Objective: The aim of this study was to describe how women experience vaginal mesh complications after optimized tertiary care level treatment.

Methods: We conducted telephone interviews in 2012 with women at least 6 months after presentation to our tertiary care clinic between 2006 and 2011 for complications related to vaginal mesh and transcribed verbatim responses to 2 open-ended questions about their experiences surrounding vaginal mesh complications. We analyzed data using qualitative description with low-inference interpretation in a team-based setting followed by consensus meetings to arrive at descriptive trajectories of their experiences.

Results: Of 111 women, we successfully contacted 88, and 84 agreed to the interview. The mean duration from index mesh surgery to interview was 4.5 years, and the mean duration from presentation to our clinic for complications to the interview was 2.3 years. The effects of mesh complications caused both physical and emotional pain, in addition to the discomfort of the original pelvic floor dysfunction. The women’s experiences followed 1 of 3 recovery trajectories. In “cascading health problems,” the women experienced a spiral of health problems, anxiety, and desperation. In “settling for a new normal,” the women who once considered themselves healthy now believed that they are unhealthy and worked to adjust to their degraded health status. In “returning to health,” the women described a return to health. The women still symptomatic discharged from tertiary care clinic expressed hopelessness and abandonment.

Conclusions: Concomitant with ongoing research to improve the safety of vaginal mesh procedures, there must be dedicated efforts to develop and study a range of therapies for holistically treating women with mesh complications.

Key Words: pelvic organ prolapse, stress urinary incontinence, mesh complication, vaginal mesh, qualitative analysis

(Pelvic Organ Prolapse/Urinary Incontinence/Reconstructive Pelvic Surgery 2014;20:131–136)

Pelvic organ prolapse (POP) and stress urinary incontinence are both common disorders among women, with up to 50% of the general female population developing POP and 30% developing stress urinary incontinence.1,2 As many as 19% of women will undergo surgery for POP by the age of 80 years.3 High recurrence rates associated with native tissue repairs for these disorders have increased the popularity of synthetic mesh procedures. Their prevalence has been followed by an increased incidence of complications specific to this repair method, as stressed in the 2008 Food and Drug Administration Public Health Notification4 and 2011 Update.5 Common complications include mesh exposure and contraction, with mesh exposure occurring in 10.3% of patients.6 Complications from vaginal mesh have a significant impact on patients’ quality of life. In a review of 2 tertiary institutions, 45% of patients presenting for mesh complications reported pelvic pain and 72% reported dyspareunia.7

Advances in the care of POP in the last century have become increasingly specialized and attuned to surgical options. In parallel with efforts to cure the physical symptoms of women with POP is a humanistic call to attend to women’s experiences as they undergo illness and treatment. Humanizing health care is not a call to seek complementary or alternative care, nor is it a rejection of the medical paradigm. Rather, humanizing health care is a movement that highlights the esthetic of care and communication with providers in tandem with the science of care.8,9 Qualitative research describes women’s experiences throughout the health-illness trajectory. The purpose of this study was to describe how women experience vaginal mesh complications after optimized treatment by tertiary care level physicians, a mean of 2.3 years after treatment and 4.5 years after mesh placement.

Materials and Methods

Participants in this qualitative research were women who presented to our urogynecology division for complications related to vaginal mesh between January 1, 2006, and December 31, 2011. They were identified by the following diagnostic codes: mesh erosion, 939.2; mechanical complication of graft, 996.39; pain due to genitourinary device/implant, 996.76; infection of genitourinary device/implant/graff, 996.65; unknown foreign body, 939.0; mesh excision vaginal, 57295; and mesh excision abdominal, 57296. Of these, only the participants whose initial surgery included a vaginal mesh kit for POP, an abdominal sacrocolpopexy with mesh for POP, or a suburethral mesh sling for urinary incontinence were included. Women presenting with complications from nonsynthetic grafts and from sutures were excluded from this study. We did not consider recurrent POP and/or incontinence as mesh complications.

After evaluation by 1 of 3 urogynecologists, the women underwent various types of treatments designed to optimize their presenting symptoms to the best degree possible; symptoms, therapies, and quantitative outcomes of treatments are summarized in a companion article.10 For the most part, therapies were administered by urogynecologic surgeons, a pelvic pain specialist, and women’s health physical therapists.

