The Experience of Living With Dementia in Residential Care: An Interpretative Phenomenological Analysis

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Purpose: The subjective psychological experience of people with moderate to severe dementia living in residential care is insufficiently understood. In the present study we aimed to explore the subjective experience of life with dementia in residential care from the perspective of the person with dementia, and to understand the psychological impact of being in this situation. Design and Methods: This was an exploratory qualitative study. Eighty individuals with dementia who were living in residential care homes engaged in unstructured conversations with a researcher. We subjected the transcripts of the resultant 304 conversations to interpretative phenomenological analysis in order to develop a thematic account. Results: The experience of living with dementia in residential care was fundamentally one of experiencing difficult and distressing emotions relating to loss, isolation, uncertainty, fear, and a sense of worthlessness. Participants generally tried to cope by accepting and making the best of things and affirming their past sense of self and identity, but some also expressed frustration and anger. Implications: Participants were able to describe aspects of their situation and their emotional response to it, grounded in a strong retained sense of self and identity. The participants’ experience emphasizes the importance of improving the living situation of elders with dementia in residential care settings.

Key Words: Awareness, Coping, Identity, Quality of life, Self, Well-being

An accumulating body of evidence provides valuable insights into the subjective experience of living with early-stage dementia in community settings. We have known for some time that the subjective experience of people with moderate to severe dementia is less well delineated (Downs, 1997), although it is increasingly accepted that people in the middle to late stages of dementia retain the capacity for emotional expression (Magai, Cohen, Gomberg, Malatesta, & Culver, 1996) and many can reliably report aspects of their own experience, such as mood (Kolanowski, Litaker, & Catalano, 2002) or quality of life (Logsdon, Gibbons, McCurry, & Teri, 1999; Thorgrimsen et al., 2003).

Although the subjective meaning of aspects of living and dying in residential care has been explored in a number of studies (e.g., Gubrium, 1993; Kayser-Jones, 2002), these studies do not focus specifically on people with dementia. The experience of dementia has been widely explored in personal accounts and interview-based qualitative studies, but these have largely focused on people who have early-stage dementia and are living in the community. A number of personal accounts vividly describe the impact of developing dementia (Lee, 2003; Snyder, 1999; Taylor, 2006). Qualitative researchers have attempted to capture the essential elements of this experience. Steeman, de Casterlé, Godderis, and Grypdonck (2006) identified 28 qualitative studies published between 1990 and 2004 that merited inclusion in their comprehensive review, mostly utilizing variants of grounded theory (e.g., Harris & Sterin, 1999; Keady & Nolan, 2003; Menne, Kinney, & Morhardt, 2002) or phenomenological methods (e.g., Clare, 2002, 2003; Phinney, 2002; Phinney & Chesla, 2003).

Studies using direct accounts and interviews as a means of understanding the subjective experience
of living with moderate to severe dementia are rare. To date, the understanding of the experience of people with moderate to severe dementia is largely derived from observational and questionnaire-based studies. A number of observational studies provide an insight into the experience of life for people with moderate to severe dementia in residential care homes or hospital units (Barnett, 2000; Perrin, 1997; see also Brooker, 2005). Perrin found minimal levels of well-being and a lack of meaningful occupation. Lack of meaningful occupation was also reported by Cohen-Mansfield, Marx, and Werner (1992). Ethnographic studies describe a complex framework of social interaction, both verbal and non-verbal, among care home residents (Hubbard, Cook, Tester, & Downs, 2002; Hubbard, Tester, & Downs, 2003; Kontos, 2004). The extent to which selfhood or identity is preserved has been an important focus in many of these observational studies, with results suggesting that although the self is affected by dementia, manifestations of selfhood do persist even in severe dementia (Small, Geldart, Gutman, & Scott, 1998; Tappen, Williams, Fishman & Touhy, 1998), along with the capacity to develop positive and therapeutic relationships (Williams & Tappen, 1999). Questionnaire-based studies have also begun to address this issue; for example, recent studies have elicited information from residents, staff, and family members about residents’ occupational and family roles and preferred activities, concluding that aspects of identity were preserved even in severe dementia (Cohen-Mansfield, Golander, & Arnheim, 2000; Cohen-Mansfield, Parpura-Gill, & Golander, 2006a, 2006b).

