Mobile dementia counselling: an instrument to support informal carers in rural areas in Germany

“When you stand in front of a mountain of problems and do not know where to start, you may go there and get some guidance.“ (B_E3)

Project duration: 01.04.2012 – 30.06.2015
Funded by: The German Ministry of Health

25th Alzheimer Europe Conference
“Dementia: Putting strategies and research into practice”
The interior of the counselling bus
Project description

- The counselling service can be used with or without prior appointment.

- If needed: A qualified care of the person with dementia is ensured during the counselling interview.

- The counselling service is free of charge.

- Counselling-teams are composed of one qualified full-time staff (from one of the co-operation partners) and one qualified honorary consultant (currently: ca. 80 counsellors: 30 volunteers, 50 professionals).

- Counselling is offered on 14 locations in 7 municipalities (planned for 2015: 6 additional locations in 3 further municipalities).
Tasks of the mobile counselling

- **Improving the situation of people with dementia & relief of their carers**
  - „Helping people to help themselves“ (B_E9)
  - Give encouragement and reduce fear („talking about what is going on at home [...]. So as they say: ‘Thank God. Now I was able to speak about it‘.“ (B_E7))

- **Guiding function within the local care system**
  - Give information about local offers
  - Facilitate the access to established supply and support offers
  - „Be a guide“ (B_E5); „pass on to other institutions“ (B_H1)

- **Improving public awareness of dementia**
  - „Not everything concerning dementia is automatically terrible“ (B_H1)
  - The bus has „another attention“ than a fixed counselling institution in a building for which you have to search for specifically (B_H3_P2)
Some data with regard the mobile counselling

- **552 counselling interviews** are documented *(status: 31.03.2015)*

- Duration of interviews: on average **25 minutes**

- In **93 %** counselling was used **spontaneously** *(without a previous appointment)*

- **80%** of the persons seeking advice were attracted to the counselling because they have seen the bus
Socio-demographic characteristics of carers using the mobile counselling and the persons with dementia they care for

- **Carers:**
  - 65% women, 35% men
  - Average age: 59 years
  - 45% of them were employed

- **Care receivers:**
  - 60% women, 40% men
  - Average age: 77 years
  - in 61% of the cases: diagnosis „dementia“ already existed

photo: www.für-sie-ins-quartier.de
Mobile counselling as an important contact point

Previously contacted institutions
Multiple answers (632 namings; status: 31.03.2015)

- None: 25%
- Physician: 30%
- Specialist: 16%
- Municipal care counselling: 4%
- Health insurance / care insurance: 9%
- Hospital: 6%
- Professional care: 4%
- Other: 7%
Reason for the use of mobile counselling - I

Multiple answers (560 namings; status: 31.03.2015)

- Concerning own family: 65%
- Concerning friends and neighbours: 8%
- (Suspecting) illness on yourself: 14%
- Concerning the work: 5%
- General interest: 4%
- Other: 4%

40%: mother (in law) of the person seeking advice
17%: father (in law) of the person seeking advice
4%: parents
16%: companion / husband
10%: companion / wife
Reason for the use of mobile counselling - II

1. Unspecific issues
   - „First we hardly asked anything. We just said, 'we came to get some information about the illness dementia. In our family we now have a case.'“ (PA04)
   - „actually I just wanted to take a note with me…. But then questions came within the conversation…“ (PA03)

2. Specific issues
   - „He gave me the number. I did not had to search for it in the phone book […] And then I just made it…. also because of this. It was the trigger. Because of this mobile. […] I knew what day care looks like, I was informed about it. But I did not this final step.“ (PA02)
Some reasons for the use of mobile counselling

„I cannot leave her alone. It is not possible. I am scared.“ (PA06)

„My wife is ill and I am in pain.“ (PA01)

„… and then I leave the things I did and go with him and this is unbearable slow exhausting…“ (PA02)

„… to get help from somewhere and to get informed, because no one of our relatives or friends has ever had something to do with this illness.“ (PA04)

„There is always suddenly a deterioration. [...] And then you stay there with no chance for a real decision making.“ (PA08)
Persons sought advice for ....

