

Public perception on infertility and its treatment: an international survey

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The first large survey on the public perception of infertility and its treatment was conducted in six European countries, the USA and Australia. A representative sample of 8194 adults was polled, using standard validated methodology. The results obtained highlighted the following major aspects: (i) infertility is perceived as a disease by less than half of the people surveyed (38%), in contrast to the accepted medical opinion; (ii) awareness about the definition and incidence of infertility is relatively low, despite the fact that half of the people polled claimed to know someone affected by infertility; (iii) close to 90% of the adults surveyed knew about in-vitro fertilization (IVF), but less than one-quarter of them knew about the chances of success of this assisted reproductive technology; and (iv) when confronted with the knowledge that the cost of three IVF cycles is roughly equivalent to the cost of a hip replacement (a commonly reimbursed procedure), a large majority (70%) of the individuals interviewed agreed that IVF should be reimbursable.

Key words: assisted reproduction/infertility survey/public awareness/public perception/treatment reimbursement

Introduction

The understanding of the causes of infertility has made enormous progress during the past 20 years (Edwards, 1996). In parallel, a number of treatments have been successfully tested, and they can be tailored to individual problems, depending on the factors contributing to the infertility of a couple. Assisted reproductive technologies are no longer considered experimental, and the success rates obtained are improving and in some cases comparable with the fecundity of normal fertile couples who are attempting to conceive (Hull, 1992; Hull *et al.*, 1992; Templeton, 1995; Van den Eede, 1995; Wilcox *et al.*, 1995; Guzick, 1996; Jennings *et al.*, 1996).

In contrast to the great scientific and medical developments, access to treatment varies depending largely on the country, and even on the region within a country, as in the UK. The attention of the media often focuses on controversial cases

with extreme outcomes, but little effort has been put into providing balanced and complete information to the general population on the subject of infertility and its treatment. As a result, the public is confronted with claims that may offer a distorted vision of the real therapeutic possibilities.

The survey presented herein was undertaken with the aim of investigating how the public in Western countries perceives infertility. Infertility is a rather common problem (Templeton, 1995; Chandra and Stephen, 1998; Stephen and Chandra, 1998), and yet this prevalence seems not to be matched by an awareness of what the condition really is, i.e. the scientific definition of infertility, its frequency, and what solutions modern medicine can offer.

This is the first time that such a large international survey has been conducted on the topic of infertility. The results presented here are an important starting point to identify strategies for a wider public appreciation and understanding, which in turn is the best basis to obtain public support for sound reimbursement policies.

Materials and methods

Between May and October 1998, a representative sample of 7036 adults aged ≥ 15 years were interviewed in a telephone survey in six European countries (Belgium, France, Germany, Italy, Sweden and the UK) and the USA. The survey was conducted in Australia in March 1999, polling 1158 respondents aged 18 years and over. Demographic information about each respondent's age, sex and social classification was also collected. The questions asked are presented in Table I. The answers were mutually exclusive; in other words, the responder was allowed only one answer among those presented.

At least 1000 people were interviewed in each country. Samples larger than 1000 would have brought only a marginal increase in accuracy. The sample structure was so designed as to be representative of the country concerned.

The individuals surveyed were selected from the electoral registers on a 1 in n basis; telephone numbers were then appended to the record. This procedure generated a 'household' telephone number; the individual actually interviewed was selected within each household. Quota controls, standard practice in telephone research, were applied to ensure correct representation. For example, in the UK the sample was designed to be representative of the population in terms of region, sex, age and social class. A similar procedure was applied in all countries surveyed (details on the methodology used in each country are available upon request).

The data were also weighted to reflect the differing country sizes in the survey. In this way, a real 'total' figure was produced. Without this weighting, a small country such as Belgium would have had an equal effect on the total as a larger country such as Germany. Clearly, a representative sample of Belgium and Germany would need to have more Germans in it than Belgians. Tables IIa and b provide an

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Table I. List of questions and possible answers given in the survey

