Young people's contact with healthcare before and after suicidal behaviour

Hans Idenfors
To Frida, Elsa and Signe
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ABSTRACT

Background

Self-harm is a major and growing public health issue among young people worldwide. Self-harm is an important risk factor for suicide, which is one of the leading causes of death for young people. Although suicide rates are declining overall, this trend is not seen in young people. Young people with mental distress and/or suicidal thoughts are reluctant to seek help, and often drop out of treatment initiated after a self-harm episode. Many young people who self-harm have had contact with healthcare before their first self-harm episode, but often for reasons other than suicidal thoughts or psychiatric problems. In this context, physical illness is associated with increased risk for self-harm and suicide among young people. The present thesis investigated how young people perceived the help and support they received before and after an episode of self-harm. A further aim was to map the inpatient somatic healthcare contacts young patients had before an episode of self-harm, and determine any relationship to risk for self-harm and suicide.

Method

Four studies were conducted using qualitative and quantitative methods. Participants were people aged 16-24 years. The definition of self-harm was based on the intentional self-harm criteria in the International Classification of Diseases, tenth revision, which includes all forms of self-harm without ascribing suicidal intent. In the first two studies, 10 respective 9 participants with a first healthcare contact for self-harm were interviewed during 2009-2011. The interviews covered participants’ knowledge and experience of professional care before their healthcare contact for self-harm. Participants were interviewed a second time 6 months later about their experiences with professional care during the period since their initial interview. Qualitative content analysis was used for all interviews. For the next two studies, we selected 16,235 participants with a first hospitalisation for self-harm during 1999-2009 from the Swedish National Inpatient Register. These cases were compared with matched controls to determine the odds of having been admitted with a non-psychiatric
diagnosis during the year preceding the self-harm admission. To assess risk for suicide, data were retrieved from the Swedish Cause of Death Register for all deceased participants until 2013, and group differences were determined using survival analysis.

Results

In the first interview, participants described how they wanted more information on where they could turn for professional help. They also wanted different help-seeking pathways and emphasised the importance of the quality of professional contact. After 6 months, participants stressed the importance of being able to rely on professionals and treatment. Their life circumstances significantly affected their treatment, and practical help was appreciated. The register studies showed that young people admitted for self-harm were more likely to have been hospitalised with symptomatic diagnoses such as abdominal pain and syncope/collapse, and somatic illnesses such as epilepsy and diabetes mellitus type 1. A higher proportion of cases (4.5%; women 2.6%, men 8.8%) died during the study period than controls (0.3%; women 0.2%, men 0.6%) ($p<0.001$). For both cases and controls, a higher proportion of those with a previous somatic admission died from suicide during the study period than those without a somatic admission (cases: 4.2% vs. 2.8%, $p<0.05$). For cases with a somatic admission, the hazard ratio was 1.43 (95% confidence interval 1.04-1.98) compared with those without somatic admissions (controlled for age, sex and psychiatric admission). Survival of cases with a previous somatic admission compared with those without was 98.4% versus 99.2% after the first year, 97.8% versus 98.9% after the second year, and 95.5% versus 96.9% after the tenth year.
Conclusion

These findings suggest that healthcare providers need to find new ways to reach young people at risk for suicidal behaviour. Access to professional help should be easy and direct. Treatment for young people after self-harm should be flexible, and be receptive to input from the patient. The importance of and need for basic practical help should not be overlooked. Somatic healthcare contact provides an opportunity for intervention, particularly as psychiatric problems can manifest as physical symptoms, and physical illness is a risk factor for self-harm and suicide.

Key words

Young people, Self-harm, Interview study, Help-seeking, Treatment experiences, Case-control, Register study, Somatic disorders, Suicide risk
SAMMANFATTNING PÅ SVENSKA

Bakgrund


Syftet med denna avhandling var att undersöka hur ungdomar upplever den hjälp och det stöd de fått före och efter en självskadeepisod. Ett andra syfte var att kartlägga i vilken utsträckning unga patienter vårdats inneliggande på grund av kroppslig sjukdom eller kroppssliga besvär, innan en självskadeepisod, samt relatera detta till risk för självskada och suicid.

Metod

Avhandlingen fokuserar på unga människor i åldern 16 till 24 år, och baseras både på intervjamaterial och registerdata.

I de två första studierna, med tio respektive nio deltagare, rekryterades under 2009 till 2011 unga personer som under denna period först gången kommit i kontakt med sjukvården på grund av självskada. I en första omgång intervjuer, kort tid efter självskadan, utforskade vi vad de visste sedan tidigare om vilken professionell vård man kan få och vilka eventuella tidigare erfarenheter de haft av
professionell hjälp. Sex månader senare utforskade vi deras erfarenheter av professionell hjälp under den gångna sexmånadersperioden. Alla intervjuer analyserades enligt kvalitativ innehållsanalys.


Resultat

Under de intervjuer som genomfördes direkt efter självska beskrev informanterna att de önskat mer information om var de kunnat vända sig för att få professionell hjälp. De ville ha olika alternativa möjligheter för att söka hjälp och betonade hur viktigt det var att träffa en person de kom överens med då de var i kontakt med sjukvården. I uppföljningsintervjuerna betonade de vikten av att kunna förlita sig på att personal var professionell och att de erhöll rätt behandling. Deras livsomständigheter, med boende och möjligheter att färdas till sjukvården, hade stor påverkan på den behandling de fick och praktisk hjälp var mycket uppskattad.

I de två registerstudierna fann vi att de som varit inlagda för självska hade umkring sex gånger större sannolikhet för att tidigare ha varit inlagda på sjukhus med diagnoser som endast beskriver vilka symptom de haft, till exempel buksmärta och svimning. De hade också cirka tre gånger större sannolikhet för att ha varit inlagda med sjukdomar som inte var psykiatriska, såsom epilepsi och diabetes mellitus typ 1.

En större andel av de som varit inlagda för självska avled på grund av suicid (2,9 %) under studieperioden jämfört med kontroller (0,08 %), $p<0,001$. Även bland de med tidigare kroppsliga vård tillfällen avled en större andel på grund suicid under studieperioden jämfört med de utan sådana vård tillfällen. I gruppen
som varit inlagd för både självska och kroppslig orsak avled 4,2 %, jämfört med 2,8 % i gruppen med självska men utan kroppsliga vårdtillfällen, $p<0,05$, med en hazard ratio på 1,43 (95 % konfidensintervall 1,04 - 1,98, kontrollerat för ålder, kön, och psykiatrisk inläggning).

**Slutsats**

ORIGINAL STUDIES


# ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full form</th>
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<tbody>
<tr>
<td>CI</td>
<td>Confidence interval</td>
</tr>
<tr>
<td>DSH</td>
<td>Deliberate self-harm</td>
</tr>
<tr>
<td>DSM-5</td>
<td>Diagnostic and Statistical Manual of Mental disorders, fifth edition</td>
</tr>
<tr>
<td>HR</td>
<td>Hazard ratio</td>
</tr>
<tr>
<td>ICD-10</td>
<td>International Statistical Classification of Diseases and Related Health Problems, tenth revision</td>
</tr>
<tr>
<td>IQR</td>
<td>Interquartile range</td>
</tr>
<tr>
<td>NSSI</td>
<td>Non-suicidal self-injury</td>
</tr>
<tr>
<td>OR</td>
<td>Odds ratio</td>
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INTRODUCTION

History

Views about suicide and how people with suicidal problems should be treated have changed over time. In antiquity, suicide was described as a means to maintain honour after military defeat, and as loyalty among subjects and wives. During the Roman imperial period, suicide was tolerated but was illegal for those accused of crimes, soldiers and slaves. Suicides due to mental disorders were also known in antiquity, but were seen as a moral rather than a medical problem. Among early Jews and Christians, suicide through martyrdom appears to have been frequent and increased in some periods, which resulted in attempts to control the desire for martyrdom. Christianity began to oppose suicidal behaviour and in CE 563, suicide was condemned by the church. It was equated with murder and associated with three penalties: confiscation of property, degradation of the corpse, and refusal of burial in consecrated ground. Those deemed insane were exempt from criminal considerations.

During the middle ages, despair was seen as a dangerous suicidal symptom. Despair was thought to be a spiritual problem, and helping the sufferer resist this attack from the Devil was a task for a priest. Confession was a widely used treatment, along with strategies such as prescribing ‘busyness’ for sloth and giving comfort. However, it was also recognised that mental and emotional disorders could lead to suicide. Melancholy was commonly described and was seen as either a vice leading to the sin of suicide or a mental and emotional disorder caused by a humoral imbalance. Someone deemed to have excessive melancholic humours needed to see a physician rather than a priest. In the 17th century, a sufferer might be told to keep sober and to trust in God.

