

Final Report

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Review of Consumers' Perspectives

On

Electro Convulsive Therapy

Service User Research Enterprise (SURE)

Institute of Psychiatry

Commissioned by Department of Health

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Review of consumers' perspectives on ECT

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EXECUTIVE SUMMARY

Introduction

In June 2001, the Service User Research Enterprise (SURE) at the Institute of Psychiatry was commissioned to conduct a review of consumers' perspectives on ECT (Electro-convulsive therapy). The review team included clinicians and consumers. Both consumer members of the team have direct experience of ECT. This commission forms part of a wider Review of ECT being undertaken on behalf of the Department of Health.

ECT is a treatment that attracts controversy. There is a consumer viewpoint that is highly critical of ECT. However the Royal College of Psychiatrists' fact sheet on ECT maintains it is a safe and effective treatment that is sometimes life-saving.

Aims

This Review will focus on the following aims:

- Systematically to describe and summarise consumers' perspectives on ECT
- To understand the sources and nature of the controversy about ECT between some consumers and professional bodies representing practitioners of ECT.

The review has the following four themes:

- Persistent memory impairment following ECT (chapter 5)
- Consent and information about ECT (chapter 6)
- Perceived benefits of ECT (chapter 7)
- Emotional responses to the experience of ECT (considered in chapters 5, 6 and 7)

Assembling the material

The following sources of information were used:

- Studies that have tried to ascertain consumers' views about ECT in their own terms.
- 'Testimonies' or first-hand accounts of the experience of receiving ECT, sourced from internet sites, various print media and a video archive
- Advice from an internal Reference Group

Methodological evaluation

35 research studies were identified. Nine were reports by individual consumers, consumer organisations and collaborative works, the remainder were 'attitude' studies conducted by clinical researchers. All the studies were reviewed in terms of their methodology and found

to be very diverse and of variable quality. All the studies start with certain assumptions and values concerning ECT and this leads to both differences in the participant selection and interpretation of data.

Testimony data is now available in a wide variety of formats including a video archive and ‘threads’ of correspondence sourced from email forums. E-mail forums introduce the arena of group discussion or beliefs into the data. The contexts in which the testimonies are elicited do constrain what can be expressed and how it is expressed. However the different sources each provide checks on the perspectives expressed in the other formats.

Template for analysis of consumer perspectives on ECT

A template for analysing the substantive themes was developed which ensured that no single approach to ascertaining consumers’ views on ECT was privileged. Where research studies using a range of methodologies produce similar results, the review makes a statement of the form ‘at least, X% of consumers experience Y’. Where different methodological contexts produce different results, conclusions cannot be drawn with confidence. The different strategies used by clinical and consumer research to summarise data are also examined to see how diverse conclusions may be reached on the basis of very similar data.

The quantitative analyses are combined with the testimony data, using a form of qualitative analysis that occupies a middle ground between formal content analysis and discourse analysis. It takes from content analysis the existence of a set of themes decided in advance of examination of the data. At the same time, discourse analytic methods allow the content and detail of themes to emerge from the data and attend to the interactive nature of e-mail forums and interviews.

Combining research and testimony data gives more confidence when similarities of results are disclosed. Conversely, discrepant data from a range of sources must be treated with caution.

Persistent memory loss

In all types of information gathered for the Review it is evident that memory loss is a persistent reported side effect for at least one third of recipients of ECT. For some people, memory loss causes great distress and profoundly affects their sense of identity. Despite a considerable overlap in basic data, clinical and consumer studies tend to be polarised in their conclusions. Clinical research typically refers to a ‘minority’ or judges the problem to be insignificant or limited whereas consumer research concludes that persistent memory loss is a significant problem for the recipients of ECT.

Neuropsychological assessments of memory loss following ECT used in standard clinical studies tend to measure encoding and retrieval of information learnt after receiving ECT. This is called anterograde memory. Few studies measure the loss of memories which were laid down prior to the ECT (retrograde memory). However, consumers' accounts of memory loss, which correspond across all forms of testimony data, focus on the distress caused by the absence of significant portions of retrograde biographical memory rather than anterograde problems. All attitude research studies report substantial proportions of consumers experiencing this persistent memory loss. Even when levels of depression are controlled in these analyses, significant numbers of people who have received ECT are found to have memory loss into the organic ranges on a number of memory tests.

Information and consent

In almost all research papers, there is a consistent finding that 45-55% of users feel they have been given an inadequate explanation of ECT. There are even higher figures from some consumer-led research. This may be because their sample is drawn from a pool of people who have high expectations about what level of information should be provided about ECT.

It is not clear how more detailed information might impact on consumers' decisions to undergo ECT. In the past information has mainly been provided by treating doctors or leaflets written by professional bodies. More recently the internet has become a new source of information. A short period on the World Wide Web will yield information about ECT from an extremely wide range of sources. There are strong indications from the testimony data that the Internet will have a dramatic impact on whether consumers decide to consent to ECT.

On the question of consent, it is reasonable to conclude that a significant number of patients who sign a form consenting to ECT do so under pressure or in the belief that they cannot refuse. Some clinical papers argue that even though many patients felt they had no choice or where resigned to consenting to ECT they were nevertheless content to leave the decision to their doctor. Other evidence suggests that consumers lack the confidence to contradict the prescriptions of professionals even when they wish to do so.

This Review had difficulty in assessing the effects of legal compulsion because of cross-national differences in sample structures, the nature of the data and the variable proportions of consumers subject to legal compulsion between studies even within the UK.

Perceived benefits of ECT

Methodological variables exert a powerful effect upon consumers' expressed satisfaction with ECT. This conclusion can be drawn with confidence particularly in relation to *when* consumers are asked about or express their view on having the treatment again. In clinical and consumer research studies and in the testimony data, the length of time that has elapsed since treatment is strongly associated with expressed satisfaction. Studies which interview consumers immediately after treatment, especially if they do so in a medical setting, using brief interviews, conducted by the treating doctor, over-estimate to a considerable degree the extent of satisfaction with ECT. Estimates of 80% to 95% of consumers as content with the treatment are, in the judgement of this Review, not valid.

The testimony data makes it clear that 'perceived benefit' from ECT may be both discrepant from and much more complex than clinical concepts of symptom improvement. The testimony data does display a continuum of opinion about perceived benefits. However 61% of those providing testimonies said they would not have ECT again and 43% describe their experience of ECT in extremely negative terms. In addition there is evidence that individuals who would have ECT again will tend to trade-off benefits and risks. For example some consumers say that they are willing to suffer a degree of permanent memory loss in exchange for some relief from depression. Some consumers may be so concerned with the manner in which the treatment was given that whether or not it helped them is not the major issue. There is not a uni-dimensional 'consumer attitude towards ECT' even on the question of whether or not it is helpful.

The testimonies uncovered issues that are never touched upon by clinical research. These include extreme trauma, lying about improvement in order to stop treatment, becoming manic or feeling more suicidal following treatment, the desire to take legal action and the need to seek support and validation from other individuals and organisations.

Conclusions

Consumers who are opposed to ECT are often characterised as a vocal minority. However, this Review found that dissatisfaction with ECT maybe more widespread than is often supposed. Consumers' views are not simple and there is no one 'consumer perspective' on ECT. However, of those providing testimonies, few were equivocal about the treatment, .

Professional failure to acknowledge the different facets of dissatisfaction on the part of recipients of ECT may be a reason for the emergence of organisations providing support and a

forum for those who experience the treatment as negative and coercive.

Future research

It is clear from the review that there are many methodological inadequacies in the studies of ECT. The variation in the complexity of the questions, the timing of the assessments and the professional status of the interviewer need to be considered in the design. Future research questions should include:

- What is the extent of autobiographical memory loss?
- What information on the treatment would potential recipients require in order that they feel adequately informed?
- What trade-offs in benefits and risks are likely to be made by consumers leading to their acceptance or refusal of ECT?
- What are the limits of these trade-offs in relation to compulsion?

The answers to these questions have implications for service provision in relation to information, choice, support, and help for any unwanted effects should a consumer undergo ECT.

CHAPTER 1

INTRODUCTION

BACKGROUND

In June 2001, the Service User Research Enterprise (SURE) at the Institute of Psychiatry was commissioned to conduct a review of consumers' perspectives on ECT (Electro-convulsive therapy). This commission forms part of a wider Review of ECT being undertaken on behalf of the Department of Health.

There exists a psychiatric consensus which holds that ECT is a safe, effective and sometimes life-saving treatment, exemplified by the Royal College of Psychiatrists Factsheet on ECT (see Appendix 6). There is also a clear and sometimes very public consumer viewpoint that is highly critical of ECT. In the context of such polarisation, this Review will focus on describing as comprehensively and systematically as possible what is known about users' views regarding the treatment and attempting to understand the sources of controversy.

AIMS

1. Systematically to describe and summarise consumers' perspectives on ECT.
2. To understand the sources and nature of the controversy about ECT between some consumers and professional bodies representing practitioners of ECT.

To accomplish the above Aims, the following sources of information will be used:

1. Studies that have tried to ascertain consumers' views about ECT in their own terms.
2. First-hand accounts of the experience of receiving ECT, unedited or commented upon by others. These will be called 'Testimonies'.
3. Advice from an internal Reference Group (RG) composed of user representatives of organisations with an interest in ECT (including organisations who are in favour of ECT) and researchers who have conducted work on ECT from the consumer's perspective and/or have expertise in qualitative research.

CONTEXTS

Rise of the user movement and consumer-led research

Consumer groups are engaged in a range of activities all designed to put forward the consumer perspective on mental health services. The number of groups and the scope of their activities have grown rapidly in the last 15 years. A recent survey (SCMH, personal communication) has identified more than 1,000 consumer groups in England. It is

government policy that consumers should be involved in policy development. In this context, the aim of consumer-led research has been to establish users' views on the whole variety of mental health services. Consumer-led research is distinguished from more traditional research in that the researchers are themselves consumers. Consumers also conduct critiques of orthodox research.

Previous research

In 1986, two review papers appeared that described studies on attitudes towards ECT (Freeman, 1986; Freeman and Cheshire, 1986). Freeman (1986) focused particularly on the attitudes of users and included in his review a paper authored by a recipient of the treatment. He identified five studies that had assessed consumer attitudes up to 1986, all of them conducted by clinical researchers.

The present Review has located 21 clinical research studies published since the 1986 reviews and an additional nine reports from consumer or voluntary organisations or consumers collaborating with clinical academics. These consumer studies only began to appear eight years ago and most were not identified by any formal search procedure.

Dimensions of new technology

New technology such as video and the internet have increased the ability of consumers and organisations which represent them to both produce and access digital information. The internet has extended these networks internationally and made it much easier for individuals to become active participants in debates about treatments and services.

Summary

The emergence of consumer-led research and of a mental health consumer movement have changed both the context for a contemporary review of consumers' perspectives on ECT and its actual content. New information technologies have broadened fundamentally consumers' access to information about ECT and enabled them to express their views about their treatment in new formats and in new ways. Both these developments mean that there have been profound changes in the scope of a Review such as this since the initial ones were published in 1986.

STRUCTURE OF THE REPORT

There are two main sections to the report. The first is methodological and begins by describing the strategies used to assemble the material for the review. There follows a methodological discussion of both the research studies and the testimony data. Difficulties

encountered in compiling the research studies made this an essential part of the Review. Without this, it would not be possible to assess the specific findings and results with sufficient clarity. Similarly, the new formats which testimony now takes require further methodological discussion on which to base the subsequent analyses.

The body of the report comprises the main findings. It is a summary and analysis of specific issues or themes concerning ECT of interest to consumers and the DH Review generally. The themes are summarised and analysed by means of a consistent template that is described in chapter 4. They are:

- Persistent memory impairment following ECT
- Consent and information about ECT
- Perceived benefits of ECT

The additional theme of emotional responses to the experience of ECT will be considered in each chapter.

These themes or ‘outcomes’ are clearly different to those investigated in most clinical research. There is overlap between the two types of research in some specific areas such as the assessment of treatment benefits. But whereas clinical research tends to measure this as changes on symptom rating scales, consumer-led research asks about the consumer’s own perception of benefit.

The report concludes with a summary of what can validly be said about consumers’ perspectives on ECT and questions that remain open and require further research or review.

CHAPTER 2
ASSEMBLING THE MATERIAL

General inclusion criteria

1. Research participants and all consumers who provide testimony have received ECT.
2. The research ascertains consumer views by asking directly about experience of ECT.
3. Papers have a publication date of 1975 or after.
4. All materials are in the English language

RESEARCH STUDIES

DATABASES

Four initial databases were used to compile a list of studies. Where the database included a facility for mapping search terms onto subject headings, this was used. Free text searches were always used. The databases were: Psychinfo, Medline, Web of Science and the King's Fund.

Search strategies

Main search term	Subsidiary term	Main search term
ECT		Client / Patient Attitudes
(Electro-convulsive therapy)	Memory loss	(Client satisfaction)
(Electro-shock therapy)	Information	(Client rights)
(Shock therapy)	Consent	(Treatment drop-outs)
	Benefit/helpfulness	

Table 2.1: Search strategy for identifying research studies

Each database was searched once with the main terms. Subsidiary terms were added individually.

Scientific databases: search results and problems

The initial searches delivered 16 studies but it was known that some UK research had not been located. The Royal College of Psychiatrists' website journal pages were then searched to identify work that might have appeared in the British Journal of Psychiatry or Psychiatric Bulletin. Photocopies of the articles located were obtained. It became clear that referencing of previous work was extremely patchy in most papers. The bibliographies were therefore

searched by hand to locate additional work. The process led to a final set of 26 clinical research studies. Nearly all the empirical papers take the form of ‘attitude studies’ using the concepts and techniques of social psychology. There are two review papers and one based on four case histories.

Two sets of studies were ambiguous regarding the inclusion criteria of eliciting consumers’ views *in their own terms*. In the first set, Cowley (1985) and Lisanby et al (2000) heavily filter the views expressed by their respondents through additional criteria of the researchers. Although apparently violating inclusion criterion 2, these papers were included on the advice of the Advisory Group.

In the second set, research aiming to educate consumers about ECT (eg. Battersby et al, 1993) assumes that the researcher’s views about the treatment are correct and studies consumer views from the perspective that differences between these and the researchers views are misconceptions and reflect a need for education about ECT. Educative research was included on the advice of the Advisory Group.

Subsidiary themes

Adding the subsidiary themes into the main search always reduced the results to zero. Therefore, studies addressing particular themes had to be located by hand.

King’s Fund Library

There were nine entries in the King’s Fund library under ECT or a synonym. One was a research papers written by social scientists (Rogers and Pilgrim, 1993) and conducted in collaboration with MIND. The others were review or policy documents. Four were from MIND and included quotations from ECT recipients. However, most of these were taken from Rogers and Pilgrim.

Locating consumer-led research

Consumer-led research is rarely published in the peer-reviewed literature. It was anticipated that the King’s Fund holdings would include consumer-led work but this was not the case. SURE therefore used its own prior knowledge and contacts to assemble this part of the research database and asked the Reference Group for assistance. Nine consumer-led or collaborative studies were identified.

All but one of the consumer-led studies was conducted in the UK and so there is a possibility of publication-bias here.. Three of them included ECT as part of more general surveys of

consumer views of treatment in psychiatry (Rogers and Pilgrim, 1993; MHF, 1997; MDF, in press). Although, it was not possible to identify the methodology for ECT Anonymous survey, it was included on the advice of the Advisory Group. The US study (Donahue, 2000) is a review of the literature on memory loss following ECT conducted by a consumer who experienced severe memory loss following her own treatment. This paper, the only one picked up through the Medline and Psychinfo searches is, in our view, very thorough.

Research studies - conclusions

The final set of 35 research studies is described in Appendix 1. Some of the difficulties encountered in assembling this material implied at an early stage that it was not a systematic body of work. Papers are not always mapped onto subject headings consistently in the scientific databases. Referencing of previous papers is poor and the emergence of user-led research that does not appear in the peer-reviewed literature makes the picture even more complex.

ASSEMBLING CONSUMER TESTIMONY

Testimony was defined as an individual speaking or writing directly about their own personal experience of ECT. Such testimony might be contained in a variety of source materials: articles in consumer group newsletters, on websites and e-mail discussion forums, as part of oral history archives and so forth. Consumer group campaign literature was generally not admissible. However, if it contained individual testimony as defined above this was included.

