RISK EMPOWERMENT AND DEMENTIA

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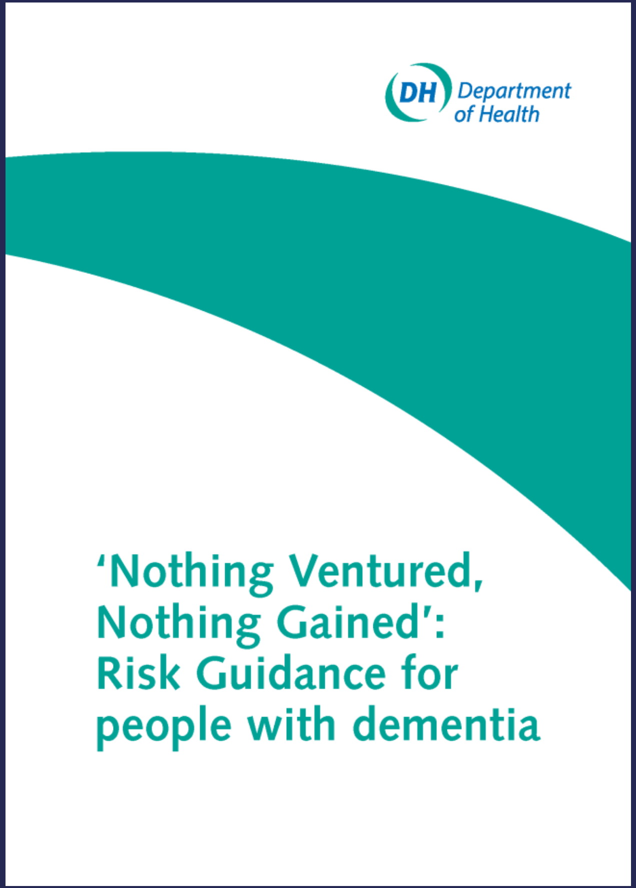
SOCIAL CARE WORKFORCE RESEARCH UNIT

WHERE WE STARTED

- Asked by the Department of Health to develop a guidance document that could be used by social care and health practitioners in different settings
- Have identified new material published since then looking at risk and impact of MCA



DH Department of Health

'Nothing Ventured, Nothing Gained': Risk Guidance for people with dementia

RISK – LIKELIHOOD AND SEVERITY

- Both help with empowerment or positive risk taking
- Also help with safeguarding and protection
- Making Safeguarding Personal ethos

- Impact of COVID on risk literacy?
- Many parallels with health literacy
- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7156243/
- https://lordslibrary.parliament.uk/covid-19-health-literacy-and-public-health-information/

THREE BROAD CATEGORIES

Causes

- What risk factors make it more likely a person will develop dementia?

Physical risk

- ‘Wandering’; getting lost; personal safety

Impact of diagnosis

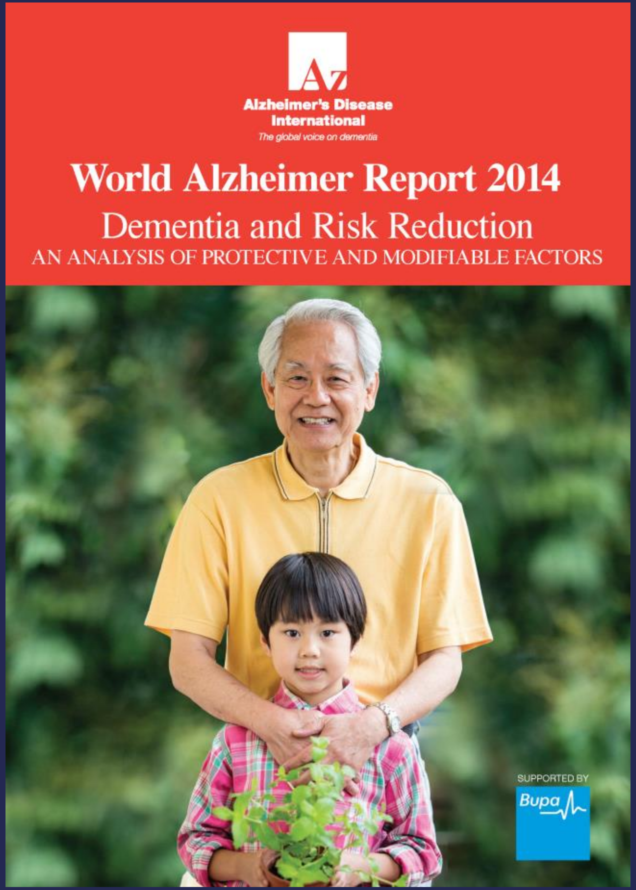
- Advantages and disadvantages of early (or timely) diagnosis

