



## Social determinants of self-rated health among Japanese mothers of children with disabilities

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### ABSTRACT

Caregivers of children with disability are more likely to be affected by social determinants that lead to poor health. Additionally, a previous study revealed that although mothers of a single child with disability wanted to have another child, various obstacles including social, cultural, economic, and biological factors existed and some had to give up on having another child. Since the mental health and well-being of these mothers were poorer than those of mothers with multiple children with and without disabilities, such family composition may also affect maternal health. This study aimed to investigate and compare the social determinants of self-rated health of mothers only having children with disabilities and those having multiple children with and without disabilities. Through parents' associations of children with disabilities throughout Japan, 2311 self-administered questionnaires were distributed to mothers of such children from January to March 2016. Out of the 1133 responses (return rate 49%), 1012 (43.8%) mothers of children with disabilities under 20 years of age were used for this study. Logistic regression showed that poor financial situation was most strongly related to poor self-rated health among all mothers. Other factors related to poor self-rated health were a lack of existence of child without disability, social isolation, low health consciousness, child's sex (girl), and severity of disability (mild/moderate). However, these relationships differ based on the existence of a child without disability. Investigating how socioeconomic and cultural conditions relate to family composition including child birth, and how they determine health is needed in the future.

### 1. Introduction

The social determinants of health—that is, the conditions in which people are born, live, work, and age—are primarily responsible for health inequities according to the World Health Organization (WHO, n.d.). In other words, economically or socially disadvantaged people are more likely to suffer the burdens of social determinants that lead to poor health (WHO South Asia, 2009). This is clearly reflected in people with disability. Currently, > 1 billion people (or about 15% of the world's population, i.e., one in seven people) have some form of disability, making it a global public health issue (WHO, 2015). Compared with their non-disabled peers, people with disabilities are more likely to experience poorer health outcomes as well as be affected by socioeconomic disadvantages (Emerson et al., 2009, 2011).

The caregivers of such people with disabilities also experience burden. Caregivers of adults with disability tend to have worse employment opportunities and income, while caregivers of children with disability are more likely to experience divorce and delayed workforce entry (Emerson et al., 2009). Hock and Ahmedani (2012) also reported that the parents of children with autism spectrum disorder (ASD) were

more likely to report poor neighborhood social capital, difficulty coping, lower levels of relationship satisfaction and mental health, and greater aggravation than did parents of children without ASD. Therefore, caring for people with disabilities might be associated with lower socioeconomic status and poorer health status.

Previously, my colleagues and I collected data from the mothers of children with intellectual disabilities (ID) in Japan, and found that although mothers' sense of coherence and subjective social capital predicted their mental health and positive changes (in their lives, health, and interpersonal relationships), financial difficulties were significantly and consistently related to poor maternal mental health and less positive change (Kimura and Yamazaki, 2016).

Moreover, although mothers of a single child with disability in the study wanted to have another child, various obstacles existed (e.g., recurrent risks, lack of support, and financial difficulty) and 42.5% had to give up on having another one (Kimura and Yamazaki, 2017). Since the mental health and well-being of these mothers were poorer than those of mothers with multiple children with and without disability, whether mothers could have another child without disability may be an important factor to determine mothers' health. However, whether these

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implications could be applied to other health measures, such as self-rated health, is unclear.

Self-rated health is considered an inclusive measure of health (Jylha, 2009), and a powerful predictor of future health and the utilization of health care services (Bath, 1999; Pappa and Niakas, 2006; Su et al., 2011). In addition, poor self-rated health is related to negative clinical outcomes (e.g., higher mortality and poorer QOL) and has been used as a screening tool for the assessment of general health (Jylha, 2009). Therefore, assessing self-rated health might be helpful for understanding the overall health of caregivers of children with disabilities.

This study aimed to investigate and compare the social determinants of self-rated health of mothers only having children with disabilities and those having multiple children with and without disabilities.

## 2. Method

### 2.1. Data source

The present study used secondary data, which were collected from January to March 2016 with the primary purpose of exploring the experiences related to pregnancy, child birth, and child-rearing among mothers of children with disabilities in Japan. I asked parents' associations in all 8 regions (47 prefectures) of Japan to cooperate with the survey, who then provided the number of possible participants in their corresponding region. In total, I distributed 2311 self-administrated questionnaires to the mothers of children with disabilities through these parents' associations, obtaining 1133 (49%) responses by postal mail. To be eligible for the study, participants had to be mothers of children with disabilities (intellectual disability, physical disability, chromosomal abnormality, or internal impediment) and the child had to be < 20 years of age. After excluding mothers of children with disabilities aged 20 years or over and other relatives, 1012 (43.8%) responses were considered in the analysis.

