The Construction of Identity in the Accounts of Informal Carers for People with Dementia

TREVOR ADAMS
European Institute of Health and Medical Sciences, University of Surrey, United Kingdom

ABSTRACT This article examines the conversational processes that give rise to the construction of the identity in families caring for relatives with dementia. The data comprised tape recordings of 24 semi-structured interviews between the researcher and informal carers for people who had been diagnosed as having dementia. The interviews were fully transcribed. The transcripts were analysed using techniques drawn from conversation analysis and discourse analysis. The analysis identified four forms of story within the accounts: pre-onset stories, recognition stories, searching stories and dependency stories. It was found that these stories allowed inferences about the identity of family members and were used as a means of accomplishing informal care. The article argues that through these inferences the identities of particular family members are progressively transformed into 'the person with dementia' and 'the informal carer'. The implications of these findings for education and training are discussed.

Introduction

It is estimated that there are presently 650,000 people with dementia in the United Kingdom (Department of Health, 1997). The Government's response to people with dementia has been through the provision of community care that consists of support from informal agencies such as family, friends and neighbours that is augmented by formal care from health and social care agencies (Department of Health, 2001). As a result of this system of care, the identity of family members changes to meet changing expectations and responsibilities that are placed upon families

(Opie, 1992). This article examines the conversational strategies that give rise to changes in identity of people caring for relatives with dementia.

Informal Care for People with Dementia

Various approaches have emerged towards informal carers for people with dementia. Firstly, a substantial number of studies have used various psycho-social approaches to describe the experience of informal carers to people with dementia, such as transactional models of stress (deLongis & O'Brien, 1990) and the idea of loss (Jones & Martinson, 1992; Loos & Bowd, 1997). Secondly, other studies have adopted a temporal and longitudinal approach to informal caregiving. These studies have identified various stages relating to informal caregiving to relatives with dementia (Willoughby & Keating, 1991; Wuest et al, 1994). Thirdly, numerous studies have identified the social processes associated with informal caregiving. These studies have often adopted a feminist perspective and have examined such issues as obligation and responsibility in families and the subjective experience of giving informal care (Ungerson, 1987). While many of these studies examine the social processes associated with the provision of informal care to people with a range of physical and mental conditions, Opie (1992) specifically focuses on carers for people with dementia.

Critique

These three approaches are problematic as they are underpinned by realist assumptions in which 'reality [is] independent of the researcher [or social actor] whose nature can be known and that the aim of research [or knowledge acquisition, or professional practice] is to produce accounts that correspond to that reality' (Hammersley, 1992, p. 43). Firstly, these approaches construct the experience of carers in objective terms, as something that happens 'out there' that is independent from the observer. This tendency gives rise to the reification of phenomena as having an objective existence outside of the carers. Moreover, the construction of caregiving in objective terms gives rise to the production of 'an analyst account'. In this form of account, carer's talk is understood in the terms and categories of the researcher rather than as a resource that carers use to accomplish informal care.

Secondly, these approaches to informal caregiving are based on the understanding that language is a neutral medium that does not affect the message it is communicating. This view of the language used within carers' accounts is similar to that adopted by Opie (1993, pp. 1-2) who argues that:

> the creation of text is not a neutral action. It consistently involves choices about audience, language, density of analysis, the positioning

> of theory in the text, and epistemological issues – what is included and excluded? What is foreground, what is marginalised? Whose voices dominate? What constitutes a valid generalisation?

Moreover, carer's talk does more than just communicate what carers think about the world, it provides a means of enabling people to make sense of their social world and thereby provides a version of the world that enables them to undertake informal care. As Askham (1995, p. 13) suggests carers may use 'different accounts [..] in different contexts to achieve different ends'.

Approaches within the social sciences, such as conversation analysis and discourse analysis, have developed that have taken issue with the realist approach to language (Potter, 1996; Hutchby & Wooffitt, 1998; Taylor & White, 2000). Conversation Analysis (CA) emerged out of ethnomethodology that was concerned with the methods that people use to carry out everyday activities. CA was developed by Harvey Sacks in conjunction with Emanuel Schegloff and Gail Jefferson in the late 1960s and early 1970s (see Hutchby & Wooffitt, 1998). The approach shares many of the assumptions of ethnomethodology but has a much clearer focus upon the use of talk within interaction to generate meaning, particularly through the use of conversational structures such as turn taking and adjacency pairs. Hutchby & Wooffitt (1998, p. 1) state that the aim of CA is to:

> ... reveal the tacit, organised reasoning procedures which inform the production of naturally occurring talk. The way in which utterances are designed is informed by organized procedures, methods and resources that are tied to contexts in which they are produced, and which are available to participants by virtue of their membership in a natural language community. The analytic objective of CA is to explicate these procedures, on which speakers rely to produce utterances and by which they make sense of other speakers' talk.

While there are many varieties of discourse analysis, the approach adopted in this present paper draws on the work of Potter & Wetherell (1987) whose work is based on Foucault's notion of discourse. This approach shares with ethnomethodology and CA an understanding that it is through the local organisation and management of language that meaning is generated.

