

Suicide Cases in a Population-Based Cohort of Persons With Intellectual Disability in a 35-Year Follow-Up

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Suicides of persons with mental retardation are considered rare. In a 35-year (1962-1998) follow-up study of a nation-wide, population-based cohort of 2,677 persons with intellectual disability, only 10 suicide cases were discovered. Suicide risks of persons with mental retardation include psychiatric morbidity with challenging care needs, social problems and difficulties in adjusting to them and ageing. Those working with intellectually disabled individuals need to be aware of these risks in order to recognize severe depression, emotional instability and lack of will to live, possibly leading to either attempted or completed suicide.

Keywords: depression, developmental disability, Finland, intellectual disability, mental retardation, mood, psychiatric disorder, suicide

Suicides are regarded as rare among people with intellectual disability (ID) in contrast to individuals with other mental disorders or to the general population. There are no comprehensive epidemiological studies on the prevalence of suicides among this population, but a few reports on attempted and successful suicides, dating from 1899 have been published.^{4,6,7,9,11,17,23,27} Based on one comprehensive population-based follow-up study in Finland, the suicide rate of men with ID was one-third of the general male population suicide rate, but among women with ID, the rate was similar to the general population.¹⁹ In the general population high suicide rates are associated with mental disorders, physical illness and social disintegration.² Affective disorders are less common in people with ID, varying from 1.7% to 8.9%,¹³ but these disorders may simply be under diagnosed among this group. Symptoms of depression in ID are often expressed in the form of somatic complaints, vegetative symptoms, or regression, making diagnosis of depression difficult to determine.²¹ More over, the brain damage, which causes ID, is often associated with reduced frustration tolerance and increased explosivity, leading to behavioral problems and anxiety.²² This report focuses on suicide cases of persons with ID.

METHODS

Suicide cases were taken from the mortality study of the 35-year follow-up study conducted in Finland between 1962 and 1997.¹⁹ In 1962 the

municipal officials were asked to report all persons suspected of or known to have an intellectual disability. From a total of 4,013 suspected individuals tested by psychologists and physicians, 2,667 had ID or borderline intellectual functioning, while 1,155 evidenced normal intelligence. The original study found the prevalence of ID in Finland to be 0.65%. In this study all persons with ID, identified from the original study (n=2369), form the study population. The follow-up period was 35 years from 1/1/63 to 12/31/97 and the identification rate was 96%.

Statistics in Finland, which maintains a registry of causes of death, provided the death certificates.²⁰ All persons with an external cause of death were examined for suicide cases.²⁰ In Finland, forensic medical investigation is always carried out when the cause of death is uncertain, unexpected, sudden, unnatural, or even suspected to be unnatural. Forensic practice remained consistent throughout the follow-up period.

Although death certificates provided information on the methods of suicide, medical records were examined for further details. Eight persons had patient records from hospitals and community care. Two persons did not have any patient records, but a nurse was used as an informant in one case while the other remained without patient documents. Patient records contained a vast variety of information such as copies of juridical decisions, letters and psychological test results. All cases are presented in Table 1.

STUDY APPROVAL

The Ministry of Social Affairs and Health, and the Ministry of Education approved the study. The Data Protection Ombudsman approved the data protection and the combining of the original material with national databases. Personal details of each suicide case have been concealed to conform to the law for the protection of human rights of the persons in this study.

PATIENT CASES

Case 1

A 33-year-old man with moderate ID (IQ 52), youngest child of three. The mother's attitude toward him was ambivalent. Though attached to her youngest son, she showed inconsistency in her care of him and problems of coping with him from childhood. A further traumatic occurrence was the murder of his elder brother. He lived in a boarding school from the age of seven and was hospitalized for the first time at the age of 17 for four months because of his aggressiveness. Then he returned home for a short period. He was again hospitalized at age 18 for five and a half years. His records during that period showed that he suffered from hallucinations and, on one occasion, stole medication, but no further details were given. After rehabilitation he lived in the community hospital near his home for five years. At the age of 30 he was transferred to a mental hospital because of psychotic behavior. At that point he abused alcohol on vacations and was increasingly aggressive. His psychiatric problems included depression, psychotic sequences and behavioral disturbances and he expressed death wishes several times. He suffered from epilepsy with infrequent, but massive, attacks. His first suicide attempt, which was documented as such on his patient record occurred at age 30 when he ate cigarettes and drank a large amount of water. At age 32 there was a possible attempt of suicide using previous method. During the two years leading up to his death, vacations at home seemed to work better and he and his mother requested them more frequently. At the age of 33, he committed suicide by ingesting cigarettes.

