

'LONELINESS, FRUSTRATION AND JOY': THE COMPLEXITIES OF CARING FOR SOMEONE WITH DEMENTIA

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SOCIAL
CARE
WORKFORCE
RESEARCH
UNIT

BACKGROUND

Most of this will be very familiar!

NOW A POLITICAL PRIORITY

The status of national dementia strategies in Europe



From the Alzheimer Europe website:
<http://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Plans>

HUGE INCREASE IN PUBLISHED RESEARCH

From 1966

...just as

...concerns the association
...organization and attitudes
...the effects of the patient's
...obvious that similar disabilities
...different impacts depending on the
...A patient living with his mother
...to meet far less responsibility than a
...patient: often little is expected of him in
...helping about the house, in leisure
...and sometimes even in the show of
...Important differences also occur
...married men and women patients. There
...indirect evidence of the effect of this in
...ent study. Since the numbers of married
...st-admitted patients are small, and sim-
...ults occur among previously admitted
...I quote results for all patients admitted
...Of patients ever married at admission
...4% of the 52 men and only 24%
...women had divorced or separated
...in their lives by the end of the five
...y-up. A survey of a representative
...of 3,000 married couples in 1959
...those married between 1930 and
...separated or divorced would
...% (Rowntree 1964). Wives
...more problems which
...the patient. Double
...husband or

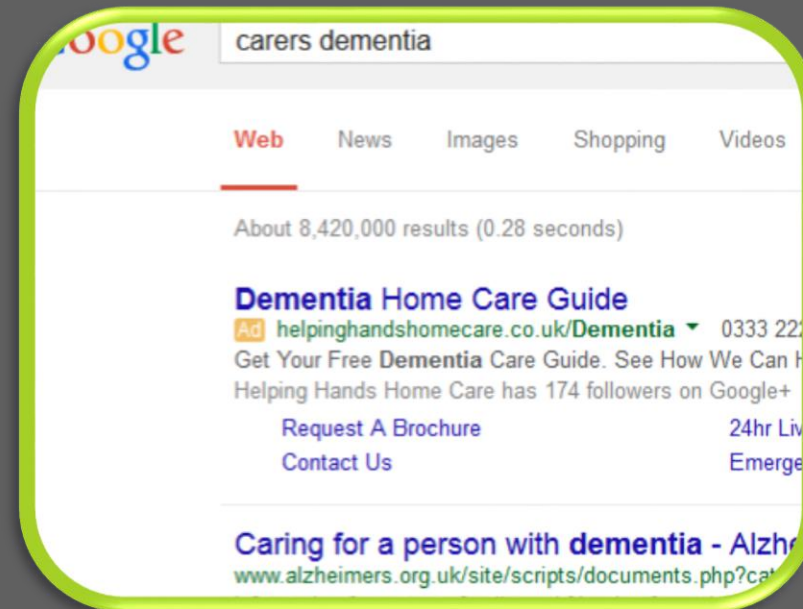
Problems of Caring for the Mentally Ill at Home

by Jacqueline Grad PhD
and Peter Sainsbury MD MRCP
(MRC Clinical Psychiatry Research Unit,
Graylingwell Hospital, Chichester)

Since the Mental Health Act in 1960, community care as opposed to hospital treatment for psychiatric patients has become increasingly common. We have attempted to evaluate the new approach by comparing the community-based service in Chichester with the hospital-based service in Salisbury. The aspects compared were referral rates, hospital admission rates and the effects of the differing policies on patients' families and on clinical outcome after two years.

The proportions of patients referred to Chichester and Salisbury in different social and clinical categories were compared. Except for a higher proportion aged 65 and over in Chichester, they did not differ on social characteristics (sex, social class and employment). They were also matched clinically and did not differ in severity of illness as assessed from the duration of symptoms and amount of previous illness. The burden the illness imposed on the family was referred (see below).

To 2014



MESSAGES FROM RESEARCH (1)

- It is a global problem – no research in whatever country (Schneider et al, 1999; Prince et al, 2012) has ever suggested that carers do not find it challenging and in many instances stressful
- Complexity and variety of carers' responses (Bunn et al, 2012) means there is no single 'silver bullet' in providing support
- Probably it's more about providing multi component interventions (Vernooij-Dassen et al, 2011)

MESSAGES FROM RESEARCH (2)

- Adaptation of US 'Coping with Caregiving Programme' clinically (Livingston et al, 2013) and cost effective (Knapp et al, 2013)
- But problems with timeliness of and quality of interventions (Lamura et al, 2008)
- Difficulties 'mainstreaming' research interventions into everyday practice (Mittelman & Bartels, 2014)

WHY THIS STUDY?

