

RESEARCH REPORT

Avoidable mortality among child welfare recipients and intercountry adoptees: a national cohort study

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Objective: To compare rates of avoidable mortality in adolescence in child welfare recipients and intercountry adoptees with the general population.

Design: A register study of the entire national cohort of 989 871 Swedish residents born 1973–82 in the national census of 1990. Multivariate Cox analyses of proportional hazards were used to analyse avoidable deaths between 13 to 27 years of age during 1991–2000.

Participants: 12 240 intercountry adoptees, 6437 foster children, 15 868 subjected to other forms of child welfare interventions, and the remaining 955 326 children in the cohort.

Results: Intercountry adoptees had a high sex and age adjusted relative risk (RR) for suicide death only (RR 3.5; 95% CI 2.3 to 5.0) in comparison with the general population, while foster children and adolescents who had received other kinds of child welfare interventions had high sex and age adjusted RRs for suicide death; 4.3 (2.8 to 6.6) and 2.7 (1.9 to 3.9) respectively, as well as for other avoidable deaths; RRs 2.5 (1.6 to 3.7) and 2.8 (2.1 to 3.6). The RRs of avoidable deaths for foster children and other child welfare recipients decreased considerably when compared with youth brought up in homes with similar psychosocial characteristics as their original home.

Conclusion: Children in substitute care in early childhood were at particular risk for suicide death in adolescence and young adulthood. Child welfare interventions were insufficient to prevent excess deaths in children at risk.

The need for substitute care for abandoned and orphaned children is as old as mankind.¹ In modern welfare societies the responsibility of substitute care has been extended to children from troubled homes. In Sweden about 1% of recent birth cohorts have experienced more than five years of foster or residential care during childhood.² Through government sponsored international adoptions the Swedish society has also taken on the ambition of providing substitute care for children from the developing world. Sweden is the country with the largest population of intercountry adoptees in Europe, 43 000, and per capita (1%–1.5% of the cohorts born after 1965) in the whole world.³ In Sweden foster children and intercountry adoptees are raised in quite different kinds of substitute care. Foster children are placed in families who are given financial compensation for doing a job while adoption carries considerable costs for adoptive parents. Foster children are cared for until their 18th birthday under the condition that they may be returned to the original home on short notice, while adoptees become permanent members of their family. A third category of children at risk is supported by child welfare agencies within the framework of the biological family.

The reason for substitute care and other child welfare interventions in early childhood is usually a home environment that is judged to be unsatisfactory to meet the needs of the child, often because of addictive or other deviant parent behaviour. As children raised in such homes have been shown to have an excess death rate during adolescence and young adult years,^{4 5} one important goal of child welfare interventions is to improve the chance of survival into adulthood. Previous studies of mortality of child welfare populations in Europe have questioned whether this goal is adequately met, demonstrating comparatively high mortality rates.^{6–9} In this study we used the Swedish national registers to evaluate outcomes in avoidable mortality between 13 and 27 years of age in intercountry adoptees, foster children and

children that had received other child welfare interventions started before age 13 in a comparison with the general population in an entire national cohort. Do child welfare interventions during early childhood in Sweden improve survival during adolescence? Are there differences in death rates between the two categories of children in substitute care in early childhood; foster children and intercountry adoptees?

METHODS

This study was based on data from national registers held by the Swedish National Board of Health and Welfare, and Statistics Sweden. The key to these registers is the unique personal identification number, which follows each Swedish resident from birth to death. This number was used to link data from the registers to each participant.

Study population

The study population consisted of the entire Swedish population born 1973–82 who had settled in Sweden before 7 years of age and were recorded to be living in family households in the November 1990 census, 989 871 people. Four study groups were created within this population in a stepwise hierarchical fashion so that every person could only be included in one study group.

