Attitudes towards and satisfaction with services among deliberate self-harm patients: a systematic review of the literature

The main objective of this study is to systematically review the international literature on patients' attitudes toward and satisfaction with health services (specifically physical management, in-hospital psychiatric management and post-discharge management) following deliberate self-harm (DSH), to inform the development of improved services. DSH is defined in this study as any intentional self-poisoning or self-injury, regardless of suicidal intent.

This research summary outlines the main findings of a review of 31 studies from eight countries analysing attitudes towards and satisfaction with services among deliberate self-harm (DSH) patients. Sixteen of the studies draw on UK service users' experiences; the remaining 15 reflect patient experiences in Ireland, North America, Australia, New Zealand, Finland, Sweden and the Netherlands.

Quantitative data provide evidence about the general experiences of a larger population of DSH patients, while qualitative data are used to deepen our understanding by recounting specific examples and incidents.

Findings are discussed in the context of government and professional recommendations regarding the management of DSH patients and recommendations for future research are made.

The review was commissioned in 2007 by the NIHR Service Delivery and Organisation Programme (SDO) and carried out by a research team led by Professor Keith Hawton, Director of the Centre for Suicide Research at the University of Oxford, England.

Target audiences will include NHS Mental Health Services and Trusts, NHS Primary Care Trusts, Regional Suicide Prevention Leads and members of the National Suicide Prevention Strategy Group, Royal College of Psychiatrists, MIND, SANE, ReThink, The Mental Health Foundation, Self-Harm Network and other services, including relevant websites.

Key findings

In presenting the findings, this review:

- Focuses on DSH patient experiences with emergency services involved in transporting them to hospital.
- Considers study findings regarding perceptions of hospital staff.
- Summarises findings of investigations about patients' experiences relating to discharge from hospital and aftercare, in the community and psychiatric hospitals.
- Discusses users' suggestions for service improvement.

- Considers studies of patient experiences in the Accident & Emergency (A&E) department, including waiting times, environment and physical treatment.
- Reviews studies of service users' experiences of psychosocial management in hospital.

The terms patients, participants, service users, and respondents are used interchangeably in this report.
### Background

Suicide is among the leading causes of death for men and women in the UK and other countries. The strongest predictor of suicide is a previous episode of deliberate self-harm. Suicide risk increases significantly after an individual's first DSH episode: for example, risk within the first year after an episode is reported to be 66 times the annual risk in the general population of England and Wales.

Information collected at general hospitals in England suggests that at least 200,000 individuals per year present to hospital following DSH. However, an accurate estimate of prevalence is difficult because not all people seek help after a DSH episode.

While prevalence is difficult to accurately assess, the known prevalence of DSH in the UK and many other countries, combined with the strong possibility of repetition and/or suicide, makes DSH a global healthcare problem. Managing individuals presenting to hospital after a DSH episode and decreasing the number of people engaging in DSH is a goal for governments around the world.

Several reports published in the UK and other countries suggest ways of improving management of people who self-harm. However, services for people who self-harm vary in nature and quality. Furthermore, characteristics of some individuals engaging in DSH can add to the difficulty of translating management guidelines into practice. Studies show that many DSH patients have difficulties, such as impaired problem-solving skills and poor self-esteem, which may influence interaction with services.

Drawing on the views and recommendations of individuals who self-harm, this systematic review provides a range of suggestions for service improvements which may contribute to reduction of DSH and increased quality of care across the world.

### Practical findings

#### Overview

Studies incorporated in the review address the experiences of individuals who self-harm and perceptions of a range of services as well as views of family members and carers.

Treatment received in hospital and satisfaction with that treatment vary greatly. However, many participants from different countries and health systems recount similar hospital experiences.

The findings of this review suggest that including service users’ perceptions and experiences of hospital services in recommendations for care and service planning may increase the probability that individuals will seek help before or after engaging in DSH and their compliance with hospital management and aftercare.

Patients’ views on treatment following an episode of DSH offer insights into the success and failure of services in meeting needs – for example, levels of satisfaction are connected to perceptions of staff behaviour towards patients. Service users are found to be more satisfied with treatment when they feel the professional is genuinely concerned about them, respects them and does not try to belittle them.

