Scaffolding and working together: a qualitative exploration of strategies for everyday life with dementia

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Title

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Abstract

Background: Living with dementia has been described as a process of continual change and adjustment, with people with dementia and their families adopting informal strategies to help manage everyday life. As dementia progresses, families increasingly rely on help from the wider community and formal support.

Methods: This paper reports on a secondary analysis of qualitative data from focus groups and individual interviews with people with dementia and their carers in the North of England. In total 65 people with dementia and 82 ~~family~~ carers took part in the research: 26 in interviews and 121 in focus groups. Focus group and interview audio recordings were transcribed verbatim. A qualitative, inductive, thematic approach was taken for data analysis.

Findings: The paper applies the metaphor of scaffolding to deepen understanding of the strategies used by families. Processes of scaffolding were evident across the data where families, communities, professionals and services worked together to support everyday life for people with dementia. Within this broad theme of scaffolding were three sub-themes characterising the experiences of families living with dementia: doing things together; evolving strategies; and fragility and fear of the future.

1

Conclusions: Families with dementia are resourceful but do need increasing support (scaffolding) to continue to live as well as possible as dementia progresses. More integrated, proactive work is required from services that~~,~~ recognises existing scaffolds~~,~~ and provides appropriate support before informal strategies become unsustainable; thus enabling people with dementia to live well for longer.

Key words: dementia, scaffolding, community, informal care, care services

Key points:

- People with dementia and their informal carers develop strategies to manage everyday life with dementia~~.~~

- These strategies can be usefully described as scaffolds as families draw on a range of supports to manage everyday life~~.~~

- As dementia progresses, life gets more difficult and scaffolds built by families need additional support from formal services~~.~~

- Scaffolds to support people with dementia may be at risk of collapse due to the changing nature of dementia~~.~~

- Professionals should work collaboratively ~~with those providing informal support,~~ and recognise and enhance rather than replace existing scaffolds.

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Introduction

Living with dementia is a process of continual change and adjustment. How an individual

manages life with dementia will be affected by their biography and social location [1] and

their coping and adaptive strategies [2,3]. People with dementia adopt active strategies to

help maximise functioning [4] and maintain wellbeing [5]. For carers, adapting to life with

dementia similarly involves active strategies to adjust to the caregiving role [6].

The complexities of the caring relationship, such as perceived mutuality [7] and wider

relationships in the family [8], also impact on daily life with dementia. It has been shown

that people with dementia and their families work together to develop strategies for dealing

with the practical and social consequences of cognitive impairment [9]. People with

dementia and their partners are also found to collaborate to make sense of dementia and to

adapt at a practical level [10].

Managing transitions is a particularly prominent aspect of living with dementia, for instance

dealing with the grief associated with admitting a partner into long-term care [11]. With the

ongoing experience of transition associated with dementia, couples develop strategies and

approaches for managing and living with changes throughout this journey [12].

Friendships and the wider community are significant for living with dementia. Friendships

are important for maintaining social connectedness [13], wellbeing [14] and quality of life

[15]. Social networks are particularly important for people with dementia where family is

geographically diverse [16], however social isolation can occur due to alterations in

relationships and interactions following a diagnosis of dementia [17].

People with restricted social networks are more likely to report high unmet needs [15] and

therefore may need to rely upon formal services to live well with dementia. For carers, the

4

progression of dementia is often associated with increased responsibility and the need for

outside support [18]. Consequently, families may need to rely increasingly on formal

support to manage life with dementia as their condition progresses and their social

connections diminish.

This paper draws on the metaphor of 'scaffolding' to illustrate the interplay between

individualised informal and formal supports in the lives of people affected by dementia.

Scaffolding has its roots in educational psychology [19] and has been used in the dementia

field to describe different ways that people with dementia may be supported without

overcompensating for difficulties. For example, scaffolding has been used to conceptualise

how people work together to achieve successful communication or interaction [20,21,22],

or to understand couples' experience of adjusting to life with dementia from a relational

perspective [23,24]. Merrick et al. identify 'flexible scaffolding' where 'care partners

adapted the level and nature of support they provided, to reflect the fluctuating abilities

and deteriorating function of the person' [24, p.43] and Schrauf and Iris identify 'domestic

scaffolding' where ~~family caregivers~~carers work adaptively to take over tasks such as

shopping, driving or paying bills [25, p. 759]. We extend these uses of the scaffolding

metaphor to 1) illustrate the sometimes precarious relationship between informal and

formal supports and 2) argue for the importance of working collaboratively to introduce

timely, individualised formal support to extend existing scaffolds used by families and

communities.

Methods

This paper presents the secondary analysis of a qualitative data set from a user engagement

project funded by Cumbria County Council and NHS Cumbria (UK) to inform their regional

5

dementia strategy [26]. The qualitative component of this project involved 19 interviews

and 21 focus groups with 65 people with dementia and 82 carers in 2012 and 2013. <u>Within</u>

<u>the paper we use 'carer' to refer to people who identified themselves as the main carers for</u>

<u>a person with dementia, and 'families' where interviewees referred to a wider family</u>

<u>structure.</u> Semi-structured questions focused on experiences of services and broader

questions about how people lived well in their communities. The original analysis focused

on the evaluation objectives: to understand the impact of services and highlight best

practice and gaps in provision. The richness of data gathered in the project prompted the

secondary data analysis described below.

Participants

In 2012, interviews were conducted with people with dementia (n=5) and carers (n=12) and

ten focus groups with people with dementia (n=25) and carers (n=34). In 2013, interviews

were conducted with carers (n=8) and one person with dementia and eight focus groups

with people with dementia (n=34) and carers (n=28). A purposive sampling approach was

taken to ensure a mix of genders and ages; participants were recruited from different

geographical areas, with different levels of need, and with a variety of family and support

structures. This approach provided a diverse range of experiences of dementia and services.

Interview participants were recruited through gatekeepers within local third sector

organisations. People with dementia were offered the opportunity to be interviewed alone

or with a supporter. All but one chose to include a supporter. Interviews were conducted

at a place chosen by the person with dementia. Table 1. provides more information and

participant codes for the interview participants.

Insert Table 1. here.

