Healthcare costs and productivity losses associated with county-based home-care service for sick children in Sweden

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Aims: The aim of this study was to estimate the healthcare costs and productivity losses associated with county-based home-care services (HCS) for sick children.
Methods: In this observational follow-up study, a combination of hospital care and HCS was compared to estimated alternative care solely at the hospital. Data on one year of healthcare utilisation for 32 children, supplied by the hospital and HCS, were collected from administrative systems. Corresponding healthcare unit prices were collected from healthcare pricelists. The human-capital approach was applied to estimate productivity losses and the value of productivity losses for 25 parents. Family characteristics, including parental work absenteeism and income, were collected by a questionnaire distributed to parents at five time points during a year. Descriptive and comparative statistics were used for analysis and carried out with ethical approval.

Results: Healthcare costs for children receiving a combination of hospital care and HCS varied among children with estimated average healthcare cost savings of SEK 50 101 per child compared to the alternative of care provided only in the hospital. The reduced costs were related to children receiving nonpalliative HCS care tasks. Average annual productivity losses due to parental work absenteeism were estimated at 348 hours with an associated monetary value estimated at SEK 137 524 per parent.
Conclusion: County-based HCS, provided as complement to and substitute for hospital care for ill children, does not increase healthcare cost and should be a prioritized area when organising paediatric health care. Productivity losses vary greatly among parents and are pronounced also when children receive HCS with signs of gender-related differences.

Keywords: child, healthcare costs, home-care service, opportunity costs, paediatric, productivity losses.

Submitted 20 August 2019, Accepted 11 December 2019

Background

Home-care service (HCS), described as a healthcare service in the ill child's home and provided by healthcare professionals as a complement to and/or substitute for hospital care, is offered for a variety of acute, long-term and chronic illnesses (1–4) and for end-of-life care (3–5). Families often prefer care at home to hospital-based care only (3,4,6–8). It can strengthen (7) and normalise everyday family life (9,10) without negative impact on family economy such as the family's disposable income (11–13) or out-of-pocket expenses, for example, for travelling (10,14). Systematic reviews indicate that HCS can offer care with medical safety equal to hospital care (2,4).

However, models for organising and providing HCS differ both between countries and within different regions of the same country (15,16). For example, HCS can be based in the hospital or in the county and be either diagnosis-specific or customised for a population regardless of illness. Accessibility and competence vary from single hours during weekdays to 24-hour services, with single- or multi-professional services (15) resulting in country- and region-specific HCS (15,16) and diverging societal costs such as healthcare costs and productivity losses (2). For example, several recent studies suggest that

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healthcare costs may decrease (12,14,17,18). Others suggest no significant differences in healthcare costs between HCS and hospital care (11), that healthcare costs associated with HCS are comparable to costs associated with outpatient visits to the hospital (6,19) and that healthcare costs may be related to the child's diagnosis (20). Productivity losses, for example the loss of production on the labour market due to, for instance, parental absence from paid work, are rarely included in published studies of HCS for children (2). The available evidence is ambiguous, suggesting that HCS has either no or limited effect on the productivity levels of the parents (12) or that HCS leads to a significant increase in the productivity level (14,19) if the number of hospital visits can be reduced (14). Furthermore, the effects of HCS on societal costs are to a large extent dependent on the prevailing health and social security systems and there is a lack of consensus among researchers on what methods and outcome measures to prefer in studies to increase comparability (21,22).

Thus, the transferability of results regarding health-economic impacts of HCS between contexts may be limited. This means that the current increase in the provision of HCS for ill children, in the Scandinavian countries (16) as well as internationally (4), is based on insufficient and ambiguous scientific evidence on how to organise cost-effective, high-quality HCS. In particular, additional health-economic assessments of different models of HCS for children with various diagnoses and conditions are required in order to support policymakers' allocation of scarce resources between HCS and alternative healthcare services (2,23). The aim of this study was to estimate the healthcare costs and productivity losses associated with county-based home-care service for sick children.

Methods

Design

This was an observational health economic follow-up study.

