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An Examination of the Validity of the Health Risk Screening Tool: Predicting Mortality in People With Intellectual Disabilities

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Background and Purpose: The Health Risk Screening Tool (HRST) is a 22-item instrument specifically designed to assess the health risk of persons with developmental disabilities. The predictive validity of the HRST was investigated by examining its ability to predict mortality. **Methods:** The sample consisted of 12,582 people with an intellectual or developmental disability residing in Georgia (U.S.). Data were analyzed using survival analysis (Kaplan–Meier estimate and Cox regression) and a binary logistic regression. **Results:** All models supported the prognostic value of the six-level health risk classification. The Kaplan–Meier procedure showed clear separation among functions. The Cox proportional hazard regression revealed that hazard is inversely related to the health risk level, even after controlling for potential confounding by gender, ethnicity, and race. **Conclusions:** The HRST can predict mortality. Therefore, it can serve as a basis for establishing healthcare needs and determining nursing care acuity.

Keywords: health risk assessment; intellectual and developmental disabilities; survival analysis; nursing acuity

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For some time, nurses have been providing care to persons with intellectual and other developmental disabilities (Nehring, 2005). More recently, standards for nursing practice in intellectual and developmental disabilities have been formulated (Nehring, Roth, Natvig, Betz, Savage, & Krajicek, 2004), along with guidelines for implementing an educational curriculum (Hahn, 2003; Nehring, 2005). With the advent of these advances, a nursing specialization in developmental and intellectual disabilities is now possible. Significantly, in 1992, the Developmental Disabilities Nurses Association (DDNA) was formed (https://ddna.org/about-us/) to represent the interests of Developmental Disabilities Nurses (also known as Special Needs Nurses). This association now offers Certification in Developmental Disabilities Nursing (CDDN), based on work experience and a standardized examination.

Nonetheless, maintaining optimal health and preventing premature death among people with intellectual disabilities continues to be a major societal concern. As a background for understanding this issue, we start by reviewing the literature on the life expectancy of people with intellectual disabilities and how their longevity compares to that of the general population. Health conditions responsible for the premature mortality observed among many people with intellectual disabilities are identified. Included in this narrative is identification of the possible reasons for the frequently mentioned disparity in the quality of medical services provided to people with intellectual disabilities relative to the population at large.

We go on to argue that a major improvement in healthcare delivery could be achieved by greater reliance on a type of instrument known as a health risk assessment (HRA). We identify and focus our attention on a pioneering scale of this type that is appropriate for use with individuals with intellectual and developmental disabilities. Next, we point out that any HRA, including the one studied in this report, needs to demonstrate validity, and we provide a justification as to why a relevant criterion for an HRA is life expectancy (which is the subject of the investigation discussed in this report). Appendix B provides a short tutorial on survival analysis, which is intended to help the reader unfamiliar with this methodology to better understand our results.

Differences in Life Expectancy Between the General Population and People With Intellectual Disabilities

In a number of countries, studies have found that people with intellectual disabilities have a shorter average life span than the country's general population (Balakrishnan & Wolf, 1976; Dayton, Doering, Hilferty, Maher, & Dolan, 1932; Dieckmann, Giovis, & Offergeld, 2015; Dupont, Vaeth, & Videbech, 1987; Durvasula, Beange, & Baker, 2002; Eyman, Grossman, Tarjan, & Miller, 1987; Forssmann & Akesson, 1970; Lavin, McGuire, & Hogan, 2006; McGuigan, Hollins, & Attard, 1995; Tyrer, Smith, & McGrother, 2007). With remarkable consistency, research also shows that longevity among people with intellectual disabilities is a function of their degree of impairment, such that the greater the degree of intellectual disability, the shorter the life span (Bittles et al., 2002; Coppus, 2013; Eyman, et al., 1987; Patja et al., 2000; Strauss & Eyman, 1996). For instance, a study in Australia by Bittles et al. (2002) reported median life expectancies of 74, 68, and 59 years for people with mild, moderate, and severe levels of intellectual disability, respectively. To a considerable extent,

such differences in longevity as a function of degree of intellectual disability reflect the frequency of underlying medical problems (Thorpe et al., 2012).

Differential Mortality in Terms of Gender, Ethnicity, and Race

The U.S. population at large, as well as that of numerous other countries, experiences a differential mortality by gender, favoring women, but historically the magnitude of this difference has not remained constant (Thorslund et al., 2013). Arias (2015) reported that between 1900 and 1975, the survival gap between the sexes in the U.S. went up from 2.0 years to 7.8 years, but the size of the difference has dropped in more recent years. In both 2010 and 2011, female life expectancy was just 4.8 years higher than that of men.

Racial differences in life expectancy are also well documented. The Black population in the U.S. has a lower life expectancy relative to the White population. In 2011, the White–Black difference stood at 3.7 years, which marked a historical low (Arias, 2015). Persons of Hispanic origin in the U.S. survive longer than people of a comparable race who are not of Hispanic origin. In 2011, Hispanic White life expectancy was 2.8 years longer than non-Hispanic White, and Hispanic Black life expectancy was 6.7 years longer than non-Hispanic Black (Arias, 2015).

Whether there exist discrepancies in longevity in terms of gender and race among people with intellectual disabilities remains a relatively unexplored question. Studies conducted by Janicki, Dalton, Henderson, and Davidson (1999), Bittles et al. (2002), Thorpe et al. (2012), and Dieckmann et al., (2015) support a female advantage. However, Patja et al. (2000) found this sex difference to be smaller than in the general population (of Finland), and Plioplys (2003) failed to observe any sex difference (but he was studying a sample that was profoundly impaired and institutionalized). We could not identify any U.S.-based studies that considered racial differences in life expectancy among people with intellectual disabilities. But researchers in Australia found shorter life spans for indigenous Australians with intellectual disabilities relative to their nonindigenous Australian counterparts (Bittles et al., 2002).

