Hospital readmissions among older people with intellectual disability in comparison with the general population

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Abstract

Background Older people with intellectual disability have high multimorbidity and poor physical and mental health compared with the general population. Consequently, they have a greater need for health care. Hospital readmissions may be an indicator of the quality of health care. However, so far, only a few studies have investigated this outcome in populations of people with intellectual disability. None has focused on older people.

Method We identified a cohort of people with intellectual disability aged 55+ years and alive at the end of 2012 (n = 7936). Moreover, we established a reference cohort from the general population, one-to-one matched by sex and year of birth. Data on hospital visits during the period 2002–2012 were collected from the Swedish National Patient Register. Readmissions were defined as unplanned visits with the same diagnosis occurring within 30 days of discharge and with no planned visit for the same diagnosis during this time.

Results Compared with the general population, people with intellectual disability had increased risk of readmissions for diseases of the nervous system [relative risk (RR) 2.62], respiratory system (RR 1.48), digestive system (RR 1.40) and musculoskeletal system and connective tissue (RR 2.10). Within these diagnostic groups, increased risks were found for arthropathies (RR 3.73), disorders of gallbladder, biliary tract and pancreas (RR 1.78), other diseases of intestines (RR 1.30), and other forms of heart disease (RR 1.23). Decreased risk of readmissions was found for mental and behavioural disorders (RR 0.78) and diseases of the circulatory system (RR 0.64).

Conclusions The increased risk for readmissions related to diseases of the nervous and musculoskeletal systems has a clear relation to the prevalence of comorbidities in these areas. People with intellectual disability often also have inborn limitations and damages in these systems which with time lead to complications and risk for diseases, which can be difficult to discover. The increased risk for readmissions for disease of the respiratory system, together with the already known increased prevalence of such diagnoses and their occurrence as a cause for death, warrants further investigations and considerations of potential preventive measures. The pattern of readmissions among older people with intellectual disability cannot be explained solely by a higher prevalence of disorders in this group. Our finding of increased risks for readmissions for diseases in the digestive system...
could be interpreted as communication problems, which sometimes result in too rapid discharges and their consequential early readmissions.

**Keywords** age, health care disparities, hospitalisation, quality of health care, registries, Sweden

**Introduction**

Older people with intellectual disability (ID) are a group with high multimorbidity and poor physical and mental health compared with the general aged population (Hermans & Evenhuis 2014). Although it has been suggested that they have difficulties accessing health care services, there is a lack of knowledge about how well health care services meet the needs of people with ID (Kelly et al. 2015).

According to World Health Organization (WHO), quality of care is defined as ‘the extent to which health care services provided to individuals and patient populations improve desired health outcomes’ (WHO 2018). Thus, even if two people are provided the exact same care, the quality of their care may differ if they have different needs and conditions. Hospital readmission has been used as an indicator of the quality of health care both by government bodies (Health and Social Care Information Centre 2013; Australian Commission on Safety and Quality in Health Care 2015; Statistics Canada and Canadian Institute for Health Information 2018) and by scientific studies (e.g. Ottenbacher et al. 2014; Ammori et al. 2018; Goldfarb et al. 2018). The relevant time period between discharge and readmission may differ between, for example, diagnoses, age groups and countries. However, readmission within 30 days from discharge has been proposed as a generic definition (Rumball-Smith & Hider 2009).

A range of factors, for example, diabetes mellitus, obesity and polypharmacy, have been suggested to be risk factors for readmission (Morath et al. 2017). These are all more prevalent among people with ID than in the general population (e.g. O’Dwyer et al. 2016; McCarron et al. 2017; Axmon et al. 2017a; Flygare Wallén et al. 2018). Moreover, social determinants of health, including barriers to learning, have been found in themselves to be risk factors for early (within 1 week) readmissions (Graham et al. 2015). Thus, ID is associated with several risk factors for readmission. Still, if health care is provided according to individual needs and conditions, these risk factors should be considered and the care given adapted accordingly.

