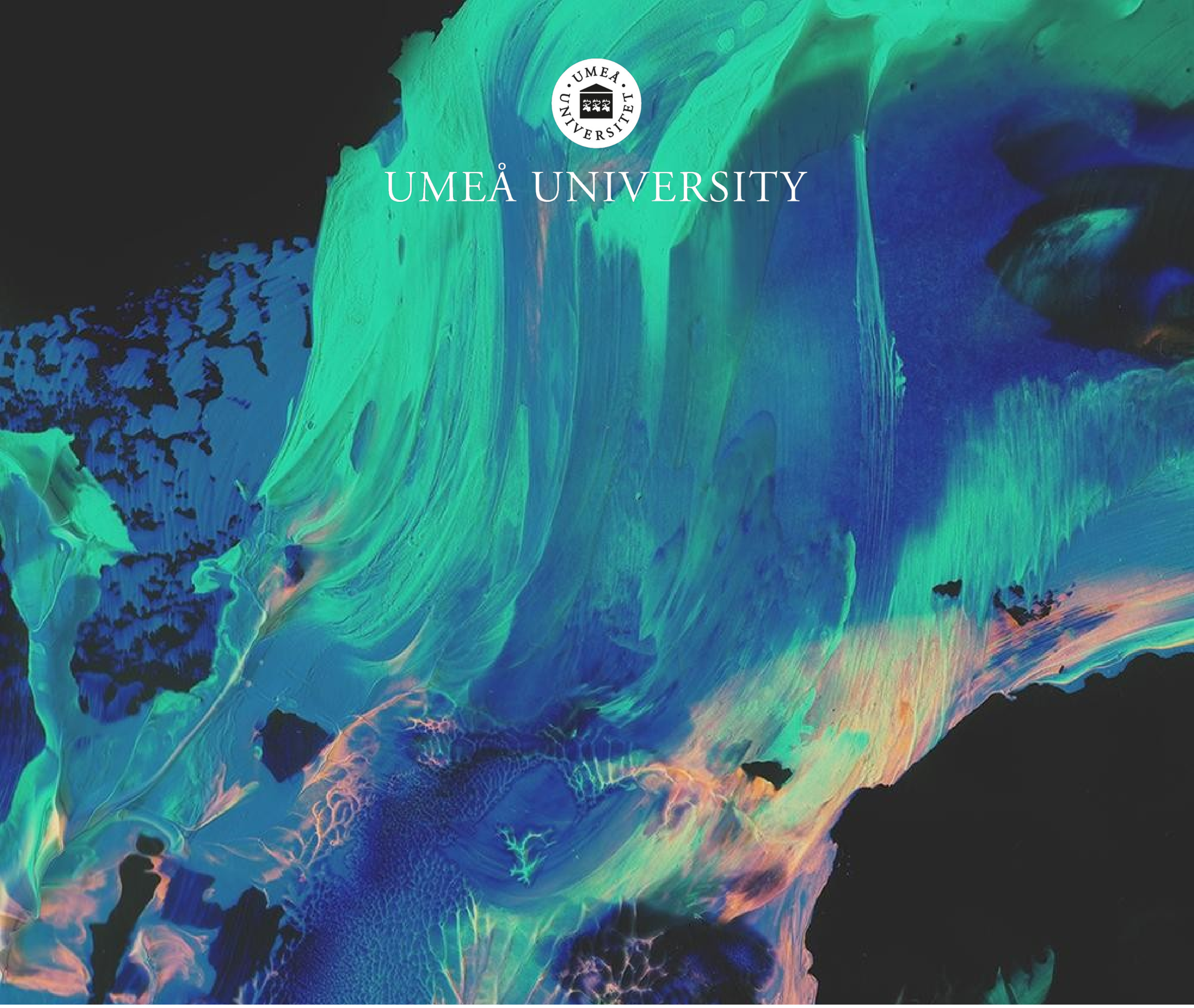

A longitudinal study of how disability affects mortality in Swedish Populations from the 1800s, 1900s and 2000s

Lotta Vikström, Johan Junkka, Fredinah Namatovu, Erling Häggström Lundevaller and Kateryna Karhina

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Abstract

Background: Studies from across the world show that disability limits people's health and social wellbeing in present-day populations. This disadvantage can lead to premature death, but there is dearth knowledge about the relationship between disability and mortality and changes over time.
Objectives: Unique access to longitudinal micro data on comprehensive Swedish populations enabled us to examine how disability affects premature death in men and women from the 1800s until 2010.
Methods: Cox proportional regressions were used to estimate mortality hazards by disability status,gender and socio-economic indicators in three study populations from the 1800s, 1900s and 2000s. We followed all adults having disability from age 25 to compare their premature death risks (< age 43) relative to non-disabled groups.
Results: Irrespective of gender and century studied, the adjusted hazard ratios show that adults with disabilities had a significantly higher premature death risk relative toadults without disabilities, and it increased over time. In the 1800s, disability about doubled this risk (HR: 2.31, CI: 1.65–3.22) and it tripled from 1900–1959 (HR 3.01, CI 2.60– 3.48). At the turn of the 21th century, the mortality risk was almost ten-folded (HR 9.90, CI 8.03–10.5).
Conclusions: This study provides the first comprehensive estimates on how disability increased mortality in Swedish populations from the 1800s until the 2000s. Across three centuries, disability was associated with a profoundly higher relative death risk in adults aged 25–42. This risk grew when the general survival in Sweden improved and it was the highest in the 1990–2010 period. Fundamental societal changes and extensive welfare provisions promoting equality in gender, health and social wellbeing of all citizens have not come to include younger generations with disabilitie.

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A longitudinal study of how disability affects mortality in Swedish Populations from the 1800s, 1900s and 2000s*

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Keywords: Death, Disability, Health, Life course, Mortality, Sweden

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Introduction

The UN's Convention on Rights of Persons with Disabilities (UNCRPD 2006) states the highest attainable standard of health (Article 23) irrespective of the functionality in individuals. Yet reports from the EC (2017) and WHO (2011, 2018) and research (cf. below) show recurrent evidence that health is significantly worse in individuals with disabilities than those without. This suggests that disability can render premature death and of a sizeable proportion, indeed. Estimations suggest that people with disabilities make up the largest minority group worldwide of about 15% or 1 billion (UN Factsheet 2020), some 65–80 million in the EU countries (EC 2017). In Sweden, which this study concerns, they comprise between 1.3–1.8 million (12.5–17.5%) of the total population of 10.3 million (http://www.funka.com/design-for-alla/tillganglighet/statistik/), and found to have lower health and opportunities in society at large (National Board of Health & Welfare 2009, 2010).

While a vast body of research reports lower health outcomes in people with disabilities than those without (Reichard, Stolze & Fox 2011; Roland et al. 2014), relatively few studies provide longitudinal results on how disability affects mortality risks at a population level and differences over time and from life course perspectives (Land & Yang 2006; Clarke & Latham 2014; Majer et al. 2011). Hence, there is dearth knowledge about the magnitude of the relationship between disability and mortality and its temporal variation. Scholars as well as people in general might assume that the mortality in individuals with disabilities was far higher some 100–150 years ago, because the health care systems and access to welfare provisions were rudimentary back then. The recent century has seen profound economic, medical and technological advancements benefitting the health and survival overall in most populations, especially in Sweden which is internationally known as one of the most advanced welfare states (Esping-Andersen 1990; Ginsburg 1992; Lundmark & Åberg 2001). Our study provides new insights into whether such developments have reduced the mortality risks over time in disabled groups of people relative to other groups. Using longitudinal micro data on Swedish populations from the 1800s, 1900s and 2000s, we can follow men and women with and without disabilities over their lifetime to estimate how disability affected premature death across three centuries.

