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GENDERED DEATH RISKS AMONG DISABLED INDIVIDUALS IN SWEDEN: A CASE STUDY OF THE 19th-CENTURY SUNDSVALL REGION *

This study follows about 500 disabled individuals over their lifespan to examine their risks of dying in 19th-century society, in comparison to a reference group of non-disabled people. The aim is to detect whether people, due to their disability, had a higher probability of meeting an untimely death. We use Sweden’s 19th-century parish registers to identify people the ministers defined as disabled, and to construct a reference group of individuals who were not affected by these disabilities. By combining the deviance theories from sociology studies with demographic sources and statistical methods, we achieve new insight into how life developed for disabled people in past societies. The results suggest that disability significantly jeopardized the survival of individuals, particularly men, but also that the type of disability had an impact. Altogether, we can demonstrate that the disabled constituted a disadvantaged but heterogeneous group of people whose demography and life courses must be further researched.

Keywords: disability, gender, life course, mortality, 19th century

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Introduction

From contemporary disability studies we know that some illnesses and impairments jeopardize individuals’ health status, and according to theory disabled people run the risk of constituting the ‘otherness’ in society. In history, most disability studies have concerned institutionalized individuals for whom the sources tell little about their life beyond institution. The research design and data of this paper enable us to analyse the life courses of a group of disabled persons and to compare the findings with a group of non-disabled. As a result, this study will advance the picture of the ‘price’ people paid for their disability in the past and how it differed between the genders and with regard to type of disability.

We have used 19th-century parish registers from Sweden, which allow us to research disabled people’s demographic experiences. These registers have been digitized by the Demographic Data Base (DDB) at Umeå University in Sweden, and have not yet been explored systematically from a disability perspective. As the registers are recorded longitudinally, we can follow disabled people over time to obtain data about their life and death. The disabilities chosen to identify disabled people in this study are labelled blind, deaf mute, crippled, idiot and insane by the ministers in the parishes. The DDB digitization further enables us to supplement the dataset with a reference group of individuals who do not have any of the selected disabilities. The people in the reference group lived in the same time-space context as the disabled individuals. As a case study, the Sundsvall region in Sweden has been chosen.

Gendered mortality patterns and disability in history

From the 18th century onward, mortality patterns have been investigated through both macro and micro studies, especially in the Western world. These studies demonstrate gendered variations in mortality across different time-space contexts and age groups. Tabular Commission (Tabellverket) started with population statistics in 1749, and since then we can see that the mortality among Swedish men has been higher than that among women, except for some brief time periods and mainly among young people. This male excess in mortality persisted throughout the 19th century although the gap between the genders decreased. During the latter part of the century, improving social, working and housing conditions promoted individuals’ longevity, particularly the men’s, as the gendered gap in mortality continued to decrease. Explanations for this gap in life expectancy have been discussed among scholars, some of whom highlight biological or genetic differences inherent in the female sex. Rough working conditions associated with particularly men’s occupations in agricultural production or dirty industries, their lifestyle and the abuse of alcohol are among the major socio-cultural factors historians suggest as explanations for the male excess in mortality. Similar to other countries, the general decline in mortality in late 19th-century Sweden was due to advancements in nutrition and to towns becoming less unhealthy places for urban populations to live in as sanitary water supplies and systems gradually improved.

Whereas there are many studies analysing mortality and its gendered variations in past societies, few, if any, concern how it looked among a larger number of disabled individuals and whether their mortality differed from general patterns. In her recent thesis on deaf people in East Flanders, Belgium, 1750–1950, Sofie De Veirman is one among the first historians to present statistical results indicating the risks of premature deaths that this group of disabled individuals ran over their lifetime. Comparing their death risks with those of their hearing siblings, who constitute
De Veirman cannot find that deafness significantly impacted on the survival chances of the non-hearing selection of disabled men and women she analyses. Ingrid Olsson provides some results in her study of disabled people in 19th-century Linköping, a town in central Sweden. Average measures of their longevity demonstrate that disabled women grew older than their male counterparts, which does not make their mortality patterns different to the gendered death differentials outlined above. However, Olsson finds that the gendered gap in the life expectancy of 234 disabled individuals at age 15 (men: 38 years; women: 48 years) was greater than the national average gap found among men (41–45 years) and women (45–48 years) at the time. These results indicate that disabled men experienced a shorter life expectancy than their female peers. Olsson concludes that impairment did not severely affect the gendered mortality patterns, but that men’s life expectancy particularly suffered from the urban environment of Linköping, regardless of whether they were disabled.

Of course, being ill or disabled limits people’s opportunities to find work and subsistence, which might cut their life short in terms of years. However, historical research shows that individuals with disabilities confronted difficulties in life, not only with respect to a possibly less healthy status but also due to discriminatory attitudes based on social classifications and prevailing norms in contemporary society, which made them represent the ‘otherness’ in society. According to Anne Borsay, disabled people in past Britain were denied citizenship through policymaking, which denied them full rights and inclusion in society, causing them to differ even more from ‘abled’ and ‘normal’ citizens. Studies further indicate that the economic modernization in terms of industrialization promoted disabled individuals’ exclusion from society as agricultural work and handicraft were replaced by factory work. These economic developments particularly undermined the occupational options among those who suffered from disabilities and inflicted unemployment and poverty on them, which jeopardized their chances to fit into society. Catherine J. Kudlick argues that the attitudes towards disabled people were of a broad spectrum in which policy, religion and norms played an overall role. She concludes that this was further fuelled during industrialization by the capitalism system, which celebrated the able-bodied ideals of independence, self-mastery and control, and held the male, non-impaired person as the most ‘normal’. Mike Oliver asserts that the industrial process stimulated the economic changes and ideals, and built on the negative view of the disabled as a ‘social problem’. The scientific development in medicine further contributed to this view, calling for a classification of those who were ill or disabled. According to Deborah Stone, this was regarded as necessary for policy reasons, in order to determine whether these individuals were to enjoy certain governmental benefits. Disabled people thus became subject to definitions depicting them as normal or abnormal, healthy or insane and sick, which partly formed the basis for whether they should be separated from society, institutionalized and possibly cured. This made them appear even odder in society, and increased the perception of them as both a social and a medical problem. However, in his study of disabled people in 19th-century Scotland, Ian Hutchison finds that they did not have a uniform experience of marginalization simply due to having a disability. The main issue was rather whether they possessed any ability to work and could support themselves, which of course varied given their different disabilities. This makes Hutchison conclude that individuals’ disability was above all an economic concern for society and themselves.
Linking the life course concept to labelling theories