Existing groups provided by adult social care and third sector services were recruited for

focus groups. Key gatekeepers within organisations facilitated access. Groups included

peer support groups; Dementia Cafes; day care services, and singing groups. These

comprised carers only, people with dementia only and mixed groups. Focus groups took

place within the normal timings and locations of the groups or immediately afterwards to

minimise travel. Table 2. provides more information and participant codes for the focus

group participants.

Insert Table 2. here.

Ethical considerations

Informed consent was obtained from all participants. The process of consent followed

Dewing's [27] ongoing consent process. This process began with familiar professionals in

gatekeeping organisations establishing initial interest amongst potential participants. With

permission for access, researchers arranged to meet for an interview or focus group several

days later. All participants were given an information sheet and researchers ensured this

had been understood by each individual before asking them to sign a consent form.   All

interviewers were experienced in communicating with people with dementia and carers

through active listening that was sensitive and respectful to both the person and their

views. Time was taken to put people at ease at the start of interviews and focus groups,

and to round off the interaction and check for any adverse impact at the end. Interviewers

ensured they communicated at a pace sensitive to individual abilities, monitoring both non-

verbal and verbal cues that might indicate a person was uncomfortable. If any signs of

discomfort or distress were evident, interviewers stopped recording and checked the person

wanted to continue; no participants chose to stop participation. For participants with

dementia, researchers used orientating statements to remind the person they were conducting an interview or focus group. If there was any concern about capacity during the process, researchers stopped to check the person understood they were taking part in research before continuing. Participants' anonymity and confidentiality were guaranteed by utilising a cypher and removing names from the transcripts before analysis commenced.

The study received ethical approval from the [Ethics Committee blinded for peer review]. In addition, the project was approved by the research governance bodies within Cumbria County Council, Cumbria Partnership NHS Foundation Trust and NHS Cumbria Primary Care Trust.

Primary data collection and analysis

Focus groups and interviews have been used successfully with people with dementia and their carers in previous research [28]. Interviews and focus groups were semi-structured discussions informed by a topic guide [26]. Fieldwork was conducted by a team of six researchers, with interviews conducted by one member of the research team while two members facilitated each focus group. Researchers brought fruit and biscuits to meetings as a way of thanking participants and facilitating rapport [29]. Focus group and interview audio recordings were transcribed verbatim. The primary data analysis focused on understanding the impact of services, providing examples of best practice and highlighting any gaps in provision. Findings are reported elsewhere [26].

Secondary data analysis

A secondary analysis of the qualitative data was conducted by the same three researchers who conducted the primary analysis [30]. This analysis took a more intensive focus on people's experiences of managing everyday life. While open questions in the original topic guide had explored people's experiences of living well, the data generated from these questions had not been analysed in depth for the purposes of the evaluation. A new set of questions guided the secondary analysis to explore how people combined informal supports with formal services to live well in their communities:

- What strategies are used by people with dementia and ~~family~~ carers as they manage everyday life?

- How do wider communities and informal support contribute to these strategies?

- How do services and formal support contribute to these strategies?

An inductive interpretative approach was taken using thematic analysis to understand how participants represented their experiences of informal and formal supports. Thematic analysis involved looking across the data set for repeated patterns of meaning associated with this topic and coding these using NVivo8 software. Following the process set out by Braun and Clarke [~~2006,~~ 31], the researchers independently read the transcripts and generated initial codes and, once all the transcripts were examined, worked together to sort the codes into themes and sub-themes to generate a thematic map of the analysis. Themes were defined and refined following discussion between researchers about any discrepancies in coding. The main themes from this process were defined as: people with dementia using informal support by 'doing things together' with their ~~partners~~carers, families and broader communities; evolving strategies that incorporate formal services as challenges increase;

9

concerns about the fragility of support and fear of the future as dementia progresses or

crises occur. Once themes had been defined and refined, the literature was reviewed to

relate the identified themes to theoretical constructs and frameworks in the existing

literature.

Methodological limitations

We recognise this is an exploratory study that draws on data from a specific region of the

UK limiting its generalisability. More in-depth data from individual participants would have

enabled differences to be highlighted between, for example, people with different types

and levels of dementia.

Findings

Our analysis depicted families, communities, professionals and services working hard to

build and structure support for living with dementia. Common experiences were evident of

families drawing on changing levels and types of support to manage everyday life as needs

changed. The manner in which strategies developed can be conceptualised as scaffolding

processes that ~~were~~ built upon immediate and wider family support, then support from

communities and later from formal services. Within this overarching framework of

scaffolding three sub-themes emerged: doing things together; evolving strategies; and

fragility and fear of the future.

Doing things together: ~~partners~~carers, families and communities:

For dyads of the person with dementia and their ~~main~~ carer, there was a strong sense of

being in this together; people worked together to find solutions for the challenges daily life

brought. One carer described having treatment for cancer while caring for her mother.

10

Since her mother could not be left alone due to her dementia, she took her mother with her to the hospital.

Follow up appointments and things like that, we just kind of went together… 12 of the 15 days she would be with us. (FG06.C4.F)

For another couple of working age, the carer structured each day to fit the needs of her husband.

But he's got to do that routine and then he'll go down for the paper in the morning when I'm at work. Then I'll phone and say, I'll be round in about ten minutes.., put the soup on…Then I go back to work and then D, will go for his walk, and I know the routine of his walk as well, just in case if anything did happen. Then, when I'm home at four, he sort of has a cup of tea and all that ready for me coming in. (FG14.C.F3)

For those living as a couple, getting on with things meant adjusting to the diagnosis together, something that other people outside their relationship could not always help with.

It's only we can do it ourselves really nobody else can really help; it just comes to you, this is how it is going to be and to adjust to that. (FG02.C1.F)

Dyads were also supported by wider family and community. People with dementia stressed the importance of family visiting and helping with housework and carers emphasised the value of family support for offering respite.

My daughter said I'll have mum on Sundays so you can go off into the hills … I found that brilliant because it just gave me time to just completely immerse myself in something that I wanted to do and not even have to think about anything, and that really did work for me. (I02.C.M)

11

However there were risks and limits associated with family and informal support, often linked to stigma and misunderstanding of dementia. One carer described how his children could not cope with their mother's dementia.:

> *And they all walk right by … because N can't accept what's wrong with his mum.*
>
> (FG06.C1.M)

Not all social connections were maintained following a diagnosis of dementia due to increasing cognitive deterioration and stigma.