- Home care (35%):
  - especially low threshold support (18%), household-related services (9%), care services (8%)

- (emotional) support:
  - Further education (22%), self-help group, care courses, promotion of personal strength

- physicians/ hospitals (17%), especially specialists

- partial stationary care (14%)

- living arrangements (6%)

- leisure and holiday offers (5%)

Multiple answers (2584 namings; Status: 31.03.2015)
Impending factors for the use of the mobile counselling service

- **Name of the offer:** „‘What does it mean?, […] This keeps them away, this name 'psychiatric' […] ,Oh my god, I am not crazy’“ (B_E6)
  → *door-opener: additional put-up hinge that clearly identifies ‘dementia’ as topic of the counselling was used*

- **Taboo / ‘Stigmatization’** (E2, E8); „if I go to the counselling everybody knows I need help“ (PA04)

- **accepting help:** people may not want to „the problem to be a subject of discussion“ (B_E2_P2)

- **winter mode/ weather conditions:** „It may is difficult when it rains.“ (PA06); „because doors are closed and from the outside you can not see if there is someone inside.“ (B_E2_P2)

- **location**
Satisfaction with the mobile counselling service

„I felt like a king.“ (PA01)

„They helped us good and said what we could do and how to do. We do not know our rights and we do not know the whole procedere.“ (PA06)

„They encouraged me.“ (PA02)

„They were so nice, I instantly started crying. …This week was really exhausting anyway because of her, every day she missed her keys, wallet and so on.“ (PA04)

„They checked my official documents … after this they said ‘it is not correct’ and then I wake up and realised it.“ (PA06)
Effects of mobile counselling on the daily care routine of family carers

First changes can be measured shortly after the counselling concerning the following topics:

- **Attitude/ communication:**
  - „She will not notice real changes in her daily life, but we implemented every advice they gave us.“ (PA04)
  - „When you know some things about it, this illness, you just can deal with it differently.“ (PA05)

- **Use of (care) services:**
  - „…he goes once a week to it [day care centere] […] Then I have at least these few hours per week for me only. I think he will like it, too.“ (PA02)
  - They tried to connect us to a service […] so that our daily life gets a little bit more varied. […] We then may get more time for some other things“ (PA06)
Necessary ressources for the establishment and transfer of mobile counselling service to other districts – I

- Implementation of mobile dementia counselling requires an **extensive preliminary** and long-term planning together with local actors:
  - Comprehensive network consisting of volunteers who know local structures as well as other cooperation partners
  - In the run-up phase of the project all partners need to be brought together + support of the idea by local policy makers

- **Appropriate vehicle** (→ important: winter mode)

- **Appropriate locations** – nearby lively places that can be easily reached
  (*e.g. market place, „where already something happens“ → spontaneous situations*)

- Comprehensive **public relations**

- **Regular „success control“**:  
  - Check opportunities to bring mobile counselling to public attention as well as
  - Check opportunities for networking (e.g. in the GP sector)
Necessary ressources for the establishment and transfer of mobile counselling service to other districts – II

- **Addressing** the needs of people seeking advice
  - „The problem is to find balance between a neutral name and to call a spade a spade.“ (E2)
  - „Maybe the time is right. Name it (dementia) directly“ (E10)

- **Personal ressources** to coordinate and to organize the whole project have to be ensured continuously and in the long term i.a. for
  - Coordination and shift planning for currently approx. 80 counsellers
  - Training courses
  - Comprehensive public relations

- **Creative and individual local approaches** are necessary to achieve an open atmosphere of exchange and to make the project visible.

→ Offer can be transferred to regions, which are „quite similar“ (E3), („badly connected“ (E4), „badly informed“ (E9).). But also: suburbs (E4, E8) or remoted districts
Thank you for your attention!

Contact:

Scientific evaluation:
sarah.hampel@tu-dortmund.de
vreuter@post.tu-dortmund.de
monika.reichert@fk12.tu-dortmund.de
www.mobidem.tu-dortmund.de