Care home staff and family carers perspectives on passive suicide ideation and behaviour of older people in care homes

presentation to Mary Butterworth Care Home Forum on 5 June 2019, Kings University College, London

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Key contexts

• Ageism
• Transition to long-term care
• National suicide strategy
Lack of consensus in the literature with regards to distinguishing between some suicide behaviours and the relationship between suicide attempts and suicide completion.

We need to talk more about the indirect or passive forms of life-threatening behaviours as suicide such as in the care home setting where there is inconsistent terminology and different risk factors.

Understanding suicide as a developmental process to which risk and protective factors contribute in defining a trajectory to suicide over time. Translation of that developmental perspective into preventive interventions next requires identification of opportunities to intervene, the sites or “points of engagement” where older adults can best be detected and interventions made to alter their suicidal trajectories.

Conway et al, 2011
The majority of studies (n=8) focused on identifying risk factors associated with the individual. The most common individual risk factors included:

- Depression (documented or diagnosed in 67% of NH residents who suicided)
- Duration of residence in the nursing home (<12 months)
- Decline in physical health

Other individual risk factors examined included:

- Prior suicidal behaviour
- Cognitive function
- Personal loss

Only one study (Osgood, 1990) examined any organisational risk factors associated with the nature of the nursing homes in which suicides occurred.

No broader structural risk factors such as policy factors or those relating to the broader community were considered among eight the studies.

None of the studies formally examined interventions nor discussed recommendations for organisational or structural change to reduce suicide risk in nursing homes.
The ONS in England and Wales, define suicide as deaths given an underlying cause of intentional self-harm or injury/poisoning of undetermined intent (ONS, 2017).

‘Care home’ includes a variety of NHS, local authority and private nursing/care/residential homes. Also included are homes for the chronic sick; homes for people with mental health problems and non-NHS multi function sites. Figures are for people who died in a care home, and so do not include, for example, care home residents who were transferred to hospital shortly before their death’.

ONS data provides the number of suicides by place of death, sex and age-group, England and Wales, registered between 2011 and 2016.

<table>
<thead>
<tr>
<th>Date</th>
<th>Male</th>
<th>Female</th>
<th>Total</th>
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<tbody>
<tr>
<td>2011</td>
<td>5</td>
<td>4</td>
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<td>4</td>
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<tr>
<td>2016</td>
<td>3</td>
<td>2</td>
<td>5</td>
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</table>
‘Giving up’ /‘Turning to the Wall’

• ‘Everyone knows someone’

• Passive ideation and behaviour

• Discourse of silence

• Significant role of the care home workforce

• Organisational factors and professional expertise
Study design

Exploratory design with 2 Target groups – Care home staff (n=33) and family carers (n+10)

What is meant by the term ‘giving up’ from the perspective of care staff working in care homes and how is this described, conceptualised and understood by those who are involved?

What happens in care homes when an older person is identified as ‘giving up’ and what can we learn from care staff experiences about their needs and the needs of care staff looking after them within these situations?

What factors are commonly identified by care staff in relation to prevention, early intervention and support for older people ‘giving up’ and their loved ones?

What can we learn from the perspectives of family carers on the experiences of having a loved one giving up?

- Co-produced with stakeholders
- 3 peer researchers
- Focus groups using a vignette
- Inductive approach to data analysis
<table>
<thead>
<tr>
<th>Home</th>
<th>Focus group participants</th>
<th>Care Quality Commission rating</th>
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</thead>
<tbody>
<tr>
<td>1 Private sector</td>
<td>8 carers</td>
<td>Overall ‘good’</td>
</tr>
<tr>
<td></td>
<td>Recently acquired ‘Nursing Home’ status</td>
<td>Accommodation for persons who require nursing or personal care, Dementia, Diagnostic and screening procedures, Physical disabilities, Treatment of disease, disorder or injury, Caring for adults over 65 yrs</td>
</tr>
<tr>
<td>2 Private sector</td>
<td>8 carers</td>
<td>Overall ‘good’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Accommodation for persons who require nursing or personal care, Dementia, Caring for adults over 65 yrs</td>
</tr>
<tr>
<td>3 Charity sector</td>
<td>1 manager, 6 carers</td>
<td>Overall ‘good’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Accommodation for persons who require nursing or personal care, Dementia, Caring for adults over 65 yrs</td>
</tr>
<tr>
<td>4 Charity sector</td>
<td>1 deputy manager, 9 carers</td>
<td>Overall ‘good’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Accommodation for persons who require nursing or personal care, Dementia, Caring for adults over 65 yrs</td>
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<tr>
<td></td>
<td>Total 33</td>
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Key findings

