The psychosocial preferences of older adults: A pilot examination of content...

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The Gerontologist Vol. 40, No. 3, 335–348 Individualizing care for older persons depends on knowing about a care recipient's psychosocial preferences. Currently, however, no comprehensive, empirically derived instruments exist to assess these preferences. As part of an effort to develop such an instrument, this pilot study examined the content and structure of psychosocial preferences in older adults using the statistical technique known as concept mapping. Results suggest two underlying dimensions to psychosocial preferences (Enrichment–Self-Maintenance and Extrapersonal–Intrapersonal) and six distinct content domains (Social Contact, Growth Activities, Leisure Activities, Self-Dominion, Support Aids, and Caregivers and Care). Both the dimensions and the content domains provide valuable information for the construction of psychosocial preference instruments. They also might assist formal and informal caregivers in tailoring their interventions to provide individualized care that enhances quality of life for older adults.

Key Words: Preferences, Psychosocial Care, Assessment

The Psychosocial Preferences of Older Adults: A Pilot Examination of Content and Structure¹

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Older people with functional limitations often require assistance with a variety of tasks ranging from traditional activities of daily living (e.g., grooming, cooking, managing finances) to more abstract expressions of their will and personality (e.g., participating in hobbies, maintaining contact with friends and family, choosing the attributes of their living environment). Depending on the nature and extent of their impairment, each individual has a unique pattern of care needs. So too does each individual have different thoughts and feelings about how those care needs should be met. For example, two people may require a comparable amount of assistance getting dressed, but they may have different thoughts about what time to get dressed, who they want present when they get dressed, and what they prefer to wear.

A recent emphasis in gerontology has been on promoting the perspective of the individual, the care recipient, in the design and execution of personal care (e.g., Cotrell & Schulz, 1993; Kane & Caplan, 1990; Kane & Degenholtz, 1997; Rader & Tornquist, 1995). Indeed, in advocating improvement in nursing home quality, the 1987 Omnibus Budget Reconciliation Act (OBRA) gave a prominent position to resident preferences as a guide to care. Acknowledging that people have unique notions about their care reflects a respect for the individual, an awareness of individual differences, and a sensitivity to the continued importance of choice and autonomy in late life (Rodin & Langer, 1977). Allowing individuals to exercise control in their environment and integrating personal preference into their care are ways to enhance consumer satisfaction and quality of life (Kane, 1995; Kane & Kane, 1988; Kearney & McKnight, 1997; Rader & Tornquist, 1995).

One area in which the importance of personal preference has been recognized for some time is in the case of advance directives (e.g., Cox & Sachs, 1994; Mold, Looney, Viviani, & Quiggins, 1994; U.S. Senate Special Committee on Aging, 1987). Advance directives offer individuals the opportunity to plan the kind or degree of medical intervention they would like if at some point they are unable to express their wishes. While the value of documenting aspirations for medical care has been widely acknowledged, relatively little theoretical or empirical work has been done regarding the assessment and implementation of preferences in the area of psychosocial care (for notable exceptions see the work of Froberg & Kane, 1989; Kane, 1995; and Kane & Degenholtz, 1997).

Just as people have unique wishes about the medical care they receive, they may have unique wishes about the personal care they receive as they become more dependent on others. It may be useful to document psychosocial preferences while an individual is capable of expressing them in order to use that information if they are incapable of expressing prefer-

¹Dr. Brian Carpenter was supported in part by a National Research Service Award postdoctoral training fellowship on National Institute on Mental Health Grant 5-532-MH19931-05, Psychiatric–Medical Comorbidity in Aging, Dr. Ira Katz, principal investigator. The authors also wish to acknowledge the generous support of the Harry Stern Family Center for Innovations in Alzheimer's Care at Philadelphia Geriatric Center and the Fam Fox and Leslie R. Samuels Foundation. Ms. Kim Heminway provided valuable assistance in the administration of this project and the gathering of data.

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ences in the future. Currently, however, few empirically derived instruments exist to help caregivers assess psychosocial preferences or broad qualities of a person that might be important to how care is planned or delivered. Without such a tool, care decisions often are based on a best guess about what an individual might like, particularly if they are unable to express their preferences directly. Or, more often, care is provided using a "cookie cutter" approach in which two or three standard service plans are used regardless of personal preferences (Kane, 1995). Previous assessments of preferences in older adults have been limited to important but brief appraisals of personal values (e.g., Degenholtz, Kane, & Kivnick, 1997) or relatively narrow aspects of everyday living (e.g., Brennan, Moos, & Lemke, 1988; Firestone, Lichtman, & Evans, 1980), or have been constructed with no detailed psychometric analysis (e.g., Moore, Staum, & Brotons, 1992); see Note 1, Apprendix B. Brennan, Moos, and Lemke (1989) developed a questionnaire to assess preferences for policies and services in group residential settings, but questions on the instrument were framed in terms of broad communal policy (e.g., "Should residents be allowed to drink a glass of wine or beer at meals?") rather than personal preference (e.g., "I would like to drink a glass of wine or beer at meals."). The authors did suggest, however, that the instrument could be used to compare current policies with residents' preferences when deciding whether a particular care setting was appropriate for a resident. A comprehensive, person-specific assessment is necessary in order to individualize care in all the realms in which it might be needed. With little yet known about how to make such an assessment, significant conceptual issues exist.

Conceptual Issues in the Assessment of Psychosocial Preferences

One consideration in the assessment of psychosocial preferences is whether there are overarching domains or content areas in which preferences are organized. For example, preferences regarding social activities might be distinct and qualitatively different from opinions about more solitary leisure activities. Similarly, individuals might have a collection of opinions that focus on family involvement in caregiving, which could be distinct from their preferences regarding professional caregivers such as physicians, home health aides, or nursing home staff. Currently, little is known about the breadth of people's preferences and whether those preferences fall into cohesive categories. Knowledge about categories of preferences could help guide the construction of preference instruments and the implementation of program and care plans.

A second consideration concerns the specificity of preferences. In their study of community-dwelling elders, Degenholtz and colleagues (1997) identified broad domains of preferences related to care (e.g., privacy) and specific categories within those domains (e.g., personal privacy, financial privacy, and social privacy). Domains of preferences could be arranged, of course, in almost infinite detail. Preferences regarding apparel, for instance, could be divided into preferred clothing for warm weather and preferred clothing for cool weather. Warm weather clothing, in turn, could be divided into preferred clothing for casual occasions and preferred clothing for special occasions, and so on. There is clearly a limit to the specificity that is feasible in an assessment, just as there are limitations in terms of the accommodation to preferences in actual care settings. Theoretically, one could sketch out preferences regarding every aspect of every minute of the day, but the burden of documenting that detail would be great, and the reality of most caregiving environments would prohibit its implementation.