The Renaissance and the Reformation represented a moderation in this view of suicide, and a more tolerant perspective of suicide developed during the 16th and 17th centuries. Treatment of those at risk for suicide (mainly melancholics) was described, with sufferers advised to avoid solitude and heights, and to be careful when handling knives. The leaders of the Enlightenment questioned the Christian view of suicide, leading to a more secular approach. By the early 19th century, suicide began to be
considered less as moral and religious failings, and more as a social and medical problem. Dealing with suicide became the responsibility of psychiatry. Some people, called alienists, attributed suicide almost exclusively to insanity. They acted to protect suicidal people and their families from religious and legal persecution, and urged early intervention for suicidal persons with confinement and institutional treatment. Early methods of restraint were prohibited during the 19th century, and other means of preventing suicides in asylums developed including strict surveillance and use of sedatives.

During the 19th century, suicide was studied as a social problem. Two major approaches were developed to understand suicide: a statistical-sociological approach and a medico-psychiatric approach. A standard view emerged in which hereditary factors, mental illness, and social factors were seen as contributing to the problem of suicide. By the beginning of the 20th century, suicide was more often considered a social disgrace than a sin.

Suicide and suicide attempts were decriminalised in Sweden in 1864, Finland in 1910, England and Wales in 1961, Canada in 1972 and Ireland as late as 1993. Suicide and suicide attempts still remain an offence in several countries such as India and Ghana.

Self-harm, history and definitions

For a long time, suicide attempts were seen as failed suicides. However, in Victorian England it was noticed that people who attempted suicide had different characteristics than those who died by suicide; they were younger, more impulsive and more often female. Suicide attempts were also connected more to drunkenness than insanity. Many professionals claimed these people did not wish to kill themselves, but acted to achieve sympathy. Such behaviour was to be punished, not rewarded, although it was considered difficult to distinguish ‘sham’ from ‘real’ suicide attempts. The view that suicide attempts were failed suicides was still common in the mid-20th century. More interest was directed to the physical consequences of the suicide attempt than to the circumstances leading to the self-destructive act.

In the 1950s, Stengel began research with patients who had attempted suicide, leading to new understanding. He found that there was a social element in many suicide attempts, often including an appeal to other
people, and called this the appeal function\textsuperscript{10}. The need for psychological treatment was highlighted during the late 1950s and early 1960s\textsuperscript{8}.

In 1965, Kessel introduced the term \textit{self-poisoning} to replace suicide attempt, as he noted that many of those alleged to have made a suicide attempt actually had no suicidal intent\textsuperscript{11}. He found that suicidal intent was often difficult to ascertain, and that there were small differences in the risk of death in those with an expressed intention to die compared with those without such expressed intent\textsuperscript{11}. He concluded that all cases of self-poisoning warranted psychiatric examination\textsuperscript{11}. Furthermore, he noted how self-poisoning had increased during the past 20 years, especially among young women\textsuperscript{12}. During the 1980s, models of emotional self-regulation started to become dominant\textsuperscript{8}.

In 1969, Kreitman proposed the term \textit{parasuicide} to replace the terms deliberate self-poisoning and deliberate self-injury, as these terms did not link to suicide or take the person’s intention into account\textsuperscript{13}. Parasuicide became widely used in the research community, but its use decreased during the 1990s because of varying definitions and semantic problems\textsuperscript{14}. Many other definitions, such as self-mutilation, self-injury and pseudocide were also used during the second half of the 20\textsuperscript{th} century\textsuperscript{8}.

Morgan introduced \textit{deliberate self-harm} (DSH) in 1975 as a descriptive term free from implied motive, and including both physical injury and self-poisoning\textsuperscript{15}. It was introduced as the term parasuicide was seen to imply a resemblance to suicide\textsuperscript{15}. Since then, DSH has been used with different meanings in different parts of the world. In North America it has been used to indicate bodily harm without suicidal intent\textsuperscript{16}, and in Europe and Australia, DSH includes self-poisoning and self-injury without ascribing suicidal intent\textsuperscript{17}. It has been suggested that it is more practical to describe the behaviour first (self-harm) and clarify the suicidal intent later\textsuperscript{18}, as suicidal intent is not easy to determine\textsuperscript{19}.

More recently, DSH has been replaced by \textit{self-harm}, as the previous term could be considered judgemental and because it is not always easy to say that an action was deliberate\textsuperscript{20}. This is similar to the definition \textit{intentional self-harm} used in the International Classification of Diseases, tenth revision (ICD-10) (diagnoses codes X60-X84)\textsuperscript{21}, which includes all forms of self-harm without ascribing suicidal intent.
The term non-suicidal self-injury (NSSI) has also been used in North America, and defined as direct and deliberate destruction of one’s own body tissue in the absence of lethal intent. It was suggested for inclusion in the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders, fifth edition), but has also been questioned. The prevalence of self-harm and NSSI has been found to be quite similar.

The European definition of self-harm is used throughout this thesis (Figure 1).

**Figure 1.** The associations between some of the terms used to describe suicidality. Self-harm is based on the European definition, which includes all forms of self-harm without ascribing suicidal intent

**Epidemiology**

Suicide represents a large part of the global disease burden, particularly for young people. This is a serious issue, as there has been no decline in suicide rates in this age group, in contrast to a decline in other age groups in most Western countries.

There is a close relationship between self-harm and suicide. It is estimated that about 25% of all suicides are preceded by self-harm in the previous year, making self-harm the clearest single risk factor for suicide. There is also a high risk that young people who have harmed themselves repeat acts of self-harm.

Self-harm primarily affects young people aged 15-24 years, with a lifetime prevalence ranging from 9-26%, and a past year prevalence from 3-8%. The lifetime prevalence among Swedish 17 year-old students was estimated at 17%. Self-harm among young people has increased during
Introduction

recent years\textsuperscript{25,35-38}. It is not clear why, but several explanations have been put forward, including increased stress for adolescents, more use of alcohol and drugs, easier access to medication and social transmission of self-harm behaviour\textsuperscript{39}. However, there are now reports that rates have started to stabilise\textsuperscript{23}.

Self-harm is more common among young women\textsuperscript{33,37}, whereas suicide is more common among young men\textsuperscript{40,41}. This pattern is evident worldwide, with the exception of countries such as China and India, where suicide is more common among women\textsuperscript{42}.

Self-harm entails substantial costs for health and social services, and patients with multiple self-harm episodes have higher levels of resource use\textsuperscript{43}. Psychiatric care constitutes the largest proportion of the cost, whereof inpatient care is the most resource-demanding. The indirect cost of self-harm for society is likely to be significant given the high prevalence of self-harm in the community, although it is difficult to estimate the exact cost due to the multifaceted nature of self-harm\textsuperscript{20}.

Reasons and risk factors for self-harm

No single factor can explain why young people harm themselves. It is thought to result from an interaction between genetic, social, psychological and psychiatric components\textsuperscript{39}. However, there is a wide array of identified risk factors and possible explanations.

Mental health problems are the most prominent risk factor, estimated to be present in 87-90\% of young suicide victims\textsuperscript{42} and in 80\% of young people presenting to hospital for self-harm\textsuperscript{44}. Risk for self-harm and suicide is also associated with specific mental disorders such as depression, substance misuse, attention-deficit hyperactivity disorder (ADHD), anxiety, conduct disorder and antisocial behaviour\textsuperscript{44,45}.

Another important risk factor is hopelessness, which has also been associated with the level of suicidal intent\textsuperscript{46}. Additional risk factors include trauma, interpersonal difficulties, low self-esteem, bullying, poor parent-child attachment, concerns about sexual orientation, social isolation, impulsivity and family history of suicide or self-harm\textsuperscript{39}. Socioeconomic disadvantage has also been associated with risk for self-harm\textsuperscript{47}.

Comprehensive theories have been developed that incorporate known risk factors. One such theory to explain suicidal behaviour is the
interpersonal theory of suicide. This theory proposes that thwarted belongingness and perceived burdensomeness in combination lead to passive suicidal ideation, which leads to suicidal desire if there is also hopelessness about the future. According to this theory, acquired capability for suicide arises from habituation in relation to physically painful or fear-inducing experiences. This leads to a lowered fear of death and consequently, suicidal intent. Increased pain tolerance is the last step needed before suicide or a near-lethal suicide attempt. Another theory is the cry-of-pain model, which describes how suicidal behaviour arises from a situation that has three components: defeat, no escape and no rescue. This theory perceives the suicidal act as a cry of pain, rather than the earlier prevailing explanation that it is a cry for help.

