

Sexual Health–related Quality of Life in Women with Pulmonary Arterial Hypertension Compensating for Loss

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Abstract

Rationale: Health-related quality of life in patients with pulmonary arterial hypertension (PAH) has become increasingly important in disease management as numerous treatment options have improved prognosis and time to clinical worsening. Sexual health–related quality of life (SHRQoL) is poorly understood in patients with PAH, but previous work has shown that patients may face unrecognized challenges, especially related to parenteral prostanoid analogue therapies.

Objectives: Using qualitative methods, to describe challenges and perspectives related to SHRQoL among women with PAH.

Methods: We conducted 13 semistructured in-depth interviews at the Pulmonary Hypertension Association’s International Pulmonary Hypertension Conference and Scientific Sessions among female attendees with World Symposium on Pulmonary Hypertension group 1 PAH. A coding structure using both deductive and inductive coding was developed to organize and analyze data using applied thematic analysis. Salient themes were identified and are presented here using summary and illustrative quotations.

Results: Ninety-two percent (12 of 13) of participants reported declines in the frequency of sex after diagnosis of PAH. A

significant portion (62% [8 of 13]) experienced fear of having sexual intercourse because of cardiopulmonary symptoms. All participants (100% [13 of 13]) reported compensatory behaviors/strategies during and around sexual intercourse; some participants on subcutaneous prostanoids also reported timing intercourse to coincide with infusion site changes and, as a result, interrupted treatment during this time. Participants reported changing positions during sex to reduce breathlessness, and some reported removing oxygen to avoid interrupting intimacy. Most participants endorsed negative body image related to their medications, external oxygen supplementation, and/or body weight fluctuations (54% [7 of 13]). Many participants revealed that they had never discussed sexual practices with healthcare professionals and desired increased communication and discussion with their providers.

Conclusions: Women with PAH face significant burdens and challenges regarding SHRQoL. PAH therapies directly affect SHRQoL. Further targeted qualitative and quantitative studies are needed to better characterize and improve SHRQoL in patients with PAH.

Keywords: pulmonary arterial hypertension; sexual health–related quality of life; prostanoid analogue–related side effects; quality of life; patient-centered care

(Received in original form June 10, 2021; accepted in final form February 2, 2022)

Supported by a 2015 CHEST Foundation research grant and National Heart, Lung, and Blood Institute grant R01-HL141268.

Author Contributions: D.C.Y.: interview coding, analysis, and drafting and revision of the manuscript. D.B.: study concept and design, conduct of interviews, and revision of manuscript. S.E.V.: analysis and revision of manuscript. M.A.: view coding and analysis. M.E.W.: review of analysis and revision of manuscript. N.P.: review of coding and analysis. C.E.V.: study concept and design and revision of the manuscript. K.M.G.: conduct of interviews, review of coding, analysis, and drafting and revision of the manuscript.

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This article has a related editorial.

Ann Am Thorac Soc Vol 19, No 7, pp 1122–1129, July 2022

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DOI: 10.1513/AnnalsATS.202106-692OC

Internet address: www.atsjournals.org

Pulmonary arterial hypertension (PAH) is a debilitating disease in which pulmonary vascular remodeling leads to activity limitation (1). Therapeutic developments have significantly improved prognosis and time to clinical worsening (2). With myriad treatment options now available, health-related quality of life (HRQoL) is an increasingly important component of disease management (3, 4). Despite a more consistent focus on HRQoL in PAH research, *sexual* health-related quality of life (SHRQoL) in patients with PAH is not well understood (5).

SHRQoL may be uniquely affected by PAH and its treatments. Two studies in Europe and China that focused on general HRQoL noted impacts on intimacy and intercourse in patients and partners/caregivers as a result of PAH (6, 7). Studies among patients with other chronic pulmonary diseases similarly demonstrated that patients fear experiencing dyspnea during sex and have varying degrees of sexual dysfunction (6–8). Targeted PAH therapies alleviate the physical limitations of PAH, but how these gains are balanced against HRQoL for individual patients is not known. Patients with PAH may experience sexual dysfunction related to PAH therapies themselves, as pumps, catheters, and skin sites required for continuous infusion therapies present physical challenges to sexual intercourse; phosphodiesterase inhibitors may also have off-target effects on sexual function (5).