However, there are two important features that differentiate discourse analysis from ethnomethodology and CA. Firstly, in discourse analysis the focus of interest is much broader and this allows the inclusion of textual materials such as Government reports and case notes together with practices such as bodily movement (Parker, 1999). Secondly, the ideological basis of discourse analysis, as developed by Potter & Wetherell arises out of structuralism, particularly the work of Saussure (1974) who argued that the meaning of words is arbitrary but

that once words become attached to particular meanings they become fixed, within a system, to that meaning. In this way, discourse analysis goes beyond ethnomethodology and CA and incorporates a wider socio-political context (Wetherell, 1998; Taylor & White, 2000).

These approaches to language reject the idea that language is a transparent medium and argue that through language 'descriptions and accounts construct the world or at least versions of the world ... [and] these descriptions or accounts are themselves constructed' (Potter, 1996, p. 96). Underpinning these approaches are a number of ideas originally developed by Garfinkel (1967). Firstly, 'accountability' in which 'the activities whereby members produce and manage settings of organised everyday affairs are identical with member's [people's] procedures for making those settings 'accountable' ... observable-and-reportable' (Garfinkel, 1967, p. 1). Secondly, 'reflexivity', in which descriptions maintain or alter 'the sense of the activities and unfolding circumstances in which they occur' (Heritage, 1984, p. 140). And, thirdly, 'indexicality', in which descriptions are understood in terms of their immediate context.

With reference to identity, these approaches reject the idea that identity is an innate property of an individual and argue that identity is socially constructed through the use of language (Antaki & Widdicome, 1998). Moreover, various empirical studies have demonstrated the means by which identity is created in a diversity of social settings such as in youth subcultures (Widdicombe & Wooffitt, 1995), divorcing couples (Hopper, 2001) and television talk shows (Lowney & Holstein, 2001).

Two studies of particular interest that reveal how accounts may be used to identify people as being mentally ill are those of Pollner & McDonald-Wikler (1985), and Smith (1978). Pollner & McDonald-Wikler (1985) describe a family who presented themselves to the psychiatric services saying that at home, their five and a half year old child Mary was acting normally but that in public she was displaying peculiar and difficult behaviour. Following a thorough assessment, the unanimous agreement of the health care professionals was that Mary was severely retarded and had mild cerebral palsy, petit mal seizures, poor language development and could not be toilet trained. This diagnosis was at odds with the family's opinion that Mary was just like any other child her age. What is of interest in the study are the conversational techniques Mary's parents used to ensure that their account had optimal impact rhetorically.

Smith's (1978) description of an account that one of her student's Angela, gives of how a friend K, became mentally ill reveals similar concerns to those of Pollner & McDonald-Wikler (1985). Smith demonstrates the student's use of various conversational strategies to support the account. For example, early in the account Angela is described as a friend of K. Smith argues that the use of the word 'friend' supports the inference that as Angela is a friend, K is not described as

mentally ill out of any negative motive but that 'Angela is constrained to recognise that fact that K is mentally ill' (Smith, 1978, p. 35). Again, the paper supports the argument that accounts are never totally transparent and simply 'tell it as it is' but rather that they are rhetorical in their orientation.

To summarise, while studies on informal caregiving to people with dementia have typically been underpinned by realist assumptions, these approaches are problematic as a result of their tendency to reify social phenomena and their failure to address the creation of inferences about identity within the course of conversational exchanges. The present study examines three issues raised by the literature: firstly, how do carers talk about relatives with dementia? Secondly, what are the conversational strategies that carers use when they talk about relatives who have dementia? And, thirdly, what do carers accomplish through the use of conversational strategies?

The Data

The data comprised a sample of 24 tape recordings taken from domiciliary meetings between primary informal carers and their CPN; these were all tape recorded and fully transcribed. Field notes were made and were used to enhance the analysis of the tape-recorded data.

The sample was recruited from the caseloads of CPNs. Prior to agreeing to participate in the study, sample members were given a full explanation of the procedure and were asked to sign a consent form. The study was approved by all the local NHS Ethics Committees representing the NHS Trusts participating in the study together with a University Advisory Committee on Ethics. The sample comprised 24 informal carers (n=24) of whom nine were male and 15 were female. Of these carers, nine were husbands, nine wives and six daughters of people diagnosed by a medical practitioner as having dementia. Of the 24 carers, 22 co-habited with their relative who has dementia. One of the people with dementia was under 60 years of age. The length of the interviews ranged from 25 minutes to 55 minutes. Confidentiality was maintained throughout the study. The only people to hear the tapes and read the transcripts were the researcher and the professional transcriber. In reporting the study's findings, the names of the people involved in the study are anonymised.