There is obviously a problem of selection-bias with material gleaned from the internet. However, contrary to expectations, e-mail forums are very lively and the very anonymity of the internet seems to allow people to contribute as they like. Some are very supportive and some downright angry. We also conducted a positive search for favourable testimonies.

A total of 139 testimonies contained in a variety of media were finally included and analysed for the review. They were assembled in the following way:

Electronic searches

Internet

The Worldwide Web was approached in much the same manner as a consumer or potential consumer of ECT might if they were looking for information about ECT. Searches using the term 'ECT' or 'Shock treatment' were done via the popular search engines YAHOO, Lycos and GOOGLE. The following websites were identified as appearing repeatedly in the results:

www.ect.org

www.members.aol.com/noshock

Testimony appeared on the websites in the form of personal accounts of ECT. Newspaper and magazine articles were also available either as part of the website or via hyperlinks. It became clear that most of these websites were opposed to ECT and so a specific search was undertaken to try to find testimony which was favourable to ECT. This search concentrated on non-consumer sources, such as public health and hospital sites. Some admissible material was located, the main website being:

www.healthyplace.com/depression/ect

E-mail forums

The chief sources of testimony from the web sites identified were e-mail forums. These allow people to post e-mail messages that can be read by anyone who accesses the forum. In addition visitors to the forum can post their own messages, creating 'threads' of messages.

Legal testimony

Several websites had links to legal cases in the USA where advocacy groups were attempting to prevent an individual from having ECT without consent. If these contained a consumer's accounts of their own first-hand experience, they were included. Several public health hearings about ECT in North America had consumer depositions that sometimes contained first hand testimony. Legal testimony is clearly not unbiased but it can bring forward issues that do not come to light in other forms of testimony.

Newspaper database

The Proquest Newspaper database contains a complete record of: Daily and Sunday Telegraph, Daily and Sunday Mail, Evening Standard (London), Financial Times, Guardian, Independent (London), Observer and Daily and Sunday Times. It was searched on 13th June 2001, between that date and 1st January 1999 using the search terms 'ECT' and 'Shock Treatment'. This search yielded 21 results but very few articles contained admissible testimony.

Reference group

The Reference Group was asked to suggest possible sources of testimony. This resulted in a large amount of printed material and a further website:

www.mindfreedom.org

By request to other organisations and individuals

A message asking for testimony was posted on *Uksurvivors egroup*, a US notice board and to contacts in Canada. The voluntary organisation, *Mental Health Media* was contacted and asked to supply any testimony held in their library. Sara Dunn, editor of *Open Mind*, *National MIND*'s bi-monthly magazine, was asked to give references for any issues that contained ECT testimony. These networks produced additions to the internet material and two further sources of testimony.

Mental Health Media Testimony Archive

The Mental Health Media Testimony Archive contains 50 four-hour interviews with people who have experience of long-stay psychiatric institutions in all parts of the UK. The interviewers were all themselves consumers. The archive is in the form of videotape, full transcripts and transcript summaries. The material is held at the British Library and by Mental Health Media. The entire archives' transcript summaries were read and 23 that contained substantial references to ECT were selected. The full transcripts for these 23 interviews were then searched on disc and the sections that related to the individual's experience of ECT were extracted.

Miscellaneous testimony

This consists of material from local consumer group newsletters, consumer-authored chapters in books and collections of accounts of ECT. It is not comprehensive as an attempt to extensively cover a literature that is very locally distributed would be impossible. However, it does distil the main points made in a much wider network of accounts according to both the Reference Group and the experience of the authors.

CONCLUSION

In the case of research studies, the aim has been to identify all clinical 'attitude' studies published in the English language and all consumer-led research based in the UK. For testimony, the aim has been to be representative not only of different opinions but of the different formats in which such first-hand accounts are now available. The representation of formats is not the same as the representation of experiences. However, we felt that using the internet might cast light on the forms and content of experience that is being increasingly represented on the world wide web.

CHAPTER 3

METHODOLOGICAL EVALUATION

RESEARCH STUDIES

Appendix 1 lists the 35 research studies referred to in chapter 2 in date order and according to basic aspects of their methodologies. From here on studies will largely be referenced by their number in Appendix 1. A simple inspection of the table makes clear the methodological diversity entailed. The social science literature (Kidder and Judd, 1986) demonstrates that the conditions under which attitudes or beliefs are elicited can influence the resulting data. This chapter will consider methodological issues that may have a bearing on the substantive analyses.

Basic assumptions

There are several studies (eg. 6, 12, 15, 18) where ‘correct knowledge’ is explicitly defined with reference to a psychiatric consensus or to standard psychiatric textbooks. This is then set against the ‘myths’ about the treatment that are said to be widespread in society. The commonest hypothesis is that actual experience of the treatment changes attitudes in favour of ECT. This starting point of many studies has an impact on the design and analysis of the research.

The consumer surveys also make assumptions about the ‘real’ experience of consumers, claiming that this is often at variance with how it is perceived by many clinicians. Consumer surveys are frequently criticised because they are based on anecdote or ‘subjective’ accounts. However, the scientific work has its own built-in assumptions and values.

Consumer and clinical research

Two comparative studies have examined the responses of interviewees according to the status of the researcher (Clark et al, 1999; Polowycz et al, 1993). Using randomised designs, both found that users were more critical about mental health services when the interviewer was a fellow consumer rather than a professional. Column 7 in Appendix 1 describes the setting where attitudes about ECT were elicited and who, if anybody, conducted the interview. According to the above studies, if satisfaction interviews are conducted by a doctor at the treating hospital, it is more likely that some will be reluctant to express negative views held about their experience.

Sampling and selection bias

Consumer surveys are often criticised on grounds of selection bias. This charge is made as there is no way of knowing who responded to the surveys. It has been suggested (28) that only those with negative experiences will be motivated to complete them as they come from organisations with known doubts or outright hostility towards the treatment. It is impossible to calculate response rates to these surveys as they are typically distributed through membership networks (23, 33, 37) and are only relevant to those with experience of the treatment.

However, clinical research studies may not entirely avoid the problem of selection bias. Some patients have ECT as a relatively routine treatment and maintenance ECT is frequent in some countries. People who have ECT routinely at the same hospital *because they feel it helps*, are more likely to appear in cross-sectional designs which thereby over-select satisfied customers.

Sample structure

Appendix 3 details the demographic characteristics of the study samples as well as UK norms for the use of ECT in the first three months of 1999 (DoH, 1999). There is wide demographic variation in the groups and no sample that mirrors UK norms. This may affect some results and will be referred to where appropriate.

Interval since ECT

In the clinical research, some users are interviewed about their satisfaction with ECT within days of treatment. In other cases, the interval between treatment and interview is several years. This may have consequences for consumers' views about ECT. If treatment is immediately helpful, users are likely to be positive. If the interval between treatment and satisfaction interview is long, return of depression or time to reflect on the experience may diminish favourable attitudes. For the consumer surveys, it is clear (23, 24, 33) that the interval is typically a number of years.

Construction of Questions

There is little attempt to replicate the questions asked of consumers across studies. Since questions vary widely, there is a dilemma about what counts as the 'same question'. Question design is a possible source of bias in studies of any type, but the consumer questions to which we have access (23, 33, 34) are relatively simple and this is true also of some questions reproduced in clinical papers (26, 30). It is in the quasi-experimental designs that the statements put to users are more clearly value-laden (6, 12). For example, Kerr et al (1983)

included the questions: ECT turns patients into zombies. They do not discuss the fact that 19% of their ECT recipients agreed with this statement.

How are attitudes about ECT distributed?

This simple question cannot be answered as the types of quantitative scale vary widely between studies. There are dichotomous scales (6, 26), likert scales (16, 18), semantic differentials (2) and complex interviews (3, 14). The nature of the scale may pre-determine the distribution of responses: dichotomous scales force polarisation. This is significant as it is often suggested that attitudes are polarised or that those with negative experiences are a small minority. Again, attitudes to ECT may not be organised on simple dimensions at all. But may be fluid and contradictory. Research that takes a more qualitative approach (17, 19, 29) suggests that users often qualify or even contradict statements made at one point in time with later ones and that consumer beliefs about treatments are complex.

Analysing data

There is a clear difference between most consumer research and that done by clinicians in the way information is analysed and summarised. Most consumer work adopts the strategy of reporting descriptive statistics on each question and then giving examples of quotations that show what these statistics 'mean' in terms of experiences with ECT. In contrast, clinical research often undertakes statistical analysis of its data. Commonly, the quasi-experimental designs report group differences but not group frequencies of response (12, 15). Although not unusual in scientific writing, the lack of raw data makes it difficult to know how many people depart from the main conclusion drawn. This main conclusion is usually that direct experience of ECT changes attitudes in a positive direction. When some raw data are reported (6, 12, 18), it is clear that a proportion of consumers continue to endorse 'myths' but this is never discussed.

Research studies – summary

Most of the work reviewed here is methodologically flawed. Rather than building on the quite thorough and descriptive early work of Freeman and Kendell, later studies contain a range of methodological pitfalls. Secondly, the different studies cannot be grouped as 'scientific and value-neutral' on the one hand and 'biased and self-selecting' on the other. All start with certain assumptions and values concerning ECT although, again, the degree to which this is done varies. Finally, despite the different assumptions on which clinical and consumer-led research are based, the methodological diversity of the work extends beyond a neat clinical / consumer dichotomy.

TESTIMONY

The testimony material is clearly not filtered through the kind of research protocols that were documented above. However, this does not mean that it is entirely unstructured. The contexts in which the testimonies are elicited do constrain what can be expressed and how it is expressed. It is also apparent that some e-mailers flood the internet with their posts and so the material from the internet cannot be called 'representative'. We have dealt with the existence of repeated e-mailers by counting their contribution once only but this does not resolve the problem of people who read posts but do not contribute.

Email Forums

E-mail testimony is distinguished from research data by its immediacy and interactive nature. It can violate the rules of grammar and narrative by using a short-hand that increases its 'group' quality. The forums use the term 'threads' to refer to series of messages that are like dialogues. The forums are sometimes less spontaneous than 'live' discussions as they are 'moderated' according to the list's ground rules. The moderator may stop very heated exchanges if they contain personal attacks. However, e-mailers are clearly able to criticise others' views due to the anonymity of the format.

The Testimony Archive

Lengthy conversations from the Testimony Archive will clearly result in a different form of information to an e-mail message. Firstly, the Testimony interviews were posed very generally and the interviewer only pursued the topic of ECT if the interviewee raised it. Secondly, although the distinction between 'quantitative' and 'qualitative' techniques of eliciting experience is often over-stated, the format of such a long interview provides scope for reflection on past experience. This 'biographical' approach is used increasingly in the social sciences (Smith, 1994).

Interval since ECT

The testimony data presents the same problem as the research studies. Some individuals in the e-mail forums have only just finished their course of ECT or are even still undergoing treatment. Consumers in the Testimony Archive will usually have experienced ECT years or even decades before. Although their treatment might be deemed out-dated (30), the interview format does not 'freeze' experience in the way other formats do. It also allows scope to reflect on the experience.

Legal depositions

Legal depositions have a legal purpose and in the case of those collected here it is to prevent compulsory ECT or to review its use. They are clearly heavily filtered through the prism of their legal purpose and this will be discussed where relevant

Testimony – summary

The variety of contexts in which testimony data is now available is a methodological strength. The different sources each provide checks on the perspectives expressed in the other formats. E-mail forums particularly introduce the whole arena of group discussion or beliefs into the data. This is currently central in social psychology, the discipline on which the attitude research rests.

CHAPTER 4

TEMPLATE FOR THE ANALYSIS OF CONSUMER PERSPECTIVES ON ECT

The aim of this chapter is to produce a template for analysing the substantive themes outlined in the Introduction. These are: memory loss, information and consent, perceived benefit of the treatment and emotional reactions to ECT. Initial themes were first identified by the Review team and then refined by both the Reference Group and the Advisory Group.

The themes represent issues or ‘outcomes’ that are priorities for consumers and indicate the different value structures of consumers and clinicians in relation to ECT. The paramount question for clinicians is the effectiveness of the treatment and this clearly matters to users as well. However, the other issues identified may assume equal importance from the perspectives of consumers. Emotional reactions to ECT will also be explored for each of the three themes. In clinical research, this is usually only examined in terms of anxiety about treatment itself. However, in consumer research and testimonies it is clear that other emotions may also be involved, at the time of treatment or subsequently.

Emotional reactions are accessed in qualitative research through analysis of the language in which they are expressed. Free comments, such as testimonies, may simply describe an experience – e.g. persistent memory loss – but may also elaborate that experience in a language that reveals how the person has responded to it emotionally. The analysis of emotional language has been given equal weight to other forms of information in this Review because qualitative research routinely conducts such an examination of its data.

Research evidence

35 studies have been assembled in total but a much smaller number will give basic numerical results on each theme. For the first two themes, the analyses will usually describe the proportion of people whose experience was *negative* or of concern to them. For the theme of perceived benefit the proportion of people who had *positive* experiences will be the focus. Because it is known that the studies vary methodologically, it is likely that they will vary likewise even in very basic findings. So, it will not be possible to ‘measure’ the extent of negative or positive experiences in any precise fashion. It would not be justified to take an average or mean of all relevant data. However, this is not a counsel of despair – that nothing can be said. Where research studies using a range of methodologies produce similar results, it is reasonable to make a statement of the form ‘at least, X% of consumers experience Y’.

Even if descriptive statistics show some consistency across studies, the conclusions drawn about users' experiences of ECT may still differ because of further analysis performed on the data. The different strategies used by clinical and consumer research to summarise data can then be examined to see how diverse conclusions are reached.

Analysing testimony

The quantitative analyses will be combined with the testimony data, using a form of qualitative analysis that occupies a middle ground between formal content analysis and discourse analysis (Bauer and Gaskell, 2000). It takes from content analysis the existence of a set of themes decided in advance of examination of the data. At the same time, discourse analytic methods allow the content and detail of themes to emerge from the data and attend to the interactive nature of e-mail forums and interviews.

The set of key themes are organised as a grid. The themes form the horizontal axis of the grid and the individuals whose experience is represented form the vertical axis. As well as the testimony itself, additional information is noted where this is available. This information includes gender and age as well as the length of time since completion of treatment. Each source of testimony has its own grid so that features of the participants, the internal patterns in the text and the balance of opinion can be examined. This will also enable a comparison, for example, between different e-mail forums (cf. Appendix 4).

The extent to which each theme appears in each grid will be ascertained. This will be done quantitatively in terms both of the proportion of individuals who mention the theme and the balance of negative to positive experiences. For the e-mail forums, if one individual is sending e-mails repeatedly their contributions will be counted only once.

The inter-rater reliability of allocating testimonies to categories in the grids was assessed with a sub-set of 25 testimonies coded independently by two raters. Agreement was high at 83%.

Illustrative quotations from these analyses will be presented for each theme and any sub-themes. These will be chosen to represent views that appear often but not because they are particularly articulate expressions of an experience. Because of the grammatical and narrative structures peculiar to e-mail and also spoken testimony, these quotations will be reproduced exactly as printed on the internet (including transcripts from the Testimony archive). To preserve the flavour of these testimonies, the orthodox 'sic' will not be used.

The dominant theme

Preliminary analysis showed that persistent memory loss was the most frequently mentioned theme in the testimonies and so this comprises the first substantive chapter. The analysis of combinations or concordances of themes will take persistent memory loss as the main topic with which other themes may be combined. Patterns of concordance will be examined for each individual and each grid and summaries presented. Additional qualitative analysis will indicate the emotional tone of reported experience in terms of the content and strength of the language used, as discussed above.

CONCLUSION

This template for analysing the substantive themes does not give an advantage to any one approach to ascertaining consumers' views on ECT. The attempt is to rest with the aims of *describing* the views of consumers and understanding controversy. The extent of methodological diversity uncovered means that it is reasonable to be modest, to ask some basic questions about the 'consumer's perspective on ECT' and supply some provisional answers.

The diversity of conditions under which attitudes towards and experience of ECT have been elicited and expressed will be an occasion for caution but may also sometimes be a strength. If a range of different research designs and formats for testimony reveal consistency of attitudes and values about ECT, then it may be concluded that these are a significant perspective. But if it appears that the findings are contingent on protocols and formats, the conclusion that any one of these findings is significant must be treated with caution.