- Q.1** Do you agree or disagree with the statement ‘Infertility is a disease’? PROBE Is that strongly or slightly?
Agree strongly / Agree slightly / Disagree slightly / Disagree strongly
- Q.2** Infertility is recognised as a disease by leading medical societies. It is defined by the World Health Organization (WHO) as ‘the inability of a couple to achieve conception or to bring a pregnancy to term after a period of regular, unprotected, intercourse’. How long do you think that period is?
6 months to a year/1 to 2 years / over 2 years / being unable to conceive at all
- Q.3** The period defined by WHO is one year or more. In developed countries, roughly how many couples do you think seek medical assistance to overcome an infertility problem? READ OUT
1 in 6/1 in 10/1 in 50/1 in 100/1 in 1000
- Q.4** Do you personally know anyone who has admitted having difficulty becoming pregnant? In other words, experiencing infertility?
Yes / No
- Q.5** Have you heard of in-vitro fertilization, commonly known as IVF? This is where an egg and sperm are joined outside the body and then implanted in the womb.
Yes / No
- Q.6** If a woman under 40 years old undergoes an IVF treatment cycle today where up to three fertilized eggs are placed in her womb, what chance do you think she has of having a baby as a result, compared with a fertile couple trying to have a baby through regular unprotected sexual intercourse during one month? Would you think the IVF patients’ chances were...?
Much higher / Higher / Roughly the same / Lower / Much lower
- Q.7** The chance is roughly the same, about 25%. Today, in developed countries, one couple in six seeks medical assistance for infertility. In <country name inserted> the cost of <country-specific data inserted> IVF treatment cycles is roughly equivalent to the cost of a hip replacement operation. Knowing this, do you think that IVF treatment for couples who cannot otherwise have a baby should be paid for by the State/available through general medical insurance?
Yes / No

Table II. Example showing the effect of weighting survey data according to population size

(a) *Unweighted data*

Base	Sample size		
	Total 2000	Belgium 1000	Germany 1000
Answer 1	750	500	250
Percentage of respondents	38	50	25
Answer 2	1250	500	750
Percentage of respondents	62	50	75

(b) *Weighted data*

Weighted base	2000	220	1780
Answer 1	555	110	445
Percentage of respondents	28	50	25
Answer 2	1445	110	1335
Percentage of respondents	72	50	75

example of weighting, done with fictitious numbers. In the weighted tables it was noted that the total answer was much closer to the result from Germany, reflecting its greater population size. The examples shown in Table IIa and b were deliberately inflated and do not show real survey data.

Statistical significance of the answers was analysed with *t*-test for independent samples. The test was carried out at the 95% confidence level; hence *Z* (or *t* level) was 1.95.

Results

Perception of infertility

Infertility is recognized and defined as a public health problem and is the manifestation of one or more pathological conditions

either of female or male origin (World Health Organization, 1991). The first question of the survey addressed the level of agreement with this definition. The general perception among adults in Europe, Australia and USA was different. The percentage of people agreeing or strongly agreeing with the statement proposed varied from a low 18% in the UK to a high 57% in Italy. The range was smaller in continental Europe (from 35% in Belgium to 57% in Italy), and contrasted with the percentages reported in the UK, Australia and USA (Table III). The differences observed between countries were statistically significant.

In Belgium, the UK, Australia and USA, a majority of adults disagreed or strongly disagreed with the statement proposed, whereas in the other countries surveyed, less than 50% of the people did not concur with the medical definition. In all the countries surveyed, with the exception of the UK and Sweden, women were more likely than men to disagree strongly or slightly with the statement proposed (data not shown).

Knowledge of infertility definition and incidence

The World Health Organization (WHO) defines infertility as the inability of a couple to conceive after a period of regular, unprotected intercourse (World Health Organization, 1995). When asked about how long they thought this period was, an average of 20% of people declared not to know the answer, and another 24% said that it was a total inability to conceive. Only slightly more than 50% gave an answer that came close to the WHO definition. The percentage of people who either did not know or gave an incorrect answer was lower in Australia, Sweden and the UK (38, 37 and 36% respectively), and higher in Italy (56%). These differences were statistically significant. Interestingly, the general level of knowledge in the USA and Europe as a whole was similar. It is possible that some differences in public opinion are due to religious beliefs. However, this point cannot be addressed or supported by

Table III. Breakdown of answers to Question 1: ‘Do you agree or disagree with the statement ‘Infertility is a disease’?’

	Agree strongly (%)	Agree slightly (%)	Total agree (%)	Disagree slightly (%)	Disagree strongly (%)	Total disagree (%)	Can’t say (%)
UK	6	12	18	28	48	76	6
Australia	6	14	20	33	34	67	13
USA	10	13	23	26	34	60	17
Belgium	15	20	35	22	37	59	6
France	21	28	49	19	26	45	6
Sweden	25	21	46	13	32	45	9
Germany	25	29	54	13	24	37	9
Italy	17	40	57	22	15	37	6
Total Europe	18	27	45	19	29	48	7
Total	16	22	38	22	31	53	9

published data. Younger people (between 15 and 25 years old) were less knowledgeable than older age groups, particularly in Italy and the UK. This tendency was reversed in Australia and Germany, where a higher percentage of people in the age group 34 to 54 years provided an incorrect answer. In the USA, the percentage of people who answered ‘I do not know’ significantly increased with increasing age (data not shown).

