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Balancing rights and risks— conflicting perspectives in the management of wandering in people with dementia

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Project team

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Conflicting perspectives ?

“Sometimes I just go out.... haven't any idea where I am going just enjoy the fresh air.”

Person with dementia 1



Conflicting perspectives ?

“When we were looking for a home, the one thing we wanted... to allow him to go out and walk because he enjoys it so much....it’s his main activity and it keeps him healthy but a lot of the homes wouldn’t allow it..... I would make it clear to the nursing home that I was prepared to take a risk.... I’d even put it in writing.”

Family carer 2



Conflicting perspectives ?

“We’re in an ideal situation... they can walk around a huge area...but there were too many untoward incidents, some were physical, some sexual, we had to block it off. Its about making a risk assessment.”

Nursing home manager





WALKING



WANDERING



Wandering in dementia

- **Complex** (Hope et al, 1994; Algase, 1999)
- **Common** (15-60%)
- **Benefits:** exercise, cognitive function
- **Risks:** physical injuries, mortality, earlier institutionalisation, carer stress.





- Rowe & Glover, 2001
 - 493 episodes of PWD getting lost
 - head injury (5), skin injury (20), dehydration (4), hypothermia (1)
- Koester & Stooksbury, 1995
 - 42 people with AD who got lost - no fatalities if found within 24 hours but > 24 hours 40% mortality



Risk management

- **RISK** – negative connotations in society
 - » Dealing with hazards and insecurities
 - » Probability of adverse event
- **Risk management**
 - » Focus of attention
 - » Balance between practice and policy
- Dementia care – perceived risk of harm



Management of wandering

- **Promotion of safe walking**
 - balance between PWD need for autonomy and independence, and carers' concerns
- **Wide range of interventions:** – physical activity, aromatherapy, electronic devices, environmental modifications, behavioural, distraction (music) and sensory therapies.



WANdering in DementiA project (WANDA)

Aims

To assess:-

- i) clinical and cost-effectiveness of non-pharmacological methods to prevent or reduce wandering and
- ii) acceptability and ethical issues associated with their use.



WANDA - methods

- i) Clinical / cost-effectiveness - systematic review
- ii) **Acceptability / ethical issues**
 - **systematic review (narrative review)**
 - **qualitative study (focus groups)**



Methods – systematic review

Data sources - electronic searches, grey literature / conference proceedings, hand searching, personal contact with specialists

- Acceptability - which are acceptable? Degree of acceptability?
- Ethics – use of relevant terms (e.g. dignity), principles (beneficence), moral judgements.



Systematic review

- 27 papers included for detailed review
 - 10 ethical issues
 - 12 acceptability issues
 - 5 both ethical and acceptability
- Quality of papers
 - acceptability issues - empirical research (surveys, qualitative studies)
 - ethical issues - discussion papers



Qualitative study

- 4 focus groups (n = 19) with relevant stakeholders
 - 1 with PWD (n = 6)
 - 3 with carers – family (n = 3),
formal (n = 6),
health professionals (n = 4)
- Task group methodology with carers groups



Data analysis

- Two data sets analysed independently using thematic framework approach
- Review papers coded thematically as "original transcripts"
- NUD*IST programme for data organisation



Results

- Number of themes identified
- Considerable consensus between narrative review / focus groups