A third issue is whether some preferences are more important than others. Holmes and colleagues (1994) asked nursing home clinical staff, administrative staff, and families of residents with Alzheimer's disease to rate the importance of attributes of special care units. They found a limited range but definite hierarchy of what people thought was important in special care units. In a study of community-dwelling elders receiving case management services (Degenholtz et al., 1997), clients rated the importance of various issues in their current and future care. Here, too, a definite hierarchy emerged. The trade-off between freedom and safety was the issue most important to clients, followed by family/friend involvement in care, privacy, avoiding pain, being able to participate in some future event, and daily routine (in declining order of importance). These results suggest that personal significance might vary *across* domains of preferences (e.g., health care issues might be more important, in general, than aspects of leisure activity) as well as *within* domains of preferences (e.g., having control over one's medications may be more critical than the kind of training one's medical practitioner has). All items in an assessment of preferences may have some worth, but certain items may have higher priority. Importance rankings could be useful in prioritizing care planning and guiding interactions between care providers and care recipients.

The current study grew from the idea that knowing psychosocial preferences is an essential component in providing respectful, individualized personal care. Because little is known about the breadth or organization of preferences, we sought to explore aspects of everyday life that older people consider important and how those aspects are organized. The statistical approach known as concept mapping was used as a data-gathering and analytic technique to investigate, in a preliminary manner, the structure and pattern of psychosocial preferences. What follows is a brief review of concept mapping. For additional details readers are referred to works by Trochim and Linton (1986) and Trochim (1989a).

Basics of Concept Mapping

As its name suggests, concept mapping is a data analytic approach that produces a pictorial representation—literally a map—of items, ideas, or concepts. Like a traditional geographical map, a concept map portrays how close (i.e., similar) or distant (i.e., dissimilar) items are, based on ratings from a group of individuals. Items that are close to one another on the map were rated as similar, and those far from one another were rated as dissimilar. The value of this type of analysis is that it allows investigators to explore interrelationships among items and thereby refine a theory, with the assistance of a picture. Concept mapping has been used to address a wide range of issues including social service planning and implementation (Galvin, 1989), mental health programming (Trochim, Cook, & Setze, 1994), articulation of the facets of special care units (Holmes et al., 1994), and a variety of other evaluation and planning issues (see Trochim, 1989b).

Concept mapping involves a series of data gathering steps that yield a number of products. First, investigators must have a list of items whose similarity/dissimilarity they would like to map. Item generation can occur through a brainstorming process, a literature review, or even a qualitative analysis of transcripts. Next, participants are instructed to sort items into groups based on their perceived similarity. The sorting is done independently by each individual, without consultation with other participants. No explicit guidelines are provided about the strategy they should use for sorting; participants can create any number of groups and can place any number of items in each group. The only definitive instructions are that each item must appear in a group, and each item can appear in only one group. The purpose here is to provide a relatively open-ended task that enables participants to impose on the items the structure that is intuitive to them. In this way investigators can learn how people naturally organize items into conceptual categories. Next, each item is rated, usually on a Likert-type scale, in terms of its importance to the concept under consideration. Finally, as an optional step, participants name each group to indicate what the group represents to them.

Data analysis begins with the construction of a similarity matrix for each participant, usually a square N \times N matrix, where N equals the number of items. In the matrix, a 1 is entered when two items have been sorted by the participant into the same group, 0 if the two items were sorted into different groups. A total similarity matrix for all participants is constructed by summing the values in each individual matrix. In the total similarity matrix, where M equals the total number of participants, the value of any cell can range from 0 (two items were sorted together by none of the participants) to M (two items were sorted together by all of the participants). The total similarity matrix provides the data for subsequent statistical analyses.

The first step in the statistical analysis is a nonmetric multidimensional scaling (MDS) of the total similarity matrix. This analysis generates a concept map that is a visual representation of similarity: Items that were sorted together frequently appear closer to one another on the map, whereas items sorted together less frequently appear farther from one another on the map. Qualitative interpretation of the concept map involves (a) examining the content of items and their relative positions on the map to determine if there is some underlying thematic organization to the items, and (b) exploring opposite sides of the map to detect unifying dimensions that may describe the basis of item similarity.

Next, the two-dimensional concept map itself provides *xy* coordinates that are the input for a hierarchical cluster analysis. In this analysis items are grouped into non-overlapping clusters, which are interpreted for conceptual significance. Finally, importance ratings for the items are reviewed.

Concept Mapping of Preferences

The purpose of this pilot study was to use concept mapping to derive an empirical structure for the psychosocial preferences of older adults. Knowing more about domains of preferences and their ranked importance would (a) help guide how to structure assessments of preferences, and (b) provide preliminary information relevant to clinical intervention. For this study, items for concept mapping were generated from a number of sources.

First, an extensive literature review was conducted to identify scales and theories that described areas in which preferences might exist. Second, focus groups were held with older individuals at three senior centers, two assisted living facilities, and one nursing home to generate additional areas of preference that older individuals felt were important for the satisfaction of their everyday needs and the maintenance of a good quality of life. Because the ultimate goal was to apply preference measurement to frail elders, item content excluded preferences regarding activities that demand full physical vigor or those identified strongly with the interests of young cohorts.

These efforts yielded approximately 470 items; see Note 2, Appendix B. In the case of medical directives, a number of authors have emphasized that an assessment of broad values may be useful in addition to an investigation of preferences in specific situations (Cox & Sachs, 1994; Lambert, Gibson, & Nathanson, 1990). Consequently, using level of specificity as a demarcation, questions were divided into two categories: broad items that explored a general area, and nested items that addressed precise preferences within a general area. An example of a broad item was, "I enjoy reading," and one of its nested items was, "At what times of day do you enjoy reading?" Items were reviewed for redundancy, rewritten using the broad-then-nested format outlined above, and edited, resulting in a final pool of 80 broad items (see Appendix A). Those 80 items served as the items for concept mapping. The nested items (363 of them) were not analyzed in this study but were retained for use in another pilot project.

Method

Participants

Twenty-eight individuals were contacted to participate in this pilot study. All were over age 60 with established records of research and service in the area of gerontology. Older gerontologists were sought for participation because of their simultaneous perspectives as older individuals and scientific experts. Although the participants in this pilot study represented a select group of individuals and therefore a limited perspective on elder preferences, they were thought to have personal insight into late life as well as professional experience with the issues of importance to elders. Of the 28 individuals contacted, 20 (11 men and 9 women) provided completed protocols. A majority had completed doctoral work (67%), and most worked in research or academic settings (78%). This sample size is comparable to those used in other studies employing concept mapping (see Trochim, 1989b).