When asked about how many couples seek medical assistance to overcome an infertility problem, only an average of 16% of respondents answered correctly (i.e. one in six couples seek medical help for infertility problems), and another 29% came close to the right figure (i.e. gave the figure of one in ten). Country-specific variations were not pronounced, and no differences were seen when Europe was compared with Australia or the USA. Interestingly, about 20% of those surveyed underestimated the size of the problem by one or even two orders of magnitude. Gender and age differences in the response were not very prominent, although in some countries, like the UK, men were less likely than women to come close to the correct answer. Again, older people were significantly more likely to answer ‘I do not know’ to this question, particularly in the USA and Australia (data not shown).

This widespread unfamiliarity with infertility definitions and incidence was in contrast with the fact that 52% of the people polled declared to know personally somebody who had admitted difficulty in becoming pregnant. This percentage varied little among the countries (showing a peak of 62% in Sweden). However, within individual countries, in all cases women were more likely than men to know someone who had experienced infertility, and a higher percentage of people belonging to age groups in the mid- to late reproductive age also declared to know someone who had difficulties becoming pregnant. These gender and age differences were statistically significant in most cases.

Therapeutic possibilities: IVF

A very high proportion of adults across Europe and in the USA had heard about IVF. This percentage was higher in Sweden (97%), Australia (95%), Italy and the UK (both 92%), and USA (90%), and lower—though still relevant—in Germany (77%). In all countries, the age groups between 25 and 54

years old were more likely to know what IVF was, except in Germany, where only 68% of young adults knew what IVF was, compared with a total average of 89% and a national average in Germany of 77%.

In contrast to this seemingly high awareness about the therapeutic possibilities for infertility, a large percentage of people did not know what the chances of success of this assisted reproductive technique were (Question 6, see Table IV). The percentage of people who thought that the chances were either lower or much lower than those of a fertile couple trying to have a baby through regular unprotected sexual intercourse during one month varied from a low 39% in Italy to a high 56% in the UK and 55% in Australia (Table IV). Within individual countries, women consistently seemed to believe less than men did in the therapeutic possibilities of IVF. In all countries, significantly more women than men thought that the chances of having a baby after IVF were either lower or much lower compared with a fertile couple. Age differences in the percentage of replies given did not show a particular consistent pattern, although in the USA a significantly higher number of younger people underestimated the therapeutic potential of IVF (data not shown).

Should IVF be reimbursed?

The last question (Question 7, Table I) began by informing the respondent about the fact that the cost of an average of three IVF cycles was approximately equal to a common surgical procedure, hip replacement (this figure varied somewhat among the eight countries, from a high of 4.0 in Belgium to a low of 2.5 in France, and the average was 3.08). With this information, the respondents were asked whether IVF should also be reimbursable. A significant majority of individuals in all countries agreed that IVF should also be reimbursed. This percentage varied from a low of 60% in the UK to a high of 82% in France (Table V). In most countries, namely in France, Italy, Sweden and the UK, significantly more women than men thought that IVF should be reimbursed. In all countries, younger people were more favourable to reimbursement than older people. If the respondents knew personally somebody who had infertility problems, they were more likely to favour reimbursement (data not shown).

Table IV. Breakdown of answers to Question 6 concerning the chances of successful IVF treatment compared with a fertile couple

Chances of becoming pregnant on IVF	Much higher (%)	Higher (%)	Total higher (%)	Roughly the same (%)	Lower (%)	Much lower (%)	Total lower (%)	Can't say (%)
Belgium	7	19	26	27	29	8	37	10
Germany	7	15	22	24	31	10	41	13
Italy	3	21	24	24	33	6	39	13
France	4	16	20	23	37	9	46	11
USA	6	17	23	21	31	14	45	11
Sweden	5	16	21	23	39	10	49	7
UK	5	13	18	19	43	13	56	7
Australia	4	14	18	18	40	15	55	9
Total	5	16	21	22	35	11	46	10

Table V. Breakdown of answers to Question 7 asking whether IVF should be reimbursed