NEW RISKS

- To mental health – depression, anxiety, agitation, distressed behaviour
- Social – isolation, loneliness, abandonment fears
- Covid – lack of contacts and touch
- Abuse and neglect – scams/theft, physical, and others

INTEREST IN MODIFIABLE RISKS

- Alzheimer's Disease International report
- Theory is that it may be possible to help people reduce their risks of getting dementia
- Increased emphasis in public health policy in these factors



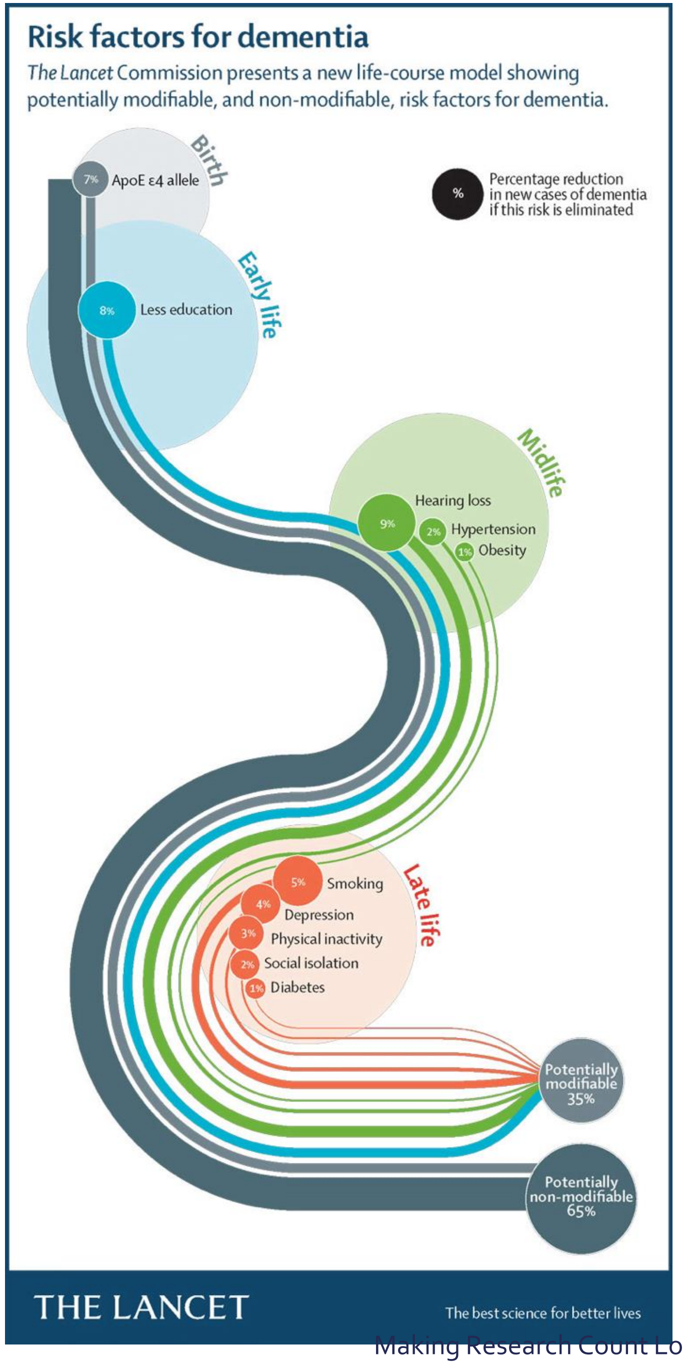
Alzheimer's Disease
International
The global voice on dementia

World Alzheimer Report 2014
Dementia and Risk Reduction
AN ANALYSIS OF PROTECTIVE AND MODIFIABLE FACTORS

SUPPORTED BY
Bupa

MOST OFTEN PRESENTED IN TERMS OF 'RISK OF' DEVELOPING DEMENTIA

- Best summary of risk factors Lancet Commission on prevention of dementia https://www.thelancet.com/journals/lancet/article/PIIS0140-6736