Factors Associated With Life Expectancy for People With Intellectual Disabilities

Although most people with intellectual disabilities are quite healthy and have medical needs similar to those of the general population (Kerr, 1997), some do have biological conditions that predispose them to a greater-than-normal health risk (Emerson & Baines, 2010; Tyrer & McGrother, 2009). Specifically, among people with intellectual disabilities, there is a higher incidence of respiratory diseases, coronary disease, gastrointestinal cancers, buccodental problems, obesity, diabetes, epilepsy, thyroid problems, and sensory deficits (Salvador-Carulla, Rodríguez-Blázquez, & Martorell, 2008). Frequent causes of death among people with intellectual disabilities are respiratory disease, particularly pneumonia, followed by cardiovascular disorders (Eyman, et al., 1987; Eyman, Grossman, Chaney, & Call, 1990; Molsa, 1994).

As might be expected, many health conditions that occur with greater frequency in the more-severely impaired individuals are also effective indicators of life expectancy. These

conditions include congenital malformations and acquired postnatal disorders (Molsa, 1994). Eyman et al. (1990) contend that the best single predictor of early death is impaired mobility, probably because immobility renders the person more susceptible to respiratory infections (Roboz, 1972). Notably, the prognostic value of certain variables depends on the age of the person. According to Eyman et al. (1990), inability to feed oneself is a strong predictor of mortality in children, whereas incontinence and lack of toileting skills are good indicators among older adults. More recent reports confirm the prognostic value of immobility and feeding impairments (Plioplys, 2003; Tyrer, Smith, McGrother, & Taub, 2007).

Disparities in the Delivery of Healthcare

Reports from various countries have identified problematic deficiencies in the provision of healthcare to people with intellectual disabilities (Fisher, 2004; Jones, Mcqueen, Lowe, Minnes, & Rischke, 2015; Krahn, Hammond, & Turner, 2006; Lennox et al., 2007; Lewis et al., 2002; Mencap, 2007; Michael, 2008; Ouellette-Kuntz, 2005; Ouellette-Kuntz et al., 2005; U.S. Public Health Service, 2002; Webb & Rogers, 1999; World Health Assembly, 2013). According to Heslop et al. (2014), a diminished lifespan in some people with intellectual disabilities should be expected in view of comorbidities and exposure to polypharmacy, but nonetheless many early deaths in people with intellectual disabilities could be avoided with adequate healthcare. Based on an analysis of death certificates for adults with moderate to profound intellectual disabilities, Tyrer and McGrother (2009) concluded that there is a need to reduce mortality attributable to ". . . potentially preventable causes, such as respiratory infections, circulatory system diseases and accidental deaths," p. 896.

People with intellectual disabilities may experience inadequate healthcare due to a variety of factors, such as: difficulties in communication, diagnostic overshadowing of comorbid conditions, inadequate training for medical personnel, and because they continue to be marginalized by society (see Bond, Kerr, Dunstan, & Thapar, 1997; Cooper, Melville, & Morrison, 2004; Fisher, 2004; Fisher, Haagen, & Orkin, 2005; Horwitz, Kerker, Owens, & Zigler, 2000; Jones et al., 2015; McCarron et al., 2013; Merrick, Morad, Kandel, & Ventegodt, 2004; Sullivan et al., 2006).

Health Risk Assessment

One approach to improving healthcare among intellectually disabled individuals is to train all concerned workers—both healthcare and direct care—to recognize rudimentary indicators of health status and to record these observations on a simple screening tool that will enable accurate identification of high health risks (Jones et al., 2015). Tools of this type are known as HRAs. The Centers for Disease Control and Prevention (Goetzel et al., 2011) provides the following definition: "An HRA involves collecting and analyzing health-related data used by health providers to evaluate the health status or health risk of an individual" (p. 14–15). According to Alexander (2000), an HRA has three essential features: (a) a questionnaire, (b) quantification of the answers into a risk score, and (c) feedback (either a written report or a conversation with a health practitioner). In addition to the hundreds of HRAs in use today for various specific conditions (e.g., cancer, diabetes), there also exist instruments designed to predict global (overall) health status. Broad-spectrum instruments of this nature allow for the consideration of the joint effects of multiple risk factors (Murray, Ezzati, Lopez, Rodgers, & Vander Hoorn, 2003).

While HRAs meant to be used in the field of intellectual and developmental disabilities share many features in common with scales intended for the population at large, there are two major points of distinction. First, the instrument should not require that the person being assessed be the one who answers the questions on the form. Rather, HRA instruments intended for individuals with intellectual disabilities should be designed so that they can be completed by a knowledgeable third party. Second, the form should be simple enough so that professionals other than physicians or nurses can answer them with minimal training. In this way, the nonmedical personnel can act as a "funnel," bringing only the truly at-risk individuals to the attention of the health professional. The cost of providing healthcare to people with intellectual disabilities is under scrutiny (Polder, Meerding, Bonneux, & van der Maas, 2002), so by conserving precious resources, the HRA should appeal to parties promoting fiscal conservatism in medical care. Also, the use of the HRA to screen patients with intellectual disabilities may lessen physicians' fears about overwhelming demands being made on their workloads by such patients (Bond et al., 1997). There already is some evidence that when used correctly, HRAs tend to focus physicians' attention to the health needs of people with intellectual disabilities (Lennox et al., 2007) and to improve the delivery of healthcare to them (Webb & Rogers, 1999).

