# Long-term Care Residents' Preferences for Health States on the Quality of Well-Being Scale

# RON D. HAYS, PhD, ALBERT L. SIU, MD, EMMETT KEELER, PhD, GRANT N. MARSHALL, PhD, ROBERT M. KAPLAN, PhD, SANDRA SIMMONS, DARYL EL MOUCHI, JOHN F. SCHNELLE, PhD

The Quality of Well-Being Scale (QWB) quantifies health-related quality of life with a single number that represents community-based preferences for combinations of symptom/problem complexes, mobility, physical activity, and social activity. The aim of this study was to compare preferences of a long-term care population with those of the general population, determine whether preferences vary by the age of the hypothetical (target) person depicted in the health-state case description, and derive weights for new symptom/problem complexes of particular relevance to frail, older individuals. A sample of 38 female and 12 male long-term care residents with an average age of 86 years was asked to rate health-state scenarios that combined the four health domains of the QWB. This sample rated quality of life 0.10 units lower on average (on a 0-1 scale) than did the general population sample from which the QWB preferences were originally developed. Ratings of the same health state for younger versus older target persons did not differ significantly (all p values > 0.05 for t statistics). Weights derived for 11 new symptom/problem complexes were: disturbed sleep (-0.252), sit-to-stand requires maximal effort (-0.259), lonely (-0.265), walking a short distance causes extreme fatigue (-0.273), agitated (-0.284), hallucinating (-0.355), incontinent (-0.359), unable to control one's behavior (-0.360), urinary catheter (-0.374), restrained in bed or chair (-0.374), and feeding tube through the nose or stomach (-0.402). These new weights increase the relevance of the QWB for cost-utility evaluations of health interventions for long-term care residents. Key words: health state preferences; long-term care; patient preferences; Quality of Well-Being Scale; quality of life; age factors. (Med Decis Making 1996;16:254-261)

Cost-effectiveness analysis is increasing in popularity, because it allows for simultaneous consideration of the costs and outcomes of health care.<sup>1</sup> Direct and indirect costs can be used in tandem with health states to summarize the costs and levels of effectiveness of different interventions. Cost-utility analysis is a variant of cost-effectiveness analysis in which utilities or preferences are assigned to different states of health. Health outcomes in cost-utility analyses are typically expressed in quality-adjusted life years (QALYs), in which years alive are adjusted

Address correspondence and reprint requests to Dr. Hays: RAND, 1700 Main Street, Santa Monica, CA 90407-2138. e-mail: (Ronald\_Hays@rand.org). downwards for poor health by quality multipliers reflecting subjective evaluations of their desirability. Thus, a year of complete wellness equals 1.0 QALY and time dead has no value (the quality multiplier = 0.0). A year alive with less than complete wellness has a value between 0.0 and 1.0. (Although the zero point has most frequently been used to represent death, it is possible to anchor the scale with states worse than death.<sup>2</sup>) The Quality of Well-Being Scale (QWB) is one of a select few measures that provide estimates of the value of health states necessary for cost-utility analyses.<sup>3-5</sup> QWB scores are derived from preference weights for combinations of symptom/problem complexes and classification of functioning in terms of mobility, physical activity, and social activity obtained from a San Diego general population sample of 867 individuals.<sup>5</sup> These preference weights were obtained in the mid 1970s, but a recent study of Oregon citizens yielded very similar results.<sup>6</sup>

The QWB is a particularly attractive method for cost-utility estimates for interventions involving frail, older persons. However, usefulness of the QWB in this population is limited by the omission of some

Received March 7, 1995, from RAND, Santa Monica, California (RDH, EK, GNM); Mount Sinai School of Medicine, New York, New York (ALS); the University of California, San Diego, La Jolla, California (RMK); and Jewish Home for the Aging, Tarzana, California (SS, DEM, JFS). Revision accepted for publication September 22, 1995. Presented at the meeting of the International Society for Quality of Life Research, October 16, 1994, Montreal, Quebec, Canada. Supported by a grant from the National Institute on Aging Claude D. Pepper Older American Independence Center (#AG10415-01).