Self-reported motives for self-harm include a wish to die, to get relief from a terrible state of mind or to punish oneself.

Young adulthood

Young people are of particular importance when studying self-harm for a number of reasons. As mentioned, self-harm is most common among young people, and 16 years is the most common age for a first episode of self-harm. Adolescence is a vulnerable age, particularly as it also marks the onset of many different psychiatric disorders. It is also an age where people tend to be more affected by peer influence, which may sometimes lead to health-risk behaviours such as substance abuse. The onset of puberty in itself has also been shown to be related to the onset of substance abuse.

When people reach late adolescence and young adulthood, they are expected to start their own independent life, including leaving their parents and making decisions about employment or higher education. Such times of change can put considerable pressure on a young person.

Treatment

Treatment of people who have self-harmed should be tailored to individual needs. If associated conditions such as depression or anxiety disorders are present, they should be treated with appropriate psychological, pharmacological or psychosocial interventions. Psychological interventions that are specifically structured to reduce self-harm are recommended, but there is less evidence to support the use of
drug treatments. Several interventions have been designed to reduce the risk for self-harm among young people, such as attachment-based family therapy (ABFT). A review of intervention studies found that mentalisation-based therapy (MBT) and integrated cognitive behaviour therapy (iCBT) showed the strongest effects. A more recent study found that dialectical behaviour therapy adapted for adolescents (DBT-A) showed a long-term reduction in self-harm and a rapid decline of suicidal ideation.

Help-seeking

Young adults, especially men, who experience mental distress are reluctant to seek help and this is even more pronounced among those with severe suicidal ideation. It has also been reported that half to one-third of adolescents who had self-harmed did not seek help for this behaviour. The presence of suicidal ideation was associated with even poorer help-seeking behaviour. When those who made suicide attempts were distinguished, the proportion of those who sought help was even smaller, with a previous study showing that two-thirds of male adolescents had no healthcare contact before their suicide attempt.

Adolescents with self-harm episodes who sought help primarily turned to friends and family. However, multiple episodes of self-harm have been associated with less ability to talk to friends and family. In general, young adults do not consider general practitioners to be a source of help for mental health problems. Efforts have been made to enhance access to primary care services for young people in crisis, but with poor results. The same can be said about interventions designed to increase help-seeking behaviour in young people who self-harm.

It has been suggested that mental health services need to be better designed to meet young people’s specific needs and preferences.

Help-seeking for non-psychiatric causes

Most people who intentionally harm themselves had contact with health services before they harmed themselves. However, young people often seek care for non-suicidal or non-psychiatric causes, despite having suicidal thoughts. This has been identified among junior high school students who self-harmed and sought help from their school nurse, as only 10% of those with frequent contacts discussed their psychological
distress. A similar situation was found among young people who had been in contact with primary care during the years before they killed themselves, where just over half had sought help for psychological disorders. This might be linked to the fact that symptoms related to psychological disorders, such as chest pain caused by panic disorder, may be interpreted as primarily physical, preventing an important suicide risk assessment. Severe depression increases suicide risk, and may lead to physical symptoms in affected adolescents. There is also a clear link between depression and physical illness. A Danish register study reported that young people who had been in contact with medical services had a higher risk for a subsequent suicide attempt.

Physical conditions

It has been documented that various physical illnesses lead to an increased risk of self-harm, although these studies mainly included adult samples. However, an increased risk for self-harm in young people has been shown for several conditions, including epilepsy, diabetes mellitus type 1 and asthma.

Physical illness has been associated with an increased risk for suicide among adults with cancer, diabetes, multiple sclerosis, stroke, myocardial infarction, allergy, epilepsy and chronic pain. The association between physical illness and suicide risk is not as established in young people, although studies have confirmed this link for asthma, epilepsy and multiple sclerosis. However, for other conditions, such as diabetes mellitus type 1, an association has only been shown for self-harm, with no significant association found for suicide.

Adherence to care

Young people show low compliance with psychiatric treatment initiated after self-harm. Many do not attend planned outpatient psychiatric treatment after their initial assessment, or withdraw from treatment during the first 18 months. There is also a lack of clinical interventions aimed at improving this poor treatment adherence. However, more recent interventions have been successful in increasing treatment adherence for adolescents following emergency visits due to self-harm. One such intervention is crisis therapy sessions to motivate for treatment, which improved linkage to outpatient psychiatric
treatment\textsuperscript{102}. An enhanced therapeutic assessment improved treatment engagement, but did not reduce the number of subsequent self-harm episodes\textsuperscript{103}. An intervention using a problem-solving format to enhance compliance found increased treatment adherence after controlling for barriers to services in the community\textsuperscript{104}. A review of intervention studies to prevent self-harm concluded that addressing commitment to treatment is a key factor for consideration in future interventions\textsuperscript{58}. 
AIMS

The present thesis aimed to investigate how young people perceived the help and support they received before and after an episode of self-harm. We also mapped young patients’ somatic healthcare contacts before an episode of self-harm and relate this to risk for self-harm and suicide.

Specific aims:

- To explore young people’s experiences, views and awareness of professional help, before their first healthcare contact for self-harm (study I).

- To explore young people’s perceptions of care and support during a 6-month period following their first contact for self-harm (study II).

- To investigate the extent to which young people received non-psychiatric inpatient care during the year before their first hospital admission for self-harm. We hypothesised that a higher proportion of individuals admitted for self-harm had previous non-psychiatric admissions than a control group (study III).

- To test two hypotheses: that there would be a higher proportion of suicides among individuals admitted for self-harm than in a control group; and that there would be more suicides among subjects with prior somatic inpatient admissions than among those with no such admissions (study IV).
METHODS

Studies I and II

A qualitative research design was used as it best suited our investigation of young people’s perspectives.

Procedure

Participants were recruited from March 2009 until March 2011. The study population comprised people aged 16-24 years who had contacted healthcare for the first time owing to self-harm. We chose the first contact as we wanted to investigate experiences relating to self-harm before that contact (study I) and initial experiences of care after self-harm (study II). Staff working at the emergency department, psychiatric emergency services, child and adolescent psychiatry clinic, and a psychiatric ward in a catchment area in northern Sweden identified suitable patients and invited them to participate in the study. We included young people who had harmed themselves both with and without suicidal intent, consistent with the ICD-10 criteria for intentional self-harm (X60-X84)\(^2\).

Participants

Seventeen eligible patients were identified for potential inclusion. There were challenges in keeping all medical staff across all recruitment sites informed and aware of the study, meaning many potential participants might have been missed and not approached for inclusion. Five of the 17 patients declined to participate and two were discharged before they could be approached about participation in the study. In total, 10 patients were recruited for the initial interviews (study I). Six months later, nine of these participants took part in a follow-up interview, with one person declining to participate (study II). The first interviews were conducted from April 2009 to March 2011, and follow-up interviews from October 2009 to September 2011.
Table 1. Study participants (studies I and II)

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<th>Age (years)*</th>
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<th>Recruitment source</th>
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<td>Emergency department</td>
<td>Self-poisoning</td>
<td>Counselling, social services</td>
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<td>22</td>
<td>Male</td>
<td>Emergency department</td>
<td>Self-poisoning</td>
<td>Counselling, medication</td>
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<td>17</td>
<td>Female</td>
<td>Child and adolescent psychiatry</td>
<td>Cutting/attempted jump</td>
<td>Counselling, medication</td>
</tr>
<tr>
<td>23</td>
<td>Female</td>
<td>Psychiatric emergency services</td>
<td>Cutting</td>
<td>Counselling, social services, medication, inpatient care</td>
</tr>
<tr>
<td>20</td>
<td>Female</td>
<td>Psychiatric emergency services</td>
<td>Self-poisoning</td>
<td>Declined follow-up interview</td>
</tr>
<tr>
<td>17</td>
<td>Female</td>
<td>Child and adolescent psychiatry</td>
<td>Cutting/self-poisoning</td>
<td>Counselling, medication</td>
</tr>
<tr>
<td>21</td>
<td>Female</td>
<td>Psychiatric emergency services</td>
<td>Cutting</td>
<td>Counselling, medication</td>
</tr>
<tr>
<td>20</td>
<td>Male</td>
<td>Psychiatric emergency services</td>
<td>Cutting/hitting</td>
<td>Counselling, medication</td>
</tr>
<tr>
<td>24</td>
<td>Female</td>
<td>Psychiatric emergency services</td>
<td>Cutting</td>
<td>Counselling, medication</td>
</tr>
<tr>
<td>19</td>
<td>Male</td>
<td>Psychiatric ward</td>
<td>Self-poisoning</td>
<td>Counselling, inpatient care</td>
</tr>
</tbody>
</table>

* Age at self-harm episode

Ethical considerations

The study was approved by the Regional Ethical Review Board in Umeå, Sweden (Dnr. 09-001M). Staff at the recruitment sites provided potential participants with brief information about the study and asked if the interviewer could contact them. Participants were informed by the interviewer that participation was voluntary and they could terminate the interview at any time without giving a reason and could choose not to answer any of the questions. They were also informed about the confidentiality of the study. All participants provided written informed consent before their first interview. The interviewer was a physician and resident in psychiatry with several years’ experience in psychiatric work, but was not the doctor responsible for the patient, nor had he met any of the patients before recruitment.

