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Tom Seekins Ph.D.

University of Montana Rural Institute - Research and Training Center on Disability in Rural Communities

Craig Ravesloot Ph.D.

University of Montana Rural Institute - Research and Training Center on Disability in Rural Communities

Kaye Norris Ph.D.

University of Montana Rural Institute - Research and Training Center on Disability in Rural Communities

University of Montana Rural Institute scholarworks-reports@mso.umt.edu

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Prevalence and Disability Outcome of Secondary Conditions Experienced by Adults with Disabilities Living in a Rural State:

Validation of a Surveillance Instrument

Tom Seekins, Ph.D. Craig Ravesloot, Ph.D. Kaye Norris, Ph.D.

Rural Institute on Disabilities University of Montana

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All correspondence and requests for reprints should be sent to the first author, Tom Seekins, Ph.D., Director of Research, Rural Institute on Disabilities, 52 Corbin Hall, University of Montana, Missoula, MT 59812.

Prevalence and Disability Outcome of Secondary Conditions

Experienced by Adults with Disabilities Living in a Rural State:

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Running Head: Prevent Secondary Conditions

Abstract

Objectives. People with disabilities can lead healthy lives but may be at risk for secondary conditions. This study investigated prevalence rates and disability outcome of secondary conditions using the Secondary Conditions Surveillance Instrument (SCSI). The reliability and validity of the SCSI for measuring self-reported limitation due to secondary conditions was also investigated.

Methods. Three-hundred-fifty-four handicapped parking permit holders and 22 non-disabled undergraduate students completed the SCSI. Eighteen people with spinal cord injuries completed the SCSI twice approximately 3 years apart.

Results. Respondents reported experiencing an average of 14 secondary conditions during the past year with 73% experiencing more than 10 conditions during that time period. Prevalence rates ranged from 51 per 1000 to 785 per 1000 people for various conditions. The SCSI demonstrated reliability and validity.

Conclusions. These results suggest a high prevalence rate of disability due to secondary conditions and support the reliability and validity of the SCSI. This instrument may be very useful for departments of public health working to prevent secondary conditions. These results also suggest that an effective wellness program for people with a physical impairment could substantially reduce disability.

Prevalence and Disability Outcome of Secondary Conditions Experienced by Adults with Disabilities Living in a Rural State: Validation of a Surveillance Instrument

Disability has been recognized as one of the nation's largest public health problems.¹ The National Health Interview Survey (1989) reported that 33.1 million noninstitutionalized persons have some degree of activity limitation due to chronic conditions; of these, 13 million people are experiencing limitations in their major activities, and 9.7 million are unable to perform major activities (e.g. work, child care, etc.). Within these three categories respectively, approximately 8.3 million, 3.3 million, and 2.4 million people live in rural areas.²

In addition to personal limitations, disability imposes an enormous economic cost on society. Pope and Tarlov report that 15 percent of noninstitutionalized persons experiencing activity limitation due to chronic conditions accounted for 29 percent of the visits to physicians and constituted 40 percent of the hospitalizations. These authors also reported that people with activity limitations visited physicians twice as often and were hospitalized almost four times as often as persons with no activity limitation.¹

Technically, the term disability is distinguished from pathology and impairment. While pathology and impairment refer to cellular and tissue changes that may result in loss of function, the term disability "refers to an inability or limitation in performing socially defined roles and tasks expected of an individual within a socio-cultural and physical environment"(p. 315). This distinction is important because pathologies and impairments do not necessarily lead to disability.

As such, disability as an outcome of impairment may be prevented or mitigated. Indeed, personal and economic costs have led to disability prevention becoming a major national goal¹.

An important new concept of disability prevention involves secondary conditions which may be experienced after an individual acquires a primary impairment. Secondary conditions include medical complications such as pressure sores and urinary tract infections, problems of psycho-social adjustment such as depression, and environmental issues such as difficulties with access. Secondary conditions can contribute to disability outcome through further deterioration in health status, functional capacity, and quality of life 7. In a prevention framework, having a primary impairment is viewed as increasing one's risk for secondary conditions. It is important to consider secondary conditions in disability prevention because they can further limit a person's ability to perform the tasks that define their social roles (e.g., work, family, recreation, etc.).

