Extended abstract: Life course outcomes of individuals growing up with a sibling with a disability.

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Short abstract

Research suggests that having a sibling with a disability may substantially affect individuals' social, demographic, and economic trajectories, often leading to life course disadvantages. However, findings are scarce and based on small convenience samples. This study explores life course trajectories from adolescence to early adulthood of individuals who grew up with a disabled sibling (e.g., educational outcomes, leaving the parental home, family formation). Using total population Finnish register data, we compare their outcomes to those who grew up without siblings with disabilities, matching the individuals' sociodemographic characteristics. We envision siblings of disabled individuals to be polarized in their outcomes, either being highly performing or very vulnerable. Our study will be the first to provide a comprehensive overview of how demographic processes may be influenced by disabilities in the family and thereby will make a significant contribution to understanding the far-reaching family consequences of disability.

Extended abstract

Problem statement and relevance

Research suggests that being confronted with the disability of a sibling in the family may substantially affect the well-being of individuals, shaping their social, demographic, and economic trajectories over their life courses. While the life courses of individuals with a disability are relatively well researched, the ones of family members such as siblings are undeniably overlooked in current research. At the same time, exploring the life course outcomes and demographic transitions of individuals who grew up with a sibling with a disability contributes relevant insights into this frail population group. They may experience negative physiological and psychological effects, such as higher level of anxiety, stress, and uncertainty (Milevsky & Singer, 2022), and have fewer family resources, time, and energy to pursue their own life goals.

Only a few studies address behavioural, educational or family life course outcomes of individuals who grew up with a sibling with a disability. The results, however, vary according to the studied outcome. Some literature, for example, suggests that these individuals may well adjust to the limitations within the family environment associated with their sibling's disability and may even develop pro-social behaviours (O'Brien et al., 2009; Shivers, 2019) and character traits (Fjermestad et al., 2019; Milevsky & Singer, 2022; Orm et al., 2022). Likely, they show little impact on educational and employment trajectories over their later life courses (Wolfe et al., 2014). On the contrary, other research emphasises disadvantages, for example, behavioural problems (Knott et al., 2007), poorer schooling outcomes (Hannah & Midlarsky, 1999) and evident mental health problems (Marquis et al., 2019) during childhood. In addition to these imminent adverse life course outcomes, these individuals are more likely to divorce later in their lives (Hodapp et al., 2010). While the path dependency of these life course outcomes concerning their general well-being is not entirely clear, the literature points towards life course disadvantages that individuals with siblings with a disability face from early childhood onwards and carry until adulthood.

The theoretical assumptions of the life course approach aid in formalizing the life course outcomes in individuals who grew up with a sibling with a disability, using the idea of intertwined family life courses (Macmillan & Copher, 2005), the sensitive period and risk accumulation models within the life course approach (Ben-Shlomo et al., 2014). Specifically, children and adolescents are highly susceptible to stressors, as the confrontation with the disability of a sibling and its related challenges for the family may pose. Thus, early-life exposure to such stressors can lead to long-term adverse health and life course outcomes (Kuh et al., 2013). Moreover, the family stress model (cf. Masarik & Conger, 2017) may contribute

theoretical insights into the challenges families with a child with a disability face and additionally contribute to the experience of the other siblings, for example, parental relationship problems or economic worries due to underemployment (cf. Hondralis & Kleinert, 2021; Nes et al., 2014; Powers, 2001).

Overall, research on life course outcomes of individuals who grew up with siblings with a disability is inconclusive, lacking a comprehensive investigation of various demographic and life course outcomes and identifying important mechanisms of moderation and intersectionality. These shortcomings of current research are – at least partially – due to findings relying on small convenience samples and being scattered across different cultural and welfare regime contexts. Any impacts of having a sibling with disability are subject to strong intersectionality and are thus influenced by, yet not limited to, for example, the family socioeconomic background, the severity of disabled siblings' limitations for the family (O'Brien et al., 2009) or other factors influencing the family coping with a child's disability (Marquis et al., 2019), suggesting a significant role of the overall resilience and capability of the family where both children grew up.

Objective and research questions

The proposed study aims to explore relevant life course outcomes and trajectories from adolescence to early adulthood of individuals who grew up with a sibling with a disability. Specifically, we will analyse individuals' mental health, educational outcomes, initial employment trajectories, age of leaving the parental home, and family formation.

We do so by answering the following research questions:

RQ1 To what extent are individuals' life course outcomes from adolescence to early adulthood shaped by having grown up with a sibling with a disability?

RQ2 Is there any heterogenous effect of a sibling's disability on an individual's age at leaving home, employment and family formation outcomes depending on parental SES and family structure (intact vs. single parent families)?