Risk factors for dementia

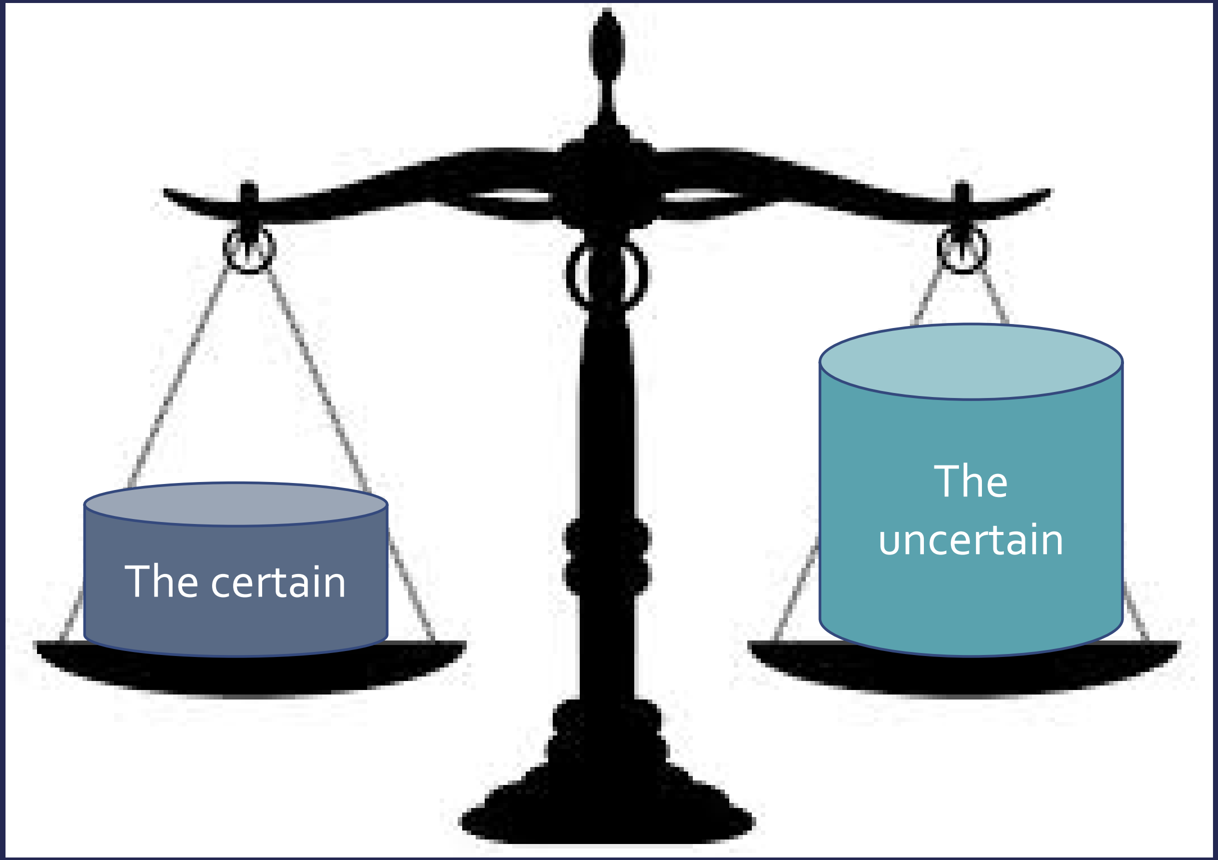
The Lancet Commission presents a new life-course model showing potentially modifiable, and non-modifiable, risk factors for dementia.

WHAT IS SOCIAL WORK ROLE IN PREVENTION? (LANCET 2020 REPORT)

Wellbeing is the goal of much of dementia care. People with dementia have complex problems and symptoms in many domains. Interventions should be individualised and consider the person as a whole, as well as their family carers. Evidence is accumulating for the effectiveness, at least in the short term, of psychosocial interventions tailored to the patient's needs, to manage neuropsychiatric symptoms. Evidence-based interventions for carers can reduce depressive and anxiety symptoms over years and be cost-effective.