Materials and Procedure

Participants were mailed an introductory letter and instructions for the concept mapping procedure. Along with the instructions were 80 index cards, and on each was printed one of the 80 broad preference items. Participants were instructed to sort the items into groups that reflected areas of preferences for everyday living. After completing the sorting procedure, respondents were directed to record which items they had grouped together. Finally, participants rated each item in terms of its importance as a preference for their everyday living. Ratings were made on a 5-point, Likert-type scale ranging from "minimum importance" (1) to "maximum importance" (5).

Data Analysis

The general approach to the concept mapping process was taken from Trochim (1989a); see Note 3, Appendix B. One item was dropped because of a typographical error, leaving 79 items for analysis. The total similarity matrix was analyzed using MDS. The ALSCAL procedure in Statistical Procedures for the Social Sciences (SPSS) was used, which requires for input a dissimilarity matrix rather than a similarity matrix (SPSS, 1994). To obtain a dissimilarity matrix, the value in each cell of the total similarity matrix was subtracted from 20 (the total number of raters).

During MDS, solutions for different numbers of dimensions can be requested (i.e., a two-dimensional solution with two axes, a three-dimensional solution with three axes, etc.), although interpretation becomes difficult when the number of dimensions exceeds two or three. One statistic that can help determine what number of dimensions best represents the data is the stress value. The stress value is a percentage measure of goodness of fit, with values approaching zero representing better fit. Figure 1 portrays the stress values in this study for solutions with different numbers of dimensions. Although the stress value for the two-dimensional solution was moderately high (26%, compared to the 10% that is considered good), Kruskal and Wish (1978) suggest that two-dimensional solutions are generally acceptable, particularly when combined with cluster analysis, which was the case here. In addition, concept mapping studies typically report stress values

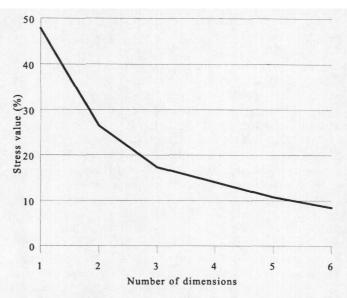


Figure 1. Stress values for multidimensional scaling solutions of different dimensions.

higher than those presented in the multidimensional scaling literature (Trochim, 1989a; Trochim et al., 1994). Therefore, a two-dimensional solution was chosen for interpretation.

XY coordinates for each item on the two-dimensional MDS solution were used as the input for the hierarchical cluster analysis, with Ward's algorithm as the cluster method (after Trochim, 1989a, based on Everitt, 1980). Although no standard mathematical criterion exists for determining the number of clusters that best represent the data, one piece of suggestive evidence is the coefficient generated on the agglomeration schedule. This value is the squared Euclidean distance between clusters. One recommendation is to stop the clustering process at the number of clusters that precedes the first most significant jump in the agglomeration coefficient (SPSS, 1994). (During a cluster analysis, the number of clusters decreases at each step, as additional items/clusters join one another.) In the current sample, the first most significant change in the coefficient occurred between a solution with six clusters and a solution with five clusters, thereby recommending a six-cluster solution. Coefficient change at this stage was 4.45. The coefficient change prior to this stage was 1.96, and the coefficient change at the next stage was 6.71. Another method for determining the most reasonable number of clusters is a qualitative analysis of how items are grouped in successive stages of the cluster analysis (Trochim, 1989a). Here again, the six-cluster solution appeared to provide the best balance between detail and interpretable categorization. Substantive interpretation of the concept map and the clusters was undertaken following procedures suggested by Trochim (1989a).

Results

Figure 2 shows the two-dimensional concept map generated by MDS. Each item is represented by its

The Gerontologist

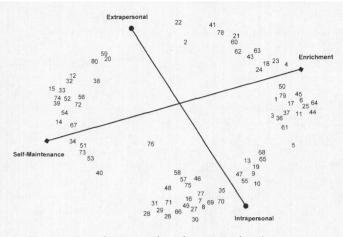


Figure 2. Two-dimensional configuration of preference items.

item number (see Appendix A for a list of the items and their numbers). One of the first things to note is that the items form a fairly coherent circle around an empty center. The centrifugal and distributed arrangement of items suggests, first, that the items represent preferences in a range of content areas, and second, that the participants were relatively consistent in sorting the same items together (J. Arbuckle, personal communication, May 1998). In other words, the individuals in this sample appeared to have a systematic and comparable method of organizing the items into distinct substantive categories.

Dimensions of Psychosocial Preferences

One approach to interpreting the array of items in a concept map is to look for overarching dimensions that characterize the two-dimensional arrangement of items. To accomplish this, one strategy suggested by Trochim (1989a) is to examine patterns among items (a) adjacent to one another, and (b) at opposite sides of the figure. This approach was used to interpret the concept map in Figure 2. As an example of interpretation using adjacent items, those that are near 3 o'clock in Figure 2 include preferences for traveling (item 6), reading (25), doing crafts and hobbies (64), listening to music (44), and spending time outside (11). As a group, these items all seem related to leisure activities. (A more detailed analysis of adjacent items is part of the cluster analysis described later.) As an example of interpretation based on items opposite one another on the map, across from the leisure items, the items at approximately 9 o'clock have a more pragmatic, utilitarian tenor. These items refer to preferences regarding the use of herbs and vitamins (34), having environmental restrictions in place to ensure personal safety (67), having routine medical and dental exams (14), accessibility of alternative medicine providers (54), and the use of assistive devices (51). Unlike the 3 o'clock items, which emphasize discretionary, leisure activities, the preferences at 9 o'clock seem to relate to practical and self-maintaining endeavors. By pursuing similar qualitative comparisons of opposite sides throughout the figure, two primary dimensions emerged. The dimensions appear as lines in Figure 2, drawn on the basis of consensual agreement among the researchers.

The first dimension (roughly east-west in Figure 2) represents a continuum of different types of activities that are pursued throughout life. Items at the eastern end of this continuum represent activities that are purely discretionary, such as attending cultural activities, traveling, spending time outside, and watching television. These are activities people choose to pursue because they find them enjoyable or rewarding. They contribute to a sense of personal growth, cultivation, and pleasure. Items at the western end of this continuum, by contrast, represent activities that are more utilitarian, such as maintaining cleanliness, using assistive devices, taking nutritional supplements, and having regular medical examinations. These are activities that people pursue in order to maintain an optimum functioning in life, and as such they have a more routine, obligatory quality. Overall, this first continuum seems to reflect a range of preferences that are elective versus pragmatic, and the poles were named Enrichment and Self-Maintenance.

The second dimension (roughly north-south) represents a continuum of items that relate to a self versus other focus. Items at the northern end of this continuum address outward-directed, or extrapersonal experiences involving other people, such as keeping in weekly contact with family, being a member of clubs, and meeting new people. These items all reflect preferences for interaction with others. In contrast, items at the southern end of the continuum deal with more self-focused, or intrapersonal lifestyle choices, such as choosing what to wear and eat, maintaining a regular routine each day, and establishing a certain living environment. These items reflect preferences associated with oneself, both in terms of tangible conditions and daily habits. Overall, the second continuum seems to reflect an outward versus inward focus, and poles were named Extrapersonal and Intrapersonal.