The transcripts were analysed using techniques drawn from CA and discourse analysis (Potter & Wetherell, 1987; Hutchby & Wooffitt, 1998). Initially, the transcripts were read while listening to the appropriate tape recording. Secondly, extracts were identified and coded in terms of the particular issues they represented. Thirdly, a detailed analysis of the extracts was undertaken to provide insights into how meaning was constructed within the dialogue. The integration of analytic techniques that share a performative understanding of language has been a feature of

recent studies including those relating to the construction of health-related settings (see Wetherell, 1998; Frith & Kitzinger, 1998; Wilkinson & Kitzinger, 2000). For instance, Miller (1997, p. 25) argues that in CA and DA 'each of these perspectives stress how social life may be organised within multiple social realities ... how the realities are socially constructed through our use of language' and suggests that they 'may be linked and made mutually informative, while also respecting the distinctive contributions and integrity of each perspective' (Miller, 1997, p. 24). The overriding analytic question in the study concerned the ways in which carers construct identity within their accounts and what purpose it accomplished. Thus identity was viewed as a 'participant resource', that is, a tool created and used by carers through their use of talk within accounts to make social accomplishments (Widdicome, 1998).

Findings

The findings revealed that four forms of story were located in the carers' accounts: pre-onset stories, recognition stories, searching stories and dependency stories. It was found that within each of these forms of story inferences were made available about the identity of informal carers and the person with dementia. These stories constructed this relationship in terms of progressive dependency: the person with dementia increasingly becoming dependent upon their relative. Moreover, they were found to display two orientations: an action orientation in which the story makes a social accomplishment and an epistemological orientation that supports the credibility of the story (Potter, 1996).

Pre-onset Stories

The main interest in the interviews was the provision of care to relative with dementia. While not specifically requested, carers included stories about what their relative was like before they had dementia. One way in which these stories displayed an action orientation was by allowing inferences that gave rise to the construction of identity. In these stories, three ways in which informal carers constructed identity and thus allowed carer's to make sense of their social world were found.

Firstly, it was repeatedly found that carers constructed the identity of the person with dementia by contrasting their present identity with what they were like before they had dementia.

Extract 1

Mrs Dawson: And naturally I left it to my husband to put
the loft ladder back who'd al:::ways done all
those sorts of things without any thought at all.
I would just say 'Oh, yes would you put the loft
ladder back' or what ever and that he would

do. And I found him quite puzzled and whereas
normally there would be no difficulty and the loft
ladder would have gone up and that would have
been that he was fiddling.

In Extract 1, Mrs Dawson is talking about her husband's inability to do jobs around the house. She says that he was once able to do various jobs around the house that he can no longer do. This strategy is identified in other studies, notably that of Smith (1972) who describes this strategy as a 'contrast structure' in which speakers represent another person's identity as abnormal by setting inferences about that person alongside references to what is considered to be normal.

The idea of contrast structures may be supplemented by the notion of membership category device (MCD). According to Sacks (1992), MCDs occur when people assign other people or themselves to a particular category which then automatically mobilises a set of expectations about that person relating to their category-bound activities (CBAs). In the extract, Mrs Dawson assigns to the person she is talking about the category of 'husband' (line 1). As a result of this MCD, numerous CBAs are mobilised that relate to the category 'husband', one of which being his ability to do household tasks such as putting the loft ladder back. However Mrs Dawson's story portrays her husband as someone who is no longer able to put the loft ladder back and therefore allows the inference that he is not living up to society's expectations of a husband. Thus through the use of a contrast structure together with MCDs, Mrs Dawson allows her husband's behaviour to be heard as abnormal.

Secondly, the carers repeatedly constructed identity through the inclusion of discursive materials within the story. Extract 1 contains fragments of discourse that relate to the sexual division of labour in the home that make available inferences about the identity of the carer's husband. In the extract, Mrs Dawson says that her husband was not able to do household jobs. The inference is made available that there has been a breach of the natural order. As with the previous strategy, through these discourses Mrs Dawson positions her husband as someone who is not living up to society's expectations.

Thirdly, carers constructed identity by making available inferences about the relative having similar characteristics to those they possessed prior to developing dementia. This is seen in Extract 2 in which the carer is talking about his wife's difficult behaviour.

Extract 2

Interviewer: If she'd done that say twenty years ago, would she
have expressed guilt?
Mr Jackson: Oh yeah.
Interviewer: She would have said something, at least
Mr Jackson: Yeah, yeah. She's always been a bit devious

> and quiet because of the way she's brought up,
> her mother was ever so strict, and I think that's
> part and parcel of this feeling, you know, if they
> told the truth I reckon they would have got hit, you
> know. But it's terrible to live with 'cos most of my,
> well, all my family they're all right pretty liberal and
> they like honesty as much. She always accusing,
> you know, I'll leave money lying about out there,
> and she's always, I mean it'll be the same if you
> was here.

In the extract, Mr Jackson indicates that certain characteristics of his wife existed before she had dementia. He says that his wife has always 'been a bit devious and quiet' (lines 5-6) and allows the inference that she has always been the sort of person who can act in that way. By constructing his wife as someone who had 'always' (line 5) acted in this way, Mr Jackson allows the inference that she had acted like this prior to having dementia, at a time when she was in control of her actions. Mr Jackson thus allows the inference that his wife has some responsibility for her behaviour. This identity would have not have been created if the inference were made available that these characteristics arose as the result of illness. Moreover, by constructing his wife as someone who is responsible for her deviousness, Mr Jackson positions himself as a victim. The accomplishment of this latter identity is important as it provides the carer with a subject position in which they are seen as having the moral right to voice their needs and grievances. Furthermore, it places upon people talking to carers an obligation to listen to what carers are saying.

