Computers, communication and confidentiality: tales of Baron Munchausen

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Abstract
The aim was to examine the use of computer and paper based systems in accident and emergency (A&E) departments in the management of patients who are frequent attenders. More than half of the A&E consultants in the Thames regions who were sent a questionnaire responded (44 of the 80). 82% of the respondents use such systems predominantly to monitor violent patients, those with Munchausen syndrome, and children on the “at risk” register. Systems currently in use fail to fulfil many of the functions that would be required of an ideal system. When using computers to store and communicate clinical data, several ethical problems were identified but these appeared to be outweighed by the practical need and were also present with paper based systems. Safeguards could also be built into computer based systems to reduce some of the ethical problems. Computer systems should be deliberately chosen and implemented in response to a specific management problem. The potential benefits should be weighed against possible damaging side effects, such as a breach of confidentiality.

Key terms: computer records; confidentiality; accident and emergency departments.

Among those patients who attend accident and emergency (A&E) departments there is a heterogeneous subgroup whose needs are quite different from those who attend following trauma or first onset of an illness. This subgroup is characterised by frequent attendance at one or more medical units and a complex and difficult clinical or social history. Typical examples would include patients with sickle cell disease, haemophilia, or a child on the “at risk” register. The subgroup also contains intimidating and threatening patients, those who may become violent, and those with Munchausen syndrome. Management of the subgroup as a whole is often hampered by the relative inaccessibility of past information. The use of a “black list” is an informal, unaccountable, and unverified response to part of this problem.

Difficulty with communication represents a major problem, not only for the process of diagnosis but also for providing continuity of care. Using computers to store and communicate clinical information across units, districts, regions, and potentially across the nation could be a reality in this country1 and provide an effective solution. This wide net of communication could be considered as a treatment in its own right.

Our hypotheses were (1) that there are many systems (of which the “black list” is but one) currently in use, (2) that the existing systems fail to fulfil all the functions required of them, and (3) that there are ethical and pragmatic obstacles to the development and implementation of such a system, but that these were outweighed by the clinical need.

Methods
To examine these three hypotheses the study obtained data from a sample of A&E consultants in the four Thames regions. A questionnaire was used to ascertain firstly how and what information they currently held on patients who were difficult to manage, secondly what an ideal computer system should provide in this area, and thirdly some of the ethical implications that these systems present.

In December 1992 a single questionnaire was sent to all 80 A&E department consultants in the four Thames regional health authorities. The questionnaire contained 17 closed questions. For 11 questions a positive response could be indicated and for six a Likert-type response was required. In addition, respondents were asked to comment on the name of systems in use in their department and to identify any ethical problems.

Of the 80 questionnaires posted, 47 (59%) were returned, 44 (55%) of which were usable. A postal survey was chosen because the data set required could be clearly defined and encoded, confidentiality of the respondents could be objectively assured, and the entire project could be carried out in a short time. (Copies of the questionnaire are available from the first author.)

Results
The results have been grouped under two headings: (1) the description of systems currently in use, together with the perceived attributes of an ideal system; (2) the ethical and practical issues related to the use of the hypothetical ideal system.

DESCRIPTION OF CURRENT SYSTEMS IN USE
Only 18% (8/44) of those responding did not keep records of those patients who are difficult to manage. The majority of the respondents (82%, 36/44) did keep records; 57% (25/44) used a paper based system, 16% (7/44) used a computer based system, and 9% (4/44) used both.
The questionnaire identified that the records were maintained informally on 37% (13/35) of the sites. On 37% of the sites (13/35) they were formally maintained by nursing staff, on 29% (10/35) they were maintained by medical staff, and on 11% (4/35) they were maintained by the receptionist. A record was kept of the personnel responsible for entering the data on 31% (8/26) of the sites, and on 69% of the sites (18/26) no such record was kept. When the hospital had received fax messages and circulars on difficult patients, only 7% (3/41) did not keep them.

Consultants were asked to identify firstly which types of patients are held on existing systems and secondly which patient groups should be held on an ideal system. These responses are shown in table 1.

When asked what type of system they would prefer, 7% (3/41) preferred a paper based system, 39% (16/41) a single stand alone PC in the department, 49% (20/41) a system attached to the main hospital system, and 5% (2/41) either a PC or a mainframe.

Responses showing the level of information held for each patient and the preferred level of information are shown in table 2.

**Table 3** Response to the question asking the degree of benefit in holding information on a computer system for different groups of patients who attend frequently.

