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labs

The Dima Lab: Lewy Body Dementia & Parkinsonian Symptoms

FACILITATION GUIDE

For Families & Care Professionals

INSTRUCTOR VERSION

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embodied labs framework

Uses & Goals

Knowledge & Training

To educate and provide information on the symptoms and unique challenges of living with **Lewy Body Dementia** (LBD), **Parkinson's Disease** (PD), and transitions to residential community care.

Insight & Transformation

To empower healthcare professionals and professional care partners to be able to provide more compassionate, person-centered care to persons living with these two progressive diseases.

Communication & Team Building

To have meaningful dialogue across your team about the shared experience of embodying the same person with LBD/PD.

1. Prepare by taking a pre-assessment and discovering your existing knowledge.

PREPARE

2. Embody someone by putting on a VR headset and transporting yourself into their perspective.

EMBODY

3. Take a post-assessment, then use this facilitation guide to further reflect on how the VR experiences changed your views, mindset, and knowledge based on the insight you gained by embodying someone else.

REFLECT

BEST PRACTICES FOR USING EMBODIED LABS IN DIFFERENT SETTINGS

Depending on how you will be using Embodied Labs for individuals or a large group, your setup needs may differ to maximize the user experience. Here are suggested equipment and discussion formats for each mode.

Individual Mode

Technology	• Computer, sensor, and headset from kit
Environment	• Quiet, separate area • Moderate amount of privacy while in the headset
Materials	• Facilitation Guide for individual reflection while waiting for the headset or right after the experience

Group Mode

Technology

- Computer, sensor, and headset from kit
- Big screen (if available). Use HDMI cord **AND** adapter that come with your VR kit to attach screen to back of computer
- Mirrored sound through both the computer speakers **AND** headset
- Set volume on audio set all the way up to 100

Note: The computer defaults to the Rift headphones when the headset is plugged in. To get audio through computer speakers so that the group can hear, click on sound icon at the bottom right-hand side of your screen and choose “Speakers”)

Environment

- Quieter area, separate from larger area where most people are congregating
- Space for people to gather around without crowding the person in the headset

Materials

- Facilitation Guide for partner and group reflection while waiting for the headset or right after the experience
- Adult learners often can use the guide themselves; younger learners may need more direction on which question to discuss

THE DIMA LAB

Introduction

From the Creators

Embodied Labs is excited to release our next embodied experience: “The Dima Lab: Lewy Body Dementia & Parkinson’s Disease.” This lab allows learning to embody a Lebanese-American woman named Dima (pronounced “DEE-mah”) as she begins to have symptoms resulting from Dementia with Lewy Bodies (DLB). DLB, the umbrella disease that encompasses both the more commonly known Parkinson’s Disease (PD), in addition to Lewy Body Dementia (LBD) — affects millions of Americans and people across the world, causing changes in physical moment, motor control, personality, sleep habits, and cognition, among many other symptoms.

By embodying Dima, you will experience what it is like to have a progressing brain disease that makes your body and brain often feel out of your control. You will also feel what it is like to reach the point where you and your family need to make a transition from you being at home to living in a residential care community that can meet more of your needs.

We invite you to again put on the headset and embody another older adult with Embodied Labs.

— The Embodied Labs Team

Please Note

This Embodied Lab was created by documenting first hand accounts of patients, families, and care teams in actual continuing care communities. Embodied Labs does not endorse any particular practice, treatment, or care plan detailed in this lab; rather, this is meant to provide perspectives for informed discussions about the many facets of care for older adults.

Insight Statements

After experiencing The Dima Lab: Lewy Body Dementia & Parkinson’s Disease, learners will develop insights around the following themes:

Recognizing Symptoms

Care partners should recognize that people who have stiff muscle movement, a jerky/uneven gait, tremors, hallucinations, anxiety, agitation, extreme personality changes, and/or sleep disturbance may have Dementia with Lewy Bodies — which includes both Parkinson’s Disease (PD) and Lewy Body Dementia (LBD).

Engaging Effectively with Expressions of a Changing Brain

Care partners may be able to help a person with advanced PD/LBD who is experiencing anxiety, agitation, or hallucinations by:

- Taking away the source of stress or by helping the person move into another less stressful space.
- Entering into the “role play” of the hallucination and/or connecting it to something that the person did in their past daily life.

Insight Statements (cont.)

