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

Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO)

May, 2007

prepared by
Tatiana L Taylor
Centre for suicide research, University of Oxford

Keith Hawton
Centre for suicide research, University of Oxford
Sarah Fortune
  • Academic unit of psychiatry and behavioural sciences, School of Medicine, University of Leeds

Navneet Kapur
  • Centre for suicide prevention, University of Manchester

Address for correspondence
Professor Keith Hawton
Centre for Suicide Research
Department of Psychiatry
University of Oxford
Warneford Hospital
Oxford OX3 7JX
E-mail: csr@psych.ox.ac.uk
Executive Summary

The prevalence of deliberate self-harm (DSH) and the possibility of repetition and/or eventual suicide make DSH a major health care problem, both in the UK and in many other countries. The main objective of this study was to conduct a systematic review of the international literature on patients’ attitudes to, and satisfaction with, health services (specifically medical management, in-hospital psychiatric management and post-discharge management) following DSH to inform the development of improved services.

Method

We sought to identify all relevant qualitative and quantitative studies where participants of either gender or of any age group had engaged in deliberately initiated self-poisoning or self-injury and had contact with hospital services. We also included studies of patients’ friends or relatives. Search terms relevant to DSH patients’ experiences of care were used to search electronic databases. Reference lists of relevant studies were searched and experts in the field were contacted.

Data was extracted by two reviewers. Quality assessments examining study design, centrality, analysis and reporting, and generalisability were carried out by at least two reviewers. All studies were included in the review, regardless of quality. However, more weight was given to studies of stronger design. Relevance to the review was also taken into consideration. Studies were considered separately for adults and adolescents.

Findings

Thirty-one studies met the inclusion criteria. The majority (62%) were solely qualitative studies, while three used solely quantitative methods and ten used both. Sixteen studies were based on service users’ experiences in the UK. Service users who had self-poisoned accounted for the majority of participants in 16 studies. The main findings are presented below.

General perceptions of management:

- Participants (the terms participants, patients, service users, and respondents are used interchangeably in this report)
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 they could not understand the information provided to them by staff.
- Many wished staff were better educated about both 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 their physical problems rather than their mental health.
- Participants called for sensitivity to personal preferences.
- Many service users said they were told a member of staff would contact them regarding their care but they were never contacted.
- Some service users said they would not return to hospital if they experienced another DSH episode.

Accident and emergency (A&E) department:
- Wait times were perceived to be too long by many participants.
- Participants’ reactions to having 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 while in A&E.
- Perceived threats to withhold treatment, for example anaesthetic during suturing, were reported by several participants.

Psychosocial assessment:
- Not all patients receive a psychosocial assessment while in hospital.
- Participants had a more positive experience of assessment when they were 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 was often a negative experience for participants as many felt they were not ready to leave hospital, for either physical or psychological reasons.
Several service users said they did not receive referrals for aftercare.

Contact numbers for helping organisations were often provided but some participants did not feel comfortable making contact with services they had no connection to.

Post-hospitalisation management:

Several participants experienced long waits for aftercare.

Opportunity to talk was described by many participants as a positive result of aftercare.

Participants who did not attend aftercare appointments said this was for a variety of reasons, for example did not think they needed the help, did not think therapy would be helpful, referral instructions were difficult to understand.

Service users who ended treatment early cited difficulties opening up to therapists, feeling that the sessions did not help, feeling uncomfortable with the therapist or the location of the sessions and feeling that 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 while on the ward. Some suggested that staff give patients more responsibility for preventing their self-harm.

Participants who had been admitted to psychiatric inpatient care had positive experiences of constant observation when staff kept them occupied and engaged, while others reported negative experiences when staff were perceived as ignoring them.

Lack of privacy was an important issue for participants during constant observation.

Some older adolescents (the terms adolescents, young people, and youth are used interchangeably in this report) said they experienced difficulties when put on adult or adolescent psychiatric wards.

Family involvement in therapy was beneficial for some adolescents but not for all.
• Parents who were involved in their child’s management reported positive experiences.
• Parental and adolescent reactions to medication were mixed.

Suggestions by participants for service improvement:
• Increased sympathy towards those who self-harm.
• Greater staff knowledge of DSH.
• Increased and improved communication between service staff and those who deliberately self-harm.
• Provision of better information about DSH for patients, carers and the general public.
• Improved access to local services and aftercare.

