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From Insight to Action:

Understanding and Preventing Loneliness among Informal Dementia Caregivers

1. BACKGROUND

- Informal caregivers: crucial role in caring for people with dementia
  - Great responsibility → emotional, physical and social challenges that increase the risk of loneliness

2. RESEARCH QUESTIONS

1. What is the specific ***experience*** of informal caregivers of people with dementia in terms of loneliness?
2. What are their ***needs*** in relation to loneliness?
3. How can we ***support*** them in relation to their loneliness?

3. METHODS

Multi-method research

- Quantitative analysis of secondary survey data on informal caregivers of people with dementia (N = 461)
- 5 qualitative focus groups
  - 3 with informal caregivers (N = 19)
  - 2 with professionals (N = 21)

5. DISCUSSION & CONCLUSION

What works?

- Essential: an **informal-care friendly society** as starting point
- From this starting point on, different needs on different levels and in different directions can be tackled to ***support (3)*** informal caregivers of people with dementia (e.g., social support from the close environment (3) to the informal caregiver (1) vs. realistic expectations from the informal caregiver (1) towards the close environment (3))

4. RESULTS

Loneliness

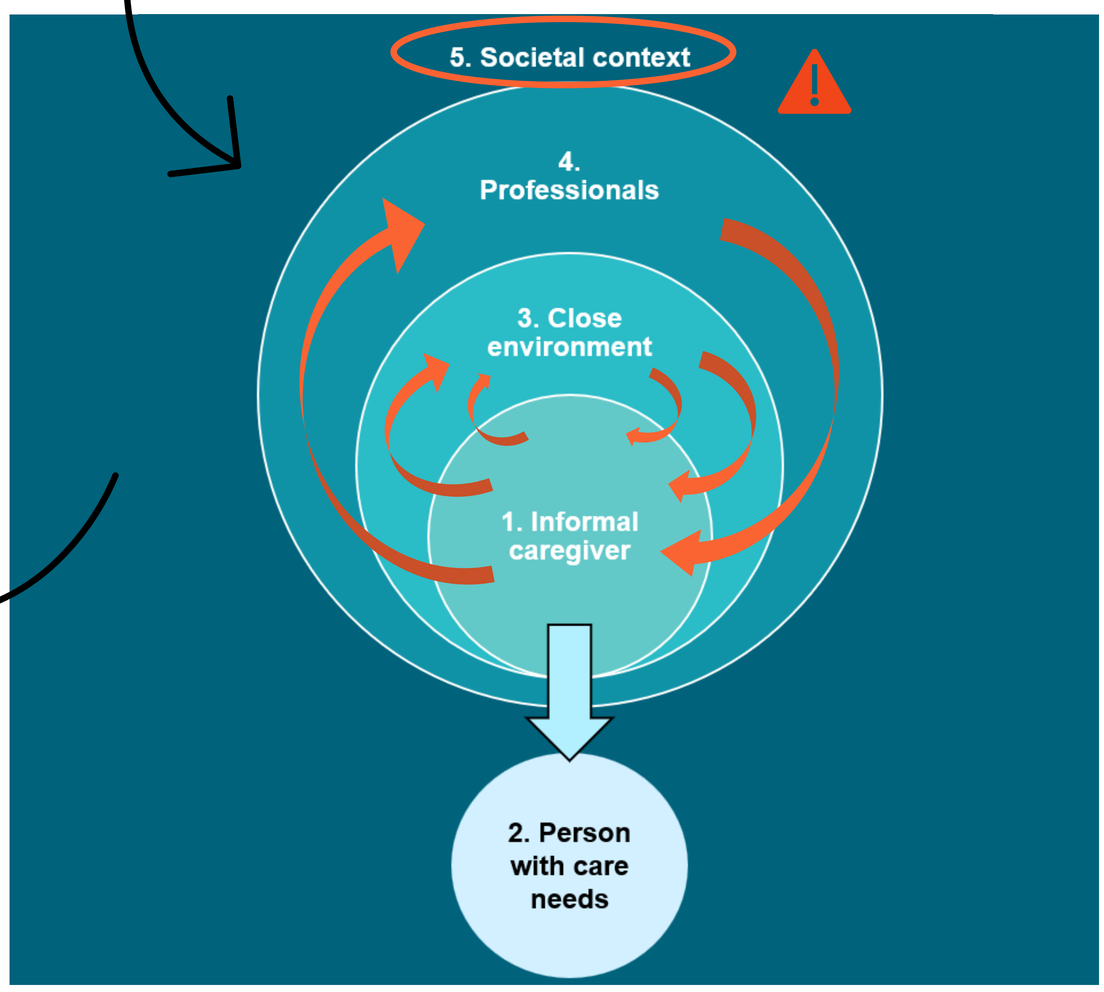
- 54.4% of informal caregivers of people with dementia experience moderate to severe loneliness
  - Social loneliness: 39.1%
  - Emotional loneliness: 30.7%

Experience (1): what causes loneliness?

- Other occupations (than taking care) fall away
- Everything is about the person with care needs
- Taboo & little recognition
- Responsibility of taking decisions alone
- Continuous grieving process

Needs (2)

- Reciprocal needs in different directions



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