Despite the potential significance of secondary conditions to disability outcome, little is known about how often they occur, how many people with disabilities experience them, their impact on people's lives, or their social cost. To begin investigating the prevalence and severity of secondary conditions, Seekins and his colleagues surveyed adults with physical disabilities served by three independent living centers (ILCs) and a selected sample of American Indians living on three reservations in Montana using the Secondary Conditions Surveillance Instrument (SCSI).^{8,9} The instrument has respondents indicate the amount of time

limitation they experience due to secondary conditions. Those surveyed reported experiencing an average of 13 of 40 possible conditions during the previous year.

A number of the conditions assessed with this instrument (e.g., problems with mobility, chronic pain, depression, communication problems, isolation, pressures sores, problems with physical conditioning, etc.) were reported by many individuals to limit activity more than eleven hours per week.

While these studies indicate the prevalence and severity of secondary conditions, generalization of the results is limited by two factors. First, the samples in both studies were drawn from populations of adults who were identified through community service programs. As such, the unexpectedly high rates of secondary conditions might be explained by a selection bias in favor of those receiving social services -- i.e., those most severely disabled. Second, the reliability and validity of the SCSI had not been established. Thus, the purpose of the present study was two-fold: 1) to assess secondary conditions experienced by a broader sample of people with disabilities, and 2) to examine the reliability and validity of the Secondary Conditions Surveillance Instrument.

In addition to calculating descriptive indices for the SCSI, three hypotheses were tested in this study. First, we hypothesized that a sample of university students would score significantly lower on the SCSI and report significantly fewer secondary conditions than a sample of people with a primary impairment. Second, using a longitudinal design, we hypothesized that the SCSI scores collected at time 1 would predict SCSI scores at time 2. Finally, using the same longitudinal design,

we hypothesized that a measure of perceived health status at time 1 would predict SCSI scores at time 2.

Methods

Study Participants

In Montana, an individual may obtain a handicapped parking permit by applying to the Department of Motor Vehicles Title and Registration Bureau. The law requires that an individual obtain a physician's statement documenting some impairment that has led to a temporary or permanent disability and pay a one-dollar fee. The process, however, does not require the specification of impairments nor are these tabulated, if provided by the physician.

At any one time, there are just over 4,000 listed holders of handicapped parking permits. Surveys were mailed to 1000 individuals selected from the list of permit holders. Selection was accomplished by eliminating agencies holding permits and then selecting every fourth individual holder until a total of 1,000 had been selected. Without follow-up of any kind, 354 people responded.

To examine issues of reliability and validity, two other samples were collected. First, 22 non-disabled undergraduate students were recruited from Introductory Psychology courses at the University of Montana. Second, 43 respondents with Spinal Cord Injury, who originally completed the SCSI as part of the handicapped parking permit sample, were mailed another survey approximately 3 years later. Of the 43 surveys mailed out, 4 were not delivered because of either

a lack of forwarding address or death of the respondent. Eighteen of the remaining 39 surveys were returned for a 43.6% response rate.

Study Procedures

The Secondary Conditions Surveillance Instrument (SCSI), a self-report measure of activity limitation due to secondary conditions, was mailed to selected individuals by the State Department of Health and Environmental Sciences staff. The mailing included a cover letter from the State Disability Prevention Coordinator describing the purpose of the SCSI. No follow-up procedures were employed to increase response rate.

The sample of students completed a slightly altered version of the SCSI during a single session conducted at the university.

Finally, the longitudinal data was collected from individuals three years after they had responded to the original handicap parking survey. The SCSI along with psychosocial and health behavior measures was sent to these individuals as part of another study. One follow-up post-card was sent to individuals who did not respond within two weeks of the original mailing.

Study Measures

In addition to demographic questions, the SCSI has respondents rate the disability outcome of 40 secondary conditions they may have experienced during the previous year on a scale of 0 to 3. The 40 secondary conditions are listed along with a brief description of the condition. For the response scale, zero indicates the condition has not been a problem, one that it is a mild or infrequent problem (limits

activity 1-5 hours per week), two that it is a moderate problem (limits activity 6-10 hours per week), and three that it has been a significant/chronic problem (limits activity 11 or more hours a week). In addition to the measures of secondary condition severity, measures of perceived health and independence are also included in the SCSI questionnaire. For these items participants are asked to rate their overall health and independence during the previous year as excellent, good, fair, or poor. A more detailed description of the SCSI has been published elsewhere.⁷

In this study, Coefficient Alpha for the summation of ratings for all secondary conditions was computed at .88. Thus, items on the SCSI were summed to calculate a total score. This total score represents the overall degree to which individuals are limited by secondary conditions.