> *If people would just ignore the fact that there's supposed to be something wrong*
>
> *with me, and talk to me properly…you feel you're not wanted anymore.* (I06.D.M)

Maintaining wider social connections beyond family contributed to living well with dementia. This carer described a strong network of friends and neighbours whom he saw regularly and whom he could call on for help.

> *They just live in town so when we're in town we pop in to see B and W and B and W*
>
> *pop up to see us. C next door - we've got fantastic neighbours. If I want help - I just*
>
> *phone up* (I20.C.M)

Carers discussed the particular benefits of living in a close-knit community.

> *My wife used to walk off like that but she always went to the village shop and then*
>
> *they kept her there and then they gave me a ring and said can you pick her up.*
>
> (FG1.C2.M)

A commonality was that adapting to life with dementia involved utilising existing, or developing new, scaffolds of support from families, friends and communities.

12

Evolving strategies

Amongst the participants there were many who were coping with dementia at a point where they needed more support than they could access within their family and ~~informal~~ social networks. The initial scaffolding provided by families and communities often became insufficient as time passed and our findings revealed that managing together without formal services became more challenging.

> *But it becomes a way of life and you just get used to it and it just becomes normal in a way, and then normal becomes harder and harder and harder.* (I02.C.M)

Findings indicate that both people with dementia and carers needed someone with expertise about dementia to talk to; people with dementia wanted someone to ask questions of and to provide company; carers wanted information and someone they could unburden with when stressed. For some it was important that this person was not a family member or friend.

> *We've got family, but sometimes you want to talk to somebody that doesn't know him as he was, if you understand what I mean.* (FG16.C1.F)

Regular day care, home care or help at home were reported as important as individuals' support needs increased.

> *You're meeting different people and you're listening to different conversations as well … whereas at home you're just on your own all the time.* (FG11.D4.F)

These services could support couples to remain living together at home and alleviate loneliness for people with dementia.

We have someone every morning for half an hour to get J showered and dressed. He

can do most of it himself, but he needs supervision. That half hour is…that is £7 well

worth spent every day …so I've not got that stress first thing in the morning.

(FG18.C2.F).

For many ~~families~~ there was a need to utilise a range of services and activities, patching

together different types of support to find a manageable solution.

B can go to the day centre on a Tuesday from half past nine to half past two. He

quite enjoys it. Then we come here [peer support group] on a Wednesday afternoon.

Then the fourth Thursday in the month…Young at Heart. (FG18.C4.F).

People with dementia recognised change and tended to discuss practical changes such as

the loss of their driving license.

And slowly we go down; we have trouble now because I was told I had to stop

driving, and [spouse] *doesn't drive … we've lost that*. (FG5.D2.M)

These examples illustrate participants' increasing need for emotional and practical support

beyond that provided by family and informal community. This involved developing

progressively more complex scaffolds using more formal services. The strength or fragility of

the scaffold was contingent on the availability of services and co-ordination between service

providers.

Fragility – fear for the future

While many ~~people~~ participants felt they managed fairly well, their accounts demonstrated

the relentless nature of caring and the losses experienced as dementia progressed. As the

needs of the person with dementia changed, for many ~~people~~ carers current strategies were

14

likely to become unsustainable. For a man of working age whose wife had dementia, his only option was to take her with him while he worked as a driver; a strategy that was unlikely to be sustainable and potentially risky.

> *I'm a lorry driver, I just go out and do cash in hand work when I can, take G with us, she sits in the wagon with us.* (FG15.C1.M)

Strategies could also add to carers' exhaustion. Having worked all day, some carers went walking with their spouses to meet their need for exercise, and were consequently exhausted.

> *I'm home at four …. I find then he's wanting to do something and I'm usually shattered by this time… I think, I just want to sit here for 20 minutes, just close my eyes, 20 minutes, that's all you want, and he's getting frustrated, so then you're going out walking, so he's on the go the whole time.* (FG14.C3.F)

The future was a time of uncertainty and change for families living with dementia. This is illustrated in the concern expressed by a carer about the possibility of becoming ill herself.

> *So it's things like that [becoming ill], you don't know what's going to happen to yourself but you've no idea what to do if you've got an emergency like that… If you're ill yourself there's nobody really.* (FG.06.C2.F)

Fear of advanced dementia was an issue for some, with death considered a release before the person's condition deteriorated significantly.

> *It may be a bad thing to say but I'm hoping before she starts really seriously deteriorating she'll pass on.* (I20.C.M)

Other carers worried about potential financial difficulties in the future, which was

associated with giving up work to care for a relative with dementia.

> *I still feel very worried about the future because I don't know how I am going to*
>
> *continue paying the bills if I don't work. So that'll be the next stage of our life, what*
>
> *am I supposed to do about that? … just have to see how it goes.* (I13.C.F)

Uncertainty was an overarching theme in the accounts of many carers in this study,

reflecting the need to take one day at a time given the precariousness of their situation.:

> *She's not deteriorating as fast as I thought she would, but I can tell the slight*
>
> *difference in the day by day … That's why I say I just do it for today and tomorrow - I*
>
> *look at tomorrow when I get out of bed*. (I20.C.M)

This section illustrates that scaffolds that worked at one point in the journey may not be

sufficient as time progresses. Scaffolds were fragile and at risk of failing as needs changed.

Access to support from outside the family and from formal services become more important

to bolster existing scaffolds and enable families people to continue to live well with

dementia.

Discussion – building and maintaining scaffolds

The concept of scaffolding is a useful metaphor for describing how carers and people with

dementia build supports for living with dementia. At first these scaffolds are built with

family, friends and the community, however, as dementia progresses, more complex

scaffolds are needed and are likely to involve more formal services. This finding builds on

current literature that shows the collaborative and adaptive ways that dyads work together

[20,24] by demonstrating how strategies evolve to support families people with dementia,

16

starting within caring dyads and evolving to include the wider community and formal

services.

