

A Multidimensional Profile of Dyspnea in Hospitalized Patients

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e-Appendix 1.

Cohort C Patient Daily Assessment Verbal Script- Recruitment

Hello, my name is _____ and I'm from the Pulmonary Research Lab. I'd like to ask you to help us collect information that we hope will help the hospital do a better job of caring for patients who experience breathing discomfort. To do that, we are asking patients about their breathing discomfort while they are in the hospital.

We'd like to ask you to help us. May I tell you more about this research?

(If yes: Great, Thanks.

If no: Gently probe about why – they are not required to tell us, but we might be able to improve our approach if they do.)

We would visit you each day while you're here so that we can fill out a questionnaire about your breathing discomfort on that day.

Your participation in this study is entirely voluntary. You may withdraw from the study at any time by simply telling us and this will not affect your care in the hospital.

There is no direct benefit to you, but we think this information will help future patients. There is always a slight risk of breach of confidentiality. All of our staff members receive training in privacy protocols and we protect your privacy in several ways that are detailed on the information sheet I'll give you.

Do you have any questions about any of that?

Are you willing to participate?

If you do have questions at any time please ask us. I'm giving you an information sheet that contains the phone numbers and contact information for our lab, for the independent Beth Israel Deaconess Human Subject Protection Office, and for any publications that come from this study. If you have any questions later, you can call one of the numbers listed, or I can answer them on my next visit.

Would you be willing to go through the questionnaire now?

Standard Room Entry

PUMP IN AND OUT FOR ALL ROOM ENTRY!!

CONTACT/GI CONTACT: Patients with MRSA/VRE or GI illness.

Hand hygiene, gloves and a gown are required upon entering these rooms. When leaving these rooms, you must wash your hands with soap and water **AND** pump using Calstat.

AIRBORNE RESPIRATORY: Patient requiring negative pressure room. Patients in this room either have TB or are suspected to have TB.

Hand hygiene and an N95 respirator (Must be fit-tested) must be worn.

DROPLET and SPECIAL FLU DROPLET: Patients with a respiratory virus (influenza, parainfluenza, etc).

Hand hygiene and a mask with fluid shield required upon entering this room.

*If patient is on special flu droplet and has either a nebulizer or another aerosolizing machine you must wear the N95 respirator you are fit tested for **AND** a mask with fluid shield over that mask

NEUTROPENIC: patients who are immunocompromised after chemotherapy and at a high risk to develop infection.

Hand hygiene before entering room. If you are sick, these rooms should be avoided (if you **must** enter you need to wear a mask).

ZOSTER: patients with chicken pox/shingles.

Hand hygiene upon entering the room. If you have never had chicken pox you must wear your N95 respirator you are fit tested for, mask, and gloves. If you have had chicken pox, PPE described on signage needs to be worn.

Room Entry Sequence:

Put on gown

Put on mask

Pump in, allowing hands to dry

Put on gloves

Knock, open door with elbow

Greet patient and introduce self

Exiting Rooms:

Take off gloves IN the room.

If wearing a gown, take off gown (inside-out) AS YOU ARE LEAVING the room.

Take off Mask OUTSIDE of the room.

Pump out.

Additional information about challenges faced conducting a survey with hospitalized patients

e-Appendix 2. Time elapsed before first interview:

Most patients in this cohort arrived on the medical-surgical unit after spending time in the Emergency Department; there was generally a further delay of hours between arrival at the unit and our interview due to the time needed to identify and locate the patient and wait until clinical care activities permitted time for an interview.

e-Appendix 3. Change in study protocol:

Initially, patients were asked to complete the full MDP for both current dyspnea and recalled worst dyspnea in the past 24 hrs (If $A_1 = 0$, ie no dyspnea, further items were not completed). After 86 patients had completed the study, we simplified and shortened the patients' task. Subsequent patients completed the A_1 scale for both worst and current dyspnea, and fully completed all items of the MDP only one time, focusing on their worst dyspnea in the 24 hrs including the time of interview (on 85/317 patient-days the worst dyspnea was at the time of interview). Before this protocol change the percent of missing or incomplete MDPs was 63% (523/832), after the change missing MDPs fell slightly to 57% (270/472, IQR 5, p-value=.04).

e-Appendix 4. Incomplete questionnaires:

For analysis, we dropped MDPs in which the 11 rating items were incomplete (either single inadvertently missed items, or instances where the patient decided not to complete that day's interview). However, we included in analysis MDPs that had all ratings complete, but that lacked a single choice for SQ in the forced-choice panel – 'Did not choose' is shown in the graphs because patient comments indicated omission of the forced choice was by intent (see following paragraph). The cohort diagram for this study is available under supplementary materials, e-Figure 1.