Finally, the SCSI was modified slightly for administration to the student sample. Secondary conditions that are specific to using a wheel chair (e.g. pressure sores) or specific to having an impairment (e.g. dysreflexia) were eliminated from the student version of the SCSI. Fourteen conditions on the original SCSI were eliminated from instrument administered to students.

Data Analysis

Three measures of each secondary condition were calculated as descriptive indices of the SCSI. These indices were the prevalence rate and average severity of each secondary condition as well as a problem index used to rank-order the secondary conditions. The prevalence of secondary conditions for this population

was calculated by totaling the number of respondents rating the secondary condition 1, 2 or 3. Because the "0" rating indicated no problem, only those who rated an item 1, 2 or 3 were counted as endorsing it. The frequency was then converted to a prevalence rate by dividing all new and pre-existing cases during a given time period by the population during the same time period and then converting this number to cases per 1000.

A disability outcome measure or average severity rating was calculated for each secondary condition by dividing the sum of severity ratings by the number endorsing the item. This measure helps identify the conditions causing high levels of difficulty for those who experience them. For example, carpal tunnel syndrome has a relatively low prevalence rate but was rated highly severe by those who endorsed it.

A Problem Index score for each item was calculated by multiplying the average severity rating by the percentage of respondents endorsing the item. This measure helps identify the most significant problems reported by the most people giving weight to both frequency of report and severity. For example, problems with eating and weight regulation had a lower severity measure than carpal tunnel syndrome but were experienced by many more people.

Lastly, differences between the sample of non-disabled students and the sample of people with an impairment were examined using independent samples tests. It is important to note that for these analyses, comparisons were made using only the 26 secondary conditions included on the student version of the SCSI rather

than all 40 conditions normally included on the SCSI. To control for age-related effects, comparisons were also made between the student sample and the youngest possible sample of people with an impairment using a paired-samples test. For the persons with SCI who responded to the SCSI twice over a three year period, a Pearson Product Moment Correlation Coefficient as well as a paired samples test was computed between scores on the SCSI at time 1 and time 2. Additionally, a Pearson Product Moment Correlation Coefficient was computed between the measure of perceived health at time 1 and scores on the SCSI at time 2. Scatteplots of these relationships were also produced to assess for homoscedasticity and outliers.

Participant Characteristics

Three-hundred fifty-four (35.4% of those surveyed) handicapped parking permit holders living in 44 of the 56 counties of Montana completed and returned the survey. One-hundred sixty-three (46%) men and one hundred ninety-one (54%) women responded. The mean age was 62.3 (<u>SD</u> = 15.6). Three hundred thirty-six (96%) listed their race as white, nine (3%) listed their race as Native American, two (1%) listed their race as Black, three (1%) listed their race as Asian, one listed race as Hispanic, and three (1%) did not specify race.

Ninety-six (27%) respondents indicated they were unemployed, nine (3%) were students, twelve (3%) worked at part-time jobs, sixty-one (17%) were homemakers, two hundred twenty-five (64%) were retired, and eighteen (4%) worked at full-time jobs. Of those employed, nine (31%) were self-employed, eight

(28%) were clerical workers, seven (24%) had white collar jobs, and 4 (14%) reported being laborers.

The primary impairments reported by the respondents are presented in Table 1. The total number of impairments reported by the respondents adds up to more than 354 as some respondents endorsed more than one.

Table 1 - Primary Impairments

The average length of time since acquiring the primary impairment was 18 years with a range of 1 year to 81 years, and a median of 13 years. The average income was \$17,060 (SD = \$14,620), with a range of \$0 to \$100,000. The average years of education was 12.2; with a range of 3 to 22 and a standard deviation of 3.1 years. Because health care insurance coverage may be an important determinant of health status, the health care insurance coverage reported by respondents is included in Table 2.