The findings suggest that building and maintaining scaffolds could be hard work and it was

difficult to plan ahead, resulting in scaffolds that were at risk of collapse as people's needs

increased. Carers often felt that there were no solutions to their predicament, suggesting a

lack of available information or support to help them cope and plan for challenges,

reflecting previous research that has established the need for greater support and practical

management strategies after diagnosis [3].

The data revealed a wide range of experiences amongst individuals, couples and families

living with dementia, however, commonalities were found in the strategies undertaken and

the necessity to build increasingly complex scaffolds to continue to support everyday life

with dementia. Families shared a sense of fear for the future and the need to draw on

different sources of support as they faced increasing challenges; living with dementia was

hard work.

Families ~~and couples~~ were found to be resourceful and creative: they made the best of the

situations they found themselves in and worked hard to pull together different supports to

enable them to live as well as they could with dementia. Adopting active strategies has

been shown to maximise functioning and maintain wellbeing [4,5]. The people with

dementia within this research did not cope alone and there is a strength in using the family

as a system to better understand how people integrate practical strategies and support

networks to manage life with dementia. For the ~~couples and~~ families here, mutuality and

togetherness were crucial. The families worked together to develop and sustain practical,

17

emotional and relational strategies for everyday life with dementia. Shared resources and mutuality are processes identified in other studies [7,9]. Rural communities were ~~perceived to be~~ particularly valued in providing extended support networks, reflecting previous work on living with dementia in rural areas [30]. Families worked with what resources they had and added support where necessary, providing the person with dementia with the initial scaffolding needed to live well with dementia. Merrick et al. [23] discuss how carers provide flexible scaffolding to adapt to the fluctuating needs of the person with dementia, here we see how families and communities adapt and develop scaffold~~sing~~ as dementia progresses. However, informal strategies can become more fragile as challenges increase ~~with the progression of dementia~~, with families requiring more formal services to manage in the present and ~~help cope~~ as they look to the future.

The findings here demonstrate the increasingly complex scaffolds involving family, friends, community, and formal support and services that are built as the needs of the person with dementia increase over time. Much research highlights the importance of friendships and social networks for people with dementia [13,14,16] and ~~and~~ there is a need to recognise that networks often diminish as dementia progresses. ~~Loneliness follows the loss of informal support as dementia progresses suggesting the need for formal support to fill in those gaps. The findings here demonstrate the increasingly complex scaffolds involving family, friends, community, and formal support and services that are built as the needs of the person with dementia increase over time.~~ However, we suggest that more proactive and collaborative approaches may prevent or slow the breakdown of social networks and enable stronger scaffolds to be sustained for people with dementia with less need for formal services. ~~We suggest that the scaffolds that work best are those that integrate existing informal support~~

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with more formal services through collaborative working. ProfessionalsPractitioners need to

to-identify existing scaffolds and ways they can be supported and strengthened rather than

replaced. Co-production (33) and asset-based (34) methods are promising approaches that

could be adopted to guide this work, by drawing on the mutual resources of formal service

providers, communities, families and individuals and informal care networks to deliver

better outcomes for people living with dementia. In this way, formal services can build on

assets and capacities in families and communities by adopting asset-based development

models for integrating services with existing scaffolds. can achieve this by finding ways to

support strategies that use existing social networks and by introducing individualised, timely

formal services before informal scaffolds collapse.

Conclusion

We have shown that people with dementia and their family carers adopt active strategies to

manage daily life with dementia and that managing dementia starts as a collaborative

exercise involving the carer and the person with dementia. Families living with dementia

may also rely on wider social networks and, as the condition progresses, require input from

formal services. This paper demonstrates the hard work undertaken by families to build and

maintain scaffolds that become more complex as dementia progresses. The scaffolding

metaphor is useful for illustrating how families, communities and formal services can be

integrated to support people living with dementia. Our data suggest that the ad hoc

addition of services in response to changing needs or circumstances may compound rather

than alleviate challenges associated with living with dementia. More proactive,

individualised and integrated support is required to support and build on existing scaffolds

before informal strategies within families become unsustainable.

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Table 1. Interview participants

Participants	Participant codes
2012	
Man with dementia, his wife and daughter	I01.D.M, I01.C.F1, I01.C.F2
Carer	I02.C.M
Carer	I03.C.F
Carer	I04.C.M
Carer	I05.C.F
Couple with dementia	106.D.F, I06.D.M
Man with dementia and his wife	I07.D.M, I07.C.F
Carer	I08.C.F
Woman with dementia and daughter	I09.D.F, I09.C.F
Daughter of person with dementia	I10.C.F
Daughter of person with dementia	I11.C.F
Partner of person with dementia	I12.C.F
2013	
Carer	I13.C.F
Carer	I14.C.F
Carer	I15.C.F
Carer	I16.C.F
Carer	I17.C.M
Carer	I18.C.F
Carer	I19.C.F
Carer	I20.C.M
Woman with dementia	I21.D.F

Table 2. Focus group details

Description of group	Participants	Codes
2012		
Peer support group	9 carers	FG01.C1/9.M/F
Memory Lane Café	2 people with dementia, 1 carer	FG02.D1/2.M/F; FG02.C.F
Singing for the brain	1 person with dementia, 6 carers	FG03.C.1/6.M/F; FG03.D.M
Dementia Centre	5 people with dementia	FG04.D1/5.M/F
Singing for the brain	5 people with dementia, 5 carers	FG05.C.1/5.M/F; FG05.D1/5.M/F
Cross Keys Centre	4 carers	FG06.C1/4.M/F
Carers' support group	3 people with dementia, 8 carers	FG07.C1/8.M/F; FG07.D1/3.M/F
Dementia Club	3 people with dementia, 1 support worker	FG08.D1/3.M/F
Day Centre	3 people with dementia	FG09.D1/3.M/F
Day Centre	3 people with dementia	FG10.D1/3.M/F

2013		
Day centre	5 people with dementia	FG11.D1/5.M/F
Sheltered housing complex	5 people with dementia, 4 carers	FG12.D1/5.M/F; FG12.C1/4.M/F
Singing for the brain	4 people with dementia, 5 carers	FG13.D1/4.M/F; FG13.C1/5.M/F
Peer support group	1 person with dementia, 4 carers	FG14.D1.M; FG14.C1/4.M/F
Memory services support group	2 people with dementia, 4 carers	FG15.D1/2.M/F; FG15.C1/4.M/F
Memory café	6 people with dementia, 5 carers	FG16.D1/6.M/F; FG16.C1/5.M/F
Sheltered housing complex	6 people with dementia, 2 carers	FG17.D1/6.M/F; FG17.C1/2.M/F
Singing for the brain	5 people with dementia, 4 carers	FG18.D1/5.M/F; FG18.C1/4.M/F

Title

Scaffolding and working together: a qualitative exploration of strategies for everyday life with dementia

Abstract

Background: Living with dementia has been described as a process of continual change and adjustment, with people with dementia and their families adopting informal strategies to help manage everyday life. As dementia progresses, families increasingly rely on help from the wider community and formal support.