Only a few studies have investigated hospital readmissions among people with ID. Three studies focused on people with ID, with two that either specifically studied (Chang et al. 2017) or included (Kelly et al. 2015) physical care. The third investigated resubmission to a specialised dual diagnosis unit for people with ID and mental health (Lunsky et al. 2010). A further two studies identified ID as a potential risk factor among other demographic factors rather than assessing ID specifically (Stewart et al. 2014; Li et al. 2018). Both these studies investigated readmission to mental health care. Thus, there is a substantial need for more knowledge regarding readmissions among older people with ID, especially readmissions associated with physical disorders. Such knowledge is needed to better understand how the health care system may adapt to meet the special needs of people with ID.

In the general population, increasing age has been found to be associated with increased risk for unplanned readmissions (Considine et al. 2017). The life expectancy of people with ID has increased over recent decades (Coppus 2013), and the number of older people with ID is increasing rapidly (Fisher & Kettl 2005). Even so, none of the studies mentioned earlier focused on older people with ID. If hospital readmission indeed is an indicator of the quality of care, it is important to describe and understand possible differences in readmissions between older people with ID and their age-peers in the general population across different somatic and psychiatric disorders. The aim of the present study was to investigate hospital readmissions for physical and psychiatric diseases among older people with ID in comparison with the same age group in the general population.

**Methods**

**Setting**

In Sweden, people with functional impairments, including a diagnosis of ID or autism spectrum disorder (ASD), can apply to their municipality for service and support to manage their daily lives. For adults, available support comprises eight specified measures: daily
activities, counselling and other personal support, companion service, contact person, personal assistance, relief service in the home, short stay away for informal caregiver and special housing. Special housing can be granted in different forms. Group homes are intended for people who need access to around-the-clock service staff. In service housing, staff is always available, but not necessarily on site. In both types of housing, the staff provides help to facilitate activities of daily living. This includes accessing the mainstream health care. Health care is normally not provided at the housing facilities. Although some facilities are supported by nurses with specialist education in geriatric care, the staff generally have no special education in health care.

Study cohorts

All support provided is recorded in a national register (the LSS-register) at the Swedish National Board of Health and Welfare. People receiving support are classified as (1) people with ID or ASD from birth or an early age, (2) people with considerable and permanent intellectual functional impairment after brain damage in adulthood, the impairment being caused by external force or physical illness, or (3) people with some other lastling major physical or mental functional impairment manifestly not due to normal aging that causes considerable difficulties in daily life. Through this register, we identified all people in group 1 who had received support in 2012 and who were at least 55 years old and alive at the end of that year. These 7936 people comprised the ID cohort. A reference cohort (gPop) from the general population, one-to-one matched by sex and year of birth, was obtained through Statistics Sweden. Each cohort comprised 3609 (45%) women and 4327 (55%) men. The mean age on 31 December 2012 was 64 years (55–96).

Diagnoses

The Swedish National Patient Register contains information on visits to inpatient and outpatient specialist care. For each visit, one primary and up to 21 secondary diagnoses are recorded according to the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10). Information is also available on whether the visit was planned (i.e. the appointment was made beforehand). We collected information on all visits to inpatient care for all people in the two study cohorts for the period 2002–2012. The primary diagnosis for each record was used to categorise visits according to ICD-10 chapters and ICD-10 blocks. Only diagnoses corresponding to diseases and disorders were included, that is, we excluded chapters XVIII (symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified), XIX (injury, poisoning and certain other consequences of external causes) and XXI (factors influencing health status and contact with health services). Moreover, we excluded diagnoses of ID (F7 in ICD-10) and Down syndrome (DS; Q90).

Readmissions

We defined a readmission as a visit recorded (1) within 30 days of discharge, (2) as unplanned, (3) with the same primary diagnosis (on ICD-10 chapter/block level) and (4) as the first visit following the index visit (i.e. without any planned visits for the same diagnosis in between). Percentage of people with readmissions was based on number with diagnosis, and not the total number of people in the cohort.

Statistics

Comparisons of readmissions in the two cohorts were performed using generalised linear models, estimating relative risks (RRs) with 95% confidence intervals (CIs) adjusted for sex and year of birth. The primary analyses were performed on ICD-10 chapter level. Where statistically significant differences between the two cohorts were found, analyses were also performed on ICD-10 block level. However, analyses were only performed when both groups to be compared comprised at least five observations.