Interviews

The first interviews were conducted as soon as possible after the participant’s contact. These interviews focused on past experiences of professional care, knowledge about available help and barriers to seeking help. The follow-up interviews, conducted 6 months later, focused on participants’ experiences of professional care during that 6-month period, including shortcomings, positive aspects and barriers. The
interviewer had no access to medical records and obtained all information from the participants.

The interviews were semi-structured with an interview guide covering the above topics. Open-ended questions were used to encourage participants to speak freely. Any unexpected or interesting information that emerged during the interviews was explored further. The participants chose where the interviews took place. Many different locations were chosen, including home, the clinic, a museum and outdoors. One participant could only be reached by phone for the follow-up interview, but this was a viable alternative as the interviewer had met him during his first interview. Nine of the initial interviews lasted 27-50 minutes, and one interview lasted 14 minutes. The follow-up interviews lasted 22-41 minutes. Interviews were digitally recorded and subsequently transcribed verbatim in Swedish.

**Analysis**

The interviews were systematically analysed using qualitative content analysis. The interview transcripts were first read thoroughly to get an overall view. The text was then divided into meaning units consisting of words, sentences or paragraphs related to each other by content and context. Each meaning unit was condensed to shorten the text without losing any information, and assigned a code. Next, these codes were joined into categories, based on similarities and dissimilarities. All steps in the analysis were continuously reviewed in relation to the original interview texts. Common themes were constructed from the underlying meaning in the categories.

Four of the initial interviews were coded separately by the first and last authors to verify that the coding was performed in a similar way. The rest of the coding was performed by the first author and verified by the last author. The process of creating categories and themes was conducted by the first and last authors in a series of meetings and discussions. OpenCode software was used for the analysis of the follow-up interviews.
Studies III and IV

Participants and procedure

Studies III and IV used a nested case-control design. First, we selected all people aged 16-24 years with a first admission for self-harm (ICD-10 diagnoses X60-X84, intentional self-harm) during the period 1999-2009 from the Swedish National Inpatient Register. The register has high validity for most diagnoses. To allow investigation of the time before first admission for self-harm we excluded those with prior self-harm admissions (1987-1999) and those with self-harm admissions from when they were younger than 16 years old. In total, 16,235 cases were included in the study.

Second, we randomly selected two controls for each case, matched by sex, age and home municipality, from the Total Population Register. The age of the control group ranged from 15-25 years, as matching was based on year of birth and not exact birth date. In total, the study included 48,705 participants (16,235 cases and 32,470 controls), and 68.5% were female. The median age at inclusion was 19 years (interquartile range [IQR] 18-22 years). Women had a median age of 19 years (IQR 17-21 years) and men had a median age of 20 years (IQR 18-22 years).

In the third stage, we registered the main ICD-10 diagnosis from the Swedish National Inpatient Register for all admissions during the year before the cases’ first self-harm admission. The investigation time was limited to 1 year to ensure a more direct correlation between self-harm and previous admissions.

For the fourth study, we linked our data with the Cause of Death Register and recorded all deaths to the end of 2013. Cause of death diagnoses were based on the ICD-10. Follow-up time varied from 4 years (end of 2009) to 15 years (beginning of 1999), with an average follow-up of 9 years and 18 days. Participants were censored if they were still alive at the end of the study or if they died from a cause of death other than suicide. The Cause of Death Register is nationwide and participants were only lost from follow-up if they did not remain Swedish citizens. In an investigation of suicides and accidents that included the Swedish Cause of Death Register, few cases were reclassified (except for events due to undetermined intent). When accessing data from the register, we found five controls had deceased
before the date of inclusion, meaning they were excluded from the study, leaving 32,465 controls (48,700 participants in total) for the fourth study.

**Table 2. Registers used in study III and IV**

<table>
<thead>
<tr>
<th>Register</th>
<th>Swedish name</th>
<th>Data</th>
<th>Used in studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Population Register</td>
<td>Registret över totalbefolkningen</td>
<td>Sex, age, home municipality</td>
<td>Study III and IV</td>
</tr>
<tr>
<td>Swedish National Inpatient</td>
<td>Slutenvårdsregistret</td>
<td>Admissions, with main diagnosis</td>
<td>Study III and IV</td>
</tr>
<tr>
<td>Cause of Death Register</td>
<td>Dödsorsaksregistret</td>
<td>Cause of death, date of death</td>
<td>Study IV</td>
</tr>
</tbody>
</table>

**Ethical considerations**

All data were anonymised before delivery to us. As patients were not identified, they were not asked about participation in the study. The study was approved by the Regional Ethical Review Board in Umeå, Sweden, Dnr 2010-407-31M.

**Statistical analyses**

Differences in age between men and women, and differences in number of admissions between cases and controls were calculated using independent-samples $t$-tests. Odds ratios (ORs) were used to calculate the probability of being admitted to compare cases and controls, and men and women.

In the fourth study, we used survival analysis for group comparisons. The Kaplan-Meier method was used to estimate survival as a function of time, with log-rank tests to analyse survival differences. Cox regression analysis of factors potentially related to survival was performed to identify factors that might jointly have had a significant influence on survival. The significance level was set at 0.05. We used SPSS Version 23 for the analyses.
RESULTS

Study I

Six categories and two themes were constructed from the first interviews that focused on professional care and help-seeking before self-harm (Figure 2).

| A need for a more flexible, available and varied healthcare | • Lack of knowledge about where to turn  
| • Need for many possible routes to professional care  
<table>
<thead>
<tr>
<th>• The importance of immediate help</th>
</tr>
</thead>
</table>
| A struggle to be independent and yet being in need of reliable support | • The importance of family and friends when overwhelmed by emotional storms  
| • The importance of the perceived quality of contacts  
| • One should not communicate distress |

Figure 2. Themes (left) and categories (right) in study I, constructed from interview data using qualitative content analysis

The first theme, “A need for a more flexible, available and varied healthcare” reflected participants’ lack of knowledge about where to turn when they experienced emotional distress. They did not know much about healthcare facilities and had little knowledge of how to make contact. They searched the Internet for information, but had difficulty finding useful information on local healthcare services. Participants reported different preferred ways of making contact; for example, by phone, email or a visit in-person. The time factor was of particular importance.

The second theme, “A struggle to be independent and yet being in need of reliable support” reflected how participants received support from family and friends who also helped them find professional help. It was important for participants to meet someone they had confidence in, who listened to them and treated them seriously. Referrals were perceived as negative, but could also be positive if combined with efforts to facilitate a smooth transfer. Participants mentioned various reasons why they did not ask others for help, including prejudice about psychiatric problems, fear of being a burden to others or the perception that it was their own responsibility to get better.
Study II

From the second interviews focused on professional care after self-harm, we extracted three themes and six categories (Figure 3).

| Am I really in good hands?                  | • Speaking the same language  
|                                          | • Having trust in the care of professionals  
| Help should match life circumstances       | • The influence of structural factors on contact  
|                                          | • In need of practical help  
| Making yourself better                     | • Personal input  
|                                          | • Asking for help  

Figure 3. Themes (left) and categories (right) in study II, constructed from the interviews using qualitative content analysis

The first theme, “Am I really in good hands?” reflected how participants wanted to meet someone they had confidence in, and who listened to them in a non-judgmental manner. They wanted someone who was familiar with their problems, read the medical records before consultation and kept promises. The prescription of medication without proper evaluation led to insecurity. Considered prescription-making was seen as taking the problem seriously. Participants reported feelings of abandonment and adverse outcomes when they were left without arrangements for scheduled appointments, without a formal referral when changing to a new contact or when their treatment ended too early. Participants also noted communication problems and delays in transfers, both within healthcare services and between healthcare and other authorities.

