Humanistic Sensibilities in The Assessment of Dementia Patients

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ABSTRACT: A humanistic sensibility in contemporary geropsychology is thematized and encouraged. Dementia, in which the brain loses its world-gathering and functional capacities, is described phenomenologically as a disintegration of being-in-the-world. The humanistic perspective encourages the discipline to approach the question of diagnosis holistically, especially with regard to an exploration of the context and meaning of features such as depression and delusions. Phenomenological accounts of depression and delusions in dementia are offered as a corrective to humanistic psychology's traditional concern with the client's subjective experience. The clinical interview as a type of conversation is described; appropriate self-disclosure and feedback are emphasized. Three clinical vignettes are presented.

At least part of the legacy of the humanistic psychology movement is to have encouraged a professional sensibility and an ethics that have to some extent been taken up by psychology as a whole, consistent with the fundamental values of western culture. Looking at some of the mainstream literature on the assessment and care of people with dementia, it is heart-warming to be reminded of a humanistic sensibility that runs through much of it. It therefore seems less useful to think of humanistic psychology as offering an alternative approach to geropsychology than as a sensibility within geropsychology that is worth thematizing and encouraging.

Unfortunately, we still have to contend with the dehumanizing language of behavior management plans, the staple of nursing home care. More generally, we continue to face the vaguely militaristic metaphors of psychiatry and much of clinical psychology, in which symptoms are "targeted" for "elimination" by effective "strategies," while pharmaceutical researchers search for the "magic bullet." The forces of reductionism and objectification are insidious, and we need to be reminded regularly of those humanistic values and themes that make us better psychologists. At its core, to be a humanistic psychologist is to be present to the psychological through metaphors of hospitality rather than through metaphors of war.

Dementia

The term dementia in this chapter refers to the loss of a range of cognitive functions, most prominently memory, and includes dementia in various forms, due to various conditions (see DSM IV and Nussbaum, 1997). It might be helpful to sketch what happens to someone in a progressive dementia such as Alzheimer's. With cerebral atrophy, the brain loses its world-gathering and functional capacities. The world itself disintegrates, as it fails to cohere in time, space, and language. In addition, the loss of executive functions means that the person is less able to deal with the disintegration of being-in-the-world. "Alzheimer's is the closest thing to being eaten alive slowly" (DeBaggio, 2002, P. 41).

The loss of memory is the disintegration of narrative coherence. Things and events no longer have stories to tell, and their presence tends to become uncanny. In first person terms: strangers walk in and out of my house yet seem to feel at home; my young wife suddenly appears as an old woman and tells me she is seventy; my daughter tells me it is not time for breakfast now as we have just eaten lunch.

As visuospatial functions disintegrate, the world loses its coordinates and things lose their place. One day my bedroom is not where it has been for the past twenty-five years; I get lost on walks in my own neighborhood; I become confused while writing a check; I struggle with my shirt until some kind person helps turn sleeves into trouser legs and puts them on me.

Developing aphasias compounds the loss of temporal structure. Things lose their associations and their history. As they retreat from the realm of communal understanding, the world becomes increasingly homogeneous, devoid of habitability. I can no longer speak for things or for myself in complex, imaginative ways, when others speak, words tumble into incoherence as though they are a foreign language. What was once my wedding ring gradually deteriorates until it becomes merely a piece of metal, although it might comfort me in some accountable way when I am lonely.

There is a progressive loss of executive functions; thoughts detail, and the person becomes unable adequately to sustain or shift
attention as required. *I am increasingly confused by what is going on around me; I can’t plan my activities, or sequence simple tasks such as dressing or cooking a familiar meal; I no longer seem able to solve my own problems; and I cannot even control my own evaporating thoughts.* In sum, coherence, meaning, reliability, identity-in-context, and the management of life are increasingly impossible and are carried by others.

Some lucky souls seemingly have that delightfully empty, nonattached presence that is a caricature of satori. They are blessed by their ability to regress trustingly into unintegration, where functions are carried by smiling faces, reassuring sounds, gentle hands, and physical comforts such as being dry and warm. On the other hand, given the above experience of disintegration, it is hardly surprising that so many dementing patients suffer from depression, anxiety, and delusions.

