Patient safety in community dementia services: what can we learn from the experiences of caregivers and healthcare professionals?

Abstract

Objectives

This study aims to explore how patient safety in community dementia services is understood by people with dementia, caregivers, and healthcare professionals.

Methods

Cross-sectional analysis of guided one-to-one interviews with 10 caregivers, and 10 healthcare professionals.

Results

Caregivers and healthcare professionals identified a range of issues including medication errors, mis-communication between professionals, unclear service pathways, and the effects of stress on caregivers' behaviour. Caregivers and professionals differed in their attitudes to balancing safety with patient autonomy and who is responsible for managing safety. People with dementia were unable to adequately recall their experiences to provide useable data.

Conclusions

This paper helps to define the nature of safety issues in the context of community care for people with dementia. In contrast to hospital medicine, where the ideal treatment world is safe with all risks managed or minimised, in dementia some risks are actively taken in the interests of promoting autonomy. Caregivers' views differ

from those of health professionals. Further work to develop methods to empower caregivers for collaborative identification and management of patient safety issues in community dementia care is needed.

Introduction

Patient safety is an increasingly important indicator of service quality; this is recognised in the Francis Report and subsequent Berwick Report [3], which concluded that “patient safety improves when patients are more involved in their care and have more control”.

Patient safety research has focused on patients in hospital, and there is evidence that the active participation of individual inpatients in their clinical care can reduce the risk of adverse events [5]. Hospital based harm of patients with dementia has also been studied to a small extent [6] as have adverse events in general community health care services [7, 8] but not specifically in the care of people with dementia. Views and experiences and patients and caregivers have not been researched.

Healthcare is increasingly being delivered outside hospital, and the new risks this poses are still being determined [10]. In community care, patients and carers play a more active and take on many responsibilities that are the prerogative of professionals in hospital [11]. Identifying unintended injury may be harder in the community than in hospital, but could be a potential role for caregivers.

When caring for a person with dementia, the pursuit of the eradication of harm may not always be in the patient's best interests and some degree of risk may be necessary to maximise patient autonomy and wellbeing. This has been termed "dignity of risk" (dignityofrisk.com).

The aim of this exploratory study is to better define and understand safety in this context of community healthcare of people with dementia to help to optimise patient and caregiver experience in the future. We believe that involving caregivers and attempting to involve patients in this study is a first step towards amplifying their voice on this important issue.

Methods

Study design

A cross-sectional qualitative study using guided interviews to identify and compare patient safety concerns in community dementia services reported by patients, caregivers, and healthcare professionals.

Ethical approval was granted (South Wales REC 14/WA/0102). Participants were recruited through community mental health teams, memory clinics and the local research network. Participants were purposively selected to ensure that a maximum range of experiences were explored.

For caregivers, inclusion criteria included:

- aged 18 years or above.
- currently caring for a close friend or relative with dementia who has been under the care of community mental health team and/or memory clinic in the last year.
- caregiving involves an average of two or more in-person contacts per week, over at least a six month period.

For healthcare professionals, inclusion criteria included:

- clinician with professional registration involved in provision of community mental health and/or memory clinic services to people with dementia.

Author 1 conducted qualitative in-depth one-to-one interviews lasting up to one hour which were informed by a pre-designed topic guide and audio recorded (see Appendices 1 and 2). Verbatim transcripts were coded using structural frameworks based on the key research questions (see Appendix 3). Frameworks were subsequently populated by inductive themes for both of the participant groups. Key extracts of supporting text were linked to each theme [13] and subsequently condensed and confirmed by checking of random transcripts during the first and final cycle of analysis by authors 3 and 1. Data analysis was managed using NVIVO version 9 (www.qsrinternational.com).

Results

Participant characteristics

Participant characteristics are summarised in tables 1 and 2.

Tables 1 and 2 around here

Themes

Three key themes and 11 sub-themes emerged.

1 What safety means in the context of community dementia services

All caregivers were able to identify actual and potential safety problems although few had formally reported them. Some were concerned that people with dementia would not be able to report them. Healthcare professionals were well aware of the need for risk assessments, but noted such assessments' limitations.

Well, you should do a risk assessment on every patient you see... but you never know all the risks. HCP7.