CHAPTER 5

PERSISTENT MEMORY LOSS

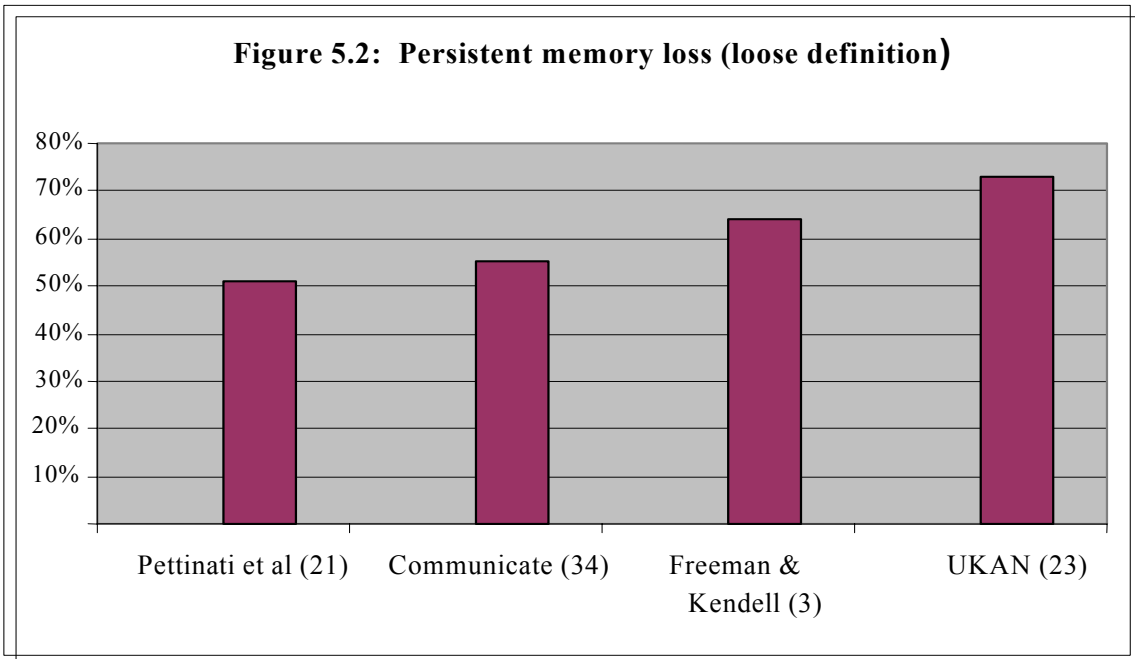
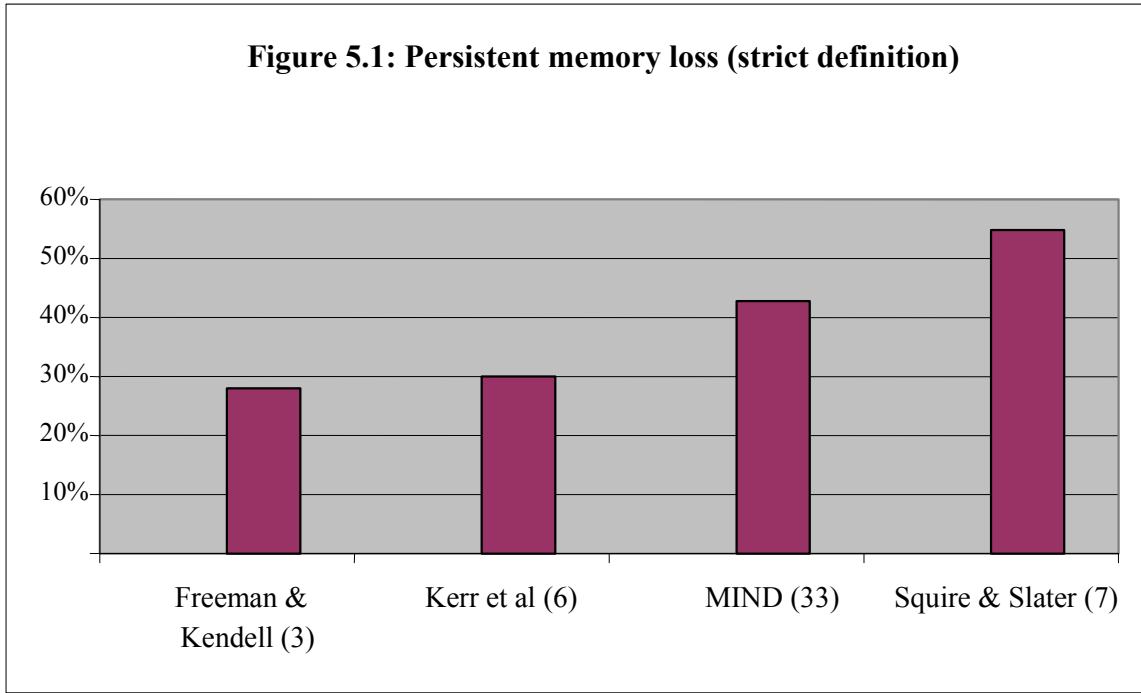
RESEARCH STUDIES

Long-term memory loss was defined as subjective amnesia or gaps in memory still present at least six months after the course of treatment. 20 papers or reports made reference to long-term memory loss following ECT in their abstracts or had a section devoted to this topic. All papers suggested some memory loss associated with ECT but:

- 6 did not meet the six month assessment criterion.
- 4 stated that memory loss was the ‘most frequent’ side-effect reported but did not give the actual numbers involved.
- 3 reported statistical associations or differences but not the raw data on which these were based.
- Only 7 of the original 20 papers identified included basic numerical information.

These final 7 papers were split into two groups according to the strictness of their definition of memory loss. A strict definition means the words ‘permanent’ or ‘persistent’ are included in the question consumers were asked about their memory loss (shown in Figure 5.1). A loose definition includes *any* memory problem reported after 6 months (shown in Figure 5.2). These data show that findings on memory loss are not polarised between clinical research and work carried out in collaboration with consumers. The results for MIND (33) are inside the range of the clinical studies for the strict definition and although in the less strict definition UKAN (23) reports the highest proportion of consumers with memory loss, their figure is less than 10% higher than that of Freeman and Kendell (3), and the Communicate (34) study falls in the mid-range.

The relative consistency of findings means that it is possible to make statements of the form ‘at least X% experienced persistent memory loss’. The lowest figure reported is 28.1% (3) and as this is a study that is conducted in a hospital setting by a doctor but where the questions seem to have been straightforward, this may be taken as a lower limit (see Chapter 7 for a discussion of setting effects on perceived benefit).



Differences of interpretation

Despite the considerable overlap in basic data, clinical and consumer studies tend to be polarised in their conclusions. Clinical research typically refers to a ‘minority’ (3) or judges the problem to be insignificant (6) or limited (7). Consumer research concludes that persistent memory loss is a significant problem for recipients of ECT.

Consumer research adopts the strategy of illustrating descriptive statistics with direct quotations. These are two examples from the MIND survey:

I can't remember hardly anything about my past life, only very little bits. As for bringing up my three daughters I can't remember a thing. (Woman – Yorkshire)

Several times people have greeted me in social situations as if they were long lost friends and I haven't a clue who they are! My son talks about times I spent with him before I had ECT and I have no recollection of them. (Man – South West)

The different interpretations of clinical researchers might be explained by a focus on group differences rather than absolute values. For example, Kerr et al (6) report that 30% of people with direct experience of ECT endorsed the statement: ECT permanently wipes out large parts of memory. However, this finding is never discussed because the authors focus on the significantly greater number of people with no experience of ECT endorsing this statement.

Some papers explore their data further for the association between memory loss and ECT. In their first study, Freeman and Kendell (3) state that a 'significant minority' of consumers report long-term memory loss but suggest this may be due as much to depression as to the ECT. In a second paper (4), the authors recruited subjects who specifically had complaints about the treatment and found the most common complaint to be persistent memory impairment. The authors are careful to say that none of their subjects held extreme views about ECT or psychiatry. A battery of cognitive tests showed the group did indeed have impairments compared to a control group and for some these were 'well into the organic range on some measures' (p.22) and remained even after controlling for the effects of age, medication and symptoms.

A significant effect on the evaluation of the association between ECT and memory loss is the difficulty of differentiating between memory loss caused by ECT, memory loss due to the depression that it is treating and the maintenance of depression caused by the memory loss itself. This is a particular difficulty when the evidence is made up of correlations and is without any time dimension about the onset of memory loss and depression. There is much evidence that depression is associated with memory difficulties. These are often difficulties in recalling specific autobiographical experiences by substituting categorical memories or "general memories" (Williams, 1996). However, there is little scientific evidence that traditional effective treatments such as anti-depressant medication or cognitive behaviour therapy are associated with increased levels of memory difficulties, particularly long term

memory difficulties. As most controlled studies (e.g. Lasenby et al, 2000) do indicate both personal and impersonal memory loss associated with ECT we can only conclude that this is the most parsimonious interpretation of the results but it is of course possible that this memory loss increases the likely maintenance of residual depression if the forgotten events are part of the personal makeup and identity of the recipient (cf Chen et al, 1999).

The difficulty with statistical analysis is also evident in the strategy used by Squire and Slater (7) whose work probably represents the most thorough analysis of long-term memory impairment. They conclude that there is a period of ‘actual’ retrograde amnesia for eight months prior to the treatment and of anterograde amnesia for two months afterwards. They then suggest that the experience of actual memory loss leads some users to be doubtful about *all* their memory capacity. This argument has the merit that it suggests practical help for consumers. The estimates are based on complex statistical procedures but are essentially averages. This must mean that memory loss is more serious for some people as Freeman et al (4) and quotations later in this chapter show. Donahue (2000), a consumer who conducted her own review of the literature after profound memory loss following ECT, even refers to herself as an ‘outlier’. There appears to be no assessment in the literature of the number of such ‘outliers’.

TESTIMONY

The effect of ECT on memory is the most common theme across all sources of testimony. Memory is mentioned in 99 testimonies out of a total of 139.

The issue is important across all age ranges and there is little variation between people who have recently had ECT and people who had ECT 50 years ago. Even when people feel that ECT is an appropriate treatment for them they are often still very concerned with the issue of memory loss. In 13 testimonies, consumers say that ECT has had little or no effect on their long-term memory but 7 of these are writing immediately following treatment.

Widespread memory loss – the erasing of years of memory

Many people describe how several years of their lives and occasionally as much as 15-20 years have been wiped from their memory. They may describe this whether or not they feel helped by ECT.

I had 20 ECT treatments over a 6 month period with positive results...The painful ongoing side effect of the treatment is this though. I have three children and many of the memories of their childhoods are lost. There is no pattern to the memory loss. I don't even realise that I've

forgotten something until my family starts reminiscing about something I have no memory of...then the loss hits all over again.

Megan 38, 20 ECTs over 6 months in 1992 (Healthy place Depression community)

Some consumers experience no long-term effects on their memory:

I never had any long-term effects. I haven't suffered any sort of permanent memory loss, you could lose memories for the, you know, the few hours before you have the shock treatment, but no, I haven't suffered any long-term damage.

Pauline Stott, age 58, several series of ECT (Testimony archive)

Emotional response to memory loss

People's emotional responses to persistent memory loss are a complex and important part of their experience of ECT. The quotation below illustrates the initial disorientation and fear produced by the onset of memory loss.

I came back from the ECT suite and I thought something awful has happened and I'm not having that again. I couldn't remember anybody on the ward, and even when they told me who they were, I couldn't remember them. I struggled to remember the names of my children it was near Christmas, and I was terrified. I was terrified cause I thought.. you know how am I going to sort everything out, because I can't remember anything.

Mo Hutchinson, age 52, nine ECTs in 93 or 94 (Testimony archive)

At this stage some people completely recover their memories except perhaps for a short period immediately prior to treatment. However in the majority of testimonies in which memory loss is a major theme, consumers then start to discover the extent of the damage:

Unless you have taken notes or put a note in an obvious place about where you put them or have an informant willing to tell you what happened to you before your ECT, you are just like a baby, waiting for the never to be realised promise that your memory will come back after a couple of months.

Chris h, age unknown, number of ECTs unknown (ECT.org/ lets talk)

The effects of damage to the memory are present in almost every aspect of people's lives. A language of frustration and humiliation is used to express how the simple tasks of daily living and social interaction become problematic following ECT:

I do remember after that period, and I don't know how long that lasted, going back to work at the National Hospital and the awful situation of, of going into work and not knowing the names of my colleagues, people who I'd been working with for a year, I didn't know who they were. They were familiar to me but I didn't know what their names were and I had to be retrained to do, to do the job I'd been doing for twelve months and, which was, I found, deeply humiliating, deeply humiliating.

Carole Bessington, age 70, 1st series of ECT 1955 (Testimony Archive)

Permanent loss of memories may also directly affect a consumer's sense of personal identity and this may contribute to the maintenance of depression:

Sometimes one fact or piece of information will sound right to me and for a couple of seconds I can hold onto it and fill it as a long lost memory. It is very reassuring and gives me a good feeling. Unfortunately, it passes all too quickly and becomes a very small part of a jigsaw puzzle floating around in the darkness.... Everybody I come in to contact with knows more about me than I do and this makes me feel inadequate, confused, very frustrated and angry about my loss.

Susan Witte, age unknown, 20 ECTs 1987 (Views from off Center 1991)

Information, the role of others and memory loss

When consumers complain of these difficulties to their doctors, they are frequently told that they must be mistaken:

The docs say there is nothing wrong with me. Well something is wrong when you cannot remember events in your child's life or your own.

Kelly, 20 treatments, 1989 (Noshock email forum)

In some testimonies consumers' frustration and anger is further expressed because there is no support available for people experiencing memory loss:

I'm more depressed for having to live with the memory loss and other problems, which began at the time of treatments. (or die with it) IS THERE ANY HELP FOR RECOVERING FROM ECTS??? If so I can't find the link...still need help.

Michel, age unknown, number of ECTs unknown (going mental noshock website)

Effect of ECT on specific skills and abilities

Memory loss and other cognitive impairments may affect some people's ability to return to their former profession or to continue their education.

'Well what is the sense of ruining my head and erasing my memory, which is my capital, and putting me out of business? It was a brilliant cure; but we lost the patient. It's a bum turn. Hotch, terrible

Ernest Hemmingway, two series of ECT in 1962 (Asylum 1995)

I've got 13 GCEs, top grade, but no professional qualifications since ECT I've sat Only one exam, and despite it being 70% project work and continual assessment, I struggled to just pass, well bottom – my memory sand impaired concentration can't cope.

Oliver, age 29, number of ECT unknown (going mental no shock web site)

However there are a few consumers who testify that ECT helped them to recover their skills and get back to work:

I have problems remembering things. But these effects are short-lived – I am fine within a fortnight. Since having ECT I have been promoted and continued my writing; I don't feel I have suffered any cognitive impairment.

Rachel Perkins, age 45, three courses of ECT (Open MIND 1997)

THE MEASUREMENT OF MEMORY LOSS

Besides research that directly asks recipients of ECT about their experience and the testimonies assembled here, there is another body of work that assesses memory impairment through formal neuro-psychological testing. This body of work provides the evidence-base for statements on the Royal College of Psychiatrists' leaflet for patients about to undergo ECT that there is no known risk of permanent memory damage (cf. Appendix 6).

When researchers ask patients directly about their memory loss following ECT, they find significant numbers of consumers who report persistent memory impairment. This is so regardless of whether researchers are clinicians or consumers and is confirmed by testimonials. Formal memory researchers, on the other hand, consistently report few memory difficulties following ECT.

This discrepancy is probably largely due to the use of formal measurements of memory being inappropriate to the phenomena that consumers report. Neuropsychological measures of

memory loss tend to concentrate on short-term list learning. These formal measures are also assessments of memory loss called anterograde memory loss i.e. memory difficulties for information which follows the experience of ECT. What most consumers report is memory loss over long periods of time and which is retrograde, i.e. memories prior to the ECT treatment. Forgetting some novel words in a list is clearly totally different to the memory loss that the consumers report. When more appropriate tests are used autobiographical memory is noted to change compared to controls receiving different treatments e.g. Lisanby et al (2000). This is one of the few papers to have similar results to that of consumer testimony data.

