Self-harm, capacity, and refusal of treatment: implications for emergency medical practice. A prospective observational study

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Objectives: In the context of increasing attention to the rights of adults to make treatment decisions for themselves, this study investigated, among patients who have engaged in self-harm (i) the extent of valid decision making; (ii) the impact of mental disorders; and (iii) the effect of systematically providing relevant clinical information.

Design: A prospective observational study.

Setting: The emergency department of a large teaching hospital in southeast England.

Participants: Seventy one adult men and women who had presented for treatment following self-harm.

Main outcome measures: Semi-structured interviews were used to make clinical judgements about participants’ capacity to consent before, and following, the presentation of simple written information about the proposed treatment(s). Demographic data, and data about mental disorder and alcohol misuse, were also collected.

Results: Based on accepted legal criteria, only 28/71 (39.4%) of the patients were judged to have capacity to consent to the proposed intervention(s) initially. However, the number of patients judged to have capacity improved significantly (p < 0.001) after the presentation of written information, to 45/71 (63.4%). Those judged incapable were significantly more likely (p < 0.01) to refuse treatment. Continuing incapacity was significantly associated only with cognitive impairment (p < 0.001) and/or severe psychiatric disturbance (p = 0.01).

Conclusions: Consistent with current views, capacity is not static, even among patients who have engaged in self-harm, but can be improved through a simple intervention. The findings are consistent with recent guidance about supporting this vulnerable group of patients, many of whom are ambivalent about treatment.

People who have engaged in self-harm form a significant proportion of the patients attending emergency departments (EDs). In striking contrast with most other patients, it is not uncommon for this group of individuals, many of whom may have a mental disorder and/or have misused alcohol, to refuse treatment. Such situations can result in complex ethical and legal dilemmas for healthcare practitioners.

In the UK, as in most democratic countries, adults have the right to make healthcare decisions for themselves. However, this right is only meaningful if the person is aware of the relevant information, is free to decide without coercion, and is able, or has the “capacity”, to make the particular decision. In the context of increased emphasis on the principle of self-determination there has been a growth in interest in the assessment of capacity. In many jurisdictions, a “functional” approach to decision making capacity, which involves establishing the extent to which an individual’s abilities meet the demands of a particular decision, has attracted most empirical and legal support.

A substantial empirical literature has developed on the capacity of different groups of adults to make decisions about treatment. Generally, but by no means inevitably, people with mental disorders, including intellectual disabilities, are more likely than their “general population” counterparts to experience impairments in their decision making capacity. However, so far, no studies have specifically considered men and women who have engaged in self-harm, a situation where the consequence of a refusal of a healthcare treatment may be an end to life. As statutory legislation is more widely introduced, appreciation of the central importance of capacity, its assessment, and ways in which it may be maximised in clinical settings, is essential.

In this study, we aimed to investigate:

- the extent to which men and women who engage in self-harm have the capacity to make treatment decisions
- the relationship between capacity and variables including cognitive functioning, mental disorder, and alcohol misuse
- the extent to which the high rates of incapacity we anticipated might be reduced by changing the way in which routine clinical information relevant to the patients’ treatment(s) is presented.

METHODS

As far as possible, participants were recruited consecutively on different days of the week (including weekends). They all came from the ED of a local general hospital, serving a population of approximately 0.5 million people. The sample
comprised adults (18 years or older) who were conscious and required healthcare treatment following a self-reported act of self-harm. In accordance with the accepted terminology at the time the data were collected, self-harm was as defined as

an act with non-fatal outcome in which an individual deliberately initiates a non-habitual behaviour, that without intervention from others will cause self-harm, or deliberately ingests a substance in excess of the prescribed or generally recognised dosage, and which is aimed at realising changes that the person desires via the actual or expected physical consequence.17