Preference Clusters/Categories

In addition to the broad dimensions suggested by the multidimensional scaling, results of the cluster analysis revealed distinct preference categories. The polygons in Figure 3 represent the six clusters that were identified. (Layers for each cluster represent average item importance ratings, which are discussed later.)

Beginning at the top of the figure, the first cluster includes items that relate primarily to social contact. The items address general preferences for social contact, such as a desire for visits with family members and preferred size of social groups, as well as specific social activities, such as participating in clubs and celebrating holidays and birthdays. This cluster is named *Social Contact*. Moving clockwise around the figure, the second cluster also contains items about activities (some with a social component, some not) whose commonality is a potential for personal growth, achievement, or self-enhancement. Examples include preferences for attending cultural activities, traveling,

Vol. 40, No. 3, 2000

339

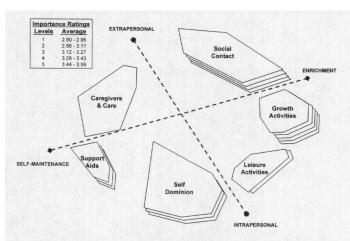


Figure 3. Preference clusters and average importance ratings.

reading, being challenged, keeping busy, and being physically active. This cluster is named *Growth Activities*. The third cluster also includes items about activities, but here they are less goal-directed than those in the previous cluster. Relaxed leisure, diversion, and entertainment appear to be the focus of these items, which include questions about watching television, eating at restaurants, staying around the house, using alcoholic beverages, snacking, and having times during the day with nothing in particular to do. This cluster is named *Leisure Activities*.

At the bottom of the figure, the items shift from specific activities to environmental features, including characteristics of the living environment as well as the ability to control one's schedule and routine. Concrete environmental features addressed in these items include preferences for keeping personal mementos on display, room temperature, floor covering, and lighting. Additional items focus on daily routine involving meals, bathing, and bedtime. More abstract items deal with the general desire for control over one's life, such as preferences for having a plan for the day, choosing when to eat, choosing what to wear, and having privacy. The fourth cluster is named *Self-Dominion*.

Continuing clockwise, the fifth cluster includes items about the use of external resources and aids to maintain well-being. Items address preferences for the use of sensory aids, the availability of ramps and handrails, the consumption of vitamins and nutritional supplements, and the use of medications for pain. This cluster is named Support Aids. Finally, the sixth cluster contains items that address access to medical care, relationships with caregivers, and specific individuals preferred to be involved in care. For example, items assess preferences for routine medical and dental exams, access to alternative medical providers, availability of counseling support, and expected professional training of caregivers. Questions in this cluster also address the quality of the relationship expected with caregivers, such as its level of formality, and the preferred involvement of family and friends in care. This final cluster is named Caregivers and Care.

Topical movement around the cluster map reaf-

firms the content of the two broad dimensions discussed earlier (see Figure 3). The Caregivers and Care and Social Contact clusters have clear social substance and are grouped near the Extrapersonal pole. At the same time, the far edge of Social Contact abuts the Enrichment pole, as does the Growth Activities cluster. Some social activities appear to include an element of personal improvement and development. Moving clockwise to Leisure Activities and Self-Dominion, the emphasis shifts from others to self (Intrapersonal), and items reflect increasingly pragmatic content (Self-Maintenance). Further clockwise, Support Aids has an obvious focus on utilitarian Self-Maintenance, as does Caregivers and Care, although the focus of the latter is more on people who assist with self-maintenance, reflecting the Extrapersonal pole. In summary, the clusters represent distinct categories of preferences that are components of a larger framework of preference dimensions.

Ratings of Item Importance

Table 1 includes a list of items within each cluster, ranked by average importance rating. Overall, respondents expressed a wide range of sentiment about the importance of items, extending from very important (the mean for "I like to feel in control of my life" was 4.8 out of a possible 5.0) to minimally important (the mean for "I like that direct care providers address me by my first name" was 1.9). The five highest ranked items addressed preferences for feeling in control of one's life (item 58), having weekly contact with family (22), reading (25), getting around town independently (13), and being challenged (37). In contrast, the five lowest ranked items included preferences for being in a lively place (50), having caregivers with the same background as oneself (32), obtaining help to get motivated (56), being active the same time each day (35), and having caregivers use one's first name (72).

Items from different clusters were evenly distributed throughout the rankings, suggesting that no one cluster was more important than another. In Figure 3, clusters are layered to indicate the average importance of their items. The cluster with the highest mean importance rating was Growth Activities (M =3.59, SD = 0.81). Next important was the Social Contact cluster (M = 3.35, SD = 0.71), followed by Self-Dominion (M = 3.21, SD = 0.68) and Support Aids (M = 3.29, SD = 0.83). Finally, the Leisure Activities cluster (M = 3.03, SD = 0.71) was followed by Caregivers and Care (M = 2.86, SD = 0.71). For this group of healthy elders, with relatively high education and continuing work involvement, preferences related to self-growth and self-determination appeared most important. It should be noted, however, that the differences among average importance ratings were small. In fact, a one-way analysis of variance indicated that there were no statistically significant differences between cluster mean importance ratings, F(5,73) = 1.73, p > .10. Despite considerable spread within the clusters, the categories themselves all appeared moderately important.