Methods: This paper reports on a secondary analysis of qualitative data from focus groups and individual interviews with people with dementia and their carers in the North of England. In total 65 people with dementia and 82 carers took part in the research: 26 in interviews and 121 in focus groups. Focus group and interview audio recordings were transcribed verbatim. A qualitative, inductive, thematic approach was taken for data analysis.

Findings: The paper applies the metaphor of scaffolding to deepen understanding of the strategies used by families. Processes of scaffolding were evident across the data where families, communities, professionals and services worked together to support everyday life for people with dementia. Within this broad theme of scaffolding were three sub-themes characterising the experiences of families living with dementia: doing things together; evolving strategies; and fragility and fear of the future.

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Conclusions: Families with dementia are resourceful but do need increasing support (scaffolding) to continue to live as well as possible as dementia progresses. More integrated, proactive work is required from services that recognises existing scaffolds and provides appropriate support before informal strategies become unsustainable; thus enabling people with dementia to live well for longer.

Key words: dementia, scaffolding, community, informal care, care services

Key points:

- People with dementia and their informal carers develop strategies to manage everyday life with dementia

- These strategies can be usefully described as scaffolds as families draw on a range of supports to manage everyday life

- As dementia progresses life gets more difficult and scaffolds built by families need additional support from formal services

- Scaffolds to support people with dementia may be at risk of collapse due to the changing nature of dementia

- Professionals should work collaboratively and recognise and enhance rather than replace existing scaffolds.

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Introduction

Living with dementia is a process of continual change and adjustment. How an individual

manages life with dementia will be affected by their biography and social location [1] and

their coping and adaptive strategies [2,3]. People with dementia adopt active strategies to

help maximise functioning [4] and maintain wellbeing [5]. For carers, adapting to life with

dementia similarly involves active strategies to adjust to the caregiving role [6].

The complexities of the caring relationship, such as perceived mutuality [7] and wider

relationships in the family [8], also impact on daily life with dementia. It has been shown

that people with dementia and their families work together to develop strategies for dealing

with the practical and social consequences of cognitive impairment [9]. People with

dementia and their partners are also found to collaborate to make sense of dementia and to

adapt at a practical level [10].

Managing transitions is a particularly prominent aspect of living with dementia, for instance

dealing with the grief associated with admitting a partner into long-term care [11]. With the

ongoing experience of transition associated with dementia, couples develop strategies and

approaches for managing and living with changes throughout this journey [12].

Friendships and the wider community are significant for living with dementia. Friendships

are important for maintaining social connectedness [13], wellbeing [14] and quality of life

[15]. Social networks are particularly important for people with dementia where family is

geographically diverse [16], however social isolation can occur due to alterations in

relationships and interactions following a diagnosis of dementia [17].

People with restricted social networks are more likely to report high unmet needs [15] and

therefore may need to rely upon formal services to live well with dementia. For carers, the

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progression of dementia is often associated with increased responsibility and the need for

outside support [18]. Consequently, families may need to rely increasingly on formal

support to manage life with dementia as their condition progresses and their social

connections diminish.

This paper draws on the metaphor of 'scaffolding' to illustrate the interplay between

individualised informal and formal supports in the lives of people affected by dementia.

Scaffolding has its roots in educational psychology [19] and has been used in the dementia

field to describe different ways that people with dementia may be supported without

overcompensating for difficulties. For example, scaffolding has been used to conceptualise

how people work together to achieve successful communication or interaction [20,21,22],

or to understand couples' experience of adjusting to life with dementia from a relational

perspective [23,24]. Merrick et al. identify 'flexible scaffolding' where 'care partners

adapted the level and nature of support they provided, to reflect the fluctuating abilities

and deteriorating function of the person' [24, p.43] and Schrauf and Iris identify 'domestic

scaffolding' where carers work adaptively to take over tasks such as shopping, driving or

paying bills [25, p. 759]. We extend these uses of the scaffolding metaphor to 1) illustrate

the sometimes precarious relationship between informal and formal supports and 2) argue

for the importance of working collaboratively to introduce timely, individualised formal

support to extend existing scaffolds used by families and communities.

Methods

This paper presents the secondary analysis of a qualitative data set from a user engagement

project funded by Cumbria County Council and NHS Cumbria (UK) to inform their regional

dementia strategy [26]. The qualitative component of this project involved 19 interviews

and 21 focus groups with 65 people with dementia and 82 carers in 2012 and 2013. Within

the paper we use 'carer' to refer to people who identified themselves as the main carers for

a person with dementia, and 'families' where interviewees referred to a wider family

structure. Semi-structured questions focused on experiences of services and broader

questions about how people lived well in their communities. The original analysis focused

on the evaluation objectives: to understand the impact of services and highlight best

practice and gaps in provision. The richness of data gathered in the project prompted the

secondary data analysis described below.

Participants

In 2012, interviews were conducted with people with dementia (n=5) and carers (n=12) and

ten focus groups with people with dementia (n=25) and carers (n=34). In 2013, interviews

were conducted with carers (n=8) and one person with dementia and eight focus groups

with people with dementia (n=34) and carers (n=28). A purposive sampling approach was

taken to ensure a mix of genders and ages; participants were recruited from different

geographical areas, with different levels of need, and with a variety of family and support

structures. This approach provided a diverse range of experiences of dementia and services.

