Seeing oneself as a carer in the activity of caring: Attending to the lifeworld of a person with Alzheimer's disease

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Abstract
In this paper, I show that the notion of lifeworld is central to phenomenology, and that (in particular) it is only in our reflection on the lifeworld that we have a grasp of our selves. If this is so, it provides an approach to the task of caring. In hard instances, such as caring for the person with Alzheimer’s disease, the main difficulty is one of sociality—to see the patient as a person. A suggested answer is that a carer who tries to grasp the lifeworld of the patient may be enabled to see the personhood of the patient, to have their own project of caring thereby enhanced, and (on reflection) to see themselves as a carer in the activity of caring.

Key words: Alzheimer's disease, phenomenology, lifeworld, caring, respect, patient experience.

Introduction: a rehearsal of the history of intentionality
The qualitative researcher who wishes to get “qualitative research out of the doldrums” must insist that it is not sufficient to define their work in terms of technique (the use of qualitative data or a qualitative approach to analysis); nor should they be stuck at the level of theory or method (where a researcher might say, I am following the procedures of symbolic interactionism, or discourse analysis, or phenomenological human science), but that they should always have regard for the methodological level, the paradigmatic level, the level of awareness of epistemology and ontology. In this paper, then, we start with some basic ontological and epistemological debates of phenomenology and frame our research in that context.

The challenge of dualism
The distinction between the mental and the material world, which is so woven into western languages and thinking, is such a major problem that I am surprised that discussion of it does not occupy a large slice of any undergraduate programme in the human, caring and psychological sciences. (I shall say “human sciences” from now on for short.) It is odd, is it not, that we discuss perception continually without any attention given to the two elements of the process of perception—the mentality of the perceiver and the material thing perceived. It is odd, is it not, that we discuss “psychosomatic medicine” with no attention at all given to the two elements of the term “psychosomatic”—the mind and the body. We are happy to think of caring as being “holistic”, without wondering how the different elements of the person, the mental and the physical, are to be considered together.

Dualism, if true, would mean that the human sciences would have to cover two incommensurable kinds of being: material facts (occupying space; having a location in the physical world) and mental experiences (not located in this way, and accessed solely by their ‘owner’). As soon as human reality is considered in this dualistic way, there is a problem of how to relate the mental and the physical. Each theoretical approach to the human sciences has to take a position on the question of the mental and the material world.
One way of solving the problem is the one embraced by the behaviourist B F Skinner (1964; 1993) and others. Behaviourism achieves monism by “bracketing” the question of mind and consciousness, and claims that everything that the human sciences must deal with can be covered by behavioural concepts. There is no need for “mentalist” concepts—concepts to do with experience and the mind. Instead, our material behaviour within the material environment is sufficient to account for everything of interest to the human sciences. Skinner writes:

Our increasing knowledge of the control exerted by the environment makes it possible to examine the effect of the world within the skin and the nature of self-knowledge. It also makes it possible to interpret a wide range of mentalistic expressions . . . Some can be ‘translated into behaviour’, others discarded as unnecessary or meaningless. (Skinner, 1993, p. 17.)

Therefore, everything becomes a material response to a material stimulus—and is explicable in terms of the organism’s objective history of reinforcement. This is a kind of positivism, of course. However, Lewis (1982) reminds us of our own inner experience—the very thing that behaviourism omits. We must remember the actuality of our personal experience:

[If the separate reality of my experience is denied], I can only confess complete mystification; if my opponent tells me that his . . . thoughts and mine are open to inspection in the same way as we observe external things, I know not how to answer him. For what he affirms is in the most direct contradiction to what myself find to be the case in having thoughts and sensation of any kind, or any experience. (Lewis, 1982, p. 9.)

Skinner’s approach to the dualism, which Lewis so strongly asserts here, is to set aside consciousness for all scientific purposes (though he can talk of us being conditioned to be “aware” of certain things—by which he means that we can be behaviourally affected by them, we respond to them). We have a curt response to Skinner’s kind of thinking from the phenomenologist Maurice Merleau-Ponty (1962, p. ix):

Scientific points of view, according to which my existence is a moment of the world’s, are always both naïve and at the same time dishonest, because they take for granted, without explicitly mentioning it, the other point of view, namely that of consciousness, through which from the outset, a world forms itself around me and begins to exist for me.

How can we find an approach to human science that allows a proper place to experience and yet does not attract the difficulties of dualism?

The phenomenological reduction

What if, instead of adopting Skinner’s way of dealing with dualism, we take the opposite line and start with conscious experience? Instead of taking the material world as the starting point and regarding mental matters as deriving from it, we begin with our experience of the world, and see where that gets us in dealing with the things the human sciences are interested in. This move—“bracketing reality” (a move referred to as the epoché) and dealing only and entirely with experience – is called the phenomenological reduction. It seems a simple matter—set aside the question of whether what is experienced is real or not, and to attend simply to the experience as it is given to consciousness. In research practice this is complex and hotly debated (Ashworth, 1996). Consider a qualitative research interview in which the researcher is trying to adopt the phenomenological approach. What is to be sought is the interviewee’s experience—not ‘reality’. Nevertheless, it is the interviewee’s experience that is sought, not the experience of the researcher, nor the accumulated knowledge of scholarship. These, too need to be set aside. It is sometimes argued that the epoché is not possible and should not be attempted, but this is a counsel of despondency. It is definitive of phenomenological work that the epoché be attempted – first of all bracketing the link between the realm of experience and the realm of reality and then bracketing the presuppositions which cloud our description of the phenomenon in its appearing.