Glen H. Elder was among the first to define the life course in terms of pathways. With the term ‘from cradle to grave’ he reveals a line of development that includes phases such as childhood, adolescence, education, career, adulthood and parenthood, as well as old age; phases that affect individuals’ status, behaviour, identity, social activities and rights in society. Getting a job or having a child, marrying or moving away – all exemplify life events that impact this line of development. But being disabled might jeopardize one’s chances to take the path one would otherwise have taken, or the path of the non-disabled. Some disabilities more than others might impede people’s chances to work, or entail harsh living conditions resulting in increased risk of dying. The concept of life course constitutes the basic theoretical assumption of our analysis, as it reflects people’s living conditions and thus helps us trace their experiences in life. In disability studies life course analyses are still rarely employed, particularly with regard to the quantitative examination of the prevalence and impacts of disability. As for the past, the infrequency of such examinations is greatly due to historians’ incomplete access to sources documenting a comprehensive number of disabled individuals and their development over their lifetime.

According to sociological theories, the labelling concepts refer to those aspects of a person’s behaviour or attributes considered deviant by society. Edwin M. Lemert divides the labelling effect into a primary and a secondary type of ‘deviance’. The former concerns the perceived social reaction in a variety of social, cultural and psychological contexts, which has minimal consequences for those labelled. Secondary deviance is when the perceived label gives rise to a new social role, status and/or self-identity for the person it afflicts. Lemert further argues that secondary deviance is a societal reaction of the primary counterpart. In the 1960s, Erving Goffman explored how society categorized people through social interaction, and concluded that the ‘differences’ from normality provide the basis for deviance, which he called the ‘stigma’. According to him, the notion of what is a ‘normal’ human being is based on medical grounds and normative systems in society, and thus a stigmatized person could be seen as ‘not quite human’. In Joan Susman’s overview of the concepts of disability, deviance and stigma, she contends that Goffman’s theories about stigma and deviance have not escaped criticism from other social scientists, as he treats disabled people as passive and victimized. Susman concludes that perceptions of disability influence disabled people’s life experiences, and that deviance is caused by negative perceptions and therefore evokes a negative response implying stigma. Colin Barnes et al. argue that the social construction of deviances and individual experiences of stigma raise a great deal of questions in disability studies which need to be further explored.

Previous research indicates that disabled individuals run the risk of constituting a group of people who do not match perceptions of normalcy, and are thus highly likely to be subject to a stigma according to the theory of ‘secondary deviance’. The disabled individuals in this study are recognized by the ministers’ marks of impairment of the parishioners, which signify the primary deviance. However, we focus more on the secondary deviance, which concerns the major consequences a primary label can cause. As discussed above, social exclusion is often the result of labelling and secondary deviance. This is difficult to overcome because it negatively affects individuals’ social networks and occupational options, which in the longer run risks ruining their life and thus increases the risks of experiencing untimely deaths.

To determine whether higher mortality risks were associated with disabled people, we use statistical methods to compare their death risks with a reference group of non-disabled cases in the
same age and time-space context. If the results show significant evidence that the disabled group confronted markedly higher mortality risks, we find it likely that this was implied not only by a possibly poor health status but also because disabled individuals were subject to a stigma associated with secondary deviance, as discussed above.

Research area, data and methods

The Sundsvall region in the 19th century

19th-century Sweden witnessed large-scale transformations in economic and demographic terms. The pre-industrial dominance of occupations connected to agriculture, fishing and minor foundries was replaced by labour work. People moved to urban-industrial areas where they increasingly found employment. The Sundsvall region reflects much of these large-scale transformations; in the 1860s and 1870s, this region became one of the fastest growing industrial areas in Europe. The regional population grew rapidly, from 13,272 inhabitants in 1800 to 18,793 in 1840, and to 46,418 in 1880.31

FIGURE 1: Map of Sweden showing the Sundsvall region and the parishes included in the study.

Most of the population lived in the countryside, but as sawmills were being established primarily along the coast, the industrial production came to characterize the socio-economic makeup and labour market in particularly four parishes (Alnö, Njurunda, Skön and Timrå).32 Other parishes were less directly affected and remained relatively untouched by this industrial development, depending mainly on agricultural production. The study covers a total of 13 parishes: the urban parish of Sundsvall, eight mainly rural parishes (Attmar, Hässjö, Indal, Ljustorp, Selånger, Sättna, Tuna and Tynderö) and the four abovementioned parishes where the shift from rural to industrial production was obvious. These urban-industrial changes make this area and its population both interesting and useful for our study, as they might have influenced the living conditions of disabled people.
Evidence of disabilities in the sources

Our sources consist of digitized parish registers stored at the Demographic Data Base (DDB) at Umeå University, Sweden. It provides linked parish records composed of original records of birth and baptism, marriage, migration, death and burial, as well as catechetical examination records. From selected parishes in Sweden from the 18th and 19th centuries, the DDB registers are linked on an individual level and thus provide demographic data summarized for each parishioner. Sweden’s catechetical examination records are exceptional, as they were constructed on a yearly basis when the ministers fulfilled their obligation to check the parishioners’ knowledge of the catechism and their reading ability, first stated in the Church law of 1686.

<table>
<thead>
<tr>
<th>TABLE 1: The categorization of disability based on the marks of impairment in the parish registers from the Sundsvall region, 1800–1892.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Blind</strong></td>
</tr>
<tr>
<td><strong>2. Deaf mute</strong></td>
</tr>
<tr>
<td><strong>3. Crippled</strong></td>
</tr>
<tr>
<td><strong>4. Idiot</strong></td>
</tr>
<tr>
<td><strong>5. Insane</strong></td>
</tr>
<tr>
<td><strong>6. Multiple disabilities</strong></td>
</tr>
</tbody>
</table>

Source: Digitized parish registers, the Sundsvall region, Demographic Data Base (DDB), Umeå University, Sweden

Comments: About categorization of mental dysfunctions see: BiSOS. A. Befolknings-statistik page XLV and Drugge, Om husförhörslängder som medicinsk urkund.