Potential participants were approached before any of the proposed treatments had been carried out. Background information was collected, including details of age, sex, marital status, ethnicity, employment, contact with primary and secondary services for the treatment of mental health needs or substance misuse, and previous history of self-harm. Then, a semi-structured interview was used to elicit the person’s capacity to consent to the treatment(s) proposed by the medical staff. The responses were written verbatim and, if the patient consented, also audiotaped. If capacity was in doubt after this first “spontaneous” account, a simple intervention was introduced. An information sheet, meeting clinical and legal requirements for appropriate disclosure was presented.18 The sheet did not contain material which was new, but it was structured and, to ensure it was not too complex, its reading ease had been assessed using an established formula for analysing medical texts.19 In addition, the information was explained verbally, encouraging questioning to increase participants’ engagement with the material. Using the same semi-structured interview framework, the participant was again invited to give an account of the proposed treatment. Finally, the following assessments were undertaken: the Mini-Mental State Examination (MMSE)19 for cognitive function; the Hamilton Depression Rating Scale (HDRS)20 and the Brief Psychiatric Rating Scale (BPRS)21 to determine the presence and severity of mental disorder; the Beck Suicide Intent Scale (BSIS)22 and the Alcohol Use Disorders Identification Test (AUDIT)23 to determine alcohol dependence. An Alcohol Breathalyser was used to assess current blood alcohol level.

Data analysis
Participants’ capacity before and following the presentation of the information sheet was compared with McNemar’s test. Associations with the demographic measures, assessments of cognitive functioning, mental disorder, and alcohol use were examined using χ² or Fisher’s exact tests for categorical variables, and Mann–Whitney tests for non-categorical variables.

The responses of 25 (35%) participants (with audiotapes, where available) were randomly selected and independently rated by a second psychiatrist (AJH). Overall agreement between the two raters’ clinical judgements was high (k = 0.92 (95% CI 0.81 to 1.00)).

RESULTS
Participant characteristics
All conscious adult patients presenting to the ED with self-harm on the data collection days were invited to take part in the study. Of the 80 patients approached, 71 (88.7%) agreed to participate and were included. Nine patients did not participate: four were physically too unwell, and five made an informed choice not to take part. Of the 71 participants, two thirds (67.6%) were able to consent to the research; the remainder assented. The mean (SD) age of the participants was 35.11 (13.2) years (range 18–93), of whom the majority were women (63.6%). Reflecting the local population, most participants (94.4%) were from a White British background. Although there is almost full employment locally, less than a third (29.6%) were in paid or voluntary employment. The majority (77.4%) of participants reported current or previous contact with primary or secondary healthcare services because of mental health or substance misuse problems, and almost two thirds (63.4%) gave a history of previous episodes of self-harm. The overwhelming majority (91.5%) had attempted to injure themselves by overdosing on medication; the remainder (8.5%) had engaged in self-injury, usually by cutting their wrists.

Of the 71 participants, only 49 (69.0%) were able and/or willing to complete all the psychiatric rating scales. The mean (SD) scores for all the scales were as follows: HDRS 13.98 (7.83); BPRS 24.5 (7.07); MMSE 28.5 (2.39); and BSIS 9.93 (5.39). These scores indicated that the participants were not markedly cognitively impaired or mentally disordered and were of only moderate risk on the suicide intent scale. However, there was a high rate of alcohol misuse; 37 participants (52.1%) had used alcohol at the time of their episode of self-harm. The mean (SD) blood alcohol level was 31.8 (76.6) mg % (range 0–340 mg %). The mean AUDIT score was 11.3 (14.48) (range 0–36). Almost half (48%) of the 50 participants who completed the measure of alcohol dependence obtained a score above 8, the “cut-off” for harmful use of alcohol.

Decision making capacity
As expected, rather few participants were initially able to make valid decisions about the proposed treatment(s). Based on their accounts at the beginning of the interview, only 28 of the 71 (39.4%) men and women were judged to have capacity. However, after the presentation of the information sheet and the verbal explanation the number of patients judged to have capacity increased significantly from 28/71 to 45/71 (p<0.001). It appeared that this was due, primarily, to improvements in their understanding of the purpose of the treatment. Nevertheless more than a third (36.6%) of the participants remained unable to give or withhold consent to treatment.

Factors associated with incapacity
Table 1 indicates that there was no statistically significant relation between incapacity and any of the demographic variables; nor were there any specific associated clinical characteristics. Perhaps surprisingly, it also appeared to be unrelated to suicidal intent, depression, alcohol dependence, and current blood alcohol levels. However, incapacity was significantly related both to cognitive impairment at the time of the assessment (MMSE, z = −3.89, p<0.001) and with the severity of participants’ current psychiatric symptomatology (BPRS, z = −2.77, p<0.01).