In terms of epistemological orientation, three further conversational strategies may be identified in the stories. It should be noted though that these strategies are not unique to pre-onset stories but were repeatedly found throughout the data. Firstly, each extract contains utterances that describe aspects of their relative's behaviour as an 'extreme case formulation' (Pomerantz, 1986). In Extract 1, Mrs Dawson is talking about her husband's difficulty putting back the loft ladder, she says that he had 'al:::ways done all those sorts of things without any thought at all' (lines 2 and 3). In Extract 2, Mr Jackson uses 'always' on three separate occasions (lines 5 and 6; line 12, and line 14). These five references (Extract 1 'al:::ways' and 'without any' and Extract 2 'always') describe their relative's past behaviour in extreme forms that do not allow the possibility that their relative sometimes fell short of this behaviour. The use of extreme case formulations within each story strengthens the argument the carer is making.

Secondly, in Extract 1, Mrs Dawson describes what she said to her husband through the use of reported speech: 'Oh, yes would you put the loft ladder back' (lines 4-5). Wooffitt (1992) describes the use of reported

speech as 'active voicing' and argues that it is a means that speakers use to strengthen the immediacy and authenticity of their account and gives it a sense that 'this is what really happened'. In this way, the factual status of the carer's claim is strengthened and the possibility of a sceptical response from the listener is fended off.

Thirdly, in Extract 2 Mr Jackson supports his claim that his wife has 'always been a bit devious and quiet' (lines 5-6) by saying that it was 'because of the way she's brought up, her mother was ever so strict' (lines 6-7). By giving this additional detail about his wife's upbringing Mr Jackson, firstly, provides anecdotal evidence to support his claim about his wife's past behaviour and, secondly, distances himself from his wife's behaviour by suggesting that it existed before they were married and therefore allows the inference that he did not share responsibility for the behaviour. This latter inference supports other inferences that the story makes available that construct Mr Jackson as someone that is the victim and also allows the additional inference that he is not the cause of his wife's behaviour. Lastly, the additional detail defends Mr Jackson from the accusation that he was just making the story up, perhaps for his own gain.

Recognition Stories

At the beginning of the interview, carers were asked how they first recognised that their relative had dementia. This question allowed carers to tell a 'recognition story' about events early in their experience of being an informal carer. Extract 3 is an example of a recognition story taken from the data. This story was chosen because it contains many characteristics commonly found in other recognition stories identified in the data. While recognition stories informed the listener about what had happened, they also accomplished inferential work that reconstructed the identity of family members, previously constructed in pre-onset stories to have optimal rhetorical force within the recognition story.

Extract 3
(Case 4/1)
Mr Lawler: I remember on one evening
in particular a couple of
her friends came in and we
had a chat and some niblets
and so on and she asked them
if they would like a cup of tea erm.
They said yes, so she went off and
got this cup of tea on a tray and
brought it in and she seemed to
be having difficulty in she'd left
something in the kitchen you

know, she hadn't brought spoons
or she hadn't brought the sugar,
or something rather like that and
I thought well you know she's
just not, just not concentrating.
What's, what's the problem? Not
thinking there was a problem, but er
it was quite erm out of character. And
er I think that's probably, looking back,
I mean I didn't realise at the time but
looking back that that was probably the
first time that it had occurred to me now
that er you know there was something
starting to go astray.

In Extract 3, Mr Lawler who is looking after his wife in the early stages of dementia is talking about when he first realised his wife might have had dementia. In the story, Mr Lawler describes how he noticed that his wife was finding it difficult to get the tea tray ready when a couple of his wife's friends were visiting. As in Extract 1, an action orientation is displayed through the mobilisation of inferences that concern the abnormality of his wife's behaviour through the carer's use of a contrast structure. Mr Lawler contrasts his wife's difficulties (lines 8-13) with his own ease at socialising with her friends (lines 2-4). By making this contrast, Mr Lawler mobilises the inference that his wife is failing to live up to everyday expectations and represents her as someone who is different from other people.

Moreover, Extract 3 displays an epistemological orientation by addressing what Potter (1996) calls a 'dilemma of stake' in which what is said may be discounted as merely a product of the speaker's stake or interest. As we have seen, in the extract Mr Lawler describes his wife's behaviour and makes available the inference that she was odd. By allowing this inference, Mr Lawler places himself in a tricky and difficult position that might lead to the accusation that he has an interest in describing his wife in this way.

