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How to improve informal caregiver's quality of life and health literacy? – a NGT approach

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Background: Previous studies revealed that informal caregivers have a large number of unmet needs, reinforcing the necessity of national policies that ensure an adequate sustainability of the provision of informal care and takes into account the needs of caregiving dyads in the planning process. This study aimed to identify and consensualize initiatives and action strategies to improve the Portuguese Informal Caregiver's reality and health literacy levels.

Methods: A Nominal Group Technique (NGT) was conducted with 10 experts. The NGT panel was asked about feasible action strategies to improve informal caregiver's reality, consensualized and voted them according to perceived relevance in a semantic differential (1 pts to nothing relevant and 6 pts to very relevant), allowing a score calculation.

Results: Thirty-two initiatives emerged from the NGT. The five most relevant initiatives were identified based on an average score namely: 1) Pressure political decision-makers on the need for an effective implementation of the Informal Caregiver status, which is not being done (score=56); 2) Creation of a specific emergency social line for informal caregivers, as a measure of greater equity (score=52); 3) Raise employers awareness about caregiving demands (score=52); 4) Creation of a proximity social manager, linked to primary care services, that facilitates caregiver connection to health and social care services (score=51); 5) Decentralization of respite care services support, with multidisciplinary teams (score=49).

Conclusions: The informal caregiver's role needs to be recognised and understood by healthcare and social care providers. (Re)design political, economic and social policies that address both caregiver and care recipients' needs is critical to enable the continuity of informal care provision.

Key messages:

- Informal caregivers play a fundamental social role but still have many needs to be addressed, particularly at the level of the official definition of their role.
- (Re)design political, economic and social policies targeted to informal carers is imperative to enable the continuity of informal care provision.