The second theme, “Help should match life circumstances” discussed how the location of health services and access to public transportation affected participants’ options in accessing treatment. They might lack a driver’s license and might also have difficulties using public transportation. Some possible solutions put forward were home visits, assistance getting to the clinic and contact by phone. Participants also suggested a phone reminder the day before an appointment. Financial problems might also prevent participants from buying prescribed medicine, as they did not know whether social welfare would cover the cost. Other structural problems were long waits for specific
investigations, and a change to a new clinic because of a change of residence or because they turned 18 years old. Participants appreciated practical help, such as financial aid, help finding employment or an apartment, help with household tasks and transportation assistance for their healthcare appointments. Everyday structure and interaction with others was also appreciated. Participants suggested that healthcare staff could support them at home, and some also wished for inpatient treatment for more support. At the same time, participants described the difficulties they had in coping with a stay in the adult psychiatric ward due to its confined environment. Participants also described how family and friends gave support and helped arrange contacts with professionals. Some participants had moved back with their parents as they were unable to manage on their own.

The third theme, “Making yourself better” addressed how participants took an active part in their treatment and tried to influence its direction. This was important as treatment was perceived as less effective when it did not align with their needs. Participants expressed desire to manage on their own and tried to manage without help. Some felt that they did not need psychiatric care, but in some cases this feeling changed during the 6-month study period. Participants also discussed how they did not want to talk about their problems out of consideration for relatives. They saw it as their own responsibility to get better. Other participants wished for more frequent contact with healthcare services and medication for emergency use.

Study III

The main result of study III was that the odds of having been admitted were about eight times higher for cases than for controls during the year preceding the cases’ first self-harm admission. There were four main diagnostic groups. The first group comprised somatic diagnoses (ICD-10 Chapters I-IV, VI-XIV and XVII) excluding mental disorders, pregnancy-childbirth, injuries, symptoms and signs, and influencing factors. In this group, 6.0% of cases had been admitted, compared with 2.1% of controls (OR 2.9, 95% CI 2.6-3.2). The second group, symptoms and signs comprised one ICD-10 chapter (Chapter XVIII), but had many admissions (cases 4.0%; controls 0.7%). In this group, the odds of having been admitted were six times higher in cases than in controls (OR 6.0, 95% CI 5.2-7.0). The injury, poisoning and certain other consequences of
Results

The external causes group had 5.3% of cases with admissions, compared with 0.9% of controls (OR 6.4, 95% CI 5.6-7.3). The factors influencing health status and contact with health services group had 2.0% of cases with admissions, compared with 0.2% of controls (OR 10.7, 95% CI 8.1-14.0).

When controlled for psychiatric admission, sex and age, the ORs were: somatic causes 2.6 (95% CI 2.3-2.9), symptoms and signs 4.9 (95% CI 4.2-5.8), injury and poisoning 5.4 (95% CI 4.7-6.2), and influencing factors 6.4 (95% CI 4.8-8.5).

The numbers of admissions per 10,000 people in the main diagnostic groups and the most common diagnoses in each group are listed in Table 3. When comparing cases with controls on the number of admissions in each diagnostic group, cases had significantly more admissions in all four groups ($p<0.001$, $t$-values 15.1-21.6).

Table 3. Number of admissions per 10,000 people in the main diagnostic groups and the four most common diagnoses in each group

<table>
<thead>
<tr>
<th>Diagnostic group with the four most common diagnoses (number of admissions)</th>
<th>Admissions per 10,000 people</th>
<th>Cases</th>
<th>Controls</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Somatic causes</strong></td>
<td>920</td>
<td>273</td>
<td></td>
</tr>
<tr>
<td>1. Type 1 diabetes mellitus (176)</td>
<td>85</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>2. Acute appendicitis (135)</td>
<td>40</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>3. Chronic diseases of tonsils and adenoids (126)</td>
<td>37</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>4. Epilepsy (81)</td>
<td>41</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td><strong>Injury and poisoning</strong></td>
<td>630</td>
<td>99</td>
<td></td>
</tr>
<tr>
<td>1. Intracranial injury (247)$^a$</td>
<td>97</td>
<td>28</td>
<td></td>
</tr>
<tr>
<td>2. Poisoning by other/unspecified drugs, medicaments and biological substances (117)</td>
<td>68$^b$</td>
<td>2$^c$</td>
<td></td>
</tr>
<tr>
<td>3. Poisoning by psychotropic drugs, not elsewhere classified (65)$^b$</td>
<td>39</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>4. Fracture of lower leg, including ankle (62)</td>
<td>25</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td><strong>Symptoms and signs</strong></td>
<td>561</td>
<td>77</td>
<td></td>
</tr>
<tr>
<td>1. Abdominal and pelvic pain (641)</td>
<td>293</td>
<td>51</td>
<td></td>
</tr>
<tr>
<td>2. Convulsions not elsewhere specified (114)</td>
<td>64</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>3. Syncope and collapse (84)</td>
<td>43</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>4. Pain in throat and chest (54)</td>
<td>25</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td><strong>Influencing factors</strong></td>
<td>230</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>1. Medical observation and evaluation for suspected diseases and conditions (236)$^d$</td>
<td>134</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>2. Examination and observation for other reasons (54)</td>
<td>24</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>3. General examination and investigation of persons without complaint and reported diagnosis (19)</td>
<td>11</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>4. Other problems related to primary support group, including family circumstances (18)</td>
<td>11</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

$^a$ Of which, concussion = 214. $^b$ Not classified as intentional. $^c$ Six admissions: four not classified as intentional, two classified as intentional. $^d$ Of which, mental and behavioural disorders = 109, toxic effect from ingested substance = 63.
Asthma was not one of the four most common somatic diagnoses, and admissions with a main diagnosis of asthma were not common (n=38). However, the difference between cases and controls was notable, with 21 asthma admissions per 10,000 people among cases, compared with one admission per 10,000 people among controls.

Sex-stratified analyses produced a similar pattern, with higher odds of admission among cases compared with controls. The odds of having been admitted with a main symptomatic diagnosis were higher for women than for men. Among cases, 4.6% of women had been admitted compared with 2.8% of men (OR 1.66, 95% CI 1.37-2.00), and in controls, 0.8% of women had been admitted compared with 0.4% of men (OR 2.11, 95% CI 1.50-2.97).

The odds of having been admitted with a main somatic diagnosis were also higher for women than for men (cases: 6.3% of women vs. 5.3% of men, OR 1.18, 95% CI 1.02-1.37; controls: 2.4% of women vs. 1.7% of men, OR 1.44, 95% CI 1.21-1.71). Conversely, the odds of having been admitted for injury and poisoning were lower for women than men (cases: 4.4% of women vs. 7.3% of men, OR 0.59, 95% CI 0.51-0.68; controls: 0.7% of women vs. 1.2% of men, OR 0.57, 95% CI 0.45-0.72). There were no significant sex differences in the influencing factors diagnostic group.

**Study IV**

In the case group, there were 451 deaths per 10,000 people compared with 33 deaths per 10,000 people in the control group (log rank-test, $\chi^2 (1) = 1129$; $p<0.001$). There were also more suicides (including events of undetermined intent) among cases, with 293 suicides per 10,000 people compared with 9 per 10,000 people in the control group (log-rank test, $\chi^2 (1) = 866$; $p<0.001$).

As seen in study III, 3.4% of participants had somatic admissions during the year preceding the cases’ self-harm admissions (6% of cases, 2.1% of controls). There were more suicides among those with somatic admissions (264 suicides per 10,000 people, n=44 out of 1665) compared with those without (98 per 10,000 people, n=460 out of 47,035) (log-rank test, $\chi^2 (1) = 44$; $p<0.001$).
Results

Figure 4. Suicides per 10,000 people in the case and control groups. Both the case and control groups had significantly more suicides if previously admitted for somatic causes.

The difference was also significant when cases and controls were analysed separately (Figure 4). Cases with a previous somatic admission had 423 suicides per 10,000 people (n=41 out of 969) compared with 285 suicides per 10,000 people for cases without a previous admission (n=435 out of 15,266) (log-rank test, \( \chi^2 (1) = 6; p=0.013 \)). Among controls with a previous somatic admission, there were 43 suicides per 10,000 people (n=3 out of 696) compared with 8 per 10,000 people for those without (n=25 out of 31,769) (log-rank test, \( \chi^2 (1) = 10; p=0.002 \)). However, overall there were few suicides among the controls (three among those with a previous somatic admission, and 25 among those without).