BUT

- Perspectives of PWD not included in narrative review



Results

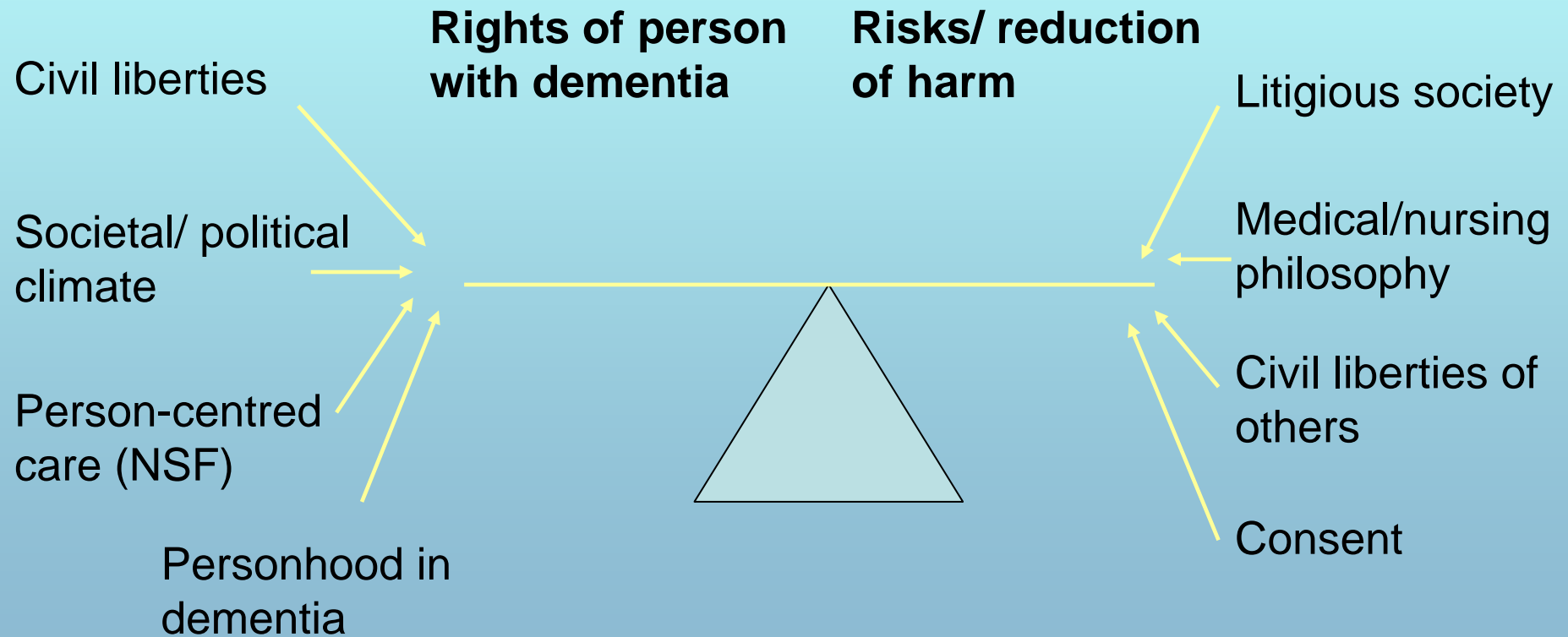
Main theme – prevention of harm through risk assessment

"Balancing rights and risks"

Use of interventions did not abolish risk
Highlighted with use of electronic tracking/tagging devices



Balance between rights and risks



Balancing rights and risks

"It is a constant compromise....what's best for the individual but what you have to do to protect yourself within the organisation"

Health professional 3



Balancing rights and risks

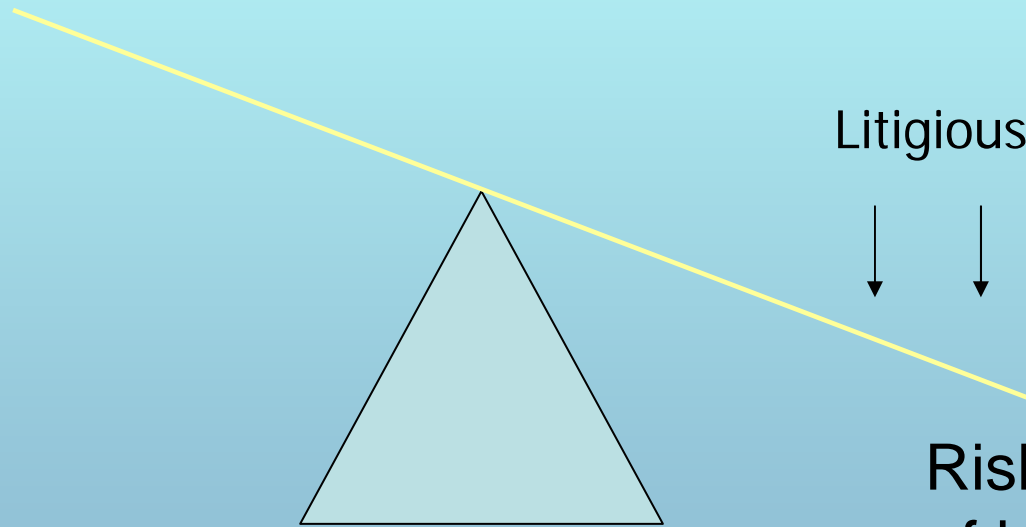
“ I think one of the main dilemmas about caring for people with dementia is always bringing up the safety aspects and yet giving them some sort of freedom.....walking might be the only thing they can do independently when they have lost nearly everything else.”

