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Living with Dementia: exploring the challenges and needs of informal Dementia caregivers in Portugal

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Background: Dementia profoundly impacts not only those diagnosed but also their informal caregivers. The Nova Center for Global Health at NOVA-IMS, in collaboration with the Alzheimer Portugal Association, embarked on a comprehensive study to explore the various aspects of daily life that affect informal caregivers of people with dementia in Portugal. Understanding these impacts is important for developing targeted interventions that address the caregivers' needs effectively, particularly given the current lack of research on informal dementia caregivers.

Methods: The study utilized a crafted survey developed through initial scripting on key topics identified by informal caregivers and validated by experts on dementia. This phase was followed by a series of in-depth interviews with professionals in neurology, psychology, and social work, as well as with the caregivers themselves. The final survey was distributed among members of the Alzheimer Portugal Association and other volunteers, resulting in 305 valid responses.

Results: Preliminary findings reveal significant emotional, physical, and financial challenges faced by caregivers, underlining the diverse needs across 14 key areas of their lives. The study highlights specific areas where support is lacking, providing a grounded basis for developing more effective support mechanisms.

Conclusions: The 'Living with Dementia' project underscores the complex reality faced by informal caregivers. It calls for innovative, practical solutions that can alleviate the burden on these caregivers and improve their quality of life. By addressing the specific needs identified through this research, policy-makers and support organizations can better tailor their interventions to help those at the front lines of caregiving in dementia.

Key messages:

- Informal caregivers of people with dementia face challenges that necessitate a comprehensive understanding to tailor effective support systems.
- Interventions are needed that address the emotional, physical, and financial hardships caregivers face, improving their overall well-being and capacity to care.