For all participants, the hazard ratio (HR) for suicide was 1.51 (95% CI 1.11-2.07; controlled for case/control group, age, sex and psychiatric admission). When focusing on cases, those with a somatic admission had a HR of 1.43 (95% CI 1.04-1.98) compared with those without a somatic admission (controlled for age, sex and psychiatric admission). The survival rate of cases with a previous somatic admission compared with those without was 98.4% versus 99.2% after the first year, 97.8% versus 98.9% after the second year, and 95.5% versus 96.9% after the tenth year.

More men than women died by suicide; 181 per 10,000 men (n=277 out of 15,328) compared with 68 per 10,000 women (n=227 out of 33,372).
(log-rank test, $\chi^2 (1) = 135; p<0.001$). In the case group, men had 515 suicides per 10,000 people (n=263 out of 5,110), and women 191 (n=213 out of 11,125) (log-rank test, $\chi^2 (1) = 136; p<0.001$). Male controls had 14 suicides per 10,000 people (n=14 out of 10,218), and women 6 (n=14 out of 22,247) (log-rank test, $\chi^2 (1) = 5; p=0.031$).

There were more deaths due to poisoning in the undetermined group (89.2%; n=99 out of 111) compared with the suicide group (27.7%; n=109 out of 393), ($\chi^2 = 135, p<0.001$).
DISCUSSION

The present thesis comprised four studies focused on young people’s contacts with healthcare before and after self-harm. In the first two studies we explored the views of young people about healthcare before their first contact for self-harm, and their experiences of professional care during the 6 months after their self-harm episode. Participants described health services that not entirely conformed to their own ideas of how a treatment contact could be designed. They wished for more information and increased flexibility, and were appreciative of practical help in daily life. In the two register studies we found that young people admitted for self-harm had significantly more hospitalisations for symptomatic diagnoses and somatic illnesses than matched controls. Those with a previous somatic admission also had a higher risk for subsequent suicide.

Many young people with mental health problems do not seek help. We explored several explanations for this, with a focus on issues that may facilitate early intervention.

Studies I and II

Not telling and not seeking help

Before their contact for self-harm, participants felt that they did not need help and that they should be able to handle their problems on their own. Stigma and embarrassment also prevented them from seeking help. The desire to manage on one’s own, perception that help is unnecessary and stigma are major barriers for young people in accessing healthcare for mental health problems or self-harm. The feeling of shame when seeking professional help for self-harm makes young people particularly vulnerable, and future help seeking may be negatively affected if they are not validated by healthcare professionals.

Make contact

Participants described a lack of knowledge about where to turn when experiencing psychological distress, which sometimes prevented them from seeking help before they harmed themselves. In an older study, young people described how they thought that posters/pamphlets and billboards were a good way to inform suicidal young people where they
could seek help\textsuperscript{114}. However, participants in our study used the Internet as a source of information, although information on local health services was often inadequate. Participants’ preferred methods of contacting health services included phone, email and in-person visits, indicating that health services need to have some degree of variability in how they can be contacted. Participants also emphasised that they wanted help quickly, which is consistent with previous findings that appointment delay is associated with a lower rate of kept appointments\textsuperscript{115} and that accessibility of services is important for young people\textsuperscript{116}.

Support and independence

Participants’ abilities and energy diminished when their emotional problems began, making them dependent on others. Family and friends provided support and helped participants find suitable professional help. When this contact had been established, participants received help from professional care, including practical help to manage everyday life. Social services were often available to provide such help, which was appreciated by participants. Healthcare providers should be aware of the need for practical help as a means to improve treatment function, and should be prepared to involve social services at an early stage if needed.

Our participants’ emerging independence was reversed, and they became increasingly dependent on help from family and professional care. This stood out in the interviews regarding the time before and after participants’ self-harm episodes. Involving family or other non-professional sources of support is crucial in treating young people in a suicidal crisis. A review of interventions to prevent young people from self-harm found that family involvement was a common factor in the majority of successful interventions\textsuperscript{58}.

If the established contact was interrupted; for example, if no further appointments were scheduled while waiting for a new contact, it could lead to a feeling of abandonment and adverse outcomes. A lack of support while waiting for treatment after self-harm has been identified as problematic and related to the occurrence of new episodes of self-harm\textsuperscript{117}. As participants had difficulties seeking help on their own, formal referral was essential when they were to receive care at another healthcare facility.

At the same time, participants strived for independence and tried to manage without help. When treatment had started, interventions that did
Discussion

not consider their opinions were less effective. This supports the use of shared decision-making in treatment (when the patient’s preference for treatment is investigated, respected and adhered to)\textsuperscript{118}. Shared decision-making has been used successfully among young people with mental disorders to increase engagement with ongoing treatment\textsuperscript{119,120}.

Contact and trust

In contacts with healthcare, participants felt it was important to meet with someone they got along well with. When they explained their problems, they wanted to be listened to and taken seriously. It is important for young people with mental health problems to feel that they meet the ‘right’ person\textsuperscript{121}. The importance of being listened to and taken seriously is well recognised\textsuperscript{113,122}, and the ability to listen to a patient’s narrative is a central issue for clinicians in improving the quality of interactions with suicidal patients\textsuperscript{123}. Young people presenting to healthcare for mental distress or because of self-harm are vulnerable; feeling ignored at their first contact may deter them from keeping subsequent appointments or seeking help in the future. Therefore, the initial contact is crucial in establishing a continued working alliance.

Participants felt trust in ongoing treatment after self-harm if the mental health professionals were competent and reliable. This perception was based on the professionals’ level of knowledge and their ability to prepare for the consultation. If professionals made promises they could not keep, they were seen as less reliable. Knowledge and ability are an integral part of professionalism\textsuperscript{124,125}. However, this must also be combined with efforts to prepare before each meeting, be honest and avoid unrealistic promises, which may also be seen as a professional responsibility\textsuperscript{124,125}.

Structural problems during treatment

A change in treatment venue for administrative reasons affected participants’ motivation for continued treatment. An example of such a change was when they turned 18 years old and had to change from child and adolescent psychiatry to psychiatric services for adults. They already had an established contact and were not keen to change to a new contact. This is not a new problem, and the transition is associated with high risk for treatment interruption\textsuperscript{126}. It has been suggested that these
transitions should be more flexible, with a focus on current needs rather than a patient’s exact age\textsuperscript{126}.

A similar situation was reflected in the discomfort participants expressed about adult inpatient wards, which might be related to their young age. A previous study showed that many young people in medical and surgical care feel misplaced during their stay in an adult ward, and prefer to be treated in a ward designated for young people\textsuperscript{127}. It is likely that young people treated in psychiatric care have similar views. Treating young people in adult wards may be problematic, especially if they experience reduced independence with psychological problems, perhaps not feeling as adult they normally do. This supports the use of wards solely for young people in psychiatric care. An intermediate stage could be created for young people for in- and outpatient care to facilitate the transition to psychiatric care for adults.

Participants noted how it was sometimes difficult to reach health services for face-to-face counselling, and suggested several alternatives. One solution was to have telephone contact instead of a meeting in person. This is consistent with the successful implementation of online treatment such as Internet psychotherapy\textsuperscript{128}, where an identified advantage is convenience\textsuperscript{129}. Other ways to supplement face-to-face counselling include email counselling, which gives more time for self-reflection and may facilitate more openness\textsuperscript{130}, and mobile phone text counselling, which is flexible, easily accessible and gives more control to the young person\textsuperscript{131}. Automated texting services may also be used to remind patients about appointments\textsuperscript{132}; something participants noted as being difficult to remember.

These questions might mirror the situation when participants wished for more alternatives when seeking initial contact. A greater degree of flexibility with more use of technology may prove advantageous in managing treatment and counselling with young people. Such services could also be created with the involvement of young people, who otherwise might not be included in the design of health services. It may also be necessary to update these services due to the rapid development and use of technology. The use of technology among young people has been described to be more accepted if it enhances rather than replaces face-to-face contact, and technology is best used in the context of an already established contact with a healthcare provider\textsuperscript{133}. 
Participants’ suggestion for home visits is another way of removing barriers to accessing health services. Home visits could be used, perhaps in combination with distance communication, for those who have the greatest difficulty in accessing health services. An advantage of home visits is that healthcare can reach those who are unable or unwilling to contact health services. This may be a sign of deteriorating mental state, consistent with participants’ description of how they were unable to contact health services during periods when they were feeling worse. Specialist community-based interventions are also preferred by patients with repetitive self-harming behaviour\textsuperscript{134}.

