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The Perspective of the Person with Alzheimer Disease: Which Outcomes Matter in Early to Middle Stages of Dementia?

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Summary: As more persons with Alzheimer disease are diagnosed earlier in the disease progression, their perspectives, values, and preferences warrant closer attention from clinicians, service planners and providers, and the research community. Demographic changes suggest that more persons with early-stage Alzheimer disease will be living alone. Their treatment, housing, and service preferences, as well as values about desirable health, mental health, and cognitive and functional outcomes may differ from those of their concerned families. Clinicians and researchers must identify relevant domains of life quality from the perspective of the person with dementia and develop individually sensitive, reliable, and valid instruments to assess, monitor, and evaluate outcomes of care and services. **Key Words:** Dementia—Outcomes—Values.

A PERSON WITH ALZHEIMER DISEASE

Tommy Thompson is a 59-year-old divorced, "retired" song writer, banjo player, singer, playwright, and founder of North Carolina's well-known folk music group, the Red Clay Ramblers. Before his diagnosis of probable Alzheimer disease, Thompson wrote and starred in a Broadway play and performed his original music in U.S. government-funded concerts throughout Europe.

In early 1996, Thompson agreed to be interviewed live and unrehearsed in front of 500 participants at an annual Duke University Alzheimer disease conference. The morning of his presentation, Thompson acknowledged that it was "a bad day," his Cognex was not working, and he "needed some Aleve to clear the fog" in his head. [He is a believer in the protective effects of non-steroidal anti-inflammatory drugs (NSAIDs).]

Fifteen minutes later, Thompson was on stage and the consummate performer. When asked an open-ended question about how he wanted to be treated, he grinned,

and sure he would not make a mistake, replied simply, "Well!" Later he added, "Alzheimer's isn't my whole life," and proved it by singing two of his original songs, without the banjo, which he can no longer manipulate, and with necessary cuing from a written lyrics prompt.

The following month, Thompson appeared on a public radio program describing what it is like to live with Alzheimer disease. He lives alone in a small apartment, but considers himself lucky to be recognized, well connected, and loved in his small town. Recent research indicates that his social relationships may be a survival asset and may even protect him from poor outcomes (Gurley et al., 1996).

Indeed, Thompson is one of an increasingly vulnerable group of 9.5 million older people living alone with chronic illness, in part because the constraints of work, finances, location, and divorce limit what families can do for chronically ill older relatives (Campion, 1996). Thompson reminds us that future discussion of which outcomes matter to patients with early-stage Alzheimer disease must address the likelihood that more people will be diagnosed earlier and live alone for some time after diagnosis. If 1990 estimates are correct and 10-25% of persons with Alzheimer disease live alone,

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that translates to 375,000–937,000 persons (Fox, 1996). Many of these people are members of racial, ethnic, or other minority groups with limited financial resources. Often they live in less-than-desirable housing or residential board and care facilities (Maslow, 1995). This suggests that future discussion of patient-valued outcomes for Alzheimer disease care must further acknowledge heterogeneity and the significance of subjective measures sensitive to ethnic, cultural, and socioeconomic experience, beliefs, and expectations.

Thompson thinks he is in “a good situation” for someone with a memory disorder because he has been a major public figure for more than 20 years. “People know it . . . I don’t have to explain it . . . and I can walk to everything I need.” Thompson walks to a favorite diner, close to his apartment, and is close to a grocery, pharmacy, and music hangouts. A local movie critic and friend ensures that Thompson has rides to movies and helps him keep track of story lines. Thompson pays a social worker to keep track of his medicine and appointments and to help him with occasional travel logistics. The social worker pays a bookkeeper to keep up with Thompson’s mail and bills. The bookkeeper leaves Thompson seven envelopes per week with “daily walking cash.”

Thompson has a married daughter who lives nearby for emotional support. “Everyone I’m close to . . . the Ramblers and my children . . . get it and I welcome help. It’s a great life. . . . I’m not afraid to die.” His major complaint is that he feels “tired and in a fog for no good reason.” Thompson reminds researchers that survival and disease progression are not the only outcomes of interest to people with chronic conditions (Lynn and Virnig, 1995).