CONCLUSION

In all types of information gathered for the Review it is evident that memory loss is a persistent side-effect for at least one third of recipients of ECT. For some, this memory loss profoundly affects their lives and sense of self.

CHAPTER 6

INFORMATION AND CONSENT

INTRODUCTION

The topics of information and consent are treated together because they are routinely linked in the issue of ‘informed consent’. However, consent in particular can be over-ridden in psychiatry by legal compulsion and this then becomes a separate issue. This chapter will therefore first deal with the question of information, then that of consent and finally link the two sets of analyses in order to discuss what ‘informed consent’ means to consumers.

In terms of legal compulsion, this chapter considers only consumers’ experiences in the UK. The recipients in the North American research papers were all voluntary patients and those from other UK countries are not reported as to legal status. Some of the UK papers do include consumers who were treated under legal compulsion. Further, legislation to compel patients to receive ECT in countries such as the USA and Australia are state or territory specific and not federal. It is quite beyond the scope of this review to include such variation.

INFORMATION

RESEARCH

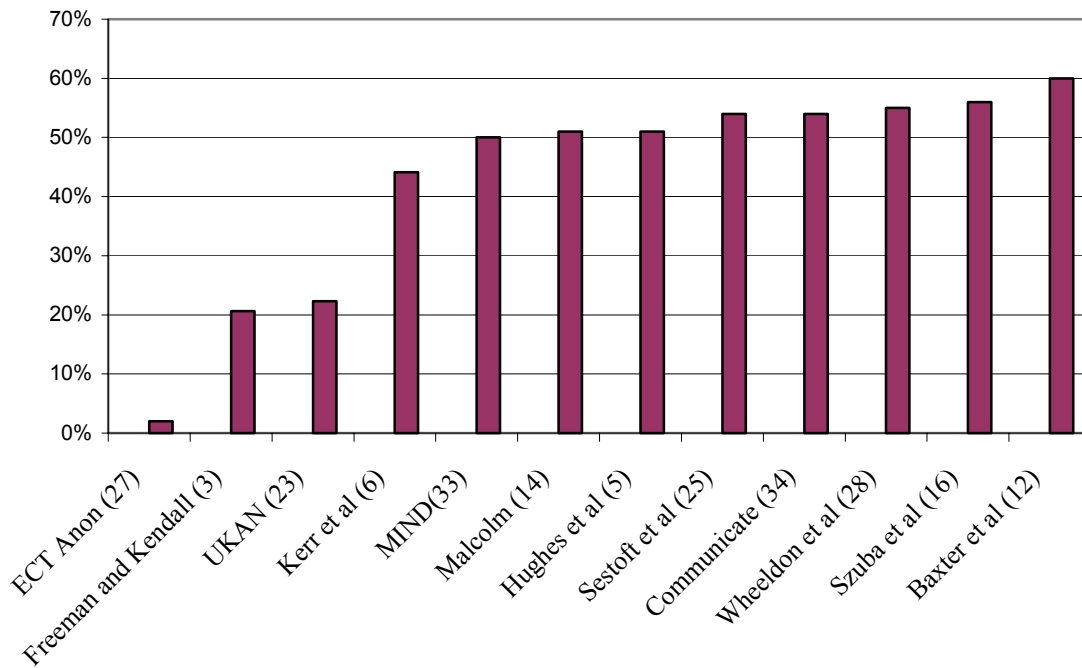
16 papers and reports were identified that included questions on information and/or consent. In 4 cases the data in these papers could not be used either because responses to the questions were not reported (30) or the papers focused on group differences (12, 15, 18).

12 studies asked whether the user felt that they had been given sufficient information about ECT prior to treatment but, as anticipated in chapter 3, it is often difficult to know exactly how the question was phrased. Seven clinical studies asked in a post-treatment interview whether information was adequate and all but one appear to have used terms such as ‘adequate information’ or ‘sufficient information’. The statement reproduced in Kerr et al (6) is: patients are never told what is going on. This is a stronger statement than seems to have been used in the other clinical studies.

Four consumer-led or collaborative surveys ask questions about information. The UKAN (23) and Communicate (34) questions mirror those in the clinical research. MIND’s (33) questions are very detailed and the one used here is whether respondents were told why they were being given the treatment. The ECT Anonymous question specifically mentioned full

explanation of the *risks* of ECT. With these differences in mind, figure 6.1 shows what proportion of respondents said they were given sufficient information in each study.

Figure 6.1: Proportion of consumers with adequate information



Although the questions asked were not always directly comparable, 9 of the 12 studies depicted give a consistent picture of 45-55% of consumers reporting that they were not given an adequate explanation prior to treatment. Of these nine studies two involved collaboration with consumers (33,34) and they fall between clinical reports. There is no absolute polarisation between clinical and consumer research on the question of information.

It can be argued that some patients do not want information. The question arises too in physical medicine where patients are argued not to wish to know a serious diagnosis. However, in mental health the issue is bound up with informed consent and against the background of possible legal compulsion.

It might also be argued that due to memory loss for the time around ECT, consumers forget information they have been given. Nonetheless, even the study by Baxter et al (12), which claimed to make very thorough efforts to inform consumers, found that 40% felt ill-informed.

These issues run as differences through the clinical and consumer research. Whilst some clinical attitude studies argue that consumers forget information, other claim that consumers do not want involvement and prefer instead to put their trust in their doctors. MIND on the other hand concludes, on the basis of very similar findings, that consumers are denied even basic information about ECT and that this is unacceptable. We return to this issue in respect of consent below.

Two studies report only one fifth of users saying that they were given sufficient information. One is a clinical report (3) and the other is by UKAN (23). The Freeman and Kendall (3) finding raises interesting questions. Since this paper is scrupulous in reporting its results, it is clear that there were six possible responses to the question about information. 20.6% of the users said they *did have* an adequate explanation about ECT. However, only 49% said they had an *inadequate* one. Nearly all other studies report results in ‘yes/no/don’t know’ form and some only the proportion endorsing a statement (6, 12).

The clinical researchers tend to conclude that patients trust their psychiatrists. An explanation of the UKAN finding, and even more so that from ECT Anonymous, is that members of those organisations do not share this trust. It is also possible that these users have more knowledge about ECT than other groups and therefore have a different standard against which to assess information given by doctors.

OBJECTIVE KNOWLEDGE

Four studies assessed consumers’ ‘objective knowledge’ concerning ECT. There are, of course, problems in defining objective knowledge and also the extent to people wish to know. However, four UK studies did assess ‘objective knowledge’ about ECT (5, 13,14 and 20). They assessed how far people knew three things: that anaesthetic is used, an electric current passed through the head and a convulsion or ‘fit’ is achieved. Table 6.1 shows the findings of these studies.

Study	Percent with full knowledge of ECT
(5) Hughes et al (1981)	7%
(13) Benbow (1988)	12%
(20) Riordan et al (1993)	12%
(14) Malcolm (1989)	16%

Table 6.1: Objective knowledge of ECT amongst consumers in four UK studies

The authors of these studies quote patients making remarks such as ‘I should think not!’ when asked if they knew a convulsion was involved. In light of Table 6.1, what looks like an absurd figure from ECT Anonymous regarding information becomes more comprehensible. If the vast majority of patients, at least in the UK, do not know what the treatment involves then either it was never explained to them, they forgot what was told them or have even denied the explanation. Consumers who know exactly what the treatment involves are not typical and may have gained this knowledge through membership of groups such as UKAN or ECT Anonymous. If the explanation they were given at the time of treatment was a typical one, most in retrospect will regard it as inadequate.

INFORMATION - CONSUMER-LED RESEARCH AND TESTIMONY

As indicated above, the MIND study asked very detailed questions about information as well as consent. The following quotation is typical.

I felt under a lot of pressure from the staff to go ahead with ECT. I personally don't remember receiving information about how it would work, side effects etc. (Woman - London, ECT in last 6 months)

In the testimony data, there are also examples of complaints about insufficient information that begin to hint at a relationship between lack of information and a feeling of powerlessness.

No one told me what the side effects could be. No one even explained to me what would happen...I didn't even know what the letters ECT stood for. I didn't know and it wasn't explained to me that I would have electrodes attached to my head and that they would put an electric current through my brain.

(Pat Butterfield, age unknown, 12 ECT in 1990 (BBC online 2000))

The quotations from the MIND report were in response to specific questions about adequacy of information. The testimony quotes show that when consumers write or speak more spontaneously about their experiences that this is still a concern. Appendix 4b shows that over 50% of more spontaneous comments about inadequate information were specifically linked to the issue of long-term memory loss. MIND found that consumers were less satisfied with information about side-effects than about the procedure itself.

CONSENT

Legal compulsion

In the first 3 months of 1999 in the UK, 25% of those who received ECT were detained under section. 19% received the treatment under a specific section of the MHA or as an emergency. Consumers may be given compulsory treatment because they are too unwell to sign a consent form or because they simply refuse the treatment. As Appendix 3 shows, no research group has the characteristics of the UK norms although MIND and UKAN approximate them in terms of users on section.

As MIND points out, the difficulty is that an estimate of detention is not an estimate of compulsory ECT in a legal sense. This is because detained patients may consent to ECT and in the three months assessed by the DH in 1999, 29% did so. It is therefore not possible to estimate numerically what percentage of respondents to these consumer studies received ECT under legal compulsion, although a good proportion must have done.

FELT COMPULSION

It is widely reported in the clinical as well as the consumer literature that even where patients sign a consent form for ECT, they often feel that they had no choice but to agree. Malcolm (14) writes: '(many) commented that it was futile to refuse as they would end up getting treatment anyway' (p.163). Johnstone (29) reports that a majority of her respondents either felt so desperate that they would try anything or felt unable to disagree with their psychiatrist.

To estimate what proportion of voluntary consumers felt they had no choice but to have ECT, we focused on questions about whether the user knew they could refuse or felt pressured to have treatment. The statement that Kerr et al (6) put to consumers was: ECT is given if patients don't behave. UKAN asked their respondents if ECT had ever been used as a threat.

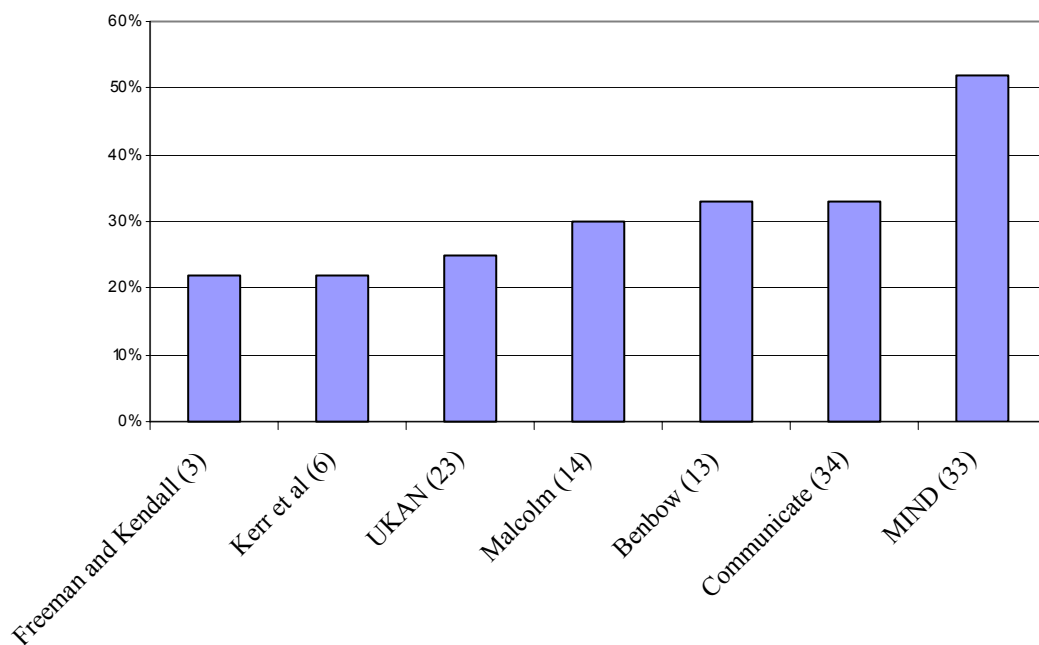
In the case of ECT Anonymous, 87% report that they felt compelled to have the treatment but the report states that this typically included respondents who felt it had been "'oversold' by psychiatrists as 'quick, safe and effective'" (p.4). It would appear this question was much broader than those in the other surveys and for this reason it has not been included in figure 3.

Seven studies asked questions about 'felt compulsion'. In all cases except Freeman and Kendall (3) and Riordan et al (20), the denominator is *consenting* patients. The proportion is of those who were not legally compelled but nevertheless felt they had no choice.

Once again, the methodological diversity of the studies is relevant here, particularly in terms of the different questions asked. Although the figures in 6.1 should be treated with caution in this instance, the consistency of results would seem to make the methodological diversity a strength. It is unusual to get such consistent results from methodologically diverse sources.

Once again, the results do not polarise according to a clinical / consumer division as UKAN is in the mid-range and the Communicate results are identical with those of Benbow. The MIND results are significantly higher but their questionnaire was very detailed on this issue.

Figure 6.2: Proportion of consenting patients who felt they had no choice



It is reasonable to conclude that between one quarter and one third of patients who sign a form consenting to ECT do so under pressure or in the belief that they cannot refuse.

According to the UKAN data and that from Kerr et al (6), this pressure can take the form of threat or punishment. These are two statements made by respondents to MIND's survey:

If I had known I had the right to refuse I would have done so. My understanding was that I had no choice in the matter and that they could do it by force. (Woman - Wales, ECT in last year)

I was given no information and had to sign for it after all my medication at night so I was very drugged when I signed the form for my consent. (Woman - Yorkshire, ECT 3-5 years ago)

One respondent to the UKAN questionnaire wrote:

I was told my baby daughter would be put into foster care if I didn't have ECT (even though my husband could have looked after her).

These are not bland accounts of signing or not signing a form. The language signifies fear, an almost total absence of choice and this is apparent too in the testimonies.

TESTIMONY

Emotional Responses to compulsion and felt compulsion

When the issue of consent is mentioned in testimonies it is usually to explain why a person did not feel that they freely gave informed consent. It has already been shown that consumers may believe that they were not given a truthful explanation of the treatment procedure or of long-term side-effects. In the UK particularly, users speak of the threat of compulsion.

...I was asked to give consent for ECT and I refused. I believe it is our human right to do this. A series of persuasions started in a doctor's room. When this failed they asked my daughter saying that if I didn't agree they would transfer me to a hospital a good few miles away. My daughter said she wouldn't be able to visit. What a case for disempowerment. I refused again, and they left a letter on my locker saying I had been sectioned under the mental health act. No explanation was given...

Jean Taylor age 71, 19 ECT in 1989 and 1993 (Mental Health Nursing 1996)

Frequently, consumers feel they did not freely consent as they were so distressed and disorientated at the time that they would have done anything to relieve this. The first respondent below believes the doctor was right to have taken the decision for her:

There was pressure but it was right (Communicate respondent)

I just went along with it but I don't think it was... I mean I would have gone with anything at that stage quite honestly, if they'd ask to do brain surgery or a lobotomy I would have gone with it.

(Premila Trevidi, age 51, two series of ECT 1974 ;Testimony archive)

INFORMED CONSENT

As already discussed, some clinical researchers (13) conclude from their findings that consumers do not want too much information and are happy to let the doctor decide what is best for them. Other authors (3, 14, 20) are unsettled by the degree to which patients will do whatever doctors say, at least according to their own findings.

This trust in doctors was not shared by many of those who responded to the consumer-led surveys. The testimony data also revealed feelings of distrust and betrayal. There are two kinds of data that may further illuminate this question. The first is the qualitative material collected by Johnstone (29) and the second is demographic data that may show differences in satisfaction with consent procedures.

Johnstone specifically recruited participants who felt they had been damaged by ECT and in that sense her study is comparable to Freeman et al (4). Of the 20 consumers she interviewed, 14 said they had signed the consent form. When probed on this, some said they were so desperate they would try anything. However, many also expressed a sense of total powerlessness when faced by a medical professional so confident in their proposed treatment. One woman said:

I was a very compliant young woman, I was frightened of everybody and that was part of the problem.....I wouldn't have known how to object, it wasn't on the horizon. You didn't disagree with doctors, you did what they said (p.74).