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important symptoms and problems. These omitted symptoms include incontinence, disturbed sleep, agitation, and lack of control over behavior. For example, 13% of nursing home residents 65 years of age or older have some anxiety disorder, 38% have behavioral problems, 42% have mood disorders, and 55% are incontinent.<sup>7</sup>

This study had three primary aims: 1) to compare preferences of long-term care residents with those of the general population; 2) to determine whether the preferences of long-term care residents vary by the age of the target person depicted in the healthstate case descriptions; and 3) to derive weights for symptom/problem complexes especially relevant for frail, older individuals. These new weights will increase the relevance of the QWB for cost-utility evaluations of health interventions for long-term care residents.

# Method

#### SUBJECTS

The board-and-care facility at the Jewish Homes for the Aging has a population of 375 residents, who range in age from 65 to 108 years. People are admitted to board-and-care only if they are independent in most activities of daily living skills and are cognitively intact to the point that they do not require extensive supervision. Board-and-care residents, with very few exceptions, have Folstein Mini-Mental Status Exam scores of 22 or higher. Board-and-care residents are offered meal services and assistance with bathing. In addition, a licensed nurse is available 24 hours a day for emergency service and medication administration.

The second of the three primary aims of the study, the determination of whether or not the age of the target person would affect ratings, required the largest sample. We calculated that a sample of 50 individuals would allow us to detect a 0.25 SD (0.045 units on the 0-1 QWB scale) difference in pooled ratings with 80% power and two-tailed 5% significance.<sup>8</sup> The 50 participants in this study were selected by approaching board-and-care residents and asking for their verbal consent to participate in the interview. Six of the 56 residents approached refused to be interviewed, resulting in a sample of 38 women and 12 men. All of the residents had had to meet minimal medical stability and functional status criteria to qualify as board-and-care residents. There was no indication that the residents who refused to be interviewed were sicker or more functionally impaired than those who agreed to be interviewed.

The respondents' ages ranged from 72 to 108

years (mean age = 86). All respondents were white. Self-reported health status ranged from excellent (n = 3), to very good (n = 10), to good (n = 20), to fair (n = 16), to poor (n = 1). Educational attainment was less than high school for 48% of the sample, high school graduate or GED for 32%, vocational school or some college for 16%, and college graduate for 4%.

Because all board-and-care and nursing home residents were housed on the same campus, the respondents in this study had had similar experiences with the symptom/problem complexes to be rated.

# PROCEDURE

Respondents were interviewer-assisted in rating 34 scenarios combining the four health domains of the QWB (physical activity, mobility, social activity, and symptom/problem complexes). The interviews took approximately 45-60 minutes to complete, and about 20% of the interviews had to be completed in two sessions. As with the original preference studies with the QWB, ratings were made on a 0-10 ladder, with the zero point labeled "Death" and 10 labeled "Perfect Health," and divided by 10 to obtain a number between zero and one. The scaling method was the same as that applied in the original QWB scaling studies.<sup>5</sup> In pilot testing, respondents sometimes had difficulty tracking and remembering the task assignments. Thus, we created poster-sized charts displaying the instructions and the scenarios to provide a visual aid for the rating task and minimize effects of poor memory. Warm-up items were included to familiarize respondents with the rating task.

To assess the similarity of the preferences of the residents in this sample to those of the general population, we administered six standard QWB scenarios (see appendix A) to the respondents in this study. These scenarios were presented twice, varying the age of the target person depicted in the case description ("Adult, age 18-65" versus "Adult, age 66 or older"), to assess the influence of the age of the person being rated. These two age categories, although broad, were chosen to provide an initial estimate of possible age-related effects on preferences.

We also evaluated 11 new symptom/problem complexes: incontinent, restrained in bed or chair, unable to control one's behavior, disturbed sleep, agitated, hallucinating, lonely, feeding tube through the nose or stomach, urinary catheter, sit-to-stand requires maximal effort, and walking a short distance causes extreme fatigue. These new symptom/problem complexes were chosen for three reasons: 1) they represent common problems that afflict longterm care residents; 2) most or all of these symptom/ problem complexes are amenable to treatment; and 3) interventions have been described that may affect

Adult (age 66 or older) Adult (age 66 or older) In special care unit (operating room or intensive care unit of a hospital) In house Walked with physical limitations In bed or chair Had help with self-care activities (bathing, dressing, eating, using bathroom) Limited in amount or kind of work, school, or housework Feeding tube through the nose or stomach Feeding tube through the nose or stomach Perfect Health 10 Perfect Health 10 9 9 8 8

FIGURE 1. Example 1.

these symptom/problem complexes. The data described in this paper will facilitate cost–utility analyses of these interventions.