Neither uniform guidelines for the management of PAH nor validated clinical measures to evaluate SHRQoL in patients with PAH exist (5). Consensus guidelines for sexual activity among individuals with left heart disease issued by the American Heart Association note both the importance of psychosexual counseling and the limitations in physician knowledge and training in this area (9). Adding to the existing uncertainty among both providers and patients, sexual health and sexual practices are sensitive topics for many providers (and patients) and are often overlooked, especially in patients with complex disease (10).

We previously noted a high prevalence of sexual dysfunction in a convenience sample of patients with PAH (5). High degrees of sexual dysfunction were observed in women treated with parenteral prostanoids. Statistically significant differences in sexual dysfunction scores

across functional classes or with different treatment modalities were not noted, calling into question whether the current available HRQoL measures adequately capture the complexities of sexual health in this population. This analysis builds on those data, with the goal of better characterizing SHRQoL via semistructured in-depth interviews (IDIs).

Methods

Participants

Participants were patients with self-reported histories of World Symposium on Pulmonary Hypertension group 1 PAH who attended the 2016 Pulmonary Hypertension Association (PHA) International Pulmonary Hypertension Conference and Scientific Sessions. Pulmonary hypertension diagnoses were collected by the PHA Conference Research Room program and shared, with patient permission, with all researchers approved to conduct research at the meeting.

Procedures

Conference attendees were invited to participate in Research Room studies. Volunteers approached research staff members and were given a study description. Written informed consent was obtained, after confirmation of group 1 status (self-report and/or medical data). Participants were assigned unique research identification numbers to maintain confidentiality. Volunteers were informed of study goals before and during the consent process. Researcher interests in the conduct and outcome of the research were divulged as per participant interest during orientation to the study. Demographic and medical data were collected by the PHA online before the conference or by PHA staff members in the Research Room. Participants were interviewed in private for 60–90 minutes: no participants withdrew before study completion. Trained female interviewers (one a clinical psychologist, one a pulmonary physician) with combined experience conducting patient-oriented qualitative research of more than 20 years (K.M.G. and D.B.) used a semistructured interview guide designed to elicit 1) sexual experiences in the years leading up to a diagnosis of PAH, through treatment stabilization, and thereafter (including therapeutic transitions); 2) perceptions of barriers and facilitators' sexual activity, including participants'

perceptions of partner barriers and facilitators; 3) childbearing and/or contraception experiences; and 4) discussions about sex with healthcare providers. No prior relationships between interviewers and participants existed. IDIs were audio recorded and transcribed verbatim. The study was approved by the PHA Conference's Research Room Leadership Committee and the Rhode Island Hospital institutional review board (#408516).

Data Analysis

Applied thematic analysis was conducted by a team of analysts (K.M.G., M.A., S.E.V., and C.E.V.) who developed a coding structure on the basis of the interview agenda (deductive), as well as emergent topics raised by participants (inductive) (11). Each transcript was independently coded by two coders, who then entered agreed-on codes into NVivo qualitative data software (QSR International). The coding team met regularly to discuss codes, clarify definitions, and track use. Codes associated with key research questions were reviewed, summarized, and interpreted (D.C.Y., K.M.G., and C.E.V.). Illustrative quotes were identified for presentation.

Results

Thirteen women with PAH completed IDIs and specifically discussed the topics presented here. As per methods guidelines by Guest and colleagues (2006), and according to our own review of results, data saturation was achieved on primary aims (12). The average age was 46 years, and the most common race was White. Average time since diagnosis was 4 years, and the most common etiology was associated with connective tissue disease or idiopathic. The vast majority of participants ($n = 10$) were in World Health Organization functional class II. Of those reporting therapies, 4 participants were on intravenous or subcutaneous prostanoids, and the majority were on endothelin receptor antagonists ($n = 8$) or phosphodiesterase inhibitors ($n = 7$). See Table 1 for specific demographic and medical information.

