15.1% (23.1% when including women who had undergone hysterectomy for UP). In this group, 59% exhibited POP (i.e., UP with cystocele and rectocele), 25% had UP, and 5% had vault prolapse. Regarding treatment practices for UP, 84% (N=70) received treatment from hospitals in Bhaktapur and Kathmandu, including surgery (34%) and pessary (37%), compared with 28% who used exercise (physical and Kegal) and medicine (for pain and infection only) [54].

Paper IV: Uterine prolapse and its impact on quality of life in the Jhaukhel-Duwakot Health Demographic Surveillance Site, Bhaktapur, Nepal

Socioeconomic characteristics of participants

Phase 1: Participant characteristics of the household survey

During the household survey, 267 (8.8%) women reported UP problems from 3,124 households in Duwakot and Jhaukhel (62.5% and 37.8%, respectively) (self-reported UP prevalence, treated and untreated). Mean age of participants was 45 ± 13.1 years. Caste/ethnic groups included Brahmin/Chhetri (64.4%), Newar (25.5%), Janajati (5.6%), and Dalit (4.5%).

Phase 2: Participant characteristics at the screening camp

Among camp attendees (N=70 with UP diagnosis), 48 women participated in Phase 2. Among interviewees, 73.9% were from Jhaukhel and 26.1% from Duwakot. Most participants were Newar (39.1%), followed by Chhetri (34.8%), Brahmin (21.7%), and Dalit (4.3%). Mean age was 50.1 ± 10.9 years and mean age at marriage was 18.0 ± 1.9 years. Major occupations included business and service (34.8%) and agriculture (17.4%). The mean duration of UP suffering was 4.63 ± 5.5 years.

Phase 3: Participants characteristics of case control study

In Phase 3, 402 women participated in a case control study. Among these, 277 women were UP-affected (cases), including 267 identified during Phase 1 and 10 detected during Phase 3). Among all participants, 48% were from Duwakot and 52% from Jhaukhel. The dominant ethnic group in Jhaukhel was Newar (42%), compared with Chhetri (34%) in Duwakot. Mean age was 43.7 ± 14 years and mean age at marriage was 17.7 ± 3.1 years. Regarding educational background, 47.8% were illiterate. Men were the decision makers in most families (72.9%). Most participants (53.4%) lived in extended families. The most common occupations were service (44.5%) and agriculture (23.6%). The mean duration of UP suffering was 9.6 ± 10.5 years.

Stages of uterine prolapse and total score of quality of life

Among 48 interviewees, two thirds had stage II UP and one third had stage I or stage II UP (Table 7). In Table 7, column II, N (%) indicates the distribution of the number and percentage of participants according to diagnosis of stages I, II, and III. In column III, N (%) shows the distribution of total score for quality of life in the scoring system for nine domains of analysis (Table 8).

Table 7: *Distribution of stages of uterine prolapse and scores of quality of life perceived by screening camp attendees in the Jhaukhel-Duwakot Health Demographic Surveillance Site, Bhaktapur Nepal (Phase 2).*

Stage of prolapse	Participants N (%)	Quality of life scores N (%)
Stage I	8 (16.7)	20 (4.62)
Stage II	32 (66.7)	139 (32.17)
Stage III	8 (16.7)	72 (100)
All stages	48 (100)	231 (53.48)

Women with Stage III UP scored highest (100%) (i.e., worse effect on quality of life) and women with Stage I UP scored lowest (4.62%) (i.e., lowest effect on quality of life).

Correlation with stage of uterine prolapse and quality of life

Table 8 presents the score values in each domain of analysis for quality of life (variables) out of the total number (N) of participants with stage I, II, or III UP. The different domains of quality of life according to scoring system (Matrix 3), including physical or social limitation and severe symptoms (i.e., severe pain and pulling of the uterus and the need for a pad or other supportive material), correlated significantly with all three stages. Thus, women with stage III UP perceived a worse effect on quality of life due to physical limitation, social limitation, and severe symptoms. However, general health perceptions, UP impact, emotional stress, sleep energy, and personal relationships did not correlate with disease stage. Therefore, any UP-affected woman perceives problems regarding general health, UP-related symptoms, emotional stress, sleep energy, and personal relationships.

Table 8: Association between stages of uterine prolapse and effects on quality of life as perceived by screening camp attendees in the Jhaukhel-Duwakot Health Demographic Surveillance Site, Bhaktapur, Nepal (Phase 2).