Family carer 1



Professional carers

Rights of person
with dementia



Litigious society



Risk/reduction
of harm

"Favour rights to safety over individual freedom"



“One of the things we haven’t mentioned is the affect of wanderers on other residents in the home.... If you have one person on the go how that affects everybody else”

Formal carer 4



Lay carers

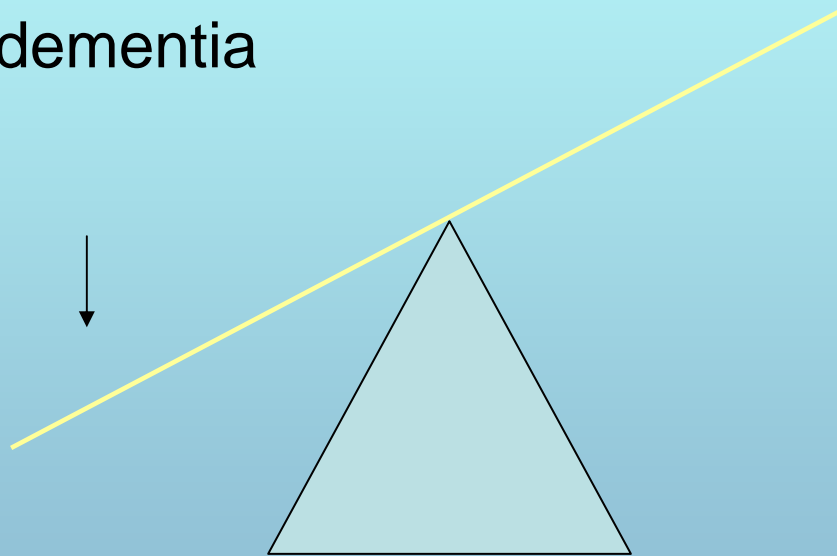


Quality of life for
people with dementia
and carers

Risk/reduction
of harm



Rights of person
with dementia



"People with dementia are overprotected"



"When my father wandered off ...I thought it would be ideal if he'd had something in his pocketI could have just phoned up and got the coordinates of exactly where he was. I'd have just got in the car and picked him up."

Family carer 2



Process of risk assessment

Differs between carer groups:-

- i) Professional carers - "team approach"
"informed consent"
"getting to know individual"
- ii) Family carers - "own personal decisions"
grounded in experience
greater risk tolerance
favour quality of life



Carers' perspective

Focus groups:

- Family carers - "PWD over protected"
"Challenging professional decisions"
- Formal carers - Conflicting perspectives of risk-
"What is an acceptable risk?"
- Care home staff - "Making compromises" - individual
versus other residents



People with dementia views

- Need for independence and choice
- Benefits of walking
 - enjoyable
 - tension relief
 - keeping fit

“ I want to feel as if I’ve got a bit of independence....while I can I just go out.”

Person with dementia 2



Use of technologies

- Familiarity with intervention

“ I mean during the second World War we had identity cards and never thought anything about them!”

Person with dementia 4

“ I carry a form of identity card and stick it in my pocket - I am happy with that.”

Person with dementia 3



Use of technologies

- Tracking devices – mixed response

“ I am not in need of it but I wouldn't mind wearing one – think it would be sensible”

Person with dementia 5

“ No! I don't feel the need at all”

Person with dementia 6



Use of technologies

- Intervention may increase risk
 - ie. mobile telephones and crime

"It would be more confusing when you're walking along ..., this thing would be more distracting."

Person with dementia 1



Identity of “big brother”



Concern over surveillance and identity of big brother

"If someone was keeping an eye on you it would depend who it was ... you might feel alright about it, you might not. You might not want your partner to always know where you are!"

Person with dementia 3



Conclusions

- Individualised approach.
- Balance between person's right to walk safely, and carer's duty to minimise harm.
- Family carers exhibit greater tolerance of risk; professional carers wary of litigation.
- Interventions e.g. electronic devices do not abolish risk.



Future research



Where next ?

- Practical management of risk and wandering
 - Assessment tool
- Environment and neighbourhood
- Potential of assistive technologies
- Involve users in development and evaluation – USER LED



Potential of technologies

- House of Lords Select Committee on Science and Technology
- Dott 07 – National Design Council
- National Healthcare Technology network



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