Consciousness as intentional

(a) Intentionality is a relation between consciousness and its object. Turning from objective reality to experience as such, we discover intentionality, that is, the fact that experience is about something, or directs itself towards something. However, there is a history of debate concerning how intentionality is to be characterised, and this question is of central interest to the human sciences. Brentano (1995) regarded immediate experience as a process or act, and different kinds of experience are to be distinguished by the particular ways in which consciousness relates to the object of experience.
Every mental phenomenon includes something as an object within itself, although they do not all do so in the same way. In presentation something is presented, in judgement something is affirmed or denied, in love loved, in hatred hated, in desire desired and so on. (Brentano, 1995, p. 88.)

It is clear that, by the phrase ‘mental phenomenon’, Brentano meant only the conscious phenomenon. Different kinds of conscious phenomena (remembering, experiencing emotions, perceiving, thinking and so on) are distinguished by the particular way in which consciousness relates to the object of experience. Judgment and perception, for instance, each involve a different orientation to the object. The definitive feature of conscious activity for Brentano was its intentionality. “All consciousness is consciousness of something”. There is a research task in delineating the various ways in which consciousness could relate to its objects. To describe a particular act of awareness we must describe both the mental orientation to the object of experience and the object of experience itself.

(b) Intentionality is a non-dualistic feature of experience as such. Husserl (1983) refined Brentano’s statement of intentionality, for Husserl believed that, as stated by Brentano, it could be misunderstood as picturing the world as divided into the “outer” reality and its “inner” correlate. In other words, it was in danger of re-establishing the dualistic ontology that phenomenology sets out from the start to set aside or bracket. Husserl tells us:

[N]othing is accomplished by saying... that every... judging relates to something judged, etc... For without having seized upon the peculiar ownness of the transcendental attitude [the focus on consciousness] and having actually appropriated the pure phenomenological basis, one may of course use the word, phenomenology; but one does not have the matter itself. (Husserl, 1983, §87, p. 211.)

How is it that Brentano’s account of intentionality does not reach the phenomenological approach proper? Husserl writes emphatically:

...[I]t should be well heeded that here we are not speaking of a relation between some psychological occurrence—called a mental process—and another real factual existence—called an object—not of a psychological connection taking place in Objective actuality between one and the other. Rather we are speaking of mental process purely... (Husserl, 1983, §36, p. 73.)

Husserl is clear here that both the ‘mode of consciousness’ (for example, judging) and the “object of this consciousness” (the judgement and the thing judged, etc.) are within personal experience. The mental orientation to the intentional object he called the “noesis”, and the object of awareness itself he called the “noema”. Doing phenomenology is to describe the experience of the thing we are interested in, in its appearing to us, just as given.

(c) Intentionality is a fact of our activity in the world (“comportment”). Heidegger (1982) provided a development of Husserl’s version of intentionality, which is of great consequence. For, as well as asserting that noema and noesis are both aspects of experience rather than a relation between the mental and the material, he also dismisses the distinction between them. Though noema and noesis are analytically separable, they are never actually apart in experience. He emphasises further the fact that the meaning of the noema is not simple but embedded in the full, lived context. So the thing judged or the thing perceived is judged or perceived within the whole web of meanings that it has for us in lived experience. More than this, not only conscious experience has an intentional character; our every action (our total ‘comportment’) is built on a set of assumptions about our world:

... the Dasein’s comportments have an intentional character and... on the basis of this intentionality the subject already stands in relation to things that it itself is not. (Heidegger, 1982, p.155).

The use of the notion of comportment is tied in with the idea of the Dasein (approximately “human being”) as “being-in-the-world” in the sense of being already, before everything, a participant in the world—physical actions or mental acts are within and directed to the world. Comportment (not just the discriminably mental), then, is intentional. If we are to say that ‘all comportment is within and towards a world’, as a new Heideggerian expression of intentionality founded on being-in-the-world (see Heidegger, 1982, §15c, p. 161), then another aspect of intentionality comes into view. This is critical. It is the inevitable subjectivity of the world—my world:

The surrounding world is different in a certain way for each of us, and notwithstanding that we move in a common world. (Heidegger, 1982, §15c, p. 164.)

Heidegger goes on to develop the phenomenology of intentionality by utilising an old distinction in the theory of the self: (a) the “anonymous” self, which is the subject of consciousness; and (b) the self as an
object of reflective awareness, the self which we take as having certain characteristics (so I can reflexively say that I have particular personality traits, etc.). For Heidegger (as with Husserl) there is a primary, pre-reflective “understanding” of self—in the sense of subjectness, and this is without personal characteristics. However, self-characterization is made possible by reflection on comportment and world:

[The Dasein] never finds itself otherwise than in the things themselves, and in fact in those things that daily surround it. It finds itself primarily and constantly in things because, tending them, distressed by them, it always somehow rests in things. Each of us is what he pursues and cares for. In everyday terms, we understand ourselves and our existence by way of the activities we pursue and the things we take care of. (Heidegger, 1982, §15, p 159)

It seems that Heidegger wants to say that to exist in the human way (Dasein) is already to find oneself as within the structure of meaning designated by “world”. In intentionality, therefore, we find ourselves in the subjective world to which our comportment is directed. Any phenomenological research will expect to see subjectivity in an experience of a particular phenomenon.

Heidegger is—and this must be emphasized—still thinking within the reduction. He is concerned with the world as the manifold of intentional objects. He is not taking an external stance—world is lifeworld, as it is experienced by the Dasein. In addition, the criticisms of Husserl that are often seen in these moves of Heidegger do not stand investigation. Husserl himself stated very clearly that, within the reduction, we are speaking about my world. Therefore, the subjectivity of the world being underlined by Heidegger here remains an elaboration or explication of Husserl’s insight that the world revealed in intentionality has a “peculiar ownness”.