Domains of quality of life	Association* between effects on quality of life in three different stages of uterine prolapse (N=48)			
	Stage I (N=8)	Stage II (N=32)	Stage III (N=8)	p
1. General health perception	5	28	8	0.09
2. Impact	4	27	8	0.026
3. Role limitation	0	18	8	0.000
4. Physical limitation	0	8	8	0.000

Domains of quality of life	Association* between effects on quality of life in three different stages of uterine prolapse (N=48)			
	Stage I (N=8)	Stage II (N=32)	Stage III (N=8)	p
5. Emotional stress	5	24	8	0.190
6. Sleep energy	2	15	8	0.005
7. Social limitation	0	6	8	0.000
8. Personal relationship	4	11	8	0.003
9. Severe measure	0	2	8	0.000

* ANOVA: one-way analysis of variance

Association between uterine prolapse and socioeconomic characteristics

Table 9 describes UP-associated factors associated among women with different socioeconomic characteristics. Bivariate and multivariate logistic regression analysis showed that UP associates with education level, parity, and family type. The odds of having UP were threefold higher among illiterate women (OR=3.02 CI, 1.76–5.17). Similarly, women from nuclear families were 50% less likely to have UP compared with women from extended families (OR=0.56 CI, 0.35–0.90), and the odds were lower among women with 3–4 parity compared to > 5 parity (OR=0.33 CI, 0.14–0.75). However, subsequent multivariate analysis showed no significant association with UP for age at first pregnancy, gender of decision maker in the family, or caste/ethnic group.

Table 9: Associated factors of uterine prolapse among 402 study participants in the Jhaukhel-Duwakot Health Demographic Surveillance Site, Bhaktapur, Nepal (Phase 3).

Variables	Bivariate		Multivariate	
	Odds ratio	CI odds ratio	Odds ratio	CI odds ratio
Education				
Literate and educated	1		1	
Illiterate	3.7	2.3–5.9	3.0	1.7–5.1
Dalit and non-Dalit groups				
Dalit (disadvantaged)	1		1	
Non-Dalit (advantaged)	0.1	0.0–1.1	0.1	0.0–1.1
Family type				
Extended	1		1	
Nuclear	0.4	0.2–0.6	0.5	0.3–0.9
Decision maker in family				
Male	1		1	
Female	1.0	0.6–1.7	0.8	0.5–1.4
Age at first pregnancy (years)				
> 20	1		1	
15–19	1.5	1.0–2.4	1.4	0.8–2.4
Parity (number)				
> 5	1		1	
3–4	0.2	0.1–0.4	0.3	0.1–0.7
1–2	0.2	0.1–0.5	0.4	0.1–0.9

CI, confidence interval

DISCUSSION

This Thesis contributes to the exploration of possible factors of UP prevention and health care seeking practices. Paper I investigated women’s experiences resulting from UP, their perception of the causes of UP, and health care seeking behavior in a rural setting of Nepal. This is the first time that a national study has assessed the women’s UP knowledge level alongside its associated factors (Paper II) and compared with a peri-urban site (Paper III). Similarly, Paper III is the first study to identify self-reported UP prevalence, knowledge level, and perception (i.e., symptoms, preventive measures, and management options) in a population-based study in JD-HDSS. Finally, Paper IV assessed the impact of UP on the quality of life of affected women and identified the causes of UP in a peri-urban setting of Nepal.

Approaches to assess knowledge and operational definition of uterine prolapse

The scientific literature uses uterine prolapse, genital prolapse, vaginal prolapse, and pelvic organ prolapse synonymously due to similar symptoms and preventive strategies [5]. To establish reliability for women’s level of UP knowledge, we used an assessment tool standardly used in population-based studies [72]. While assessing knowledge of UP, researchers may encounter some variation in the proper understanding of the term UP in the local context. To avoid this ambiguity, we used two similar Nepali terms—“*Patheghar khasne*” (UP) and “*Ang khasne*” (POP)—that address knowledge items with a wide range of topics directly related to extracting information about early symptoms and prevention of UP, as described in the national campaign toolkit that was developed for Nepal in the Nepali language [54]. For knowledge assessment, we used the term UP because women generally perceive that they

are affected by UP even when they are affected by POP. However, clinical management may use different approaches to UP and POP, based on clinical diagnosis [81]. Therefore, we developed an operational definition of UP to include only those women who were diagnosed as having UP with or without cystocele and rectocele.

