

Original Research

Exploring Patient Experience with Noninvasive Ventilation: A Human-Centered Design Analysis to Inform Planning for Better Tolerance

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Supplement E1

Journey map creation:

In human-centered design (HCD) methodology, in-context, empathetic interviews are aimed to surface hidden challenges and mental models that underly a problem. By probing deeper into the emotional experience, the researcher seeks to understand the patient's relationship with the systems, people, and technology they interact with. The logical steps of the patients' experience are captured in a stepwise narrative. Our main goal was to create a journey map as a framework describing the overall patient experience while using NIV, and highlight the key processes, tensions, and flows. We broke the journey into phases, steps, emotions, and themes to get a clear picture of the overall experience levers for patients. First, we recognized the *phases of the journey*, which are the big picture stages that all patients experience and describe the journey at the highest level. We coded the interviews by phases and then subcategorized each phase into *steps*, which are discrete aspects of the experience described by the patient. Only steps that at least 1 patient described as very important and other patients also mentioned, were included in the framework. Not all patients experienced each step and not all patients experienced the steps in the same order. Each patient's description of a step was analyzed for *emotions*. In many cases, the patient named emotions directly; in other cases, the investigators discussed the statement in the context of the patient's interview and classified the emotion the patient described. If we could not identify an emotion, the step was deemed "unimportant" and dropped from the analysis. Of note, patients could have more than one emotion per step; however, each discrete emotion could only be listed once per step per patient such as that it will not dominate the findings. We combined quotes that described the

same step and emotion pair. We then coded each emotion as negative, neutral, or positive, and we tallied the number of negative, neutral, and positive emotions for each step. We calculated a *sentiment score* for each step as a percentage of negative, neutral, and positive emotion.

Finally, we reviewed each phase and step and discussed *themes* that were emerging by phase.

Themes were then divided into 2 categories, *themes that promote NIV tolerance* and *themes that deter NIV tolerance* for each phase. Verbatim quotes were first checked for context within the overall patient's experience and attributed to themes. The presence of in-context quotes by multiple patients supported the identification of the theme.

INTERVIEW GUIDE FOR QUALITATIVE STUDY TO UNDERSTAND PATIENTS' EXPERIENCE WHILE USING NIV

This script is intended as a guide. The interviewer will seek to set a conversational tone, diverging at some points from the script. They will use discretion in phrasing and in using probes and additional questions to fully understand the interviewee's perspective and to consider prior responses.

All interviews will be audio-recorded and transcribed upon completion. Be sure to ask patients if they're comfortable in the space, or if they would need to be elsewhere to feel comfortable completing the interview. As appropriate, remind participants they do not have to answer questions if they're not comfortable responding.

Be sure to start the conversation by identifying yourself as not being a member of the medical team.

While the abbreviation NIV is used throughout this guide, please read it to the participant as 'noninvasive ventilation/ BiPAP'.

INTRODUCTION SCRIPT

Good afternoon, this is [name] calling from Baystate Medical Center. May I speak with [patient name]. I am calling regarding the study which the [clinician] mentioned about us asking you some questions about your experience with noninvasive ventilation.

How are you today? How's your family doing? How is recovery going? How would you like for me to address you? Is [Ms/ Mr...] ok or would you prefer [first name?]. Is this still a good time to talk?

I have a lot of time to dedicate to this interview, so I do not want you to feel like we need to rush through this. If you need to take a break at any time during the interview, just let me know and we can pause.

*Here is a brief overview of how today's conversation will go. I have my colleague [name] here with me and she will take notes and ask questions periodically if needed. Are you ok with [name] being on the call with us today? **[wait for the response].***

*Before we get started with the interview, I will go over the consent form and answer any questions you may have. After that, I will begin the audio recording and we will start the interview. Are you ready to proceed with the process? **[Wait for the patient to acknowledge the steps]***

Before you were discharged from the hospital, your [clinician] gave you an information package and in that package was a copy of the consent document. Did you have the time to read through the documents? ... I'm going to walk you through the key components of the consent form, and at the end you can ask me any questions you may have.

- You are being invited to participate in this research study because you were admitted to the hospital for a flare-up or exacerbation of chronic obstructive pulmonary disease or COPD and you were treated with noninvasive ventilation (the mask that was used to blow the air in your lungs).
- I would like to get suggestions on how we can improve your experience of the treatment.
- This interview should take approximately 30 minutes. To thank you for your time, you will be offered a \$50 gift card at the end of this interview.
- You are free to skip any question for any reason. To keep this interview confidential, I will not record any identifying information in the transcripts of the interview.

- If you have any follow up questions or concerns, feel free to contact me or Baystate's Institutional Review Board (explain who IRB is). All of our contact information is provided in the hard copy of the information sheet we provided you with.
- Just to remind you, this interview will be audio-recorded. We are recording the interviews so we don't need to take notes during the interview. We can just focus on the conversation. By continuing forward, you're agreeing to participate in this study. Before we start, do you have any questions for me?"