The meaning of ‘giving up’

Staff are well aware of residents’ emotional states and observed:

- not eating, talking, slowly withdrawing
- statements :“ready to go”, “what’s the point of living?”
- “he really went down”, “it was his time and that was it”
- anger & aggression over their circumstances
- trying to assert their power & identity

“he was determined, he wouldn’t get out the bed, the family were brought in here, and I thought it might help. He was really charming, you’d sit with him and he just made you feel warm inside you know. But he thought that his wife should have looked after him though and she shouldn’t have given up on him. Then he went to hospital and that was it … The son used to get mad and cross with him, because he’d got the grandkids, but that wasn’t, it was his time he’d decided, and that was it.”

(Care worker, focus group 2)
Responding to a ‘giving up’ situation

“I had my friends and now I’m here with strangers, I don’t know who they are. I’m here with people who have to look after me yes. When I was in my own home it would take me two and a half hours to get myself washed and dressed but I did it myself. Here somebody is washing me. It could be somebody who could be my granddaughter’s age … It’s a lot to take on board when you go into a residential home”.

(Care worker, focus group 1)

Recognition that residents were coping with multiple losses:

- Independence
- Health
- Partners
- Family
- Network of friends, neighbours etc
- Resources e.g. homes, financial
Prevention, intervention and support

- In the discussion groups staff described some of the strategies, both practical and psychological, they used to try to alleviate the sadness and emotional pain that residents displayed:
  - Talking 1-1 and spending time with individual residents
  - Building special relationships
  - Distraction e.g. with other activities
  - Giving space, & showing respect
  - Encouraging families to visit in order to maintain a sense of connection
  - Recording changes in mood and behaviour
  - Referring on to senior staff, managers or other specialised services

“Most time what staff does is to try to prompt him, divert his attention from there. We will never accept that fact, oh you want to die, okay oh go on with it – no we will try to get him out of it, if there is a football or TV show going on, how to catch their focus and get them out of their … or do you want a cup of tea, to make them happy. But this strategy we always use”.

(Care home deputy manager, focus group 3)
Other challenges:

- Preferred familiarity of care setting against the need for hospital care
- Tension between relatives and residents’ perspectives on wishes about dying
- Need for meaningful relationship as well as practical care
- Respecting and acknowledging residents’ feelings
- Importance of developing personal relationships with residents
- Meeting spiritual/religious needs

“You never get used to it, I said you find ways of dealing with it, but I said I never think of this job that this is their last stop before they go on to heaven or wherever, you don’t think of the job like that.”
(Care worker, focus group 2)

“But what we feel, I think all of us together, we feel that if just someone would listen to us, instead of all this, there’s a medical thing, there’s a psychiatric thing, and they’d come together and work together, because this gentleman needs help and help now and things need to be put in place which would stabilise him.”
(Care Worker”, focus group 2)
<table>
<thead>
<tr>
<th>Relationship to loved one</th>
<th>Age /Gender of loved one</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daughter</td>
<td>91 M</td>
</tr>
<tr>
<td>Granddaughter-in-law</td>
<td>92 F</td>
</tr>
<tr>
<td>Daughter</td>
<td>85 M</td>
</tr>
<tr>
<td>Daughter</td>
<td>80 M</td>
</tr>
<tr>
<td>Wife</td>
<td>76 M</td>
</tr>
<tr>
<td>Husband</td>
<td>80 F</td>
</tr>
<tr>
<td>Daughter</td>
<td>84 F</td>
</tr>
<tr>
<td>Daughter</td>
<td>80 M</td>
</tr>
<tr>
<td>Daughter</td>
<td>79 F</td>
</tr>
</tbody>
</table>