Knowledge and perception of uterine prolapse

Paper III determined a 37% prevalence of comprehensive knowledge of UP in the national level study and 55% in a peri-urban setting of Nepal. Knowledge UP linked with geography (both ecological and administrative region), education, and caste/ethnic group (Paper II), possibly due to women's high level of awareness (93%) of UP (Paper III). Moreover, the peri-urban study site has easy access to primary health care services and referral hospitals [76]. Our study confirmed an overlapping understanding (59.3%) of women's self-perception and clinical diagnosis of UP and POP, and we determined UP prevalence in only 25.6% of camp attendees (Paper III). Like most women in Nepal, our participants most commonly perceived reason for UP was household chores conducted even during pregnancy and the postnatal period. This could be due to their experience with obstetric complications, risky home delivery practices, and postnatal workload during previous deliveries (Paper I). Women from Bangladesh also perceived that household chores or sexual intercourse shortly after childbirth may cause UP [82].

Prevalence of uterine prolapse

UP prevalence was 2.11% in our population-based study in a peri-urban site of Nepal (Paper III), compared to 7% in the national survey [19]. This could be due to the availability of health services and transport facilities and better

socioeconomic status of the women in our study site [76]. Paper III also identified a 15.18% UP prevalence among all screening camp attendees, which is within the range of national UP prevalence (20—37%) [4, 20-22].

Possible risk factors of uterine prolapse

Biological

Paper IV established that parity associates with UP. Indeed, multiparity is a determining factor of UP [83, 84]. UP also associates significantly with joint hypermobility [85]. Chronically increasing pressure on the pelvic organs (i.e., uterus, bladder, and rectum) is a determining factor of UP [84].

Social

Paper IV also determined a link between education status and UP. An increased level of education associates directly with the use of contraceptives, indicating an indirect relationship between parity and empowerment [36]. Compared to nuclear families, the structure of extended families could be a risk factor for UP due largely to women's greater workload (Paper IV) and possibly due to the heavy daily workload (Paper I). Key risk factors for UP in Nepal include extensive physical work, both during pregnancy and immediately after delivery, and unsafe delivery care by unskilled birth attendants [52].

Amnesty International reported that UP is prevalent in low-income countries like Nepal due to gender bias and poor access to health care [86]. Other studies have suggested that UP results from carrying heavy loads on a daily basis, which also links with gender roles and the culture of wearing a *patuka*—a cloth worn to tighten the abdominal musculature—which also increases pressure on the pelvic organs [4, 22].

Challenges for prevention of uterine prolapse (primordial and primary)

The challenges for UP prevention are diverse due to differing access, sociocultures, media exposure, and policy barriers.

Sociocultural barriers for health communication

In Nepal's rural (Paper I) and urban settings (Paper II), even educated women do not disclose the existence of UP due to the traditional perception of shame, lack of family support, and gender-based violence (Paper I). Because women perceive maternal health care as personal, there is still a gap in the utilization of maternal health care services for antenatal care, childbirth, and postpartum follow-up [87, 88]. The Nepal Demography and Health Survey 2011 demonstrates that class, caste/ethnic group, and education significantly interrelate with health knowledge and reproductive healthcare seeking practices [89]. Awareness of reproductive health issues associate with age, education, occupation, place of residence, and economic status [55]. In Nepal, social norms prevent women from discussing reproductive health problems with other family members or elders, mostly due to embarrassment, stigma, and harassment by family members and/or spouse [3].

Knowledge gap and exposure to media

Paper II determined that health workers, friends/relatives, and female community health workers are most effective, as opposed to mass media (e.g., radio or television) (Figure 3). However, fewer women can access health information from health service providers and female community health workers. Thus, lessened exposure means that health providers and female community health workers are not providing health education during childbirth (Paper II). Media exposure and interpersonal communication with

public health intervention programs are useful approaches to increasing awareness of public health issues [90]. Most women do not know the symptoms of UP [91], and health professionals play a more significant role in providing information about UP-related symptoms and available health services than printed media (brochures and public media) [92]. Sustainable approaches to prevent UP in Nepal include clear, targeted strategies that integrates awareness of cultural risk factors with health and women's empowerment programs [93]. Our review of the government protocol for reproductive health [94]; the current national communication strategy for maternal, newborn, and child health [95]; and the national document for a minimum package of maternal and neonatal health care showed that all three [96] lack a specific strategy for counseling UP prevention.

Geography

Our rural participants perceived parity and unsafe delivery practices as risk factors for UP (Paper I). Multiparity and unsafe delivery associate with barriers to accessing services for family planning and maternal health care. Health care accessibility and availability associates with availability of transport facilities (e.g., road, bridges, and rural local means of transport) [97]. Difficult topography and lack of rural transport facilities create barriers to accessing health services in low-income countries [98]. In the rural hill and mountainous regions of Nepal, access barriers are relatively common due to physical distance, time needed to reach to a facility, the perception of distance, and lack of transport [99].