For historical time, statistical examination of disability is almost unexplored territory as data enabling such analysis are limited. There is only about a handful of studies on how disability affected mortality risks in historical populations (De Veirman 2014; Haage et al. 2016; Lundevaller, Vikström & Haage 2018; Olsson 1999), which indicate that disability implied higher death risks or lower life expectancy with some variations across gender and disability type. While there are many statistical studies on mortality in past populations, they do not concern disability or only implicitly through diseases or epidemics, some of which could cause disability such as smallpox, TB or polio (Axelsson 2009; Sköld 2002; Edvinsson & Lindkvist 2011). To what extent disability determined death there is usually no or only scant data on in historical population records. Swedish parish registers from the 19th and 20th century make an exception in reporting individual-level disability data beneficial for our long-term study.

For contemporary time, there is an extensive literature list on how disability associates with ill health or health disparities and can lead to socio-economic inequalities (Drum et al. 2005; Horner-Johnsson et al. 2013; Kang et al. 2016; Kavanagh et al. 2013, 2015; Kran & Fox 204; Kyu et al. 2018; Mithen et al. 2015; Rowland et al. 2014; Shandra 2018; Wisdom et al. 2010). Many of these works are cross-sectional and benefit the investigation of health outcomes from disability, but often without mortality data. A considerable body of research further shows a reduced life expectancy in individuals with disabilities compared to those without (Bahk, Kang & Khang 2019; Thomas & Barnes 2010). The longitudinal works are fewer and tend to center on the incident of disability rather than the trajectory of disability following onset due to insufficient statistical power (Majer et al. 2011; Nusselder & Peeters 2006).

The literature list is considerably shorter concerning studies on mortality risks using longitudinal micro data (Forman-Hoffman et al. 2015; Karlsson et al. 2007; Landes 2017; Majer et al. 2011; Ng, Wallén & Ahlström 2017; O'Leary, Cooper & Hughes-McCormack 2018). Although these studies suggest that disability is associated with high mortality, this association and differences over time remains unclear, especially in younger age groups. This is because the incidence of disability as well as death increases with age, which has promoted an interest in researching ageing population (Clarke & Latham 2014; Freedman 2014). However, disability in young life might advance death before even getting old. In previous works, most study populations are restricted to relatively small samples providing few control variables concerning older adults or certain diseases that can bring disability where the focus risks to turn to mortality determinants linked to secondary health conditions arising from disabilities instead of disability itself (Campbell, Sheets & Strong 1999; Kinne, Patrick & Doyle 2006; Newman et al. 2006). Some studies recognize disability as an independent determinant of death in adult or old ages, however, after adjusting for health status indicated by physical activity or specific diseases or depressive symptoms, and for socio-economic status (Forman-Hoffman et al. 2015; Majer et al 2011; Murphy et al. 2016; Kattainen et al. 2004; Pudaric, Sundquist & Johansson 2003; Tager et al. 2003; van den Brink et al. 2005).

To our knowledge, no analysis has yet identified the effects disability can have on premature mortality hazards in younger populations and across an extended time. The aim of this study was thus to assess long-term developments of the relationship between disability and mortality by estimating the premature death risks in ages 25–42 among groups with and without disabilities in Swedish populations from the 1800s, 1900s and 2000s. First, we expected these risks to decline over time in disabled groups given the overall increase in survival of Swedish populations along with improvements in health care systems and welfare support. Second, we expected the disability-mortality risks to vary depending on gender because women survive more than men in general.

Methods

We base all results on longitudinal micro data from Swedish population records from the 1800s, 1900s and 2000s to assess how disability affected mortality across life over a long time. Due to data availability for this extensive timeframe, we turned the focus to premature death in young age groups with disabilities relative to non-disabled groups. All use of data in this study have obtained ethics approvals.

As for the 1800s and the 1900–1959 period, we examined two populations originally recorded in digitized parish registers hosted by the Demographic Data Base (DDB) and Centre for Demographic and Ageing Research (CEDAR), Umeå University (https://www.umu.se/en/centre-for-demographic-and-ageing-research/). Swedish parish registers detail birth and death data on all parishioners and on their sociodemographic characteristics across lifetime (e.g. sex, occupation, marital status), and if they had disabilities. This registers are considered unique from both international and longitudinal perspectives. Scholars have found them highly credible and useful for research in historical demography, epidemiology and population studies, and in recent years for statistical life-course analysis of disability (Edvinsson & Engberg 2020; Westberg, Engberg & Edvinsson 2016; Junkka et al. 2020; Lundevaller et al. 2018). Our study population from the 1800s lived in the Sundsvall region (DDB's POPUM database). It consists of all aged 25 years old in 1835–1854 or 1865–1884, hence born in 1810–1829 or 1840–1859. Out of these in total 14,511 individuals, 272 had a disability reported in ages 15–24, as defined below. The historical study population from the 1900s resided in the Skellefteå region (DDB's POPLINK database). It includes in total 69,496 individuals born in 1877–1924 being 25-years old in 1900–1950, out of whom 1,249 had a disability in ages 15–24.

Similarly, our recent study populations includes 25-year old individuals but born in 1968–1970 and from all Sweden. The total number born these years was 440,220 of whom

39,248 (9.7%) are not included in our analysis due to death or emigration before age 25, missing information on sex, or because the PIN was recycled. This left us with 400,972 individuals out of whom 3,392 had a disability before age 25. All data on this population we obtained from the Longitudinal Integration Database for Health Insurance and Labour Market Studies (LISA database). It contains micro data on the entire Swedish population, e.g. sex, educational attainment, income, marital/cohabit status, birth and death, and on disability pension (DP), possible to follow over time. Statistics Sweden anonymized all LISA data before making it available for analysis through the Swedish Initiative for Research on Microdata in Social and Medical Sciences, Umeå SIMSAM Lab, Umeå University (Lindgren et al. 2016). Scholars have made extensive use of the LISA database, some of whom address the DP information (Namatovu, Häggström Lundevaller & Vikström 2020; Karlsson et al. 2007; Söderberg et al. 2020).

Measures

Definition of disability

Disability refers to various dysfunctions in the body or mind but is complex to both define and measure (Grönvik 2009; Palmer & Harley 2012). In our study, the disability definition differs between the study populations as they originate from records maintained in different periods. As for the two historical study populations, parish ministers assisted Swedish authorities with collecting socio-demographic data on the population and its health status. Following guidelines from Statistics Sweden and medical expertise at the time, the ministers reported impairments *(lyten)* regarded as disabling in the parish registers. Thus, we could identify and code this disability information into a binary variable, focusing on disability reported in ages 15–24. Those having no disability recorded accordingly were treated controls to assess the disability effects on mortality during our follow-up duration.