It is clearly different to put one's faith in a doctor from a positive sense of trust than to do so because it is not felt possible to disagree with a powerful professional.

DEMOGRAPHIC ISSUES

Age

Malcolm's (1989) sample was almost evenly split between those under and over 65 years of age. Whilst 71% of the younger patients were aware they could refuse ECT, only 27% of those over 65 knew this. Malcolm concludes that the older patients "seemed to think this was a satisfactory state of affairs. Elderly patients appeared to have greater faith in the doctor doing what was in their best interest" (p.164).

Gender

Appendix 2 shows that research studies typically have twice as many women as men. However, very few studies analyse the issues of information and consent according to gender.

Malcolm (1989) reports that men tended to be more aware of the possibility of refusing treatment than women and also to have better objective knowledge of the procedure. MIND and UKAN have an over-representation of men compared to national figures (DoH, 1999) and this, as well as their younger samples, may account for some of the differences discussed in this chapter.

Consumer culture and the internet

Hillard and Folger (2) demonstrated that consumers gain a great deal of information about ECT from each other and explained this with reference to the 'ward culture'. The extension of this culture with the advent of the internet is especially significant for this chapter. In the past a worried consumer would need to make a concerted effort to access information about ECT especially if they were interested in material that questioned the official view. Now a short period on the World Wide Web will yield a wealth of information about ECT from an extremely wide range of sources. There are indications from the e-mail forums that the Internet is set to have a dramatic impact on how consumers actually decide to have ECT.

I'm actually supposed to get ECT this morning but after reading the information on this web-site IM NOT GOING!! I'm scared to death!! I really didn't think the treatments were actually working for me anyways but after some of the info ive read I now realize im not the only person with post ECT problems

Stacey, age 25, receiving 1st series of ECT, 8 or 9 so far (Noshock e mail forum)

In March of 1997 I was truly suicidal for the first time in 30 years of dealing with recurrent depression. I was admitted and my pdoc also recommend ECT. I requested a Medline search of all the articles from our local medical school library and a friend picked them up. I read every single one and decided to go ahead. I had 9 initial treatments (3 a week for 3 weeks) and 4 or 5 monthly maintenance treatments until I had a bad reaction to the anaesthesia. They helped me greatly and I'm very glad I agreed to them.

Madeline, age unknown 14 ECT 1997 (Healthy Place Depression community)

CONCLUSION

The data presented in this chapter show that across research studies at least 50% of users feel they have been given an inadequate explanation of ECT. There is consistency across clinical and most consumer research studies on this issue and confirmation from the testimony data. Where consumer-led research reports very low numbers of people feeling sufficiently informed about ECT, this has to be set in the context of clinical research which demonstrates

that consumers typically are very misinformed about the procedure and that members of 'anti-ECT organisations' may be better informed than most consumers.

It is estimated that some 35% of consenting patients feel pressurised to have the treatment. Clinical researchers tend to conclude that putting trust in one's doctor is the explanation for this. Consumer-led research and testimonies, on the other hand, often use a quite different language – one of threat and manipulation.

It is entirely possible that some consumers have absolute faith in their doctors and others none at all. Some demographic dimensions have been suggested which may affect how likely consumers are to occupy the poles of these positions and how strongly. These arguments will be developed in the chapter on perceived benefits of ECT where the link between perceived benefit and the questions addressed in this chapter will be considered further.

CHAPTER 7

PERCEIVED BENEFIT OF ECT

This chapter more clearly overlaps with the meta-analysis of effectiveness in the review by Carney et al (2001). In their review, however, effectiveness was measured by a change on a symptom rating scale, which is usually but not always completed by an observer. These sorts of ratings may not always correspond with the subjective relief of distress. For example, Hughes et al (1981) report that the same number of people improved according to a clinical measure and according to subjective reports but that in 20% of cases these were not the same individuals. This discrepancy anticipates the possibility that consumers' perspectives on ECT in terms of its helpfulness or otherwise may not correspond to clinical concepts of outcome.

Research

20 research studies asked about the perceived benefit of ECT. There were two main kinds of question: perceived helpfulness and whether the user would agree to ECT again. Figures 7.1 and 7.2 overleaf show the charts for each type of question.

Three studies are not included in the charts because the nature of the question or the context in which it was asked was different to the other studies. Sestoft et al (25) gave ECT and medication as options to their respondents and 29% said they would choose ECT as a first preference. Pettinati et al (21) report that 98% of their consumers would be willing to have ECT again but the results show that half of these would have ECT only if other treatments had been ineffective. Johnstone (29) reports that 45% of very unhappy consumers gained some initial relief from the treatment but said that it did not last and the costs outweighed the benefits.

The first figure shows a gradually rising curve of the proportion of satisfied customers but unlike other charts in this report, the studies are grouped in terms of clinical and consumer research. The second figure shows a similar pattern but it should be noted that the UKAN question was: would you *request* ECT again (italics ours).

The variability between the studies can be considered in light of the issues raised in chapter 3 and this in turn may illuminate the differences between the clinical and consumer research.

Figure 7.1: Helpfulness of ECT

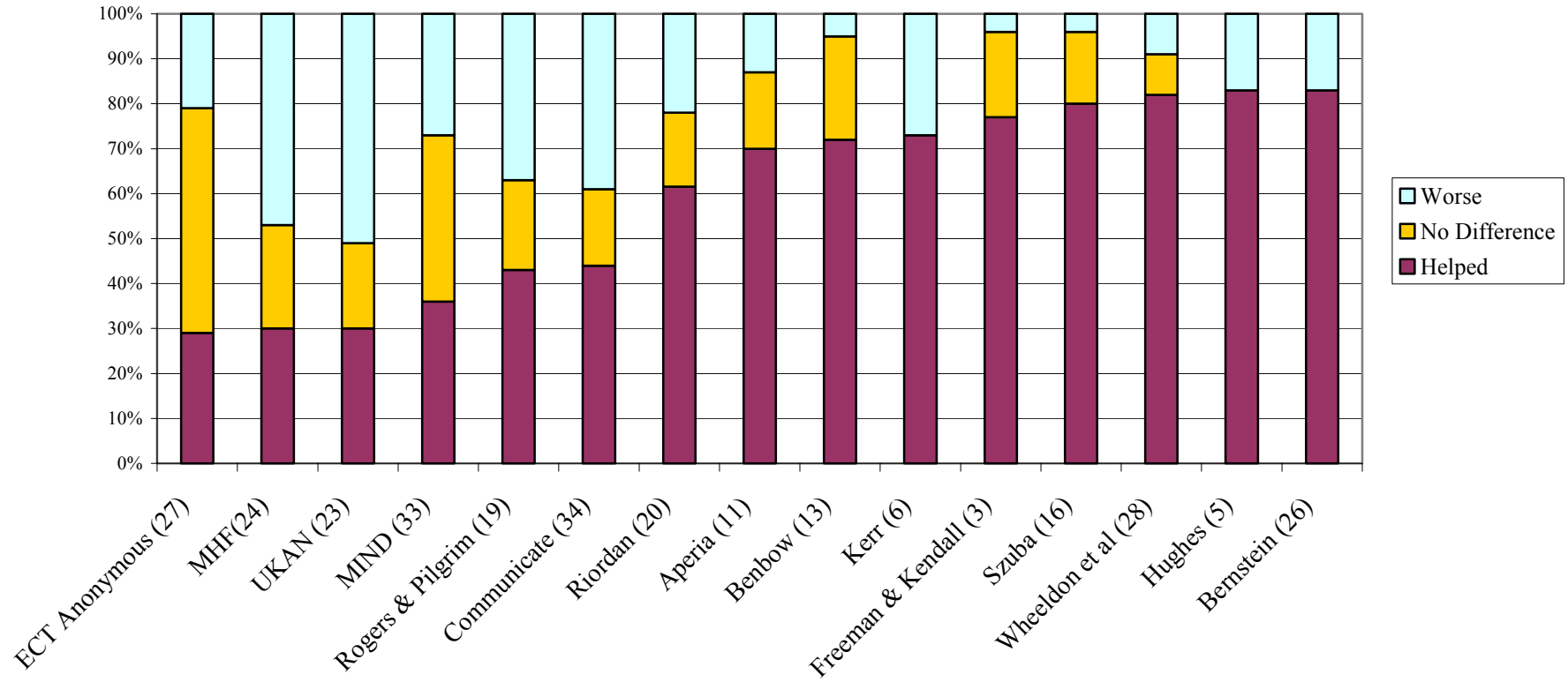
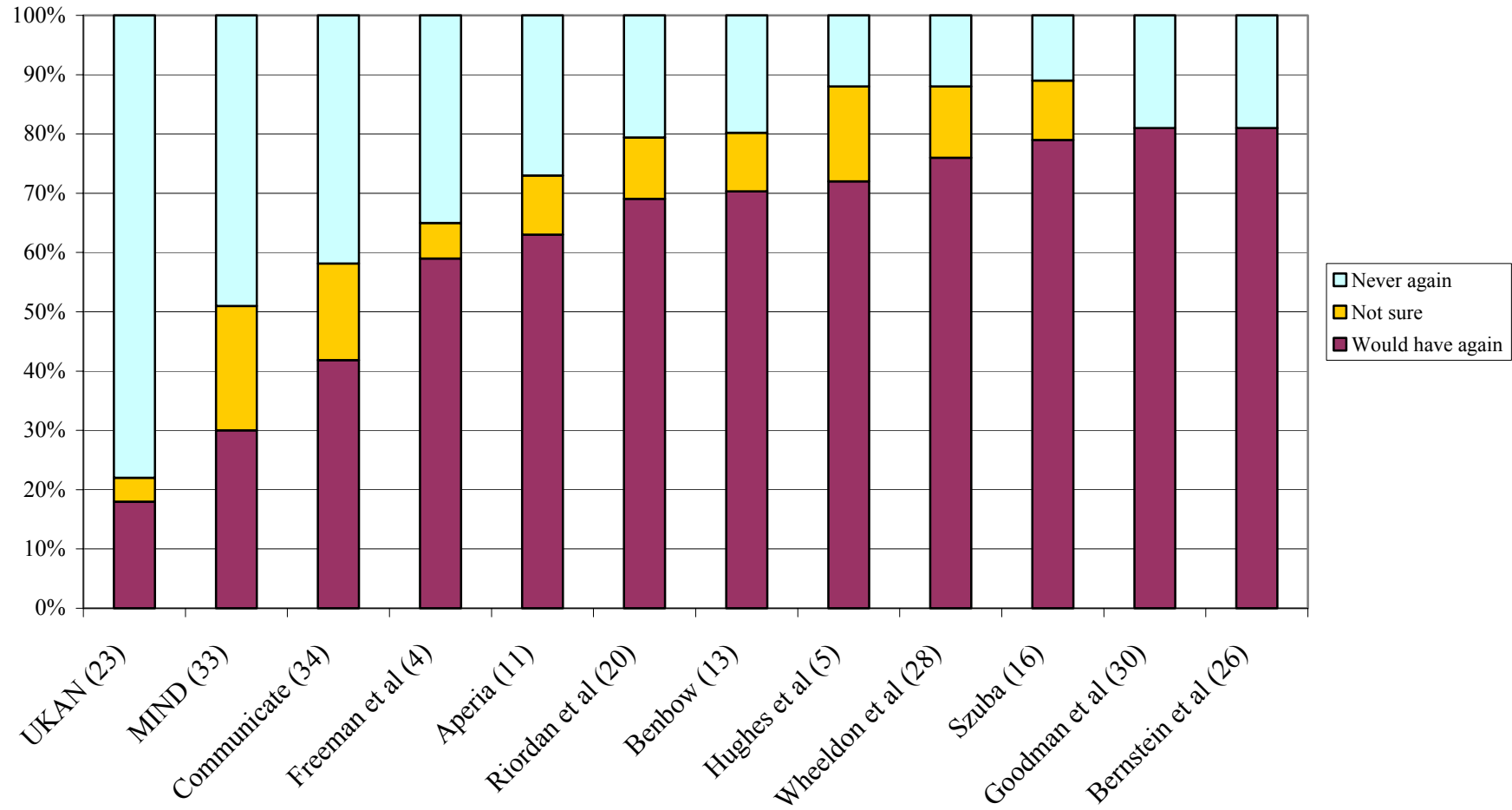


Figure 7.2: Willingness to have ECT again



Methodological correlates of perceived benefit

Appendix 2 shows the results in the charts against five methodological dimensions of the research: interval since ECT, setting and interviewer, number of questions, complexity of schedule and whether the study was carried out by clinicians or consumers. The table suggests that these variables are inter-correlated and also correlated with perceived benefit. These correlations were therefore calculated using Spearman's rho and omitting the clinical/consumer dichotomy as it is already known that this differentiates the results. In the tables, * means significant at the .05 level, ** at the .01 level and *** at the .001 level.

HELPED	Have again	Interval since ECT	Setting	No. Questions	Complexity Schedule
Helped	.83** (n=9)	-.79*** (n=15)	-.9*** (n=16)	-.73** (n=15)	-.4 (n=14)
Have Again	1.00	-.84** (n=10)	-.79** (n=11)	-.68* (n=11)	-.58* (n=11)
Interval		1.00	.81*** (n=17)	.61** (n=16)	.77*** (n=15)
Setting			1.00	.61** (n=16)	.46 (n=16)
No. Questions				1.00	.77*** (n=16)
Complexity Schedule					1.00

Table 7.1: Correlation matrix for perceived benefit and four methodological variables – all studies.

Table 7.1 shows the correlation matrix for the complete sample of research studies, omitting the consumer/clinical dichotomy as this is known to differentiate the studies. Nearly all correlations are statistically significant suggesting that the methods used to elicit users' experiences of benefiting from ECT have a strong bearing on the level of benefit reported and that different studies combine the methodological elements in systematic ways.

Chapter 3 noted that some methodological variables distinguish clinical from consumer research. It is therefore possible that the results in table 7.1 are an artefact of this distinction.

To check for this, the correlations were run again for the clinical research studies only and table 7.2 gives the results.

HELPED	Have again	Interval since ECT	Setting	No. Questions	Complexity Schedule
Helped	.63 (n=7)	-.57 (n=8)	-.48 (n=9)	-.75* (n=9)	-.47 (n=9)
Have Again	1.00	-.84** (n=8)	-.6 (n=9)	-.6 (n=9)	-.95*** (n=9)
Interval		1.00	.57 (n=10)	.46 (n=10)	.73** (n=10)
Setting			1.00	.52 (n=11)	.42 (n=11)
No. Questions				1.00	.5 (n=11)
Complexity Schedule					1.00

Table 7.2: Correlation matrix for perceived benefit and four methodological variables – clinical research studies only.

Although there are fewer significant correlations the pattern of relationships mirrors that in Table 7.1. In the clinical studies, the length of time between treatment and interview and the complexity of the schedule are very highly correlated with each other and with whether the user would agree to have ECT again. If a consumer is interviewed immediately after a course of treatment, on the ward and asked only a few questions then the highest levels of perceived benefit are reported. If interviewed at least six months after treatment with a complex interview, the likelihood of agreeing to ECT again in particular decreases. The complexity of the schedule appears particularly important. A semi-structured interview can be conducted as a conversation and is more likely to elicit thoughtful and complex answers and to engage consumers.

Freeman and Kendell's (3) study illustrates a further effect of interval since treatment on satisfaction. Figure 7.1 gives the answer to a question about how helpful ECT was *at the time*. An additional question concerned the lasting effects of treatment. Only 9% said the effect had

been permanent and 35% that it had lasted a year or more. The transient nature of perceived benefit may affect decisions about the worth of having the treatment again.

The issue of comparing ECT to other treatments is also important and absent in most studies. Even a check-list giving preference options rather than asking about ECT alone can give distinctive results as shown by Sestoft et al (25). Rogers and Pilgrim (19) show that consumers who have received ECT are more likely to regard it as unhelpful than those who are prescribed neuroleptic drugs. Half of Pettinati et al's (21) much-quoted 98% of consumers who would agree to ECT again actually wanted to try other treatments first.

Clinical and consumer research

Only three consumer studies asked about willingness to have ECT again. The highest response was in the Communicate survey and this had the shortest interval between treatment and survey and a simple questionnaire.