This humanistic approach to the assessment of dementia patients will highlight the following themes: holism and the exploration of contexts, the clinical interview as conversation, and the principle of minimum intervention. I shall follow these with three assessment vignettes.

**Holism and the Exploration of Contexts**

The presence of brain damage is seductive; we can be lulled into speaking as though the head injury itself offers a sufficient explanation for the presenting problem. The medical model encourages a DSM diagnosis, and insurance and Medicare payments reimburse only for diagnostic activities with billable codes rather than for a comprehensive understanding. Diagnostic reductionism can also be easy ("He’s got vascular dementia with depression"), which can appeal to one’s laziness, especially late on a weekend afternoon. I too do not always practice as well as I preach.

A humanistic sensibility means that one sustains the discipline and effort to think holistically. Except perhaps at the end stage of a progressive disease, the diagnosis of dementia can never provide a sufficient explanation for the clinical profile of the person in front of one. A holistic perspective reminds us that there is always a person first, and that that person is using whatever cognitive and psychological resources he or she has to understand and deal with the disintegration of a world. The person’s experiential and behavioral responses are part of the clinical picture, even if the person "lacks insight" and denies cognitive problems. It is incumbent upon the psychologist to represent the way the person’s experience is organized and how his or her behavior is motivated. This is true with regard to neuropsychological testing as well. At their humanistic best, clinical neuropsychologists are psychologists first. As Paul Nussbaum remarked, "All tests are projective tests" (personal communication, 1999). By the same token, I sometimes administer a projective test such as the Senior Apperception Test to obtain a clearer appreciation of how the patient with cognitive deficits concretely experiences his or her world. For instance, I have been struck by the loss of imagination, empathy, and capacity for interpersonal conflict resolution even in early Alzheimer’s type dementia.

**Depression**

Nearly a quarter of people with dementia suffer from depression (Koenig, 1997, p. 54). Diagnostically, the person is said to have dementia with depressed mood. This diagnosis seems to imply that the depressed mood is merely a concurrent condition with this person’s dementia. Little or no exploration of the mood, apart from a symptom check list, or a severity score (e.g., Geriatric Depression Scale), is required for a diagnosis to be made or medications to be selected. However, the psychologist assessing this person is interested in how she experiences her problems, what it is like to be losing her physical health, independence, home, and those family and friends who have recently died. We are interested in knowing how she makes sense of what is happening to her. We want to know if she has financial worries. We want to observe how she responds to us in the interview, and whether her mood is at all responsive to human contact and empathy.

It is well known that depressed elderly people, especially those with dementia, often do not admit to depressive feelings. Instead, depressed mood may be evident in the person’s preoccupations with his family’s perceived neglect, his failing health, in mood congruent or paranoid delusions, or in depressive vegetative and behavioral patterns. This can be disconcerting for the uninhibited humanistic psychologist, for whom the language of feeling states is more familiar. It is thus important for us to remember that feelings are not primarily private and interior states, and they do not require the language of feeling words (sadness, loneliness, etc.) to be communicable. Concretely, feelings are immediately revealed through the
things, events, and memories with which we are engaged (Gendlin 1978–79), and it is up to us as psychologists to sense the feelings in the dementing person’s engagements and to see them in his or her gestures.

As a diagnostic matter, I often add an adjustment disorder as a secondary diagnosis to a primary diagnosis of dementia, especially if there has been a recent move from home to nursing home. In this way, I formally recognize the person-in-context with regard to the depressed mood, and I spell out some of the relevant contexts (on the DSM’s Axis 4). For deeper or more long-standing depressions, I still try to differentiate in the notes between what are probably comorbid depressed states rooted in the same organic processes as the dementia, and depressed moods that are either a recurrent pattern or responsive to the person’s decline (Kasl-Godley, Gatz, & Fiske, 1998). My impression is that such differentiations and contextualizations are more helpful than we psychologists might imagine, and that psychologizing the person’s milieu is perhaps the most important function we serve. Staff at the nursing homes and hospital units in which I have worked are hungry for psychological insight, and become noticeably more caring and personally engaged with the people in their care once they develop an imaginative and empathic understanding of them.