As for the recent study population, DP defines disability from data in the LISA database. DP is part of Sweden's welfare program that provides economic benefits to working-age citizens (16–64) unable to support themselves due to long-term limits in functionality. DP is granted upon medical assessments and diagnoses ranging from physical to psychological conditions (Namatovu, Häggström Lundevaller & Vikström 2020). We included individuals entitled DP in ages 20–24, coded into a binary variable. Those not granted any DP served as controls to assess the disability effects on mortality during our follow-up from age 25. For comparative reasons, this onset age is consistent for all the three study populations.

Definition of premature mortality

We restricted our focus to premature deaths occurring below age 43 due to all-cause mortality. This follow-up covers a substantial period of individuals' lives to observe how disability affected mortality in the three study populations. There were another two reasons for focusing on premature death. First, as disability increases with ageing due to illnesses or overall decline in health, both the definition of disability and the effect of it would become difficult to estimate for older groups in comparison with younger groups. Second, the recent study population includes relatively young individuals (born 1968–1970) that we can only follow until December 31, 2010, due the availability of the LISA dataset. By then, they were 39–42 years old. To hold our temporal comparison consistent, we applied the identical follow-up duration on the historical study populations and defined premature death below age 43.

Statistical analysis

Variations in premature mortality risks by disability status we analyzed using event history analysis (Broström 2012). We tested whether these risks between individuals with disabilities or without differed by gender using Cox proportional hazard regressions for all three study populations (Cox 1972). In these regressions, each individual was observed from age 25 until death during the follow-up time (age 42) or until December 31 the final registration year per dataset/study population (1892, 1959, 2010). Migration was another censoring event, either out from the regions covered by the two historical populations or by emigration in the recent population. Age is a particularly strong determinant of death, which we adjust for using age as time-age scale in all models. The Cox regressions were ran separately for each study population not possibly to merge due to ethical considerations, and because the recent study population is only accessible in the Umeå SIMSAM-Lab.

As we were interested in whether disability affected men and women's mortality differently over time, we split the analyses by gender and ran interaction models between disability and gender in the regressions of all our study populations. For the 1900–1959 population, we tested changes over time by cohort decade. For both historical study populations, we adjusted for geographical location by parish for two reasons. First, ministers might differ in their reporting of disability among parishioners even though all ministers were obliged to follow general guidelines from Statistics Sweden. Second, mortality was considerably lower in rural-agricultural parishes in the past than in urban-industrial areas, which were more densely populated and unhealthy (Edvinsson & Nilsson 1999). During the time we study, this mortality difference decreased in Sweden and diminished in the 1940s. For the recent study population we tested geographical variations in mortality at the county level but found no significant difference and thus excluded this from further analysis.

We estimated the total effect disability had on premature mortality, both directly and indirectly. Intermediating effects from variables like SES and marital status can affect mortality indirectly and are often used in studies, many of which show that employment or education as well as a partner or spouse bring resources beneficial for people's social wellbeing and health (Kawachi, Subramanian & Kim 2008; Koball et al. 2010; Mithen et al. 2015; Ross, Mirowsky & Goldsteen 1990; Sandström et al. 2020). As disabilities significantly limit employment (Lengnick-Hall, Gaunt & Kulkarni 2008; Jones 2008; Vornholt et al. 2018) and partnership (Haage, Vikström & Häggström Lundevaller 2017; MacInnes 2011; Namatovu, Häggström Lundevaller & Vikström 2020; Tumin 2016; Vikström, Shah & Janssens 2020), accounting for SES or partnership status gives problems of estimating the disability effect on mortality because the explanatory power of disability can go through the SES or partnership variable (indirect effect). This made us refrain from adjusting for SES and partnership/marital status in the study subjects. Instead, we adjusted for SES background based on father's highest SES, derived from occupational data in the historical study populations (stratified by parish of residence). Beside a group of no fathers or whose occupation was missing, all occupations were coded using the HISCO scheme (a historical extension of the International Standard of Classification of Occupations) (Leeuwen et al. 2002), categorized into four social classes (elite, farmers, skilled and unskilled workers) following the Social Power scheme (SOCPO) (Putte & Miles 2005). For the recent study population (born 1968–1970), we used data from 1970 on father's educational level (university, higher, secondary) in addition to a group of cases holding no information on fathers or their education.

Provided the above considerations, we opted for presenting the Cox regression results from our adjusted models showing hazard ratios (HRs) with 95% confidence intervals (CIs) and statistical significance set at $p < 0.05$. All models estimate the mortality risks in individuals with disabilities using those without disabilities as reference group. The Appendix details the adjusted as well as unadjusted estimates and descriptive statistics on the study populations. All analyses we carried out using R software for Windows, version 4.0.2.

Results

Descriptive statistics

In Sweden, the mortality has been relatively low in ages 25–42, showing a slight male excess (Figure 1). In the 1800s, this mortality varied from 6–12 per 1000. After 1900, it declined to about 2 per 1000 in the 1950s, to below 1 by year 2000. The mortality peak of 1918 was because the Spanish flue killed about 38,000 individuals in Sweden, many of whom were young (Bengtsson, Dribe & Eriksson 2018).

Figure 1: Gender specific mortality in ages 25–42 in Swedish populations 1800–2016. Periods covered in this study marked in grey.

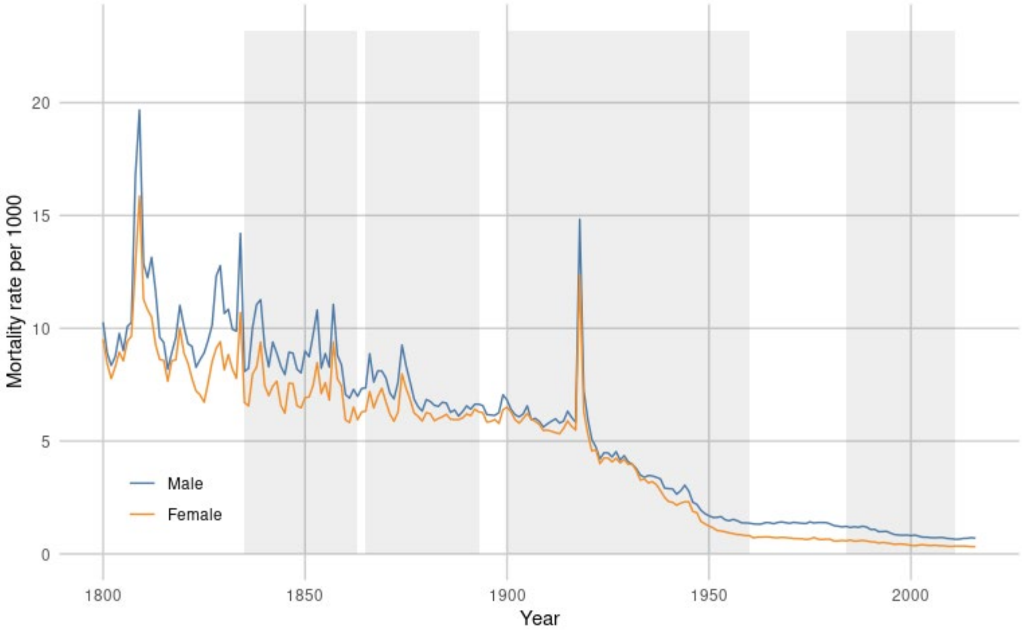


Table 1 shows basic data on our three study populations and the mortality rates during observation, while the Appendix details descriptive statistics (Tables A1–3). In the 1800s, the mortality rate in the disabled group was more than twice as high (14.9 per 1000) as in the non-disabled group (6.8). In the 1900–1959 period, the corresponding rates were 13.1 vs. 4.7, and in the 1990–2010 period 5.41 vs. 0.53. Although the mortality rates dropped substantially for both groups over time, these rates indicate that disability advanced death and increasingly did in relative terms. We assess this notion further using Cox regression models.