If I am to describe myself, then, I do not ‘look inside’. It is my experiential world that speaks of me. The priorities, the foci, the ignored, the attended-to of my world are mine. In intentionality, therefore, we find our selves in the subjective world to which our comportment is directed. With the new formulation of intentionality that Heidegger puts forward, we find that experience is embedded in a world that already speaks of the individual perspective of the “experiencer”. I wish to emphasize very strongly that logic of what has been said so far leads inevitably to the conclusion that the theory of the lifeworld is part of the theory of intentionality.

The lifeworld: care and identity

All experience whatsoever is “within a world”, which is for each of us “my subjective world”, nevertheless with certain ever-present characteristics. This is designated the “lifeworld”. We contend that “the lifeworld” can be taken as an essential structure, to which any particular lifeworld will conform. As Karlsson (1993) has pointed out, the classic phenomenological and existentialist authors do not provide a detailed account of the phenomenology of the lifeworld, though we do have good pointers to the essential features of the lifeworld in the work of (for example) Husserl (1970), Heidegger (1962), Merleau-Ponty (1962), and Sartre (1958). Many writers on phenomenological psychology and phenomenological psychiatry (Pollio, Henley & Thompson, 1997; Spinelli, 1989; Dahlberg et al., 2001; Valle & Halling, 1989; Binswanger, 1963; and van den Berg, 1972) mention certain features of the lifeworld. The fullest account of the lifeworld may be Medard Boss (1979), translating Heidegger from the philosophical realm to that of psychological and medical science. Nevertheless, he includes speculative elements like being-towards-death, which seems to us to entail more deeply interpretive thinking than the phenomenological description of that which is apparent would allow.

It is fundamental, then, that all thought and action is within the lifeworld. The lifeworld is ever-present. Within the reduction, we still find the lifeworld. This means that in any phenomenological research project we may always ask questions which centre on these interrelated elements of the lifeworld:

- **Selfhood.** (See Gallagher & Shear, 1999; Atkins, 2005; Harre’, 1998.) What does the situation mean for social identity; the person’s sense of agency, and their feeling of their own presence and voice in the situation? (For example, powerlessness might be a feature of the psychological situation for the individual.) Identity is undeniably part of sociality—our identity links us to others and is provided by interaction with others.
- **Sociality.** (See Gurwitsch, 1979; Schutz, 1962; Crossley, 1996.) How does the situation affect relations with others? There is no doubt of the intrinsic relatedness of one and the other. Other people are a central part of our lifeworld especially because the evidence from them of our selfhood is so direct.
- **Embodiment.** (See Stam, 1998; Welton, 1998; 1999; Crossley, 2001.) How does the situation relate to feelings about their own body, including gender, “disabilities” and emotions? Here
we can see vulnerabilities and physical strength. In addition, we shall see later that, since it is through the body that we are able to pursue our projects, illness—though bodily—may well be most felt through the way in which our projects are thwarted.

- **Temporality (and its events).** (See Pollio et al., 1997.) How is the meaning of time, duration, biography intrinsic to the situation in which one finds oneself?

  Each present reasserts the presence of the whole past which it supplants, and anticipates that of all that is to come, and by definition the present is not shut up within itself, but transcends itself towards a future and a past. (Merleau-Ponty, 1962, p. 420.)

- **Spatiality (and its things).** (See Seamon, 1979; Buttimer & Seamon, 1980; Dovey, 1999.) How is space laid out? Perception of a house, for instance, is not approached in the same way by phenomenology as by cognitive psychology (the focus is not on the interpretation of stimulus variables, but on the meaning of the visible situation). A house is a potential abode; it is a space that I can enter, etc.

  How is the person’s picture of the geography of the places they need to go to and act within affected by the situation? (Frustrations? Possibilities?) Moreover, this “geography” will not merely be a physical, but there will be social norms and a host of other meanings associated with the place. Dyck (1995) has provided a telling phenomenology of the spatial as it relates to a patient with multiple sclerosis, which illustrates exactly the importance of this element within the lifeworld.

- **Project.** How does the situation relate to the person’s ability to carry out the activities they are committed to and which they regard as central to their life? (The emotions of regret and pride, among others may relate to such pursuance of projects.) All the things and events of the lifeworld may be related to the notion of project.

  The thing is inseparable from the person perceiving it, and can never be actually in itself because its articulations are those of our very existence, and because it stands at the other end of our gaze or at the terminus of a sensory exploration which invests it with humanity. (Merleau-Ponty, 1962, p. 320.)

  For “project”, we may also use the word “care” (Heidegger, 1962, pp. 238–239), in the sense of having a personal concern for something. Phenomenologists have from time to time emphasised the idea that it is the fact that people have cares or projects that differentiates them from machines. We need to notice that this meaning of care is a bit different from the sense we use it in “the caring professions”, where it means “solicitude” for others; thinking of them and noticing their needs and trying to fulfil them. This is a more restricted use of the word.

- **Discourse.** (See Harré & Gillett, 1994.) What sorts of terms are employed to describe the situation—educational, social, commercial, ethical, etc.—and thence to live? It has been considered by many that, since a great deal of philosophical emphasis has been given to language in the last century—it is the “house of being” (Heidegger); it’s limits are the limits of my world (Wittgenstein)—consideration of discourse supplants phenomenological description. However, this is not so, even if speech is a powerful factor in the lifeworld.

  Speech is . . . that paradoxical operation through which, by using words of a given sense and already available meanings, we try to follow up an intention which necessarily outstrips, modifies and itself, in the last analysis, stabilizes the meanings of the words which translate it. (Merleau-Ponty, 1962, p. 389.)

- **Mood-as-atmosphere.** This aspect of the lifeworld remains under-researched. The locus classicus is Heidegger (1962, §29) where he describes “Being-there as a state of mind” (p. 172), and tells us that

  In a state-of-mind Dasein is always brought before itself, and has always found itself, not in the sense of coming across itself by perceiving itself, but in the sense of finding itself in the mood that it has (p. 174).