Firstly, 12 240 intercountry adoptees were identified by having a record of being born outside of Europe, no record of a biological parent in the Swedish Parent Register, immigration to Sweden before 7 years of age and parent(s) who were recorded to have been born in Sweden without any record of emigration or immigration after 1968. Secondly, 6437 long term foster children were defined by records of foster care for at least two years before their 13th birthday in the Swedish

Abbreviations: RR, relative risk; HR, hazard ratio; SES, socioeconomic status

Table 1 Definition of avoidable mortality. (ICD-9 was used 1990–96 and ICD-10 in 1997–2000)

Outcome variable	Diagnostic concept	ICD-9	ICD-10
Avoidable "natural deaths".	Disorders related to illicit drug misuse:	292, 304, 965.0, 968.5, 969.6, 969.7	Z722, Z503, F12, F11, F14, F16, F19
	Disorders related to alcohol misuse	291, 303, 305.0, 357.5, 425.5, 535.3, 571.0–571.3	F10, G621, I426, K294, K70
	Appendicitis	54	K35
	Asthma	493	J45
	Diabetes	250	E11–E14
	Epilepsy	345	G45
	Pneumonia	48	J10–J18
	Tuberculosis	460–478	J00–J06
	Unintentional injuries and homicide	Unintentional injuries	E800–E929
Homicide		E960–E969	X85–Y09
Suicide		E950–E959 or E980–E989	X60–X84 or Y10–Y34

Register of Children and Young Persons subjected to Child Welfare Measures. The mean time in care in this group was 7.7 years and the median time 7.3 years. As long term placements in residential care are very rare for children who enter Swedish care before their teens,⁶ care experience in this group is dominated by foster family care.

Thirdly, 15 868 other children in families where at least one child had been subjected to child welfare measures before their 13th birthday were identified. The measures ranged from temporary placements in foster or residential care for less than two years to regular support by an adult outside of the family. For the purpose of simplification, this group will be referred to as having received "other child welfare interventions" in the text. The remainder of the population; 955 326 children, were labelled the general population.

Sociodemographic variables

Mother was defined as the biological mother in the Swedish Parent Register with the exception of the intercountry adoptees where the female caregiver in the household in the census of 1990 was considered to be the mother. The Swedish Population and Housing Census 1990 was the source of the following information about the mother: year of birth, sex, socioeconomic status (SES) of the household, housing situation, family status (lone parent household), and geographical location of the home (residency). SES was defined according to a classification used by Statistics Sweden, which is based on occupation but also takes educational level of occupation, type of production, and position at work of the head of the household into account.¹⁰ The Total Enumeration Income Survey for 1990 was the source for social welfare benefits received (yes/no) in 1990 by the mother.

The ethnicity of the study subjects was classified according to the country of birth of the adults in the household of the mother in the census of 1990. When the adults in the household had diverse ethnicity the child was classified according to the oldest woman, and if there were no female adults in the household, the oldest man in the household. If at least one, but not all, adults in the household were born in Sweden, the child was classified in an intermediate group.

Parental morbidity

Risk factors related to psychiatric illness and addiction in the biological parents (thus excluding intercountry adoptees) were obtained through individual record linkage to the Swedish Hospital Discharge Register for the years 1987–1990. The variables were defined according to the 9th revision of the WHO International Classification of Diagnosis (ICD-9)

- Any psychiatric disorder: a main diagnosis of 290–319 (ICD-9)
- Drug misuse: a main or contributory diagnosis of 292, 304, 965.0, 968.5, 969.6, 969.7.
- Alcohol misuse: a main or contributory diagnosis of 291, 303, 305.0, 357.5, 425.5, 535.3, 571.0–571.3, E860, E980+980

Outcome variables

The concept of avoidable mortality has been developed within research on the quality of medical and psychiatric care.^{11–12} This concept is intended to increase the value of mortality rates as quality indicators of care by focusing on deaths that could possibly have been avoided by prevention or adequate medical care. In this study the concept included deaths from natural causes related to alcohol and substance misuse, deaths from natural causes that could possibly have been avoided by proper medical care, and intentional and unintentional injuries (table 1).

