The development of Best Practice Recommendations to enhance access to formal community care services

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Referral/information/care management

Don’t know about existing services

Don’t know how to access the services

Don’t think the service will suit them

Being picked up by the centre’s bus in the morning is embarrassing

The service is too expensive

Home-dwelling person with dementia

Monetary support

Information

Care management

Daytime activity services

Awareness/reduce stigma

Information

Care management

Daytime activity services

Awareness/reduce stigma
Work package 5 Delphi process

Purpose:
To reach consensus on statements considered important enough to be included in Best Practice Recommendations for access to formal care

The Delphi process had 3 rounds
Work package 5 Delphi process

Experts participating in the Delphi-process

- 5-8 professional experts recruited by each national Actifcare team
- 3 experts by experience recruited by each national Actifcare team
- 5 experts by experience recruited from the European Working Group for People With Dementia
Delphi process - rounds

- Round 1: The Actifcare research teams provided statements
- Round 2: The first round of rating of statements
  - Experts by experience (34)
  - Professional experts (48)
- Round 3: The second round of rating of statements
  - Experts by experience (29)
  - Professional experts (42)
Acknowledgement

We thank the European Working Group for People With Dementia (EWGPWD) for invaluable feedback in the phrasing of the statements for the experts by experience and for participating as experts in the Delphi process.
Delphi process

Results:

First rating

- 28 statements (of 72) reached consensus as important
  (median of 6 or 7, Quartile deviation 0.5 or lower and 75 % or more of the ratings being within two adjoining values)

- 44 statements did not reach consensus and needed to be rated again

Second rating

- 35 statements (of 44) reached consensus as important

- 9 statements did not reach consensus
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Results:

- 23 Best Practice Recommendations based on
  - the statements which reached consensus in the Delphi process
  - supporting findings from the Actifcare project
  - other available supporting findings

- The recommendations categorised as:
  - A. Recommendations to enhance access
  - B. Recommendations to enhance use
  - C. Recommendations that can *facilitate* access or use indirectly: enabling factors
A. Recommendations to enhance access

- Contact person
  - Competence, resources, tasks
- Financial support
- Provision of information, online and through traditional channels
- Information about and referral to services from all parts of the health system
- Pathways
- Psychoeducation after diagnosis
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B. Recommendations to enhance use

- Transport
- Coordination and cooperation
- Building up use of services gradually
- Flexibility in the delivery of services
- Continuity of staff and predictability in the provision of services
- Dementia-specific services available
- Services enhancing independence
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C. Recommendations that can facilitate access or use indirectly; enabling factors

- Equitable and needs driven access to services
- Support groups
- Training for health care professionals
  - The responsibility of the services provider
  - Includes training in safeguarding dignity and showing empathy and respect and how to deal with conflict regarding care decisions
C. Recommendations that can facilitate access or use indirectly; enabling factors

- General practitioners;
  - training in diagnosing dementia
  - have an overview of the person with dementia’s situation
- Building services on the principles of person-centred care
- Raising awareness through education and use of mass media
Thank you for your attention

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