Defining ‘disability’ – or who is disabled or not – is complex because definitions work as identity markers that are not clear-cut but rather socio-culturally constructed of their time and also individually experienced. However, scholars in the field of disability history conclude that the concepts and definitions used by society originate from some kind of dysfunction, inside or outside the body. In the parish registers, particularly the catechetical examination records, the ministers made marks regarding parishioners’ impairments (lytesmarkeringar). Although it is difficult to interpret these marks to know how severe or painful the disabilities were, they show commonly used terms in this historical context to report limits in people’s physical and mental functions. We use the ministers’ marks of impairment to identify the disabled individuals, and view the concept of ‘disability’ as socially constructed in relation to a physical or mental status that was perceived to be ‘normal’ or ‘healthy’. The parish registers reflect these circumstances and inform us about differences distinguishing ‘normal’ or ‘able’ parishioners from others who the ministers recognized as ‘disabled’ due to their behaviour, ability or health status. This means that those who the ministers recognized as disabled in the 19th-century context are defined as such in our study. Governed by these considerations, 508 disabled individuals were categorized into disability groups (Table 1). Parishioners with physical disabilities consist of: firstly, those who were labelled blind or somehow visually impaired; secondly, those labelled deaf/deaf mute or with other speaking or hearing problems; and thirdly, those labelled crippled. Those with mental disabilities were mostly made up of: firstly, those who were labelled idiot or somehow mentally impaired; secondly, those labelled insane or with other cognitive problems; and thirdly, those labelled multiple disabilities.
of parishioners labelled ‘insane’ or ‘idiots’.\textsuperscript{37} Finally, the dataset includes a group of individuals with more than one mark of impairment.

In 1860 Statistics Sweden, to which the ministers annually reported demographic data on their parishioners, provided the first general guidelines for making the ministers’ notes on disabilities more consistent.\textsuperscript{38} This desire was based on the advancement in medical knowledge and a desire to assist the government’s and authorities’ intention to trace the health status of the population in Sweden. From this point on, ministers were to account for parishioners who were blind, deaf, idiots, insane or who suffered from epilepsy; but the ministers already did report information to Statistics Sweden about these disabilities and even more, such as whether someone was crippled. However, due to the lack of instructions in the past they had largely developed their own practices. Their individual attention to detail and the guidelines of 1860 affect the disability marks we came across in the parish registers, as likely did the number of parishioners each minister was to keep records on.

\textit{A dataset comprising both disabled and non-disabled individuals}

A dataset of 36,118 observations from 31,790 unique individuals was extracted in order to compare the mortality risks over the life course. Migrations between the parishes in the Sundsvall region explain why the number of observations outnumber the number of individuals. If people moved from one regional parish to another, a new observation of them starts. As a result, there are cases where we have two or more observations of the persons and usually from different parishes. Out of all the unique cases, 508 individuals had marks of impairment in the parish registers.\textsuperscript{39} Both the disabled and non-disabled cases resided in the Sundsvall region and were 15–35 years old at observation start, but a vast majority of them were under 20 years old. Because of the vital industrialization the region witnessed in the 1860s, all cases are grouped into two cohorts. The first covers the pre-industrial period and consists of individuals born in 1800–1829, and their individual observation starts when they were 15–35 years old in 1835–1844. The second cohort is selected from the industrial period and covers individuals born in 1830–1859, whose observation starts when they were 15–35 years of age in 1865–1874. The reason for choosing rather young people was to target individuals when they were in the phase of beginning to seek a livelihood, and study how their life developed. All individuals were followed over time in the parish registers to detect whether and when they died, and for 18 years at the longest. Even if many of them did not die during the observation time, this method enables us to detect the occurrence of untimely deaths. Unfortunately, we cannot detail the causes of death, as this data is infrequent or vaguely reported in the registers.

\textit{Event history analysis and description of covariates for investigating the total effect disability has on mortality}

Event history methods are employed in this study to reveal variations in the individuals’ life courses over time.\textsuperscript{40} This method models the time it takes before the event in question occurs, in this case death, and enables us to highlight distinctions and similarities to explain the death risks between disabled and non-disabled individuals on a longitudinal basis. As an analytical tool we use Cox regression, using the statistical computing environment of R.\textsuperscript{41} The regression models incorporate the individuals’ demographic characteristics, such as their gender, disability, socio-economic status and residence, to statistically control and assess their influence on the mortality. Such characteristics
are termed covariates. Cox regression is a standard technique for modelling time to event data, such as the data at hand, and allows the study of the combinational effects of several variables, making it a suitable choice for this study. Hazard ratios estimate the covariates’ effects on the propensity to experience the event of death during the observation time. These tools make it possible to observe how mortality differed according to, for example, people’s gender and disability. The longitudinal observation starts when the individuals were 15–35 years old and ends when they died, migrated from the region of residence, or at the end of 18 years of observation time (until 1892 at the latest, as this year constitutes the end of DDB’s registration). Because the individuals enter the study at different ages (left truncation) and the period of observation is quite extended, using time to event as the time scale is not appropriate. To both control for the effect of age on mortality and handle the effect of left truncation, we use age as the time scale in the Cox regressions. This means that the individual’s age at observation start is the enter-value, and the exit-value is their age when observation stops due to death or right censoring.