  I wish to insist that “having a mood” and other similar locutions involve presuppositions about source or cause which should be set aside. Using the phrase “mood as atmosphere” reminds us that a feeling-tone is an essential element of any situation for us, and that we must represent this in describing the lifeworld.
Therefore, to summarize this part of the paper, the history of the notion of intentionality culminates in Heidegger's insight that the self is not “internal” but is to be seen in the nature of one’s concerns within one’s world. In experiencing my world, I implicitly see in its priorities and foci, my own projects, cares and concerns. My world is laid out in terms of the objects and events that matter to me. Therefore, I see my self in the experienced lifeworld.

The carer’s lifeworld and the question of sociality

A person is to be understood, not by “looking inside” (so to speak), but by getting as full a view of their subjective lifeworld as possible. This is true whether the person to be understood is myself—reflecting on my own lifeworld—or the person to be understood is someone other than me. Within the confines of this paper, we cannot do the considerable idiographic and then typological work that seems necessary to describe the lifeworlds of the formal or informal carer. Among the accounts in the literature that provide a starting point for such a piece of work are Aggarwal et al. (2003); Benner and Gordon (1996); Bledin, MacCarthuy, Kuipers and Woods (1990); Briggs and Askhalm (1999); Haggstrom, Jansson and Norberg (1998); Harding and Palfrey (1997); Innes (2000); James, Powell and Kendall (2003); Moniz-Cook, Woods and Gardiner (2000); Pietruckowicz and Johnson (1991), Pool (2000a; b), Tanner, Benner, Chelsa and Gordon (1996); Todres and Galvin (2006), Vittoria (1999) and Ward, Vass, Aggarwal, Garfield and Cybyk (2005). However, within the carer lifeworld, it seems likely that the major challenge is how to relate to the patient as a person, that is, how to care. The lifeworld element of sociality is central.

Lack in human sociality

There does seem to us to have been progress (in our observations of the UK care scene) over the last thirty or so years in the nursing care of the frail elderly. The “geriatric ward” housed the elderly, and the elderly mentally infirm were housed in what were known as “back wards”. (“Out of sight and out of mind”, the back wards were neither perceptible nor within anyone’s realm of concern). Thus, it was particularly striking, sixteen years ago, that the growing interest in understanding and systematizing nursing practice around the needs of patients had begun to touch the care of the elderly dementia patient. Nevertheless, the study by A. Ashworth (1990) of a long-stay ward for the frail elderly showed a continuing culture in which the patients were characterized disrespectfully. They were “don’t knows”. Moreover, the attempts by the nurse leadership to reorganize working practices and the associated nurse attitudes around the individual seemed to be misconstrued. One nursing assistant is reported as saying, “We are on total patient care here. That means that we have to do three baths.” Thus, a concept supposed to engender holistic concern for the individual patient was reduced to an impersonal task.

Malignant social psychology: excess disability

Several writers (Brody, 1971; Sabat, 1994, and Kitwood, 1997) have pointed out problems in the interaction of carers and elderly patients with dementia. They argue that the patient’s behaviour is less skilful than it might otherwise be, because they are cast as incapable.

Kitwood (1990) advocates a person-centred approach to care. Taking the view that dementia can be affected social interactions of a certain kind, which can damage self-esteem and diminish personhood, he calls the relevant forms of social interaction malignant social psychology (Kitwood, 1997). He describes seventeen aspects of this “malignancy”, or interactional disrespect (see Table I).

Kitwood and Bredin (1992) argued that maintaining personhood in dementia care is of primary importance, emphasising that each person is worthy of respect. Pool (2000a; b) offers anecdotal evidence from her own professional experience, which suggests that although Kitwood’s philosophy of person-centred care is recognized and supported, it is difficult to implement in practice. What is to be done about this? Kitwood (1997, p. 118) takes one path in his book, emphasizing the maintenance of personhood by a carer who acts according to inner rules of “person-enhancing interaction”:

We . . . examine what dementia care work requires on the part of a caregiver, and the kind of personal development that may be involved. First . . . we explore the caregiver’s part in creating person-enhancing interaction. Then we . . . move on to a less-obvious topic—that of the hidden motives

| Table I. Aspects of “malignant social psychology” according to Kitwood (1997). |
|---------------------------------|---------------------------------|---------------------------------|
| Treachery                       | Outpacings                      | Withholding                     |
| Disempowerment                  | Invalidation                    | Accusation                      |
| Infantilization                 | Banishment                      | Disruption                      |
| Intimidation                    | Objectification                 | Mockery                         |
| Labelling                       | Ignoring                        | Disparagement                   |
| Stigmatization                  | Imposition                      |                                 |
that often draw people into care work. I ... suggest that when these motives are ‘owned’, understood and integrated, they can become a powerful resource.

This suggests that solicitous caring requires a change in attitude, a process whereby the carer constantly recalls the need to treat the patient with humanity.

**Is the appropriate caring sociality a “solicitous attitude”?**

The Bill of Rights, created by Bell and Troxel (1994; see also, Hellen, 1998), indicates a very concrete and welcome commitment to provide more than the feeding, toileting and bathing that were seen as adequate to meet the needs of the frail elderly in the recent past. The list of recommendations for good practice that is provided by Bell and Troxel is welcome. The Bill of Rights is really an emphatic way of saying that the person with dementia ought to be treated respectfully. However, saying what ought to happen will not ensure that it will happen. The extent of the endeavour that remains after a right has been asserted is obscured by talk of “rights”. How will respect actually be assured? Is the solution, the inculcation of a “caring attitude”?