These new symptom/problem complexes were included in 22 scenarios by combining them with two configurations of physical activity, social activity, and mobility. The first configuration was: in house, walked with physical limitations, and limited in amount or kind of work, school, or housework. The other configuration was: in special care unit, in bed or chair, and had help with self-care activities (see appendix B).

The 34 scenarios (six standard scenarios by two target person ages plus two configurations for each of the 11 new symptom/problem complexes) were randomly ordered three different ways, and each respondent was administered one of the three versions. Ratings for two of the 34 scenarios differed significantly by order of administration (p < 0.05), whereas 1.7 differences were expected by chance alone.

# ANALYSIS PLAN

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We evaluated the extent to which the ratings of the QWB scenarios varied by the age of the person in the hypothesized health state using t statistics. We also regressed the quality-of-life ratings for 12 sce-

narios (six QWB scenarios repeated for the two age categories of the target person) on the QWB preferences from the general population for each scenario, including a dummy variable for whether the person described in the case description was 18-65 years old or 66 years old or older (i.e., one regression model with 50 people providing 12 ratings). In addition, we estimated the interaction between the QWB general-population preferences and the age dummy variable. QWB general-population preferences were centered to have a mean of zero, and quality-of-life ratings obtained in this study were recoded as deviations from the mean (0.66) of the corresponding uncentered QWB general-population preferences. Individual ratings were the unit of analysis and we therefore adjusted for within-rater correlation using the Huber method,<sup>9</sup> a nonparametric correction. Regression coefficients were considered significant if the probability was less than or equal to 0.05.

Finally, we estimated the weights our sample assigned to the new symptom/problem complexes. If the raters in this sample had preferences similar to those of the individuals in the San Diego general population and a symptom/problem complex had no impact on quality of life, the scenarios under the first configuration above should receive a rating of 0.817 [i.e., decrements from 1.0, perfect health, as-



7 6

5

4

3

2

1

0

Death



FIGURE 2. Example 2.

sociated with being restricted to the house (-0.062), walking with physical limitations (-0.060), and being limited in amount or kind of work, school, or housework (-0.061)]. Similarly, if a symptom problem/ complex had no impact on quality of life, ratings for the scenarios under the second configuration should be 0.727 [i.e., decrements from 1.0, perfect health, associated with being in a special care unit (-0.090), being in a bed or chair (-0.077), and having help with self-care (-0.106)]. The difference between these values and the observed ratings provided estimates of the weights uniquely associated with the symptom/problem complexes.

# Results

Missing data rates were 2% or lower for ratings of the QWB scenarios. Table 1 presents descriptive statistics for ratings of the six QWB scenarios that were administered twice, varying the age of the person depicted in the case description. Ratings for the younger (18–65 years old) target person are presented above ratings for the older (66 years old and older) target person. Published QWB preferences from the general-population sample are provided in the second column. Ratings for each of the six health states did not differ significantly (all t statistics were 1.39 or lower; all p > 0.05) for younger versus older target persons.

The adjusted R-squared for the regression of quality-of-life ratings on the general-population preferences, the age of the target person rated, and the interaction between these two main effects was 0.53. However, the main effect of age and its interaction with the general-population preferences were not significant (p > 0.05), indicating that quality-of-life ratings did not vary by age of the person depicted in the case description. Dropping the two nonsignificant effects did not change the adjusted Rsquared for the model. The unstandardized coefficient for the general-population preferences was 1.01 and the intercept was -0.10. The large, significant effect of the general-population preferences indicates a strong linear relationship between the ratings of the respondents in the sample compared with the general population. The constant was significantly less than zero, indicating that the qualityof-life ratings of this long-term care sample were significantly lower, on average by 0.10 units, than those of the general population. Controlling for age, education, and self-rated health status (excellent to poor) of the rater did not change the adjusted Rsquared for the model, but better health was significantly associated with higher quality-of-life ratings (unstandardized beta = 0.03, p < 0.05).

