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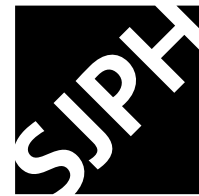
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ORIGINAL ARTICLE

Needs and care of older people living at home in Iceland

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Abstract

Background: The Icelandic old-age care system is universal and the official goal is to support older people live independently for as long as possible. The aim of this study is to analyse living conditions and use of formal and informal care of older people in Iceland. **Methods:** The results are based on the new study ICEOLD, a telephone survey which included questions on social network, health, activities of daily living, and received support from the community and/or from relatives, neighbours, and friends. **Results:** Almost half of the sample (47%) receives some kind of care, with 27% of them receiving only informal care, which is understood to mean that informal care is of great importance and families are the main providers of help. For hypothetical future long-term care, older people wish to be cared for in their homes, but those already in need of assistance prefer to be cared for in institutions. **Discussion:** Caring relatives are the main providers of support to older people in their homes and it is important to provide them with suitable formal support when the care responsibility increases. **Conclusions:** **As the care system in Iceland is now under reconstruction, the important contribution of informal carers must be recognised and taken into account when planning the care of older people.**

Key Words: Aged, caregivers, care system, Iceland, older people, social support

Introduction

Iceland, as a nation, is rather young compared to most other European countries, but with increasing longevity and declining fertility the trend is towards an older population. The population of Iceland is 318,000, of whom almost 12% are 65 years of age and older. The population aged 80+ is at 3.2% today and growing steadily [1]. Icelandic society has changed drastically in a few decades due to very rapid modernisation. A special Act on the Affairs of the Elderly was implemented in Iceland in 1982 [2] to ensure older people access to health care and social services and to guarantee older people the ability to enjoy a normal domestic life as long as possible. Home care services for older people have developed rapidly and most municipalities offer home help (HH), home health care (HHC), meals-on-wheels, and day care services [1]. HHC is free of charge but municipalities may charge fees for HH and other

services. Iceland had for several years the highest institutionalisation rates among the Nordic countries [3]. In 2007, 8.7% of older Icelanders (67+) and 23.9% of the population aged 80+ lived in institutions or full-service housing [1]. Compared with the other Nordic countries, in Norway 23.7 of 80+ are living in institutions, 18.4% in Finland, 16.6% in Sweden, and 14% in Denmark [4]. In spite of these high rates there still has been a perceived lack of institutional care and the effect of long waiting lists for older people has for many years been highly debated [5,6]. It is of high interest to understand the various patterns of care, interactions between formal and informal care, and also their adequacy for the planning for the future care system for older people in Iceland, which now is under reconstruction.

Caring for older people is often a mix of formal and informal care in a complementary relationship to each other [7]. Formal care is provided by

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institutions, HH professionals, or additional services (meals-on-wheels, day care centres, alarm systems, etc.) and is paid for either by the recipient or by the municipality or state. Formal care is usually carried out in accordance with certain laws or regulations. The concept of informal care is often used for both care provided by relatives and non-governmental organisations, especially if it is the English concept of “informal care” [8]. The informal care is in other words given by family, friends, neighbours, and other people from the social network and is mostly unpaid. It may be the only help that the older person receives or care provided together with formal support [9,10]. The formal and informal care have different characteristics and qualities of the assistance provided and they play varying roles in the lives of older people [9]. However, when the need for help is increasing, both formal and informal care helps out to maintain the elderly person’s autonomy [11].

Studies indicate that the contribution of family care of older people is high in Europe and still increasing [12]. Further, indicators show that the service of the families is becoming more substantial and provided for longer periods than previously [13]. In the Nordic countries, where older people are entitled to different formal care, the informal care is considered even more than expected [14,15]. A good deal of European research on family care shows that between 60–70% of the informal service is provided by women. Spouses, usually the wives, are the largest group providing care for older people and in the absence of a wife adult children fill in, mainly daughters [8]. Relatives of older people are more likely to provide support with the instrumental activities of daily living (IADL) care, rather than the personal activities of daily living (PADL) care [16,17]. This suggests that the formal assistance becomes more important when problems to perform activities of daily living (ADL) tasks increases. Access to social support plays an important role in the use of care [17] and there is for example, a lower likelihood for those living alone to receive only informal support and a higher probability of receiving only formal support [18].