Benner and Gordon (1996) discuss the assertion that medical staff have a “caring” attitude to their patients (meaning that they entertain feelings of goodwill to them and generally wish them well) and contrast this with overt practices which plainly embody caring, e.g. giving time and space for consultations and being open to hearing and understanding the patient. There is a need to differentiate between caring as an abstract slogan or generalized sentiment and a practice which is revealed quite distinctly not only in the hospital, but ... anywhere that people are asking others to attend to their problems, dilemmas, or need for growth and empowerment (pp. 42,43)

A nurse may care about a patient, but without a “set of care giving skills and practices” the care cannot be embodied, caring cannot move “from concern to presence, from emotional interest to attention or attunement” (p 43). Benner and Gordon point out that “a practice such as authentic caring cannot be completely objectified or formalized”, so the evaluative strategies “fashioned according to the various criteria of disengaged reasoning cannot replace being-in-relationship to particular persons/situations” (p. 45). In a similar vein, Dahlberg et al. (2001) emphasize the technical rationality of the paradigm of caring science and the difficulty of speaking about care.

It is difficult to put forward changes that accentuate the importance of focusing on the unique and individual in the treatment of disease and health promotion when the ruling paradigm emphasises the opposite (p. 36).

**A fundamental problem for the carer: extending “sociality” to the patient**

A fundamental problem with attempting to inculcate a “caring attitude”, maybe by using the notion of rights, is that it is in interpersonal relations that respect for the personhood of dementia sufferers needs to be maintained, and it is precisely interpersonal relations that are damaged in this condition. To put it in the context of the phenomenology of sociality, we have, in Husserl’s 5th Cartesian Meditation (1973), what amounts to a description of the essence of the phenomenon of understanding another as a person (see also, Scheler, 1954, and Schutz, 1962). Among the essential characteristics of understanding another to be a “person” are:

- The other is a subject in the world, a minded being like myself. This is the assumption of the other as an alter ego.
- The world is, for both of us, an intersubjective one—there for everyone. Thus, for example, we can share the same object of attention.
- There is reciprocity of perspectives such that, standing in my position (and analogously, sharing my biographical standpoint) you can take my mental perspective—and vice versa.

In people with Alzheimer’s disease and other dementias, personhood is threatened by an apparent lack of these features of sociality. In some respects, sufferers do not seem to embody such truths in relation to others, and carers and other non-sufferers find it hard to maintain a belief in these as capacities of the person with dementia. Social participation (Ashworth, 1997) is thereby subverted.

**Lifeworld and intentionality as grounding personhood**

The individual with dementia is to be regarded as a person, despite the issues that we have already rehearsed. Nevertheless, how is this to be grounded? We must assume at the minimum that he or she is a conscious actor. In phenomenological terms, this entails at least that intentionality is characteristic of their existence. This means that the person with dementia has a world to which their thoughts and actions (limited though they may be) relate.

The path to be taken in understanding the person with dementia is now clear—we should focus on the
description of the person’s lifeworld. The carer becomes an informal phenomenologist of a kind. Attempting to set aside presuppositions drawn from their own knowledge of the person’s situation or history; attempting to suspend their knowledge of the kinds of cognitive deficits which the scholarly literature regards as typifying dementia, and setting aside their own criteria of truth and reality, the carer is asked to turn their attention to the actual talk and activity of the person so as to discover the meanings of that person’s—possibly quite unique and idiosyncratic—lifeworld.

Tanner et al. (1996), in a paper entitled “The phenomenology of knowing the patient”, observe that clinical judgement in nursing is generally taken as involving the accumulation of “formalized and explicit information ... used through complex reasoning processes to identify problems and issues, and/or to develop a plan of care” (p. 201). However, nurses speak of “knowing the patient”. This is regarded by Tanner et al. as a different kind of knowing to the formalized and explicit information which is usually treated as the evidence-base of practice. ‘Knowing the patient’ is a reference to “how they [nurses] understood the patient, grasped the meaning of the situation for the patient, or recognized the need for a particular action” (p. 201, italics added). Knowing the patient—if it is taken in the sense of “grasping the meaning of the situation for the patient”—is very much the approach we are advocating here (cf. Pietrukowicz & Johnson, 1991, see also Kontos, 2003). In summary:

a. The Alzheimer’s sufferer is a person.
b. This means they are living consciousnesses, acting in accordance with the meaning of situations for them—and that the analyses of phenomenology apply to them.
c. To understand the Alzheimer’s sufferer as a person, it is not a matter of an external analysis of their cognitive capacities and deficiencies, but a description of their lifeworld—from their own point of view. There is a belief here that, if carried out carefully, the phenomenology of the lifeworld of an Alzheimer’s sufferer has features that are understandable.
d. It is postulated that the task of caring may well be made more bearable and satisfying if, instead of regarding the individual with dementia as malfunctioning, they are seen as a person acting in terms of a meaningful lifeworld which the carer can attempt to discover and may even enter in interaction.

The patient’s lifeworld

In what follows, I attempt to describe the lifeworld of one person with Alzheimer’s disease using the structure outlined in section 2 above. I do not know whether any claims to typicality can be made—I suspect some aspects may be similar in some ways to the worlds of other sufferers while other aspects may be idiosyncratic. The point is to describe the lifeworld of this person to reinforce the fact that she is a person, and understandable as such. This gives the basis for respectful care that statements of rights, acknowledgements of various cognitive deficiencies, and admonitions to regard the individual as an adult, cannot provide.

Self

Self, considered as part of the lifeworld, includes the attributions of identity, “I’m your Mother” as well as the person’s experience of her own presence, agency and voice within a situation. Perhaps most fundamentally, it is plain that the person with dementia is a self in the sense of being the centre—the point of view—on her physical and psychological world. In Sabat’s (2001, 2002) terms, she can say “I”. However, just as we later find that the world of spatiality and temporality is not segmented in the conventional way, with thresholds and boundaries, so the limits of the self are not self-evident. Certainly, distinctions of ownership are lacking, so that the self is not associated with some objects (my slippers, my clothes) and dissociated from others. It can be said, therefore, that the self is quite inclusive.

