INTERNATIONAL UROGYNAECOLOGY CONSULTATION CHAPTER 1 COMMITTEE 4:

PATIENTS’ PERCEPTION OF DISEASE BURDEN OF PELVIC ORGAN PROLAPSE

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Word count: 13 160

Funding: None

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CONFLICTS OF INTEREST

DR: Research and Consultancy – Astellas, Allergan, Ferring, Ixaltis

LP: None

SC: None

MS: None

SL: None

JL: Hitachi Chemical
Abstract

Introduction and Hypothesis: This manuscript from Chapter 1 of the International Urogynecology Consultation (IUC) on Pelvic Organ Prolapse (POP) reports on the patient’s perception of disease burden associated with pelvic organ prolapse.
Materials and Methods: An international group containing a team of eight urogynaecologists, a physiotherapist and a statistician performed a search of the literature using pre-specified search terms in PubMed and Embase (January/2000 to August/2020). The division of sections within this report includes: 1) Perception of POP and the relationship with body image and poor health; 2) A vaginal bulge as it impacts health and well-being in women; 3) The impact of POP on Sexual life; 4) Body image and pelvic floor disorders; 5) POP and mood; 6) Appropriate use of treatment goals to better meet patients expected benefits; 7) Using health related quality of life questionnaires to quantify patient’s perception of POP; 8) The financial burden of POP to patients and society. Abstracts were reviewed and publications were eliminated if not relevant or did not include populations with POP or were not relevant to the subject areas as noted by the authors. The manuscripts were next reviewed for suitability using the Specialist Unit for Review Evidence (SURE) checklists for cohort, cross sectional and case-control epidemiologic studies.

Results: The original individual literature searches yielded 2312 references of which 190 were used in the final manuscript. The following perceptions were identified: 1) Women were found to have varying perceptions of POP including shame and embarrassment. Some regard POP as consequence of ageing and consider there is no effective therapy. 2) POP is perceived as a vaginal bulge and affects lifestyle and emotional wellbeing. The main driver for treatment is absence of bulge sensation. 3) POP is known to affect frequency of sexual intercourse but has less impact on satisfaction. 4) Prolapse specific body image and genital self-image is an important component of a women’s emotional, physical and sexual wellbeing. 5) POP is commonly associated with depression and anxiety symptoms which impact HRQoL although are not correlated with objective anatomical findings. 6) Patient centered treatment goals are useful in facilitating communication, shared decision making and expectations before and after reconstructive surgery. 7) Disease specific HRQoL questionnaires are important tools to assess bother and outcome following surgery and there are now several tools with Level 1 evidence and a
Grade A recommendation. 8) The cost of POP to the individual and to society is considerable in terms of productivity. In general, conservative measures tend to be more cost effective than surgical intervention.

**Conclusions:** Patient’s perception of POP varies in different patients and has a far-reaching impact on their overall state of health and well-being. However, recognizing that it is a combination of body image and overall health (which affects mental health) allows clinicians to better tailor expectations for treatment to individual patients. There are HRQoL tools that can be used to quantify these impacts in clinical care and research. The costs to the individual patient (which affects their perception of POP) is an area that is poorly understood and needs more research.

**KEYWORDS**

Pelvic Organ Prolapse, Body Image, Sexual function, Expectations, Goals, Productivity

**BRIEF SUMMARY**

This narrative literature review, headed by the International Urogynaecology Consultation investigates the disease burden reported by patients with pelvic organ prolapse.

**INTRODUCTION**

This report is part of a series of articles that are the product of the International Urogynecology Consultation (IUC) that is sponsored by the International Urogynecological Association (IUGA). This
is a 4-year, 4-chapter project with 16 reports dedicated to reviewing and summarizing the world's literature on pelvic organ prolapse (POP). This report is from the first year and chapter of the project, which is dedicated to defining POP. Subsequent years will be devoted to evaluation of POP, non-surgical management of POP, and finally, the surgical treatment of POP. This report will focus on patients’ perception of the disease state of POP.

POP is a prevalent condition that is often associated with a variety of other symptoms and functional complaints none of which impart significant mortality but can result in an impaired body image and sense of well-being. This can have other impacts on a patient’s quality of life and lead to anxiety and depression. Understanding these issues and finding ways of accurately measuring them will influence how patients with POP are managed and counseled for treatment. Finally, gaining more insight as to the costs of POP as an additional financial burden to patients will help allow clinicians to better understand how patients perceive this disease and how this aspect of POP may influence decision making on the patient’s part.

Estimates of the prevalence of POP range from 3% to 50% [1]. An accurate prediction is difficult to pin down due to the poor help-seeking behavior of women afflicted with POP, despite its significant impact on overall health and quality of life (QoL). The severity of prolapse symptoms and the degree of bother are not necessarily synonymous and can vary in women with the same stage of prolapse. This stems from several factors but main among them are the patients’ perception of the disease of POP and its impact on their body image, lifestyle, sense of well-being and possibly their finances.

The aim of this chapter is to evaluate how patients perceive POP and its disease burden on the individual by providing a narrative review of the published literature. This manuscript has been divided into sections looking at the impact of POP on health seeking behaviors, their sense of health and wellbeing, their overall QoL, sexual health, mood and finances. In addition, it will evaluate, the
appropriate use of treatment goals based on patients perception of their disease, how QoL assessment tools can quantify the disease burden suffered by patients and the financial cost to patients and society for POP.

MATERIALS AND METHODS

This manuscript is a narrative review that includes a systematic search of the literature using the terms listed in table one from the following databases: PubMed and Embase (January/2000 to August/2020). Only human studies involving adult women and limited to the English languages were included. The terms for searching the literature were developed by the authors of this report and were presented to the IUGA membership at the annual scientific meeting in 2019. MESH terms used are noted in Table 1. The titles and abstracts were reviewed by two of the authors to determine if they met the inclusion criteria. All discordant results were decided by a third-party reviewer. The manuscripts were next reviewed for suitability using the Specialist Unit for Review Evidence (SURE) checklists for cohort, cross sectional and case-control epidemiologic studies [2] This was done to assess data presentation, population description and bias. Only studies that included populations with clear definitions of patients with POP were included.

The full text manuscripts were then reviewed to confirm that information corresponded to predefined inclusion criteria. There were various inclusion and exclusion criteria for each subheading. Those manuscripts that qualified were then reviewed in depth and summarized in the results section.