A NEGLECTED PERSPECTIVE

Tommy Thompson illustrates the neglected perspective of the person with Alzheimer disease who retains some awareness of his disability (Cotrell and Schultz, 1993). For the purposes of this article, discussion will focus primarily on Thompson as a representative of the perspective of persons with early- to middle-stage Alzheimer disease. Subjective perceptions of people with Alzheimer disease about meaningful goals and outcomes for Alzheimer disease research will be highlighted. Less will be said about measures and more about outcome domains of perceived relevance to diagnosed individuals. In some cases, valued outcomes for persons with dementia will have positive outcomes for their families and communities, just as positive outcomes from family interventions can have positive effects on people with Alzheimer disease (Montgomery and Karner, 1996).

Finally, this author starts with the assumption that given increasing numbers of people affected by dement-

ing illness, consideration of effectiveness and generalizable outcomes are more relevant than efficacy of specific treatments tested under tightly controlled experimental conditions. Unresolved questions of cost and/or willingness to pay will not be addressed.

GENERIC VERSUS DISEASE-SPECIFIC OUTCOMES

Thompson, like other persons with Alzheimer disease, wants to be treated “well.” He seeks normalcy, inclusion, and a focus on the person as “more than memory, more than a diagnosis.” On public radio, Thompson wonders aloud, “Am I a case? I thought I was just one of the Ramblers. They are my closest friends.” He reminds us that Alzheimer disease affects people, not just brains (Ronch, 1996), and a range of interventions that support remaining cognitive capacity, respect adult needs, and offer meaningful activity may be helpful or supportive of people living within the limits imposed by dementia (Koenig-Coste and Raia, 1996).

A former teacher with Alzheimer disease asks for “common courtesies, simple acts of caring” (Sawyer, 1996). This request for common courtesies would argue for generic versus symptom- or disease-specific outcomes.

One valued generic outcome from the perspective of a person with Alzheimer disease is the provision of effective general health care, particularly given some evidence for similar numbers of comorbidities among people with Alzheimer disease and age-matched controls (McCormick et al., 1994). Physician visit frequencies, hospitalization rates, or emergency room utilization to some extent measure “adequacy” of medical care, but further delineation of appropriate medical care planning would be a patient-valued outcome (McCormick et al., 1995).

For example, more than 50% of persons with Alzheimer disease with at least one psychiatric symptom in one study received no symptomatic treatment (Semla et al., 1995). At a minimum, people with Alzheimer disease seem to express a preference for reduction of symptoms that affect quality of life and relationships. This could include enhancing remaining physical function (especially mobility), treatment of acute conditions, minimizing occurrence of inappropriate prescribing, adverse drug reactions, iatrogenic complications, and negative psychiatric symptoms.

Many older persons with chronic or degenerative illnesses face stigma, shame, fear of discrimination or rejection, altered self-image, restricted life style, social isolation, discrediting of oneself as a burden, and loss of control, work, money, driving, and reciprocal relationships (Conrad, 1987). However, reducing anxiety and fear, although a generic outcome for people with a

variety of chronic illnesses, takes on special meaning for people whose defenses and typical coping strategies for responding to anxiety deteriorate with progressive cognitive loss just when the sources of potential anxiety and fear increase (Ronch, 1996).

PROCESS VERSUS OUTCOME MEASURES

In reviewing the literature from transcripts of people with Alzheimer disease, process measures seem to rival outcome measures in salience to quality of life (Cohen, 1991; Cotrell and Lein, 1993; Cotrell and Schultz, 1993). Robert Davis, a minister with early onset dementia, wrote, "don't treat me like a child at camp. I want the right of refusal if not entertained or too overwhelmed" (Davis, 1989). For Davis, valued process outcomes were comfort, reassurance, soothing, and normalcy when he lost confidence and control of his behavior.

Members of a patient support group at Duke wrote the following about valued process outcomes: "Because I cannot remember does not mean I am dumb . . . I still want to be part of something . . . I think of myself as normal . . . please don't ignore me" (*The Caregiver*, 1994). Thompson wants to be treated "well," others express wishes to be treated "normally," arguing more for process measures than outcome measures.