Aim

The aim of this study is to describe the living conditions and needs of older people in Iceland and how these needs are met. The new survey ICEOLD is used to examine formal and informal care and the relationship between these spheres. The following research questions will be pursued:

- How are their needs met by public services and informal care?

- How do factors such as social support and health affect the needs and care of older people?

Methods

Sample

The survey Icelandic older people (ICEOLD) was accomplished in the autumn 2008. The study used a national sample of 700 persons in ages 65–79 years and 700 aged 80+, living in Iceland. The older age group is overrepresented and the sample is weighted to represent the Icelandic population aged 65+. Persons living in nursing homes or living abroad were excluded. Discounting excluded and deceased individuals the final sample consisted of 1189, to whom an introduction letter was sent. From the 1189 selected persons, 782 agreed to participate giving a response rate of 66%. The drop-out consisted of 292 who refused to participate and 115 persons who could not be reached. Among those 292 persons who refused to answer, 147 were men and 145 were women with a mean age of 78. Among those 115 who could not be reached, 64 were men and 51 were women with a mean age of 79. A brief description of the sample that finally participated is given in Table I. There were 341 men and 441 women who participated. The mean age of the sample was 77 years, 76 for men and 77 for women, with a range between 65 and 98 years of age.

Method

The results in this study are based on telephone interviews, which included questions on social network, health, ADL, and received support from the community and/or from relatives, neighbours, and friends. Also, the respondents were asked about their wishes, preferences for help, and living arrangements if they became dependent and in need of long-term care.

Their social network situation was assessed by three questions: *How often do you meet your children?* with the answer alternatives (1) daily, (2) 4–6 times a week, (3) 2–3 times a week, (4) once a week, (5) 2–3 times a month, (6) once a month, (7) more seldom than once a month, and (8) never. The second question asked: *How often do you have telephone contact with your children?* using the same answer alternatives. Thirdly, the participants were asked about the distance to their nearest child, with the answer alternatives (1) living in the same household, (2) in the same

Table I. Description of the sample.

	Men (n = 341)	Women (n = 441)	Total (n = 782)	Statistic
Age				
Mean age (years)	76	77	77	$T = -2.11^*$
65–79 years	205 (60)	242 (55)	447 (57)	
80–98 years	136 (40)	199 (45)	335 (43)	
Civil status				
Never married	38 (11)	42 (10)	80 (10)	$\chi^2 = 3.8^{**}$
Married	204 (60)	169 (39)	373 (48)	
Widow/widower	78 (23)	193 (44)	271 (35)	
Divorced	19 (6)	35 (8)	54 (7)	
Household structure				
Lives alone	106 (31)	215 (49)	321 (41)	$\chi^2 = 2.32^{**}$
Having child/children				
Yes	307 (90)	424 (96)	731 (94)	$\chi^2 = 1.27^{**}$
Subjective health				
Good/rather good	228 (68)	270 (62)	498 (64)	$\chi^2 = 5.118$ (ns)
Medium	77 (23)	105 (24)	182 (24)	
Bad/rather bad	32 (10)	64 (15)	96 (12)	
Need of care				
No need	130 (38)	195 (44)	325 (42)	$\chi^2 = 1.21^{**}$
Only with IADL	183 (54)	194 (44)	377 (48)	
Both with IADL and PADL	28 (8)	52 (12)	80 (10)	
Care received				
No help received	169 (51)	220 (54)	389 (53)	$\chi^2 = 5.138$ (ns)
Only informal care	97 (29)	104 (26)	201 (27)	
Only formal care	17 (5)	11 (3)	28 (4)	
Both informal and formal care	47 (14)	70 (17)	117 (16)	

Values are *n* (%) unless otherwise stated.

* $p < 0.05$; ** $p < 0.01$.

IADL, instrumental activities of daily living; PADL, personal activities of daily living.

house, (3) in less than 1 km distance, (4) in 1–5 km distance, (5) in 6–25 km distance, (6) more than 100 km distance in Iceland, and (7) living in another country.

Subjective health was assessed with a general question about how they rated their health, ranging between (1) very good, (2) good, (3) moderate, (4) poor, and (5) very poor.