A few studies have attempted to seek the perspectives of people with moderate to severe dementia on specific issues such as factors relating to quality of life and quality of care, or to use residents’ own accounts to address specific aspects of experience such as preservation of selfhood or the meaning of disturbing behavior. The need to consider multiple perspectives, including those of the residents themselves, has been emphasized in relation to understanding quality of life by Sloane and colleagues (2005) and by Edelman, Fulton, Kuhn, and Chang (2005). It has been suggested that residents with severe dementia show some awareness of cognitive decline alongside indications of preserved selfhood (Mayhew, Acton, Yauk, & Hopkins, 2001). Recurrent issues of loss, communication difficulties, frustration, and sadness, along with various attempts to cope, have been highlighted in several studies (Aggarwal et al., 2003; Barnett, 2000). Relationships and desirable social roles, for example being part of a family, seem central to the preservation of self, although the ability to create narratives about one’s life and past experiences is also important (Surr, 2006).

In their attempts to elicit the views of care home residents with dementia about the care they receive, researchers have identified dissatisfaction with lack of activities and social contact, and lack of choice and independence, as important (Aggarwal et al., 2003; Train, Nurock, Manela, Kitchen, & Livingston, 2005). Graneheim and Jansson (2006) described residents said to display disturbing behavior as feeling surrounded by disorder and trapped by restriction, leading to the conclusion that disturbing behavior could be seen as a way of communicating one’s story and maintaining a self within the residential care context.

Although these studies have provided valuable information, research on the experience of living with dementia in long-term care that is based on direct accounts from the person with dementia remains rare. Focusing on predefined constructs such as experiences of care, preservation of selfhood, or the meaning of disturbing behavior, although relevant and useful, provides a specific, delineated perspective shaped by particular research questions. In the present study, we aimed to take a broader approach to understanding the experience of living with dementia in long-term care, focusing in particular on people with moderate to severe dementia, by examining accounts elicited directly from the residents themselves. We set out to explore the subjective experience of life with dementia in residential care in a large sample of residents, to understand the psychological impact of being in this situation, and to develop a thematic framework for making sense of this experience that could contribute to improving quality of life and quality of care.

### Methods

For this exploratory qualitative study we used an existing data set, consisting of unstructured conversations between researchers and people with dementia living in residential care homes. EB and CS were involved in collecting the data between 1999 and 2001 in the course of a study of well-being in people with dementia living in residential care homes in England and Wales (Bruce, Surr, & Tibbs, 2002). The University Research Ethics Committee granted a favorable ethical opinion for the present analysis.

### Participants

The researchers held conversations with 81 people with dementia; 69 were women (85%) and 12 were men (15%). The participants resided in one of 10 residential care homes; these included 3 care homes specializing in the care of people with dementia (45 participants), 4 care homes for older people with designated sections devoted to the care of people with dementia (21 participants), and 3 homes catering to a mixed resident group (15 participants). The participants were aged between 59 and 96 years ($M = 83.4, SD = 8.2$). On entry to the study, the
participants’ scores out of a maximum of 30 on the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) ranged from 0 to 20 (M = 9.76, SD = 6.66). Over half of the respondents scored 11 or fewer points, and the modal score was zero. Thus, the participants could be described as having moderate to severe dementia.

We drew the participants from a wider study of well-being among people with dementia living in the 10 residential care homes, involving 94 participants. The researchers took the opportunity to record conversations with the subsample of 81 participants described here. They excluded the remaining 13 conversations with the subsample of 81 participants had moderate to severe dementia. The participants’ scores out of a maximum of 30 on the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975) ranged from 0 to 20 (M = 9.76, SD = 6.66; range = 0–19) from audio recording for the following reasons: they had little or no verbal communication (8 participants), they refused permission (1 participant), the researcher was unable to gain a clear agreement for audio recording (1 participant), or the researcher was unable to spend individual time with the participant (3 participants).