The covariate of major theoretical concern is whether or not the individuals in the dataset were labelled disabled, due to our assumption that disabled people had a higher mortality. To identify differences or similarities according to type of disability, the disabled individuals are grouped into three categories: blind/deaf mute, crippled and idiot/insane. The last group also consists of cases labelled with two or more disabilities, as at least one of their marks of impairment shows idiocy or insanity. The non-disabled cases constitute a category of their own in the analysis. The second covariate of major concern we want to investigate is the effect of gender, as previous research documents gendered differences in mortality. We also include another three covariates in the models, which can impact on people’s mortality risks. The first one is socio-economic status, here manifested by the father’s occupation, which is grouped into three categories: lower strata, upper/middle strata and the unknown/undefined cases. This covariate serves as a proxy for the individuals’ socio-economic origin. Their father’s occupation was categorized according to occupational codes that researchers at the DDB have developed from the parish registers. These codes facilitate the construction of social groups ranging from higher to lower strata, according to the classification scheme in Table 2. The second covariate concerns cohort by distinguishing between individuals depending on when in time they lived and are under observation: during pre-industrial time (observation starts between 1835 and 1844), or during industrial time (observation starts between 1865 and 1874). The third covariate shows the type of area the people lived in, considering whether they resided in a rural, urban or rural/urban parish (see above section on the Sundsvall region).

TABLE 2: The social classification scheme we use based on the DDB’s occupational codes.

<table>
<thead>
<tr>
<th>Upper strata</th>
<th>1. Large-scale business entrepreneurs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. Higher civil officials</td>
</tr>
<tr>
<td>Middle strata</td>
<td>3. Small-scale entrepreneurs in trade and industry, master artisans and craftsmen; farmers, tenant farmers</td>
</tr>
<tr>
<td></td>
<td>4. Lower civil officials</td>
</tr>
<tr>
<td>Lower strata</td>
<td>5. Skilled labourers, craftsmen and artisans below the rank of master</td>
</tr>
<tr>
<td></td>
<td>6. Unskilled labourers in trade and industry; farmhands, crofters, maidservants</td>
</tr>
</tbody>
</table>

Source: Digitized parish registers, the Sundsvall region, Demographic Data Base (DDB), Umeå University, Sweden
This study focuses on the total effect disability has on mortality by investigating the death risks that individuals run. This means that we are interested in the sum of the direct effect disability has on mortality and the indirect effect that goes through intermediating variables, such as marital and occupational status (see Figure 2). Marital status is commonly used as a covariate in mortality studies, many of which have shown that it has an effect on mortality. Unmarried people and especially unmarried men tend to have higher death risks than others. As some of the explanatory power of disability can go through the marriage variable (indirect effect) making it difficult to assess the total effect of disability on mortality if marital status is included, we have not incorporated marriage as a covariate in the statistical model. This reasoning holds true both for marital and occupational status and further explains why the father’s occupational status is accounted for in subsequent mortality analyses and not the status of the individuals themselves. Finding subsistence through work or a spouse to marry are two examples of circumstances likely influenced by people’s disability, which can have indirect effect on their health status in providing socio-economic resources. Measuring the total effect disability has on mortality means that we account for how disability affects individuals’ death risks both directly and indirectly, as Figure 2 illustrates. This is achieved by not including the intermediating variables.

Table 3 shows some descriptive statistics regarding how the entire dataset is distributed according to the above covariates. It appears that the disabled men constitute 1.7% of all men in the dataset, whereas disabled women comprise 1.1% of the women. That the proportion of disabled men is slightly higher is probably due to men being regarded as household heads and breadwinners. If the men were not able to work, the ministers were more concerned with noting why this was so than for the women.
TABLE 3. Descriptive statistics of demographic characteristics concerning the disabled and non-disabled cases under observation in the Sundsvall region 1835–1892: frequencies and relative number percentages.

<table>
<thead>
<tr>
<th>Covariates</th>
<th>Men N=17,909</th>
<th>Women N=18,209</th>
<th>Total N=36,118</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
</tr>
<tr>
<td><strong>Disability</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blind/deaf mute</td>
<td>91 (0.5)</td>
<td>60 (0.3)</td>
<td>151 (0.4)</td>
</tr>
<tr>
<td>Crippled</td>
<td>110 (0.6)</td>
<td>57 (0.3)</td>
<td>167 (0.5)</td>
</tr>
<tr>
<td>Idiot/insane</td>
<td>109 (0.6)</td>
<td>81 (0.4)</td>
<td>190 (0.5)</td>
</tr>
<tr>
<td>Non-disabled</td>
<td>17,599 (98.3)</td>
<td>18,011 (98.9)</td>
<td>35,610 (98.6)</td>
</tr>
<tr>
<td><strong>Cohort</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-industrial (1835–44)</td>
<td>6,485 (36.2)</td>
<td>6,803 (37.4)</td>
<td>13,288 (36.8)</td>
</tr>
<tr>
<td>Industrial (1865–74)</td>
<td>11,424 (63.8)</td>
<td>11,406 (62.6)</td>
<td>22,830 (63.2)</td>
</tr>
<tr>
<td><strong>Socio-economic status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lower strata</td>
<td>3,875 (21.6)</td>
<td>3,800 (20.9)</td>
<td>7,675 (21.2)</td>
</tr>
<tr>
<td>Upper/middle strata</td>
<td>5,747 (32.1)</td>
<td>5,775 (31.7)</td>
<td>11,522 (31.9)</td>
</tr>
<tr>
<td>Unknown/undefined</td>
<td>8,287 (46.3)</td>
<td>8,634 (47.4)</td>
<td>16,921 (46.8)</td>
</tr>
<tr>
<td><strong>Residence</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural parish</td>
<td>8,755 (48.9)</td>
<td>8,968 (49.3)</td>
<td>17,723 (49.1)</td>
</tr>
<tr>
<td>Urban parish</td>
<td>3,949 (22.1)</td>
<td>4,007 (22.0)</td>
<td>7,956 (22.0)</td>
</tr>
<tr>
<td>Rural/industrial parish</td>
<td>5,205 (29.1)</td>
<td>5,234 (28.7)</td>
<td>10,439 (28.9)</td>
</tr>
</tbody>
</table>

Source: Digitized parish registers, the Sundsvall region, Demographic Data Base (DDB), Umeå University, Sweden

Comments: Number (N) refers to total number of observations generated from 31,790 unique individuals aged 15–35 years old: 16,181 men and 15,609 women. The longitudinal study of the pre-industrial cohort starts between 1835 and 1844, and between 1865 and 1874 for the industrial cohort.