Even though a diagnosis of either ID or ASD is required to receive the support described earlier, no diagnoses are recorded in the LSS register. However, by using diagnoses from the Swedish National Patient Register for the time period 2002–2012, we were able to identify 1338 people with diagnosis of ID but not ASD, 211 people with diagnosis of ASD but not ID and 190 people with diagnosis of both ID and ASD among the 3781 people with at least one inpatient episode. Subgroup analyses were performed on the 1528 people with at least one diagnosis of ID.

All analyses were performed using IBM SPSS Statistics version 23.0. A two-sided P-value below 0.05 was considered statistically significant.

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Results

In the ID cohort, 3781 (48%) had at least one inpatient care episode during the study period. Of these, 749 (20%) had at least one hospital readmission within 30 days. The corresponding numbers in the gPop cohort was 2756 (35%) and 460 (17%), respectively. This corresponds to a 20% increased risk of readmissions in the ID cohort (adjusted RR 1.20, 95% CI 1.08–1.33). Diagnoses of mental and behavioural disorders were most commonly associated with readmissions in both cohorts (Table 1). Increased risk of readmission in the ID cohort was associated with diseases of the nervous system, diseases of musculoskeletal system and connective tissue, diseases of the respiratory system and diseases of the digestive system. Decreased risk was associated with diagnosis of mental and behavioural disorders and diseases of the circulatory system. In the analyses including only those in the ID cohort with at least one F7-diagnosis during the study period, the results showed even greater effects for readmission for people with ID compared to the gPop cohort.

When analysing on ICD-10 block level, statistically significantly increased risk for readmission for the ID cohort was found for arthropathies (M00-M25), disorders of gallbladder, biliary tract and pancreas (K80-K87); other diseases of intestines (K55-K63); and other forms of heart disease (I30-I52; Fig. 1).

Discussion

Older people with ID had an increased risk of readmissions compared with their age-peers in the general population. Moreover, the underlying diagnoses causing the readmissions were different in the two cohorts. People with ID were more likely to be readmitted due to diseases of the musculoskeletal system and connective tissue and diseases of the nervous, respiratory and digestive systems. In contrast, people in the gPop cohort were more likely to be readmitted due to mental and behavioural disorders, and diseases of the circulatory system.

A major strength of the present study is the use of a national register to collect information on hospital readmissions. The patient register has a close to complete coverage and overall high validity for primary diagnoses (Ludvigsson et al. 2011). However, a potential weakness may be the use of a register containing information on support for people with ID and/or ASD as a proxy for having ID, as this could result in two types of misclassification. Firstly, people with ASD but without ID will have been misclassified as having ID. However, ID is common in ASD (Bourke et al. 2016; Postorino et al. 2016). We were able to find a diagnosis of ID for 2147 people (27%) and a diagnosis of ASD for 606 people (7%) in the whole ID cohort. Among the 3781 people with at least one inpatient episode, a diagnosis of ID was found for 1528 people (40%) and a diagnosis of ASD for 401 people (11%). At a first glance, this may be interpreted as people without ID or ASD being included in the ID cohort. However, as a diagnosis of ID or ASD is required to receive support according to the LSS law, the lack of an ID or ASD diagnosis does not imply the lack of ID or ASD but is rather a reflection of the age group studied. It lies within both these diagnoses that they should have been present from an early age. Thus, the people in the ID cohort may be expected to have their diagnoses since at least 30 years. A diagnosis of ID or ASD would only have been recorded in the patient register during 2002–2012 if the health care episode was due to the ID/ASD or if the ID/ASD was considered relevant for the diagnosis or treatment of the primary cause of the health care episode. Thus, we do not believe that the inclusion of people without ID/ASD is of concern in the present study. Another potential cause of concern is the inclusion of people with ASD but without ID. However, among those without an ID diagnosis, a diagnosis of ASD was found for only 8%. Thus, the possible inclusion of people with ASD but without ID should not have caused any major effect. Secondly, people with ID who did not receive support according to the LSS law and therefore not included in the register would not be included in the ID cohort. Still, in Sweden, social services are generally relied upon for taking care of those who cannot provide for themselves. It is uncommon that an adult person’s main care is provided without support from the municipality. This, in combination with the age group studied, makes it plausible that the ID cohort comprises a vast majority, if not all, of older people with ID in Sweden.