RESULTS

A). PERCEPTION OF POP AS A DISEASE AND BARRIERS TO HEALTH SEEKING
A search of the database of PubMed was made using the terms “pelvic organ prolapse and perception”, “pelvic organ prolapse and help-seeking”, “pelvic organ prolapse and care-seeking”, “pelvic organ prolapse and behavior”. (Table 1) A total of 299 articles were cited in the English language. Articles and abstracts were reviewed for relevance and duplication. Of these, 12 were included in this review. [PRISMA Appendix 1]

How and why women seek healthcare resources to manage their POP is complicated and influenced by many factors. Women often only seek intervention when the POP is at an advanced stage and some women do not seek help for their condition even in the presence of severe prolapse symptoms based on uninformed preconceived notions about the disease of POP and the treatment options and their outcomes [3–6].

The perception of POP as a disease state is influenced by various factors including age, ethnicity/race, level of education, and socio-cultural issues. The patient’s desire to seek help for their POP would likewise be influenced by these factors. Not all women with the same stage of POP will experience the same level of bother. Women in the 6th or 7th decades of life have a higher risk of bother than younger or older women with the same stage of POP [1, 7]. The level of symptom bother and severity have also been shown to vary in women of different races or ethnicities [8–11]. Previous studies have shown that Latino and white women had 4 to 5 times higher risk of symptomatic POP compared to African-American women even though white women had only a 1.4-fold higher risk of objective POP by examination [11]. In women, with Pelvic Organ Prolapse Quantification system (POP-Q) stage II POP, Hispanic and Native American women have a higher level of bother compared with non-Hispanic white women [8]. No difference in the level of symptom bother was seen between ethnicities in women with more advanced stages of POP (POP-Q stages III and IV).
The frequency and severity of associated symptoms that impair quality of life with respect to physical mobility, pain, social isolation, energy, emotional distress, sexual function and sleep are often the driving force for health care seeking behavior. Increasing severity of these symptoms is often the impetus to seek treatment. Despite this there is poor help-seeking behavior of women with POP and associated pelvic floor disorders (PFD). Several studies have described obstacles and barriers to help-seeking even among postpartum women with PFD [3, 5, 10, 12, 13]. The barriers to seeking care include: perception of POP as a normal part of aging, shame and embarrassment, feeling of self-blame, low bother, trivialization of symptoms by the patient and (more concerning) by the healthcare provider, lack of awareness of prolapse and its treatment options, poor understanding of anatomy, lack of information on pelvic floor dysfunction, cost of and poor access to care. Davidson et. al [6] have also shown that many women perceive prolapse as an inevitable consequence of aging and childbirth that is either untreated (23 -38%) or that spontaneously resolves.

Coping strategies are often used to provide symptom relief and include adaptive behaviors such as digitation to facilitate bladder and/or bowel emptying, dietary modification to prevent constipation, refraining from heavy lifting and strenuous exercises, use of tight underwear to hold the prolapse in place, using alternative positions during intercourse, and toilet mapping if associated with urinary incontinence [3, 5].

Community-based studies have shown that the impact of POP on women’s overall health is reflective of the poor understanding of what POP is and management options. The severity of symptoms and level of bother are not solely dependent on the severity of the POP itself. Increased awareness and education on prolapse should help women overcome the barriers to help-seeking and improve healthcare delivery.

Conclusion
Women have various perceptions of POP and whether or not it is a normal consequence of aging, a shameful embarrassing condition or even more concerning a condition for which there is no effective therapy. Education on what POP is and the various treatments available to treat it would address many of the patient’s misconceptions of what POP is and would hopefully lead to better health seeking behaviors. Research in the area of patient education on POP and how this would influence health seeking behaviors is necessary.

B). VAGINAL BULGE AND IMPACT ON HEALTH AND WELL-BEING IN WOMEN

Using PubMed and search terms “vaginal bulge, pelvic organ prolapse”; “vaginal bulging, pelvic organ prolapse”; “bothersome bulge symptoms, pelvic organ prolapse”; and “vaginal bulge, cystocele or rectocele or uterine prolapse or vaginal vault prolapse” (Table 1); 347 articles were cited. After eliminating duplicates, and assessing titles and abstracts for relevance, the list was narrowed to 203 articles. Finally, using SURE checklist criteria, 7 articles were included for final review. [PRISMA Appendix 2]

Vaginal bulge, described as a sensation of heaviness and something hanging outside the vagina or sensation of a ball coming out of the vagina, is regarded as the defining symptom of POP. Women describe POP as vaginal bulging, vaginal discomfort, vaginal pressure, weakness in muscle/connective tissue, urinary/bowel symptoms, or the vaginal wall being visible [4]. Among these terms, the most common cited by patients is the presence of a vaginal bulge [4].

In women who have symptomatic POP, more reported a feeling of bulging, pressure or protrusion from the vagina compared with those describing visually a vaginal bulging or protrusion [14]. When women were asked to report their severity of symptoms of vaginal bulging using daily diaries, their
symptoms varied depending on the time of day with more severe symptoms in the evenings. Their symptoms also varied on a day-to-day basis [15].

With regard to the impact of POP, women regarded the feeling of a bulge from the vagina and pelvic pressure to be most bothersome symptoms [14]. Almost half of the women reported moderate to severe distress associated with POP. In addition, some women reported mechanical symptoms arising from the “bulging” [16]. Nearly one quarter of women reported an adverse effect of POP on brisk walking and strenuous exercise [14]. POP symptoms were aggravated by straining and heavy lifting, particularly in older women [17]. There was also a higher proportion of young women reporting vaginal and/or vulval chafing and a rubbing feeling when compared with women of older age [17]. Around one third of the women reported that POP affects at least one of their physical, social or sexual activity. [14]

In both questionnaire survey research and qualitative studies, women frequently reported that POP restricted or interfered with their physical activities because it exacerbated their physical discomfort [4, 15]. As a result, POP exerted different levels of impact on women and women responded in various ways. Some would either avoid certain physical activities altogether (not participate), or limit (adapt the intensity) their activities. Some would continue as normal but they reported that the bulge was “annoying” during certain activities [15]. This in turn had an impact on their satisfaction with physical function.