People with Alzheimer disease may be less concerned with outcomes than they are with what is offered, how it is delivered, and subjective perceptions of its salience or adequacy relative to immediate need. Subjective utility and benefit measures become more salient than objective measures of cost. What people with Alzheimer disease seem to want is to have their subjective needs for assistance met appropriately and individually rather than being offered too much, too little, or services perceived as irrelevant to self-determined needs or preferences. When Thompson was presented with the availability of a local adult day program, his preferences were quite specific, "I would rather hang out with the folkies at the diner."

QUALITY OF RELATIONSHIPS

Once one is affected by a progressive dementia, quality of life or lives (connection through relationships) takes on new meaning. This may reflect changing priorities throughout the degenerative disease trajectory. One daughter of a Cleveland man with Alzheimer disease suggested that "intellectuals are not a jury of Dad's peers in determining his satisfaction, quality of life or pleasure" (Post, 1994).

A growing body of aging research in the social sciences suggests the validity of subjective, global, multi-

dimensional measures of quality of life for chronically ill older persons (George, 1993). George suggests that even for people with Alzheimer disease, it is the subjective consequences of the disease that threaten well-being. "Subjective" in this context refers to whether a valued outcome is perceived as available, dependable, or enough to make a difference in how one feels.

Objective measures of health, wealth, and relationships explain less than half the variance in perceived quality of life for most older Americans. However, people with Alzheimer disease are especially vulnerable in reporting subjective satisfaction with what may be objectively substandard conditions, such as neglect or exploitation (George, 1993). In fact, Tommy Thompson feels secure and comfortable living alone despite instances of well-documented but fortunately minimal financial exploitation.

George maintains that chronically ill people frequently are willing to rate life quality high at lower levels of health if perceived social support is adequate. The maintenance of reciprocity in relationships, feeling valued and loved despite disability, and feeling continuing connection to a group often becomes a measure of quality of life. Thompson's identity and quality of life is maintained by seeing himself as "a Rambler, not an Alzheimer's patient."

At the same time, George found that cognitive and mental impairments are bigger threats to perceived quality of life than physical impairments. Again, it is not diagnosis, but the limits imposed by the disability that predict quality of life. George found that psychic pain frequently is perceived as a bigger threat than prognosis. This may be the case for persons with Alzheimer disease who are anxious, agitated or fearful, but who are unable to project themselves into the future to understand an abstract concept like prognosis. Alleviation of psychic pain as an outcome of Alzheimer disease care or treatment would suggest a preference for relief of depression, anxiety, fear, and agitation, without the well-recognized side effects of neuroleptics.

There also is evidence that people with chronic illness lower expectations or aspirations. For example, George found that chronically ill older persons who are able to stay in familiar housing are not only settling for less but genuinely want less, finding meaning through adaptation or acceptance of notions of having received an equitable deal from life. People with Alzheimer disease seem to be reassured by lifetime achievements, time well spent and viewed, in retrospect, as precious.

Vulnerable persons with dementia who genuinely want less may be at risk from policies or research related to "perceived need." Talking with Thompson, there is no

question of equity, and he wants little other than to continue his present lifestyle. Perhaps outcomes for people like Thompson should be evaluated in terms of enhancing objective resources associated with quality of life, such as meaningful time use, social engagement, safety, amenities, and choice (Lawton, 1996), and nurturing a sense of control.

Loss of a sense of control is a major articulated complaint of many persons with early-stage Alzheimer disease. Other subjective aspects of quality of life that seem relevant to people with Alzheimer disease in early and middle stages are satisfaction with health care, social support, housing, and self-esteem (Lawton, 1996). These domains of quality of life meet criteria for being relatively distinct from measures of cognition or function (Rabins and Kasper, 1996). Thompson rates his quality of life rather high because his self-defined "pleasant events" (Teri and Logsdon, 1991) still are experienced as enjoyable and available frequently.