Interview participants were recruited through gatekeepers within local third sector

organisations. People with dementia were offered the opportunity to be interviewed alone

or with a supporter. All but one chose to include a supporter. Interviews were conducted

at a place chosen by the person with dementia. Table 1. provides more information and

participant codes for the interview participants.

Insert Table 1. here.

Existing groups provided by adult social care and third sector services were recruited for

focus groups. Key gatekeepers within organisations facilitated access. Groups included

peer support groups; Dementia Cafes; day care services and singing groups. These

comprised carers only, people with dementia only and mixed groups. Focus groups took

place within the normal timings and locations of the groups or immediately afterwards to

minimise travel. Table 2. provides more information and participant codes for the focus

group participants.

Insert Table 2. here.

Ethical considerations

Informed consent was obtained from all participants. The process of consent followed

Dewing's [27] ongoing consent process. This process began with familiar professionals in

gatekeeping organisations establishing initial interest amongst potential participants. With

permission for access, researchers arranged to meet for an interview or focus group several

days later. All participants were given an information sheet and researchers ensured this

had been understood by each individual before asking them to sign a consent form.   All

interviewers were experienced in communicating with people with dementia and carers

through active listening that was sensitive and respectful to both the person and their

views. Time was taken to put people at ease at the start of interviews and focus groups,

and to round off the interaction and check for any adverse impact at the end. Interviewers

ensured they communicated at a pace sensitive to individual abilities, monitoring both non-

verbal and verbal cues that might indicate a person was uncomfortable. If any signs of

discomfort or distress were evident, interviewers stopped recording and checked the person

wanted to continue; no participants chose to stop participation. For participants with

7

dementia, researchers used orientating statements to remind the person they were

conducting an interview or focus group. If there was any concern about capacity during the

process, researchers stopped to check the person understood they were taking part in

research before continuing. Participants' anonymity and confidentiality were guaranteed by

utilising a cypher and removing names from the transcripts before analysis commenced.

The study received ethical approval from the [Ethics Committee blinded for peer review]. In

addition, the project was approved by the research governance bodies within Cumbria

County Council, Cumbria Partnership NHS Foundation Trust and NHS Cumbria Primary Care

Trust.

Primary data collection and analysis

Focus groups and interviews have been used successfully with people with dementia and

their carers in previous research [28]. Interviews and focus groups were semi-structured

discussions informed by a topic guide [26]. Fieldwork was conducted by a team of six

researchers, with interviews conducted by one member of the research team while two

members facilitated each focus group. Researchers brought fruit and biscuits to meetings

as a way of thanking participants and facilitating rapport [29]. Focus group and interview

audio recordings were transcribed verbatim. The primary data analysis focused on

understanding the impact of services, providing examples of best practice and highlighting

any gaps in provision. Findings are reported elsewhere [26].

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Secondary data analysis

A secondary analysis of the qualitative data was conducted by the same three researchers who conducted the primary analysis [30]. This analysis took a more intensive focus on people's experiences of managing everyday life. While open questions in the original topic guide had explored people's experiences of living well, the data generated from these questions had not been analysed in depth for the purposes of the evaluation. A new set of questions guided the secondary analysis to explore how people combined informal supports with formal services to live well in their communities:

- What strategies are used by people with dementia and carers as they manage everyday life?

- How do wider communities and informal support contribute to these strategies?

- How do services and formal support contribute to these strategies?

An inductive interpretative approach was taken using thematic analysis to understand how participants represented their experiences of informal and formal supports. Thematic analysis involved looking across the data set for repeated patterns of meaning associated with this topic and coding these using NVivo8 software. Following the process set out by Braun and Clarke [31], the researchers independently read the transcripts and generated initial codes and, once all the transcripts were examined, worked together to sort the codes into themes and sub-themes to generate a thematic map of the analysis. Themes were defined and refined following discussion between researchers about any discrepancies in coding. The main themes from this process were defined as: people with dementia using informal support by 'doing things together' with their carers, families and broader communities; evolving strategies that incorporate formal services as challenges increase;

9

concerns about the fragility of support and fear of the future as dementia progresses or

crises occur. Once themes had been defined and refined, the literature was reviewed to

relate the identified themes to theoretical constructs and frameworks in the existing

literature.

Methodological limitations

We recognise this is an exploratory study that draws on data from a specific region of the

UK limiting its generalisability. More in-depth data from individual participants would have

enabled differences to be highlighted between, for example, people with different types

and levels of dementia.

Findings

Our analysis depicted families, communities, professionals and services working hard to

build and structure support for living with dementia. Common experiences were evident of

families drawing on changing levels and types of support to manage everyday life as needs

changed. The manner in which strategies developed can be conceptualised as scaffolding

processes that built upon immediate and wider family support, then support from

communities and later from formal services. Within this overarching framework of

scaffolding three sub-themes emerged: doing things together; evolving strategies; and

fragility and fear of the future.

Doing things together: carers, families and communities:

For dyads of the person with dementia and their carer, there was a strong sense of being in

this together; people worked together to find solutions for the challenges daily life brought.

One carer described having treatment for cancer while caring for her mother. Since her

mother could not be left alone due to her dementia, she took her mother with her to the

hospital.

Follow up appointments and things like that, we just kind of went together… 12 of

the 15 days she would be with us. (FG06.C4.F)

For another couple of working age, the carer structured each day to fit the needs of her

husband.

But he's got to do that routine and then he'll go down for the paper in the morning

when I'm at work. Then I'll phone and say, I'll be round in about ten minutes.., put

the soup on…Then I go back to work and then D, will go for his walk, and I know the

routine of his walk as well, just in case if anything did happen. Then, when I'm home

at four, he sort of has a cup of tea and all that ready for me coming in. (FG14.C.F3)

For those living as a couple, getting on with things meant adjusting to the diagnosis

together, something that other people outside their relationship could not always help with.

It's only we can do it ourselves really nobody else can really help; it just comes to you,

this is how it is going to be and to adjust to that. (FG02.C1.F)

Dyads were also supported by wider family and community. People with dementia stressed

the importance of family visiting and helping with housework and carers emphasised the

value of family support for offering respite.