Conversations

The number of conversations recorded with each participant ranged from 1 to 8, giving a total of 307 transcripts. One participant with 3 transcripts (MMSE score = 0) was excluded because we could not distinguish any intelligible words in the participant’s communication. The final data set for analysis therefore consisted of 304 conversations (number of conversations per participant, M = 3.43, SD = 2.22; range = 1–8) with 80 participants (MMSE score, M = 9.76, SD = 6.66; range = 0–20). The conversations were unstructured and largely led by the participants themselves. Thus, participants did not respond to a standard set of questions. Equally, the number of recorded conversations varied between participants for a variety of reasons (e.g., at the time of the researcher’s visit a participant may have been unwell, occupied with other visitors, unwilling to talk, or asleep). Alongside the conversation transcripts, field notes made by the researchers and contextual information derived from records kept by the residential homes were also available for consultation. We used these, for example, in those instances in which we needed clarification of events mentioned in the transcripts.

Data Analysis

We conducted an interpretative phenomenological analysis (IPA) of the transcripts to produce a thematic account and interpretative model of participants’ subjective experience of living with dementia in residential care. IPA, which is rooted in philosophical traditions of phenomenology and symbolic interactionism, explores lived experience and the way in which individuals make sense of their experience by focusing on the internal psychological meanings evident in their accounts (Smith, Jarman, & Osborn, 1997; Smith & Osborn, 2004). IPA is descriptive in the sense that it seeks to identify individual perceptions and develop a credible account of subjective experience, but it is also expressly interpretative, acknowledging that any account will also contain elements of interpretation on the part of the researcher. Thus, IPA draws on both descriptive and hermeneutic traditions within phenomenology.

We conducted the analytic process with the assistance of QSR International’s NVivo 2.0 software for computer-assisted data analysis (QSR International, Doncaster, Victoria, Australia). The analysis proceeded in the following way (see also Quinn & Clare, 2008; Smith, Osborn, & Jarman, 1999). First we analyzed each transcript individually. Having become familiar with the transcript through reading and rereading, we identified key points through a detailed line-by-line coding. We then listed all the key points and clustered them into groups reflecting initial emerging themes, and we recoded the transcript according to these themes. Once we had analyzed all transcripts in this way, we proceeded to the group-level analysis. We compiled a list of all emerging themes across all transcripts, and we clustered these into groups on the basis of similarity and overlap. We further refined the resulting groupings in a process resulting in the identification of the main themes, with each main theme comprising a number of subthemes. We labeled themes and subthemes as far as possible by using participants’ own words, through the selection of a representative quotation. We then recoded all transcripts according to this list of themes and subthemes, and we listed all relevant extracts under each thematic heading. This formed the basis for the thematic account presented here, which outlines the four main themes identified in the analysis.

We attempted to maximize the credibility and trustworthiness of our account (Elliott, Fischer, & Rennie, 1999; Yardley, 2000) in three main ways. First, an independent researcher analyzed 15% of the transcripts, followed by discussion, so that we resolved any differences through consensus. Second, we sought reactions to the results from relevant groups. We held focus groups for care workers in residential homes, family carers of people with dementia, and professionals in dementia care, and we held individual discussions with people who have early-stage dementia. Finally, in presenting the results, we have illustrated our account with relevant extracts to demonstrate that the results are grounded in the data (Whitemore, Chase, & Mandle, 2001). In addition, although IPA studies do not typically report quantitative data, such data can make an important contribution to the interpretation of meaning in qualitative accounts (Sandelowski, 2001). We have sought to demonstrate the rigor of our analysis.
by presenting, for each theme and subtheme, details of the frequency of occurrence, the number of participants involved, and the mean number of statements relevant to that theme per participant conversation. We have also considered the relationship between the number of themes represented in individual participants’ accounts and the participants’ level of cognitive functioning, as indicated by their MMSE scores.

Results

The experience of living with dementia in residential care was eloquently conveyed in many of the conversations. In total, of the 80 participants, 71 individuals (MMSE score, $M = 10.54$, $SD = 6.45$; range = 0–20, modal score 0; see Figure 1) with 283 conversations (per participant, $M = 3.99$; range = 1–8) spoke about aspects of their subjective, psychological experience and thus contributed data to the thematic analysis. Of these 71 participants, 34 lived in care homes specializing in the care of people with dementia, 20 lived in care homes for older people with designated sections devoted to the care of people with dementia, and 17 lived in homes catering for a mixed resident group. The remaining 9 participants did not talk about the nature of their subjective experience, and when analyzing their transcripts we did not find any material that shed light on this issue. These 9 participants had a mean MMSE score of 3.56 ($SD = 5.1$; range = 0–14) and represented a total of 21 conversations (mean per participant, $M = 2.33$; range = 1–7).