In 36 of 460 instances patients who otherwise completed the MDP did not choose a single SQ descriptor group as instructed – but chose none or chose two. Seven subjects commented that it was difficult to

discriminate sensory descriptors, e.g., “can’t distinguish between muscle work and mental work”, and four subjects commented that it was difficult to narrow the choice to a sensory quality descriptor, e.g., “They all work in conjunction”. It is possible that in the future completion rates could be enhanced by reinforcing the instruction to subjects: the interviewer should insist on a single choice – for example “Please choose one and only one phrase. We know it is sometimes difficult to choose, but we find that making an intuitive choice, even if you think you are guessing, provides the best information”.

e-Appendix 5. Challenges in enrollment:

During the first 10 ½ weeks of this study (39 patients), there was no electronic documentation of dyspnea, and study staff visited each unit daily to ask the resource nurse whether there were any patients admitted in the past 24 hours who had rated dyspnea ≥ 4 ; this undoubtedly resulted in missed opportunities, and was time-consuming. During the subsequent 22 ½ weeks (117 patients), each morning electronic initial patient assessments for all patients admitted the previous day were available and were used to identify patients.

Recruitment and interviews depended on research staffing. Most, but not all, weekend days were covered. Finding the patients, and finding a time to talk with them between care activities, was time consuming and often unsuccessful. The staff member assigned to recruit and interview patients was able to consent 4.8 new patients each week, and found it very time-consuming to find each patient and arrange a suitable time for interview each day. Some patients, especially the severely ill, found it tiresome to respond to 5 or 10 minutes of questioning every day solely for the purpose of research. As part of our study, the MDP interview could not be conducted on some study days for many reasons – patients were occupied or absent from the medical floor as they underwent clinical testing and treatment, patients were occupied by visits from family or by meals, patients were transferred to the intensive care unit, or patients reported themselves too exhausted to participate – all of which speak to demands of inpatient care. Research staff must, appropriately, defer to the immediate needs of acute care.

e-Appendix 6. Usefulness of the MDP for clinical assessments and for research:

Because people are unaccustomed to describing their breathing sensations, the MDP takes two approaches to the question: asking subjects to rate the intensity of several sensations, and asking subjects to choose sensations that apply and pick the single sensation that most aptly describes their experience. The former approach allows parametric analyses, such as averaging, but often suffers from the tendency of subjects to fail to clearly distinguish simultaneous and unfamiliar internal sensations. The descriptor-choice approach does not lend itself to parametric analysis, but does sharpen the subject’s discrimination. In theory, the two approaches should be internally consistent – the most apt

descriptor ought to be the highest rated descriptor. Indeed, this was usually true in practice – 87% of the time the descriptor chosen as most accurate was also the descriptor receiving the highest rating.

Two patients commented on the burden of completing the MDP, and two commented that the MDP was helpful. A single first-time administration of the MDP requires 3-4 minutes which, does not exclude the MDP as a useful tool for clinicians seeking in-depth information on patients with problematic dyspnea. However, a unidimensional measure, such as the A₁ scale from the MDP, is adequate for routinely screening and tracking dyspnea, and fits nursing routines nicely. Nurses at our institution have been using such a unidimensional scale, and report that it does not impede, and may even help their workflow ¹.