The Gerontologist

Table 1. Ranked Mean Importance Ratings of Preference Items, by Preference D	omain
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Social Contact	Rating	Leisure Activities	Rating		
22. have weekly contact with family	4.53	13. get around town independently	4.45	57. learn things in particular ways	2.47
62. physical contact with someone	4.30	10. display mementos	3.80	28. bathe at specific time	2.42
23. celebrate holidays/birthdays	4.00	65. eat at restaurants	3.40	46. nap	2.25
43. meet new people	3.74	55. have times with nothing to do	2.85	35. be active same time each day	2.00
21. spend time with small groups	3.68	68. do household tasks	2.70		
2. live in same room as someone	3.65	5. watch TV	2.60	Support Aids	Rating
24. volunteer to help others	3.26	47. snack	2.55	53. decide when to take medications	4.40
60. be a group leader	3.10	19. stay around the house	2.50	73. use hearing aids, glasses, etc.	3.60
18. reminisce about the past	2.90	9. alcoholic beverages	2.40	40. keep clean	3.53
63. be a member of clubs, etc.	2.80			34. use herbs, vitamins, supplements	2.58
4. participate in religious activities	2.85	Self Dominion	Rating	51. use ramps, hand rails, etc.	2.35
78. be center of attention	2.35	58. feel in control of life	4.80		
41. spend time with large groups	2.26	77. have privacy	4.30	Caregivers and Care	Rating
		7. choose what I eat	4.05	74. know about medical condition/treatment	4.35
Growth Activities	Rating	8. choose what I wear	3.75	20. people to be courteous	3.68
25. read	4.47	66. choose when I eat	3.65	59. family members help with care	3.68
37. be challenged	4.42	27. eat three meals/day	3.53	33. talk to a professional about problems	3.53
1. spend time by myself	4.25	48. pay attention to appearance/dress	3.50	15. receive medical care from MD only	3.30
45. cultural activities	4.16	76. do things to feel better	3.50	14. have routine medical/dental exams	3.15
17. do new things	4.05	70. live in a colorful environment	3.35	80. have friends involved in my care	3.00
61. be physically active	4.00	30. be where it is quiet	3.32	38. caregivers call me by a particular name	2.89
44. listen to music	3.95	75. have a plan for my day	3.30	54. use alternative medicine providers	2.80
11. spend time outside	3.85	49. bright lighting	3.15	52. formal relationship with caregivers	2.55
36. keep busy	3.74	69. keep blinds/curtains open	3.10	67. accept restrictions for my safety	2.35
6. travel	3.65	31. have a place to lock things	3.05	12. discuss personal things with staff	2.30
64. do crafts, hobbies, etc.	3.00	71. have carpeting around	3.00	39. have people take care of me	2.26
3. contact with animals	2.30	29. warm temp. where I live	2.84	32. caregivers have same background	2.05
79. shop for bargains	2.30	26. follow sleep/wake routine	2.79	56. help to get motivated	2.00
50. being in lively, noisy place	2.16	16. keep to regular routine	2.50	72. caregivers to use first name	1.90

Note: Questions began with the stem, "I like ..." or "I like to ...". The rating scale ranged from "minimal importance" (1) to "maximum importance" (5).

Discussion

This study used concept mapping to explore the structure of the psychosocial preferences of older adults. Two overarching dimensions and six domains were identified from 80 items that addressed preferences regarding everyday activities. The preference dimensions and domains contribute to our understanding of how psychosocial preferences are organized, and they suggest implications for future scale development as well as clinical intervention.

The two preference dimensions are consistent with continua described in other psychological literatures. Enrichment versus Self-Maintenance is a continuum that emerges, in some form, throughout the research on time use and human activity (e.g., Chapin, 1974; Robinson, 1977). In the context of psychosocial preferences, this dimension implies that older adults pursue some preferences that have as their goal personal growth and development, whereas other preferences are associated with activities related more to selfpreservation and basic functioning (cultural pursuits and travel vs eating and grooming, for instance). What is interesting is that, at least in this sample, importance ratings were uniform along this dimension; enrichment preferences were as important as selfmaintenance preferences. It is possible that the relative good health and high education of this sample enabled respondents to emphasize what might be seen as discretionary activities (e.g., travel), preferences for activities that might seem secondary to the basic tasks of life. On the other hand, consistent ratings throughout this dimension also emphasize the importance to older adults of continued growth, selfimprovement, and enrichment. Care planners and providers who focus solely on the pragmatic aspects of everyday life risk overlooking another facet of life, more abstract perhaps, but equally important to older adults.

The second dimension identified in the concept map, Extrapersonal versus Intrapersonal, reflects an "other" versus "self" focus for preferences. This dimension is reminiscent of broad constructs identified in theory about human personality (e.g., Eysenck, 1967). In terms of preferences for everyday living, older adults seem to have preferences that correspond to their social engagement as well as preferences related to the management of the world more immediately around them (preferences related to time spent with friends vs preferences related to wardrobe, for instance). Importance ratings along this dimension were also uniform, and it therefore seems important for care planning to address preferences both "far from" and "near to" the individual.

Along with the two dimensions, the six preference domains identified in this study also suggest areas of focus for care providers, whether formal or informal, as they consider how to promote a high quality of life for older adults. The six domains are: Social Contact, Growth Activities, Leisure Activities, Self-Dominion, Support Aids, and Caregivers and Care. The Social Contact domain suggests that older individuals have a coherent attitude about engagement with other people that should be assessed during a preferences evaluation. Considerable research has demonstrated the value of social support in enhancing psychological resiliency and well-being (e.g., Taylor, 1990). Yet, while social contact can be a source of support

for some individuals at some times, it is not always beneficial. Social contact that is ineffective, excessive, unwanted, or unpleasant can elevate distress and disrupt well-being (Krause, 1995; Rook & Pietromonaco, 1987; Silverstein, Chen, & Heller, 1996). In order to ensure that social contact has a positive effect, it is important to assess what kind of social engagement individuals prefer. Sensitivity to individual wishes is particularly important in light of the finding that it is the *perception* of support, that is, subjective social support, that seems to be the key ingredient to its beneficial effects (Antonucci, 1990; Helgeson, 1993). Enhanced social contact is an important element in the lives of older individuals, but care planning needs to recognize that the preferred timing, amount, and nature of social contact may differ from individual to individual.

Two other domains of preferences, Growth Activities and Leisure Activities, suggest the importance of paying attention to pursuits that enable growth and pleasure. Humanistic perspectives in psychology have long emphasized an innate striving for personal growth and attainment of one's potential as a human being (e.g., Maslow, 1971; Rogers, 1961), and older individuals may continue to value opportunities for self-education and personal accomplishment even in the face of functional limitations. In fact, the onset of functional limitations may prompt a reassertion of activities that bring meaning to life or a reevaluation of how an individual can maintain a sense of purpose and worth given changes associated with aging. Enjoyable leisure activity also appears to add to the quality of life of older individuals (Kelly, Steinkamp, & Kelly, 1986; Riddick, 1993; Smith, 1993). How salient such opportunities would be among a group of highly disabled or at-risk elders remains to be demonstrated.

Another domain of preference that emerged in the current study, Self-Dominion, is consistent with what is known about the importance of personal choice and control in late life. A desire to remain in control over one's life is an essential human attribute, important in older as well as younger individuals (White, 1959). Particularly for older individuals who face multiple and mounting losses both physiological and psychological, the importance of control may be heightened. Providing opportunities to exert control can have a profound and positive effect on health, as feelings of efficacy and agency are associated with positive physical and psychological outcomes in older individuals (Johnson, Stone, Altmaier, & Berdahl, 1998; Menec & Chipperfield, 1997; Roberts, Dunkle, & Haug, 1994). In fact, the simple act of asking about individual's preferences communicates that their opinion is valued and that their wishes are important. Moreover, following individual preferences delivers another powerful message that the individual has control over their life. An assessment of preferences regarding personal routine and activities of daily living would enable care planners and providers to include client input in their efforts.