However, currently, there are few HRAs that are fully appropriate for use with people with intellectual disabilities residing in community settings. Perhaps the most extensively used HRA of this type is the Health Risk Screening Tool (HRST), which is published by Health Risk Screening, Inc. (http://hrstonline.com/). It has its roots in the deinstitutionalization movement, whereby a method was sought for identifying the medical support former residents of large institution would need in order to thrive in small community residential settings. By identifying a person's degree of health risk, and providing the appropriate medical oversight on that basis, the HRST can prevent premature death in a vulnerable population. Among other things, it can also allow for the detection of health destabilization, resource allocation, and cost containment.

The HRST meets health and safety requirements established by the Centers for Medicare and Medicaid Services. To date, the HRST has been used in Tennessee, Louisiana, Alabama, New Hampshire, Kentucky, Maryland, Illinois, and Georgia. Four of these states (Georgia, Kentucky, Maryland, and New Hampshire) have adopted the HRST approach statewide.

HRST Scores and Mortality

For an HRA to be used with confidence, it is essential that there be empirical evidence to demonstrate that the instrument is actually measuring the construct that it claims to measure, a psychometric property known as validity (Hoogerduijn, Schuurmans, Duijnstee, de Rooij, & Grypdonck, 2007). Generally, one wants to know whether a statistical association exists between the score from an HRA and a specific outcome. A common criterion for testing the validity of an HRA is to determine the instrument's ability to show an association with mortality (Foxman & Edington, 1987; Kim, Park, Kim, Park, & Cho, 2011). This criterion is logical given that healthier people tend to live longer (World Health Organization, 2000). Thus, one would expect that people with higher health risk scores would experience shorter longevity (higher mortality) than people with lower health risk scores.

A good example of this approach to HRA validation can be found in the study by Inouye et al. (2003). These researchers developed a "burden of illness for elderly people" score

based on the presence of high-risk diseases, physiologic abnormalities (in albumin and creatinine levels), and functional impairments (dementia and ambulation). The resultant scores, which could range from 0 to 7, were used to place the study participants into one of four groups reflecting progressively higher risk: I (scores of 0 or 1), II (score of 2), III (score of 3), and IV (scores of 4–7). In the sample of elders (70 years old or greater) on which the index was created, the 1-year mortality rates differed by risk group: 8%, 24%, 51%, and 74%, for groups I–IV, respectively. The instrument and scoring algorithm were then used on a new sample (age 65 years plus), and the "burden of illness" score, when collapsed into the four categories, was statistically associated with 1-year mortality rates, with the following respective 1-year mortality rates occurring in groups I–IV: 5%, 17%, 33%, and 61%. In other words, the researchers were again able to demonstrate differences in 1-year mortality rates as a function of their "burden of illness" score. They had produced evidence for the instrument's predictive validity.

Our aim was to determine if a statistical association exists between HRST derived healthcare levels (risk) and mortality experienced by people with intellectual disabilities. Showing that the HRST can predict longevity would support the HRST's validity. The appropriate statistical procedure for investigating the issue is a family of techniques known collectively as survival analysis. Since many readers may not be familiar with this set of techniques, we provide a brief overview in Appendix B, which should allow for a better understanding of the results. In the results section itself, we will also give a rather detailed explanation about how to interpret the statistics being reported.

This may be atypical, but we feel that it is warranted given that survival analysis remains a relatively unfamiliar technique outside of a few fields. Readers with backgrounds in biostatistics, engineering (quality control), and actuarial science are probably more familiar with this technique than those with backgrounds in the behavioral and social sciences (compare Luke [1993] to Altman, De Stavola, Love, and Stepniewsk [1995]). The subject is still approached with some trepidation, as evidenced by the use of the title "Surviving Survival Analysis" in primers (e.g., Bhiwandiwalla, 2016; Cassidy, 2010; Williams, 2008) and book reviews (e.g., Szydlo, 2001) addressing this topic.

METHOD

Participants

Health Risk Screening, Inc., the corporate name of the instrument's publisher, operates a database containing information on residents of the state of Georgia (U.S.) with a primary diagnoses of intellectual or developmental disability who receive Medicaid Waiver services administered by the Georgia Department of Behavioral Health and Developmental Disabilities. As of late 2015, the database had records on 12,590 individuals. Ages were missing for eight of the individuals, so the final population studied numbered 12,582. The file contained each person's most recent HRST scores (including Healthcare Level), demographic characteristics, and an indicator of whether the person was alive or deceased in 2015. The proposed study was submitted to the Institutional Review Board (IRB) for the Protection of Human Subjects in Research, operated independently of the Center for Outcome Analysis, and it was determined to be exempt from review under the "Common Rule" regulating IRB activity under 34 CFR 97.101.

Measure

The HRST is a rating scale that consists of 22 items (see Appendix A). With the exception of item Q, which is a yes-or-no question, all other items are scored on a 1-to-4 scale, with higher scores indicating greater health risk. These item scores are then summed, with the physiological item scores being weighted by 2. Ranges on the resultant sum score are then used to assign a 1-to-6 risk classification. However, bumping up into the next higher risk level may occur depending on how many ratings of four the sum score contains and whether item Q received a yes answer. The 1-to-6 classification, called "Healthcare Levels," was the basis for the survival analysis in this study.