When considering social function, Sung et al. [15] found out that women also restricted or adjusted social activities that had a physical component. For example, some might avoid dancing or doing exercise at the gym or going for a walk. This negatively impacted their ability to feel connected with others. Women also reported psychological limitations related to POP. The most common emotions described as a result of POP included “annoyance” and “embarrassment”. Some women also reported more severe emotions including fear, anxiety, humiliation, and sadness, although this was less
They were also frequently preoccupied with the POP and reported always having to think about it before doing certain activities; and some reported that POP was always on their mind [15]. Increasing symptoms and interference with physical activity are factors that lead women to seek healthcare services and even surgical treatment [4].

Kousgaard et al. [16] evaluated women’s goals before anterior colporrhaphy, most women listed resolving of bulge as one of their goals. In fact, the majority of the goals concerned resolution of the symptoms of bulging. This was similar to the qualitative study where the desired outcome of the operation was to “get rid of the ball/bulge”, or discomfort associated with the bulge [18]. They reported that they can “do things without having to always think about the bulge” which leads to improvement in the cognitive function [18].

Relieving voiding symptoms, improvement in quality of life on physical activity and quality of life in the emotional aspect were also goals following resolution of bulge symptoms [16]. Therefore, from the patient perspective, the most important definition of POP treatment success was absence of vaginal bulge symptoms postoperatively [18, 19]. The absence of vaginal bulge symptoms after an operation has a significant correlation with a patient’s assessment of overall improvement and achievement, while anatomic success alone does not [16, 19].

**Conclusion**

POP is perceived by patients as the sensation of a “vaginal bulge” that impacts their daily activities negatively. Their symptom intensity is variable throughout the day and on a day-to-day basis, but consistently impacts the individual’s lifestyle and emotional well-being. The leading indicator for successful management of POP is the absence of the sensation of a “Vaginal bulge” following treatment.

C). THE IMPACT OF PELVIC ORGAN PROLAPSE ON SEXUAL FUNCTION
Using PubMed and search terms “sex, pelvic organ prolapse”; “sexuality, pelvic organ prolapse”; “sexual function, pelvic organ prolapse”; and “sexual dysfunction, pelvic floor” (Table 1) 234 articles were identified. After eliminating duplicates, and assessing titles and abstracts for relevance, the list was limited to 34 articles. Finally, using SURE checklist, 16 articles were included for final review for this narrative. [PRISMA Appendix 3]

Many studies have found an associated decrease in sexual function and satisfaction in women with POP. However, there is little agreement in the literature about the nature of this relationship and is it impacted by the altered physical anatomy, vaginal dryness following the menopause, the patient’s perceptions of their body image or partner related issues. Understanding the relationship between pelvic organ prolapse and sexual function is paramount to fully understanding how POP affects a patient’s sense of well-being.

Female sexual function is multifactorial and a complex aspect of quality of life. Pelvic floor dysfunction, to include POP, assessed with POP-Q examination, PFDI and personal standardized questionnaires were associated with increased rates of impaired arousal, infrequent orgasm and dyspareunia. The more severe stages of POP (POP-Q stages III and IV) were significantly associated with decreased orgasm among all the sexual function domains surveyed [20].

Women with POP may experience sexual dysfunction such as dyspareunia, reduction in sexual interest that leads to a decline in their frequency of sexual activity. Of women with POP, 31-44% were found to have some degree of sexual dysfunction [21]. Interestingly, the frequency of intercourse is lower in women with POP, even though no differences were reported in patients' or partners' sexual satisfaction nor in the stages of sexual excitement. Overall, women with POP and urinary incontinence had poorer sexual functioning than women without these PFDs [22]. In a recent study, it was noted
that the vaginal compartment involved with the POP did not seem to play an important role in the sexual dysfunctions in women with POP [23].

**Conclusion**

POP negatively affects the frequency of coitus but has less impact on satisfaction with sexual activity. Patients with advanced POP (POP-Q stage III and IV) seem to have more concerns with body image which can also lead to sexual health concerns. Understanding why POP limits sexual activity, particularly in patients with less advanced disease, needs more research.

**D. PATIENT'S PERCEPTION OF BODY IMAGE IN PELVIC ORGAN PROLAPSE**

**BACKGROUND: BODY IMAGE (GENITAL IMAGE) AS A PSYCHOLOGICAL CONSTRUCT**

Body image is a psychological construct that refers to an individual’s attitudes, thoughts and feelings toward, and perceptions of, her own body [24]. Specifically, body image is the mental image an individual has of one’s self and includes physical details (e.g. height, weight, hair color, body shape, etc.) and details learned about themselves through personal experiences, direct interactions with others, and/or perceptions of reactions and internalized judgements of others [25]. Body image affects multiple aspects of psychosocial functioning and has been shown to be important in a woman’s perceived quality of life [26]. In a 2019 survey by the Mental Health Foundation in the UK, 20% of adults felt shame about their body image in the last year, 34% felt “down” or “low”, and 19% felt “disgusted” [27].

Body dissatisfaction, which can be assessed using body image measurements, has been associated with anxiety and depression which can negatively impact quality of life [24]. Some researchers have used the term ‘genital self-image’ or genital body image to describe the perceptions, attitudes, and internal
mental image an individual has of her external genitalia [25]. Genital body image may include one’s mental image of the appearance and attractiveness of their external genitalia and may be affected by comparison to others (i.e. photographs, movies, etc.), scarring (i.e. from birth injury, trauma, surgery, radiation, etc.), function and perception of others (e.g. partners, friends, family, healthcare providers) [25]. Of note, Hullfish et al. [28] identified the theme of “self-image/social relationships” in a written questionnaire study assessing patient surgical goals to help determine if self-reported goal achievement as a better way to evaluate surgical success in patients with POP. Utilizing the body image construct in research on PFDs, specifically POP for the purposes of this document, may allow us to understand more fully the psychological impact of POP on women and improve the evaluation of treatment outcomes.