Effortful Behavior

Participants with PAH unanimously reported experiences of breathlessness, fatigue, and pain during sex, with nearly all participants also noting decreases in the

Table 1. Participant characteristics (N = 13)

Characteristic	Median (IQR) or n (%)
Age, y	46 (33–68)
BMI, lbs, in ²	27 (25–30)
Ethnicity	
Hispanic	1 (9.1)
Not Hispanic	10 (91)
Race	
Black	1 (8.3)
White	9 (75)
Other*	2 (17)
PAH diagnosis	
Associated with congenital heart defect	1 (8.3)
Associated with connective tissue disease	4 (33)
Heritable PAH	1 (8.3)
Idiopathic PAH	6 (50)
Years since diagnosis	4 (2–10)
WHO functional class	
I	1 (7.7)
II	10 (77)
III	2 (15)
Intravenous or subcutaneous prostanoids	4 (36)
Oral therapy only	7 (64)
Oral or inhaled therapy	11 (100)
Phosphodiesterase type 5 inhibitors	9 (82)
Endothelin receptor antagonists	8 (73)
Riociguat	0 (0)
Oral prostanoids	1 (9.1)
Inhaled prostanoids	1 (9.1)
Calcium channel blockers	3 (27)
Loop diuretics	8 (73)
Oxygen use	6 (46)

Definition of abbreviations: BMI = body mass index; IQR = interquartile range; PAH = pulmonary arterial hypertension; WHO = World Health Organization.

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frequency of sex after diagnosis ($n = 12$ of 13 [92%]; Table 2). One participant remarked that she gets short of breath with normal activities, so during sex, she can only “just [lie] there and [do] nothing.” Another reported that sex felt “like a ton of bricks” on her chest, while another noted that she has to rest during sex because the effort of sexual activity is so exhausting. Still another participant described a confluence of symptoms during sex (see Table 3, quotation 1 [T3Q1]). This same participant reported overall daily fatigue that interfered with the frequency of sex (T3Q2, T3Q3).

One participant made a clear distinction between her *desire* to have sex and the limitations of sexual activity as a function of her PAH. “I don’t really think [PAH] affected . . . *desire*.” Despite having unencumbered desire, she went on to describe the physical limitations to comfortable intercourse, identifying the challenges presented by specific sexual positions (“top” vs. “bottom”) and the compromises inherent to each (T3Q4).

The Etiology of Fear

Participants reported a range of fears and concerns associated with sexual activity, both from prior sexual experiences and in anticipation of worsening PAH. Many reported fears of experiencing breathlessness

and increased heart rate, as well as lacking the energy required for sexual activity ($n = 8$ of 13 [62%]; Table 2).

Before PAH diagnosis, participants described increasing breathlessness without a known cause, creating a cycle of avoidance of physical activities and deconditioning, making sexual activity increasingly effortful and leading to greater concerns about physical activity tolerance. Participants reported avoiding many activities that cause breathlessness, including sex. This feed-forward trajectory contributed to decreases in sexual desire for many and a shift in primary focus to concerns about health, as illustrated by these voices: “I was so consumed by my health”; “My health takes up a lot of my energy.”

Impact of Therapeutics

About half of the participants commented on various medication side effects, as well as the interaction between these side effects and changes in body, mind, and quality of life ($n = 6$ of 13 [46%]; Table 2).

Supportive Therapies. Lubrication was noted to be a common issue in the context of sexual health side effects. For one participant, “moisture tends to be a problem,” which she attributed to furosemide. Another similarly noted that sex after starting treatment felt like her “insides were being torn apart,” an experience her doctor also attributed to inadequate lubrication. Two participants noted their frustration that they could not use hormonal creams for vaginal dryness and to increase lubrication because of provider concerns of thromboembolic complications.

Table 2. Summary of interview topics and participants affected

Experiences Discussed	Number of Participants	Percentage
Decline in frequency of sexual intercourse after diagnosis	12	92.3
Fear of experiencing symptoms during intercourse	8	61.5
Negative impact of therapeutics on SHRQoL	6	46.2
Interruption of subcutaneous or i.v. therapies during intercourse	2	50.0*
Impact of disease on primary relationships	9	69.2
Conflict with partner over intercourse	5	38.5
Compensatory behaviors to overcome symptoms during intercourse (positioning during sex, foreplay)	13	100
Negative body image related to therapeutics (tubing, lines, scars, weight gain)	7	53.8

Definition of abbreviation: SHRQoL = sexual health-related quality of life.