Sample Status at Time of Study

Table 1 reports the descriptive statistics on the status of the sample at the time of the study as a function of Healthcare Level. It shows the number of cases at each Healthcare Level, the percentage dead and alive at each level, the age at death for the deceased participants, and the current age of the participants who were still alive. It is evident that the number of cases is not constant across the Healthcare Levels [$\chi^2(5) = 407.56$, $p = .000$]. As the severity of the Healthcare Level progresses from 1 through 6, there are fewer cases at each successive level (exception: Level 6).

The average age at death differs across the Healthcare Levels, and while these differences are statistically significant [$F(5, 12{,}576) = 41.15$, $p = .000$], they are not markedly different from each other (eta-squared = .02). Because it would take years to determine what exactly happens to each living member of the cohort, it is necessary to employ statistical estimation procedures to analyze the patterns in the data, projecting the age at death of the people who are still alive. Only then can a complete picture can be obtained.

Statistical Procedures

Data were analyzed by means of survival analysis (Kaplan–Meier estimate and Cox regression) and a binary logistic regression.

TABLE 1. Current Status at Each HCL

HCL	Total	Deceased				Alive (Censored)			
	n	*n*	Percent	*M* Age at Death	*Md* Age at Death	*n*	Percent	*M* Age in 2015	*Md* Age in 2015
1	5,077	44	10.86	53.39	53.5	5,033	41.33	39.99	37
2	3,680	94	23.21	50.55	51	3,586	29.45	42.24	40
3	1,609	55	13.58	53.47	56	1,554	12.76	43.69	43
4	881	67	16.54	50.85	54	814	6.68	43.72	42.5
5	623	59	14.57	54.54	57	564	4.63	44.67	45
6	712	86	21.23	49.21	51.5	626	5.14	43.64	42
All	12,582	405	3.21	51.6	53	12,177	96.78	41.78	40

Note. HCL = Healthcare Level.

RESULTS

Analysis in Terms of the Kaplan–Meier Procedure

The Kaplan–Meier procedure was used to calculate the cumulative probability of surviving to a certain age. The cumulative probability can be presented in a table, but typically it is plotted on a graph showing the percentage surviving (Y-axis) versus time (X-axis). This chart displays the portion of people in a given group still alive over time. A cumulative survival curve always starts out with 100% survival at the first point of observation (time zero), and thereafter, it can either move downward or stay level, but it can never go up again. Our aim was to determine the prognostic value of the six-point risk score; therefore, it is necessary to create an individual survival function for each Healthcare Level and then compare them.

Figure 1 plots the cumulative proportion of people surviving against the survival times (i.e., years since birth) for each of the six risk groups. That is, this graph displays the probability of remaining alive at any given year after birth for members of each of the six groups formed on the basis of their risk rating (i.e., Healthcare Level). One may notice that the upper portion of each curve approximates a smooth line, whereas the bottom portions of these curves are step-like in appearance. This is due to the number of cases at the early parts versus the latter parts of the curve. Each time a death occurs, the proportion of cases decreases (a step-down), but it remains flat during any period during which no deaths occurred. The smaller the sample, the more evident is the size of each step. The number of survivors is larger at the early portions of the curve than in the later portions of the curve. Hence, the steps are more pronounced in the later portions of the curve, when the number of remaining cases becomes progressively smaller.

Visually, the survival function plots in Figure 1 show considerable separation among the six Healthcare Levels, although Healthcare Level 4 and Health care Level 5 do overlap or cross at some points. The same is true of Healthcare Level 2 and Healthcare Level 3. While a visual inspection (eyeballing) of such curves can reveal differences in survival patterns when two or more groups are investigated, it is standard practice to also test for statistically significant differences among the survival functions. These tests consider the entire curve, not just certain points, such as the median or a summary statistic like the mean. To analyze for overall differences between survival curves among different groups, three tests are available: (a) Mantel-Cox Log Rank, (b) Breslow, and (c) Tarone-Ware.

All three procedures test the null hypothesis that there is no difference between the population survival curves. The major difference between these tests is how the time points are weighted by the number of cases at each time point: weighted equally (Mantel-Cox Log Rank), weighted by the number of cases at risk (Breslow), and weighted by the square root of the number of cases at risk (Tarone-Ware). As such, differences in their results are possible. The Mantel-Cox Log Rank test is the one most commonly reported. In this study, all three tests for overall differences in cumulative survival rates achieved statistical significance: [Log Rank (Mantel-Cox): χ^2 (5) = 207.69, p = .000; Breslow (Generalized Wilcoxon): χ^2 (5) = 216.42, p = .000; Tarone-Ware: χ^2 (5) = 232.95, p = .000].

To evaluate whether the difference was consistent when the scores were grouped, the six groups were collapsed into two (1–3 and 4–6). Again, all three tests point to a linear relationship between survival rates and the risk score such that higher Healthcare Levels are associated with shorter longevity [Log Rank (Mantel-Cox): χ^2 (1) = 180.29, p = .000;