For this reason, Mr Lawler makes available inferences that support the credibility of his story and through which he displays an epistemological orientation. This is achieved by Mr Lawler allowing the inference that he would not tell tales about his wife acting strangely. Mr Lawler does this by allowing two utterances. The first about his wife, that she was 'just not concentrating' (line 16), a condition within everyone's experience and one that does not lead to social stigmatisation. The second inference is about himself, that he did not think his wife's behaviour was a problem (lines 17-18). Through these two utterances, Mr Lawler provides himself with the identity that he is just an ordinary person who would not unthinkingly go out of his way to draw

unwarranted conclusions about his wife. The construction of people's identity in terms of their ordinariness as a means of providing epistemological support has been found in various studies of accounts of unusual social phenomena such as highjackings, shootings and paranormal experiences (see Wooffitt, 1992). By constructing his identity in this way, Mr Lawler makes his account more credible and thus provides the account with epistemological support.

Searching Stories

After telling a recognition story, some carers included in their accounts 'searching stories' which described their efforts and difficulties as they tried to find out what was happening to their relative. As with recognition stories, an important function of searching stories is to describe what has happened. In addition, searching stories allowed the various inferences to be heard about personal identity. Through these inferences, identities mobilised previously within pre-onset stories and recognition stories are reconstructed so that they have optimal rhetorical effect within the searching story.

Extract 4 is part of a searching story that describes Mrs Pritchard's contact with her husband's General Practitioner (GP). Mr Pritchard was in his early sixties and only mildly affected by dementia. It was quite possible to talk to him for some time without realising that he had any mental impairment.

Extract 4
(Case 15/2)
Interviewer: What did the doctor say to you at this time?
Mrs Pritchard: There was one time he did offer for him to
go to a brain scan two or three Christmasses
ago, and I couldn't get him there. But the
doctor gave me the impression, I wasn't
pleased actually, he gave me the impression
that it was probably a break-up of a marriage,
it was the time I thought about perhaps going
or something.
Interviewer: Did, I mean, I'm just thinking from the doctor's
point of view, or from the point of the other,
how do you think they knew who to believe?
Mrs Pritchard: Well.
Interviewer: You know what I mean?
Mrs Pritchard: Yes that is a worry, that is a worry, I did think of
that, but I thought he must of picked up something
from John, I mean he wouldn't tell me anything
about my husband due to confidentiality but why
would I go and see him and tell him these different

> things that was happening. I had also, this had also
> gone through my mind, whether there was something
> wrong with me, I went and checked up with all
> my friends, I kept saying am I ill or not, and they
> said no, it is John. I went to a counsellor through work,
> to see where I could get help, and she too went back
> and said it's your husband, he needs help.

In the extract, Mrs Pritchard describes her difficulties finding out from her husband's GP what was wrong with him. While Mrs Pritchard acknowledges that the GP had referred her husband for a brain scan and thereby sought a diagnosis (lines 2-4), she allows the inference that the GP is resistant to describing her husband as having an illness. This is achieved by Mrs Pritchard allowing inferences that the GP firstly, thought what was wrong the result of a marital problem and, secondly, was not prepared to tell her what is was wrong with her husband on account of his professional and moral responsibility to maintain confidentiality. Mrs Pritchard displays to the listener that she found neither of these explanations acceptable (lines 5-6 and lines 18-20).

Having failed to get a diagnosis from the GP, Mrs Pritchard continues her story by saying that she initially asked all her friends, people who might be expected to know Mrs Pritchard well, whether it was she or her husband who was ill (lines 22-24). Mrs Pritchard uses an extreme case formulation, 'all my friends' (lines 22-23), to suggest the large number of people whom she consulted and therefore the generalisability of her finding that it was her husband who was ill. She then describes how she went to a counsellor, someone who is culturally accepted as an expert in identifying disturbed behaviour (lines 24-26). Each of these two sources, she reports, told her that it is not she but her husband who is the one who needs help.

In terms of action orientation, the extract illustrates how searching stories can reconstruct the identity of family members initially constructed within pre-onset and recognition stories. In the extract, Mrs Pritchard identifies herself as someone who goes out of her way to find out what is happening to her husband. Moreover, she allows the inference that her husband is ill (lines 23-24) and that he needs help (line 26). By identifying her husband in this way, Mrs Pritchard resolves any ambiguity or confusion that might exist about who it is that is the problem. This accomplishment is particularly important since Mr Pritchard's symptoms are not particularly visible. In addition, by constructing her husband as someone who is in need, Mrs Pritchard mobilises the inference that her husband is dependent upon other people for some, at least, of his needs, while Mrs Pritchard maintains her identity as someone who has control over her life. The clear and unambiguous way in which the identity of the person with dementia and their informal carer is constructed corresponds to studies about other areas of social

life, notably marital disputes, which have found that identities such as the blameworthy party and the initiator of a divorce are similarly constructed through the use of language (Hopper 2001).