Just as there may be a tendency to compliance in hospital settings so critics may be right that consumers are more likely to respond negatively to a questionnaire or interview conducted by other consumers if that is their opinion. However, this is not a matter of 'bias' but a robust research finding as described in chapter 3. Although postal questionnaires are anonymous and so 'impersonal' they do allow the service user to think carefully about how to answer. A consumer could easily mull over a questionnaire from MIND or UKAN before completing it as the time limits for completing the form are usually several weeks. The typical 'please comment' space after each question in these forms also allows the kind of engagement referred to above.

Some clinical schedules are more complex than some consumer ones. However, there is no clinical study in which consumers are interviewed in a place of their choice by a non-medical person. Thus the similar patterns in the two correlation matrices may indicate that the methodological diversity of the complete set of studies is strongly associated with overall differences in the perceived benefit of ECT.

Subject selection

Cross-sectional designs may over-select satisfied customers (see chapter 3). Bernstein et al (1989) report that nearly half their respondents were receiving maintenance ECT and it is difficult to see how users would agree to this unless they found it helpful.

Because this Review had access to the questionnaires from the Communicate study, they were analysed to see whether there was an association between having previous experience of ECT and willingness to have it again. Respondents who said they had had ECT before were more likely to say they would agree to it again (Chi-Square = 4.91; df = 1; $p < 0.05$). Only 4 of the total 17 people who had ECT for the first time said they would definitely have it again, one commenting that she would if she thought it would do any good which it had not this time.

MIND reports that nearly half their respondents had more than one course of ECT. MIND gives no breakdown of the relationship in their sample between having more than one series and satisfaction or having more than one series and compulsion. These would be the important variables to validate the above paragraphs.

Historical and cross-national comparisons

Goodman et al (1999) argue that much of the research reviewed here is out-dated as ECT procedures and patient care have improved in recent years. However, there are no relationships between the date of the clinical research studies and satisfaction rates that cannot be explained either methodologically or demographically. The best data in this respect come from the MIND survey (33) as results are divided according to when the respondents experienced ECT. The evidence is of marginal improvement in the UK at least. However, statistical analyses are not performed so it is unclear whether this is statistically significant.

Consumers in the USA appear to be more satisfied with their treatment than those elsewhere. The exception is the UK study by Wheeldon et al (28). As will be seen, this is not borne out by the internet testimony data. Again the difference may be partly explained in terms of the methodological issues discussed above. There are also demographic differences between the groups studied, including the fact that all US respondents were voluntary patients.

Demographic factors

Appendix 3 shows the demographic features of the samples for each research study considered in this chapter as well as the demographic averages for recipients of ECT in the UK in the first three months of 1999 (DoH, 1999). The figures from each study that approximate those averages are marked in bold in order to show which are the most representative in terms of UK norms. The first point to note is the extreme variability of the samples except in the case of gender. There is a lack of overall conformity to UK norms and no reason to suppose that the populations receiving ECT in other countries are different to the UK.

The UK studies are more likely to include older participants and in that sense be representative. Riordan et al (20) and Malcolm (14) report older consumers to be more likely to trust their doctors and to be satisfied with, or at least resigned to, the treatment. The younger age structure of the consumer-led studies may therefore partially account for lower satisfaction rates in the UK. However, since age is confounded with both occupational status and the country in which the research was conducted, no firm conclusions can be drawn at an international level.

The consumer-led studies which report demographic data (23, 33) have a relative over-representation of men and, since men report lower levels of satisfaction with ECT, this may partly account for lower satisfaction rates in these studies.

Legal and felt compulsion

Wheeldon et al (28) found no difference in satisfaction between patients legally compelled to have ECT and those who consented. However, this is based on 11 formally treated patients, 9 of whom said they found the treatment beneficial. Of all the UK clinical studies that report the legal status of their consumers with respect to ECT, only Malcolm (1989) has a proportion that approximates the national figure. The others are approximately one third of what would be expected given national statistics. Indeed, it is the consumer-led studies (23, 33) and the work of Johnstone (29) that are the more representative in this regard. UKAN reports a negative association between legal compulsion and satisfaction, particularly in the case of men. The MIND report does not state whether there was any relationship between legal compulsion and satisfaction. However, MIND does report that users from black and ethnic minority communities were more likely to be compelled to have ECT and more likely to find the treatment unhelpful, damaging or very damaging.

In terms of felt compulsion, no study analyses its relation with perceived benefit. The Communicate questionnaires were examined and a strict definition was adopted. Feeling compelled to have ECT was defined as saying both that the consumer did not make a fully informed decision and that there was pressure or force to have the treatment. 13 people meet the definition of felt compulsion. Only one of these was treated under a section of the MHA specifically for ECT. Of the 12 remaining, 10 (83%) said they would refuse to have ECT again. This is double the total sample figure of 41%.

TESTIMONY

ECT is a treatment which attracts controversy. The polarisation of opinion about the benefits of ECT expressed in the testimonies reflects this, as does the especially strong language used in many testimonies. People at one end of the continuum of opinion say ECT is a lifesaver and people at the other say ECT is a profoundly damaging treatment. However within the testimonies there is also some graduation of opinion. For example not all those who found ECT unhelpful think it should be banned and many of those who derived benefit accept that others have found it damaging. Out of a total of 139 testimonies, 83 either said they would not want to have ECT again under any circumstances or were very negative about their experience of ECT. 43 people were positive about ECT and/or indicated that they would be prepared to have the treatment again. 14 people said they were unsure whether they would be prepared to have the treatment again or their testimony did not make their view clear.

Different formats of testimony attract contrasting views on ECT. Legally sourced testimony is completely against ECT. However most sources are more equivocal. For example 37% of people contributing to a forum called NOSHOCK said that they would have ECT again. The *Testimony Archive*, which contains accounts by people who may have received less sophisticated forms of ECT in large asylums, has a relatively even spread of responses to ECT: 48% would not have the treatment again, 21% would have it again and 30% are unsure.

ECT Has Benefits

31% of the consumers represented in the testimonies were positive about their experience of ECT.

I know that there is something I can do to stop it [depression] –something that will quickly restore me to my life and self.

Rachel Perkins age 45 3 series of ECT (Open Mind 1999)

We did the ECT and I can truly say that it saved my life. After the first treatment I already felt a difference. I had a total of 6 treatments and I am back to the same person I used to be. I went back to work and I am functioning and performing great. I feel so good and blessed. I feel I owe my life to ECT. It's been 4 months since the treatments and I pray that it doesn't come back. ECT was a miracle for me. It truly saved my life.

Sasha, age 29, 6 ECT (Healthy Place Depression community)

However very forthright and positive testimonies are usually from people who have had ECT very recently or at least within the last six months.

My experience has been great, and I would like to share it in the hope that anyone out there looking for info on this controversial procedure can be that much more informed. Today 2 months after my ECT treatments, which did happen to be BILATERAL, I have no lingering side effects and I feel like the proverbial cloud of depression that has smothered me for at least the last 5 years has been lifted. I am on 'maintenance doses of Effexor and Buspar, and while not 100 % little Miss Mary Sunshine all the time who is? I feel like a normal person.

Layla23 age 21, one series of ECT (ECT.org lets talk)

I can tell you I feel really good and am no longer depressed. That has to say something for this treatment when nothing has ever worked for me before. I do see memory loss as a problem and hope it is a short lived one. I honestly do feel better inside though and I am loving it so far.

Molly age 23, 6 ECT just finished (Health Place Depression community)

Of a total of 139 testimonies, 108 specified a timescale. As Table 7.3 shows, those who have had ECT most recently are more likely to be willing to have it again. This is the same pattern of results as was found in the research studies.

TIMESCALE	Never again	Not sure	Would have again
After 6 months	61	10	17
Within 6 months	4	1	15

(Chi - Square = 12.9 df = 2 p < .01)

Table 7.3: Contingency table of interval since ECT and willingness to have treatment again.

The effect is temporary

No consumer testimony reviewed said that ECT has a long lasting effect and some people refer to the short-lived nature of the benefits:

I finally tried ECT. I was amazed at how good I felt. I had short-term memory loss. I would say that I felt good for about a year. The depression came back and I was back to square one. All I wanted to do was die.

Laura, age unknown, one series ECT (Healthy Place Depression community)

Trade offs

Many people's testimonies describe how they trade off damage to their memory, cognitive ability and personality in order to gain relief from depression:

But I did the ECT treatments and let me tell you; it pulled me out of my suicidal stage. Things began to look brighter in my life. Unfortunately I am now having a relapse. I am starting again my ECT treatments Monday. Yes is it scary, yes it is expensive, yes some people do not benefit, but I have completely benefited by it. The only problem is now is that I need more of it to go on. The only problem that I had during my sessions and even now is the memory loss that I have. I cannot remember things back to 2 years ago.

Shari, age unknown, 15 ECT (going mental no shock web site)

My wife thinks the memory loss is from ECT and doesn't want me ever to have another treatment. My Psychiatrist says it could be from either the ECT or the anxiety of returning to work or a combination of both. I am still an ECT advocate, I don't believe it is a total cure for depression, but perhaps we don't have a total cure for everybody yet. I know from my own experience when you are in so much pain that you want to die in order to stop the pain and a moderately simple procedure is available that can eliminate that pain even if only temporarily then I want to use it.

Jim, age unknown, 3 series of ECT (windsofchange website)

It is a common belief expressed in the testimonies that the main benefit of ECT is selective memory loss:

..It just helped me. It helped me get my act together, and get my life together and I forget. Could.. forget the horrible bits, deep down within side of me for a while as well.

Ann Marie Randell age 41, number of ECT unknown (Testimony archive)

Consumer dis-satisfaction is represented as satisfaction

There are indications in several testimonies of how professional and consumer perceptions of the outcome of a course of ECT may seem to be uniform yet differ greatly. It appears that one consequence of the patient/doctor power imbalance might be that some patients are unable to express their true feelings to their psychiatrist:

After every treatment he would say how do you feel and I'd say God I feel awful, just awful. What I finally realised was that as long as I said I felt bad I kept getting them because he thought I needed more treatment. So the next time I said I feel much better now ...He said oh maybe we'd be able to stop these soon. After the next one I said I feel great. And then he stopped them. That was what all the other patients around the hospital taught each other- that if you wanted to stop getting these things, don't say how bad you feel, say how good you feel. Then they will think they're working and leave you alone.

Anita Courtney, age 32, number of ECT unknown (Southern Exposure 1989)

Unsure

9% of people whose testimonies were collected were unsure whether or not they would have ECT again:

Would I undergo ECT again? I have no idea. Where medication does not work, I believe the doctor's judgement that ECT is still the most effective treatment. For people who are sick enough to be considered for ECT- as I was – I believe the benefits justify the potential loss of memory. Losing my memory, my career, my connections to people and places may seem too much to bear, but I see all that as not a huge price to pay for getting better. What I have lost is enormous, but if it is health I have gained, that is obviously far more valuable than what I lost.

Ann Lewis, age 37, 18 ECT, 1999 (Washington Post 2000)

ECT offers no benefits

61% of the consumers whose testimonies were collected said they would not have ECT again. Some people describe their experience of ECT as damaging but not overwhelming so:

I had a series of ECT treatments several years ago and I am still recovering. I would say that the ECT sort of numbed my brain. It's not paralysing to my life because I still work and have a family and my memory is not too bad.

Eric, one series several years ago (noshock e-mail forum).

Others say that they have experienced some benefits but that overall it was a negative experience:

I would never have ECT again, I know it was beneficial in some respects I am no longer depressed; I can have fun now . But I am a totally different person.

Colleen Tate, age 34, Eight ECTs 1991 (Special report 1991)

Some people believe so strongly that ECT damaged them that they are determined never to have it again:

So I..I would never have it again and I...I am quite determined that if I was ever sectioned again, I ...I would never have it again and I..I had somebody, like my solicitor or somebody there, who...who was going to...to make sure that I wasn't given it without my consent... 'cause I just feel that ..it was going to do me damage.

Mo Hutchinson, age 52, nine ECTs in 93 or 94 (Testimony archive)

Within the testimonies some people say that it is ECT that pushed them toward suicide:

It is a barbaric practice. Psychiatrists say it saves lives, but I would say it is more likely to push you towards suicide. It ruined my life and robbed me of my personality and memories.

Beryl Manklow, age 61, 3 or 4 ECT before treatment was terminated by her husband (BBC online 2000)

Several people say that ECT catapulted them into manic or psychotic states, which they had never experienced before.

Two days after the second ECT treatment, I was hospitalised with mania. I was manic for four days: this was my first episode of mania.

Leigh Murry, age unknown, 6 ECT (Healthy place Depression Community)

In 43% of the consumer testimonies reviewed, people describe their experience of ECT in extremely negative terms and said that for them ECT was damaging and traumatic:

I call ECT a rape of the soul. Psychiatrists call it life saving therapy.

Barbara Cody age 59 13 ECT in 1983 (Texas Public Health committee 1995)

ECT equals EVERY CELL TRAUMATISED, I've been tortured in civilised fashion, and all the time have to struggle against the victim mentality its helped produce in me.

Oliver, age 29, one series ECT in 1990s (going mental no shock web site)

Some individuals are so convinced that ECT has damaged them that they are considering taking legal action:

Please help me ..I had ECT 3 years ago and my life has been ruined. What can I do? I want to sue the doctor. Can I ? someone please get back to me.

Annie, age unknown, number of ECT unknown (Healthy place Depression community)

Some people seek validation for their experiences through involvement in campaigns against ECT.

I am finding strength in speaking out against this biased, archaic, barbaric, poorly researched, unscientific and detrimental psychiatric treatment.

Susan A Whal, age unknown, ECT 3 yrs ago (Healthy place Depression community)

CONCLUSION

Despite the evidence that critical consumers are somewhat over-selected by consumer-led research, it has been shown that other methodological variables exert a powerful effect upon consumers' expressed satisfaction with ECT. This conclusion can be drawn with confidence particularly in relation to *when* consumers are asked about or express their view on having the treatment again. In clinical and consumer research studies and in the testimony data, the length of time that has elapsed since treatment is strongly associated with expressed satisfaction. The conclusion is that studies which interview consumers immediately after treatment, especially if they do so in a medical setting using brief interviews, over-estimate to a considerable degree the extent of satisfaction with ECT. Estimates of 80% to 95% of consumers as content with the treatment are, in the judgement of this Review, not valid.

The evidence that legal or felt compulsion affects satisfaction suggests that both do so negatively. There is one clinical study Wheeldon et al (28) that reports that compulsion does not reduce satisfaction rates (which are found to be high) but there is other evidence that compulsion has a negative effect upon consumers' expressed satisfaction with ECT.

The testimony data makes it clear that 'perceived benefit' from ECT may be both discrepant from and much more complex than clinical concepts of symptom improvement. The testimonies covered issues that are never touched upon by clinical research. These include extreme trauma, lying about improvement in order to stop treatment, the desire to take legal action and the need to seek out support and validation from other individuals and organisations. No clinical research paper asks respondents if they became manic or if they felt more suicidal after ECT. Additionally, it is clear that many consumers' views are complex. Individuals will make trade-offs between side-effects and benefit and some may be

so concerned with the manner in which the treatment was given that whether or not it helped them is not the major issue. For these reasons, it is over-simplistic to assume that there is a uni-dimensional 'attitude towards ECT' even on the question of whether or not it is helpful.

ECT is a treatment that provokes strong reactions in those who have experienced it. Despite the variety and complexity of responses, only 9% of those testifying express uncertainty or ambivalence about the treatment. It is common among those convinced of the effectiveness of ECT to characterise consumers who are opposed to it as a small and vocal minority. In the context of the testimony material, people who receive benefit from ECT are in the minority. However, people who clearly feel the treatment works for them do not feel silenced by those who oppose it and a noteworthy feature of the consumer discourse is an awareness of and respect for diversity of opinion.

CONCLUSIONS

1. METHODS

- 1.1. The methodological diversity and variable quality of research studies examining users' 'attitudes' to ECT posed problems in both assembling and drawing conclusions from this material.
- 1.2. The inclusion of the testimony data therefore increased the validity of the conclusions, when it complemented the more robust research evidence.
- 1.3. The strongest methodological correlate of consumer satisfaction with ECT is the interval since treatment. In all data sources, the time elapsed since treatment was negatively associated with satisfaction with ECT.
- 1.4. The testimony data in particular suggests that consumers' beliefs and perspectives on ECT do not take the form of a small set of 'uni-dimensional attitudes'. They should therefore not be measured as if they do take this form.