We identified four main themes, reflecting the emotional stances taken by participants in relation to their lives in residential care. Participants contributed to at least one, but usually several, of the themes. The four themes, labeled in the participants’ own words (with prevalence rates among the 80 participants given in parentheses), were as follows: “Nothing’s right now” (89% of participants); “I’m alright; I’ll manage” (76% of participants); “I still am somebody” (76% of participants); and “It drives me mad” (48% of participants).

The themes and associated subthemes are summarized in Table 1, together with details of the frequency with which they were identified. The association between the number of themes identified for each participant, the number of conversations held, and the level of cognitive functioning as indicated by the MMSE score is summarized in Table 2. The number of conversations held did not differ significantly according to the number of themes identified, $F(4, 75) = 1.063$, ns, but MMSE scores did differ significantly according to the number of themes identified, $F(4, 75) = 5.125$, $p = .001$, indicating that participants for whom fewer instances of themes were identified tended on average to have lower MMSE scores. We conducted a further analysis for the theme “It drives me mad.” There were no significant differences between participants who did and did not contribute to this theme in terms of age ($t_{69} = 0.404$, ns) or MMSE score ($t_{69} = 1.789$, ns), although there was a trend toward higher MMSE scores in the group who did contribute (score for contributors, $M = 11.69$, $SD = 5.51$; score for noncontributors, $M = 8.95$, $SD = 7.08$).

Next we describe each of the themes in turn, supporting our description with illustrative extracts.

Nothing’s Right Now

This theme conveyed a sense that the participants’ psychological experience was characterized to a considerable extent by suffering, with expressions of distress centered on feelings of uncertainty, loss, isolation and loneliness, fear, and worthlessness.

Participants felt uncertain about why they were in the home in the first place, what would happen while in the home, and how long the arrangement was meant to last. As one participant said, “Well, I don’t know what they’re going to do with me in here, but they haven’t said what they’re doing, [and] I don’t know why they’ve put me in here...”(BG06). Another said, “I don’t know why they’ve put me in here...”(GR03).
explained that he “...used to see football and things like that, you know. ...But lately it’s been drifting away. I dunno why, but it’s just drifted away like, you know. ...I used to be er...a bloke that knew different things and all that, you know. ...I’ve lost it. ...Really lost it ... and er, I don’t do like I used to” (MB05). One participant said that “Things you like to remember, you can’t remember, and things that you can remember easily drift away in front of you” (CG03).

The result was a degree of unhappiness, with feelings of isolation and alienation amounting for some to real suffering. One participant said that “It isn’t a very happy life” (CB04); another exclaimed, “I’m so lonely here. I don’t know what’s the matter with me, and what’s the matter... why people don’t talk to me much. I feel to be an outsider...” (AL04). One participant explained that “You just wish you didn’t have to come in here. ...I just wish my family would show up now and again” (GR07). Another stated, “I feel I’m not attached to me family” (FP05).

For a few participants, the sense of isolation contributed to feelings of fear and terror, which were sometimes extreme. One participant begged, “Please help me to know. ...I’m frightened. ...Please help me. Please help me. I’m

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<th>Table 1. Prevalence of Themes and Subthemes</th>
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<td>Theme</td>
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<td>1. Nothing’s right now</td>
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<td>4. It drives me mad</td>
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Notes: CP = contributing participant.
For sample percentage, n = 80. The mean number of conversations per participant = 3.43, calculated for the number of participants expressing the given theme or subtheme.

