

Caregivers' beliefs towards undertaking Advance Care Planning

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Advance Care Planning

“Advance Care Planning (ACP) is a process that supports adults at any age or stage of health in understanding and shaping their personal values, life goals and preferences regarding future medical care” (Sudore et al., 2016).

Ways to undertake ACP

- **Advance directives**
- **Durable power of attorney**
- Informal discussions with family members and professionals

Advantages of undertaking ACP

For people with dementia :

- Enables respect for the person's values and preferences.
- Strengthens the person's autonomy.
- Improves quality of life at end of life.

For family caregivers:

- Reduces decision making burden.
- Decreases worries about the future of the sick person.
- Reduces stress, anxiety and depression.

Family caregivers

Spouses or adult children.

Face significant risks.

Make decisions for the person with dementia.

ACP in Israel

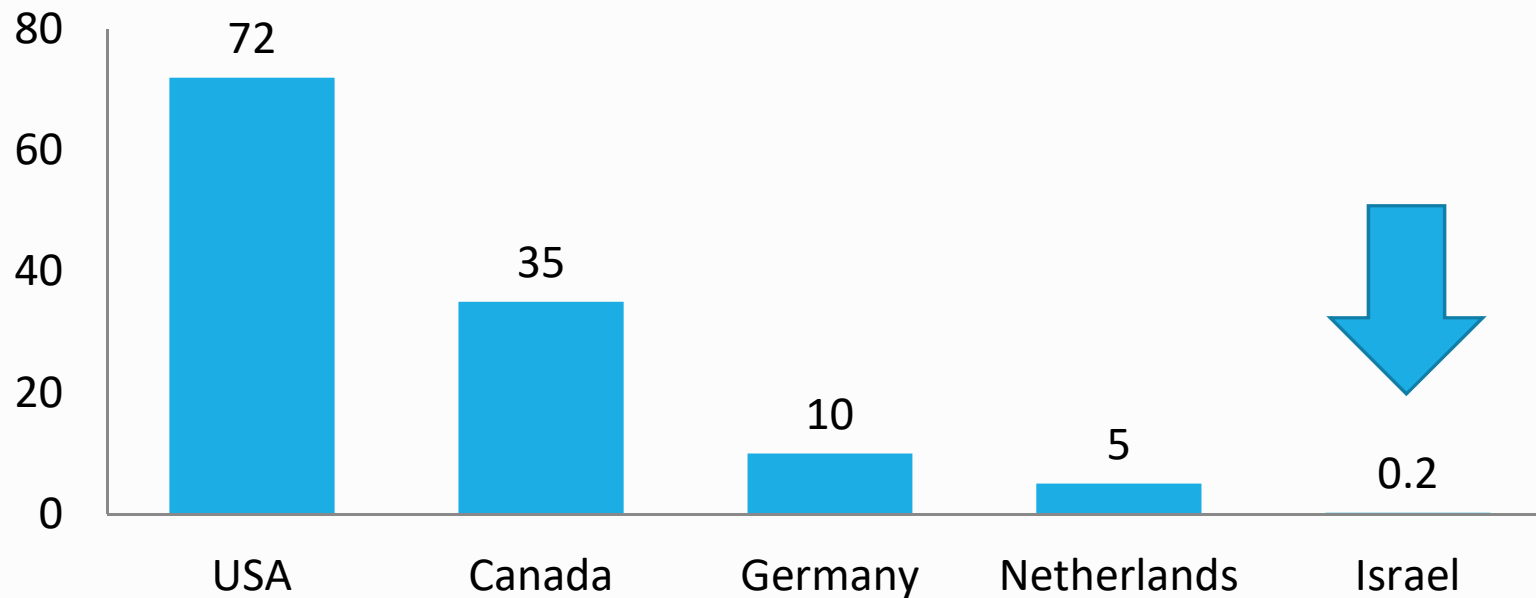
“The Dying Patient Act” (2005).

ADs and Durable Power of Attorney (Ministry of Health).

Only 0.2 percent of the Israeli adult population undertook ACP.

Completion of ACP

(percentage of the adult population)



Aim of the study

To examine dementia family caregivers' beliefs regarding ACP.

Participants

20 family caregivers

75% were female

65% were spouses

55% were born in Israel

Mean age = 66.25

Mean number of years of education = 14.6

Mean number of years as caregivers = 8.2

Methods

Procedure: face to face interviews using a semi-structured questionnaire to elicit the main beliefs of undertaking ACP.

Analysis: Theory-led thematic analysis was used to analyze the data.

Ethical consideration

Results

Three main beliefs were expressed:

Respecting the person's autonomy and freedom to choose.