Table 1: Descriptive statistics by disability status and mortality in ages 25–42 in the three study populations.

Study populations	**N**	**Deaths**	**Mortality rate**
1800s *(born 1810–29, 1840–59)*			
Disability	274	37	14.9
No disability	14,342	806	6.8
Total	14,616	843	7.0
1900–1959 *(born 1877–1924)*			
Disability	1,249	193	13.1
No disability	68,247	3,792	4.7
Total	69,496	3,935	4.8
1990–2010 *(born 1968–2010)*			
Disability	3,392	279	5.42
No disability	397,580	3,192	0.53
Total	400,972	3,471	0.57

Regression results

As for the study population from the 1800s, the premature death risk was more than twice as high for people with disabilities than those without (HR 2.31, CI 1.65–3.22) (Table A4). This risk stayed relatively intact during the 1800s and generated a great disability-mortality difference in both men and women, as the hazard estimates plotted in Figure 2 demonstrate. According to our adjusted interaction model (Table A4), the gender difference in death risks (Men HR: 2.56, CI 1.74–3.76; Women HR: 1.78, CI 0.92–3.46) were not coupled with disability. Men with disabilities ran higher mortality risk than their female counterparts, just as average men in 19th-century Sweden did compared to women.

Figure 2: Estimated hazard ratios in mortality in ages 25–42 by disability and gender in the study population from the 1800s (N=14,616).

Turning to the study population from 1900–1959, disability continued to be associated with premature death significantly and even more than in the 1800s. In fact, the death risk was three times higher in individuals with disabilities than in those without (HR 3.01, CI 2.60–3.48) during this period (Table A5). The hazard estimates in Figure 3 show that this high mortality held for men as well as women with disabilities. As for the entire period, the death risks from disability were almost equal between the genders, as our adjusted interaction model suggests (Men HR: 2.95, CI 2.44–3.56; Women HR: 3.10, CI 2.47–3.89) (Appendix Table A5). However, there were some significant variations across both time and gender regarding how disability affected the premature death risk, as shown below.

Figure 3: Estimated hazard ratios in mortality in ages 25–42 by disability and gender in the study population 1900–1959 (N=69,496).

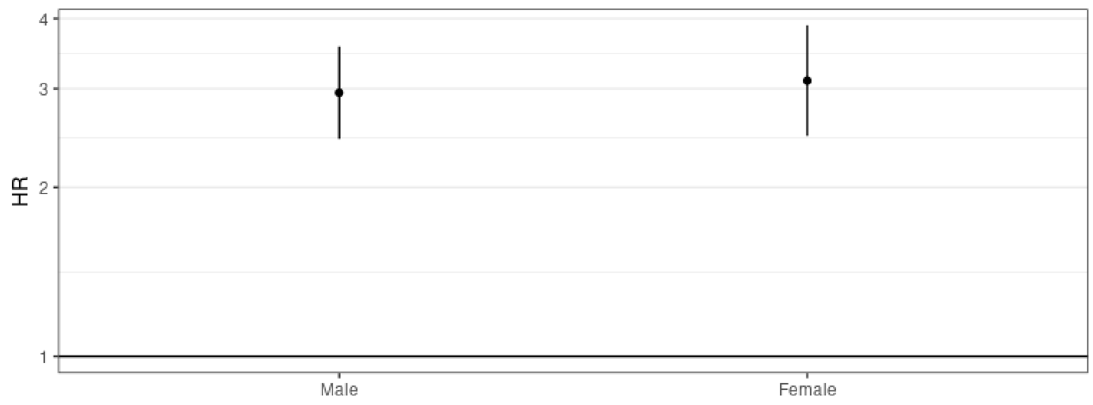


Figure 4 plots the hazard estimates per decade during the first half of the 1900s and reveals temporal variations in the relationship between disability and premature mortality (Table A6). People entering observation in the 1930s, ran 4 times higher death risk when having disabilities than those without, while the corresponding risk during the preceding decades was about 3 or below. In the 1940s, this risk increased further to above 5.

Figure 4: Estimated hazard ratios in mortality in ages 25–42 per decade by disability in the study population 1900–1959 (N=69,496).

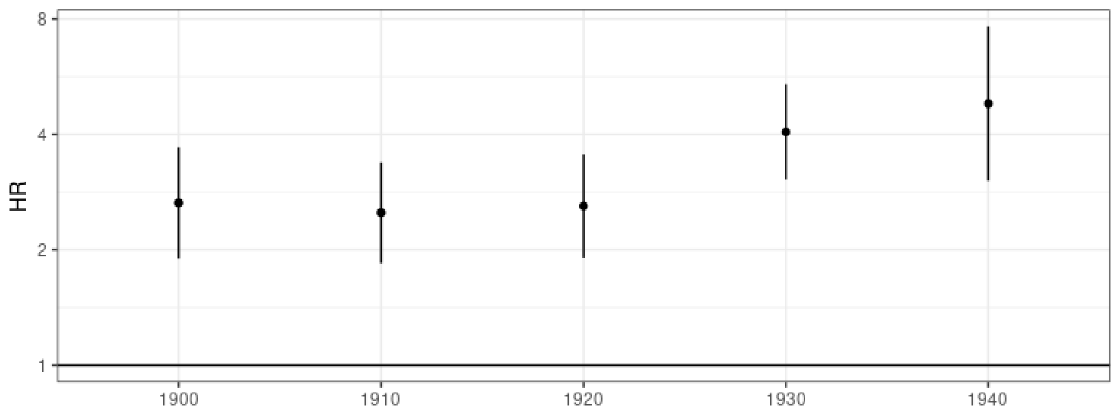
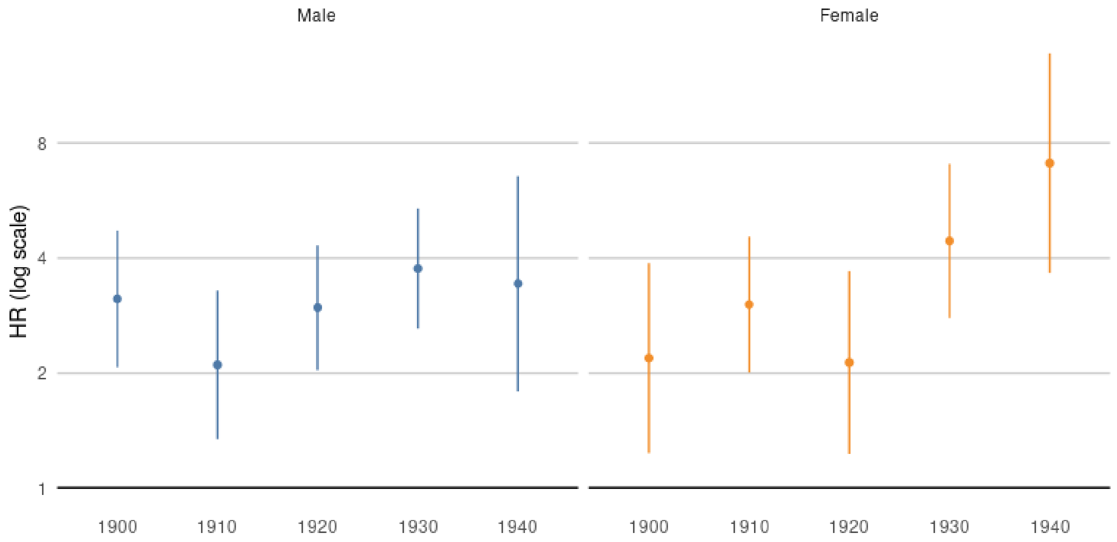