A literature search of commonly used medical and scientific databases (PubMed, Embase, PsycInfo) was performed using key words and terms. The search strategies for each database are as follows: 1) PubMed: ("Body Image" OR “body image” OR “genital image” OR “self image”) AND ("Pelvic Organ Prolapse" OR “pelvic organ prolapse” OR “POP” OR “urogenital prolapse” OR “vaginal vault prolapse”) [75 results]; 2) Embase and PsycInfo: (’body image’ OR ‘body image’ OR ‘genital image’ OR ‘self image’) AND (‘pelvic organ prolapse’ OR ‘POP’ OR ‘urogenital prolapse’ OR ‘vaginal vault prolapse’) [Embase: 81 results, PsycInfo: 0 results] (Table 1). The search strategy results were reviewed, duplicates removed and a list of articles was created (n=105). Articles were reviewed for topic relevance and selected if they were original research (n=36); articles representing previously reported data or datasets, review articles, articles not available in English, articles in which body image not measured in pelvic organ prolapse, methods papers, or studies with significant methodologic issues were removed unless new information was presented (n=69). The reviewed studies are presented by themes identified in the literature. [PRISMA Appendix 4]
Jelovsek et al. [26] first explored the concept of body image in women with advanced POP (POP-Q stage 3 or 4) in a case-control study design comparing women with prolapse to women with “normal” pelvic floor support (stage 0 or 1). Using a modified version of the body image scale (modified BIS (MBIS)) developed by Hopwood et al. [29], the authors found that women with advanced POP were more likely to feel self-conscious about their body, less likely to feel physically attractive, less likely to feel feminine, and less likely to feel sexually attractive compared with normal controls. The authors did not find a difference between cases and controls in regard to the body image themes of dissatisfaction with appearance when dressed, difficulty looking at themselves naked, avoiding people because of appearance, or overall dissatisfaction with their body.

Lowder et al. [30] performed a qualitative study to assess perceptions of prolapse-specific body image in women with POP for use in development of a condition-specific body image measure. The authors found that as a condition, symptomatic POP can have a significant impact on a woman’s body image and the authors identified 3 main themes and 25 secondary body image-related themes. The 3 primary themes included: 1) the impact of prolapse on a woman’s body image; 2) prolapse-related body image and its impact on personal relationships; and 3) the effect of prolapse-specific body image on work and other daily activities. In 2014 Lowder et al. [31] published the first validated prolapse-specific body image measurement based on their prior work. The Body Image in Pelvic Organ Prolapse (BIPOP) questionnaire is a 10-item scale with 2 subscales (general attractiveness, partner-related prolapse reactions) that was found to have face and content validity, high internal consistency, strong correlation with general prolapse and body image measures, and strong test-retest reliability.

Moroni et al. [32], in a multicenter cross-section study used the BIPOP to evaluate the sense of attractiveness, body image and sexual function in Brazilian women. Women with prolapse (105 across
both sites) and (100 controls across both sites) were enrolled. In addition to the BIPOP, the Attractiveness subscale of the Body Attitudes Questionnaire (BAQ), a general body image instrument initially evaluated in women with eating disorders, was used; the Attractiveness subscale was chosen as it relates to general (i.e. whole body) attractiveness [33]. While cases (women with prolapse, POP-Q stage 2-4) and controls (women without prolapse, POP-Q stage <2) differed by age (prolapse group older), parity (higher in prolapse group) and education level (lower in prolapse group), the author found that BAQ scores did not differ significantly between cases and controls and BIPOP scores did not differ between cases (analyzed by all, POP-Q stages 1-2, POP-Q stages 3-4 and inter-group comparison) by total BIPOP score, and Attractiveness and Partner subscales. However, BIPOP and BAQ Attractiveness subscale scores were independent predictors of sexual dysfunction as assessed by the FSFI in multivariable analyses. The authors concluded that in their population, women with genital prolapse did not significantly relate extent of their prolapse stage with their body image, however worsening body image (general and prolapse-specific) is associated with decreased sexual function. POP did not appear to have a major impact on worsening body image, but worsening body image did have a negative impact on sexual functioning.

**Patient’s Perception of Body Image and Pelvic Organ Prolapse – General Themes Identified**

Pakbaz et al. [3] performed a qualitative study of 14 women with POP prior to surgery and found that POP negatively affected self-esteem, sexual attractiveness to their partner, and caused a sense of loss of self as a sexual being. Zielinski et al. [34] utilized a case-control design (13 women with POP, 24 with surgically corrected POP, 37 without POP) to better understand how prolapse-specific body changes influence genital body image and how genital body image affects sexual health. The authors utilized the Genital Self-Image Scale-20 (GSIS-20), which was initially designed to assess genital body
image in women seeking treatment for sexual dysfunction, and the Body-Esteem Scale (BE), a general BI scale, to control for the effects of overall body image on sexual health [35, 36]. The authors found a statistically significant difference between groups in GSIS-20 scores. Women with POP had worse genital body image (lower scores) compared to those never diagnosed with POP and women who had undergone corrective surgery for POP had scores that were not significantly different than those never diagnosed with POP. The authors concluded that women with prolapse negatively impacts genital body image and negative genital body image is associated with worse sexual health [37]. Sung et al. [15] developed a conceptual framework for patient important outcomes of women seeking treatment for POP using qualitative research methods. Participants described “not feeling normal” and “not feeling natural” and reported that the negative impact of POP on BI affected their sexual health by decreasing desire. Improvement in body image perception was ranked as the fourth most important outcome.

**Pelvic Organ Prolapse, Body Image and Patient’s Knowledge, Attitudes & Beliefs Regarding the Role of the Uterus**

Good et al. [38] performed a cross-section study of English-speaking women presenting with pelvic organ prolapse symptoms utilizing a self-administered questionnaire to assess knowledge and attitudes regarding the uterus and included questions about body image. The authors found that the majority of respondents did not believe that the uterus was important for body image and sexuality.

Van IJsselmuiden et al. [39] performed a similar study in Dutch women utilizing a questionnaire to assess attitudes toward uterus preservation versus vaginal hysterectomy in surgical treatment of pelvic organ POP and to assess perceptions and opinions regarding the impact of uterus preserving surgery and vaginal hysterectomy on body image and sexuality. The majority of women expected an
improvement in body image and that there would be no difference between vaginal hysterectomy or uterine preserving surgery.

In conclusion, prolapse-specific body image and genital self-image in POP has become recognized as an important component of a woman’s emotional, physical and sexual well-being. In addition, it is an important psychological construct to be evaluated so as to better understand the lived experience of women with pelvic organ prolapse and the impact of treatment. Multiple measures have been utilized to assess body image, all with different psychometric properties. In 2020, Touza et al. [40] conducted a scoping study focused on the psychosocial experience of women diagnosed with and/or treated for POP. The authors concluded that there is considerable variability in the psychosocial outcomes that have been measured and the length of follow-up after intervention.