Refusal of treatment
The participants often reported that they had been encouraged by others to seek treatment following their act of deliberate self-harm. Nevertheless, all of them were attending the ED voluntarily. Yet, when they were interviewed initially, a significant minority (29.6%, n = 21) stated that they intended to refuse the proposed treatment(s), in part (19%) or in its entirety (81%). Only 8 (38.1%) of these “treatment refusers” were judged to have capacity; the other 13 remained incapable, even after the intervention. Compared with participants who accepted treatment (n = 50), those who intended to refuse (n = 21) were significantly more likely to lack capacity (χ² = 8.21, p<0.01). However, only two people, both requiring only
observation, discharged themselves against medical advice. There were no fatalities in the study group.

DISCUSSION

Using a naturalistic methodology and a decision making task of practical and legal significance, almost two thirds of a representative sample of patients attending the ED following self-harm were initially incapable of giving or withholding consent to proposed treatments. That is, they were unable to make an emergency, and possibly life preserving, healthcare decision for themselves. The important medicolegal implication of these findings is that, in routine clinical practice, some patients probably accept interventions which are, unwittingly, given to them unlawfully, whereas others refuse treatment which they do not have the capacity to reject.

In Scotland, legislation has been introduced which permits treatment to be carried out in individuals without capacity if this is likely to be of “benefit” to them. In England and Wales, the Mental Capacity Act, which is due to be extended to England, and is currently being extended to Scotland, under the Mental Health (Scotland) Bill, provides a similar legal defence for such action. The intent of the relevant legislation in the UK, as in other jurisdictions, is that, as far as possible, the principle of self-determination should be respected.

Importantly, we found that the decision making capacity of patients who have engaged in self-harm can be improved quite easily through the use of a simple information sheet accompanied by a detailed verbal explanation, presented in a supportive manner. Further analysis indicated that the procedure improved participants’ understanding of the purpose of the treatment. Consistent with a “functional” approach, then, capacity should not be viewed as static and unchangeable. Initially impaired decision making may simply reflect the difficulties that people who are physically unwell or mentally distressed appear to have in coping with the intervention.

There were no fatalities in the study group.

Our findings must be viewed in the light of the limitations imposed, primarily, by carrying out the study in a clinical setting. Almost a third of the participants stated that, though they had attended the ED voluntarily, they intended to refuse treatment. Most of these patients lacked capacity. However, following the intervention, almost all of them changed their minds and accepted at least part of the treatment(s) proposed by doctors and other healthcare practitioners. This seemingly inconsistent behaviour was evident in other ways—for example, one patient consented to being interviewed by the researcher but was adamant that she would not accept medical and psychiatric treatment. It seems that the initial “choice” of refusing treatment should not necessarily be considered as final, even when a person apparently makes the decision with capacity; instead, this group of patients is ambivalent about seeking help. This issue is considered in recent guidelines relating to self-harm, produced for the UK by the National Institute for Clinical Excellence (NICE). A useful algorithm is proposed for dealing with refusals of treatment for the physical effects of self-harm. It is suggested that, following a “functional” assessment of capacity, concerted efforts should be made to support the person in making a valid decision. In situations in which patients with capacity refuse treatment, which is required immediately, legal guidance should be sought. When such treatment is refused by patients with continuing incapacity, it may need to be carried out using the relevant legal frameworks; on occasion, and providing the necessary criteria are fulfilled, the use of mental health legislation may be appropriate.

Our findings were not at all extreme, their performance on the measures of psychiatric disorder and/or cognitive impairment suggested that they may have had a more marked “impairment of, or a disturbance in the functioning of mind or brain.” However, the impact on each of the relevant tests or abilities of the difficulties underlying their scores is uncertain.

Consistent with previous findings, almost a third of the participants stated that, though they had attended the ED voluntarily, they intended to refuse treatment. Most of these patients lacked capacity. However, following the intervention, almost all of them changed their minds and accepted at least part of the treatment(s) proposed by doctors and other healthcare practitioners. This seemingly inconsistent behaviour was evident in other ways—for example, one patient consented to being interviewed by the researcher but was adamant that she would not accept medical and psychiatric treatment. It seems that the initial “choice” of refusing treatment should not necessarily be considered as final, even when a person apparently makes the decision with capacity; instead, this group of patients is ambivalent about seeking help. This issue is considered in recent guidelines relating to self-harm, produced for the UK by the National Institute for Clinical Excellence (NICE). A useful algorithm is proposed for dealing with refusals of treatment for the physical effects of self-harm. It is suggested that, following a “functional” assessment of capacity, concerted efforts should be made to support the person in making a valid decision. In situations in which patients with capacity refuse treatment, which is required immediately, legal guidance should be sought. When such treatment is refused by patients with continuing incapacity, it may need to be carried out using the relevant legal frameworks; on occasion, and providing the necessary criteria are fulfilled, the use of mental health legislation may be appropriate.