2. Aim 1 - Systematic Description of Consumers' Views on ECT

- 2.1. There is some evidence of subjective short-term benefit from ECT from all data sources although it is likely that some research studies over-estimate this because of the methods used.
- 2.2. The short-term nature of subjective benefit reduces satisfaction with the treatment in the long-term and the willingness to have it again.
- 2.3. There is conclusive evidence of persistent subjective memory loss for a significant number of consumers.
- 2.4. This memory loss is retrograde and not detected by measures that focus on anterograde amnesia.

- 2.5. All data sources show that approximately one half of consumers feel they were inadequately informed about ECT.
 - 2.6. All data sources show that a significant number of those who sign a consent form do not feel that they freely consented to ECT.
 - 2.7. Memory loss, felt compulsion and inadequate information are not specific to dissatisfied consumers.
 - 2.8. Consumers may respond with feelings of anger about their experience with ECT particularly when this is dismissed or not acknowledged as valid by health care professionals.
3. Aim 2 - Controversy Between Some Consumers and Mainstream Medical Opinion
 - 3.1. Different issues are interpreted differently by consumers and clinicians:
 - 3.1.1 Relief of depression on a symptom rating scale may not correspond with subjective relief.
 - 3.1.2 Persistent memory loss that consumers understand as a side-effect of treatment is, when acknowledged, understood by clinicians as a consequence of other factors including concurrent symptoms, age and alcohol use.
 - 3.1.3 Some research papers conclude that consumers do not wish to be overburdened with information and wish to leave medical decisions to doctors. What clinicians perceive as trust in the medical profession some consumers experience as powerlessness when confronted with a confident professional.
 - 3.1.4 There are research papers that represent the views of consumers dissatisfied with ECT as insignificant. However, consumer discourse accommodates and allows diversity of opinion.

3.2 The testimony data show that disagreements between consumers and their clinicians about ECT can lead service users to take up a stance against the treatment generally:

3.2.1 Failure to acknowledge the factors under 3.1 on the part of professionals may lead an individual to seek the support of others with similar experiences and of consumer organisations.

3.2.2 In the context of this Review, it is not surprising that organisations should emerge which provide a forum and platform for those consumers who feel that their experience of ECT has been damaging and coercive.

SUGGESTIONS FOR FUTURE RESEARCH

Persistent memory loss

A comprehensive piece of research should be undertaken on persistent memory loss as a consequence of ECT. The main issue arising from the Review has been to differentiate autobiographical memory from anterograde memory, which, while distressing, seems to be less important and more temporary for consumers. Studies need to have long follow-up because losses of memories prior to ECT may only become apparent after a long interval. One approach could be to adopt the lead of the small-scale work of Janis undertaken in 1950 and which has never been repeated. This study adopted a narrative approach to memory, asking individuals to relate their life story in their own terms, highlighting what was important to them and with a limited number of prompts about significant life events. The study would not only collect this observational data on loss of memories but would also ask about subjective distress following the discovery of persistent memory loss. The effects of medication levels and current symptoms in relation to memory loss and levels of subjective distress would also need to be investigated.

Information and consent

A systematic research programme should be undertaken on legislation concerning ECT, the effects of this legislation on consumers' attitudes towards compulsion and on 'felt compulsion' in the absence of legal coercion. This research programme should be cross-national and cross-state and territory for the U.S.A. and Australia. It will need to include non-English speaking countries and will require a team of researchers who are attuned to cultural differences. It should also examine countries, states or territories where there have been major changes to legislation or to central guidance concerning ECT in the last 30 years.

Factors which should be investigated include:

- i. The relationship between legal compulsion and beliefs, attitudes and feelings about ECT at a later point in time (at least six months)
- ii. The relationship between felt compulsion and perceived coercion and the general legal context and between felt compulsion and post-treatment attitudes.
- iii. The extent of the belief that patients should have absolute confidence in the medical profession and the relationship of this to the general legal and cultural context.
- iv. For countries or states that have seen major recent changes to legislation or central guidance concerning ECT, the forces that brought this about and the subsequent responses on the part of professionals, consumers and policy-makers.

- v. The relationship between the use of ECT and access to resources, particularly in developing countries but also for poor consumers in developed countries based on insurance systems.

The difficulty of such a research programme should not be under-estimated. For example, the EPSILON study (British Journal of Psychiatry, Special Issue, 39, 2000) encountered great difficulty in translating instruments between languages/cultures *within* Europe. However, as the UK becomes more integrated into Europe and subject directly to the European Convention on Human Rights, and as Western forms of psychiatry spread to other parts of the world, it would seem that such a programme of research is timely. Care should be taken to avoid Euro-centrism.

Perceived benefit

As the Review has shown, estimates of perceived benefit seem to be related to several different methodological factors, the main one being the timing of the assessment. The effects of this should be more thoroughly investigated and may be transferable to other mental health domains. In particular, first-time recipients of ECT should be interviewed immediately after treatment and then at a 6-9 month interval with other methodological factors found to be important in this review controlled. This could include a comparison between user-interviewers and clinical interviewers in the UK context as previous studies were conducted in North America.

The way in which both new and experienced consumers trade off, or balance, the risks and benefits of ECT should also be examined. This could be done through vignette studies depicting various scenarios associated with ECT which the users would rank or cluster in terms of the risks and benefits. The full range of experiences should be depicted including very negative and very positive experiences on a range of different dimensions. Some of these have been delineated in this report.

APPENDICES

Appendix 1: Full corpus of research studies tabulated by methodological variables

Authors	Country and date	Design	Sample size	% Returns	Interval since ECT	Interviewer/ setting	Quantitative/ Qualitative	Author type
1. Gomez	UK 1975	?	96	N/A	Same day	Medic/ same Hospital	Quantitative	Clinical
2. Hillard & Folger	USA 1977	Quasi-Exp.	20 v 10	N/A	Varied	Non-treating doc / Mixed	Quantitative	Clinical
3. Freeman & Kendell	UK 1980	Retrospective	166	89%	Mean 1 year	Medic /Same Hospital	Quantitative / Mixed	Clinical
4. Freeman et al	UK 1980	Survey	26	N/A	Varied	Non-treating doc /Mixed	Mixed	Clinical
5. Hughes et al	UK 1981	Retrospective	72	90%	Mean 19 wks	Med student/ Same hosp.	Quantitative	Clinical
6. Kerr et al	Australia 1982	Quasi-Exp.	88 ECT	52.8%	Varied	Medic/Mixed	Quantitative	Clinical
7. Squire & Slater	UK 1983	Prospective	31 ECT	88%	3 years	Medic, Research	Quantitative	Clinical
8. Cowley	UK 1985	Part of RCT	96 + 23	N/A		Medic/ Same Hospital	Q-sort	Clinical
9. Freeman &Cheshire	N/A 1986	Review	N/A	N/A	N/A	N/A	N/A	Clinical
10. Freeman	N/A 1986	Review	N/A	N/A	N/A	N/A	N/A	Clinical
11. Aperia	Nordic 1986	Prospective	30	86%	2-8 years	Medic/ Same Hospital	Quantitative	Clinical
12. Baxter et al	USA 1986	Quasi-exp.	35+20	75%	During	Same hosp.	Quantitative	Clinical
13. Benbow	UK 1988	Prospective	54	92%	Pre-discharge	Medic/ Same hospital	Quantitative	Clinical
14. Malcolm	UK 1989	Prospective	100	98.5%	Before 1 week	Non-treating doc/ Hospital	Mixed	Clinical
15. Calev et al	USA 1991	Experimental / Time	23	56%	Repeated up to 6 months	Medic/ Mixed	Quantitative	Clinical

16. Szuba et al	USA 1991	? + Quasi-exp.	25 pts 25 rels	56.8%	Before/soon after?	Medic/ Same Hospital	Quantitative	Clinical
17. Fox	USA 1993	Case studies	4	N/A	Years	N/A	Histories	Clinical
18. Battersby et al	Australia 1993	Quasi-Exp.	24 ECT	85%	Varied	Self/ Hospital	Quantitative	Clinical
19. Rogers & Pilgrim	UK 1993	Survey	231	N/A	Varied	Researchers/ Day Care	Mixed	Social Science
20. Riordan et al	UK 1993	Prospective	37	75.5%	Mean 2 months	Non-treating doc/ Mixed	Quantitative/ Mixed?	Clinical
21. Pettinati et al	USA 1994	Quasi-Exp.	78	64%	6 months	Mixed	Quantitative	Clinical
22. Wallcraft	UK 1995	Pilot survey	10	N/A	Varied	Self / Postal	Mixed	Consumer
23. UKAN	UK 1995	Survey	308	N/A	Varied	Self / Postal	Mixed	Consumer
24. Mental Health Fnd'n	UK 1997	Survey	107 ECT	N/A	Varied	Self/ Day Care	Mixed	Vol Org/ Consumer
25. Sestoft et al	Nordic 1998	Retrospective	113	54%	Varied	Self /Postal	Quantitative	Clinical
26. Bernstein et al	US 1998	Survey	52	??	Varied	Mixed	Quantitative	Clinical
27. ECT Anonymous	UK 1998	Survey	200+	N/A	Varied	Self / Postal	Mixed	Consumer
28. Wheeldon et al	UK 1999	Prospective	150	93%	5-10 days	Medic/ Same hospital	Quantitative	Clinical
29. Johnstone	UK 1999	Survey	20	N/A	Varied	Researcher/ Choice	Qualitative	Clinical (Psychol)
30. Goodman et al	USA 1999	Quasi-exp.	24 ECT	45.3%	During + 2 weeks	Researcher/ Mixed	Quantitative	Clinical
31. Lisanby et al	USA 2000	Quasi-Exp.	33 ECT	60%	1 week + 2 months	Medic?/ Same	Quantitative	Clinical
32. Donahue	USA 2000	Review	N/A	N/A	N/A	N/A	N/A	Consumer
33. MIND	UK 2000	Survey	418	N/A	Varied	Self / Postal	Mixed	Vol Org / Consumer
34. Communicate	UK I.p	Survey	45	48.6%	Mean 19 weeks	Mixed	Mixed	Collaborative
35. MDF	UK I.p.	Survey			Varied	Self / Postal	Mixed	Consumer

Appendix 2: Studies tabulated by year, perceived benefit, willingness to have ECT again and five methodological variables (ranked).

Authors	Country and date	% Benefit	% Have Again	Interval since ECT (Note 1)	No. Qs (Note 2)	Complexity Schedule (Note 3)	Setting/Int. (Note 4)	Clinical
Freeman & Kendell	UK 1980a	78	59	3	3	4	2	Yes
Hughes et al	UK 1981	83	72	2	3	2	2	Yes
Kerr et al	Australia 1982	73		2	3	1	3	Yes
Aperia	Nordic 1986	70	63	3	2	3	2	Yes
Benbow	UK 1988	73		1	3	2	1	Yes
Szuba et al	USA 1991	76	72	1	1	2	1	Yes
Rogers & Pilgrim	UK 1993	43		3	3	3	4	
Riordan et al	UK 1993	56	67	2	3	4	3	Yes
Pettinati et al	USA 1994		98	1	1	1	1	Yes
UKAN	UK 1995	30	18	3	3	2	5	
Ment Health Fnd'n	UK 1997	30		3	2	3	5	
Bernstein et al	US 1998	83	79	0	2	1	1	Yes
ECT Anonymous	UK 1998	29		3			5	
Wheeldon et al	UK 1999	81	77	1	1	1	1	Yes
Goodman et al	USA 1999		82	0	3	1	2	Yes
MIND	UK 2000	36		3	3	3	4	
Communicate	UK Forthcoming	44	41	2	3	1	4	
MDF	UK Forthcoming	30		3	3		5	

Note 1: 0 = during course or maintenance ECT; 1= within 4 weeks or pre-discharge; 2 = 1– 6 months; 3= > 6 months

Note 2: 1 = 5 questions or less; 2 = 6-14 questions; 3 = 15 or more questions

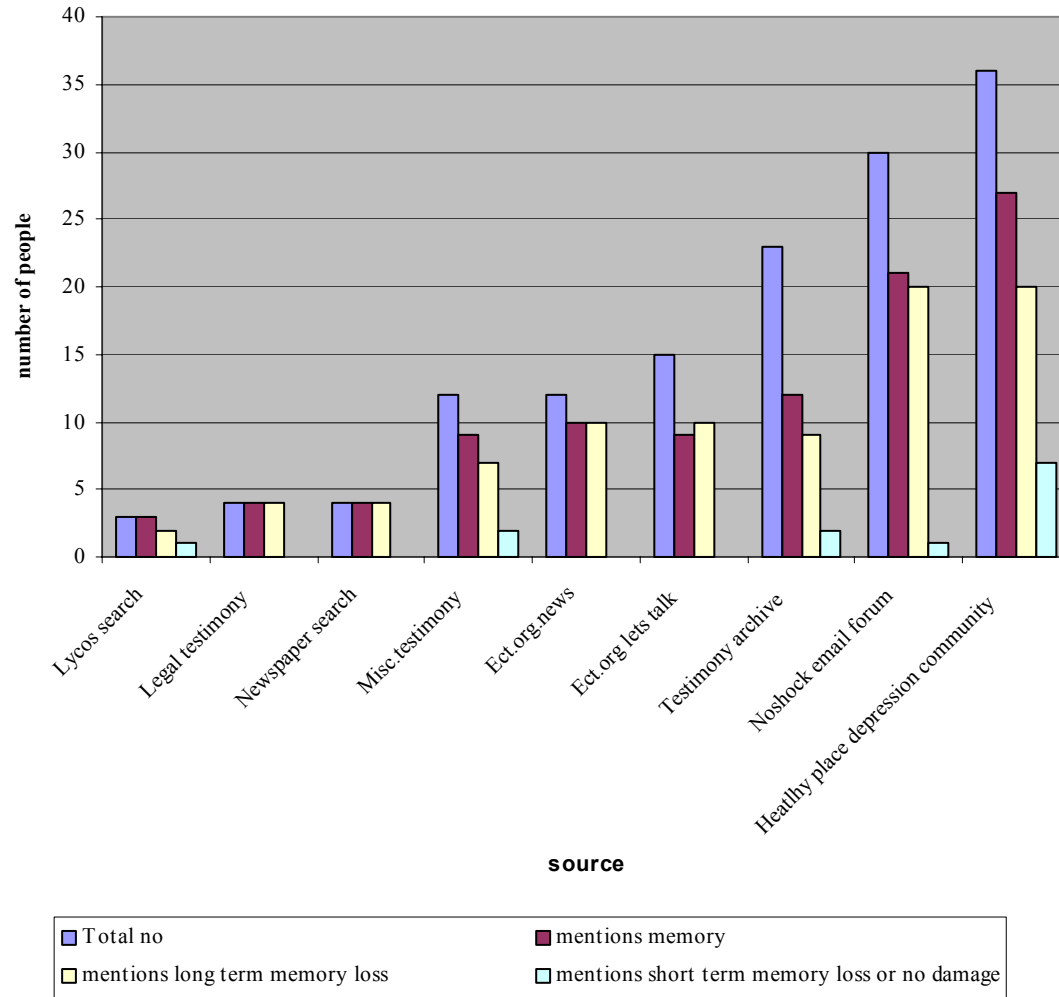
Note 3: 1 = 3-pt likert; 2-simple likert; 3 = complex likert/ multiple choice; 4 = semi-structured interview

Note 4: 1 = in-patient; 2 = same hospital/treating doctor; 3 = non-treating doctor/at home; 4 = voluntary or collaborative, day care or choice; 5 = source is consumer organisation, choice of setting.