One hundred eleven women met the study criteria and were sent letters with a description of our project, notification that we would contact them, and options to either decline participation.
or request a mail-in survey instead of the telephone interview. In addition to validated measures described in our companion article, the interviewer asked 2 open-ended questions: (1) What can we do to improve our clinic to help women in the future with problems related to vaginal mesh? and (2) Is there anything else you’d like us to know about how your problems related to your initial surgery have affected you?

Two researchers conducted all telephone interviews and transcribed verbatim the women’s responses to the open-ended questions. Data were analyzed using qualitative description11 with low-inference interpretation. The goal of the analysis was to provide a straightforward, unadorned description of women’s experiences of mesh complications to humanize the experience as personal, contextual, and embodied. The data were downloaded into an Excel file and coded in a team-based setting, followed by independent coding and subsequent consensus meetings. Two researchers achieved consensus on the meaning, coding, and categorization of each response.

The University of Utah institutional review board reviewed this project before we began any data collection and concluded that it does not meet the definitions of Human Subjects Research according to Federal regulations.

RESULTS

Contact information was incorrect or outdated for 10 women, 1 woman was excluded because of language barrier, 1 was deceased, and 11 women did not respond to contact attempts. Thus, we were able to contact 88 women. Of these, 5 requested the mail-in paper survey (and 2 returned it) and 1 declined participation. Thus, 84 (76.1%) of 111 ultimately provided follow-up information. For these 84 women, the index surgeries in which mesh was placed were midurethral sling (29), vaginal mesh kit for POP (41), abdominal sacrocolpopexy (10), and vaginal mesh kit plus midurethral sling (4). The mean length of time from the index surgery in which vaginal mesh was placed to the interview was 4.5 years, and the time from presentation to our clinic for complications to the interview varied from 209 days to 6.5 years (mean, 2.3 years). For those women who provided qualitative data, the mean age at presentation to our clinic was 54.1 years (range, 30–81 years).

Sixty-four women were married or living as married (77.1%), 11 were divorced (13.3%), 6 were widowed (7.2%), and 2 were single (2.4%). Most women (72%) were referred to our clinic by someone other than the original surgeon.

Of the 84 women who were interviewed, 82 responded to question 1 (What can we do to improve our clinic to help women in the future with problems related to vaginal mesh?), and of these, 51 provided enough data to be coded for qualitative analysis to identify trajectories of recovery. Eighty-three women responded to question 2 (Is there anything else you’d like us to know about how your problems related to your initial surgery have affected you?), and of these, 71 provided enough data for qualitative analysis. Examples of data considered insufficient for coding were answers to question 1 such as “nothing” or “I have no complaints” or “you guys are fabulous.” An answer of no to question 2 rendered the data noncodeable.

The women described their experience with vaginal mesh related to both their perceptions of the initial mesh placement/subsequent treatment of complications and how such complications have affected their daily lives.

The effects of mesh complications caused both physical and emotional pain, in addition to the discomfort of the original pelvic floor dysfunction. Living with that pain, the women’s experiences followed 1 of 3 trajectories: cascading health problems,
settling for a new normal, and returning to health. These paths share some characteristics but remain distinct in the severity and the resolution of the mesh complications in terms of the women’s everyday lives. Figure 1 illustrates the relationship of the major codes to each of the 3 trajectories and areas of experiential overlap between the trajectories.

The women with experiences following all 3 trajectories described physical symptoms, such as pain, bleeding/spotting, or discharge. These symptoms, especially pain, were generally described with more severity among the women with cascading health problems and those settling for a new normal.

Cascading Health Problems

Nine women had cascading health problems and felt that their health was out of control. They expressed experiencing a spiral or cascade of health problems attributed to the mesh complication that left them feeling that they had run out of options to regain their health. They felt anxious, discouraged, and desperate as they felt that their health was persistently deteriorating. Their descriptions of their health were emotional and evocative.

The uncertainty of cascading health problems required the women to be vigilant, watching for changes in health status. “This is a very emotional thing. Every time something unusual happens to me, I wonder if it’s the mesh. Now I feel like I can’t stay out of the hospital. It’s very scary.” Part of the vigilance was monitoring known complications and constantly wondering whether new problems were related to the mesh.

“I have to constantly think about and worry about infections.”

“I was thinking she’d be able to take all the mesh out, but I wonder if the remaining piece is where the pain is. [I’m] still worried about remaining mesh.”

Hope for a pain-free, symptom-free future was dampened for the women who had been told by their physicians that little more could be done to alleviate their mesh placement symptoms. Many accepted this and drifted into hopelessness. Others were critical of what they perceived to be the inability or unwillingness of their physician to help them.