Patterns of received help were measured by asking about assistance with various ADL needs, both IADL (shopping, cooking, cleaning their home, and laundry) and PADL (bathing, using toilet, getting in and out of bed, and dressing), with the answer alternatives (1) always, (2) often, (3) sometimes, (4) seldom, and (5) never. In relevant cases the respondents were asked whether the help came from formal carers, informal carers, or both.

The participants were also asked if the care received from informal and formal carers was enough due to their needs, with the answer alternatives (1) too much, (2) just right, and (3) too little, and if they preferred more help with the answer alternatives (1) yes, (2) no, and (3) do not know. Wishes of future assistance were assessed by two questions. First with the question; *if you were to*

become dependent and in need for regular help and long-term care – would you prefer to be cared for in your own home, in a nursing home or in the home of a relative? Second, by asking if the respondents would prefer to be cared for by private, informal or public carers. The research project was announced to the Icelandic Data Protection Authority (Persónuvernd) according to regulations.

Analysis

Persons aged 80+ were oversampled and the sample has been weighted to represent the Icelandic population aged 65 years or older. Descriptive analyses (independent samples t-test and chi-squared tests) were performed to analyse gender differences but also differences among other categories, such as age groups, living arrangements, and receiving different types of care. Pearson correlation analyses was performed to find relations among gender, age, household structure, having children, subjective health (very good/good, moderate, bad poor/very bad poor), ADL needs (functional ability), and patterns of care. To explore associations among care patterns and factors of socio-demographics, health, and ADL,

nominal logistic regressions models were performed. For all analyses, the 95% confidence interval were used to determine significance. SPSS 16.0 and SPSS 17.0 for Windows were used for statistical analyses. Percentage totals in the tables may differ from 100 due to rounding.

Definition of concepts

The boundary between *care*, *support*, and *service* is imprecise and the difference between the terms is often unclear and may be difficult to translate between languages. The meaning may also vary between cultures and individuals. Waerness [19] defines *personal service* as something that is done for someone who can do it him/herself, while *care work* is assistance given to persons who are not able to do it themselves or carry it out with great difficulty. It is sometimes unclear what may be perceived as care or just help received as normal exchanges or support between spouses and family members as a part of an ordinary family life [20]. In this study, the experience of the older respondents is used to define the tasks to be an act of help or support. These terms are used interchangeably to describe the support of older people in need of help.

Results

Of the respondents, 59% were living with a spouse, cohabitant, or another person; 48% were married. There are significant gender differences in both marital status and household structure as more men are married and living with their spouses (Table I). In total, 94% had children, of which 89% had a child living within a 25 km radius. Women report to have children more often than men. A majority (85%) met their children once a week or more and 90% had telephone contact with their children at least once a week. Most of the sample rated their subjective health as very good/good (64%). There were 42% in no need of care and 48% needed help only with IADL tasks. More than half of the sample (53%) stated that they received no help.

Needs

About half of the respondents considered that they need help with one or more activities of daily life but a majority of them only need help with IADL. There is a significant gender difference in reporting the need of care (Table I) where women report more need of help with both IADL and PADL whereas men more often report need of help with IADL only.

Independence in ADL is higher in the youngest age group, 65–79 years (54%) whereas almost one-fifth of the oldest age group, aged 80+ (19%), reported need of help with both IADL and PADL ($\chi^2=71.81$, $p<0.001$). Of the respondents with one or more ADL problems, 10% are in need of help with PADL; two-thirds of them are 80 years and older and two out of three are women.

The panorama of care

As demonstrated in Table I, almost half of the sample (47%) receives some kind of care with 27% of them receiving only informal care from family, friends, and neighbours, 4% receiving formal care only, from HH and/or HHC, and 16% receiving both formal and informal care. The main caregiver of those using only informal care is a spouse (49%) or another relative (42%), most frequently daughters (27%).

Other community services than HH/HHC, such as meals-on-wheels, alarm system, transportation services, day care, and respite care should also be considered when describing the panorama of care. Frequently, service overlap is demonstrated in Figure 1 with 14% receiving one or more other public services, such as alarm system (10%) and transport services (7%).