Results: Event history analyses of the death risks

This section begins by providing some descriptive statistics on the extent to which the individuals experienced death in the area under study during the observation time. Table 4 shows that among the individuals labelled disabled the men have higher mortality rates than their female counterparts in all disability types. The mortality percentage is also higher for men than women among the reference group of non-disabled cases. These results echo the gendered death differentials found in Sweden at the time. However, the mortality percentage is considerably higher among the disabled individuals and exceptionally high among disabled men compared to the non-disabled reference group (6–8%). Depending on type of disability, 15–27% of the disabled men were dead at the end of observation, whereas the same percentages among disabled women varied between 8% and 17%. These findings indicate that people suffered severely from their disability in terms of untimely death, particularly the disabled men. Now it remains to be investigated whether these indications persist in a multivariable setting.

TABLE 4: Percentage experiencing death among the cases under observation in the Sundsvall region 1835–1892 during the longitudinal study covering a maximum of 18 years: comparisons between the genders and types of disability.

<table>
<thead>
<tr>
<th>Death characteristics of the individuals</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Percentage of all within each category</strong></td>
<td>All</td>
</tr>
<tr>
<td>Blind/deaf mute</td>
<td>12.6</td>
</tr>
<tr>
<td>Crippled</td>
<td>23.4</td>
</tr>
<tr>
<td>Idiot/insane</td>
<td>21.6</td>
</tr>
<tr>
<td>Non-disabled</td>
<td>7.3</td>
</tr>
</tbody>
</table>

Source: Digitized parish registers, the Sundsvall region, Demographic Data Base (DDB), Umeå University, Sweden

Comments: See comments, Table 3.
Results from three Cox regression models are presented in Table 5, which accounts for the abovementioned covariates that might influence people’s propensity to die. Due to assumed differences in the results between the genders, Models 2 and 3 show separate outcomes for men and women, while Model 1 includes both genders. The individual’s age is compensated for, as age is used as a time scale in the regressions. A look at whether the control covariates in Table 5 influenced the propensity to die to any noticeably degree reveals that disability, gender, cohort and residence did, whereas socio-economic status did not.

It is possible that the effect of disability differs for different categories of the other covariates. To check for this, interactions were run between disability and all the other covariates. The only statistically significant effect found is between disability and residence; therefore, this interaction is kept in the regression models of Table 5.

<table>
<thead>
<tr>
<th>Covariates showing disability and demographic characteristics of the individuals</th>
<th>Cox Regression Model 1</th>
<th>Cox Regression Model 2</th>
<th>Cox Regression Model 3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Both genders N=36,118</td>
<td>Men N=17,909</td>
<td>Women N=18,209</td>
</tr>
<tr>
<td>Disability</td>
<td>Hazard ratio</td>
<td>P-value</td>
<td>Hazard ratio</td>
</tr>
<tr>
<td>Non-disabled (ref.)</td>
<td>-</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Blind/deaf mute</td>
<td>1.696</td>
<td>0.097</td>
<td>1.950</td>
</tr>
<tr>
<td>Crippled</td>
<td>2.864</td>
<td>0.000</td>
<td>3.232</td>
</tr>
<tr>
<td>Idiot/insane</td>
<td>3.200</td>
<td>0.000</td>
<td>3.724</td>
</tr>
<tr>
<td>Gender</td>
<td>-</td>
<td>3.0e-14</td>
<td>-</td>
</tr>
<tr>
<td>Women (ref.)</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Men</td>
<td>1.343</td>
<td>0.000</td>
<td>-</td>
</tr>
<tr>
<td>Socio-economic status</td>
<td>-</td>
<td>0.171</td>
<td>-</td>
</tr>
<tr>
<td>Lower strata (ref.)</td>
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<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Upper/middle strata</td>
<td>0.973</td>
<td>0.596</td>
<td>1.032</td>
</tr>
<tr>
<td>Unknown/undefined</td>
<td>0.909</td>
<td>0.079</td>
<td>0.858</td>
</tr>
<tr>
<td>Cohort</td>
<td>-</td>
<td>0.943</td>
<td>-</td>
</tr>
<tr>
<td>Industrial (ref.)</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Pre-industrial</td>
<td>0.997</td>
<td>0.943</td>
<td>1.131</td>
</tr>
<tr>
<td>Residence</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Rural parish (ref.)</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Urban parish (Sundsvall)</td>
<td>1.978</td>
<td>0.000</td>
<td>2.276</td>
</tr>
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<td>Rural/industrial parish</td>
<td>1.274</td>
<td>0.000</td>
<td>1.334</td>
</tr>
<tr>
<td>Disability*Residence</td>
<td>-</td>
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<td>-</td>
</tr>
<tr>
<td>Blind/deaf mute: Urban</td>
<td>0.239</td>
<td>0.173</td>
<td>0.289</td>
</tr>
<tr>
<td>Crippled: Urban</td>
<td>1.608</td>
<td>0.314</td>
<td>1.486</td>
</tr>
<tr>
<td>Idiot/insane: Urban</td>
<td>1.245</td>
<td>0.636</td>
<td>1.151</td>
</tr>
<tr>
<td>Blind/deaf mute: Rural/ind.</td>
<td>0.836</td>
<td>0.706</td>
<td>0.838</td>
</tr>
<tr>
<td>Crippled: Rural/industrial</td>
<td>0.718</td>
<td>0.351</td>
<td>0.654</td>
</tr>
<tr>
<td>Idiot/insane: Rural/industrial</td>
<td>0.386</td>
<td>0.007</td>
<td>0.292</td>
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<tr>
<td>Overall</td>
<td>-</td>
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<tr>
<td>Global proportionality test</td>
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<td>0.087</td>
<td>-</td>
</tr>
</tbody>
</table>

Source: Digitized parish registers, the Sundsvall region, Demographic Data Base (DDB), Umeå University, Sweden