*Percentage based on total number of patients on subcutaneous or intravenous prostanoids ($n = 4$).

Table 3. Illustrative quotations

Concepts/Themes	Description/Explanation Illustrated in the Data	Quotation Number	Illustrative Quotation
Effortful behavior	Confluence of symptoms experienced during sexual activity	Q1	"My heartrate, like I can see on my Fitbit, will go up to like 150's, 160's even, and a few times, I have felt like really short of breath, and I'm like grabbing the oxygen and checking my sats, and my sats can . . . drop down to the 80's and stuff."
	Frequency of sexual activity affected by fatigue	Q2	"I was just fatigued all the time, always tired, and I was going to bed earlier; and on my days off, I would just sleep all day . . . so it definitely affected the [frequency of sex]."
		Q3	"As soon as I . . . get into bed . . . you got like a five-minute window cuz I'm gonna fall asleep."
	Positioning limitations during sexual activity	Q4	"We haven't found any position that . . . is without difficulty . . . [when I am on the top during sex] I'm doing more of the work, so then my heartrate goes up more . . . [when I am on the bottom] it is easier to keep oxygen on, but, the problem is the weight [of my partner] is putting more pressure, so it's squeezing, which makes it harder to breathe."
Impact of therapeutics	Quality of life, self-esteem, body image with oral medications	Q5	"When you get back . . . I was on meds. I could do sports again. I could move. I started to feel better about myself, as well, and that gives you back some more confidence So that's why I'm saying, when you're more confident with your body . . . you feel better. You feel more open and more relaxed."
	Removing pump during sexual activity	Q6	"[When I remove the pump during sex] I feel good. I feel desired. I feel uninhibited. I feel awesome as a woman not having to worry that he's looking at [this pump. 'You're] not seeing me being sick. You're seeing <i>me</i> .' That's when I will wear the lingerie."
Impact on relationship	Perceived partner fears of disrupting pump during sexual activity	Q7	". . . he flips over and he says he wants to snuggle . . . he's afraid of interfering with the pump . . . he's afraid to touch, [saying] 'where [are] we going with the pump . . .?'"
	Participant guilt over declining to engage in sexual activity	Q8	"So you decide how tired are you that night to be able to say, 'Babe, I'm too tired tonight.' And I try not to use it that much because, if I do, I want him to know that I'm really too tired that night."
	Partner support for discontinuing sexual activity	Q9	"He was never that guy that just didn't listen to you... he always listened . . . Usually, you could hear when I was really [wheezing] so it didn't need too much communication. I just said, 'I really can't.' and he's like, 'Okay.'"
	Relationship conflict over decreased frequency of sexual activity	Q10	"He'd get upset . . . I think he would feel like I was, like rejecting him, when really it's just that I was tired and couldn't breathe. . . . A lot of that's what led up to me leaving . . . he was taking it personally, against him, instead of understanding that this is me being sick now."
Compensatory behaviors	Timing of activity for availability of contraceptive devices	Q11	"I mean, you have to think about it beforehand . . . it's more of a planned event. . . . You always need to think, okay, do I have something with me or not?"
	Self-conscious in public using assistive devices	Q12	"I look like an idiot. Like everybody's looking at me like, 'This fat girl's too lazy to walk around' . . . they look like, 'There's nothin' wrong with her.' . . . nobody knows what PAH is."
Resilience	Participant perspective on priority of sex in overall quality of life	Q13	"[Sex] is kind of like, on your list of priorities, way down and you want to be able to do the other stuff first. . . . I want functioning. I want to work. I want to walk somewhere. And then comes sex. I don't feel frustrated about sex or not being able to have sex because I just want to first be able to walk somewhere."
	Participant perspective on resilience in the face of disease	Q14	"Husband's tired . . . he comes home from work, he's tired. And the weekends, he's tired. But I've been sick, so his buddy [the patient-participant] can't go out and do much gardening with him as she used to. If I've changed site, I can't jump on the tractor and go cut grass . . . I can't be

(Continued)

Table 3. (Continued)