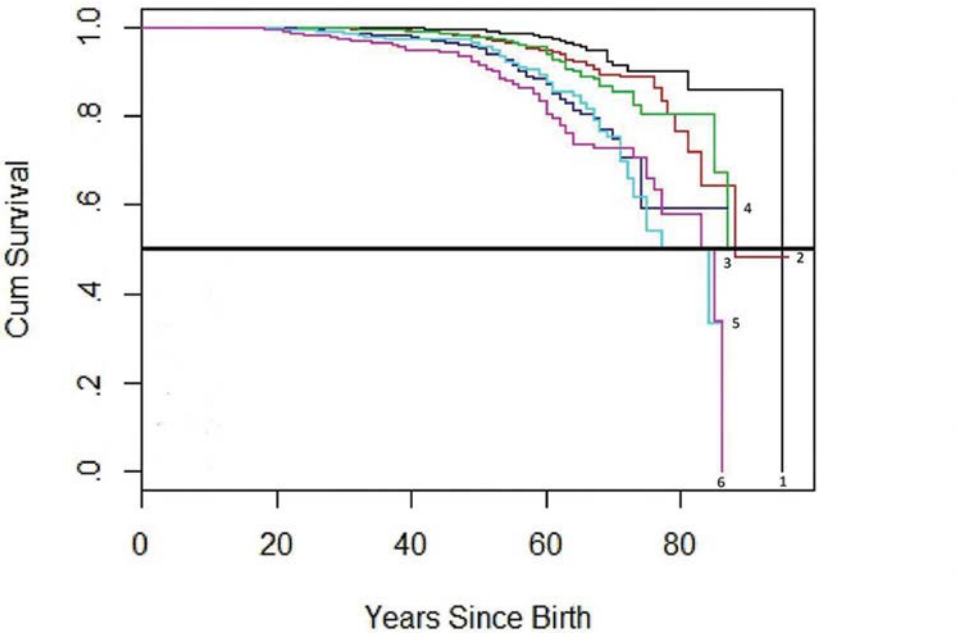

Figure 1. Survival function for each healthcare level.
Note. The numbers (1–6) shown below each cumulative probability curve identify the Health Risk Screening Tool (HRST) level.

Breslow (Generalized Wilcoxon): χ^2 (1) = 171.28, p = .000; Tarone-Ware: χ^2 (1) = 191.26, p = .000].

Cox Proportional Hazards Regression Modeling

Interpretative Guidelines. The Kaplan–Meier method permits one to study the effect on survival of one variable at a time. However, it does not allow for control for possible confounding factors, which are a threat when the groups being compared differ on demographics known to be related to mortality, such as gender. If one wants to determine how several variables in combination affect longevity, it is necessary to model the data using a procedure called the Cox proportional hazards regression. It allows one to determine the effect of a given variable, holding the other variables constant. Thus, it permits the investigator to control for potentially confounding variables when examining the role of a variable that is of primary interest. In our case, it is of interest to see whether the six-point risk level reflected in the Healthcare Level classification is related to survival, even when one controls for other variables potentially related to both longevity and the risk score (such as gender and ethnicity). In other words, it can give an estimate of the prognostic value of the six-point risk score after adjusting for other explanatory variables.

The Cox regression produces an equation which presents a baseline hazard (analogous to the intercept in multiple regression) and a weight for each explanatory variable. These weights, called betas, are the regression coefficients that show the proportional change in the hazard relative to the baseline rate. The weights are evaluated for statistical significance with the Wald test. The sign of the beta indicates the direction of the relationship between

the independent variable and risk of death. A positive value indicates that the risk of death (hazard) is higher for individuals with larger values on this independent variable. On the other hand, a negative regression weight (beta) means that the given variable is associated with a lower hazard (lower risk of death). If the independent variable is meant to be prognostic, then a positive regression coefficient indicates a poorer prognosis, whereas a negative regression coefficient indicates a better prognosis (with higher values of that variable). Given the direction of scaling of the HRST, in the current study, one would expect the six-point risk score (Healthcare Level) to have a positive regression weight.

The Cox model also produces a hazard ratio for each explanatory variable. The hazard ratio is the exponential (antilog) function of the regression weight. A hazard ratio may be conceptualized as a ratio of the risk in one group versus the risk in another group. Thus, a hazard ratio equal to exactly one implies that the independent variable has no relationship with death rates. That is, there is an equal risk of dying no matter what is the value of the independent variable. The further the hazard ratio is above or below one, the stronger is the variable's association with the incidence of death. The direction of the relationship is revealed by whether the hazard ratio is above or below one.

Hazard ratios above one indicate that there is an increased probability of death with increasing values on that variable. For example, a hazard ratio of 1.50 indicates that each unit increase in the value of the independent variable is associated with a one-and-a half greater incidence of death. Hence, there is a 50% greater risk. Similarly, a ratio of two means that a unit increase in the value of the independent variable results in twice as many cases experiencing the adverse event (e.g., death) in the group with the higher value of the independent variable. In the case of the HRST, each value is compared to the Health care Level 1 group in terms of mortality. A hazard ratio of three for the Healthcare Level 4 group would then mean that the Healthcare Level 4 group had a three-fold increased risk of mortality outcomes compared to Healthcare Level 1.

In turn, a hazard ratio of less than one means that the risk of the adverse event (e.g., death) goes down with each unit increase on the independent variable. In other words, the variable in question plays a protective role. For instance, a hazard ratio of .5 indicates that an increase of one unit in the value of the independent variable (e.g., going from one to two) results in half as many cases experiencing the negative event (e.g., death). To interpret the magnitude of a hazard ratio of less than one, it may help to invert the value (i.e., divide one by the hazard ratio). For instance, suppose that the hazard ratio equals .5. Dividing one by .5 results in two, which means that each unit increase on the independent variable leads to a two-fold decrease in the incidence of an adverse event, such as death.

In our case, we expected the hazard ratio for Healthcare Level to be above one (without inversion), given that on the six-point scale, higher values indicate greater risk. Two Cox proportional hazard models were developed. The difference between the models are described below, along with the results of each reported in Table 2.