Setting

The study was performed in a southern county of Sweden with a population of approximately 300 000 children aged 0–17 years (24). HCS is provided by the county to all inhabitants, regardless of diagnosis, prognosis or age, and hence includes children. It is provided by 24-hour nurse and physician services, supplemented by daytime provision of physiotherapist, occupational therapist, dietician and counsellor services. HCS is organised by eight sites throughout the county, either as multi-professional palliative care or as specified care tasks (SCT). The most common SCT provided to children during the study period was administration of intravenous antibiotics by an HCS nurse prescribed by a hospital physician who also maintains the medical responsibility. In a collaterally executed study, Castor et al. (3) found that 57 children per year received HCS and that cancer was the most frequently reported diagnosis (30%) during the study period. The median age of children receiving HCS was 5.5 years, and care was carried out for a median number of seven days (3). Hospital care in the county is provided by one university hospital and two local hospitals.

The Swedish social insurance system. The Swedish social insurance provides basic financial security to all families with children under the age of 18 through a system of government-funded insurances and allowances (25). Temporary parental benefits are paid to parents who stay home from work to care for their ill child and are comprised of a fixed amount and an income-related part. The benefit makes up for approximately 80% of the benefit-qualifying income and can be paid for a maximum 60 days per year per child or, when the child's condition is regarded by a physician as life-threatening, such as cancer, for an unlimited number of days to both parents simultaneously.

Sample

All children resident in the county and receiving HCS in the period March 2015 to 2018, and their parents (caregivers or legal guardians), met the inclusion criteria when parents had the ability to understand and respond to study instructions written in Swedish. The recruitment to the study was conducted in two steps. First, parents who met the inclusion criteria were informed about the study by the HCS healthcare personnel and contact information on families that responded positively to receiving further information was forwarded to the first author (CC). Second, 48 families were reached with more detailed information about the study. Thirty-two families returned informed consent and were thus included in the study.

Costs

This study applied the opportunity cost concept and a human-capital approach to estimate societal costs in terms of healthcare costs and productivity losses. The opportunity cost of a specific use of resources is the value of the best alternative given up (21).

Healthcare costs. The values of goods and services traded in perfect markets are given by the prices established in those markets. However, health care is not provided in perfect markets, and hence, the value of healthcare

Table 1 Unit costs of healthcare services per type of service

Healthcare service	Unit costs (SEK)
HCS	
Special care task (per visit)	413
(maximum 5 times per 24 hours)	
HCS palliative care (per day)	2065
Assessment/consult team meeting HCS	6182
Estimated costs for hospital care*	
Hospital overnight care (per night)	9813
University hospital outpatient	
daytime hospital care (per day)	
Physician	9359
Nurse	1876

1SEK = 0.11–0.096 Euro/ 0.12–0.11 USD.
*Based on mean for minimum unit prize from each available department of units providing care corresponding to the specified care service over the years 2015-2018.

resources relies on administrative physical unit prices which are, at least to some extent, arbitrarily determined. Therefore, to illustrate the effect of unit prices on costs we report the utilisation of physical units, unit prices and total costs separately. The care given included a combination of care at the hospital and care in the home supplied by HCS. The estimated alternative healthcare utilisation was care carried out in the hospital without the possibility of care in the home supplied by HCS.

Productivity losses. The human-capital approach was used to estimate the value of productivity losses. The human-capital approach measures the productivity losses such as the reduction in the amount of time supplied to the labour market and the value of productivity losses as the changes in number of hours worked times the value of each unit of time. The value of each unit of time was assumed to be equal to the reported wage rate including labour taxes (21).

Data collection

We employed data on utilisation of HCS and hospital services from local medical records and administrative systems and physical unit prices for healthcare services, from the Swedish southern regional pricelists healthcare 'cost per patient' database for the years 2015–2018 (Table 1). Data were collected for each child from the initial period of HCS and 1 year forward. Questionnaires for information on family-specific characteristics were sent to the participating families on five different occasions, at the initiation of HCS (T1), and at one (T2), three (T3), six (T4) and twelve (T5) months after the initiation of HCS. Parents were asked to fill out the questionnaires either together with the children or by themselves. The questionnaire contained questions directed to each family member and

Table 2 Family members' background characteristics as stated in the first month of HCS (T1) sick children N = 32, siblings N = 33, parents N = 41