Concepts/Themes	Description/Explanation Illustrated in the Data	Quotation Number	Illustrative Quotation
	Creativity to maintain satisfactory sex life	Q15	doing that and bouncing around on it. [And at another point in the conversation] If you're gonna go down swinging, you might as well go down that way . . . you've gotta do what you feel . . . if you feel like going for it and you're gonna be short of breath for 20 min to half an hour afterwards, go for it. . . . If that is what feels good at the time, you do it. Don't stop. Just carry on your life as normal as you can."
Role of healthcare providers	Discomfort discussing sexual experience with providers in PAH versus other sources of SHRQoL information and support	Q16	"[Talking about sexual experience and functioning are] scary subjects for some women: 'I don't get pleasure from sex the way we used to because I'm dry. I need something else. Meaning I need lube. Maybe I need a toy.' . . . Those are very uncomfortable conversations, maybe, for some women."
		Q17	"I mean . . . Because nobody tells you . . . and these are the questions. Who are you gonna tell this to? Who are you supposed to ask this to?"
		Q18	"I think that I see more people in the online communities. . . . Because people are more comfortable there, and then, also, they have more anonymity there, so they'd be more likely to access it and ask."

Definition of abbreviations: PAH = pulmonary arterial hypertension; SHRQoL = sexual health-related quality of life.

One commented that she uses a vaginal cream but that it does not improve her lubrication enough to make vaginal sex a normal part of her routine. Other participants with histories of lubricant use noted an increasing need for supplemental lubrication during intercourse.

Several participants reported a range of medication effects, not associated directly with libido, breathlessness, or fatigue during sex, that they believed affected their experience or quality of sexual activity. For example, one participant noted that anticoagulants "hinder sex because your period's lastin' like seven, eight days!" Despite difficulties breathing from the effort, weight, and physical pressure of sexual activity, some participants disclosed that they remove their oxygen during sex, and choose an optimal position, because they believe the oxygen is "a turnoff," especially during foreplay.

Targeted PAH Therapies. Participants who were treated and improved with targeted (oral and parenteral) PAH medications noted that they were able to return to more normal daily activities such as exercise, and their global quality of life improved (T3Q5). No participants

mentioned phosphodiesterase inhibitor side effects as affecting their SHRQoL.

Although participants who were successfully treated with oral and inhaled medications continued to contend with breathlessness and fatigue in their sexual activity, participants treated with parenteral therapies noted additional functional and logistical challenges surrounding the physicality of sex. Several reported the need to consider pump location itself during sex: placing it under a pillow, setting it to the far side of the bed, or hanging it from a hook on the wall or headboard. Another reported putting her pump in a money belt to more freely be able to move it around during sex. Tubing can also be obstructed or disconnected during sex; one participant noted that she takes the time to tape tubing down so it does not get tangled or in the way during sex. Another participant noted that inhaled treprostinil causes her to cough after inhalation, limiting sexual positions to those least likely to aggravate coughing.

Some participants on subcutaneous treprostinil therapy reported timing sexual activities to coincide with infusion site changes, disconnecting completely from

treprostinil infusion, and having sex before starting a new infusion site. One noted that when she does a site change and takes off her pump, she feels more freedom during intercourse (T3Q6); she also noted that the lack of tubing allows her to concentrate on her partner rather than worrying about her site being disrupted (T3Q6). Another noted that she cannot disconnect her pump for long before experiencing symptoms of chest tightening and losing her breath; she noted, "The half-life of [drug] is not that good. But it's good enough to get you by! Right?!"

Finally, participants on parenteral therapies had additional concerns, from the very functional concerns of where to position pumps and cannulas, and sites becoming dislodged (e.g., "Don't unplug. . . . If I have to do a new site, I'm gonna kill you [sexual partner] 'cuz of the pain"), to the more emotional and relational concerns of "killing the mood" because the participants had to remind their sexual partners to be careful and because they were afraid that they would not be able to enjoy sex or even the buildup to sex (e.g., "I'm scared. . . . I haven't [had sex since diagnosis] because I am . . . afraid"). Site pain from treprostinil

therapy was so significant that, as one participant noted, it was the primary reason for her decision to avoid dating.