“I want everything to be as I want it to be in situations where I won't be able to express myself” (R)

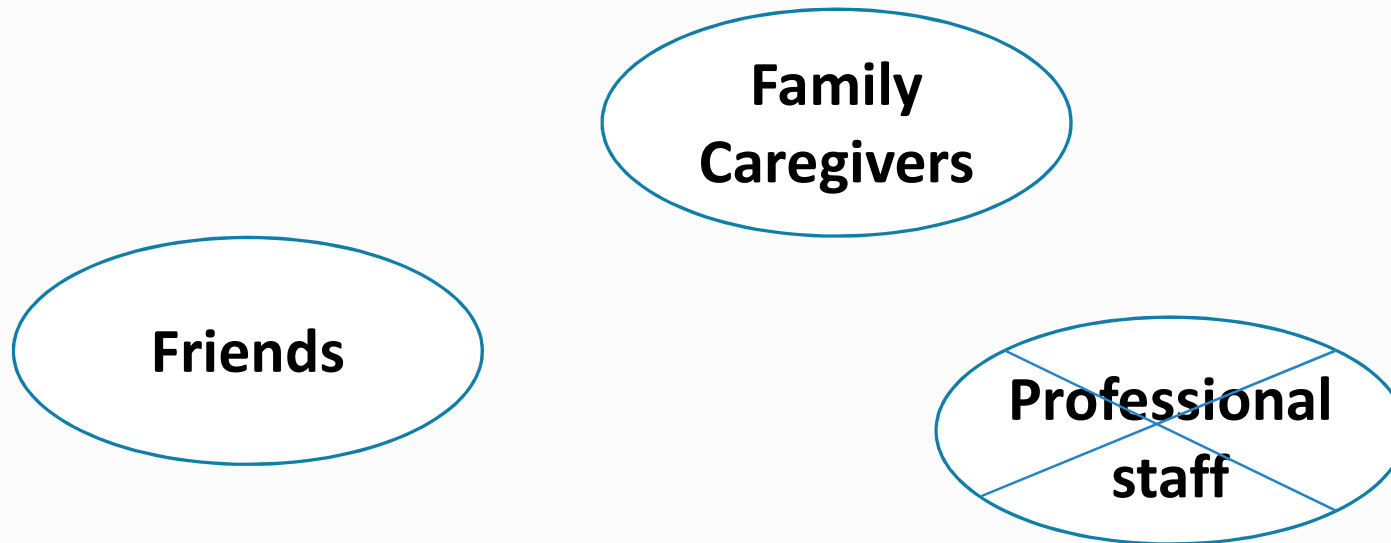
Avoiding prolonging life and suffering of the sick person.

“We need to avoid suffering, when life is not life for the sick person and for the family” (A)

Alleviating the decision making burden of the family members.

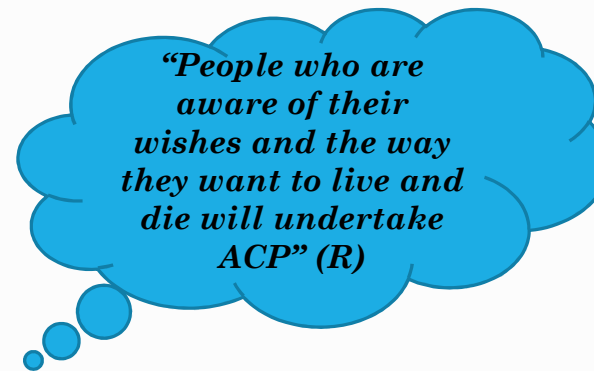
“It’s good for family members to know the sick person’s wishes. Their wanting to respect the wishes will help with decision making” (M)

Main persons who can encourage or discourage decision making



Characteristics of the people that are more likely to undertake ACP:

- Secular
- Highly educated
- Old age
- Self-awareness



Facilitating factors of undertaking ACP:

Previous familiarity or experience with Alzheimer's disease and pain.

“I see what happens with my husband, he doesn't have control and he can't decide for himself. It makes me think (about undertaking ACP)” (N)

Worries about a worsening of their own health.

“If I will be sick and will be in a bad condition, I will do it (ACP), to be ready for the moment” (E)

Barriers of undertaking ACP:

Lack of knowledge and lack of awareness regarding ACP.

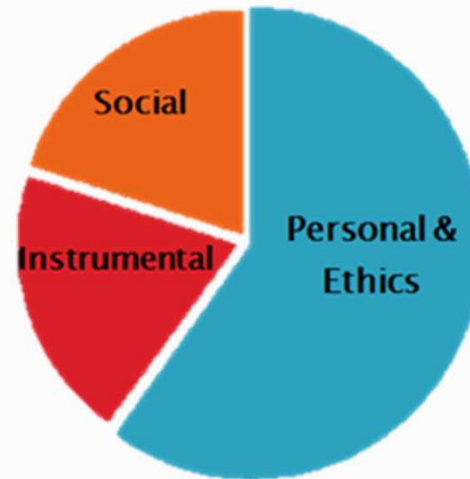
“There is no knowledge and awareness, nobody knows about it (ACP)” (H)

Instrumental difficulties associated with the completion of ACP.

“It is not accessible, it is a long drawn-out process, everything is hard, the state wants to exhaust us” (K)

Discussion

Dementia caregivers' beliefs were guided by personal and ethical, social and instrumental issues.



Conclusion

- The findings showed that family caregivers believed undertaking ACP is a complex process.
- Interventions should be developed in order to increase the knowledge and alleviate concerns regarding completion of ACP.
- Professionals should be more involved in the process of undertaking ACP.
- Further research should be done.

