Online Data Supplement
Outcomes Important to Patients Diagnosed with Both COPD and Sleep Apnea: Findings from the O_2VERLAP Study Focus Groups

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Online Data Supplement 1: Moderator's Focus Group Script

Oxygen Therapy/CPAP Therapy (15 minutes)

1) Please describe your use of your oxygen. When do you use it and what type(s) of devices do you use at home and out of the house? How long have you been using oxygen?

2) What was your experience with your insurance company as it relates to your CPAP device?

3) Think back to when you were first prescribed oxygen and a CPAP device. What were the biggest challenges you had with either therapy when they were first prescribed?

4) Which therapy was prescribed first or were they prescribed at the same time?

Problems/Challenges (15 minutes)

1) Do you feel that you benefit from using supplemental oxygen?

2) For those of you who are using oxygen at night, please describe the <u>problems</u> you have continued to encounter. Please describe the things that you have done to make the therapy work for you.

3) For those of you who are using CPAP, please describe the <u>problems</u> that you have encountered. Please describe the things that you have done to make the therapy work for you.

4) What would have helped you deal with the <u>challenges</u> you have faced with your oxygen and CPAP therapy?

Other Related Issues (15 Minutes)

1) If you share a room with someone, do you feel your use of oxygen and CPAP at night impacts them? How so? Does this impact your use of therapy?

2) How often do you use your therapies as prescribed? For example, do you use it every night, most nights, less than half the week, rarely? Do you use it for the entire night; typically remove it during the night or other?

3) Do you notice a difference in the quality of your sleep when you do not use your therapies as prescribed?

Impacts (15 minutes)

1) What are the biggest impacts that breathing troubles have on your life?

2) What are the biggest impacts that poor sleep quality has on your life?

Medical Information (15 minutes)

1) Where do you get most of your health information about your conditions?

2) How likely would you be to use an online based program that is designed to help you learn more about your COPD and OSA therapies?

3) How much time per day would you be willing to participate in an online activity like this?

Online Data Supplement 2: Coding Summary

Category	Sub-Category	Count	Code
Effects of COPD		1	Shortness of breath upon exertion
Use of Both CPAP and Oxygen	**Beneficial Effects**	3	Improved sleep
		1	Improved mood
		4	Improved energy
		1	Improved oxygenation
	Problems	1	Dryness
		1	No reported problems
Barriers & Motivators of O2 Use	**Barriers of O2 Use**	1	Feeling self-conscious
		1	Dryness
	Motivators of O2 Use	2	Addition of humidifier
		1	Inform/educate others about oxygen use
Knowledge of COPD		1	Use of spacers
Effects of Oxygen Therapy		1	Generally feel better
Knowledge of sleep apnea	**Apnea**		Stop breathing in middle of night
			Snoring
		1	Pauses in breathing cause awakenings
			Brain signals body to start breathing
			Lack of oxygen
			Breathing airway close
			Not only occurs in obese people
			Doesn't know much about OSA
		1	Surprised to find out about diagnosis
	Health Consequences		Sleep loss in patient and partner
			Tired/sleepy during day
			Concentration issues
			Cardiovascular problems
			Never woke during night
Effects of sleep apnea	**Physical**		Poor sleep
		2	Decreased energy
			Morning headaches
		1	Snoring
		2	Napping
	Mental/emotional		Patient or spouse scared due to apneas
			Irritable
	Interpersonal		Sleeping in separate rooms
			Snoring disrupted partner's sleep
			Spouse frustrated
Effects of CPAP	**Initial experience**		No problems
		1	Determined to use it
			Problems with equipment