Impact on Relationships

Patient-Participant Concerns. Many participants noted concerns about the impact of PAH on their primary relationships ($n = 9$ of 13 [69%]). One woman noted that she was scared and worried that she would not be able to maintain her relationship: “[I worried] that I wouldn’t be able to hold my own. Will [I be able to] be intimate, like giving love, affection, attention to my partner?” Some participants reported feeling guilty about their disease and its impact on their relationships overall, as well as its impact on their decreased interest in sexual activity and physical limitations during sex. Participants noted guilt regarding how much time and effort their PAH treatment requires of them and their family members and/or caregivers; one surmised that her partner probably feels as if her life revolves around PAH, with its medication regimens and restrictions. Another surmised that her husband may also be more tired because of the need for him to take on more of the household responsibilities that she used to take care of: “We always did everything together. Always. So . . . is his tiredness coming home from work and having to do all this extra work himself taking down his drive and desire?”

Participants realized that their reduced (or nonexistent) desire for sex led to decreases in the frequency of sex, which strained their relationships: “[She thinks to herself] ‘Oh, my god. Poor bugger.’ It’s like, what have I done to him?” Another participant reported that she would occasionally desire sex but would tell herself that she would feel worse afterward because of exacerbated symptoms, causing inner conflict and leading to relationship disengagement. Some participants described blaming themselves for limitations on sex, being exhausted physically and mentally from their focus on their health and being concerned about the logistics of sex in the context of parenteral therapy: “It’s my fault. It’s me. It’s me.”

Partner Concerns. In addition to personal fears and anxieties about sexual activity, participants also noted fears expressed by their sexual partners: being afraid of disrupting infusion sites, concerns about comorbid conditions that could be exacerbated during sex (e.g., atrial

fibrillation), concerns about how a participant’s physical responses to sexual exertion (e.g., increased respiration) reminded partners of PAH symptoms, and partners’ overall concerns about the appropriateness of having sex when one has PAH. This is illustrated by one participant’s comment that provides a glimpse of the nuance and how the dynamic affects the relationship further: “I could get short of breath sometimes, but . . . I think he’s more scared than me . . . he’s scared to touch me.” Another participant described the dynamic similarly (T3Q7).

Conflict and Support. Approximately one-third of participants noted conflict with their partners in the context of sex ($n = 5$ of 13 [38%]). On one hand, participants themselves tried to balance symptoms, fears, and their/their partner’s needs and desires themselves, with little, if any, communication. One participant admitted to faking orgasms to end sex early and “sneak[ing into] bed” to avoid having sex. Another admitted to getting extremely tired during sex but allowing her partner to continue, seldom asking him to stop, “because I love him.” Still another participant noted that sex was very important to her partner, and she notices that he is not in a good mood if they do not have sex for a week or two (T3Q8). On the other hand, participants also shared stories of communication and support with partners who turned down intercourse when their significant others was too symptomatic (T3Q9). Another noted that even though her partner misses their prior frequency of sex before her diagnosis of PAH, he is patient and tells her, “I’m not gonna push you.”

The initial PAH diagnosis itself triggered substantial conflict in several instances; a few participants even noted that their partners at the time left the relationships when they were diagnosed. One of these women noted that her boyfriend “dumped [her]” right after her diagnosis because he “wasn’t going to deal with it.” One participant noted how she eventually had to leave her partner because of conflict over the frequency of intercourse (T3Q10). Several participants noted that they knew other patients with PAH who lost their relationships after they were diagnosed because partners could not accept the illness and its prognosis.

Compensatory Behaviors. Across all interviews, participants reported learning new ways of behaving during sex to