Of those in need of care, 81% receive assistance from relatives, neighbours, or friends and nearly half of those (45%) use informal services as the only help. There is no gender difference in received care from different sources but those who are living with someone receive significantly more; often a combination of informal and formal care ($\chi^2=15.37$, $p<0.01$). There were also age differences where the oldest age group receive significantly more care in all categories ($\chi^2=108.59$, $p<0.001$). Among those who received some kind of care, one out of 10 received formal care four times a week or more often whereas twice as many received the equal amount informal help.

There is a significant difference between those living alone and those living with someone; the majority (78%) of needy persons living with someone receive help from their spouses ($\chi^2=231.654$, $p<0.001$) whereas persons who live alone mostly receive help from their children, children-in-law, and grandchildren (76%). The most frequent carers are, as mentioned, daughters.

Table II demonstrates the nominal logistic regression with “use of help” as a dependent variable and “no help” as reference. The respondents’ use of informal care only was affected strongest by ADL needs, followed by subjective health. The household structure and having children were also significantly

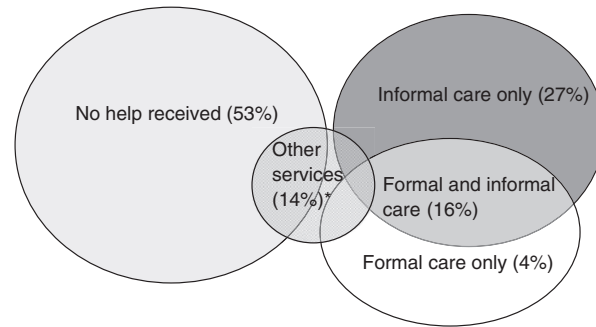


Figure 1. The panorama of care.

*Other services, provided in all four categories: 4% of those receiving no care used some kind of other services, so did 8% of those receiving informal care only and 28% of those using formal care only. Other services were also used by 52% of those using a combination of formal and informal care.

Table II. Nominal logistic regression: variables associated with help received from informal carers, formal carers or both.

	Informal care only (<i>n</i> = 200) ^a	Formal care only (<i>n</i> = 28) ^a	Both formal and informal care (<i>n</i> = 117) ^a
Gender	1.243 (0.704–2.195)	0.828 (0.305–2.247)	1.366 (0.676–2.761)
Age	1.046 (0.999–1.095)	1.159 (1.078–1.247)**	1.195 (1.129–1.264)**
Household structure	1.732 (1.028–2.919)*	0.854 (0.343–2.125)	1.319 (0.691–2.516)
Having children	0.313 (0.100–0.988)*	2.499 (0.549–11.368)	0.239 (0.049–1.177)
Subjective health	1.597 (1.228–2.078)**	1.369 (0.888–2.110)	1.958 (1.418–2.704)**
ADL needs	71.479 (38.733–131.910)**	283.239 (87.351–918.411)	256.955 (109.980–600.345)**
Intercept ² (15): 52.23**	–7.173	–18.860	–19.426

Values are odds ratio (95% confidence interval) for Exp(B).

^aReference category no care (*n* = 383), coded as 0 = no care, 1 = only informal care, 2 = only formal care, 3 = both informal and formal care.

p* < 0.05; *p* < 0.01.

ADL, activities of daily living.

related to receiving informal care only, but gender and age was not. Receiving formal care only, was highly correlated with ADL needs and age, but not to any other of the variables. Furthermore, receiving both informal and formal help was affected primarily by ADL needs, but also by age and subjective health.

Perceptions of family and public care

A majority are satisfied with the care, both formal and informal. Only 2% are dissatisfied with the informal help received and 4% wish to get more help from their relatives and friends whereas 14% state that they are not satisfied with the formal care. Further, 18% wish to receive more help from the community, and among those receiving informal care, 22% claim that they would like to get more help from formal carers.

After describing different ways of getting assistance if one becomes dependent, the question was raised how the older persons wished to be looked after if they hypothetically would need regular help and long-term care. Two-thirds of all respondents (68%)

prefer to be looked after in their own home and one-third (28%) in a long-term care institution. Among persons with at least one PADL problem, roughly one-third (30%) prefers to be looked after in their homes and more than half (57%) in an institution.