Comments: See comments, Table 3. The rural/industrial parishes are Alnö, Skön, Timrå, Njurunda. Socio-economic status is based on the father’s occupation. The hazard ratio column shows estimates of the relationship between the levels of the categorical variable with regard to the instantaneous risk of the event. The hazard ratio of the reference category is always set to 1. If the estimated hazard ratio of one category is above 1, its impact is higher than that of the reference category, e.g. 1.5 means 50% higher hazard. If the p-value is below 0.05, it demonstrates that the impact is statistically significant with a 5%-level of significance.
The impact of disability and gender on individuals’ mortality risks

We expected the disabled individuals to experience higher mortality risks than the non-disabled. Model 1 in Table 5, which accounts for the whole dataset, reveals that this was indeed the case and that even the type of disability impacted on people’s mortality propensity. Those labelled with mental disabilities, such as idiot or insane, were the most afflicted by their disability, as their hazard ratios of dying were 3.2 times higher than that of the non-disabled. Those labelled blind/deaf mute (1.7) or crippled (2.9) also show higher mortality risks than the non-disabled.52

Previous research contends that men more than women suffered from an excess of mortality in Sweden, and the findings presented in Table 5 parallel this gendered pattern. Men confronted a significantly higher hazard ratio (1.3) to die during the observation time compared to women. Models 2 and 3 suggest that disability shaped the mortality risks differently within each gender and particularly limited men’s survival. Men labelled as idiot or insane experienced the highest hazard ratios, 3.7 times higher than non-disabled men. Men labelled crippled or blind/deaf mute demonstrate 3.2 and 2.0 times higher hazard ratios, respectively, in comparison with non-disabled men. No matter the type of disability, disabled women show lower hazard ratios (in the range 1.2 to 2.4) than the disabled men. In short, the multivariate outcome shown in Table 5 echoes and details the cross-tabulated results presented in Table 4.

Figure 3 plots the cumulative hazard ratios of experiencing death when stratified on disability and gender (all three categories of disability are merged into one category of disabled individuals) with all the control covariates in Table 5 included. The larger and more rapidly the curve raises upwards, the more events of death occurred for individuals within each group during observation.

FIGURE 3: Plotted cumulative curves showing the mortality hazards by gender among the disabled and non-disabled cases under observation in the Sundsvall region 1835–1892.

Source: Digitized parish registers, the Sundsvall region, Demographic Data Base (DDB), Umeå University, Sweden
The results of Figure 3 further emphasize that men with disabilities confronted the highest risk of dying early in life. Even though disability increased women’s mortality too, the gap between them and the curves of non-disabled women is smaller than that separating their male counterparts. Figure 3 clearly illustrates that the mortality hazards for disabled men were higher compared to both disabled woman and all non-disabled people.

The influence of residence, cohort and socio-economic status

Besides the impact of gender and disability, type of residence is a most obvious factor in shaping people’s mortality. Table 5 shows that this impacted on mortality in all three models. Type of residence did not rule out the gender differences, however, as men but not women consistently show the highest mortality hazards no matter where they resided. Men living in urban or rural/industrial areas were 2.3 and 1.3 times as prone to die, respectively, compared to men in rural settings. The same pattern is found among their female counterparts, although they show lower hazard ratios (1.7 and 1.2). All results of the impact of residence were statistically significant. The outcome of the interaction between disability and residence shows a hazard ratio of close to 0.3 in both Models 1 and 2 for those labelled idiot or insane and with rural/industrial residence. This means that men labelled idiot or insane residing in the coastal area, which underwent industrialization during the latter part of the 19th century, ran lower mortality risks than the main effects proposed by the model. For women (Model 3), there was no such statistically significant interaction effect.

The covariate of cohort, indicating the time period in which the individuals lived, had a statistically significant effect on the mortality risk for men (Model 2) and women (Model 3), but was insignificant in Model 1 covering the whole dataset. A comparison of men (Model 2) and women (Model 3) suggests that there were reversed period effects as regards the mortality risks between the genders. During the pre-industrial period (Cohort 1) men experienced a higher risk of dying (1.1) compared to men living in industrial time (the reference). Women experienced a lower risk of dying (0.8) in the pre-industrial period compared to industrial time. These period effects in mortality hold true for both disabled and non-disabled individuals. Even though we found no statistically significant interaction effect between disability and cohort, this reveals an interesting tendency. We stratified the covariates of disability and cohort to explore whether the disabled individuals also show these gendered differences. The result is shown in Figures 4 and 5, which present cumulative hazard curves for each gender.

The reversed gendered pattern according to cohort in Table 5 is still valid for the non-disabled men and women when stratifying on disability and cohort, but for the disabled we found another pattern. Figure 4 shows that for disabled men mortality rose in industrial compared to pre-industrial time. For the disabled women (Figure 5) we see indications that they show an opposite result compared to the disabled men, with higher mortality in the pre-industrial period than the industrial one. The socio-economic status, here represented by the father’s occupation, had insignificant effects on the individuals’ death risks regardless of their disability, gender or any other demographic characteristics. In all, the statistical results suggest that both gender and disability affected the mortality to a substantial and significant extent. The highest risks of dying are found among individuals who were men and disabled.
FIGURE 4: Plotted cumulative curves showing the mortality hazards by cohort among the disabled and non-disabled men under observation in the Sundsvall region for 1835–1892

Source: Digitized parish registers, the Sundsvall region, Demographic Data Base (DDB), Umeå University, Sweden

FIGURE 5: Plotted cumulative curves showing the mortality hazards by cohort among the disabled and non-disabled women under observation in the Sundsvall region for 1835–1892

Source: Digitized parish registers, the Sundsvall region, Demographic Data Base (DDB), Umeå University, Sweden
Concluding discussion

The aim of this study was to detect whether individuals with disabilities in a 19th-century context had higher death risks compared to non-disabled people. Event history analyses were employed to measure the risk of dying and differentiate it with regard to gender and type of disability, among populations in the 19th-century region of Sundsvall, Sweden. Making use of longitudinal parish registers digitized by the Demographic Data Base, Umeå University, we identified 508 disabled individuals aged 15–35 years and observed them over a lifetime of maximum 18 years to compare their probability of meeting an untimely death, with a reference group comprising more than 30,000 observations from individuals of similar age and residing in the same time-space context.