minimize pain and/or discomfort and maximize their sexual relationships ($n = 13$ of 13 [100%]; Table 2). This included consideration of the availability of contraception (T3Q11). One participant noted that she maintains her sex life, but it has become more “creative” (T3Q15). Some couples learned to minimize weight compression on the chest when the patient is on the bottom during sex, with partners balancing themselves on their elbows to keep some of their weight off their partner or finding other positions, such as “spooning” on their sides. Other participants described the effort of sex as a more acute concern leading to breathlessness and fatigue; for these participants, “doggy style” on all fours with their partners behind them, or participants on the bottom lying on their back, was simply less tiring. Some participants elevate their heads on pillows during sex to help with their breathing, while another noted that she and her partner have adjusted their timing of sexual activity to having sex during the day because she is more rested and able to tolerate the effort. Another form of compensatory behavior noted by participants was changing the dynamic of sex initiation, with partners letting patients take the lead and signal when they have the energy and desire for sex. Finally, one participant noted that she and her partner hug more and have more foreplay “getting me relaxed, getting me comfortable before we actually do the act”; in addition, because she is afraid of breathlessness, she does breathing exercises (i.e., slow breathing) during sex to minimize her anxiety.

Although one participant reported that her ability to achieve orgasm has not changed since the onset of PAH symptoms/diagnosis, several others note that achieving orgasm has decreased. Some attributed this to decreases in overall comfort during intercourse; others attributed it to their disease process, either in a need to decrease the frequency of intercourse overall or a change in intensity of experience. Another participant noted that because their frequency of sexual activity has decreased, her partner ejaculates quickly, and she has had to learn to achieve orgasm in that context.

Body Image

More than half the participants discussed body image as an issue in their social interactions and, specifically, in their SHRQoL ($n = 7$ of 13 [54%]; Table 2). With

respect to body image within a social context, one participant noted that people assume she is pregnant because her pump sticks out. She also noted that she uses her oxygen only at night, expressing fear that when she begins to need oxygen during the day, “the entire world’s gonna see it. . . . Right now people . . . think I’m healthy.” Another reported that she requires a scooter to get around but feels self-conscious (T3Q12).

Several participants commented on weight gain since their diagnosis, noting that weight gain affected their self-esteem and SHRQoL, including their confidence in their sexual relationships, as illustrated by this woman: “I’m like, ‘Oh, I don’t feel like you’re attracted to me.’ He’s like, ‘What? Why? Why would you say that?’ I’m like, ‘Well, cuz I’ve gotten fat’”; another remarked, “I said I wouldn’t let anybody ever see me without my clothes again.” In contrast, another participant who “hated my body” after weight gain countered that her husband was not judgmental about body shape and weight gain and told her, “This is the way it is. We have to deal with it.”

Resilience

Despite the challenges and hardships of care when one receives a diagnosis of PAH, and the toll it takes on the entire family structure, several participants reported resolutions, or at least coping strategies, in their ongoing process with SHRQoL and the quality of intimate relationships. For these participants, an understanding of the difference between physical intimacy and emotional/psychological intimacy, and finding ways to nurture and express the latter, was essential. One participant noted that, in the context of sometimes struggling just to bend down or do small things, just holding hands, a snuggle, or saying, “Hi, Honey. How was your day?” can be invaluable. This sentiment was echoed by other participants: “holding hands . . . just being together [is sufficient for intimacy].” Another noted that the care her partner took in caring for her helped her feel loved: “he enveloped me all the time.” Still another participant emphasized quality over quantity of sex, saying, “we may not . . . have sex as often as we want, but it’s much more . . . meaningful.” This experience illustrates a merged understanding of sexual intimacy with physical and emotional intimacy: her and her partner’s definitions of intimacy were different, with her believing that sexual contact is intimacy, while her partner

believes that “spending time and holding each other, having moments” was intimacy.

Another form of resilience was articulated in participants’ overall attitudes and/or approaches to living their lives as fully as possible. For some, it was a matter of meaning and priorities, where overall HRQoL was prioritized over sexual quality of life (T3Q13). One participant talked about how hard it was for both her and her partner and also how she aspires to not let PAH control her quality of life (T3Q14). Another noted that she maintains her sex life but has become more “creative” (T3Q15).

Role of Healthcare Providers

When asked how the healthcare team can be more responsive to SHRQoL, and quality of life in general, participants were clear. Whether through direct conversations with providers and/or patient support communities, participants in this study requested more information and more communication. Many participants cited such support communities (usually online) as their primary resource for information on SHRQoL (T3Q16, T3Q17, and T3Q18).