Gap between primary care of uterine prolapse and reproductive health services

In Nepal, most women access health services through UP screening camps; in rural areas, and they wait another camp for follow-up treatment. The most frequent reason women seek health care is urinary incontinence (Paper I). Delayed treatment indicates that there is no regular primary care for UP in rural health facilities. For early diagnosis of UP, all health workers should assess urinary symptoms (i.e., frequency, urgency, incontinence) among women who have had multiple childbirths [100]. This would be possible if health workers were trained and health services were accessible at the community level. Health workers should provide family planning and maternal health services, but most lack proper training for counseling and early detection of UP [86, 101].

Challenges for timely care of uterine prolapse (secondary and tertiary prevention)

The challenges related to timely (early) care of UP have been categorized as factors that affect health care seeking practices. These include personal factors (women's experiences and perceptions of impact of UP on quality of life, perception of UP and health care seeking practices due to gender inequality in decision making, low socioeconomic condition of women, lack of availability and accessibility to health services, and gaps in policy and programs.

Women's experiences and health care seeking behavior

Participants with stage I or stage II UP experienced many physical difficulties, resulting in extreme discomfort while sitting, white and bloody uterine secretions, infections on part of the prolapsed uterus, and pain during intercourse [82]. In rural Nepal, UP-affected women have low self-esteem,

which they described as anxiety, aggression, frustration, and despondency [3]. Moreover, spouses and other family members humiliate and harass women with UP (Paper I). Acute physical symptoms result in reduced desire for sexual intercourse as well as urinary incontinence, often restricting women's social lives, regardless of severity [77]. Various symptoms of UP influence women's quality of life. In Bangladesh, women perceive that the physical discomforts often interfere with their ability to do household chores, care for children, and satisfy their husband's sexual demands, leading to marital violence and desolation over time [82]. Our study participants also demonstrated shared experiences including physical discomforts and emotional stress that were often accompanied by vaginal and urinary symptoms (Paper I). Our quality of life assessment, which studied perceived variations in quality of life during UP stages I–III, demonstrates the importance of early diagnosis and care of UP. Compared to women with stage I and stage II UP, women with stage III had the lowest quality of life. (Paper IV). Despite such discomfort, participants continued to do their household chores and gradually developed more symptoms that eventually rendered them incapable of engaging in household chores (Paper I).

Socioeconomic status of women

In our study, most UP-affected women were of low socioeconomic status; 75% were illiterate and 56% worked in farming or unpaid jobs (Paper I). This substantial educational gap impacts women's employment and decision-making roles regarding their health. Lack of education and choice of occupation lower women's social and economic and increase dependence on spouses or other family members, contributing to a delay in seeking health care for UP treatment (Paper I). Only 27% of our participants exercised

autonomy for early-stage health care; most did not know about the availability of health services (Paper I). Compared to men, women generally delay reporting health problems, but this difference varies according to the nature of the problems [102]. Women's economic, educational, and empowerment status associates with health [103]. In Bangladesh, barriers to treatment seeking practices include lack of awareness about UP, low socioeconomic condition, and UP's association with a female sexual organ, which make women ashamed to share their condition [82]. In Nepal, women's socioeconomic condition precludes them from reporting health problems and taking necessary initiatives for health care [44, 86]. A study in India reports that only one third of women used health services; barriers to health services include caste/ethnic group (i.e., Scheduled Castes/Scheduled Tribes caste group), duration of illness, and distance to health facilities [104]. Another study in Bangladesh reported that socioeconomic indicators (e.g., education status, gender, and type of illness) are possible barriers to using health services [105].

Gender inequalities and cultural barriers

Our qualitative study showed that most UP-affected women were dependent on their families; men were the main decision makers in most families (Paper I, Paper II, and Paper III). Family members often suppressed and harassed our participants (Paper I). Experiences expressed from qualitative data analyses demonstrated that Nepal's patriarchal system expects women to conduct domestic chores, plant crops, collect fodder, and care for livestock. Other studies also reported that men are the decision makers in most Nepalese families in both rural and urban areas, and men often treat women as subordinates [44, 86]. Even educated women face challenges in seeking and

accessing health care due to fear of divorce, abandonment, or separation as well as the stigma surrounding genital issues [3, 106]. In a patriarchal system, men set the rules and make most of the decisions and women merely follow men in every sphere of life [107]. This patriarchal attitude and gender-biased value system promote harmful practices toward women and do not support women's reproductive health issues, including UP [86]. As a result, women may not be able to demand health care for UP [108]. In India, economic, gender bias and social status are barriers to accessing reproductive health services [109]. Most Indian women lack freedom to discuss these issues and the men are apathetic toward their wives' reproductive health issues [110]. Gender bias and age also play an important role in Bangladesh, interfering with household decision making for health care and treatment seeking behaviors [111].