A desire for control also seems to be an important

dynamic as individuals think about the care they receive. The Caregivers and Care domain reflects preferences regarding access to services as well as opinions about who should be providing services or assistance. Older individual's preferences regarding the frequency and nature of formal services—what they feel comfortable discussing, how they would like to be addressed, the overall level of formality they would like to maintain with professionals—are important to their satisfaction with care (e.g., Kasper & Riley, 1992; Ross, Steward, & Sinacore, 1993). In the current study it appeared that these concerns extend to informal caregivers as well and include which friends and family members an individual would like to have involved in their care.

Finally, the Support Aids domain suggests that individuals have clear preferences about how assistive devices are integrated into their daily lives. Just as individuals may have derogatory opinions about others who use assistive devices (Stephens, Kinney, & Mc-Neer, 1986), they may have negative feelings about their own use of such instruments. On the other hand, for some individuals the use of prosthetic devices or tools may be welcomed because they increase mobility, independence and, subsequently, self-esteem and quality of life (Harless & McConnell, 1982). In either case, it seems useful to determine how individuals perceive assistive devices before they are implemented.

Some additional comments may be made about the ranking of preferences and the importance ratings found in the current study. First, the rankings in this study are somewhat different from those found by Degenholtz and colleagues (1997). In their study, the trade-off between freedom and safety was rated as most important, whereas here participants in this study rated safety restrictions as relatively unimportant. Instead, being able to get around independently was one of the highest ranked items in the current study, an issue not addressed explicitly by Degenholtz and colleagues. Privacy issues, meanwhile, were relatively important in both studies. Family involvement in care was somewhat less important to the current group; more important was simply having weekly contact with family rather than full-fledged caregiving. These differences between studies might reflect the relative health and functional independence of the participants in the current study. Differences in wording and item specificity between the two studies also could be responsible for the variations in ranking.

A second consideration is that the difference in the mean importance ratings across preference domains was small. This may reflect a reluctance to rate *any* life activity as unimportant. At the same time, the lack of a statistically significant difference does not mean there are not clinically significant differences. Degenholtz and colleagues (1997) also found a narrow range of importance ratings in their assessment of care values and preferences but implied that even those differences might be worthy of a more detailed investigation. In future work it may be helpful to have participants rank categories of preferences in a more direct comparison with one another. Asking participants to rank all 80 items in this study would have been burdensome, but ranking the six general domains would be a feasible way to establish a coarse hierarchy of importance. [Additional measurement and scaling issues in the assessment of preferences are discussed in a series of comprehensive articles by Froberg and Kane (1989)].

In one sense, of course, aggregating importance rankings across individuals runs counter to the idea that preferences are unique to the individual. It may not make sense to summarize ratings when these ratings differ widely across people. In the current study, even the item that had the lowest average importance rating ("I like to have caregivers address me by my first name.") included the full range of ratings; for some people having caregivers use their first name was quite important, for others entirely unimportant. Different people are likely to have different opinions about the prioritization of their preferences.

At the same time, in devising a standardized assessment instrument it is necessary to settle on some organization and structure. How items are placed within an assessment deserves careful consideration, although the best structure might not emerge from purely mathematical considerations such as item importance ratings. Perhaps items that are rated consistently as important should be placed first so that they can be answered before individuals fatigue. Or perhaps highly important items should be placed later, after some rapport has been established between interviewer and interviewee or after the purpose of the task is fully understood. A discussion of preferences is a complicated, abstract undertaking, and it demands a type of self-reflection to which respondents may be unaccustomed at first. The strategy we have adopted in our ongoing work is to place items together that are related to one another and arrange general topics in a logical sequence, progressing from the more straightforward to the more complex. For example, items regarding time preferences ("What time do you like to get up in the morning?") appear together and precede a discussion of activities of daily living ("What do you like to wear when the weather is cold?"), both of which are followed by more sensitive questions about caregivers ("Are there any friends or family members you do not want to have involved in your care?"). The most effective way to structure a preference assessment, one that allows respondents the freedom to consider carefully their answers, awaits further empirical investigation.

So too does the issue of whether it is more useful (theoretically or practically) to think about preferences in terms of the dimensions or in terms of the clusters identified in this study. From the perspective of future instrument development, assessment tools that aim to provide a comprehensive picture of psychosocial preferences will need at least to include items that reflect each of the conceptually distinct preference categories. Similarly, clinical interventions that promote a high quality of life for older adults will need to recognize the broad array of preferences that contribute to an individual's conception of what makes everyday life meaningful. An instrument for assessing preferences is certainly an important element in learning about an individual, but it has limits, as do all standardized tools. Perhaps more important is that the act of completing a preference assessment provides an opportunity for discussions about what is important to an individual, conversations that are rarely undertaken spontaneously. In this way an assessment of preferences can serve as a springboard for in-depth conversations about personal histories, values, and choices.

Limitations of the Current Study

The findings of this study should be interpreted with several sampling and methodological limitations in mind. First, the 20 individuals who sorted preference items represent a convenience sample of highly educated, active researchers and clinicians. Consequently, the clusters identified in the current study and the ranking of preferences might differ from those provided by another group of elders. In some of our additional pilot work, more frail individuals used a smaller number of categories and different rankings of item importance compared to the gerontologists (Carpenter, Van Haitsma, Ruckdeschel, & Lawton, 1998). The participants in the current study may have had experience in research and academia that influenced the intellectual set with which they approached the sorting task, resulting in a relatively high number of preference categories or categories that reflected their knowledge of research in gerontology. Other research on preferences for policies and services in residential settings also found differences between experts and residents (Avant & Dressel, 1980; Brennan et al., 1989). When considering preference importance, one could imagine different rankings between many social subgroups. Leisure activities might be most important for those who are retired; caregiving issues may be most meaningful for individuals with functional impairment; participation in social groups may be vital to more extroverted people. The potential variations are as numerous as the individuals who complete the rankings, which is, of course, the principle that underlies individualized care. Future studies will need to sample larger and more diverse groups of people if useful norms are to be assembled (if normative information is useful at all).

A second limitation relates to the items included in the concept mapping. The full universe of preferences may not have been covered by the items used in this study, and the item generation process itself might have influenced the results. We distilled 80 general items from 470 specific items, and if topic areas were missing the sorting and clustering would have been affected. We feel some confidence that the 80 items included all important areas because (a) the focus groups with older adults generated no new

topic areas, and (b) the individuals who sorted the items were asked to indicate preference areas that were missing, and none felt any area had been overlooked. It is prudent to keep in mind, however, that our item generation process might have had a subtle influence on what categories could be generated during concept mapping. That is, our participation in writing items might have imposed a latent structure that constrained the possible preference domains. Future studies will benefit from including open-ended guestions where individuals can note preferences absent in a standardized questionnaire. Furthermore, it should be noted that, as in the entire literature on leisure studies (Lawton, 1978), a White middle-class bias was probably present in the processes of both sampling items and rating their importance.