The MDP provides much more information than a unidimensional scale, but the cost may be failure of a few patients to grasp the more complex reporting task. In individual patients who do not respond to palliative efforts, or who do not have an adequate diagnosis, the MDP may be useful for follow-up questioning, especially if used by a resource nurse or physician with some added training in dyspnea assessment and management. The mean profiles we provide for different levels of overall discomfort provide a basis of comparison for individual patients; large departures from the mean profile (e.g., a breathing-related anxiety level of 9 with overall breathing discomfort of 4) could highlight issues for further investigation. There are no published studies on use of the MDP at the individual patient level, but there is some information on the clinical use of sensory quality descriptor lists, which are predecessors of the MDP SQ ratings²⁻⁵. The MDP improves on earlier descriptor lists because it 1) provides parametric data for analysis, 2) gives equal weighting to sensory qualities, and 3) includes emotional responses to dyspnea, which we believe are important to treatment of the whole patient. The MDP is available in several languages at no charge for clinical use. (<https://eprovide.mapi-trust.org/instruments/multidimensional-dyspnea-profile>)

We also believe that routine use of the MDP in clinical studies would improve our understanding of how various therapies act. (For instance: Does the therapy reduce immediate discomfort or does it reduce anxiety without affecting discomfort? Does the therapy work on all patients, or only on patients reporting predominantly air hunger?)

We found that 57% of patients find dyspnea A₁ levels above 4 unacceptable, and that air hunger (also termed unsatisfied inspiration) is the dominant sensation at these higher dyspnea levels, suggesting that laboratory models could include a prominent component of air hunger (or unsatisfied inspiration).⁶⁻⁹ In contrast, models employing inspiratory resistive loads, which lead to a sense of increased work and effort of breathing, may be less likely to produce the sensations and emotions of interest. Our data suggest that to study neurophysiology of, and palliative interventions for, the severe dyspnea that exists in hospitalized patients, it may be most appropriate to utilize stimuli that generate air hunger.^{6,8,9}

e-Appendix 7. Protocol for enrollment and interaction with patients:

1. Screening

- a. Each day look up the patients admitted in the **last 24 hours**, from the time you are checking, in the Nursing Initial Patient Assessment. You must assess them within 24 hours of their admission time.
 - i. Patients that have been recently admitted might not have an IPA uploaded yet; check back later in the day.
 - ii. Patients must **currently** have a dyspnea rating ≥ 4 , and speak English.
 1. In the Nursing IPA, 'Preferred language for healthcare discussions', and 'Preferred language for written healthcare instructions' should be **English**. If only one is recorded as English, you can assess their ability to comprehend the MDP and answer when you meet with them.
 2. Should not need an interpreter

2. Recruitment

- a. Attempt to locate the patient's nurse to introduce yourself and explain the reason for your visit. Try to ascertain if this is a good time.
- b. Go to patient room to recruit, using provided script (see Appendix)
- c. Check their name and dyspnea ratings, recorded on the Patient Care Flowsheet, located either outside the room or at the foot of the bed
- d. Before entering the room, make sure to note any hazard precautions on door and follow the appropriate steps (see Appendix).
 - i. Gloves, gown, face mask, etc. if necessary
 - ii. Use hand sanitizer each time you enter and leave the room
 - iii. If gloves are needed, put gloves on before entering room, and take them off before you exit in the room, throwing them away inside the room.
 - iv. If gowned, take gloves off first, then gown, turning it inside out as you leave the room. Deposit gown outside room in soiled linen cart.
- e. Knock before entering room and introduce self.
- f. If patient is busy with nurses or doctors, come back later
 - i. If patient is sleeping, do not wake them up; come back later
 - ii. If patient is away for tests, come back later.
- g. If patient is with visitors, ask if it is ok to talk to them. However, be sure the patient is giving responses – if family member interferes, remind them that we want the opinions of the patient.
- h. If patient refuses to participate, gently probe to find out why.