Incorporating service users’ perspectives in service design and delivery is particularly important, given the consistent finding that a DSH episode is one of the strongest predictors of further episodes, including those resulting in death, and the knowledge that large proportion of individuals do not seek treatment following an episode. Investigating service users’ experiences of care is integral to improving the management of DSH patients and to the possible prevention of DSH and suicide.

#### General perceptions of management

Patient involvement in treatment and treatment administration decisions was among the most important aspects of hospital care for many UK participants.

Almost half (45%) of service users in a UK study said they received enough information from staff about the nature of their injury or condition. Service users appreciated when “they tried to tell me what they could”. Inclusion in treatment decisions was not universal. In one study, some patients said they were left with no information about blood-test results and felt staff carried out procedures without discussing options or providing explanations.

Some UK service users said staff did not address their needs and concerns: insufficient information about treatment options was reported by 49% of participants in one study. Some UK A&E service users...
perceived that they were treated differently from other A&E patients and attributed this to their DSH.

Perceived threats and humiliation were common reasons for negative experiences of management: some service users reported staff threatening to withhold anaesthesia or treatment if patients returned with another episode.

Negative interpretations of A&E care may result from characteristics often found in this group, such as a range of interpersonal problems and difficulties, deficits in problem-solving skills, low self-esteem, a tendency to become pessimistic or hopeless in the face of adversity and seeing problems in all-or-nothing terms.

A Swedish study found DSH patients commonly hold prejudices or negative expectations regarding hospital admission. When patients were involved in their treatment decisions, they responded with mixed feelings. While patients preferred inclusion, UK and Swedish studies showed some participants did not fully comprehend the information given.

Main findings
- Participants appreciated when staff kept them informed and engaged in their management but for many this was not the case.
- Several patients that were kept informed said that they could not understand the information provided to them by staff.
- Many wished staff were better educated about DSH and how to manage patients after a DSH episode.
- Some service users said staff lacked sympathy for patients.
- Many participants said staff focused on physical problems rather than their mental health.
- Participants called for sensitivity to personal preferences.
- Some service users said they would not return to hospital if they experienced another DSH episode.

Accident & Emergency departments

Many US and UK patients and carers interviewed experienced long wait times at A&E departments. Some patients interpreted this lack of immediate care as resulting from staff attitudes towards self-harming patients. However, in one study more than half of UK service users were treated within two hours. An Australian study found that 75% of service users were attended to within 30 minutes of arrival at A&E; only 9% waited an hour or more before being seen.

In one UK study, most service users did not require immediate physical care on entry to A&E. Positive waiting experiences were associated with ‘regular check-ups’.

Many service users had negative opinions of A&E waiting areas. While many advocated a separate waiting area, several reported that having to wait in a general waiting area increased their inability to soothe themselves after a DSH episode and left them feeling exposed and vulnerable. One patient said: “All they have to say is: we’re here if you need us – don’t think you’re on your own…”

Main findings
- Wait times were perceived as too long by many participants.
- Participants’ reactions to a separate waiting room were mixed.
- Many service users said they were not informed of possible effects of physical treatments.
- Several participants described a lack of privacy in A&E.
- Perceived threats to withhold treatment (such as anaesthetic during suturing) were reported by several participants.

Psychosocial assessment

Official guidelines indicate that psychosocial assessment is a requirement of care for patients presenting at hospital after a DSH episode, but not all patients receive them. Individuals who are not assessed may be more likely to repeat self-harm.

One study found patients leaving hospital without a psychiatric assessment to be more likely to have a previous DSH history and display non-cooperative behaviours.

Patients receiving a psychosocial assessment may encounter a wide range of experiences with regard to the assessor, the assessment and its administration and the environment.

Service users’ experiences of psychosocial management following a DSH episode varied across studies. Many patients welcomed the chance to discuss problems and issues leading to their DSH episode. Service users’ expectations of assessment and the way they interpreted staff’s management of psychosocial assessment had a large impact on levels of satisfaction.

Most participants (83%) in a UK study found assessment helpful and that the assessor understood their feelings. Participants were found to display significantly decreased levels of hopelessness and a near-significant increase in self-esteem after assessment. Assessment offered some individuals hope for recovery: “It left me feeling more positive about the future and what I am going to do.”