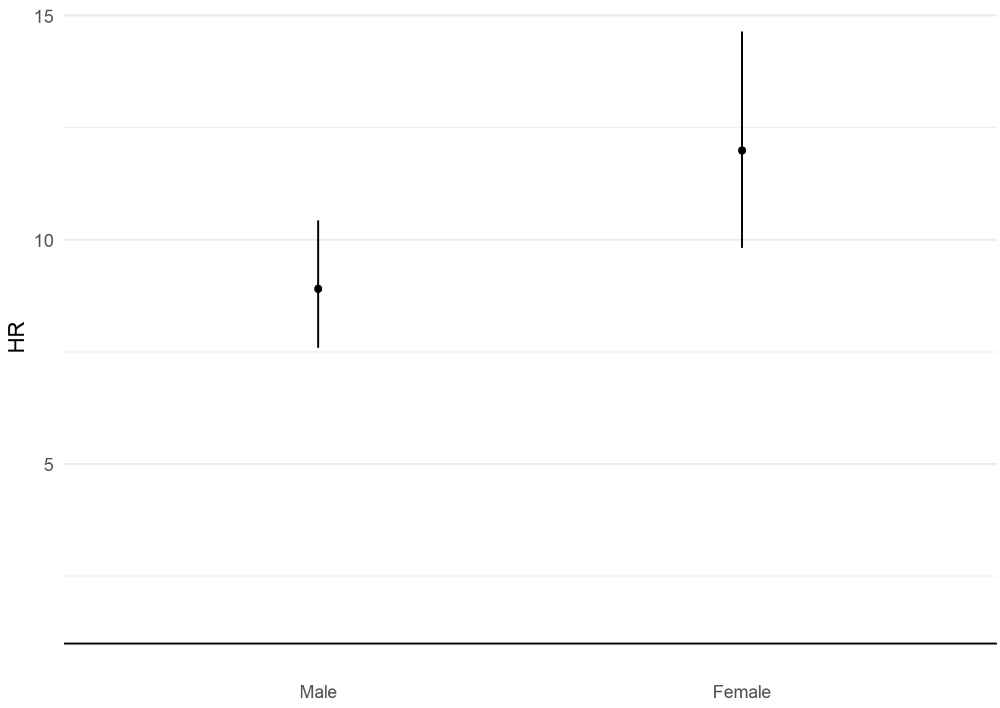
Figure 5 suggests that the increasing risks in premature death linked to disability over time (Figure 4), was primarily driven by exceeding risks for women with disabilities compared to other women. From 1900–1909, the former had about twice as high death risk (HR 2.19: CI: 1.23–3.88), which rose to above 4 the 1930s and to above 7 in the 1940s (HR 7.09: CI: 3.66–13.73) (Table A7). For men with disabilities the premature death risks were slightly less fluctuating relative to other men and showed a declining trend from the 1940s in opposite to women with disabilities.

Figure 5: Estimated hazard ratios in mortality in ages 25–42 per decade by disability and gender in the study population 1900–1959 (N=69,496)



In our study population from 1990–2010, adults with disabilities were almost at a ten times higher risk to die in ages 25–42 compared to the non-disabled group (HR 9.90, CI 8.03–10.5) (Table A4). Even though disability was coupled with high mortality in men as well (HR 8.89, CI 7.59–10.4), the hazard estimates (Figure 6) were exceptionally high for women with disabilities (HR 12.02, CI 9.83–14.69) compared to women without disabilities (HR 8.89, CI 7.59–10.4). That disability was significantly associated with higher premature death risks in women than in men marks a temporal shift in the gender effects of disability on mortality, as these effects were insignificant back in the 1800s up until 1959.

Figure 6: Estimated hazard ratios in mortality in ages 25–42 by disability and gender in the study population 1990–2010 (N=400,972).



Discussion

This study provides comprehensive estimates on how disability affected premature death risks in ages 25–42 from the 1800s, 1900s and 2000s. The results suggest that today's high mortality among people with disabilities dates back in time and has not decreased relative to non-disabled groups in the same age span, rather the reverse, in spite of general improvements of the health conditions and survival in Swedish populations during the centuries studied. The high HRs in premature death we found were associated with disability in recent time show similarities with previous research. One study from the USA in 1994–2006 found significant mortality HRs in adults (ages 18–65) with disabilities, being about 1.5 times more likely to die than those without disabilities (Forman-Hoffman et al. 2015). According to a Swedish study following a regional population in ages 16–64 during 1985–1996, both men and women granted DP faced significantly higher mortality risks (men HR

2.97; women HR 2.79) and particularly in younger ages (Karlsson et al. 2007). Our results confirm the latter study and suggest that the death risks were even significantly higher in ages 25–42 and afflicted women more than men. Other studies show that women in DP programs were at higher mortality risks than men although these results primarily concern old-age pensioners (Söderberg et al. 2020). Our premature death findings propose that disability indicated by receiving DP in young ages (20–24) lowered people's survival up to age 43 profoundly and already in the prime years of life.

As for historical time, there exist only a few studies to compare our estimates on premature mortality with because our access to longitudinal data on historical populations including disabilities is unique. In her study on the mortality risks in Flanders 1750–1950, De Veirman (2015) found no significantly higher death risks among people with hearing difficulties compared to their hearing siblings. Another study on 19th-century Sweden included all-type of disabilities using the same data as us (Haage, Häggström Lundevaller & Vikström 2016) shows that disability doubled or even tripled the death risks for both genders in ages 15–55 and that the highest risks were linked to mental disabilities followed by physical and sensory disabilities.