“I wish it could be fixed.”

“I hope the pain and ache goes away, but I’m told it will likely not, which is depressing but not surprising.”

“I wanted someone to tell me they could help me, I was alone and afraid. Elsewhere they were able to do that.”

The women’s imagery of the mesh emphasized its “otherness” inside their bodies and its unpredictable effects. They envisioned the mesh as a foreign body ruining their health from within.

“Not all of the mesh is out so I still have some problems.”

“The mesh is balled up and I think it affects my bowel movements.”

The women perceived a sense of danger or injury from vaginal mesh. “I felt like a victim and afraid.”

“If there was any way you could help educate women in the dangers of surgical mesh…”

Two women captured the severity and the constancy of the pain for the women with cascading health problems: “I hurt all the time, all day, every day. I have not woken up pain-free since the surgery. I don’t know if I will ever not have pain again, which is very frustrating.” Another added descriptive language, saying that the pain was “awful” and like being “ripped apart from the inside.” If the mesh was not removed, she feared that she would endure the ripped-apart feeling for the rest of her life. The buffer of resources the women used to cope with their cascading health problems and the uncertainty of new symptoms was often depleted after months of difficulties related to their complication. The depletion was emotional but also practical.

“I’ve used up all of my sick pay and much of vacation,” said 1 woman.

Settling for a New Normal

The women who once considered themselves healthy individuals now believe that they are unhealthy. Thirty-two women followed this trajectory. Their stories were longer than those of the women whose mesh complications had resolved and frequently held more emotion. Their symptoms and complications were static, although for some women, these stable conditions were still unpleasant and relentlessly bothersome. The women settling for a new normal felt that their degraded health status was permanent. Some women had come to peace with this change; others had not. They were all, however, in some stage of adaptation or acceptance to what they perceived to be the new normal.

These women experienced a spoiled identity as a result of mesh complications. They describe a sense of not returning to the state they were in before mesh surgery, which was already a state of coping with a health condition. They experience degraded self-esteem and body image or have lost their sense of femininity.

“It’s really diminished my self-esteem. It has diminished my health … I used to consider myself a lovely woman—I don’t anymore.”

“I’m only about 15% the person I used to be.”

“I just never did bounce back to what was normal—as good as I felt when I went in.”

“Everything has changed. Really—mentally, physically, emotionally—I am a different person. It’s hard. I was a superstar, high-performing person and the mesh just put me down. I misjudged people who have health issues—I used to have no patience. It is the challenge of my life.”

The women settling into a new normal health state were adapting to loss of function and altering their lifestyles to accommodate problems related to mesh complications. Some dealt with daily predictable, annoying symptoms. Others coped with a diminished quality of life they directly attributed to mesh complications.

“It has destroyed my life. I cannot drive, I cannot travel, I cannot watch movies, I cannot wear heels; I can’t drive my car because it’s painful. My life has totally changed.”

“I had expected the surgery to make my life better, but it has permanently altered my life in multiple ways … many of them are devastating.”

“It’s hard to live with this, constantly, especially when I am traveling and have to be constantly changing my pads. It’s changed my lifestyle—it’s most unpleasant.”

“The initial surgery took a year off my life.”

“It’s almost [begins to choke up] ruined it [my life].”

Some women grew too emotional to discuss how the mesh has impacted their lives.

“[I] can’t go into how this has changed my life right now” (said weepily).

“I can’t even think about it [how the initial surgery has affected her] because that’s when the depression kicks in.”

The women settling for a new normal shared many experiences. They most notably regret, compromised intimacy, and unhappiness. They frequently mentioned their original mesh surgery or surgeon as part of their personal complication experience. They also expressed feelings that their emotional health had been compromised.

Both the women who are settling for a new normal and those with cascading health problems regretted having mesh placed. They felt as if they did not understand the risks for complication before surgery and would not have gone through
with the surgery if they had. Some blamed the surgeon and did not believe that their physicians fully explained the risks.

“He [the original surgeon] was irresponsible, he did not explain to me any consequences, he was dishonest, he said the surgery would be easy for me, I was so much worse.”

“I wish I had never had it done. The doctor who placed it was supposed to be a good doctor, but it really messed things up and made my life miserable for a while.”

“I wish I hadn’t had the surgery. The mesh was probably the worst thing I’ve ever done.”

“I wish I had never had the mesh surgery on my bladder. I don’t think it helped the problem and just created a new problem.”