Table 2 - Health Care Insurance Coverage

Results

All 354 people surveyed reported that they had experienced at least one secondary condition in the previous year. Seventy-four percent reported experiencing 10 or more, 49% experienced 14 or more, and 19% experienced 20 or

more. Table 3 presents measures of secondary conditions for all respondents, including the calculated prevalence, average severity, and problem index for each secondary condition. Respondents rated their overall health as fair $\underline{M} = 1.9$ ($\underline{SD} = .8$) and their overall independence as fair to poor $\underline{M} = 2.3$ ($\underline{SD} = .8$). The average number of secondary conditions endorsed was 13.6 ($\underline{SD} = 6.6$).

All three stated hypotheses of this study were supported by these results. The sample of university students reported experiencing significantly fewer secondary conditions than the sample of people with a primary impairment. The disability outcome scores (total SCSI scores) for people with SCI reported at time 1 were predictive of their scores at time 2 as was the measure of perceived health at time 1. Additionally, the results of this study were consistent with those reported in previous studies using the SCSI.^{7,9}

The average number of secondary conditions reported by the student sample was 5.5 (\underline{SD} = 3.5) and by people with a primary impairment was 9.5 (\underline{SD} = 4.8; \underline{t}_{374} = -3.87, \underline{p} < .000; recall that these scores are based on responses to only 26 of the 40 conditions included in the SCSI). Additionally, the SCSI total scores from the student sample averaged 6.9 (\underline{SD} = 4.9) and for the sample of people with an impairment averaged 19.4 (\underline{SD} = 11.7; \underline{t}_{38} = -10.31, \underline{p} < .000). These results support the discriminant validity of the SCSI. However, the construct validity of the SCSI is not addressed by these results because of the age difference in these two samples. The difference in SCSI scores may be due to an aging process rather than to having a primary impairment.

To investigate this aging process hypothesis, the youngest possible sample of people with a primary impairment was selected from the total handicap parking sample. The average age of this sample was 30.7 (SD = 7.8) and for the student sample was 20.7 (\underline{SD} = 2.7; \underline{t}_{27} = -5.75, \underline{p} < .000). Although the average age of these samples also differed significantly, we felt the incidence and severity of secondary conditions for this younger sample of people with an impairment would be less associated with an aging process. The average number of secondary conditions reported by the youngest possible matching sample of respondents with a primary impairment was 9.6 (SD = 5.0). A paired-samples \underline{t} -test (\underline{t}_{21} = 2.88, \underline{p} < .01) between this group and the student group indicated the groups differed significantly. Additionally, the SCSI scores for the youngest matching sample of people with an impairment ($\underline{M} = 19.1$, $\underline{SD} = 12.8$) was also significantly different from the non-disabled student sample (\underline{t}_{20} = 3.67, \underline{p} < .01). Overall, these results support both the discriminant and construct validity of the SCSI for measuring the self-reported limitation due to secondary conditions experienced by people with an impairment.

To assess the temporal stability of the SCSI over a three-year time-period a Pearson Product Moment Correlation Coefficient was computed for the SCSI scores at time 1 and time 2 (\underline{r} = .51, \underline{p} < .05). Given the lengthy time period between these assessments, this coefficient suggests striking stability in SCSI scores over time. Additionally, paired-sample \underline{t} -tests for the incidence of secondary conditions between respondents scores at time 1 and time 2 indicated the average number of secondary

conditions reported by this sample did not change significantly even over a three year period ($\underline{M}_{time 1}$ = 14.6, \underline{SD} = 5.7; $\underline{M}_{time 2}$ = 12.5, \underline{SD} = 7.8; \underline{t}_{16} = -1.37, \underline{p} = .19). Likewise, the results for the overall level of severity of secondary conditions as measured by total SCSI scores also remained unchanged during this time period ($\underline{M}_{time 1}$ = 24.1, \underline{SD} = 10.3; $\underline{M}_{time 2}$ = 26.0, \underline{SD} = 20.6; \underline{t}_{15} = 0.42, \underline{p} = .68).