Next, we compared quality-of-life ratings for the 22 new scenarios with those expected from the combination of physical activity, mobility, and social ac-

 Study Participants' (Nursing Home Residents') Preferences for Six Target Health States, by Age of Target Person: Central Tendency, Variability, and Comparisons with General Population Preferences for Quality of Well-being Health States

Scenario*	General Population Preference	No. of Participants	Participant		Preference Limit	
			Preterence			
			Mean	SD	Minimum	Maximum
Scenario A						
18-65-year-old target person	0.939	50	0.73	0.20	0.20	1.00
66+-year-old target person	0.939	50	0.77	0.18	0.40	1.00
Scenario B				•		
18-65-year-old target person	0.856	49	0.76	0.20	0.10	1.00
66+-year-old target person	0.856	48	0.77	0.17	0.30	1.00
Scenario C						
18-65-year-old target person	0.716	50	0.68	0.19	0.30	1.00
66+-year-old target person	0.716	50	0.68	0.20	0.20	1.00
Scenario D						
18-65-year old target person	0.642	49	0.66	0.17	0.20	1.00
66+-year-old target person	0.642	.49	0.65	0.18	0.20	1.00
Scenario E						
18-65-year-old target person	0.470	50	0.28	0.19	0.00	0.70
66+-year-old target person	0.470	49	0.27	. 0.22	0.00	1.00
Scenario F		•				
18-65-year-old target person	0.320	49	0.21	0.20	0.00	. 0.90
66+-year-old target person	<b>p.320</b>	49	0.19	0.17	0.10	0.80

\*Scenario designations refer to the scenarios in appendix A.

tivity alone. The observed rating was subtracted from the QWB rating expected (based on published general-population preferences) if symptom/problem complexes had no impact, in order to estimate the weight associated with the symptom/problem complex. We also subtracted 0.10 from this difference to adjust these estimates for the mean difference between the quality-of-life ratings of the longterm care residents in this sample and the general-population preferences. Table 2 provides the adjusted mean differences (estimates of the symptom/problem complex weights) and standard deviations of differences. All differences from zero were statistically significant (p < 0.01).

We produced final weights for the 11 new symptom/problem complexes by averaging the estimates for the two configurations. The final weights, from least negative to most negative, are as follows: disturbed sleep (-0.252), sit-to-stand requires maximal effort (-0.259), lonely (-0.265), walking a short distance causes extreme fatigue (-0.273), agitated (-0.284), hallucinating (-0.355), incontinent (-0.359), unable to control one's behavior (-0.360), urinary catheter (-0.374), restrained in bed or chair (-0.374), and feeding tube through the nose or stomach (-0.402).

# Discussion

Three major results were obtained in this study. First, the preferences for QWB health states of the long-term care residents differed from those reported previously for a sample from the general population.<sup>5</sup> In particular, the long-term care residents rated the quality of life associated with QWB health states to be lower than did the general-population sample. Second, we found that quality-of-life ratings did not vary by age of the target person depicted in the health-state case descriptions. Finally, weights for 11 new symptom problem/complexes of particular relevance to older populations were derived.

This is the first study to document differences in preferences for the QWB health states by age of rater, with very old respondents assigning lower quality-of-life ratings than younger respondents. Previous studies with the QWB have found that arthritis patients<sup>10</sup> and cancer patients<sup>11</sup> have preferences similar to those of the San Diego general-population sample. In other research, the time-tradeoff utilities for imagined health states were consistent with those obtained after actual experience with those states in laryngeal cancer patients.<sup>12</sup> Moreover, a recent study showed that utilities for health states provided by younger and older respondents using a time tradeoff did not differ significantly.<sup>13</sup>

 
 Table 2
 Unique Contributions of New Symptom/Problem Complexes to Preferences for Quality of Well-Being Health States\*

Symptom/Problem Complex		First Scenario		Second Scenario	
		Mean	SD	Mean	SD
1.	Incontinent	-0.34	0.16	0.38	0.18
2.	Restrained	-0.34	0.18	-0.41	0.16
З.	Unable to control	-0.32	0.18	-0.39	0.20
4.	Disturbed sleep	-0.18	0.19	-0.33	0.20
5.	Agitated	-0.20	0.21	-0.37	0.19
6.	Hallucinating	-0.29	0.20	-0.42	0.14
7.	Lonely	-0.21	0.24	-0.31	0.25
8.	Feeding tube	-0.36	0.21	-0.44	0.15
9.	Urinary catheter	-0.36	0.20	-0.39	0.20
10.	Sit-to-stand	-0.17	0.22	-0.35	0.18
11.	Walk short distance	-0.17	0.21	-0.38	0.18

\*The labels refer to symptom/problem complexes included in the scenarios. The first scenario for each symptom/problem complex includes the following combination of physical activity, mobility and social activity: in house, walk with physical limitations, limited in amount or kind of work, school, or housework (general population preference for this combination with no symptom/problem complex = 0.817). The second scenario for each symptom/problem complex includes the following combination: in special care unit, in bed or chair, and had help with self-care activities (general population preference for this combination model of the special care unit, in bed or chair, and had help with self-care activities (general population preference for this combination with no symptom/ problem complex = 0.727). All means represent decrements in health and were significantly different from zero (p < 0.01). SEs ranged from 0.02 to 0.03.