Because of their negative experiences with the mesh, many women felt the need to warn or educate other women against its use. They suggested that physicians use more caution with the product or stop using it altogether.

“I just want help because that doctor—he closed his clinic and moved to [another state]. And he is still doing those surgeries on other women.”

“Let everyone know not to get mesh.”

“Never have vaginal mesh. You should go to another doctor if they suggest it to you. I hate it; it’s not good for anything. Has totally ruined my life.”

The women experienced significant problems with sex either for an extended period or persisting until the interview. They found intercourse painful, felt as if their sex life was ruined, were unable to have any sexual relations, or were afraid to try. These issues had a negative impact on the women’s relationships.

“It took a big toll on my marriage as we were unable to be intimate for a year and a half.”

“I haven’t been able to have sex since my surgery. I told her how important my sex life was with my husband but she acted like it didn’t matter.”

“I’ve had gentlemen ask me out and I’ve hesitated because I wouldn’t want to face marriage not knowing how that [sex] would be affected, so I avoid it.”

“Not being able to have sex is causing my married life to just fall apart. All that testosterone [my husband has] and no release is just ... I’m always upset and he is too. It’s awful.”

The women experienced isolation from people and relationships. They felt frustrated, devastated, and miserable. Some felt as if they were living in their personal hell or nightmare in their new, postmesh “normal” state.

“I feel like I’ve lost my family.”

“I can’t imagine anyone was any worse than me. My life was hell for 5 to 6 years.”

“I can’t function as a woman; I don’t feel like a woman. I don’t know how I will possibly find a relationship.”

The range of experiences in the settling for a new normal trajectory were varied, with some women making modest adjustments to accommodate changes in their physical health and others merely settling into a new and unpleasant state of compromised well-being physically and emotionally.

**Returning to Health**

Ten women described their experience with vaginal mesh complications as returning to health and a resolution of symptoms and issues. They tended to answer succinctly and did not express significant emotion throughout the interview. Although some women mentioned their initial problems from mesh complications, the responses were focused on their return to health in a broad sense. Minor lingering symptoms persisted for some women, but their overall trajectory of recovery was still positive. The women were no longer concerned with their initial mesh placement and did not discuss the original surgeon. These women are no longer experiencing the symptoms that caused them to seek treatment of mesh complications.

“The repair surgery made everything better. It [the mesh and related problems] had incapacitated me for 2 years. It was horrid before, but so much better [after the mesh removal].”

“I feel 100% better since I had it fixed.”

For some women, the benefits of mesh as a treatment of POP outweighed the drawbacks of their complications. If given the chance, these women would make the same decision regarding surgery with vaginal mesh.

“It wasn’t that big of a deal. The complication was little and I would do the surgery over again.”

Treatment of mesh complications left many women with a sense of relief after a previous state of desperation. This was experienced by the women whose complications resolved as a result of treatment.

“I was desperate when I came there; I was in bad shape. I was thoroughly dissatisfied [with my initial surgery] and it was a relief to find someone who understood and knew what to do ... There are no long-term effects.”

This sense of relief was also experienced by those whose symptoms had improved with treatment, even if remaining symptoms still detracted from their overall quality of life to some degree. The women worked around mesh complications so as to enjoy life in much the same way as they had before mesh placement. They talked about taking a flexible approach to their lifestyle, sex life, or incontinence management in the process of returning to health.

“I still have some ongoing problems. I am creative and try to adjust and work around the problems, but sexual relations with my partner are not enjoyable a lot of the time.”

Some found relief from mesh complications through nonmedical means.

“I went through extensive counseling for my bowel, and that was huge. They [provider of bowel counseling] taught me what to eat, when and how to eat. It kept me from being an invalid—I can actually control it now.”

**DISCUSSION**

We identified 3 trajectories through which women experience vaginal mesh complications: cascading health problems, settling for a new normal, and returning to health. In this sample, a minority of the women interviewed fell into the returning to health trajectory. Most continued to have problematic recovery trajectories, even after a mean of 2.3 years from treatment of the mesh complication and 4.5 years from index surgery.