We included people who were 55 years, or older, at the time when the ID cohort was established. As analyses were performed on retrospectively collected data, this means that people were 44 years or older at
| Chapter Description | gPop Diagnosis | gPop Readm. | ID Diagnosis | ID Readm. | ID vs. gPop Readmission RR (95% CI) | F7 vs. gPop Readmission RR (95% CI) |
|---------------------|----------------|------------|--------------|-----------|-------------------------------------|-------------------------------------|
| I: Certain infectious and parasitic diseases | 131 (1.7%) | 8 (6.1%) | 351 (4.4%) | 30 (8.5%) | 1.44 (0.68–3.04) | 1.78 (0.81–3.94) |
| II: Neoplasms | 427 (5.4%) | 18 (4.2%) | 344 (4.3%) | 13 (3.8%) | 0.88 (0.42–1.85) | 0.97 (0.40–2.34) |
| III: Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism | 36 (0.5%) | 3 (8.3%) | 137 (1.7%) | 7 (5.1%) | 0.54 (0.16–1.76) | 0.73 (0.21–2.46) |
| IV: Endocrine, nutritional and metabolic diseases | 139 (1.8%) | 9 (6.5%) | 300 (3.8%) | 27 (9.0%) | 1.52 (0.73–3.19) | 2.05 (0.93–4.50) |
| V: Mental and behavioural disorders | 237 (3.0%) | 65 (27.4%) | 674 (8.5%) | 145 (21.5%) | 0.78 (0.60–1.00) | 0.80 (0.62–1.05) |
| VI: Diseases of the nervous system | 193 (2.4%) | 9 (4.7%) | 637 (8.0%) | 86 (13.5%) | 2.62 (1.35–5.07) | 3.31 (1.68–6.52) |
| VII: Diseases of the eye and adnexa | 39 (0.5%) | <5 | 189 (2.4%) | 5 (2.6%) | 1.52 (0.73–3.19) | 2.05 (0.93–4.50) |
| VIII: Diseases of the ear and mastoid process | 31 (0.4%) | <5 | 25 (0.3%) | <5 | 1.52 (0.73–3.19) | 2.05 (0.93–4.50) |
| IX: Diseases of the circulatory system | 992 (12.5%) | 235 (23.7%) | 827 (10.4%) | 124 (15.0%) | 0.64 (0.53–0.78) | 0.60 (0.45–0.81) |
| X: Diseases of the respiratory system | 373 (4.7%) | 44 (11.8%) | 951 (12.0%) | 166 (17.5%) | 1.48 (1.09–2.02) | 1.52 (1.08–2.15) |
| XI: Diseases of the digestive system | 714 (9.0%) | 77 (10.8%) | 1095 (13.8%) | 165 (15.1%) | 1.40 (1.09–1.81) | 1.65 (1.24–2.21) |
| XII: Diseases of the skin and subcutaneous tissue | 28 (0.4%) | 3 (10.7%) | 76 (1.0%) | 5 (6.6%) | 0.61 (0.13–2.75) | 0.26 (0.02–3.01) |
| XIII: Diseases of the musculoskeletal system and connective tissue | 583 (7.3%) | 19 (3.3%) | 400 (5.0%) | 26 (6.5%) | 2.10 (1.16–3.82) | 3.19 (1.64–6.19) |
| XIV: Diseases of the genitourinary system | 254 (3.2%) | 15 (5.9%) | 564 (7.1%) | 36 (6.4%) | 1.05 (0.58–1.89) | 1.11 (0.57–2.13) |
| XV: Certain conditions originating in the perinatal period | <5 | <5 | <5 | <5 | | |
| XVI: Congenital malformations, deformations and chromosomal abnormalities | <5 | <5 | <5 | <5 | | |

Relative risks (RRs) with 95% confidence intervals (CIs) are adjusted for sex and year of birth.
Bold is to highlight statistically significant results.

1Percentage based on the whole cohort, that is, 7936 persons.
2Percentage based on number with the diagnosis, that is, n under the heading ‘diagnosis’.
3Analyses based on the subgroup of the ID cohort with at least one F7 diagnosis (i.e. diagnosis of ID) during 2002–2012.
the start of the study period. This is younger than the definitions of ‘old’ used by the WHO and United Nations, which are 65 and 60 years, respectively. However, aging occurs at an earlier chronological stage among people with ID (Haveman et al. 2010).