2 Where safety failures lie

2a: Unclear pathway through services (lack of guidance and information)

Many caregivers reported not knowing who to approach for advice resulting in potentially unsafe care.

I suppose it was sometimes a bit muddly as to who is, who you're actually supposed to be communicating with. CG1.

2b: Services not coherent (discontinuity and poor communication)

Most healthcare professionals and caregivers expressed dissatisfaction with the complexity of the care system and communication between professionals, leading to unsafe care.

There is not enough joined up thinking between professionals … I think the onus is often on the person or the carer. HCP8.

2c: Services not person centred

Healthcare professionals believed that offering person centred care means accepting some risk, balanced with autonomy and quality of life, and that a lack of autonomy may make a patient feel unsafe.

It should be based on the needs of the patient, but it's not like that…You're pushed to go for the cheapest option…. HCP5.

2d: Poor medication management

Most professionals and some caregivers had witnessed safety problems with administering medication to people with dementia. Caregivers spoke of the impact of frequent changes of medication formulation on the patient's compliance and some reported making changes to the dosing of prescribed medication or administering medication covertly without medical advice. Professionals were concerned by such practices.

… they come in a different form, the tablets... he says "no this isn't my tablet" because he doesn't recognise it.... CG5.

2e: Caregiver stress and burn out

All caregivers reported stress while all professionals described a link between poor caregiver physical and mental health and safety risks to both parties.

You can snap…you an get to the stage when you really are at your wits' end…when K was being particularly difficult I have slapped her. CG1

2f: Lack of engagement

Professionals reported difficulty engaging some patients, especially those living alone without an active family caregiver, leading to safety risks.

There's a minority of people who don't have an active relative or friend. It's very difficult to help those people access things when they need it. HCP6.

2g: Safety issues specific to dementia getting lost and violence)

Professionals and caregivers were concerned about the risk of people with dementia getting lost. Several caregivers had experienced their relatives being violent towards them.

I had one case who …was really quite aggressive to his wife…he was clearly quite dangerous. HCP4.

3 How safety failures are reported and managed

Most professionals mentioned the local formal safeguarding process (the procedures by which agencies collaborate to protect vulnerable adults) [14]. .

3a: Barriers to raising concerns

A common theme was the caregivers' wish not to trouble professionals or to make a fuss. Many were worried that their family member might receive substandard care if they raised a concern. However, professionals believed that people who complain receive better care.

I was really worried about saying anything to them because she's social services funded and they'd say "oh well, if you don't like it find her somewhere else". CG3.

3b: Differing views on who is in control

Both professionals and caregivers felt it was their role to manage the patient's care, including managing safety and balancing risk with autonomy; both agreed that collaboration with the other should be possible. Professionals recognised that patients and caregivers vary in their ability to raise concerns and some did not wish to burden caregivers with organisational responsibilities.

There are some patients with years of insight into their illness and the risks …and the same is for carers…but it can't be expected that patients take ownership of their risks. HCP7.

3c: Healthcare professionals' and caregivers' views on the balance of safety and autonomy

Caregivers took a more pragmatic view of maintaining patient safety at odds with their perception of professionals' reliance on bureaucracy. Professionals talked about the struggle to balance optimisation of quality of life of the patient with the elimination of risks.

we requested the carers be allowed to give my mum ...medication…, covertly. The agency wouldn't do that… they quoted some European legislation. CG2.

The original protocol included interviews with ten people with dementia. However, recruitment of people able to consent to participation was difficult and those recruited were unable to provide usable data.

Discussion

This was a small study based in a single healthcare trust and further research with a larger sample would be required to reveal if our findings held salience beyond this setting. Nevertheless, some of the themes mirror the findings of the United Kingdom Alzheimer's Society's report into challenges facing caregivers [16], in particular mis-communication between professionals and problems involving medication management. Surprisingly, although it is known from previous studies that caregiver stress is associated with abusive behaviours [17], professionals did not raise this as a safety concern.