Studies III and IV

Young people admitted for self-harm were more likely to have been admitted for non-psychiatric causes during the preceding year than controls. Study III covered all types of non-psychiatric admissions categorised into four main diagnostic groups: symptoms and signs, somatic causes, injury and poisoning, and influencing factors. In all of these groups, the odds of having been admitted were 3-10 times higher for cases than for controls. The symptoms and signs diagnostic group was large and showed marked differences between cases and controls. Patients with a previous somatic admission also had a higher risk for suicide (study IV). As expected, there were considerably more suicides among those with a previous self-harm admission than among controls from the general population, an association that is well documented\textsuperscript{28}.

Symptoms and signs

This group included admissions with a main diagnosis that described the patient’s symptoms without providing a causal explanation. It was one of the biggest diagnostic groups in our study, and cases were six times more likely to have been admitted with such a diagnosis during the year before inclusion in the study than controls.

Although underlying, undiscovered physical conditions might explain the symptoms, it is unlikely that all admissions of this type could be explained in this way, especially as the diagnoses were made after a period of observation and investigation in hospital.

We found that the four most common diagnoses in this group were abdominal pain, syncope and collapse, unspecified convulsions and chest
pain; conditions that might sometimes be associated with or even caused by mental distress (e.g., chest pain caused by panic disorder\textsuperscript{71}, or a conversion disorder with pseudoseizures, which is associated with mood disorders and severe mental stress)\textsuperscript{135}. Abdominal pain was the most common diagnosis in the group, and is associated with an increased risk of depression among adolescents\textsuperscript{136}. Severe abdominal pain leading to an operation on a normal appendix has also been linked to an increased risk for suicide attempts\textsuperscript{137}. Several of these conditions have been found in a subgroup of children with separation anxiety and school refusal, who started to report headaches and abdominal pain, which later progressed to pseudoseizures\textsuperscript{135}. A high prevalence of psychiatric disorders has also been found among those with medically unexplained syncope, where psychiatric treatment led to improvement among those who accepted treatment\textsuperscript{138}.

Underlying mental distress as a major reason for young people to contact healthcare with somatic symptoms is supported by the fact that somatic symptoms are common among depressed adolescents; multiple symptoms indicate a more severe depression with increased risk for future suicide attempts or completed suicide\textsuperscript{72,139,140}. In such cases, medically unexplained symptoms might be interpreted as primarily physical, preventing an important suicide risk assessment\textsuperscript{71}.

**Somatic causes**

We found that the odds of having been admitted with a somatic diagnosis were about three times higher for cases than controls (study III). Those with a previous somatic admission also had an increased risk for suicide (study IV). The risk for suicide applied to both cases and controls, although there were considerably more suicides in the case group.

The presence of psychiatric problems (e.g., depression) might help to explain why suicidal ideation is more common among people with physical illness\textsuperscript{141}. However, it is not certain that this is a definite explanation for increased risk of self-harm and suicide. Study III showed the odds of having been admitted were higher for cases than for controls after controlling for psychiatric admission, sex and age. In study IV, the association with an increased HR remained after controlling for psychiatric admission (and for self-harm). We only investigated inpatient diagnoses, and many participants might have had psychiatric problems
without admissions. However, other studies have shown that an increased risk for suicidal ideation related to different physical conditions remained for several conditions after controlling for depression\textsuperscript{141}.

A possible explanation for this association relates to the functional limitations resulting from physical illness, as this has been shown to be associated with suicide risk\textsuperscript{142}. Young adults on disability benefits due to somatic conditions have been shown to have more problems with depression and anxiety\textsuperscript{143}, conditions that are related to increased suicide risk\textsuperscript{144}. Perhaps more attention should be directed to impairment of function rather than specific physical conditions.

Other explanations relate to the young age of these patients. When young people are affected by chronic physical conditions, their life and development are negatively affected. The condition may affect their contacts with friends and lead to bullying, social isolation and feelings of not being normal\textsuperscript{145}. Traumatic events are also associated with physical illness independent of mental disorders\textsuperscript{146} and are associated with risk for suicide\textsuperscript{147}. Chronic physical illness (lasting over 6 months) among young people has been shown to be related to health-risk behaviours such as smoking, alcohol, drugs and antisocial acts\textsuperscript{148}. High-risk behaviour among young people is also associated with risk for suicide and self-harm\textsuperscript{149}, and could therefore partly explain why physical illness is related to risk for self-harm and suicide.

In study III we identified the most common somatic diagnoses with the greatest difference between cases and controls, although we tested the whole diagnostic group for significance rather than testing each diagnosis separately. Type 1 diabetes mellitus was the most common diagnosis, and was about seven times more common among cases than controls. Although an increased risk for psychiatric disorders and suicide attempts among young people with type 1 diabetes mellitus has been reported\textsuperscript{79}, the pronounced difference in our material is noteworthy. Another common somatic diagnosis was epilepsy, which was about nine times more common in cases than controls. Earlier research has shown more psychiatric disorders and higher rates of suicidal ideation, suicide attempts and suicides among young people with epilepsy\textsuperscript{78,150}. Another diagnosis with a notable difference in the number of admissions was asthma, which was 17 times more common in cases than controls. There were relatively few admissions, but the difference between cases and controls was striking. Previous research has shown that asthmatics
(including young people) have a greater risk for suicidal ideation, suicide attempts and suicide\textsuperscript{80}. It has been noted that many young people with asthma and suicidal behaviour demonstrate a high degree of risk-taking behaviour, which may lead to poor asthma control and poor medication adherence\textsuperscript{80}. A possible consequence is more admissions due to asthma, which might explain the substantial difference between cases and controls in study III.

Other diagnoses, such as chronic tonsillitis, might have been among the common diagnoses, as people are routinely admitted for surgery for this kind of condition. Here, the difference between cases and controls was smaller, but there were still more admissions among cases.

\textit{Injury and poisoning}

Poisoning, not classified as deliberate, constituted a large proportion of the \textit{injury and poisoning} diagnostic group, which might explain why this diagnostic group was larger among cases. Patients might have been unconscious during some of these admissions, making it difficult to determine if the poisoning was intentional or accidental. At times staff might be reluctant to classify poisoning as intentional, instead coding it as uncertain or as an accident. However, it was not surprising to find a connection between accidental injuries and self-harm, as this connection has been reported in earlier studies\textsuperscript{151-153}.

\textit{Influencing factors}

The two most common diagnoses in this group were observation for suspected toxic effect from an ingested substance and observation for suspected mental and behavioural disorders. These diagnoses are similar to self-harm and psychiatric diagnoses and the higher proportions among cases than controls were therefore to be expected.

This group also contained diagnoses concerning observation for suspected somatic or unspecified disorders. These diagnoses are similar to the symptomatic diagnoses above, where no underlying condition was found. These diagnoses were also more common among cases than controls.
The size of the difference

We only investigated inpatient care in our studies. An admission generally means that a condition is serious or potentially dangerous; otherwise it would have been managed in outpatient care (with the exception of conditions where admission was for planned surgery, such as chronic tonsillitis). This might explain why the differences between cases and controls were quite large. A previous study showed smaller differences in prior healthcare contacts between suicide attempters compared with controls. However, that study examined both in- and outpatient care, which might explain why the differences were smaller than in our study.

As noted above, the association between physical illness and self-harm may partly be explained by psychiatric illness. The causal relationship between physical and psychiatric illness is not clear. The association between physical illness and self-harm in our study might therefore be explained in several ways. Serious physical problems that prompt an admission might cause distress and psychiatric symptoms, which in turn lead to a greater risk for self-harm. Another explanation starts with serious psychiatric symptoms or distress with an associated risk for self-harm, which causes such severe physical symptoms that an admission follows (e.g., a panic attack causing chest pain). It is also possible that a common etiologic mechanism could cause both psychiatric and physical problems (e.g., genetic vulnerability or abuse of alcohol and drugs). The fact that the cases were selected because they were admitted for self-harm makes them a high risk-group for suicide. Therefore, the suicide rate was quite high among the cases.

There are also other related risk factors. Low socioeconomic status and abuse of alcohol or drugs among young people are associated with physical health problems, mental health problems and an increased risk for self-harm and suicide. Different kinds of medication for physical and psychiatric conditions may also cause psychiatric or physical symptoms as side effects. For example, a person with psychiatric problems at risk for self-harm and suicide who is treated with medication that causes physical side effects, links physical symptoms with increased risk for self-harm and suicide. Similarly, a person with physical problems who is treated with medication that causes psychiatric side effects has an increased risk for self-harm and suicide.
Sex differences

There were more women than men in the case group, reflecting that self-harm is more common among women than men\(^{33,37}\). However, suicide was more common among men than women. This is consistent with previous research describing the gender paradox, with more self-harm among women and more suicides among men\(^{40,41}\). In study III, we noted that the odds of having been admitted with a somatic or symptomatic diagnosis were higher for women than for men. Previous research has also shown this pattern, with young women being more likely to use healthcare (including inpatient care) than young men\(^{161}\). Injury and poisoning were more common among men, again consistent with earlier research showing that young men have more admissions for injuries than women\(^{162}\). The differences between cases and controls for the main diagnostic groups in study III were evident in both men and women.