- https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)30367-6/fulltext

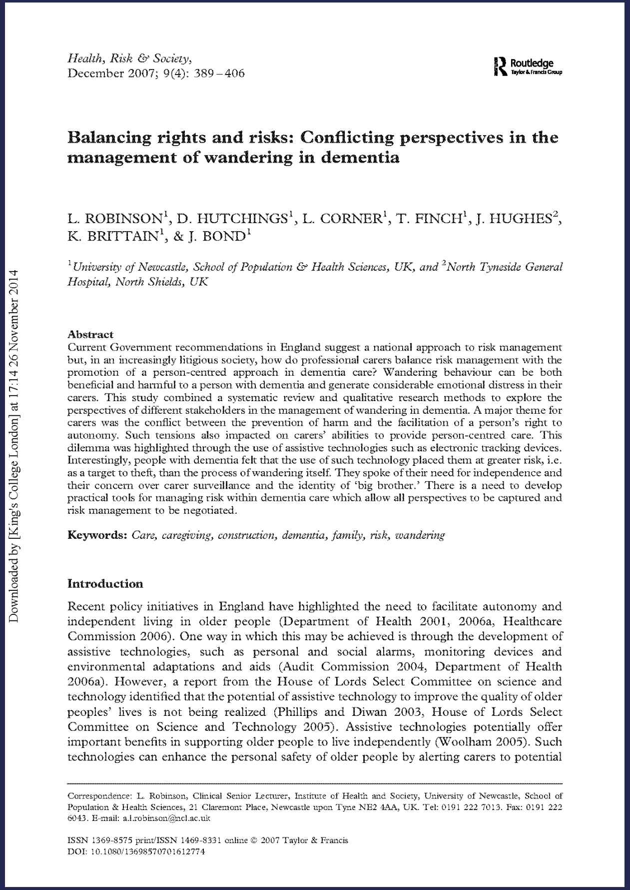
SOCIAL WORK GETS INVOLVED IN RISK LATE ON



BALANCING RISKS AND RIGHTS

Study looking at effectiveness of non-pharmacological interventions to reduce ‘wandering’ (for instance tracking devices)

- Systematic review
- Focus groups
- Combined both data sources



Health, Risk & Society,
December 2007; 9(4): 389 – 406

Balancing rights and risks: Conflicting perspectives in the management of wandering in dementia

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Abstract

Current Government recommendations in England suggest a national approach to risk management but, in an increasingly litigious society, how do professional carers balance risk management with the promotion of a person-centred approach in dementia care? Wandering behaviour can be both beneficial and harmful to a person with dementia and generate considerable emotional distress in their carers. This study combined a systematic review and qualitative research methods to explore the perspectives of different stakeholders in the management of wandering in dementia. A major theme for carers was the conflict between the prevention of harm and the facilitation of a person's right to autonomy. Such tensions also impacted on carers' abilities to provide person-centred care. This dilemma was highlighted through the use of assistive technologies such as electronic tracking devices. Interestingly, people with dementia felt that the use of such technology placed them at greater risk, i.e. as a target to theft, than the process of wandering itself. They spoke of their need for independence and their concern over carer surveillance and the identity of ‘big brother.’ There is a need to develop practical tools for managing risk within dementia care which allow all perspectives to be captured and risk management to be negotiated.

Keywords: *Care, caregiving, construction, dementia, family, risk, wandering*

Introduction

Recent policy initiatives in England have highlighted the need to facilitate autonomy and independent living in older people (Department of Health 2001, 2006a, Healthcare Commission 2006). One way in which this may be achieved is through the development of assistive technologies, such as personal and social alarms, monitoring devices and environmental adaptations and aids (Audit Commission 2004, Department of Health 2006a). However, a report from the House of Lords Select Committee on science and technology identified that the potential of assistive technology to improve the quality of older peoples' lives is not being realized (Phillips and Diwan 2003, House of Lords Select Committee on Science and Technology 2005). Assistive technologies potentially offer important benefits in supporting older people to live independently (Woolham 2005). Such technologies can enhance the personal safety of older people by alerting carers to potential