**Conclusion**

Further research is this field is needed to further elucidate the ideal POP-related body image measure, completing psychometric properties testing of existing measures, identifying potential additional body image-related themes, understanding the impact of expectant management of POP on body image, and determining the impact of other PFDs on body image.

**E). THE EFFECT OF PELVIC ORGAN PROLAPSE ON MOOD**

Using PubMed and Embase and search terms: “Pelvic organ Prolapse”, “pelvic organ prolapse”, “urogenital prolapse”, “vaginal vault prolapse”, “vaginal prolapse”, “POP” and “Mental Health”, “Attitude”, “Mood Disorders”, “Anxiety”, “Sleep”, “mental health”, “mental wellbeing”, “mood”, “patient attitude”, “depression”, “depressive”, “anxiety”, “psychological health”, “psychological wellbeing”, “sleep”, “sleeping” (Table 1). 232 and 242 citations were identified. After duplications were removed 289 citations were found. Only articles in the English language were included. Titles...
and abstracts were assessed for relevance to baseline relationship between pelvic organ prolapse and mood and using Wales criteria, 17 articles were included in final review and in this narrative. Additional literature exists regarding mood symptoms and urinary incontinence as well as the relationship of these symptoms to incontinence treatment. These are topics are not reviewed here.

[PRISMA Appendix 5]

Symptoms of POP affect many dimensions of a woman’s life with profound impact on quality of life. Studies have shown that quantitative symptom scores do not always correlate to anatomic findings and the extent of anatomic POP does not correlate with symptom bother [41–43]. We are still understanding the concerns of women with POP, the full impact of these symptoms, and the relationship they have on a woman’s psychosocial experience and quality of life, well-being and emotional-mental health [44, 45].

For over a quarter century, the World Health Organization (WHO) has consistently reported mental health disorders as contributing to more than 14% of age-standardized years lived with disability (YLDs), and mental health disorders have a prevalence of greater than 10% with depressive and anxiety disorders constituting over half of the reported cause-specific global estimates of prevalence of mental health disorders in all 21 Global Burden of Disease regions [46].

Depression prevalence rates vary by age and lifetime prevalence varies by country but peaks in older adulthood and reaches over 7.5% in women aged 55-74 [47]. Anxiety disorders are frequently co-morbid with depressive disorders and are the most prevalent psychiatric disorders [46, 48]. Bandelow et al. [48] conclude based on large population surveys that one third of the population is affected by an anxiety disorder during their lifetime. Depressive symptoms and depressive disorders have been shown to negatively impact wellbeing and are associated with functional impairment in patients with and without chronic conditions [49, 50]. Depressive and anxiety symptoms have been shown to
interface with pelvic floor disorders, most notably with urinary incontinence. Melville et al. [51] found major depression to be associated with symptom amplification and with a decrease in quality of life in women with urinary incontinence. Anxiety has been associated with greater functional loss in patients with urinary incontinence [51–60]. While there is a growing body of literature exploring the relationship of mood symptoms and urinary incontinence, the psychosocial experience of women with pelvic organ prolapse and specifically the relationship of depression and anxiety disorders and symptoms with POP symptoms is just beginning to be understood [40].

**Depressive symptoms in Patient's with pelvic organ prolapse**

Initial data regarding depressive and anxiety symptoms in women with POP were gathered using a variety of measures as secondary outcomes of studies investigating quality of life. In a 2006 prospective cohort study investigating quality of life of women undergoing reconstructive vs obliterative surgery, subjects completed condition-specific quality of life measures and the Beck’s Depression Inventory (BDI) [61]. Barber et al. found that 17-20% of subjects reported mild to moderate depression symptoms (BDI scores 10-18) at baseline with 3-7% reporting moderate to severe symptoms (BDI score > 19). In a 2009 secondary analysis of a case-controlled study, Ghetti et al. [62] reported 22% of 75 subjects with POP had moderate to severe depressive symptoms measured by Patient Health Questionnaire (PHQ-9) score ≥10 compared to 6% in controls. Depressive symptoms were associated with higher (worse quality of life) Pelvic Floor Impact Questionnaire (PFIQ) scores in women with prolapse. In a 2016 secondary analysis of cross-sectional data of patients with POP participating in a prospective pessary study, Pizarro et al. [63] used a validated Chilean version of the Goldberg Health Questionnaire (GHQ-12) to assess depressive symptoms. In the 91 subjects included, authors report a depressive symptom prevalence of 51.6% defined as GHQ-12
score of five or greater. Subjects with depressive symptoms reported higher symptom bother by Pelvic Floor Distress Inventory (PFDI).

Additional findings include those published by Cagnacci et al. [64] who investigated the association of climacteric symptoms to POP in a cross-sectional study of 1382 postmenopausal women attending a menopause clinic. Subjects completed the Greene’s climacteric scale which consists of 21 items of which 11 items relate to depression and anxiety symptoms, as well as the State-Trait-Anxiety-Inventory (STAI) (a measure of anxiety trait or tendency toward being anxious) and the Zung’s scale (SDS) to evaluate depressive symptoms. While women with POP scored significantly higher on the climacteric scale, STAI and SDS scores were not different between patients with and without POP.

In a planned ancillary study of 103 women undergoing surgery for POP in the Restricted Convalescence Outcomes following Urogynecologic Procedures study, Bochenscka et al. [65] evaluated the relationship between preoperative condition-specific quality of life questionnaire scores and the Patient Reported Outcomes Measurement Information System questionnaire (PROMIS-57). The PROMIS includes 3 components: physical, mental, and social and includes depression and anxiety as two of its 8 domains. Authors found that PFDI-20 scores were significantly correlated with all PROMIS domains. In particular higher PFDI-20 scores (worse pelvic floor symptoms) were associated with higher scores in anxiety and depression domains alongside worsened physical function, fatigue, sleep disturbance, and lower satisfaction with participation in social roles.

One study investigated depressive symptoms in women with POP as a primary outcome. Ai et al. [66] performed a cross-sectional study of 177 post-menopausal women diagnosed with POP (≥POP-Q stage II) utilizing the PHQ-9. The prevalence of depressive symptoms (PHQ9 ≥ 10) was found to be 32.8%. Authors did not find an association between depressive symptoms and extent of anatomic prolapse. However,
authors did find that PFIQ-7 and PFDI-20 subscale scores, were significantly higher in subjects with depressive symptoms compared to those without symptoms.