Model 1: No Control Variables. The first model only included the six Healthcare Levels as the independent variables. It was meant to assess the prognostic value of the six-level risk score without simultaneously considering possible confounding variables. The omnibus test of overall effects for this model was statistically significant [2 Log Likelihood: χ^2 (5) = 186.81, p = .000]. The regression coefficient equaled .82 for Healthcare Level 2 and increased to 2.05 at Healthcare Level 6, which was significant [Wald test (5) = 174.20, p = .000]. The hazard ratios equaled 2.26 and 7.79 respectively, which means that there are 226% and 779% increases in the risk of death over baseline, with each unit increase compared to the Healthcare Level of 1.

Model 2: Gender and Race as Control Variables. Gender and race are associated with longevity in the general population, and may also be associated with life expectancy for people with intellectual disabilities. Consequently, the second Cox regression model examined the value of the six-point risk score when considered in conjunction with gender and ethnic background. Due to 135 cases with missing race information, only 12,447 cases were eligible for analysis in models containing covariates. The sample without any missing cases had more males than females (7,257 versus 5,190), and was primarily White (6,472 White, 5,590 Black, and 385 other). Many racial groups were subsumed under the "other" category because the modeling method cannot estimate relationships with sample sizes as small as those races presented. Therefore, the Cox regression was run on 405 deceased and 12,177 censored cases; 357 and 12,090 in the case of the models that used the race variable. The holdout category (reference group) for the categorical control variables were: male (for gender) and Black (for race).

The second model with nine variables was also statistically significant [−2 Log Likelihood: χ^2 (8) = 174.1, p = .000)]. Inspection of Table 3 reveals that the six-point risk score remained a significant prognostic indicator even when controlling for the other independent variables. For example, the hazard ratio of 2.22 means that a unit increase on the six-point Healthcare Level scale (e.g., from 1 to 2) results in a 221% greater risk of death, holding the other predictors constant. The hazard ratio is essentially of about the same magnitude as in the first model with no controls.

However, the prognostic value of the control variables is worth considering. The other significant estimator of hazard of death was race. Considering only the statistically significant racial differences, the results showed that compared to Black people, people of non-White and non-Black backgrounds ("other") were at higher risk of death (approximately, 2 times higher). White people were not at higher or lower risk compared to people of Black race.

Logistic Regression

A binary logistic regression was run with Healthcare Level and covariates (i.e., age, gender, race, region, and living situation) as predictors and life status in 2015 (alive versus dead) as the outcome variable. In this analysis, Healthcare Level was treated as a categorical variable, with Healthcare Level 1 serving as the baseline group. Gender, race, region, and living situation were not statistically significant predictors at α = .01 and were therefore dropped from the final model shown in Table 4. Age and Healthcare Level were retained.

TABLE 2. Cox Regression With Healthcare Level (Model 1)

Variables in the Equation	Regression Coefficient	Wald	*p*	Hazard Ratio
Healthcare Level 2	.82	4.47	.000	2.26
Healthcare Level 3	.94	4.65	.000	2.57
Healthcare Level 4	1.73	8.90	.000	5.67
Healthcare Level 5	1.79	8.92	.000	5.98
Healthcare Level 6	2.05	10.97	.000	7.79

TABLE 3. Cox Regression With Gender and Race as Controls (Model 2)

Variables in the Equation	Regression Coefficient	Wald	*p*	Hazard Ratio
Healthcare Level 2	.79	4.08	.000	2.21
Healthcare Level 3	.94	4.35	.000	2.56
Healthcare Level 4	1.77	8.56	.000	5.88
Healthcare Level 5	1.75	8.07	.000	5.73
Healthcare Level 6	2.02	9.99	.000	7.51
Male	.17	1.58	.114	1.18
White	.12	1.03	.300	1.13
Other	.90	2.59	.010	2.45

TABLE 4. Current Status at Each Healthcare Level

Variables in the Equation	Regression Coefficient	Wald	*p*	Odds Ratio
Healthcare Level 2	1.00	5.08	.000	2.71
Healthcare Level 3	1.24	5.71	.000	3.47
Healthcare Level 4	2.13	10.19	.000	8.44
Healthcare Level 5	2.23	10.09	.000	9.28
Healthcare Level 6	2.55	12.47	.000	12.83
Age	.03	9.77	.000	1.04

Relative to Healthcare Level 1, the odds ratio of being dead in 2015 increase with each successive increase in Healthcare Level (2–6). The odds ratios shown in the table indicate the increase in the odds of having died in the study period for persons assigned Healthcare Levels 2–6 compared to ones with a Healthcare Level of 1 (the baseline category). For example, persons with a Healthcare Level of 2 have a 2.71-times increased odds of having died compared to individuals with a Healthcare Level of 1. For the group with the highest health risk (Healthcare Level of 6), the odds of being dead in 2015 are 12.83 greater relative to persons with the lowest health risk (Healthcare Level of 1). In other words, Healthcare Level was associated with an increase in odds of being dead at the end of the study period, even when controlling for age.

DISCUSSION

Conclusion

An accepted criterion for establishing the validity of an HRA is to show that it is prognostic of mortality. All three methods of analysis employed in our study (Kaplan–Meier, Cox regression, and binary logistic regression) indicate that the six-point health risk score

(i.e., Healthcare Level) produced by the HRST was prognostic of mortality in a sample of persons with intellectual disability. That is, the instrument is able to identify the degree of vulnerability in such a population. Merrick and Morad (2011) recommend that an HRA become a standard component of the life plan of a person with an intellectual disability because it would allow for the detection of conditions that could compromise longevity, and our results suggest that the HRST can meet this need.