A third limitation is that concept mapping, as a technique, is relatively new in the behavioral and social sciences. Previous research has found the technique useful in theory development (e.g., Linton, 1989) and exploration of consumers' attitudes (e.g., Kane, 1992), but the technique has been used infrequently for instrument development projects. Additional psychometric information about the procedure, including its reliability and validity, await further exploration. For instance, studies that employ factor analysis with larger samples would provide factor structures to which the results of concept mapping could be compared.

Further Research

Many complex questions remain about the assessment and implementation of psychosocial preferences of older adults. This study was an attempt to explore the content and structure of those preferences, research we are continuing in a number of additional projects that explore other theoretical and methodological issues. Here we describe some of that ongoing work, the issues we have chosen to address at this stage, and the questions that remain for future research.

We have assembled the 80 general items used in the concept mapping study, along with detailed items that assess quite specific preferences, into one instrument, the Preferences for Everyday Living Inventory (PELI). The PELI is being administered to 500 older adults to establish its psychometric properties in a diverse sample that includes elders from different socioeconomic backgrounds, ethnic and cultural heritages, elders of both genders and with different family statuses, and elders with a variety of health/illness characteristics. Confirmatory factor analyses will allow us to examine the stability of the preference categories identified by the gerontologists in the concept mapping.

The study also provides information about the stability of preferences by monitoring them prospectively, in a longitudinal analysis. In the case of medical advanced directives, preferences for acute care at the end of life have shown both stability and instability (Berger & Majerovitz, 1998; Danis, Garrett, Harris, & Patrick, 1994; Emanuel, Emanuel, Stoeckle, Hummel, & Barry, 1994; Everhart & Pearlman, 1990). Although we may document psychosocial preferences at one point in time, it is possible that normal development, life events, or simply time to reflect on one's preferences might evoke changes in care wishes. This raises the question of the optimum timing for an assessment of preferences. Should psychosocial preferences be assessed when an individual is healthy and living independently, with no imminent physical decline? Later use of such assessments runs the risk of relying on dated estimates. Perhaps, instead, more realistic information about preferences can be generated after people have experienced significant changes in their physical, social, or environmental status, or after they are aware of the potentials and limitations of care services (Kane & Degenholtz, 1997). Degenholtz and colleagues (1997), for instance, found that values and preferences differed between experienced and new consumers of health care services. An acute physical illness, an abrupt change in social network, or relocation to a new residence may prompt a shift in lifestyle preferences or a reevaluation of life's possibilities that is then reflected in stated preferences. Indeed, there has been debate about whether the "present self" can in fact make reliable, valid decisions for a "future self" (Post, 1994). We know little about changes in attitudes and preferences following major (or minor) life events. Likewise, we know little about how long it takes for preferences to "settle" after a significant life change.

Another important issue relates to the mode of assessment. Preferences can be gathered from selfreports or structured interviews. Interviews themselves can be performed by different types of individuals. Family members may have an advantage of intimacy that allows individuals to speak freely about their preferences. On the other hand, some individuals may prefer not to have their family involved, and professional or paraprofessional workers may be the best interviewers. We are attempting to administer the PELI in a number of different formats (e.g., selfadministration, professional interviewer, family interviewer, nurse interviewer) to address the issue of administration feasibility.

As with medical advanced directives, the ideal is to have preferences documented while individuals are still capable of describing their wishes. Unfortunately, few people take the time to complete advanced directives, and they later find themselves in situations where they are no longer able to express their preferences for care. In this situation we might consider whether other individuals can provide reliable, valid information about what an individual might want. Research with caregivers of Alzheimer's patients, for instance, has found that they can provide reliable information about premorbid personality (Strauss, Pasupathi, & Chatterjee, 1993). In contrast, a recent study by Teresi and Holmes (1997) found that family members underreported the prevalence of cognitive impairment in older adult day health care clients, suggesting that family impressions may be biased in some domains. In our research we are exploring whether informants (i.e., family members and home health aides) can provide valid information about psychosocial preferences.

In addition to issues of administration, researchers will need to determine the optimum level of detail in an assessment of psychosocial preferences. The concept mapping study used broad questions about preferences (e.g., "I enjoy being physically active."), but other levels of specificity involving timing ("What time of day do you enjoy being physically active?"), duration ("For how long do you usually like to be physically active?"), and content ("What kind of physical activity do you enjoy?") are required for a comprehensive assessment. In the PELI we have included both broad and specific items. What remains unknown, however, is the level of detail that individuals find most constructive and the level of detail that has the greatest clinical utility.

Theoretical questions also remain about how preferences might be shaped by forces inside and outside the individual. For instance, the Extrapersonal-Intrapersonal dimension hints at an underlying personality trait such as extraversion (Eysenck, 1967). Similarly, the Enrichment-Self-Maintenance dimension might be related to sensation seeking (Zuckerman, Buchsbaum, & Murphy, 1980). Psychological distress also could influence how preferences are communicated. The amotivation and anhedonia that accompany depression could engender a generalized flattening of preferences, making an "I don't really care" response more common. How preferences and their expression are related to personality, psychiatric symptoms, and basic demographic variables remains unexplored. We are attempting to examine relationships among preferences and these ancillary constructs in our ongoing study.

Finally, implementation and outcome are additional issues that present challenges to both researchers and clinicians. What, for instance, is the most useful point of entry to introduce an assessment of preferences to consumers? Perhaps it is upon initiation of services, although for some individuals this may be too late for them to record preferences themselves. Once preference information has been obtained, we then need to convey that information to care providers in ways that can have a genuine impact on care. One goal of our ongoing study is to determine the most parsimonious way to summarize information and the most effective way to present that information to care providers (e.g., graphically vs short narratives vs categorized by care task) without losing the essence of the individual.

Beyond issues of assessment, of course, looms the question of whether (or, more optimistically, how) paying attention to preferences has an impact on quality of life, satisfaction, or other outcomes such as physical and mental health. It will be important to determine whether the implementation of certain preferences, or groups of preferences, is associated with different results. We may find that preferences related to social contact, for instance, have more power to promote well-being compared to preferences related to environmental modifications. Previous research has established the importance of social support (George, 1996; Hays et al., 1998) and control (Menec & Chipperfield, 1997; Rodin & Langer, 1977) to the well-being of older adults, and perhaps these preference domains will emerge as being most influential. The relative potency of different preferences remains an important empirical question. Although it may be that preferences have a differential impact on outcomes, a more salient overarching issue may be the congruence between preferences, we anticipate the best outcomes; when care is incongruent with preferences, we expect the worst outcomes, regardless of the actual domain of preference.