Thus, in using a lower cut-off for inclusion in the present study, we aimed at capturing early effects of aging among people with ID.

The use of readmissions as an indicator of the quality of health care has been discussed (Rumball-
and have lower disposable income than the general adults with LSS support commonly are unmarried. National Board of Health and Welfare states that the present study. However, a report from the Swedish sociodemographic variables for the people included in socio-economic status. We have no information on sociodemographic variables for the people included in the present study. However, a report from the Swedish National Board of Health and Welfare states that adults with LSS support commonly are unmarried and have lower disposable income than the general population (Socialstyrelsen 2010). As sociodemographic variables are associated with health and health is related to hospital readmission, sociodemography fulfills two of three criteria for being a confounder (Rothman 2002). They are associated with both the ‘exposure’ (having ID) and the outcome (readmissions). However, the third criterion for identifying a factor as a confounder is that they should not be on the causal pathway between the exposure and the outcome. In the present study, we were interested in investigating the role of ID as a phenomenon rather than a diagnosis. Thus, we do consider socioeconomic to be on the causal pathway between ID and readmissions and removing it as a potential confounder.

The remaining confounding factors listed by Rumball-Smith and Hider are, however, relevant in the present setting and need to be considered in the interpretation of the results. We have failed to find any official statistics or scientific publications presenting data on self-discharge among older people with ID. However, according to the clinical experience of the authors, this is rare. If early self-discharge (1) leads to increased risk of readmission and (2) is more common in the general population, an increased risk of readmission would be found for the general population given similar quality of care in the two cohorts. If the quality of care was lower for people with ID, the readmission risk caused by early self-discharge in the general population could balance the readmission risk caused by lower quality of care among people with ID. This could result in a bias of the risk estimate towards the null (i.e. no difference between the cohorts). People with fast disease progression will be more likely to have readmissions regardless of the quality of care. Thus, when we find an increased risk of readmission for older people with ID, it might not necessarily imply substandard care but that their disease progression is faster than among people in the general population. As many people with ID have difficulties expressing their feelings and needs, they are often diagnosed later than other people. Therefore, when first diagnosed, their diseases are often in a more advanced stage and often more rapidly progressing. A similar reasoning may be made for clinical variables, such as comorbidity and disease severity. Groups of people that differ in post-discharge care may differ in readmission rates even when the quality of the care given is comparable. In the present study, more than half of the ID cohort were living in special housing for people with ID during the entire study period (Axmon et al. 2016). It may be reasoned that as these are monitored by service staff on a daily basis, a deterioration would be more likely to be discovered and thus increase the risk of readmission. However, most service staff do not have health care education. Hence, for them to recognise deterioration, the physician and the hospital staff must have provided them with the necessary information. Thus, any potential difference in post-discharge care would most likely work in the favour of the general population. If so, the differences found in readmission rates in the present study could to some extent be explained by differences in post-discharge care rather than the quality of health care.

Rumball-Smith and Hider (2009) list self-discharge as a potential risk factor for readmissions (in the form of a confounder when using readmissions as indicators of the quality of care). However, self-discharge may not be the only cause of too early discharge. This may also occur if the discharging physician fails to notice remaining symptoms in the older patient with ID and thereby discharges a person who actually should be kept under observation. This

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may be a consequence of communication difficulties, or of the person with ID not understanding the need for help for his or her symptoms. Thus, in addition to the reasons discussed earlier, increased risk of readmissions among older people with ID may be a consequence of rapid discharges in this population.