A nominal regression, showed in Table III, shows factors associated with future wishes on receiving help from informal carers, formal carers, or both. Future wishes on receiving help were used as a dependent variable and the only factor related to any of the wishes concerning future care was help received at the time of the interview. Care recipients wished to be cared for by both informal and formal carers. Factors associated with the place/location for desirable future care were age and subjective health, which affected wishes' of care in the respondents' own home.

Discussion

Understanding the panorama of older people's needs of care and how these needs are met is important in

Table III. Nominal logistic regression: variables associated with future wishes for receiving help from informal carers, formal carers or both.

	Informal care only (<i>n</i> = 128) ^a	Formal care only (<i>n</i> = 470) ^a	Both formal and informal care (<i>n</i> = 23) ^a
Gender	0.882 (0.515–1.508)	1.052 (0.679–1.632)	1.594 (0.600–4.235)
Age	1.007 (0.965–1.050)	0.984 (0.951–1.019)	1.060 (0.984–1.142)
Household structure	0.789 (0.487–1.279)	0.852 (0.582–1.249)	0.494 (0.197–1.240)
Having children	0.303 (0.085–1.079)	0.785 (0.364–1.693)	1.224 (0.188–7.960)
Subjective health	0.829 (0.641–1.072)	0.867 (0.708–1.060)	0.784 (0.494–1.245)
ADL needs	0.616 (0.334–1.134)	0.898 (0.559–1.441)	0.388 (0.121–1.251)
Help	1.399 (0.964–2.030)	1.248 (0.918–1.698)	2.138 (1.188–3.848)*
Intercept ² (15): 52.23**	1.885	3.290	–5.600

Values are odds ratio (95% confidence interval) for Exp(B).

^aReference category no care/no answer (*n* = 107), coded as 0 = no care/no answer, 1 = only informal care, 2 = only formal care, 3 = both informal and formal care.

p* < 0.05; *p* < 0.01.

ADL, activities of daily living.

supporting older people in their home to prevent move to institutions. Finding out what factors are affecting the help situation and who is the main caregiver sheds light on the interplay between different help providers and informal and formal carers. In Iceland, such information is of great importance, now when the future eldercare is under reconstruction. The planning and the responsibility of home care for older people has been divided between the state and the municipalities, belonging to two different ministries, the Ministry of Social Affairs and Social Security and the Ministry of Health. This has led to many difficulties and made the home care services less successful. From January 2011, these ministries will be merged into one welfare ministry and all issues of the elderly will be moved to the municipalities in year 2012. This integration of services to one administrator will expectantly contribute to a better eldercare.

This study shows that over half of this sample of the old respondents living at home needs help with ADL (58%), the vast majority only with IADL (48%). The largest part has a modest need for help, and although many are helped by HH/HHC most recipients only receive little help. The respondents' needs are met both by formal and informal caregivers but only 10% received formal care several times a week in comparison to 21% who received informal care several times a week. This result suggests that the informal help is of great importance for older Icelanders but at the same time, the tasks provided by informal caregivers are more often with IADL rather than with PADL. Older people in need of care are obviously depending on their relatives for help and assistance, especially when the care is not too extensive. Other studies have found that informal assistance is available in the beginning of the period of

dependence but the formal care providers take over when problems with ADL increases [17]. This study supports those findings but also demonstrates that older people prefer to receive assistance from their relatives when it is possible.

The results also demonstrate that many older individuals use HH and HHC, but that most only use a few hours a month. This seems to be unique for the Icelandic care situation in comparison with some of the other Nordic countries, such as Sweden, where individuals receiving public eldercare are fewer but use more hours of help [15]. The relatively small amount of provided HH can have consequences for older people's demand for institutional care. There was only a small part of those living in their homes that needed help with PADL tasks which might suggest that older people in Iceland are submitted to institutions to get more suitable services instead of increasing the service at home. This may also explain the high amount of older people living in institutions in Iceland compared to, for example, Sweden. A more generous HH/HHC and increased community services such as day care, alarm system, and respite care could encourage older people in Iceland to live longer in their homes with benefits both for the older individual and the state [21].