Despite mean differences in preferences, the variability in the ratings in this sample (SDs ranged from 0.17 to 0.22 for QWB states) was similar to that obtained in the San Diego general-population sample.<sup>14</sup> In addition, mean preference ratings in this sample and the general-population sample were significantly associated with one another (productmoment correlation = 0.94, intraclass correlation =0.86, n = 12, p < 0.001). This level of correlation is equivalent to that obtained in a study by Balaban and colleagues that demonstrated similarity of preferences between arthritis patients and the general population.<sup>10</sup> Although there was a strong linear relationship, this sample differed from the generalpopulation sample, because long-term care residents offered systematically lower ratings.

Studies in the original validation of QWB preferences also showed that older respondents provide lower average ratings than do younger respondents.<sup>15</sup> However, these differences have been given less consideration because the model emphasizes average response from a demographically representative sample. Further, age of rater accounted for only a small percentage of the variance in ratings. However, the participants in this study were much older than those in the original validation sample, suggesting that the effect of age may have been underestimated in previous studies.

The implications of the differences in preferences by characteristics of the rater are difficult to evaluしいいとないのないないない

ate. Although many argue that the standard-gamble and time-tradeoff methods are based on better theory than the QWB, it has also been noted that the complexity of these tasks leads to cognitive errors, that some respondents are unwilling to consider any tradeoff between length and quality of life, and that gamble data do not meet the properties of an interval scale of measurement.<sup>11,16</sup> The standard gamble and time tradeoff are especially problematic for frail, older persons because these individuals often have sensory and cognitive deficits. For example, in one recent study only 15 of 41 nursing home residents approached provided complete and usable preference data that were collected using the standard-gamble, time-tradeoff, category-scaling and rank-order methods.<sup>2</sup>

Nord<sup>17</sup> argued that different scaling methods produce different results and that all ratings should be obtained using a person-tradeoff method. His criticism of the QWB was that ratings tend to be compressed toward the middle of the scale. This study suggests that the compression may be more severe for older individuals than for the general population. This compression may result in different estimates of QALYs if preferences from older persons are used. On the other hand, the linear relationship between the preferences of this sample and those of the general population suggests that prioritization of programs (that affect equal numbers of people) would be relatively unaffected by which group provided the preferences. More research is needed to determine which scaling method produces the most reliable and valid weights.

We found no difference in preference weights with respect to the age of the target person (i.e., individual depicted in the scenario being rated). In contrast, Busschbach et al.<sup>13</sup> reported that age of target person was inversely related to the quality of life rated using the time-tradeoff technique—an association found for both younger and older raters.

The weights associated with the 11 new symptom/ problem complexes ranged from -0.252 to -0.402. "Disturbed sleep" was estimated to have the smallest negative impact on quality of life, with a rating of -0.252. This is approximately equivalent to the weight assigned to having a cough, wheezing, or shortness of breath (-0.257). The most negative impact for a new symptom/problem complex was observed for having a feeding tube through the nose or stomach (-0.402). This weight is approximately equivalent to the impact of loss of consciousness (-0.407). A person with a feeding tube would most likely also receive a -0.090 weight for mobility (being in a special care unit), -0.077 for physical activity (being in a bed or a chair), and -0.106 for social activity (having help with self-care activities). Thus, the QWB score would be 0.325, indicating that quality of life is perceived to be about a third of the distance above death on the death (0.0)-to-perfect-wellbeing (1.0) continuum.

As with the original QWB studies, we anchored the category rating scale in this study at "death." Because there is evidence in previous studies that some health states are rated worse than death,<sup>2</sup> we examined the extent to which our method may have affected the ratings. Floor effects (i.e., rating health states to be as bad as death) were rare; the highest percentage of floor effects was 8.2% (for age 66 or older, in special care unit, in bed or chair, had help with self-care activities, and loss of consciousness). Thus, the impact of anchoring health-state ratings with death as opposed to allowing states to be rated worse than death appears to be negligible in this study. Because the current study was not designed to examine this issue in detail, further research is warranted.