- Central and local government investment in support for carers
- Growth of 'carers workers' (e.g. carers support workers) but under-evaluated
- Not just about dementia
 - High proportion of social care expenditure by local councils is on supporting people with dementia (although hard to quantify how much)

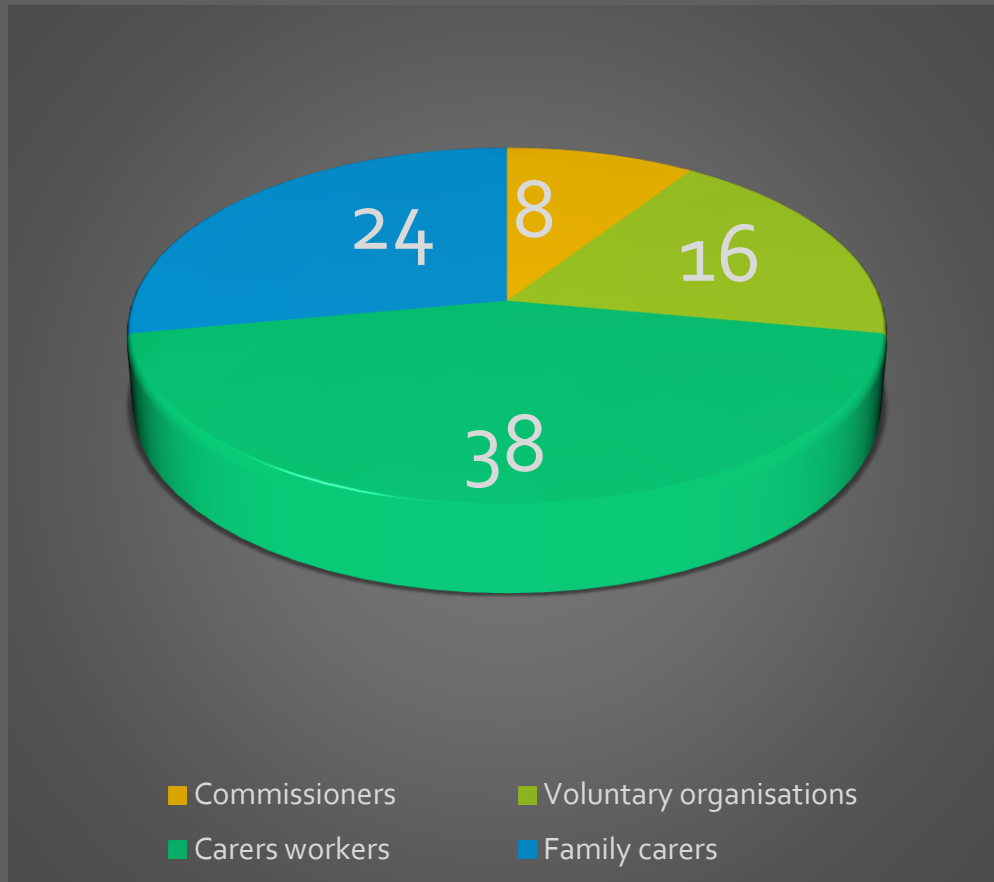
METHODS

Summary of study methods

CONCURRENT MIXED METHOD DESIGN



INTERVIEWS



- Sampling aimed to cover different types of caring experiences:
 - Long term conditions
 - Learning disability
 - Mental health
- 53 per cent of interviews referred to dementia
 - Especially dominant in interviews with commissioners and voluntary organisations
- Not just artefact of sampling

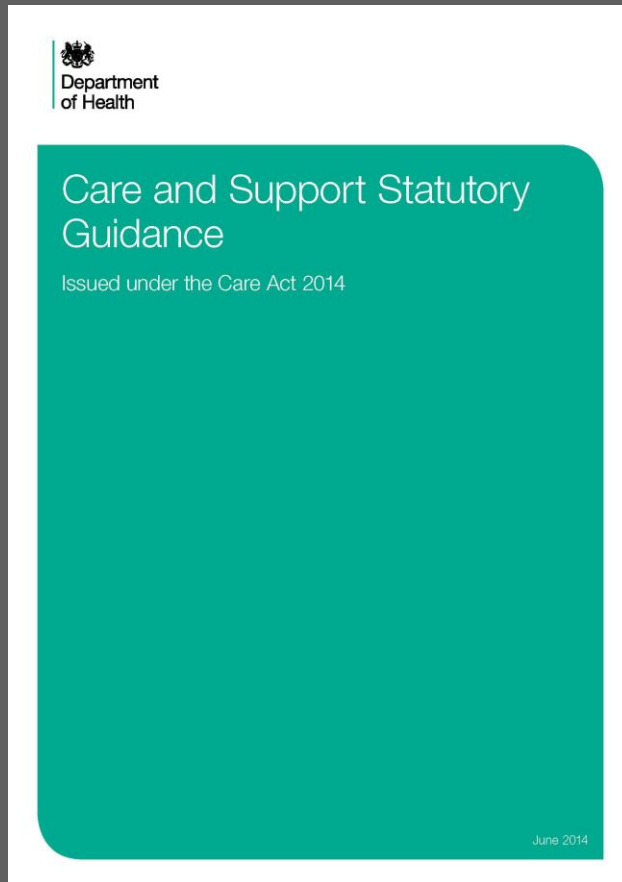
FINDINGS

Commissioning, types of support, two illustrative examples

COMMISSIONING SERVICES

- Policy favours joint commissioning of dementia services by clinical commissioning groups and local councils with responsibilities for social care
 - May be more variable in practice (Burns and Wilkinson, 2014)
 - Concerns that benefits of better diagnosis rates may be muted by lack of ongoing support services
 - Commentators (e.g. Hudson, 2011) have questioned whether there is evidence of effective joint commissioning of services for older people