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<th>Table 2. Number of Themes Expressed in Relation to the Mean Number of Conversations Held and Mean MMSE Score</th>
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<td>Conversation No.</td>
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<td>Total sample</td>
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Notes: MMSE = Mini-Mental State Examination.
Theme number refers to the number of themes represented in the conversations.
frightened. I’m frightened of it. … I’m really frightened, you know … of being alone, I’ve no one here at all” (GW02). Another asked, “Don’t lose me, will you? Please don’t lose me” (WG05). Not surprisingly, a sense of worthlessness was also prevalent: “It’s all a lot of rubbish, and I’m a lot of rubbish now” (WW02).

There was a sense of being unable to contribute in a useful way as one had done in the past. At times when better ways of coping failed to come to mind, the situation simply had to be endured, as there seemed to be no alternative: “You have to bear it. … I don’t really like being here. You know, it’s a sort of community, isn’t it. … And I don’t like it. But what can I do? I don’t know what to do. … I’m an old woman and nobody wants me. I mean, that’s the case, nobody does. If I was wanted by anybody, I’d go, and I could be quite useful. But nobody knows that I want a job” (GW02).

The experience of living with dementia in residential care, for our participants, was essentially one of living through a difficult situation over which they had little control, and suffering the resulting thoughts and emotions. However, most participants found constructive ways to cope, and this is reflected in the next two themes.

I’m Alright, I’ll Manage

This theme, the first of two that focused on ways of coping with a difficult situation, emphasized active attempts at acceptance, involving making the best of things, valuing the contacts and friendships that remained possible, letting go of worry and anxiety, and coming to terms with getting older. Although they felt that the residential care setting was not ideal, and could seem impersonal, it was possible for some to try to make the best of it, trying to be satisfied or finding ways of being useful. As one resident said, “It’s not as nice as I’d like it to be but I have to be … satisfied with small things these days” (GR06). Another explained: “I wouldn’t say it was as good as home, like… er … you haven’t got that same feeling or love or anything is… a … at a place like this. You’re just … one of a number, group, who are pretty well in a similar position… but you do your best and… give as much help. I’ve been sorting books out all morning” (CB04). One resident said, “I haven’t got to… do any shopping, I haven’t got to cook any meals, and that’s a lot, isn’t it. … You’ve gotta get used to it, haven’t you?” (CB01). In this way it could be possible to achieve a degree of contentment: “I never thought I’d come to a place like this but I’m quite happy” (BG06).

Perceiving other residents as generally friendly, even if one did not know them well, and feeling to some extent accepted by others, seemed crucial, demonstrating the importance of positive social contact: “Well, I’ve just gone on day to day and I’ve been quite happy here. People are all quite friendly”. (BG05). One resident said, “But er … it’s the people, you get to know them. I didn’t at first. I’m not very good at, you know, getting to know people. I’d rather do without knowing them, you know, you know what I mean. But they have been friendly, it’s been nice. And I think I’ve got in, at last. I hope I have, anyway” (CG01).

Having a particular friend within the home made a great deal of difference. One participant said, “I’ve got a pal; she helps me out” (MP01). Contact with family members was also central for some residents in enabling a sense of acceptance; one resident said this about a family member: “I only see her about once a week, but then again … I’m wondering if she’ll be coming today” (MB07). However, an attitude of acceptance involved the notion that younger family members had their own lives and could not be expected to devote much time to visiting the home. One resident said, “I don’t want them to think that they’re putting themselves out for me, because it’s, you’ve had, I’ve had my life and it’s not fair to take other people’s lives away from them.” (BG06). Another explained that “They’re not fair to take other people’s lives away from me, because it’s, you’ve had, I’ve had my life and it’s not fair to take other people’s lives away from them.” (BG06). Another explained that “They’re very good, but you know what I mean, you can’t be expecting ‘em to come to you all the time, can you?” (FP01).

Finally, integral to acceptance was an acknowledgement of getting older and its implications: “Time marches on, doesn’t it. … I think, ‘Oh well, all the while I’m well enough to keep going I’ll k’ keep going.’ And that’s it” (GR03). As one resident said, “Oh well. … it’s alright, lovey, I’m not. I’m not complaining at all. I mean, I’m getting older. You accept that, don’t you?” (GR04)

I Still Am Somebody

This theme, again perhaps reflecting a way of coping with a difficult situation, conveyed a sense of pride in oneself and one’s life, reflected in affirming one’s own sense of identity. The psychological experience was one of pride in one’s origins and family, appreciation of the chance to review one’s life, a degree of nostalgia for the past, a sense that achievements were still possible, a sense that one was managing well despite limitations, and feeling sorry for those less well off than oneself.