Firstly, the statistical findings demonstrate that disability definitely increased the risk of dying. Aside from possibly bad health, of course, social exclusion caused by the secondary deviance we associate with disability helps explain the high price disabled people paid in terms of their markedly higher mortality. Our findings are consistent with the suggested assumption that disabled individuals living in 19th-century society were, according to the labelling theory, subject to intolerant attitudes from society and people around them because they did not match contemporary perceptions of normalcy. This did not bring them immediate death but seems to have entailed social exclusion, which was hard to overcome as it generated negative consequences concerning their social networks and occupational options. An accumulation of such disadvantages across a person’s lifetime increases her/his level of marginalization according to life course theories.53 Our demographic data and statistical findings indicate that this process of marginalization contributed to making social and working life difficult for disabled people, particularly disabled men, and gradually undermined their means to find subsistence and integrate into society, which ultimately resulted in untimely death, as this study has shown.

Secondly, our findings show gender differences in the way that disabled men faced a higher risk to experience an untimely death in comparison to disabled women. The statistical outcome from the Cox regression demonstrates these gender differences whereby disability made the men’s mortality risks to increase more evidently than the women’s. This difference is also clearly visible in the cumulative mortality hazards when stratified on type of disability and gender. The labelling concept appears to be more relevant for men than women; we thus propose another explanatory factor here, the breadwinner concept, because the socio-cultural expectations linked to the male gender presupposed men to be independent providers according to the contemporary breadwinner ideal. Historical research on the contemporary expectations associated with the genders shows that it was prevalent in the Western world that the man was idealized as independent and was expected to be the breadwinner. The ideal man, husband or father should provide for the family, whereas the woman was primarily expected to work with household tasks and care for the children.54

Thirdly, we found that type of disability also differentiated the mortality pattern. The descriptive statistics show that those labelled blind or deaf mute, both men and women, show the lowest mortality among the disabled, while those labelled crippled and idiot or insane demonstrate higher mortality. This result remained in the Cox regression, where the propensity to die among the disabled was lowest for blind and deaf mute individuals and highest for those labelled idiot or insane. The profound mortality risks associated with people representing mental disability labels suggest that they were subject to high levels of marginalization because a stigma worked to promote social exclusion among them more than among individuals with other disabilities. Our statistical
findings support one frequent notion in disability history according to which people with mental disabilities were negatively viewed by society.\textsuperscript{55} This added to their difficulties in life and helps explain why the lowest survival chances characterized them and not blind or deaf individuals in our data. From these death differentials we conclude that disabled people should be treated as a heterogeneous group with different obstacles and opportunities which impact on their life courses.

When including covariates such as residence, cohort and socio-economic status in the models, as expected, we found that people living in urban areas suffered from higher mortality rates. In previous mortality research, this ‘urban penalty’ worked to limit the survival chances of individuals living in towns, such as Sundsvall, regardless of whether they were men or women, disabled or not.\textsuperscript{56} This ‘penalty’ was also at work in the coastal parishes which underwent industrialization (called rural/industrial parishes in this study), probably because their environment resembled that found in urban areas.\textsuperscript{57}

The effect of time period, pre-industrial or industrial (Cohorts 1 and 2), presented for all people – disabled or not, women or men – shows no significant differences between the two time periods. But when comparing the genders, we found differences whereby the men had a slightly higher risk to die in pre-industrial time, while the women demonstrate the opposite pattern, with a slightly higher risk to die in industrial time regarding both disabled and non-disabled people. When we stratified on disability and cohort for each gender, the disabled men show a result opposite that of their non-disabled counterparts, with the disabled men having a slightly higher mortality in the industrial period than the period before. Previous research argues that the living conditions of disabled people grew worse during the industrialization processes,\textsuperscript{58} and our mortality results for the disabled men are in line with this statement. The disabled women, on the other hand, show the opposite result compared to the disabled men: the disabled women residing in pre-industrial time experience higher mortality than their disabled sisters in the industrial period. In accordance with the statement above, that disabled people had worse living conditions during industrialization, it did not result in higher mortality for disabled women according to our findings.

When investigating the effect of socio-economic status, there was no impact on the death risk of neither the disabled nor the non-disabled. This parallels the findings of previous mortality researchers, such as Peter Razzel and Christine Spence, who found no correlation between social status and mortality in England until the late 19th century.\textsuperscript{59} For the case of Sweden, neither did Sören Edvinsson found any connections between social status and mortality during the 19th century in the Sundsvall region nor did Tommy Bengtsson and Martin Dribe found any in Scania in southern Sweden.\textsuperscript{60}

This study is rare in providing statistical evidence based on a comprehensive quantity of cases on how disabled individuals in past societies experienced death. The results confirm what other researchers have argued, that disabled people were seen as the ‘others’ in society and therefore ran the risk of being excluded from social life. Our mortality findings reflect how disabled people fared in life and were viewed by society and the people around them. The death differentials outlined above demonstrate that they constituted a disadvantaged collection of people whose demography and pathways must be further researched. It remains to be learned more about their demographic experiences while alive. Our future studies will show the marital and occupational possibilities among the disabled people whose deaths we have just explored.
Acknowledgments
This disability research is partly conducted within a project led by Lotta Vikström, “Experiences of disabilities in life and online: Life course perspectives on disabled people from past society to present”, which enjoys funding from one Wallenberg Foundation (Stiftelsen Marcus och Amalia Wallenbergs Minnesfond). The authors are grateful to the two reviewers for their useful comments on the paper. We are also grateful for the feedback we received from the discussant and chair, Professor Alicia Bercovich, when an earlier draft of this paper was presented at the session ‘Trends and differentials in disability: Challenges in measurement’, at the International Union for the Scientific Study of Population (IUSSP) Conference in Busan, Republic of Korea, in August 26–31, 2013. We are also grateful for the feedback we received when the results were presented at The Nordic Network for Health Research within Social Sciences and the Humanities (NNHSH) conference, ‘Creative and Able Citizens: Managing Health and Illness during the Life Course’, in Helsinki, in May 22–23, 2014. We also wish to thank our colleagues at the Centre for Demographic and Ageing Research (CEDAR) and the Demographic Data Base (DDB), Umeå University, for providing suggestions for how to advance our analytical approach and for being most helpful with constructing the data retrieval from the digitized parish registers.
References