[Answer any questions, and then start audio recording]

QUALITATIVE QUESTIONS

The interviewer should be mindful to probe for emotion after each question. Be sure to use the language that the patient uses, and do not paraphrase what was said in your own words. Make note of any suggestions that the patient may bring up (in the margins next to the question) and be sure to go back to these comments at the end of the interview to make sure you have captured the patient's full idea.

Be sure to pause after the patient gives their answers and try not to move on to the next question so quickly.

Follow up on questions that elicit emotions. Find out the cause of the emotion and repeat what the patient said.

When the patient does not answer a question, reformulate the question and ask it again.

PHASE 1: Knowledge about NIV prior to hospital admission

I want you to think of your most recent hospitalization.

1. What prompted you to come to the hospital?
 - a. What time of day was it? (will help to prompt about meals and sleep- if they provide # of hours later)
 - b. How were you feeling?
2. What comes to mind when I say NIV/ventilation/mask?

Prompt: You came to the hospital feeling short of breath because your COPD was worsening

3. What did you know about NIV before coming to the hospital?
 - a. How did you learn about NIV before coming to the hospital?
 - b. Do you know anyone that has used NIV? What have you heard about it?

If the patient describes that this is not their first time receiving NIV...

4. How do you remember your prior experience with NIV and how did that experience influence your decision?
5. What other forms of ventilation (oxygen, high flow nasal cannula, CPAP) have you experienced? Have you ever been placed on a ventilator (Having a tube in your throat?)
6. How long have you had COPD?

PHASE 2: Pre-Treatment Discussion

Prompt: You have arrived at the hospital and you're getting checked out by the nurses, respiratory therapists, and physicians.

7. How was NIV treatment presented to you? (*Probe – did someone explain it to you?*)

- a. How well do you think the physician/ respiratory therapist explained NIV treatment to you? What details do you remember? Did you have family members present with you during the explanation?
 - i. Who explained it to you? (respiratory therapist or physician?)
 - ii. What were your questions? How were they answered? What was going on in your mind?

If they didn't have questions, ask: Why didn't you have any questions?
 - iii. Were you given other options? If so, what were they?
 - iv. Were you a part of making the decision to use NIV? What did that look like?
 - v. How did this conversation make you feel? What were you thinking?
 1. Make sure to capture the **emotion** and ask them to explain why they felt this way and to explain it
8. How did you feel after they explained NIV to you?
 - a. Was it enough of an explanation for you?
9. How was the decision made to use NIV?
10. What was going on in your mind before receiving treatment?
 - a. *Capture the emotion*
 - b. What did you expect?

If the patient describes that this is not their first time receiving NIV...

11. How was the discussion with your clinicians this time different from past NIV treatment discussions with clinicians?
12. Did they discuss any options with you in the event that NIV was not successful? If yes, what were they?
 - a. What did they say would happen if this does not work?
 - i. *If they mention intubation-* How was intubation explained to you?
 - b. What were you thinking during this conversation? How did you feel?

PHASE 3: NIV Initiation and Receiving NIV

NIV was decided to be the best treatment option for you

Initiation of NIV

13. Tell me what it was like to have the mask placed on you? Did they try different masks?
 - a. *When the patient responds, ask follow-up questions based on their response. –e.g. tell me more about the nurse. What else did she do for you?*
 - b. What was going on in your mind/ what were you thinking?
 - c. How did you feel?
14. What was breathing like when the mask was on your face?
 - a. How did you feel? Tell me more
15. What other details do you remember? (*Probe—Were you in the emergency room, on the floor, or in the intensive care unit?*)
 - a. What were you thinking and feeling during these times?
16. What can you tell me about the care from physicians...nurses... respiratory therapist during your NIV experience? (*Probe –Ask one by one about the clinicians*)
 - a. How did these interactions make you feel?
17. How did your physician... nurse... respiratory therapist attend to your comfort when NIV was started? Do you think that they cared about your comfort? (*Probe –Ask one by one about the clinicians*)

- a. How did you communicate with caregivers about your comfort during the start of NIV (the mask fit, your breathing, and feelings you were having)?
 - b. What were your needs for comfort during treatment? –eg. Did you want more pillows, someone to check on you more often, call your family on the phone, a snack, breaks during treatment...?
 - i. How were these needs addressed, and who addressed them (physician, RT, nurse)?
18. Did anyone attend to your psychological comfort? (ex. Easing your anxiety and stress?) –Probe-- What do you suggest for future treatment?
19. Was anyone from the family with you when they placed the mask on your face? How did you feel about that?