	Yes (%)	No (%)	Can't say (%)
France	81	13	6
Belgium	80	14	6
Italy	71	22	7
Germany	69	20	11
Sweden	68	22	10
USA	66	26	8
Australia	65	26	9
UK	60	32	8
Total	70	22	8

Discussion

The results of this survey bring a new dimension to the debate about infertility and its treatment: public opinion. This survey is a first attempt to gauge people's perception of this problem. The percentage of couples experiencing infertility involves all regions of the world (Zargar *et al.*, 1997), and in some countries it may be growing (Stephen and Chandra, 1998). There could be many reasons for this phenomenon (spread of sexually transmitted diseases, pushing back the age at which reproduction attempts are begun, environmental factors interfering for example with sperm production, etc.).

The perception of infertility is different in different countries. The gap between the UK and the USA—and Australia to some extent—on one side, and continental Europe on the other, could have many causes. Since within the Anglo-Saxon countries there were no significant differences in the replies among age groups and gender, it seems likely that a general cultural difference lies at the bottom of this contrasting result. The term 'disease' used in the survey was chosen to adhere to the WHO definition. In English-speaking countries, the word 'disease' may have the connotation of a rather severe, possibly communicable condition. Conversely, the terms 'maladie', 'malattia' and 'Krankheit', in French, Italian and German respectively, have a broader and softer meaning, bringing to mind any condition which should fall under medical attention, without a specific connotation of severity or communicability. Other factors may play a role in the perception of infertility in the Anglo-Saxon countries. Many purchasing authorities,

especially in the UK, consider infertility treatments as not curative, and thus not reimbursable (Evans, 1995). This approach may affect the public's perception of infertility as a social, rather than biological, illness (Redmayne and Klein, 1993).

People surveyed show little understanding of the medical issues surrounding infertility, and little understanding about real chances of successful treatment. The opinions vary little among countries, age, gender and socioeconomic status.

The treatment options are no longer experimental and offer excellent probability of achieving pregnancy (Bergh *et al.*, 1995; Glander, 1996; FIVNAT, 1998; Forti and Krausz, 1998; Hargreave and Mills, 1998; Guzick *et al.*, 1999). However, state-of-the-art diagnostic approaches and treatment are not widely used by clinicians, even specialists, in many countries (Helmerhorst *et al.*, 1995; Glatstein *et al.*, 1997).

The number of couples seeking medical help for infertility is probably lower than the number experiencing it (Templeton *et al.*, 1991). This may depend to a considerable extent on the lack of knowledge about success rates and chances to become parents (this is supported by the results of this survey). The costs associated with assisted reproductive technologies could also play a role. Ethical, religious and personal beliefs may influence the decision not to seek treatment. Mass-media descriptions of 'extreme' rather than 'normal' cases also may influence this decision. The issue of infertility is still surrounded by taboos (this may vary in different countries). It is often difficult for couples to address this problem openly, and this lack of openness stifles their chances to identify a solution.

The results of the survey indicate that there is a lack of balanced information about chances of success of assisted reproductive treatment. Doctors (mainly general practitioners), midwives and medical personnel in general should be able to provide more complete information. This capability to inform the patients correctly may in part stem from the lack of a reliable source that could easily be accessed.

The lack of reimbursement is also a major obstacle in many countries. It is common in most countries to have expensive and time-consuming work-up procedures reimbursed, or even therapeutic micro-surgical procedures that are of limited benefit (Evans, 1995; Hamberger and Janson, 1997). Reimbursement should be 'neutral' and not related to the type of technique applied to overcome the infertility problem.

Recently, there has been much debate in the medical press about reimbursement of medical procedures (Dicker and Armstrong, 1995; Millns, 1995; Bowling, 1996; Kleinert, 1998). It is difficult to gauge correctly the public opinion on reimbursement issues, especially if a number of procedures dealing with widely different diseases and age groups are compared (Bowling, 1996). Public support for reimbursement of infertility treatment seems to be high (present survey and Granberg *et al.*, 1995), and contrasts with a general trend in most countries towards leaving this expense to the individuals (Gleicher, 1998a,b). However, infertility is becoming a political problem in the Western world, as an ageing population can no longer be supported by a constantly decreasing number of children (Lunenfeld, 1999).

In conclusion, the public's concern and awareness on infertility is similar in Western countries. Spread of best practices and support for sound reimbursement policies should be the objectives of the medical community in the field.

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