Looking back over one’s life and reliving past events could be a pleasurable experience, compensating to a degree for current losses. One resident made this statement: “I can remember all those things, you see, and they come back, and I know I can’t do them now, but er if I think about them I’m sort of living them again, if you know what I mean. So that’s nice really” (BG06). There were good memories of childhood and adult life, carrying a sense of one’s position in the world: “Well, I was respectfully brought up by me parents, and I had
brothers and si’, a brother and two sisters, so it was quite nice” (TM03). Hope for the future could be sustaining, whether or not the prospect of change was realistic: “I used to do a lot. . . . I may get back to it. And especially if we get a nice, er. . . spring, sort of thing, it might be better for me” (BG03).

At the same time, reflecting on current abilities led to a sense of gratitude for the things one believed one could still do, as well as a determination to continue. One resident explained, “I’m th . . . thankful for what I can do, you know what I mean, I won’t give in” (FP01). Another stated, “I can do everything I make up me mind to. . . . I read all, well, when I can get hold of a book, I read all the time, dear. . . . I’ve always read. Ever since I was old enough to learn to read” (GW01). For some, there was a sense that all things considered they were doing very well: “I’m marvelous considering, aren’t I?” (FP01). One resident explained, “I’ve b’ been surprised f’ me age what I could do, and . . . I think me brain’s kept fairly sensible too. . . . Sometimes you do silly things, don’t you…” (GR02). Another said, “Well, I ebb and flow a bit because I’m older and I’ve had heart trouble for years, so I think really I do ever so well. . . . I’ve got no complaints at all. Yes. I feel that I do very well” (GR04).

Another aspect of affirming one’s own identity and worth involved commenting on, and feeling sorry for, others who were perceived as less well off or as lacking family relationships. One resident explained, “I’m not . . . I’m not the kind of a person, I . . . I can do with me own company, which is something, and I think . . . a lot of people can’t do with their own company, I don’t know why because it must be very awful if they come to be on their own and there’s nobody there but themselves and they, it must be terrible must that. . . . It must be very sad for people who haven’t any family” (BG06). Another exclaimed, “There’s another one. That poor woman, you don’t know what she’s been through” (MG05).

Although many participants found constructive ways of coping with their situation, for some there were times when this gave way to anger and frustration, and this is reflected in the final theme.

It Drives Me Mad

This theme, in contrast to the two previous themes, reflected frustration and anger at the nature and implications of the current situation. Participants complained that they felt confined and wanted more independence. The psychological experience was one of boredom, of annoyance with others, including staff and residents, and of frustration with oneself.

There were complaints about the dullness and boredom of life in the care home, and the lack of activity. One participant said, “I’d rather be doing something, yes, al . . . although I . . . I . . . I . . . there’s not a lot I can do, I’m capable of doing” (AL03). Another said, “What’s making me drum? The lack of life” (CG03). One noted, “I get bored here . . . they, they go to sleep, I feel like throwing something at them, because they, nobody talking or got nobody goes walking. . . . It’s, you’ve gotta do something, haven’t you, to help you go through, because it wasn’t the things I’ve been used to. . . . They just sit here, it drives me mad” (MB03).

For some, there was a desperate longing for freedom. One resident stated that “I want to be free . . . or die. I don’t mind dying but I don’t want to be . . . coddled here” (GW02). Another said, “I . . . hopes that I’ll be, get loose one of these days” (AL06). For others, living with a group of other people who all had their own difficulties could be stressful, irritating, frustrating, or distressing: “Gets on your wick sometimes; I feel I . . . I could blow it up” (CB04). Indeed, the behavior of other residents could be hard to tolerate. One resident noted, “They do shout, don’t they?” (BG05). Another explained, “I’ve had everything, everything pinched this morning” (MP01). Yet another said this about a fellow resident: “She did. . . drive you crazy like. I mean, you don’t mind being with her and helping her, but all that rubbish you talk . . . .” (CG01).