INSIGHT AND SELF-OBSERVATION IN EARLY- TO MIDDLE-STAGE ALZHEIMER DISEASE

There is evidence that people with Alzheimer disease retain some capacity for self-observation (Cohen and Eisdorfer, 1986; Davis, 1989; Henderson, 1994; Rose, 1996). Recognition of functional limits is preserved partially, especially in persons who can focus and maintain attention (Kiyak et al., 1994). Thompson is quite aware of his dependency in instrumental activities of daily living, his inability to drive, and his dependency on telephone reminders, but he is only partially aware of the risks of living on his own. His awareness of risk probably fluctuates and, as limited research concludes, he is more likely to overestimate his remaining capacity relative to professional or family observers.

Tim Brennan (1995) described the effects of Alzheimer disease: "life has to be downsized with each further deterioration . . . my mind is in a fog and any thinking only makes it worse . . . 2 hours of volunteer work took a day and half to recover." Although both Brennan and Thompson highlight the psychic pain caused by cognitive fatigue, both express a normative urge to feel useful. The need for respect outlasts memory (Jenny, 1996).

PATIENT-VALUED OUTCOMES

People with Alzheimer disease may seek research outcomes that help them believe their lives matter. When one woman with Alzheimer disease could not operate her washing machine, her children quickly reassured

her with "we're here." She replied sadly, "Only trouble is that I'm here too" (Ketchel, 1995). Ruth Januzik, a woman with probable Alzheimer disease, described her positive response to an opportunity to volunteer at a food bank, "I have to feel like I'm useful to somebody" (Januzik, 1995). Dr. Cary Henderson, a historian with biopsy-confirmed Alzheimer disease, suggests, "I get tired of asking when or what is going to be, but I don't want to keep my mouth shut all the time. I want to be part of something."

Although there is no gold standard for global well-being for persons with middle-stage dementia, there are interventions that produce dementia-specific outcomes of increased socialization and satisfaction, and enhanced perceived control and dignity (Snyder et al., 1995; Rovner et al., 1996; Sloane and Barrick, 1996). People with Alzheimer disease describe vividly their exacerbated isolation, limited expression and comprehension, and difficulty initiating actions to make the system work for them—"the worst part is feeling cheated, belittled or alone with it" (Henderson, 1994).

Kane suggests focusing on clinical outcomes that can be influenced by care, despite expectations of decline even with the best care (Kane, 1995). Although Kane focuses on long-term care outcomes, his emphasis on global outcomes related to quality of life and satisfaction with the process of care is relevant to persons with early- to middle-stage Alzheimer disease. Clinical outcomes of relevance include domains of function, affect, comfort, meaningful participation and relationships, and satisfaction with environment or housing. Maslow suggests that outcomes of current and future relevance to affected cohorts include reduced or managed comorbidities, dementia-capable or -knowledgeable care providers, reduced hospitalization rates (because hospitalization is notorious for exacerbating negative cognitive and functional outcomes in middle-stage patients), reduced negative behaviors like agitation, and catastrophic reactions and appropriate access to specialists (Maslow, 1995).

RECOGNITION OF DEMENTING SYMPTOMS: A VALUED OUTCOME

"Do you think there's something wrong with me? I don't seem to think well anymore." People with mild signs of cognitive impairment describe terror in not knowing what is wrong and anger at having their concerns discounted by well-intentioned professionals. "People with Alzheimer's actually do think . . . we wonder how things happen and why" (Henderson, 1994). One salient and valued outcome for persons in early stages

is access to knowledgeable and sensitive health professionals who take their complaints or those of their families seriously.

Recognition of dementing symptoms is one outcome that meets criteria for being of interest to some or most persons with Alzheimer disease and their families (Lynn and Virnig, 1995). It also meets criteria for feasibility, generalizability, relatively low cost, and high utility or benefit in terms of prevention of comorbidity, accidents, or other risks. Increasing recognition and referral for diagnosis is an outcome whose time has come if we are to generate more precise estimates of incidence, prevalence, and natural history of dementing illness.