- *Diagnoses in patient documents:* Epilepsy, Mental Retardation, Behavioral disturbances
- *Medication at time of death:* phenytoin, thioridazine, lorazepam, emeprium

Case 2

A 33-year-old male with mild ID (IQ 61), the oldest son of three. The mother was mentally retarded, but the father had normal intelligence. The mother was dedicated to her son, but was incapable of taking care of him. Both siblings suffered from mental disorders. He developed slowly and attended school only four classes; his formal education was interrupted because of his ID and intensive bullying. At the age of 17 he was hospitalized for aggressiveness and delusions and diagnosed as psychotic schizophrenic. In later years he was hospitalized with short periods at home or in a care home. His father died when the patient was 25 years old and at that time he suffered depression accompanied by aggressive behavior and verbal threats. After rehabilitation in a hospital, he returned home for a year. He was again hospitalized for hallucinations for which he received electrotherapy with good results and was deemed capable of living in a home environment. During this period of his life, when he was 28, his sister was hospitalized for mental disturbances. He reverted to psychotic behavior with hallucinations, fears and suicidal thoughts, and grew more aggressive. Five months before his own suicide, his sister committed suicide and his brother was hospitalized for mental disturbances. The subject's behavior changed from aggressive to depressive manifested by withdrawal into speechlessness and apathy. A regimen of antidepressants was initiated two weeks before his suicide. He went for a walk, disappeared and was found drowned five days later.

- *Diagnoses in patient documents:* Schizophrenia and Mental Retardation
- *Medication at time of death:* chlorprothixene, perphenazine, haloperidol, chlorpromazine

Case 3

A 37-year-old woman with mild ID (IQ 62), one of three children whose siblings were healthy. Both parents, however, suffered from mental disorders. She went to a special school for pupils with ID, but it was interrupted because of mental disturbances. In her teens she was hospitalized six times for anxiety, delusions and aggressive behavior and was later diagnosed with schizophrenia. She also suffered from epilepsy, sarcoidosis and severe rectal prolapses. Her behavior was dominated by the desire for

constant attention. Psychiatric problems included depression, psychotic sequences, suicidal behavior and other behavioral disturbances including prolonged shouting and destruction of property. The first suicide attempt at the age of 29 was by overdosing on medications and she was permanently hospitalized. The second attempt took place at the age of 32 by trying to drown in a swamp and later by running into traffic. In addition other suicidal behavior occurred repeatedly, e.g. eating glass, drinking water, tearing the rectum open. She suffered from anxiety and hallucination several weeks before her suicide. Her attempt to steal antipyretics prior to suicide failed, but shortly thereafter she succeeded in stealing rifampicin and committed suicide at the age of 37.

- *Diagnoses in patient documents:* Schizophrenia typus schizo-affectivus, Epilepsy NUD, Mental Retardation
- *Medication at time of death:* lithium, chlorprothixene, zuclopenthixol, lynestrenol

Case 4

A 66-year-old male (IQ 52), born into a farm family. This subject suffered asphyxia at birth and convulsions as a child. He lived at home until the age of 46 and then moved into a rest home. In his early years he worked on a farm where he seemed quiet and withdrawn, but generally contented with his life. He had neither psychiatric diagnosis nor medication. In the rest home he ate alone and in summers lived in a tent and cycled daily. On a cycling trip, he narrowly missed being struck by a car, whose driver reproached him rudely. In shock he went to the cowshed, where he had worked earlier and hanged himself. There was no history of suicide either in his family nor in the rest home. He had given no indication of suicide.

- *Diagnosis in patient documents:* Mental Retardation
- *Medication at time of death:* none

Case 5

A 64-year-old female with moderate ID (IQ 54). The medical documents of this patient contained no information about her childhood. She was married at the age of 34, gave birth to a daughter and lived in primitive circumstances with her family. Over the years, the subject visited the general practice clinic where her records

frequently document her reported fear of abuse by men. At the age of 43, she was admitted to the psychiatric hospital for depression and delusions of men stalking her around her home. The initial hospitalization lasted a few months before she returned home. At the age of 49, she was hospitalized again for depression and suicidal behavior, but seemed to improve sufficiently to return home after six months. At age 54 hallucinations, accompanied by suicidal threats, led to permanent anti-depressive medication. She received electro-convulsion therapy (ECT) with promising results and was released at age 55. Within two years, hospitalization was again initiated for similar symptoms. The depression was more severe and ECT did not improve her situation. Autistic symptoms were followed by her first serious attempt at suicide by drowning at age 59. During the next three years, the subject was hospitalized except for short periods at home, where she was prevented from carrying out suicide by jumping under a train. At age 64 she was found drowned in a lake near the mental hospital.