**ANXIETY SYMPTOMS AND PELVIC ORGAN PROLAPSE**

Few studies investigated anxiety symptoms in women with POP as a primary outcome. Ai et al. [67] report the prevalence of anxiety in the cross-sectional study of 177 women with ≥POP-Q stage II POP using GAD-7. Authors report a 19.2% prevalence of anxiety symptoms (GAD-7 scores ≥ 10). As with their findings regarding depressive symptoms, the authors did not find an association between anxiety symptoms and degree of prolapse. PFIQ-7 and PFDI-20 subscale scores, were significantly higher in subjects with anxiety symptoms compared to those without symptoms.

Collins et al. [68] report anxiety state scores in a prospective study of 90 women having surgery for pelvic organ prolapse. Subjects completed STAI and PFDI-20 before and after surgery. Of these 35% percent were classified with anxiety trait (STAI- T score > 38). Authors found no difference in PFDI scores or leading edge between subjects with and without anxiety trait.

**Conclusion**

Depression and anxiety symptoms are common, significantly impact quality of life and well-being and disproportionately affect women. The interrelationships between POP symptoms, quality of life and mood symptoms appear to be complex and have yet to be fully understood. Studies to date have used a variety of outcome measures to quantify mood symptoms and overall suggest that women with POP may have a high prevalence of depressive symptoms. Depressive and anxiety symptoms do not appear to correlate to anatomic findings; however, they may have an impact on condition-specific quality of life measurement and satisfaction score. As providers of women with POP, it is important to recognize depression and anxiety symptoms in the patients we treat, the role these symptoms may
play in patients’ pelvic floor symptomatology and quality of life and the possible impact they may have on postoperative outcomes and satisfaction.

F). PATIENT’S PERCEPTION OF TREATMENT GOALS IN WOMEN WITH POP.

WHAT IS IMPORTANT TO PATIENTS?

Using PubMed and search terms “goals, pelvic organ prolapse”; “goals, pelvic floor”; “expectations, pelvic organ prolapse”; and “expectations, pelvic floor” (Table 1); 363 articles were cited. After eliminating duplicates, and assessing titles and abstracts for relevance, the list was narrowed to 74 articles. Finally, using Wales criteria, 33 articles were included for final review for this narrative.

[PRISMA Appendix 6]

To advance our understanding of POP and its treatment we need measures of how patients perceive themselves and the disease state of POP. Most of the work in developing patient perceived subjective measures has been accomplished in the arena of pre-defined surgical outcomes. This arena has evolved from defining treatment outcomes for POP by narrow surgeon-centric domains (anatomic restoration), to more broad-based objective (e.g., POP-Q) and subjective domains, including patient-centric measures (quality of life, goals, and expectations). As quality of life is inherently personal and different for every patient, determining a “one size fits all” subjective measurement of treatment success is not possible. As a result of an increased emphasis on patient-centeredness, in the early 2000’s investigators in the field of Female Pelvic Medicine & Reconstructive Surgery began to more formally evaluate patient treatment goals as a part of outcome assessment.

Early work in this area was pioneered by Hullfish et al. [28] and Elkadry et al. [69]. In both of these small prospective series, patients scheduled to undergo pelvic reconstructive surgery provided their own treatment goals as determined by their perception of what was diseased and what needed to be corrected, which were then characterized and assessed after surgery for attainment. While enrollment
was small and follow-up short for both studies, the concept of using patient treatment goals uncovered novel concepts and questions. In these early studies, patient-centered goals (predominantly symptom and activity-related goals) were achieved in 75% - 84% by three months. Goals were less likely to be attained in patients with perioperative complications [70], or if patients perceived themselves to be unprepared for surgery [69]. Of note, goals were associated with higher patient satisfaction in one study [28] but not the other [69]. In other work, Mahajan et al. [71] noted that urge incontinence was the most common reason for not meeting goals in patients undergoing pelvic floor reconstructive surgery. Lowenstein et al. [72] noted that patients changed their goals from symptom relief to treatment following initial urogynecological consultation, and the number of patient goals increased.

Investigations further evolved to assess evaluate patients’ goal attainment for non-surgical treatment. In a follow up study in 2008, Hullfish et al. [73] found that at one year, surgical patients were more likely to achieve complete goal attainment, compared to non-surgical patients. Similar findings between surgical and non-surgical goal attainment were noted in a study by Mamik et al in 2013 [74]. More specifically, Komescu and her colleagues [75] used goals to assess satisfaction with pessary use, noting that if one or two goals were met, patients were 17 times more likely to continue with pessary use. In a comparison prospective study, Sung et al. [18] found that at 8 months, pessary patients experienced comparable goal attainment to surgical patients, but that surgical patients had higher symptom and functional goal attainment than pessary users. In evaluating patient centered goals Whiteside et al. [76] noted in a cohort of 90 patients that those with more severe stages of prolapse did not predict a desire for surgery, but that patients with activity-related goals trended towards surgery for treatment.

Almost all authors in this field of study agree that assessing patient goals can serve as an effective communication tool, in effort to guide appropriate, individualized treatment [77–79]. Patient-centered
goals can be used as an adjunct, not a replacement, to other established subjective and objective outcome measures. This blended outcome concept was piloted in an investigation by Srikrishna et al. [80]. These investigators measured after one year follow up of 89 pelvic reconstructive surgery patients using a composite to define “cure”, including a POP-Q exam, PGI-I score, and patient goal achievement. Interestingly they found that all patients showed an improvement in QOL, and there was no difference between groups when success was measured with the POP-Q or composite endpoint. They concluded that their chosen composite endpoint was not valid for defining successful pelvic reconstructive surgery.

Conclusion

More research is needed in our field to better define, understand, and standardize patient centered outcome measures or goals. Larger, multi-centered trials should assess similarities and/or differences in goals and goal attainment across diverse populations. For the time being, the primary utility of patient-centered treatment goals is to facilitate communication, enhance shared decision-making, and clarify patient desires and expectations before, during and after pelvic reconstructive surgery.