Discussion

In this qualitative analysis we report on the broad range of SHRQoL perceptions, experiences, and coping strategies among women living with PAH. In combination with earlier survey results (5), these data highlight both the unique challenges around SHRQoL that women with PAH face, as well as their attempts to overcome challenges or, at least, minimize PAH’s impacts, including patient understandings of relationship dynamics overburdened by medical treatment and caregiving.

A Case of Reciprocal Inhibition

Participant narratives allude to more universal dynamics in sexual relationships that can affect SHRQoL. Good communication and/or openness to hearing another’s experience can obviate poor outcomes: discussing fears and concerns, clarifying and taking responsibility for feelings, and problem solving can all help optimize a healthy sex life. Individuals may not have the energy or skills for these conversations and, instead, may fall into assumptions regarding their partners’ sexual

desire or experiences. These assumptions can lead to negative affect, poor body image, and miscommunication, ultimately having a significant impact on SHRQoL. Fears and the attributions those fears give rise to (e.g., that sex will dislodge medical equipment or that increases in respiration and/or heart rate are exacerbations of PAH rather than responses to sexual stimulation), as well as exhaustion or fatigue, decreased mobility, and more individualized concerns, can all lead to assumptions and/or miscommunications, creating tension, apathy, or hopelessness in relationships.

These relational dynamics around sex described by women living with PAH fit within a larger conceptual model of how couples cope together with chronic illness (13). Given that the fields of sexuality and health psychology are rarely integrated in a dyadic context (14, 15), further theory building is needed to understand how relational processes affect SHRQoL for patients living with chronic illness, such as PAH.

Although we could not objectively assess depressive or other mental health symptoms in a qualitative IDI, we posited that participants who took part in this study may have been more engaged in the PAH community and thus exhibited more psychosocial resilience (5). It would be important for future studies to assess depressive and anxiety symptoms beyond those captured by the Short Form 36 and consider the role of SHRQoL in these conditions. For instance, validated SHRQoL tools (e.g., the Female Sexual Distress Scale–Revised) could be used to better screen for sexual health distress in clinic populations in which integrated behavioral health services can be offered. Furthermore, in acknowledgment of the potential resiliency of the present sample, we suggest that resilience, as a protective trait, and both instrumental and psychosocial support systems also be assessed in this population. Although this sample may be unique, their words provide an opportunity to explore what helps and hinders these women as they progress through PAH treatment and disease. Healthcare providers could undoubtedly play a significant role in supporting SHRQoL, although from the present study, it is unclear whether opportunity constraints versus deficits in provider knowledge, capabilities, or comfort regarding specific counseling in SHRQoL contributed more to the deficiencies in patient–provider communication observed.

A provider-specific study is warranted to address these gaps.

Inherent in qualitative studies is the necessity for small samples but in-depth exploration. Given that these narratives spoke convincingly of both the facilitating and challenging aspects of relationships between patients and partners/caregivers, future studies should investigate caregivers (both sexual partners and other types of caregivers), as well as sexual partners with fewer caregiving responsibilities, to gain greater understanding of these relationships, and their challenges and needs, and consider next steps in clinical intervention to support SHRQoL. The present study did not include men with PAH, who may face unique challenges and issues related to SHRQoL. A

dedicated study of men with PAH is a goal of future work. We relied on participants' self-reports of their diagnoses and data supplied by the PHA, which, although it is unlikely, may have introduced bias.

Since these narratives were collected, advances in two areas offer specific opportunities for researchers and healthcare providers. First, the reach and affordability of wearable mobile health technology could be used to help understand and discern differences in physiologic responses that herald distress and those that are responsive to sexual arousal, as well as provide more accurate and nuanced data for a range of cardiopulmonary indices in this patient population (16). Second, we note a participant comment regarding mobile/

remote technologies for patient support. That participant believed that the online community could be especially helpful with sexual health issues: "People are more comfortable [in online communities] than [in] actual, support groups. . . . Because people are more comfortable . . . they have more anonymity there, so they'd be more likely to access it and ask." As we move forward into a healthcare world forever changed by the coronavirus disease (COVID-19) pandemic and its necessity for telehealth services, future studies should prioritize the role of technology in improving HRQoL generally and SHRQoL specifically. ■

Author disclosures are available with the text of this article at www.atsjournals.org.

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