- *Diagnoses in patient documents:* Schizophrenia NUD, Mental Retardation
- *Medication at time of death:* chlorprothixene, chlorpromazine, haloperidol

DISCUSSION

The prevalence of ID and the distribution of its levels in the 1962 study are comparable to subsequent population studies from the same period.³ The 1962 study, designed to be nationally representative, found that the regional distribution followed the preconceptions of lower prevalence in urban areas and higher in rural ones.¹ The high retention rate increased the reliability. The linkage of the study databases was carried out by means of individual identification numbers, which have been proven to be the most reliable.²⁶ Since identification of death by suicide relied on death certificate notations, all external causes of death were closely examined. It is possible that forensic investigation missed suicide cases of deceased with ID. This study, therefore, examined all cases of death from uncertain causes in greater detail. Four cases of suspected suicide were identified among the death certificates, but no support from patient records was forthcoming. Common features in the risk factors for suicide occurred in most of these cases. In the present study, for example, eight out of ten suicide victims

were in contact with mental health services at the time of death.
 These persons had a long history of

TABLE 1. PERSONS WHO COMMITTED SUICIDE DURING THE 35-YEAR FOLLOW-UP PERIOD BY AGE AT THE TIME OF DEATH, SEX, METHOD, DEGREE OF INTELLECTUAL DISABILITY, ASSOCIATED DISORDERS AND COGNITIVE SKILLS AND RESIDENCY AND ANTI-DEPRESSIVE MEDICATION IN A POPULATION-BASED FOLLOW-UP STUDY BETWEEN 1962-1997								
AGE AT TIME OF SUICIDE	SEX	DEGREE OF MR	METHOD	ASSOCIATED DISORDERS	DEGREE OF ID	COGNITIVE SKILLS	RESIDENCY	ANTI-DEPRESSIVE MEDICATION
29.1	Male	Mild	Hanging	Epilepsy, erotic behavior, sleeping disorder, needed help in dressing and toileting	Mild	Unknown	Home	No
32.2	Female	Mild	Drowning in mineshaft	Dyslalia	Mild	Reading and writing poorly	Home, vacation from mental hospital	Yes
33.0	Male	Mild	Drowning in a lake		Mild	Reading and writing	Mental hospital	Yes
33.6	Male	Mild	Intoxication by eating cigarettes	Sleeping disorder	Mild	Reading and writing	Mental hospital	Yes
36.8	Male	Mild	Lying on a railway		Mild	Reading and writing	Mental hospital	Yes
37.3	Female	Mild	Intoxication by taking rifampicin	Epilepsy, sarcoidosis, rectal prolapses	Mild	Reading and writing	Mental hospital	Yes
61.9	Male	Mild	Hanging		Mild	Reading and writing	Mental hospital	No
62.7	Female	Mild	Running under a train		Moderate	Unknown	Home	Yes
64.6	Female	Moderate	Drowning in a lake		Mild	Reading and writing	Missing data	No
65.7	Male	Mild	Hanging				Rest home	No

psychiatric hospital care. Another common denominator was the lack of capacity to handle socially difficult situations or abuse. A different etiological factor was an unexpected incident (car accident) leading to violent reaction. However, the small number of cases does not allow assumptions, which can be generalized to this population.

PREDICTORS OF SUICIDE

Persons at risk of suicide tend to be those suffering from severe psychiatric problems with early onset and resistance to treatment. Six out of ten persons had attempted suicide before completing the act, using a similar method. In four cases, there was a family member who had either committed or tried to commit suicide. Personal awareness of this ultimate solution might increase the risk of considering it. Although the competence to commit suicide may be limited, the suicidal act does not require extensive planning skills nor complicated means. Therefore, any suicide attempts or serious threats should be taken seriously and lead to an examination for depression.

Most likely, four cases had suffered from untreated or undertreated depression, though their symptoms were not always similar to depression symptoms in the general population.¹⁵ These suicides occurred between 1972 and 1989 when institutionalized care was more common than at present. Since then, new antidepressants have been introduced. Judging by modern clinical guidelines, all persons with depressive symptoms were undertreated earlier. One subject started antidepressants two weeks prior to suicide, a particularly high-risk period for suicide also in the general population if not supported by sufficient co-treatment such as counseling.¹⁴ However, symptoms of depression in ID are often expressed in the form of somatic complaints, vegetative manifestation, or regression, making diagnosis of depression difficult.²¹ The dual diagnosis hampers diagnostic thinking, since acquiescence, or irrelevant responding can also be seen as part of ID.^{16,24} Most clinical scales for diagnosing depression in the general population fail to work in ID because a certain level of linguistic skills is required. Fortunately, however, specially designed scales for persons with ID have been developed fairly recently.¹⁶

Abuse has been found to increase the risk of suicide in the general population.¹⁰ It is evident that individuals with ID are especially vulnerable

to abuse, which is encountered in all residential settings.⁸ In one case, hospital staff ignored indications of abuse of a woman because she was married to her putative abuser. Sexual abuse of a person with ID is a very delicate issue and psychopathology can complicate the management of the problem. Depression, however, could be the very first symptom of abuse.