In summary, the experience of living with dementia in residential care was largely characterized by the sense that “nothing’s right now,” with prominent feelings of loss, isolation, uncertainty, fear, and worthlessness. Participants often managed to find ways of accepting the situation and affirming their identity, emphasizing that “I’m alright; I’ll manage” and that “I still am somebody.” However, anger sometimes emerged, with the sense that the situation “drives me mad” by provoking feelings of confinement, boredom, irritation, and frustration.

Discussion

Although a number of studies have provided insights into what it may be like to live with moderate to severe dementia, the inner psychological meaning that people with moderate to severe dementia living in residential care ascribe to their experience has been directly explored through participants’ own accounts only to a limited extent. To the best of our knowledge, our findings contribute the first detailed interpretative phenomenological account of the subjective, psychological experience of living with moderate to severe dementia in residential care based on participants’ own descriptions. The thematic account conveys a powerful impression of participants’ psychological experience, highlighting four interrelated stances as central to this experience. For most of the participants, daily experience was shaped by the losses resulting from dementia and was characterized to a considerable degree by distressing thoughts and feelings. Many
participants acknowledged positive aspects of the care they received, but some indicated that living in a home was an unwelcome development in their lives. The participants tried to endure the challenges of living with dementia in residential care with good grace, bringing to bear a number of constructive coping strategies, but some found the situation confining and frustrating.

The psychological impact of being in this situation was characterized by uncertainty and lack of control or self-determination. This was compounded by multiple experiences of loss, as described also by Barnett (2000) and Cohen-Mansfield and colleagues (2000). Some elements of loss were related to the direct effects of dementia, for example in terms of memory problems; this is consistent with reports by Aggarwal and associates (2003) and Mayhew and colleagues (2001). This could lead to feelings of being worthless, useless, or unwanted, as also noted by Cohen-Mansfield and colleagues.

There were some expressions of extreme fear and terror, relating particularly to the fear of being alone or being “lost.” Granneheim and Jansson (2006) describe this as reflecting a loss of involvement and exclusion from relationships and activities, while also being confined; this amounts to what they call “homelessness.” However, through their accounts, the participants emerged as agents actively seeking to cope with their situation. Many found ways to fit in and contribute, focused on the positive aspects of being in the home, and rationalized the dearth of family contact by limiting their expectations. Positive relationships with others were often crucial in maintaining a sense of well-being, a factor that was also identified as important by Surr (2006), Granneheim and Jansson, and Hubbard and associates (2003). The absence of positive relationships contributed to feelings of distress.

Although participants displayed many constructive ways of coping, the effects of changes resulting from dementia, coupled with the context of institutional care, placed limitations on their expression of personal agency. Consequently, there were some expressions of frustration and anger. Participants complained of boredom caused by a lack of activities; this factor was also identified by Train and colleagues (2003) and Aggarwal and associates (2003) and was confirmed in observational studies (Perrin, 1997; Ballard et al., 2001). The lack of freedom and independence was experienced as restrictive by some residents; indeed, this was identified by Granneheim and Jansson (2006) as a factor contributing to “disturbing” behavior. In line with Hallberg, Holst, Normark, and Edberg (1995) and Aggarwal and associates, we found that residents’ conversations were mainly brief, task focused, or superficial, with little scope to explore feelings. Communal living could be difficult, with the behavior of other residents causing annoyance or distress. This was also noted by Hubbard and colleagues (2003) and by Granneheim and Jansson. Thus, although the task of living with dementia in institutional care could often be managed, it could at times be experienced as deeply frustrating and annoying, provoking an emotional resistance.

The negative aspects of institutional care have long been recognized (Goffman, 1961). It is sometimes assumed that these are of limited importance because people with dementia lack awareness of their situation, but evidence from our participants’ accounts suggests otherwise. There is an urgent need to improve the quality of dementia care in residential settings (Ballard et al., 2001). Our participants’ accounts indicate that a central focus for improvement would be the extent to which residents are engaged in appropriate activity and occupation (cf. Cohen-Mansfield et al., 1992, 2006a, 2006b); similarly, it would be important to find ways of supporting the continued expression of agency and of maximizing autonomy. Alongside this, participants’ descriptions of difficult and distressing emotions, and in some cases of the challenge of adjusting to communal living, highlight the importance of genuine staff–resident relationships that can result in sensitive responses to individual emotional needs (see also Wellin & Jaffe, 2004). This suggests that, in care planning, emotional, occupational, and social care should be given as much priority as physical aspects of care. On the basis of the findings described here, residential homes might usefully focus on developments in the following areas.