Staff sensitivity to cultural differences and religious and personal preferences was important during psychosocial management.
Main findings

- Not all patients receive a psychosocial assessment in hospital.
- Participants had a more positive experience of assessment when given information about it beforehand.
- Several participants perceived assessment to be superficial.
- Several service users felt they were not given enough time to talk.

Discharge and referral

Discharge

Several patients felt their problems had not been adequately addressed and were frightened of being alone on discharge: “[I was] sent home still feeling very alone and unsafe.” Some carers received little or no information on what to do when they got the patient home. Participants described inappropriate behaviours by staff: one Irish adolescent was told he was ‘lucky’ and sent home without a follow-up referral.

Referral

Many patients never receive follow-up care after a DSH episode. Participants were often provided with helping organisations’ contact details instead of or in addition to a referral. While many participants used these, some felt uncomfortable initiating aftercare in this way: “If you’re really down, the chances of you picking up the phone are really slim.”

Many service users were told they would be contacted to schedule aftercare but heard nothing. Some receiving referrals faced a long wait for psychotherapy. Long waits for appointments may leave patients discouraged and decrease compliance. Several individuals interviewed were concerned about how A&E staff determine aftercare needs.

All adolescent participants in one UK study were offered aftercare. Several adolescents presenting at hospital in New Zealand after a DSH episode felt relieved when provided with aftercare at a community mental health service. A few adolescents perceived their parents’ discomfort with their contact with psychiatric services. Some New Zealand parents said their adolescent’s aftercare referral increased their own feelings of failure, fear and stigma. Fathers worried more than mothers about stigmatisation.

Adult service users who had negative experiences at A&E were less likely to report that they would return.

Main findings

- Discharge was often a negative experience for participants as many felt they were not prepared to leave hospital for physical or psychological reasons.
- Several service users said they did not receive referrals for aftercare.
- Many patients said they were told upon discharge that a member of staff would contact them regarding their care but they were never contacted.
- Contact numbers for helping organisations were often provided, but some participants did not feel comfortable contacting services with which they had no connection.
- Several participants experienced long waits for aftercare.

Post-hospitalisation management

Some patients given referral appointments were positive about aftercare; however, some service users never attended referral appointments. Those with negative experiences may have left treatment earlier.

Most patients were willing to engage in services to help minimise self-harm; others found opening up to a stranger difficult and anxiety-provoking.

Failure to start or continue treatment was linked to patients finding referral instructions difficult; not believing aftercare would be helpful; thinking they didn’t need help; stigma associated with seeing a psychologist or psychiatrist; and fear of repeating stories. Some patients terminated aftercare early because they had got as much out of treatment as possible, were uncomfortable with the professional or location, or found care unhelpful.

Most adolescents in one study felt that treatment was useful and they were taken seriously by service staff, while some thought talking did not make a difference to the way they felt. One UK study found individuals unwilling to use aftercare were more likely to have a history of repeated DSH or feel ‘beyond help.’

Some patients presenting to hospital are admitted to a psychiatric ward after discharge. Individuals admitted had mixed reactions to care and respondents believed ward management could be improved. In one study, patients wanted staff to give them more responsibility for themselves and their management.

In a New Zealand study, 84% of service users rated seeking help from a general practitioner as positive. Patients in the UK were more likely to describe experiences as positive when the general practitioner seemed non-judgemental and genuine.
Main findings

- Many participants described opportunity to talk as a positive aftercare result.
- Participants who did not attend aftercare appointments said this was for a variety of reasons, such as thinking they did not need the help, did not think therapy would be helpful, or found referral instructions difficult to understand.
- Service users ending treatment early cited difficulties in opening up to therapists, feeling sessions did not help, feeling uncomfortable with the therapist or session location and feeling they had got all they could out of therapy.
- Some participants said they did not have a good rapport with their therapist, which led to negative experiences.
- Many patients admitted to psychiatric hospital inpatient care felt they had no sense of personal control on the ward. Some suggested that staff give patients more responsibility for preventing their self-harm.
- Participants admitted to psychiatric inpatient care had positive experiences of constant observation when staff kept them occupied and engaged; others reported negative experiences when staff were perceived as ignoring them.
- Lack of privacy was important for participants during constant observation.
- Some older adolescents said that they experienced difficulties when put on adult or adolescent psychiatric wards.
- Family involvement in therapy was beneficial for some adolescents.
- Parents involved in their child’s management reported positive experiences.
- Parental and adolescent reactions to medication were mixed.