Statistical methods

The study population was followed up prospectively from the time of the Swedish Population and Housing Census in November 1990 or from the 13th birthday, whichever came last, to December 2000 in the Swedish National Cause of Death Register. Multivariate analyses were conducted with Cox regressions of proportional hazards of time to event with the variables defined in table 1 as the outcome variables. Time in the study was calculated with date of birth from the census of 1990, date of death from the National Cause of Death Register and date of emigration from the Total Enumeration Income Survey. Birth year was entered as a continuous variable in the regression models, as death rates increased in a linear fashion with this variable. Other sociodemographic variables were entered as categorical variables (using dummy variables) into the models. Missing values in socioeconomic variables were included in the models as a separate category.

Hazard ratios of relative risk (RR) were analysed in three regression models. The first model was adjusted only to the year of birth and sex of the study population. This model was used for comparisons between the study groups as we did not have information about to what extent intercountry adoptees had been exposed to the other confounders. The second and third models were created to allow for a comparison with children who had not received child welfare intervention but had been raised in homes with similar parental (model 2) and social characteristics (model 3) as the biological homes of the child welfare recipients. Model 2 included indicators of

addiction and psychiatric illness in the biological parents and model 3 added socioeconomic indicators of the household of the biological mother to the variables in model 2. The intercountry adoptees were excluded from the second and third models because of the lack of information about their biological parents. The SPSS software package, version 11.0, was used in all statistical analyses.

RESULTS

The sociodemographic characteristics of the intercountry adoptees stand out among the study groups with a strong female preponderance (59%), the highest SES of the household, the highest maternal age at birth of the child (mean: 32.2 years) and the highest proportion living in houses (86%). The original homes of the long term foster children, on the other extreme, had the youngest mothers at the birth of the child (mean: 25.4 years), the lowest SES, the lowest level of maternal education, and most often received social welfare in 1990 (51%). Forty one per cent of the long term foster children had one or two parents who had been admitted to hospital because of alcohol misuse, substance misuse, or psychiatric disorder, or all three. Children who had received child welfare interventions but had mainly grown up in their original family had characteristics somewhere in between the general population and the original families of the long term foster children for psychosocial risk factors as well as socioeconomic variables (table 2).

There were 2170 deaths (26/10 000 person years) in the general population, 52 (89/10 000 person years) among the long term foster children, 53 (50/10 000 person years) among the intercountry adoptees, and 90 deaths (66/10 000 person years) in children who had received other kinds of child welfare interventions. Deaths because of severe congenital disorders, such as Down's syndrome, tended to be most common among the long term foster children and other recipients of child welfare; 5/10 000 person years compared with 1/10 000 person years in the general population (table 3).

Long term foster children and intercountry adoptees had increased age and sex adjusted hazard ratios for suicide, relative risks (RRs) 4.3 and 3.5 (table 4) compared with the general population, while those that had received other kinds of child welfare interventions had a hazard ratio between these groups and the general population (RR: 2.7). When the analysis was adjusted to the morbidity and socioeconomic situation of the biological parents, to create a comparison with adolescents raised in similar psychosocial circumstances as the original home, the RR decreased considerably but were

still significantly higher than those of the general population for long term foster children (RR 2.2) as well as for children with other forms of child welfare interventions (RR 1.7).

Children in long term foster care as well as children that had received other kind of child welfare interventions had higher age and sex adjusted hazard ratios for "other avoidable deaths" (avoidable natural causes, addiction as well as unintentional injuries and homicide) in comparison with the general population (RRs 2.5 and 2.8 respectively) as well as the intercountry adoptees (table 4). When the hazard ratios for other avoidable deaths were adjusted for the morbidity and socioeconomic status of their biological home the risks decreased considerably for children in long term foster care, and remained significantly higher than those in the general population for children with other forms of child welfare interventions only (RR 1.8).

The hazard ratios of all avoidable deaths were analysed in two age specific groups; 13–17 years and 18–27 years. In the younger age group the RRs after adjustment for year of birth and sex were 2.3 (95%CI 1.3 to 3.8) for intercountry adoptees, 2.5 (95%CI 1.2 to 5.0) for long term foster children and 2.8 (95%CI 1.9 to 4.6) for other child welfare recipients compared to the general population in the age group 13–17 years, while the RRs in the age group 18–27 were 1.8 (95%CI 1.2 to 2.7) for intercountry adoptees, 3.3 (95%CI 2.4 to 4.7) for long term foster children, and 2.6 (95%CI 2.0 to 3.3) for other child welfare recipients compared with the general population.