Barriers to availability and accessibility of health services

Before visiting the UP screening camp, we found that rural Nepali women do not visit a health facility for UP treatment. Additionally, most women lacked UP knowledge, availability of medical care, and family support. Moreover, they had no money to pay for treatment. The presence of only male service providers in health institutions was an intimidating factor (Paper I). Even in peri-urban sites, 53% of women with UP symptoms did not seek health care despite exhibiting a high level of UP knowledge and having access to nearby hospitals (Paper III). The main barriers to care seeking for UP are lack of information and confirmation of UP symptoms. Clinical health care workers are responsible for counseling women who are vulnerable to UP [91]. Pelvic floor exercise and pessary insertion are primary care for UP to prevent hysterectomy with proper follow-up [112]. However, hysterectomy is

commonly used according to protocol developed for UP management in hospital and outreach camps [40]. Because any life-saving surgical procedure carries a risk of complications, the indication for surgery requires careful evaluation [113]. Hysterectomy can cause multiple changes in quality of life, especially for the reproductive age group, so surgery is not always a suitable approach. About 20% of women experience deteriorating sexual function [114]. All clinicians should counsel women with stage II UP, even when they lack symptoms. Such counseling will prevent unnecessary hysterectomies for the next 5–7 years [115].

The Government of Nepal conducts regular UP screening camps throughout the country. In September 2008–December 2011, approximately 34,000 women received surgical services for UP in outreach camps and hospitals [94]. Because surgical care is easier to measure and quicker to show results, external partners often donate funds for surgical care [40]. However, surgical care is not a mitigating measure for reducing UP cases. It is better to focus on preventive programs and early treatment and care of its symptoms. In contrast, there are various challenges in coordinating concerned development sectors (e.g., health and women’s development and education, including local health governance) to accomplish the desired outcomes of prevention programs with multi-sectorial approaches [116]. For comprehensive reproductive health services, the Government should invest proportionately, targeting both primordial and primary preventive health care of UP. This approach will benefit a far larger part of the population by addressing harmful cultural practices related to UP [86, 117].

CONCLUSION

After exploring specific issues related to UP, this Thesis adds new perspectives regarding prevention at primordial, primary, secondary, and tertiary levels. Our results clearly determined that UP is the product of various factors connected to a multi-sector development agenda. Women's empowerment programs, which seek to ensure gender equality and economic, educational, and political development, also link directly with Nepal's development program for women.

This Thesis confirms that UP is prevalent in rural and peri-urban sites of Nepal. The study of UP prevalence is a challenging task due to women's perception, which is largely influenced by cultural barriers and difficulties in organizing screening camps. This Thesis also deduces that women perceive POP and UP as the same problem. It also determined that parity associates with UP and that education and family structure are non-obstetric risk factors of UP.

Major challenges for prevention identified by this Thesis are knowledge gaps, coupled with geography; caste/ethnic group, and education level. The challenges for timely care of UP are lack of quality UP services, including lack of counseling and primary care (e.g., reproductive health care, lack of follow-up services by screening camps, and lack of referral services according to need of UP diagnosis). More importantly, other key barriers to prevention and timely care of UP include women's low social and economic status and gender inequalities.

FUTURE PERSPECTIVES

By exploring prevention and timely care of UP, this Thesis highlights the importance of specific target-based strategies and policy development for health promotion and UP prevention in communities and health facilities. Health promotional activities should target different subgroups of the population with appropriate strategies that consider issues like geography and caste/ethnic groups among both literate and illiterate populations. Future studies should explore women's empowerment, UP service utilization, and their effect on quality of life.

Assessing the quality of health care for the prevention and timely care of UP will require further studies on the availability and accessibility of primary (e.g., counseling on UP during reproductive and maternal health care) and secondary (e.g., counseling, pessary, and physical exercise) health care.

To aid understanding of the multifaceted issues related to UP, future research could undertake an ethnographic study to explore the sociocultural aspects and gender perspectives of community and men's perspectives. Such research would deepen understanding of the multifaceted issues related to UP.

Further interventional design studies would help identify appropriate strategies for health promotion and care of reproductive health problems. Finally, research that investigates the health system perspectives of service providers, policy analysis, policymakers, managers, and other concerned stakeholders could provide a more comprehensive picture of Nepal's current UP situation and suggest the most efficient levels for addressing the UP problem.

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