			Concerned with noise from CPAP
		1	Improvements in sleep and energy
			Worried about appearance with mask
			Partner concerned when patient no longer snoring
			Partner provided support
	Physical	1	Improvements in sleep
			Less snoring and apneas
			More energy
			Refreshed in morning
			No improvements in sleep
	Mental/emotional		Improved mood
			Less irritable
			Irritated couldn't get mask adjusted
			Felt ashamed
	Interpersonal		Resume bed sharing
		1	Relationship improved
			Impedes intimacy
Barriers and motivators of CPAP use	**Barriers**	2	Dryness
		4	Insurance/cost
		1	Difficulty breathing with CPAP
		8	Mask uncomfortable
		2	Inconvenience when traveling
			Cold/sinus infection
		2	Don't want to put CPAP back on after getting up during night
			Intimacy
		1	Hard to sleep with CPAP
			Appearance with mask
			Felt ashamed
	Motivators		
		3	Tracking CPAP
		5	Comfortable mask
			Better sleep
		2	Feeling refreshed in morning
		1	Less sleep disruption for partner/family
			Able to engage in activities again
		4	Spouse support
		1	Doctor/DME company support
New user support program	**Format options**	5	Patient advocacy organizations
		7	Peer support
		6	Social media channels

Components	1	In-person small groups Lead by respiratory therapist and/or current CPAP user Online video Question and answer session Demonstration of CPAP equipment Hands-on experience with equipment Overnight experience with CPAP in lab with partner Education about OSA and CPAP Partner participation Early follow-up/interaction

Online Data Supplement 3: Selected Quotes from Focus Group Participants

“I like the COPD, the 360 Social, because there's some good information on there. I wish it was more updated. Some of the things I think are not updated as frequently as they should be. Facebook, if you get into a good group and there are a few of them out there, there's a lot of information but what's even more important is real life experiences that you can share. There are some doctors and there's some nurses in each of the groups or in most of the groups. More importantly it's the real life. "How do I empty the dishwasher? How do I do the laundry?" Good suggestions on how to make life easier on a day-to-day basis, and it's sharing your experiences, and knowing that you're not alone.”

“I like this one b/c while it seems to knock our non-profits, it is actually saying that they are a go-to resource and provide entrée to peer support. The key for us is the entrée . . . the content, the format to be sure that we serve folks in the best way we can.”

“I have often thought that it would be good to be a mentor to help others through the same issues I faced.”

“And I think probably everyone has problems with leaks initially till they find that right combination of what works best for them. It took me probably 6 months to find the right mask, pillow, strap tightness, etc. It was a lot of trial and error and I think what really would be the biggest factor in someone not continuing with therapy (just my opinion). “

“I can't say enough about education. I think if I would have known what to expect and some of the challenges I might face up front, it would have helped me immensely. Having a mentor or resource I could have called in the middle of the night when I was frustrated and didn't know what to do to fix the leak, etc. I had checked all the information on the Resmed website but sometimes you just want something that is specific to what you are going through right at that very moment and not very vague suggests that apply to a large group of people.”

“Better access to the Dr. I KNOW they are busy and have lots of patients....I understand but it is frustrating when it takes a day or MORE for the nurse to get back to you, it can be aggravating and makes you just want to throw your hands up in the air.”

“I agree, which is why I found the info and support I needed through online forums--LOTS of info on an individual basis, reports of experience, helpful hints, and even free software to download in order to see our own stats any time!”

“360 social has a wealth of information I use. Speaking with others with COPD has been extremely important. Doctors not so much. Hard to find one with the time and knowledge for your specific situation. One size fits all does not work for lung patients.

“I would dedicate several hours, several days a week to something like that if I could help others.

Walt Disney World has a "Mom's Panel" that helps vacationers by answering their specific questions with advice on everything from tickets to dining. It is a panel of about 12-15 "moms" that apply and receive some education but are equipped to help others. And if there is something that they can't answer, then there are resources that they can refer guests to in order to get their questions answered. Something similar could be very useful here. You would just have to be careful that the panel is offering actual health advice that should be coming from their Dr. Maybe even some of the information that comes out of these sections about specific problems, challenges, successes that we have faced that could be beneficial to others. I personally LOVE this idea."