<table>
<thead>
<tr>
<th>Patient group</th>
<th>Essential</th>
<th>Beneficial</th>
<th>Irrelevant</th>
<th>Detrimental</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical problem (n = 37)†</td>
<td>10 (27%)</td>
<td>24 (65%)</td>
<td>3 (8%)</td>
<td>0</td>
</tr>
<tr>
<td>Psychiatric problem (n = 34)</td>
<td>8 (24%)</td>
<td>26 (76%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Munchausen syndrome (n = 42)</td>
<td>18 (43%)</td>
<td>22 (52%)</td>
<td>2 (5%)</td>
<td>0</td>
</tr>
<tr>
<td>Social problem (n = 40)</td>
<td>13 (32%)</td>
<td>23 (58%)</td>
<td>4 (10%)</td>
<td>0</td>
</tr>
</tbody>
</table>

†n = number of respondents consulting.

**Table 4** Number of respondents who would support dissemination of patient details to differing areas around the country.

<table>
<thead>
<tr>
<th>Respondents supporting dissemination of data by geography</th>
<th>None at all</th>
<th>District</th>
<th>Region</th>
<th>Bordering regions</th>
<th>Nation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of responders (n = 42)</td>
<td>0 (9%)</td>
<td>6 (14%)</td>
<td>17 (40%)</td>
<td>3 (7%)</td>
<td>16 (38%)</td>
</tr>
<tr>
<td>Cumulative total</td>
<td>0</td>
<td>42 (100%)</td>
<td>36 (86%)</td>
<td>19 (45%)</td>
<td>16 (38%)</td>
</tr>
</tbody>
</table>

When asked if they would support dissemination of patient details to differing areas around the country, 9% (4/42) of respondents would not support dissemination to any area, 14% (6/42) would support dissemination to the district only, 36% (15/42) would support dissemination to the region only, 5% (2/42) would support dissemination to the bordering regions only, and 14% (6/42) would support dissemination to the nation only.
systems appear to be varied. A comparison
between the types of patients and information
currently recorded on a system and what would
be required on an ideal system (tables 1 and 2)
show that current systems are far from ideal
and fail to fulfill the functions required of
them.

ETHICAL ISSUES

Despite their widespread use it was evident
that the systems were not free of ethical
difficulties. A significant minority (41%) felt
that there were some ethical problems associ-
ated with these systems. The most consistent
and frequent concern was maintaining con-
fidentiality. The clinical information itself can
cause harm once it has been linked to the given
individual outside the clinical domain. With
well developed systems there are practical ways
in which access can be restricted. Further
areas of concern are the quality of the
information and the effect of this information
on patient management. The information held
on the patient represents a model of the real
patient. The degree to which this model is
accurate will depend on the complexity, quality,
and quantity of the information held, which
would in turn be determined by the system and the
frequency with which the data were refreshed.
What is not clear is optimum amount of informa-
tion, as more is not always better. Further work is
needed in this area, but it would seem sensible to
start with the data set requested by clinicians
given in table 2 above.

If the information system is regarded as a
measure in its own right this emphasises the
need for adequate training, not only in the
mechanics of extracting appropriate data from
the computer, but, more importantly, in how
to integrate this information appropriately into
clinical decision making. For the majority of
patients the ethical problems associated with
the use of the system can be circumvented by
the use of informed consent. The most
significant exception to this is the patient with
Munchausen’s syndrome.

The successful management of a patient
with Munchausen’s syndrome appears to have
three phases in common.\textsuperscript{6,7} The first is
to collect sufficient information to make a
diagnosis. The second is to contain the patient
emotionally and, if necessary, physically, so
that a supportive, planned, and non-punitive
confrontation can be achieved. The third stage
is to continue containment and long term
support.

Work in other fields\textsuperscript{11} has shown that the
expediency offered by a computer system over
a paper based system is not the ethical issue.
The key ethical issue is whether confidential
information can be communicated between
different clinical units without the patient’s
consent. From our survey it is evident that
confidential information on patients is already
disseminated widely, as 74% of the respondents
keep a record of patients with Munchausen’s
syndrome, and 93% keep records sent to them
on difficult patients by other units. Further-
more, 95% of respondents believe that a
computer tracking system is either essential
or beneficial in managing patients with
Munchausen’s syndrome. Some system that
communicates information on these patients
would appear appropriate, as the alternative is
to leave what is regarded as a psychiatric
illness\textsuperscript{12} untreated, with the attendant mor-
bidity, mortality, cost to society, and occasion-
ally damage to other individuals.\textsuperscript{13}

Attending health care workers have a
responsibility not to use the information they
obtain from the system in a punitive manner
which is likely to perpetuate the cycle of self
discharge and readmission. This can be achieved
by training and by having a clearly stated
management policy for the unit.\textsuperscript{14}

Conclusion

Patients who attend A&E departments fre-
cently can present a challenging management
problem. There is widespread use of systems
that provide additional clinical information on
these patients, thus improving communication
between different doctors. This is a response to
the difficulties in managing these patients and
a course of action that appears to have wide-
spread support. Now that it is cheap and easy
to access any computer remotely through a
modern it may be appropriate and cost-
effective to develop a universal system that
would function in a more structured manner,
with safeguards to protect both patients and
clinicians. There are technical ways in which
the ethical difficulties associated with such a
system could be reduced.

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