Despite our ability to catalog a comprehensive list of preferences, in all reality only a limited number are likely to be implemented. Perhaps those with the most significant impact should be singled out first. Another way to prioritize the implementation of preferences, however, would be to examine rankings by respondents themselves. In the PELI, respondents are allowed to express something akin to importance, or the strength of their opinion, with five response options. As an example, for the question, "Do you like spending time outside?", responses can be "not at all" (essentially, an expression of dislike or an aver-sion), "a little," "somewhat," "a lot" (a strong preference), or "no preference." This kind of rating can provide one index of importance or value. Strong preferences and aversions might be those that deserve the most attention when caregivers are trying to prioritize their efforts.

The actual accommodation to different preferences is also likely to be influenced by their costs. In a nursing home setting, for instance, accommodations at the level of the individual, such as allowing a resident to choose her own clothes for the day, are relatively easy to make and have few costs associated with them. Accommodations at the level of the unit, such as adjusting waking or bathing schedules, may be more difficult to implement because they depend on larger factors such as staffing levels. At the highest level, accommodations that require institutional or systemic modification may be least likely to be implemented because of the difficulty of changing larger structures and policies. For instance, some facilities may have strict policies about the use of alcohol, despite a resident's preference to have a glass of wine with dinner on occasion.

The expression of preferences and their implementation also raises ethical issues that will need to be addressed. One can imagine situations where personal preference conflicts with others' beliefs about the best interest of an older adult. What if, for instance, a penchant for sweets contradicts dietary recommendations for diabetes? Preference assessments are not meant to be adopted as rigid demands, just as clinical judgment is not expected to override client or patient wishes. Instead, preference assessments are meant to add information to the conversation between care recipients and care providers. Still, paternalism, autonomy, and the status of preferences as

"rights" are complex issues that will require thoughtful consideration in future research.

Summary

Individualized environments and individualized care are important elements in maintaining quality of life for older people. Providing individualized care depends, however, on the availability of comprehensive, reliable, and valid ways of assessing what is important to individuals. The current study was a first attempt to clarify the breadth and organization of psychosocial preferences. Future studies can continue this work by verifying the overarching constructs in preferences and exploring the practical issues regarding assessment and implementation.

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The Gerontologist

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Received March 2, 1999 Accepted December 28, 1999

Decision Editor: Vernon L. Greene, PhD

Appendix A

Preference Items

- 1. Lenjoy spending time by myself.
- 2. I enjoy living in the same room as someone else.
- 3. 1 enjoy contact with animals.
- 4. I like to participate in religious/spiritual activities.
- I enjoy watching TV.
 I enjoy traveling.
- 7. I like to choose what I eat.
- 8. I like to choose what I wear.
- 9. Lenjoy alcoholic beverages.
- 10. I like to keep certain personal mementos on display where I live.
- 11. Lenjoy spending time outside.
- 12. I like to discuss personal things with the staff who care for me
- 13. I like to be able to get around town independently.
- 14. I like to have routinely scheduled medical/dental examinations.
- 15. I like to receive my medical care from an MD rather than a physician's assistant or nurse practitioner.
- 16. I like to keep to a regular routine each day.
- 17. I like doing new things.
- 18. I like reminiscing about the past.
- 19. I like to stay around the house.
- 20. I like people to be courteous.
- 21. Lenjoy spending time with small groups of people.
- 22. I like to keep in weekly contact with my family.
- 23 1 like celebrating holidays and birthdays.
- 24. I like to volunteer my time to help others.
- 25. Lenjoy reading.
- 26. I liké tó follow a routine when I go to bed and when I get up.

Vol. 40, No. 3, 2000

- 27. I like to eat three meals a day.
- 28. I like to bathe at a specific time.
- 29. I like to have the temperature where I live to be on the warm side.
- 30. 1 like to be where it is quiet.
- 31. I like to have a place to lock my things.
- 32. I like the people who care for me to have the same background as me.
- 33. I'd like to have the chance to talk to a professional if I had an emotional problem or worry.
- I like to use herbs, vitamins, and supplements. 34.
- 35. I like to be most active at the same time each day.
- 36. 1 like to keep busy.
- I like to be challenged.
- 38. I like people to call me by a particular name.
- I like having people take care of me. 39
- 40. I like to be careful about being clean.
- 41. Lenjoy spending time with large groups of people.
- 42. I like to keep in frequent contact with my friends.*
- 43. I enjoy meeting new people.
- 44. I enjoy music.
- 45. I enjoy cultural activities.
- 46. I like to nap.
- 47. I like to snack.
- I enjoy paying attention to my appearance and dress.
- I like the lighting where I live to be on the bright side. 49.
- 50. I enjoy being in a lively, noisy place.
- 51. I like being in a place that has ramps, hand rails, etc.
- 52. I like to keep my relationship with someone providing care to me formal.
- 53. I would like to be able to decide whether to take medications for pain or other symptoms.
- 54. I like to have access to alternative medicine providers, e.g., chiropractors, acupuncture.
- 55. I like to have times during the day when I have nothing particular to do.
- 56. I like to be given help to get motivated to do things.
- 57. I like to learn things in particular ways.
- 58. I like to feel in control of my life.
- 59. I like having particular family members involved in my care.
- 60. I enjoy being a group leader.
- 61. I enjoy being physically active.
- 62. 1 enjoy physical contact with someone I care about.63. 1 like being a member of clubs, community, or other organizations.
- 64. Lenjoy doing crafts, handiwork, and hobbies.
- 65. I like to eat at restaurants.
- 66. I like to choose when I eat.
- 67. I like to have some restrictions imposed to insure my safety.
- 68. I enjoy doing household tasks.
- 69. I like to keep blinds, shades, and curtains open.
- 70. 1 like a colorful environment.
- 71. I like being in a place that has carpeting.
- 72. I like that direct care providers address me by my first name
- 73. I like being able to use hearing aids/glasses/dentures.
- 74. I like to know about every aspect of my medical condition and treatment.
- 75. I like to have a plan for my day.
- 76. I like doing things to make me feel better when I'm upset.

*This item was dropped due to a typographical error on the

Appendix B

Notes

1. The literature on assessing preferences for individuals with

developmental disabilities is somewhat more advanced,

77. I like privacy

347

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78. I like being the center of attention.

concept mapping questionnaire.

- 79. I like to shop around for the best bargains.
- 80. I like having particular friends involved in my care.

and a review can be found in Kearney and McKnight (1997).

- 2. The method used in this study was slightly different from the procedure used in traditional concept mapping wherein participants typically both generate items and then sort them; here the investigators constructed the items and research participants sorted them.
- 3. Trochim has created a computer software package that facilitates the entire concept mapping process, from item generation through reporting, although the statistical procedures themselves are available in most standard statistics packages, including SPSS, which was used here.