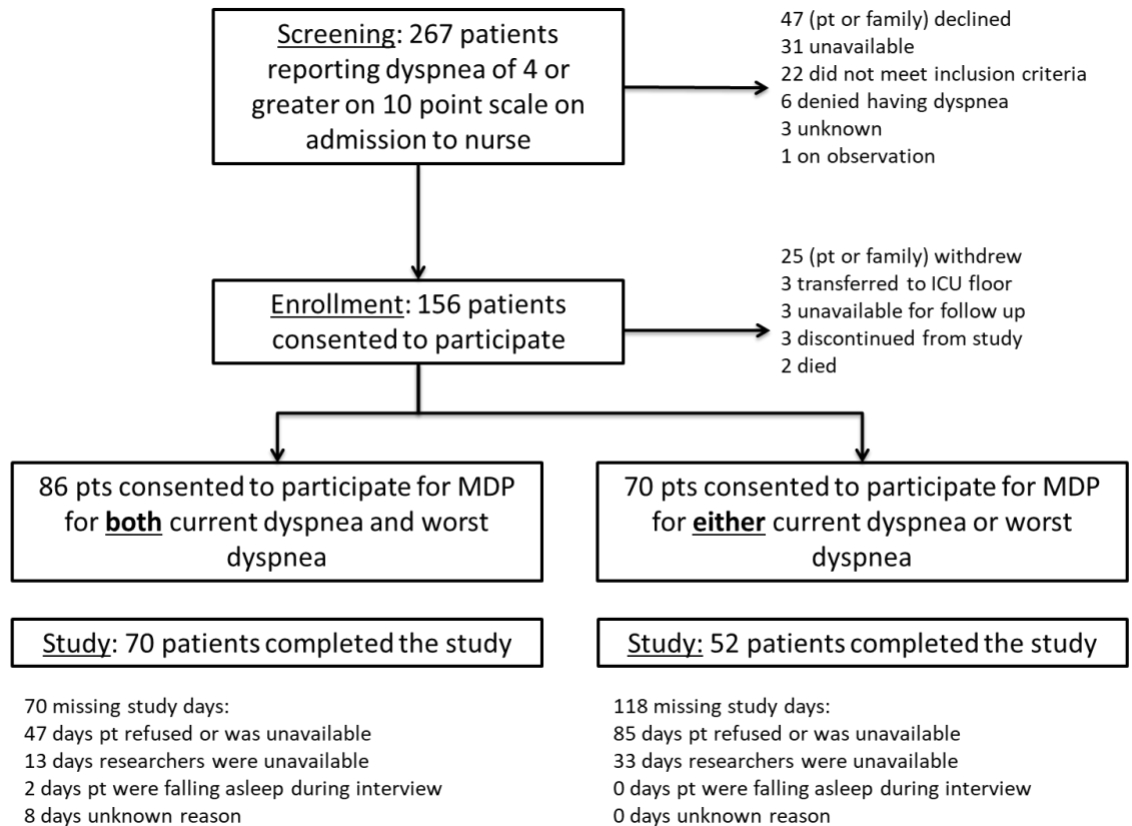
3. **Multidimensional Dyspnea Profile (MDP)**- Most recent version from 4/10/14
 - a. Follow MDP script, as written on the questionnaire
 - b. Patient can either fill it out themselves (still read through it with them), or you can ask them the questions and write it for them. The latter is preferred. If patient take the clipboard and pen, please sanitize with wipes.
 - c. On first page, make note of what the patient is doing (lying down, sitting up, etc.), if they seem alert or confused, etc. Record if they are filling out the MDP themselves, or you are asking them the questions.
 - i. **Make note of the start and end times**
 - d. Ask subject to rate their breathing discomfort **right now**.
 - e. Ask subject to rate their worst breathing discomfort **in the last 24 hours**.
 - f. If their breathing discomfort now > breathing discomfort in the last 24 hours, continue with first half of MDP, which focuses on **how they are feeling right now**. They will only do the first half of the MDP. Remind the patient that they are rating how they feel right now.
 - g. If their breathing discomfort now < breathing discomfort in the last 24 hours, skip to the second half of MDP (starting on page 6), and have the patient answer the questions pertaining to how they felt during that time in the last 24 hours when they were short of breath/having breathing discomfort. Remind the patient that they are focusing on the period where they felt the worst.
 - h. On page 2 (SQ choice), make sure that patient checks off only one of these items. If they check off more than one, ask them which **most accurately describes** how they feel.
 - i. Page 3- Have patient rate the following statements on a scale from 0 (none) to 10 (as intense as you can imagine).
 - j. Page 4- Have patient rate these feelings and emotions as they pertain to their **breathing discomfort at the moment**. Make sure they understand that this is not to assess their general feelings, but only feelings associated with breathing.
 - k. Page 5- Ask the subject if they are feeling any pain **right now**. The pain does not have to pertain to shortness of breath.
 - i. Ask subject if they are feeling any nausea **right now**. This nausea does not have to pertain to shortness of breath, just general.
 - l. After this page, skip to last page (page 11), and ask patient questions that pertain to how they are feeling right now. For patients that have filled out the first half of the MDP about their current discomfort, this page will seem redundant, but you should still go through it with them.