G). USING HEALTH RELATED QUALITY OF LIFE QUESTIONNAIRES (HRQOL) TO QUANTIFY PATIENT’S PERCEPTION OF POP

An electronic literature search, updating the 2016 literature search performed for a previous narrative review was performed using Pub-Med accessed until up to August 2019 using the following key words separately or in combination; “questionnaire,” “pelvic organ prolapse,” “quality of life” AND “Pelvic Organ Prolapse” (Table 1) [81]. Overall 262 papers were retrieved and after review 25 were selected for further analysis and review. Questionnaires reported in the prior narrative review were also reviewed and included in the literature search. [PRISMA Appendix 7]
There are currently a number of validated questionnaires available to use in the subjective clinical assessment of women complaining of symptoms suggestive of POP. Evidence from previously reported studies [82] has shown the importance of patient reported outcome measures and subjective assessment may provide a more meaningful assessment tool when compared to more traditional objective measurements from examination. The use of these subjective outcomes has been shown to be robust and correlated with objective assessments during long term follow up [83].

Although the number of HRQoL questionnaires available to assess impact of POP is not as great as those associated with lower urinary tract dysfunction there are now a number of recommended and validated questionnaires available. However, it is also important to consider that where specific problems associated with POP need to be considered, such as lower urinary tract symptoms or sexual function, then it may be preferable to consider the use of one of the questionnaires designed specifically for that purpose.

**HRQoL Questionnaires: Pelvic Organ Prolapse**

There are now a number of HRQoL questionnaires that have been validated for the assessment of POP (Table 2).

**Prolapse Quality of Life Questionnaire (PQoL)**

The Prolapse Quality of Life questionnaire (P-QoL) [85] is a validated questionnaire which has been shown to be reliable and responsive. HRQoL scores have been shown to strongly correlate with objective assessment of prolapse using the Pelvic Organ Prolapse Quantification Questionnaire (POPQ) and women with symptomatic prolapse had a significantly higher score in each domain.

**Pelvic Floor Distress Inventory (PFDI) and Pelvic Floor Impact Questionnaire (PFIQ)**
The PFDI and PFIQ are based on the structure and content of the Urinary Distress Inventory (UDI) and the Incontinence Impact Questionnaire (IIQ) and also include specific domains covering pelvic organ prolapse and colorectal dysfunction.

The PFDI assesses symptom distress in women with pelvic floor dysfunction and includes the Urinary Distress Inventory (UDI), Colorectal-anal Distress Inventory and Pelvic Organ Prolapse Distress Inventory.

The PFIQ assess HRQoL impact and includes the Incontinence Impact Questionnaire (IIQ), Colorectal-anal impact questionnaire and the Pelvic Organ Prolapse impact questionnaire.

In addition the Pelvic Organ Prolapse distress inventory and Pelvic Organ Prolapse impact questionnaire correlated with POPQ objective prolapse assessment whilst the Colorectal-anal Distress Inventory and Colorectal-anal impact questionnaire significantly correlated with episodes of fecal incontinence and defecatory dysfunction.

**Pelvic Organ Prolapse Symptom Score (POP-SS)**

The POP-SS consists of seven items each with a 5-point Likert response and has been shown to have good construct validity, internal consistency and to be sensitive to change [94]. It has been validated using data from three large studies of women with POP.

**INTERNATIONAL CONSULTATION ON INCONTINENCE QUESTIONNAIRE (ICIQ)**

The ICIQ modular questionnaire (www.iciq.net) was developed to meet the need for a universally applicable standard guide for the selection of questionnaires for use in clinical practice and clinical research for lower pelvic dysfunction [95, 96]. Sixteen ICIQ modules/questionnaires are currently available.
available for use (with further modules in development) and clinicians or researchers are able to select module(s) to meet the particular requirements of their study or clinical practice.

ICIQ: Core Modules

These questionnaires assess the core symptoms and impact on (HRQoL) of pelvic floor dysfunction in addition to impact on sexual function. The core modules provide evaluation of; lower urinary tract symptoms, urinary incontinence, vaginal symptoms and bowel symptoms.

Specific Patient Group Modules

ICIQ Vaginal Symptoms questionnaire (ICIQ-VS)

The ICIQ-VS is one section of the modular ICIQ questionnaire and is a validated measure of the severity and impact of vaginal symptoms and sexual function related to POP [89]. In common with all of the modular questionnaires it has Level 1 evidence and a Grade A recommendation.

HRQoL QUESTIONNAIRES; PELVIC ORGAN PROLAPSE AND SEXUAL DYSFUNCTION

Pelvic Organ Prolapse Urinary Incontinence Sexual Questionnaire (PISQ)

Both POP and urinary incontinence are known to have an important impact on HRQoL although until relatively recently there was no disease specific questionnaire available.

The Pelvic Organ Prolapse Urinary Incontinence Sexual Questionnaire (PISQ) has now been validated in women who complain of symptomatic POP in addition to asymptomatic controls. Those women who complained of POP were noted to have a greater impact on HRQoL related to sexual function when compared to asymptomatic women and the instrument was found to correlate well with the Incontinence Impact Questionnaire-7 (IIQ-7) and the Sexual History Form-12 (SHF-12).
Pelvic Organ Prolapse Urinary Incontinence Sexual Questionnaire – IUGA Revised (PISQ-IR)

One of the difficulties with PISQ was that it was only applicable to women who were sexually active.

More recently an International Urogynaecology Association (IUGA) revised version (PISQ-IR), for both sexually active and inactive women, has been validated using the Incontinence Severity Index (ISI), Pelvic Floor Distress Inventory -20 (PFDI-20), Epidemiology of Prolapse and Incontinence Questionnaire (EPIQ) and the Female Sexual Function Index (FSFI). POP was assessed objectively using the POPQ system. Overall both sexually active women and non-sexually active women with symptomatic POP were found to have greater bother and there was good correlation with other, previously validated questionnaires.

Conclusion

POP is a common condition that is known to have a significant effect on HRQoL in addition to sexual dysfunction. In order to quantify and better measure its impact on patient’s perception of their disease there are now a number of validated, disease specific HRQoL questionnaires available, all of which have Level 1 evidence and a Grade A recommendation. HRQoL questionnaires allow an objective assessment of bother related to symptomatic POP and should be used in the clinical setting as an adjunct to the clinical history and physical examination.