Delusions

The diagnosis of delusions is also too often understood reductionistically, as though the cerebral damage alone offers a sufficient explanation for delusions the person might suffer. But, as Karon and VandenBos (1998) argue:

The most important basis for delusions, and the most important thing to understand, is the patient’s need to make sense out of his or her world and experiences. It is not a pathological process, but the normal and universal process of trying to make sense out of one’s life, except that the patient has bizarre subjective experiences to explain (p. 224).

Although these authors are talking about: delusions in schizophrenia, the essential point is the same. Cognitive chaos seems to be utterly unbearable, and, if need be, psychotic defenses will emerge to will emerge to defend against it. Delusions in dementia can generally be understood as attempts to maintain consistency and coherence in a world that no longer holds together in time, language, or space. Delusions are rational, concrete, and seldom complicated. For instance, it is striking how many dementia patients suffer from delusions of theft: of money or things left in their rooms. But persons with dementia have memory problems, and they typically underestimate their severity. The result is that they forge: where they have placed things as well as the fact that they have forgotten. This is in addition to increased anxiety about a world that no longer makes sense as it used to, a world that is subject to strange forces outside of the person’s understanding or control. When things are not where they are thought to be, theft offers an explanation that contains anxiety and averts the experience of disintegration. At another level, delusions of theft describe the experience of the dementia’s theft of the person’s cognitive faculties. Similar interpretations can be made of other delusional states. Delusions of sexual abuse, for instance, describe the experience of disintegrated sexual feelings and fantasies within an overall history of sexual experience, including, perhaps, sexual trauma. Delusions of being poisoned explain the experience of losing one’s mind or physical health, or the side-effects of psychotropic drugs.

In severe dementia, delusions tend to lose their symbolic function. More typical are delusional transpositions of time and space, based on the profound loss of orientation and large segments of history (e.g., “I am forty-five and my mother is in the kitchen”). Such delusions are not symbolic in the representational sense. Instead, they reveal in concrete images the fundamental relational patterns that formed the person’s identity—what some of our psychoanalytic colleagues would call primary object relations. Such delusions (and concurrent hallucinations) might be all the end stage dementing patient has left, but they continue to communicate psychic reality: the person’s current mood and most primitive experience of care givers and immediate milieu.

This seems the place to confront an historical awkwardness in humanistic and phenomenological psychology when addressing delusions and hallucinations, an awkwardness that stems from a reluctance to name perceptions and beliefs as distortions. Humanistic psychology has emphasized concern for subjective experience, and has often drawn loosely from phenomenology for its legitimacy. Phenomenology, says Giorgi (1986), is “concerned with phenomena in the strict sense: that is, how things and events are
in the strict sense: that is, how things and events are for the consciousness that beholds them and not how they are in themselves" (p. 6). He elaborates this distinction with a discussion of the Muller-Lyer perceptual illusion. Two parallel lines of equal length are perceived as being of unequal length if one line is enclosed by arrowheads directed outwards and the other line is enclosed with arrowheads directed inwards. With "subjective experience" privileged phenomenologically, the humanistic psychologist is encouraged to honor only the perception of the lines' different lengths and to "bracket" the question of whether or not that perception is real. From this perspective, to identify an experience as a delusion or hallucination seems like a failure of the phenomenologist's commitment to "bracket" assumptions about reality. For the psychologist personally, it feels like a lack of empathy for the client's experience, especially in the face of dogged insistence on the part of the dementing psychotic patient.

However, this overly "subjectivist" interpretation of phenomenology is not only theoretically weak; it has unfortunate consequences for the clinical geropsychologist. To put ontology and theory in brackets is too often interpreted as a requirement to put on blinders; the phenomenologist's cherished naivete, which means a radical openness to the phenomenon, is then shut down from the beginning. With regard to the Muller-Lyer optical illusion, the existential phenomenologist is interested not only in the "subjective" experience of different lengths, carefully ignoring the question of whether or not the lines are "really" the same length. The phenomenon of the illusion as an illusion is also of interest: the perception of different lengths in the context of geometrically identical lines.