Patients’ attitudes to care following a DSH episode were remarkably consistent across the 31 studies from eight different countries and health-care systems. Several patients reported overall satisfaction with their management, while many were unhappy with specific aspects of care.

The review:

- suggests that service users’ experiences of services following a DSH episode might assist in developing more patient-oriented care and services, ultimately increasing effectiveness of interventions.
- shows that much can be done to improve service user satisfaction among patients presenting to services after a DSH episode, from developing and implementing protocols for staff to follow in caring for individuals after a DSH episode to adding a personal touch when providing care. It recommends that service providers ensure conformity with national mental health service standards.
- advocates research to strengthen understanding of service users’ needs and address issues affecting specific groups not focused on in the identified studies, such as older adults, lesbians and gay men and ethnic minorities.

Key implications for clinical practice and service improvement

In-hospital management

- Education and training for clinical and non-clinical staff on DSH and patient management after a DSH episode, possibly including service users as educators and addressing sensitivity, communication and appropriate behaviours.
- Patients regularly informed of health status and engaged in management decisions.
- Staff sensitivity to patients’ preferences.
- Protocols for DSH patient management (such as psychosocial assessment) designed to maximise positive effects on well-being of patients.
Patients presenting with DSH receive psychosocial assessments from appropriately trained professionals.

Patients discharged only when they have recovered from physical and/or psychological effects and have a discharge plan.

Local alternatives to A&E may be effective in providing physical treatment for those not wishing to attend hospital.

**Aftercare**
- Hospital protocols to ensure all patients have an aftercare plan on discharge.
- Patients given advice and help regarding specific problems, such as substance abuse and/or low self-esteem, and information about local services upon discharge.
- Flexible aftercare arrangements planned according to the acuteness of patients’ problems.
- Staff act as a link by contacting local services (with patient’s permission).
- Therapists build rapport before discussing DSH-related problems.
- Aftercare is evidence-based and tailored to individual patients’ needs.
- DSH information, advice and support available to carers.

**Adolescents**
- Staff managing adolescents have relevant specialist training.
- Adolescents kept informed and involved in their management.
- Parents encouraged to be involved in management, where appropriate.
- Attention paid to possible care difficulties experienced by older adolescents.
- Therapists work with adolescents and families to create effective treatment plans.
- Community services easily reached by public transport.

The review recommends that gaps and weaknesses in the literature should be addressed by four broad research categories:

1. Improvement of service evaluation
2. Improvement of service delivery
3. Improvement of services for specific groups of individuals who self-harm (e.g. older adult, gay, lesbian, bisexual or learning disabled patients)
4. Provision of support for those affected by deliberate self-harm.

A more complete understanding of consumer perspectives is essential if services are to be improved and developed and the prevalence of deliberate self-harm reduced world-wide.

**Future research**
The objective of this review was to synthesise DSH patients' experiences of care in order to inform clinical practice. It sought to identify all relevant qualitative and quantitative studies where participants of either gender or any age group had engaged in deliberately initiated self-poisoning or self-injury and had contact with hospital services. Studies of patients' friends or relatives were included. Search terms relevant to DSH patients' experiences of care were used to search electronic databases. Reference lists of relevant studies were searched and experts contacted.

Thirty-one studies met the inclusion criteria. Eighteen were solely qualitative, three used solely quantitative methods and ten used both. Sixteen were based on service users' experiences in the UK. Service users who had self-poisoned were in the majority in 16 studies.

Two reviewers extracted the data. Quality assessments examining study design, centrality, analysis and reporting and generalisability were undertaken by at least two reviewers. Studies were included regardless of quality, with studies of stronger design given more weight and relevance taken into account. Adult and adolescent studies were considered separately. Patients whose care was provided solely in the community were not included.

**References**


Disclaimer

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Addendum

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