Lastly, the Pearson Product Moment Correlation Coefficient was computed for the perceived health measure at time 1 and SCSI scores at time 2 (<u>r</u> = .68, <u>p</u> < .01). This coefficient indicates that nearly 50% of the reliable variance in SCSI scores at time 2 can be accounted for by participants ratings of perceived health at time 1. Inspection of the scatter plots for each of the statistical relationships reported here indicated homoscedasticity in the covariance of the scores. Additionally, outliers that might unduly influence the magnitude of the correlation coefficients reported here were not observed.

Discussion

This paper reports on the prevalence and disability outcome of secondary conditions experienced by adults who held handicapped parking permits in Montana, the nation's second most rural state. These respondents reported experiencing an average of 13.6 secondary conditions over the past year with 73% experiencing 10 or more. They also indicated that their overall health was fair and their overall independence was poor. Prevalence rates ranged from 51 per 1000 people to 785 per 1000 for various conditions. These data extend results of similar field studies of two other sample populations.

Before discussing the results of this study in detail, a few considerations regarding the study must be addressed. First, the SCSI is a self-report instrument. As such, the incidence of secondary conditions reported in this paper is the incidence of self-reported limitation (i.e. disability) from secondary conditions. The incidence of secondary conditions may be somewhat different had the presence or absence of conditions been verified by a physician. Although verification of responses to the SCSI would add to the validity of the instrument, it is not clear from whom these proxies could be drawn. Physicians may be able to diagnose the presence or absence of secondary conditions with more reliability, however, they could not address the disability outcome of secondary conditions as reported.

Without a reliable data source from which to draw a proxy for the SCSI, it would be impossible to obtain acceptable validity estimates. In fact, only the person with an impairment can assess the disability outcome of a given secondary condition in a specific environment.

The population of handicap parking permit holders from which the sample for this study was drawn raises another consideration. Inclusion in the population of handicap parking permit holders was gained by the needs of each individual as assessed by a physician. Thus, the composition of the sample is somewhat unclear. Overall, the sample of handicapped parking permit holders was older than that of respondents reported in the independent living center and Native American samples.^{8,9} It also had a slightly different distribution of impairments than those in the ILC and Native American samples (primarily more arthritis, amputations, and

"other" primary impairments with fewer people reporting spinal cord injuries or multiple sclerosis). Nonetheless, the prevalence, severity, and pattern of secondary conditions are similar across the samples. Thus, although the exact composition of this sample is not entirely clear, the results remain consistent: many people who experience a primary impairment experience significant disability from secondary conditions.

The results of this study support the validity of the Secondary Conditions Surveillance Instrument (SCSI). First, measures of internal consistency were high. indicating that the items measure the disability outcome of secondary conditions. reliably. Second, retest measures taken from a subset of respondents three years after the initial assessment suggest SCSI scores are somewhat stable over time. Additionally, the strong relationship between respondent's report of overall health at time 1 and SCSI scores at time 2 supports the validity of the SCSI as a measure of disability outcome that is related to health status. Third, the substantial differences between the sample of university students and the sample of people with an impairment supports the discriminant validity of the SCSI. The SCSI clearly discriminates between people with and people without a primary impairment. Perhaps more importantly, however, the tremendous difference between SCSI scores of the student sample and sample of people with an impairment highlights the role of a primary impairment in putting people at risk for limitation due to secondary conditions.

Taken together these results indicate that secondary conditions increase the

level of disability people experience and that this level of disability is consistent over time. Additionally, peoples' experience with secondary conditions is closely related to their perceived level of overall health. Based on these findings, the reduction of secondary conditions experienced by people with a primary impairment is clearly a legitimate and much needed public health activity. These data point to the need to develop means for reducing the disability outcome associated with secondary conditions. The extraordinary incidence of secondary conditions reported by respondents in this study indicate that such public health efforts could have a substantial impact on the health and quality of life of people who experience a primary impairment.

As with the previous two samples, the top ranked secondary conditions tend to involve environmental (e.g., access) or behavioral components (e.g., physical conditioning problems, depression, etc.). Many of these issues may be effectively addressed within a wellness program that includes exercise, behavioral management techniques for such problems as pain and depression, and environmental modifications. For the general population, such wellness programs are often provided directly by larger employers or through Health Maintenance Organizations. Unfortunately, the vast majority of individuals with severe disabilities are not employed nor do they have access to private health insurance. Further, neither Medicare nor Medicaid currently fund such health promotion services. Other mechanisms for delivering these supports, ranging from self-care to inclusion in mainstream programs, need to be explored. For example, Departments of Public

Health could sponsor wellness programs for people with primary impairments that target reduction in disability due to secondary conditions. An effective wellness program could substantially reduce disability. Such a reduction may result in reduced health care costs and increased productivity among people with disabilities.