	Total	Female	Male
Sick children	**n = 32**	**n = 12**	**n = 17**
Age, median [IQR]		7 [4–12]	4.5 [1.5–10.5]
Diagnosis, n (%)			
Neoplasm	15 (46.9)		
Lyme disease	5 (15.6)		
Circulatory	3 (9.4)		
Hepato-nephrological	3 (9.4)		
Digestive illness	2 (6.3)		
Other*	5 (15.6)		
Living with both parents	32 (100)		
Siblings		**n = 17**	**n = 16**
Age, median [IQR]		8.0 [4.5–11]	8.0 [4.6–11.3]
Living with the ill sibling, n (%)			
Full-time	29 (87.8)		
50% or more	4 (12.1)		
Parents F/M		**n = 26**	**n = 25**
Age, median [IQR]		36 [31–45]	42 [35.5–44]
Education, n (%)			
Mandatory school (?)		0 (0.0)	2 (8.0)
High school (?)		8 (30.1)	8 (32.0)
University		14 (53.8)	13 (52.0)
Other/missing		2/2 (15.4)	0/2 (7.7)
Present status of work, n (%)		n = 24	n = 24
Student		3 (11.5)	1 (4.0)
Unemployed		1 (3.8)	
Gainfully occupied		9 (34.6)	14 (56.0)
Temporary parental benefit		10 (38.5)	9 (36.0)
Absent by other reason		1 (3.8)	
Before-tax income (SEK), mean (SD)		n = 21	n = 20
		29,972 (10,554)	40,324 (17,628)

*Infection, arthritis, neuromuscular and respiratory illness.

were identical on each occasion except that the questionnaire at T1 included questions on parental age and level of education. The questionnaire further comprised questions about (I) parental occupation, (II) estimated time at work had the child not been sick, (III) estimated actual time at work for the last month and the last week, (IV) monthly income, for parents as well as for relatives or friends who took time of work to care for the sick child, and (V) estimated earned before-tax income had the child not been ill. Further questions comprised (VI) the number of adults other than the parents in the household, (VII) children's age, (VIII) whether or not the children lived at more than one address, (IX) progression of the child's illness, (X) experienced impact of illness on everyday family life and (XI) school attendance.

Data analysis

An overview of family members' background characteristics as stated in the first month of HCS (T1) is presented in Table 2, and an overview of the child's illness and effects on everyday life throughout the observation period is presented in Table 3. Healthcare costs, for the care given and for the alternative care, were calculated as the number of physical units of healthcare utilised times the unit price. Six children died during the follow-up period. Total healthcare costs for these children were calculated from time of inclusion to death. The estimated alternative utilisation of palliative HCS if provided in the hospital was estimated as one visit per week in day care up until

one week before death and one week of hospital overnight stay for the last week of life based on local historical reports of healthcare utilisation at the end of life for children before 2013. Significance test for comparison of healthcare costs was not performed due to the diversity of healthcare utilisation.

Parents (n = 25) who reported data on income and work absence for two or more observations were included in the analysis of estimated productivity losses (Table 5). Missing data on time supplied to the labour market and of before-tax income were replaced with mean value of data from the two nearest available time points. A standard 1700 hours was used as the average annual number of working hours in Sweden. The

Table 3 Overview of illness and everyday life throughout the observation period of one year for sick children, N = 32