CARE ACT 2014



- Local authorities should encourage services that respond to the fluctuations and changes in people's care and support needs and support the transition of services throughout the stages of their lives to ensure the services provided remain appropriate

(para 4.23)

FLEXIBILITY AND COST EFFECTIVENESS



[What] seems to have worked well in our dementia day centres [is] a flexible day, where people can phone in on the day if they are already attending but it's not their normal day to attend but the carer needs a break ... You don't tend to get 100% occupancy, not everybody turns up every day. It's a bit like on the airline principle

Hilton, COMMISSIONERo8

OR IS IT DOWN TO PERSONALISATION AND INTEGRATION?



We are trying to do this in the world of personal budgets and ... [how we] influence the market ... for people who want to go and purchase it themselves is a bit of a conundrum ... Clinical commissioning groups will [also] have an impact on what is seen as a priority now as well ... We need to make sure we are influencing that, as indeed do carers need to make sure they are influencing that too

Delia, COMMISSIONER06

TENSIONS IN COMMISSIONING

New models

- Commissioning new service from social enterprise where emphasis on positive experiences for person with dementia

Traditional services

- Providers' concern that spouse carers of people with advanced dementia are 'forgotten'
- Impact on terms and conditions of workers

LEAFLETS ARE NOT ENOUGH!



...trying to get [this carer] to understand the terminologies that are being used ... is really difficult on the phone. Hence [I am] going to ... take ... leaflets that have information about the diagnosis that [her husband] has ... I think I need to go and do a home visit and sit down and do a face to face and get her to understand a little bit

(Ifrah, Worker20)

AND IT'S NOT JUST ABOUT INFORMATION

- [Carers] feel very, very isolated. There still is the stigma. People don't talk about it. So by us having things like information courses, peer support like memory cafes, people come along and they actually discover that they're not on their own. To me that's really important ... It's not just about practical information about benefits
(Nell, VOL12)

- [As well as separate and joint social and support groups and Singing for the Brain] ... We also have this ... therapy group which is where we have trained therapists as in reflexologists and people coming in and giving back massages, Indian head massage and all these different things. And that is for carers and people with dementia. That is very popular
(Brooke, WORKER32)

TWO DAUGHTERS: KATHRYN



“A couple of years... well, four or five years ago really, it became apparent that she had deteriorated, she wasn't changing her clothes, washing, she really didn't know what was happening. She couldn't even really make herself a cup of tea. My sister organised meals on wheels for her, and she'd go in on a Saturday morning and find half of the meal in the fridge”

CARER07

... AND KLARA



“Just over about two years ago, I noticed her short term memory was getting very poor. And that’s when things started to go slightly more downhill. Her long term memory is still as good as ever. In fact it’s better than most. She can remember her schooldays and her young married life and bringing up all the children. Things that actually happen today, this week, or last week, is very poor”

CARER20

SUPPORT THEY RECEIVE

Kathryn

- Mother goes to day centre twice a week
- Has break planned with granddaughters while mother will go for short stay in care home
- Incontinence pads provided by council
- Attends a carers group
- Joined a walking group
- Some limited support from sister

Klara

- Mother attends weekly social club
- They attend monthly Age UK reminiscence group together
- Mother had successful short stay in care home
- Attends carers group and now runs carers café
- Went on a self esteem course
- Some limited support from siblings

CARERS ON SOCIAL SUPPORT

I never had a big social life ... one of my neighbours has become a good friend and she brings over a bottle every now and again and we shut ourselves in the dining room and have a good old natter

Kathryn

Being a trained counsellor, [Keira's] s been able to give me a lot of sort of support and just someone to talk to who is just there for me and I know that I can call ... She's always got time to talk, which is lovely. She's been a real rock

Klara

THEIR SHARED CONCERNS

- About their own health
- About the future
 - For themselves as women on limited incomes
 - For their mothers in terms of arranging long term care
 - About prospect of cutbacks to services
- How to capture the difference between mechanistic and personalised care?

CONCLUSIONS

CONCLUSIONS

- Research rarely mentioned in discussions
 - So how do researchers influence agendas?
- Need to consider wider structural issues
 - Equalities – pre-existing inequalities often accentuated in old age as well as new ones
 - Income and funding
- Consider wider social context
 - Need for long term support
- Challenges in capturing relational aspects of support

DISCLAIMER

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- To you for listening!



THANKS TOO FOR IMAGES

Slide number	Image
Slide 1	Gill and Bernard Stoneham, photographed in The Telegraph May 2013
Slide 3	Alzheimer Europe
Slide 14	From FeaturePics
Slide 15	From Smart Innovative Woman
Slide 17	From Getty images
Slide 19	Stock image used in Huffington Post article on depression, May 2013
Slide 20	Photograph of Isabella Rossellini by Linda Nylind in The Guardian, July 2012