DISCUSSION

This study shows that long term foster children, other child welfare recipients, and intercountry adoptees have threefold to fourfold increased risks for suicide deaths during adolescence and young adulthood compared with the general population. Both groups of welfare recipients—in contrast with the adoptees—also displayed increased risks of other types of avoidable mortality. It is very rare that an undesirable outcome for adoptees in this age group resembles that of long term foster children.^{2 13} This seems to indicate that other factors than those related to the socioeconomic context during adolescence are important in explaining the high risk of suicide in children in substitute care (foster children and adoptees). Many foster children as well as intercountry adoptees have been exposed to multiple risk factors during early childhood, factors such as child abuse and neglect, malnutrition, intrauterine exposure to narcotics, alcohol, and psychotropic drugs as well as the hereditary influence of having parents with psychiatric disorders.^{14–16} All children in substitute care are also subjected to separations from their biological parents and the task of creating new bonds with the substitute parents. Attachment theory provides a framework for linking these separations to suicide as recent studies^{17 18} have demonstrated that insecure attachment patterns are related to suicidal ideation and suicide attempts in adolescents. Juffer *et al*¹⁹ have shown that insecure attachment patterns in adoptive families are common but can be identified and modified by counselling. Further studies are needed to clarify the role of this mechanism in suicidal behaviour in children in substitute care. It is also possible, however, that the high risks of suicide for long term foster children and intercountry adoptees are caused by parallel causal mechanisms. For instance, racism²⁰ during adolescence and discrimination on the labour market in young adult years²¹ may explain at least a part of the higher risk for suicide among international adoptees, while there is a strong overrepresentation and an aggregation of various risk factors among long term foster children compared with other child welfare recipients.¹³ Several studies have affirmed that children with poorer dispositions, more damaging early adverse experiences, and more behavioural

Key points

- Children in long term foster care and children subjected to other child welfare measures are at high risk for suicide death and other types of "avoidable death".
- Intercountry adoptees are at high risk for suicide death, but not for other "avoidable deaths".
- Child welfare interventions before adolescence were insufficient to prevent excess deaths in children at risk during adolescence and young adulthood.
- Further studies are needed to clarify the potential of attachment intervention in substitute families in suicide prevention as well as other intervention programmes, for example, aftercare services for adolescent foster children.

Table 2 Age and sex of the study subjects. Psychosocial indicators of the household of the parents in the 1990 census

		Non-European adoptees* n = 12240	Long term foster care† n = 6437	Other child welfare‡ n = 15868	General population† n = 955326
Mean age in Nov 1990 (y)		12.7	13.5	12.7	13.1
Sex (%)	Male	41.0	51.9	54.5	51.3
	Female	59.0	42.8	45.5	48.7
SES of maternal household (%)	Unclassified	13.0	65.0	42.3	19.1
	Manual labour	14.8	23.7	32.4	27.4
	Skilled labour	6.8	4.1	7.9	9.7
	White collar 1	21.7	4.2	9.1	17.5
	White collar 2	28.1	2.2	6.1	18.8
Maternal education (%)	White collar 3	15.6	0.7	2.3	7.6
	0-9 years	9.0	21.9	9.0	10.1
	10-11 years	8.3	35.0	27.0	16.1
	12-13 years	40.1	39.0	46.2	46.9
Maternal age at birth of child (y)	14+years	42.7	4.1	10.1	26.9
	Mean	32.2	22.9	25.5	26.8
Housing (%)	Missing information	0.2	27.6	8.0	1.5
	Rents apartment or unclassified	8.5	55.5	61.2	23.3
	Owns apartment	5.7	5.1	8.3	7.5
	Own house	85.6	11.8	22.4	67.8
Received social welfare 1990 (%)	yes	1.3	51.4	45.3	6.9
	Missing information	0.2	26.7	7.1	1.0
Single adult household (%)	yes	6.4	33.2	42.8	11.3
	No	93.4	40.1	50.1	87.7
	Metropolitan area	26.8	35.4	33.1	27.6
Residency (%)	Smaller city	54.5	47.9	50.3	51.0
	Rural	18.6	16.7	16.6	21.4
	Parental alcohol misuse	‡	26.7	12.2	1.4
Psychosocial risk factors (%)	Parental substance misuse	‡	9.1	3.3	0.2
	Parental psychiatric disorder	‡	20.8	13.3	2.2
	At least one psychosocial risk factor	‡	41.2	23.3	3.4
	Ethnicity (%)	Swedish	‡	83.1	72.8
Mixed		‡	8.8	9.6	8.8
Finnish		‡	4.4	6.1	2.3
Other European		‡	2.2	4.9	2.8
Non-European		‡	1.5	6.5	3.5