In terms of epistemological orientation, the identification of her husband as someone who is ill and needs help is accomplished through the use of reported speech. It is friends who told Mrs Pritchard that her husband was ill and a counsellor who told her that it was her husband needed help. This use of active voicing (Wooffitt, 1992) allows Mrs Pritchard to address the dilemma of stake that exists that might lead to the accusation that she is just saying these things to get back at her husband. Indeed, the plausibility of these accusations is made more likely through Mrs Pritchard's construction of her own identity as someone who has made great efforts to find out about her husband's condition. This identity might allow it to be heard that she is someone who goes out of her way to label her husband as someone who is mentally ill. If this inference were made available within the story, it would undermine Mrs Pritchard's identity as someone who would give a reliable accurate account. Thus, the use of active voicing provides a means by which a third party, rather than herself, may be heard as providing her husband with a socially disadvantageous identity. In this way, Mrs Pritchard resolves the issue of stake as it can not be claimed that she is deliberately giving her husband a socially disadvantageous label but rather that it is something that other people have told her.

Dependency Stories

After the relative is identified as having a problem, informal carers allow inferences relating to the increasing dependency of the person for whom they are caring.

In Extract 5, Mr Price is talking about his difficulties caring for his wife Alice who has severe dementia. In the interview, Mr Price talks about various aspects of the care he gives to his wife.

Extract 5
(Tape 17/1)
Interviewer: Yeah, in what way, how does it make
you feel?
Mr Price: Helpless.
Interviewer: Helpless?
Mr Price: Helpless, because I can't understand
what she's saying all the time, I'm not
sure whether I'm doing the right thing.
Interviewer: No.
Mr Price: I'm not sure whether
I'm getting for her what she
wants me to get her.

Interviewer: Yes.
Mr Price: And I feel when I'm trying to get her
dressed she doesn't co-operate like
a child would, you know, a child
would be flexible, when you're
putting its arm through a sleeve.
Alice's doesn't, she, folds it, you
know, holds it rigid, much more
difficult, and when I ask her
you know to, she'll get angry.

This extract was chosen because it shares features commonly found in the collected data. Immediately prior to the extract, Mr Price had been talking about an incident he had found difficult to deal with while caring for his wife. The extract begins by the interviewer providing a conversational space that enables Mr Price to talk about his feelings (lines 1-2). To clarify these feelings, Mr Price describes two situations that had made him feel helpless. The first situation was when his wife was saying something to him that he could not understand and made him unsure whether what he was doing was what she actually wanted (lines 5-7). The second situation was when his wife was resisting being dressed. In this latter illustration, Mr Price compares his wife to a child and suggests that his wife is even more resistant than a child (lines 13-21). Through these stories, Mr Price allows two inferences about his wife's identity. Firstly, she is someone who is difficult to help. And secondly, she is someone who is dependent upon her husband. Through these inferences, Mr Price constructs himself as someone who is acting without any expectation of reciprocation. In this way, the identities of family members previously established within the account are reconstructed in terms of dependency and informal care.

Discussion

The findings revealed that carers' accounts contained various forms of story. It was shown that these stories contained various conversational strategies that gave rise to the mobilisation of various identities relating to different family members. Through these stories, carers progressively transformed not only the way their own identity was constructed but also that of the person with dementia. While initially, family members did not identify the person with dementia as someone who was dependent other family members, the conversational strategies employed in the stories mobilised various inferences that refigured their respective identities in terms of the dependency of one family member upon another.

Askham (1995, p. 113), in a study of carers' accounts of relatives with dementia, raised the possibility that their use of language may not be transparent but rather that 'different accounts are used in different

contexts to achieve different ends'. The present paper supports Askham's comment and suggests that their accomplishment of informal care that occur as the result of their production and use of identities within their accounts.

This paper provides an alternative view of informal care to that offered by such writers as Atkin & Twigg (1996) and Nolan et al (2001). Whereas these studies give what Widdicome (1998) describes as 'an analyst's account' of informal care, the present study provides a 'participants' account' that carers use as a means of accomplishing informal care through the production and inferential use of identities. Whereas previous studies have been underpinned by realist interests such as uncovering a typology of informal care and describing carers' inner mental states, the concern of the present study is with the ways in which informal care is accomplished by participants.

To conclude, there are a number of issues that are worthy of attention that relate to the study's findings by setting them within a broader framework. Firstly, the findings reveal various strategies that give rise to the construction of identity within carers' accounts. In one sense, the identity of the carer and their relative is created out of meanings generated within accounts that are projected upon the social world. In another sense though, culturally available discourses set 'conditions of possibility' (Foucault, 1979) that make certain practices acceptable and through which the organisation of the social world occurs. In both these senses, language is understood to be performative and orientated towards social accomplishment. It is in this latter sense that Foucault develops his work on disciplinary society and the associated notion of governmentality (Dean, 1999). The study's findings may be understood in the light of theoretical and empirical work that has described the relationship between the family and the state in terms of the family's ability to control its members within the context of wider society (Donzelot, 1980; Nettleton, 1991).

Secondly, various writers (Dean & Thompson, 1996; Heaton, 1999) have pointed out that the notion of 'informal carer' has arisen since the mid-1970s through its availability within social policy documents such as '*Growing Older'* (HMSO, 1981) and more recently *'Caring about Carers'* (Department of Health, 1999). This present paper reveals the conversational processes through which the identities of family members are progressively refigured into informal carers. Through these processes, the identity of one family member is gradually transformed into someone who oversees and gives care to another family member while at the same time the identity of another family member is progressively identified as someone who is dependent.