My daughter said I'll have mum on Sundays so you can go off into the hills … I found

that brilliant because it just gave me time to just completely immerse myself in

something that I wanted to do and not even have to think about anything, and that

really did work for me. (I02.C.M)

11

However there were risks and limits associated with family and informal support, often

linked to stigma and misunderstanding of dementia. One carer described how his children

could not cope with their mother's dementia.

> *And they all walk right by … because N can't accept what's wrong with his mum.*
>
> (FG06.C1.M)

Not all social connections were maintained following a diagnosis of dementia due to

increasing cognitive deterioration and stigma.

> *If people would just ignore the fact that there's supposed to be something wrong*
>
> *with me, and talk to me properly…you feel you're not wanted anymore.* (I06.D.M)

Maintaining wider social connections beyond family contributed to living well with

dementia. This carer described a strong network of friends and neighbours whom he saw

regularly and whom he could call on for help.

> *They just live in town so when we're in town we pop in to see B and W and B and W*
>
> *pop up to see us. C next door - we've got fantastic neighbours. If I want help - I just*
>
> *phone up* (I20.C.M)

Carers discussed the particular benefits of living in a close-knit community.

> *My wife used to walk off like that but she always went to the village shop and then*
>
> *they kept her there and then they gave me a ring and said can you pick her up.*
>
> (FG1.C2.M)

A commonality was that adapting to life with dementia involved utilising existing, or

developing new, scaffolds of support from families, friends and communities.

12

Evolving strategies

Amongst the participants there were many who were coping with dementia at a point where they needed more support than they could access within their family and social networks. The initial scaffolding provided by families and communities often became insufficient as time passed and our findings revealed that managing together without formal services became more challenging.

> *But it becomes a way of life and you just get used to it and it just becomes normal in a way, and then normal becomes harder and harder and harder.* (I02.C.M)

Findings indicate that both people with dementia and carers needed someone with expertise about dementia to talk to; people with dementia wanted someone to ask questions of and to provide company; carers wanted information and someone they could unburden with when stressed. For some it was important that this person was not a family member or friend.

> *We've got family, but sometimes you want to talk to somebody that doesn't know him as he was, if you understand what I mean.* (FG16.C1.F)

Regular day care, home care or help at home were reported as important as individuals' support needs increased.

> *You're meeting different people and you're listening to different conversations as well … whereas at home you're just on your own all the time.* (FG11.D4.F)

These services could support couples to remain living together at home and alleviate loneliness for people with dementia.

13

We have someone every morning for half an hour to get J showered and dressed. He

can do most of it himself, but he needs supervision. That half hour is…that is £7 well

worth spent every day …so I've not got that stress first thing in the morning.

(FG18.C2.F).

For many there was a need to utilise a range of services and activities, patching together

different types of support to find a manageable solution.

B can go to the day centre on a Tuesday from half past nine to half past two. He

quite enjoys it. Then we come here [peer support group] on a Wednesday afternoon.

Then the fourth Thursday in the month…Young at Heart. (FG18.C4.F).

People with dementia recognised change and tended to discuss practical changes such as

the loss of their driving license.

And slowly we go down; we have trouble now because I was told I had to stop

driving, and [spouse] *doesn't drive … we've lost that*. (FG5.D2.M)

These examples illustrate participants' increasing need for emotional and practical support

beyond that provided by family and informal community. This involved developing

progressively more complex scaffolds using more formal services. The strength or fragility of

the scaffold was contingent on the availability of services and co-ordination between service

providers.

Fragility – fear for the future

While many participants felt they managed fairly well, their accounts demonstrated the

relentless nature of caring and the losses experienced as dementia progressed. As the needs

of the person with dementia changed, for many carers current strategies were likely to

14

become unsustainable. For a man of working age whose wife had dementia, his only option

was to take her with him while he worked as a driver; a strategy that was unlikely to be

sustainable and potentially risky.

I'm a lorry driver, I just go out and do cash in hand work when I can, take G with us,

she sits in the wagon with us. (FG15.C1.M)

Strategies could also add to carers' exhaustion. Having worked all day, some carers went

walking with their spouses to meet their need for exercise, and were consequently

exhausted.

I'm home at four …. I find then he's wanting to do something and I'm usually

shattered by this time… I think, I just want to sit here for 20 minutes, just close my

eyes, 20 minutes, that's all you want, and he's getting frustrated, so then you're

going out walking, so he's on the go the whole time. (FG14.C3.F)

The future was a time of uncertainty and change. This is illustrated in the concern

expressed by a carer about the possibility of becoming ill herself.

So it's things like that [becoming ill], you don't know what's going to happen to

yourself but you've no idea what to do if you've got an emergency like that… If

you're ill yourself there's nobody really. (FG.06.C2.F)

Fear of advanced dementia was an issue for some, with death considered a release before

the person's condition deteriorated significantly.

It may be a bad thing to say but I'm hoping before she starts really seriously

deteriorating she'll pass on. (I20.C.M)

15

Other carers worried about potential financial difficulties in the future, which was

associated with giving up work to care for a relative with dementia.

> *I still feel very worried about the future because I don't know how I am going to*
>
> *continue paying the bills if I don't work. So that'll be the next stage of our life, what*
>
> *am I supposed to do about that? … just have to see how it goes.* (I13.C.F)

Uncertainty was an overarching theme in the accounts of many carers in this study,

reflecting the need to take one day at a time given the precariousness of their situation.

> *She's not deteriorating as fast as I thought she would, but I can tell the slight*
>
> *difference in the day by day … That's why I say I just do it for today and tomorrow - I*
>
> *look at tomorrow when I get out of bed.* (I20.C.M)

This section illustrates that scaffolds that worked at one point in the journey may not be

sufficient as time progresses. Scaffolds were fragile and at risk of failing as needs changed.

Access to support from outside the family and from formal services become more important

to bolster existing scaffolds and enable people to continue to live well with dementia.

Discussion – building and maintaining scaffolds

The concept of scaffolding is a useful metaphor for describing how carers and people with

dementia build supports for living with dementia. At first these scaffolds are built with

family, friends and the community, however, as dementia progresses, more complex

scaffolds are needed and are likely to involve more formal services. This finding builds on

current literature that shows the collaborative and adaptive ways that dyads work together

[20,24] by demonstrating how strategies evolve to support people with dementia, starting

within caring dyads and evolving to include the wider community and formal services.