*Sociodemographic indicators of the household of the adoptive mother; †sociodemographic indicators of the household of the biological mother; ‡no data about biological parents of adoptees.

problems tend to stay longer in care, or return after failed reunification attempts.^{22, 23}

The higher risk of death in foster children compared with adoptees after they leave care (over 18 years of age) highlights the difference of being a permanent and transitory member of a substitute family. It may be speculated that the lack of support during late adolescence after

leaving care may be important in explaining this finding.²⁴ Both US and European research has for example consistently shown that former foster children are heavily over-represented in homeless populations, even though the links between care experiences and homelessness are unclear. Also, studies that have found increased mortality risks for foster children have noted that these risks are

Table 3 Total numbers and rates (per 10000 person years) of death by diagnostic category

		Non-European adoptees† n = 12240	Long term foster care n = 6437	Other child welfare n = 15868	General population n = 955326
1 All deaths	Cases	53***	52***	90***	2170
	Death rates	49.6	88.6	65.6	25.5
Chronic disorders	Cases	3	3*	7***	83
	Death rates	2.8	5.1	5.1	1
2 Suicide deaths	Cases	27***	22***	30***	709
	Death rates	25.3	37.5	21.9	8.3
3 Other avoidable deaths	Cases	10	18	48	696
	Death rates	9.3	30.6	35	8.1
3a Deaths related to substance and alcohol misuse	Cases	4	9***	16***	206
	Death rates	3.7	15.3	11.7	2.4
3b Other avoidable natural causes	Cases	3	3*	6**	104
	Death rates	2.8	5.1	4.4	1.2
3c Unintentional injuries	Cases	1	4	21***	309
	Death rates	0.9	6.8	15.3	3.6
3d Homicide	Cases	2	2	5**	77
	Death rates	1.9	3.4	3.6	0.9
2+3 Suicide + other avoidable deaths	Cases	37***	40***	78***	1405
	Death rates	34.6	68.1	56.9	16.4

*p<0.05 compared with general population in Pearson χ^2 ; **p<0.01 compared with general population in Pearson χ^2 ; ***p<0.001 compared with general population in Pearson χ^2 .

Table 4 Cox regression models of suicide and other avoidable deaths during 1990–99 for the study groups compared with the general Swedish population

	Suicide deaths			Other avoidable deaths		
	Model 1 OR (95% CI)	Model 2 OR (95% CI)	Model 3 OR (95% CI)	Model 1 OR (95% CI)	Model 2 OR (95% CI)	Model 3 OR (95% CI)
General population	1	1	1	1	1	1
Inter-country adoptees	3.5 (2.3 to 5.0)	–*	–*	1.1 (0.6 to 1.7)	–*	–*
Long term foster care	4.3 (2.8 to 6.6)	3.0 (1.9 to 4.8)	2.2 (1.4 to 3.6)	2.5 (1.6 to 3.7)	1.7 (1.1 to 2.7)	1.4 (0.9 to 2.1)
Other child welfare recipients	2.7 (1.9 to 3.9)	2.2 (1.5 to 3.2)	1.7 (1.1 to 2.5)	2.8 (2.1 to 3.6)	2.4 (1.8 to 3.1)	1.8 (1.4 to 2.4)