**Themes:**

**For the older person:**

Catalogue of incidents and stressful events leading to sudden or significant loss of independence

- Unmanaged physical pain
- Sensory impairment key issues compounded by lack of attention to these
- Unplanned admissions to care
- Feeling abandoned by partners - perceived burdensomeness and thwarted belongedness
- Cumulative losses in their social life inc loss of enjoyment of everyday things (food; reading; contact with community)
- Lack of opportunities to ‘try out’ different ways of living/options
- Incidents of anger and defiance
- No active treatments for mental health

**For the family carer:**

- Notably, no one had any social work involvement or care professional coordinating
- Feeling helpless, visceral descriptions
- Lack of support from employers to respond to crises
- Not being able to make decisions
- Not being able to talk about the older person giving up either with them or with a person for fear of being seen to endorse
- Unable to express own needs and loss at the time – unspoken loss

“She cut herself off and shut her eyes when people visited, so she couldn’t see them”

“Its not a Hollywood film, is it?”
Daughter of father that died in 2004. He was aged 85yrs and had four strokes. He had lost his wife about 20 yrs before and he lived independently near the participants sister and was very engaged with the family which was affected by his health and particularly deafness. After the fourth stroke and a fall, he made the decision to go into a care home supported by his daughter. They both had a lot of knowledge about health, he as an active member of the medical corps during the war and his daughter was a nurse. He was very sociable and mentally sharp at the time of admission and got irritated when staff interfered with his care without consulting him (example of him switching his earing aid off to get some quiet time and the staff switching it on, without asking him). He was an avid reader and followed current affairs. In the care home, started to joke about the need to be put down and made frequent gestures about feeling the need to be shot or getting the vet to come and shoot him. He was a compliant and law abiding person so the daughter felt that he would never ask anyone to help him, but he did indicate that he was ready to go. Following a recurring stomach cancer, he decided to refuse treatment and talked about his time to go. He wasn’t depressed and interacted with his carers and probably had opportunities to talk to them, but he was ready to go and wanting to die. He didn’t speak much to her, but more to his daughter who lived close by. Not being able to speak with him on the phone as his deafness made communication difficult and then visiting made her father jolly along and they didn’t really talk about it. He said he felt like he was in a station waiting for the train to come
Summary

Our findings paint a complex picture, highlighting tensions in providing the right support and creating spaces to respond to such challenging situations. ‘Giving up’ requires skilled detailed assessment, better conversations, to respond to risks alongside improved training and support for paid carers, to achieve a more holistic strategy which capitalises on significant relationships within a wider context.
Some reflections and recommendations

We need to maintain and review research and knowledge about depression, self-harm, and suicide ideation and behaviours impacting on older people transitioning to and living in care homes to understand and predict risk better and to understand mental health in the context of the institutional environment in which it occurs in order to develop appropriate and applicable prevention strategies.

Increased standardisation of recording suicide behaviour in care homes is needed to be able to understand fully the extent of ‘giving up’ in residents and to plan and understand ways to respond to it.

Know more about what works and how to promote and sustain interventions.

Wider involvement of older people themselves and those involved (Paid carers/family carers/community based professionals) in both talking about the issues and developing community based interventions.
Thanks for listening

If you are interested in following our next project steps or want to be involved, please contact:

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This study has been published as:
https://doi.org/10.1017/S0144686X18001447

Acknowledged thanks to funding from Department of Mental Health and Social Work, Small Grants, Middlesex University