Latimer (1998) argues that nurses use conversational processes to create identities as a means of moving their patients from one area of health care to another and from one geographical space to another.

Moreover, other studies have shown that contact with people whose identity relates to bodily changes, notably people whose bodies are dying (Lawton, 2000) or are pregnant (Longhurst, 2001) they are 'matter out of place' (Douglas, 1966, p. 35) and are therefore their presence is not acceptable in public spaces and results in them being located in hospices and places of confinement, respectively. Gilleard & Higgs (2000) have discussed how people with dementia have bodies are uncivilized and that, as with people who are dying or are pregnant, their bodies are out of place in public spaces. The findings of the present study suggest that similar social process may occur with people who have dementia. From this point of view, the construction of identities such as those found in the study gives rise to the movement of people with dementia in time and space, out of public spaces and into the private, family space of the home. This is not to say that people with dementia never go out into public spaces but rather that their presence in the social world is limited and that the preferred location is in the home. Moreover, the domestication of dementia care in this way brings about reliance upon the informal care of the family and the identification of one or more family members as informal carers. It would therefore be worthwhile to examine whether people whose minds are dementing and whose bodies are decaying encounter exclusion from public places and find themselves confined within the home. Furthermore, it would be worthwhile to examine the construction of identities associated with the relocation of people with dementia from their home to residential care and the extent to which people with dementia come to occupy a marginal position in society. Studies by Lawton (2000) and also Longhurst (2001) found that hospitalisation was associated with cultural notions of risk and the seepage of body fluids. It may therefore be that difficulties relating to the control of the uncivilised body of people with dementia is a significant factor in their admission into permanent residential care.

Finally, Potter (1996) develops the idea of 'fact construction' and argues that social phenomena are understood by hearers as factual through the rhetorical organisation of talk within the accounts that people give of everyday life. The findings of the present study reveal how informal carers construct their social world as factual through the organisation and management of their accounts. Thus, carers do not merely 'tell it as it is' but rather, construct social phenomena as factual as a means of addressing their social situation. This does not mean that carers deliberately manipulate the truth when they are talking about their relatives but rather that they skilfully and artfully use language to address issues they are presently encountering as they give care. For this reason, the paper provides an alternative epistemology than that which typically exists within studies of informal care and it is one that may be useful to educators when conveying something of the carers' world to adult learners.

Transcription Notation

(0.5) The number in brackets indicates a time gap in tenths of seconds.
( ) Empty parentheses indicate the presence of an unclear fragment on the tape.
: Colons indicate that the speaker has stretched the proceeding sound or letter. The more colons, the greater the extent of the stretching.

Correspondence

Trevor Adams, Lecturer in Mental Health, European Institute of Health and Medical Sciences, University of Surrey, Guildford GU2 5XH, United Kingdom (t.adams@surrey.ac.uk).

References

Antaki, C. & Widdicome, S. (Eds) (1998) *Identities in Talk,* Sage: London.

Askham, J. (1995) Making Sense of Dementia: Carers' Perceptions*, Ageing and Society,* 15, pp. 103-114.

Audit Commission (2000) *Forget Me Not,* London: The Audit Commission.

Dean, M. (1999) *Governmentality*, London: Sage.

Dean, H. & Thompson, D. (1996) 'Fetishizing the Family: The construction of the informal carer', in H. Jones & J. Millar (Eds) *The Politics of the Family,* Aldershot: Avebury.

Department of Health (1995) *Carers (Recognition and Services) Act*, London: HMSO.

Department of Health (1997) *A Handbook on the Mental Health of Older People,* London: HMSO.

Department of Health (1999) *Caring about Carers*, London: HMSO.

Department of Health (2001) *National Service Framework for Older People,* London: Department of Health.

DeLongis, A. & O'Brien, T. (1990) 'An interpersonal framework for stress and coping: an application to families of Alzheimer's disease', in M. Stephens, J. Crowther, S. Hobfoll, & I. Tennenbaum (Eds) *Stress and Coping in Later-Life Families*, New York: Hemisphere.

Donzelot, J. (1990) *The Policing of Families: Welfare Versus the State,* London: Hutchinson.

Douglas, M. (1991) *Purity and Danger: An Analysis of the Concepts of Purity and Danger*, London: Routledge.

Foucault, M. (1979) *Discipline and Punish*, Harmondsworth: Penguin.

Frith, H. & Kitzinger, C. (1998) 'Emotion work' as a participant resource: a feminist analysis of young women's talk-in-interaction, *Sociology,* 132(2), pp. 299-320.

Garfinkel, H. (1967) *Studies in Ethnomethodology,* Cambridge: Polity Press.

Gilleard, C. & Higgs, P. (2000) *Cultures of Ageing: Self, Citizen and the Body,* London: Prentice Hall.

Heaton, J. (1999) The gaze and visibility of the carer: a Foucauldian analysis of the discourse of informal care. *Sociology of Health and Illness,* 21(6), pp. 759-777.