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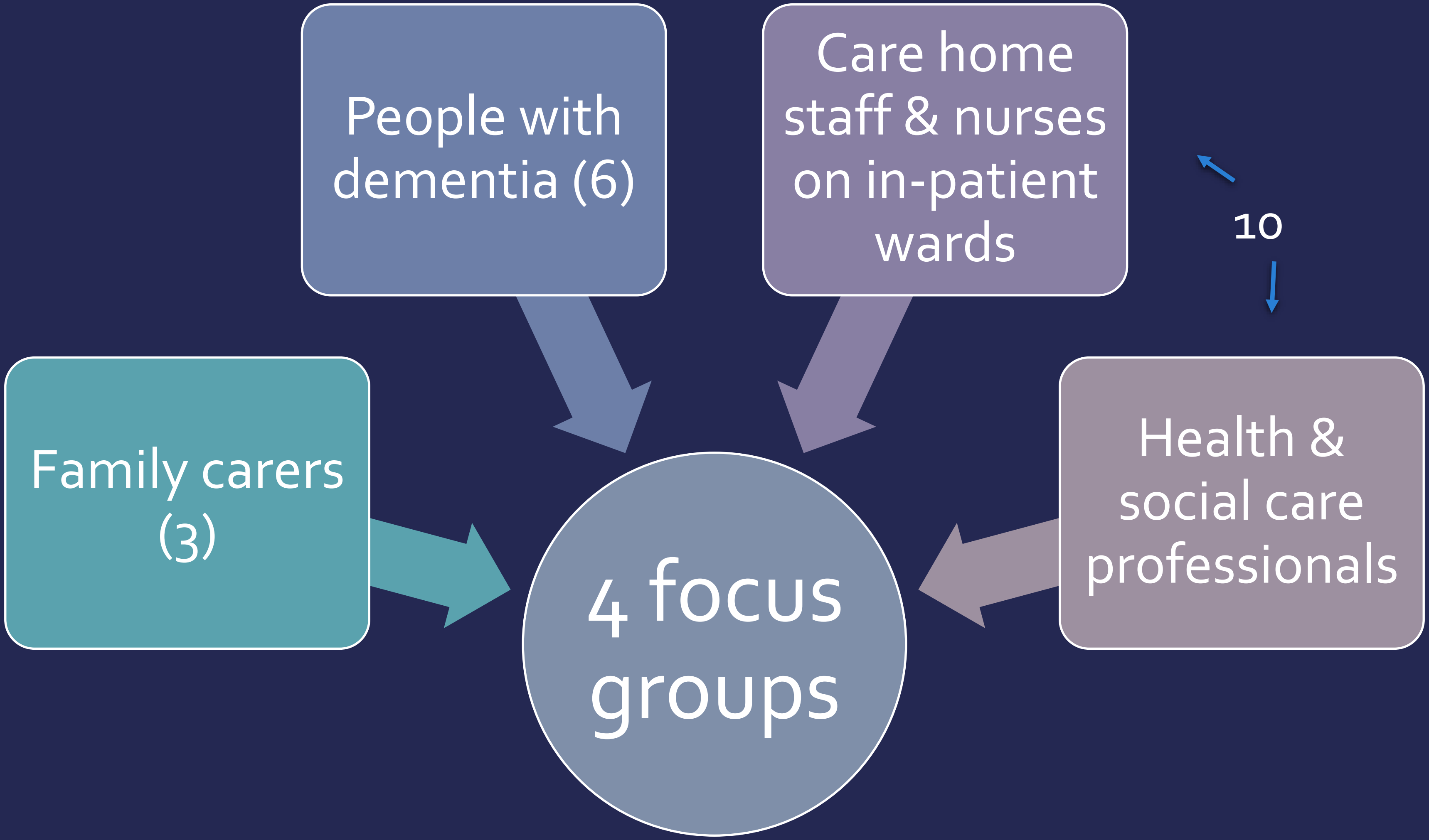

People with dementia (6)

Care home staff & nurses on in-patient wards

10

Family carers (3)

Health & social care professionals

4 focus groups

KEY THEME 1: DIFFERING PERSPECTIVES

- Professionals tended to focus management strategies on the *future* emphasizing the *physical* domain of risk, for example falling and risk of *litigation*
- Family carers focussed on the *present* and the *interpersonal* domain of risk, for example loss of the partnership role. Generally supported 'tagging' devices
- People with dementia appeared most concerned with the *biographical* domain of risk, for example, the loss of independence. Mixed views on 'tagging'

YOUR VIEWS

- Advantages and disadvantages of their research approach?
- How do their findings fit in with your experience?

LIVING ALONE WITH DEMENTIA

- Sub-set of people from a large study of older people living alone in Northern Ireland
- Interviews
- Mainly qualitative
- A pre-social media/online world

ARTICLE

Living alone with dementia

A case study approach to understanding risk

dementia
© 2003
SAGE PUBLICATIONS
www.sagepublications.com
VOL 2(3) 403–420
[1471-3012(200310)2:3;
403–420;034586]

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Abstract As the number of people with dementia is increasing alongside the social trend of a greater proportion of the population living on their own, this article seeks to explore a number of issues arising from these circumstances. It summarizes a qualitative study of ten people with dementia who live alone in their own homes. The views of these individuals, their families and care staff, GPs, district nurses and social workers are described and analysed, providing insights into the different perceptions of risk. The findings and discussion highlight issues relating to assessing and managing risk and problems and opportunities related to living alone with dementia. In this study no incidents of major harm were reported and daily contact with others was considerable. However, resources and support are needed to enable professionals, families and people with dementia to achieve a sense of shared negotiated responsibility for risk taking.