First, provide more opportunities for conversation with conversational partners who are able to sustain meaningful interaction, and offer basic training in the necessary skills to staff, volunteers, and family members. Second, support agency by offering choices, encouraging as much independence as possible, offering information, and consulting residents about their wishes and preferences. Third, provide care in a way that takes emotional experience seriously and offers support for difficult feelings, thus helping to contain anxiety and provide a sense of safety, security, and reassurance, and recognizing the need for attachment and the possible importance of continuing bonds with deceased family members. Fourth, maintain continuity by supporting role identities, engaging with residents’ life stories and past memories, promoting opportunities to feel useful and helpful, and encouraging a sense of continued social roles. Fifth, alleviate boredom and feelings of worthlessness by encouraging and facilitating appropriate and meaningful activity and occupation, helping to promote remaining abilities and identify ways of substituting or compensating for loss of abilities. Sixth, encourage a sense of community and belonging within the home by facilitating the development of friendships among residents, for example by introducing residents to one another repeatedly and engaging them in group activities, and supporting the development of positive attachments to staff. Seventh, remain sensitive to the difficulties and demands of
living a public or semipublic life in an institutional setting alongside people whose company one has not chosen, working with residents to manage difficult relationships, offering opportunities for quiet and privacy, and supporting those who find communal life difficult because they are not outgoing or gregarious.

It is important to acknowledge that the nature of our sample and our data set places some limitations on our findings. The participants’ accounts were elicited in unstructured conversations, which were designed to place minimal demands on participants but offer them the space to share their thoughts and feelings. Future studies could explore the use of semistructured interviewing techniques alongside the more open-ended approach adopted here. Not all participants made reference to their subjective, psychological experience in the conversations, but the majority did, and it should be noted in any case that ours was an exceptionally large sample for an IPA study. In this account we have included quantitative data on the prevalence of themes and contributing subthemes within the participants’ accounts (Table 1), and on the relationship between level of cognitive impairment, as defined by MMSE score, and the extent to which participants expressed issues relating to the identified themes (Table 2). This indicated that, on average, greater cognitive impairment tended to be associated with more limited responses, although having a low MMSE score did not preclude an extensive contribution, as some participants with MMSE scores of zero were represented under all four of the main themes. However, in view of the research design, one should exercise caution in attempting to interpret the quantitative information.

The extent to which participants disclosed their thoughts will also have been influenced by their relationships with the researchers. However, we have considered possible influences resulting from the researchers’ prior expectations, relationships with participants, and interaction with the data and resulting interpretations, and we have taken a number of steps to maximize the credibility and trustworthiness of the findings (Elliott et al., 1999; Yardley, 2000). We do not seek to generalize our findings to all residents with dementia; for example, all our participants by definition were able to communicate verbally, so we cannot draw any inferences about those residents who have little or no speech. Similarly, we cannot comment on the experience of people with moderate to severe dementia living in the community. Our participants’ experiences will have been shaped by the challenges of living with dementia and by the specific context of residential care, and it is not possible to distinguish the specific impact of each of these two factors. Nevertheless, through a rigorous process of analysis, we have identified key elements of the subjective experience described by 71 individuals with moderate to severe dementia living in residential care homes; we have identified a framework for understanding this experience that may be helpful for practitioners and policy makers as well as researchers; and we have enumerated some practical implications of the results.

Conclusion

The present study adds a new dimension to our understanding by conveying a thematic account of the subjective psychological experience of living with moderate to severe dementia in residential care from the perspective of the person with dementia. It demonstrates that participants were able to describe aspects of their situation and present a very understandable emotional response to it, grounded in a strong retained sense of self and identity. The participants’ accounts of their experiences emphasize the importance of improving the living situation of elders with dementia in residential care settings.

References

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