Getting Support from Professional Services

Care partners of people living with LBD/PD who are experiencing emotional and/or physical burnout, financial burden, or are worried about the safety of themselves or their loved one may need to utilize the options available to them from professional home care agencies or in residential care communities.

Transitioning to Residential Care

Care communities can better support people with LBD and PD in their transition to care by:

- Creating a supportive environment for the whole family system to process the emotional aspects of the transition of a loved one to continuing care.
- Creating calm environments with low stimulus, not assuming low cognitive function, and moving slowly when introducing new information, people, or places.
- Making sure enough activities are available that allow them to expend physical energy and connect to activities they enjoyed at home.

THE DIMA LAB

Recognizing Symptoms

Lewy Body Dementia vs. Parkinson’s Disease

1. What are some of the early symptoms of Lewy Body Dementia? Parkinson’s Disease? How are they the same and different?

Talking points:

- The earliest signs of PD often are tremors, muscle stiffness, and slurred/soft speech.
- The earliest signs of LBD often are sleep disturbance, hallucinations, personality changes, and going into sensory overload.
- As people with LBD and PD progress in their diseases, all of the symptoms above may become increasingly present AND include some cognitive impairment.
- In late stage PD and LBD, symptoms usually include all of the above and the two diseases are hard to distinguish from one another.

Lewy Body Dementia vs. Other Dementias

2. How is Lewy Body dementia the same and different compared to Alzheimer’s disease?

Talking points:

- Because cognitive impairment and typical memory problems associated with dementia come later, people with LBD retain their abilities to engage with people around them in more typical ways.
- Professional and family caregivers should be particularly sensitive to including people with LBD in conversations, decisions, and activities.
- Because Lewy Body Dementia most commonly includes expressions such as anxiety and paranoia, which can lead to aggression, it can be one of the most difficult types of dementias for families to cope with effectively.

THE DIMA LAB

Engaging Effectively with Expressions of a Changing Brain

Difficult Situations for People with LBD or PD

1. What were some of the situations that made it difficult for Dima and/or made more symptoms of increased Lewy Bodies in her brain more obvious to her and her family?

Talking points:

- Anxiety from not being able to write what her grandson wanted.
- Going a different way to the bakery was hard because it was a disruption to the routine.
- Loud noises from her grandchildren, the TV, and her hallucinations all happening at once.
- Moving more slowly and stiffly.
- Feeling tired from not sleeping well make all symptoms worse.

Calming a Person Experiencing Anxiety or Paranoia

2. What are some ways that you saw professional and family caregivers help Dima cope better when she experienced symptoms of her changing brain?

3. How does this relate to your own experience or work with families?

Talking points:

- Isabel recognized she would need to begin being the primary caregiver of the children.
- Bassam non-judgmentally entered into his mothers “bug” hallucination to help her “get rid of them”.
- Isabel recognized Dima’s stress in the car, offered ear plugs, and helped her breathe to calm herself.
- Alexis saw Dima’s stress in the community room and helped her leave the situation to do something else.

Getting Support from Professional Services

Challenging Symptoms that Require Additional Support

1. What were some of the symptoms of Dima's changing brain that were especially challenging for her and the family?

2. How does this relate to your own experience or your professional work with families?

Talking points:

- The symptoms of tiredness, stiffness, and sensory overload made it necessary to find another primary caregiver for the children.
    - Isabel became a primary care partner for her mother-in-law and stay at home mom to her children as a result, affecting her well-being, the family dynamics and finances.
- The symptoms of agitation, hallucination, and being prone to wander/fall caused the family to need to pursue care options that would be safer for Dima and themselves.

Support from Home Care

3. How could home care effectively support this family and keep Dima living in her home longer?

Talking points:

- Non-medical care professionals, also called home health aides (HHA) could assist Dima and the family with house-keeping, meal preparation, personal care, errands, and fall prevention.
    - Depending on your state, this costs $9-12/hour on average.
- A certified nursing assistant (CNA) has more training in the areas of personal care (bathing, toileting, etc.) and basic medical care (wounds, dressings, catheters, blood pressure, etc.) and safety (fall prevention, lifting, etc.).
    - Depending on your state, this costs $10-15/hour on average.

Getting Support from Professional Services (cont.)