Moreover, the HRST can serve as one basis for objectively determining nursing staffing allocations in facilities serving individuals with intellectual disability. "Acuity" is defined as the amount of nursing care that a patient requires. It is now recognized that nursing staffing decisions should be made on the basis of acuity rather than on just headcounts (Morrow & Riley, 2018; O'Keeffe, 2016). Acuity is frequently calculated on the basis of diagnosis (Harper & McCully, 2007; Mark & Harless, 2011), but such an approach may not suffice because there is considerable variability even within the same diagnostic category, especially among populations with chronic conditions such as developmental disabilities. It is therefore preferable to ascertain acuity more precisely in such cases on the basis of risk (Morrow & Riley, 2018; O'Keeffe, 2016; Pappas, Davidson, Woodard, Davis, & Welton, 2015), which is captured by the HRST. Nursing staffing decisions relying on objectiveHRA would serve to properly allocate nursing resources, thereby reducing cost and improving patient outcomes.

Some other patterns observed in this study are worth highlighting. The purpose of this study was not to examine the life expectancy of people with intellectual disabilities in terms of gender or race. Rather, given prior literature, we felt that these demographic characteristics needed to be used to control for possible confounding when evaluating the prognostic value of the HRST. The Cox regression analysis showed that holding the Healthcare Level constant resulted in hazard ratios predicting nonsignificant differences in life expectancy between men and women with intellectual disabilities; Likewise, controlling for Healthcare Level, we did not detect differences in hazard between White and Black people with intellectual disabilities.

It is relevant to consider the number of people at each Healthcare Level. Approximately 40% have a Healthcare Level 1 classification, while less than 6% have a Healthcare Level 6 classification. The distribution of people with intellectual disability at each of the Healthcare Levels is of interest because it reaffirms that the majority of such individuals are quite healthy. The fear by some health providers that they will be overburdened seems unfounded. However, the healthcare system should anticipate an increasingly aging population with intellectual disabilities. As they enter old age, people with intellectual disabilities are prone to many of the health ailments associated with aging that occur in the general population (Factor, 1997; Janicki & Dalton, 2000).

It was noted in the introduction that, to some extent, longevity is a function of degree of intellectual impairment, mainly because many health impairments are related to degree of intellectual impairment. It might, therefore, be tempting to forego the use of an HRA and simply rely on degree of intellectual impairment as a proxy for health risk. However, degree of intellectual impairment by itself cannot be used as a prognostic indicator because there is considerable variability even within a given level of intellectual impairment. For example, consider a study by Plioplys (2003). The sample consisted of people who mainly (93%) exhibited a profound degree of impairment, but differed in health status. The more-healthy group in the sample had a 10-year survival of 90%, whereas for the less healthy group, the rate was only 45%

Limitations

To begin with, the participants in our analyses were monitored and subject to healthcare interventions. It is possible that this acted to attenuate the HRST's ability to estimate the hazard of mortality. The difficulty in studying validity in groups receiving intervention is that, if the treatment is successful, it will change the outcome. That is, the criterion is contaminated, which can make even a valid instrument look invalid, or at least less valid (McDowell, 2006).

Second, data analyzed in this study are administrative and clinical information used to manage the health and outcomes of a population. These data were not collected for the intended purpose of establishing the psychometric properties of the HRST. Moreover, the dynamic process used to administer the HRST in Georgia potentially captures health risk data at different times across a time period (e.g., a year), and may have affected the scale's statistical association estimates in some unknown way. That is, the administering nurses and case managers in the state are asked to "update" the HRST at regular intervals as well as when a change in health condition occurs by changing only the items that capture that particular change in the person's health status. Thus, items were changed one at a time, at varying intervals, whenever conditions changed in individual lives. Using clinical and administrative data to determine psychometric properties of the HRST is unlike the typical or ideal psychometric study in which all 22 items would be administered at once to all study participants at the same point in time.

A third limitation of our study is one of external validity. This study was based on residents in only one state who qualify for and receive services through a specific government program. Though the "sample" (actually a population) was large, there is no certainty that different state systems, with very different Medicaid and waiver processes, would look similar to Georgia's. Moreover, Georgia has had more than 5 years to practice, learn, enhance, and refine the HRST administration process. It is possible that in the first or second year of HRST administration in some new system or state, random error could impair the instrument's validity given that reliability is a prerequisite to validity. Hence, we would urge new implementers to include reliability studies as a required and ongoing feature from the start.

Suggestions for Further Research

In this study, the validity of the HRST was examined in terms of life expectancy of people with intellectual disabilities. It may be of interest to see how well this scale can also predict longevity in other vulnerable populations, such as the elderly. It also would be of value to consider the HRST's relationship to other criteria, such as inpatient hospital admissions, emergency department use, use of behavioral crisis services, extent of undiagnosed disorders, quality of life, cost, and staffing.