H). THE FINANCIAL BURDEN OF PELVIC ORGAN PROLAPSE TO PATIENT'S AND SOCIETY

A recent comprehensive review of relevant literature entitled “Economics of Urinary & Faecal Incontinence, and Prolapse” was recently published and covered the period 2007 to June 2016. This
included a comprehensive computerised medical literature search (PubMed) for the years 2007-June 2016 to identify all economic, health-related quality of life and cost-effectiveness analyses published on urinary incontinence, faecal incontinence or pelvic organ prolapse. The initial search strategy was very broad and meant to be very sensitive but not specific. We performed a search for the following Medical Subject Headings (MeSH) and keywords: cost-effectiveness analysis, health care costs, quality-adjusted life years, costs and cost analysis, sickness impact profile, or utilities and urinary incontinence, overactive bladder, faecal incontinence, anal incontinence, uterine prolapse or pelvic organ prolapse (Table 1).

To update this and provide more recent information, a search of Medline was undertaken on 3 August 2020 focusing on the period from 2016 to July 2020. The results of the search are summarized in a Prisma diagram in the Appendix. [PRISMA Appendix 8] The previously published summary [97] of prolapse-related economic analyses covered the years 2007-2016 and included 14 articles the results of the search covering 2016-2020. Nineteen new studies were identified after abstract screening. This was reduced to 14 after full-texts were reviewed: 1 quality of life, 2 non-surgical management, 11 surgery-related. There was a mix of study designs including reviews, surveys, retrospective studies, RCT’s, qualitative, case series, comparative studies, cost-effectiveness analysis, database studies, cross-sectional studies and cohort studies.

Patients perceptions about POP should include financial costs for treating and managing a disease that has little if any significant mortality. Therefore, having an understanding of costs that patient face for the treatment of POP is important as this can have profound effects on patient’s seeking the various treatment options available. This is an area with little literature outside of surgical costs. Surgery only affects a small number of patients and the variety of surgical options is beyond the scope
of this review and will be covered in detail under chapter 4 of the IUC that discusses surgical management of POP.

Cost of POP as measured by Quality of life

Gazibara et al. [98] studied the occupational quality of life of working women transitioning through the menopause. They undertook a cross-sectional questionnaire survey to identify the factors affecting occupational quality of life in 335 peri/post-menopausal women aged 40 to 65 working full-time in Serbia. Having uterine prolapse was found to be significantly associated with poor occupational quality of life, which could lead to reduced productivity and a negative economic impact. The authors cited an earlier study which estimated that uterine prolapse accounts for a loss of 217.0 disability-adjusted life years (DALYs) per 1000 women at age 50 years and 324.8 DALYs per 1000 women at age 60 years [99].

Non-surgical (n=2)

Two RCTs by the same team reported on the cost-effectiveness of non-surgical treatments for POP. Panman et al. [100] conducted a trial comparing PFMT with pessary in women with symptomatic POP-Q stage II or III prolapse from 20 general practices in the Netherlands. There was no significant difference between the groups in the primary outcome, the PFDI-20 at 2 years, but pessary was superior in terms of cost-effectiveness. Direct medical costs for pessary and PFMT after 2 years were $309 and $437 respectively.

In a second trial Panman et al. [101] compared PFMT with “watchful waiting” in women with symptomatic POP-Q stage I or stage II prolapse from 20 general practices in the Netherlands with 2-year follow-up. The PFMT group had statistically significantly more improvement in PFDI-20 than the watchful waiting group, although the difference may not have been clinically significant.
medical costs in the PFMT group were higher at €330 per person compared to €91 for watchful waiting: an additional cost of €239, 95% confidence interval €116-€319.

**Surgery: national costs**

Based on the National Inpatient Sample Database, Sanses et al. [102] reported that the mean total cost (adjusted for inflation) of an admission for prolapse surgery in the US increased significantly between 2001 and 2011 ($6,233 [95% CI: $5,859, $6,607] to $9,035 [95% CI: $8,632, $9,438]), despite a decrease in the mean length of stay.

Previously the annual treatment cost of surgery for prolapse in the US in 1997 had been reported to be $1.012 billion (95% CI $0.775-$1.251 billion) based on analysis of the National Hospital Discharge Survey database [103].

**Conclusion**

The cost to individuals due to lack of productivity with the disease of POP is not well understood but in the scant literature suggest a loss of up to 324.8 disability-adjusted life years per 1000 women. There are now a few publications about the cost-effectiveness of non-surgical treatments for POP such as pessaries and PFMT. Pessary was found to be more cost-effective than PFMT for prolapse, and PFMT was more costly than watchful waiting although potentially more effective. The cost of all prolapse surgery in the US has been estimated in two studies and it would seem that the amount of surgery being undertaken and the overall cost increased from 2001 to 2011. Considering only the treatment costs, non-surgical options are less expensive than surgical options but there have been no direct comparisons that take into account the long term treatment pathway of women with prolapse.
DISCUSSION

Patient’s perception of POP as a disease is extremely complex and difficult to define. However, as POP is a disease that adversely affects quality of life, understanding how patients perceive POP as a disease will allow us to better understand how to evaluate and treat it. For many patients, and healthcare providers, POP is not perceived as a disease or is perceived as a disease with no effective therapy. These misconceptions stem from a lack of education in both women and our healthcare colleagues that needs to be addressed. As a barrier to healthcare this misconception is the most troubling and should be a major area for educational resources from involved societies.

A full understanding of how POP affects our patients on a day to day basis will allow healthcare providers to provide meaningful expectations for management outcomes. Finding ways to measure this and denote change will provide for better outcomes and a better understanding of when and how to intervene. Deciding when or how to intervene will also involve financial decisions on our patient’s part. Fully understanding how financial decisions impact therapy and response to treatment modalities may influence a patient’s decision and should be a larger part of future research.

Currently our field is making strides to better understand POP as a quality of life disease and we are gaining knowledge as to how patients define this disease and its impact on their life. Further quantifying this and providing more meaningful discussions regarding outcomes and benefits to therapy will help our patients make the best choices in how to proceed with their lives after developing POP. Defining and understanding how patients perceive the disease state of POP and finding ways to improve care based on these perceptions may be the most important aspect in care of the patient with POP going forward. We have gone from POP being a physician defined anatomic disease to a patient defined quality of life disease. Future research should continue us on a course to best define
POP in populations to better understand the disease and for individuals to better define and document outcomes for therapeutic interventions.
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