Although many people with early-stage Alzheimer disease are reluctant to seek evaluation, others with early symptoms report having their legitimate concerns (or those of their families) dismissed with false reassurance. Even worse are the reports of those with early-stage Alzheimer disease who were encouraged to "use it or lose it." As one angry daughter of a formerly brilliant and productive woman with Alzheimer disease said, "Mother's intellectual activity failed to hold back the darkness" (LaBelle, 1995).

The U.S. Agency for Health Care Policy and Research recently released a clinical practice guideline on recognition and initial assessment of Alzheimer disease and related dementias. Broad dissemination efforts should provide feasible, practical algorithms to enhance knowledge and tools available to health professionals most likely to influence access to diagnostic services. In turn, adequate diagnostic and functional assessment should help translate research findings into practical criteria for insurance eligibility, an outcome with profound implications for meeting unmet needs in Alzheimer disease effectiveness research (Alexich and Lutzky, 1996).

DIAGNOSIS AS OUTCOME

"I'm glad I have a diagnosis . . . I think I can control things better if I know . . ." (Sawyer, 1996). Outcomes related to accurate diagnosis are underestimated in terms of their value and salience for persons with early-stage Alzheimer disease (Holroyd et al., 1996). A significant measure of effectiveness in Alzheimer disease care could be to increase access to and use of increasingly specific or predictive, noninvasive and minimally burdensome or costly diagnostic evaluations. Currently, most people are presumed to have Alzheimer disease without benefit of a comprehensive evaluation. An outcome of immediate relevance to persons with probable early-stage Alzheimer disease would be access to a diagnostic evaluation with early positive predictive value beyond current exhaustive but inconclusive diagnoses of exclusion.

Process issues in diagnostic evaluation are especially important to persons with dementing illness. A comprehensive evaluation is burdensome, anxiety-provoking, expensive, and still inconclusive. Thompson's only memory of his diagnostic evaluation was of "some well-known woman doctor at Duke rolling him around two machines (neuroimaging) and telling him "his case looks like Alzheimer's."

Recent evidence suggests the potential to increase the positive predictive value of early diagnosis of symptomatic people with sporadic Alzheimer disease using apolipoprotein E (APOE) genotyping (Saunders et al., 1996). "Multiple prospectively collected series, with post-mortem diagnoses, have confirmed a high positive predictive value for APOE genotyping as an adjunct for diagnosis of Alzheimer's disease in cognitively impaired patients" (Roses, 1996). Cost and convenience for the licensed E4 test may be enhanced in the future with the availability of self-addressed buccal swabs (vs. blood testing) and the potential for Medicare, Medicaid, or private insurance reimbursement.

If the time and cost could be reduced for diagnostic evaluation, and the accuracy of clinical diagnosis enhanced, anticipated outcomes would include increases in the number of appropriately evaluated patients with Alzheimer disease. From the perspective of a person with Alzheimer disease, a more definitive diagnosis would expand options for adequate interpretation of treatment options. If it is possible to predict which probable patients with Alzheimer disease will have autopsy-confirmed diagnoses, positive outcomes include the potential to identify persons most likely to benefit from specific therapies or those prone to or at greater risk of adverse consequences (Benjamin et al., 1995).

RESEARCH PARTICIPATION AS OUTCOME

One man with Alzheimer disease described his acceptance in a clinical trial this way, "I felt happy for the first time in a year. At least we were doing something. The effect of just doing something was enough . . ." (Rose, 1996). A physician-wife of a man with Alzheimer disease remarked, "Just sitting home and not getting care is not going to make things better" (Dickerson, 1996).

People with Alzheimer disease often cite participation in research as an outcome in itself (Bahro et al., 1995). It meets altruistic needs, activity needs, and attention and socialization needs, and offers catharsis for some persons with early-stage Alzheimer disease (Cohen, 1991). Several insightful early-stage research participants have suggested that at least I may be helping my grandchildren's future. Subjective descriptions by family caregivers support positive outcomes of par-

ticipation in clinical trials. For example, families of people with Alzheimer disease who participated in clinical trials of cholinesterase inhibitor therapy report their relatives are "less irritable and frustrated, less anxious or at least, not any worse" (Doraiswamy, 1996).

BEYOND COGNEX?