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APPENDIX A

ITEMS CONSTITUTING THE HRST

Risk Dimension		Items
Functional Status	A	Eating
	B	Ambulation
	C	Transfer
	D	Toileting
	E	Clinical Issues Affecting Daily Life
Behaviors	F	Self-Abuse
	G	Aggression Toward Others and Property
	H	Use of Physical Restraints
	I	Use of Emergency Drugs
	J	Use of Psychotropic Medications
Physiological	K	Gastrointestinal Conditions
	L	Seizures
	M	Anticonvulsant Medication
	N	Skin Breakdown
	O	Bowel Function
	P	Nutrition
	Q	Requirements for Licensed Interventions
Safety	R	Injuries
	S	Falls
Frequency of Service	T	Professional Healthcare Services
	U	Emergency Room Visits
	V	Hospital Admission

APPENDIX B

SURVIVAL ANALYSIS

It is necessary to employ statistical procedures to estimate life expectancy because it is practically impossible to follow a group of individuals (called a "birth cohort") from birth to death. That would take at least 100 years, and even then a few people might still be alive given that the maximum human life span is about 120 years. For instance, if one wanted to know the life expectancy of a newborn in 2018, then by tracking a birth cohort, the answer would not be available until 2138. The person asking the question likely would be long dead by then. So instead of following a birth cohort over its entire life span (which would give a definitive answer), survival analysis is used to come up with estimates.

The technique is appropriate for any situation (not just life expectancy studies) where the data have the following characteristics: (a) the dependent variable represents the time that has elapsed between an initial event and a terminal event; (b) the terminal event has not occurred for everyone at time of the study; and (c) one wants to determine whether certain variables can explain the span of time between the initial event and the terminal event. In the study of longevity, the initial event is birth and the terminal event is death. The time in-between is life span. In the remainder of this discussion, we will limit ourselves to using terminology appropriate for survival analysis in the context of studying life span since that is the focus of our study.

Survival and Hazard. Two complementary approaches to analyzing and describing longevity are possible, namely, (a) survival and (b) hazard. For each of the two, a mathematical function can be constructed for the purpose of estimating statistical association. In this context, survival means staying alive. A survival function provides the conditional probability of living up to a particular time point. It reports the probability of remaining alive until at least a certain age provided that one has already reached another given age. For example, the survival function can tell someone the probability that she or he will make it to age 80 given that her or his current age is 65. In other words, the survival function represents the proportion of people who have not died at a certain point in time.

Hazard, in turn, is the potential for death. The hazard function gives the probability that a person will die during a certain period of time, provided that he or she has survived up to that time. In other words, it is the risk of dying at a certain age. It, too, is a conditional probability. For instance, if today a person is celebrating his or her 79th birthday, the hazard function will provide the probability that he or she will not be alive to celebrate his or her 80th birthday. There is a mathematical relationship between the survival function and the hazard function; the one can be converted to the other.

Survival Probability Calculation. To calculate the probability of surviving a certain time interval, like a year, from the beginning of the period to its end, one needs to know (a) the number of people alive the previous year, and (b) the number of people dying that year. One first subtracts the number dying that year from the number alive the year before. Next, one divides this result by the number alive the previous year. The resultant figure is the survival probability. For instance, the above formula allows one to determine the probability that a person, currently 79, who is about to turn 80, will live to the end of his or her 80th year.

However, suppose the person was born today, and we wish to know the probability that this individual will live to the end of his or her 80th year of life. To get this answer, one first needs to use the above formula to calculate the probability of surviving *each year* (from

birth) for years 1–80. Once one has determined the survival probability for each year, one then has to calculate the cumulative probability of living from birth to the end of the 80th year of life. To arrive at the cumulative probability, one simply multiplies the annual survival probabilities for each year, 1–80. (i.e., it is the product of 80 individual probabilities). Eventually, the survival function will equal zero because nobody lives forever.

Hazard Probability Calculation. The hazard probability is a proportion. It is the rate of event occurrence per unit of time. Hazard probability is calculated as the number of people who have died relative to the number that have remained alive within a certain time period. In other words**,** the hazard function is the conditional probability that death will occur during a certain time interval (such as a year) given that it not has occurred before. For example, if one wants to estimate the probability that a person will die in her or his 80th year of life, one can calculate this probability if one knows how many people 80 years old died and how many remained alive at that age (i.e., reached age 81). In turn, the cumulative hazard describes the accumulated risk up to a certain point in time. Eventually, the cumulative hazard of death has a probability of 1 because everyone is certain to die. The hazard function tells one how quickly this event is likely to occur.

Relationship between Cumulative Survival and Cumulative Hazard Functions. As noted earlier, it is possible to report a longevity analysis in terms of either survival or hazard. The two are mathematically related to each other, and thus one can convert from the one to the other.

Models for Analysis of Longevity. A number of models are available to analyze longevity. These methods consider the time to death for those who are deceased as well as the fact that death has not occurred at the point of the investigation for some individuals under study. People who are alive when the study takes place are called "censored" observations. Both censored (still living) and uncensored (deceased) cases are used in calculating model parameters. If one cannot assume that longevity follows a certain known probability distribution, then it is necessary to use nonparametric or semi-parametric procedures to develop the survival and hazard functions. A popular nonparametric method for creating a survival function is the Kaplan–Meier technique, and a widely-used semi-parametric procedure to calculate a hazard function is the Cox proportional hazard regression procedure. We employed both procedures to the study of the prognostic value of the six-level risk classification derived from the HRST.

Although binary logistic regression analysis is not considered a survival analysis technique per se, the method can be applied to analyzing which variables are associated with survival versus death. The Cox proportional hazard model and logistic regression produce similar results when the time period under consideration is short and the incidence of the event (e.g., death) is low within this time span. Otherwise, the results from the two procedures can differ, and under such circumstances the Cox proportional hazard model provides more trustworthy results because it considers the time of the event under study and has greater power (Annesi, Moreau, & Lellouch, 1989; Green & Symons, 1983; van der Net et al., 2008).