16

The findings suggest that building and maintaining scaffolds could be hard work and it was difficult to plan ahead, resulting in scaffolds that were at risk of collapse as people's needs increased. Carers often felt that there were no solutions to their predicament, suggesting a lack of available information or support to help them cope and plan for challenges, reflecting previous research that has established the need for greater support and practical management strategies after diagnosis [3].

The data revealed a wide range of experiences amongst individuals, couples and families living with dementia, however, commonalities were found in the strategies undertaken and the necessity to build increasingly complex scaffolds to continue to support everyday life with dementia. Families shared a sense of fear for the future and the need to draw on different sources of support as they faced increasing challenges; living with dementia was hard work.

Families were found to be resourceful and creative: they made the best of the situations they found themselves in and worked hard to pull together different supports to enable them to live as well as they could with dementia. Adopting active strategies has been shown to maximise functioning and maintain wellbeing [4,5]. The people with dementia within this research did not cope alone and there is a strength in using the family as a system to better understand how people integrate practical strategies and support networks to manage life with dementia. For the families here, mutuality and togetherness were crucial. The families worked together to develop and sustain practical, emotional and relational strategies for everyday life with dementia. Shared resources and mutuality are processes identified in other studies [7,9]. Rural communities were particularly valued in providing extended support networks, reflecting previous work on living with dementia in

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rural areas [30]. Families worked with what resources they had and added support where

necessary, providing the person with dementia with the initial scaffolding needed to live

well with dementia. Merrick et al. [23] discuss how carers provide flexible scaffolding to

adapt to the fluctuating needs of the person with dementia, here we see how families and

communities adapt and develop scaffolds as dementia progresses. However, informal

strategies can become more fragile as challenges increase, with families requiring more

formal services to manage in the present and as they look to the future.

The findings here demonstrate the increasingly complex scaffolds involving family, friends,

community, and formal support and services that are built as the needs of the person with

dementia increase over time. Much research highlights the importance of friendships and

social networks for people with dementia [13,14,16] and there is a need to recognise that

networks often diminish as dementia progresses. However, we suggest that more

proactive and collaborative approaches may prevent or slow the breakdown of social

networks and enable stronger scaffolds to be sustained for people with dementia with less

need for formal services. Practitioners need to identify existing scaffolds and ways they can

be supported and strengthened rather than replaced. Co-production (33) and asset-based

(34) methods are promising approaches that could be adopted to guide this work, drawing

on the mutual resources of formal service providers, communities, families and individuals

to deliver better outcomes for people living with dementia.

Conclusion

We have shown that people with dementia and their carers adopt active strategies to

manage daily life with dementia and that managing dementia starts as a collaborative

18

exercise involving the carer and the person with dementia. Families living with dementia

may also rely on wider social networks and, as the condition progresses, require input from

formal services. This paper demonstrates the hard work undertaken by families to build and

maintain scaffolds that become more complex as dementia progresses. The scaffolding

metaphor is useful for illustrating how families, communities and formal services can be

integrated to support people living with dementia. Our data suggest that the ad hoc

addition of services in response to changing needs or circumstances may compound rather

than alleviate challenges associated with living with dementia. More proactive,

individualised and integrated support is required to support and build on existing scaffolds

before informal strategies within families become unsustainable.

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Table 1. Interview participants

Participants	Participant codes
2012	
Man with dementia, his wife and daughter	I01.D.M, I01.C.F1, I01.C.F2
Carer	I02.C.M
Carer	I03.C.F
Carer	I04.C.M
Carer	I05.C.F
Couple with dementia	106.D.F, I06.D.M
Man with dementia and his wife	I07.D.M, I07.C.F
Carer	I08.C.F
Woman with dementia and daughter	I09.D.F, I09.C.F
Daughter of person with dementia	I10.C.F
Daughter of person with dementia	I11.C.F
Partner of person with dementia	I12.C.F
2013	
Carer	I13.C.F
Carer	I14.C.F
Carer	I15.C.F
Carer	I16.C.F
Carer	I17.C.M
Carer	I18.C.F
Carer	I19.C.F
Carer	I20.C.M
Woman with dementia	I21.D.F

Table 2. Focus group details

Description of group	Participants	Codes
2012		
Peer support group	9 carers	FG01.C1/9.M/F
Memory Lane Café	2 people with dementia, 1 carer	FG02.D1/2.M/F; FG02.C.F
Singing for the brain	1 person with dementia, 6 carers	FG03.C.1/6.M/F; FG03.D.M
Dementia Centre	5 people with dementia	FG04.D1/5.M/F
Singing for the brain	5 people with dementia, 5 carers	FG05.C.1/5.M/F; FG05.D1/5.M/F
Cross Keys Centre	4 carers	FG06.C1/4.M/F
Carers' support group	3 people with dementia, 8 carers	FG07.C1/8.M/F; FG07.D1/3.M/F
Dementia Club	3 people with dementia, 1 support worker	FG08.D1/3.M/F
Day Centre	3 people with dementia	FG09.D1/3.M/F
Day Centre	3 people with dementia	FG10.D1/3.M/F

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2013		
Day centre	5 people with dementia	FG11.D1/5.M/F
Sheltered housing complex	5 people with dementia, 4 carers	FG12.D1/5.M/F; FG12.C1/4.M/F
Singing for the brain	4 people with dementia, 5 carers	FG13.D1/4.M/F; FG13.C1/5.M/F
Peer support group	1 person with dementia, 4 carers	FG14.D1.M; FG14.C1/4.M/F
Memory services support group	2 people with dementia, 4 carers	FG15.D1/2.M/F; FG15.C1/4.M/F
Memory café	6 people with dementia, 5 carers	FG16.D1/6.M/F; FG16.C1/5.M/F
Sheltered housing complex	6 people with dementia, 2 carers	FG17.D1/6.M/F; FG17.C1/2.M/F
Singing for the brain	5 people with dementia, 4 carers	FG18.D1/5.M/F; FG18.C1/4.M/F

25