Both the sample size and method of selection add to the potential generality of the data presented here. Still, these findings represent only one state with several unique demographic features. Future research should examine the prevalence and severity of secondary conditions in other rural areas and in urban areas where there may be greater access to health promotion and rehabilitation services. Additionally, these results support the reliability and validity of the Secondary Conditions Surveillance Instrument (SCSI). This instrument may be very useful for departments of public health working to prevent secondary disabilities. Additionally, the SCSI may be useful as a dependent measure in assessing the effectiveness of public health interventions intended to reduce disability in the community.

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Table 1

Total Number of Primary Disabilities Report

Impairment	Number	Percent ¹
Arthritis	127	36
Spinal Cord Injury	37	11
Multiple Sclerosis	36	10
Stroke	32	9
Polio	24	7
Amputee	17	5
Parkinson's	8	2
Cerebral Palsy	8	2
Traumatic Brain Injury	7	2
Muscular Dystrophy	3	. 1
Spina Bifida	2	1
Other	137	39 .

¹ Numbers reported sum to more than 100% because some respondents indicated more than one impairment.

Table 2

Reported Health Care Coverage

Insurance Type	Number	Percent
Medicare	253	42
Private Health Insurance	191	32
Medicaid	. 50	8
Medicaid eligible/not receiving	22	. 4
Veterans Administration	21	4
CHAMPUS	6	1
Workers Compensation	6	1
Indian Health Service/Tribal Health	. 3	1
Supplement	10	2
No Health Insurance	35	6

Numbers reported sum to more than 100% because some respondents indicated more than one type of insurance.

Table 3

Descriptive Indices for the Secondary Condition Surveillance Instrument

		Date de-	*:
Secondary Conditions	Prevalence Rate	Average Severity ¹	Problem Index ²
Problems with Mobility	785	2.3	198
Physical Fitness or Physical Conditioning Problems	745	2.2	182
Arthritis	681	2.4	177
Joint and Muscle Pain	709	2.2	176
Fatigue	714	2.2	175
Chronic Pain	599	2.3	162
Difficulties with Access	567	2.1	142
Sleep Problems/Disturbances	581	2.0	134
Contractures	486	2.2	128
Sexual Dysfunction	398	2.3	. 110
Eating and/or Weight Problems	477	1.9	105
Depression	454	1.9	99
Spasticity (Muscle Spasms)	404	2.1	99
Bladder Dysfunction	410	2.0	97
Cardio-vascular (Heart) Problems	. 406	2.0	94
Side Effects from Medication	319	2.2	90
Respiratory Problems	361	2.1	89
Bowel Dysfunction	359	1.9	.81
Isolation	333	1.9	73
Written Communication Problems	294	2.1	73
Hearing Impairment	341	1.8	72
Visual Problems	279	2.0	71
Osteoporosis	226	2.2	61
Postural Hypotension	305	1.6	58

Prevent Secondary Conditions 26

Carpal-tunnel Syndrome	234	2.0	57
Injuries Due to Loss of Sensation	254	1.9	56
Urinary Tract Infection	234	1.8	52
Communication Difficulties	189	2.0	45
Anemia	172	2.0	41
Heterotrophic Bone Ossification	150	1.8	35
Diabetes	124	2.2	34
Autonomic Dysreflexia	147	1.9	34
Pressure Sores	155	1.7	33
Equipment Failures	149	1.8	32
Amputation	64	2.6	21
Equipment Related Injuries to Yourself	99	1.6	19
Care Related Injuries to Others	85	1.8	18
Alcohol/Drug Use	73	1.8	16
Care Related Injuries to Yourself	65 .	1.5	12
Equipment Related Injuries to Others	51	1.6	10

Notes: ¹Average severity is computed as the average value for those who endorsed the condition as a problem. ²Problem Index is the average severity of the condition multiplied by the number of people endorsing the condition as a problem