Our findings must be viewed in the light of the limitations imposed, primarily, by carrying out the study in a clinical setting. Almost a third of the participants were unable/unwilling to complete all the assessments. Such selection effects may explain the absence of a significant association between incapacity and blood alcohol level: the most intoxicated were the most reluctant to be breathalysed. Nor was it possible to investigate as wide a range of variables as possible.

Table 1

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Demographic and clinical characteristics, and performance on standardised measures, of the participants with and without capacity to make a decision about the proposed treatment(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients judged to have capacity initially or following the intervention (n = 45)</td>
<td>Patients with incapacity (n = 26)</td>
</tr>
<tr>
<td>Demographic characteristics*</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>15 (33.0)</td>
</tr>
<tr>
<td>Mean (SD) age</td>
<td>34.38 (12.49)</td>
</tr>
<tr>
<td>Living alone</td>
<td>13 (28.9)</td>
</tr>
<tr>
<td>White British</td>
<td>43 (95.6)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>29 (64.4)</td>
</tr>
<tr>
<td>Clinical characteristics*</td>
<td></td>
</tr>
<tr>
<td>Previous self-harm</td>
<td>17 (37.8)</td>
</tr>
<tr>
<td>Psychiatric diagnosis</td>
<td>35 (77.8)</td>
</tr>
<tr>
<td>Alcohol use with self-harm</td>
<td>21 (46.7)</td>
</tr>
<tr>
<td>Illicit substance with self-harm</td>
<td>6 (13.3)</td>
</tr>
<tr>
<td>Mean (SD) scores on rating scales</td>
<td></td>
</tr>
<tr>
<td>HDRS</td>
<td>13.84 (7.36)</td>
</tr>
<tr>
<td>BPRS</td>
<td>22.56 (4.03)</td>
</tr>
<tr>
<td>BSIS</td>
<td>9.67 (5.03)</td>
</tr>
<tr>
<td>MMSE</td>
<td>29.16 (1.49)</td>
</tr>
<tr>
<td>AUDIT</td>
<td>11.43 (11.61)</td>
</tr>
<tr>
<td>Blood alcohol (mg %)</td>
<td>19.71 (50.86)</td>
</tr>
</tbody>
</table>

*Values are n (%) except for mean age.
we would have wished. In particular, it was not practical to attempt to assess the relationship between the initial rejection of treatment and a clinical diagnosis of personality disorder; this needs to be examined further.

Further research into the factors contributing to incapacity among men and women who have engaged in self-harm may enable more effective interventions to be devised to alleviate their difficulties. In the meantime, though, the implication of the findings reported here is that, both in emergency settings and in clinical practice more broadly, it may be helpful to patients who initially seem to lack capacity to consent if information relevant to the proposed treatment(s) is presented in a more structured and supportive way than is routinely the case. Such an approach may help to resolve the clinical and ethical dilemmas, which continue to challenge healthcare practitioners attempting to provide treatment for this vulnerable group of patients.

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CONTRIBUTORS
The project was initiated by RJ who designed the protocol, and collected and analysed the data, and prepared the first and final drafts of the paper. IC and AH helped in the design and development of the study and the drafts of the paper; AH also assisted in the assessment of interrater agreement. PW provided statistical advice throughout the duration of the project. CM provided practical advice and facilitated access to the participants, and MG provided legal advice, particularly around the wording of the information sheets. AH is guarantor.

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Competing interests: none declared

Ethical approval for the study was obtained from the Cambridge Local Research Ethics Committee (LREC 02/179). Following discussions with this Committee, and a medical lawyer, we decided to try to include both those with and without the capacity to consent to the research. Great care was taken throughout to ensure that the participants were assenting to their involvement.

REFERENCES
6 Re B. (Adult: Refusal of Medical Treatment) [2002] EWHC Fam, 429.