The person with dementia may find that a main way in which agency can be exercised is indirectly through requests for others to act—but in view of the inclusiveness which has just been described, this may not be seen as lack of agency but an extension of it. A time delay in response by a carer when asked to act on her behalf can be enormously frustrating. Not, precisely, blaming the carer for lack of ready help, but rather as if the dementia sufferer had set off to walk and found that her legs would not respond in the instantaneous way in which agency can be exercised is indirectly through requests for others to act—but in view of the inclusiveness which has just been described, this may not be seen as lack of agency but an extension of it. A time delay in response by a carer when asked to act on her behalf can be enormously frustrating. Not, precisely, blaming the carer for lack of ready help, but rather as if the dementia sufferer had set off to walk and found that her legs would not respond in the instantaneous way that their membership of her bodily self required them to act. A carer can be as much a part of her sense of agency as that.

There is a need for presence and voice. Frustration is expressed when carers are carrying out their own specific activities in which the person with dementia is not a participant—she experiences lack of presence in the situation and has no voice. Voicelessness is also experienced in public settings where, as a member of the audience, she is unable to follow the talk of the speaker. Here the expression of
frustration may be to ape loudly and ironically the
“yack-yacking” to which she is subject.

A considerable “as if” ability can be shown in
bodily expression. Entering fully into mock sword-
play with a carer using short garden canes; adopting
a mock-jaunty style of walking as a joke. Yet her
customary way of walking speaks of a self-image very
far from that mock-jaunty style. It has to be said that
her usual self-presentation is of an invalid. She shows
a preference for dependency and often has to be
coaxed to undertake the simplest actions (the
simplest for her—ones that she habitually carried
out without any hesitation such as walking down the
single step into the garden). This observation can be
linked to a large number, which indicates the nature
of her social identity; not reflected-on, but lived in
accordance with a certain image of dependency.

It does seem that a view of herself for herself has
been adopted in which she identifies with her late
husband in his terminal illness. She calls for a
walking stick (which he did need) though she does
not employ it with serious effect and normally
forgets it at some point. She has been heard to say
He [mentioning the name of her husband] has a
walking stick. The nature of his illness made eating
effortful; she slumps back in her chair and sighs
during eating in a way that does not seem required.
It is a self-expression. Maybe a call for compassion,
“I am this kind of person”.

However, on occasion, she can be a proud reciter
of well-remembered and quite lengthy poetry. A very
positive view of herself. When initially invited to take
part in a day centre she turned it down saying that
she was happy with her poetry books. Moreover, on
a memorable “jaunty walk” occasion, she had just
recited to an audience of four friends and received
their applause and hearty praise.

Sociality

For the dementia sufferer it may be that others have
active existence only in the here and now when they
are actually present with her. When not here, when
they are out of view, it may seem that others are
poised in readiness (as if the inhabitants of the castle
captured up in the spell in Sleeping Beauty) to be
reanimated at her call. Therefore, when she calls out
for a carer, this does not interrupt the other’s parallel
existence so much as summon them into active
existence.

For the most part others are loci of activity. As
such, they can be of immense interest. The person
with dementia can be transfixed by the here and now
activity of others. Children, or a man building a wall,
can be absolutely absorbing. Neither the children’s
play nor the man’s bricklaying need interrogation—

they just are; the why question need never be asked.
Sometimes a “locus of activity” is annoying. For
instance, their reading or writing may be irritatingly
motionless; painting and decorating by the carer may
irritatingly demand their attention—so that it is not
directed to the sufferer.

It may seem that, for the person with dementia (as
for anyone) it is others—in particular seeing what
others do and having others see what I do—that
gives life meaning. Others can be one’s audience for
the self-confident recital of poetry, or for declaiming,
without shame, some well-rehearsed opinion—
“They don’t know what they do!” “Nobody comes!”
“Nobody cares!” “It’s awful!” or “It’s good!” In this
way, as for almost everyone, the dementia sufferer is
afforded the opportunity to perform a lively self by
other’s presence. It is notable, incidentally, that the
opinions that are typically voiced refer to they or it
without actual referent.

It may be that others, though allowing the
presentation of a self, can have their treacherous
aspect. Others’ faces and voices betray motives,
which the person with dementia finds anxiety
provoking. So innocent puzzlement is met with the
complaint that the person is “scowling at me”; a
light-hearted chuckle may be for the dementia
sufferer a cackle of derision. She knows these
expressions are maliciously intended.

Embodiment

The body may seem to need no particular protection
from the gaze of others and may not be vulnerable to
negative assessment—indeed praise about her ap-
pearance is not sought. She may not need any
particular bodily embellishment (dentures, tidied
hair, special clothing or clothing at all), which might
win approval in the eyes of others. Since these are all
missing from her lifeworld, for the person suffering
from dementia it may be that embodiment just is. It
is not overlaid with meanings to do with modesty or
the appraisal of the other.

This does not mean that the body is insignificant.
Indeed her embodiment may seem to occupy con-
siderable attention as a source of discomfort or
irritation. The manipulation by a carer of hands or
feet for the cutting of nails is hardly bearable; the
feeling of shower spray or of aerosols is enough to
elicit protests.

It appears that the body is exquisitely vulnerable to
extremes of temperature. There is little that feels just
right—things are either “red hot” or “ice cold”. There-
fore, temperature especially threatens the em-
body self, and cold is particularly significant.
Evidence of the menace of cold needs to be gleaned
not only directly but indirectly—by seeing if the
central heating radiator is off (if it is off, there is a threat of cold), or seeing that the sky is overcast. Any garments within reach are available for her to use to fend off the peril of cold. A similar observation could be made about food, which is not sweet. The body is prey to “bitter” food.