Our long-term results on the difference in premature death risks between disabled and non-disabled groups has made a disability-mortality gap between the groups come to the fore, which hold strong persistence over time. There are complications with explaining this gap, however. One explanation is that disabilities make individuals subject to adverse health that affect morbidity and can advance death. Studies recurrently find that people with disabilities have higher risks for secondary conditions such as diabetes, pressure sores, obesity, urinary tract infections and cardiovascular disease (Campbell, Sheets & Strong 1999; Kinne, Patrick & Doyle 2006; Newman et al. 2006). Another explanation to the disability-mortality gap is that disability is associated with difficulties to perform work and to social interaction or family formation (Jones 2008; Namatovu, Häggström Lundevaller & Vikström 2020, 2021;

Vikström, Shah & Janssens 2020). This can lead people to isolation, drug abuse or other lifestyle behaviors jeopardizing their social wellbeing and overall health, which can render an early death. Studies further show that people with disabilities report difficulties in access to health care service (Ali et al. 2013; Whittle et al. 2018). Most likely, insufficient access to health care and welfare support contributes explanation to the disability-mortality gap our study has identified from the 1800s until the 2000s.

Yet another challenge is to explain why this gap did not narrow over time despite the societal transformation that Swedish society underwent during the study period. In contrast to our expectations, our mortality findings do not confirm that people with disabilities came to enjoy a more equal health status relative to non-disabled groups along with improving living conditions and general rise in life expectancy or due to extensive welfare programs. The disability gap in mortality risks persisted and even increased significantly over time and relative to non-disabled populations. Our findings further show that the death risks in men with disabilities decreased slightly during the 1900s but primarily because the average health of men did not improve as much as it did for women in general (cf. Figure 1). The overall improvements in women's survival did not came to include women when having disabilities it seems, and thus the disability-mortality gap grew for women. A further assessment of this gap might enhance understanding of the public health aspects of ageing with disability. If disability in young age is independently associated with death in the prime years of life and shows persistence over time, there is need to rethink strategies and support to benefit people's survival through the mid-phase in life and not only in elderly years where the research focus has been put due to disability and health issues in ageing populations.

Strengths and limits

Although our results concern Swedish populations, our study constitutes an exceptional reference on how disability has affected people's mortality from the past to the present that is of international interest. It provides comparable estimates on the magnitude of the effects disability has had on mortality and their developments across three centuries. While the longitudinal scope and persistent disability disadvantage in survival are the major contributions with our study, it is not without drawbacks. One limit is that we do not differentiate the death risks by disability type neither examine the death causes, primarily due to data availability. In future studies, we will examine these issues further to contribute more knowledge on the disability-mortality gap that this study has revealed. Another limitation is that this study does not show results for from 1960–1990 due to lack of access to comparable data for this period. Unfortunately, the data we used provide no information on lifestyle factors, which could have helped to understand the disability-mortality gap. While our use of reference group assisted us to assess the mortality risks, there could be some inconsistency due to lack of diagnosis or incomplete disability information about individuals, which means we might have treated some cases in the disabled group as non-disabled. However, this can only imply low estimates of the mortality hazards, and thus the firm association between disability and mortality our study reports holds and remains important.

Moreover, the definition of disability varies between our past and recent study populations, as they comprise records maintained in different periods. Conditions regarded as disabling largely depends on time-space contexts, and on who defines disability and on what grounds. In our study case, it was either ministers or state administrators who made the decision on the individuals we defined disabled. Yet, all our results go in the same direction showing the profound premature death risks associated with disability. These risks increased in the 1900s and were most profound in 1990–2010. While minister reported milder as well as severe disabilities, citizens were granted DP when having severe disabilities to compensate for through public benefits. Probably, this has promoted the high mortality risks we found for the recent time.

Conclusions

There is scant knowledge about whether today's disability disadvantage in health survival goes a long way back in history and has changed over time. This study provides the first comprehensive estimates on how disability increased mortality in Swedish populations from the 1800s until the 2000s. Across three centuries, disability was associated with profoundly higher relative death risks in adults aged 25–42. When the general survival in Sweden improved, these risks increased and were the highest in the 1990–2010 period. Fundamental societal changes and extensive welfare provisions promoting equality in gender, health and social wellbeing of all citizens have not come to include younger generations with disabilities.

Ethics approvals

Ethics approvals have been obtained for all use of databases in this study. The Regional Ethical Board has approved all research based on recent data on Swedish population from the Umeå SIMSAM Lab, including the present study (Dnr: 2010-157-31 Ö). Statistics Sweden made all the data anonymous before making it available for research, therefore obtaining informed consent for each individual was neither possible nor necessary with this data. Ethics approval for the use of the POPLINK data on past Swedish populations (1900–1959) has been obtained from the Regional Ethics Board in Umeå, Sweden (Dnr: 2015/192-31Ö; 2016/140-32). The data was accessed in pseudo-anonymized format, where direct personal information had been removed, i.e. names and personal ID numbers. No informed consent was needed to conduct the study. As for the use of the POPUM database covering the 1800s, it is not associated with any sensitivity or ethics issues requiring ethical approval, as it only contains data on 19th-century populations in addition examined at aggregated levels in this study.

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Appendix

Table A1: Disability status and characteristics of individuals aged 25 in the study population from the 1800s.

		Total		Disabled		Non-disabled	
var	level	mean	count	mean_Dis	count_Dis	mean_Non	count_Non
DIS	Non	98.1	14,342				
	Dis	1.9	274				
gender	Women	48.6	7,107	36.5	100	48.9	7,007
	Men	51.4	7,509	63.5	174	51.1	7,335
ses	farmers	35.9	5,253	47.8	131	35.7	5,122
	(Missing)	33.4	4,885	13.9	38	33.8	4,847
	elite	4.4	639	3.6	10	4.4	629
	skilled workers	20.7	3,029	28.1	77	20.6	2,952
	unskilled workers	5.5	810	6.6	18	5.5	792
parish	ALNÖ	4.7	687	10.9	30	4.6	657
	ATTMAR	8.6	1,253	9.5	26	8.6	1,227
	HÄSSJÖ	6.1	894	9.1	25	6.1	869
	INDAL	8.6	1,260	7.7	21	8.6	1,239
	LJUSTORP	6.3	928	3.6	10	6.4	918
	NJURUNDA	10.6	1,550	18.6	51	10.5	1,499
	SÄTTNA	6.0	883	9.5	26	6.0	857
	SELÅNGER	4.9	715	3.6	10	4.9	705
	SKÖN	8.4	1,229	10.9	30	8.4	1,199
	SUNDSVALL SF	18.4	2,687	7.7	21	18.6	2,666
	TIMRÅ	5.4	795	2.9	8	5.5	787
	TUNA	8.4	1,228	4.7	13	8.5	1,215
	TYNDERÖ	3.5	507	1.1	3	3.5	504
kohort	Pre-industiral	36.8	5,376	46.4	127	36.6	5,249
	Industrial	63.2	9,240	53.6	147	63.4	9,093
event			14,616		274		14,342

Table A2: Disability status and characteristics of individuals aged 25 in the study population 1900–1959.