Receiving NIV

20. How often did clinicians check on you while you were on NIV? Who was mostly checking on you (nurse, respiratory therapist, physician)?
- a. Tell me more about what they did during these check-ins. Do you feel that the check-ins were beneficial?
 - b. How do you feel about the efforts made?
21. How did they measure your blood gas levels? *did they take blood from your wrist?*
- a. How many times was this performed on you?
 - b. How was this process explained to you?
 - c. How did you feel?
22. Were there needs you wanted to communicate while undergoing treatment? What were they? How did you communicate these needs? Were you able to communicate them? How so?
- a. What were you thinking during these times? How did you feel?
 - b. What other methods of oxygenation therapy were used to treat you?
23. How did you eat/drink while being treated with NIV?
- a. *If they weren't able to eat*, ask: how did this affect you? How did it make you feel?
 - b. What did you do to communicate with the nurse that you wanted to have something to eat?
24. Were you given any breaks during treatment where you could take the mask off?
- a. Would this be something you recommend?
25. How did NIV affect your sleep?
26. How did you feel during the treatment process of NIV? (*probe- Did you need breaks? Did you try to take it off?*)
27. Who in your family knew you were being treated with NIV while you were at the hospital? Who else knew you were being treated with NIV?
- a. *If family did not know they were being treated with NIV*—Why didn't you call your family to tell them you were in the hospital receiving NIV treatment?
28. Would you prefer to have your family with you while receiving NIV?
- a. How would this make you feel?
29. What was the hardest/ most difficult part of the treatment for you? Why? Tell me more?

PHASE 4: NIV Weaning and after Treatment

You have gotten better, and the RT has adjusted the NIV settings to slowly take you off the NIV. The mask has been removed.

- 30. How long do you think you were being treated with NIV during this hospitalization?
- 31. Tell me about what it was like to have the mask removed.
- 32. How did you feel immediately after the mask was removed?

- a. How did your face and your breathing feel after the mask was removed?
 - b. What was going on in your mind?
33. What did you experience during and immediately after the mask was removed?
- a. How did you feel? Did you feel that NIV was good for you? Why or why not?
 - b. Do you think NIV helped your COPD?
34. How did you feel about NIV when you finished the treatment? Did your feelings change from the time NIV was started to the end?
35. What were your concerns regarding your family? How did the team that took care of you manage those concerns?
36. What would you tell other patients who are weighing the pros and cons of this treatment? How would you explain what it felt like having the mask on and the machine next to you?
37. How would you make this a better experience for someone else?
- a. What else do you recommend for future patients? *–Try to get as much information as possible from the patient*
38. What suggestions do you have for clinicians to make this treatment better for other patients?
39. If you were re-admitted to the hospital and offered NIV treatment again, what would your reaction be? What would you be thinking?
- a. Would you comply with the treatment? Why?
 - b. What other treatment option would you prefer and why?

PATIENT SUGGESTIONS FOR IMPROVING

*We have a few suggestions that may improve patient comfort. Better communication between patient and clinician, having clear expectations of NIV treatment, understanding how the treatment works and what the process is, understanding the goal of NIV, and having information for your family. **The interviewer will also bring up any ideas the patient mentioned during the interview.*

***Interviewer will present ideas from past interviews*

- 40. How would these ideas improve the experience of patients like you?
 - a. Where during the process should they communicate better?
 - b. How should clinicians communicate with you? Talking with you? Show you something?
- 41. What would you add to these ideas to make it work best for the patient?
- 42. What would you take away from these ideas to make it work best for the patient?
- 43. How might you reimagine these ideas to better suit the patient?
- 44. What impact do you think this idea will have on the overall experience for a patient?

DEFINING MOMENTS: *Defining moments are assigned to the subset that impacted the patient the most to understand what resonated with them during treatment.*

- 45. After walking me through your experience with NIV, what were your top 3 defining moments (*most important moments during the time the mask was placed on your face until it was removed*)? These moments can be good moments, or bad moments you experienced. Defining moments are the steps that you feel impacted you the most throughout the NIV process. I want you to think of how you felt about receiving NIV not only that it was successful.
 - a. *If the patient doesn't understand the question, rephrase the question to ask—“what mattered the most to you during the time NIV was started, when you were on NIV, and when you were taken off NIV?”*
 - b. After the patient says their defining moment, repeat what they said to make sure you understand what they explained (**do not say ok**)

46. Please rate these 3 defining moments on a scale of 1-5 based on how important you think these moments are. (1 being least important, and 5 being most important) – *Go through each defining moment ranking one by one*
 - a. Please explain why you rated these moments the way that you did.
 - b. *If the patient rates everything a 5, ask them*—Relative to one another, how would you rank these 3 moments on a scale of 1-5
47. Please rate these 3 defining moments on a scale of 1-5 based on your satisfaction of how well you feel these steps were executed by your care giver. You can be specific and rate your satisfaction for these defining moments based on which caregiver (nurse, RT, or physician) performed the task. (1 being least satisfied, and 5 being most satisfied)
 - a. Please explain why you rated these moments the way that you did. *—probe for each of the moments*
 - a. *If the patient rates everything a 5, ask them*—Relative to one another, how would you rank these 3 moments on a scale of 1-5
48. What would you say about your overall satisfaction of NIV treatment? I want you to think of how you felt about receiving NIV not only that it was successful.
 - a. On a scale of 1-5, please rate how satisfied you are with your overall treatment. Please explain why you feel this way.
 - b. Please explain how each of the caregivers played their role in your overall satisfaction.
 - i. Go over each clinician separately
49. How well do you think the [RT, nurse, physician] explained this interview to you when he/ she approached you about this study? What could they have done better?