However, on occasion, it is sheer embodiment—simply the movement of the body—that may set the scene for engagement with the other. For instance the movement of her hand away from where it had been protecting her face during the process of having her hair sprayed brings with it an expectant smile. Surely, “I look nice don’t I?”

The body seems typically to be enfeebled by lack of direction in movement. However, strikingly, purposive strength and vigour return with the use of artefacts which themselves speak of directed action—the walking stick (held but hardly used); the shopping trolley. They are “going somewhere with her” and she enters into this purposiveness. Perhaps the readiness with which she responds appropriately to someone standing in the pose of one about to engage with her in ballroom dancing is similar in its meaning.

**Temporality (and its events)**

It may be that for the person with dementia the world is entirely here and now. There is little talk of It may be that for the person with dementia the world is entirely here and now. There is little talk of

*temporality (and its events)*

Yet the recent past does have an effect—if not verbally expressible, expressed in action by means of definite expectations. The relatively recently-introduced twice-weekly visit to a day centre for the frail elderly is accepted as a familiar event whereas initially it was regarded with great suspicion and she had to be coaxed to “try it out”. Regular events like these structure the week so that, “Today I collect my pension”.

One remarkable skill that is retained, uniquely, from the distant past is the capacity to recite certain poems by heart. Similarly, certain songs are recalled and sung with great musical accuracy. However, is the past evoked by such performances? When the song in which she is participating is the one that she and her husband referred to as “theirs”, she is not moved. Possibly the skilful singing of songs learnt in the past do not actually now stir up the past.

What about the temporal structure of the day? Certain markers are rigorously enacted. A bedtime ritual—to switch off the central heating, to fill a hot-water bottle to warm her bed, and to get undressed—marks the end of the day (whatever the “clock time” might be). Similarly there is a getting-up ritual involving eating breakfast cereal when she gets to the kitchen (even if she has been given breakfast in bed as a treat). However, for the person with dementia these rituals and markers do not secure her in the world with others. Her space (as we shall see) lacks thresholds and boundaries; in the same way, there seem to be no temporal markers. “I think I’ll go to bed now” is an utterance made in disregard of daylight or dark or the clock time. Similarly, a visitor who telephones to say she is coming is expected immediately and is reprimanded for the hour’s delay, which was the journey time.

However, the evocation of events spoken of in the past tense seems to be much more to do with present circumstances; the person with dementia does not engage in any discussion of “past events”—either when introduced in her own talk or when raised by others. It seems that in relation to these events the past is simply acknowledged as the tense in which certain events of great current significance must be spoken; no narrative account of the past is given. Her “past talk” seems not to refer to anything that is shareable even with others who were involved at the time.

In general, shared experiences from the past are not recalled. A holiday that was enjoyed with her family cannot be evoked by a participant. Strikingly, the person with dementia does not mention or seem to know what work she and her husband had in their mature years.

*Seeing oneself as a carer in the activity of caring* 221
Spatiality (and its things)

For the person with dementia, the rescheduling or re-routing of a local bus service, or a change (at the behest of planners and developers) to previously familiar places, can shrink the world. Space no longer radiates around her as the known and familiar or the available-to-be-known. Rather, it is parcelled out in discrete spheres (some larger, some smaller) at the end of “corridors” constituted by familiar journeys.

Some spaces may be experienced as boundariless. When (as others would have it) she is a guest in their house, the internal doors are not barriers to access but invitations to look inside. There are no constraints of modesty or privacy. When (as others would have it) she is wandering into neighbours’ gardens the gate does no more than act as an object to be opened.

Thus, the person with dementia cannot rely on space: a boundary or threshold—physical or customary—can make itself felt treacherously and unaccountably. A neighbour’s refusal of admittance, a locked door into someone’s bedroom, or a request to remove shoes dirty from the garden on entry to the house can all render a place suddenly dreadful. Naming a space may no longer have power to reassure—the label may no longer indicate “here” versus “there”.

In addition, boundarilessness seems to present other difficulties. There sometimes seems to be a dizzying sense of endlessness and a task set for herself by the person with dementia is apparently that of establishing a sense of bounded space in the vastness of everything. There may be fretful and prolonged pacing to doors, windows, fences, and anxious requests to be taken to a definite place which she can name (though the name may not signify).

Although change to the previously familiar can wipe out a locality completely, or coming up against a boundary can render the previously comfortable “awful”, other places—no longer available in the worlds of others—can remain as currently existing, vivid and reassuring realities. The elementary school, a long-closed hospital and its “massage department”, her father’s allotment all take their place as happy, neatly contained and well-understood locales.

What about objects within the space? The world is filled with objects that make themselves known by their recalcitrance—the sock that resists conformity with the foot; the bracelet that stubbornly refuses to fit over a hand. Nevertheless, less frequently but very strikingly, objects can make themselves felt in a call to practised fluid, unhesitating action—curtains claim her action and are accurately drawn. She is caught up in a bodily intention. Maybe the clearest instances are where objects are part of a social situation, and call forth dexterous action—a person whose arms are held out for dancing receives a ready response; when she sees one end of a laundered sheet she immediately begins the action of folding and the other person conforms with her skilful movements (including the little snap of the linen to remove the creases), and—on being given one of a pair of short garden canes she happily enters into mock-sword-play with a “contestant”.

Project

For the person with dementia it seems that the projects that animate the lifeworld and make it hers are innocently detached from contemporary life. She is unconcerned with achievement; she sets no store by independence; she does not strive to possess things or other people. When she calls for a carer it does not seem that “their” time or attention has to be won or retained; rather, that time and attention is taken for granted—there is no gap between her agency and theirs—and to repeatedly call for a carer is rather like trying to move a limb that is temporarily numb. It is noticeable that the person with dementia, though often at a loss to name a carer in conversation, never stumbles or hesitates with the name when summoning attention into play—though sometimes the carer is called “Mam”. So, though it could be said that one project is seen in the fact that to be looked after immediately is unquestioned and thoroughly expected, rather, as indicated in discussing selfhood, her world is one in which her agency and that of carers are the same thing.