		Total		Disabled		Non-disabled	
var	level	mean	count	mean_Dis	count_Dis	mean_None	count_None
dis2	None	98.2	68,247				
	Dis	1.8	1,249				
gender	Female	50.4	35,047	38.3	478	50.7	34,569
	Male	49.6	34,449	61.7	771	49.3	33,678
father_ses	farmers	40.8	28,381	48.0	599	40.7	27,782
	(Missing)	26.9	18,719	17.1	214	27.1	18,505
	elite	6.4	4,454	6.3	79	6.4	4,375
	skilled workers	10.0	6,915	10.6	132	9.9	6,783
	unskilled workers	15.9	11,027	18.0	225	15.8	10,802
socken	BUREÅ	3.7	2,558	5.2	65	3.7	2,493
	BYSKE	10.2	7,083	5.4	67	10.3	7,016
	JÖRN	6.7	4,653	8.7	109	6.7	4,544
	MALÅ	4.6	3,199	6.5	81	4.6	3,118
	NORSJÖ	8.2	5,714	10.6	133	8.2	5,581
	SKELLEFTEÅ	28.9	20,109	29.1	363	28.9	19,746
	SKELLEFTEÅ STADS	4.2	2,951	3.0	38	4.3	2,913
	UMEÅ LANDS	19.5	13,530	24.8	310	19.4	13,220
	UMEÅ STADS	14.0	9,699	6.6	83	14.1	9,616
dec	1900	13.4	9,344	10.6	133	13.5	9,211
	1910	17.3	12,002	14.8	185	17.3	11,817
	1920	19.8	13,789	17.9	224	19.9	13,565
	1930	24.2	16,789	25.5	318	24.1	16,471
	1940	25.3	17,572	31.1	389	25.2	17,183
event			69,496		1,249		68,247

Table A3: Disability status and characteristics of individuals aged 25 in the study population 1990–2010 [to be provided]

Figure A1: Kaplan-Meier survival plots for survival probability in ages 25–42 by disability and gender in the study population from the 1800s (N=14,616).

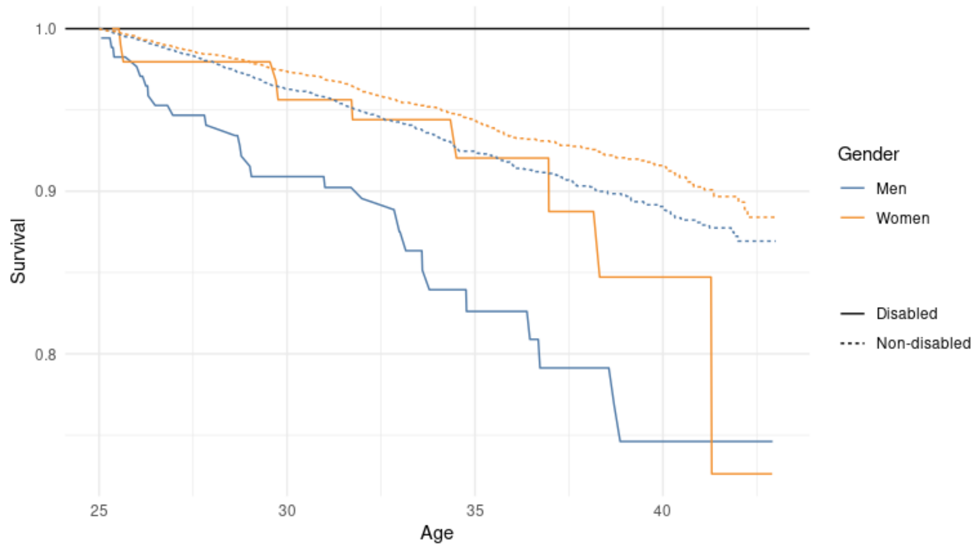

Figure A2: Kaplan-Meier survival plots for survival probability in ages 25–42 by disability and gender in the study population 1900–1959 (N=69,496).

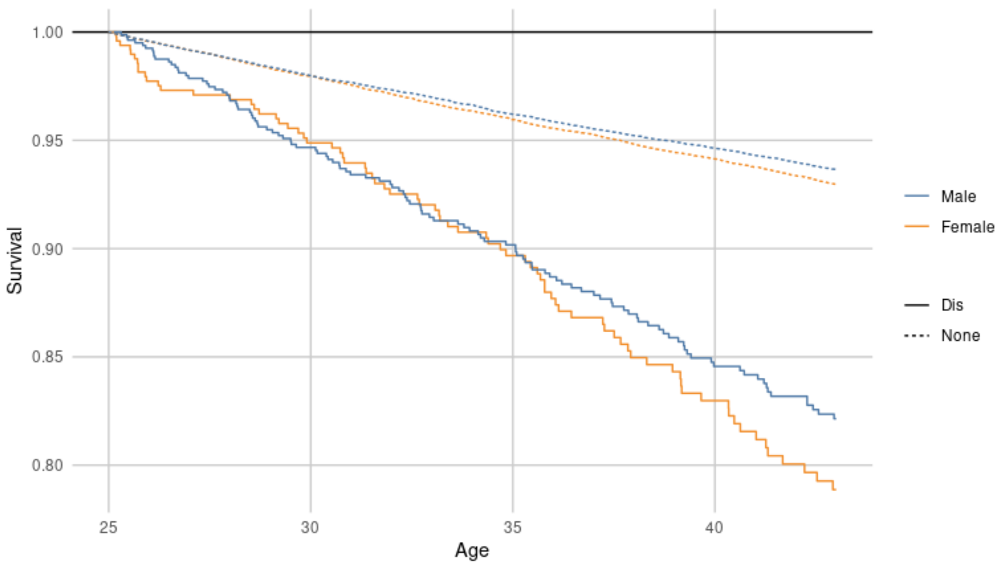

Figure A3: Kaplan-Meier survival plots for survival probability in ages 25–42 by disability and gender in the study population 1990–2010 (N=XXX,XXX).

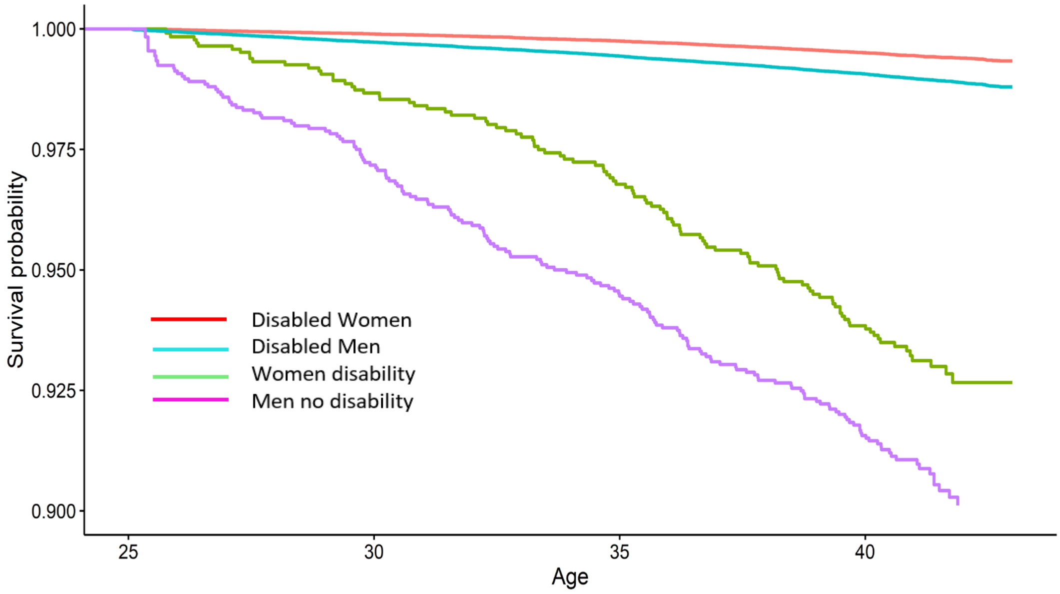

Table A4: HR and 95 % CIs for risk of dying in ages 25–42, estimated using Cox proportional hazard models, 1800s study population.