When stratifying on ICD-10 chapter, different patterns of diagnoses associated with readmission emerged for the ID and gPop cohorts. We found increased risks of hospital readmissions for diseases of the respiratory, nervous, digestive and musculoskeletal systems for older people with ID. The almost 50% increase in hospital readmissions for diseases of the respiratory system is similar to the 36% increase previously reported for adults with ID (Chang et al. 2017). Respiratory diseases have previously been found to increase with age among people with ID (Janicki et al. 2002), and to be more common among older people with ID than in the older general population (Sandberg et al. 2017). They are also a common cause of death in this population (Ng et al. 2017; Oppewal et al. 2018; Stankiewicz et al. 2018). Disorders of the nervous, digestive and musculoskeletal systems are often related to the ID itself. For example, a major disorder in the nervous system is the basis for the cognitive limitations in ID. Thus, diagnoses regarding the nervous system are often areas of great concern among people with ID. Correspondingly, in many cases of ID, a second sign of brain dysfunction or damage lies in disorders in the musculoskeletal system, with lifelong consequences to the musculoskeletal function and risk of complications (Henderson et al. 2009). With aging, these conditions worsen. The already fragile nervous system among people with ID can become subject to complications, such as increasing and changing symptoms of epileptic character or the development of rapidly progressing dementias. That a disorder known to be overrepresented among older people with ID also is a cause for hospital readmissions in this population may indicate that the health care system is not properly prepared to provide the quality of care needed. Further studies should focus on specific causes for readmissions and potential associations with particular diagnoses within the group of diagnoses related to the respiratory, nervous, digestive and musculoskeletal systems. Moreover, it is important that staff within the health and social care systems are aware of the increased risk of such disorders among people with ID and are prepared to handle them properly, so that the need for unplanned hospital readmissions can be minimised. A focus on preventive measures and improved health care for respiratory diseases among people with ID, regardless of age, has the potential of making a big impact on the health of this group.

We found decreased risk for people with ID for readmissions associated with mental and behavioural disorders, and diseases of the circulatory system. This is not due to a lower frequency of such diagnoses among older people with ID. Indeed, they are more common in this group than in the general population (Sandberg et al. 2017; Axmon et al. 2017). A possible explanation for the lower risk of readmission due to mental and behavioural disorders could be that they are expected to be found among older people with ID, and therefore, both staff and health care system are prepared to handle them and provide relevant and sufficient care. In support of this reasoning, we have previously found that inpatient care episodes in psychiatric care are longer for people with ID than in the general population (Axmon et al. 2016). The decreased risk of readmissions for disorders of the circulatory system may, however, not be explained using similar reasoning. Instead, this may be a reflection of selecting only people still alive into the ID cohort. Circulatory diseases are the leading cause of death among people with ID (Ng et al. 2017), and including only people still living may cause failure to identify frequent readmissions prior to death or even that readmissions do not occur due to deaths. This topic needs to be further investigated, for example, by examining readmissions prior to death.

We were surprised that no differences between the two cohorts emerged for infectious and parasitic diseases given the difficulty to provide sufficient knowledge regarding hygiene and spreading of infection to people with ID. Again, this is not due to a lower occurrence of these diagnoses among older people with ID (Sandberg et al. 2017). Nor can it be explained by the selection of living people into the ID cohort, as it is not a major cause of death in this group (Ng et al. 2017). A possible explanation could be that for people living in service homes, instructions on how to avoid future infectious diseases are given not only to the person him/herself but also to the service home staff, thus decreasing the risk for readmissions.

The relatively low number of people with readmissions for endocrine, nutritional and metabolic
diseases may possibly be as these disorders are normally handled in primary care. Future studies including primary care visits are needed to further investigate this.

The analyses restricted to those in the ID cohort with a recorded F7 diagnosis during 2002–2012 showed even greater effects for readmission for people with ID compared to the gPop cohort. This is most likely due to a selection of those with worse health or more severe ID rather than to a potential exclusion of people with ASD.

In summation, we found a pattern of readmissions among older people with ID that cannot be explained solely by a higher prevalence of disorders in this group. There may be several reasons for this, which all need to be considered in the health care of people with ID. In the clinical experience of one of the authors (MB), the major explanation is the difficulties common in the communication with people with ID. Not only people with ID may have difficulties to communicate signs and symptoms but also medical staff may likewise have problems in understanding what the person with ID tries (or does not try) to communicate. If not properly considered and acknowledged, these communication problems may result in too rapid discharges and their consequential early readmissions. Further studies are needed to better understand the complex picture that involves health, health care utilisation and health care quality for older people with ID, so that we may ensure that communication difficulties do not lead to lower quality of care in this vulnerable part of the population.

Conflict of interest
None declared.

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