Her positive accomplishments as mother, paid worker, and political activist, do not feature in her talk. Instead, drawing together the warp and woof of the lifeworld already discussed, meaning seems to lie in large part in her unregretted identity as sufferer of long standing. She refers frequently and great rhetorical skill, to a disability sustained because of a childhood illness and to a long and continuous dependency she needs care since she has had a life of remarkable bodily disadvantage. Medical consultations are engaged with eagerly—not as allowing hope of a cure (which is not part of her project) but as a source of further credentials, Can you find anything? With studied dignity, she frequently asks to be taken to hospital.

Dependency and disability are one project; another may be to enact the persona of a reader and reciter of poetry, and one who does drama. She
introduces lines of poetry to her conversation, and recites in an accomplished manner. For a long time she resisted any suggestion of attending a day care centre, declaring herself happy alone with her poetry books.

**Discourse**

We have already seen the place of the discourse of dependence as part of what seems to be a personal project of the person with dementia.

She also especially draws on a discourse, which speaks of a pre-reflective understanding of talk as drama. She performs her language, sometimes grandly, sometime poignantly. As a dependent, disabled person, she is (she tells us with a flourish, indicating that she cannot be expected to take any initiative) “eighty-two”; she had “infantile paralysis”. The discourse is one in which facts like these can be left hanging, portentously and theatrically for their rhetorical effect. Following on this grandiloquence, she may perform—so to speak—the hurt child, calling plaintively for the carer (sometimes named, sometimes “Mam”) to look at her sore place. This style pervades her talk and actions.

Especially when nothing is happening—as a passenger in the car, when “just sitting”, her line of talk very frequently hints at oppression by “the They”. She tells us, “They do just what they like.” “They don’t know what they do.” “They don’t know where they are going.” The referentless “they” seems now to convey that the lifeworld is adrift in a wider context which is the responsibility of no one in particular, and that this no one is not competent. “Things are not right”, “Things are getting worse”. The discourse is not new; it is continuous with her earlier history of political activism. She shakes her head as she says a rueful drawn out “Nooo” as if in judgement on the whole sorry mess they have made. It does not seem to be that she is reflecting on her own condition.

**Mood-as-atmosphere**

The day she came to her daughter’s house to be nursed, as it turned out, until her death, her son-in-law greeted her on his return from work. Her response was, “Who the hell is he?” Whatever the reaction of the man might be, the utterance embodies an implicit account of the emotional atmosphere, which her lifeworld held out for her at that moment. There is little need to multiply examples—if further ones are needed the previous paragraph provides several. The important point here is that the lifeworld is continually “mooded” in the sense that its objects and events are endowed with an emotional meaning.

**Conclusion: That the carer may see that the patient is a self: the subject of a lifeworld**

This paper has laid out a way in which the grounding of personhood can be restored in the carer’s perception of someone with dementia. The nub is that the carer becomes a kind of informal phenomenologist. Setting aside—no doubt with limited success and with considerable difficulty—presuppositions such as:

- whether the ‘thing experienced’ by the person with dementia is real or not;
- whatever previous opinion or scientific theory expects; and
- personal assumptions about the lifeworld of the sufferer;

the carer attempts to pay attention to the current experience for the experiencer.

It is argued that attention to the experience of the person with dementia is helped by awareness of the features that lifeworlds have, so that the actions and talk are considered in terms of the meaning for the person of their identity, sociality, embodiment, spatiality, temporality, project, discourse, and experience of the moodedness of the situation. These elements of the lifeworld have been used in the example of a person with Alzheimer’s disease.

There is an important issue for phenomenological research in this example, for I have throughout taken the view that the concept of lifeworld is applicable. This is because “lifeworld” is part of what is meant by intentionality and is therefore essential to all human experience, even that of the person with Alzheimer’s disease. At the same time, I have emphasised the (possible) uniqueness of this particular individual person’s experience within the general frame of the lifeworld. Of course it may well be (though it cannot be presupposed) that there is commonality—indeed, there may be an intuitable essence of the Alzheimer lifeworld. This (and a host of related questions) must await separate treatment. They demand a distinct research project.

In the present research, care and respect for a person who has dementia is based on an attempt at understanding that—while no doubt very partial—nevertheless is a more secure foundation than the call to be patient and show forbearance or the call to remember that the person is an adult with rights. Perhaps above all shown to be inadequate is the idea that reference to how the carer might feel in similar circumstances could be a reliable guide for action. It
is primarily the exotic world of the person with dementia that needs our interest and exploration. As Cohen and Eisdorfer (2001, p. 102) say, “When you talk with your relative, it is sometimes more important to listen and observe than to speak.”

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Notes

1. A version of this paper was presented at the Fourth Nordic Interdisciplinary Conference on Qualitative Methods in the Service of Health, Växjö University, Sweden. The focus of the conference was “getting qualitative research out of the dol drums”.

2. The references given for each of the constituents of the lifeworld are to sources for general debates on each constituent. The classical sources in phenomenology are Heidegger (1962) and Merleau-Ponty (1962).

3. I am very much indebted to Professor Les Todres for insisting on the centrality of the feeling-tone or mood of a situation, and the essential place of mood in the structure of the lifeworld. Of course, it would be wrong to exclude emotional meaning of a situation from the description of the lifeworld. Yet I have been resistant to using a formulation like “mood” because of its, “internal” connotations. It seems to ask that we focus on the person’s “state of mind”, disposition, or temper. This I want to avoid. Within the description of the lifeworld, then, the atmosphere of the situation for me is essential.

4. This section is very largely based on Ashworth and Ashworth (2003).

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