Informal caregiver involvement in innovative home care projects in Belgium

Lopez Hartmann Maja, Van Durme Thérèse, Maggi Patrick, Delye Sam, Schmitz Olivier, De Almeida Mello Johanna, Cès Sophie, Verhoeven Veronique, Gosset Christiane, Declercq Anja, Macq Jean, Wens Johan, Remmen Roy

Background

Innovative home care projects in Belgium “protocol 3” (2009-2013)
✓ Bottom-up approach
✓ Aim: delay institutionalization of frail elderly

Why is informal caregiver involvement important?
✓ Impact on caregiver burden, quality of care, ...

Research question

To what extent do the protocol 3 projects involve the informal caregivers?

Methods

Data sources:
✓ applications + yearly questionnaires + interviews + focus groups

Qualitative descriptive analysis:
✓ communication between professionals and informal caregivers
✓ decision-making process

Participation continuum (Hickey & Kipping, 1998)

Information / explanation consultation partnership User control

Preliminary results

✓ Communication:
  • Importance of a relationship of trust
  • Subjective feeling of professionals: Effect of ‘relationship of trust’ on accuracy of Zarit-scores

✓ Decision-making process:
  • Informal caregiver is not always involved or key person
  • Depends on complexity/urgency of care situation

✓ Participation continuum:
  • Dynamic: at some points in the course of a service provision a higher level of participation is desirable (e.g. at intake)

Discussion

✓ For now: only 1 side of the story: professionals view
  • To match with informal caregiver point of view (questionnaire)
  • To match with frail elderly / informal caregiver outcomes (e.g. interRAI HC and Zarit)

✓ Importance of in-depth qualitative data
  • To explain why the informal caregiver is or is not involved

Quote: “I involve the informal caregivers especially when I am looking for the right tool because they know the clients best. It is appreciated that you do not say here is your tool, but that you really consult with them.”
(occupational therapist)

Quote: “It is with the informal caregiver that arrangements about the care for the frail older person can be made. The informal caregiver is treated as a partner and not as a patient.”
(nurse in night care project)