- i. Write down any comments that the patient has volunteered, and make note of how the patient seemed during the questionnaire (alert, tired, etc.), and any events that occurred (coughing, etc.)

m. Page 6- for shortness of breath in the last 24 hours.

- i. The following pages ask the same questions as the first half of the MDP, but ask the patient to **focus on the time that they had the worst breathing discomfort in the last 24 hours, not on how they are currently feeling.**
 - ii. On the last page (page 11), ask them to answer the questions based on how they are **currently feeling.**
- 4.** After the MDP is finished, thank patients for their time, and ask if it would be ok if someone came in to talk to them tomorrow, and answer the same questionnaire if they haven't been discharged yet.

e-Figure 1 – Cohort Diagram of Enrollment -- The day on which the first data were collected is termed Day S1; 12 patients did not complete the interview on Day S1, but provided partial information. Eighty-eight patients provided at least partial information on Day S2 and 58 patients on Day S3.



e-Table 1. Delay between patient admission and first data collected from that patient – zero indicates that the patient was interviewed the same calendar day she or he was admitted. Patients are usually admitted in early evening (4 to 7PM), and data were collected from 9 to 5, thus most patients were interviewed within 24 hours of being admitted.

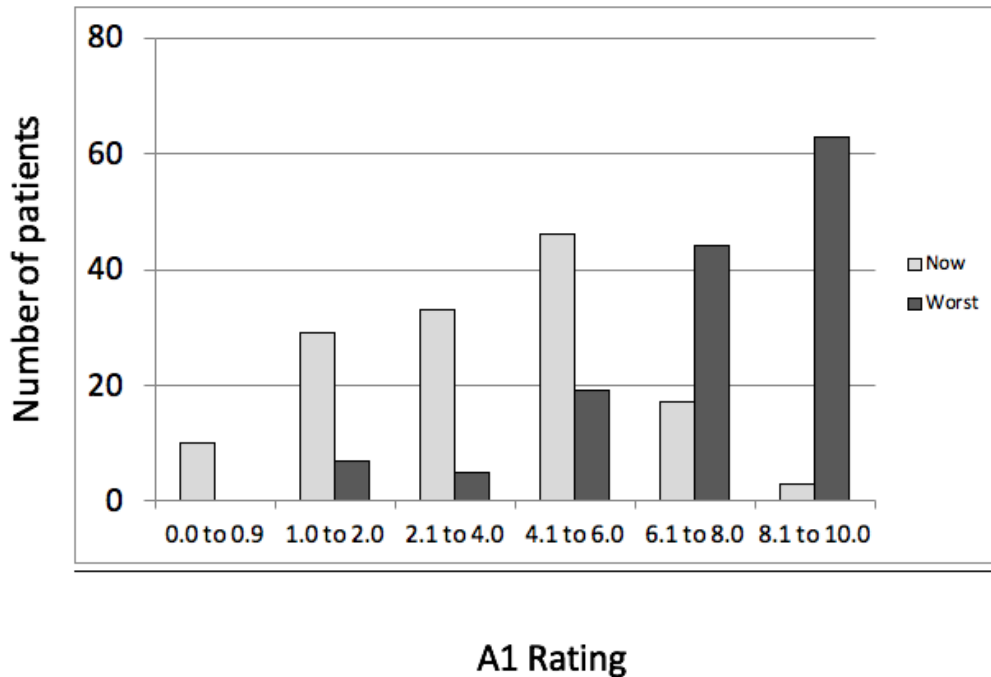
Days between day of admission and first data collection	Number of Subjects
0	23
1	115
2	10
3	1
4	3
6	1
11	1
13	1
Missing data	1
Total	156

e-Table 2. Summary of characteristics of patients.