Similarly, the phenomenologically rigorous practitioner is interested in both the client's phenomenal world and in how it differs from, and interacts with, various consensual realities. To believe things are being stolen in the context of actual theft is different phenomenologically from that belief in the context of a world that is temporally disintegrating as dementia sets in. These different contexts of "being-stolen-from" are horizons of meaning that are constitutive of two similar but different phenomena. In other words, being-stolen-from by a factual thief is a different phenomenon from being-stolen-from by dementia. In the latter case, preoccupations with theft are both understandable and delusional. Thus we do not step outside of our humanistic stance or our phenomenological discipline when affirming certain preoccupations as delusional or perceptions as hallucinatory. On the contrary, our articulated grasp of different and interpenetrating worlds is central to our humanistic holism.

The Clinical Interview as Conversation

Too much investigative focus on symptoms tends to inhibit relevant information gathering unless good rapport has been established and maintained; an interview conducted with the unrelenting focus of an interrogation is not conducive to rapport. Thus the humanistic psychologist comments lightly, watches, and listens before asking diagnostic questions, and is interested in the clinical and therapeutic potentials of a conversation. As Hobson (1985) succinctly noted:

-Diagnosis emerges in a conversation between persons.
-Diagnosis is always treatment.
-Diagnosis embodies a statement about fundamental values (p. 176).

What the clinician finds in an interview is nearly always to some extent a function of the interview itself. The patient is a fellow human being who is typically assessing the clinician as well as the other way round. In this regard, I have frequently been struck how supposed "flat affect" is constituted in those psychiatric interviews in which there is a preponderance of closed-ended questions from a hurried interviewer who seldom makes eye-contact as he writes copiously in his notes.

The humanistic interviewer is actively self-reflective regarding his or her constitution of what is found. Issues of age, gender, ethnicity, religious background, and so on, as well as countertransference issues, all have constitutive significance and can affect the reliability of the interview. In training I sometimes have students do mental state examinations by watching films of persons in distress, as long as they are not demonstrations of psychiatric interviews and diagnoses, which I have found uniformly dreadful. It is instructive to discover how detailed a psychological profile (mental state examination) can be written merely from observation and listening, at which point diagnostic possibilities have already been greatly narrowed. At best, while it is certainly useful, especially with elderly people, to ask closed-ended factual questions in a structured interview (Segal, Coelidge, & Hersen, 1998, p. 243), I prefer the inter-
view to have the atmosphere of a conversation. Attention to process as much as to content has several advantages. It is more collaborative (Fischer, 1985/1994); it elicits a wider range of information; it more effectively facilitates the communication of psychotic phenomena; it feels more respectful and helpful to the patient; it is more humble and enjoyable for the interviewer.

Although in medicine the difference between diagnostics and treatment is clear, in psychology the issue is not so simple. Psychological assessment well done helps the patient feel understood. For some patients it can awaken hope. It thus enhances the therapeutic alliance, whether for medication or psychotherapy, and is already in some senses therapeutic. Without this sensitivity to the therapeutic potential of the clinical interview, assessment can be frankly countertherapeutic, in that the patient feels misunderstood and treated impersonally. Perhaps I should add that these comments do not imply that differences between assessment and psychotherapy are to be blurred; that is not only unethical but can be therapeutically dangerous (Malan, 1995, pp. 235-238). For instance, I rarely explore feelings beyond what is immediately given, and I never make linking or affectively deepening interpretations during assessments of dementia.

What these reflections mean concretely in the assessment of dementia patients is that I communicate with my client: who I am, what I am trying to find out, some of what I am thinking, and what notes I am writing. I summarize for the patient in appropriately manageable ways what I have written on the Consult sheet. I ask if the patient has any questions for me. Not only are these respectful courtesies, they are helpful to the patient. Openness helps counteract serious misinterpretations of what is happening, it reminds the person of my role, and it helps the person feel at home in what is sometimes an alienating and confusing environment. Having said something about what I have written, I routinely ask if there is anything the patient would like me to write in the notes—and then I add that as well.