This study provides preliminary information comparing preferences of older individuals with those of the general population and yields estimated weights for new symptom/problem complexes of special relevance to long-term care residents. Obtaining preferences directly from older long-term care residents is challenging, but extremely important and feasible. However, the findings of this study need to be interpreted cautiously due to the small and unrepresentative sample of raters. The sample was drawn from a single long-term care facility, and all the participants were white. Additional research is needed to evaluate the robustness of the results reported here in a larger and more representative sample of longterm care residents. Furthermore, the QWB was designed to obtain societal (pooled) preferences for different health states. The results of this study provide support for the precision of the method for this application. The use of the QWB to derive individuallevel preferences is not addressed by this study.

We recommend that studies to evaluate programs for long-term care residents incorporate the 11 new symptom/problem complexes derived here for use with the QWB. If costs are approximately equal, then interventions that reduce the need for feeding tubes or restraints, or decrease incontinence or hallucinations, would be preferred to alternative programs that either increase physical functioning, improve sleep, or reduce loneliness.

The participation of the long-term care residents is gratefully acknowledged. Thanks are due to Jim Tebow and Craig Barela for outstanding secretarial support. The comments of two anonymous reviewers on an earlier draft of this manuscript are very much appreciated. The opinions expressed are those of the authors and do not necessarily reflect the views of RAND, Mount Sinai School of Medicine, University of California, the Jewish Home for the Aging, or the sponsor.

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#### APPENDIX A

#### Symptom/Problem **General Population** Mobility\* Physical Activity† Social Activity‡ Complex Preference 4 3 Scenario A 4 None 0.939 Scenario B 4 3 4 On medications 0.856 3 Scenario C 3 3 Eyeglasses 0.716 Scenario D 4 з 4 Hoarseness 0.642 Scenario E 2 2 2 Shortness of breath 0.470 Scenario F 2 2 2 Loss of consciousness 0.320

General Population Preferences for Quality of Well-Being Scenarios

\*4 = drove car, 3 = in house (-0.062), 2 = in special care unit (-0.090), 1 = dead.

 $\dagger 4 =$  walked without physical problems, 3 = walked with physical limitation (-0.060), 2 = in bed or chair (-0.077), 1 = dead.

 $\pm 4 = did$  work, school, or housework, and other activities; 3 = limited in amount or kind of work, school, or housework (-0.061); 2 = had help with self-care activities (-0.106), 1 = dead.

#### APPENDIX B

# Instructions for Rating and Example Cases

Each of the following cases describes a person affected by a health problem on one day of his or her life. Each case tells one or more of the following kinds of information:

- 1. Whether the person could drive or use public transportation
- 2. How well the person could walk
- 3. How well the person could perform daily activities
- 4. What symptom or problem was bothering the person

In the cases, "special unit" means a restricted area of a hospital such as an operating room or intensive care unit, and "self-care" means specifically bathing, dressing, eating, and using the bathroom.

Think about the day described on each case and rate it by placing an "X" on one step of the ladder from zero (0), representing death, to ten (10), representing perfect health. If the case describes someone who is completely well, then mark an "X" on the top step, ten (10). If you think the situation described is about as bad as dying, then mark an "X" on the bottom step, zero (0). If you think the person's situation is about halfway between being dead and being completely well, then mark an "X" on step five (5). Six (6) is one step better than five (5), five (5) is one step better than four (4) and so on. You can mark an "X" on any of the steps from zero (0) to ten (10), depending on how bad or good you think that day is.

The symptom or problem presented in most of the cases could be caused by many different diseases or injuries. The case does not tell how severe the problem is. You must judge that from how the problem affected the person's activities. Also, there is no way to tell for sure whether the problem will get much better or worse on the next day. So just assume that the person was getting the best medical treatment possible on that day, and that he or she felt and performed as well as his or her condition or treatment would permit.

Read each case, and mark an "X" on the step of the ladder you choose. Do not refer back to cases you have already rated to help you rate a case. Give your opinion about the situation on that one day only. Don't worry about what tomorrow will be like. There are no right or wrong answers—this is simply your opinion.