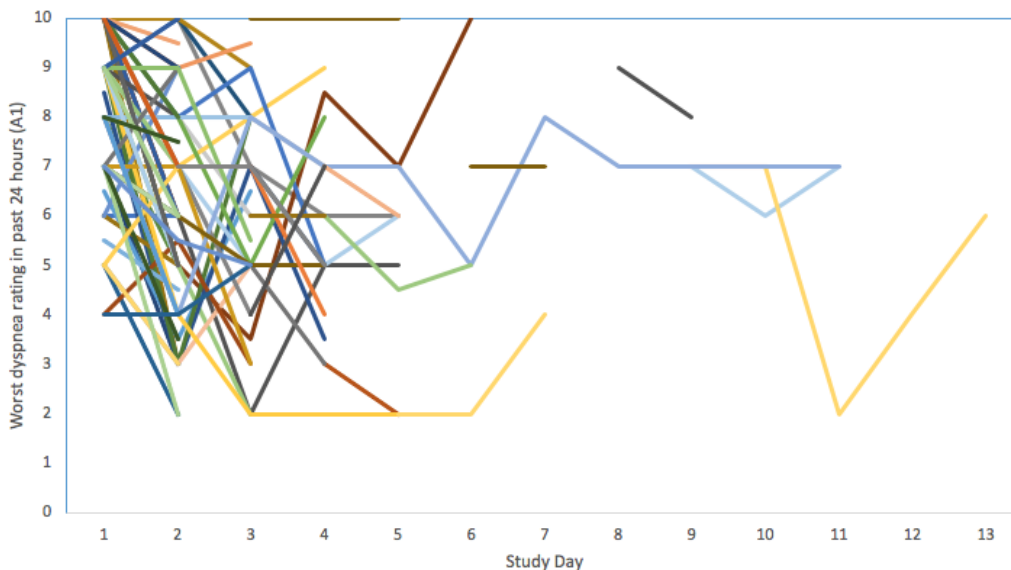
Population	
n	157
Inpatient	144
Observation	13
Female	88 (56%)
White	104 (66%)
Age (mean)	63 years
LOS (mean)	5.7 days
ICU stays	18
Among ICU stays, LOS (mean)	3.2 days
Acute on chronic diastolic heart failure	14
Top 5 most common diagnoses on discharge	
Pneumonia	13
COPD with exacerbation	11
Sepsis	4
Asthma	4
Acute kidney injury	4
Mortality	7

e-Figure 2 – The range of A₁ (level of dyspnea) ratings on the first study day when asked for current versus worst dyspnea in past 24 hours

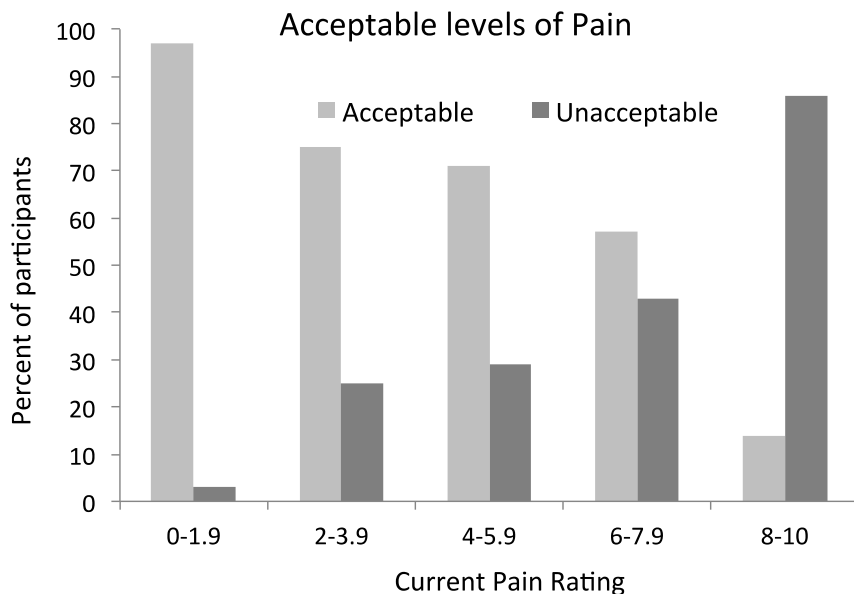
The total number of patients was 138 participants.



e-Figure 3 – All available patterns of participants' A₁ rating of worst dyspnea in the past 24 hours
 Each individual line represents a different participant's reported trajectory. In some cases, the patients were not interviewed on consecutive days, leading to breaks in their trajectories below. Among patients with completed MDPs on both study day 1 and 2, 50% (27/54) had no change in their worst A₁ measurements and 4% (2/54) indicated their worst measurements of dyspnea had increased.



e-Figure 4 – Comparison of patient’s pain ratings at the time of the interview and whether that pain was acceptable or unacceptable (n=135).



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