Social support was also minimal in all cases, diminishing the possibility of coping with anxiety and changes. In most families of suicide victims there were other family members with psychiatric disorders.¹²

Communication problems—a possible additional risk of suicide—appeared in one-third of all those studied. People with ID are usually dependent on others. As a result, ageing and loss of parents or siblings confuse and distress those with ID, causing anxiety and depression. Most of the suicide victims in this study had reached a fairly advanced age, which accounts for changes in their health and social environment; in four cases there was an emotional loss before the final fatal act. In summary, high dependence on other people, communication problems, loss of family members and emotional loneliness are undoubtedly increased risk factors for suicide among people with ID. Those working with people with ID need to be constantly aware of any psychiatric disorders underlying behavioral disturbances in order to recognize severe depression, emotional instability and lack of the will to live, possibly leading to either attempted or completed suicide.

Differences in the suicide rates between the two sexes in the general population are not seen in the ID population to a similar degree. In Finland men are three times more likely to commit suicide than women overall,¹⁸ but in this sample women took their life almost as often as men. In the general population women more commonly use drugs in their suicides than occurred in this sample. In the general population in Finland, most suicides are committed under influence of alcohol. In this sample, only one man had alcohol in his blood at the time of the suicide.

Suicide requires the will or decision, the understanding, the means and skills to commit it. Persons with mild ID have cognitive abilities sufficiently high to understand the meaning of suicide as well as the skills needed. Suicides among moderate and severe ID are very rare; e.g., this report found only one case of moderate ID and one report of suicidal behavior with self-

inflicted bodily harm by individuals with severe ID.²⁷

The suicide methods of persons with ID differ from those used by the general population.¹⁸ The five most common methods of suicide among adults in Finland are hanging (33.4%), firearms (20.9%), solids and liquids (19.2%), carbon monoxide poisoning (8.5%), and drowning (6.9%).¹⁸ The method is linked to its availability and the possibility to use it. In the general population, jumping from a height or running into traffic are classified as passive ways of committing suicide when no other means are available such as active methods like shooting or drug poisoning. These latter demand skills and/or contacts to acquire. In the ten cases of this study this characterization holds, since most of the deaths occurred in a passive manner with easy-to-access methods. In only two cases was poisoning a cause of death; namely, both with unusual substances, cigarettes and rifampicin.^{5,25} Since persons with ID have less understanding of medications, any available drug might be seen as a tempting possibility for intended suicide. However, those with ID may have more compulsive behavior, including continual eating, which would complicate the identification of true suicidal intentions.

CONCLUSION

Suicide is unusual among individuals with ID, the rate being one-third of that among the general population. The means of suicide also differ from those used by the general population. However the risk factors for suicide seem to be similar. Mental disorders of persons with ID are difficult to diagnose and treat, complicating preventive treatment. Nevertheless, threats to commit suicide among this vulnerable group still need to be taken very seriously. Any loss or adjustment to new surroundings should be managed with care. Those working with people with ID need to be aware of any psychiatric disorders underlying the behavioral disturbances in order to recognize severe depression, emotional instability and lack of the will to live, possibly leading to either attempted or completed suicide.

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ANNOUNCEMENT

CANDID: CAMBERWELL ASSESSMENT OF NEED FOR ADULTS WITH DEVELOPMENTAL AND INTELLECTUAL DISABILITIES

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The Camberwell Assessment of Need for Adults with Developmental and Intellectual Disabilities (CANDID) is a tool for assessing the needs of people with mental retardation/ intellectual disability and mental health problems. It is a modification of the *Camberwell Assessment of Need*, the most widely used needs assessment for people with severe mental health problems. The **CANDID** assesses met and unmet needs in 25 areas, covering the full range of social, physical health and mental health domains. The perspectives of staff, service users and caregivers are each assessed so that treatment and support planning is fully informed. Two versions have been developed: the CANDID-R is the full version for research use and the CANDID -S is the short version for both clinical and research use. Both versions are included in photocopyable form, along with a training program and full rating guidance.

CANDID has been rigorously developed and tested by a multidisciplinary team at the Institute of Psychiatry in London. It is suitable for use with adults with all levels of mental retardation/intellectual disability, and will be of particular interest to managers, health and social care staff and other professionals who wish to meet their legal requirement to undertake a comprehensive assessment of need.