	T1 (n = 28)	T2 (n = 9)	T3 (n = 7)	T4 (n = 4)	T5 (n = 8)
Symptom of illness					
Since birth	4 (14.3)	1(11.1)	2 (28.6)	1 (25.0)	2 (25.0)
More than one year	5 (17.9)	1(11.1)	2 (28.6)	1 (25.0)	4 (50.0)
More than one month	14 (50.0)	4 (44.4)	2 (28.6)	2 (50.0)	–
Less than a month	2 (7.1)	–	–	–	–
No longer ill	–	3 (33.3)	1 (14.3)	–	2 (25.0)
Everyday life affected by illness					
Since birth	5 (19.2)	2 (22.2)	2 (28.6)	1 (25.0)	2 (25.0)
More than one year	4 (15.4)	0	1 (14.3)	1 (25.0)	3 (34.5)
More than one month	14 (53.9)	5 (55.6)	2 (28.6)	2 (50.0)	1 (12.5)
Less than a month	3 (11.5)	0	1 (14.3)	–	–
Not relevant		2 (22.2)	1 (14.3)	–	2 (25.0)
Changes in illness and care needs					
Yes, last:	23 (88.5)	8 (89.0)	5 (71.4)	4 y	6 (75.0)
Week	4 (15.3)	0	1 (14.3)		–
Month	9 (34.7)	3 (33.3)	0	1 (25.0)	2 (25.0)
6 months	7 (26.9)	3 (33.3)	4 (57.1)	2 (50.0)	3 (37.5)
Year	3 (11.5)	2 (22.2)	0	1 (25.0)	1 (12.5)
(Pre-)school attendance					
Yes	23	8	6	3	3
HCS effects on (pre-)school attendance for ill child					
Yes					
Increased chance	4	1			1
Lower chance	2				
No	9	2			1
Vary	0		1		
Not relevant	7	4	3	4	5
Increased chance for sibling to sleep at home					
Yes	5	0	1	2	0
Relatives' participation in care* (Hours)					
Single occasions	4	4			4
A couple of times per month	8				
A couple of times per week	12	12			
	n = 21	n = 6	n = 3	n = 2	n = 5
Disposable household income (SEK)					
Mean (SD)	37 714	47 166	39 333	55 000	40 000
	12 437	23 319	9504	21 213	17 677

Data are presented as frequency (%) unless otherwise stated.

*In a way that decreases time in labour market.

observed wage rate was multiplied by 1.5 in order to account for labour taxes. Estimation of productivity losses following the death of a child for parents (n = 3) of deceased children (n = 2) was based on data on sick leave after the loss of a child to cancer (26) and calculated as 100% the first month after the death of the child and then 50% and 40% for mothers and fathers, respectively, the remaining months. The value of productivity losses was calculated for each parent separately. No discounting was applied, since the interest rates for the relevant years were close to zero. Descriptive statistics are expressed as frequencies (percentage (%)), means and standard deviations (SD), or medians and interquartile range [IQR]. Significance tests for differences between gender regarding productivity losses and the value of productivity losses were calculated with Mann–Whitney's *U*-test with a p-value of <0.05 considered statistically significant at 95% confidence interval. Statistics were analysed using IBM SPSS Statistics 23 and 25 Windows (IBM Corporation, Armonk, NY, USA).

Results

Healthcare costs

The estimated annual total costs varied among children within the range of SEK 3300 to 2.6 million. Total healthcare utilisation was higher with the care given than with the estimated alternative care, while the total number of days spent in the hospital was lower with the given care. The extra utilisation was associated with transfer from the hospital to HCS and the estimated changes in utilisation effected total alternative costs. The average annual healthcare cost of one child, when HCS was provided as part of total healthcare care, was SEK 50 101 lower than the alternative of care only in the hospital (Table 4). Six children received palliative HCS with a corresponding total cost of 927 185 SEK. This constituted 73% of the total HCS healthcare costs and an estimated total cost reduction of SEK 37 722 compared to the alternative care.

Productivity losses

One-year estimated losses of working time varied among both mothers and fathers, as did the value of productivity losses (Fig. 1) with higher productivity losses at T1 than at T5 (Fig. 2). The median level of productivity losses related to mothers was more than double those of the fathers. Twenty-five parents produced total estimated productivity losses at a value of 3.3 million SEK during one year of follow-up. Mean level of productivity losses for women was higher than for men, while mean value of productivity losses was lower although the groups did not differ significantly (p = 0.48 and 0.75, respectively)

Table 4 Healthcare resource utilisation and costs (SEK) and alternative utilisation and opportunity costs

Physical units of healthcare resource	Healthcare service utilisation (Number of visits/days)	Costs (SEK)
University Hospital		
Ambulatory care + Day care	151 + 204	4 095 097
Overnight care	346	8 659 712
Cost		12 754 809
Local hospital		
Ambulatory care + Day care	29 + 37	657 502
Overnight care	284	1 002 314
Cost		1 659 816
HCS (days of)		
Special care task (visits)	694	286 622
Palliative care (days of)	441	910 665
Palliative assessment team meeting	8	16 520
Cost	-	1 213 807
Estimated alternative healthcare utilisation of HCS converted to hospital visits and admittance		
Day care nurse	65	121 940
Day care physician	51	477 309
Overnight care	226	2 217 783
Cost	-	2 817 032
Total healthcare costs regarding university hospital, local hospital and HCS		15 628 432
Total alternative healthcare costs		17 231 657

(Table 5). Observed income and work absenteeism were to a high degree reported from parents of children who were continuously ill (Table 3). Twenty-one parents had children with long-term illness, whereof 13 had children with cancer. Parents of four children stated that a relative took time off work to care for the ill child. The extent of time varied from a couple of hours at single additional productivity losses.