Archival sources

Demographic Data Base (DDB), Umeå University, Sweden
Digitized parish registers and catechetical examination records from the following parishes:
- Alnö 1803–1894
- Attmar 1814–1896 (deficient records 1860–1868)
- Hässjö 1814–1901
- Indal 1814–1900
- Ljustorp 1803–1901
- Njurunda 1816–1891
- Selånger 1813–1894
- Skönsmon included until 1883
- Sundsvall 1803–1892
- Sättna 1806–1899
- Timrå 1803–1895 (supplemented with ‘mantalsregister’ 1852–1865)
- Tuna 1804–1896
- Tynderö 1811–1900

Official statistics


Literature


Notes


2 Lee et al., ‘New Malthusian Perspectives’, 3–4.

3 Later on Statistics Sweden. See e.g. Sköld, Kast och kontroll – Den svenska befolkningsstatistikens historia.


8 Veitman, Breaking the Silence, 526–534.

9 In Olsson’s study the disabled include those who were visually impaired, speaking/hearing impaired, crippled, suffering from falling sickness or mentally deficient, as well as those with several disabilities.


12 Jaeger and Bowman, Understanding Disability. Inclusion, Access, Diversity and Civil Rights, 10–14; Kudlick, ‘Disability History: Why We Need Another Other’.

13 Borsay, Disability and Social Policy in Britain since 1750, 1 and 12–13.


15 Kudlick, ‘Disability History: Why We Need Another Other’, 766.

16 Oliver, The Politics of Disablement.

17 Stone, The Disabled State.

18 Hutchison, A History of Disability in Nineteenth-Century Scotland.


21 Priestley, Disability. A Life Course Approach; Siminski, ‘Patterns of Disability and Norms of Participation through the Life Course: Empirical Support for a Social Model of Disability’.


28 Susman, ‘Disability, Stigma and Deviance’, 15–17; Kudlick, ‘Disability History: Why We Need Another Other’.

29 Haage, ‘Identifying Disability using Nineteenth Century Parish Registers’.


31 Alm Stenflo, Demographic Description of the Skellefteå and Sundsvall Regions during the 19th Century.


34 Nilssdotter Jeub, Parish Records, Digitalised Material from the Demographic Data Base.

35 Grönvik and Söder (eds), Bara funktionshindrad? Funktionshinder och intersektionalitet; Mont, ‘Measuring Health and Disability’; Olsson, Omsorg & Kontroll. Ein handikapphistorisk studie 1750–1930; Rogers and Nelson, ‘Lapps, Finns, Gypsies, Jews and Idiots. Modernity and the Use of Statistical Categories in Sweden’, 61–79; According to Ian Hacking, it is reasonable to treat the categories of people with disabilities as social constructions although they are genuinely human and defined by society; see Hacking, Social konstruktion av vad.

36 Grönvik and Söder (eds), Bara funktionshindrad? Funktionshinder och intersektionalitet.

37 The concepts of disabilities used in this paper are those commonly used by 19th-century society. While some concepts may be offensive to some readers due to the derogatory meaning they carry today, we have no intention to
offend. The problem of using concepts which can be apprehended as offensive has been discussed, see e.g. Eggeby, ‘Avvita, galen, sinnessvag – något om synen på mentalsjukdomar och de mentalsjuka under 1700- och 1800-talet’, 543.

38 SFS No. 64 1859, valid from January 1, 1860.

39 This means that the non-disabled people in our study were non-blind, non-deaf mute, non-crippled, non-idiot and non-insane. Non-disabled individuals could have other marks in the registers, such as ‘sick’.


41 Broström, Event History Analysis with R.


43 See e.g. Olsson, Att leva som fuly. Handikappades livsvillkor i 1800-talets Linköping, 184–187.

44 We selected the father’s occupation at the start of the observation of the individuals under study or immediately before. The socio-economic status is divided into three categories because of small numbers in some of the groups.

45 The DDB classification does not completely correspond to the two commonly used classification schemes in historical studies, SOCP and HISCLASS, but there are many similarities between them. Leeuwen and Maas, HISCO: A Historical International Social Class Scheme, Van de Putte and Miles, ‘A Social Classification Scheme for Historical Occupational Data. Partner Selection and Industrialism in Belgium and England, 1800–1918’; for a comparison between the schemes, see the appendix in Edvinsson and Broström, ‘Old Age, Health, and Social Inequality: Exploring the Social Patterns of Mortality in 19th Century Northern Sweden’.


48 Schisterman et al. ‘Overadjustment Bias and Unnecessary Adjustment in Epidemiologic Studies’, 488–495. In another paper we analyse and discuss the event of marriage among disabled people, see Haage, Vikström and Häggström Lindevaller, ‘Disabled and Unmarried?’ It appears that they confronted markedly lower marital chances compared with non-disabled individuals. While about 40% of the latter married during observation time, only 25% of the disabled people did.


50 See e.g. Alm Stenflo, Demographic Description of the Skellefteå and Sundsvall regions during the 19th Century, Edvinsson, Den osunda staden. Sociala skillnader i dödlighet i 1800-talets Sundsvall; Willner, Det svaga könet? Kön och vuxendödlighet i 1800-talets Sverige.

51 A hazard ratio for a categorical variable indicates the relationship between the reference category and another category with regard to the instantaneous risk of the event. The reference’s risk is set to 1 which means that a value above 1 for the hazard ratio of the other category expresses that the category’s impact is higher than that of the reference category, e.g. 1.5 means 50% higher hazard. The P-value gives the probability of getting the parameter estimate if the parameter in fact is zero. If the p-value is below 0.05 it demonstrates that the impact is statistically significant with a 5% level of significance.

52 With a significance level of 5%.


56 Kearns, ‘The Urban Penalty and the Population History of England’. With this concept, Kearns argues that mortality was higher in towns compared to rural areas during the 19th century, explaining that this was partly due to urbanization and changes in diet. See, for example, 233–234.