Social determinants of health included five determinant areas (economic stability, education, social and community context, health, neighborhood and environment) (Healthy People 2020, n.d.), but available four areas' data (excluded neighborhood and environment) were included in the analysis.

### 2.2. Measures

#### 2.2.1. Self-related health

Self-related health was assessed with a single question: "How do you evaluate your current health status?" Mothers responded using a five-point Likert scale (1 = "very good", 2 = "fairly good", 3 = "average", 4 = "fairly bad", and 5 = "bad"; Perlman and Bobak, 2008). Following past studies (Perlman and Bobak, 2008; Oshio and Kobayash, 2009), responses were dichotomized as "poor" (fairly bad or bad) and "not poor" (very good, fairly good, or average).

#### 2.2.2. Child's characteristics

The children's characteristics were assessed through child's age and sex, school level (under elementary, elementary/junior high school, high school or more), severity of disability, disability type, and child's behavioral difficulties. Severity of disability was assessed at the child consultation center of the municipality in which participants lived, and was divided into four categories—mild, moderate, severe, or profound. These were then dichotomized as "mild/moderate" and "severe/very severe." Children's disability type was categorized as "ASD," "Down syndrome" "other intellectual disabilities (ID) or chromosome abnormality," and "internal impediment/physical disability." Difficulty of child's behavior was evaluated with a single item: "Do you have extreme difficulty in dealing with your child's behavior?" This question was answered as "difficult to deal with" or "not difficult to deal with."

#### 2.2.3. Sociodemographic variables including economic stability, education, and health

Mother's sociodemographic variables assessed included mother's age, employment status ("employed": full time/part time/self-employed vs. "unemployed": homemaker/others), marital status ("married" vs "currently not married": unmarried/divorced/widowed), education level ("junior high school/high school," "junior college/vocational school," and "university/postgraduate"), family composition, perceived financial situation, and health consciousness. Family composition only focused on child's sibling composition, and dichotomized as "having child without disabilities" and "only having children with disabilities." Perceived financial situation was evaluated with a 5-point Likert scale from 1 (poor) to 5 (rich); this was then dichotomized as "poor" (poor/fairly poor) and "not poor" (average/fairly rich/rich).

Health consciousness was assessed with a single item, where participants chose a response ranged from 1 (no longer pay attention to your health) to 5 (pay attention to your health). Their answers were then dichotomized as "not paying attention to own health" (no longer pay attention to your health/tend to not pay attention to your health) and "paying attention to own health" (yes and no/tend to pay attention to your health/pay attention to your health).

#### 2.2.4. Social and community context

Social and community context assessed included perceived social isolation, social support, and social capital.

Perceived social isolation was evaluated a single item: "I feel isolated from society." Responses were made using a scale of 1 (agree) to 5 (disagree), and then dichotomized as "isolated" (agree/agree a little) and "not isolated" (neither agree nor disagree/disagree a little/disagree).

Social support was assessed as whether participants are able to obtain support from others (a spouse, other family members, peer group, specialists, teachers, or neighbors) or not. They responded to each question with "yes" or "no".

Social capital was assessed in terms of subjective social capital, trust for neighbors, participation in community, and two single items related to social capital for child. The subjective social capital scale (Togari, 2006) was evaluated with 6 items assessing concepts like psychological sense of community ("Our neighbors are willing to help others who need support") and neighborhood cohesion ("This neighborhood has a friendly atmosphere; we take care of others' homes when they are away"). Items are rated on a 5-point Likert scale from 1 (strongly disagree) to 5 (strongly agree), with higher scores indicating greater social capital. Mother's participation in community ("I am participating in activities held by the neighborhood community association, parent and teacher associations, or parents' associations of children with disabilities") and trust for neighbors ("I think my neighbors are able to be trusted"), two single items related to social capital for child ("child with disability can participate in local events"; "child with disability regularly interact with children without disabilities") were scored on a scale from 1 (strongly disagree) to 5 (strongly agree); the answers were then dichotomized as "yes" (strongly agree/agree/neither agree nor disagree) and "no" (strongly disagree/disagree).

#### 2.2.5. Statistical analysis

IBM SPSS Statistics 21 for Windows (IBM, Armonk, New York, USA) was used for all statistical analyses, with an alpha of 0.05 set as the level of significance. I examined differences in self-rated health (poor vs. not poor) and family composition ("having child without disability" vs. "only having children with disabilities") according to each variable using the chi-square test and independent *t*-test. All missing data were treated as missing. To investigate the determinants of poor self-rated health (the dependent variable), logistic regression analyses (univariate and multivariate) were performed to calculate the odds ratios (ORs) and the adjusted odds ratios (AORs).

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