	Unadjusted HR (95% CI)	Adjusted HR (95% CI)	Adjusted interaction HR (95% CI)
DISDis	2.18 (1.57 - 3.03)	2.31 (1.65 - 3.22)	1.78 (0.92 - 3.46)
genderMen	1.32 (1.15 - 1.51)	1.34 (1.16 - 1.53)	1.32 (1.15 - 1.52)
kohortIndustrial	1.07 (0.93 - 1.24)	0.97 (0.84 - 1.12)	0.97 (0.84 - 1.12)
ses(Missing)	1.29 (1.09 - 1.52)	0.96 (0.79 - 1.17)	0.96 (0.79 - 1.17)
seselite	2.13 (1.62 - 2.81)	1.50 (1.11 - 2.03)	1.51 (1.12 - 2.04)
sesskilled workers	1.06 (0.87 - 1.29)	1.00 (0.82 - 1.22)	1.00 (0.82 - 1.22)
sesunskilled workers	1.92 (1.46 - 2.52)	1.44 (1.08 - 1.93)	1.45 (1.08 - 1.94)
DISDis:genderMen			1.44 (0.67 - 3.09)

Table A5: HR and 95 % confidence intervals for risk of dying in ages 25–42, estimated using Cox proportional hazard models in the study population 1900–1959

	Unadjusted HR (95% CI)	Adjusted HR (95% CI)	Adjusted interaction HR (95% CI)
dis2Dis	2.82 (2.44 - 3.26)	3.01 (2.60 - 3.48)	3.10 (2.47 - 3.89)
genderMale	0.93 (0.87 - 0.99)	0.90 (0.85 - 0.96)	0.90 (0.85 - 0.96)
dec1910	0.94 (0.86 - 1.02)	0.92 (0.85 - 1.01)	0.92 (0.85 - 1.01)
dec1920	0.70 (0.64 - 0.76)	0.70 (0.64 - 0.76)	0.70 (0.64 - 0.76)
dec1930	0.44 (0.39 - 0.48)	0.44 (0.40 - 0.49)	0.44 (0.40 - 0.49)
dec1940	0.21 (0.18 - 0.25)	0.22 (0.18 - 0.25)	0.22 (0.18 - 0.25)
father_ses(Missing)	0.84 (0.77 - 0.91)	0.87 (0.79 - 0.95)	0.87 (0.79 - 0.95)
father_seselite	0.79 (0.68 - 0.92)	0.91 (0.78 - 1.07)	0.91 (0.78 - 1.07)
father_sesskilled workers	0.87 (0.77 - 0.97)	0.92 (0.82 - 1.03)	0.92 (0.82 - 1.03)
father_sesunskilled workers	0.96 (0.88 - 1.05)	0.98 (0.90 - 1.07)	0.98 (0.90 - 1.07)
dis2Dis:genderMale			0.95 (0.71 - 1.28)

Table A6: HRs and 95% CIs from Cox models estimating mortality risks per decade by disability in ages 25–42 in the study population 1900–1959 (N=69,496).

	HR	CI low	CI high
dis2Dis	2.65	1.90	3.70
dec1910	0.93	0.85	1.01
dec1920	0.70	0.63	0.76
dec1930	0.43	0.39	0.48
dec1940	0.21	0.18	0.24
genderMale	0.90	0.85	0.96
father_ses(Missing)	0.87	0.79	0.95
father_seselite	0.91	0.78	1.06
father_sesskilled workers	0.92	0.82	1.03
father_sesunskilled workers	0.98	0.90	1.07
dis2Dis:dec1910	0.94	0.60	1.48
dis2Dis:dec1920	0.98	0.62	1.54
dis2Dis:dec1930	1.53	0.99	2.37
dis2Dis:dec1940	1.81	1.02	3.21

Table A7: HRs and 95% CIs from Cox models estimating mortality risks per decade by disability in ages 25–42 per decade in the study population 1900–1959 (N=69,496).

term	Male	Female
dis2Dis	3.13 (2.07 - 4.73)	2.19 (1.23 - 3.88)
dec1910	1.00 (0.87 - 1.14)	0.87 (0.77 - 0.98)
dec1920	0.73 (0.64 - 0.84)	0.67 (0.59 - 0.76)
dec1930	0.52 (0.45 - 0.60)	0.36 (0.31 - 0.42)
dec1940	0.27 (0.22 - 0.34)	0.15 (0.12 - 0.20)
father_ses(Missing)	0.98 (0.86 - 1.11)	0.79 (0.70 - 0.90)
father_seselite	1.02 (0.82 - 1.25)	0.79 (0.63 - 1.00)
father_sesskilled workers	0.99 (0.84 - 1.16)	0.85 (0.72 - 1.00)
father_sesunskilled workers	1.06 (0.94 - 1.20)	0.91 (0.80 - 1.03)
dis2Dis:dec1910	0.67 (0.37 - 1.23)	1.38 (0.68 - 2.79)
dis2Dis:dec1920	0.95 (0.54 - 1.66)	0.97 (0.44 - 2.15)
dis2Dis:dec1930	1.20 (0.69 - 2.08)	2.03 (0.97 - 4.24)

Table A8: HR and 95 % confidence intervals for risk of dying in ages 25–42, estimated using Cox proportional hazard models in the study population 1990–2010.

	Unadjusted HR (95% CI)	Adjusted HR (95% CI)	Adjusted interaction HR (95% CI)
No disability	1.00	1.00	1.00
Disability	10.4 (9.21 – 11.8)	9.90 (8.03 – 10.5)	11.9 (9.8 – 14.64)
Women	1.00	1.00	1.00
Men	1.77 (1.66 – 1.92)	1.76 (1.64 – 1.89)	1.81 (1.68 – 1.95)
Father: University	1.00	1.00	1.00
Secondary	1.11 (0.97 – 1.29)	1.11 (0.98 – 1.31)	1.14 (0.99 – 1.31)
Primary	1.32 (1.15 – 1.51)	1.32 (1.15 – 1.51)	1.32 (1.15 – 1.51)
Missing	0.92 (0.80 – 1.08)	0.99 (0.85 – 1.12)	0.99 (0.85 – 1.15)
Disability: Female			1.00
Disability: Men			0.75 (0.58 – 0.96)

Table A8: Sex differentiated HR and 95 % confidence intervals for risk of dying, estimated using Cox proportional hazard models, for the birth cohort of 1968-1970.

	Male	Female
	Adjusted HR (95% CI)	Adjusted HR (95% CI)
Disability	1.00	1.00
	8.89 (7.59 – 10.4)	12.02 (9.83 – 14.69)
Father: University	1.00	1.00
Secondary	1.49 (1.25 – 1.78)	0.98 (0.78 – 1.32)
Primary	1.49 (1.25 – 1.78)	1.07 (0.86 – 1.34)
Missing	1.10 (0.90 – 1.34)	0.82 (0.65 – 1.04)