Somatisation and alexithymia

Numerous factors affect young people’s help seeking when experiencing psychological distress or at risk for self-harm or suicide. One factor might be that they are unable or reluctant to express their distress, either because of alexithymia (an inability to identify and describe own emotions), or because of stigma (their own, among people around them or in society). It may be easier to seek help for somatic complaints if such complaints exist. When in distress, people might also have somatic problems that become aggravated (e.g., asthma), or a physical problem that manifests because of underlying psychological distress (e.g., chest pain due to a panic attack).

There is a strong correlation between alexithymia and somatisation\(^{163}\), and people with alexithymia are less likely to seek help for psychological problems\(^{164}\). This might help to explain why the odds of having been admitted due to physical complaints were higher for those who had been admitted for self-harm than for controls in study III. As some people might have been more likely to seek help for physical problems despite their main problem being psychological, they would not have received proper help, thereby increasing their risk for self-harm.
Discussion of methodology

Studies I and II

The qualitative method used in studies I and II was best suited to investigate young people's perspectives of contacts with healthcare before and after a self-harm episode. The results should not be regarded as an investigation of how well healthcare functioned, but rather how it was experienced by young people.

Qualitative research does not focus on objectivity as quantitative research does; instead subjectivity is admitted. When presenting qualitative data, effort must be made to clearly show how the results were found and how they were interpreted. This allows the reader to determine the credibility of the results. The qualitative content analysis method includes basic concepts on how to achieve trustworthiness.

Credibility, or how true the result is, can be achieved in a number of ways. The first few interviews were coded by the first and last authors independently, followed by discussions to agree on how continued coding should be conducted. Subsequent interviews were then coded by the first author. The continued analysis involved a process of reaching agreement among the authors, which improved credibility. We used direct quotations from participants to clarify their views in each category, which also increased credibility.

Confirmability corresponds to the term reliability used in quantitative research. Confirmability was improved by the fact that the same person conducted all interviews, transcribed the majority, and together with the last author, analysed the results. During the analysis we also continuously compared the codes and categories against the original interview texts. The interview guide remained unchanged for each set of interviews to ensure that the same topics were covered during each interview. At the same time, efforts were made to further explore the intended areas in the interviews.

Transferability corresponds to the term generalisability in quantitative studies, and concerns how the findings can be transferred to other, similar settings. In studies I and II, we had a small sample size with 10 and nine participants respectively, which limited the transferability. Not all patients eligible for inclusion were invited to participate or agreed to participate, which might be a source of bias if their views differed from
those included in the study. Therefore, our findings should be interpreted with caution.

However, a small sample is acceptable in qualitative studies, where the variety of the results is most important. The variation in age, sex, place of recruitment and type of self-harm among participants strengthened this variety, as many different perspectives were represented.

That participants chose the interview location might have helped to defuse the interview situation. Sometimes participants chose places that were unexpected for the interviewer, but all of the proposed sites worked out well. For example, outdoors proved to be very secluded as background noise prevented passing people from overhearing the interview.

Studies III and IV

In Sweden, we have access to good quality nationwide registers for research. These can be linked by the use of a personal number, unique for each individual. The main advantage in using register data is that it is easy to conduct large-scale studies with many participants.

We linked the National Inpatient Register with the Total Population Register in study III. In study IV we included the Cause of Death Register. The National Inpatient Register has been deemed to be of high quality. The Cause of Death Register has also been investigated, and few suicide diagnoses were assessed as incorrect. We were able to find controls from the Total Population Register, matched for age, sex and home municipality, which is another strength of our studies.

The main weakness of our studies was that we only used inpatient data and did not have information on variables other than age, sex and home municipality. We were therefore unable to control for potential confounders such as socioeconomic factors or medication.

However, our main finding that young people who self-harmed had more non-psychiatric inpatient care than controls has implications for clinical care.

The diagnoses in study IV were retrieved from the Swedish Cause of Death register. In this study, we included events with undetermined intent among suicides. A death is classified as due to an event of undetermined intent if it cannot be definitely determined to be due to
suicide, accident, or assault. As assaults are unusual, most deaths due to an event of undetermined intent could be assumed to be suicides or accidents. A study investigating the Swedish Cause of Death Register did not find that all deaths due to an event with undetermined intent could be counted as suicides, but it was not possible to determine how big a proportion of the undetermined deaths were suicides165.

It has been suggested that deaths due to an event with undetermined intent should be included in suicide statistics as these deaths share many similarities with suicides166. However, this recommendation comes from England, where a coroner system is used that gives a suicide diagnosis only if it is ruled beyond reasonable doubt166. It is not certain that the same conditions apply in Swedish statistics/cause of death-diagnoses.

In Sweden, a forensic investigation is conducted if there is any suspicion of unnatural death (suicide, accident, or homicide)167, meaning the diagnoses of unnatural death is well-founded. In an investigation including the Swedish Cause of Death Register, 21% of the selected undetermined deaths from the register were reclassified as suicides, but a substantial amount of events of undetermined intent could not be more closely specified109. That study also showed there were more deaths due to an event of undetermined intent in Swedish data (60 of 600) than in Norwegian data (0 of 600)109.

In our data, undetermined deaths included a higher proportion of poisoning (around 80%). It is especially difficult to ascertain intent in self-poisoning and it is therefore more likely to be sorted to the group with undetermined deaths. Consequently, if the group with deaths due to an event of undetermined intent is not included in suicide statistics, a large proportion of suicides due to self-poisoning will be left out of the analysis. For this reason, we chose to include undetermined deaths as suicides.

Clinical implications

Our findings have implications for the design of health services for young people. It is important to have adequate information easily accessible on the Internet about how to make contact with health services. In addition, more flexibility in how young people can make contact with healthcare, and providing several alternatives for making contact may be beneficial.
The first contact with health services is important for future help-seeking. Genuinely listening to a patient and taking them seriously will help to improve future help-seeking for that person. It will also help to improve compliance in the continued care of that patient.

During treatment, it is important to have flexibility in treatment arrangements, be responsive to the patient’s views and find new solutions. Perhaps traditional visits may not best suit the patient, meaning other ways of communication during treatment are needed.

In addition, more practical help may be needed than healthcare providers expect. It is important to involve social services or the patient’s family at an early stage to ensure that enough practical help is provided.

Young people seeking help for physical problems might have underlying psychiatric problems, with associated risks for self-harm or suicide. It is therefore important for health services encountering young people with health concerns to be aware of this; particularly school nurses, health centres and clinics designated specially for young people.

Young people with healthcare contacts due to somatic illness have an increased risk for self-harm and suicide. Their contact for somatic care is a golden opportunity to screen for psychiatric problems or suicidal risk. Instruments have been designed for this purpose in young somatic patient populations. Somatic symptoms of the severity that an admission is necessary might be of particular importance.

Future directions

To improve how young people at risk for or after self-harm seek help and remain in treatment, it may be beneficial to design health services in collaboration with young people. Such services could then be evaluated in comparison with traditional services.

Studies could be performed to investigate new channels through which young people in crisis could be reached. For example, information on health service webpages about new ways of seeking help may convince more young people to seek help when in need. More detailed information on available treatment may also convince young people to seek help.

Studies focusing on young people with medically unexplained symptoms should focus on places where medical personnel meet a majority of
young people (e.g., school nurses, health centres and young-adult health centres). There, it may be possible to screen for risk factors for self-harm such as abuse, psychiatric and social problems, as well as suicidal ideation, thoughts of self-harm or self-harm acts.

Different arrangements for evidence-based treatment could be designed based on young people’s preferences and subsequently tested. More practical help while regular treatment is ongoing may be beneficial. Treatment programs aiming to prevent self-harm among young people could be trialled with more internet-based interventions.
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REFERENCES


130. Dunn K. A qualitative investigation into the online counselling relationship: To meet or not to meet, that is the question. Counselling & Psychotherapy Research. 2012;12(4):316-326.


167. Rikspolisstyrelsens allmänna råd om åtgärder vid dödsfall som kan ha orsakats av yttre påverkan m.m. RPSFS 2000:14 - FAP 414-1.