**Implications**

Although there were difficulties in research design in several of the studies, and a strong likelihood of participant bias, there was marked consistency in the findings. Therefore, the implications of the findings can be synthesized with reasonable confidence. The key implications for clinical practice and service improvement of the findings are as follows.

In-hospital management:
• Education and training for clinical and non-clinical staff on DSH and how to manage patients after a DSH episode. This programme might include service users as educators and address topics of sensitivity, communication and appropriate behaviours.
• Patients regularly informed of their health status and engaged in management decisions.
• Staff sensitivity to patients’ personal preferences.
• Protocols for management of DSH patients, for example psychosocial assessment, designed to maximise therapeutic benefits.
• All patients who present with DSH receive a psychosocial assessment by someone trained to do this.
• Patients observed until they may be discharged appropriately, for example recovered from physical and / or psychological effects; have a discharge plan.
Local alternatives to A&E may be an effective way of providing physical treatment for those who do not wish to attend hospital.

Aftercare:

- Hospitals’ protocols ensure all patients have an aftercare plan at the time of discharge.
- Patients given advice and help regarding specific problems, for example substance abuse, low self-esteem, and information about local services upon discharge.
- Flexible aftercare arrangements planned according to the acuteness of the patient’s problems.
- Staff assistance in making contact with local services by acting as the link (with the patient’s permission).
- Therapists build up a rapport with patients before attempting to discuss problems related to self-harm.
- Aftercare should, wherever possible, be evidence-based and also tailored to meet individual patient’s needs.
- Information about DSH, advice and support available to carers.

Adolescents:

- Staff involved in the management of adolescents have relevant specialist training.
- Adolescents kept informed and involved in their management.
- Parents, where appropriate, encouraged to be involved in management.
- Special attention to possible difficulties in care that may be experienced by older adolescents.
- Therapists work with adolescents and their families to create effective treatment plans.
- Local community services easily reached by public transport.

Furthermore, hospitals should have a planning group focused on the management of DSH patients. This might ensure that all patients receive certain aspects of care, for example pain relief, psychosocial assessment, and that effectiveness and patient satisfaction are assessed.
Future research

This review has shown that many DSH patients are unhappy with particular aspects of their management, both in and outside hospital. It has also identified several gaps and weaknesses in knowledge which need to be addressed by further research. Four broad areas for future research emerged from the literature.

Improvement of service evaluation:

• The development of a standard interview schedule to allow better evaluation of services across the UK. These components should include: satisfaction with physical treatment, psychosocial management, discharge, referral, aftercare and perceptions of, and satisfaction with, staff.

• Research evaluating DSH patients’ perceptions of specific psychosocial assessments and comparisons of different types of assessments, for example long versus short forms.

• Evaluation of service users’ attitudes towards psychosocial and pharmacological treatments offered after a DSH episode.

Improvement of service delivery:

• Research focusing on how to address the key implications and evaluate the impact of these changes on patient satisfaction.

• Development and evaluation of training and education about DSH for both clinical and non-clinical staff, including general practitioners.

• Measurement of the impact of training on staff attitudes and patient perceptions of staff.

• Examination of the most effective ways of linking changes in attitudes to changes in behaviour.

• Evaluation of the impact of community services already in place and the development of alternatives to hospital for minor physical injuries.

• Large-scale clinical studies evaluating different styles of services, for example dedicated DSH services versus generic psychiatric services, to compare the impact on patients.

Improvement of services for subgroups of individuals who self-harm:

• Research to determine the most effective way of managing older adults, as little research has been conducted this area.

• Qualitative research on older adults’ perceptions of care.
• Research to determine whether different minority groups have special needs and how these needs can be addressed during their management.

Provision of support for those affected by DSH:
• Examination of the impact of DSH on relatives, their role in management, and its effects.
• Evaluation of special information about DSH tailored specifically for the use of family and friends of individuals who self-harm.

**Conclusions**

Despite studies in this review being from different countries and health care systems, the attitudes of patients to services and their perceptions of care showed remarkable consistency across studies. While participants often reported they were satisfied overall with their management, many highlighted specific aspects of their care with which they were unhappy. Our findings highlight several key implications that may improve the experience of care and the effectiveness of management, as well as research implications that may improve services and their evaluation.
Disclaimer

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the SDO programme or the Department of Health.

Addendum

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene and Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact sdo@southampton.ac.uk.