Caregivers and professionals do not appear to share a common understanding of safety in healthcare. Caregivers interviewed often did not feel qualified to be discussing such concepts to begin, but became more engaged through the interview. Raising awareness of safety in healthcare and proactively supporting caregivers to identify and report concerns might, therefore, empower them to act in the future in collaboration with healthcare professionals. There are a number of potential interventions that could be piloted immediately, including systems for caregivers to identify and report safety risks, and improved methods of medication management.

Even patients in the early stages of dementia were unable to identify unsafe or potentially unsafe aspects of their healthcare. This may have been an artefact attributable to the study design, but it also correlates with the views of caregivers and healthcare professionals that patients would not be able to reliably inform professionals of safety concerns. Therefore, the recommendation of the Berwick report [3] that “patient safety is improved when patients are more involved in their care and have more control” needs a broader interpretation for patients with dementia, whose caregivers generally identify themselves as being responsible for identifying problems in the care.

Glossary:

CG: caregiver

HCP: healthcare professional

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Table 1 Characteristics of participants (caregivers of people with dementia) n=10

	Caregivers **(n = 10)**
Gender	Male: 5 Female: 5
Habitation status	Living alone: 2 Living with person with dementia: 8
Interview status	Interviewed alone: 8 Interviewed with person with dementia: 2
Relationship	Spouse of person with dementia: 8 Son or daughter of person with dementia: 2

Table 2: Characteristics of participants (health care professionals) n = 10

Gender	Male: 2 Female: 8
Psychiatrist	2
General practitioner	1
Nurse	2
Occupational therapist	2
Social worker	1

Clinical psychologist	1
Pharmacist	1

Appendix 1. Topic Guide, Caregiver interviews.

DiSCuSs
Dementia Safety in Community Services

Qualitative Interview Guide for Caregivers

Part 1 Opening and Preamble

Greet respondent and introduce self (name, role in study, employer name)

Discuss process (why participant approached, meaning of consent and study participation/withdrawal/anonymity etc.)

Assess capacity and, if possible, obtain consent.

Ask participant the name of the person they care for (marked as X through these questions)- inform will be changed in transcript

Recap the purpose of the study and central questions:

We are conducting a study to investigate what people with dementia, their caregivers and professionals involved in their care think about safety in health care services received in the community (i.e. not in hospital).

Clarify “safety”- broad definition:
- mistakes, near misses, anything concerning, anything upsetting, felt vulnerable. Either you OR the person you care for.

We are doing this by conducting in-depth interviews with people with dementia, their caregivers and professionals involved in their care. We believe that patients and caregivers are in a good position to identify things which might not be safe and that this may be used in the future to help build safer healthcare services.

We are particularly interested in:
- *your experiences of healthcare in the community with regards to X*
- *anything which has felt unsafe in the care*
- *potential safety problems you envisage when thinking about community healthcare*
- *specific things to do with dementia might make community care less safe*
- *things which might help or hinder you raising a safety concern*
- *ideas of how community services might be made more safe.*

Ensure comfort of participant is considered:
?physical environment ?breaks ?anyone else present

Ensure comfort and safety of self (risk assessment)

Explain the format and general approach of the discussion

Our discussion today will be fairly informal and be based around some broad open-ended questions. We are interested in your views and experiences and as such the questions serve as starting points for discussion: there are no right or wrong answers. Our questions should not upset you or make you feel uncomfortable, but if at any point you feel upset or uncomfortable please tell me and I will help in anyway I can. We can stop the interview and resume another time if need be.

Remind respondent about the importance of audio recording of the discussion and seek consent.

Ask if they have any questions

Switch the recorder on and check it is working.

Part 2: Warm up Questions

1) Can you tell me about healthcare services the person you care for receives at the moment and has received in the last year?
2) Can you tell me a bit about your experiences of the care?

Part 3: Research Questions

1) Attitudes to community healthcare and information about specific incidents:
    a) What is good about the community healthcare?
    b) What is not so good?
    c) Is there anything worrying or concerning?
    d) Has anything occurred that has upset you?
    e) Are you aware of any mistakes or near misses?
    f) Has anything dangerous happened?

    Prompt these with "can you tell me more.." or "what happened?"