Keywords caring; living alone; multi-disciplinary work; rural

Introduction

The growing literature on dementia that has emerged over the past decade reflects both the concerns and challenges of living in an ageing society alongside increasing optimism about care, treatment and cure. A subsection of this literature focuses on people who live alone (Lloyd, 1997; Tinker, 2000). It is therefore surprising that there are few studies that focus on the theme of people with dementia living alone. The related area of risk associated with this client group also appears to be relatively under-researched.

Background

The research reported in this paper carries on from a larger study of people with dementia living in a dispersed rural area in the south west of Northern

33 people with dementia

12 family members

Service users & carers

Health care

6 GPs

4 district nurses

4 social workers & 2 assistants

9 care workers

Social care

KEY THEME 2: 'SITUATED RISK'

- Community nurses emphasised the risks of falling and not having adequate nutrition
- Social workers spoke about issues such as dealing with heating, managing money, wandering, and cooking.
- Care workers' approach based on situated risk – a man who went for walks outside his own home was less at risk because he had neighbours who knew him and who would take him home if he got lost. By contrast, when he went into a care home he was thought to be at greater risk if he went out walking because he was in a new location situated near a main road.

PROFESSIONALS’ EXPERIENCES

- Workers in a small city in Canada
- Interviews with 15 people who had professional experience of supporting someone with dementia living alone
- 4 people interviewed twice (so 19 interviews)
- Included 2 social workers

Article

Dementia
0(0) 1–18

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Caring for older people living alone with dementia: Healthcare professionals’ experiences

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Abstract
Older adults living alone with dementia are at greater risk of placement in long-term care homes compared with those living with others. Healthcare professionals have vital roles in supporting them to continue living in the community. Yet, little is known about how healthcare professionals fulfill these roles and what their experiences are like. The study purpose was to describe health care professionals’ experiences of caring for older people with dementia living alone. Using a qualitative descriptive approach and qualitative content analysis method, 15 healthcare professionals were interviewed in Ontario, Canada. The overall theme of the findings, *doing the best we can for them*, involved discussing sensitive care issues with what professionals viewed as *gentle realism. Walking the tightrope* expressed tensions in meeting professional responsibilities. Constraints (*my hands are tied*) and boundaries (*it’s not my job, it’s not my decision*) described perceived limitations on professional roles. Effects of the *emotional struggle* involved in working with these older people were lessened by *believing I did the right thing*. The findings have implications for what we could do better for older people with dementia living alone, through integration of person-centered/relationship-centered principles in education programs, community agency policies, a national dementia care strategy, and culture change in community care.

Keywords
community care, dementia, healthcare professionals, living alone, older people

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KEY THEME 3: ‘DOING THE BEST WE CAN’

- Participants felt constrained in what they could do
  - ‘Gentle realism’ in helping people with dementia living alone accept help, give up driving and anticipate going into a care home
  - ‘Walking a tightrope’ because of limited resources
  - Boundaries –GPs who were meant to deal with driving cessation, families who made decisions about care homes without consulting them
  - Emotionally stressful for some

YOUR VIEWS

- Advantages and disadvantages of their research approach?
- How do their findings fit in with your experience?

OVERALL PICTURE

- Mainly small scale studies
- Often focus on people at early stages whereas most people supported by social workers at the later stages
- Differing legislative and political frameworks
- In England huge impact of MCA

MCA HELP WITH RISK ASSESSMENT AND MANAGEMENT

- Past wishes/behaviour
- Documentation eg LPA, Advance Decision
- Proxy appointment LPA
- Liberty Protection Safeguards (replacing DoLS)
- Process of assessment
- Process of record keeping & accountability

AND REDUCING RISKS TO CARERS CAN HELP – EG START

- Supporting carers to see that behaviour is a sign of the illness, not the person .. Reducing carers' anxiety and depression
- START = 8 sessions, manual-based one-to-one programme for carers, Effective and cost-effective. See Webster et al (203) re cultural adaptation https://onlinelibrary.wiley.com/doi/10.1002/gps.5868

COVID AND AFTER – TO DISCUSS

- Shielding and isolation
- Rights to take risks
- Role of Essential Care Giver?
- More on prevention …
- Always drug therapy promising …
- Evidence for social interventions is good …

DISCLAIMER

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SOURCES

Slide number	Link or reference
4	Nothing Ventured Nothing Gained: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215960/dh_121493.pdf
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