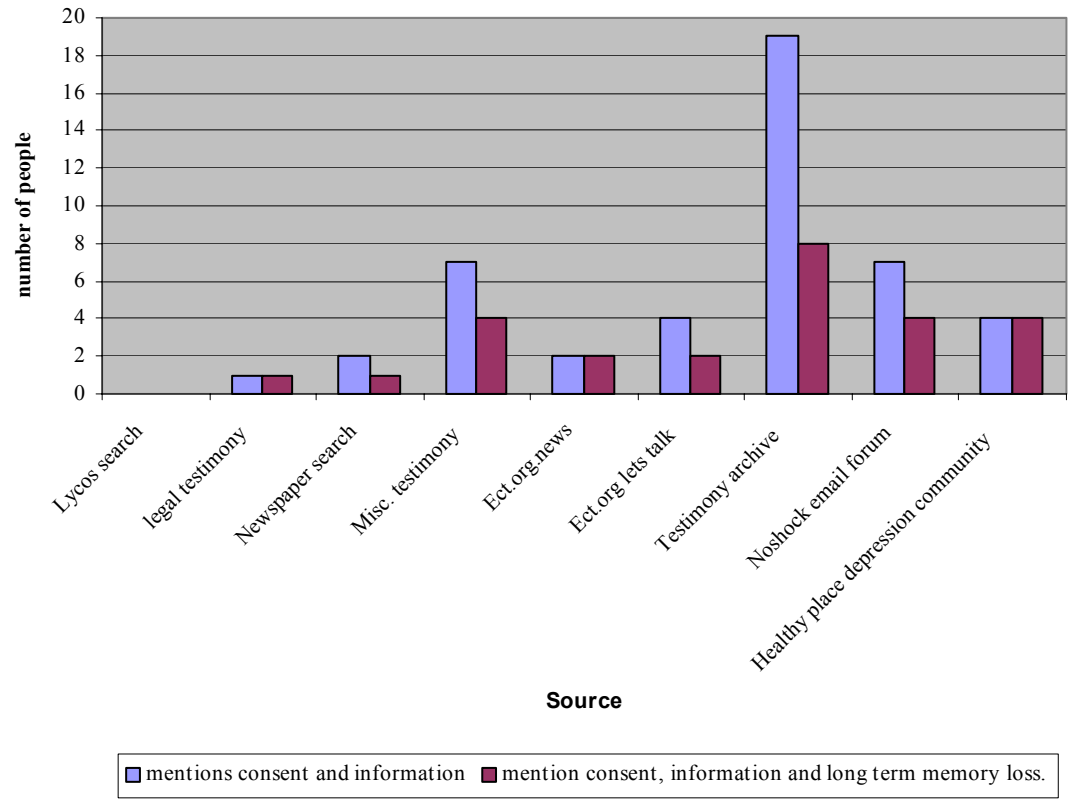
Appendix 3: Demographic Features of Study Samples in Chapter 7 and UK Norms 1999

Study	Age: Mean/ Median	Older consumers	% Female	SES	Sectioned	Legally compelled
UK norms 1999	59	41% > 65 yrs	68%	Low?	25%	19%
Freeman & Kendell (1980) (1976 sample)	50	None > 70 yrs		Med.		
Freeman et al (1980)	51.5		77.3%	Med.		
Hughes et al (1981)	49		59.7%			7%
Kerr et al (1982)			65%			
Aperia (1986)	57					
Baxter et al (1986)	E 39.6 C 60.2		E 57% C 70%			0% 0%
Benbow (1988)		41% > 60 yrs	69%			0%
Malcolm (1989)	68.5	59% > 65 yrs	68%			27%
Calev et al (1991)	48	None > 65 yrs	69.5%	High		0%
Szuba et al (1991)	45.2		72%			0%
Riordan (1993)	53.6	38% > 65 yrs	69.4%		16%	10%
Pettanati et al (1994)	60		66.7%			0%
UKAN (1995)	40	18% > 60 yrs	52.6%		27%	
Sestoft et al (1997)	68		77%			
MDF						
Bernstein et al (1998)						0%
Wheeldon et al (1999)	Inf. 55.2 S3 44.8 S 58 47.8		Inf. 65.% S3 66.7% S5 872.%		11%	7%
Goodman et al (1999)	58.3		50%	High		0%
Johnstone (1999)			60%	Low	30%	
MIND (2000)	52	10% > 65 yrs	57%		35%	
Communicate	63					2%

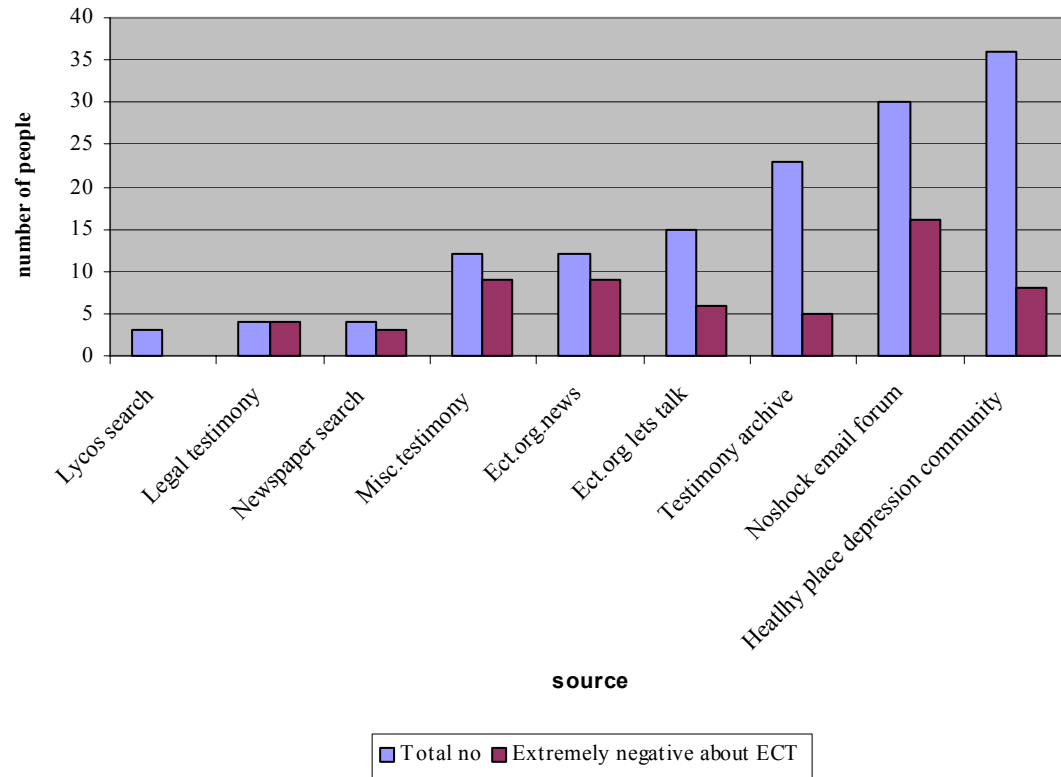
Appendix 4: a) ECT and Memory loss



Appendix 4: b) Consent, information and memory loss



Appendix 4: c) Negativity about ECT



APPENDIX: 5

SAMPLE TESTIMONIES AND ANALYSIS GRID

1) Mental Health Media Testimony Archive.

The following is extracted from the transcript of Pauline Stott's video interview. See Grid (1) for analysis.

'So it was mostly drug treatment but I did also have several courses of ECT, shock treatment as it's normally, as it's normally called. Shock treatment's in disfavour nowadays in a lot of areas. I don't know that it particularly helped me a great deal, but having said that, I have seen people make very good recoveries after ECT so perhaps it was over-used in the sixties, early seventies, but I still think, I personally still think it, it can be a very viable treatment and it can help some people. Really I, when I was in hospital, there used to be literally queues of trolleys going in for ECT. There was a long corridor, the trolleys would be lined up in the corridor then you would be pushed into this long room, the, sort of, the trolley sort of sideways, one after another. The anaesthetist would come round with the, the jabs that they give you before the actual anaesthetic. So, she, this, she were a lovely lady I remember her to this day, so, so cheerful and kind to everybody and she'd come along with her, a dish full of syringes and give you the, the pre, the thing you have before the anaesthetic and then you would be wheeled one by one into the actual room where the treatment was given. You would be anaesthetised in there and that would be it then until you, you woke up, often with a headache, but for myself I never had any, any long term effects. I haven't suffered any sort of permanent memory loss, you could lose memories for the, you know, the few hours before you have the shock treatment, but, no, I haven't suffered any long term damage. It's, it's one of those things at the moment that people are having strong feelings about it's use, but in my experiences of seeing what it's done for other people I do think it has a value, but perhaps, as is happening nowadays, it's, it's used more selectively, perhaps that's the secret.'

'Can you remember when you were first told that you would have ECT, or perhaps you were asked if you wanted it, I don't know.'

'I think it was probably more told than asked cos if you were Sectioned you weren't really asked. But having said that I wasn't unhappy to go along with it because I had seen how it had helped people.'

'You'd already seen, seen it being done to other people before you had the course?'

‘Oh yes, yes, yes, so it, no it, I was obviously a bit apprehensive because I wasn’t sure exactly what to expect, but because there was so many people on the ward who were having ECT it was done sort of, you know, on a twice weekly rota and you were seeing people go down to the ECT treatment area and coming back from it, you know, sort of, perhaps with a headache and a bit of memory loss but within a couple of hours they seemed fine. So it wasn’t a problem and I’m not, I’m not easily scared about medical procedures anyway, so, for, for me, no, it wasn’t a problem and I, I certainly wasn’t reluctant to, to have it done because it was, it was so much part of the, of the, you know, the mental health treatment plans and the hospital. It was a fact of life, a fact of life and it didn’t bother me the thought of having it done because I really hoped it would, it would help. So, yeah, some people have had bad, bad experiences of it, but my own experiences weren’t bad and I certainly feel it, it still has a role to play for some people but other people obviously feel differently.’

‘It was done quite routinely to most people was it?’

‘Well not, lots of, what would happen, people would go into hospital and they would be treated, possibly for some months, well certainly weeks, more likely months with, with the anti-depressant drugs and it was a sort of, I think, you know, they’d have a look round and think well, you know, ‘Such a body’s not doing very well are they, so we’ll try them with a course of ECT’ and of course that happened to me also, you know, I had several courses of ECT and I think it was a result of people looking and ‘oh well, she’s not really doing very well on such and such, such and such a drug so we’ll try the ECT’, and yeah, it was, it wasn’t very selective I don’t think, no I don’t.’

2)GOING MENTAL NO SHOCK WEBSITE

Web address <http://members.aol.com/noshockectforum.htm>¹

Part one: Front page:

This is the web page that precedes entry into the forum area:

ECT FORUM

Welcome to the ECT Message Board. This board has been created in order to give like-minded people an opportunity to debate one of the most controversial procedures used by psychiatrists; so that people can talk about their experiences; and as a place in which to give and receive advice.

All I ask is that we respect the opinions of others even when we don't agree with them; and that we not criticize or be abusive to people just because their views are different to ours. Messages that are abusive to other contributors will be removed. That said, enjoy the Board.

PART TWO: SAMPLE THREAD

The thread is entitled *Survivor of 9 treatments* and the originating message is from Lisa: User ID: 9823593. for analysis see Grid (2)

Apr 3rd 11:48 PM

I am 39 years old, married, with two daughters. Almost five years ago I underwent 9 E.C.T. treatments! At the advice of my husband and Dr. I have had permanent memory loss. And feel worse than I did, physically and mentally. I am a RN, but due to the memory loss I am not working. I know I have brain damage, even though I have not been properly diagnosed with it, I know it is there. I regret taking the ECT treatments. No one understands in my family, my daughters are 16 and 11 now, but husband has shown no support/compassion to my illness. A supportive, understanding, and experienced voice would help to know that there are others like me.

Barb

User ID: 9092003

Apr 4th 1:25 AM

Hi Lisa

I'm a former teacher and former RN. ECT disabled me. Depression did not stop me from going through nursing school, graduating with ECT disabled me and the damage to my brain is

¹ NB since our download, noshock and ect.org have created much closer links and merged their email forums.

verified.
I was dumb enough to have ECT three times, but the last treatments (out pt, 1983) were essentially the end of who I was.
My testimony is on this site under "Evidence."
You might try to at least get an EEG done, if you have insurance. That may help verify the damage.
There are many "like you" out here.
Take care, Lisa, and I'm glad you've posted on the forum.
Barb

Lisa
User ID: 9823593

Apr 4th 8:23 PM
Thanks for your response Barb. I have read your testimony and other messages on the board. I am an avid reader when I can concentrate. Illness and stress doesn't help that. I would like to hear from others like myself and who are still in the process of trying to raise a family. I've changed a lot and it's difficult for all of us. I can feel pretty guilty at times for the ways emotionally, physically and financially I have affected my husband and daughters. Am hoping to hear from someone. Thank you

Hoping
User ID: 0471064

May 21st 6:15 PM
Dear Lisa, My heart went out to you as i read your last post. I too am raising a family--oldest 14, youngest 10 months. ECT affected all lmy relationships with my family. I feel like a stranger in my own body. My kids, bless their hearts, continue to love me. I feel so bad that my love for them has been screwed up but i do my best to be kind and continue t didscipline them as appropriate. Also my love for my husband has been stolen. He continues to love me and listen to me but i know the rages on go into are very trying. a lesser man would have left me. sometimes i beg him to get rid of me because now i am such a mess and he deserves far better. I hope i can make good memories with my family. Someitmes i think i probably won't live very long because of how traumatic the experience of the "treatments" was. but i really have no idea. i am trying to take extra good care of myself and my family so hopefully we'll make it thru this nightmare.

Grid (1) Pauline Stott Testimony Archive

Source	Age Sex	No. ECT	timescale	Dup	Memory (m)	Consent / info (c)	Emotional response (e)	Costs and benefits (c&b)	Open Cat. (o)
Testimony archive Pauline Stott	F58	Several courses	unknown		, but for myself I never had any, any long-term effects. I haven't suffered any sort of permanent memory loss, you could lose memories for the, you know, the few hours before you have the shock treatment, but, no, I haven't suffered any long term damage.	"I think it was probably more told than asked cos if you were sectioned you really weren't asked. But having said that I wasn't unhappy to go along with it because I had seen how it had helped people"	"So it wasn't a problem and I'm not, I'm not easily scared about medical procedures anyway, so, for, for me, no, it wasn't a problem and I, I certainly wasn't reluctant to, to have it done"	"It was a fact of life, a fact of life and it didn't bother me the thought of having it done because I really hoped it would, it would help. So, yeah, some people have had bad, bad experiences of it, but my own experiences weren't bad"	

Grid (2) Survivor of 9 treatments Noshock email forum

Lisa	F39	9	5 yrs ago		"Permanent memory loss"		No one understands in my family – wants support and understanding	Feels worse physically and mentally, not working	
Barb	F	3 series	Last series 1983 as out patient	X	"ECT disabled me and the damage to my brain is verified".			"The last treatments were essentially the end of who I was"	
Lisa				X			ECT affected all my relationships with my family. I feel like a stranger in my own body.		
Hoping	F			X			treatments had profound effect on life and relationships	"sometimes i think i probably won't live very long because of how traumatic the experience of the "treatments" was.	

Appendix 6

The following are extracts from the Royal College of Psychiatrist's Factsheet on ECT that are particularly relevant to the themes covered in this Review. When the Review refers to 'the medical consensus' or 'established medical opinion' it is this published statement of a professional body that is indicated. This is the information most commonly seen by UK consumers and it was current on the Internet at the time of writing.

Royal College of Psychiatrists Factsheet on ECT - extracts

"For most people ECT is a short-acting treatment, but it does act more quickly than drugs. This can be life-saving." (pp1-2)

"Over 8 out of 10 depressed patients who receive ECT respond well to it. In fact, ECT is the most effective treatment for severe depression. People who respond well.....report it makes them feel 'like themselves again' or 'as if life was worth living again'." (p. 3)

"What are the side-effects of ECT?"

Some patients may be confused just after they wake from the treatment and this generally clears up within an hour or so. Your memory of recent events may be upset and dates, names of friends, public events, addresses and telephone numbers may be temporarily forgotten. In most cases this memory loss goes away with a few days or weeks although some patients continue to experience memory problems for several months. As far as we know, ECT does not have any long term effects on your memory or intelligence." (pp.3-4)

"Can I refuse to have ECT?"

You can refuse to have ECT and may withdraw your consent at any time even before the first treatment has been given. The consent form is not a legal document and does not commit you to having the treatment. It is a record that an explanation has been given to you and that you understand to your satisfaction what is going to happen to you.....

Very occasionally a person may become particularly seriously ill with depression. They may be suicidal, convinced they are too wicked to be treated, or even eating and drinking too little to stay alive for much longer. In these circumstances ECT may be given to patients without their consent." (p.4)

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Consumer-led and Collaborative Research

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