Support from Residential Care

4. At what point is it necessary to transition from care at home to care in a residential community?

5. Did you relate to Dima's son Bassam's feelings and struggle with making this decision?

6. Or, perhaps you related more to Isabel's needing to focus on her caregiving role as a mother, rather than being a care partner to Dima?

Talking points:

- A fall often means a transition to rehab and then to community care.
- Safety of others & person living with the disease.
- Financial burden of home care becomes greater than the cost of residential care.
- Emotional toll on family care partners becomes to great.
- Family care partners have too many work or other family responsibilities to continue providing care.

7. What are some factors that make a transition to residential care complicated for the family and/or resident?

Talking points:

- Guilt of family care partners.
- The person living with the disease does not want to transition to community care.
- Financial burden of residential care cost.
- Cultural considerations.
- Availability of beds.

Transitioning to Residential Care

Supporting the New Resident During a Transition

1. What are best practices for a care community can support a resident who is new, particularly in the first 24 hours?

2. Did you think that Dima's community showed best practices?

3. Is there a practice you think your own community could do more effectively?

Talking points:

- Talk directly to and ask questions of the new resident, not their family even if you suspect or know of cognitive impairment.
- If/when a physical exam is needed in the first 24 hours, try to do as much of it as a natural process of meeting and talking with the person as possible.
- Have resources available to support the person emotionally and/or spiritually as they experience the sadness, loneliness, irritability or even anger that may be present.
- Help adjust to new routines while maintaining what you can of the person's former way of life.

4. What were some of your feelings as you experienced the intake process from the new resident's point of view when you embodied Dima?

Talking points:

- Isolation as people talked about you instead of to you.
- Anxiety about living in a new space.
- Crowded feeling with so many people in YOUR room.

Transitioning to Residential Care (cont.)

Supporting the Resident's Family During a Transition

5. What are best practices for a care community can support a family during the initial intake and transition process?

6. Is there a practice you think your own community could do more effectively?

7. If you are a family member of someone who has made a care transition, what are some good or bad experiences you have had?

Talking points:

- Respecting preferences around diet, religion, privacy, and family structure.
- Ensuring that policies do not limit family access to residents.
- Conveying in words, actions, and body language that you care for the family's loved one and are committed to their well being.
- Acknowledging that care transitions are hard and emotional.

8. What are some of the unique aspects of a person with Lewy Body Dementia and Parkinson's Disease adjusting to community care?

Talking points:

- People with Lewy Body Dementia and particularly Parkinson's disease are not necessarily as cognitively impaired as typical memory care residents.
- It is important to engage with residents with a diagnosis of LBD or PD as if they are cognitively normal.

Resource List

Information about Lewy Body Dementia

Lewy Body Dementia Association
Information about LBD symptoms, research, resources, and support.
https://www.lbda.org/

National Institute on Aging: What is Lewy Body Dementia?
Information about LBD symptoms, research, resources, and support.
https://www.nia.nih.gov/health/what-lewy-body-dementia

Information about Parkinson's Disease

Parkinson's Foundation
Information about PD symptoms, research, resources, and support.
https://www.nia.nih.gov/health/parkinsons-disease

National Institute on Aging: What is Parkinson's Disease?
Information about PD symptoms, research, resources, and support.
https://parkinson.org/understanding-parkinsons

Information about Elder Care

Eldercare Locator
Information about local resources for older adults.
https://eldercare.acl.gov/Public/Index.aspx

PBS: Resource Guide to Caring for your Parents
Resources from national and state organizations; advice on how to talk about care decisions and transitions.
https://www.pbs.org/wgbh/caringforyourparents/index.html

Information about Care Transitions

Family Caregiver Alliance
Influential book by a practicing surgeon about living a “good life” all the way until the end-of-life.
https://www.caregiver.org/home-away-home-relocating-your-parents

Agingcare.com
Website with information about many aspects of aging, including care transitions.
https://www.agingcare.com/articles/help-senior-adjust-after-move-to-independent-living-168514.htm

Other Information

Family Caregiver Alliance
Influential book by a practicing surgeon about living a “good life” all the way until the end-of-life.
https://www.caregiver.org/home-away-home-relocating-your-parents

Dementia Action Alliance
Resources, advocacy, and information for people living with dementia
https://daanow.org/

Aging in Place
Resources and information focused on aging while remaining in your home
http://www.ageinplace.org/Practical-Advice

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