2) ONLY IF STRUGGLING Screening for specific incidents that have occurred or potential problems they can envisage
    a) Can you envisage any potential safety issues in the care X receives?
    b) I'm going to go through a list of ten potential areas that might be unsafe. I would be very grateful if you could let me know if you think these things may be unsafe or potentially unsafe in X's care:
        i. Carers/HCPs not having enough time
        ii. Staff not having enough training
        iii. Delay in care or lack of emergency support
        iv. DIfficulty getting support/advice/information
        v. Difficulty with communication between services
        vi. Unnecessary treatment/investigations
        vii. Disclosure of personal information

viii. Infection risks
ix. Medication problems
x. Violence/aggression
xi. Any other things you can think of?

3) Focussing on safety issues specific to dementia

a) Do you think a diagnosis of dementia (or “memory problems”) ever causes or could cause specific safety problems in community healthcare?
b) If so, how?

Prompt if required- through memory lapses/difficulty concentrating in an appointment or through a diagnosis of dementia eclipsing other issues.

c) Are there any other health problems you feel have a significant impact on safety?

4) Focussing on safety issues specific to caring for someone with dementia

a) Do you think there are any specific aspects of caring for someone with dementia that relate to safety?

Prompt if required- risk of violence to carer, risk of exhaustion/burn out/neglect of carer.

5) Ability to speak up about safety issues
a) Have you ever talked about or reported your concerns about something unsafe in X’s community healthcare?
b) If so prompt- who raised with? who was involved? was it investigated?
c) If something happened would you be likely to speak up in the future?
d) Who would you contact? Have you considered any other routes?
e) What do you think WOULD happen if you raised a concern?
f) What do you think SHOULD happen if you raise a concern?
g) What would make you more likely to or help you to raise a concern about safety?

○
○ 6) Responsibility
a) Who do you think should be involved in or responsible for ensuring safety in community healthcare?
b) Is it useful and appropriate to expect patients and caregivers to provide information on safety as part of a partnership with professionals?
c) Do you think healthcare professionals sometimes do too much to ensure safety, to the detriment of other aspects of care?

7) Improvements

a) Have you any ideas how safety in community healthcare might be improved for patients with dementia and their caregivers?

Part 4: Mopping up

1) Patient safety has been in the news over the last few months. Have any of the reports worried you or contributed to how you think about X's care?
2) Finally, we would like to know where you think developments in community services of patients with dementia should be focussed?
3) Is there anything else with regards to safety in community healthcare we haven't discussed today that you'd like to raise?

Part 5: Exit statement

Thank you for taking the time to talk to me today. We really appreciate your help and will keep you informed of how the study progresses and any plans for dissemination of the findings. All the information you have provided will be treated with strict adherence to data protection principles and confidentiality.

Turn off audio-recorder.

Appendix 2. Topic guide- healthcare professional interviews

DiSCuSs
Dementia Safety in Community Services

Qualitative Interview Guide for Healthcare Professionals

Part 1 Opening and Preamble

Greet respondent and introduce self (name, role in study, employer name)

Discuss process (why participant approached, meaning of consent and study participation/withdrawal/anonymity etc.)

Assess capacity and, if possible, obtain consent. (Flag up that any names will be changed in transcript).

Recap the purpose of the study and central questions:

We are conducting a study to investigate what people with dementia, their caregivers and professionals involved in their care think about safety in health care services received in the community (i.e. not in hospital).

Clarify “safety”- broad definition:
- mistakes, near misses, anything concerning, anything upsetting, felt vulnerable. Either affecting patients or caregivers.

We are doing this by conducting in-depth interviews with people with dementia, their caregivers and professionals involved in their care. We believe that patients and caregivers are in a good position to identify things which might not be safe and that this may be used in the future to help build safer healthcare services.

We are particularly interested in:

- *your experiences of healthcare in the community*
- *anything which has felt unsafe in your experience of community healthcare*
- *potential safety problems you envisage when thinking about community healthcare*
- *specific things to do with dementia might make community care less safe*
- *things which might help or hinder patients to raise a safety concern*
- *ideas of how community services might be made more safe.*

Ensure comfort of participant is considered:
?physical environment ?breaks ?anyone else present

Ensure comfort and safety of self (risk assessment)

Explain the format and general approach of the discussion
Our discussion today will be fairly informal and be based around some broad open-ended questions. We are interested in your views and experiences and as

such the questions serve as starting points for discussion: there are no right or wrong answers. Our questions should not upset you or make you feel uncomfortable, but if at any point you feel upset or uncomfortable please tell me and I will help in anyway I can. We can stop the interview and resume another time if need be.