It is obvious that many dementia patients have little or no idea why they are being consulted by a psychologist. Many deny they have any problems, including memory problems, and some dementing persons are in the grip of fixed delusions. I am respectful of the differences between our perspectives, and I have been surprised at how many patients seem to tolerate my opinion, if and when I present it, if I acknowledge that they see things differently from me and if I do not try to insist the correctness of my perspective. Sometimes, of course, I keep diagnosis to myself, and simply make some process comments that I hope will be reassuring.

The Principle of Minimum Intervention

Zarit and Zarit (1998) place this principle at the center of their care. It is a principle that guides assessment. In its respect for the dementing person's independence, rights and freedom, within the limits of safety, it is deeply humanistic and consistent with the democratic spirit of the United States. It is also good care management as it attempts as far as possible to maintain environmental familiarity and functional stability. Dementing persons can sometimes function well enough at home when a clinical examination in an unfamiliar setting such as a hospital would seem to indicate this to be impossible. Transfer to a nursing home, with its custodial emphasis, risks exacerbating disability, and it can be severely pathogenic or even lethal (ibid., p. 243). In this light, the humanistic geropsychologist includes in his or her assessment, perhaps with the aid of social work input, an account of the social resources for care in the patient's life, and looks diligently to see to what extent independent living can be maintained if that is the person's wish. In competency evaluations a home visit is often worth the effort (ibid., p. 164). When an assessment recommends permanent care—typically nursing home placement—then we advise that care givers do all they can to surround the client with things and photographs from home, so that, as far as possible, continuity in the person's world is maintained.

Clinical Vignettes

I shall close with a few vignettes that illustrate some of the above principles.

A psychologist interviewed someone who was thought to be suffering "vascular dementia with depressed mood and behavioral disturbance." The patient was 75 years old, with diabetes, and had had several transient ischemic attacks over the past year. He had been increasingly depressed and irritable for several months, and had withdrawn from acquaintances and social activities. He had recently smashed a plate in a fit of anger, and announced that he wished he were dead. The psychologist saw him and his daughter briefly in a hospital one evening, when some important background information
three weeks, during which he held her hand and she told him the story of her tumultuous life. Eight months later the psychologist received a Christmas card from her, written by her daughter, to thank him for "the great gift" he had given her. Diagnostically, this lady was suffering from mild vascular dementia, but she was significantly aphasic for comprehension. She was not that deaf either, and it must have troubled her that people tended to shout at her. Words heard were scrambled, so it was not surprising that her "replies" were incoherent or her MMSE score was so poor. Once inside her own frame of reference, especially for long term recall, she was able to speak in a highly differentiated way and to benefit from a psychotherapy that put listening first.

The final vignette involves a 78 year old nursing home resident who had numerous medical problems, including Parkinson's disease and cerebral atrophy. She was frequently delirious, with disorientation, poor balance, and visual hallucinations. She was also depressed. An assessment interview and testing found that she was "moderately" impaired, and the psychologist's working diagnosis of dementia with Lewy bodies and depressed mood was accepted. But the conversational dimensions of the assessment prompted her to show the psychologist photographs of a series of beautiful paintings that she had exhibited decades earlier. She became quite animated and asked to see the psychologist again. The photographs were worked into a collage on her wall, and a daughter brought some of her mother's original paintings from home, which were hung as well. The resident was proud to be exhibiting her work again! "Therapy" included managing the resident's environmental support but did not stop there. For weeks she needed to explain to her therapist in detail, despite marked word-finding difficulties, the processes of painting. Her mood improved significantly, no doubt with medical help as well, and she clearly found herself better able to orient herself in her room.

Footnotes

1 Thomas DeBaggio's (2002) recent book, Losing my mind, is highly recommended. Written by a gifted author, it is the autobiographical diary of a person diagnosed with dementia of the Alzheimer's type. He describes in agonizing detail what it is like for him to lose his memory and language, and his depressed mood is clearly part of his overall response to his death sentence, his guilt for burdening his wife and family, and his dread and grief at the coming
darkness of having no mind, a state more terrifying than physical mortality. Somewhat atypical is his high level of insight, which clearly contributes to his depression. Mercifully, not all Alzheimer's victims suffer this acutely.

I owe this insight and formulation to my colleague, Terry Pulver, Ph.D., whom I would like to thank for conversations and many hours of supervision when I journeyed into gerontology.

References


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