Women more often than men need help with both IADL and PADL which may imply that they have more health problems than men of the same age do; a result similar to other studies [22,23]. Men need more help with only IADL, indicating that they rely on their spouses doing these tasks. The significant gender difference in marital status and household structure can support this difference. As men more often are married and living with their spouses, one can also assume that they receive help with domestic duties without considering it as help. An inverse

difference can be seen between men and women living alone where 53% of the men and 40% of women are in need of only IADL assistance. Possibly when a spouse is not available, the need for IADL help for men increases. In the present study, women report to have children more often than men do, indicating that they have more possibilities to receive informal care from relatives outside the household. When considering patterns of care, the social network is of great importance and research implies that decline in social network resources affect men and women differently [17]. For example, women seem to get more informal care from children than men, whereas men more often get informal care from their spouse. Daughters seem to be more important carers for older people than sons, also similar to other research [13]. Women state that they need care more often than men do, but there is no significant gender difference in receiving care. This suggests that women are not receiving more help even if more need is stated.

ADL needs, age, and subjective health are, not surprisingly, significantly related to help received but the patterns of association are somewhat different. Informal care was related to subjective health and ADL needs, whereas formal care was related to age and ADL needs. It seems that when older persons suffer from declining health and difficulties in performing activities of daily living, their relatives provide help more than formal carers. On the other hand, formal carers use standardised assessment methods in assessing ADL needs of care whereas informal carers meet the needs of care more on an emotional level.

When asking how older persons would like to be cared for if they need care for a longer period, a vast majority of all respondents wish to be cared for in their home. This is interesting considering high rates of institutionalisation and low amounts of HH/HHC. However, in comparison, those who already receive help with PADL needs prefer to be cared for in a nursing home or institution in the future. This may be explained by too little and inefficient community care, which encourages older people to seek institutional care when the need of assistance increases.

When looking at the difference between various forms of housing, those living with someone other than a spouse (most often their children) with IADL difficulties only and both IADL and PADL problems, they also prefer to be cared for in an institution. This might suggest that older people do not want to burden their families with more care than they already do. The help received currently is the only significant predictor of what kind of help is preferred

in the future. This implies that those with experience of receiving care know what it means.

To understand the panorama of care, the relationship between the informal and the formal care providers is important. It can be suggested that the public services in Iceland make little difference in how older people manage a normal domestic life as long as possible, although this is one of the main purposes of the Act on the Affairs of the Elderly. As shown in Figure 1, more than half of those using a combination of formal and informal care are also using other services such as alarm systems, transport services, and meals-on-wheels. The overlap between formal and informal help increased when more care was needed, found also by Sundström, Malmberg, and Johansson [24].

There is evidence that informal care is of great and possibly of increasing importance in many countries, including some of the Nordic states, such as Norway and Sweden [10,13]. The ICEOLD study suggests that this also holds true in Iceland.

As relatives are the main providers of support to older people in their home, it is important to give relatives suitable formal support when the care responsibility increases. Support for family caregivers can be of various natures. HH/HHC and other formal services such as day care, respite care, or transport services can be an important support for informal caregivers. In the ICEOLD study, 14% of the respondents used other services, half of those most needy, it might be suggested that these services can be a support for informal caregivers. In Sweden, care by family members has been politically recognised, legislation has been changed and the government has decided to allocate special earmarked grants to local authorities to stimulate and develop support for informal caregivers [25,26].

The informal part of the panorama of care has hardly been recognised in Iceland and relatives who support older people are not mentioned in any laws or regulations. Officials must highlight the existence of this group and make a plan to support caregivers in a better way. More effective HH/HHC and other services can support informal carers and enhance their motivation to care for older relatives. This counts especially for spouses, both men and women, as the majority of needy persons living with someone receive help from their spouses, and also daughters as they are the main providers of informal care in Iceland. Increased formal services provided to community-dwelling older people can be of help to the older person and their families and reduce the demand for institutional services.

Conclusion

The needs of non-institutionalised older people in Iceland are mostly met by the family. They especially help with IADL tasks rather than PADL problems. Public services are provided to a large group but the large majority only receives a few hours a month. For potential future long-term care, older people wish to be cared for in their homes, but those already in need of a lot of help prefer to be cared for in institutions. This suggests that when an older person needs assistance with PADL, institutional care becomes the solution instead of increased formal care provided in the home. Families make vast contributions in helping and supporting older family members. They are the main providers of support when needs for services occur. This fact must be recognised in the Icelandic eldercare policy.

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