

A grayscale image of a classical building with a prominent clock tower, featuring a large clock face and arched windows, is positioned on the left side of the slide.

## **ETHICAL CHALLENGES IN DEMENTIA INFORMAL CARE AND RESEARCH: QUALITATIVE STUDY IN THE REPUBLIC OF MOLDOVA**



Taking action to  
improve health for all



***Adriana Paladi***

**School of Public Health Management  
Nicolae Testemitanu State University of Medicine and  
Pharmacy of the Republic of Moldova**

# CONTEXT

Dementia is a major global public health challenge and is currently recognized as a priority in mental health.

- In 2018, 1.57% of the European population was affected; projected to reach 3% by 2050.
- Care and support emerge as the most critical, as no effective treatment exists.
- Informal caregivers provide the majority of care for persons with dementia (PWD).
- Limited literature on ethical dilemmas experienced by caregivers.

# METHODS

## STUDY DESIGN

A cross-sectional qualitative design to explore ethical issues in dementia care as experienced by informal caregivers. The conceptual framework was grounded in the patient- and family-centered care approach (Kitwood, 1998). Participants – 12 family caregivers providing care for individuals with dementia for at least six months. Recruitment was carried out using purposive and convenience methods.

## PARTICIPANTS CHARACTERISTICS

Relationship to PwD	Gender (F/M)	Age range (years)	Mean age (SD)	Care duration range	Employment status	Religiosity level	PwD's age range
4 Daughters, 2 Daughters-in-law, 2 Granddaughters, 2 Wives, 2 Husbands	10/2	18/78	52,3 (18,3)	1 – 7 years	4 unemployed, 5 employed (2 as a personal assistant), 3 retired	5 religious, 6 traditional, 1 unreligious	60 – 86 years

# RESULTS

## THE MAJOR THEMES

- 1 Caring for Persons with Dementia (PwD)**
- 2 The Lived Toll of Dementia Caregiving**
- 3 Moral stress and resilience: between ethical tensions and inner anchors**

## SUBTHEMES

- Broad range of responsibilities; Constant Vigilance in Response to Unpredictable Behaviors
- Alone in Complexity: Navigating Care Without Guidance or Support; Financial Strain and the Weight of Unrecognized Care; The Physical and Emotional Weight of Caregiving
- Ethical dilemmas in caregiving: between the comfort of the person with dementia and the caregiver's well-being; Moral resilience and deep motivation in dementia caregiving; Everyday Practices of Good Dementia Care

# 1 CARING FOR PWD

## BROAD RANGE OF RESPONSIBILITIES

*"I feed him, I wash him, I help him get dressed... every single day. Again and again. I do it all. Every day." (Wife, urban area)*

## CONSTANT VIGILANCE IN RESPONSE TO UNPREDICTABLE BEHAVIORS

*"If I work outside, I am working for 5-10 minutes, then rush back into the house to see what she's doing; that's the situation." (Daughter-in-law, rural area)*

## 2 THE LIVED TOLL OF CAREGIVING

### NAVIGATING CARE WITHOUT GUIDANCE OR SUPPORT AND UNDER FINANCIAL STRAIN

*"No one trains you on how to care for such a patient... You learn on the go." (Daughter, urban area)*

*"I can't have a job because I should take care of her 24/7. Tomorrow or the day after, I will retire... what will I receive? How will I feed myself?" (Daughter, urban area)*

*"We have been waiting for over a year to get the status of a personal assistant." (Daughter-in-law, rural area)*

### THE PHYSICAL AND EMOTIONAL WEIGHT OF CAREGIVING

*"It's like taking care of a child, but harder... At this age [78], I don't have the strength anymore. A child grows, learns, and becomes more independent. But here... It's the opposite. Everything is going backwards." (Husband, rural area).*

# 3 MORAL STRESS AND RESILIENCE

## BETWEEN THE COMFORT OF PwD AND CAREGIVER'S WELL-BEING

*"Sometimes, when I go to the store, I have to tie him with a belt. /justifying herself/ We've had incidents when he fell and got hurt." (Wife, rural area)*

*"It's like I'm in a tunnel. I'm walking through that tunnel and can't see the way out." (Daughter-in-law, rural area)*

## MORAL RESILIENCE AND GOOD DEMENTIA CARE

*"What helps me? ... We all are under the Lord's protection. Sometimes you feel as lost and suddenly, through a crack, you solve the problem." (Wife, rural area)*

*"Hey, we have lived a life side by side... so many years...I often ask myself. What if I were in her place? Then should I be thrown into a ditch?" (Husband, rural area)*

*"It's an obligation... yes, the responsibility for a close person. There is no other way." (Husband, urban area)*



# DISCUSSION

## RESEARCH CHALLENGES

Some participants associated the researcher's presence with that of a public authority or someone in a position of power. As a result, they emphasized the negative aspects of their caregiving experience, hoping to draw attention to their difficulties and possibly receive some form of support.

Previous studies have also found that negative aspects of caregiving—such as stress, burnout, and emotional overload—tend to be more prominently reported in research, especially in contexts where formal support is limited (*Lindeza, Patrícia et al. 2020*).

Narratives of burden may dominate the data when caregivers perceive research participation as an opportunity to express unresolved frustrations or unmet needs.

# CONCLUSION

- ❖ Ethical dilemmas are inherently contextual and deeply embedded in the day-to-day realities of caregiving.
- ❖ Study data underscore that caregivers grappled with maintaining a balance between ensuring the safety of the PwD and respecting their autonomy.
- ❖ Simultaneously, they faced conflicts between attending to their well-being and fulfilling caregiving responsibilities.
- ❖ In the context of a lack of structural and systemic support, caregivers find meaning in their role and draw on personal resources such as faith, family love, or a sense of moral duty.



# THANK YOU



**[adriana.paladi@usmf.md](mailto:adriana.paladi@usmf.md)**

Sincere appreciation to all participants for their willingness to share personal and often emotionally challenging experiences. This research was initiated and coordinated within the COST Action “EDEM – Ethics in Dementia” framework, whose support is hereby gratefully acknowledged.



# THANK YOU

"Lorem ipsum dolor sit amet,  
consectetur adipiscing elit, sed do  
eiusmod tempor incididunt ut  
labore et dolore magna aliqua.



[WWW.EHMA.ORG](http://WWW.EHMA.ORG)  
[WWW.EHMACONFERENCE.ORG](http://WWW.EHMACONFERENCE.ORG)