RQ3 To what extent the impact of a sibling's disability on an individual's education/schooling and mental health outcomes is moderated by the gender and the birth order of the siblings?

Our study will address these research questions while providing an innovative approach. Specifically, we aim to adopt a family life course perspective and argue that the life courses of individuals within the same family system are intertwined (Macmillan & Copher, 2005). At the same time, having a sibling with a disability may be a significant adversity over the early life course, substantially challenging one's development. Thereby, we not only aim to explore demographic processes for individuals who grew up with a sibling with a disability. We also will provide an intersectional perspective on frailty in this overlooked population, applying an interdisciplinary approach.

Methods

Data and study population

We use data on the Finnish population obtained from the population registers for our study. The Finnish register data provide a rich pool of demographic, family, socio-economic, and health information on individuals and their family members in a longitudinal format, covering up to 30 years. Furthermore, the data allows us to identify families with children with disabilities through objective measures of, for example, disability allowances, medical diagnoses, or the utilisation of medical and social services. These recordings allow us to cover all families with children with diagnosed disabilities in Finland in the past 30 years and present a less selective and comprehensive analytical sample. The latter presents a crucial advantage of the linked register data compared to conventional survey data or convenience samples. In this study, we included children born in Finland in 1986–1995, who were followed until age 30.

Measures and operationalisation

Our *outcome measures* include several measures of life course outcomes and well-being, such as mental health, educational outcomes, initial employment trajectories, age of leaving the parental home, and family formation. (1) We measure mental health using objective information on psychotropic medication purchases from adolescence onwards (cf. Moustgaard et al., 2018), with poor mental health indicated by registered psychotropic medication use. (2) Education outcomes are indicated by the individuals' school tenure as well as final performance. Specifically, we assess three educational outcomes at age 26: first, completing any secondary-level degree, second, completing an academic secondary-level degree instead of vocational training, and third, completion or current enrolment in tertiary education. (3) Initial employment trajectories are operationalised by measures of unemployment and being neither in education nor in employment (NEET). (4) The age of leaving the parental home (i.e., not co-residing in the same household as the parents) was collapsed into six categories: 16–17, 18, 19, 20, 21–26 years, or never left by age 26. (5) Finally, we measure family formation as the age of co-residing with a partner, and any other marital status changes and transition into parenthood.

Our *main explanatory variable* is the experience of growing up with a sibling with a disability. We measure disability using information on hospital and specialized outpatient care from the Finnish Institute for Health and Welfare (i.e., ICD-10 codes), as well as reimbursement data from the Social Insurance Institution. We will mainly use “random” and untestable types of disability (based on pre- and postnatal screening) to avoid selection issues.

We further investigate heterogeneity in our analysis with regard to the socioeconomic family background, i.e., parental educational background and household income, and the family structure and sibling order.

Methodological approach

Our analysis aims to match individuals who grew up with siblings with a disability with those without. We aim to match on confounders that were not affected by themselves by the disability of the sibling, i.e., that were present before the sibling with the disability was born. These are the individuals’ gender, year of birth, the age difference to the sibling, the family socioeconomic background, and rural vs. urban living areas. Using these matched samples, we aim to conduct a time-varying regression analysis on all the life course outcomes, controlling for individual-level confounding while considering time-varying covariates at the individual, family and regional level (mixed-effects models). We observed participants from age 15 onwards with 3-monthly follow-ups. We conduct all analyses stratified by gender to account for different stress internalization and coping mechanisms that potentially affected (cf. Acciai & Hardy, 2017; Dedovic et al., 2009). We address the selection issue by providing separate analyses for first- and second-born siblings.

Expected results

Drawing on findings from existing research, we expect to find adverse mental health and educational outcomes in individuals who grew up with a sibling with a disability. At the same time, the expectations for other life course outcomes, such as initial employment or family formation, are less clear and yield further elaboration. Nonetheless, some insights on pro-social behaviour may support the assumption that life course outcomes of family formation indicate early trajectories in this population (Research question 1). Moreover, we suggest that the family structure affects the resilience of individuals to cope with the situation. Families who experience parental separation are particularly at risk of adverse life course outcomes (Research question 2). While the role of gender and sibling order is yet to be explored, we assume that women are particularly at risk of suffering internalisation-based stress consequences leading to adverse life course outcomes. At the same time, men externalise their problems (Research question 3).

The analyses for this research will be conducted early 2024 during a research visit of the co-author Elena Neri at the University of Helsinki and the remote access by the first author Lara Bister who has previously worked with the same data. All the data are already available and we are convinced that we are able

to present conclusive findings at the European Population Conference in June 2024.

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