IMPACT OF URINARY INCONTINENCE ON THE QUALITY OF LIFE OF FAMILY CAREGIVERS

Hypothesis / aims of study
An observation of family caregivers providing care to invalid family members living at home or institutionalized in nursing homes reveals that urinary incontinence is a difficult issue to cope with. Urinary incontinence has negative impacts on the quality of life (QOL) of not only the cared individuals themselves but also their caregivers. Numerous investigations have focused on the impacts of urinary incontinence on the QOL of patients; however, sufficient studies on the effects of urinary incontinence on the QOL of caregivers have not been undertaken. We conducted a survey to assess the impacts of urinary incontinence on the QOL of caregivers providing care to invalid family members with urinary incontinence. In this paper, we report the impacts of urinary incontinence of cared individuals on the QOL of their caregivers by using a modified Kings Health Questionnaire; this was a valid means that was originally established to measure the QOL of patients with urinary incontinence.

Study design, materials and methods
An Internet panel for family caregivers, managed by the Link Consulting Associate-Japan Co., includes 7,316 members who provide care to invalid family members at home in Japan. We requested the members of this panel to respond to an online questionnaire in order to assess the impact of urinary incontinence on their burden and QOL. The questionnaire included questions on the continence status and age of the invalid family members, the age and occupation status of the caregivers, the relationship of the caregivers to the invalid family members, duration of care, medication status, and expenses incurred as a result of nursing care. In order to assess the impacts of urinary incontinence on the caregivers, a modified version of the KHQ was included in the questionnaire. The KHQ is a valid questionnaire used to measure the QOL of patients with urinary incontinence, which consists of 21 questions in 8 domains (general health, incontinence impact, role limitations, physical limitations, social limitations, personal relationships, emotions, and sleep/energy disturbance) in addition to self-severity measures. The Japanese version of the KHQ was also psychologically validated. The KHQ has a four-point scoring system for each item, and the scores in each domain range from 0 to 100—a higher score indicates a greater impairment of the QOL. The KHQ was partially modified to suit the purpose of the present study; instead of posing a question such as “How much are you affected by your bladder problem?” the questionnaire asked, “How much are you affected by providing care to family members with urinary incontinence?” Further, the grade of disability of the cared individuals was assessed by enquiring about “the level of care need,” which was established in the nursing care insurance system by the Japanese Ministry of Wealth and Labor. The level of care need ranges from 0 (minimum care need) to 5 (maximum care need). This level of care need is assessed on the basis of the abilities of the invalid family members to conduct routine activities.

Results
A total of 1,203 caregivers responded to the questionnaire and relevant data obtained from 639 caregivers (34.9% male respondents and 65.1% female respondents) providing care to family members with urinary incontinence were analyzed. Most of the caregivers were rather young—68.1% of them were under 50 years of age and 87.8% were under 60 years of age. With regard to the gender of the cared individuals, 40.9% of them were males. A majority of the invalid family members were old—91.2% of them were over 60 years of age. Impairment of the QOL was mild in the domains of social limitations and personal relationships, whereas it was moderate in the other domains (Fig. 1). Impairment of the QOL was mild in the domains of social limitations and personal relationships, whereas it was moderate in the other domains (Fig. 1). In this assessment of the QOL and the level of care need (Fig. 2), the latter appeared to be correlated to the former in the domains of incontinence impact, role limitations, physical limitations, and sleep/energy disturbance; however, there was no evident correlation between the QOL and the level of care need in the other domains.
**Interpretation of results**

The QOL of caregivers providing care to invalid family with urinary incontinence is impaired in several domains. The level of care needed appeared to be correlated to the impairment of the QOL.

**Concluding message**

Urinary incontinence in cared individuals has negative impacts on the QOL of their family caregivers.

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**Fig 1** KHQ scores in caregivers taking care of the families with urinary incontinence

**Fig 2** Relationships between KHQ scores and level of care need

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