*No information about biological parents. Model 1 is adjusted for sex and year of birth. Model 2 is adjusted for the variables in model 1 and hospital admission because of alcohol misuse, substance misuse, or psychiatric illness in biological parents, or all three. Model 3 is adjusted for the variables in model 2 and socioeconomic indicators of the biological mother (social welfare, lone parent household, SES, ethnicity, and place of residence).

restricted to time after care, not while the children are in care.^{25, 26}

The risk of death for the foster children as well as other child welfare recipients decreased considerably when they were compared with youth from homes with similar psychosocial characteristics as the original homes of the child welfare recipients. This suggests that social adversity and hereditary factors related to substance misuse and psychiatric disorders are important in explaining this higher risk. On the other hand there was no indication that child welfare interventions improved the chance of survival during adolescence for children at risk, since the risk of death was worse rather than better than for youth from homes with similar psychosocial characteristics. However, it is quite possible that the inclusion of more detailed psychosocial background data of the original family would have enabled better adjustment for confounders related to the specific cause of the child welfare intervention, which naturally could have affected the analysis. The lower mortality rate of the adoptees for other types of “avoidable mortality” than suicide may be interpreted as a hopeful indication that a considerable number of deaths can be avoided with an improved content of interventions from the society.

To our knowledge this is the first study that compares mortality rates in adoptees with children who have received child welfare interventions, and also the first study that uses the concept of avoidable mortality to a child welfare population. The results suggest that this concept improves the analysis by limiting confounding through selection of children with congenital disorders. It is possible, however, that some confounding because of selection of children with acquired chronic disorders is still present in the analysis. This comparatively large national sample allowed us to study suicide apart from other avoidable deaths and to use multivariate models to compare death rates of child welfare recipients with children raised in similar psychosocial environments as the original homes of the adolescents in

the study. An important limitation of the study was the general nature of the background information of each child before entering substitute care, where factors such as malnutrition, abuse, and neglect, and multiple separations from caregivers may be important to explain differences in mortality rates between the study groups. Another limitation of the study was the indirect criteria for identifying adoptees made necessary by the limitations of the available registers. These criteria made it necessary to exclude certain smaller groups of intercountry adoptees, such as those with parents who adopted while living abroad and adoptive homes where one or two of the parents were foreign born.

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Policy implications

This study has substantial practical implications for policy in health and social work, not the least for aftercare/leaving care programmes targeting long term foster children, for example, by securing the availability of mental health services after care exits. Clinical mental health agencies should ensure in their internal guidelines that adolescent/young foster children and intercountry adoptees are granted easy access to diagnostic procedures and priority in access to treatment. The same recommendations are valid for health services that meet children and adolescents who are entering, remaining in, or having left care.

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- Working with *Clinical Evidence* Editors to ensure that the text meets rigorous epidemiological and style standards.
- Updating the text every eight months to incorporate new evidence.
- Expanding the topic to include new questions once every 12–18 months.

If you would like to become a contributor for *Clinical Evidence* or require more information about what this involves please send your contact details and a copy of your CV, clearly stating the clinical area you are interested in, to Claire Folkes (cfolkes@bmjgroup.com).

Call for peer reviewers

Clinical Evidence also needs to recruit a number of new peer reviewers specifically with an interest in the clinical areas stated above, and also others related to general practice. Peer reviewers are health care professionals or epidemiologists with experience in evidence based medicine. As a peer reviewer you would be asked for your views on the clinical relevance, validity, and accessibility of specific topics within the journal, and their usefulness to the intended audience (international generalists and health care professionals, possibly with limited statistical knowledge). Topics are usually 2000–3000 words in length and we would ask you to review between 2–5 topics per year. The peer review process takes place throughout the year, and our turnaround time for each review is ideally 10–14 days.

If you are interested in becoming a peer reviewer for *Clinical Evidence*, please complete the peer review questionnaire at www.clinicalevidence.com or contact Claire Folkes (cfolkes@bmjgroup.com).