Discussion

This health-economic observational follow-up study estimates the societal cost of county-based HCS for children including healthcare costs and productivity losses. The study shows that HCS can be provided without increased healthcare costs when ill children receive HCS as part of their care compared to care only at the hospital. Furthermore, it confirms that illness in a child is associated with extensive productivity losses due to parental work absenteeism, also when HCS is provided.

Our findings show that the transfer from hospital to HCS generated some extra healthcare utilisation of physical units though the total number of inpatient nights at the hospital was lower. This is in line with previous studies finding a reduced number of inpatient nights (20,28). Healthcare utilisation as well as costs varied greatly
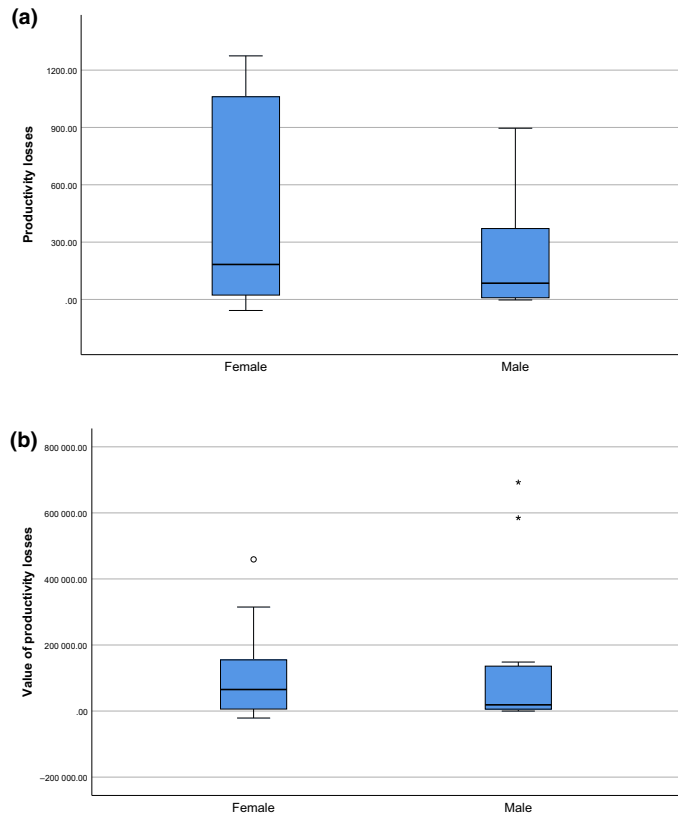
(a)

(b)

Figure 1 (a) Annual productivity losses (hours/child/year), (b) annual value of productivity losses (SEK/Child/Year).

between children in the present study. The healthcare cost reduction was pronounced for SCT, while costs of palliative care were similar to the costs related to estimated alternative care in the hospital. Fifteen of the children were diagnosed with cancer. This group of children has previously shown less pronounced reduction in healthcare costs during palliative HCS compared to children with a range of other diagnoses (20). With small groups of patients, as is often the case in paediatric care, the demand for a specific type of care may be fluctuating and a balance of resources and demands difficult to achieve. A population-based healthcare service, such as county-based HCS

Figure 2 Parents' work time and corresponding productivity losses during 12 months (hours/month).

for children in the present study, rather than condition-specific service, might help optimise accessibility (29) as it allows generous accessibility of support even when the number of children was low (3). Easy and extensive access to HCS further offers comfort and relief for families in strained periods of life (7,30).