Hammersley, M. (1991) *What's wrong with Ethnography*, London: Routledge.

Heritage, J. (1984) *Garfinkel and Ethnomethodology,* Cambridge: Cambridge University Press.

Hopper, J. (2001) 'Constructed selves in divorce proceedings', in J. Gubrium & J. Holstein (Eds) *Institutional Selves: troubled identities in a postmodern world,* New York: Oxford University Press.

Hutchby, I. & Wooffitt, R. (1998) *Conversation Analysis.* Cambridge: Polity Press.

Latimer, J. (1998) Organising context: nurse's assessments of older people in an acute medical unit, *Nursing Inquiry,* 5, pp. 43-57.

Lawton, J. (2000) *The Dying Process*, London: Routledge.

Longhurst, R. (2001) *Bodies: Exploring Fluid Boundaries,* London: Routledge.

Loos, P. & Bowd, A. (1997) Caregivers of Person's with Alzheimer's Disease: some neglected implications of the experience of personal loss and grief, *Death Studies*, 21, pp. 501-514.

Lowney, K.S. & Holstein, J.A. (2001) 'Victims, villains, and talk show selves', in J. Gubrium, & J. Holstein (Eds) *Institutional Selves: troubled identities in a postmodern world.* New York: Oxford University Press.

Jones, P. & Martinson, I. (1992) The experience of bereavement in caregivers of family members with Alzheimer's disease*, Image: Journal of Nursing Scholarship,* 24(3), pp. 172-176.

Kirsi, T. Hervonen, A. Jylha, M. (2000) A man's gotta do what a man's gotta do: Husbands as caregivers to their demented wives: a discourse analytic approach, *Journal of Aging Studies*, 14(2), pp. 153-169.

Nettleton, S. (1991) Wisdom, diligence and teeth: discursive practices and the creation of mothers, *Sociology of Health and Illness,* 13(1), pp. 98-111.

Miller, G. (1997) 'Building Bridges: The Possibility of Analytic Dialogue between Ethnography, Conversation Analysis and Foucault', in D. Silverman (Ed.) *Qualitative Research*, London: Sage.

Nolan, M., Grant, G. & Keady, J. (1996) *Understanding Family Care,* Buckingham: Open University Press.

Nolan. M., Davies, S. & Grant, G. (2001) *Working with Older People and their Families*. Buckingham: Open University Press.

Opie, A. (1992) *There's Nobody There*, Auckland: Oxford University Press.

Opie, A. (1993) Representations of Caregiving: the writing-up process. *New Zealand Sociology,* 8(1), pp. 1-20.

Parker, I. (1999) *Critical Textwork*, Buckingham: Open University Press.

Pollner, M. & McDonald-Wikler, L. (1985) The Social Construction of Unreality: a case study of a family's attribution of competence to a severely retarded child, *Family Process,* 24, pp. 241-254.

Pomerantz, A. (1986) Extreme case formulations, *Human Studies,* 9, 219-230.

Potter, J. & Wetherell, M. (1987) *Discourse and Social Psychology*, London: Sage.

Potter, J. (1996) *Representing Reality.* London, Sage.

Sacks, H. (1992) *Lecture Notes on Conversation.* Volumes, 1 & 2 (G. Jefferson, Ed.) Oxford & Cambridge, MA: Blackwell.

Saussure, F. de (1974) *Course in General Linguistics*, London: Fontana.

Smith, D. (1978) K is mentally ill: an anatomy of a factual account. *Sociology,* 12, pp. 23-53.

Taylor, C. & White, S. (2000) *Practising Reflexivity in Health and Welfare*, Buckingham: Open University Press.

Twigg, J. & Atkin, K. (1994) *Carers Perceived: policy and practice in informal care.* Buckingham: Open University Press.

Ungerson, C. (1987) *Policy is Personal*, London: Routledge.

Wetherell, M. (1998) Positioning and interpretative repertoires: conversation analysis and post-structuralism in dialogue, *Discourse and Identity* 9(3), pp. 387-412.

Widdicome, S. (1998) 'Identity as an analysts' and a participants' resource', in C. Antaki & S. Widdicome (Eds) *Identities in Talk.* London: Sage.

Widdicome, S. & Wooffitt (1995) *The Language of Youth Subcultures,* Hemel Hempstead: Harvester/Wheatsheaf.

Wilkinson, S. & Kitzinger, C. (2000) Thinking differently about thinking positive: a discursive approach to cancer patient's talk, *Social Science and Medicine,* 50, pp. 797-811.

Willoughby J. & Keating, N. (1991) Being in control: the process of caring for a relative with Alzheimer's disease. *Qualitative Health Research,* 1(1), pp. 27-50.

Wooffitt, R. (1992) *Telling Tales of the Unexpected: Accounts of Paranormal Experiences,* Hemel Hempstead: Harvester.

Wuest, J., Ericson, P. & Stern P. (1994) Becoming Strangers: the changing family caregiving relationship in Alzheimer's disease, *Journal of Advanced Nursing,* 20, pp. 437-443.