The women who seek care for mesh complications are already adjusting to a chronic pelvic floor dysfunction that alters body image and personal relationships and changes intimacy practices. Women report emotions such as self-consciousness, embarrassment, self-blame, unnaturalness, shame, and reluctance to seek care. They are in a process of adapting to successive impairments. The processes of changed expectations and adjustment to chronic conditions have been discussed in relation to other health conditions and are relevant to women with pelvic floor dysfunction. In a qualitative analysis of 14 women awaiting surgery for POP, themes expressed included women’s role limitations, poor sexual function, restricted physical activity, and decreased self-esteem. The difference between our findings and the themes from the study of women awaiting surgery for POP is the sustained, emotional, and life-changing trajectory of women who experience repair of mesh complications. The severe pain, despair, and permanent loss of physical and socioemotional health among women with mesh complications are notably amplified.
In addition, the women in our study had expectations before mesh placement that were completely reversed after the surgery. Taken in this context, the perceived failure of mesh placement constitutes an identity stressor, precipitating a perception of spoiled identity for some women. The necessity to redefine one’s identity has been discussed in the context of disability, in which participation in collective strategies such as activism has been correlated with self-esteem. The aftermath of perceived failed treatment has been discussed in the context of epilepsy surgery by Derry and Wiebe, who pointed out that “failure is a judgment based on pre-operative expectations” and advised the careful shaping of pre-operative understandings, information, and counseling to appraise the outcomes and postsurgical support groups.

After the Food and Drug Administration Public Health Notification and the release of the American Urogynecologic Society Informed Consent Toolkit, physicians now have improved information on which to shape presurgical expectations. Our study suggests that patients would value longer follow-up by their original surgeons to identify and manage complications. The psychological effects of those complications may be less severe the sooner these are addressed.

Many patients with vaginal mesh complications experience degraded emotional health, which is often not addressed by the physicians with whom they have sought treatment. We also rarely address the fact that they have been adjusting, in various ways, to pelvic floor dysfunction for years and are now in the process of adapting to successive impairments. Busy clinic schedules and the short-term nature of tertiary care often prohibit in-depth discussions about body image, personal relationships, changed intimacy, and other changes women experience after sustaining complications from mesh surgery—yet, many women have no one else with whom to share these troubling issues. Patients seeking care in tertiary centers are discharged when their complications have resolved or their physicians feel that they have exhausted all treatment options. Some of our patients surveyed described feeling hopeless when we informed them that “there was nothing else we can do” and also perceived this statement as an unwillingness to help.

We undertook this quality improvement project to better understand how women fare after we have treated them for their mesh complication to the best of our abilities. Two key facts stand out: (1) concomitant with ongoing research to improve the safety of vaginal mesh procedures, there must be dedicated efforts to develop and study a range of therapies for holistically treating women with mesh complications and (2) surgeons, in particular those at tertiary care centers caring for women with mesh complications, should recognize the emotional journey these women are on and take time in the clinical encounter to acknowledge the changes wrought in their lives. On the basis of the fact that most women fell into the 2 negative trajectories, we believe that tertiary care centers should provide a counseling component as part of a multidisciplinary care team. Because many women live remotely from the tertiary care center, this could take the form of a telephone- or web-based intervention.

We welcome creative solutions to address the problem of women feeling abandoned when discharged from the tertiary care center, their clinic of last resort. It is impractical and expensive to see patients frequently after our therapies have been optimized, and indeed, continuing visits to a surgeon creates the impression that surgery is still possible to cure the patient’s symptoms. Focus groups with patients experiencing mesh complications could be helpful in identifying strategies to aid women in each of the identified trajectories. We should also encourage collective strategies such as support groups, which are associated with improved self-esteem. More research is needed to determine what types of groups (ie, online, telephone, face-to-face) would provide the kinds of support best suited to women in each recovery trajectory.

The strength of this study lies in the patient perspective provided by our qualitative analysis. Although a quantitative study can show that vaginal mesh complications frequently affect quality of life, this study shows the extent to which those lives have been affected in a manner not feasible by quantitative methods. Other strengths include the large sample size and long-term follow-up (mean of 2.3 years from initial presentation and 4.5 years from initial mesh placement).

There are limitations to our study. Our results are not representative of all women with mesh complications, only those seeking treatment in tertiary care centers. However, as cited in our companion article, only 45% of the women seen in our clinic had previously been treated for mesh complications, and only 18% of the women who provided qualitative data had undergone further treatment of mesh complications since they were last seen at our clinic. Most women were being seen in our clinic for the first time. In addition, open-ended responses were shorter than those typically used in qualitative analysis. Many women continue to experience vaginal mesh complications, even after their physicians believe that they have been successfully treated. More than half of the women who responded consider their outcomes unsatisfactory after optimized treatment in a tertiary care center. This study suggests that we need to develop and study a new and increasingly humanistic framework for treating vaginal mesh complications.

REFERENCES