Remind respondent about the importance of audio recording of the discussion and seek consent.

Ask if they have any questions.

Switch the recorder on and check it is working.

Part 2: Warm up Questions

Can you tell me what your day to day job entails?
Can you tell me a bit about any past experience in other community healthcare teams?

Part 3: Research Questions

Attitudes to community healthcare and information about specific incidents:

a) What is good about the community healthcare for people with dementia?
b) What is not so good?
c) Are there any things in current or past services that make it difficult for your or others to provide high quality care?
d) Is there anything worrying or concerning?
e) Has anything occurred that has upset you or one of your patients?
f) Are you aware of any mistakes or near misses?
g) Has anything dangerous happened?

Prompt these with "can you tell me more.." or "what happened?" Use "someone you know" if appear guarded.

3) ONLY IF STRUGGLING - Screening for specific incidents that have occurred or potential problems they can envisage

a) Can you envisage any potential safety issues in community healthcare for people with dementia?
b) I'm going to go through a list of ten potential areas that might be unsafe. I would be very grateful if you could let me know if you think these things may be unsafe or potentially unsafe in regards to community healthcare for patients with dementia:
    i. Carers/HCPs not having enough time
    ii. Staff not having enough training
    iii. Delay in care or lack of emergency support
    iv. DIfficulty getting support/advice/information
    v. Difficulty with communication between services
    vi. Unnecessary treatment/investigations

vii. Disclosure of personal information
viii. Infection risks
ix. Medication problems
x. Violence/aggression
xi. Any other things you can think of?

3) Focussing on safety issues specific to dementia

Do you think a diagnosis of dementia (or “memory problems”) ever causes or could cause specific safety problems in community healthcare?
If so, how?

Prompt if required- through memory lapses/difficulty concentrating in an appointment or through a diagnosis of dementia eclipsing other issues.

c) Are there any other health problems you feel have a significant impact on safety?

4) Focussing on safety issues specific to caring for someone with dementia

Do you think there are any specific aspects of caring for someone with dementia that relate to safety?

Prompt if required- risk of violence to carer, risk of exhaustion/burn out/neglect of carer.

5) Ability to speak up about safety issues

a) Has a patient or their caregiver ever talked about or reported concerns about something unsafe in their community healthcare?
b) If so prompt- what happened?
c) If something happened do you think your patients would be likely to speak up?
d) What do you think WOULD happen if someone raised a concern?
e) What do you think SHOULD happen if someone raised a concern?
f) What would make a patient or caregiver more likely to raise a concern about safety?

6) Responsibility

a) Who do you think should be involved in or responsible for ensuring safety in community healthcare?
b) Is it useful and appropriate to expect patients and caregivers to provide information on safety as part of a partnership with professionals?
c) Do you think healthcare professionals sometimes do too much to ensure safety, to the detriment of other aspects of care?

7) Improvements

a) Have you any ideas how safety in community healthcare might be improved for patients with dementia and their caregivers?

Part 4: Mopping up

1) Patient safety has been in the news over the last few months. Have any of the reports worried you or contributed to how you think about your job?
2) Finally, we would like to know where you think developments in community services of patients with dementia should be focussed?
3) Is there anything else with regards to safety in community healthcare we haven't discussed today that you'd like to raise?

Part 5: Exit statement

Thank you for taking the time to talk to me today. We really appreciate your help and will keep you informed of how the study progresses and any plans for dissemination of the findings. All the information you have provided will be treated with strict adherence to data protection principles and confidentiality.

Turn off audio-recorder.

Research Questions- Appendix 3

1. Can community patients with dementia and their caregivers identify incidents which compromise or have the potential to compromise their safety? Does this differ from incident reporting by healthcare professionals?
2. What aspects of care are thought to be the most unsafe?
3. Do patients and/or caregivers feel able and motivated to speak up at the time of a potential error, and if not, why? What strategies could empower them?
4. How could patient safety in the community be improved?