When Tommy Thompson appeared on a 1996 public radio program, the moderator asked if he had any questions for a researcher from Duke in the studio. Thompson did not hesitate, "Yeah, doc, you got anything better than Cognex?"

People with Alzheimer disease may be less interested in prevention or delay of onset outcomes than they are in symptomatic treatment of primary cognitive symptoms, psychiatric symptoms, and general physical symptoms. With the growth of real treatment options, there is even greater need to understand the preferences of people with Alzheimer disease and the importance of psychosocial components of illness in determining patients' responses (Siminoff, 1996).

People with Alzheimer disease are at risk from adverse consequences that may result from unsupervised access to medications (Warshaw, 1996). Thompson had difficulty monitoring his medication, which for him, had diminishing utility. Before he had a social worker take over his handling of medical care, he suffered negative consequences of seeking multiple treatments from multiple physicians. Now his preventive routine medical care is "managed" by his family physician and social worker with the goals of maintaining his satisfaction with and capacity to remain in his apartment. His apartment has been safety-proofed, his driving restricted, and his need to cook limited by access to a convenient, "dignified and appropriate" diner.

Thompson also actively seeks treatment, clinical trials, and even self-medicates on limited evidence of efficacy (NSAIDs, vitamin supplements, diet modifications). He is acutely sensitive to his physical condition, particularly his difficulty with and fear of going up or down stairs. He sees his family doctor regularly, asks to have his blood pressure monitored at home, exercises, avoids alcohol, and has insisted on active treatment for all treatable conditions unrelated to his dementia. Other persons with early-stage Alzheimer disease have expressed concern about being written off by health professionals in determining their need for routine preventive medical care (Warshaw, 1996).

Many persons with early- and middle-stage Alzheimer disease complain about cognitive fatigue as Thompson says it, "feeling tired and in a fog for no good reason." This fatigue does not seem to relate to depressive affect.

People with Alzheimer disease describe frustration, feeling overwhelmed, and inadequacy, often attributing to fatigue and frustration subsequent negative behavioral outcomes like catastrophic reactions or abusive outbursts. If effectiveness research could address issues of the appropriate balance of stimulation and retreat, perhaps building on theoretical frameworks like progressively lowered stress threshold (Gerdner et al., 1996), research findings would reflect outcomes meaningful to the majority of persons in the early stages of dementing illness. Simple measures of affect will not capture these more persistent and frustrating disease-specific outcomes.

OTHER VALUED OUTCOMES

Access to trusted and reliable surrogate decision-makers becomes increasingly important to persons with early- and middle-stage Alzheimer disease. Thompson expressed some freedom from panic and from becoming overwhelmed when his bills, appointments, and decisions were organized and predictably routinized for him. These essentially compensatory or surrogate services free persons with Alzheimer disease from overwhelming responsibility that often leads to negative behaviors or poor outcomes resulting from diminished judgment. If persons with recent diagnoses of Alzheimer disease had adequate, accessible, and reliable care managers or compensatory services, anticipated outcomes would be reductions in moves to more expensive care settings or reductions in hospitalizations resulting from neglect or insufficient safety precautions.

There is an almost universal fear of abandonment among persons in early and middle stages of Alzheimer disease. Outcomes measuring perceived security, connectedness, control, and meeting unmet need among persons with Alzheimer disease could add considerably to the measurement of effectiveness of Alzheimer disease interventions. These outcome measures probably would vary in validity. For example, Thompson tends to overestimate the adequacy of his support system to meet his current and future needs. At the same time, he expresses willingness to move to a more protected residential setting should his physician recommend it.

IMPLICATIONS FOR EFFECTIVENESS RESEARCH

There is reason to believe that soon Alzheimer disease will be diagnosed earlier in the symptom trajectory and with greater specificity. Increasingly, more people with Alzheimer disease will express their unique perspectives on valued research outcomes. The challenge will be to find meaningful and appropriate ways to ask questions of people with dementia and to measure, with

reasonable reliability and validity, their responses to Alzheimer disease care and treatments. A further challenge will be to ensure that research findings will be relevant and accessible to the broad cross-section of people likely to be affected by dementing illness.

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