The present study shows that illness in a child brings productivity losses due to mothers and fathers absenteeism from work also during HCS. In Sweden, temporary parental benefits are granted in relation to the child's illness and care needs rather than whether or not the child is hospitalised or being cared for at home. The findings of the present study reinforce the knowledge of productivity losses due to parental absenteeism from work during illness in a child both during HCS (14,19) and during illness in general (26). The study further supports gender-related patterns in that mothers' absenteeism exceeded the fathers', while the value of productivity losses did not, also found by Tiberg et al (12). We found a trend towards decreased absenteeism during the follow-up period also when the child continued to be ill. The present study does not demonstrate whether or not this is due to HCS, but it is in line with parents' lived experience (7) of increased possibility of attending work, while a child is receiving HCS. Two Swedish reports (31,32) support research findings (33,34) in that there are long-lasting associations between
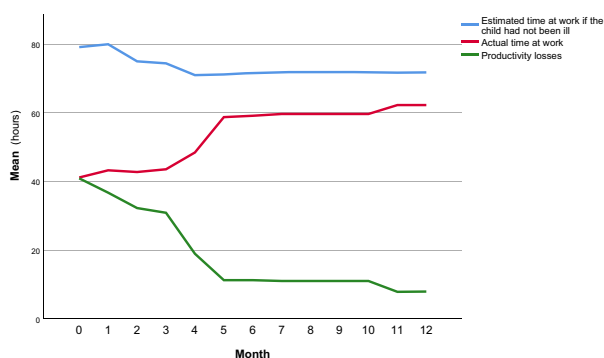
Table 5 One-year parental related productivity losses and value of productivity losses during illness in a child

Productivity losses	Units (hours/child/year)					Value (SEK/Child/Year)				
	Mean	SD	Median	Max–min	Sum	Mean	SD	Median	Max–Min	SUM
Both, N = 25	347.6	446.0	101.7	−57.7 to 1274,5	8688.7	137 524	196 579	38 555	−21 067 to 692 586	3 300 578
Female, n = 14	418.0	518.4	183.1	−57.7 to 1274.5	5850.8	127 305	149 922	105 671	−210 667 to 459 196	1 654 959
Male, n = 11	258.0	335.2	85.0	−2.83 to 896.1	2838.0	149 602	248 217	18 796	0 to 692 586	1 645 619
p-value	0.48					0.75				

parental periods of work absenteeism due to care for a sick child and lower pay. Lower pay and a less successful career limits families' potential for future investments in health (35). Therefore, if HCS in fact leads to a reduction of parental work absenteeism, the choice of HCS may contribute to optimising family health capital in a lifetime perspective. The possibility of increased school attendance for sick children and increased sibling participation in family life, reported both in the present study and in previous studies (7,36), contributes further to families' production of their own health capital (35).

Methodological considerations

The study does not provide a full health-economic evaluation. The findings are based on estimated alternative healthcare utilisation and corresponding costs. It can be debated whether these are accurate estimations, the basis for the estimations is therefore clearly presented and may thus be recalculated to fit other options. Due to design, furthermore, the study does not determine to what extent parental absence from the labour market is related to the chosen healthcare utilisation or to the child's illness. The number of parents included in the assessment of productivity losses is small and the children's illness and care needs diverse, which limits the possibility to generalise the findings. However, the demographics of the included group show congruity with the total population of children receiving HCS (3) which strengthens the findings. Furthermore, the study contributes knowledge about county-based HCS for children in Sweden not previously described and can serve as a basis for further health-economic evaluations such as cost-effectiveness or cost utility (37). Future studies should make an effort to include families with non-Swedish-speaking inhabitants. Studies of the effects of HCS on family economy, including disposable income and out-of-pocket expenses, would be an important supplement for decision-making from a societal cost perspective.

Conclusion

County-based home-care services, provided as a complement to and substitute for hospital care for ill children, does not increase healthcare costs and should, due to positive effects on family everyday life and health (3,9), be a prioritized area when organising future paediatric health care. Productivity losses due to illness are pronounced also when children receive home care, with a trend towards gender-specific differences.

Author Contributions

All co-authors have contributed to the manuscript according to requirement of full authorship. All authors were involved in design, report writing and approval of final manuscript. CC performed datacollection. CC, KB, IH and HH discussed and performed analysis.

Ethical approval

The study was approved by the Regional Ethical Review Board (Dnr 2014/818) and the Institutional Review Board at Skane University Hospital (181-17) and carried out in accordance with ICMJE Recommendations for the Protection of Research Participants (27) and Declaration of Helsinki. Written informed consent was obtained by 62 parents of 32 ill children.

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